How Mothers of Autistic Children Experience Intensive Interaction: An Interpretive Phenomenological Analysis.

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A thesis submitted in partial fulfilment of the requirements of Sheffield Hallam University for the degree of Doctor of Philosophy

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Candidate Declaration

I hereby declare that:

1. I have not been enrolled for another award of the University, or other academic or professional organisation, whilst undertaking my research degree.
2. None of the material contained in the thesis has been used in any other submission for an academic award.
3. I am aware of and understand the University's policy on plagiarism and certify that this thesis is my own work. The use of all published or other sources of material consulted have been properly and fully acknowledged.
4. The work undertaken towards the thesis has been conducted in accordance with the SHU Principles of Integrity in Research and the SHU Research Ethics Policy.
5. The word count of the thesis is 77820

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Abstract

Intensive Interaction (II) is a communication strategy used to promote social interaction and develop early communication skills in people with learning difficulties, some of whom are also autistic. Mothers are using II in their homes with their children often under the direction of a professional but to date their experiences are only minimally represented within the research literature. It is important that we know how mothers experience II before we can effectively support them through policy and practice. This research also feeds into the wider social communication interventions and disability arena where the dominant narrative is what a valuable resource parents are once trained. However, most studies including parents, evaluate only their effectiveness in delivering an intervention, few studies report on the experiential aspects of running an intervention in the home.

This study employed Interpretive Phenomenology Analysis (IPA). IPA examines how people make sense of important life experiences and situates the participants as the primary experts of their own experience. This study considered reasons for engagement with II and sought to understand how II use affected how the mothers' experienced relationships with their children. It also explored what engagement with II brought the mothers in terms of personal growth and empowerment.

Seven mothers were interviewed, and two superordinate themes emerged: seeking, finding and learning, and connecting. The mothers' experiences reveal some similarities with the wider II literature around increased understanding of social communication and enhanced connections with their child. However, the mothers also experience complex emotions bound up with identity, sense of self and the child-led element of II. From these findings recommendations for good practice in supporting mothers using II are discussed.

Acknowledgements

I would first like to thank all of the mothers who took part in this study for sharing their stories with me. Thank you for giving your time and your willingness to share your experiences. Without you there would be no thesis.

Thank you to my wonderful supervisory team. Dr Penny Furness, Professor Nick Hodge and Dr Jill Pluquailec for their unwavering support throughout this long process. They have had infinite patience and pushed and guided me to believe that I could finish this PhD. Working with them has developed my understanding of critical disability/autism studies and how parents are included in these narratives. Studying for a PhD in a supportive atmosphere is critical and the friends and colleagues I have made and met throughout this time have been instrumental as sounding boards, for reassurance and realising it's not just you who feels like that.

Thank you to my family for tirelessly supporting me throughout and for not asking was I ever going to finish, just believing that at some point I would. Finally, I would like to thank my autistic son, without whom I would never have come across Intensive Interaction and would not be where I am today. He brightens all of our family's life with his cheekiness, affection and love.

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Glossary of terms

Below I provide an explanation of relevant terminology and acronyms employed in this thesis.

AAC- Augmentative and alternative communication. Any way someone communicates besides using speech. Such as signs, gesture, pictures, or objects.

PECs- Picture Exchange Communication System. An augmentative and alternate communication system designed to promote expressive functional communication using pictures.

Makaton- a language system that uses signs, symbols, and speech. Signs are used alongside speech to give additional information about what is being communicated.

Medical model of disability- a deficit-based approach to talking and thinking about disability. It situates the disability as intrinsic to the individual, so they are disabled by their differences.

Social model of disability- a framework of understanding that argues that people are disabled by barriers within society rather than their own physicality. These barriers are said to be what excludes and discriminates against disabled people.

CAMHS- Child and Adolescent Mental Health Services. A National Health Service that covers a range of emotional, behavioural, and mental health difficulties.

MAST- Multi Agency Support Team. Provides support across a range of areas including behaviour, sleep, and toileting.

Parent Carer Forum- Independent group run by parents of disabled children in local areas. They aim to make sure local services meet the needs of disabled children and families in their area.

Communication partner- used to refer to the professional or parent engaged in II with the child/adult receiving it.

Chapter 1 Introduction

This chapter provides the rationale for the research focus. It explicates the aims, and research questions and provides an overview of the methodical framework and thesis structure. I begin with an introduction to Intensive Interaction (II) before moving onto an exploration of my personal encounters with II and how this influenced and shaped my research focus and academic learning. Next, I provide an overview of the key terminology used in this thesis and the choices surrounding the language selected. This chapter concludes with a summary of each of the chapters contained within this thesis.

1.1 Intensive Interaction

Intensive Interaction (II) (Nind & Hewett, 1988) is a communication strategy, originally designed to promote social interaction and preverbal communication skills in people with learning difficulties some of whom were also autistic. II is based on early infant-caregiver interactions and the development of these to create what are intended to be mutually pleasurable two-way social interactions for those participating (Nind, 1996). II supports development of the very fundamentals of communication. These are the skills and capabilities that underpin all communication. In most children these skills develop in early life, typically before two years of age. The fundamentals of communication encompass skills such as the use and understanding of physical contact, personal space, learning to enjoy giving attention to another person and to receive it, and taking turns in exchanges of behaviour (Nind & Hewett, 2001). In addition, II supports emotional wellbeing via relationship building and trust with another person, which enable interpersonal connections to be forged and strengthened (Nind, 2012). Keeping behaviour simple and responding to the child enables interactions to grow allowing engagement with the child/adult in a way that is meaningful for them, through behaviours they find pleasurable (Hewett, 2012). One of the central tenets of II is that it is child led, a play based relational approach that embodies child centred learning (Mouriere & Smith, 2022). For further explanation of II and its principles see Chapter 2 on page 27.

1.2 Personal context

My initial introduction to II was through my autistic son who was six at the time. This was at a time when family life was demanding: my son was frustrated and finding it difficult to get his needs met. This impacted on his behaviour both in the home and at school. School staff were struggling to engage him in anything other than self-directed behaviour and finding it problematic to manage his behaviour outbursts. The educational psychologist was brought in. Coincidentally I attended a meeting at the local Parent Carer Forum with a senior member of the Speech and Language Department who happened to be one of the professionals who had assessed my son at his diagnosis. They remembered me and asked how my son was getting on; this led to a conversation about his communication. The Speech and Language therapist told me that developmentally my son was not ready for a communication system such as PECs (Bondy & Frost, 1994) and asked me if I had heard of II. It was not something I had come across so, as soon as I got home, I googled it: this was a eureka moment for our family. I ordered Phoebe Caldwell's (2008) book and for the first time I read about autistic people who were like my son. Reading about II enabled me to realise that the way we naturally engaged with my son in the home was on the right lines, we just needed to let him lead more and embrace, rather than resist, his favoured activities, and vocalisations.

At the same time as we started honing our interaction skills at home, the Speech and Language therapist whom I had met in the meeting advised the school to start using II with pupils. This was a pivotal moment in my son's education: he started to form relationships with the staff supporting him, they adjusted his curriculum, and he began to thrive at school. I started to volunteer at the school and eventually started to work there as a teaching assistant whilst completing my master's degree in Autism. The school's use of II had started to increase by this point and my course dissertation was a case study of the use of II in school. The impact from this case study was that I was asked to support key staff in their II practice to increase sustainability and visibility of II across school. This role continued to expand as the numbers grew of staff and parents whom I was supporting in using II. Concurrently I implemented a whole school recording system to monitor and evaluate our II use with a focus on reflexive practice.

Through studying at master's level and conducting a literature review of II, I was struck by how underrepresented the views and experiences of parents were in the literature on II. For me, the key difference in my son's life was the fact that both school and home were interacting in a negotiated and agreed way with him: we worked in partnership. But my knowledge and learning of II came from my own endeavours, not through school 'training' me. The focus of the majority of the II literature is on its use in either a school or care setting, with very little consideration for how parents were included within, or excluded by, the approach. However, at professional led II conferences parents were always invited and included, held up as exemplars of the difference II can make to someone and their family. This left me wondering how parents were finding out about II, and in what ways they were supported to use it. For me personally, attending that Parent Carer Forum meeting was very fortuitous: without that things might look different for my son today.

Through supporting parents at school, I have been able to experience II from both sides, as a parent myself and as a practitioner supporting others. This has made me much more aware of the power relations that sit in these situations and the significance and value of the knowledge that parents have of their child. Working in a school I have realised that for strategies to be of use to a family they must be accessible, relevant, adaptable, usable and co-produced. Exploring how II fits in within a family environment is key to its uptake, so it is essential to identify the potential barriers for parents. At the time of starting my PhD I had very little awareness of how parents were included in research about disability; this has been something that has developed as my PhD has progressed.

1.3 Overview of II literature that informed this research

The II literature has evolved over the last twenty-five years from early small-scale efficacy studies (Kellett, 2000; Elgie & Maguire, 2001; Zeedyk et al., 2009) to longitudinal studies exploring social engagement levels over a longer period. These studies allowed for practitioner training and more experiential aspects to be measured (Kellet, 2000; Watson & Knight, 1991). As the research continued to evolve, the experiences of both the learner and practitioner started to be

analysed (Berry et al., 2014; Leaning & Watson, 2006; Rayner et al., 2016) Key topics for research have included practitioners' views on age appropriateness, touch, enhancing relationships and development of ethos (Culham, 2004; Firth et al., 2008; Nagra et al., 2016; Samuel et al., 2008). However, throughout this body of research there was a notable absence of the parental voice. Indeed, only three papers included findings from parents. Kellet (2004) and McKim and Samuel (2021) included very brief mentions of parental experiences of using II, with Berridge and Hutchinson's (2022) paper on mothers' experiences of II with learning disabled children offering an insight into the experiential aspects of mothers.

Connecting with the II literature supported the evolution of this research. As a parent engaging in II at home with my son, I struggled to find accounts of parents other than the occasional chapter in an II textbook (Harrison, 2012). Parents are currently underrepresented in this small but growing body of literature even though they are using II in their homes. To support parents, it is important to research how they experience using social communication strategies and whether those experiences are valued on the same platform as professionals. This will help counter within the development and practice of II, the system of hierarchical relationships often found in research on disabled children, where the parent's contribution to the parent-professional partnership is viewed as a lesser in terms of value (Hodge & Runswick-Cole, 2008). A detailed overview of the literature surrounding II is explored in Chapter 2 on pages 43-59.

1.4 Moving towards a critical disability and neurodiversity perspective

Throughout my master's degree and PhD, I have been influenced by the literature on critical autism studies (CAS) (Davison & Orsini, 2010; O'Dell et al., 2016) and neurodiversity (Singer, 2017). This literature has evolved my thinking further towards a strength-based perspective. Neurodiversity, encompassing autism and attention deficit hyperactivity disorder (ADHD) is considered to reflect natural variations in brain development and function. It seeks to provide a positive identity for autistic people, of individual difference and a natural variation aligned with the social model of disability (Kapp et al., 2013). The

neurodiversity movement is against interventions that seek to medicalise and ‘cure’ autism but advocates instead for strategies that support wellbeing and adaptive functioning, such as supporting an alternate way of communicating (Runswick-Cole, 2014). II aligns with these tenets: it celebrates and recognises the strengths of the learner, acknowledging the behaviours that hold meaning for the learner and joining in with them to build rapport. The expectation is on the communication partner to learn the ‘language’ of the autistic person rather than the autistic person adapting their communication style (Hewett, 2012).

Critical autism studies (Davison &Orsini, 2010), as a paradigm, is an evolution of critical disability studies. Therefore, it rejects deficit-focused pathologising narratives of autism, in preference for those that recognise the autistic identity as complex and heterogeneous. CAS encourages research that explores and pushes the boundaries on constructs of ‘normalcy’ and difference (O’Dell et al., 2016). CAS typically formulate research processes and practices that challenge the power relations that dominate the autism research arena. Instead, focussing on narratives that disrupt expected deficit-focused descriptions that dominate in much of research and popular culture (Milton & Ryan, 2023; O’Dell et al., 2016).

Informed by my concerns over the lack of parental voice in disability research generally and in relation to II in particular, in this thesis my aim was to explore mothers’ experiences of engaging in II with their autistic children through using Interpretive Phenomenological Analysis (IPA) (Smith et al., 2012). In doing so I prioritise the mothers’ experiential accounts in an idiographic way. My concern was not to evaluate the effectiveness of a development programme for autism, an approach which dominates in the communication strategy literature, but to understand and represent in detail mothers’ experience of working with II.

For me it felt important to allow the mothers to talk about their lived experience of using II without feeling that they were also going to be judged on their interaction style with their child. As a mother myself I have had many meetings with professionals where my interactions with my son have been the subject of scrutiny. This level of judgement, even though usually well-meaning, I found difficult, and it made me very self-conscious of how I interacted with my participants. This was not something I wanted the mothers in my research to feel: I wanted them to be able to discuss their II experiences without feeling

there was a value judgement being made on those interactions. The focus of this research became therefore the lived experience of using II in the home as described by the mothers who took part.

As I have developed academically and through my experience of mothering a disabled child my thinking has evolved to ascribe to a non-deficit-focused, non-pathologised narrative when talking about disability. Many of the interactions I have as a mother about my son with professionals are deficit-focused, concerned with what he 'lacks' and cannot do compared to a normative benchmark. In contrast this research challenges the hegemonic discourses surrounding parenting an autistic child who is non-speaking often with an intellectual disability and provides a space for mothers to present a different set of understandings. Comparatively the research including this population is sparse. What dominates research about the non-speaking autistic population is a focus on functional communication or cognition outcomes utilising methods such as eye tracking or neurophysiology (Tager-Flusberg & Kasari, 2013). Research carried out including families of this population frequently is efficacy based, such as Green et al. (2010) with little focus on experiential aspects. Pacia et al. (2022) advocate for research involving families that has more of a focus on experiential aspects, as families are key in implementing strategies and maintaining them in the home environment. It is also important that parents are included as key stakeholders throughout the research process (McKinney et al., 2021) to ensure that their knowledge and understanding about what works best for their children is captured within research and utilised in practice. This thesis aims to add to a growing body of research that challenges the power differential in narratives of parent-professional relationships by adding the lived experience perspective of the mothers using II to the currently dominant professional voices in the II literature.

1.5 Intensive Interaction, where it sits within autism paradigms

II is a social communication intervention, and traditionally these have been positioned within a medical model of disability that emphasises a deficit or lack of ability to do something (Burghardt et al., 2021). However, this is not the understanding of disability that underpins II. The intention from its inception was

to find a more enabling, respectful, and holistic way to engage and interact with children and adults for whom traditional behaviourist approaches were not working (Hewett, 2022), as further explained in Chapter 2.1 page 28. II does not strive to normalise the individual. Rather it focuses on how the communication partner might need to change their behaviour to enable successful shared communication, in this way II produces a rebalancing of power. Whereas some interventions seek to eliminate perceived socially unacceptable and therefore unwanted behaviours such as spinning or hand flapping, II conceptualises these behaviours as holding meaning for the individual. II then utilises those behaviours to reflect back to the person that they have been heard (Caldwell, 2008). II does not seek to cure or fundamentally change the person. Instead within its underpinning ethos and theory II recognises the strengths of the person and the value to them of their way of being. In doing so II challenges dominant discourses of certain autistic behaviours as undesirable and in need of eradication.

Even though the underpinning premise of II is one of acceptance and valuing the learner there remains a tension with CAS in how II is researched and legitimised. Particularly with the efficacy work (Zeedyk et al., 2009; Kellet, 2000; Barber, 2008) increases in social engagement measures were used as a marker for success. These normative benchmarks such as eye contact were deemed markers of success of II. This focus on normalising measures to prove the efficacy of II sets it at odds with CAS in that the focus of the research is not on expanding horizons and moving away from constructs of normalcy (O'Dell et al., 2016). Equally troubling is that there is no recognition of this tension within the literature of using normalising measures to prove the merits of a communication strategy aimed at joining in with and valuing behaviours that hold meaning for another.

Kapp et al. (2013) and Runswick-Cole (2014) describe differences between autistic self-advocacy movements and parent-led autism movements, with the most vocal and influential parents leaning towards a more medical model approach to interventions, designed to normalise, as far as possible, their autistic children. Runswick-Cole discusses how the nature of parents' views of interventions and cure and those of autistic advocates has often been an area of difference and tension. Kapp et al. (2013) discuss how learning and

understanding about the neurodiversity movement can ameliorate some of this difference by enabling parents to view the strengths of their autistic child and view autism more holistically. II similarly looks to the strengths of the autistic person and the behaviours they find meaningful. It celebrates and recognises these, enabling a more nuanced shared understanding of these behaviours. Kapp (2019) an autistic researcher and advocate encourages the use of strategies which include responsive care-giving tactics that enable parents to 'learn to speak their child's language' (pg. 6).

I subscribe to a critical disability/autism and neurodiversity perspective. I do this because I believe all behaviours have meaning and there are different ways of being in the world which should be equally recognised and valued. I feel II fits within these paradigms. It celebrates the person for who they are by recognising and valuing their interests and through the promotion of listening. In these ways II respects the intents, desires, and aspirations of autistic people. It is important for me to conduct research that does not seek to medicalise or cure the autistic individual. Rather I seek to enable autistic people through supporting wellbeing and adaptive functioning. Exploring mothers' experiences of II fits with this premise. Adding the voices of mothers to the other practitioners of II will help to correct the current power imbalance within recorded accounts.

1.6 A word about terminology

A glossary of key terms used in this research is given at the start of the thesis, however I think it is important to discuss some of the reasoning surrounding my choices regarding terminology in more detail, particularly the use of identity first language over person first language. I feel this is important to do because this is an area were regular debate takes place (Botha et al., 2023; Vivanti, 2020) and detailing this and my own position sets out my perspective within my intersectional roles of academic, mother and practitioner.

As a researcher, a mother, and a special education practitioner I seek to counter the deficit-focused narratives that have disabled my son, our family, and our autism community. A key part of my role in an autism school was to attend 'Managing Emotions Together' meetings. In these I found myself challenging the

sometimes deficit-focused, ableist narratives that inevitably creep into discussions even in the most well-intentioned and enabling schools. I sought to shift the discourse from the negative and onto identifying and valuing the strengths of the individual and what they were trying to communicate through their behaviour at that time. This involved changing the narrative from only focusing on what the *child* did to a consideration of what we could have done differently through identifying the communication or sensory cues that we missed. Throughout my PhD and academic learning, I have become more aware of the impacts that using ableist language can have on both the individual (both the autistic individual and their parent/carer) and in how society perceives and responds to perceptions of autism.

Ableism is defined as the beliefs and practices that discriminate against people with physical, intellectual, or psychiatric disabilities. The language used as well as culturally shared norms all promote ableism in society. Language choices can increase stigmatisation and marginalisation through encouraging negative reinforcement of stereotypes such as the notion that autistic people are emotionless (Bottema-Beutel et al., 2021).

Within this thesis I have tried to avoid framing disabled children, adults, and their families within a deficit discourse. Instead, in alignment with a Critical Autism Studies framework I have sought to use terms and ways of speaking about autism that are recommended by autistic self-advocates and their allies.

Throughout the literature there is discussion and increasing debate around the language used to describe autism not only in relation to the use of identity first (autistic person) or person first (person with autism) language but also the language used to describe the variation in experience of being autistic with regards to the heterogeneity of autism (Vivanti, 2020). In the 1970's a paradigm shift away from terms such as disabled or handicapped towards person first language was advocated as an effort to highlight that a person's disability was only one feature of their identity and that they were a person first. This also had a human rights bearing, an attempt to shift away from dehumanising language and practice that centred around a person with a disability being positioned as less than human (Vivanti, 2020; Botha et al., 2023). However, this approach has been challenged by some disability groups such as the Deaf and Blind

communities who have reclaimed the identity first language used to describe themselves and their communities as a move to promote a positive and cohesive social identity (Botha et al., 2023).

Similarly, there has been a shift within the autistic community led by advocates such as Sinclair (1999) and Botha et al. (2023) who refer to themselves as autistic researchers and advocates, to use identity first language to describe autism. Sinclair (1999) discusses how person first language assumes that the autism can be separated out from the person, this is not the case in their view: autism is an integral part of who they are and 'hard wired' into their brain. Without it, Sinclair asserts they would not recognise the person left. Using person first language perpetuates the narrative that autism is something bad needing to be cured such as a person with cancer. Botha et al. (2023) assert that using person first language reinforces the narrative of autism as something necessarily problematic and inherently bad, something to be got rid of. In this way the original intention of using person first language to prevent dehumanisation of the individual is corrupted and results in the opposite effect.

Identity first language represents a paradigm shift away from pathologising neurological difference towards a neurodiversity perspective whereby neurological difference is recognised as a natural part of humanity (Botha et al., 2023; Kenny et al., 2016). Nonetheless, there is still not a consensus on the language use preferred by members of the autistic community and professionals working in the field. The paper by Kenny et al. (2016) on preferred terms to be used to describe autism in the UK surveyed autistic people, their families, friends, and professionals and found no clear consensus, amongst autistic people and their families. The preference was for identity first language i.e., autistic (autistic people 61%, parents 51%) with professionals preferring person first language i.e. person with autism (49%). The authors concluded that there was no one term used to universally describe autism in the UK and that language choice was influenced by beliefs about autism and the context of the person using it. Botha et al. (2023) and Vivanti (2020) both advocate for using the person's preference around language use and when this is not known to consider the context and audience you are talking to, bearing in mind how pervasive language use can be.

My positionality around language use is to use identity first language. I feel that it is important not to perpetuate deficit or negative impressions of autism that can be associated with person first language. As a parent of an autistic child, I align with Sinclair's assertion that autism is an integral part of my son's identity; without it I would not recognise him. Recognising that my understandings of autism may differ from those of my participants, where mothers used particular terms to refer to autism, I have maintained those within the quotes to reflect and honour the position of my participants.

Another debated language issue is around the descriptors used to identify and categorise the varying heterogeneity of the autism community, with terms such as high and low functioning used to delineate between differing experiences of autism. Kenny et al. (2016) highlight how misleading this terminology can be as it does not account for the people categorised as having no intellectual disability but who still have significant needs in relation to navigating the social world. It can also underestimate the abilities of those deemed low functioning. Within more recent research in the autism field there is a growing consensus on the use of the term 'functioning' as misleading and inappropriate because it often leads to stereotyping and deficit-focused narratives (Kapp, 2023).

Currently there is debate around the introduction of the term 'profound autism' to describe members of the autism community who have high needs. However, there is no clear definition as to whom this reductionist term will apply. The suggestions are for it to be used for people categorised as having a low IQ and who do not use speech or have very limited speech (Kapp, 2023). As with other reductionist terms it goes against the heterogeneity of autism and the acknowledgement of differing profiles where needs may vary depending upon social context or the environment at that time. A piece written by a parent on Spectrum (2023) advocates for embracing the term 'profound autism'. This parent argues that terms such as this are required to distinguish the needs of their children and support them in getting medical aid for their families. This highlights the differences in agenda that Runswick-Cole (2014) discussed that operate between parent-led movements and autistic advocates. Whatever the term used however, what is apparent is the sparsity of research that explores strategies at an experiential level with families of autistic children and adults who might fit this categorisation, which look to make real world differences to

families. There remains little consensus on which intervention or communication strategies are most suitable for non-speaking autistic children, leaving families feeling marginalised and underrepresented in autism research (McKinney et al., 2021).

II is primarily used with children and adults with learning difficulties who may also be autistic. Even though II is used with a wide range of autistic children with differing profiles, it primarily is used with children who do not use the spoken word to communicate. Across the literature there is differing language used to describe this profile, from non-verbal to minimally verbal (Tager-Flusberg & Kasari, 2013), however, Botha et al. (2023) identify the inconsistencies with how these terms are used in the literature, once again highlighting the heterogeneity of not only the autistic community but also those who do not use the spoken word to communicate. They emphasise that not speaking does not mean ‘not communicating’ and often this group of autistic people use less socially valued ways of communicating such as symbols or signing. Indeed, my own son uses a combination of Makaton (1976) and gesture to communicate his functional wishes. To say he cannot communicate would be wholly inaccurate, but if subject to the ‘functioning labels’ he would be deemed low functioning or possibly profoundly autistic, and this would misrepresent his strengths and abilities. In so doing there would be a perpetuation of the ableist view that not speaking means an inability to communicate. Expressive language is only half of the communication story, terminology such as nonverbal or preverbal do not provide any information about someone’s receptive language ability and once again receptive language differs across this group (Tager-Flusberg & Kasari, 2013).

Over the years I have revised the language I use to describe my son as my understanding of the influence language use can have on our value judgements of a person have developed. I have also learnt via my interactions with my son, at the school where I worked and through my academic journey that not speaking does not mean, not communicating. However, for many parents this focus on the ability to speak or not perpetuates a deficit focus that often detracts from the recognition and value of other forms of communication. As a mother I have lost count of the number of times I have been asked by well-meaning relatives or others ‘is he speaking yet?’ Or the look of pity when I say, ‘he

doesn't use speech, he uses Makaton.' These ableist perspectives come from a society where speech is valued above all other forms of communication or where those who do not use speech are viewed as having nothing to say (Schwartz-Johnston, 2019). My personal preference is 'does not use the spoken word to communicate' but for brevity I align myself with Botha et al. (2023) and use 'non-speaking'. Where the mothers in my research have used other terms to describe their children I have adhered to their chosen terms when presenting quotes and representing their experiences.

1.7 Mothers not parents

The original intention of this research was to look at parents' experiences of using II with their autistic children. I was open to both mothers and fathers, but I made no particular efforts to actively recruit a sample with both in it. As it transpired my participants were all mothers, some were single parents and others lived in partnerships with their child's father. However, upon starting data analysis it became apparent that their narratives were bound up with their identity as mothers of disabled children and indeed gendered perspectives played a role in their stories. This was not something I had anticipated at the start of the research; certainly, I suspected my research would attract predominantly mothers as primary carers (Boyd et al., 2019) but not that their accounts would be so bound up with that identity. Ryan and Runswick-Cole (2009) and Harvey (2015) both assert the importance of acknowledging a research focus of mothers as opposed to conflating their experiences with parents in general. Maternal experiences are a legitimate and worthy focus in their own right, not least because mothers typically tend to be the primary carers of disabled children and are more likely to leave the workforce to care for their children (Ryan & Runswick-Cole, 2009). Therefore, the decision was taken post data collection to change the focus of the research study to mothers' experiences of II rather than parents. Section 2.5.1 contains a brief exploration of the history of autism and mothering.

1.8 Research aims and questions

The aims of this research informed by the literature and my intersectionality as a mother, practitioner and academic were to:

- inform knowledge and understanding of mothers' perceptions of using II with their autistic children
- explore mothers' reasons for engagement with II
- identify the practical effects on mothers of running an intervention at home
- seek to understand how the use of II affects how mothers' experience their relationship with their child
- explore what engaging with II has brought the mothers in terms of personal growth and empowerment
- enable the parental voice to inform policy and practice in working with professionals when delivering an intervention in the home

Because of this and to fore front mothers' experiences of using II with their autistic child my research question was:

How do mothers of autistic children experience Intensive Interaction?

In particular I was interested in:

- How did mothers find out about II and what were their reasons for engaging with it?
- How do mothers' experience II use with their child?
- How does II fit in with family life?

1.9 Value of this research

This research is important because a) it contributes to knowledge and understandings of how mothers' experience the nature and use of II and b) it is one of only a few studies that enables mothers to be generators of knowledge in the field of II. In doing so it challenges the hegemony of professional accounts.

It is important that we understand how mothers' experience II before we can effectively support them through policy and practice. This research also feeds into the wider social communication interventions and disability arena where the dominant narrative is the notion of the 'trained' parent as a valuable resource (Schertz & Odom, 2007). However, most studies that include parents, evaluate only their effectiveness in delivering an intervention (Green et al., 2010; Shire et al., 2015); few studies report on the experiential aspects of running an intervention in the home. This research presents the lived experience of running a social communication intervention in the home. It empowers mothers through recognition of them as generators of knowledge and understanding about the concept and practise of autism approaches. Learning from mothers who use II and the ethos it embodies has policy and practice implications for professionals working with families delivering not only II but also other social communication interventions.

1.10 Methodological framework overview

This section introduces the methodology employed in this thesis and the methods used including analysis. It is summarised in figure 1, a detailed account of the rationale and method are discussed in chapters 3 and 4.

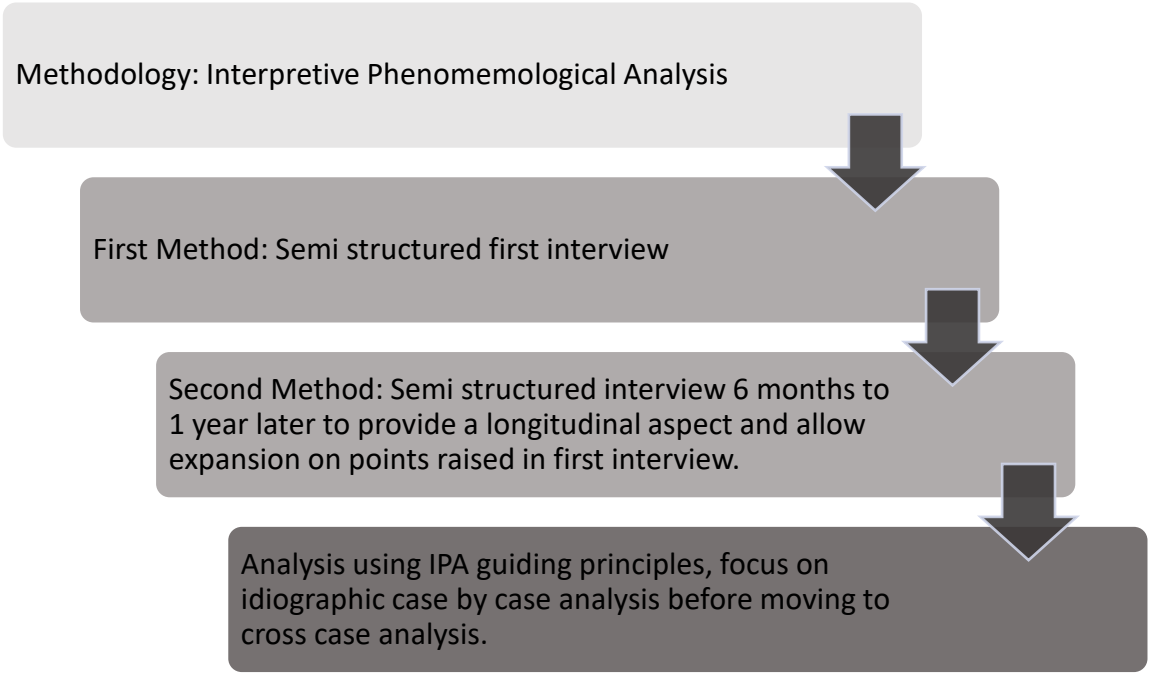


Figure 1 Methodological framework overview

1.11Thesis structure

In this section I provide a brief outline of each chapter contained in this thesis.

Chapter 1 presents an account of my personal interest in II, the research aims and questions and argues for the importance of the research. Next, it discusses terminology choices and the evolution of the overall research question from parents to mothers. It gives an overview of the methodological framework and thesis structure.

Chapter 2 analyses the II literature, moving through the historical context for II and its evolution through the research, focusing on the importance of emotional wellbeing in the II narrative as well the key role of emotional wellbeing in current education policy. The underpinning theoretical perspectives of II are examined along with the presentation of a detailed overview of what II is. The chapter sets out the positioning of parents in the social communication literature and in doing so highlights the dominant narrative of training parents to interact with their disabled children to become a useful resource for professionals.

Chapter 3 details my positionality and epistemological choices and sets out my rationale for the methodological choice of IPA. The underpinning theory of phenomenology, hermeneutics and idiography are explored with critical debates and validity of the approach detailed. This chapter also details how I have maintained IPA's focus on reflexivity throughout the research process.

Chapter 4 covers the data collection methods of semi structured interviews and subsequent analysis procedure following Smith et al. (2012) guiding principles, including reading, and reading of the text, initial noting, development of emerging themes, searching for connections, moving onto next case, and looking for patterns across cases. In this chapter I also consider the ethical implications involved in the research and highlight decisions made with regards to enabling the participation of the mothers.

Chapter 5 then provides an account of the findings from the first super ordinate theme 'Seeking, finding and learning'. Within this I detail the mothers' journeys as they search for something that works for their child and their own

experiences of engaging with II. I identify what it taught them about their own styles of interaction and how they managed the judgement placed upon them by others. The personal growth and empowerment of the mothers through II use is explored.

Chapter 6 covers the second super ordinate theme of ‘Connecting’ which narrates the motherhood relational experience and how this altered through engaging in II. It details what this meant for them as individuals and the wider family beyond.

Chapter 7 draws together the findings and addresses the research questions, discussing these in relation to the II literature and wider maternal identity and disability literature. I consider possible reasoning behind why the experience of using II seems to empower mothers and the possible implications of this for practice and policy moving forward.

Chapter 8 discusses the limitations of this study and final reflections. It concludes with a consideration of the implications for future research and a claim for the contributions to knowledge the thesis makes.

Chapter 2: Literature review: Intensive Interaction, social communication interventions and parental inclusion in disability research

This chapter starts by analysing the current literature on II. I begin by providing a historical perspective. To situate II within the evolving paradigm of critical disability and autism research it is important to gain an understanding of the context of why and how II was developed. I then critique how and where parents are included within this research. I argue here that this review of the literature suggests that the links between II and the development of emotional wellbeing and mental wellbeing in the child/adult learner mean that II is being introduced to more parents and so would benefit from further research.

In addition to the experiences of parents engaging with II, I evaluate how parents are included in research more generally around communication interventions, particularly social communication, used with their autistic children. This was necessary to do because the research including the parental voice is lacking within the specific II literature and so a broader review is useful. The recognition of how parents traditionally are included, or more pertinently not included, in research about communication interventions was critical to the development of the aims, methodology and methods of this thesis.

II is a social communication method, which is categorised under the wide umbrella of social communication interventions, for which there is a large literature base, particularly surrounding social communication, and autism. Social communication differences are a key diagnostic criterion of autism, with difficulties in social interaction, communication and behavioural flexibility being specified in the Diagnostic and Statistical Manual of Mental Disorders–Fifth Edition (DSM-5; APA, 2013). Therefore, large areas of autism research and interventions are dedicated to the differences in this area. Consequently, it is helpful for any review of II to be situated within the broader context of social communication research as there are likely to be some shared experiences for parents across the range of approaches.

In this chapter the language used to refer to the child or adult engaging in II varies to reflect the terminology used within the literature being critiqued. Terms used for the person for whom II is being provided include learner, less

experienced communication partner, client, and service user. Terms used to refer to the enabling partner in these interactions are more experienced communication partner, staff, teachers, practitioners, and parents.

2.1 Historical context

This section provides the historical context for II and identifies the main influences on its development. It situates II's evolution from its inception to where it currently sits within the practices of educational and adult services. Understanding this was pertinent to my research because I came to recognise that II is situated within broader disability debates. The growing interest in II means it is moving from a rather niche strategy to a more mainstream autism practice.

II was developed in the 1980's as a move away from the popular behavioural techniques of the time. It was developed into a specific approach by Nind and Hewett (1988). This process took place in a long stay learning disability hospital (Harperbury hospital) with an educational provision attached. The young people at this establishment were teenagers and young adults many of whom were autistic. Placement at this facility was usually because the behaviour the young people exhibited was felt to require a secure and specialist environment. Nind and Hewett felt that behaviour was driven by fundamental issues with establishing social relationships and communication. These students were categorised as being at the very early stages of development, not only cognitively but also socially and emotionally (Hewett 2022).

Special education curricula at that time centred around behavioural techniques such as operant conditioning (Skinner, 1963); behaviour modification aimed at diminishing undesirable behaviours using rewards and punishments. Skinner was a radical behaviourist who argued that all behaviour was determined (O'Donohue & Ferguson, 2001). Operant conditioning involves hypothesising as to the causes of a behaviour through, in part, an analysis of its consequences. Behaviourists such as Skinner, view behaviour as intentional and not an automatic/reflexive response to a situation. Consequently, they view behaviour as able to be modified (O'Donohue & Ferguson, 2001). Operant conditioning

involves the use of positive and negative reinforcers. Positive reinforcers strengthen certain behaviours and negative (or punishments) diminish others (Kienzler et al., 2023). Behaviour modification techniques situate the 'problem' behaviour within the person, thus reflecting the medical model of disability. It fails to recognise that behaviour is a form of communication and/or response to physical and social environments (Jordan, 2013). Therefore, it denies agency to the disabled individual and does nothing to address the concerns that cause them to act in this way.

Operant conditioning is largely used for classroom management as opposed to pupil learning; it often centres around a rewards and sanctions style of teaching. Examples of this are readily seen in many primary and secondary schools, such as negative behaviour points leading to sanctions and rewards for good behaviour leading to merit stamps (Payne, 2015). Behaviourist approaches are still popular in schools and advocated by educational psychologists despite research evidence stating they deter intrinsic motivation and autonomy of pupils (Deci et al., 2001). The use of extrinsic rewards can deter intrinsic motivation to learn, undermining the self-motivation and persistence required to be an independent learner. Behavioural approaches do little to help the teacher to understand the communicative intent behind any behaviours (Hart, 2010). Hewett (2022) argues that behaviourist approaches do not support social skills and social interaction, and such approaches employ a power balance which leaves the teacher holding the power, leading to a lack of agency for the child.

The staff at Harperbury hospital wanted to move away from this style of curriculum to a more holistic approach, placing the learner at the centre. This involved looking at the whole person and what their behaviour was communicating (Hewett, 2022). Hewett discusses how using behavioural techniques made his team feel 'we were able to admit that most of us were not comfortable working with behaviour modification and the sensation of extreme imbalance of power and authority that came with it' (Hewett, 2022, p.7). Therefore, restoring the balance of autonomy between communication partners became a fundamental principle of II.

The students with whom Harperbury staff worked were asserted to be at the very early stages of development. Nind and Hewett realised that this meant

those students were not ready for communication interventions based upon traditional standard symbolic representation such as PECs (Bondy & Frost, 1994) or Makaton (1976). Wanting to provide a more nurturing environment the staff devised a curriculum based around play, with communication needs at its centre (Hewett, 2022). For these staff it felt important to use communication strategies appropriate for the developmental level of the learner with whom they were communicating (Jordan, 2013). This led Nind and Hewett to explore the skills that came before the use of symbolic communication representations, those early stages of infant development that are a precursor to intentional communication (Hewett, 2022). They wanted to find ways to enable their students to become aware of and ready for relationship building and social exchange with another.

At the same time Ephraim (1982) was exploring what he called ‘augmented mothering’; research around the natural interactions between a parent/carer-giver and infant and the role these interactions played in language development and social interaction skills. Building on his work Nind and Hewett (1988) developed what would become known as Intensive Interaction. II differed from behavioural approaches in that the content was co-constructed between partners, each building and responding to the interaction of the other. The interactions are based around behaviours that hold meaning for the individual. The power balance is intended to be more equitable and reciprocal in nature, with the learner setting the pace and style. In II the learner is viewed as an active participant in the interaction rather than a passive recipient (Nagra et al., 2016; Zeedyk et al., 2009).

This was at a time of continuing change within the education landscape. The Warnock report (1978) and the Education Act (1981) both prioritised the educational needs of disabled children and young adults. There was a definitive move away from offensive deficit-focused terminology such as ‘handicapped’ and children who were deemed ‘ineducable’ to the terminology of ‘special educational needs’ and the rights of all children regardless of their disability, to an education. It also gave parents the right to be involved in assessment processes for the first time. These changes to policy and practice at a national level doubtless influenced the way disability was perceived by some educators.

The staff at Harperbury employed an action research project based around II (Firth, 2012). By 1988 the development of II was refined and being written about in books and journal articles, for example Nind and Hewett (1988); Nind and Hewett (1998); Watson and Knight (1991). Nind and Hewett presented their work at conferences and used videos of the technique to illustrate the different style of interaction. Hewett claims video use is an integral part of II, for both dissemination purposes and professional development. Video was used initially to illustrate II in action, since it enabled colleagues at presentations to see the difference II made, helping to portray its principles which were a radical departure from the behavioural techniques of the time (Hewett, 2022). McKim and Samuel (2021) concur with this. They argue that video use in reflective practice supports training and even though II may feel intuitive, the practitioner is learning a skill: to enhance their interaction style by sensitively tuning into another. This takes practice and being able to reflect on video-taped interactions supports the learning process. I was interested therefore to see in my research whether the experience of the participants supported these claims. Conversely however there is an argument that if II is intuitive and natural then videoing risks de-naturalising and pathologising it through its very action. The fact the interaction requires videoing places it in the realms of deficit and less than.

As interest and dissemination grew in the early 2000's, a website was launched for II, providing information and training courses. Annual conferences were also convened. II has increasingly become an international organisation, with links to Australia, Scandinavia, and Europe. Its remit extended to people with dementia and increasingly the speaking autistic population (Firth, 2012).

Intensive Interaction has therefore become much more visible over the last ten years, with services such as British Institute of Learning Disabilities (BILD) having a factsheet about II on their website (BILD, 2004). Many special schools have a section of their website with information on II and information for parents. Indeed, in Sheffield, II is advocated by the CAMHs service with the Speech and Language team now offering training for both school staff and parents in using II. Sheffield teaching hospitals also have information on their website about II (Sheffield Children's NHS, 2022).

II has progressed from a social communication strategy employed within a single setting to being widely used within the education sector. It is equally practised within adult learning disability teams and social care throughout the UK. Health authorities such as Leeds and Oxford have a dedicated Intensive Interaction Coordinator whose role is to support training and development throughout the learning disability services. In addition, there are webpages dedicated to providing information about II on their websites (Leeds and York Partnership NHS Foundation Trust, 2023; Oxford Health NHS Foundation Trust, 2023).

I have identified here, therefore how II developed as a radical move away from behavioural based curriculums of the 1980's at a time when the landscape of education was changing. Staff at Harperbury recognised the need for something different to meet the educational needs of their students, a more holistic approach that would enable relationships to develop. The following section moves onto look in detail at the principles and the underpinning theory associated with II.

2.2 Intensive Interaction and teaching and learning

II has links to teaching and learning and emotional wellbeing. The underpinning theory is varied and diffuse but embodies common elements of parent-child interactions based on responsiveness and mutual understanding through a play-based approach. These elements are the 'teaching and learning' aspects of II, but II purports to have a two-fold benefit, also supporting emotional wellbeing (Nind, 2012). Nind discusses how initially when II was evolving they looked at infant-caregiver interaction work which came from a developmental psychology perspective, the benefits of social interaction for relationship development. Little was discussed about the role of emotion or mental health in this. Even though they were seeking better relationships and connectedness for their often unhappy and distressed students which resulted in improved wellbeing, they did not explicitly think initially of II in this way. Rather the focus was on a different play-based approach as a move away from behavioural style curriculum.

It is important to discuss the principles of II and the theories that inform the approach from both a teaching and learning aspect and emotional wellbeing perspective. This situates II within current education practice and wider disability fields. Thinking about the core principles of II and any underpinning theory builds the foundations for the next section where the research literature surrounding II is reviewed, including practitioner experiences. The core principles which II embodies are what practitioners engage with, so it is important to consider how these may fit with psychological theories and to identify any potential barriers faced by practitioners and how this might translate to parents using II.

This section focusses on the teaching and learning aspects and the following section, II's links with emotional wellbeing and mental health.

Links have been made with II to theories encompassing a person-centred approach (Rogers, 1980), the theory of infant development (sense of self) (Stern, 1985), and the zone of proximal development (Vygotsky, 1978). Firth (2012) states that II can be linked to several different psychological theories each giving insight into II practice. In this section as the core principles are discussed I will draw out related psychological theories that are argued within the literature to connect with II.

Nind (1996) highlighted five central principles of II:

- Interactions are mutually pleasurable
- The more experienced communication partner adjusts their behaviours to become more meaningful for the child/adult
- Intentionality (treating behaviours as communication)
- Contingent responding (following the child/adults lead)
- Pauses and repetition are used to build simple interactive exchanges

These underpinning principles are key to using II successfully. II aims to promote social communication through its interactive style. This is defined by Kellett (2000) as a two-way engaging flow of activity based around the interests of the less experienced communication partner and the activities that they find meaningful. At II's core are the early infant-caregiver interactions whereby the

learner is responded to as being at the very early developmental stages of communication.

In these early infant-caregiver interactions the caregiver responds to whatever holds meaning for the infant, and imputes intentionality onto those behaviours, whereby the caregiver ascribes meaning to the infant's behaviours. An example would be a caregiver tickling an infant and the infant laughing and reaching out. The caregiver would ascribe meaning to the laughing and reaching out of 'Oh you like that do you, you want more tickles'. Through responding to the cues, the infant is giving, a two-way exchange builds, and a moment of interaction is shared (Stern, 1985,2018). Stern describes how this is a two-way process; the parent reacts differently to the infant's new behaviours and this in turn supports the infant's development. This encourages the shift from pre-intentional to intentional behaviour, enabling the realisation that your communication can affect another.

Nind and Hewett's (1988) seminal paper on II describes how their work was derived from the 'critical learning' that occurs throughout the first two years of life during interactive exchanges between an infant and caregiver. They discuss how as their work developed the subject of intentionality arose and this was mirrored in the literature they were exploring. The process of tuning into the behaviours of the learner enabled interpretations of those behaviours in ways they had not previously been doing. The authors found they attributed meaning to the behaviours as communicating needs and feelings and through indicating this to the learner they were imputing intentionality. Berry et al. (2014) translate this typical development phase to the practice of II: one of the underpinning practices is treating the behaviours of the learner as communicative intent. Imputing intentionality onto those behaviours, will in turn support the development of intentional communication. Caldwell (2006, p.131) talks of 'learning a person's language', sensitively tuning into the learner and observing the behaviours they find meaningful, then reflecting those behaviours back to them. Thereby, you are joining the learner in their world with behaviours which are familiar to them.

In II the more experienced communication partner uses these infant/caregiver techniques to enable frequent interactive exchanges with the learner. This

means the learner is being responded to with behaviours that are familiar (Barber, 2008; Kellet, 2000). This may involve mirroring or joining in with a favoured vocalisation or activity such as spinning around. Because the content is created together rather than directed by one partner, it is argued that the learner is actively engaged in the interaction (Zeedyk et al., 2009). The learning is co-constructed between two parties; it is a supported process that Vygotsky (1978) describes as happening in the 'zone of proximal development'. This is the area outside of what an individual can learn unaided; it is what they could achieve with the support of a more capable adult or peer (Rutland & Campbell, 1996).

The relevance of the zone of proximal development to people with learning disabilities is reviewed by Rutland and Campbell (1996). They describe the under estimation of ability for this population if what they can potentially achieve with the support of others is not taken into consideration. This is evidenced in the II literature. Elgie and Maguire (2001) describe how staff dismissed clients as not being capable of interacting in a different way. However, when using II clients exhibited behaviours that the staff had not witnessed before, such as reaching out their hand to be held (Elgie & Maguire, 2001).

Interactions are based around infant-caregiver techniques such as: imitation, exaggerated facial and vocal expression, pauses, rhythm and repetition. The more experienced communication partner initially matches the learner's rhythm, then subtly adjusts that rhythm and pace, thereby adding interest and extending the familiar. It is hoped that in turn these steps will then develop into turn-taking exchanges in behaviour and simple games. The key tenet of these is that any and every interaction should be a 'mutually pleasurable exchange' (Kellet, 2000; Nind & Powell, 2000). Indeed, Nind and Hewett (1988) describe a 'mutually pleasurable exchange' as 'critical' and that without it interactions would be likely to fail.

A further key principle of II is that interactions are learner-led, with the learner setting the style and pace of interactions and indeed deciding when they are finished (Hewett and Nind, 1998). It is the practitioner who adjusts their interaction style to match the learner using contingent responding. Firth (2012) describes a power dynamic shift within the interactions when using II. Rather

than directed learning with the learner a passive recipient, in II the learner is an active participant and in control of the learning.

This resonates with person-centred therapy (Rogers, 1980). Rogers developed person-centred therapy as a move away from behaviourism. It is based on the person engaging in therapy taking the lead and the therapist acting as active listener. In person-centred therapy there is a reduction in the power balance between therapist and client through this approach (Rogers, 2011). Berry et al. (2013) reported the language used to describe II by psychologists in their study aligned with person-centred terminology and theory. These included concepts of unconditional acceptance and developing an understanding of the world from the client's perspective. Valuing listening to the person and attending to what they are saying, even when this does not involve spoken communication, all align with person-centred working. The power balance shift from the practitioner to the learner described by Firth (2012) mirrors those in person-centred working. Within II the practitioner adopts a learner-led approach, waiting to join in with a behaviour the learner finds meaningful. This engagement in a shared activity demonstrates to the learner that they are being listened to, and valued for who they are (Caldwell, 2008), which is the essence of a person-centred approach.

Nind and Hewett (1988) describe how II was a change in teaching style for them, to one where the teacher was not in control. The physical environment of their classroom also looked very different, with tables and chairs used less and more time spent on the floor interacting with their students. In II positioning of the practitioner is central to the success of an interaction. The practitioner needs to be positioned so they can engage in face-to-face interactions, often this may mean getting down on the floor with the learners. For some practitioners, this change in style can feel very different and the requirement to mirror vocalisations and behaviours can lead to feelings of awkwardness or discomfort (Richards, 2022). Nind and Hewett (1988, p. 56) discuss how 'personal responsiveness is the teaching resource, and the teacher should feel at ease about physical contact and uninhibited use of face, body and voice.' Richards (2022) reflects that even when using II with early years children there can be apprehension from practitioners to lying on the floor and mirroring the vocalisations of their partner. This apprehension can be alleviated when there is

understanding of the principles of II and a whole team approach. The lengthy pauses sometimes involved when using contingent responding whereby the learner spends time processing actions before they are ready to re-join the interaction may feel uncomfortable for the practitioner. The natural tendency is to fill these spaces (Nind & Hewett, 1998). This caused me to wonder how my participants might experience and negotiate these potentially uncomfortable moments and feel about mirroring body position with their children.

This style of interacting, mirroring body position and perhaps lying on the floor can lead not only to feelings of awkwardness, for practitioners supporting older children or adults, this style of interaction can also mean concerns over issues such as age appropriateness and touch. As can be seen from the quote above, Nind and Hewett (1988) touched on this in their seminal work and these concerns are raised by practitioners in the literature (see 2.4.3.3 page 56 for further explanation). This is addressed in the II handbooks. Barnes (2022) details the importance of touch and how getting to know your partner well, using II's principles of learner-led activity and pausing gives the child/adult time to process. This then allows them to indicate consent or not, perhaps by offering their hand or indeed withdrawing it. For parents touch may be less of a concern, but age appropriateness may still worry parents, particularly around the perceptions of wider society. This was something I was keen to explore in my research.

Early style interactions support the development of social communication skills. These are the taken for granted complex skills most children develop without appearing to actively try (Firth, 2012). The skills encompass: using eye contact, understanding physical contact, sharing personal space, enjoying being with another person, attending to another with increasing concentration span, using non-verbal communication and taking turns in exchanges of behaviour. It is proposed that these skills all lead to joint attention; the shared focus of more than one person on an object (Smith, 2022). This is held to be a key requirement for learning. Firth (2012) describes these core skills as the 'Fundamentals of Communication', the underpinning skills that come before language or symbolic language acquisition. II purports to enable the learning of these core skills and thereby aid the acquisition of joint attention; a skill deemed necessary for further learning opportunities.

For some learners, these complex techniques take longer to learn, requiring repeated exchanges over a longer period than most developing children. An infant who has learning difficulties and/or is autistic may be less aware of and therefore have a reduced responsiveness to a caregiver's overtures, thereby disrupting the communicative process. Revisiting this interaction style as the child grows provides the learner with a prolonged exposure to these exchanges as they continue to develop and more opportunities to grasp these complex techniques (Smith, 2022). It does mean though that parents can find themselves revisiting ways of interacting that they associate with younger children and which they did not previously experience as successful. I was keen to discover how my participants responded to this.

Summary

In summary II is a social communication method based on early developmental infant/caregiver techniques. It encompasses aspects of person-centred therapy and supports the learner in the zone of proximal development. It aims to build a reciprocal social interaction that is learner-led through tuning into behaviours the learner finds meaningful to create a 'mutually enjoyable' experience. For learners who developmentally are at a pre-language stage, II is a way to connect using methods that are understandable, and, accessible for them. Interactions utilising II techniques support the learning of early pre-language communication skills. These key techniques are something all II practitioners are using, and the literature addresses the positives and negatives of them for education and adult social care staff. Very little is known about whether parents' experiences are similar or different to other practitioners and the impact of these experiences on their use and perceptions of II. My research aims to add to this body of knowledge.

2.3 Intensive Interaction and emotional wellbeing

As I have already identified the underpinning theory for II is varied but embodies common elements of parent-child interactions based on responsiveness and mutual understanding. These elements are the 'teaching and learning' aspects

of II, but II purports to have a two-fold benefit, also supporting emotional wellbeing (Hewett, 2012). The theoretical landscape has changed since the seminal work in II, with proponents such as Weare's (2004) work on emotional literacy leading to changes in the education curriculum to include a focus on the social and emotional aspects of learning. This has led to a change in emphasis for II literature to include discussions on II and emotional wellbeing.

This section focusses on II and its links to emotional wellbeing, the relevance of this to my research and why this is of importance in the wider current education policy and adult services sectors. There is little direct literature written about the links between II and emotional wellbeing, rather it is written about indirectly and can be inferred from the research. I have drawn on the current topics in policy and explored how II fits within this current context, to highlight where II fits within this evolving situation.

Emotional wellbeing and mental health are closely linked but are two distinct concepts, however, the terms are often used inter-relatedly. Nind (2012) defines emotional wellbeing as the ability to have positive thoughts and feelings, and the ability to be 'resilient' in the face of difficult or stressful situations, managing feelings effectively. Emotional wellbeing is supported through the building of rapport with others and having a sense of belonging and trust; connections with others supports this. Not only is emotional wellbeing important in the present, but also for longer term development (Nind, 2012). Mental health affects how we think and behave, it impacts on the ability to function effectively. Having good mental health supports the management of stress, reaching your potential and making and maintaining healthy relationships (Mind 2023). Poor mental health can impact upon a person's emotional wellbeing and vice versa. Someone with poor emotional wellbeing who is finding it difficult to express their emotions and manage their levels of stress may experience reduced mental health through anxiety or depression (Department for Education (DfE), 2018).

70-80% of autistic children and adults are likely to have mental health difficulties (Crane et al., 2019), so thinking about effective strategies to support emotional wellbeing and promote good mental health in this population is key. This is particularly important for the non-speaking autistic population with whom traditional approaches (talking therapies) may not be appropriate.

The emotional wellbeing of learning-disabled people has historically been dominated by behavioural approaches. Moss et al. (2000) state that emotional wellbeing is closely linked to quality of life, involving having a sense of agency and control over choices whilst being treated with respect and dignity. Traditionally these have been left unsupported, or often harmed, through behaviour management techniques.

Education policy (Department for Education, 2020) places great emphasis on mental wellbeing and the importance of this in enabling learning to take place. This is now a statutory part of the curriculum across primary and secondary schools. DfE (2018) states that autistic children are ‘significantly more likely’ to have mental health difficulties such as anxiety. The guidance states two of the protective factors for mental health problems are a sense of belonging and secure attachment experiences. Working with parents and carers in partnership is also seen as key, therefore strategies used to support mental wellbeing in schools should also be used in the home, this ensures the best chance of success of any interventions used.

Another key piece of practice across both child and adult sectors is the Trauma Informed approach. This has become increasingly popular in its use across education, health, and social care. The premise behind a trauma informed approach is to reduce the impact of traumatic experiences on mental and physical health and in an education context, educational outcomes, and mental health (Boylan et al., 2023). The approach recognises the lasting impact trauma can have on a person’s ability to feel safe and build trusting relationships with services or education staff supporting them. There are six key principles of trauma informed practice: safety, trust, choice, collaboration, empowerment, and cultural consideration (Office for Health Improvement and Disparities, 2022). This is linked to The Adverse Childhood Experiences (ACE) study (Felitti et al., 1998) a major piece of research that related childhood experiences to adult medical and public health issues decades later. The study showed that ACEs had long term associations with adult health risk behaviours, and that prevention of ACEs was required along with support to prevent adults engaging in health risk behaviours. A trauma informed approach is person-centred with a central focus on relationships, looking to a person’s strengths. It should be fully

inclusive for all, embracing diversity and cultural differences (Public Health Wales NHS Trust, 2022).

Trauma informed approaches are practised widely across education settings, with training and awareness provided as part of the teaching training curriculum at universities such as Sheffield Hallam University. Trauma Informed Schools UK (2022) advocate schools to become trauma informed and mentally healthy places whereby they support potential mental health issues before they appear rather than waiting until a child is in a crisis situation. Building relationships and trust with pupils is key to this work. Providing consistency, predictability and recognising behaviour as a means of communication are essential to a trauma informed approach.

Therefore, good mental health is reliant on having opportunities to build secure attachments and relationships in a predictable and consistent environment. There are limited approaches that are sensitive to the emotional needs of learners who are non-speaking, however, II is one such approach (Nind, 2012).

As we can see mental health and emotional wellbeing are key in current education policy, and across the adult sector, so I now turn to consider how II supports them. If we look back to the infant-caregiver development literature, the importance of mutually pleasant exchanges as a vehicle for fostering continuing engagement is discussed. This happens through frequent interactive exchanges where the caregiver responds to the emotional cues of the infant and builds and extends the interaction (Garvey & Fogel, 2007). Mutually pleasurable exchanges are an underpinning principle of II alongside the building of repetitive exchanges and games. Emotions are described alongside these exchanges with practitioners perceiving the learner as experiencing feelings of happiness, smiling and joy (Firth et al., 2008; Zeedyk et al., 2009). Managing and recognising our emotions are important for emotional wellbeing. Experiencing positive thoughts and feelings supports this recognition of emotions are therefore in turn promotes emotional wellbeing. Therefore, activities that promote these feelings and encourage them are important. Contingent responding is a crucial part of II and infant-caregiver interaction. Zeedyk (2006) describes the role of imitation or mirroring in contingent responding and how this supports emotional intimacy within an interaction.

These close face to face exchanges that are seen in infant-caregiver and II exchanges help build the flow of dyadic exchanges. The social interactions support the infants or learner experiencing themselves as ‘other’ and ‘self’ through being the object of attention; it helps develop self-awareness and emotional awareness (Zeedyk, 2006).

In typical infant development Bruner (1983) describes how the infant shows a sensitivity to the vocalisations of the caregiver by matching the level of arousal (emotions) via turn taking. When arousal levels are high, the infant matches these vocalisations, exhibiting emotions such as excitement and pleasure. Equally these arousal levels can be lowered by the caregiver reducing the intensity of the vocalisations. Bruner gives examples of infants turning their heads away from the caregiver if their reactions are sombre and closed faced. This learning about emotions can be translated to II practice. In II the practitioner has an open and ready face, often using exaggerated facial expressions to gain and maintain the attention of the learner. The practitioner matches arousal levels and supports the learner in co-regulating if they become too excited and over stimulated (Zeedyk et al., 2009).

Developing meaningful relationships and having a sense of trust and security is essential to emotional wellbeing including in the learning-disabled population (Harris, 1994). II is a way of achieving this for an often-underserved population in wellbeing strategies. II affords the learner and partner to take part in mutually pleasurable exchanges which nurture a sense of wellbeing through their emotionally contingent responding. Indeed, II fosters relationship building and a sense of belonging through the experience of being heard and valued. It is sensitive to the emotional needs of the learner as the practitioner tunes into them, responding at a pace and tempo to suit them, supporting co-regulation of emotions with pauses and waiting, taking cues from the learner as to when to engage (Firth et al., 2008).

Summary

This section explored how social interaction is important in promoting good mental health and wellbeing and how this is key in current educational policy and within the adult sector. II is one way of promoting emotional wellbeing and

therefore supporting good mental health. This is for all children, so, for children at the earlier stages of communication development it is important that there are strategies available that do not exclude them. Success of such interventions are more likely if they are used across home and school with parents/carers working alongside professionals. When mental health services such as CAMHS or the MAST teams are supporting children, they work with both the educational placement and home to ensure a cohesive approach. Thus, the parent's experience of using strategies such as II is bound up with the school's use of it also. It is important then to explore parental experiences of implementing a communication strategy aimed at not just enhancing communication but also supporting emotional wellbeing and relationship development. Exploring the differences II use made to participants' relationships with their children and their perceptions of whether its use impacted on emotional wellbeing (both theirs and their child's) was key to my research aims.

2.4 Evolution of II through research

In this section I identify the areas of particular interest that through my review of the research informed the development of my research questions. Thinking about the experiential aspects documented for professionals utilising II within children's and adult services, I argue the need for consideration of parental aspects of practice to be equally explored alongside other key stakeholders. The navigation through the literature shows the evolution of II and the direction the research is taking. I start by discussing the early efficacy studies and challenges the researchers found before moving onto more qualitative experiential studies which considered the multiple benefits to both parties involved in an interaction. I then consider the implementation and sustainability challenges of using II with the education sector and adult services. To conclude I track the evolvement of parents' inclusion in the literature, with a recognition of an increased interest in all stakeholder's experiences becoming valued.

2.4.1 Efficacy of Intensive Interaction.

The earlier studies in II tended to look at the efficacy of the strategy and the differences it made to predetermined social engagement measures such as increased eye contact, physical contact, body positioning, and vocalisations. These early studies set the scene for II, promoting its use as an intervention that increased social engagement in the learning-disabled population. The studies ranged from single case studies to small-scale (six to ten participants) quantitative studies. Some studies determined whether II produced increases in social engagement measures over a shorter time frame of a single session (Zeedyk et al., 2009), others used a longitudinal design to study II over longer time frames such as a school year (Barber, 2008; Kellett, 2000; Watson & Knight, 1997). These differences in study design highlight some important considerations that were relevant for my thesis.

One consideration when discussing these studies is the normative benchmarks used to decide on whether the intervention produced increases in social engagement or not. The social engagement scales used did not reflect on the differences in some areas such as eye contact/physical contact that autistic children and adults may find difficult due to sensory processing differences. The studies also did not consider differences between their pupils/adults who have learning difficulties or are autistic and how this may have impacted upon their results. II does not need to be driven by these normalising tendencies, other ways of establishing the merit of II could be used through more qualitative approaches.

Shorter time frame studies illustrated rapid increases in social engagement measures such as eye gaze and body posture (Zeedyk et al., 2009) after just one II session. This study was carried out with adults with PMLD and highlights the quick improvements in engagement that can be achieved using a reciprocal interaction method such as II. However, a downside to shorter studies is that they fail to evidence what happens during longer term use of an intervention. A key benefit of a longitudinal study for this population is the ability to track small increases in social engagement measures over time, giving a more holistic picture of how II impacts on the learner and whether any changes in social interaction are maintained.

For this group of learners' small steps over prolonged periods of time with many opportunities for repeated practice are the way learning takes place (Smith, 2022). This is highlighted in Kellet's (2000) study of Sam which took place over a whole academic year. Initial surges in engagement measures were seen along with plateauing and then further increases in other measures such as eye and physical contact throughout the course of the year. Concurring with Zeedyk et al. (2009), Kellett's study saw the same initial surges in social engagement measures but if the study had stopped there the longer-term plateauing and then further increases would have been missed. These are key aspects of understanding the longer-term use of II and potentially how these could impact on the practitioner. However, this study was quantitative and did not explore the impact of this on school staff. The initial rapid surges seen in Kellett's (2000) study were attributed to several reasons, enthusiasm from staff initially post training as well as the response of the child to recognising the behaviours offered within the session. Another key aspect of this study was the regression which occurred over the school holidays. The author suggested this was due to no II sessions taking place during this time and highlighted the difference extending II into the home could make. This article draws attention to the gap in II practice for this child and the difference a more holistic approach extending across settings could make.

A few of the primarily efficacy-based studies have sought to address some experiential aspects of the practitioners' experiences. Barber (2008) and Watson and Knight (1991) both sought school staff views on how they experienced the II sessions. Barber used the videos recorded for data collection purposes in reflective feedback sessions with the staff. A key finding of this study was not only increased social engagement measures for the learner but a change in how staff understood behaviour, viewing it as communication and extending their knowledge of the range of behaviours that could be responded to (Barber, 2008). This is a significant conclusion of this research; it extended the staffs' knowledge of social communication and behaviour enabling a change in practice that expanded their teaching to be more responsive communication partners.

Watson and Knight (1991) interviewed staff after the school year data collection period. Staff reported positive benefits in practising II with supporting

relationship building with their pupils. Staff felt these benefits extended beyond their sessions promoting increased knowledge and confidence when working with pupils. This enabled further awareness of behaviour cues allowing for a continuation of interactions throughout the school day. The staff not only felt more confident in their work but felt justified in their interaction work which was a move away from the usual curriculum (Watson & Knight, 1991). Both studies illuminate findings that are further explored in the experiential II literature discussed in detail in (2.4.3). These findings of increased knowledge and confidence of practitioners are important in enabling a change in practice of practitioners that extended beyond the initial remit of the II sessions. What is not known is whether these same changes occur in parents engaging in II and what the impact of this may be. It was therefore important for me to explore this with the mothers in my research.

Summary

Efficacy studies not only showed increases in social engagement scores but also provide insights into II use over the longer term. The regression of skills when gaps in practice are experienced by the learner over school holidays supports the requirement for a more holistic approach to II use, involving all care partners including parents. The rapid surges of progress with potential plateauing are key elements that are worthy of further exploration. Insight into how practitioners' experience these changes and the impact they have upon the use of II longer term is important to establish. As parents are potentially supporting their children with social communication strategies for years, it is important that my research explored whether and how the mothers in my study experienced surges and plateauing as described above and how this impacted upon that experience.

2.4.2 Perceived impact of II for the learner

As the II literature evolved there was a move away from efficacy-based studies towards qualitative experiential research looking at impact upon both the learner and practitioner.

The experience for the learner is an important consideration, it moves discussions away from a potentially medical model narrative of measuring increases in normative benchmarks such as eye contact. Moreover, examining the learner's experiences aims to study the impact of the strategy for them. This focus aligns with the philosophical underpinnings of II, recognising the person's strengths and the behaviours that they find meaningful and mirroring those to value and listen to the person. However, II is predominately used with a non-speaking autistic and learning-disabled population, who are marginalised and underrepresented within the social communication literature (McKinney et al., 2021). The II literature relies on the observations and opinions of the practitioners working with the children/adults to illuminate the perceived impact on them (Kellett, 2003; Leaning & Watson, 2006; Zeedyk et al., 2009). These perceived experiences in turn influence the practitioner's views of II particularly around issues such as sustainability (Berry et al., 2014; Leaning & Watson, 2006).

As discussed earlier in this chapter II has links with emotional wellbeing. The terminology used to describe the impact on the leaner (as perceived by the practitioner) could be argued as coming under a broad umbrella of attributes considered to indicate increases in wellbeing. However, the studies do not always describe the impact in such terms, rather documenting decreases in self-injurious behaviour, enhanced relationships or increases in happiness, smiling and laughing.

Nonetheless, some studies do directly equate the impact on the learner with increases in wellbeing. Rayner et al. (2016) highlight how II can enable the practice of enhanced person-centred care and through this improve wellbeing and quality of life for the clients. Weedle's (2016) systematic review describes several studies as demonstrating increased wellbeing. The author evidenced this through anecdotal testimony from practitioners such as perceived benefits for the learners of increased pleasure, smiling, and happiness. Weedle argues these results could all indicate enhanced wellbeing, even though the studies themselves do not describe their findings in these terms. Wellbeing is hard to quantify as it can be very subjective and these studies relied on second hand accounts, therefore it is easier to relate impact to more quantifiable measures such as a decrease in self-injurious behaviour or smiling.

Zeedyk et al's. (2009) study looked at the perceptions of the volunteers on changes in behaviour of a group of Romanian orphaned children and changes in themselves. Zeedyk's premise is that for an interaction to be 'mutually communicative', which II purports to be, both partners benefit and are changed. The perceived effects on the learner were increased attention to partner, laughing and smiling, physical proximity, coming over for a hug or hand holding (Zeedyk et al., 2009). These behavioural changes are all indicative of an increase in social engagement but also an increase in emotional wellbeing. However, the study did not label them as such. It was noted as a decrease in distress or self-harm during the II sessions rather than an increase in wellbeing. Similarly, Kellet's (2003) whole school year study of Jacob engaging with II documented school staffs' perceptions of Jacob as seeming happier and more willing to engage in group activities. Moreover, Firth et al. (2008) examined the apparent increases in pleasure experienced by people with intellectual disability in a care home setting, which in turn gave staff feelings of pleasure during the interaction. These accounts indicate increases in perceived happiness of the learners which are all indicative of positive benefits to wellbeing.

In the case study of Anna (Elgie & Maguire, 2001), II was used over a five-month period with Anna who had learning disabilities and visual impairment. Evaluation outcomes included increases in vocalisations and hand holding. Throughout the sessions Anna reached out to hold the practitioner's hands, a behaviour which she had not previously exhibited. The meaning attached to this by the practitioners was development of an emotional bond between Anna and themselves; they felt this indicated a relationship development. The limitations of this study were acknowledged to be in its use of only two measures of success and the short intervention period. However, staff training was initiated after the study period with the view to II being continued for Anna. This study highlights some initial benefits to emotional wellbeing and relationship building but also the need for long-term instigation of strategies such as II. Ethical issues surrounding introduction of a perceived beneficial technique such as II and then not necessarily continuing with it over the longer-term are highlighted in this study. Caldwell (2006) discusses the importance of maintaining II over the long term; once the practitioner has learnt to interact with the learner, progress will be observed, however, stop II and progress will regress. She equates this with

‘learning to speak their language’ (p.131); stopping II means you no longer speak their language, so, they cannot understand you and you do not understand them.

Another impact on the learner debated in the literature was decreases in self-injurious behaviour, with some studies suggesting II did indeed result in decreases in this style of behaviour (Kellet, 2003; McKim & Samuel, 2021) whilst others contest this claim, stating II had little impact on self-injurious behaviour (Elgie & Maguire, 2001). McKim and Samuel (2021) trained care staff in an adult social care setting to use II with the intention of deepening staff’s understanding of preverbal communication. This supported them with increasing rapport with clients which in turn strengthened relationships and enhanced wellbeing, resulting in a decrease in distress and self-injurious behaviour in their study.

Kellet’s (2003) yearlong study of Jacob documented how previously he had spent lots of his day engaged in self-stimulatory behaviour or, when distressed, self-injurious behaviour. The self-injurious behaviour stopped over the course of the year and staff felt Jacob’s behaviour changes extended beyond the II sessions into other areas of school life, with Jacob more willing to take part in group activities. What is not clear from the study is whether there were other influencing factors which could account for the decreases in self-injurious behaviour.

However, not all studies report reductions in self-injurious behaviour. Elgie and Maguire (2001) did not find a reduction in the self-injurious behaviour of Anna. II made no difference to this even though it did produce positive effects in other areas. They concluded that for reduction in long-term ingrained behaviour, II would need to be continued for a longer period as they would expect slow progress in reducing self-injurious behaviour of this nature. Therefore, a longitudinal approach to II use was advocated to establish if it impacted upon any self-injurious behaviour exhibited. This highlights how for this group of learners’ benefits may be slow to emerge. A continuation of II over the longer-term with perseveration when sessions plateau or regress is important.

Hutchinson and Bodicoat (2015) concluded in their systematic review that evidence for II being effective in reducing self-injurious behaviour is limited and

that further research is needed to explore this. Similarly, Sharma and Firth (2012) concur with this, their paper evaluated several research articles that purport to demonstrate II reduces incidences of unwanted behaviours. They conclude that II is still not widely used with that premise in mind, rather it is cited as being implemented to increase social engagement in learners. They attribute this to a lack of robust evidence of II's effectiveness at reducing self-injurious behaviour. Interestingly, the studies which showed decreases in self-injurious and unwanted behaviour were longitudinal studies that tracked these behaviours over time (Kellet 2003), as opposed to shorter time frame studies (Elgie & Maguire, 2001). This highlights the small steps of progress over a long-time frame that are required for changes in behaviour in the long term for this group. Rather than the effectiveness of this being down to a lack of robust evidence it could be more attributed to the type of study (shorter term) and lack of understanding of the importance of long-term intervention use for this population. Additional longitudinal studies such as Kellet's (2003) charting II over the course of a year or longer would enable a greater understanding of the longer-term benefits of using II to support distress and self-injurious behaviour. Parents are in a unique position for this; they do not come and go in the same way as school or care workers and can easily track their child's behaviour over a longer period.

Summary

II literature has moved away from efficacy studies towards more experiential aspects focusing on the learner. Increases in smiling, relationship development and reduction in distress and self-injurious behaviour are evidenced as impacts on the learner. These are described as such in the research: even though clearly linked to increases in wellbeing, they are often not reported as such. Perhaps the II literature needs to be bolder in its links of perceived impact on the learner to improvements in emotional wellbeing. With the current policy focus on mental health and wellbeing this is an under researched area. Stronger links in peer reviewed papers could move II further into the mainstream and encourage policy makers to advocate for II use for not just teaching and learning purposes but also to support relationship building and enhanced wellbeing across this population.

2.4.3 Experience of II for the practitioner including factors affecting sustainability

The focus of this thesis is on mother's experiences of using II. They are the more experienced communication partner in this context, assuming the role of practitioner. However, much of the research exploring experiential aspects of using II for practitioners focuses on support staff, teachers, and social care staff, with minimal studies discussing parents in this role. It was important for my research to evaluate the literature discussing practitioner experiences to gain a deeper understanding of the positive and negative aspects of those experiences and how issues pertaining to use, and sustainability affected the practitioners. I presupposed that this would highlight commonalities and possibly differences to consider that may pertain in experiential aspects for the mothers in my study.

I start by discussing the literature documenting relationship development and the feelings this empowered in practitioners including the impact this had on II implementation. Moving on I discuss practitioner's opinions of II when first using it and how these opinions combined with positive experiential aspects of increased connectedness can lead to attitudinal change. Training is discussed widely in the literature and its bearing on sustainability alongside areas such as leadership and organisational practices, considering these areas is important as parents also receive support and training potentially in using II and parallels can be drawn from the experiences of practitioners. Within this section I also examine the debated issues of age appropriateness and touch in II use and argue that normative benchmarks perceived by wider society influence practitioner's opinions on this.

2.4.3.1 Increased connectedness leading to attitudinal change

Enhanced relationships and increased connectedness as perceived by the practitioner are well documented within the literature (Firth et al., 2008; Nagra et al., 2016; Rayner et al., 2016; Zeedyk et al., 2009). In Nagra et al. (2016) paid carers who worked in a residential care home for people with learning difficulties

reported feelings of improvements in their relationships with the clients they supported. The authors attributed this to increases in self-confidence when supporting clients brought about by II facilitating a better understanding of behaviour and communication. This led to feelings of empowerment amongst the care staff. The staff felt that through using II they had come to know their clients better and this in turn led to feelings of increased connectedness with them.

Zeedyk et al's. (2009) study concurs with this: their study of volunteers using II with Romanian orphaned children reported participant feelings of increased connectedness with the children whom they supported. This empowered the volunteers to continue using II; the authors directly link the connectedness with the children as motivation for II's sustained use. Similarly, Firth et al. (2008) found increased motivation and confidence in staff to continue using II after positive interactions. Feelings of pleasure and reward after successful interactions fostered a sense of commitment and motivated staff to continue using II. Small positive interactions with some clients who were deemed less responsive and harder to engage, encouraged staff to spend more time with them using II to build relationships. Conversely, negative interactions with clients meant staff abandoned further attempts at II. Attitudes to II were directly affected by the feedback that they received from their interaction overtures to their clients (Firth et al., 2008).

Practitioner's preconceptions and existing attitudes towards behaviour and communication can influence their approach to engagement with newly introduced strategies such as II. Zeedyk et al. (2009) found in their study feelings of scepticism surrounding II's perceived simplicity. The volunteers expressed initial feelings of doubt that a technique that seemed 'simple' could work with the children they were being asked to support. Several volunteers described changing their opinions of II after starting using it and experiencing the difference it made to their interactions. Similarly, Firth et al. (2008) report the differing levels in care staffs' attitude to II in their paper. This included staff feeling they did not require training because II was nothing new and something they were doing anyway. Other staff stated that II wasn't needed because they knew their clients well having worked with them for long periods of time, nevertheless, they were then surprised at how their clients reacted positively to

the researchers using II with them, exhibiting interactions not previously observed. Long-term knowledge of clients was potentially highlighted as a barrier to II use. However, the mangers interviewed in the study indicated that increased client knowledge and changing perceptions due to clients exhibiting different behaviours was a positive outcome of II use. In both studies the initial reservations and preconceived ideas did not stop practitioners from starting to use II (Firth et al., 2008; Zeedyk et al., 2009). Consequently, for some their opinions changed, for others it negatively affected the quality of their interactions, and their opinions remained the same.

Conversely, feelings of validation post II training are also discussed in the literature, Nind and Thomas (2005) state teachers in their study reported feelings of validation that their instinctive interactions had been correct, with II training providing legitimisation of techniques already being used. These feelings of scepticism or II being nothing new or conversely validation that practitioners were on the right track are worthy of further exploration. I wanted to establish whether the mothers in my study negotiated any of these feelings when first introduced to II.

These changes in relationships and increased understanding of communication can be argued to produce an attitudinal change in the practitioners which lasts beyond training and any 'initiative decay'. Firth et al. (2008) characterise 'initiative decay' as the process of changes in practice being abandoned once the novelty of training wears off. Nagra et al. (2016) described the lasting changes in the attitudes of their participants, illustrated by them describing positive interactions with their clients three years on from the training. The authors assert that this is indicative of the skills of II remaining even though the participants struggled to recount key principles and requested refresher training. Zeedyk et al. (2009) similarly described the lasting difference II made to how their volunteers experienced interactions with the children they supported. This increased motivation to continue II use and build relationships with the orphaned children remained even when the volunteers struggled to recall the initial training they had received. Firth et al.'s (2008) study concurs with this: post II training the care staff illustrated a change in attitude towards more client led activities with a deepening understanding of behaviour and communicative intent.

Enhanced relationships and feelings of connectedness are positively experienced by practitioners and can lead to shifts in attitude that endure, seemingly for the long term. However, other external pressures and organisational issues can negatively impact upon this. Training, leadership, and organisational ethos are addressed in the literature, with Nagra et al. (2016) indicating that these more practical pressures can outweigh the personal attitude changes. These are discussed in the next section.

2.4.3.2 Training and sustainability

Training is widely discussed within the II research base. Most training advocates elements of videoing, reflective feedback, and opportunities for discussion (Barber, 2008; Firth et al., 2008; Rayner et al., 2014). The length and formality vary across the literature with short informal courses offering a quick and cheaper introduction to the techniques of II. This style of training risks a weaker understanding of the underpinning principles, which in the longer-term could impact upon sustainability (Zeedyk et al., 2009). Longer more formal courses with elements of supportive practice afford a deeper understanding of II's underpinning principles with opportunities to engage in reflexive practice (Barber, 2008; Firth et al., 2008; Rayner et al., 2014). However, longer training courses have time and cost pressures for organisations.

For genuine understanding and long-term sustainability of an approach a more theoretical approach to training is advocated (Nind, 2000) with regular refresher courses to mitigate against 'initiative decay' (Firth et al., 2008; Nagra et al., 2016). Nonetheless, Zeedyk et al. (2009) state that even a short introduction session to II is enough to illicit a change in perception and attitude of those undergoing it. However, without the more theoretical underpinnings or refreshers the key principles of II are diluted over time, with both Zeedyk et al. (2009) and Nagra et al. (2016) noting their participants failed to recall them six months and three years respectively post training. Both studies nonetheless commented on the changes in attitude of their participants towards a more person-centred approach with a deeper understanding of communication and behaviour that endured post training even when they failed to recall specifics of

the approach. This is key in the practitioners' experiences, the enduring culture change in practitioners despite differences in training. How parents are affected by any training they receive is important to establish. We know from the research how this impacted on practitioners, whether parents experience these same shifts in attitude and understanding of communication is worthy of further exploration and something I was keen to explore in my participants' narratives.

Leadership is another factor that impacts upon attitude and ethos change. Firth et al. (2008) argue sustainable long-term practice change requires direction and visible support from a leadership level. Culham (2004) concurs with this, finding increased support from a leadership level directly affected the motivation and continued use of II within a setting. Both these papers found that a lack of leadership investment in II directly impacted staffs' continued motivation to use II. When managerial staff were observed to be invested in II use in the setting through involvement in training or policy changes, sustainability issues decreased, and staff felt supported to continue using II.

Reflective practice is also discussed as an important part of practitioner learning and experience. Barber (2007) describes the peer review meetings his staff engaged in to provide ongoing reflective practice of their II sessions. These sessions provided opportunities for staff to come together and discuss II, with other like-minded staff. This encouraged dialogue on technique and progress which in turn helped to maintain the core principles of II and avoiding technique degradation. Collaboration with colleagues in reflective practice is advocated by Nind and Powell (2000), it is important for ensuring interactions do not become stale and enables practitioners to share good practice. Culham's (2004) paper on male practitioners' views on II similarly reported benefits felt by practitioners when they experienced a shared understanding amongst colleagues. This shared understanding can support long-term practice change particularly if supported by leadership staff.

Another dimension to this is monitoring and recording which is advocated as important throughout the literature. Elgie and Maguire (2001) state that without a record of the sessions it can be hard to see progress; particularly across the long time period required for some learners to show progress. This can be especially pertinent with staff changes occurring in adult social care work and

movement between school years in children. Leaning and Watson (2006) concur with this; long term benefits can only be realised over a longer time frame with sustained use. Sustainability could be detrimentally affected through a perceived lack of progress by the learner. If these areas of recording, monitoring and reflective practice are advocated within the literature, it is pertinent to my research to consider whether parents are being supported to use these. Whether these practices translate into the home use of a social communication interventions was interesting to consider as was the impact on sustainability if they were not employed.

2.4.3.3 Age appropriateness and touch

Within the literature practitioners' experienced concerns with II use; these centred around age appropriateness and touch. Age appropriateness is a debated topic in social care and education fields when working with learning disabled children and adults. The need to maintain the dignity and respect of the person you are supporting goes alongside communicating in an accessible way with them. This can pose challenges for professionals supporting children and adults when first introduced to II. Culham (2004); Elgie & Maguire (2001) and Firth et al. (2008) all documented staff concerns overusing II's basic techniques of mirroring vocalisations and simple games. Staff were left feeling worried that they were treating the adults like children. However, it is important to remember that people working at the earlier stages of communication development may also have a learning difficulty and the activities they enjoy and find meaningful may be those typically associated with younger children. Wider societies perceptions of what is appropriate or not using a normative benchmark for activities has a bearing on practitioners' feelings about age appropriateness. Practitioner's voiced concerns over using II techniques in public spaces (Firth et al., 2008).

Culham's (2004) study of male practitioners looked at both the adult sector and special education settings. Across both sectors male staff reported concerns over touch particularly when working with female clients and children. The author put some of the concerns surrounding this down to gendered roles within society and suggested male practitioners needed further support to be able to discuss concerns over these issues. Opportunities for an ongoing dialogue

about concerns such as these are key to not only alleviating anxieties (Firth et al., 2008) but also raising awareness of and normalising interactions of this nature both inside and outside of organisations.

Summary

It is evident from the literature discussed above that even short introductions to II can bring about differences in attitudes to the way practitioners work and support autistic and people with learning disabilities. However, practical difficulties around time pressures to complete care tasks, leadership and organisational ethos can counterbalance this. Worries around age appropriateness, and how interactions are perceived by other staff or wider society can all detract from personal changes in ethos. Refresher courses or ongoing reflective practice can support a continuing dialogue to address concerns such as these and raise the profile of II use within an organisation leading to long term wider organisational and practice change. Plateauing is discussed in the literature but only in relation to efficacy and the need for longer term II use to move past this. The impact it has on the experiences of the practitioners is not addressed; exploring how this effects the attitudinal changes and motivation over a longer term is important as this could be another factor affecting sustainability.

The sections above highlight the experiential aspects of enhanced connectedness and barriers to sustainability of II, but these are the perspectives of professionals working in education and adult social care sectors, not parents. However, it was interesting to see what parallels could be drawn from this with the mothers in my study, many of whom received training in using II and were supported by a professional in implementing it in the home. The reported literature in this section discusses II as an intervention which requires monitoring and feedback for sustainability, even though there is evidence of the attitudinal shift it can create in practitioners. Parents are supporting their children over many years, so ideally placed to explore long term sustainability issues and shifts in attitude.

2.4.4 The parents voice in Intensive Interaction

The parental voice in the peer reviewed II literature is minimal but evolving. Practitioners' views represented in the literature are teachers, support staff, social care staff and psychologists with parents largely absent. However, a few papers do mention parents usually in relation to how including parents and families would extend their research (Kellett, 2000; Weedle et al.,2016). This section discusses the studies where parents are included and the relevance of this to my thesis before moving to consider where parents are included in the grey literature on II.

Two papers include some findings from family members even though they were not the main participants in the study. Kellett's (2005) paper is about Catherine, a young person with a life limiting condition who was part of a wider study looking at the efficacy of II with children with learning disabilities. Catherine passed away before the end of the study and her story was written up some time later. The researchers included Catherine's parents in their training, and they started to use II in the home. After Catherine's death her parents wrote to the research team to say what a difference using II had made to them as a family and for them, they felt that the last few months before Cathrine's death had been some of the happiest, they had known with her. This illustrated how a research team including parents in the training even though this was not the focus of the study can make real world differences to a family. This benefitted not only Catherine and her family but also the research team who otherwise would have missed the opportunity to see the difference II made when used across two settings.

The case studies of McKim and Samuel (2021) focused on II use with adults in social care settings. The main participants of this study were the care staff in the settings. However, it also included minimal findings in the form of a quote from a family member that expressed the difference using II had made to them as a family and to their relationship with their sister. Even though the paper does not explicitly state it, the family members were obviously also included in the II training the staff received; this can be inferred from the content of the quote although no further context or information is given. This was a missed

opportunity by the researchers to consider the wider implications of their research on families.

Parents are much better represented in grey literature, with book chapters such as Harrison (2012), a parent's account of using II with her son and tips for other parents starting to use II. This chapter is written for parents by a parent, which can be especially powerful for parents. It challenges the dominant narratives and power relationships of professionals and parents, disrupting the hegemonic discourse of a hierarchy of knowledge (Hodge & Runswick-Cole, 2008).

The article by Berridge and Hutchinson (2022) focusses on mothers' experiences of Intensive Interaction with their learning-disabled children. The research used IPA to explore six mothers' experiences. An inclusion criterion for this research was that the mothers must have had some training in II or observed a professional using it with their child. The mothers in this study differed in how II use impacted upon their relationships, ranging from mothers who felt II was something they had always used, to II use having had a significant impact upon their relationship with their child incorporating feelings of sadness at lost time (Berridge & Hutchinson, 2022). This study highlighted the difficulties parents have in finding appropriate support and interventions for their children, often battling against low expectations and limited information (Berridge & Hutchinson, 2022). It is the first II study to look in detail at parents' experiences of II and my thesis will add to this developing body of literature by adding original content of extending the age range of the 'child' included in parental II research and by contributing insight into the experiences of parents of autistic children.

Summary

The inclusion of parents' voices within the II literature base is minimal but evolving with the first full published study of mothers' experiences by Berridge and Hutchinson (2022). The studies including parents give an insight into the experiences of using II and the real-world differences it can make to families as Catherine's story illustrates. Berridge and Hutchinson (2022) study extends this through examining the experiences of mothers and the impacts on their

relationships with their children, highlighting the struggle to find appropriate support families of this population of children often go through.

Overall, the research base for II is still comparatively small; the experiential studies offer insights into the benefits for the learner including impact upon emotional wellbeing and social inclusion. Experiences for practitioners included attitudinal shift through an increased understanding of social communication. This seems to be a key aspect in longevity of use and experiencing relational change. However, barriers to sustainability at an organisational level can detract from this (Elgie & Maguire, 2001; Rayner et al., 2016).

The next section considers parents inclusion in social communication research more widely and positions this thesis within this wider context.

2.5 The positioning of parents within social communication and disability research

Here I reflect on how parents are represented within the social communication and disability landscape, looking at both autism specific and general learning disability research. As there is little research within the II literature base that studies the experience of parents, it is pertinent to explore the wider disability arena. Considering how parents of disabled children historically have been included in research sets the context for this section. I argue that the dominant narrative of parents requiring training to communicate with their disabled children means the research arena focusses on efficacy-based studies, the aim of which is to evidence how efficiently parents implement the interventions under study. Rarely are the experiential aspects on and for parents of implementing a communication intervention at home explored. However, the literature focused on professionals addresses the barriers and challenges to implementation. As parents are deemed ‘valuable resources’ considering how those same challenges impact upon them is important will provide critical information.

2.5.1 A brief history of mothering and autism

This section briefly explores the entangled history of mothering and autism. My research focuses on mothers' experiences of using II with their autistic children as opposed to parents generally, so it is useful to consider the backdrop to mothering and autism that pervades through historical legacy and the media. Historically mothers were blamed for their children's differences. Kanner (1943) first described autism as a separate entity from childhood schizophrenia detailing how the children he examined showed difficulties with communicating, reciprocal social interaction and displayed stereotyped behaviours such as rocking. He also observed the parents to be aloof and withdrawn from their children, noting the mothers were more often educated, cold and worked outside the home (Douglas, 2014). However, it was Bettelheim (1972) who was synonymous with the phrase 'Refrigerator mother' putting the blame for autism firmly on the mother. Bettelheim's work concluded that autism was the child's way of coping with a cold and rejecting mother. His answer to this was to treat both the child and the mother to ameliorate any symptoms of autism by teaching the mother how to interact with her child (Douglas, 2014).

Mothers pushed against these psychogenic theories of autism and strove to represent themselves through parent-led advocacy and present themselves as loving caregivers. Through this advocacy work they succeeded in getting early intervention programmes funded (Lo Bosco, 2021). As the understanding of child psychiatry burgeoned and resistance from mothers to the psychogenic theory of autism continued, biomedical understandings of autism started to emerge. This shifted the blame from mothers as the causative agents and instead cast them in the light as warrior mothers (Sousa, 2011). This biomedical discourse cast autism as something deficit and lacking in need of curing and mothers took on the role of finding the best educational and medical interventions no matter the emotional or financial cost to themselves. It is this battling that Sousa (2011) says cast mothers in the role of warrior and fed into the intensive mothering rhetoric of 'good mother', putting your child's needs above your own. Indeed, for those mothers who are not deemed to fit this stereotypical ideal they are cast from the realms of 'good mother' to 'bad mother' (Lo Bosco, 2021; Douglas, 2014). Today this is relentlessly portrayed in

the media and social media with the autism mother shown in endless pursuit of moving her autistic child towards normative benchmarks (Sousa, 2011).

Even though mothers are no longer held up as the causative agents of their child's autism they still face intense scrutiny over their mothering practices, more so than their counter parts without disabled children (Sousa, 2011). Part of this scrutiny is from the professionals supporting their families. Below I consider how historically parents, have been included in social communication interventions.

2.5.2 Historical perspective on parental involvement in social communication interventions

Historically parents of autistic children were not included in interventions with their children; psychogenic theories such as refrigerator mothers meant they were viewed as the foundation of their child's difficulties (Schopler & Reichler, 1971). Whilst parents of learning-disabled children were actively encouraged to be part of educational interventions, this same practice happened later for parents of autistic children. Schopler and Reichler (1971) in a USA based article, highlighted some interesting points about the inclusion of parents in intervention strategies from early parental literature. Despite the deficit-focused narrative and terminology regarding autistic children, this paper illustrated some forward thinking for that time. The authors' social interaction intervention programme was designed to be used with parents as co-therapists, including both the mother and father in the sessions. The staff assumed the roles of therapist but also parent consultants, meaning parents had someone with whom to discuss difficulties and other concerns about their autistic child. The authors commented that their staff were selected for their experience and enthusiasm in working with autistic children rather than their professional qualifications.

During the early sessions, the parents watched the therapist interacting with their child and had the opportunity to ask questions. The authors noted that this demystified the sessions, enabling a more equitable power balance. The parents could observe the sessions and see any difficulties or mistakes the therapist made, as opposed to relying on second hand accounts of the

sessions. The study then went a step further, teaching the parents to become ‘expert co-therapists’ who supported other parents to deliver the intervention programme (Schopler & Reichler, 1971).

The research examined the efficacy of the interaction programme for both the therapist and parent sessions, observing that over the same time frame parents became more effective at implementing the intervention than their child’s therapist. However, these parents (primarily mothers) still sought support from the staff to continue with the intervention. There is important learning to take from this: even though the mothers became the ‘expert’ as they implemented the intervention more effectively than the professionals, they still deferred to the professionals for guidance. I find this interesting as to why this might have been. At this time attitudes towards parents of autistic children were just starting to change, therefore involving parents in this way to implement an intervention in the home was relatively novel. Mothers were used to being viewed as causative agents in their child’s differences (Schopler & Reichler, 1971) and were used to deferring to the professional as the expert. Moreover, as parents implementing an intervention in the home you do not have the same external support that a staff team does as far as reflective practice and being able to discuss difficulties or ideas. Even though some of these attitudes have changed, some remain to this day, namely the professional being viewed as the primary expert (Hodge & Runswick-Cole, 2008).

Parents of disabled children generally tend to be the undervalued partner in parent- professional relationships, with the professional deemed the expert and a hierarchy of knowledge evident that promotes professional knowledge over that of parents (Hodge & Runswick-Cole, 2008). This is apparent in the literature base surrounding parents’ involvement in communication interventions for their disabled children. The dominant discourse is represented here as parents needing training to communicate with their children as evidenced in Schopler and Reichler (1971). Even though this paper illustrated a different approach to working with parents, its premise was to train parents to interact with their autistic children. Much of the research base looks at how efficient parents are at delivering interventions (Green et al., 2010; Shire et al., 2015). There is a paucity of literature that enquires into the experiential aspects of the role of co-therapist even though parents are viewed as a valuable resource,

spending more time with their children than professionals (Bindlish et al., 2018; McKinney et al. et al., 2021; Schertz and Odom, 2007).

There is a focus on parent mediated and parent training research particularly from the USA, capitalising on the unique position parents can offer through providing long-term support for their autistic child (Roberts & Kaiser, 2011). The literature concurs that parents are this valuable resource for both clinicians and researchers (McKinney et al., 2021; Schertz and Odom, 2007) but fails to address the power imbalance, with professionals seen as holding the knowledge and parents requiring upskilling in communicating with their children (Akamoglu & Meadan, 2018; Pacia et al., 2021).

These training programmes also feed into the neoliberalist culture of autism being a commodity, with parents as a captive audience and consumer (Runswick-Cole 2014). Mallett and Runswick-Cole (2016) assert that autism's appearance as a definable condition as illustrated in the DSM is what enabled it to become a commodity. Autism indeed has become an extremely successful commodity with knowledge exchanged for large amounts of money. Interventions such as Applied Behavioural Analysis (Lovaas, 1993) and the Son Rise Programme (Autism Treatment Centre of America, 2025) are expensive and time consuming to invest in for parents. Equally other consumer areas such as retail, sell items such as sensory toys for autistic children, again buying into the sellable commodity that is autism (Mallett & Runswick-Cole, 2016). Parents are navigating this arena looking for ways to support their child and II is no different. II has courses and conferences you can pay to go on and 'how to' books you can buy. Indeed, there are modular training courses you can go on to become an in-house trainer for your organisation. II is copyrighted, this instinctive natural way of interacting has become a commodity with the knowledge available to buy (Intensive Interaction Institute, 2025).

2.5.3 The dominant narrative- parents require training to communicate with their disabled child.

Children spend more time with parents than professionals, who offer interventions for an hour or so a week. This appears to be the main reason why

parents are regarded as an important part of early intervention programmes (Bindlish et al., 2018). Meaden et al. (2009) state that parents have been repeatedly shown to be able to learn and successfully implement communication strategies, reinforcing the narrative that parents of disabled children only know how to interact with their own disabled child if they are trained in doing so. Schertz and Odom (2007) advocate for parents and families to be supported to use interventions within the home environment as primary caregivers. Parents are ideally placed to support social communication learning, having multiple opportunities for learning throughout the day, in many different environments, such as bath time, mealtimes, and the garden. Shire et al. (2015) discuss the crucial role parents play in a child's life, including the stability they provide with intervention implementation. Whereas professionals will come and go in a child's life, parents are there for decades. This makes them a valuable resource in terms of interventions. However, Meaden et al. (2009) highlight some barriers to parents' engagement with interventions, reflecting that parents need to be collaborated with to find strategies which fit in with family life, to reduce the stress of having to set aside specific intervention time.

Within autism research much is written about social communication interventions for speaking autistic children. Conversely little is written in comparison about social communication interventions for the non-speaking autistic population. McKinney et al. (2021) discuss how there is little consensus on interventions used with non-speaking autistic children. The parents of these children may feel isolated and that there is no help for their child. This lack of relevant and comprehensive research can further disempower parents. The authors advocate involving parents in the co-design of an intervention and thereby empowering them through offering a differing dynamic in the research process. The parents in their study were involved as stakeholders and included in designing and operating the study to help with overcoming barriers and aid retention of other families as the study progressed. Their contributions and expertise were valued, and they were viewed as the primary experts of their children. This aided the research team in delivering the intervention or playing the role of advisor. McKinney et al. (2021) discuss how this can provide a liberating experience for parents through someone exhibiting positive expectations for their child, listening to their views on an intervention and

recognising the expertise and knowledge they have of their child. This shift in ethos feels important and it was of interest therefore to me to see how parents were included in discussions about II use with their children by the professionals involved with them in this research.

Walz et al. (2019) highlight the importance of parent-professional relationships in parental engagement and sustainability of interventions. They acknowledged the key role parents play in supporting successful implementation and generalisability of interventions. However, barriers such as parents not feeling supported or believing that the professional had less experience than them, undermined these relationships, leading to parents abandoning interventions. This has parallels to the II literature on staff sustainability barriers. Firth et al. (2008) advocated for the importance of ongoing support for practitioners. For staff this is management and leadership teams, for parents it is the professional supporting them. Nonetheless, working with parents to support them to use an intervention to fit in with family life, drawing on parent's expertise of their child, aligns with better parent-professional relationships and is more likely to see sustained successful interventions (Koegel, 2000; Walz et al., 2019).

Considering the above, it comes as no surprise that there has been an increase in parent-led intervention literature over recent years. However, this does little to empower parents who already may feel marginalised and let down by the services, if those interventions involve being told how to interact with your child and judged on your effectiveness (McKinney et al., 2021). There is some literature which is starting to look at parental experiences of what enables a successful intervention, (McKinney et al., 2021; Walz et al., 2019), they consider qualitative views of parental perceptions to add to the professional body of literature. In my research I was interested to explore the parental experiences of this dyadic relationship between themselves, and the professionals involved in their family's use of II.

2.5.4 The inclusion of parents in social communication interventions

There is a dearth of research with autistic non-speaking children. Tager-Flusberg and Kasari (2013) highlight the overriding focus is on progress in

acquiring spoken language, meaning children and adults using alternative forms of communication are often excluded from research. The key impact of this is that only small amounts of literature are written about parents' use of social communication interventions with non-speaking autistic children; often they are an underrepresented group within this body of literature (Shire et al., 2015). McKinney et al. (2021) analyse research considerations to be used when researching with non-speaking autistic children and their families, including drawing on the valuable knowledge parents have of their children to aid the research process. Interestingly the authors discuss interventions readily available for non-speaking autistic children in the UK, naming Applied Behavioural Analysis (ABA) and Preschool Autism Communication Trial (PACT); they do not mention II. This was a research project with Sheffield as one of its locations, where II is recommended by the Speech and Language service and parent training offered. The article employed functioning labels and deficit style language in the terminology it used, including 'profound autism' and 'autism treatment' which may account for the discussion of ABA and PACT, both interventions which seek to 'treat' autism and its associated differences.

Two social communication interventions used extensively in the USA are Joint attention, symbolic play, engagement, and regulation (JASPER) and Enhanced milieu teaching. Both are naturalistic interventions incorporating a play-based approach with strong similarities in techniques to II. Studies where parents have been included in the research on these interventions are relevant for my research as parallels can be drawn on any experiential aspects. It is also important to explore similarities and differences in the ways parents are included in research compared to professionals as this highlights the positioning of parents in the social communication literature. Shire et al's. (2015) study looked at sixty-one children with a diagnosis of autism who were non-speaking (less than twenty functional expressive words). The study comprised of two stages; the first stage, parents observed a professional working with their child using the interventions named above and the second stage involved the training of the parents over a three-month period, including workshops, passive training, and active training. This method of working with parents is very similar to the methods of Schopler and Reichler (1971), even though this study was some

forty years later; thereby illustrating how little the narrative has changed in the ensuing years.

The study sought to explore how implementation accuracy by the parents impacted on the efficacy of the strategy, in this case increases in the child's joint attention and interaction skills. Parents were taught to assess their child's developmental play level and select appropriate play material, joining in by following the child's lead, imitating their play and vocalisations. These training methods bear similarities to training used with practitioners in II studies (Firth et al., 2008; Nagra et al., 2014). One finding from the study was that the parents acquired knowledge of the interventions from the early stage of the training where they observed a practitioner interacting with their child. Seeing practitioners working with their child increased the parents' implementation and sustainability prior to the workshop's theoretical training taking place. This was a novel finding for the authors and feeds into the narrative of assuming parents need training to adopt interventions with their children when just observing practitioners employing strategies empowered them to use these themselves.

This method of supporting parents enhanced the parent- professional relationship as advocated by Walz et al. (2019), whereby the parents got to watch the difficulties the professional had and ask questions before being observed themselves. Parents also had the opportunity to understand the theory behind the intervention with the workshops and then had support from a practitioner to give them feedback on their use of the interventions with their child. This strengthened the implementation and accuracy of the interventions which concurs with the II practitioner literature on the merits of short over longer-term training courses and the benefits of underpinning understanding (Zeedyk et al., 2009).

What this study did not cover was any experiential aspects of the training and learning by parents. This would have added a further dimension and enabled the researchers to understand how the training was received from the parents' perspective. It also supports the narrative of parents' requiring training as it specifically looked at parental learning and their effectiveness in delivering the intervention. In my research I was keen to explore how the mothers'

experienced II training and whether they felt empowered or disempowered through this and whether the style of training impacted upon their II use.

So far, I have discussed USA based approaches. Green et al. (2010) conducted a UK based randomised control trial of PACT a social communication intervention run by parents in a specialist setting. The authors have written three papers about this intervention (Green et al., 2010; Green et al., 2018; Pickles et al., 2016). PACT is aimed at preschool children, specifically designed for parents to implement. The intervention consisted of one-to-one sessions with a clinic therapist and the parent and child. Using video feedback, the parent adjusted their responses to their child's communication and interactions, thereby increasing their responsiveness. The intervention also used techniques such as building the parents repertoire of action routines, familiar repetitive language and learning when to pause. The authors discuss how PACT is based on early pre-language development (Green et al., 2010).

There are strong similarities between PACT and II, in underpinning theory and technique, however this seems to be where the similarities end. These studies used deficit style language such as 'symptom severity', referring to PACT as a 'treatment'. Even though the intervention itself has parallels with II, the ethos of it feels quite different. PACT is about reducing autism symptoms and stereotyped repetitive behaviours even though the results did not evidence this. II is about embracing the learner for who they are, valuing them and listening to them.

This intervention was carried out with the primary outcome of symptom reduction; both the control group and intervention group showing a reduction; however, there was no noticeable difference between the groups. A limitation of this study is that there is no acknowledgment of natural maturation as these children were very young, two to four years old. A further finding of this study was a positive increase in parent/child interactions. This was a quantitative study and did not look at parents' experiences of implementing the intervention or their experiences of the training.

The second article (Pickles et al., 2016) looked at the long term follow up of these effects, six years later. They concluded that the autism symptom reduction continued but the parent-child interaction was lost. The authors

concluded that although this aspect did not continue post intervention, because there was no deterioration in autism symptom severity, PACT and parent mediated intervention at an early intervention stage was beneficial. Whether the continuing symptom reduction can be attributed to PACT is debatable, no mention is made of whether these children continued with other interventions or strategies to support them in the intervening years. Perhaps the fact that this was a clinic-based intervention rather than embedded in the home environment with a focus on symptom reduction, has meant parents viewed this as a finite intervention. A more holistic approach to the intervention focusing on the importance of building and maintaining social communication skills might have resulted in different long-term findings.

These studies do not look at experiential aspects of parents using the intervention, just the ability of parents to do it. The researchers asked parents for their views on whether they felt PACT increased interactions but not how they found being videoed or other experiential aspects. The terminology used within these papers is deficit-focused, using medical model style language, discussing how this intervention is a treatment for autism and how it reduces the symptoms of autism. This is different to the way II writes about autism; there is an ethos difference between these two similar interventions. The difference in ethos of these two remarkably similar interventions feels important to me and I was keen to explore whether the ethos of II came through in the mothers' understanding of II and whether it had any impact on their use of II in my research.

Much of the literature surrounding parents' involvement in social communication interventions for their children is aimed at early years (below 6) (Akamoglu & Meadan, 2018; Pacia et al., 2021; Roberts & Kaiser, 2011), with little written about older children or indeed adults. The research of Johnson et al. (2012) focused on social interaction in adults with learning difficulties, looking at six adults and the positive social interactions they had with paid staff and family members. The findings were linked to connections and relational aspects associated with emotional wellbeing. All six adults in the study were non-speaking using symbolic forms of communication. This was not a parent training study, instead looking at pre-existing relationships, their development and what they meant to family members and paid staff. Lots of the interactions described

by family members and paid staff resonate with aspects of II, such as rhyming word songs, and simple repetitive games. Johnson et al. (2012) went on to discuss the importance of social interaction for learning-disabled adults and finding time for this, highlighting the tendency for social interaction to take lower priority than other forms of care. This concurs with the adult services' II literature discussed earlier in this chapter. The parents and staff in this study were not trained in these interactions, rather these were the natural intuitive ways they engaged and interacted with the adults they supported.

Interestingly this group of learning-disabled adults were successfully engaging in social relationships with their families and staff supporting them, without the need for either party to be trained. What cannot be identified from the paper is historically how much training the parents/staff had received in social communication methods. Johnson et al. (2012) looked at social interaction of learning-disabled adults rather than children, highlighting the involvement family members have on a continuing basis with their grown-up child/sibling throughout their life and how this does not stop when the child reaches eighteen. The importance of continuing opportunities for social interaction to support the building of relationships with both family members and paid staff is fore fronted in this paper.

Summary

This section of the literature review has looked more widely at parental inclusion in the social communication and disability literature. Much of this centres around parent training programmes, supporting parents to run a social communication intervention either in the home or a clinic setting. It is widely argued that parents are a useful resource to upskill in early intervention programmes, as they spend substantial amounts of time with their child and have pre-existing relationships with them. Parents are afforded greater opportunities for practice in a variety of situations naturally occurring in the home (Akamoglu & Meadan, 2018; Pacia et al., 2021). The early work of Schopler and Reichler (1971) which set the scene for parents as co-therapists seems to have largely remained stagnant; indeed, few studies take the opportunities of working with parents to support other parents as a sustainable way to move intervention work on and truly value parents as co-experts.

2.6 Concluding thoughts

In this literature review I started by exploring the historical context of II, positioning it within the education landscape before moving onto focus on the underpinning principles. These were separated firstly into the teaching and learning aspects of II and secondly how II supports emotional wellbeing. Drawing on relevant theoretical approaches, including person-centred therapy and the zone of proximal development, I discussed II's central principles. These principles are key in all practitioners' use of II and therefore considering how these might come to be known, understood, and experienced by the participants in my study was important.

A high percentage of autistic individuals will struggle with mental health difficulties, and this is across both the speaking and non-speaking autistic population. Where traditional talking therapies may not be appropriate it is important to consider other approaches that can be used to support this population. Emotional wellbeing and mental health are high on both education and adult social care agendas, with the use of trauma informed approaches extending into a variety of different sectors. The key to this approach is building relationships in a predictable way. II's fundamental principles fit with a trauma informed approach with a focus on building relationships through listening and valuing a person for who they are. Services such as CAMHS and MAST support families and educators in a cohesive way, so where approaches such as II are employed, they are typically used across both the education placement and home. Therefore, it is crucial that we start to understand how parents experience using II in the home environment to be able to better support them and learn from them to inform the development of professional practice.

A consideration of the evolution of the II literature base illuminated the direction the research in II has taken and aspects of the experience of professionals in relation to enhanced connections and changes in attitudes. Issues such as training length and leadership support affect sustainability of II. However, the evidence of longer-term II use seems to indicate positive benefits over time to the learners such as benefits to emotional wellbeing alongside social

communication developments. How parents are supported and impacted by these issues is not explored in the literature, with minimal literature evidencing parents' experience of these issues.

Parents are typically positioned in the dominant narrative of requiring training to communicate with their disabled child, putting the professional in the position of power. Most research into parent-led social communication interventions only explores the efficiency of parents in carrying out the intervention rather than looking to the experiential aspects of running an intervention in the home.

My intention for this research was to add to the growing literature base of parental voices, not only in the II literature but more widely in the social communication disability landscape. Analysing the experiential aspects of running and implementing a communication intervention in the home, including looking at the dyadic relationships between child and parent, the wider family and the parent-professional relationships are fore fronted in this study. As the landscape of literature reporting on parent-led interventions starts to move away from the dominant narrative of parents requiring training towards a recognition of the experience and knowledge parents can bring to an intervention, it is important to think about how researching parental experiences of using interventions can also provide insight into the learning of professionals that can help develop their practice.

The following chapter considers in depth the methodological choices for this research.

Chapter 3: Methodology

This chapter presents the rationale for selecting Interpretive Phenomenological Analysis (IPA) for my study. First, I identify the theoretical underpinnings of IPA and explicate why and how these were in alignment with my epistemological position. I then discuss how I employed a reflexive stance throughout this research in order to encourage a thoughtful progression through all steps of the research process. Next, I discuss the rationale for IPA, the rationale for data collections methods is covered in Chapter 4 on methods. Finally, I consider some of IPA's potential limitations.

The IPA method was updated by Smith et al., (2021) to include new terminology and a clearer step by step analysis guide reference. However, the underpinning theory and premise of IPA has remained the same. As this research project was started prior to the terminology changes and data collection completed and analysis started before these revisions were published, I have used the original terminology and analysis structure throughout.

3.1 Conceptual framework- an introduction to IPA

IPA (Smith et al., 2012) is a methodology that was originally developed within health psychologies in the 1990's. In recent years IPA has also become widely used in the fields of education, sports science, humanities and qualitative psychology. Its theoretical roots are in phenomenology, hermeneutics and idiography (Smith & Eatough, 2017).

IPA is a qualitative methodology which seeks to explore in detail the first-person perspective of the lived experience of a phenomenon. It is designed to elucidate understanding of how people make sense of those experiences. (Eatough & Smith, 2012). IPA requires researchers, therefore, come to know what a particular experience means to the individuals who encounter it. Participants are accepted and valued as the experts of their own experience. The focus of this research thesis is II. However, what I am most interested in is the impact on mothers of encountering II. In particular, how the mother's experience II use

with their child, their understanding of what engaging with II means to them, how it has affected them and how they have made sense of these impacts.

Drawing on the three philosophical theoretical underpinnings of phenomenology, hermeneutics and idiography, IPA is rooted in looking at experience on its own terms. The researcher makes a hermeneutic interpretation of the participant's experience. Smith et al. (2012) describe this process as a double hermeneutic as what results is the researcher's interpretation of how the participant is interpreting that experience. Through a case-by-case analysis the researcher seeks to reach a full account of the experience for each individual before moving on to repeat the process for each subsequent participant. This focus on the individual makes IPA idiographic by nature (Smith et al., 2012).

The two-fold aim of IPA is to produce an account of participant experience, as near to the lived experience of the participant as possible. This might never exactly capture experience of a lived account because it is constructed between the participant and researcher. But hopefully the researcher will at least capture an account that is recognisable to the participant. Moreover, through this story telling experience the participant reflects on their experience which both may enable the participant to come to know their own story in different ways whilst also allowing the researcher to engage with these reflections in the double hermeneutic (Smith et al.,2012). The second aim is to produce an interpretive account which positions the participant's experience in a more social and cultural context (Larkin et al., 2006). This involves the researcher asking how the nature of the experience affects the feelings of the participant so as to express them in that way at that time point (Larkin et al., 2006).

Below I provide more detail about each of the three philosophical underpinnings of IPA, phenomenology, hermeneutics and idiography to further explain their significance and relevance to this research project.

3.2 Phenomenology

Phenomenology is the study of a phenomenon through the perspective of the people who have experienced it; aiming to study not only what was experienced

but also how it was experienced. It is the exploration of an individual's lived experience of a situation; examining that experience enables development of meanings which may then illuminate how that experience is understood (Neubauer et al., 2019).

Key philosophers in the field of phenomenology are Husserl, Heidegger, Merleau-Ponty and Van Manen. There are two main branches of phenomenology: descriptive or transcendental phenomenology and interpretive or hermeneutic phenomenology. Descriptive phenomenology describes one true way of knowing something, the essence of something. This is achieved through suspending all pre-conceptions and prior knowledge of an object/subject to come to know the true essence of it. Interpretive phenomenology, however, is founded on the assertion that the identification of true essence is unachievable because, it is claimed, all experience is influenced by the context we experience it in. There is not one true way of knowing something but multiple ways depending on the socio-cultural context we experience something in (Sloan & Bowe, 2014).

Husserl, a forebear of phenomenology established descriptive phenomenology to challenge the dominant positivist objective philosophy prevalent at that time. He wanted to move away from the perception of a reality that was 'out there' and something that was separate to the individual. Instead, he urged a moving 'back to the thing's themselves'; a coming to know of how objects are experienced and their relationship with human consciousness (Sloan & Bowe, 2014).

Husserl's primary interest was in in how someone comes to know their own experience. Husserl believed that our everyday experience of things is distorted by our 'natural attitude', the taken for granted way of being in the world and our relationship with the objects and things around us. To be phenomenological we needed to suspend this 'natural attitude' and bracket off our assumptions by taking a reflexive stance and putting aside our everyday experiences of the world (Finlay, 2014; Moran, 2000). To do so, Husserl argues, involves a series of reductions, eidetic or transcendental reductions, through which is enabled a focus on the experience itself: the gateway to accessing the essence of the experience (Neubauer et al., 2019).

Through this transcendental approach Husserl believed that no assumptions should inform phenomenological research, thereby any individual beliefs or pre-conceptions should be suspended to allow a focus on the experience itself and allow the essence of that experience to become apparent. Husserl believed that a researcher could stand aside from their own subjective experience and view the world as an ‘essential consciousness’ (Finlay, 2014). This involves the researcher constantly assessing their impact on the research and any biases, seeking to bracket those to not influence the phenomenon under study.

Intentionality is another key concept of Husserl’s phenomenology. For Husserl this meant the relation between the individual and the object under study, believing that all conscious thought is related to an object (Moran, 2000). Therefore, consciousness does not exist by itself but only in relation to something, all our awareness is related to objects. Experiences are experiences of something, love would not be love without an object to love, chopping would not be chopping without an object to chop (Beck, 2021; Smith et al., 2012).

Many modern philosophers do not hold with Husserl’s view on the ability to completely suspend one’s own beliefs and assumptions, rather taking a more hermeneutic or interpretive approach. Heidegger was one such philosopher. Initially a student of Husserl’s, Heidegger moved away from Husserl’s theoretical stance on phenomenology towards a hermeneutic approach. He applied the concept of ‘intersubjectivity’, the shared and relational nature of our experience of the world. The fact that as humans we have the ability to communicate and make sense of one another (Smith et al., 2012).

Heidegger’s main work was on the study of ‘being’ which he termed Dasein meaning ‘being-there’. Heidegger was interested in the study of humans being in the world with things and with others (Eatough & Smith, 2012). Humans differ from other beings in that they have ability to be concerned about themselves (Beck, 2021). Phenomenology for Heidegger was about self-manifestation. Unlike Husserl who believed there was one true knowing of something, Heidegger believed that things presented themselves in many ways depending upon the mode of access we have to them. He believed that as humans (subjects) we were not just observers of objects, but subjects and objects were linked (Horrigan-Kelly, 2016). Therefore, simple description through eidetic

reduction was not enough, as how we come to know something is influenced by the social and cultural world through which we experienced it. For Heidegger this required interpretation as things are not always as straightforward as they seem, this is where hermeneutics comes into phenomenology (Moran, 2000).

IPA draws on the work of these philosophers, taking Husserl's focus on experience and one's perception of it as a key tenet. It adopts Heidegger's more interpretive hermeneutic approach to phenomenology and advocates a reflexive stance acknowledging one's preconceptions and impact upon the research process. It seeks to understand the lived experience of a participant, asserting that experience is unique to that individual's embodiment and situation in the world (Smith et al., 2012).

3.3. Hermeneutics

IPA moves beyond the simple descriptive stance of prioritising the participant's own perspective to the researcher's interpretation of the text, thereby seeking to understand, and produce an account of, the participants lived experience and identify critical meanings within that experience (Wagstaff et al., 2014). It is interpretation that brings the second underpinning theoretical framework, hermeneutics into IPA.

Hermeneutics is the theory of interpretation. Originally it was used for the interpretation of biblical texts. Predating phenomenology, this philosophy branched out from biblical text to historical texts and then into the human sciences, with theorists such as Heidegger and Gadamer being modern proponents (Smith et al., 2012).

Heidegger's development of phenomenology towards a hermeneutic approach considered the theory of interpretation. He described how when an interpretation takes place it is always influenced by fore-conception, the interpreter's prior experiences, assumptions, and pre-conceptions. So, any interpretation is always looked at considering your own prior experiences (Smith et al., 2012). Smith et al suggest these fore-conceptions are ever present and can be seen as a hinderance to the interpretive process. It is therefore

important that the object under interpretation is prioritised over one's fore-conceptions.

As noted previously Heidegger's phenomenology is more reflexive in nature, with the researcher acknowledging their pre-conceptions and influence upon the research process; this is achieved through reflecting on their own biases and beliefs (Finlay, 2014). Gadamer (1975) describes this as: "The important thing is to be aware of one's own bias, so that the text can present itself in all its otherness and thus assert its own truth against one's fore-meanings" (p.238).

Gadamer (1975) further explains Heidegger's concept of fore-conceptions as constantly evolving. When interpreting the researcher may not realise which of their fore-conceptions are relevant to the text at that time, therefore the researcher may only become aware of their fore-conceptions once the interpretive process is ongoing. This makes the process a fluid iterative process. Gadamer describes this as fore-conceptions constantly evolving throughout the interpretive process, with fore-conceptions becoming replaced with more appropriate ones as the interpretation develops. This process is reflexive by nature requiring the researcher to engage in reflexive activity, a key tenet of IPA (Shinebourne, 2011; Smith, 2007).

This leads onto the hermeneutic circle, a primary principle of hermeneutic theory. Hermeneutics is a dynamic circle moving between the whole and the part. An example of this is to understand a whole textbook you must first understand the individual words or sentences and then to understand these you need to look to the context of the whole book. However, Gadamer describes the circle not as a 'vicious circle', one which the researcher is unable to escape, but rather one whereby they are constantly gaining new knowledge, always moving through the circle (Debesay et al., 2008; Gadamer, 1975). Therefore, the hermeneutic circle is where the researcher interprets and reasons (Debesay et al., 2008). Indeed, the hermeneutic circle enables the possibility of new illumination of the phenomenon under study through this iterative reflexive process (Eatough & Smith, 2012).

In IPA this has implications for the method, as IPA is an iterative process, moving back and forth through the data. The researcher starts from a position with their own fore-conceptions and experience; they attempt to acknowledge

these and the influence they may have on the research process. From this they move to the participant being the focus and enter their lifeworld. The researcher then moves back around the circle to the analysis stage where they attempt to interpret and make sense of what the participant has shared with them. They still have fore-conceptions, but these may have changed and evolved through engagement with the data (Smith, 2007).

3.4 Idiography

Idiography is about the particular; this may be either the particular experience of the individual in a specific context or the level of detail and depth of analysis it refers to (Smith et al., 2012). In traditional phenomenological research the emphasis is on the nature of an experience as experienced by a group of people, the nomothetic (Miller et al., 2018). However, IPA emphasises the nature of the experience of each individual *in* the group, and whether the experiences are the same or different. Consequently, each case has equal weight and value whether the experience has similarities or differences (Miller et al., 2018). Eatough and Smith (2012) describe how the individual in-depth case analysis that takes place prior to moving onto the cross-case stage is what makes IPA idiographic by nature. The small sample sizes advocated in IPA research and indeed a move towards single case studies allow for the focus to be on the particular rather than the universal, enabling an idiographic focus on what experience is like for individual life. Eatough and Smith (2012) discuss how focusing on the individual can illuminate common or central themes that connect across humanity for those experiencing that phenomenon.

IPA is influenced by these three philosophical underpinnings that make up the key tenets of its methodology. Phenomenology brings the study of experience through the perspective of those who have experienced it, with hermeneutics informing the interpretive reflexive stance of the researcher. Within the hermeneutic circle the researcher engages in an iterative process, acknowledging their preconceptions and the influence upon the research process, constantly evolving, and revising those fore-conceptions as they enter the lifeworld of the participant and become the ‘researcher making sense of the

participant making sense of their experience' (Smith et al., 2012). The attention to each individual account means IPA is idiographic by nature.

3.5 Epistemological position

This section explores the epistemological position I have adopted in this research study. It discussed symbolic interactionism and its relationship to both IPA and II.

IPA positions itself as understanding people and the world they live in, including within the sociocultural context in which they experience the phenomenon (Smith & Eatough, 2017). This stems from Heidegger's vision that humans are 'Dasein'; 'being there' or 'being in the world'; people are 'being there' with things and with others and our experience is influenced by this relatedness to others and objects, the social world around us. We are always somewhere and always experiencing something (Larkin et al., 2006). Larkin uses love to illustrate this. In IPA research, the researcher is not interested in love as such but what the experience of love means to particular people; this is necessarily contextually bound as it depends on, for example, who that person is experiencing love for, a partner, a child, a pet, a lover. The experience is socially contingent and contextually bound.

Smith et al. (2012) equate Heidegger's 'being there' with tenets of Meads Symbolic Interactionism (Mead, 1934). IPA is epistemologically linked to symbolic interactionism through its clear interest in the relationship between the researcher and participant and the reflective stance the researcher takes to acknowledge pre-conceptions and adjust them through the iterative interpretive process. My epistemological position aligns itself with that of IPA and below I will illustrate how II and symbolic interactionism are linked.

Symbolic interactionism is a micro level theoretical framework, the key concept of which is that society is created and maintained through the repeated interactions between individuals. It holds that people respond to their environment through attaching meaning to objects; these meanings are created through their social interactions with others (Carter & Fuller, 2016). Blumer (1986) defines symbolic interactionism through three premises. Firstly, humans

act towards objects (chairs, mothers, dogs etc…) depending on the meaning that these objects hold for them. Secondly, the meaning of those objects is derived through the social interaction one has with others, so someone may be wary of a dog if their parent feared them. Thirdly, those meanings are constantly created and recreated through an interpretive process with others, over time through repeated interactions with others one's opinion of dogs could change. As can be seen from the discussions in the previous sections, IPA searches for meaning through an interpretive process.

Meaning in symbolic interactionism is what sets it apart from other positions such as realism. From a realist position, meaning is an intrinsic standpoint to the object itself, so a ball is a ball, meaning is derived from an objective perspective. In symbolic interactionism meaning is seen as arising from the interaction between people, as a social product defined by activities as people interact. Therefore, the ball may be a plaything or a piece of sports equipment. The self is key in symbolic interactionism, the person is interacting with themselves and through this, defining the meaning of objects. This may then be modified through the situations and social context that an object has in a place (Blumer 1986).

Blumer (1986) describes two types of social interaction: non symbolic and symbolic interaction. Non symbolic is the instinctive response to the action of another such as raising one's arm to deflect a blow. Symbolic interaction is an interpreted response to the action of another such as responding to an outstretched hand with a handshake. Blumer explains this social interaction as people responding to gestures based on what meaning they hold for them and when the gesture holds the same meaning for both people, they understand each other. Symbolic interactionism looks at how individuals use their interactions to make sense of their world from their own perspective (Carter & Fuller, 2016).

Blumer's symbolic interaction can be translated to II. In II the interactions enable the learner to feel heard and valued which supports their sense of self. The interaction is co-constructed between the parties and to be successful it needs to be meaningful for both people. The more experienced partner adjusts their gestures to become meaningful to the learner thereby interpreting the learner's

actions which enables mutual enjoyment and understanding. As with symbolic interactionism the meaning is created and recreated through the repeated interactions of the II encounters. Through these the learner makes sense of their social world in small, repeated interactions with individuals; it is a microlevel learning experience, rather than some of the more traditional social and emotional learning experiences offered at a group or class level.

This thesis explores how mothers experienced II with their autistic children, it studies the lived experience of these mothers and involves the interpretation of the texts they produced (semi-structured interviews) in which they seek to describe the social action of using II with their child and the meaning this holds for them. Blumer (1986) describes social action in symbolic interactionism as 'individual and collective activities of people engaged in social interaction' (p. 54) and this can be small social groups such as a mother/child or family or larger, like a school community.

3.6 Reflexivity

Throughout the research process I have employed a reflexive stance, considering my impact on the research process and the interaction between myself and the participants, seeking to understand how this might have influenced both the interviews and later analysis through the hermeneutic circle. As a mother of an autistic child using II this affected the nature of the social interactions, I encountered with the participants. This is something I will now go into greater detail about.

Reflexivity is a key concept in IPA research, with acknowledgement of assumptions and pre-conceptions, where these are made conscious, and the way they shape the research as an ongoing process throughout an IPA study. Indeed, the researcher plays an active role in any study from the choice of research question to the construction of the research findings; these all have bearings on what findings emerge from the study. Reflection has a role in all of this (Willig, 2007). In this ongoing reflexive position, the researcher might not know initially what their assumptions might be until they start the data collection and analysis. This could be a reflection post interview on a reaction the

researcher had to a participant's experience. They may only become more aware of them as the research continues and at that point the researcher might start to question their interpretations (Eatough & Smith, 2017; Larkin et al., 2006).

As a mother of an autistic child using II myself, I knew that I brought to this study a set of assumptions and pre-conceptions about II use as a mother. From the outset of the research, I was aware of my status as a parent researching other parents. This status of 'insider research' is well documented within the literature. Insider research is where the researcher identifies as a member of the community or culture that is the object of study (Ross, 2017). A body of literature documents the advantages and challenges of being an insider researcher (Ross, 2017; Wilkinson & Kitzinger, 2013), but this is often not a simple definition. Historically outsider research has been seen as the ideal norm, to avoid bias and support objective research. However, with the increased popularity of critical and participatory research paradigms, recognition of the value of the lived experience that insider research brings has grown (Ross, 2017). This is true of disability research where co-production involving disabled advocates in community-based research arenas has grown. Disabled advocates provide support with deciding on research priorities relevant to the local area (Hollinrake et al., 2019). Participatory research or co-production in the field of disability is relatively well established however it has been slower in its uptake in the field of autism (Chown et al., 2017). Chown and colleagues attribute this to the lasting deficit view surrounding autistic individuals.

Insider research has advantages and disadvantages associated with it. The disadvantages highlighted in the literature are associated with assumptions of difficulties surrounding objectivity. Consequently, reflexive practice is viewed as key to addressing this (Moore, 2015). The literature also discusses difficulties with participants assuming the researcher knows what they mean and therefore not elaborating in depth about a phenomenon, presuming that as an insider the researcher can fill in the detail (Ross, 2017).

Power in the researcher participant relationship is a known phenomenon. It might be thought that as an insider researcher these issues are negated, however, even as an insider researcher there can still be concerns over power

relations (Merriam et al., 2001). It is the researcher, whether an insider or not, who sets and asks the research questions. However, the participant gets to decide what and what not to disclose and often will be able to choose an interview setting they feel comfortable in. These can help redress the power imbalance somewhat. Within the research process the power is negotiated throughout and the power dynamics can be influenced by cultural factors such as age, seniority and gender. Building rapport with research participants is one key way to redress any power imbalance there may be (Merriam et al., 2001).

Having an insider perspective can bring with it a deeper understanding of which questions might be useful to ask and how questions may be received by participants as you share a common ground with the group under study. It can also feel supportive for the participants that the researcher understands the experiences they are sharing (Dwyer et al., 2009). In contrast this understanding of experiences can be problematic for the researcher. Ross (2017) alludes to the emotional side of insider research. Talking to participants about sensitive topics can bring up memories of the researcher's similar experiences which may exert an emotional toll. Therefore, consideration needs to be taken as to how this will be dealt with throughout the research process.

Insider research does however also have advantages. These include it being potentially easier to access participants or gain access to difficult to reach groups. One key advantage is the potential ability to build rapport more quickly than an outsider researcher. As an insider the understanding the researcher has of the subject under study is a common interest, both researcher and participant have a learned and possibly intuitive understanding of the terminology, community values and norms (Ross, 2017; Dwyer et al., 2009).

Moore (2015) challenges the assumption that one is either an insider or an outsider researcher. Often researchers occupy a more flexible position somewhere between insider or outsider. The researcher may identify in some ways with the group under study but may differ in others. For example, the researcher may share the identity of a particular surgical intervention but be an outsider in terms of ethnicity or gender. Insider/outsider status is not just decided by the researcher who may identify as an insider to a particular group, but participants may not view the researcher as an insider in the same way, due

perhaps to educational or cultural differences (Merriam et al., 2001). These positions are navigated throughout the research process and may fluctuate as rapport with the participants builds.

For my research I hold a number of identities, I am a parent who uses II with my autistic child. However, I was also a professional who used II in an education setting and held information sessions for parents as well as a researcher. This differing status fluctuated throughout my data collection and analysis stages. My status as a mother using II has not changed; however, my role in using II at the school I worked at did. As my PhD continued, I was given further responsibility at school for supporting staff using II and delivering parent information sessions, so my focus became II implementation within the school. These intersectional roles allowed me to see both sides of the 'experience', I was a mother using II myself, but I also supported other mothers using II with their children as well as supporting staff teams. This gave me insight into the positives and negatives of those experiences, the joyous experiences of staff and parents alongside their more difficult experiences.

These intersectional roles were just that, it was very difficult to separate out my different identities dependent upon the context and invariably they bled into one another. I particularly struggled with decisions about how much to write about my own position as a mother of an autistic child using II. This was pertinent to the research and most certainly in ascertaining my own positionality. I was conscious of the ethics of disclosing information about my son who is unable to give consent but aware of the influence my position as a mother of an autistic child had on my research and the importance of acknowledging this. Equally at times I felt my status as mother diminished my position as researcher, I was a mother researching other mothers, and this fuelled my imposter syndrome. These feelings are highlighted in the literature by Runswick-Cole (2016), who described how she worried about her position as mother-researcher opening her up to scrutiny as potentially being biased or not taken seriously in her work.

Navigating my different identities throughout the interviews was interesting. I entered the space as a researcher or so I thought, I found I was viewed differently by different mothers. Some of the mothers viewed me as a mother also, steering my way thorough parenting a child like theirs. They were keen to

hear my experiences as a mother. This supported the building of rapport throughout the interview. Other mothers viewed me more as a researcher or professional and their questions of me reflected this. Reflecting on this afterwards these interviews were slower to build rapport and required more prompts. This is discussed in further detail in 4.2.7.

Nevertheless, it was extremely helpful to be able to reflect on this evolving relationship with II throughout my research and my differing identities. Each identity brought with it its own set of knowledge and prior assumptions, and these added to research and reflexive processes I engaged in. As I engaged in my analysis and the hermeneutic circle, I was able to reflect on my fore-conceptions and assumptions and how these changed whilst I considered my interpretations and developing knowledge.

3.7 Reflexive practice throughout research process

In this section I provide details of the reflexive tools I have used throughout the research process.

3.7.1 Self-interview

At the start of my PhD my main concern was that I was a parent of an autistic child interviewing other parents of autistic children about their II use. I was acutely aware of the biases I held about my assumptions that II use would be a positive experience for my participants and would have made a highly significant difference to their families, just like it had to mine. With the desire to identify and examine my pre-conceptions before undertaking interviews I looked to the literature for a solution and found Chenail‘s (2011) practice of ‘interviewing the investigator’. Chenail advocates for the researcher to conduct a self-interview using the same interview schedule either carried out by a peer or by reading out the questions and answering them oneself. He states this has several benefits. It can replace the need for a pilot interview where there may be a limited pool of potential participants. Nonetheless, it maintains some of the advantages of a pilot interview such as trying out the questions, seeing what works or needs adjusting, enabling revision of the interview protocol prior to

participant interviews commencing. Chenail also advocates it to assess and address potential researcher bias where the researcher is a member of the community under study.

Chenail (2011) describes how using this method can support the researcher during the data collection process. It enables the researcher to experience what sharing their lived experience of a topic is like, how it feels to answer certain questions and what their prior assumptions about answers to questions may be, thereby supporting the reflexive process.

A PhD peer with methodological and subject knowledge interviewed me using the interview schedule I had designed for this study. We audio recorded the interview, and I transcribed it verbatim. The process of being interviewed about using II with my son was interesting and gave me the opportunity to tell the story of my experiences of using II. Thinking back and recalling situations that had been difficult for us as a family was emotional and gave me insight into what this experience might be like for my participants.

The only time I usually talk about my autistic son is to either medical or educational professionals. The power dynamic in these relationships feels completely different to the power dynamic in the research interview situation. In the professional parent relationship, the power is on the side of the professional, they are the ones with the power to grant services and get needs met, which is usually why as a parent you are in discussion with them. Hodge and Runswick-Cole (2008) discuss the relationship between parent and professional and how parents continue to feel disempowered during these meetings. Their research found that parents felt that working with the professionals was often the most difficult part of raising a disabled child.

During the self-interview, the power balance felt more equitable, possibly because we were both researchers, but also because I was there just to talk about my use of II with my son without the pressure of worrying how my account might affect whether services could be cut or enhanced. It was nice to be able to just talk about my son and I was surprised that the interview passed quickly.

Even though the power imbalance was not as evident, I was conscious of how I represented myself and my son. As Wall (2008) and Haynes (2011) describe, I

strove to find the right voice. This was not an unfamiliar researcher who I would never see again, this was a peer and colleague interviewing me. I was conscious of what I disclosed during the interview for fear of being judged.

I also was acutely aware of relational ethics during the process. I was careful not to talk about my professional use of II and only discussed my II use as a parent, even though my professional use has influenced my parental use.

After the interview I realised things, I had forgotten to mention or did not crop up that I felt were important. As part of the reflexive process during the research I continued to explore these in my journal writings (see section 3.7.2 for further detail). Recalling some events was difficult, whether due to the fallibility of memory or these events being difficult to recall because they happened at a point that was difficult to revisit. Taking part in the interview helped to clarify my pre-conceptions about what I thought my participants might say in their interviews. My own experience with II has been very positive but discussing events prior to it was difficult at times. My assumptions were that there would be no downsides to II use, but when discussing this in my own self-interview I found myself talking about how I felt my interactions were perceived by outsiders when out in the community. This was not something I had particularly reflected on the reasons for before. It facilitated separating out my own experiences and what they meant to me from my participants' experiences and aided recognition of issues that may have been emotional to discuss. It gave me the opportunity to work through my lived experience and consider the impact it might have on the research process.

Chenail (2011) suggests that the self-interview could be analysed as participant data and that this might help illuminate initial thoughts prior to commencing participant interviews. I have reflected at length on what to do with my self-interview, from incorporating myself into the research as a participant to using autoethnography as a second methodology. Wilkinson and Kitzinger (2013) discuss incorporating the researcher into the research when they have insider status. They argue that this has the benefit of allowing the researcher a voice in the research but unlike autoethnography affords privacy. It can also support with participant numbers where recruitment may be a problem. The potential pitfalls with this include that it can be difficult to analyse one's own account in the same

way as you would analyse other participants, so the voices may not be weighted equally. The analysis of one's own data may influence the analysis of the rest of the data, not allowing something to come forth that is there.

Autoethnography is another method written extensively about with pros and cons for this methodology. Autoethnography is a reflexive research methodology that positions the researcher within the study, as both the participant and researcher. It is a research methodology that focuses on a personal experience of the researcher (Lapadat, 2017). In writing about one's own experience, one is never just writing about themselves. Our lives are entwinned with the 'others' who appear in our narratives, be that family, friends or colleagues. In this research I cannot write about my use of II without writing about my son. This involves an ethical dilemma; my son is autistic with a learning disability and does not use speech to communicate, making him a vulnerable young man. Winkler (2018, pg. 240) asks 'do we own our stories', when writing about our lived experiences. We include the 'others' with whom we have social interaction within our stories. These stories contain information about others, who even if we change aspects of their identity can still be recognised by their association with us as the researcher. Therefore, he considers that writing of oneself is also writing of the other and so the ethics of this require close examination. Within this research I have had to consider the relational ethics of not only my autistic son but also my other immediate family members, my husband, and other children. Even though my autistic son would be the main 'other', my other family members would appear as critical characters within the narrative.

After much consideration I decided to use my self-interview for the purpose of a reflexive piece of work: I transcribed the interview verbatim and spent time rereading the transcript, reflecting on my own experience, and evaluating how this was informing the research process. I chose to prioritise the mothers' accounts in this study. I felt that my role within the school had changed and professionally I was using II more: this overshadowed my personal use of II. As I come towards the end of my PhD journey, I have come full circle: I no longer work at the school, so now my use of II is solely as a mother, which seems a fitting way to finish this thesis. It has again allowed me to take a reflexive stance

back as a mother using II with her autistic child with all the knowledge I have gained.

3.7.2 Reflexive journal

As a researcher we influence all aspects of the research process, from the selection of the topic to the interview dynamic and analysis stages. These are all affected by our actions and research is viewed as constructed between the researcher and participant in a particular social context (Finlay, 2002). Finlay explains that if a different researcher conducted the interview, they would elicit a different account of the phenomenon under study because of their influence upon the process. So, reflexivity becomes a key component of the trustworthiness of the research process. Dwyer & Buckle (2009) discuss the importance of qualitative researchers situating themselves within their research, acknowledging their pre-conceptions and biases and how these might influence what they are trying to access and understand: the dynamic hermeneutic circle at work. Keeping a research journal is one way of keeping a reflexive account of thoughts and feelings throughout the entire research journey and support identification of how subjective experiences have influenced the research process (Finlay, 2002).

I have kept a research journal since the proposal stage of my PhD. I found that this became particularly important during the data collection and analysis stages as a place to record and explore my thoughts and feelings during those stages.

Goldspink and Engward (2018) discuss the use of a reflexive journal for evidencing what they termed ‘echoes’, resonating experiences during the interview process. Goldspink herself was an insider researcher at that time. The journal gave her space to explore how those experiences resonated with her own and to reflect on what that meant for her analysis. Goldspink found it enabled her to revisit the data to look for potential further insights. I certainly found that keeping a reflexive journal has been a place to reflect and explore my thoughts and feelings about the interviews, how they went and how I felt afterwards. During the analysis phase it was also useful when I came across ‘echoes’, particularly ones that I had not consciously thought about in such

terms before (see 4.3.1 on p.112 for an example). Exploring this in the research journal allowed me to look after my own emotional wellbeing as an insider researcher and separate my experiences from those of my participants.

Writing things down is an invaluable tool for me as a researcher. Studying part time for this PhD alongside working and caring responsibilities has meant there have been gaps in progress over the years. Having the journal to look back on as an audit trail for my thought processes during the analysis stages has been vital.

3.8 Rationale for choosing IPA

Choosing a research methodology is something that happens at the early stages of the research process as methodological differences will potentially determine aspects of the research such as data collection and research questions. What the researcher seeks to come to know is a key aspect of this and will influence the choice of methodology. For this research I was interested in finding out what the experience of using II was like for mothers, and how they made sense of it.

II is about the social interaction that is co-constructed between two people to create a meaningful interaction that is mutually enjoyable and enables the less experienced communication partner to feel valued and heard. I felt it was important to replicate this in the research process. The mothers in this study are the marginalised voice, underrepresented within the research and IPA enables them to be conceptualised and appreciated as the experts in their own experience. It looks to maintain an idiographic focus on the sense making experience of that lived experience prioritising their voice, thereby representing them in the research.

There is already a precedent of IPA use in II research; in studies such as Nagra et al. (2016) and Berridge and Hutchinson (2022). Both studies utilised semi-structured interviews as data collection methods, each exploring the lived experiences of II use by certain homogeneous groups: carer workers and mothers. Nagra et al. (2016) interestingly used participant validation as a methodological tool to support rigour; they took the results back to the

participant prior to writing up for discussion. Participants used this platform to emphasise the need for top up training in II. Berridge and Hutchinson (2022) chose to use an expert by experience to look at their interview schedule prior to participant interviews commencing, to advise on its accessibility. They did not call this a pilot interview, rather they state that this person was not included in the research. The methodological choice of IPA for that study was chosen by the authors due to its idiographic focus which the authors felt aligned with the dyadic nature of II's interactions.

IPA is also used in research within the wider field of disability studies. Taylor (2016) used IPA as the methodology for their research utilising semi-structured interviews to explore parents' experiences of engaging with Video Interaction Guidance. To support the reflexivity of this research the researcher engaged in two 'bracketing interviews' to aid with identifying any prior assumptions they had about the research. Thackeray and Eatough's (2018) study explored the experiences of fathers of disabled children using IPA. The authors felt IPA's idiographic nature with a focus on lived experience was important for their research on fathers because fathers of disabled children are typically an underrepresented group within disability studies. Viewing the participants as the primary experts in their own experience and the idiographic focus as opposed to a focus on generalisability (Smith et al., 2012) is suited to research exploring the lived experience of what can be a very personal experience of parenting a disabled child.

3.9 Criticisms of IPA and limitations

This section considers the debates surrounding IPA in the academic literature before going onto discuss limitations, validity and rigour of the methodology.

3.9.1 Critical debates surrounding IPA

Within the literature there are criticisms of IPA, particularly surrounding whether it is true phenomenology and whether it is too descriptive and not conceptual enough. Some critics state that IPA analysis is just at the descriptive level and does not move to the interpretive; Larkin et al. (2006) argue that this is often a

pitfall inexperienced researchers fall into and urges researchers to look to the essences of the participants' experiences.

Amongst phenomenologists there are differing views of what constitutes phenomenology and what it means to move away from it, so that it can no longer be claimed as a phenomenological method. Van Manen, Giorgi, and Smith have had an ongoing debate about whether IPA can claim to be phenomenological. Van Manen (2017) critiques IPA for not being phenomenological: for a methodology to be truly phenomenological in his view it must practise the eidetic reduction of Husserl to get to the essence of the experience under study. He discusses phenomenology as the study of how things show themselves, and argues that approaches that aim to interpret, using constructivist ideals are not phenomenology. In his opinion it is important for phenomenological questions to be determined prior to interview to elicit the pre-reflective lived experience under study rather than reflective experiences.

The IPA tenet of participants making sense of their experiences, Van Manen asserts is therapist psychology not phenomenology. Indeed, his main criticism of IPA is that it is an interpretive psychological analysis rather than a phenomenological one. Smith's (2017) rebuttal of this criticism discusses the phenomenological field as diverse with many proponents, each with differing interpretations of phenomenology's core concept; letting experience appear on its own terms. Smith maintains the pre-reflective experience is key for phenomenology, however it is also important to look at the reflective experience as this enables the sense making for the participant in understanding their own experience and allows for a more holistic phenomenological stance. Smith also points out that he has never been a therapist, thereby IPA has no intended links to a psychological therapy.

IPA draws not only on phenomenology but also hermeneutics and idiography as its core concepts, it does not purport to be entirely phenomenological but rather takes elements of each theory to make up its methodology. The ongoing debate illustrates how academia and research can be a contentious field to navigate.

3.9.2 Limitations, validity and rigour

One perceived limitation of IPA is that it is primarily concerned with the experience of the individual person-in-context as opposed to the wider socio-cultural contexts. Todorova (2011) discusses the widening of IPA to become more sensitive to context and thereby more socio-culturally sensitive. They discuss how this may mean widening the epistemological position of the researcher to a more constructivist approach when exploring gendered identities or other social meanings. In my study I am exploring mothers' experiences of using II, which is linked to socio-cultural theories itself: the mothers' experiences are entwined with their gendered identities and socio-cultural theories around the concepts of good mothers and maternal identity. Even though the study is focused on the personal meaning- making of the participants it also needs to be sensitive to the social and cultural worlds those experiences exist within as Todorova (2011) discusses. Smith (2011) agrees with Todorova, explaining how initially IPA was developed to prioritise the experience of the individual as he felt this was missing in qualitative psychology. However, as the research body of IPA work has grown, Smith welcomes the extension into social, historical, and cultural context which he views as a natural extension of this flexible methodology as its use grows and widens.

The topic of validity and quality of qualitative research is widely discussed in the academic literature. Initially validity was used as a measure for quantitative studies however, there was a realisation that this was of equal importance for qualitative research and as such a number of guidelines were devised (Smith et al., 2012). Yardley (2000) is one such set of guidelines. Yardley's guidelines comprise of four categories: sensitivity to context, commitment and rigour, transparency and coherence, and impact and importance. Smith et al. (2012) discusses how these guidelines can be applied to IPA research in his text on IPA.

Yardley (2000) describes sensitivity to context as being demonstrated through areas such as exhibiting sensitivity to the socio-cultural elements of the research, through the narration of the existing literature surrounding a topic or the data obtained from the participants. Smith et al. (2012) states that in good IPA research this is demonstrated from the initial stages of the research project,

as sensitivity is applied to considerations surrounding IPA's appropriateness for the phenomenon under study as well as the interactions of the researcher in building rapport and trust with the research participants. In my study I carefully considered whether IPA was the correct choice for exploring the mothers' experiences of II. I also spent time during the interviews making sure the participants felt at ease, showing empathy and negotiating my insider status and the power dynamics of the research situation (see Chapter 4 for a detailed exploration of this).

Commitment and rigour detail the commitment to the research process and the thoroughness of the study. Smith et al. (2012) state as IPA involves the in-depth analysis of data which tends to be a lengthy process this therefore demonstrates commitment. Rigour can be shown through the quality and completeness of the interviews and data analysis. For this study the personal commitment and time involved in conducting an IPA study was considerable. It is important in an IPA study to move beyond description to interpretation of the data and to maintain sufficient idiographic focus as you analyse the data. In this study my supervisors were instrumental in providing space to sense check my findings and engage in discussions about the convergences and divergences within the mothers' experiences. This supported the rigour of my research.

Transparency and coherence refer to how transparent the stages of the research process and data analysis have been and whether the narrative of your overall thesis and findings hangs together coherently (Smith et al., 2012). Chapter 4 provides a detailed overview of the research process and steps within the data analysis that illustrate how the superordinate themes were arrived at.

Lastly, impact and importance, Yardley (2000) states that it does not matter how well a research project is conducted if it does not tell the readers something interesting or illuminating. Chapter 5 and 6 provide the research findings for this study, they provide narratives of the mothers' accounts of using II with their children. This includes novel findings which add to the growing body of II research.

Summary

IPA is a qualitative research methodology with three philosophical underpinnings. It is phenomenological in the sense of it focuses on lived experience, utilises hermeneutics to interpret the participants' meaning- making experiences, and includes an idiographic focus on the individual. By its nature IPA is a reflexive methodology advocating that the researcher needs to recognise and acknowledge any pre-conceptions and the potential influence these may have on the interpretive analysis. Recognising that these pre-conceptions may change throughout the analytical double hermeneutic process is key.

IPA's strengths are in exploring the in-depth lived experience of a particular phenomenon, recognising the participant as the expert of their own experience, and prioritising their voice. This makes it ideal for researching under-represented or marginalised voices, where the participant's experience is fore-fronted.

The next chapter reflects on the methods of data collection and process of analysis that were used within this research. In presenting these I illustrate how these are consistent with working within the paradigm of IPA.

Chapter 4 Methods

This chapter starts with an account of the ethical considerations and data collection methods employed and the reasons for those choices. I then move onto discuss the data analysis methods used including a synopsis of each of the participants to provide some context for the findings chapters to follow. Where relevant I have added in reflective summaries at different stages of the data collection and analysis. I have chosen to provide reflections throughout this chapter to illustrate both the reflexive process and how my insider status and intersectional roles have shaped and influenced the research process.

4.1 Ethical considerations

Ethical considerations were incorporated into this research study from the outset guided by the British Psychological Society (BPS) guidance (BPS, 2021). This research project was approved by Sheffield Hallam University ethics committee ER6420051 (Appendix 3 page 255) on 31/7/2018. In particular I carefully considered issues such as respect and power relations within the research process through decisions such as disclosing my own insider status. In accordance with ethical principles participants were fully informed about the research study and what taking part would involve whilst being made aware that their contribution was entirely voluntary. Each participant was given an information sheet (Appendix 5 on page 264) detailing what was involved in taking part in the research and a consent form (Appendix 6 on page 267) to complete. Full details of the ethical considerations that I engaged with, and actions taken during the various stages of the study are described during the relevant sections of this chapter. These include areas such as trying to be inclusive with mode of participation and consideration of protecting the anonymity of my participants.

Consideration of ethics has been an ongoing process throughout this research project as I have navigated the distinct stages. At each stage I have considered my participants and any ethical implications such as how best to anonymise the

data. These decisions have been taken with the best interests of my participants in mind.

4.2 Data collection

This section details the data collection choices for this study including considerations of sample size, recruitment measures, semi-structured interviews as a data collection method, the participants, and recording and transcription processes. Ethical considerations pertinent to the different stages are discussed throughout this section.

4.2.1 Sample size

IPA is primarily concerned with a small homogeneous sample and as such can be criticised for a lack of generalisability of its findings. It does not claim to be able to generalise its findings, however the findings from an IPA study can illuminate the thinking around a phenomenon and add to the range and depth of knowledge on that topic (Smith et al., 2012).

Sampling in IPA is purposive as it looks to explore a significant experience for participants, rather than convenience sampling (Smith et al., 2012). IPA traditionally utilises a small homogenous sample size, allowing for the focus on the idiographic. It aims to develop a full and rich interpretation of the data from this homogeneous group. The analysis focusses on the detailed examination of each case before moving to look for convergences and divergences across cases (Brocki & Wearden, 2006). The boundaries of the homogeneous sample vary from study to study, dependent upon the population involved and phenomenon under study. For some the population may be rare and the sample determined by the limited number of available participants. McGregor et al's. (2014) living liver donation paper followed a dyad of recipient and donor from pre operative to post operative with three semi structured interviews. This in-depth case study used IPA to explore the intra and interpersonal relationships of the dyad throughout the pre and post operative phases. By focusing on just

one couple the researchers were able to look at the lived experience for both the donor and recipient for this very risky procedure and this provided insight into the risk assessments and demands such surgery required. In other studies, it may be possible to determine the boundaries of your study participants by characteristics such as age or gender (Smith & Osborn, 2015). In Anderson et al's. (2020) study of ten mothers of autistic girls the sample was bounded by the inclusion criterion that participants had to be mothers of autistic girls; they gave no reasoning for their sample size in their paper.

Within the literature there is acknowledgement that focusing on a smaller homogeneous sample allows for a deeper, and more thought-provoking analysis (Wagstaff &Williams, 2014). There is no correct sample size for an IPA study, however as an idiographic method, between six and ten participants are advocated. For this study I have recruited seven participants, the inclusion criteria are discussed in 4.2.2. Within IPA studies there are also some single case studies using this methodology (Eatough & Smith, 2006; Clouston, 2019); these studies had the benefit of allowing a greater depth to be achieved with the study of just one participant. Both studies formed part of wider IPA studies, but the authors felt that these individual cases required separate single case study analysis. Eatough and Smith (2006) because of the richness of the data from this particular case study at illuminating the experience under discussion; anger. Clouston (2019) because it illustrated a phenomenon not mentioned by other participants in their study. Typically, therefore, a smaller sample size is viewed as the norm within IPA. Studies with larger numbers of participants tend to have unwieldy amounts of data to manage, meaning the idiographic focus can become lost (Smith et al., 2012).

Because of the homogeneous nature of this potential group of participants and the potential for them to be difficult to find, I realised that I may need to rely on not only purposive sampling but also snowballing to find participants. Snowballing is where participants refer other potential participants to the project and is often used with small groups or under researched groups. This is a widely used method of recruiting participants where it is recognised reaching potentially the right people might be difficult. For example, Odame et al. (2020) used snowballing to recruit their disabled participants. Within a small sample size this then means careful consideration needs to be given to anonymity and

confidentiality to make sure that identifying features such as name, job, health conditions etc… of a participant's account have been removed from their transcripts. Further details of these considerations are given in 4.2.3.

4.2.2 Recruitment

I recruited participants for this study through the existing networks that I had with the Intensive Interaction Institute in the UK. The institute provides training courses, holds annual conferences, and publishes a quarterly newsletter. I attended the annual conference and spoke briefly about my research to the delegates, leaving recruitment flyers for them to take away (Appendix 1 page 252). A contact at the Intensive Interaction Institute also placed an advert on the parents' Facebook page for me. These activities allowed me to direct my recruitment purposively towards my target group, parents of autistic children using the II networks I already had contacts with. At this point in the study my focus was not exclusively on mothers, rather on parents more generally.

These activities generated interest from several parents through either seeing my advert directly or through third-party gatekeeper health/education professionals passing the flyer on and snowballing of parents. Prior to the interviews I either had email correspondence or brief telephone conversations with participants to answer any questions about the research.

I decided to disclose on my recruitment flyer that I was a parent of an autistic child using II myself. I felt it was important to be upfront about this, and I also hoped it would gain me access within a potentially small pool of participants. For the reasons discussed in section 3.6 on page 82 my insider status felt prominent in my research and not disclosing I was a parent would have felt dishonest. There is a rich tradition of researchers acknowledging their insider status on recruitment material to aid access to certain populations (Fish &Wilkinson, 2003; Wilkinson & Kitziniger, 2013). However, for me the overriding reason was one of transparency in the research process. The act of not acknowledging my status as a parent of an autistic child using II, would, I felt, have hindered the interview process. I would have felt restricted by withholding

this piece of information. I will discuss how I negotiated my position as a parent during the semi structured interviews in section 4.2.7 on page 107.

My only inclusion criterion for this research was that the participants had to be parents/carers of an autistic child. I did not place an age limit on the child as this would have excluded some parents from the research. Thackeray and Eatough (2015) discuss the need for more in-depth lived experienced research of parents' experiences of adult children with developmental disabilities. They advocate for research that moves away from emotional burden accounts towards more nuanced and contextual accounts. As Intensive Interaction is primarily used with autistic people with co-occurring learning difficulty the process of caring for their child does not stop when that child turns eighteen, often continuing long into adulthood. As already discussed, much of the social interaction intervention literature focuses on research with parents of preschool aged children. II typically is advocated from early years right through to end of life for people with developmental disabilities and/or autism. As a parent you are always a parent, advocating long into adulthood for your child. As it turned out, the first participant to contact me was a mother with an adult child.

4.2.3 Participants

I interviewed seven mothers, all of whom have an autistic child. The participants were from across England. Five mothers had sons and two had daughters. Five of the children had siblings. Five of the mothers lived with their partner, the other two were divorced or single. All the children had attended or were attending special schools with the adult child residing in a residential home.

I provided the participants with pseudonyms along with their children and identifying features such as place names, school names, co-occurring conditions anonymised in the transcripts. As some of the participants were recruited via snowballing, I needed to pay particular attention to confidentiality and anonymity. Only two of my participants had daughters, this potentially made them easier to identify amongst the mothers recruited through snowballing.

With confidentiality concerns in mind, I decided to make the pseudonyms for the autistic children a gender-neutral name to support anonymisation. Different

approaches can be taken to anonymisation of interview data, I assigned pseudonyms for my participants rather than assigning numbers as I did not want the data to feel impersonal (Saunders et al., 2015). However, it is not just the participants' names that require anonymisation: relational ethics means that there are many others who appear within a participant's story and for other family members I used generic labels: father, sibling, and grandparent. However, as the mothers' autistic children featured so heavily in their stories, I did not want to give them a generic label of 'autistic child' as this felt too impersonal. Tolich (2004) discussed the external and internal confidentiality in research ethics in relation to Ellis's (1986) Fisher Folk ethnography where her pseudonyms for the 'others' in her participants narratives enabled them to be identifiable amongst the small fishing community. Tolich advocates for careful consideration of what could make the 'others' potentially identifiable to other insiders in a write up. The gender of the autistic children did not seem to feature in the mothers' experiences of their II use with their children, so assigning gender-neutral names to the autistic children felt like a compromise that supported the anonymity of the mothers and children.

4.2.4 Introducing the participants

Below I have provided a brief outline of the individual participants to set the context with which to read the findings chapters.

Participant pseudonym	Child pseudonym
Abigail	Ali
Bethany	Jamie
Clare	Harley
Elaine	Drew
Fiona	Riley
Georgia	Gerry
Helen	Charlie

Table 1. Introducing the participants

Abigail

Abigail is married to Ali's father and is a full-time mother. Ali is primary school age and attends a local special school as a day pupil.

Abigail was a member of the school II parent mentoring group and had been introduced to II by the school II co-ordinator. She had been using II for a few years.

Bethany

Bethany is married to Jamie's father and is a full-time mother. Jamie is primary school age and attends a local special school as a day pupil.

Bethany was a member of the school II parent mentoring group and had been introduced to II by the school II co-ordinator. She has been using II for a few years.

Clare

Clare is married to Harley's father and is a full-time mother. Harley is primary school age and attends a local special school as a day pupil.

Clare was a member of the school II parent mentoring group and had been introduced to II by the school II co-ordinator. She has been using II for a few years.

Elaine

Elaine is a single mother who has a partner who does not live with her. Drew is of primary school age and attends a special school which is local to the area as a day pupil. Drew has regular contact with dad.

At the time of the first interview Drew was receiving support from the local CAMHS team and Elaine was being supported to use II with Drew by them. Elaine has been using II for a relatively short space of time, only 3-4 months at the time of the first interview.

Fiona

Fiona is a single parent to Riley who is an adult and lives full-time in a residential home. Riley comes home every other weekend. Riley has no contact with dad. Riley attended special schools on a boarding basis prior to moving into a residential setting. II was recommended to Fiona by another parent and Fiona was supported in her use of II by an organisation. She paid for the organisation to support the care staff in the residential placement to use II. Riley's residential placement broke down as Fiona did not feel Riley's needs

were being met there and she paid for further II training for the new staff team at the new residential placement.

At the time of the first interview Fiona had been using II for several years. By the second interview Fiona had a role within the organisation.

Georgia

Georgia is married to Gerry's father and works part-time. Gerry is primary school age and attends a local special school as a day pupil.

Georgia was introduced to II by a professional who was supporting her family and school. II had been used with Gerry by the professional at school and Georgia had been supported to use II at home. At the time of the first interview Georgia was looking for a residential placement for Gerry and had been using II for about six months. By the second interview Gerry was settling into the residential placement, and Georgia was using II when she visited Gerry there.

Helen

Helen is married to Charlie's father and is a full-time mother. Charlie is primary school age and attends a local special school as a day pupil.

Helen was a member of the school II parent mentoring group and had been introduced to II by the school II co-ordinator. She has been using II for a few years.

4.2.5 Rationale for semi structured interviews

The nature of data collection in IPA is flexible, however, it needs to be one which lends itself to the participant offering a first-hand detailed account of their experience. Smith and Osborn (2003) describe semi-structured interviews as the exemplary method as they offer the medium for participants to speak at length about a topic. Seidman (2013) describes interviews as a way of hearing people's stories. Recounting stories is a way throughout history that people have made sense of their experiences and been able to share them.

Other data collection methods are described in the literature such as diary extracts or focus groups (Flowers et al., 2001). Nevertheless, semi-structured

interviews are predominately the method of choice (Brocki & Wearden, 2006). More recently creative methods have been used alongside the traditional interviews to add a further dimension into the research. Morrey et al. (2022) used photographs of the counselling rooms alongside interviews in their study, with Boden et al. (2019) similarly using drawing as an impetus for further discussion in their study. Both these visual methods enabled subjective expression of experiences by providing a starting point for discussions thereby enabling the participants to articulate their lived experience more easily (Morrey et al., 2022).

Even when these alternate creative methods were used, they were done so in conjunction with the semi-structured interviews to produce the detailed rich account required for IPA analysis. The one-to-one semi-structured interview allows for open ended questions and the participant to tell their story in their own words in their own time. Rapport is developed through the interview process and having the space to tell one's story and feeling listened to and heard can feel very powerful for the participant. This is the start of the hermeneutic process, the participant making sense of their experience through the act of recounting their story in this reflective space (Finlay, 2013; Smith et al.,2012).

I chose to use semi-structured interviews to allow the participants to speak at length about their experiences of using II with their child, enabling them to develop their narrative and reflect as they talked (Smith et al., 2012). My research is exploring the mother's lived experience of using II with their child. This happens through the participant's reconstructing that experience (Seidman, 2013) and I felt that semi-structured interviews would best enable me to achieve this. The interviews gave the participants the space to narrate their stories at their own pace. For my project the choice of mode of interview, either in person or over the telephone meant that implementing some of these alternate creative methods would have been difficult and influenced my decision to use semi-structured interviews only.

Finlay's (2013) description of being a participant in a semi-structured interview really resonated with me as a mother of a disabled child, researcher and II practitioner. She states:

> From a participant's perspective, the experience of engaging deep description while being truly seen by another can be profound. In addition to knowing that one's perspective is witnessed, being listened to opens up potentially transformative space and time, allowing the person to make sense of their experience, perhaps going beyond previous understandings (Finlay, 2013, p.181)

As a parent of a disabled child, we are not often listened to without judgement; most often we recount the same answers to the same questions to different professionals. We do not get to talk at length or in depth about topics. From my position as a researcher, I wanted my participants to feel they have been listened to and their perspective heard. These sentiments chime with the practice of II, feeling valued and heard.

4.2.6 Semi-structured interview schedules

Semi structured interviews have an interview schedule, but this does not have to be strictly adhered to as in a structured interview. It is accepted practice to allow the participant much more direction and control in the interview so that they might narrate their story as they wish. The schedule supports the focus of the research without restricting it (Rabionet, 2011). The interview schedule is used as a guide to which areas the researcher feels need to be covered. Prompts are used to elicit further detail from participants such as 'can you tell me a little more about that', 'how did that make you feel?' There is little guidance in the IPA literature as to how many questions or how many prompts to use as it varies from paper to paper, depending upon the experience of the researcher and type of research (Brocki & Wearden, 2006). However, Smith et al., (2012) textbook on IPA gives some guidance on the subject. They suggest having open ended questions that move between being descriptive and narrative in style. I made sure that my questions were opened ended allowing for in-depth responses and built the questions around three areas (see table 2 below). I used the extant literature to help me think about what I wanted to know about the participant's experiences, particularly around experiential aspects and any downsides, which were rarely addressed in the literature.

I conducted two semi-structured interviews with participants between six months to one year apart. The first interview focused on the experiential aspects of their II use with their child, looking at broad topics of: discovering II, experience of using II and fitting in with family life.

Discovering Intensive Interaction:	• What happened leading up to you choosing to use Intensive Interaction? • Can you tell me how you came across Intensive Interaction? • What made you decide to start using Intensive Interaction with your child? • What appealed to you about this approach?
Experience of using Intensive Interaction:	• How did you find using Intensive Interaction when you first started? • How do you find using Intensive Interaction now? • How is it different now from how it has been previously? • What have been the effects of engaging with Intensive Interaction? • Do you think it has changed how you see/relate to them or them to you? • Could you tell me about the best things about using Intensive Interaction with your child? • What are the downsides or challenges in your experience of Intensive Interaction? • Could you tell me about the hardest things about using Intensive Interaction with your child?
Fitting in with family life:	• Can you describe how you use Intensive Interaction in a typical day with your child? • How do your family feel about Intensive Interaction use with your child? • Why do you think they feel that way? How do they show this? • Does your child use Intensive Interaction in any other settings and how does it look there?

Table 2. Interview schedule

The second interview provided participants with an opportunity to expand on points raised at their first interview and for me to ask about topics I felt had not been covered in the first interview. It also provided a longitudinal aspect to the

research through recording whether II use had been continued or not. Smith et al. (2012) describe using a first interview as a prompt for further discussion at a second interview. The longitudinal aspect to the research proved fruitful, revisiting the participants enabled a clearer understanding of their II use over time and how this impacted upon their experiences.

There was no set interview schedule as such for the second interviews. Prior to each interview I revisited the original first interview audio file and re-immersed myself in the data. From this I listed a set of points to discuss or revisit for each participant individually along with the broad question of whether they were still using II. For example, with Bethany and Helen the role of the II parent group had featured heavily in both of their narratives for differing reasons, I was keen to explore further the impact that attending the group had on their II use. Georgia was reaching a transition point in their family life at the point of her first interview, I was keen to understand if and how her II use had continued as their family circumstances changed.

Flowers (2008) presents the pros and cons of multiple interviews. The benefits include rapport building with the participant with further opportunities for disclosure. A second interview also provides the researcher with the potential to probe further into any missed opportunities from the first interview. The drawbacks to a multiple staged interview process can be at the analytical stage where analysis and writing up will be more complex.

Within this research project as discussed in chapter 3 I have kept a reflexive diary; I found this particularly useful to write in after each interview. This allowed thoughts and feelings after each interview to be attributed to each individual interview and supported alongside relistening to the audio files the second interview schedules and analysis of the data. One example of this from my journal notes is my initial impressions of the importance of the professional supporting Georgia with II. Her narrative contained lots of detail of the professional using II to build a relationship with Gerry. Moreover, together with the professional the family were looking for a residential placement that would use II. I reflected in my journal that I was finding it difficult to disentangle Georgia's II use from the professionals. I was struggling to distinguish her voice and experience in the narrative. Acknowledging this and reflecting on it I

decided to look more closely at her account prior to conducting the second interview. I particularly paid close attention to her use of first-person pro-nouns, this helped me to identify within the narrative the more personal experiences of II for Georgia. In Georgia's second interview the professional was no longer involved, and I was able to clarify some of Georgia's personal experiences of using II that I had identified from a closer examination of the first interview and reflections in my journal.

In the writing up stage any quotes used were clearly identified as to which interview they are from. This is in keeping with the hermeneutic nature of IPA, the dynamic circle moving between researcher and participant, the iterative process of analysis.

4.2.7 Interview modes

The interviews ranged from thirty to sixty minutes long for the first interviews, and for the second interviews slightly shorter, between fifteen to thirty minutes long. All but one participant engaged in two interviews; one participant chose not to have a second interview due to personal circumstances. Even though the second interviews were shorter in length, they provided valuable insights into how and why II use had continued, which would not have been captured without them.

The participants were offered a choice in the mode of their interview, either face to face or via telephone. This was to try to be more inclusive, so parents did not feel that to take part in the research they had to allow me to come to their home if they did not have access to another suitable space for the interview to take place. Telephone interviews are not uncommon in IPA studies as a mode of data collection (Murdoch & Chang, 2022; Spiers et al., 2020); they allow ease of access to participants who are geographically distant or have time constraints.

The first interviews were all was face to face, bar one participant who requested a telephone interview. With the second interviews a larger number of participants requested telephone interviews; some for practical reasons: they could fit it in easier around busy schedules and others because face to face interviews had been rescheduled due to illness. See table 3 below for details.

Name	First Interview	Second Interview
Abigail	Face to face	Declined
Bethany	Face to face	Telephone
Clare	Face to Face	Face to face
Elaine	Face to face	Telephone
Fiona	Telephone	Telephone
Georgia	Face to face	Telephone
Helen	Face to face	Face to face

Table 3. Participant interview modes

During the interviews I made sure to leave time to answer any questions prior to the interviews starting about the study and anything on the participant information sheet. I particularly drew the participants' attention to the right to withdraw from the study and that they did not have to answer any questions they did not feel comfortable about. Throughout the interviews I gave the participants time and space to narrate their stories at their own pace. If they did become emotional, I paused the interview and checked they were ok to continue. All the participants had my university email address, and I impressed upon them that they could email me if they had any questions.

Just as with any data collection method there are pros and cons to telephone interviews. They allow participants more flexibility with their time and the ability to pick a place in their home where they feel comfortable to speak freely. For some people, not being face to face with someone aids the process of discussing a potentially sensitive topic and facilitates inclusion in the research process (McCann & Polacsek, 2020). Mealer and Jones (2014) discuss the downsides of telephone interviews and techniques to alleviate them. The authors discuss how often rapport building can take longer as visual cues are missing from the interactions, but with skilful interviewing techniques and careful listening skills this can develop over the course of the interview. Techniques such as using more initial general questions and not worrying about pauses in conversation allow the participant to process their emotions and support the process. They recommend that the researcher remains active and engaged using active listening techniques. As the participant cannot see the researcher's non-verbal cues such as nodding encouragement to continue, phrases such as

‘please continue’ and affirmations become necessary throughout the interview (Mealer & Jones, 2014).

I found during the interviews that the mode of the first interview did impact on the feelings of rapport with the participants. Reflecting during and after the interviews I realised that during the telephone interviews it was harder to gauge the rapport with no access to the cues that body language provides as Mealer and Jones (2014) suggest. I found I needed more prompts for Fiona who asked for a telephone interview for both interviews. I also recorded in my reflexive journal after the interview that I needed to give more information about myself to build rapport and that I was very conscious of not being able to see her non-verbal body language. This made me wary of probing some questions as I did not want to risk upsetting her when I was not in the room with her, particularly as she discussed some difficult topics around her child’s mental health. However, the second interviews that were via telephone were easier as I had already met most of the participants in person and established some rapport with them.

McCann and Polacsek (2020) found in their study where all their interviews were telephone interviews that they recorded rich textual data and that the benefits of using the telephone outweighed the downsides. When I analysed the telephone interviews there was no difference in the richness and depth of the experiential accounts. Reflecting on the interviews afterwards I think that some of my consciousness of a potential slow build of rapport was around my own reliance on non-verbal cues. II is about tuning into someone and responding to them socially and emotionally, I prefer my interactions to be through a medium where I can see the person and respond to not only their verbal interactions but also the non-verbal ones.

The participants differed in their level of interest in my own experience; however, I found that having disclosed that I was also a parent supported the building of rapport in the interview situation. Some mothers asked me questions about my son and the things he did; not necessarily about my use of II but more generally about his autism. I tried to answer questions briefly without seeming rude during the interview and then once the interview had finished chatted further about the topics they had asked me about during the interview. Some of

these were around my experiences of using SEN transport and what my son's favoured activities were. I was mindful of the power dynamic during these situations and of my role as a researcher in that space, so I was careful about what I disclosed and any opinions I gave. I found that having the space to chat with the mothers informally once the interviews were finished was an effective way to debrief and make sure that they were ok after talking about what can be an emotional topic. It gave them space to ask me questions and for us to just chat generally.

This data collection was all carried out pre COVID and I wondered if it had happened later whether participants and I would have requested interviews via a virtual platform, which would have allowed the same flexibility as the telephone but with the ability to see the participant and utilise body language cues. As II is based around the importance of social communication and builds on the body language cues that your communication partner gives you, in retrospect offering a virtual platform such as Zoom may well have provided a happy medium for some parents.

4.2.8 Recording and transcription

IPA requires a verbatim record of the data collection (Smith & Osborne, 2015): in this case the audio files of the interviews. All the interviews were audio recorded on a voice recorder so they could then be transcribed and anonymised. The audio recordings were uploaded onto the University secure server and then deleted from the voice recorder. They are stored in accordance with the data management plan and ethics permissions (Appendix 2 on page 253 and Appendix 3 on page 255). The anonymised transcripts were also stored on the secure server and any hard copies for analysis were kept in a locked drawer.

Each transcript was transcribed verbatim. I made the decision to include extra linguistic utterances such as sighs and laughs and pauses in the transcripts. Smith et al. (2012) advocate that the transcript is part of the interpretation itself and the social interactions within the interview hold value within the analysis. Willig (2007) notes that in her phenomenological research study she felt she

struggled to capture the emotional tone of her participants' accounts with just the written word, and advocates for the inclusion of extra linguistic features in phenomenological research. As this is a research project about social interaction and social cues, I felt it was important to include more than just the words within the transcription. I included pauses, sighs, laughing, and although I did not include paralinguistic features (tone of voice, gestures, facial expressions) I did record if something was uttered particularly loudly or quietly or if a gesture provided context to a quote, such as clapping hands. The words alone do not give a researcher the whole story, and eliminating the non-verbal utterances leaves part of the participants' stories unheard. I felt that the extra linguistic features I included provided additional meaning and context to the mothers' words which supported the analysis process. The non-verbal cues we give when communicating are a valuable part of what we are communicating and can give added depth to our interpretations. Smith and Osborne (2015) state that for IPA semantic level transcription is ideal. For an example of transcription see Appendix 4 on page 261.

4.3 Data analysis

IPA has an idiographic focus with each case looked at in detail before patterns of convergence and divergence are examined across cases. The analysis is an iterative process committed to understanding the participant's experience of that particular phenomenon (Miller, Chan & Farmer 2008). Eatough and Smith (2017) state that it is important not to lose sight of the particulars of the individual experiences when the convergences and divergences are considered at a cross-case level. IPA has no set steps for analysis. Rather it provides a set of guiding principles (Smith et al. 2012). I followed these principles from Smith et al. Below I go into details about these principles and how I applied them to this research study.

4.3.1 Immersion in the data

I started the analysis by immersing myself back in the interviews through relistening to the audios and reading the transcripts. I found relistening to the audio files a useful way to reimagine myself in the interview situation and it helped to unite again the context into the written transcript, particularly when time had passed since the interview. Smith et al. (2012) advocate relistening to the audio at least once to support subsequent readings of the transcript. The repeated rereading of the transcripts helps to get a feel for how the rapport was developed throughout the interview and the overall narrative. Smith et al. (2012) argue that understanding how this developed within an interview supports with potential locations of rich in-depth data, as the participant was more likely to disclose such experiences once rapport was established. It also helps the researcher to grasp how sections of a participant's narrative fit together. This is the whole of the hermeneutic circle, a holistic overview of the narrative before diving into the iterative process of the parts. For each participant I analysed both of their interviews together, one after the other prior to moving onto the next participant, rather than analysing all the first interviews and then going back and analysing all the second interviews. I did this as the second interviews provided a longitudinal aspect to the data and were a continuation of that participant's story. Analysing them together before moving on enabled me to maintain the idiographic focus on each individual experience.

According to Smith et al. (2012) starting the analysis can feel like a daunting prospect and the initial readings of transcripts can feel overwhelming with lots of thoughts fighting for attention. They advocate the use of a reflexive journal to note down these thoughts, so they are documented somewhere but then set aside while the reading and familiarisation continues.

Upon starting my analysis, I felt both slightly overwhelmed and excited at the prospect of getting started. The overwhelming feeling was one of wanting to do my participants justice; they had shared emotional accounts with me, and I wanted to do a good job for them. I found the use of a reflexive journal invaluable: as Smith maintains, when reading the transcripts lots of initial thoughts and feelings threaten to overwhelm the process. Initial noting of those reflective thoughts supported this first stage of analysis. As an insider

researcher I found reading and listening to the transcripts an emotive experience; some of the mothers' stories resonated with me on a personal level. Using my reflexive journal gave me a way to document and unpick these somewhat. For example, Elaine narrates a story of Drew's first time of knowing Elaine was 'mummy' by tapping her when asked 'where is mummy' but this was tinged with sadness at the thought that Drew might never call her mummy. This story stood out to me at the time of the interview and again on reading the transcript because it resonated with my own experiences. Using the journal gave me a place to reflect on the reasons for this and separate my own experience from Elaine's.

I found that for some of my participants I asked the opening question, and they talked at length, naturally covering the other questions I had and requiring little prompts. For other participants I needed to ask most of the questions on my schedule, and they required more prompts. However, I expected this to affect the quality of the data, which to my surprise it did not. The interviews that required more prompts elicited just as much rich in-depth data as the interviews with very few prompts. In fact, the interview which had very few prompts I found the hardest to analyse and it took me the longest to do. This required me to spend a great deal of time reflecting on the interview and the process of analysis and what I was finding so difficult. I concluded that with very few prompts I had not been able to elucidate some of those experiences and therefore it took me longer to analyse. The process of prompting perhaps required greater engagement in the interview in the moment and through this co-creating of the narrative I was more involved in the sense-making at that time which aided the analysis later. Whereas the interview requiring very few prompts I felt covered lots of ground but in a very meandering way, I had to spend longer unpicking the experiences. The hermeneutic circle of the researcher making sense of the participant making sense of their experience was harder to enter.

4.3.2 Initial noting to examine the semantic content.

This is the most detailed and time-consuming part of the analysis process. It involved repeated reading of the transcript to identify the ways in which the participant understands and discusses the phenomena under analysis (Smith et al., 2012). Generally, this is split into different elements for each reading of the text: initially noting descriptive elements of the narrative and staying close to the literal meaning of the words. Then moving onto look at linguistic components of the narrative such as metaphor, repeated words, laughter, and fluency. The third element of noting is for more conceptual or interpretive comments. This is a very iterative phase involving moving back and forth between the data, looking to identify the participant's overall understanding of their experience. Smith et al. (2012) consider it important at this stage to draw on the researcher's own knowledge and understandings of the experience working within the hermeneutic circle. This involves using one's own pre-conceptions and new understandings to reflect on the data and probe what the meanings the researcher is noting might mean. As the researcher I came to the data with a set of fore-conceptions which as I read and started to initially note on the transcripts developed into new understandings. Taking the time to reflect on these altered my fore-conceptions as I further engaged with data as the iterative process continued. Smith et al. (2012) describe this entire process as a fluid process, moving back and forth through the data, underlining, and noting things as they occur. It involves close reading of the transcript, considering what the participant's words mean and why they may have used them.

The double hermeneutic is at work during this stage of the analysis, "the researcher is trying to make sense of the participant trying to make sense of what is happening to them" (Smith et al., 2012, p. 3). Eatough and Smith (2017) describe how the double hermeneutic also applies to the researcher delving beyond the literal meaning of the text to the 'hidden' meaning beyond. This involves the researcher both producing experiential interpretations which remain close to the participants' accounts whilst also exploring deeper layers of possible meaning within the participants' texts. The concepts of sense of self and feeling like a mum in the sub-themes 'Being accepted' and 'Becoming mum' are illustrative of this. When working iteratively on the participant accounts, I

became aware that something deeper than just the literal meaning of the mothers' words expressing enjoyment and joy at their interactions was occurring. Moving back and forth through the data, reflecting on what the participants were narrating I tried to make sense of the mothers making sense of their experiences. Through this iterative reflective process, I concluded that identity and sense of self were important factors of the mothers' experiences. For a detailed account of this see Chapter 6.1 and 6.2. I have highlighted some examples of the double hermeneutic at work throughout the two analysis chapters.

At this stage of the analysis, it is advised to have the transcript on pages with wide margins so that notes can be made in these during the differing stages of the analysis, either electronically or on hard copy (Smith et al., 2012). I decided to work on hard copies of the transcripts and for each participant I used an A3 artist sketch pad. I stuck the transcript down the centre of the A3 pages leaving room along each side for annotation at each level of analysis. I used different coloured pens for each different stage of this part of the analysis. The initial noting is annotated on the text itself and down the left-hand margin. See figure 2 for example page of A3 sketch pad. Each participant had an individual artist sketch pad with both their transcripts in.

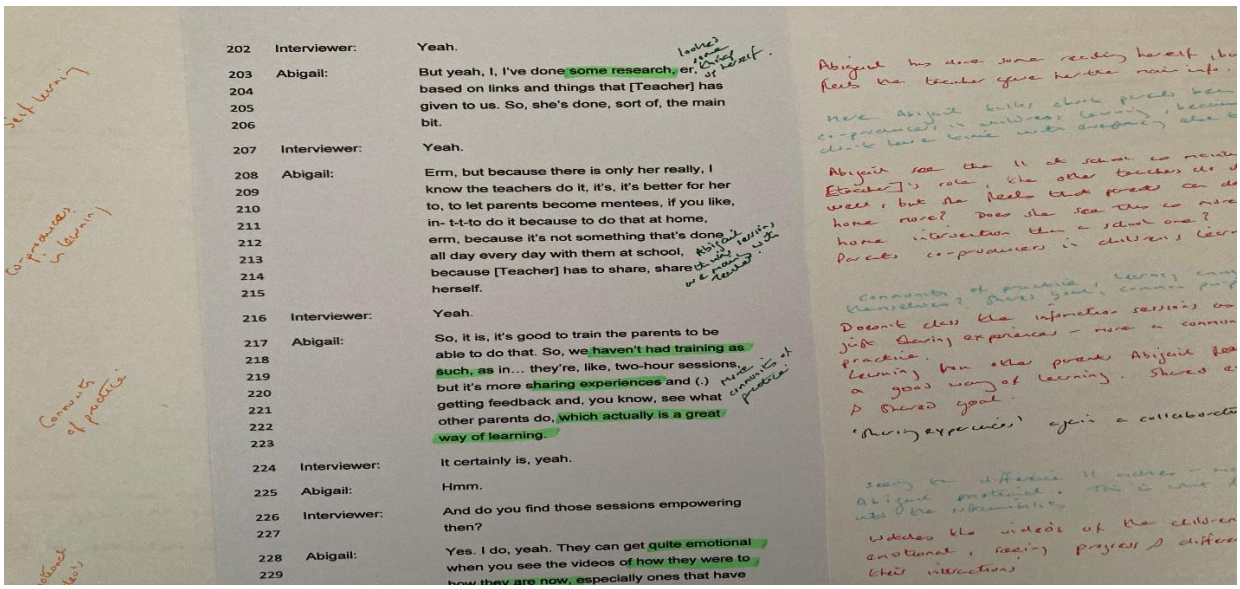


Figure 2. Photograph of A3 sketch pad used for data analysis

In the example above Abigail is discussing the parent group she attends. The highlighted green text are the initial words/phrases that stood out to me on the first reading. As you can see, I have highlighted phrases such as ‘some research’, ‘sharing experiences’ and ‘which is actually a great way of learning’. The green ink was used to make initial notes on the text and the red ink initial descriptive comments. These describe what is happening in the text, the fact that she has researched II a little herself and did not class the parent sessions with the teacher as training. The blue ink was used for the more interpretive or conceptual comments. As illustrated in the photo, you can see this is where I started to interpret what was happening in the text, such as ‘Here Abigail talks about parents being co-producers in the children’s learning…’ and ‘community of practice, shared goals, common purpose’. The black ink was used for linguistic comments, such as ‘shared experiences’, I noted illustrated a collaborate process, which was coming through in this piece of text.

For each transcript I used the same coloured pens and iterative process of repeated reading of the text to go through the steps outlined above. Working on hard copy as opposed to electronically appealed to me for this stage of analysis. It made the process more fluid as I could jot down notes easily and annotate on the text as well. This felt a more immersive way of analysing for me and enabled me to connect with the data more readily. Personally, there is something more immersive and physical in using pen and paper to analyse. I have always preferred to read a hard copy of something as opposed to an electronic version. I also found going back and forth with the iterative nature of IPA much easier on a hard copy. However, it also involved more work at the next stages when I needed to use electronic means to organise excerpts and themes.

4.3.3 Development of emergent themes.

After the initial noting the next step is to develop emergent themes. Developing emerging themes involves a move away from the transcript itself to the initial notes the researcher has created to produce short statements to summarise what the initial notes have commented on. Smith et al. (2012) call these

statements emergent themes. These statements map the interrelated connections and patterns across the data set (Smith et al., 2012). Smith et al describe how this involves working primarily with the initial noting the researcher has made and attempting to summarise what a section of transcript is about. The themes should summarise not only what the participant was describing but also the researcher's interpretations. It is advised to try to have theme names that speak to the psychological spirit of the text, if possible, at this stage. Each theme captures the key aspect of a piece of text but undoubtably the researcher is also influenced by the whole transcript at this stage (Smith et al., 2012).
In the photograph above the emergent themes are written in orange. At this stage I stayed working on the hard copies of the transcripts. In the photo example above, for that section of Abigail's transcript I wrote down the emergent themes of 'self-learning', 'co-producers in learning' and 'community of practice'. Other examples of emergent themes from Abigail's transcript included 'feeling known', 'affirmation', 'emotional well-being' 'power', 'resignation' to name a few. I jotted the emergent theme names down the right-hand margin of the transcripts.

4.3.4 Searching for connections across emergent themes, including overlapping and polarising themes.

The next step is to make connections across the emergent themes by deciding how they fit together. The objective is to move from a chronological list of themes to map them into clusters that belong together and produce an overarching new theme title for those themes. This consists of looking for patterns throughout the themes (Smith et al., 2012). Smith et al also recommends at this stage to produce files of themes with transcript excerpts relevant to that theme saved in them. This stage is once again an iterative process whereby theme titles are moved around to find the way they most make sense together.

Initially at this stage I once again worked in hard copy, I typed all the theme names out, printed them and cut them up so I could then place them on a table and move them around until I was happy with the groupings at this stage. I found that some of the theme names naturally fitted together. Once I was happy

with this, I then moved to electronic forms of documenting this. For each participant I produced a theme table with the groupings of individual themes (figure 3 page 118). Below is Helen's theme groupings. The emergent themes which were originally written in orange on the left margin of the transcript are in the middle column. The right column shows the mapping of the themes after I had grouped them together and developed a new overarching theme title for Helen.

This process was time consuming in the amount of time it took to move from hard copy working to electronic word documents. However, the process of working through the initial stages in hard copy meant that I felt I had a very clear knowledge of the participants' narratives and their stories. Working with the themes was an iterative activity. I found some themes naturally fitted together such as 'family bonds, building extended relationships and hanging out together' and others where harder to decide where they best fitted. I revisited the supporting extracts to reconsider what the data was saying and to reflect on the meanings in those parts of the participants' narratives. For example, in Helen's themes, originally 'pride in video' was placed with other themes around parent/prof dyad. However, on revisiting the data and reflecting upon it I decided that what actually was going on in that extract was to do with Helen wanting more involvement in the mentoring group and having a video deemed good enough to show to other parents as an example of good practice. Continuing reflection supported the process of grouping themes together. At the end of the process, I had word documents with relevant extracts in and from then on, I worked with these documents.

Helen	Being asked to play Permission to be late Becoming experienced Fear of rejection Pride in video Working way up hierarchy of parent gp Confidence building Intuitive Guilt Questioning parenting skills Importance/normalcy of play Community/support Family bonds Permission to play Building extended relationships Autonomy of child	**Looking for something** Importance/normalcy of play **Being known** Being asked to play Permission to be late Fear of rejection Confidence building Intuitive Guilt Questioning parenting skills **Identity beyond mum** Pride in video Working way up hierarchy of parent gp Becoming experienced Community/support **Connections**

	Child led positive and negative limitations shared activities learning journey together Hanging out together Videos to document progress Power of video Witnessing other like me logistics Intervention or just interaction Power lies with school Validation by teacher	Family bonds Building extended relationships Hanging out together **Common meeting ground** Permission to play shared activities learning journey together **Power balance** Autonomy of child Child led positive and negative Limitations **Hijacked play** Videos to document progress Power of video Witnessing other like me Logistics Intervention or just interaction **Parent/prof dyad** Power lies with school Validation by teacher

Figure 3. Example of theme table

4.3.5 Moving onto the next case.

IPA is an idiographic method, so each participant is treated individually. Moving onto the next case involves in some part starting afresh with each participant, trying to not let what has come before unduly influence the researcher to the new participant's experience. However, this is difficult and undoubtedly the analysis will be influenced by the analysis of the transcripts of previous participants. Smith et al. (2012) state that within the hermeneutic circle the researcher's fore-structures will have shifted considering previous findings, and these will influence the researcher as they move forward. Acknowledging these and trying to see the new case in its own terms to let new themes emerge is a key skill required for IPA research.

For each participant I had a new A3 sketch pad and the act of sticking the transcript into a new book psychologically signalled starting afresh to me. Moving through the various stages of the analysis, starting with relistening to the audio recording supported this. I also purposively chose the order I analysed the transcripts in, so I decided to not analyse the mothers in the parent group straight after each other. I felt this lessened the influence of their experiences on the next mother from the parent group. This meant I

interspersed the mothers from the parent group with the other mothers, and this supported the idiographic process.

4.3.6 Searching for patterns across cases

Searching for connections across the cases is the main process in this stage of analysis. Smith et al. (2012) describe how this can often mean reorganising themes and potentially relabelling them. The process of looking across the cases and searching for patterns can illuminate themes that were originally thought of as individual but later became apparent as representing shared concepts across cases.

At this stage I looked for commonalities across the cases and differences. I used the theme tables for each case to look for convergences and divergences and developed broad themes from them. For example, I grouped themes together that were about how the mothers came across II, and other themes that were about identity and relationships. Some themes joined with others and other themes split as their importance across the data became apparent. The initial themes grouped together under three superordinate headings (see figure 4 page 122 for details). I named these ‘Finding and learning’, ‘Connectedness and disconnectedness’ and ‘Identity outside motherhood’.

This was an iterative process and as the writing stages of the analysis began, I found some themes did not hang together correctly. Smith et al. (2012) argue that the writing stage is a part of the analysis and a continuation of the hermeneutic circle. The analysis does not cease once the researcher starts to write; it continues to illuminate and consolidate thought processes. As the researcher writes about one theme and the extracts, the researcher find may find they seem less important than originally thought or would fit better elsewhere in their narrative. This was certainly the case for me, I continued to interpret as I started writing up the findings and this gave me pause to reconsolidate some of the themes and move others. The result is illustrated in figure 5 page 123 below. As I started writing I realised that ‘Identity outside motherhood’ was not comprehensive enough to be classed as a superordinate theme in its own right. It was really a continuation of the learning process that

was going on for the mothers. Therefore, I turned this into a sub-theme in the ‘Finding and learning’ superordinate theme. I also renamed this superordinate to better reflect the experiences it represented for the mothers to ‘Seeking, finding and learning’. Equally ‘Learning to do less’ and ‘I was kind of already doing it’ were both about the same thing ‘doing it right’ so these two sub-themes became one. This also applied to the rebranded ‘Connecting’. ‘Fear of rejection’ and ‘I get down and we play together’ were two sides of one experience ‘Being accepted’. So, I merged these sub-themes.

Starting this process, I found extremely overwhelming: moving from being immersed in the individual cases and identifying what the findings were within these to exploring connections with the volume of data and themes was difficult. I was conscious of not wanting to miss out parts of the participants’ experiences. At times, the process was frustrating, and messy, with lots of refinement of themes involving going back to the data and reflecting on the analysis. As stated above this process continued as the writing process started, but putting pen to paper supported my thought process of what the data was telling me. Equally, frequent supervisory meetings throughout the long analysis process supported the iterations of the data analysis process and decisions around theme consolidation.

The next two chapters present the research findings for this study. Each chapter presents one superordinate theme. Chapter 5 ‘Seeking, Finding and Learning’ and chapter 6 ‘Connecting’.

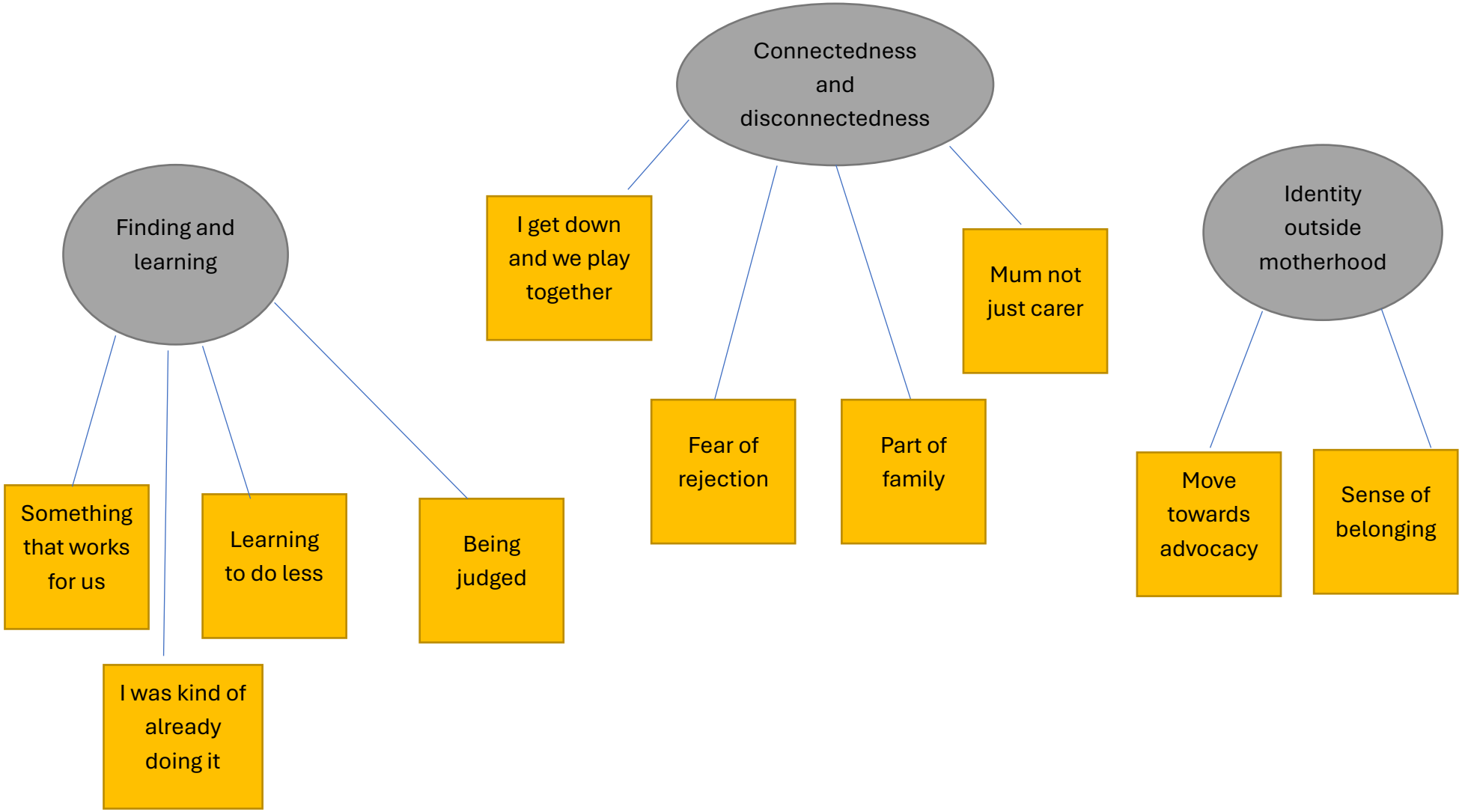


Figure 4. Initial 3 superordinate themes

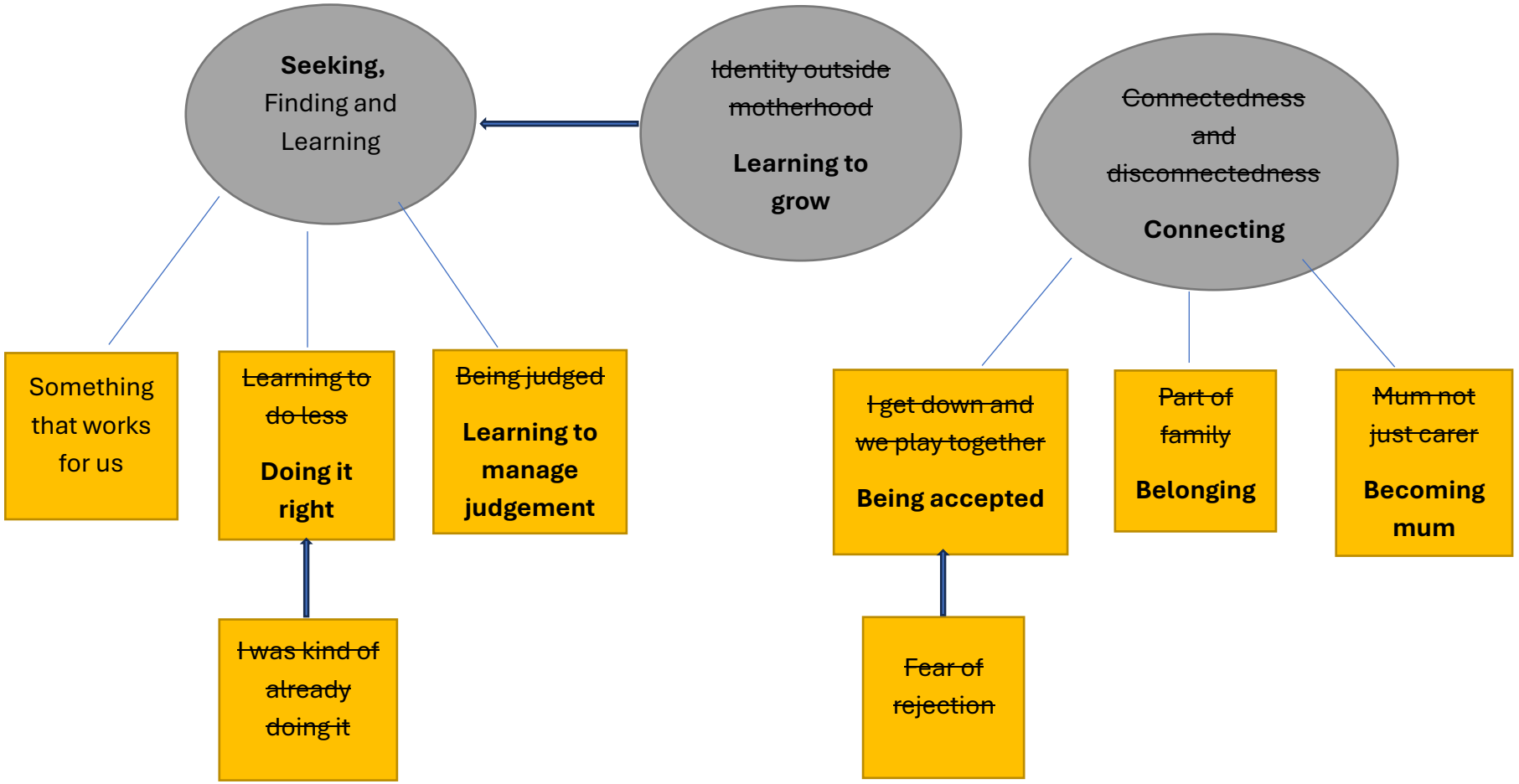


Figure 5. Final superordinate themes illustrating collapsing of themes and superordinate themes.

Chapter 5 Research Findings- ‘Seeking, Finding and Learning’

Chapters 5 and 6 present the research findings for this study. Chapter 5 presents an in-depth exploration of the superordinate theme ‘Seeking, Finding and Learning’. I start chapter 5 with an overview of the superordinate theme and the related sub-themes. The second superordinate theme of ‘Connecting’ is presented in chapter 6.

The thematic map (Figure 6 page 125) presents an overview of the superordinate themes and related sub-themes. From the central research question the two superordinate themes branch out, indicated by a blue arrow. The related sub-themes branch out further from each superordinate theme. For the superordinate theme ‘Seeking, Finding and Learning’ these are indicated by green arrows and for superordinate theme ‘Connecting’ these are indicated by yellow arrows. The numbers alongside the sub-theme titles indicate their position in relevant chapters. The superordinate theme and related subthemes discussed in this chapter use brighter colours and are highlighted in bold.

In keeping with the decision to use gender neutral names for the children in order to protect the mothers’ anonymity, the quotes presented in chapters 5 and 6 have had the pronouns changed to ‘they’, ‘them’ and ‘their’ to support this. This took a lot more work and consideration to make sure the excerpts included in the findings made contextual sense. One way I achieved this is by inserting the child’s pseudonym sometimes when the participants used a pronoun to refer to them for clarity.

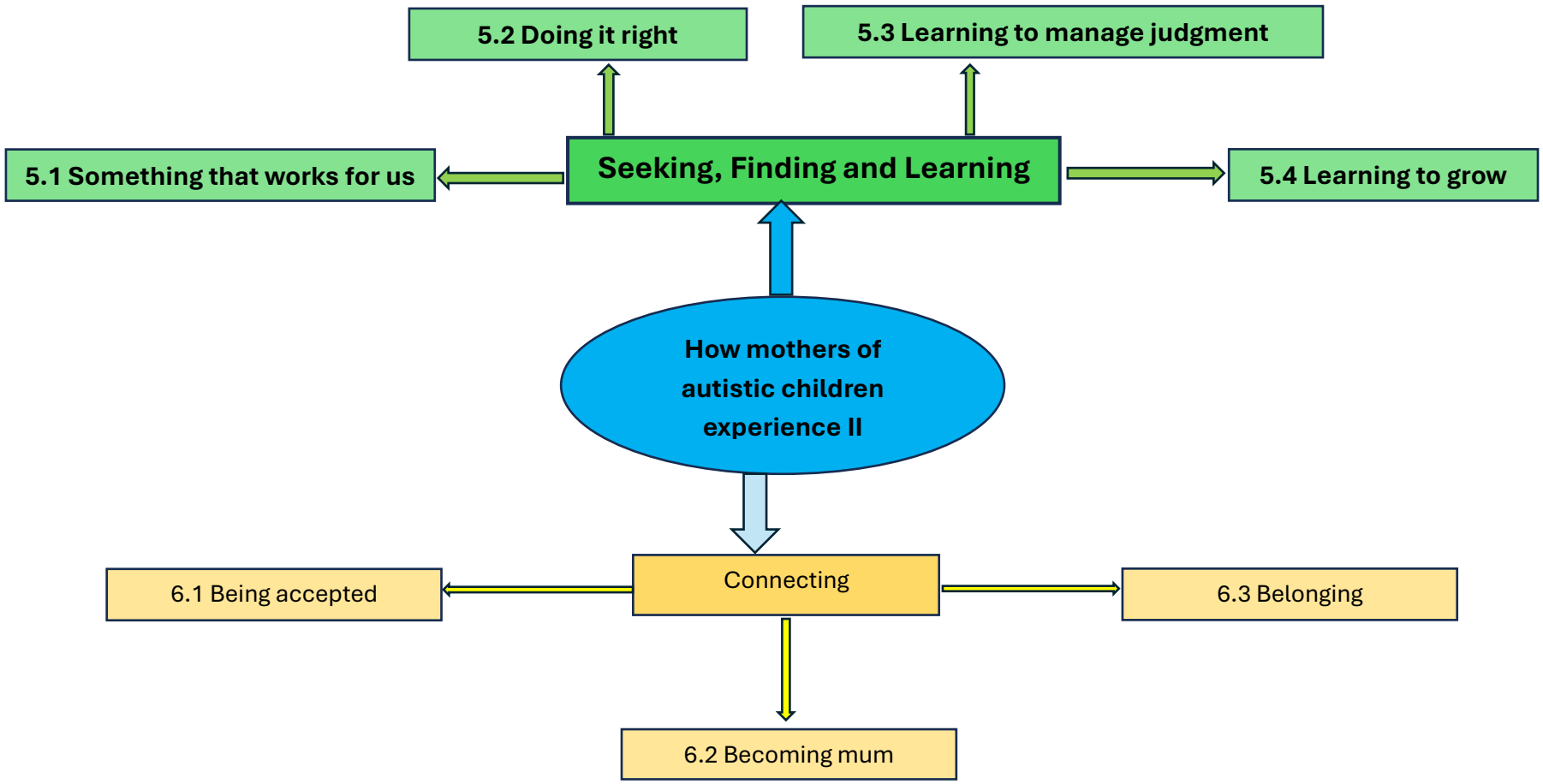


Figure 6 Thematic Map, highlighting superordinate theme ‘Seeking Finding and Learning’

‘Seeking, Finding and Learning’ identifies and explicates the mothers’ reasons for engaging with II. Here I narrate the participants’ experiences of looking for a strategy to support their child that worked for them as a family. The process of finding II and the subsequent learning for them as they practised becoming a communication partner, within II, is explored. There are four sub-themes presented in this chapter. These are:

- ‘Something that works for us’ considers the tension between the mothers knowing there must be ‘something’ out there and the litany of failed interventions which have threatened to deskill and demotivate them.
- ‘Doing it right’ explores the learning that takes place in using II. The mothers learn to adjust their own interaction styles through simplifying their behaviour and find an increased understanding of, and appreciation for, their child’s world. The mother’s experience validation of their interactions through a realisation of their own natural practice of mothering and/or through the approval of the professionals supporting them.
- ‘Managing judgement’ considers how the mothers navigate the ‘training’ aspects of II which involve elements of performance and ‘hijacked play’.
- ‘Learning to grow’ encompasses the ways in which engaging with II enables the mothers to move towards extended identities that are more than solely mother of a disabled child.

5.1 Something that works for us.

Something that works for us explores the experiences the mothers went through in seeking an intervention to make a difference for their family and finding II. The mothers in this study were seeking something to make a difference for their child for a variety of reasons, from support with development of communication to improving quality-of-life. Often beholden to the professional’s advocating strategies and interventions to try the mothers continued in their belief that there would be something out there to work for their family, they just had to find it. The experience of finding II involved elements of chance.

This cohort of autistic children may find that some of the routinely recommended strategies for autistic pupils such as visual timetables or social stories are not appropriate to meet their needs. This can leave parents themselves looking for strategies to support their child's development. The mothers in this study found that they had to employ a lot of emotional labour in the seeking of something that worked for their child and family, standing firm in the belief that there was something that would make a difference even after trying other interventions that had not been successful.

Elaine described how she had always been looking for something, right from the moment Drew was diagnosed:

> You know I've always been looking for something, always, I tried many things and nothing, so yeah I was always looking for something from the start. (Interview 1)

Elaine talks about looking for something from the start, this implies from Drew's initial diagnosis, and it has taken until now, with the use of II, to find something that works for them. Elaine has continued to look for something, despite the failed interventions that provided 'nothing'. Elaine has had input from professionals before for Drew. However, the strategies suggested by the professionals did not work for her child. Despite this Elaine turned once again to CAMHS when she needed support for Drew.

> Drew has been under CAMHS before and I was trying loads of different things and stuff and you know nothing really worked. (Interview 1)

She later goes onto to say:

> This is the start and it's massive you know, 6 and 71/2 years nothing you know and then since I started this boom (claps hands) loads of things it's amazing. (Interview 1)

Elaine's use of the word 'nothing' indicates the failure of previous interventions in producing the progress she was looking for. She clarifies what this means further:

> Just seeing Drew's progress you know, they didn't do this yesterday they didn't do this last week. You know it just makes me excited what is Drew going to do tomorrow, what is Drew going to do next week.

Elaine expresses optimism that this is something that will continue to work for them. There is a real temporal element to Elaine's narrative, before II and after.

All the mothers apart from one were using II under the guidance of a professional who introduced it to them. The professionals seem to hold the power to advocate which interventions the participants should use with their children; the mothers follow the guidance of the professionals. There seems to be little other choice, Elaine illustrates this in one of the excerpts above, even though the interventions the professionals recommended had failed to make a difference she still went back to the service.

What the mothers were seeking support for differed. Georgia and Fiona were both seeking something to make a difference to their child's quality of life. For both mothers II was much more of a last resort. They felt that they had exhausted most other possibilities. For Georgia II was one of the only things at school that seemed to work for Gerry: it was the time when Gerry was happy and safe and because of this it had become something they were looking for on offer in a residential placement.

> I just want Gerry to be happy. I just want Gerry to be safe and happy. I want Gerry to just be with adults and carers, whoever it's going to be, that they feel safe with. That's what Intensive Interaction is, because it's all on Gerry's terms, isn't it? (Interview 1)

Fiona was in the position of Riley living full time in a residential placement and Riley's needs not being met:

> So basically Riley ended up in their bedroom 24/7 for about three years. Not even coming out to go to the toilet or out of their room to eat. All very miserable, so Riley ended up on medication. Yes the staff would just leave them alone. (Interview 1)

Fiona and Georgia were seeking something that would support with emotional wellbeing. Something to enable the most basic of psychological needs; to feel safe.

Fiona goes onto to describe how she felt she had no voice and was being dismissed by professionals as the stereotypical overprotective parent. The

ethos of the services she came across were that they were the professionals and therefore they knew best:

> So it was all very difficult, and I didn't really realise the bad press that mothers have, that we're just emotional and overprotective and that sort of thing, so no one listened to me. (Interview 1)

The mothers' steadfast belief in continuing to strive for better for their child is evident in their narratives. The seeking continued despite failed interventions or the general positioning of disabled parents in society that left them feeling deskilled and undervalued. Fiona held onto the notion that there was something that could make a difference:

> But I knew Riley needed something, but I didn't really know what it was. That's when I came across Intensive Interaction. (Interview 1)

Elaine similarly described II as 'what Drew needed', Drew's right to something that will work for them. Again, this echoes the sentiment that there must be 'something' out there because the mothers felt that this was not all that life held for their child:

> I think this is what Drew needed you know. Because Drew's definitely very intelligent. (Interview 1)

Other participants were seeking support with communication or behaviour. Bethany wanted to see a change in Jamie's social interaction skills and said, 'I'm quite happy to give anything a try' (Interview 1).

Abigail wanted an intervention that would translate into the home environment because other interventions such as PECs were not successful at home: 'Ali will use them at school, but not at home' (Interview 1). Abigail explained further how Ali separated home and school activities:

> I know. It's so, it's so funny and, yeah, so lots of things Ali does, they separate between the two. (Interview 1)

The importance of having a successful transition of an intervention is evident for Abigail, because using II at home is her contribution to Ali's education. Ali enjoys school and Abigail seems to feel this acutely saying:

> And Ali just absolutely adores this school. Erm, as I sometimes say, I wish I knew what they did here (Laughter) (Interview 1)

This statement highlights the fact that Abigail would like something at home that Ali enjoys doing as much as school. It is almost as if she feels excluded that school are doing something for Ali which she has not so far managed. She seems to feel less capable than school in this role, marginalised and deskilled. The fact that Ali is engaging in II at home and it is 'theirs' is important to her:

> So, it is quite nice to have our little things at home that's separate to School. (Interview 1)

Clare was looking for something to support with promoting positive behaviour for Harley:

> One summer we'd been having, it was just before the- They were breaking up, we'd been having some challenging behaviour, erm, and Harley had been working with one of the, er, Intensive Interaction coordinators in the class, and they were saying how well Harley was, erm, coping and dealing with that. (Interview 1)

Even though the mothers' reasons for seeking support for their child differed, their accounts are laden with emotional labour. The seeking is time consuming and emotionally charged, with an ongoing belief from some that there was something out there that would work for them as a family; they just had to keep looking.

Finding II came in different ways to the participants. Six out of seven participants were introduced to it by a professional supporting either their family or their child. Fiona found II through a parent network. For some of the mothers finding 'something that works for us' had an element of chance to it. Georgia and Elaine were both introduced to II by professionals engaging in II training themselves who needed parents to work with as part of their course. Fiona's and Clare's narratives also depicted the fortuitousness of certain actions.

Fiona found II through a follower of her social media recommending it to her:

> No, it was actually – I used to [social media] and I got many followers, and a lady in [country], she emailed me and said, "Have you heard of Intensive Interaction?" Which obviously I hadn't. So a lady I didn't even

> know, she'd been following my [social media], just thought it would suit Riley. So then I googled it, and I was ecstatic, because yes, that's what I want. (Interview 1)

This highlights the importance of parent networks for information sharing and support; without social media Fiona may never have come across II. Fiona found II without the support of a professional almost by chance and had to evaluate for herself whether she thought it would be useful for Riley. As soon as she googled II, she saw her family represented within its community: it spoke to her straight away as something that could work for them. This resonates with Elaine's excerpt earlier in this chapter where she stated, 'this is what Drew needed', the mothers' belief that this was not all there was to their child's life, that there would be something out there that would make the difference they were seeking, they just had to find it. The seeking and finding was an emotional journey for the mothers. Fiona goes onto talk about the how emotional she found attending her first regional meeting of II:

> So I just went along to their regional meeting, which is a meeting of their practitioners … there was psychologists and play therapists and OT's. I just sat there, in floods of tears listening to all the wonderful things they were doing with people. (Interview 1)

This was a key turning point for Fiona: she had found what she had been seeking. The attitude and ethos of the people at that meeting were completely different to what Fiona had been dealing with up to then. She found some like-minded people who believed in the difference they could make to a person's life. This was a relief for Fiona, there was something out there; she did not have to give up on striving for better for Riley.

Being able to see yourself as represented within a particular community of practice is important so as not to dismiss a strategy as 'not for us'. Clare sat in on the II workshops at her child's school but felt it was not something that would work for them. Harley uses speech to communicate, and Clare was looking for something to promote positive behavioural change. She did not see Harley or herself as represented in the workshop with its focus on children who are non-speaking:

> So whenever I'd heard about Intensive Interaction, I always thought it could only be used for children with- That were non-verbal. So I sort of dismissed it before, er, until having the conversation with [teacher], and she said, "Oh, no, absolutely not." So, erm, that was always a misjudgement of mine. Erm, yeah, because of the videos I had seen of other children, you know, where they were completely withdrawn and non-verbal and then, you know, drawing that, that verbal communication out. (Interview 1)

Clare blames herself for not understanding that II could be used with children who use speech to communicate, rather than the way the information about II was portrayed to her. Generally, the information surrounding II is focused on non-speaking users and children with high needs. By her only being introduced to videos of non-speaking children, this reinforced the idea that II was not for her child. Clare's experience suggests that seeing children with similar profiles to their own is key to mothers having a sense of resonance; I am watching families like mine, and I can visualise using it with my child. Without this sense of belonging, it can be easy to dismiss a potentially useful strategy. It took the act of Clare approaching school for support with Harley's behaviour and school saying they had successfully been using II with Harley for Clare to realise II was for them. Watching videos of Harley using II gave Clare the realisation that II could be used with speaking children as well. It was fortuitous that Clare reached out for support to the school:

> Once I'd met with [teacher] and we'd spoken about, that Harley had been doing it in class and you know, and that she showed me some videos, erm, so, yeah, so I took it away that summer and started doing it at home. (Interview 1)

Throughout some of the mothers' narratives there was a level of scepticism expressed when they first found II. Elaine was surprised by the simplicity of II; she perceived II as easy and uncomplicated and this made her sceptical. Elaine's judgement on the validity of an intervention was based on its level of difficulty. She talked about the simplicity of II in relation to other interventions she had come across, that were expensive, time consuming and she felt she would not know where to start. Elaine had researched some of the highly

marketed interventions for autism which involved a large financial cost. In comparison II was accessible and free:

> I was looking for something and I was always very interested especially in the Son-Rise program, coz just the videos I'd seen about it, you know was just wow. So yeah but it's really expensive and you know what you have to do and where do you start and when [professional] brought this to me, I was like wow this is so simple, so easy wow. So, I was a bit sceptical you know because it was so simple you know but yeah, it's amazing like wow. That something so simple can you know it's incredible. (Interview 1)

However, Bethany's scepticism was at the speed with which she achieved desired results with Jamie. For her the increase in levels of interaction and engagement between them when using II surprised her:

> You could see, and I guess, erm, you know, I went into it with, kind of, hoping that… you know, I'm quite happy to give anything a try really, erm, but just pleasantly surprised how quickly, seeing (.) improvements in the way that Jamie was engaging with me. (Interview 1)

This seems to set II apart from some of the other interventions they had tried with their children and was a positive for the mothers; this was an easy simple intervention that showed improvements in the areas the mothers wanted.

For Georgia though her scepticism was more around the benefits of II on Gerry's communication. So even though finding II enabled Gerry to feel happy and safe, Georgia did not feel it had developed communication skills, even though she admitted the professional supporting her might not agree:

> That's not changed, even with Intensive Interaction, I don't think that's changed. I'm like well [professional] might say, "Well actually, no I disagree." From my point of view, that's still the same (Interview 1)

Georgia's scepticism is ongoing even with the benefits she sees for Gerry, there are other areas that II purports to develop but Georgia has not witnessed these changes in Gerry. For her II has only delivered on some of its promises. The professional does not share this view, perhaps because Georgia is looking with a wider view of what progress in communication looks like (using symbols or

speaking) and the professional is thinking about the small steps of progress with the fundamentals of communication.

Finding II for the participants involved both feelings of resonance and initial doubt. The accounts narrate tales of fortuitousness in the finding of II, rather than II being a recommended intervention such as PECs (Bondy & Frost, 1994). For these mothers it was dependent upon the professionals supporting them being advocates for II or signposting by other parents. The feelings of resonance with II and being represented within its community seemed to be of key importance to some of the mothers in their willingness to try it out. For others they were willing to try anything recommended to them. The whole seeking and finding process for the mothers is emotional filled with anxiety, frustration and determination. Their experiences then move through emotions of relief which for some is tempered with scepticism.

5.2 Doing it right

In finding out about II to support their children's development the mothers became the learners, revaluating their own interactions styles, and taking a step back, simplifying their own interactions to find a common meeting ground with their child. The mothers learned to embrace II's simplicity and by altering their own interactions they saw the benefits of adopting a seemingly less complicated interaction style. The mothers' experienced learning it is okay to do less and let go of the feelings of guilt bound up with this. Through increasing their understanding of social interaction, the mothers' experienced validation of their pre-existing interaction overtures with their children. Alongside this learning and the positives, the mothers see in their interactions with their children they experience feelings of frustration when progress stagnates or does not continue at the initial pace.

Even though II is viewed by mothers as a simple intervention, it was not always easy for them to achieve. As the adult they naturally tended to try to drive interventions forwards with set outcomes that they were hoping to achieve. In learning about II the mothers were realising how their own interaction style differed from their child's. The paradox is II being seen as simple and yet it

involves a learning or re-learning from the mothers. II is about meeting the child where they are with behaviours they find meaningful. The mothers become the learners and through using II gain insight into their own interactions and an increased understanding of their children. This could be a mindset change for the some of the mothers. The mothers explore below learning how to simplify oneself and interact in another way.

Georgia described this as uncomplicating yourself, and tuning into your child, to look at what they find meaningful, which for many children will not fit with their chronological age:

> That was the thing that made me really think, “Actually, we over complicate. I over complicate things.” Just talking about, thinking about where Gerry is developmentally. What you do, the way that you sometimes interact with Gerry is too complicated for them. Gerry can’t get to that level. What you’ve got to do is you’ve got to uncomplicate yourself and bring yourself down to a level that they understand. (Interview 1)

She talks about looking at where Gerry is developmentally and using this benchmark to set her interactions at, bringing herself down to that level. As the adult she is altering her interactions to meet Gerry, not expecting Gerry to meet her and this is a different way of thinking for her.

Clare also uses ‘getting down on their level’ to describe her interactions with Harley: ‘It was so bizarre, sort of getting right down on Harley’s level’ (Interview 1). The concept of simplifying oneself so the child can understand is different for mothers who are used to interventions which require the child to do things they find difficult; II requires meeting the child where they are at and embracing that. Clare found it strange that it was her who had to alter her interactions rather than her child. As the mother you are not trying to ‘teach’ them anything but connecting with them where they are and through this approach the learning happens. II initiates this learning, the child is modelling, and the mother learns from this how to simplify her interactions.

The use of the phrase ‘down to a level, getting down on their level’ may have a double meaning here, meaning both adjusting yourself to where your child is developmentally and physically getting down on their level. II advocates

mirroring body position, so if the child is sitting, you sit, if they are lying down you lie down. Once again this may be a different way of interacting for the mothers as generally parents tend to stop lying on the floor with children once they get beyond their toddler years.

Clare talks about learning to adjust her own interaction style; to allow those pauses for processing and accept that it is okay to be doing nothing, just waiting for Harley to be ready to re-join the interaction:

> You know, not having to fill all the air with speech. You know, sometimes I forget how long it takes Harley to process things, and Harley does need that time, erm, to process. And I've learned that that's okay and we- I can just, you know, get along and play and when Harley's ready, you know, come back in and pitch back in with something. (Interview 1)

So even though II is seen as simple it has still meant the mothers looking at their own natural interaction style and making adjustments. The mothers described this as them learning, so it is not the child that has to do something different in II, but the onus is on the adult to alter themselves to fit in with the child. The sense was that for some of the mothers this differed to other interventions they had used, where the child fitted around their agenda. This had been a change in mindset for the some of the mothers.

Georgia goes onto discuss how she has had to adjust to not driving things on, learning that it was okay to interact at a pace that suited Gerry and finding acceptance that this was okay:

> As I said, it's just uncomplicated, isn't it? That's been quite hard to know it's okay not to try and make it into more than what it is for Gerry but just keeping it very simple for them. (Interview 1)

Again, there is an element of emotion in this learning. In both above extracts Georgia and Clare describe learning that it is okay to do less. This simple interaction style takes effort on the part of the mothers, they are the ones learning, or relearning. This is linked in with the phrase 'getting down on their level' that the mothers use; this signifies lessening oneself and perhaps working at this level is perceived as holding the child back or patronising them. Typically, as a mother you would be striving to push your child forward. The 'getting down

on their level' phrase can be linked with negative connotations but with II this is what is required for the intervention to be successful.

Elaine reflects on this, her own feelings around mirroring Drew's behaviour. She talks about how she felt nervous about doing this and when Drew responded negatively Elaine put this down to Drew perceiving her as 'taking the mick':

> Yes because we started I obviously felt really nervous and stuff, I literally just had to sit there and respond to Drew making sounds and I thought oh my god but at first Drew got quite angry with me because kind of thought I was taking the mick out of them you know Drew was annoyed with me. (Interview 1)

Behaving in this way felt wrong to Elaine, it felt as if she was making fun of her child's communication difficulties. However, Elaine goes onto to say:

> And yeah it was difficult at first, but it was just so easy after that, once I knew what I was doing you know it was just natural you know. (Interview 1)

For Elaine learning about II meant that her mindset moved from something perceived as initially difficult or uncomfortable, as it was a different way of interacting, to something which felt natural.

Abigail also talked about II taking you out of your comfort zone. For her the change in mindset was towards one of letting go and enjoying the freedom that interacting in a more childlike way can bring:

> Ali thought I was nuts, (Laughter) but, erm, that's, that's quite a big part of it actually isn't it, is being nuts. You need to let your hair down and do what they do. Erm, once you, sort of, get in there, if you like it and make it fun, they realise. (Interview 1)

She acknowledges the awkwardness of how this made her feel 'once you, sort of, get in there' and how Ali perceived this as atypical behaviour for her.

Helen discusses altering one's sense of what a parent should be doing, moving away from a mindset that her role as a mother is to make her child do x y and z. Instead, what was required now was doing less and waiting for the child to respond, just being ready and available for them and not driving the interaction

on. Using II has supported Helen to learn to take a step back and slow down. This style of supporting your child within a strategy is different to what Helen is used to doing.

> Yeah, because [teacher] says don't push them if they don't want to do it. If they don't want to do it, don't do it, erm, whereas you tend to think you need to make the child do things, don't you? And so we've learnt that if Charlie's not doing something, that's fine. We're not doing it. Erm, then there was also that thing where you don't, kind of, get them to hurry up what they're doing just to fit in with what you need to do. (Interview 1)

This adjustment in interaction style and simplifying of oneself seems to produce feelings of anxiety or doubt initially in some of the mothers, 'hard to know it's ok (Georgia); I've learned that it's ok (Clare); I thought oh my god' (Elaine). There is a learning process involved for the mothers in understanding how and why to pare their interactions back and tune into their child. This is an example of the double hermeneutic, as the researcher I am making sense of the participants making sense of their experiences of learning about II.

Part of the mothers' learning was about the flexibility and adaptability of II. Bethany discussed how because of the simplicity of II you do not need lots of resources and this in her view made it much more flexible and inclusive. II does not require you to be able to access printable resources or mean when they get lost or damaged you are beholden to professionals for reproducing them for you:

> And I think it's… to me, that's what makes Intensive Interaction such a great intervention because you don't feel like you've got to make 300 resources and print out 5- you know, 30 pictures and have duplicates of all these different things in order to be able to have some kind of meaningful interaction with your child. It- that's- you don't have to have anything. You can just go with it, and that's what I think makes it so, kind of, useful as an, as an intervention really, because you don't have masses of time or ways to be able to do all of those things, or necessary, the sort of, skills to be able (Laughter) to do it. (Interview 1)

To have a 'meaningful interaction' with your child you just need you; it does not rely on anything external and fore-fronts you as 'mum'. Instead of needing

special equipment to communicate with your child you can just be you and this makes it feel more inclusive and less of a setting apart from other families. Bethany feels empowered using II, in part because it does not rely on a professional to keep it resourced and is something that she can fit in with family life in a way that suits her.

The flexibility extends to timing as well, Elaine described how if she had to find a specific set time to sit down and do II it probably would not happen: her life is busy and finding set times for things is tricky. The fact that II can be done anywhere and anytime works for her:

> Like I said I do it when I can and like before bath and you just do it you know. Within your usual routine, like it is busy if I had to find specific times for it you know to go sit and do you know I'd probably not. (Interview 1)

Helen talks about the flexibility of being able to use it when they are out: she did not realise she and her child were using it in different places other than the home. It translated into different environments, and it was only when Helen learnt about II that she recognised this was what she used in those spaces to interact and connect with Charlie:

> Yeah, it… yeah, we, we didn't realise we were doing it in places like the supermarket, and people must have thought we were bonkers, some of the stuff we do in the supermarket, but you realised, actually, that's what we're doing. (Interview 1)

Fiona discussed the adaptability of using II with Riley when they came home for a visit:

> It actually opened my eyes, that instead of just being with Riley, I could actually use it for things. So I didn't realise I could, so if Riley started head banging or something, that I could actually use it. Or when Riley was in the old home, they would cry a lot, and I started using it when Riley cried and that made a huge difference as well. So I realised it had applications, it wasn't just a passing the time type of being with my child. I could actually make a difference with them. (Interview 1)

Fiona realised that she could use II to support Riley when they were distressed and that as well as enjoying spending time together, she could use II at these difficult times. This empowered Fiona to feel that she was making a difference to Riley's wellbeing.

The mothers' increased understanding of their child's view of the world and acceptance of where they are enables them to have confidence in accepting and supporting their child wherever they are developmentally, whilst still striving for better for them.

Elaine explained how learning about II has increased her understanding of Drew and this in turn means she feels she has more patience with them. She described this in the context of an increased connection and enjoying activities together:

> I just feel like I understand Drew a bit better, and I have a little bit more patience. It's little things but you know it's definitely helped I understand them more. (Interview 1)

Through this increased understanding the mothers are finding a common meeting ground with their child, a way to share their time together in a meaningful way. Georgia explains how learning about II has meant she now recognises how her interaction overtures impact upon Gerry:

> That was interesting actually because there's times when I'm with Gerry and I think I'm doing the right thing. Then I've started to reflect a little bit on how I'm doing things with them and thinking, "No, that's going to switch Gerry off. It's not going to switch them on and keep them interacting as long. It will just switch Gerry off." (Interview 1)

Georgia expands on this describing how without knowledge of II she would never have thought to join in with Gerry's favoured activity:

> But we weren't going alongside Gerry in the same way if that makes sense? I would never have thought to stand by Gerry and [favoured activity] with them. I would never have thought to do that. (Interview 1)

Georgia refers to it as 'going alongside' Gerry, to join in with them and show them that this is something they can do together.

Clare also discussed this, describing how II not only increases her knowledge of engaging in a meaningful way but also boosts Harley's sense of self. Thereby making Harley feel valued by the things they enjoy being recognised and acknowledged:

> Erm, so just being able to enjoy Harley's world and- Erm, and then giving Harley that, erm, self-confidence that, you know, "Oh, people want to enjoy the things that I want to enjoy and, and I'm important" sort of thing. (Interview 1)

This enjoyment of the child's world is about the mothers adjusting their behaviour to meet the child where they are at rather than the children joining in activities on the mother's agenda. The mothers find value in this and the insight it gives them into their child. Clare revisits this point in her second interview when she explains how II has enabled her to access Harley's world rather than expecting Harley to access hers. Clare feels this impacts on Harley's sense of self and this is important to her:

> 'It's… it's opened up me into Harley's world and, erm, you know, us enjoying time together. Erm, and I guess it's like their self-worth, like, oh, "I'm worth listening to," and things like that. So, yeah. I… I love it.' (Interview 2)

II has enabled Clare to increase her understanding of the things that interest her child; she is more tuned into Harley, and this means she can recognise opportunities to interact with them in a more naturalistic way, fitting it into the flow of the day, rather than it always being a set session. Clare describes herself as always listening:

> Yeah, all the time. I'm always listening for what Harley's doing so then, you know, later on … I can interject with things, and Harley loves that. (Interview 2)

Clare talks about how this is the way she was taught about II: to always be on the lookout for opportunities. This seems to be part of the journey towards becoming more intuitive.

The increased understanding that learning about II brings also extends to other people supporting the mothers' children. Fiona discussed how the use of II has meant the staff supporting Riley have an increased understanding of Riley and the things they enjoy. This has enabled the staff and Riley to build relationships, and Riley has started to trust the staff supporting them:

> So it has actually made Riley enjoy – Riley's got closer to staff, because they understand Riley ... I think it's brilliant for building trust it is one of the main things for them. (Interview 1)

Finding this common meeting ground has enabled Riley to start to engage in activities outside of their room:

> So we're finding things Riley either hasn't done for a long time or because the way that things are being done with Riley, they're realising they actually enjoy things, more than we realised. (Interview 1)

Similarly, Helen has found that learning about II has opened up activities to share with Charlie which previously she could not:

> Well, yeah, Charlie seems to want it more now. Like, every night, we can read a bedtime story. Some days, you'll read 10 stories because Charlie just wants you to constantly read to them, whereas before, you could not touch Charlie's books. It was Charlie's, they read and that was it, but now Charlie will read to us or we'll read to them, or we'll read it together. (Interview 1)

Having that increased understanding and joining in with Charlie through II has enabled reading to become a joint activity, a time for connection. This is important for the mothers; Helen's primary reason for engaging with II was so she could play with Charlie and enjoy doing some of these typical activities with them. Adjusting her own interaction style and finding this common ground has enabled this.

The learning experience brought about feelings of validation for some of the mothers: self-validation around a realisation of what they were already doing with their child. This is part of the learning the mothers are going through, the increased understanding of their own interactions and reflections enables this

validation process. For some of the mothers there is a realisation, an ‘ah ha’ moment where they think I am a good mother, I do interact with my child. For some of the mothers this meant they only needed to adjust their interaction style slightly to get the best out of the interactions. Helen reflected on this:

> [Teacher] did a talk on it (..) and when you're sitting there and listening to her, you actually realise, “Well, I do that, I do that, I do that.” You do it in silly places like supermarkets, (Laughter) and you realise that, actually, you’re doing loads, and you may not think you’re interacting with the child, but actually you are, (Laughter). (Interview 1)

Helen experiences learning about II as confirmation that she did interact with her child but just did not realise it. The process of sitting and listening to the teacher explain what II is, and how you do it, enabled Helen to reflect on her interactions with Charlie. This brought about the realisation that this was something that as a mother she already engaged in with them. Only when they do this do they realise how much they already do, and this gives self-validation. For Helen this is important; later in the interview she revisits this point:

> Once you know what you're doing (.) and see that you’ve actually been doing it before, it, kind of, gives you a little bit more confidence in what you're doing with your children. I think you, kind of, think, “Oh, I don’t do enough because they don’t respond to anything,” but actually, when you see- go to that first meeting with [teacher], you realise you’re doing a lot more than you actually thought you were. (Interview 1)

This highlights how a lack of expected response from a child can lead mothers to feelings of guilt that they are not doing enough or even are not a good parent. For this mother it takes a professional to talk about social interaction for her to realise just how much she was doing but that she just needed to adjust it slightly. For some of the mothers in this study the professionals hold the position of expert, they hold the power to show mothers they are doing the right thing. Helen explains:

> And you realise, actually, you were doing it the whole time in a slightly different way. (Interview 1)

This links back to earlier in this theme; Helen has learnt through her knowledge of II how to adjust her interactions and build on what she was already doing.

Elaine also discusses this point but for Elaine, however, she gives the impression of slight frustration. She was already sort of using it and if she had found out about it earlier then she would have been 'getting so much more' from Drew sooner:

> Err. Well to be fair I was kind of using it, (sighs) but I was kind of leading it, more than basically just leading it (laughs). So now it's Drew leading it so it's different but it's a different you know approach but we're still kind of doing the same thing but I'm just getting so much more from Drew you know than the old way (laughs). (Interview 1,)

For Elaine and Helen this validates the feeling that I do know how to interact with my child and all we needed were these small adjustments. These mothers went into this thinking there was something they were not doing, but they were. II gives the validation to pre-existing relationships and supports in extending them for some of the mothers. The naming of their interactions makes it become an intervention, the mothers are carrying out an intervention with their child and this chimes with the 'something' the mothers were looking for in the first subtheme. This enables the mothers and shifts the power balance away from the professionals towards them. For these mothers this validation seems important, they discuss how learning about II has legitimised or increased their understanding of their child and the need to simplify oneself but also raised their awareness of what they already were doing and given a basis to build on that.

Fiona describes below how she has always used II without realising it but only through labelling it as an intervention has, she recognised the value of it:

> But I think I've always used it but just didn't know what it was. Because obviously as a baby, when they're a baby you use it, but because Riley didn't develop as usual, obviously I just carried on using it. It was just something we did. I never thought anything about it, I didn't realise it was actually a thing. (Interview 1)

She states that she never stopped using II, that it just continued as a way they interacted together because that was where Riley was developmentally. To

Fiona II was intuitive, a natural way a mother would interact with their child, and she did not stop when Riley reached a certain age. Learning about II has legitimised the way her instincts told her to interact with Riley and the way she wanted the residential home to interact with them. For some of the other mothers this was a different experience, using II meant them revisiting different interaction styles that they had perhaps moved away from as their child grew older.

For Fiona, the validation was in the affirmation that what she wanted for her child was not unreasonable, the organisation she found provided this. This gave Fiona the self-belief that she had been right all along, there was something better out there and she was right to employ emotional labour in looking for it. II acted as repairer for the other failed interventions and dysfunctional parent/professional relations she had encountered on her journey:

> Well, to believe in myself that it wasn't just me wanting this. It's not just there's a group of other people but up and down the country, yes, it is happening. It can happen. Reassurance that what I was wanting was right and could be achieved. Yes, just other people with the same outlook as me. (Interview 2)

Another aspect to the learning process for some of the participants was the way II became part of the communication repertoire of the family. It moved from being an intervention to a way of being. Bethany describes this:

> Well, I think we definitely… like I say, it's permanently embedded into the way that we communicate with each other. So, I don't really see that kind of, changing. (Interview 1)

In the second interview Bethany talks further about II being part of everyday communication with Jamie:

> Obviously, Intensive Interaction with Jamie, it's, it's just kind of, just part of the way we roll within the household now, you know? (Interview 2)

Fiona also describes II as a way of life:

> That connection, it's just so deep and meaningful. Because, I think severely autistic people, it is difficult to always engage with them, but

> with Intensive Interaction you can always. So it's just a way of life for us. (Interview 1)

However, as much as II is just a natural way of them interacting, Bethany still looks to the teaching and learning aspect of II. This causes her some frustration at Jamie's reluctance to engage in anything that is not initiated by them and feels this limits the number of opportunities for her to use II more as a teaching tool:

> I guess Jamie's got very, erm…, kind of, mindset at the moment, anything Jamie perceives as being (.) not initiated by them, Jamie doesn't really want to have anything to do with. So, the kind of, days of having… you know, maybe, kind of, setting up a scenario that you would like to, kind of, encourage them, which maybe would feed in to, kind of, maybe drawing out some new vocabulary or whatever, erm, yeah, has, kind of- we've hit a bit of a stumbling block with that, but hopefully we'll, we'll get back on track with that. That would be something that I would like to be able to do. (Interview 1)

Bethany is not the only parent to feel this frustration with some of the initial bursts of progress plateauing and the opportunities to use II to increase communication becoming less frequent.

Elaine expands on this describing in her second interview what their II sessions looked like:

> That's what every interaction session turns into you know. It's signing you know, it's very much with Drew's iPad, I've got to sign what Drew's watching and things like that. But I have to say Drew is understanding a lot more. (Interview 2)

The initial burst of progress is tempered, but Elaine is aware that there is no magic wand and that it is a case of keeping going with the things that make a difference, II being one of them:

> Because there's not much they can do for Drew now, Drew's got a plan that they've got to follow, and you know it's just keeping up with that really. (Interview 2)

This is a realisation of the long-term reality of caring for a disabled child.

Clare equally would like to develop II into other areas, in her second interview she described how they used II at that point:

> Yeah, I mean, because erm, Harley's got the speech there, erm, you know, that… that… that's there and although I am trying to develop it in different areas, erm, but Harley likes the mimicking side of it (Interview 2)

Going onto to say:

> Erm, but, er, yes, so no, it's… it's… it's pretty much on the same path and we haven't really bought it on, er, anymore since then. (Interview 2)

Even though for some mothers II has become a more intuitive way of interacting, the initial progress the mothers witnessed leaves a desire to continue with that progress. However, the plateauing in the development of their children that the mothers' experience brings a resignation with it. Nonetheless, it does not seem to deter the mothers from continuing to use II.

In summary 'Doing it right' is about the mothers looking beyond any initial scepticism and embracing the simplicity of II, for some altering their own sense of what a mother should be doing and adjusting to the shift in agenda from their own to their child's. For others it confirmed what they were already doing and empowered them to make minor adjustments to enhance their interactions with their child. Through this learning the mothers become aware of their own interaction styles and any adjustments that might be useful for them to make. The labelling of II as an intervention seems to support a lessening of guilty feelings around doing what could be perceived as very little and encourages mothers to go with the flow and fit II in with their usual day. It takes the pressure off the mothers to be doing an intervention at set times of day and frees them to enjoy spending time with their child, at whatever stage their child is developmentally. The paradox of the mothers naming the intervention as simple but the complicated learning and realisations taking place for the mothers, as they increase their understanding of their child, is evident throughout their narratives. This increased understanding leads to the mothers finding a common meeting ground for their interactions and through this they find alternate ways to be and spend time together.

5.3 Learning to manage judgement

This sub-theme is around the scrutiny the mothers find themselves under whilst learning about II, from the professionals supporting them or the videoing they underwent as part of the learning process. The mothers expressed positive benefits of affirmation of 'doing it right' and negative aspects of performing parenthood. Tangled up with this judgement was the influence of societies normalising gaze on the mothers' experiences.

Six of the seven mothers in this study were engaging in II with the support of a professional. These professionals were providing differing kinds of support. Part of this learning process involved them videoing their own interactions or being watched whilst they interacted with their child. Videoing is not an integral part of learning within II but as the mothers' narratives unfolded it became apparent that it was a part of this group of mother's experience of learning about II. Four of the mothers were part of a parent group who used videoing and feedback to support each other and enhance their own practice. The two other mothers were both involved with professionals who used videoing as part of their practice.

Clare found that having a professional to ask advice of was useful for her. She looked to the professional supporting her for affirmation that what she was doing was correct. For her this was a different way of interacting and counter intuitive to the usual way she interacted with Harley:

> Erm, and the question I had, I remember, after doing it was- Because Harley just wanted to run about... Erm, and we were sort of running about and, and that, and I said to [teacher], "Should I be doing that?" She said, "Yeah, as long as Harley's, getting that from it and they're not getting too high. (Interview 1)

Bethany explained how being part of the parent group meant that they watched their videos together and discussed them with the professional supporting them:

> Erm, and (.) it was, I suppose, quite a relaxed way of approaching something which I suppose- you know, when you, kind of, look at it on, on paper that, you know, you're learning how to, erm, deliver an intervention, you know? Erm, it was very, er (.), sort of, a, a sociable kind

> of thing, and it made you feel quite relaxed about opening yourself up, because, you know, when you first start to do Intensive Interaction, a lot of people, kind of, think, “God, I must look like a complete twit,” you know, if anyone was watching, whereas you do- I mean, I get to a point, I just don’t care, you know? (Interview 1)

Bethany is conscious of the learning taking place, ‘learning how to deliver an intervention’, but the group setting makes this a more sociable experience and lessens the scrutiny she feels. She is aware of the potential judgement of outsiders of interacting in this way. However, Bethany talks about how she is now at a point where she does not care what other people think. As a mother of a disabled child, you often encounter the scrutiny of others. Bethany having spent years of being judged is at a point where she does not care anymore, she has become thick skinned about it.

Georgia watched videos, but of Gerry engaging in II with the professional supporting them. Watching the videos, the thing that struck Georgia was what outsiders looking in must think. Her immediate thoughts were of a self-conscious nature; what will other people think if I behave in this way with my child:

> It’s really interesting. Quite funny to watch sometimes, you know, if you came in as a stranger. I’ve watched videos of her [professional]. That was when she was here with Gerry and they were playing with balloons and blowing bubbles. I’ve watched videos of her at school and she’s been lay with her head hanging down next to Gerry because that’s how they’ve been. To come in as an outsider, you’d probably look at that as… erm, not always knowing. (Interview 1)

Georgia is aware of the perceptions of wider society and how others might misconstrue interacting in this way; meeting the child developmentally where they are, rather than the normative benchmarks set by others. This is an example of the double hermeneutic, as the researcher I am making sense of Georgia making sense of her experience. Using II places the mothers in a position that could potentially open them up to the judgement of outsiders, as it involves interacting in a way that can make you feel self-conscious, employing infant/caregiver techniques with chronologically older children.

The mothers who used videoing as part of their learning explained how this impacted on their experiences of II. Elaine finds being videoed inhibiting; she presents a different self when her interactions are watched and judged, a more reserved self:

> no (laughs) no (laughs loudly) but you get used to it don't you, no I just kind of feel that like (sighs) not like I can't be myself but I (sighs) I don't know but it's just always been this thing you know, I will not be a movie star or anything like that anytime soon (laughs) or actress or anything it's not my thing, I don't know I just kind of feel it a little when [professional] has got the camera on pointed on you like you can't quite 100% be yourself. I don't know. (Interview 1)

Going onto say:

> but when it's just me and Drew I just go for it (laughs) no but yeah when she [professional] records me I always just kind of tone it down a little bit. (Interview 1)

As a parent of a disabled child Elaine's social interactions with her child are subject to judgement and scrutiny by the professionals supporting her. If she wants this service this is what is expected of her, to allow her interactions to be recorded. The sighs and laughs in these two excerpts seem to illustrate those feelings of self-consciousness, just talking about being videoed brings out those feelings.

Bethany and Abigail both found the logistics of videoing tricky. They felt you needed two people really. They were both members of the parent group which met a few times a year to show their II videos and provide feedback and support each other. Abigail described one of her videos:

> Like, in one of my videos, it was difficult because (.) it was a, it was in the bath where I was getting because when Ali was younger, I used to be able to get in there with them. So, my husband was there and it was a rare occasion he was there. So, I was like, "You need to video this and, erm, cut me out." (Laughter) (Interview 1)

Bethany talked about how you cannot interact and video yourself:

> I think the difficult thing about the videoing… but it's actually the logistics of doing it is really quite… much harder than you would think. Yeah, you need a third person really. (Interview 1)

Videoing is a way for the professional to provide feedback and the mothers to reflect on their interactions, but when the interactions are taking place in the home there is not necessarily a third person around to support with the videoing as there would be in a school or clinic setting. These logistical implications are not always thought through by the professional's supporting parents.

Bethany elaborated further on her experiences of using video:

> Erm, but also, I suppose, learning… you're, you're doing, erm, Intensive Interaction all the time, but you haven't always, kind of, got a video, sort of, set up to be able to capture it, and you're trying to create a scenario where you'll know it'll happen, and that doesn't always work. Erm, and also, you want it to feel natural, and you want your child to feel relaxed about it and it's getting them used to having a camera around, because inevitably, they are going to be like, "Why are you looking at me with a camera?" (Interview 1)

> So, er, more, kind of, recently, we just, kind of, let things, kind of, go. If it stops, it stops, and if it does go on, it goes on, and not trying to set it up, so to speak, as much with it. (Interview 1)

The pressure of videoing has led Bethany to viewing interactions as false and set up, rather than natural and intuitive as II should be. Her understanding of II however, enables her to recognise this and take a decision to remove that pressure from herself and let the interactions unfold naturally. She has removed the performative element from her interactions with Jamie; she still tries to video them but lets them unfold naturally, rather than focusing on getting a good video to show to the group.

The mothers also experienced benefits from videoing their interactions. Elaine describes the positives as being able to look back and see the enjoyment Drew gets from the interactions, something that in the moment it is difficult to fully appreciate:

> I do, it was quite awkward the first time but it's actually quite good to see myself you know and what I was doing and I can actually see how much Drew was enjoying, because you don't actually see it while you are doing it you know. (Interview 1)

Abigail similarly talked about the joy she gets from having videos to look back on, particularly when she is feeling Ali is not making any progress:

> Really happy, and I do have to do that quite a lot because, obviously, you do get a bit down and you think that the progression isn't happening. So, I do have to look at those to remind me that it is. (Interview 1)

Both Clare and Helen attend the parent group. Clare tended to be self-critical of her interactions and showing videos of her and Harley to the group meant the other parents pointed out the bits she had missed; this gave her affirmation that she was doing a good job:

> As I say, a group of us that get together, erm, picking out, you know, lovely bits that I hadn't spotted and 'cause I think, yeah, sometimes you're quite critical as well of yourself, and then they can- "Oh, look at that lovely moment there" and so, no, that's nice to be able to share it with a group as well.' (Interview 1)

For Helen, the approval of the teacher supporting the mentoring group is important. Helen wants to do well in the eyes of the teacher and group. The excerpt below is Helen's description of the teacher's response to watching her video. The teacher was emotional watching the video and provided Helen with feedback on what to do differently:

> 'And the only thing that [teacher] said to me about it is, I said to Charlie, "Are we finished yet?" when Charlie braked [paused], and [teacher] was like, "Really we would say don't do that." But she was nearly crying, [teacher] was, watching it. (Laughter)' (Interview 2)

The ability to have her interactions judged by the professional through showing her videos is key in Helen's experience. She felt pride that the teacher enjoyed her video, it affirmed that she was doing a good job.

In summary 'Learning to manage judgement' illustrates the positive and negative aspects of video use in parent learning. For some mothers, the use of

video or a professional observing them falsified their interactions leaving them unable to be completely themselves. For others it left them feeling that they were putting on a performance. Having professionals supporting the mothers came with an attached level of scrutiny that the mothers must undergo. The mothers had differing experiences of how they managed this judgement. It left some of the mother's conscious of how their interactions would be perceived by others in wider society whilst for others it provided a reassurance that what they were doing was correct.

5.4 Learning to grow

This sub-theme explores the additional aspects that experiencing II brings for the mothers outside of their relationship with their child. It narrates the move the mothers made towards becoming advocates of II to other parents and the empowerment of their identity outside of motherhood.

Almost all the mothers were involved in advocacy of II to other parents. The use of II enabled the mothers to move outside of their identity of mother of a disabled child and either advocate to other parents or reclaim previous identities outside of motherhood. The sense of community that II seemed to bring with it is key throughout the mothers' narratives; they belonged to something that enabled and fostered friendships with a common purpose.

The four mothers belonging to a parent group engaged in the mentoring of other parents and provided a support network to share experiences and receive feedback from others. This was a supportive group that gave the mothers a sense of community and friendship that extended beyond the remit of the group.

For Clare, her role in the group as one of the more experienced parents was to represent others like herself whose children were verbal. This was important to Clare, having initially overlooked II herself, she wanted to widen that representation and showcase her family and what II could do for verbal children. This advocacy for others is one role of the group:

> Yeah. Just showing them, erm, because, for me, I always thought it was for children that weren't speaking, so to just show them Harley, you

> know, although Harley's not, erm, age appropriate for their, erm… er, verbal voice, you know, it's just showing them that, you know, what is still achievable from that, and what else you can get out of it. (Interview 2)

Bethany shared how engaging with the parent group and mentoring had enabled her to make use of her professional skill set and support other parents:

> I'm happy to continue, you know, supporting with the mentoring side of things, erm, because I feel like it's quite an important thing to do really. I think the, the more people know about it, the more chance (Laughter) we've, kind of, got of helping our, helping our kids in a positive way. (Interview 1)

Being able to support parents seems key to Bethany's involvement in the group; she does not seem to do it for herself but rather for others, to be actively involved with getting other parents on board and supporting them.

For Bethany this role is a key part of her identity outside of motherhood, it has two-fold benefits: advocacy to other parents and it allows her to reconnect with her other identity as a professional, one that she gave up to care for her child:

> Yes, definitely. I mean, I think, erm, you know, it's kind of a bit of an opportunity for me to sort of be, be a bit more productive, rather than just being, you know, a mum and a carer, if that makes any sense? Obviously I used to [profession] before, and you know, it's kind of, when you're part of that mindset of wanting kind of to sort of share your learning, erm, with people, and I think knowing how helpful it's been for me, erm, if I can kind of, you know, transfer those skills in any, any way to another person, then hopefully they find it as useful as, as I have, you know? I'm definitely on board for that. (Interview 2)

Being a part of the mentoring group is a way for Bethany to feel part of something outside of her identity as mum and carer, something that enables her to re-establish that part of herself.

Clare's experience of the group is one of support and a counterbalance to her natural inclination to be self-critical of her own interactions. The group gives her affirmation of her interactions and that she is doing a good job:

> I'll bring it to the group and we'll- They'll still pick out different things that I haven't seen and, erm, pick up on moments that Harley. We've glanced at each other and, Harley's waiting for me and- Yeah, no, it's, it's, it's great. It's really great. (Interview 1)

Helen's experience of the group is one of striving to become an experienced parent who can show a video at the school workshops:

> I showed my first videos and things on the first one in October for the new parents. (Interview 1)

This is something she is proud of and the recognition she gets from the teacher who supports the group:

> It's nice because [teacher] really loves the video (Interview 2)

This is important to Helen, the recognition of the teacher and being selected to show her video to other parents empowers her and supports her identity outside of motherhood as an advocate and mentor to other parents.

For Fiona, her identity outside of motherhood went further than this and she ended up with a job with the organisation that supported Riley. This happened between the first and second interviews:

> Yes. I'm now their [role in organisation]. Yes, because I wanted to be part of it and to remember that it's not just the person that they are working with they make a difference to. They make a difference to a whole family. (Interview 2)

Being a part of the organisation was important to Fiona; she wanted to contribute to the difference II could make to families in the same way the organisation had done for her family. Using her own experience as a platform Fiona supports other families using II. For her II has opened other avenues and extended her identity outside of being mum and advocate for Riley. She describes this as her giving back to the organisation and that it is a benefit for both them and her.

> I mean, it's me giving back to them. It's win-win. (Interview 2)

Fiona explains in her first interview the difference finding II made not just to Riley but also to her. She describes her relationship with the organisation and

the person who worked with Riley; this had moved from a purely professional relationship to one of friendship:

> Because of Riley's story, I basically think she [organisation boss] saved their life, because Riley's head banging was so bad, I really thought Riley was going to kill themself. So we'd all had this fantastic journey together from being so isolated to now having a life. We've all become very close and became friends and I couldn't ask for better support than that. (Interview 1)

The experience of working with the organisation from a period when things were very dark for Fiona has cemented that relationship, the positive outcome for her family and the close working relationship she had with the organisation has enabled it to develop into something else, friendship and the different level of support that that brings.

Not all the parents are advocates for II, Elaine talks about how this would be something she would like to do in the future, but she lacks the self-confidence currently, she does not feel she is quite 'expert' enough yet:

> I've actually talked about it once because I know a lot of mums and dads and I know so many people who would benefit but I just want to know what I'm doing first before I you know, but I've told them a little bit about it and all that because I just know that for their kids they're a lot like Drew, you know and they are also just looking for something you know everyone is looking for that something and I reckon this is it. (Interview 1)

In summary 'Learning to grow' describes the empowerment the mothers seem to get from engaging with II. Helen's experience of striving to get a video shown and the empowerment this brings her as an advocate to other parents is an example of the double hermeneutic in IPA at work. Helen's choice to tell me about showing her first video and the obvious pride she takes from that is evidence of me as the researcher making sense of Helen making sense of that experience. The mothers' experience with II seems to give them confidence to advocate and spread the word about II, they step outside their identity of motherhood and take on other roles.

Summary

For the mothers in this study the experience of II is about reclaiming your intuition and skills as a mother. It is about learning about yourself, your child and how you relate to each other. The mothers experienced being given permission to stop striving for demanded norms of development and instead met and enjoyed their child where they were. It is about persisting in the belief that there would be something out there that would work for them as a family and navigating the elements of chance and initial scepticism over II's validity. II is about mothers continuing to accept the hegemonic power structures that privilege professional knowledge over parental and levels of scrutiny and negotiated feelings of performative motherhood. However, that learning process provided validation of intuitive interactions and reinforced feelings of being a good mother. Yet II is also experienced as a site of resistance as mothers become expert in its use and advocates within the community.

The next chapter discusses the second superordinate theme 'Connecting'. It provides an account of how II has impacted on the relationships between the mothers and their children and reports on how this influences the mothers' sense of self.

Chapter 6 Research findings- ‘Connecting’

‘Connecting’ captures the mothers’ experiences of feelings of connection through the relationship they have with their child and how using II impacts upon these as a mother and the wider family unit. There are three sub-themes presented in chapter 6:

- ‘Being accepted’ represents the mothers’ experiences of being accepted further into their child’s world through using II. Power plays a significant role in this sub-theme: the child-led elements of II mean that the mothers not only experience feeling more involved in their child’s life but also experience the wounding possibility of their advances being rejected.
- ‘Becoming mum’ explores the mothers’ sense of self as ‘mum’ and the deepening of their relationship with their child through engagement with II.
- ‘Belonging’ encompasses the relational differences using II has made to the wider family unit and others caring for their child.

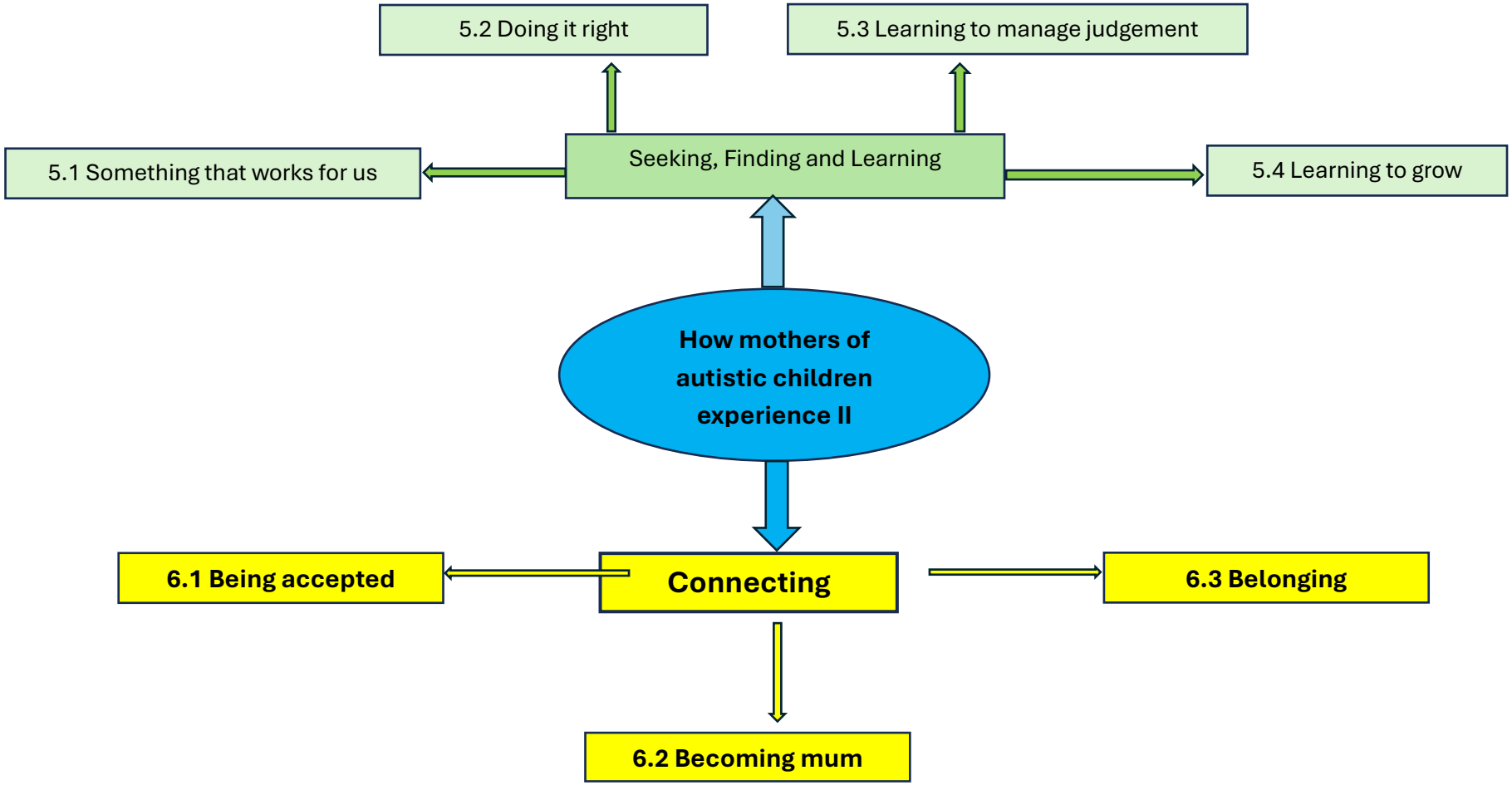


Figure 7 Thematic map, highlighting superordinate theme ‘Connecting’

6.1 Being accepted

The first sub-theme I will discuss is 'being accepted'. This captures the mothers' experiences of feeling accepted by their child through using II.

'Being accepted' has two opposing facets: that of acceptance, primarily through the vehicle of play, and the possibility of rejection. Power plays a primary role in this theme; there is a power balance shift from the mothers to their children when using II and this both enables the mothers' feelings of acceptance and equalling enables feelings of rejection. Being accepted is the start of the mothers' experiences of connecting with their children. The initial moments of realisation that their child understood their overtures to interact in a meaningful way enabled these feels of acceptance and connection. The shift towards the child-led element of II is discussed by the mothers and the impact this had upon them. This was experienced as two sides of a coin: the shift to a child-led focus meant for the mothers that their engagement and connections with their child enabled feelings of acceptance into areas of their child's life they previously had felt excluded from. The other side of this is that the child-led element equally meant the child could say no or reject the mother's interaction attempts or conversely request interaction at inconvenient times.

Throughout the mothers' accounts play comes across strongly in their narratives. For some mothers this is about them re-establishing a play routine with their child, perhaps one they had moved away from. Play is the vehicle through which some of the mother's experience acceptance.

Helen's prime reason for starting II was enabling her to play with Charlie. This is what appealed to her about the intervention; it was a way to spend time with her child through play:

> I just think it's the being able to get down and play with Charlie. (Interview 2)

Once again, as discussed in the superordinate theme 'Seeking, Finding and Learning' the idea of getting down on your child's level is raised. This seems to be a metaphor for the parents reprising their play and interactions to where the child is at developmentally and often this may involve floor play as with younger children. Helen goes onto say:

> The fact that before Charlie came here they wouldn't have none of it. You couldn't read to Charlie. You couldn't play with Charlie. You couldn't do anything. (Interview 2)

Prior to using II Helen could not do any of the things with Charlie that she would have liked to do; the usual ways that a mother spends time with their child. Charlie excluded her from these activities. Being asked to play is the acceptance into Charlie's world that Helen has been looking for.

Clare also uses the metaphorical language of 'get down on their level', like Helen; engagement through play is the vehicle through which she is 'being accepted'. This is an example of the double hermeneutic at work. It links with the earlier theme of 'doing it right'. Through getting down on their level and playing with her child in a way they find meaningful Clare experiences being accepted into Harley's world:

> Yeah, just so that I- You know, I've learned to, erm, you know, get down on Harley's level and play with them, erm, and that Harley's then accepting me being, erm, in that area and playing with them. Erm, so, yeah, just that we're able to enjoy more things together. (Interview 1)

II has provided a vehicle through which the mothers have been able to engage in playful interactions with their children. Rather than just playing alongside their children they are being allowed to join in the play, in a more interactive two-way process. Clare refers to Harley 'accepting' her joining in with the play, it is on Harley's terms. The mothers are reliant on the child letting them in. This is a shift in the power balance from mother to child and through this Clare gets to spend time with Harley engaging in things that are meaningful to Harley and becomes something they enjoy together.

Helen laughs when she talks about being asked to play, it is almost as if she has taken on the role of a child again, waiting on the outside to be invited into play. When she is invited in it allows her to be a part of Charlie's world and share the things that are important to her child:

> So it has, yeah… It means that Charlie asks me to play. (Laughter) (Interview 2)

Helen discusses play numerous times throughout her narrative: it holds great importance to her, the normalcy of just being able to play with your child is very powerful for her. Through this act of invitation Helen feels noticed and welcomed by her child.

II enables Clare to take the time to 'play'. It gives her permission to take that time and spend it with Harley having fun:

> And it's taking that time out because we were always so busy. (Interview 1)

Clare is a busy mum and 'taking time out' can be difficult to justify. However, because II is an intervention advocated by professionals this seems to make it easier for the mothers to balance their time.

II has enabled play to look more conventional for Elaine; Drew interacts with her in simple games that most mothers would take for granted with their children. Using II has enabled Elaine to play in a way that she had not been able to previously. This is progress in Elaine's eyes, that Drew now understands what is involved in a game of chase. For Elaine, the importance of these little moments are very powerful:

> Like Drew can actually play a little game, there and chasing Drew around the house as well you know they understand what chasing is, it's fun they have to run away, and Drew never used to do that. So yeah, it's lovely that. (Interview 1)

Another way the mothers experience being accepted, and connection are through the realisation that their child understands they are being listened to. The mothers describe this from the viewpoint of their children. The moment when they realised that their child knew what they were doing, they perceived their children as feeling listened to and their interests valued. This was very powerful for both the mothers and children; the learning undergone by the mothers' results in these 'eureka' moments. Bethany describes this below:

> it was almost like this little eureka moment, "Oh, well, you know, what, you're actually listening to what I'm saying?" kind of thing.' (Interview 1)

Clare describes this as being 'opened up into Harley's world'; this is the way she feels accepted into Harley's world. She equates this with Harley's self-

esteem, Harley feels listened to and this then means Clare is accepted to share activities together:

> It's opened up me into Harley's world and, erm, you know, us enjoying time together. Erm, and I guess it's like their self-worth, like, oh, "I'm worth listening to," and things like that. So, yeah. I… I love it. (Interview 2)

Abigail talks about a 'lightbulb' moment for Ali:

> So, yeah it was really good and it is, it's lovely because it's almost like a lightbulb moment for them, and you see their eyes light up, and Ali's eye contact has become amazing. (Interview 1)

Similarly, Georgia also uses the phrase 'light up':

> Gerry looks at us sometimes in like that desperation of like, "Come on, work out what I want." You know, really intense look. Then when you get it their eyes just light up. (Interview 1)

The mothers expressed this as their child having a 'lightbulb moment' or 'lighting up' when they realised, they were being listened to; the connection the mothers felt in that moment with their child gave them an insight into what II could achieve. The excerpts above illustrate how this is not something the mothers see often with their children; these children often have interventions done to them rather than with them. When Clare says 'you're actually listening to what I'm saying' as her perception of what Harley thinks, this illustrates how these children are often not listened to, or their interests valued.

Georgia describes how Gerry 'looks at us sometimes in like that desperation'. Again, this illustrates the frustration these children feel at not being able to express what they want in a conventional way and the mother's acute awareness of this. Using II gave them a way to show they are listening and join in with their children in a meaningful way for the child. The feeling these lightbulb moments gave the mothers is what makes them continue with II and realise its potential as Elaine illustrates in the excerpt below:

> So I was kind of like kind of just sitting like that and Drew grabbed both my hands and went up like that (moves hands up in air) and I was like oh that's weird but as I was looking down, on their iPad was donkey, donkey

> and I was like you want me to sign donkey? And Drew's face when they knew that I knew what they knew it was magic, it was just amazing, Drew's face just lit up you know. (Interview 1)

These moments are precious for both the mothers and children; it is the start of their shared connections and interactions. For Elaine this was a moment of wonder, the start of something new for her and Drew. An acceptance of Elaine into Drew's favoured pastimes and activities.

Clare talked about why she keeps on using II: to her there is nothing else out there that she has come across that can replicate II. She describes it as an 'unlocking' experience: II enabled her to find a way to connect with Harley. It provided the key to connection:

> Because the opportunity, erm, that can unlock in your child and your relationship with your child, is absolutely priceless. And I don't think there is, for me, there isn't any other sort of, erm, intervention that will provide anything like what this could do. (Interview 1)

Alongside the process of discovering the power of play and feelings of acceptance, the mothers also experienced feelings of rejection. The child led element of II puts the power firmly in the hands of the child and this is a shift in the usual power balance between mother and child. For most of the mothers this was at times a challenge, a balancing act between wanting to interact with their child and the difficulties that arose sometimes with the power balance shift. This manifested in two ways, the mothers' experienced feelings of rejection when their child indicated they did not wish to interact and also the mothers found it hard to say no to their child when the timing was inconvenient.

The shift in power from mother to child means that there was almost a role reversal with them assuming the role of child, being on the outside waiting to be asked to interact. They waited patiently, expectantly for their children to ask them to play. For Helen, she spends a lot of time on the outside of Charlie's life, wanting to join in but feeling left out. The excerpt below illustrates the rejection she feels when Charlie's play is solitary. This is the norm for Helen: Charlie says 'no' and II gives her a way for Charlie to sometimes say 'yes':

> Yeah, I think it's just really satisfying when they let you join in with them because you spend so much time watching them do things on their own, and they don't want you anywhere near 'em. Like, if I try to read a book with Charlie sometimes and they're like, "No," Charlie will just go in the bedroom, it's like, "Well, okay, you obviously don't want me in your space." (Interview 2)

Helen goes on to talk about how she will literally drop whatever she is doing when Charlie does want to engage because those moments are rare and precious. Helen laughs about this; the fact that she is at her child's beck and call in this way. Those moments of interaction are of such importance to her that she will go out of her way to engage with Charlie on Charlie's terms:

> So, it's really nice when they actually want you to do things. And like if you're in the middle of something you drop that straight away. (Laughter) Like, if Charlie says to me, "Build me a Lego house," that's it, whatever I'm doing… (Laughter) There's only a few occasions where I would be able to say, "No." It's like if I'm cooking dinner I'd have to say to them, "Well, we'll do it after dinner 'cause otherwise dinner's going to burn." But, apart from that I'll drop whatever I'm doing and get down and do it with Charlie, because it doesn't happen often. (Laughter) (Interview 2)

Helen acknowledges this power shift can make life difficult sometimes:

> So, I find that sometimes, because it's all on their terms, it can make it a little bit difficult, because they generally pick the time that's not the easiest, (Laughter)' (Interview 1)

This was the answer given when asked about any downsides to using II: Helen is aware of being torn between wanting the interaction and it not necessarily being at a convenient time. The power does seem to truly lie with the child where Helen is concerned. The pleasure she gets from interacting and because it only happens infrequently overrides most other considerations. The laughter throughout Helen's discussion of this seems to indicate her acknowledgment of the unusualness of this situation. This is a negative in the mothers' eyes sometimes, a different way of being and can leave them feeling torn.

Bethany also talked about the difficulties of the child-led element and how it made her feel when she has to say no, not right now. She is torn between her role as mother who has jobs to get done and her role as mother who plays and interacts with her child. The joy she obviously experiences when Jamie does interact with her means she is acutely aware when she does have to say, 'not right now':

> Erm, sometimes, you know, (Laughter) you're, kind of, at a time when you really have to, sort of, you know, say… and I did found that, find that really hard to do, is to sometimes say, "Actually, I can't do that right- with you right this minute because I've got to get this done," because you're just so lapping up the fact that they want to initiate some communication with you. (Interview 1)

Bethany describes this joy as 'lapping up', this chimes with Helen's 'so satisfying'. Both mothers are expressing the meeting of a need; the joy of the fulfilment of a desire to feel connected with their child is expressed within the language they use to describe these moments. This experience of II is linked with their sense of self and becoming known to their child; they are experiencing something new that they previously had not experienced or experienced infrequently.

Abigail expressed a fear of rejection and the awareness of when Ali was not in the mood. She described how engaging with Ali made her feel but acknowledged that the power of II is in its child-led element, so if she were to push Ali to engage it would just push them further away:

> So, if Ali lets me, then I will, but y-y-you know because Ali, like- Ali pushes you away if they don't. (Interview 1)

Abigail continued to say:

> Sometimes when they, they aren't feeling it, erm, and that's quite hard because it makes me feel happy when Ali's engaging with me. Erm, but as you know, if they're not feeling it, Ali's not feeling it, and I'm not going to push that because then that's going to make them unhappy and they're not going to want to do it. (Interview 1)

In the excerpt above the power Ali holds is clear in Abigail's words 'if Ali lets me'. This chimes with Helen's remark 'it's all on their terms' that II leads to a role reversal with the mothers being the child waiting to be asked to play. Emotion is heavy in Abigail's account; engaging with Ali makes her happy, and she must wrestle with her own happiness because she does not want to push Ali to do something they do not want to. The feeling of being rejected and pushed away by your own child is hard for the mothers, II opens a world of connection and shared experiences with their child but the child-led element means that it is when their children say so. II tantalises with possibilities but does not always deliver in the way the mothers want all the time. This produces feelings of being torn in the mothers, balancing their own needs and wants with their child's. However, for these mothers it is critical that the child-led element is observed and that the shift in the power is honoured. They know that it is this that makes II different to the other interventions they may have tried.

Helen verbalises this below: the reality that if you force the child to interact, it will not happen. This is the difference between II and other interventions the mothers have tried. The strategy is used with the children and not done to them:

> And being child-led, I think is the big, the big thing that makes it better. You're not trying to force them to do something they don't want. (Interview 1)

Not all the mothers felt this way; Elaine was very pragmatic about how if it was not a convenient time she would just move away from her child.

> You just don't (laughs) you just want to lie down and sleep and so yeah sometimes you don't feel like doing it. And then Drew wants to as well and then I just move away, coz I find like if I sit next to them that's when and I'm tired I just don't want to do it and then Drew's like slapping me and I always have to move and then later on you know (laughing) when I'm more awake. (Interview 1)

Elaine does not seem to be as concerned as some of the other mothers over saying 'no'; she uses a clear signal to Drew of moving away to say, 'not right now' and will engage with them later. Elaine goes onto describe in the second interview how the child-led element can be a difficultly and 'annoying' when she is busy. For her it is important that the interaction timing works for both of them;

she does try to accommodate Drew whenever she can but not like some of the other mothers who will prioritise the interaction over most other things:

> Drew constantly wants to sign, actually sometimes it's quite annoying when you are trying to cook and they're like screaming at you to sign you know. Coz Drew doesn't know that I'm busy and that, Drew just wants it when they want it. But I do try and do it whenever I can when Drew requests it but sometimes if you've got like a hot pan in your hand. (laughs) (Interview 2)

For Helen, the importance of realising that your child will say 'no' and that this is usual and not to get disheartened is key. She describes how she lets other parents know this at the school workshops:

> Just so that they know it's quite normal, and you won't always, you're more likely to get a no out of them than you are a yes. And it's nice for them to know it's not just their child that refuses. (Laughter) (Interview 2)

In summary these mothers all relish the interactions with their children and the feeling of acceptance into their child's world that these give them. However, the child-led element can mean that they do not access interaction as frequently as they would like, and this is something that is completely out of their hands; the power lies with the child. The is hard for the mothers, they recognise the key element of II being child-led is what makes it work. This flip side of the coin of possible rejection means that they are much more willingly to put aside what they are doing to engage with their child whenever. The mothers' narratives are laden with the emotional labour involved in the balancing of their own needs with that of their children.

6.2 Becoming mum

The second sub-theme is 'becoming mum'. The mothers' experience a shift in their identity and sense of self. It is a move from sometimes feeling like just the carer of their autistic child to feeling like their mum which impacts upon their emotional wellbeing. The mothers' experience a deepening of their relationship with their child connecting with them in previously unobtainable ways. This

involves sharing moments of deep connection whereby they feel their child ‘sees’ them as ‘mum’.

The mothers talked about how using II makes them feel as an individual. Georgia described how the typical things you would expect to do as a mother with your child do not necessarily happen when your child is autistic. She was conscious of the things that she has not got to do with Gerry that she did with their sibling. This is a loss for her; she has not got to experience those aspects of mothering:

> What is it we’re going to miss out on? Doing those things that we used to do with [sibling]; they just didn’t come with Gerry. You just don’t do them. Actually, those times you do interact with them and get that time when Gerry’s totally with you are really precious actually. They don’t come along very often. (Interview 1)

So, for her the times when she felt that connection with Gerry through using II were especially important to her. The mothers described those close moments with their child when they felt that complete connection, when their child wanted to spend time with them. Elaine described how the more she engaged with II the more she noticed Drew’s focus had shifted: Drew was no longer purely focused on the iPad, but also was interacting with her:

> The more I did it the more I could notice Drew was focused less on the iPad and more on me, (Interview 1)

Throughout Elaine’s account the role the iPad plays in Drew’s life features heavily. If the iPad breaks Elaine must replace it stating, ‘it’s Drew’s whole world, Drew cannot function without this iPad, one breaks I have to get another one.’ The iPad is Drew’s security blanket; it is predictable and makes them feel safe. Elaine initially thought the iPad would be a barrier to II use but has incorporated its use into their II interactions.

Through using II Elaine has reaffirmed her place in Drew’s life. By using those underpinning principles and reconnecting with her child in a way that holds meaning for Drew she feels she has re-established her bond and is getting the iPad to relinquish the hold it has over Drew. The iPad is the vehicle through

which Drew found a sense of control, security, predictability, and pleasure in the world around them. Elaine goes onto say:

> So it may look like Drew's concentrating on the iPad but Drew's not, their focus is with me, they're looking at me. Drew's got a hand on me to scratch them and all that, so we've established quite a nice, kind of like games almost to play that Drew initiates you know. (Interview 1)

Clare describes how Harley looked to her for her reactions: Harley was anticipating Clare's responses in those shared moments when they looked at a book together:

> Oh, amazing, really, really good. Erm, it- You know, especially sitting there with the- With the [book name] and Harley looking at me, like for my reactions and, erm, just sharing that moment with them is really, really nice. (Interview 1)

These shared moments support the mothers' emotional wellbeing: they made the mothers feel good about themselves and their relationship with their child. This is evidenced through the mothers' use of words such as 'amazing', and 'nice', along with the repetition of the word 'really' to emphasise this. This shows the interpretive layers of the double hermeneutic, the researcher exploring the meaning beyond the literal account of the words themselves, delving to the experience itself.

Georgia and Elaine both described bedtime as a time when they received quality one to one time with their child. Using II has enhanced these interactions. Georgia discussed how often Gerry is too tired after school and does not want to interact. However, bedtime was a special time for them:

> There are times through the day where Gerry, like putting them to bed, Gerry likes you to be with them. It's like Gerry's time where I usually settle them to bed unless I'm at work and we close the door. We've got the light on, but we'll get into bed and that's when we have quite a lot of our time together when it's just the two of us. (Interview 1)

Elaine similarly described how bedtime is a time without the iPad, just the two of them. Drew wants Elaine with them at this time whereas previously they would sit on their own:

> Bedtime, before Drew goes to, up to bed is when I take the iPad, so we have a lovely like 10mins in Drew's room, where we don't have the iPad and it's a lovely interaction there you know we've bonded so much more you know, they want to be with me, Drew doesn't want to sit on their own. (Interview 2)

For both mothers this was a time when they felt wanted as mum, to put their child to bed and through using II they experienced this closeness and precious time of day. These moments are times when both mothers take II back to its basics, just them and their child, interacting and sharing time together. This altered the mother's sense of self and their maternal identity; they are wanted at this special time of day.

The mothers are establishing routines with their children that enable them to connect and share time together through reading books, playing together on the iPad or at bedtime. Using II at these times enhanced the interactions and feelings of connection the mothers experienced; this made them feel in tune with their child, that those moments were truly shared.

Bethany described the life changing experience II has been for her, the difference it has made to her communication with her child. Being able to communicate with someone is key to relationships and that sense of belonging:

> But I mean Intensive Interaction for me has been, kind of, quite… well, it's been a m-massive life-changing experience because for- it's just hugely improved the communication that I have with Jamie. (Interview 1)

She describes this as 'life-changing'; this terminology shows the size of the impact using II has had on Bethany. For Bethany, this excerpt illustrated how using II has supported the connection between Bethany and Jamie and how to Bethany this was something that she felt needed improving.

The mothers go onto to talk about how their use of II has allowed them to go beyond feeling like a carer of their disabled child to feeling like a mum once more. It is the difference of feeling connected and sharing moments together that moved the relationship and their own sense of self from the role of carer to mum. Bethany candidly spells this out, what that closeness is. Using II makes her feel more than just Jamie's carer, she was Jamie's mother:

> It really… it you, kind of it's that closeness that you're looking for all the time, erm, those kind of little moments where you feel, like, that real, kind of, connection beyond someone who feeds me or clothes me or washes me, you know? (Interview 1)

For Abigail that feeling was even more rudimentary for her:

> It's like… so, it's, "Oh, you, you're, you're there, you're a person." So, yeah, it's been really good. (Interview 1)

She goes onto say:

> Well, I'll be honest, I felt like Ali didn't know I existed, and as I said to you, it's- it was almost a bit of a, a lightbulb moment, "Oh. Oh, you're there. You, you can do that as well," and, yeah, it, it just felt like a bit of a lightbulb moment to us, erm, and it is, kind of, sad to think that Ali didn't, didn't think that before. (Interview 1)

Abigail's experience of II has become central to her relationship with Ali. The fact that prior to using II, Abigail says Ali did not know she existed. It was the feeling of being known, affirming her role in Ali's life, not just the person who feeds, baths and clothes them, but her role as Ali's mum. Engaging in II has allowed her to feel like a 'mum', it has reaffirmed her identity as Ali's mother and her sense of self. Thinking of this made Abigail feel sad, that she and Ali have missed out on this type of relationship up to now. There was great emotion in her narrative. Prior to using II she did not feel there was this type of connection with Ali; they were not aware of her as a person. Abigail's maternal subjectivity as a parent of a disabled child with a differing set of norms to navigate has meant she has an altered identity role to the one she may have originally envisaged. Through using II she has been able to feel a connection to Ali. They see her as someone like them who enjoys the things they enjoy. Abigail's experience with II has allowed her to start to feel like mum and not just Ali's carer.

Fiona's sense of self and maternal identity was always there but became overshadowed by the role of advocate that she had to play to get Riley's needs met. Finding II and a setting that would use it with Riley meant she could relinquish her role as Riley's advocate and become mum once more.

> I found I felt like a mum again. I felt like, “Why didn’t I find this sooner?” (Laughter) I felt in disbelief to start with that there is, out there, what Riley needed. (Interview 2)

Like Abigail, Fiona expressed regret and sadness that she did not know about II earlier in Riley’s life. The feeling of being mum came at a cost to the mothers, the joy they felt in their relationships with their children and the feeling of becoming known is tinged with a sadness and regret that they did not find this sooner. The mothers were aware of the lost time.

Elaine recounted a story of Drew acknowledging that Elaine is their mum, affirming the role Elaine plays in Drew’s life:

> And for years as well now I went mummy (exaggerated) and tap myself on the chest and I’d tap Drew, and I’ve done that swear to god about 3 or 4 years now and then I asked the other day where’s Drew? And Drew tapped themself (voice goes quiet) and I sat there and nearly cried, amazing and I said where’s mummy and Drew tapped me, and you know amazing, they never said mummy ever, but it will come one day you know. (Interview 1).

This account is full of emotion illustrating the importance of being known for who you are; the importance her identity as mum has and feeling that your child knows who you are. This was still bittersweet, that Drew does not call her mummy, but she has hope that one day they will. These are simple things that most mothers take for granted, the ability of your child to call you mum, whether that be through the spoken word or other alternate forms of communication. However, to call you mum they need to know who and what mum is.

Bethany talked about being ‘selfish’ for wanting attention and closeness, for craving that connection with Jamie and the reaffirming of her identity as mum:

> Yeah. I mean, I, I guess it’s partly that, sort of, selfish sort of thing, where you just want to be able to just… obviously, you can’t just sit and have a chat with your child because Jamie’s not able to do that, but to feel that closeness and connection with them, and having those, kind of, moments where… obviously, seeing the enjoyment and happiness on their face, and feeling a bit more like I’m not just there as, you know, Jamie’s carer. I

> am actually import- an important part of their experience, and for- that is, I suppose, the biggest boost for me. (Interview 1)

Bethany wanted to experience more from her relationship with Jamie, she wanted to feel that she was important to Jamie in ways other than being their carer. II enabled that connection and for her to experience the closeness she associates between a mother and child.

Fiona discussed the difference finding II made to her personal wellbeing. The situation with Riley prior to starting with II was exceedingly difficult and through II being used in the residential placement Riley was happier and less distressed and withdrawn. Fiona describes in the excerpts below how II gave not only Riley their life back but her also:

> Huge. It gave me back my life as well. Yes, I was very depressed and suicidal at times. All of that has gone now…, I am just human again. (Interview 2)

Through her experience with II Fiona's emotional wellbeing has improved massively. She is very candid about this in the excerpt, she describes herself as 'just human again', when she was suffering with mental health issues this made her feel inhuman; she did not recognise herself.

In summary the mothers experience of II has altered their sense of self and reaffirmed their maternal identity, it has enabled them to move beyond feeling like a carer to mum once more. The feelings the mothers have when they experience a close connection with their child is important to them. They appreciate those moments of closeness and interpret them as feeling like a mum.

6.3 Belonging

This theme centres around the relationships and connections the mothers describe within the wider family and society. It is an exploration of how II has impacted upon the family unit and the sense of belonging it brings to both them and their child. Using II enables ongoing connections to be fostered outside of

the mother/child relationship. This supports feelings of family. The role gender plays in the interactions with their child is explored.

Elaine's experiences of using II centre around her bond with Drew and feeling like Drew is more part of the family rather than wanting to be alone. Being a family holds importance for Elaine; she uses this phrase several times throughout the interviews. It is not just about her own bond with Drew but wider, for Drew to be included in family life. Elaine describes this as Drew wanting to be with them as 'people'. This feeds into the family's sense of identity as well as the individual's sense of self. Simple things like just spending time in the same room even if they are doing their own things make a difference to that feeling of family and what it means to be part of a family, spending time in each other's company.

> But at home definitely Drew just wants to be with us as people you know and it's just not how Drew used to be, Drew wanted to be alone. You know and that's changed and that's amazing you know, they're part of the family now and it's lovely.
>
> You know I just I just I love that, and you know the fact that Drew is starting to be more part of the family, we have that nice little bond it's just amazing. I could have never thought that it could happen you know yeah so, t's awesome. (Interview 1)

Using II gave Georgia and her family a way to reconnect once Gerry moved into the residential placement. It fostered the sense of belonging; they belong together as a family unit and II enabled a close 'quality' connection with Gerry in the weekly time they had together:

> But if I think about yesterday if we didn't do the [favourite pastime] with them, we would not have had very much interaction with Gerry. So, you would have come away thinking well you know they sat on my phone or and it's just nice to be with them whatever we choose to do it's just nice to be with Gerry. Erm. but it would be very easy to not to join in when they were [favoured pastime] Gerry was very happy doing it on their own, Gerry would have been quite happy it would have been quite easy to just sit and watch them do it and just sit back and say oh they're happy, they're content. But actually, all of us just naturally got up, and did it with

> Gerry. Which is lovely because you feel like you've spent some quality time with Gerry when you go rather than, Gerry taking my phone and doing what Gerry does. Nice to be part of the time with Gerry and I think that when you don't have very much time with them it's actually better quality than what it was when we were here because we were just so tired, just exhausted here it was really tricky. (Interview 2)

Continuing to use II with Gerry in joining in with their favoured activity allows the whole family to feel like a family, enjoying an activity together and reestablishing their bonds as a family. Georgia describes it as better-quality time even though it is for a shorter period than they had at home. She uses this phrase twice in the above excerpt, to describe how using II to interact when they visit Gerry enables the family to feel close to Gerry still and maintain their bonds. This is viewed as 'quality' over just sitting with Gerry while they play on her phone. Georgia describes it as being 'part of the time with Gerry'. Using II enables Georgia to feel included and part of Gerry's life in the residential placement. She reflects that because of the difficult situation at home prior to Gerry moving to the residential placement it was hard to get that 'quality' time together then.

Fiona similarly uses II with Riley when they visit home and described how she used it to not just spend time together but to support Riley's wellbeing when they were distressed. Both Georgia and Fiona are using II to maintain their bonds with their children when they visit their placements or their child visits home.

Bethany likewise used II to strengthen the connections that Jamie had with their wider family. As a family they worked hard so that Jamie knew they could approach others for social interaction. Bethany achieved this through advocating about II to the wider family, starting with Jamie's sibling and dad:

> I was the one that communicated, and it's still, to a point. Obviously, I'm still the main focus, but we've worked quite, quite hard to try and get Jamie to feel comfortable with the other adults and particularly their [sibling] now, and we've, kind of, seen… again, I do think it's partly to do with the Intensive Interaction, that Jamie now will initiate that, kind of, play with their [sibling], whereas, erm, before, it would probably would've only have been me. (Interview 1)

She continues to say:

> But seeing how Jamie's developing now with the way that they're trying to communicate with other people, particularly, you know, obviously, their family, and my husband particularly has worked really, really hard to (Laughter), kind of, "You are going to interact with me. You are," erm, and, you know, you can, kind of see it now. (Interview 1)

For Bethany, Jamie's relationships, and connections beyond her are important. She wants them all to be able to interact with Jamie as a family, so it is not just her that has the connection. This is what a family has, interwoven connections. This has taken time and effort on the part of the family, particularly Jamie's dad. Bethany describes her husband as working hard to build their relationship with Jamie. Bethany has supported this process with members of the family through explaining about II. This has meant Jamie has started to build on their relationship with grandparents:

> And seeing the way that, you know, just with my mum and her husband a couple of weeks ago, the way that Jamie was… I mean, I actually managed to catch a video of it. It was really sweet. So, yeah, it's just nice to see that they're, kind of, more on-board and more comfortable with communicating here as well, because I mean, it is difficult for yeah, for even, sort of, quite close family members sometimes to know how best to calmly approach Jamie and engage them. So, it's just a learning curve for everybody all the time. (Interview 1)

This highlights the difficultly even close family members can have in understanding the communication difficulties of a loved one. II is giving Jamie a way to have connections with their extended family. The pleasure this gives Bethany in seeing them interacting together and the fact that she viewed the interaction worthy of being videoed shows that these moments are important to her. There is evidence of labour in Bethany's account, establishing these connections has taken work from all parties involved.

Ali's relationship with their father is different to the one they have with their mother Abigail. Abigail seems to feel a little envious of the rough and tumble style fun that Ali has with their father, and that Ali will seek out their dad for this style of play. Abigail puts this down to gender stereotypes; dad is for fun; it is

easier when you are a man because you are physically stronger and therefore it is easier to engage in that style of play:

> Ali and their dad have great Intensive Interaction as well, but theirs is different to Mummy's because theirs is rough-and-tumble play.
>
> It is, yeah. It is, it's completely different. It's really funny, but then he's a man isn't he, and he can pick Ali up and throw them around.
>
> I think daddies are always for fun as well, aren't they? Always for fun (Laughter) and mummies just do everything else. (Laughter) (Interview 1)

However, she goes onto acknowledge the importance for her husband to have a relationship with Ali, and that he has not got the imagined relationship with Ali he hoped for. Both have a different relationship with Ali to the ones they imagined:

> But erm, no, it is quite sweet how they, they have their little time, and because Ali doesn't have any, sort of, hobbies as such, like I think Daddy would really like it if Ali played [sport] and things like that, it's nice that they do have their little, little time together. (Interview 1)

Even though Abigail and her husband's employment of II looks different it still enables each of them to enhance their connections with Ali.

Georgia equally described how her husband and her own use of II looked different. Her husband had to work harder at interacting with Gerry; it did not feel as if it was as intuitive. The activities they engaged in also looked different, Gerry had separate routines and games they played with each parent:

> [Husband] finds it harder. He does say it doesn't come naturally to [husband].
>
> They do little things like that. The things that I – they're different. Gerry almost knows, "This is the sort of thing I do with dad, and this is the sort of thing I do with mum." It's different. (Interview 1)

In Clare's account II gave her and her husband a joint framework to work with, a shared way of approaching Harley's behaviour. As a family they were working towards the same goal in the same way:

> Yeah. Erm, yeah, because obviously, if it's all, you know, it becomes all negative, erm, you know, and, and Harley's doing things to try and get my reaction and, erm, you know, it's just all negative, negative, negative, whereas, you know, where we're- Harley knows how to get my reaction positively and, you know, it is a lot more positive. I mean we still do have challenging behaviours, but, er, yeah, we're all- Erm, we're all on the same page and we all know what works and- You know, to keep it positive. (Interview 1)

These excerpts illustrate the role that gender plays in the way II is enacted by the mothers and fathers. The way the fathers engage in II is viewed as differing from the mother's own overtures by the mothers. The descriptions the mothers gave of how their children's fathers learn about and carry out II interactions aligns with traditional parenting roles. These included fathers not being as intuitive as the mothers and using more rough and tumble style play.

Fiona and Georgia's children were both in residential placements and II was used to encourage feelings of belonging in those communities. Georgia had it written in Gerry's EHCP and Fiona searched for a home that would use II. For both mothers II became non-negotiable in their search for suitable residential placements for their children. They wanted it to not only be used by them but also by staff to support relationship building, feelings of trust and belonging. Georgia said:

> Actually, it's one of the things now that we're looking for when Gerry goes to residential, that they [residential placement] use Intensive Interaction and that they're confident to use it and they will use it with Gerry. (Interview 1)

Fiona paid for training for the staff at the residential placement but they failed to carry on using II so she took the decision to look for another placement that would use it:

> Riley started doing that once a week, and the home staff could sit in on the session and watch, which I was very excited about, because I thought the staff would then see what an affect it had and then would carry it on. But they didn't. Enough was enough and I decided to move Riley to a new house. So I found a new home and the staff at the new

> home actually went on the training course before Riley even moved in. (Interview 1)

Fiona described how II changed the way the new staff viewed Riley, they saw Riley as someone with likes and dislikes, as a person:

> Yes, it's such a great way in to build that trust and that connection. When you've got that, you can do practically anything.
> Yes, and they see Riley differently. Whereas the old staff in the old home, I think they just saw Riley as a, I don't know what they saw, oh, "They're autistic, that's what they do." Now they see Riley as a human, as a person with needs and wants and likes. Yes, it changes relationships. (Interview 2)

This is very powerful, not only does II enable the mothers, families, and carers to feel they are recognised for who they are but also enables them to look to the person and what their preferences are. This is particularly important for the children who are being supported by carers outside the family unit. The increased understanding and learning that occurs in the practitioners enables enhanced connections and the mothers value this. They feel their children are valued and seen.

In summary the mothers' experiences of II include connections within their family, enabling relationship development of their child with other family members which encourage a sense of 'family' and belonging. Through using II themselves the mothers recognise its value in supporting others and their child to make connections outside of their own relationship. This fosters a sense of belonging with the wider family and communities the children live in.

Summary

For the mothers in this study, they experience II as enhancing the connections they had with their child. This included increased acceptance into activities with their child they previously felt excluded from. There is a tension in this acceptance with the possibility of rejection as the powerful child-led element is observed by the mothers. The child-led elements of II can leave the mothers

feeling torn between wanting to accept any and all overtures for interaction balanced with other responsibilities.

The mothers experience a shift in their identity beyond their caring role to re-identify with feelings of motherhood. This supports the mother's emotional wellbeing but equally is tinged with regret at lost time. These connections continue into the wider family, fostering a sense of belonging for the whole family. II enables relationship development for other family members and carers involved with the children, often due to the additional labour employed by the mothers in facilitating these. II is also experienced as a site of gendered parenting roles.

The next chapter moves onto discuss the implications of these findings in relation to research, practice, and policy.

Chapter 7 Discussion

This study explored mothers' experiences of using II with their autistic children. In particular it sought to:

- Inform knowledge and understanding of mothers' perceptions and experiences of using II with their autistic children.
- Explore mothers' reasons for engagement with II.
- Identify the practical effects on mothers of running an intervention at home.
- Understand how the use of II affects how mothers' experience their relationship with their child.
- Explore what engaging with II has brought the mothers in terms of personal growth and empowerment.
- Generate knowledge that might then enable the parental voice to inform policy and practice in working with professionals when delivering an intervention in the home.

This chapter positions the research findings from chapters 5 and 6 in relation to the extant literature surrounding II, highlighting both similarities and differences in the mothers' experiences. I evaluate what this study has to say about how the mothers' navigated their experiences of II and the impact it had upon them and their families. I discuss how the themes interlink and build towards the mothers' key experiences. Some of the discussion points are thematic: something that works for us, doing it right, learning to manage judgement and being accepted, and are discussed separately. However, others are more overarching: identity and motherhood and additional labour, and the implications are discussed with input from several themes. The implications of this discussion for policy and practice alongside the studies strengths and limitations is provided in chapter 8.

7.1 Something that works for us

In the mothers' accounts how they found out about II featured prominently in their narratives. For some of the mothers there was a temporal element to these stories, with tales of what their child was like before discovering II and after. The act of discovering II was often a laborious one, featuring elements of chance in discovering this social communication strategy. Even when they did get introduced to or discover II the resonance they felt with the intervention influenced their decisions to try it. Equally, scepticism over II's ability to make a difference featured in the mothers' accounts of their initial considerations over using II.

The data from this study established that the mothers had a driving belief in the need to identify and access useful support for their family with enabling their autistic child. The findings in this study illustrate how it was often only by chance and fortuitousness that the mothers found out about II. Six of the mothers in this study were introduced to II by a professional supporting them (who were either training themselves or strong advocates for II), Fiona found II through parent networks. These findings resonate with previous literature discussing how parents seek and access support for their disabled children (Clarke, 2013; McKinney et al., 2021). Moreover, the visibility and local area policies play a role in how parents come across II. There is a postcode lottery involved with whether the Integrated Care Board or Local Authority advocates II in your area. This can be seen in adult learning disability services, with areas such as Oxford and Leeds having an Intensive Interaction Coordinator and II being promoted to and used routinely by their care staff. However, this is not commonplace across all areas of the country. The Intensive Interaction Institute is working to increase its visibility but II seems to have a long way to go to achieve the same commonplace status as PECs or Makaton. There is a disparity around the country of information and support about II, with parent's employing additional labour, and also remaining hostages to luck, in searching for support for their children (Berridge & Hutchinson, 2022). The additional labour that is required by the mothers of disabled children in seeking support is a critical issue and weaves through the narratives of the mothers in this study; I will discuss this separately in this chapter as it features in numerous themes.

McKinney et al. (2021) highlight how there is little consensus on which communication interventions to use with the non-speaking autistic population. A lack of research with this population leaves parents marginalised and relying on either their own endeavours or the preferences of the professionals supporting them or as evidenced here, chance encounters with approaches and practices. Indeed, Hines et al. (2011) found that parents came across AAC via chance recommendations from others as opposed to the professionals actively supporting them at that time or any other structured method of informing parents of available supports. This resonates with my own experience: a fortuitous meeting with a professional who recommended II. If I had not attended that particular meeting, my own family situation may have looked very different. These elements of chance are evident across the parents seeking support literature. Clarke (2013) similarly described elements of luck in parents finding support for their children with mental health conditions, recounting chance encounters with knowledgeable parents or happening upon workshops advocating certain interventions.

The mothers in this study were continually actively researching the possibilities in search of something to support their children. Similarly, within the II literature Berridge and Hutchinson (2022) discussed how mothers' experiences of support and information prior to using II was dominant throughout their narratives. This illustrates the importance of this topic for mothers and the time and energy spent on these pursuits. Berridge and Hutchinson also found that the II information the mothers found or received was often limited. This differs from my findings somewhat, the majority of mothers in this study were accessing ongoing support from professionals which involved elements of 'training' as opposed to mothers using II in isolation with no support from social care or education staff.

Feelings of resonance with an intervention when making informed decisions featured in the mother's accounts. Even when II was advocated by a professional the findings from this study highlight the importance of being able to recognise your child and family in the representations of II to which you are exposed. Clare initially dismissed II as not relevant for her child, and then later blamed herself for what she felt was a personal oversight. Really though the issue is with the II workshops that are presented to parents. These need to

showcase differing profiles of children and adults engaging in II, to avoid the potential of alienating parents from a prospective strategy. Edwards et al. (2018) describe parents as moving through a continuum from novices to experts in their knowledge and understanding of strategies and interventions to engage in with their disabled children. It is argued that parents move from a stage of dependence on professionals to direct and advocate which strategies to try to later becoming more expert at evaluating for themselves which interventions may and may not work for their families. This often involves parent's researching, looking and evaluating interventions for themselves as evidenced by some of the mothers in this study. It is therefore important that material and resources about potential strategies are presented in a way that provides comprehension information for parents to be able to make informed decisions about what would be appropriate for their child.

The mothers in this study were seeking support for differing reasons. However, the fact that II resonated with them featured in their reasons as to why they were attracted to it. Fiona, for example, instinctively felt that II would work for them, describing how when she googled it, she was 'ecstatic'. For Helen it was the play aspect of II that attracted her to it. Carlon et al. (2015) described how meeting an individual need is a primary thing parents of autistic children look for in an intervention. As autistic children are heterogeneous, parents become expert in looking for interventions that will meet the individual needs of their child, or the primary need they would like support with, be it communication, behaviour etc… For the mothers in this study this was support with positive behaviour (Clare), being able to play with your child (Helen), feeling safe (Georgia).

Resonance with an intervention and it meeting the need you would like support with are clearly key reasons for the mothers starting using II, however, this did not prevent feelings of scepticism over various aspects of II. Elaine reported initial reservations over II's simplicity and whether that meant it would work when far more complicated strategies had failed. This concurs with the II literature, Elaine's experiences are mirrored by practitioners supporting learners across both adult and children's settings. The volunteers in the study of Zeedyk et al. (2009) reported initial scepticism that II's perceived simplicity could work with the children they were supporting. However, these reservations did not

prevent Elaine from trying II. Again, this resonates with the wider II literature, Zeedyk et al. (2009) and Firth et al. (2008) participants expressed reservations about II but still implemented it and this then affected a change in attitude.

Further stories of scepticism and surprise were recounted by Bethany and Georgia. Bethany was surprised by the speed with which she saw improvements in interactions with her child. Conversely, Georgia's reservations were ongoing, around the perceived lack of progress in her child's communication. Even though Georgia could see positives from using II, she was not convinced it had made any difference to Gerry's communication. These mothers were anticipating how effective they thought the strategy might be or evaluating retrospectively what they viewed as progress. Within the wider literature on class-based interventions, implementation is said to be affected by teachers' beliefs about the efficacy of interventions. This also included any beliefs about the acceptability of interventions within the wider school environment. Anticipated effectiveness is said to be a factor in teachers' willingness to implement interventions (Hans & Weiss, 2005). Mothers are similarly making these judgements, whether an intervention will fit in the wider family environment and work for them.

What is demonstrated in my study is that the mothers were evaluating and making informed decisions about II and whether it was worth trying. Using their prior experience of interventions and expert knowledge of their children and families they put aside initial reservations to give it a go. Therefore, consideration needs to be given to how and what information parents receive about II as this can factor in its uptake.

7.2 Doing it right

This theme centred around the learning taking place as the mothers engaged in II. II was viewed as a simple intervention that did not require lots of resourcing, a revisiting of skills and interaction styles they had perhaps moved away from. This learning was not always easy for the mothers, bound up with feelings of guilt the mothers learnt to let go and slow down, finding a common meeting

ground to enjoy spending shared time together. Labelling II as an intervention legitimised the mothers' interactions and enabled the reclaiming of skills.

Within this theme one key point that emerged was the degree of reflective practice with which the mothers were engaging. A process that they did not always find easy. They narrated how they had to learn to 'uncomplicate themselves' (Georgia), 'to leave more processing time' (Clare), 'let their hair down' (Abigail): these all illustrate a level of awareness and reflexivity from the mothers as they discuss their overtures to their children. Within the II literature reflective practice is strongly advocated for II practitioners as a way to maintain the integrity of the technique and foster a sense of a shared understanding and common purpose (Barber, 2007; Nind & Powell, 2000). However, practitioners are typically engaging in reflective practice in groups with other colleagues which provides a space to share concerns and triumphs. For the mothers in this study, this varied. The mothers attending the parent group had access to a reflective space to share their practice and found this to be a positive space (this is discussed further in 7.5.3). However, the other mothers did not have access to this in the same way. They had the input from professionals supporting them but engaged in reflective practice on their own. What is evident is that the mothers were engaging in reflexive thinking about their interactions and this formed part of the ongoing learning and increasing their understanding of their child's social communication.

The mothers narrated various emotions of the learning they experienced, bound up with feelings of guilt and it being 'hard to know' (Georgia) and 'learning it is ok' (Clare, Helen) to do what may be perceived by others as simple or not very much. This novel aspect is evidenced clearly in this thesis; however, the wider II literature makes little reference to these feelings in practitioners. The volunteers in the study of Zeedyk et al. (2009) express scepticism at something seen as simple working but any emotions tied up with this are not explored. Within the adult social care literature concerns over age appropriateness and treating clients with respect, feelings of self-consciousness and time factors were all reported (Firth et al., 2008; Nagra et al., 2017) however, issues pertaining to learning it is ok to do less were not.

The emotions tied up with the learning sets the mothers experiences apart from those of practitioners. These mothers were emotionally engaged in the practice of II, this differs to how it is reported to be experienced by professionals. Their position as mother brings with it a differing set of values and expectations, leaving them navigating a different set of experiences.

Throughout western culture ‘good mothering’ and ‘intensive mothering’ ideology pervades (Sousa, 2011). Mothers of disabled children and particularly autistic children are ‘othered’ in that they do not necessarily fit the dominant ideological norms of motherhood. Douglas et al. (2021) describe the trajectory of the literature surrounding the mother of a disabled child: from ‘refrigerator mothers’ blamed for their child’s difficulties to the stress and coping models and difficult mothers making unfair demands for services and support. Moreover, the narrative of a mother of a disabled child being naturally superhuman and doing everything in their power to move their child towards normative benchmarks pervades (Sousa, 2011). Engaging in II challenges this narrative by giving the mothers permission to take a step back, slow down, and enjoy their child where they are. It enables a deeper understanding of social communication and how to support their child, freeing them from striving for their child to reach developmental norms. However, this is a learning process, not just about what II is but also learning about themselves and letting go of any guilt bound up with what they perceive as simple. Sousa (2011) discusses mother-blame the premise of good mothers and therefore bad mothers who are responsible for their children’s difficulties. Sousa states that the mother-blame of mothers of disabled children is a historical legacy still enacted today. The premise that to be a ‘good mother’ you must be self-sacrificing and search for professional support to meet your child’s needs. Doing something which feels like doing less is difficult for the mothers who are judged constantly against the normative ideological ‘good mother’- ‘intensive mothering’ rhetoric.

Hegemonic power structures obliged the mothers to look to the professionals supporting them for permission to do less and simplify their actions, even though for some (Fiona, Elaine, Helen) they already were intuitively using these techniques. This aligns with the assertion of Edwards et al. (2018) that parents of disabled children move through a continuum from reliance upon professionals to becoming more expert in their own knowledge. These findings

pertain to the dominant narrative that holds that parents of disabled children require training in order to know how to parent their child and which privilege professional knowledge over the lived experience of parents (Hodge & Runswick-Cole, 2008). For these mothers a critical element of accepting letting go of the notion of the only good approach is a complex one is the way in which II is, labelled as an 'intervention'. Knowing they were carrying out an intervention seemed to enable the mothers to let go of the feelings of guilt and to make space for II within their daily routines.

Within the II literature enhanced relationships and increased understanding of communication are key aspects of practitioners' experiences. Zeedyk et al. (2009) and Nagra et al. (2016) discuss the impact that increased understanding of social communication had on practitioners becoming more person-centred in their approaches. Similarly, the mothers in this study narrated the impact of developing through II their understanding of their child's communication and interaction methods. Learning about II fostered the creation of a common meeting ground between the mothers and children; II provided a legitimate platform to spend shared time together. Elaine described how she 'understands Drew better' and has 'more patience' with them. Georgia's increased understanding of Gerry meant she engaged in reflective practice when interacting realising 'no that's going to switch them off'. Findings from this study evidence a shift in attitude for the mothers as with other practitioners. As a result, their use of II endures over the long term and the key concepts which were learnt initially pervade through their continued interactions.

This common meeting ground has echoes of the 'double empathy problem' (Milton, 2012). Milton described this as a difference in reciprocity between two people, namely one autistic and one 'neuro-typical'. It occurs within the social interactions of two people and is experienced by both people, so each struggle to understand the meaning of the other. Conducting II seems to give the mothers a way to breach this and rather than 'othering' their child and locating the difficulties with social interaction in the child, they come to recognise breaches in communication as resulting from a difference in styles and methods of interaction. The mothers then seek to find a mode of interaction to join the child in a way that holds meaning for them. II enables the mothers to increase their understanding of social communication and 'open up' (Clare) their child's

world to them. As a mother of a disabled child, you do not fit within the normative mother-child dyad but equally you are not disabled yourself, the experience of disability is through your child (Ryan & Runswick-Cole, 2008). Green (2002) describes this as feeling like an outsider looking in on her daughter's experience, one which she can never truly understand. This concurs with the mothers' experiences in this study. For them it was II that provided a window into a deeper understanding of their child's world.

For some of the mothers learning encompassed the reclaiming of skills and a realisation of techniques they were already engaging with. Intuitively there were already using some II techniques without realising it (Elaine, Bethany, Fiona). For others II was different to the way they currently interacted with their child (Abigail, Clare). Within the literature there are some claims that II is nothing new and just a packaging of what people are doing anyway in relation to autistic people (Firth et al., 2008). The literature also reports the validation that can be felt when instinctive skills are acknowledged and labelled (Nind & Thomas, 2005).

Parents know their children well and have established relationships with them which at some time will have included early infant-caregiver interactions. This could mean they exhibit attitudes similar to the care staff in Firth et al's (2008) study. Indeed, Berridge and Hutchinson (2022) found that some mothers in their study reported little effect with II as they already had reciprocal relationships with their children and used II techniques naturally. Conversely, some of the mothers in my study expressed experiences of validation at what they already were doing with a realisation that they were on the right track. This fed into the mother's sense of self, it gave self-validation of being a good mother. Berridge and Hutchinson suggest that a perceived lack of responsiveness can reduce a mother's feelings of competence as a mother. However, for the mothers in my study experiences were not around what they perceived they were not doing, more around what, with reflection they realised they were already doing. Potentially, this may be due to how II was introduced to the mothers. All but one mother in my study at the time of the first interview was actively supported by a professional in their use of II. This illustrates the hegemonic power structure of professional as expert, privileging professional knowledge over the lived experience of parents (Hodge & Runswick-Cole, 2008). Some of the mothers in

this study relied upon this professional knowledge to illuminate they were a good mother and provide affirmation of their parenting skills.

Validation came in differing forms for the mothers. For some it was validation that they were interacting with their children in supportive ways. However, for Fiona validation took an additional form in that she felt finding II justified her long held and steadfast belief that there must be something out there to make a difference to Riley and that she could not be the only mother looking for this. Fiona felt that she had been cast by professionals into the role of unreasonable mother, wanting the world for her child at the expense of others. The idea of the mother who wants everything for her own child at the expense of other disabled children is a dangerous and entrenched trope that pervades through disability services. It is often resorted to by professionals who label parents as difficult if they do not accept limited and inappropriate provision for their child (Hodge & Runswick-Cole, 2008).

The mothers were continuing to use II over the longer term. This was not an intervention used for a short time and then discarded. Rather it became a site of naturally occurring social interaction within the family, embedded in everyday practices. Bethany and Fiona both described how II had become a natural mode of communication with their child. However, there was also a tension in this for some mothers, a level of frustration at perceived plateauing of progress. Bethany described hitting a ‘stumbling block’ and Elaine voices resignation that each session turns into the same thing. Equally, Clare described how it was ‘on the same path’ in her second interview. Within the wider II literature rapid initial surges of progress with plateauing are mentioned in relation to efficacy (Elgie & Maguire, 2001; Kellett, 2000; Zeedyk et al., 2009) but their impact on practitioners is not explored. The findings in this study shine some light on this phenomenon and the tension it brings. There is a juxtaposition for the mothers: initial progress in the areas the mothers wanted, and a deepening of understanding of social communication with their child affords longer term use of II as it becomes embedded into everyday family routines. However, the initial progress leaves the mothers wanting more and experiencing frustration when interactions remain static in their eyes. Nonetheless, these experiences do not seem to dissuade the mothers from continuing with II in the longer term.

These findings illustrate how the mothers in this study experienced II as giving them permission to relax, to let go of the search for something complex and costly that would help their child and instead to trust in and develop their own capacity to know and relate to their child. My study reveals a value and importance of people needing permission when supporting autistic children to interact in ways that may feel instinctively right to do but seem too simple to be effective with children and adults made ‘different’ and ‘disordered’ by professional systems of categorisation.

7.3 Learning to manage judgement

The mothers in this study were all involved with professionals in one form, or another and the experience of being evaluated and judged as parents featured in their stories. As discussed in Chapter 2 the dominant narrative is one of parents requiring training to interact with their disabled child (Blindlish et al., 2018). This narrative inevitably means that parents, typically mothers as primary carers, are navigating a legitimised scrutiny of professionals in their interactions. The mothers also discussed other forms of judgement namely the perceptions of outsiders to their interactions.

As the mothers were primarily engaging in II with the support of a professional this meant a level of scrutiny was employed in their learning of II. Even though videoing is not necessarily a part of all mother’s experiences of using II for the mothers in this study six out of seven of them had used videoed as part of their learning experience. Therefore, videoing was discussed throughout their narratives. As videoing for reflective feedback and learning is advocated in the II literature (McKim & Samuel, 2021) and indeed within the wider parent training literature (Gibson, 2014) it is pertinent to discuss the implications of this here.

The mothers considered the positives of the group experience of sharing video or being able to look back on interactions, plus gaining feedback on aspects they were unsure about. They also discussed the limitations of videoing that they encountered, including feelings of self-consciousness, awareness of others’ perceptions, logistical issues and the performative nature of their interactions. They did not overtly discuss how they felt being judged by the

professionals supporting them, perhaps this was just an expected norm for them. Their reflections were more around how being videoed made them feel.

Being able to use the videos to reflect on the nature and practice of their interactions enabled the mothers to affirm their engagements in a variety of ways. For the mothers involved with the parent group, sharing their videos with the teacher and other parents provided what felt to them a positive space where they could reflect on their interactions with other parents who had similar experiences. Clare found the group a useful place to be able to draw on the teacher's experience and check she was doing it right and Bethany enjoyed the social aspect of the group learning. For her the group setting provided a supportive atmosphere to learn in. Videoing is advocated for training and continued reflective practice in the II literature. Nind and Hewett (1988) use video from II's inception to illustrate its use. In both education and adult social care settings videoing is recommended for reflective practice to empower practitioners and support a collective shared interest in II (Barber, 2007; McKim & Samuel, 2021). McKim and Samuel (2021) discuss how even though II can be seen as intuitive you are learning a skill and therefore video use for reflection is an important tool. This chimes with the mothers' experiences, some were intuitively using II but still talked about it using the language of learning.

The watching back of the videos also provided a reflective space for the mothers to realise the lovely interactive moments they had with their child which when in the moment may pass you by. Having videos to look back on countered feelings of awkwardness and empowered the mother's self-belief when they saw the enjoyment their child was getting from the interactions. Abigail, Clare and Elaine all described the benefits of being able to watch their videos back including contributing to emotional wellbeing (Abigail), lessening self-doubt (Clare) and increasing self-belief (Elaine). These findings are positive aspects of been videoed and having a reflective space to share them in. However, this is dependent on the sharing of any videos whether with a professional or other parents being a supportive environment, where any feedback is constructive. Equally, the reason the mothers were videoing themselves or being videoed was for 'training' purposes and they were evaluated and judged on their interactions by professionals to aid their learning. This is problematic and supports the narrative of professionals in the position of expert with their

knowledge privileged above parental knowledge (Hodge & Runswick-Cole, 2008). This poses a power imbalance leaving the mothers in a position where potentially their own knowledge and expertise of their child is not valued in the same way as the professional's knowledge. Reeder and Morris (2021) discuss the power imbalance that exists in traditional hierarchical relationships such as that of a parent of a disabled child and the professional supporting them. The authors describe how parents would often under value their own contributions to knowledge of whether interventions were working and instead defer to the professional for their guidance. This aligns with the experiences of the mothers in this thesis, Clare deferred to the professional supporting her for affirmation of her interactions and Helen strove to produce a video worthy of being shown to other parents, both devaluing their own expertise and knowledge of interacting with their children. Instead, they sought the validation of the professional supporting them.

The use of video is widely advocated for supporting parents with interactions with their disabled children; however, the literature focuses on its use as a teaching and efficacy tool rather than evaluating the impact its use has on parental wellbeing (Gibson,2014; van den Broeck, 2017). Video use to promote parent-child interaction is widely used across social work and education sectors, not just for parents of disabled children. Video interaction guidance (VIG) is used to promote positive parent-child interactions across a range of sectors including social work, however there are limited studies exploring its use with autistic children and their parents (Gibson, 2014). Concurring with the findings in this study, a mother in Gibson's study found watching the videos of her interactions with her son back gave her the opportunity to witness the progress her son was making and to notice how happy he was during their interactions. Gibson asserted that the use of video supported the parent participants to renegotiate the deficit narrative surrounding parenting a disabled child and reframe it positively through redefining their skills and confidence and building on existing strengths. The findings in this study support this notion, having a reflective space to watch videos supported the emotional wellbeing of the mothers through affirmation of their mothering abilities and enabled them to strengthen their existing interactions.

However, the use of video was not without its challenges as the mothers' narratives illustrated. Downsides to video use are not discussed in the literature on II, rather it is just advocated as good practice. The mothers' experiences in this study start to address some of the difficulties and provide an opportunity to start discussing these. One key area discussed was the practicalities of videoing. Difficulties with logistics of videoing in the home were narrated, Abigail and Bethany both found difficulties with using video in the home due to privacy issues or the lack of a third person to hold the camera.

In addition, feelings of self-consciousness featured in the narratives. Elaine described not being completely herself during videoing: she was more reserved and held something of herself back, conscious of the camera and how she portrayed herself. Reflecting on videos affords you, to some extent, the perspective of an outsider and how others might perceive you. Bethany, Georgia and Elaine were all aware of how their interactions could be perceived by others, perhaps not always positively. This concurs with the practitioner II literature with staff reporting concerns over using techniques such as mirroring and how interacting in this way out in the community could be viewed by others (Firth et al., 2008; Culham, 2004). Moving away from normative benchmarks and wider societies perceptions of what parent-child interactions should look like at certain chronological ages is important. Firth et al. (2008) advocate for normalising interactions using techniques such as II to raise awareness within society. However, for mothers this legacy pervades, as a mother of a disabled child you are judged and scrutinised on your child's behaviour particularly in public spaces (Williams & Murray, 2015). Ryan (2005) discussed how invisible disabilities such as autism can mean others judge interactions and behaviour by normative standards and in doing so are liable to consider parents lacking. Williams and Murray (2015) describe how ideological norms of motherhood leave mothers of disabled children negotiating the judgement of others. They state that for some mothers this can lead to a redefining of that judgement, so they develop a 'thick skin' and position the judgement as the other persons problem. Similarly, in my findings Bethany described how she had moved from 'feeling like a twit' to 'I just don't care'. For the mothers this seems to be a continuum that they perhaps move through; some were acutely aware of the perceptions of others and feelings of self-consciousness whereas Bethany had

moved past this, perhaps because she was one of the more experienced mothers in using II.

A further key challenge to the use of video highlighted in this study is the disruption of natural interactions. The added element of videoing interactions and the logistics involved meant for Bethany there was an element of performance in her interactions. The premise of II is on intuitively tuning into your partner and responding to their interaction overtures (Nind & Hewett, 1988). Bethany found that wanting to capture a 'good' video to show at the parent group detracted from this and meant interactions felt staged. This moves the interactions from celebrating the play and interactions of your child towards 'othering' the child and through the actions of creating a situation it 'problematises' the interaction. Introduction of videoing disrupts the natural flow of an interaction, it requires elements of staging, and the logistics considered. It risks undermining the interaction itself, pathologising and ruling it as deficit by the very action of it needing videoing in the first place. Goodley and Runswick-Cole (2010) discuss how structured 'play' sessions set up to enable parents to learn interventions deprive parents of spontaneous play, placing parents under pressure to meet the 'play' standards for that intervention. Disabled children's play is often viewed as deficient if it differs from normative benchmarks for play and as such is the object of intervention from professionals (Goodley & Runswick-Cole, 2010). Parent mediated interventions to support development of play are widely used, often social communication interventions use a play-based approach (see Chapter 2.5). Indeed, II is a play based relational approach, however videoing parents to provide feedback on their techniques is also widely used (Gibson, 2014). Assessment of play or parent-child interactions places them in the category of 'non-normal' and means the parent is being scrutinised and judged on their capabilities of interacting with their child (Goodley & Runswick-Cole, 2010). This is a challenge for II, the benefits of video use for reflective practice must be weighed up against risking de-naturalising interactions and therefore perceiving them as less than. Particular consideration needs to be given where the videoing forms part of the 'offer' for learning about II for parents. One of II's key strengths is in its ability to fit into the normal rhythms of the day. It does not need to be done at a particular time in a particular setting and is bespoke to each mother and child pair. II is about

tuning into your child and responding to the behaviours they find meaningful. Videoing these interactions detracts from the spontaneity and natural flow of interactions between mother and child. The action of videoing mothers' interactions so they can receive feedback on them pathologises the interaction itself, placing it in the category of there is something wrong with what the mothers were already doing. This feeds back into the narratives of mother blame, leaving mothers negotiating the judgement of others on their skills as mother of an autistic child.

As the findings in this study illustrate video use has pros and cons which the mothers narrated in their stories. The use of video can empower mothers' self-belief and negate against good mother ideology; however, it can also feed into the narrative of mothers needing training and their interactions as deficit. This is a far more nuanced area than I previously had recognised. There can be benefits to being videoed for the mothers and indeed practitioners in general but, the ethos this is carried out in is vital to detract from feelings of judgement that what you were doing was not good enough. The opportunity to reflect on interactions and see the enjoyment of your interaction partner can empower mothers and other practitioners in their self-belief of their abilities. However, this needs to be counterbalanced with considerations of how the practical issues of videoing can mean interactions feel staged and unnatural. The action of suggesting an interaction requires videoing risks putting it in the category of deficient which goes against II ideology. Further research in this area is warranted to explore in depth the experience of video use in parent-interaction social communication interventions, moving away from efficacy-based studies.

7.4 Being accepted

This theme illustrated the feelings of acceptance and sometimes rejection the mothers could feel when engaging in II with their child. The findings in this theme highlight a key contribution to knowledge from this thesis; the impact of the child-led element of II on the practitioner, in this case the mothers. The mothers discussed the acceptance into areas of their children's lives they had previously felt excluded from: II's techniques enabled them to feel more

included and connected to their children. The increased understanding that II affords empowered the mothers to adjust their interactions and enabled them to experience acceptance and shared experiences. This acceptance was experienced largely through play and the joining in of activities. However, there was a tension in the mother's experiences when they either had to say 'no' to their child or they child rejected their interaction overtures.

The child-led element was discussed by several of the mothers. This was the reason they thought II worked but child-led practice brought with it some difficulties. Helen and Georgia both talked about how it was the child-led element of II that made it different to other interventions they had tried and that this was the aspect in their eyes that meant it worked.

Within the II literature, being child-led is one of the underpinning principles of II (Nind, 1996). Firth (2012) describes this as a power shift in the interactions; the learner directs the interactions not the communication partner. However, the impact of this on the practitioners is not explored in any detail. The child-led aspect is discussed from a pedagogical aspect and for professionals, particularly early years practitioners this is not a new concept (Richards, 2022). Indeed, Richards' chapter on II in the early year's classroom discusses child-led practice and the importance of allocating higher adult to child ratios to ensure dedicated quality interaction time devoid of the distractions of a busy classroom. This is obviously not easy to achieve in the home in the same way. Even though this key principle is described in the 'how to' books there is limited exploration of what this means in practice in the II studies. Within the adult social care literature, the client-led aspect is touched upon in McKim and Samuel's (2021) case studies. One staff member in the research described how the fact that II is led by the client meant they felt in control and is what made it work. This was seen as a crucial aspect to the success of II for this client who had frequent behavioural episodes. However, they did not discuss any difficulties with this. The authors described how they increased the one-to-one time with clients in order for II to be used, to encourage a focus on interaction as opposed to care task-based activities. In the home this is harder to do, and the impact of this crucial aspect needs consideration from professionals advocating and supporting mothers using II.

The acceptance the mothers felt from being allowed to join in with aspects of their child's life from which they may have previously felt excluded is a key outcome of the power of II being child-led. The mothers in this study narrated this through descriptions of play. Clare, Helen and Elaine all described how using II had enabled them to play with their child in ways they had previously not experienced. Being asked to play and join in with favoured games is one way the mothers' experienced acceptance. The importance of play for development and the 'atypical' play of autistic children is written about expensively in the literature (Kasari et al., 2013). Indeed, Kasari et al. discuss how the play of autistic children has been described as atypical since Kanner's original identification of autism. Play is pathologised and problematised and as such parents are exposed to ideological norms of play that their children fail to meet (Goodley & Runswick-Cole, 2010). Moreover, play is often a site for intervention, a situation to intervene with and 'improve' (move towards normalisation), in areas such as pretend play (Marwick et al., 2022). The child-led element of II means that the mothers are responding to the child with behaviours they find meaningful; they are not trying to teach their child to play in a set 'age-appropriate' way. This moves them away from normative benchmarks associated with chronological age and therefore enables more intuitive and naturally occurring play to take place (Goodley & Runswick-Cole, 2010). The mothers' experienced playing with their child in a way that valued the child's play and enabled deeper connections to be felt. The mothers value these moments with their child; they had adjusted their perspectives of what play may look like and this fed into their sense of self. This is congruent with Williams and Murray (2015) study of mothers of disabled children. The authors narrated how the mothers adapted activities to suit their children and through this found value in simplifying things which altered their understanding of what a 'good mother' was.

Goodley and Runswick-Cole (2010) argue that as play continues to be a site for intervention parents' experience it only through this lens of development. The mothers in this study seem to experience aspects of this as discussed in 'management of judgement', the performative aspects of sessions detracting from the natural spontaneity of interactions. However, the mothers' stories also narrate a move away from this towards spontaneous play, valuing all types of

play. These play overtures enable shared connections, and the mothers describe these as their children feeling recognised and listened to. Terminology such as ‘lightbulb moment’ (Abigail) or ‘lighting up’ (Georgia) are used to describe this. It is the emotional aspect of this realisation by the mothers, they witness an understanding and recognition by their child that the way they are interacting with them is ‘with them’ rather than ‘to them’. This feels as if it sets II apart from other play-based approaches, where the adult often sets the agenda for play through choosing the toys or directing the play. Kasari et al. (2013) state that autistic children require intervention in order to develop the skills to play, stating that ‘naturalistic’ methods where the child leads with their own play preferences are most effective. However, in their study the adult then directed the play to facilitate ‘higher levels of play’. In II the onus is firmly on a child-led approach.

Concurrent with my findings are those by Berridge and Hutchinson (2022) whose mother participants equally expressed feelings of joy and amazement in their interactions with their children and attributed the child-led element as an important factor in this. In this way II is providing resistance to the hegemony of the age-appropriate norms that traditionally dominate the play agenda for disabled children and their families.

There is no doubting the difference using II makes to increasing understanding and rapport with autistic children and adults. However, the impact of the child-led element of the intervention is not explored. For mothers the impact this change in power balance can exert on their identity, sense of self and emotional wellbeing has not been sufficiently investigated through research.

Mothers are managing competing demands without the luxury of increasing their one-to-one time through another adult relieving them of some jobs, as often happens in professional settings. The impact that this has upon their experiences is highlighted by some of the mothers in this thesis. II was viewed as flexible. The mothers in this study found that helpful because they did not need to have a set time they engaged in II. But this flexibility could also inadvertently prove a difficulty in that their children could approach for interaction at times that were not convenient for their mother. Helen, Elaine and Bethany discussed difficulties with their children choosing, what were for them,

inconvenient times to request interaction and how this made them feel when they had to say no. The mothers were negotiating competing demands of running the home whilst being mother to their disabled child. The key point here is the emotional response the mothers have to saying no. This is experienced as two sides of a coin: acceptance and the joy this brings verses having to say no or the child rejecting the mothers' advances. This role reversal which placed the power of interaction firmly in the child's hands was difficult for some of the mothers. The joy of been asked to play was tinged with regret when they had to say no. This felt like a difficult choice to make.

For some of the mothers the child-led element meant they often felt on the outside of their child's life looking in: they experienced acceptance when they were allowed to play but at other times their children rejected their overtures. Abigail and Helen both agreed with the concept of the importance of the child-led element and anticipated that if they pushed their child to interact with them then it would only serve to distance them. This tension is not explored in the II literature, even Berridge and Hutchinson's (2022) study of mothers did not explore any downsides to the power relations within II and how mothers might experience being positioned within this. This is a significant finding of my research.

The findings in my study indicate that the mothers feel more than just the satisfaction of an intervention showing progress in the nature and degree of a child's interaction. Abigail, Helen and Bethany, all describe it as 'hard' when their child rejects them, or they have to say no to their child. They are conflicted between wanting what is best for their child and what they need for themselves, or being required to prioritise other demands of motherhood, in that moment. This aligns with 'good mother' ideology and the premise that a good mother is a selfless mother, putting her child's needs above all else. As a selfless mother they should be able to juggle it all, delivering the intervention and managing the house; this is the dominant narrative that mothers judge themselves against (Pedersen, 2016). However, the reports from the mothers in my study illustrate resistance to this through narrating their difficulties with saying 'no' or equally being rejected by their child. They are doing what is best for the child, but this is not always easy for them. Interestingly, Elaine story has a differing narrative. She did not seem to feel guilty in the same way as some of the other mothers. If

the timings of interactions did not work for her, she moved away from Drew and interacted with them later. Elaine resisted the dominant good mother = selfless mother narrative and redefined what 'good mother' meant to her. She interacts at a time when she can fully commit to the interaction so that it will be mutually pleasurable as per II's key principles.

These particular findings cannot be found in the research into the experiences of professionals with II. In this way the mothers' experiences are set out as separate in this respect. This needs to be openly discussed, acknowledged and normalised. The impact of the emotional aspect on mothers of balancing conducting II with the other responsibilities in life needs more recognition by professionals. Mothers may well need support with when and how to say 'no' when their children initiate interaction.

7.5 Identity and motherhood

This study revealed that II brought about changes in the mothers' feelings about what being a mother meant to them. This was an unexpected finding in the data for me, I had expected the mothers to discuss their relationship with their child but more in terms of enhanced communication and understanding and perhaps sometimes a reduction in difficult to manage behaviours. Indeed, the mothers did discuss these topics in their stories, and these findings are repeatedly discussed in the professional literature as being experienced by professionals too. What surprised me was the mothers' discussions about their identity as a mother and what using II brought about in terms of their sense of self. The differing facets of the mothers' identities threaded through the themes and so I will discuss these together here.

7.5.1 Maternal identity

This study revealed accounts of maternal identity and what that meant to the mothers. This included accounts of both an altered envisaged maternal identity and stories of affirmation of maternal identity. Throughout the data the influence

of good mother ideology can be seen across the themes. This has been discussed where relevant in relation to the discussion points so far in this chapter, here I discuss the key findings relating to maternal identity.

Georgia articulated how her maternal identity with Gerry differed to that with their sibling: she has a significantly different mother-child relationship to the one she has with her other child and the one that she envisaged she would have with Gerry. Williams and Murray (2015) discuss the dominance of research of mothers of disabled children focusing on the negative aspects of what the mother-child relationship is missing as opposed to the value the relationship has and the positive experiences that it brings. This pervades throughout the research and the stereotypical ideals associated with motherhood permeate society through the media (Pedersen, 2016). Furthermore, the research surrounding autism focuses on stress and the 'coping' mechanisms of mothers of autistic children (Knight, 2013). Moreover, the non-speaking autistic population and their families are excluded from the research agenda completely, thereby further marginalising and 'othering' the mothers (McKinney et al.,2021). So, it was not surprising that Georgia articulated her maternal identity in this way.

Harvey (2015) asserts that the majority of studies explore mothering a disabled child in relation to the impact upon the child. There is a paucity of research into the impact of parenting a disabled child upon the mother's own sense of self and identity. Maternal experiences of idealised mother-child relationships predominate the literature, promoting notions of the 'good mother' and 'intensive mothering' ideology (Brock, 2014). Mothers who are categorised as occupying marginalised positions such as mothers of disabled children or LGBTQ+ mothers find themselves 'othered' when their mother-child relationships do not conform to the stereotypes promoted, celebrated and expected within society and the media (Harvey, 2015). The findings in this study add to the literature on the impact of parenting a disabled child on the mother's sense of self.

The mothers narrated other accounts of maternal identity, of key importance was how when using II they felt like a 'mum.' The impact on one's identity as a mother through using II is a key finding of this research as so little is yet known about the lived experience of parents and families using II. The findings of this

study illuminate this under researched area. Bethany candidly described how using II enabled her to feel more than being 'just a carer,' she felt like a mother. For some of the other mothers (Abigail, Clare, Elaine, Georgia) feeling like a mum was experienced through enjoying precious shared moments with their child, or through feeling recognised by their child as 'mum'. This was extremely powerful for the mothers and suggests a reframing of their identity from long-term carer of a disabled child. This role often embodies elements of the selfless good mother who puts her child's needs above anything else and embraces the role of carer (Knight, 2013). The mothers' experiences and feelings enabled an identity shift towards feeling just like a 'mum'. Brock (2014) described mothers as having differing identities. They were either dependent on motherhood or separate with some mothers shifting between the two, depending on social context. One mother in Brock's study distinguished her role of carer as separate from her role of mother and she asserted that she would not wish to be just defined as a carer but was happy to be just defined as a mother. The role of carer was viewed as restrictive and repetitive whereas the role of mother was seen as someone who was emotionally connected to their child. Bethany articulated how she felt selfish for wanting the closeness and connection with her child: as a mother of a disabled child, she felt that she should be completely self-sacrificing and not admit to her own needs for a reciprocal relationship. Brock (2014) states this is a perpetuation of the good mother ideology, a reinforced narrative of good mothers are selfless mothers. Similarly, Ryan and Runswick-Cole (2009) describe how mothers refrain from discussing their own needs for fear of scrutiny from others and seeming selfish.

For Fiona using II enabled her to reframe her identity from advocate to mum. Landsman (1998) asserts that advocacy forms part of the identity of a mother of a disabled child. Fiona resists the dominance of this identity though in how she separates her advocacy out from her role as mum. II enabled her to move beyond just spending all her time and energy as an advocate to get her child's needs met and reclaim her identity as mother.

The mothers in this study narrated accounts of maternal identity and the effect using II had on this. Being enabled through II to share moments together with their child, particularly around times of traditional mothering activities such as reading, or bedtime, supported the mothers' sense of self. These moments

enabled feelings of connection where the mothers felt wanted and in tune with their child and enabled them to feel that finally they were meeting the expectations of the good mother.

7.5.2 Family identity

Using II not only impacted upon the mother-child relationship but also on the wider relationships in both the family unit and with other carers who supported their children. The mothers experienced this as their child coming finally to belong to, and claim their identity within, the family. The mothers adjusted their expectations of what family time ought to consist of and instead negotiated a new normal.

As with maternal identity, family identity similarly gets discussed in the research in terms of normality and any deviations from this norm can be viewed unfavourably (Mason & Pavia, 2006). Family identity is defined by the shared values and rituals adopted by families such as bedtimes and mealtimes, watching television together (Mason & Pavia, 2006).

For the mothers in this study engaging in II provided them with the opportunity to adapt some of their family rituals such as sharing time together on an evening or at bedtime or when they visited residential placements, enabling engagement in a joint activity and thereby supporting the family unit and its identity. Elaine described this as ‘feeling like Drew was part of the family’ and Georgia stating that using II gives them ‘better quality time’ together. Ryan and Runswick-Cole (2008) discuss mothers adjusting their idea of what normal looks like to accommodate difference which may involve aspects of family life being lost, altered or created. For families of disabled children these rituals get renegotiated and adapted, according to Mason and Pavia (2006) at key transition points such as diagnosis. This is evidenced by some of the mothers in this study who embraced the changes that using II brought to their family life, from simple things such as spending time in the same room together (Elaine) to be able attend family gatherings (Bethany).

Another aspect to this is the relationships outside of the mother-child dyad, with fathers and other family members. These experiences for the mothers had gendered perspectives; the mother's perceptions of how their children's fathers experienced II differed from their own. Bethany and Georgia felt that their husbands had to work hard to use II with their children: it was not as intuitive for the dads. It is difficult to know what reasoning gave rise to these thoughts as this was not explored further in the interviews. However, the mothers were not necessarily negatively focussed on their partner's interaction attempts. Rather the mothers praised the fathers for working hard at it. As mothers tend to be the primary carers of disabled children (Boyd et al., 2019) they understandably spend more time with the child and as such may already have developed a particular set of interaction styles; they might just need to adjust these slightly as witnessed with the mothers in this study. The fathers may be starting from a different place, possibly only being around at certain points of the day. In contrast, Gibson's (2014) case study of a mother's use of VIG found the mother initially held a very deficit view of her husband's interaction style with their autistic son. The author concluded that engaging in the VIG sessions enabled the dad and mum to see the positive aspects of his interactions and enabled the start of a more holistic family approach to interactions. This chimes with Clare in this study who found II enabled her and her husband to 'be on the same page'. Having a defined approach to interaction set boundaries for both parents and enabled a shared understanding of their goals.

Interestingly, Abigail related how her husband had a totally different way of interacting with their child, much more along the gendered roles of rough and tumble play. Even though she saw the positives in this and the relationship her husband was building with their child there were elements of enviousness in her account, that he got to come in and do the fun things while she did 'everything else'. This aligns with the gendered roles placed on parenting by society, particularly when it comes to parenting a disabled child whereby the mother tends to be the primary carer, and the father is the 'breadwinner' (Gray, 2003). By enabling relationships with wider family members, the mothers are socialising their children in the wider world (Kittay, 2009) and encouraging a sense of belonging within the family unit.

Georgia and Fiona both found placements for their children that would use II. The connections this fostered between the staff and child is concurrent with the wider professional literature on II. Firth et al. (2008); Nagra et al. (2016); Rayner et al. (2016) all found II use enhanced connections between professionals and their clients and enabled a greater awareness of the clients likes and dislikes. In conjunction with this II supported the maintaining of family bonds when these mothers no longer saw their children every day. Georgia described how through using II they spent ‘quality time’ with Gerry when they visited. It enabled feelings of family and truly connecting in their time together. For them this was the way they spent time together, it was their renegotiated family ritual (Mason & Pavia, 2006).

The mothers narrated stories of renegotiating and adapting what family meant to them through the shared activities II enabled with their children. Using II supported fostering a sense of belonging and family.

7.5.3 Identity outside of motherhood

The findings in this study illustrate how some of the mothers engaged with advocacy and activism in promoting II use to other parents. Engaging with II seemed to promote an alternate sense of self in the mothers, an identity outside of ‘mother of a disabled child’. For the mothers in the parent group and Fiona who took on an advocate role in the II organisation that had supported her, II advocacy enabled a widening of their social networks and the opportunity to share their skill sets. The sense of belonging and shared common identity also featured in the mothers’ narratives.

Clare and Bethany both used the parent group as a place to share their knowledge of their experiences of II and support other parents to use it. It provided a space to reconnect with their professional skill sets (Bethany) or develop new skills (Helen). The social aspect of the group and the organisation Fiona attended enabled a sharing of successes and challenges. It was a space with like-minded people who understood the shared experiences. Healey et al. (2018) similarly found the social aspect of the parent mediated physical activity intervention was rated highly by the parents. The connecting with others over a

period of time to share experiences of an intervention supports the development of social bonds and a sense of belonging. Jackson et al. (2018) assert that parents of disabled children typically find support groups to be beneficial in providing spaces to share and exchange knowledge and they can reduce feelings of isolation. Clare and Helen both benefitted from sharing their videos at the group and receiving positive feedback and affirmation from the other parents. This empowered their feelings of being a 'good mother' after all. For Helen having her first video shown at the meetings was a sense of achievement; she had 'made it', become expert enough to warrant her video being shared with new parents. Not only does this reinforce for her an identity as a 'good mother' but also it enables the development of a different identity: mentor to other parents. Ryan and Runswick-Cole (2008) discuss in their study of mothers of autistic children involvement in advocacy and activism that within the realms of a support group the mother of a disabled child has a valued skill set. This can be viewed as an asset with which to support other parents and the authors suggest that this can feed into the sense of 'good mother' whilst also supporting a move towards a different sense of self.

The groups the parents attended were not support groups in the traditional sense as they were tightly bound by the use of II. The groups were more along the lines of community of practices, a common identity focused on the shared practice of learning about something (Wenger, 1998). This gave the mothers a separate identity outside that of mother of disabled child: they were collective learners of II, a social communication intervention. Wenger describes how communities of practice value the knowledge members bring and having a shared sense of identity is an important aspect of the learning process. Reflective practice is advocated for II, primarily through video (McKim & Samuel, 2021) and the value of this is discussed throughout the literature (Barber, 2008; Firth et al., 2008). However, the II literature has not explored the impact of communities of practice on those involved. Culham (2004) advocates for having a shared understanding amongst colleagues and the impact this has on long term use of II. Barber's (2008) study had a reflective community of practice style staff group throughout the intervention period but the impact of involvement in this group was not explored further.

Fiona's experience with II left her wanting to do more, and her relationship with the staff at the organisation has moved from parent-professional to one of friendship and then to a role within the organisation. II utilised strength-based narratives and moves away from a deficit focus. Through learning about II and advocating to other parents about it the mothers have experienced a different representation of motherhood (Sousa, 2011). Not all the mothers were actively involved in advocating about II, However, Elaine expressed an interest in 'spreading the word' once she felt expert enough herself.

II seems to empower the mothers who traditionally may be marginalised in mainstream autism culture and often excluded from research if their children are in an under-represented group (McKinney et al., 2021). Through II the mothers involved with groups in this study found an identity outside of motherhood where their expertise was valued and acknowledged. The mothers found a new sense of self through their advocacy work (Ryan & Runswick-Cole, 2008). Membership of a group is not routine for parents using II however, there is an active II community with a parents' Facebook group. As professionals support parents in using II, the benefits of reflective supportive groups should be considered. A sense of belonging, common purpose and shared identity is empowering for the mothers: it reduces isolation and makes the mothers feel part of something that has the potential to make a difference for their child and families like theirs. As their expertise becomes valued, for some mothers this provides a reconnection with a past self or a new self.

7.6 Additional and emotional labour

Running as a thread throughout the mothers' narratives are the concepts of invisible and emotional labour. Numerous aspects of the mothers' stories tell of instances of them employing additional labour in the forms of emotional or invisible labour. The mothers in this thesis employed emotional and invisible labour before they found II, in the seeking of it, in the finding of it and in the practice of the approach. Even though emotional labour is discussed in the disability literature more generally (Kittay, 2009; Laurin & Andersson, 2024;

Runswick-Cole, 2013) it is not discussed in the II literature. The findings in the study shine a light on this under researched area.

Kittay (2009) defined invisible labour as the work disabled people, and their families undertake to enable others to understand and interact with them or their loved one. Ruddick (1989, cited in Kittay, 2009) goes further by describing the act of socialisation. This is defined as the mother's role in socialising their children to be able to make their way in the world. As a mother of a disabled child this has an added dimension of the mother also socialising the world to accept their child. The emotional aspects of this work are described as emotional labour and include the masking of emotions to portray a more socially acceptable emotional state (Runswick-Cole, 2013).

Throughout the mothers' narratives they articulated instances of emotional labour in the language used to describe their actions of seeking and finding. For example, Fiona described how the situation with Riley was 'all very miserable' and 'the bad press mothers have' to feeling 'ecstatic' and sitting in a meeting 'in floods of tears'. The relief Fiona felt at finding something and like-minded people meant she did not mask her emotions in this meeting, she did not follow the rules for how mothers are supposed to behave when meeting professionals (Runswick-Cole, 2013). Other examples of emotional labour in the mothers' accounts included the mothers' wishes for what the intervention might bring. These included Georgia narrating how she just wanted Gerry to be 'safe and happy', Bethany 'went into it just hoping'. Additionally, Clare felt self-blame for not realising II could be used with children who used speech 'that was always a misjudgement of mine'. Laurin and Andersson (2024), describe how mothers are often managing multiple interactions between various professional services such as medical and education. These interactions are often information seeking interactions to better understand and support their children and involve emotions such fear, guilt and blame. This concurs with the findings in this thesis. Throughout the long process of seeking and finding the mothers experienced emotional labour in their interactions with professionals and their own hopes for what benefits an interaction might have. Laurin and Andersson (2024) describe the extra emotional effort parents undergo in navigating information surrounding diagnoses and interventions and how this needs acknowledgment from professionals.

This study highlights how learning about II equally involved emotional and invisible labour. The mothers questioned their predetermined ideas of what an intervention should look like and what a good mother should be doing to support their child. Enacting the simplicity of II was difficult for some of the mothers.

In addition, the mothers were negotiating interactions with professionals and outsiders when learning about II, thereby both living and anticipating the emotional responses of others to their interactions. In their interactions with professionals the mothers discussed their experiences of being videoed. Evidence of emotional labour was narrated in these accounts. Elaine described how she presented a reserved self in the videos, conscious of how she interacted when being videoed by the professional. Similarly, the mothers strove to present videos deemed suitable and of a good enough standard to show to others, evidencing navigating emotional labour in the expectations of others of their videos. Runswick-Cole (2013) states that vast amounts of emotional labour are spent on anticipating the emotions of others by mothers of disabled children. Equally, the process of creating the videos employed lots of invisible labour in orchestrating them, via the requirement of a third person or setting up of suitable scenarios.

The emotional responses of outsiders to their interactions using II was talked about by Bethany and Georgia; both were aware of how others may view them in a public space using II. Georgia was conscious of a potential need to manage outsiders' emotions, whereas Bethany seemed to have moved beyond this to stating she did not care what other people thought. Bethany renegotiates the narrative of conforming to a normative expectation of what interactions should look like in a public space.

Emotional labour was equally evident in the mothers' interactions with their children. The acceptance and rejection they felt throughout their interactions meant large amounts of emotional labour were happening. The joy and eureka moments were articulated as 'lovely' (Elaine, Bethany), 'amazing' (Abigail, Elaine) contrasting with managing feelings of rejection, selfishness or guilt at having to say no. The mothers were managing these emotions for the sake of their child; with a realisation it was hard when their children pushed them away.

The wider family dynamics and supporting fathers and other family members to use II also required invisible and emotional labour. Bethany ‘worked hard’ to support Jamie and other family members to interact together: she actively supported the socialisation of her child with others (Kittay, 2009). This took time and energy on her part. Equally, Fiona organised and paid for the staff at Riley’s new care home to receive II training to support their relationship building with Riley. Abigail managed her emotions of enviousness at her husband’s interaction style acknowledging the importance of them having space to build their relationship.

Throughout the mothers’ accounts are illustrated numerous narrations of invisible and emotional labour. They thread through the dialogues and all aspects of the mothers’ experiences. The emotional labour mothers of disabled children employ on a daily basis is an under researched or acknowledged area and one which warrants consideration from professionals when engaging with parents. Just as emotional labour is recognised within service industries it equally needs to be acknowledged and addressed in the caring role of mothers of disabled children. However, rather than professionals recognising emotional labour from a deficit stress and coping narrative they should strive to acknowledge the amount of emotional labour employed by mothers as they navigate complex care and education systems, often multiple times simultaneously (Laurin & Andersson, 2024).

7.7 Summary of discussion

This chapter has discussed the themes in relation to the extant II literature and wider mothers of disabled children literature. Whilst some of the mothers’ experiences such as reservations over II perceived simplicity and the increased understanding they acquired through learning about II are in keeping with other practitioners represented in the literature, other experiences illuminate new areas for consideration. It is evident that engaging in II in the home brings with it some different issues for the mothers. Of significance is the power balance shift that engaging in a child-led intervention can bring. The benefits of this are an intervention that works through valuing, respecting and listening to the child

through a play-based approach, enabling feelings of acceptance and connection in shared activities. What is not explored in the wider literature is the logistics of negotiating this in the home without the option to staff more one to one time to facilitate this. Knowing how to say ‘no’ or navigate feelings of rejection are not acknowledged in the literature.

Learning about II which can be perceived as a simple intuitive intervention is not always easy for the mothers. Tied up with the learning are complicated issues of accepting it is okay to be doing what may be perceived by others as less. The labelling of II as an intervention supported the legitimisation of the skills the mothers used. It gave them permission to stop striving for costly or complicated interventions and trust their own abilities to develop their relationships with their child.

The topic of videoing for reflective practice and learning is highlighted in this thesis as presenting challenges to II practice and training. What is apparent is that this is not a straightforward issue, videoing can provide a site for empowerment through self-belief but is countered by the dominant narrative of parents requiring training which is why professionals are videoing them in the first place. The very action of videoing de-naturalises interactions and positions them as ‘less-than’.

The mothers discussed identity in a number of guises throughout the findings. II influenced their mean-making of what feeling like mum to their autistic child meant to them. The increased connections through feeling they better understood their child’s social communication enabling a shift in their representations of mother of a disabled child. Engaging in II enabled them to feel like ‘mum’ through traditional shared activities such as reading a book or bedtime. This was very important to the mothers, feeling known and recognised as ‘mum’ by their child.

What is evidenced in this chapter is that the role of mother of disabled child pervades through the mothers’ experiences of learning about and using II. The fact that II makes a difference in different ways to the mothers is evident in their narratives and concurrent with the II literature. However, the additional labour employed by the mothers in their journeys with finding II, learning about it and implementing it in their families is not illustrated in the wider literature however,

this thesis starts to illuminate these issues. It is important that these experiences are acknowledged by professionals and platforms available for mothers to discuss these feelings.

The next chapter presents the implications of these discussions for policy and practice. It also addresses the limitations of this study, some personal reflections and the original contribution to knowledge this study makes.

Chapter 8 Conclusion

This chapter draws together final reflections on this project alongside recommendations and implications for future practice. I also consider the limitations of this study and its original contribution to knowledge. Finally, I discuss possible future research directions.

The overarching research question for this project was:

How do mothers of autistic children experience Intensive Interaction?

With a particular interest in:

- How did mothers find out about II and what were their reasons for engaging with it?
- How do mothers' experience II use with their child?
- How does II fit in with family life?

8.1 Implications for policy and practice

Below I summarise the key findings that answer each research question with possible implications for policy and practice.

8.1.1 How did mothers find out about II and what were their reasons for engaging with it?

The mothers had varied experiences of finding out about II. Most were holding onto an enduring belief that if they continued searching, they would find something to provide the support they were looking for, for their child. Elements of chance and luck played a role in the seeking and finding of II for these mothers. This is echoed in the disability literature with parents often finding out about interventions and support via alternate routes rather than through the professional supporting them at that time (Clarke, 2013). Upon finding II the factors that influenced engagement with it included feelings of resonance with the strategy and being able to visualise it working for their family. How II was presented to them impacted upon these decisions. The mothers used their

expert knowledge of their child to make informed decisions about whether to try interventions or not often researching information for themselves.

The analysis of these experiences leads to the following implications for practice:

- II information needs to be accessible and presented in a format that fully explains its potential benefits for a variety of profiles of autistic people. It is important that mothers considering starting II can visualise its use with families like theirs.
- Local authority and Integrated Care Boards who advocate II use should consider how and where they disseminate information about II in their area, ensuring information is readily accessible in appropriate formats for parents looking for support.

Consideration of both of the above points by professionals advocating II could aid parents when seeking support to find readily accessible relevant information. Parents would then be in a position to use their expert knowledge of their child to make informed decisions about the support on offer and to evaluate whether it would be of benefit for their family.

8.1.2 How do mothers experience II use with their child?

The mothers' experienced II as a learning process through which they came to embrace II's perceived simplicity. This was not always easy for them. One of the particularly significant findings of this project is that the learning of these mothers was bound up with complex feelings of guilt and validation. They felt guilty because of doing what was perceived as less, and by sometimes having to say no to their child. The validation that they sought was that their instinctive overtures were correct and they did know how to interact with their child. This sets their experiences apart from the practitioner literature on II and is a key contribution to knowledge of this thesis. Using II freed the mothers from striving for the ideological norms of development. Whilst the labelling of II as an intervention seemed to both legitimise their interactions and provide a platform for mother and child to share quality time together. Despite this though the

mothers still looked to the professionals supporting them for affirmation that they were doing the right thing and were competent at interacting with their children.

The mothers continued to use II over the longer term as it became embedded into daily routines and became a ‘way of being’ (Rogers, 1980). However, this provided a tension in the mothers’ experience. The rapid initial surges and plateauing within relationship building are briefly discussed in the wider II literature in relation to efficacy and the need for a longitudinal approach (Elgie & Maguire, 2001; Kellett, 2000; Zeedyk et al., 2009), but no further. The mothers in my study expressed frustration at the sometimes static quality of their interactions, voicing desires to re-capture some of the early progress they saw in their interactions. These findings add to the limited information about plateauing by highlighting not only that it occurs but also the nature of the feelings this can cause in mothers and potentially other practitioners. Plateauing or static interactions potentially could cause mothers and other practitioners to lose faith in II and stop using it. This then has the possibility of impacting upon long term use if not sufficiently acknowledged and addressed.

A level of external scrutiny was employed alongside the mothers’ learning of II. For this group of mothers this was primarily through the use of video. The positives of this included affirmation of their interactions through feedback and seeing the pleasure of their child. However, the negatives were feelings of self-consciousness and the consequent de-naturalising of interactions through elements of performance. The nature of interactions requiring videoing places them in a position of being viewed as deficient in some way and perpetuates power imbalances in parent-professional partnerships.

A further significant finding of this research is the impact of using II on the mothers’ sense of self. The child-led aspect of II is one of its key components (Nind, 2012). However, there is a tension in the mothers’ narratives at the effects of the role of the child-led element. In one respect it brought with it feelings of acceptance and opened the door into areas of their child’s life they previously felt excluded from. In another respect it meant the mothers felt rejected by their child at times or experienced being asked to interact at inconvenient times, leaving them wrestling with feelings of guilt if they said no.

These emotive experiences are not explored in the wider II literature. Identifying as a mother was another important finding in this research. Through engaging in II the mothers reframed their identity from carer of a disabled child to feeling like ‘mum’. This was something that was important to them, to feel and be recognised by their child as ‘mum’. The enhanced connections and interactions they shared with their children enabled them to reaffirm the mother-child relationship.

Having a shared identity with a sense of belonging and common purpose through advocacy work was empowering for the mothers. It encouraged them to share their expertise and support other parents with II use. For some of the mothers this enabled a reconnection with their past selves and their identity outside of motherhood.

The additional labour employed by the mothers coloured every aspect of their experiences of seeking, finding and using II. The mothers were required to navigate extra emotional work in their II journeys with not only their interactions with their children but equally with other family members and staff supporting their children.

The analysis of these experiences led to the following implications for practice. I have split these into general implications for all practitioners including mothers and parents and those pertinent in particular to the experiences of mothers:

Implications for consideration during training for all practitioners:

- Plateauing needs to be discussed openly and normalised with the emphasis on II being a long-term strategy that can be used to enjoy spending time together.
- Reflective practice is important particularly in the early days of using II. However, the use of video over the longer term needs to be considered as it risks de-naturalising and pathologising interactions. This is pertinent for all practitioners using II.

Implications for consideration when supporting mothers:

- The experience of engaging in II as a mother has different aspects to those for practitioners, bound up with identity. The additional labour in these experiences should be recognised and acknowledged by other

practitioners. It is essential for practitioners to recognise that the mothers whom they support may have different emotional experiences to other practitioners.

This key implication has the following sub-points within it-

- Recognising that additional emotive feelings may be bound up with some of the learning processes for mothers: sometimes doing less is not always easy. Providing a platform for discussion of these issues could support mothers in their II use and validate those feelings. This could be started during any ‘training’ that takes place by incorporating discussion about the simplifying of one’s interactions and how this can be more difficult than one expects.
- Acknowledging the instinctive overtures mothers make during interactions and legitimising them is important during the learning about II process.
- The child-led element is not always as straightforward as just letting the child lead. Mothers can experience rejection and feelings of guilt over not being able to honour an interaction overture. Professionals supporting mothers could address these issues in any ‘training’ they provide.
- Sharing of expertise and valuing the experience mothers have to support other parents benefits not only the mothers but also other parents. Community of practices for parents in local areas could provide reflective spaces to share good practice and facilitate dissemination of information about II.

These implications are important to consider for professionals who are supporting mothers with their II practice and need to be incorporated into workshops and support packages. However, not all mothers starting with II will be supported by a professional. They may be researching, reading and implementing II themselves. Therefore, written and online material needs to address these areas as well.

8.1.3 How does II fit in with family life?

II was seen as a flexible intervention which did not require any resources. The mothers were able to share their knowledge of II with other family members and used it to support feelings of family identity. Integrating II into family life enabled feelings of belonging for the mothers through being able to adapt family rituals to include their child. For the mothers with children in residential settings, continuing to use II allowed for the enhanced connections to continue when they visited and for care staff to form their own relationships with the children.

The analysis of these experiences led to the following implications for practice:

- Sharing of knowledge of II with other family members can enable an increased sense of family identity. Encouraging mothers to share their expertise with family and friends could support this. Equally encouraging extended family to attend workshops and support sessions could facilitate this.
- Threading II throughout the day can support it to become a natural reoccurring site of interactions.

These findings add to the II literature base, and particularly the minimal parental II literature. The findings meet the aim of informing knowledge and understanding of the mothers' experience of using II. These findings have also met the aim to explore mothers' reasons for engagement with II and to understand how II use impacts upon the relationships of mothers with their child. This was achieved through highlighting how chance can play a role in finding II and the importance of strategies resonating with mothers as they make informed decisions on whether to try an intervention. This study also illuminated how learning about II increased understanding of social communication which in turn enabled enhanced connections and enriched the mother-child relationship. The fore-fronting of the voices of mothers in this study adds to a small but growing literature on the experiential aspects of running an intervention in the home.

8.2 Limitations

There are a number of limitations to this study that I consider below: namely sample size, diversity and representation of II use.

IPA typically requires a small sample size (Brocki & Wearden, 2006). As discussed in Chapter 3 it is argued that this enables an in-depth emotive analysis of lived experience (Wagstaff & Williams, 2014) and relies on purposive sampling (Smith et al., 2012). I recruited seven participants for this study which is within the recommendations of six to ten participants for this type of study. The relatively small sample size meant that the idiographic focus could be maintained and a detailed examination of the mothers' experiences of using II carried out. Generalisability is difficult with small sizes, but IPA does not seek to generalise rather it seeks to shine light on a phenomenon and add depth of knowledge to a topic (Smith et al., 2012). This research adds to the small body of literature on II and forefronts these mothers' voices in using a social communication intervention with their children.

One of the concerns I had was the need for snowballing due to the potentially small pool of participants. Four of the mothers I recruited attended one parent group. I had some reservations that their experiences might overshadow the data if they were very similar. However, due to the heterogeneous nature of autism and the differing reasons for the mothers seeking an intervention, their experiences proved to be wide ranging.

Diversity of participants is something that lots of research projects have difficulty with (Routen et al., 2022). This research was no different, there was a lack of participants from minority ethnic communities. Due to this lack of diversity this study misses out on how someone's culture may or may not impact upon their experience of using II. I recruited primarily through the Intensive Interaction Institute and only white potential participants contacted me. I relied on third party gate keepers to pass information about the project on for me. With hindsight I could have actively tried to find areas using II with minority ethnic communities to increase the diversity of my sample. However, I did have mothers from a range of varied backgrounds: some had a professional background and others a working class background. With such a small sample

size representing a breadth of cultural experiences would always have been difficult.

I purposely did not set an age limit for the child so as to not exclude any mothers from taking part. This meant that Fiona could be a participant, whose perspective of using II with an adult child provided an added dimension to the data. I was fortunate that the children varied in their profiles, and this meant that the data included experiences from mothers of speaking and non-speaking autistic children.

A further consideration is that recruiting participants for a study on II inevitably will attract people who are pro-II. All of the mothers I interviewed were current users of II and positive about the intervention. However, one of the benefits of conducting two interviews over a period of a year enabled a longitudinal aspect to their II use to be explored. This gave me the opportunity to see how their II use differed between the two time points and enabled some of the more nuanced data around the static quality of interactions to be discussed. This also enabled aspects of their experience such as their identity outside of motherhood to be further understood. Without the second interviews the data surrounding advocacy work would have been lost.

Reflecting on the interviews after analysis there are areas where the questioning with hindsight could have explored points raised further. One such example is the discussions around how the fathers interacted with their children particularly surrounding the mothers' perceptions that II did not come naturally to the fathers. Recognising these potentially interesting points within the interview situation is something which improves with experience and something I feel I have got better at as my academic career has progressed. However, the reflexive process of data analysis meant these interesting points were not completely lost and provided information to consider when thinking about future research directions.

8.3 Personal reflections

Conducting this research as a part-time PhD student has not been without its challenges. Navigating my intersecting positionalities as mother, researcher and

professional using II has fluctuated throughout my time as a student. As I described in section 3.6, throughout my studying I have come full circle and my main involvement now with II is as a mother using it with her autistic son. Having experience of II from both a parental and professional standpoint enabled me to reflect on what the data was telling me and consider how that might have impacted upon my own practice as a professional. This supported me to consider what recommendations for practice were pertinent and realistic.

Covid started part way through my PhD; I was lucky that I had just finished my data collection when the restrictions started. However, this meant I commenced the analysis during lockdown whilst supporting two children through home-schooling. For me the main drawback was the sudden withdrawal of the PhD community at the university: this slowed progress and felt rather isolating.

My studies part-time have ebbed and flowed depending on the other demands on my time from family and work. This is something I have found difficult: studying for a PhD can be all consuming and I found I needed the 'headspace' to focus on the research. I found it incredibly difficult to jump in and out of the process for short periods of time such as on an evening. Therefore, I needed to carve out dedicated days to fully re-immerse myself in the research: this was the way I worked best and made progress.

Learning about IPA as a methodology has been something I have enjoyed. It has been at times both rewarding and challenging. Coming from a scientific background, learning about the underpinning philosophy of IPA has opened up a new avenue of literature and thought. There is a thriving IPA community made up of academics and researchers who pose and answer queries about IPA. Engaging in this has supported the deepening of my understanding of the methodology. Choosing IPA as the right methodology for this research meant a commitment to the time and process of conducting an IPA study. However, using IPA for a PhD meant I had the luxury of being able to have that time to spend on the deep analysis required and really get to explore the mothers' stories in detail.

Analysing and writing up the mothers' stories has been a privilege and throughout this long process I have had the opportunity to reflect on my own use of II both personally and professionally. I have found that the stories have

influenced my work with other parents and enabled me to reflexively consider the way in which I supported others in their II practice. I tried always to start from a standpoint of how parents were already engaging their children in interactions and support parents to build on these. Recognising the emotional impact learning about II can have on mothers I felt it was important to be more bespoke in the support offered to the parents whom I was supporting. For some, group settings were positive and affirming. However, these situations do not always suit everyone. Sometimes the opportunity for a one-to-one chat about how things are going worked best for some parents.

Reflecting on my insider status and differing positionalities I think the impact of this on the research process has varied over time. When I was working in the school I feel this was the time, I found it hardest to separate out my identities and having my reflexive journal to acknowledge this helped the research process. Working with school staff and parents gave me insight into the triumphs and challenges they found when using II. Using my journal gave me a chance to reflect on these and how they shaped my fore-conceptions as part of the hermeneutic circle. Changing career away from the school towards the end of my PhD enabled me to take a step back and untangle my identities of mother, practitioner and researcher. I found this helpful in fully focussing on the worldview of mothers of disabled children and how they are represented in research.

8.4 Original contribution to knowledge

Through fore-fronting the mothers' stories this thesis adds to the small but growing body of literature that moves away from the primarily efficacy based studies aiming to provide evidence of how effective parents are at implementing interventions (Meaden et al., 2009). Rather, this study sought to explore the experiential aspects of using a social communication intervention in the home. By doing so it adds mothers' voices to those of other practitioners of II, countering the power imbalance currently existing within the literature.

This study has contributed new knowledge about mothers' experiences of using II with their autistic children in highlighting how mothers' experiences centre

around learning to re-engage with intuitive interaction techniques and the re-naming of what they are doing as an intervention, which supports them with some of the emotional learning processes.

A further contribution to knowledge is the illumination of the under-researched areas of the impact of both the child-led element and potential plateauing of interactions on practitioners. These areas are mentioned in passing in the literature but not how they impact upon the experience of II. Not only is this of importance for sustainability and long-term use by parents but also potentially for other practitioners.

The final area of significance is in the impact of II on the mothers' identity and sense of self. Using II not only enriched their connections with their children but also facilitated them feeling like 'mum' in those moments.

These contributions to knowledge challenge the deficit narrative of parents as requiring training on how to parent. It also challenges the tendency to focus research on how efficient parents are at delivering an intervention, viewing them as a support resource for practitioners. These contributions to knowledge highlight how taking a more holistic approach, through exploring what using an intervention is actually like and what difference it makes to mothers personally can enlighten professionals to the far more nuanced experience that is happening for mothers. This provides valuable insights for practitioners supporting mothers in both adult social care and education settings into some of the complex emotional processes mothers may be experiencing when using II.

8.5 Future research avenues

II research is still a relatively small arena, but parental experiences are adding to our understanding of II use. It is important for future research about II to consider all key stakeholders when considering which participants to include and this should equally include the voices of those with lived experience such as parents. Not only should parents be included as participants but also as stakeholders on advisory boards for research projects. As social care and education research advances, public involvement work is becoming more common and advocated by funding authorities such as the National Institute for

Health and Social Care Research (NIHR) (NIHR, 2024). Recognising and valuing the contributions of public members such as parents and carers can make to research is critical.

This study has highlighted areas worthy of future research. One such area is the possible differences in how II is used by fathers. This work illuminated possible gender differences in II use and fathers tend to be an underrepresented group in disability research (Davies et al., 2024). It would be interesting to carry out a study which explores father's experiences of using II, so they could be better supported and inform the development of II as a practice.

Equally, the use of video as a teaching and reflexive tool is worthy of further exploration. Most studies address only the positives of video use as a method of training parents and professionals, not what the limitations are specifically around the disruption of natural interactions. This applies to both parents using II in the home but also professionals using II in social care and education settings.

In any future research it is important to try to recruit a more diverse sample of parents both from minority ethnic and LGBTQ+ communities, as these are both underserved populations and their experiences would add valuable insights into how II is experienced.

I plan to produce a lay summary of the research findings and implications for practice to share the findings from this research with my participants. Equally, a lay summary would support dissemination of this research to II practitioners, particularly school support staff and adult social care staff who may not have time to read academic outputs.

8.6 Concluding thoughts

II has made a significant difference in my own life: not only personally for my son but also professionally for me as it opened doors to further my career through carrying out this PhD. For me personally the impact of II use on the sense of self of these mothers and identity has been of most significance.

Reading the literature on mothers of disabled children and the ideology of ‘the good mother’ has resonated with me as a mother of a disabled child myself. Reflecting on what these experiences meant for the mothers has been a learning experience for myself and my own experience as I continue to parent my son into adulthood.

Having the privilege of hearing the mothers’ stories and representing them in his study I am struck by the importance of future research needing to continue to move away from only valuing efficacy based studies. As this thesis evidences there is far more to implementing a social communication in the home than how effective you are at delivering it. This is just one aspect of successfully using a strategy, the nuanced experiences of how that strategy impacts on mothers and other family members are key to uptake, use and truly supporting parents in finding and choosing the correct support for their families.

References

Akamoglu, Y., & Meadan, H. (2018). Parent-Implemented Language and Communication Interventions for Children with Developmental Delays and Disabilities: a Scoping Review. *Review Journal of Autism and Developmental Disorders, 5*(3), 294-309. https://doi.org/10.1007/s40489-018-0140-x

American Psychiatric Association, DSM-5 Task Force. (2013). *Diagnostic and statistical manual of mental disorders: DSM-5™* (5th ed.). American Psychiatric Publishing, Inc.. https://doi.org/10.1176/appi.books.9780890425596

Autism Treatment Centre of America (2025). *What is the Son-Rise Program.* Retrieved May 10, 2025, from What is The Son-Rise Program? - Autism Treatment Center of America

Barber, M. (2008). Using Intensive Interaction to Add to the Palette of Interactive Possibilities in Teacher-Pupil Communication. *European Journal of Special Needs Education, 23*(4), 393-402. https://doi.org/10.1080/08856250802387380

Barnes, J. (2022). Touch: the cement that binds us. In Mouriere, A. & Smith, P. (Eds) *The Intensive Interaction Classroom Guide* (pp. 114-126). Routledge.

Beck, C. T. (2021). *Introduction to phenomenology : focus on methodology*. SAGE Publications, Inc.

Berridge, S., & Hutchinson, N. (2022). Mothers' experience of Intensive Interaction. *Journal of Intellectual Disabilities, 26*(2), 391-406. https://doi.org/10.1177/1744629521995374

Berry, R., Firth, G., Leeming, C., & Sharma, V. (2014). Clinical Psychologists' Views of Intensive Interaction as an Intervention in Learning Disability Services. *Clinical Psychology & Psychotherapy, 21*(5), 403-410. https://doi.org/10.1002/cpp.1846

Bettelheim, B. (1972). *The Empty Fortress: Infantile Autism and the Birth of the Self.* The Free Press.

Bindlish, N., Kumar, R., Mehta, M., & Dubey, K. (2018). Effectiveness of parent-led interventions for autism and other developmental disorders. *Indian Journal of Health and Wellbeing, 9*(2), 303-307.

Blumer, H. (1986). *Symbolic Interactionism. Perspective and Method*. University of California Press.

Boden, Z., Larkin, M., & Iyer, M. (2019). Picturing ourselves in the world: Drawings, interpretative phenomenological analysis and the relational mapping interview. *Qualitative Research in Psychology, 16*(2), 218-236. https://doi.org/10.1080/14780887.2018.1540679

Bondy, A. S., & Frost, L. A. (1994). The Picture Exchange Communication System. *Focus on Autism and Other Developmental Disabilities, 9*(3), 1-19. https://doi.org/10.1177/108835769400900301

Botha, M., Hanlon, J., & Williams, G. L. (2023). Does Language Matter? Identity-First Versus Person-First Language Use in Autism Research: A Response to Vivanti. *Journal of Autism and Developmental Disorders, 53*(2), 870-878. https://doi.org/10.1007/s10803-020-04858-w

Bottema-Beutel, K., Kapp, S. K., Lester, J. N., Sasson, N. J., & Hand, B. N. (2021). Avoiding Ableist Language: Suggestions for Autism Researchers. *Autism in Adulthood; Autism Adulthood, 3*(1), 18-29. https://doi.org/10.1089/aut.2020.0014

Boyd, M. J., Iacono, T., & McDonald, R. (2019). The Perceptions of Fathers About Parenting a Child With Developmental Disability: A Scoping Review. *Journal of Policy and Practice in Intellectual Disabilities, 16*(4), 312-324. https://doi.org/10.1111/jppi.12287

Boylan, M., Truelove, L., Pearse, S., O'Brien, S., Sheehan, H., Cowell, T. and Long, E. (2023) 'Developing trauma-informed teacher education in England'. *London Review of Education*, 21 (1), 29. https://doi.org/10.14324/LRE.21.1.29

British Psychological Society (2021). *BPS Code of Human Research Ethics.* Retrieved September, 23, 2024, from inf180_2021.pdf (bps.org.uk)

British Institute of Learning Disabilities (2004). *Factsheet: Intensive* Interaction. Retrieved July 4, 2022, from https://www.mencap.org.uk/sites/default/files/2016-11/Intensive%20Interraction%2004.pdf

Brock, S. (2014). The Impact of "Good Mothering" Ideology on Identity Perception for Mothers of Children with Disabilities. *Hecate, 40*(1), 20–35,169.

Brocki, J. M., & Wearden, A. J. (2006). A critical evaluation of the use of interpretative phenomenological analysis (IPA) in health psychology. *Psychology & Health, 21*(1), 87-108. https://doi.org/10.1080/14768320500230185

Bruner, J. S. (1996). *The culture of education.* Harvard University Press.

Bruner, J. & Watson, R. (1983). *Child's talk: learning to use language*. Norton.

Burghardt, M., Edelist, T., Fudge Schormans, A., & Yoshida, K. (2021). Coming to Critical Disability Studies: Critical Reflections on Disability in Health and Social Work Professions. *Canadian Journal of Disability Studies, 10*(1), 23-53. https://doi.org/10.15353/cjds.v10i1.743

Caldwell, P. (2006). *Finding you, finding me: using intensive interaction to get in touch with people whose severe learning disabilities are combined with autistic spectrum disorder*. London: Jessica Kingsley.

Caldwell, P. (2008). In Horwood J. (Ed.), *Using intensive interaction and sensory integration: a handbook for those who support people with severe autistic spectrum disorder*. London: Jessica Kingsley.

Carlon, S., Carter, M., & Stephenson, J. (2015). Decision-Making Regarding Early Intervention by Parents of Children with Autism Spectrum Disorder. *Journal of Developmental and Physical Disabilities, 27*(3), 285–305. https://doi.org/10.1007/s10882-014-9415-z

Carter, M. J., & Fuller, C. (2016). Symbols, meaning, and action: The past, present, and future of symbolic interactionism. *Current Sociology, 64*(6), 931-961. https://doi.org/10.1177/0011392116638396

Charmaz, K., & Henwood, K. (2012). *Grounded Theory*. (pp. 240-260). SAGE Publications. https://doi.org/10.4135/9781848607927.n14

Chenail, R. J. (2011). Interviewing the Investigator: Strategies for Addressing Instrumentation and Researcher Bias Concerns in Qualitative Research. *Qualitative Report, 16*(1), 255-262.

Chown, N., Robinson, J., Beardon, L., Downing, J., Hughes, L., Leatherland, J., Fox, K., Hickman, L., & MacGregor, D. (2017). Improving research about us, with us: a draft framework for inclusive autism research. *Disability and Society,* 32 (5), 720-734.

Clarke, J. N. (2013). Surplus suffering: The search for help when a child has mental-health issues. *Child & Family Social Work, 18*(2), 217–225.

Clouston, T. J. (2019). Pearls of wisdom: using the single case study or 'gem' to identify strategies for mediating stress and work-life imbalance in healthcare staff. *Journal of Research in Nursing, 24*(1-2), 61-72. https://doi.org/10.1177/1744987118809506

Crane, L., Adams, F., Harper, G., Welch, J., & Pellicano, E. (2019). 'Something needs to change': Mental health experiences of young autistic adults in England. *Autism: The International Journal of Research and Practice; Autism, 23*(2), 477-493. https://doi.org/10.1177/1362361318757048

Culham, A. (2004). Getting in Touch with our Feminine Sides Men's Difficulties and Concerns with Doing Intensive Interaction. *British Journal of Special Education, 31*(2), 81-88. https://doi.org/10.1111/j.0952-3383.2004.00333.x

Davidson, J., & Orsini, M. (2010). The place of emotions in critical autism studies. *Emotion, Space and Society, 3, 131-133.* https://doi.org/10.1016/j.emospa.2010.10.005

Davies, A., Rix, J., & Robb, M. (2024). Fathers' Relationships with Their Disabled Children: A Literature Review. *Disability Studies Quarterly, 43*(3) https://doi.org/10.18061/dsq.v43i3.8744

Debesay, J., Nåden, D., & Slettebø, Å. (2008). How do we close the hermeneutic circle? A Gadamerian approach to justification in interpretation in qualitative studies. *Nursing Inquiry, 15*(1), 57-66. https://doi.org/10.1111/j.1440-1800.2008.00390.x

Deci, E. L., Koestner, R., & Ryan, R. M. (2001). Extrinsic Rewards and Intrinsic Motivation in Education: Reconsidered Once Again. *Review of Educational Research, 71*(1), 1-27. https://doi.org/10.3102/00346543071001001

Department for Education. (2018). *Mental health and behaviour in schools.* Mental_health_and_behaviour_in_schools.pdf (publishing.service.gov.uk)

Department for Education. (2020). *Relationships Education, Relationships and Sex Education (RSE) and Health Education.* Relationships_Education_RSE_and_Health_Education.pdf (publishing.service.gov.uk)

Douglas, P. (2014). Refrigerator mothers. *Journal of the Motherhood Initiative for Research and Community Involvement*, 5(1), 94-114.

Douglas, P., Runswick-Cole, K., Ryan, S., & Fogg, P. (2021). Mad Mothering: Learning From the Intersections of Madness, Mothering, and Disability. *Journal of Literary & Cultural Disability Studies, 15*(1), 39–56. https://doi.org/10.3828/jlcds.2021.3

Dwyer, S. C., & Buckle, J. L. (2009). The Space Between: On Being an Insider-Outsider in Qualitative Research. *International Journal of Qualitative Methods, 8*(1), 54-63. https://doi.org/10.1177/160940690900800105

Eatough, V., & Smith, J. (2006). I was like a wild wild person: Understanding feelings of anger using interpretative phenomenological analysis. *The British Journal of Psychology, 97*(4), 483-498. https://doi.org/10.1348/000712606X97831

Eatough, V., & Smith, J. A. (2012). Interpretative Phenomenological Analysis. In Willig, C & Stainton-Rogers, W. (Eds) *The SAGE Handbook of Qualitative Research in Psychology.* (pp.179-194). SAGE Publications. https://doi.org/10.4135/9781848607927.n11

Eatough, V., & Smith, J. A. (2017). Interpretative Phenomenological Analysis. In Willig, C & Stainton-Rogers, W. (Eds) *The SAGE Handbook of Qualitative Research in Psychology.* (pp. 193-209). SAGE Publications Ltd. https://doi.org/10.4135/9781526405555.n12

Education Act (1981). UK Public General Acts. Education Act 1981 (legislation.gov.uk)

Edwards, A. G., Brebner, C. M., McCormack, P. F., & MacDougall, C. J. (2018). From 'Parent' to 'Expert': How Parents of Children with Autism Spectrum Disorder Make Decisions About Which Intervention Approaches to Access. *Journal of Autism and Developmental Disorders, 48*(6), 2122–2138. https://doi.org/10.1007/s10803-018-3473-5

Elgie, S., & Maguire, N. (2001). Intensive Interaction with a Woman with Multiple and Profound Disabilities: A Case Study. *Tizard Learning Disability Review, 6*(3), 18-24. https://doi.org/10.1108/13595474200100024

Ellis, C. (1986). *Fisher folk: Two communities on Chesapeake Bay*. Lexington: University of Kentucky Press

Ephraim, G. (1982). Developmental process in mental handicap: a generative structure approach. *Unpublished PhD Thesis, Brunel University*

Felitti, V. J., Anda, R. F., Nordenberg, D., Williamson, D. F., Spitz, A. M., Edwards, V., Koss, M. P., & Marks, J. S. (1998). Relationship of Childhood Abuse and Household Dysfunction to Many of the Leading Causes of Death in Adults: The Adverse Childhood Experiences (ACE) Study. *American Journal of Preventive Medicine, 14*(4), 245-258. https://doi.org/10.1016/S0749-3797(98)00017-8

Finlay, L. (2002). “Outing” the Researcher: The Provenance, Process, and Practice of Reflexivity. *Qualitative Health Research, 12*(4), 531-545. https://doi.org/10.1177/104973202129120052

Finlay, L. (2013). Unfolding the Phenomenological Research Process: Iterative Stages of “Seeing Afresh”. *The Journal of Humanistic Psychology, 53*(2), 172-201. https://doi.org/10.1177/0022167812453877

Finlay, L. (2014). Engaging Phenomenological Analysis. *Qualitative Research in Psychology, 11*(2), 121-141. https://doi.org/10.1080/14780887.2013.807899

Firth, G. (2012). Background to Intensive Interaction. In Hewett, D., Firth, G., Barber. & Harrison, T. (Eds) *The Intensive Interaction Handbook* (pp. 9-20). SAGE.

Firth, G. (2012). Intensive Interaction for inclusion and development. In Hewett, D. (Eds) *Intensive Interaction. Theoretical Perspectives* (pp. 104-120). SAGE.

Firth, G., Elford, H., Leeming, C., & Crabbe, M. (2008). Intensive Interaction as a Novel Approach in Social Care: Care Staff's Views on the Practice Change Process. *Journal of Applied Research in Intellectual Disabilities, 21*(1), 58-69. https://doi.org/10.1111/j.1468-3148.2007.00369.x

Fish, J., & Wilkinson, S. (2003). Understanding lesbians’ healthcare behaviour: the case of breast self-examination. *Social Science & Medicine (1982); Soc Sci Med, 56*(2), 235-245. https://doi.org/10.1016/S0277-9536(02)00022-9

Flowers, P. (2008). Temporal tales: The use of multiple interviews with the same participant. *Qualitative Methods in Psychology Bulletin, 5*, 24-27.

Flowers, P., Knussen, C., & Duncan, B. (2001). Re-appraising HIV Testing among Scottish Gay Men: The Impact of New HIV Treatments. *Journal of Health Psychology, 6*(6), 665-678. https://doi.org/10.1177/135910530100600605

Gadamer, H.G. (1975). *Truth and Method.* Sheed and Ward

Garvey, A. and Fogel, A. (2007) 'Dialogical change processes, emotions, and the early emergence of self', *International Journal for Dialogical Science*, 2(1): 51-76

Gibson, K. A. (2014). Appreciating the world of autism through the lens of video interaction guidance: an exploration of a parent's perceptions, experiences and emerging narratives on autism. *Disability & Society, 29*(4), 568–582. https://doi.org/10.1080/09687599.2013.844096

Goldspink, S., & Engward, H. (2018). Booming clangs and whispering ghosts: attending to the reflexive echoes in IPA research. *Qualitative Research in Psychology*, 1-14. https://doi.org/10.1080/14780887.2018.1543111

Goodley, D., & Runswick-Cole, K. (2010). Emancipating play: dis/abled children, development and deconstruction. *Disability & Society, 25*(4), 499–512. https://doi.org/10.1080/09687591003755914

Green, S. E. (2002). Mothering Amanda: Musings on the experience of raising a child with cerebral palsy. *Journal of Loss and Trauma, 7*(1), 21–34. https://doi.org/10.1080/108114402753344463

Green, J., Aldred, C., Charman, T., Le Couteur, A., Emsley, R. A., Grahame, V., Howlin, P., Humphrey, N., Leadbitter, K., McConachie, H., Parr, J. R., Pickles, A., Slonims, V., & Taylor, C. (2018). Paediatric Autism Communication Therapy-Generalised (PACT-G) against treatment as usual for reducing symptom severity in young children with autism spectrum disorder: study protocol for a randomised controlled trial. *Trials, 19*(1), 514. https://doi.org/10.1186/s13063-018-2881-3

Green, J., Charman, T., Mcconachie, H., Aldred, C., Slonims, V., Howlin, P., Le Couteur, A., Leadbitter, K., Hudry, K., Byford, S., Barrett, B., Temple, K., Macdonald, W., & Pickles, A. (2010). Parent-mediated communication-focused treatment in children with autism (PACT): a randomised controlled trial. *The Lancet, 375*(9732), 2152-2160. https://doi.org/10.1016/S0140-6736(10)60587-9

Gray, D. E. (2003). Gender and coping: The parents of children with high functioning autism. *Social Science & Medicine, 56*(3), 631–642.

Han, S. & Weiss, B. (2005). Sustainability of teacher implementation of school-based mental health programs. *Journal of abnormal child psychology*, 33(6), 665-679.

Harris J. (1994) Language, communication and personal power: a developmental perspective. In: Coupe O'Kane J., Smith B., (Eds) *Taking control: enabling people with learning difficulties*. London, David Fulton: 31–48.

Harrison, T. (2012). Doing Intensive Interaction at home. In Hewett, D., Firth, G., Barber. & Harrison, T. (Eds) *The Intensive Interaction Handbook* (pp. 125-130). SAGE.

Hart, R. (2010). Classroom behaviour management: educational psychologists' views on effective practice. *Emotional and Behavioural Difficulties, 15*(4), 353-371. https://doi.org/10.1080/13632752.2010.523257

Harvey, C. (2015). Maternal subjectivity in mothering a child with a disability: A psychoanalytical perspective. *Agenda, 29*(2), 89–100. https://doi.org/10.1080/10130950.2015.1039871

Haynes, K. (2011). Tensions in (re)presenting the self in reflexive autoethnographical research. *Qualitative Research in Organizations and Management: An International Journal, 6*(2), 134-149. https://doi.org/10.1108/17465641111159125

Healy, S., Marchand, G., & Williams, E. (2018). "I'm not in this alone" the perspective of parents mediating a physical activity intervention for their children with autism spectrum disorder. *Research in Developmental Disabilities, 83*, 160–167. https://doi.org/10.1016/j.ridd.2018.08.014

Hewett, D. (2012). Blind frogs: the nature of human communication and Intensive Interaction. In Hewett, D. (Ed) *Intensive interaction: theoretical perspectives* (pp. 4-21). SAGE.

Hewett, D. (2012). Practicalities of doing Intensive Interaction. In Hewett, D., Firth, G., Barber. & Harrison, T. (Eds) *The Intensive Interaction Handbook* (pp. 27-44). SAGE.

Hewett, D. (2022). The story of Intensive Interaction. In Mouriere, A. & Smith, P. (Eds) *The Intensive Interaction Classroom Guide* (pp. 4-14). Routledge.

Hewett, D., & Nind, M. (1988). *Interaction in Action: reflections on the use of Intensive Interaction*. David Fulton Publishers.

Hines, M., Balandin, S., & Togher, L. (2011). Communication and AAC in the Lives of Adults with Autism: The Stories of Their Older Parents. *Augmentative and Alternative Communication, 27*(4), 256–266. https://doi.org/10.3109/07434618.2011.587830

Hodge, N., & Runswick-Cole, K. (2008). Problematising parent–professional partnerships in education. *Disability & Society*, 23(6), 637-647. https://doi.org/10.1080/09687590802328543

Hollinrake, S., Spencer, S., & Dix, G. (2019). Disabled citizens as researchers - Challenges and benefits of collaboration for effective action and change. *European Journal of Social Work, 22*(5), 749–762. https://doi.org/10.1080/13691457.2018.1564736

Horrigan-Kelly, M., Millar, M., & Dowling, M. (2016). Understanding the Key Tenets of Heidegger's Philosophy for Interpretive Phenomenological Research. *International Journal of Qualitative Methods, 15*(1), 160940691668063. https://doi.org/10.1177/1609406916680634

Hutchinson, N., & Bodicoat, A. (2015). The Effectiveness of Intensive Interaction, A Systematic Literature Review. *Journal of Applied Research in Intellectual Disabilities, 28*(6), 437-454. https://doi.org/10.1111/jar.12138

Intensive Interaction Institute (2025). *Training for individuals and organisations.* Retrieved May 10, 2025, from Intensive Interaction Institute - Training

Jackson, J. B., Steward, S. R., Roper, S. O., & Muruthi, B. A. (2018). Support Group Value and Design for Parents of Children with Severe or Profound Intellectual and Developmental Disabilities. *Journal of Autism and Developmental Disorders, 48*(12), 4207–4221. https://doi.org/10.1007/s10803-018-3665-z

Johnson, H., Douglas, J., Bigby, C., & Iacono, T. (2012). Social Interaction with Adults with Severe Intellectual Disability: Having Fun and Hanging Out. *Journal of Applied Research in Intellectual Disabilities, 25*(4), 329-341. https://doi.org/10.1111/j.1468-3148.2011.00669.x

Jordan, R (2013). *Autism with severe learning difficulties*, London, Souvenir Press.

Kanner, Leo. (1943). *"Autistic Disturbances of Affective Contact." Nervous Child 2.* Retrieved May 10, 2025 from neurodiversity.net | leo kanner: autistic disturbances of affective contact (1943)

Kapp, S. (2019). *Autistic community and the neurodiversity movement: stories from the frontline*. Palgrave Macmillan.

Kapp, S. K. (2023). Profound Concerns about "Profound Autism": Dangers of Severity Scales and Functioning Labels for Support Needs. *Education Sciences, 13*(2), 106. https://doi.org/10.3390/educsci13020106

Kapp, S. K., Gillespie-Lynch, K., Sherman, L. E., & Hutman, T. (2013). Deficit, Difference, or Both? Autism and Neurodiversity. *Developmental Psychology, 49*(1), 59-71. https://doi.org/10.1037/a0028353

Kasari, C., Chang, Y., & Patterson, S. (2013). Pretending to Play or Playing to Pretend: The Case of Autism. *American Journal of Play, 6*(1), 124.

Kellett, M. (2000). Sam's story: evaluating Intensive Interaction in terms of its effect on the social and communicative ability of a young child with severe learning difficulties. *Support for Learning, 15*(4), 165-171. https://doi.org/10.1111/1467-9604.00170

Kellett, M. (2003). Jacob's journey: developing sociability and communication in a young boy with severe and complex learning difficulties using the Intensive Interaction teaching approach. *Journal of Research in Special Educational Needs, 3*(1) https://doi.org/10.1111/j.1471-3802.2003.00181.x

Kellett, M. (2004). Intensive interaction in the inclusive classroom: using interactive pedagogy to connect with students who are hardest to reach.

Westminster Studies in Education, 27(2), 175-188. https://doi.org/10.1080/0140672042000277116

Kellett, M. (2005). Catherine's Legacy: Social Communication Development for Individuals with Profound Learning Difficulties and Fragile Life Expectancies. *British Journal of Special Education, 32*(3), 116-121. https://doi.org/10.1111/j.0952-3383.2005.00383.x

Kenny, L., Hattersley, C., Molins, B., Buckley, C., Povey, C., & Pellicano, E. (2016). Which terms should be used to describe autism? Perspectives from the UK autism community. *Autism: The International Journal of Research and Practice; Autism, 20*(4), 442-462. https://doi.org/10.1177/1362361315588200

Kienzler, J., Voss, T., & Wittwer, J. ö. (2023). Student teachers' conceptual knowledge of operant conditioning: How can case comparison support knowledge acquisition? *Instructional Science, 51*(4), 639–659. https://doi.org/10.1007/s11251-023-09627-7

Kittay, E. F. (2009). The personal is philosophical is political: A philosopher and mother of a cognitively disabled person sends notes from the battlefield. *Metaphilosophy, 40*(3), 606–627. https://doi.org/10.1111/j.1467-9973.2009.01600.x

Knight, K. (2013). The changing face of the 'good mother': trends in research into families with a child with intellectual disability, and some concerns. *Disability & Society, 28*(5), 660–673. https://doi.org/10.1080/09687599.2012.732540

Koegel, L. K. (2000). Interventions to facilitate communication in autism. *Journal of Autism and Developmental Disorders; J Autism Dev Disord, 30*(5), 383-398. https://doi.org/10.1023/A:1005539220932

Lapadat, J. C. (2017). Ethics in Autoethnography and Collaborative Autoethnography. *Qualitative Inquiry, 23*(8), 589-603. https://doi.org/10.1177/1077800417704462

Larkin, M., Watts, S., & Clifton, E. (2006). Giving voice and making sense in interpretative phenomenological analysis. *Qualitative Research in Psychology, 3*(2), 102-120. https://doi.org/10.1191/1478088706qp062oa

Laurin, E., & Andersson, L. (2024). Emotion work and emotional labour, neglected facets of parental health information work. Analysing mothers of neurodivergent children. *Sociology of Health & Illness, 46*(5), 1023–1053. https://doi.org/10.1111/1467-9566.13775

Leaning, B., & Watson, T. (2006). From the Inside Looking Out--An Intensive Interaction Group for People with Profound and Multiple Learning Disabilities. *British Journal of Learning Disabilities, 34*(2), 103-109. https://doi.org/10.1111/j.1468-3156.2005.00374.x

Leeds and York Partnership NHS Trust. (n.d). *Intensive Interaction.* Leeds and York NHS Partnership Trust. Retrieved February 28, 2023, from https://www.leedsandyorkpft.nhs.uk/advice-support/intensive-interaction/

Lo Bosco, M. C. (2021). Autism 'super mums': Affectivity as a political capital in special mothering and autism advocacy. *Medicine Anthropology Theory*, *8*(1), 1-25.

Lovaas, O. (1993). The development of a treatment-research project for developmentally disabled and autistic children: Behavioral pediatrics. *Journal of Applied Behavior Analysis, 26*(4), 617–630.

Makaton. *A brief history of Makaton.* Makaton. Retrieved February 28, 2023, from https://makaton.org/TMC/TMC/The_Makaton_Charity/A_brief_history_of_Makaton.aspx

Mallett, R., & Runswick-Cole, K. (2016). The commodification of autism: What's at stake. In Runswick-Cole, K., Mallett, R., & Timimi, S. (Eds) *Re-thinking autism: Diagnosis, identity and equality*, (pp.110-131). Jessica Kingsley

Marwick, H., Jarvie, K., Cowie, H., Johnston, L., Hammond-Evans, N., & Cockayne, R. (2022). Developing Pretend Play in Autistic Children Using the Playboxes Joint Play Approach as Part of Ongoing Practice. *Journal of Autism*

and Developmental Disorders, 52(7), 3050–3060. https://doi.org/10.1007/s10803-021-05156-9

Mason, M., & Pavia, T. (2006). When the Family System Includes Disability: Adaptation in the Marketplace, Roles and Identity. *Journal of Marketing Management, 22*(9-10), 1009–1030. https://doi.org/10.1362/026725706778935637

McCann, T. V., & Polacsek, M. (2020). *Challenges in conducting an online survey and qualitative telephone interviews with affected family members (caregivers) of relatives with substance misuse*. SAGE Publications Ltd.

McGregor, L. M., Dickson, A., Flowers, P., Hayes, P. C., & O'Carroll, R. E. (2014). Reclaiming their lives: The decision-making process in living liver donation - An interpretative phenomenological case study analysis of one couple. *Psychology & Health; Psychol Health, 29*(12), 1373-1387. https://doi.org/10.1080/08870446.2014.940950

McKim, J., & Samuel, J. (2021). The use of Intensive Interaction within a Positive Behavioural Support framework. *British Journal of Learning Disabilities, 49*(2), 129-137. https://doi.org/10.1111/bld.12367

McKinney, A., Weisblatt, E. J. L., Hotson, K. L., Bilal Ahmed, Z., Dias, C., BenShalom, D., Foster, J., Murphy, S., Villar, S. S., & Belmonte, M. K. (2021). Overcoming hurdles to intervention studies with autistic children with profound communication difficulties and their families. *Autism: The International Journal of Research and Practice; Autism, 25*(6), 1627-1639. https://doi.org/10.1177/1362361321998916

Mead GH. 1934. *Mind, self and society*. Chicago: Univ. Chicago Press

Meadan, H., Ostrosky, M. M., Zaghlawan, H. Y., & Yu, S. (2009). Promoting the Social and Communicative Behavior of Young Children With Autism Spectrum Disorders: A Review of Parent-Implemented Intervention Studies. *Topics in Early Childhood Special Education, 29*(2), 90–104. https://doi.org/10.1177/0271121409337950

Mealer, M., & Jones, J. (2014). Methodological and ethical issues related to qualitative telephone interviews on sensitive topics. *Nurse Researcher, 21*(4), 32-37. https://doi.org/10.7748/nr2014.03.21.4.32.e1229

Miller, R. M., Chan, C. D., & Farmer, L. B. (2018). Interpretative Phenomenological Analysis: A Contemporary Qualitative Approach. *Counselor Education and Supervision, 57*(4), 240-254. https://doi.org/10.1002/ceas.12114

Milton, D. E. M. (2012). On the ontological status of autism: the 'double empathy problem'. *Disability & Society, 27*(6), 883–887. https://doi.org/10.1080/09687599.2012.710008

Milton, D., & Ryan, S. (2023). *The Routledge International Handbook of Critical Autism Studies* (1st ed.). Routledge. https://doi.org/10.4324/9781003056577

MIND (2011). *What is mental health and wellbeing?* Retrieved Oct 10, 2023 from What is mental health and mental wellbeing? - Mind

Moore, D. (2015). Experience of Being an Insider and an Outsider during a Qualitative Study with Men Who Have Experienced Significant Weight Loss. *The Qualitative Report, 20*(1), 87-106.

Moran, D. (2000). *Introduction to phenomenology*. Routledge. https://doi.org/10.4324/9780203196632

Morrey, T., Larkin, M., & Rolfe, A. (2022). "Screaming isolation" when is a chair more than a chair? Photographic encounters, IPA and capturing out of awareness experiencing: A novel approach to working with temporal, spatial and embodied dimensions. *Qualitative Research in Psychology, 19*(4), 1064-1093. https://doi.org/10.1080/14780887.2021.2001704

Moss, S., Bouras, N., & Holt, G. (2000). Mental health services for people with intellectual disability: a conceptual framework: Mental health services. *Journal of Intellectual Disability Research, 44*(2), 97-107. https://doi.org/10.1046/j.1365-2788.2000.00283.x

Mouriere, A & Smith, P. (2022). Introduction. In Mouriere, A. & Smith, P. (Eds) *The Intensive Interaction Classroom Guide* (pp. 1-4). Routledge.

Murdoch, L., & Chang, Y. (2022). Parental experiences of caring for children who have learning disabilities and procedural anxiety in hospital: An interpretive phenomenological study. *Child: Care, Health & Development, 48*(5), 809-819. https://doi.org/10.1111/cch.12990

Nagra, M. K., White, R., Appiah, A., & Rayner, K. (2017). Intensive Interaction Training for Paid Carers: "Looking, Looking and Find out When They Want to Relate to You". *Journal of Applied Research in Intellectual Disabilities, 30*(4), 648-660. https://doi.org/10.1111/jar.12259

Neubauer, B. E., Witkop, C. T., & Varpio, L. (2019). How phenomenology can help us learn from the experiences of others. *Perspectives on Medical Education, 8*(2), 90-97. https://doi.org/10.1007/s40037-019-0509-2

National Institute for Health and Care Research, (2024). *Involve patients.* Retrieved October, 4, 2024 from Involve patients | NIHR

Nind M. (1996) Efficacy of Intensive Interaction: developing sociability and communication in people with severe and complex learning difficulties using an approach based on caregiver–infant interaction. *The European Journal of Special Educational Needs*, 11, 48–66.

Nind, M. (2012). Intensive Interaction, emotional development and emotional well-being. In Hewett, D. (Eds) *Intensive Interaction. Theoretical Perspectives* (pp. 22-38). SAGE.

Nind, M., & Hewett, D. (1988). Interaction as Curriculum. *British Journal of special education, 15(2), 55-57.*

Nind, M., & Hewett, D. (2001). *A practical guide to intensive interaction*. BILD.

Nind, M., & Powell, S. (2000). Intensive interaction and autism: some theoretical concerns. *Children & Society, 14*(2), 98-109. https://doi.org/10.1111/j.1099-0860.2000.tb00158.x

O'Dell, L., Bertilsdotter Rosqvist, H., Ortega, F., Brownlow, C., & Orsini, M. (2016). Critical autism studies: exploring epistemic dialogues and intersections,

challenging dominant understandings of autism. *Disability & Society, 31*(2), 166-179. https://doi.org/10.1080/09687599.2016.1164026

O'Donohue, W. T., & Ferguson, K. E. (2001). *The psychology of B.F. Skinner*. SAGE.

Odame, P. K., Abane, A., & Amenumey, E. K. (2020). Campus shuttle experience and mobility concerns among students with disability in the University of Cape Coast, Ghana. *Geo: Geography and Environment, 7*(2), n/a. https://doi.org/10.1002/geo2.93

Office for Health Improvements & Disparities. (2022). *Working definition of trauma-informed practice.* Working definition of trauma-informed practice - GOV.UK (www.gov.uk)

Oxford Health NHS Foundation Trust. (n.d). *Oxfordshire Inclusive Communication.* Oxford Health NHS Foundation. Retrieved February 28, 2023, from https://www.oxfordhealth.nhs.uk/oxtc/good-advice/intensive-interaction/?highlight=Intensive%20Interaction

Pacia, C., Holloway, J., Gunning, C., & Lee, H. (2022). A Systematic Review of Family-Mediated Social Communication Interventions for Young Children with Autism. *Review Journal of Autism and Developmental Disorders, 9*(2), 208-234. https://doi.org/10.1007/s40489-021-00249-8

Payne, R. (2015). Using rewards and sanctions in the classroom: Pupils' perceptions of their own responses to current behaviour management strategies. *Educational Review*, *67*(4), 483-504.

Peckett, H., MacCallum, F., & Knibbs, J. (2016). Maternal experience of Lego Therapy in families with children with autism spectrum conditions: What is the impact on family relationships? *Autism: The International Journal of Research and Practice; Autism, 20*(7), 879-887. https://doi.org/10.1177/1362361315621054

Pedersen, S. (2016). The good, the bad and the 'good enough' mother on the UK parenting forum Mumsnet. *Women's Studies International Forum, 59*, 32–38. https://doi.org/10.1016/j.wsif.2016.09.004

Pickles, A., Prof, Le Couteur, A., Prof, Leadbitter, K., PhD., Salomone, E., PhD., Cole-Fletcher, R., Tobin, H., B.Sc, Gammer, I., M.Sc, Lowry, J., M.Sc, Vamvakas, G., M.Sc, Byford, S., Prof, Aldred, C., PhD., Slonims, V., PhD., McConachie, H., Prof, Howlin, P., Prof, Parr, J. R., M.D., Charman, T., Prof, & Green, J., Prof. (2016). Parent-mediated social communication therapy for young children with autism (PACT): long-term follow-up of a randomised controlled trial. *The Lancet (British Edition), 388*(10059), 2501-2509. https://doi.org/10.1016/S0140-6736(16)31229-6

Public Health Wales NHS Trust. (2022). *Trauma-Informed Wales: A societal Approach to Understanding, Preventing and Supporting the Impacts of Trauma and Adversity*. Trauma-Informed-Wales-Framework.pdf (traumaframeworkcymru.com)

Rabionet, S. E. (2011). How I Learned to Design and Conduct Semi-structured Interviews: An Ongoing and Continuous Journey. *The Qualitative Report*, *16*(2), 563-566. https://doi.org/doi.org/10.46743/2160-3715/2011.1070

Rayner, K., Bradley, S., Johnson, G., Mrozik, J. H., Appiah, A., & Nagra, M. K. (2016). Teaching intensive interaction to paid carers: using the 'communities of practice' model to inform training. *British Journal of Learning Disabilities, 44*(1), 63-70. https://doi.org/10.1111/bld.12111

Reeder, J., & Morris, J. (2021). Becoming an empowered parent. How do parents successfully take up their role as a collaborative partner in their child's specialist care? *Journal of Child Health Care, 25*(1), 110–125. https://doi.org/10.1177/1367493520910832

Richards, R. (2022). My journey to Intensive Interaction in the Early Years Foundation Stage. In Mouriere, A. & Smith, P. (Eds) *The Intensive Interaction Classroom Guide* (pp. 42-52). Routledge.

Rogers, C. (1980). *A Way of being*. Houghton Miffin.

Rogers, C. (2011). *On becoming a person: a therapist's view of psychotherapy*. Constable.

Ross, L. E. (2017). An Account From the Inside: Examining the Emotional Impact of Qualitative Research Through the Lens of "Insider" Research. *Qualitative Psychology (Washington, D.C.), 4*(3), 326-337. https://doi.org/10.1037/qup0000064

Routen, A., Bodicoat, D., Willis, A., Treweek, S., Paget, S., & Khunti, K. (2022). Tackling the lack of diversity in health research. *British Journal of General Practice, 72*(722), 444–447. https://doi.org/10.3399/bjgp22X720665

Runswick-Cole, K. (2013).'Wearing It All with a Smile': Emotional Labour in the Lives of Mothers and Disabled Children. In Curran, T. & Runswick-Cole, K. (Eds) *Disabled Children's Childhood Studies* (pp. 105–118). Palgrave Macmillan UK. https://doi.org/10.1057/9781137008220_9

Runswick-Cole, K. (2014). 'Us' and 'them': the limits and possibilities of a 'politics of neurodiversity' in neoliberal times. *Disability & Society, 29*(7), 1117-1129. https://doi.org/10.1080/09687599.2014.910107

Runswick-Cole, K. (2016). Understanding this thing called autism. In Runswick-Cole, K., Mallett, R., & Timimi, S. (Eds) *Re-thinking autism: diagnosis, identity and equality*, (pp.19-29). Jessica Kingsley

Rutland, A. F., & Campbell, R. N. (1996). The relevance of Vygotsky's theory of the 'zone of proximal development' to the assessment of children with intellectual disabilities. *Journal of Intellectual Disability Research, 40*(2), 151-158. https://doi.org/10.1046/j.1365-2788.1996.741741.x

Ryan, S. (2005). 'People don't do odd, do they?' mothers making sense of the reactions of others towards their learning disabled children in public places. *Children's Geographies, 3*(3), 291–305. https://doi.org/10.1080/14733280500352920

Ryan, S., & Runswick-Cole, K. (2008). Repositioning Mothers: Mothers, Disabled Children and Disability Studies. *Disability & Society, 23*(3), 199–210. https://doi.org/10.1080/09687590801953937

Ryan, S., & Cole, K. R. (2009). From Advocate to Activist? Mapping the Experiences of Mothers of Children on the Autism Spectrum. *Journal of Applied Research in Intellectual Disabilities, 22*(1), 43–53. https://doi.org/10.1111/j.1468-3148.2008.00438.x

Samuel, J., Nind, M., Volans, A., & Scriven, I. (2008). *An evaluation of Intensive Interaction in community living settings for adults with profound intellectual disabilities.* https://doi.org/10.1177/1744629508090983

Saunders, B., Kitzinger, J., & Kitzinger, C. (2015). Anonymising interview data: challenges and compromise in practice. *Qualitative Research* 15(5), 616-632. https://doi.org/10.1177/1468794114550439

Schertz, H. H., & Odom, S. L. (2007). Promoting joint attention in toddlers with autism: A parent-mediated developmental model. *Journal of Autism and Developmental Disorders, 37*(8), 1562-1575. https://doi.org/10.1007/s10803-006-0290-z

Schopler, E., & Reichler, R. J. (1971). Parents as cotherapists in the treatment of psychotic children. *Journal of Autism and Childhood Schizophrenia,* 1(1), 87-102. https://doi.org/10.1007/BF01537746

Schwartz-Johnston, R. (2019). Ableism, Personhood, and Communication for People Who Don't Speak. *Peace Review (Palo Alto, Calif.), 31*(4), 479-486. https://doi.org/10.1080/10402659.2019.1800934

Seidman, I (2013) *Interviewing as Qualitative Research*. 4th ed, Teachers college press. London,

Sharan B. Merriam, Juanita Johnson-Bailey, Ming-Yeh Lee, Youngwha Kee, Gabo Ntseane & Mazanah Muhamad (2001) Power and positionality: negotiating insider/outsider status within and across cultures. *International Journal of Lifelong Education,* 20:5,405-416, DOI:10.1080/02601370120490

Sharma, V., & Firth, G. (2012). Effective engagement through intensive interaction. *Learning Disability Practice, 15*(9), 20-23.

Sheffield Children's NHS Foundation Trust (2022). *Intensive Interaction.* Retrieved July, 10, 2022, from Intensive interaction - Resource Library - Sheffield Children's NHS Foundation Trust (sheffieldchildrens.nhs.uk)

Shinebourne, P. (2011). The Theoretical Underpinnings of Interpretative Phenomenological Analysis (IPA). *Existential Analysis: Journal of the Society for Existential Analysis, 22*(1), 16-31.

Shire, S. Y., Goods, K., Shih, W., Distefano, C., Kaiser, A., Wright, C., Mathy, P., Landa, R., & Kasari, C. (2015). Parents' Adoption of Social Communication Intervention Strategies: Families Including Children with Autism Spectrum Disorder Who are Minimally Verbal. *Journal of Autism and Developmental Disorders, 45*(6), 1712-1724. https://doi.org/10.1007/s10803-014-2329-x

Sinclair, J. *Why I dislike 'Person First' language*. Retrieved April 14, 2024 from https://www.google.com/url?sa=t&source=web&rct=j&opi=89978449&url=https://blogs.exeter.ac.uk/exploringdiagnosis/files/2017/03/Sinclair-Why-I-Dislike-First-Person-Language.pdf&ved=2ahUKEwjc_dC09sGFAxV1QUEAHb2fBpEQFnoECBUQAQ&usg=AOvVaw2qFVcYAl3VNPUyH4xgL5JI

Singer J. (2016). *NeuroDiversity: The birth of an idea*. Self-published, Amazon

Skinner, B. F. (1963). Operant behavior. *American Psychologist, 18*(8), 503–515. https://doi.org/10.1037/h0045185

Sloan, A., & Bowe, B. (2014). Phenomenology and hermeneutic phenomenology: the philosophy, the methodologies, and using hermeneutic phenomenology to investigate lecturers' experiences of curriculum design. *Quality & Quantity, 48*(3), 1291-1303. https://doi.org/10.1007/s11135-013-9835-3

Smith, J. A. (2007). Hermeneutics, human sciences and health: linking theory and practice. *International Journal of Qualitative Studies on Health and Well-being, 2007, 2*(1) 3-11. https://doi.org/10.1080/17482620601016120

Smith, J. A. (2011a). Evaluating the contribution of interpretative phenomenological analysis. *Health Psychology Review, 5*(1), 9-27. https://doi.org/10.1080/17437199.2010.510659

Smith, J. A. (2011b). Evaluating the contribution of interpretative phenomenological analysis: a reply to the commentaries and further development of criteria. *Health Psychology Review, 5*(1), 55-61. https://doi.org/10.1080/17437199.2010.541743

Smith, J. A. (2017). Interpretative phenomenological analysis: Getting at lived experience. *The Journal of Positive Psychology, 12*(3), 303-304. https://doi.org/10.1080/17439760.2016.1262622

Smith, J. A., Larkin, M. H., & Flowers, P. (2012). *Interpretative phenomenological analysis: theory, method and research*. SAGE.

Smith, J. A., & Osborn, M. (2003). Interpretative phenomenological analysis. In J. A. Smith (Ed.), *Qualitative psychology: A practical guide to research methods* (pp. 51–80). Sage Publications Inc

Smith, J. A., & Osborn, M. (2015). Interpretative phenomenological analysis as a useful methodology for research on the lived experience of pain. *British Journal of Pain, 9*(1), 41-42. https://doi.org/10.1177/2049463714541642

Smith, P. (2022). What do students with autism and learning disabilities need to learn? In Mouriere, A. & Smith, P. (Eds) *The Intensive Interaction Classroom Guide* (pp. 15-28). Routledge.

Sousa, A. (2011). From Refrigerator Mothers to Warrior-Heroes: The Cultural Identity Transformation of Mothers Raising Children with Intellectual Disabilities. *Symbolic Interaction, 34*(2), 220–243. https://doi.org/10.1525/si.2011.34.2.220

Spectrum. *It's time to embrace 'profound autism'*. Retrieved 14th April, 2024, from https://www.spectrumnews.org/opinion/viewpoint/its-time-to-embrace-profound-autism/

Spiers, J., Smith, J. A., Ferrer-Duch, M., Moldovan, R., Roche, J., & MacLeod, R. (2020). Evaluating a genetic counselling narrative group session for people

who have tested positive for the Huntington's disease expansion: An interpretative phenomenological analysis. *Journal of Genetic Counseling, 29*(6), 1015-1025. https://doi.org/10.1002/jgc4.1229

Stern, D. N. (2018). *The interpersonal world of the infant: a view from psychoanalysis and developmental psychology*. Routledge.

Tager-Flusberg, H., & Kasari, C. (2013). Minimally Verbal School-Aged Children with Autism Spectrum Disorder: The Neglected End of the Spectrum. *Autism Research,* 6(6) 468-478 https://doi.org/10.1002/aur.1329

Taylor, A. (2016). How do parents of children with communication difficulties experience Video Interaction Guidance? A practitioner research project. *Educational Psychology in Practice,* 32(3), 296-309 https://doi.org/10.1080/02667363.2016.1170000

Thackeray, L. A., & Eatough, V. (2015). 'Well the Future, that is Difficult': A Hermeneutic Phenomenological Analysis Exploring the Maternal Experience of Parenting a Young Adult with a Developmental Disability. *Journal of Applied Research in Intellectual Disabilities,* 28(4), 265-275. https://doi.org/10.1111/jar.12126

Thackeray, L. A., & Eatough, V. (2018). 'Shutting the World Out': An Interpretative Phenomenological Analysis Exploring the Paternal Experience of Parenting a Young Adult with a Developmental Disability. *Journal of Applied Research in Intellectual Disabilities,* 31, 179-190. https://doi.org/10.1111/jar.12313

Todorova, I. (2011). Explorations with interpretative phenomenological analysis in different socio-cultural contexts: COMMENTARY on J. Smith: 'Evaluating the contribution of interpretative phenomenological analysis'. *Health Psychology Review*, 5(1), 34-38. https://doi.org/10.1080/17437199.2010.520115

Tolich, M. (2004). Internal Confidentiality: When Confidentiality Assurances Fail Relational Informants. *Qualitative Sociology*, 27(1), 101-106. https://doi.org/QUAS.0000015546.20441.4a

Trauma Informed Schools UK. *What is a trauma and mental health informed school?* Trauma Informed Schools UK. Retrieved April 14, 2024, from What is a Trauma Informed School? (traumainformedschools.co.uk)

van den Broek, E. G., van Eijden, A. J., Overbeek, M. M., Kef, S., Sterkenburg, P. S., & Schuengel, C. (2017). A systematic review of the literature on parenting of young children with visual impairments and the adaptions for video-feedback intervention to promote positive parenting (VIPP). *Journal of Developmental and Physical Disabilities, 29*, 503–545.

van Manen, M. (2017). But Is It Phenomenology? *Qualitative Health Research, 27*(6), 775-779. https://doi.org/10.1177/1049732317699570

Vivanti, G. (2020). Ask the Editor: What is the Most Appropriate Way to Talk About Individuals with a Diagnosis of Autism? *Journal of Autism and Developmental Disorders, 50*(2), 691-693. https://doi.org/10.1007/s10803-019-04280-x

Vygotsky, L. S. (1978). *Mind in society: The development of higher psychological processes*. Cambridge, MA: Harvard University Press.

Wagstaff, C., Jeong, H., Nolan, M., Wilson, T., Tweedlie, J., Phillips, E., Senu, H., & Holland, F. (2014). The accordion and the deep bowl of spaghetti: Eight researchers' experiences of using IPA as a methodology. *Qualitative Report, 19*(24)

Wagstaff, C., & Williams, B. (2014). Specific design features of an interpretative phenomenological analysis study. *Nurse Researcher (2014+), 21*(3), 8. https://doi.org/10.7748/nr2014.01.21.3.8.e1226

Wall, S. (2008). Easier Said than Done: Writing an Autoethnography. *International Journal of Qualitative Methods, 7*(1), 38-53. https://doi.org/10.1177/160940690800700103

Walz, A., Wang, M., & Bianchini, J. (2019). Parental perspectives on successful parent education and behavioral intervention. *International Journal of*

Developmental Disabilities, 65(5), 359-367. https://doi.org/10.1080/20473869.2019.1611128

Warnock, H. (1978). *The Warnock Report: Report of the committee of enquiry into the education of handicapped children and young people.* Warnock Report (1978) (education-uk.org)

Watson, J., & Knight, C. (1991). An evaluation of intensive interactive teaching with pupils with very severe learning difficulties. *Child Language Teaching and Therapy, 7*(3), 310-325. https://doi.org/10.1177/026565909100700306

Weare, K. (2004). *Developing the emotionally literate school*. Paul Chapman.

Weedle, S. (2016). The use of intensive interaction with people with severe-profound intellectual disability. *Learning Disability Practice, 19*(9), 27. https://doi.org/10.7748/ldp.2016.e1780

Wenger, E. (1998). Communities of practice: Learning as a social system. *Systems Thinker, 9*(5), 2–3.

Wilkinson, S., & Kitzinger, C. (2013). Representing Our Own Experience: Issues in "Insider" Research. *Psychology of Women Quarterly, 37*(2), 251-255. https://doi.org/10.1177/0361684313483111

Williams, K. J., & Murray, D. W. (2015). Negotiating the normative: the other normal for mothers of disabled children. *Journal of Family Studies, 21*(3), 324–340. https://doi.org/10.1080/13229400.2015.1098560

Willig, C. (2007). Reflections on the Use of a Phenomenological Method. *Qualitative Research in Psychology, 4*(3), 209-225. https://doi.org/10.1080/14780880701473425

Winkler, I. (2018). Doing Autoethnography: Facing Challenges, Taking Choices, Accepting Responsibilities. *Qualitative Inquiry, 24*(4), 236-247. https://doi.org/10.1177/1077800417728956

Yardley, L. (2000). Dilemmas in qualitative health research. *Psychology & Health, 15*(2), 215–228. https://doi.org/10.1080/08870440008400302

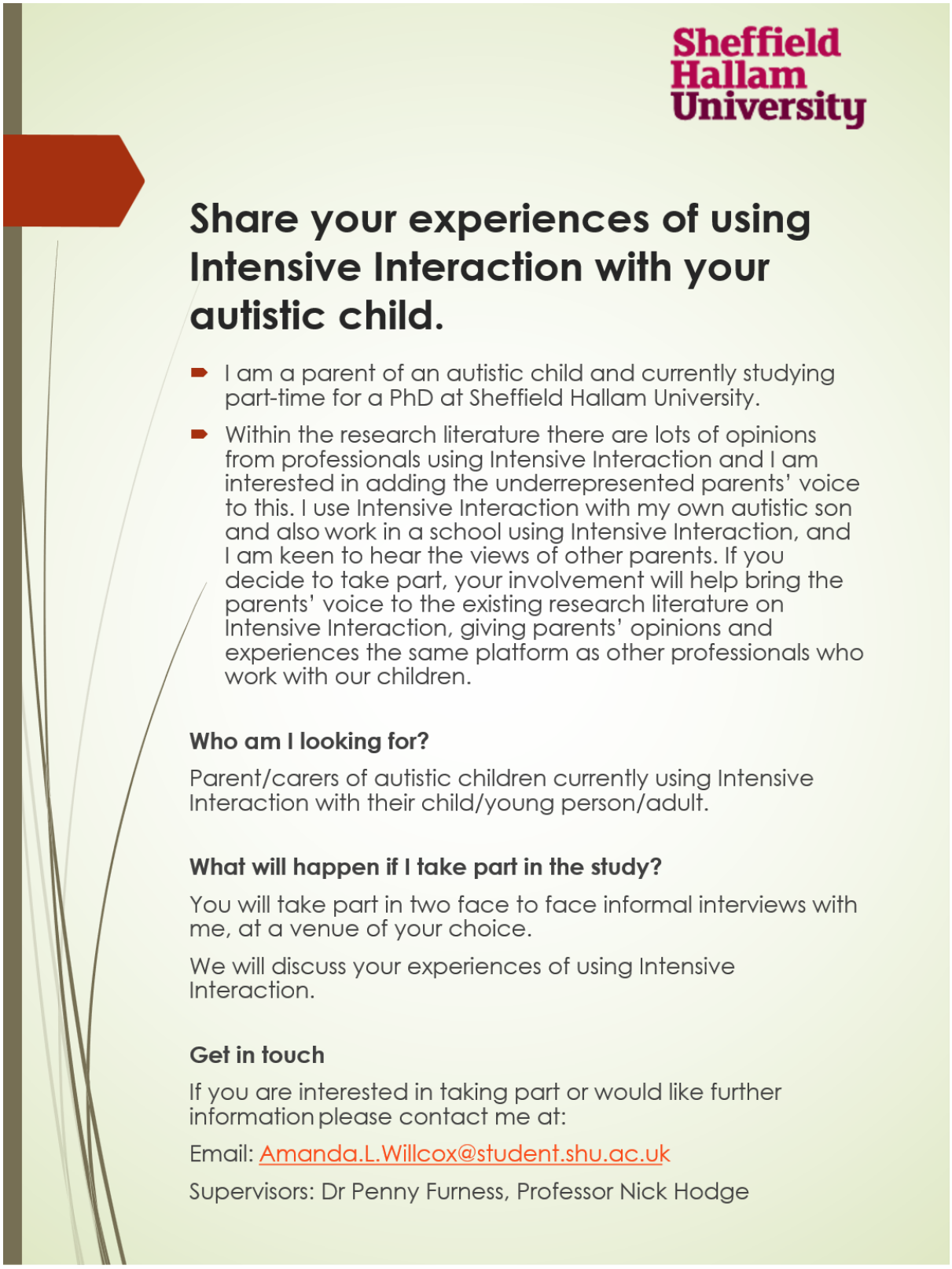
Zeedyk, M. S. (2006). From intersubjectivity to subjectivity: the transformative roles of emotional intimacy and imitation. *Infant and Child Development, 15*(3), 321-344. https://doi.org/10.1002/icd.457

Zeedyk, M. S., Caldwell, P., & Davies, C. E. (2009a). How Rapidly Does Intensive Interaction Promote Social Engagement for Adults with Profound Learning Disabilities? *European Journal of Special Needs Education, 24*(2), 119-137. https://doi.org/10.1080/08856250902793545

Zeedyk, M. S., Davies, C., Parry, S., & Caldwell, P. (2009b). Fostering Social Engagement in Romanian Children with Communicative Impairments: The Experiences of Newly Trained Practitioners of Intensive Interaction. *British Journal of Learning Disabilities, 37*(3), 186-196. https://doi.org/10.1111/j.1468-3156.2009.00545.x

Appendices

Appendix 1: Recruitment Flyer



Appendix 2: Data Management Plan

Data Management Plan

Amanda Willcox

1. What data will you collect or create?

This study will consist of interviews. The data will be audio recorded semi structured interviews which will be transcribed verbatim. There will be between 12 and 20, 60-90 min audio recorded interviews in total. The recordings will be done on a dictaphone. The audio recorded interviews will be transcribed and anonymised by hand into a word document. The participants will be given pseudonyms and a unique code identifiable only to this researcher. An electronic version will be stored on the University Q drive and hard copies will be used for analysis. Any paper copies will be kept in a locked cabinet in the PhD office in Heart of Campus 1.05.

2. How will your data be documented and described?

The metadata will be described in the methodology chapter/appendices of the thesis. Each participant's data will have a synopsis to give context of age, length of using intervention etc, but nothing that could be identifying.

3. How will you deal with any ethical and copyright issues?

There are no copyright issues anticipated and a full converis ethics application has been submitted. The transcripts will be anonymised with false names and identifying markers removed or changed. All participants will sign written consent forms with an information sheet attached explaining the study and details of confidentiality.

4. How will your data be structured, stored, and backed up?

Audio recorded data will be stored on the University password protected Q drive, which is backed up by the University and once transcribed I will store a master copy of the transcripts on Q drive. I will have a back up copy of the transcripts on an encrypted flash drive. Q drive is firewalled, password protected and backed up by two remote servers. Access to folders will be restricted to myself and the supervisors (once anonymised). Any paper copies of transcripts will be kept in a locked cabinet in [redacted] in the University. Consent forms will be stored in the confidential data locked cabinet in the PhD office [redacted] in the University.

5. What are your plans for the long-term preservation of data supporting your research?

The interview transcripts data will be stored on the University archive for 10 years. The audio recordings of the interviews will be added to Q drive and then deleted off the portable recording device. Once all analysis has taken place the audio recordings will be deleted from Q drive.

6. What are your plans for data sharing after submission of your thesis?

The transcripts will be available on request. This data may be of interest to peer researchers and myself for future publications.
The research findings will be written up and submitted as part of my thesis and shared on SHURA.

Appendix 3: Ethics Application

How parents of autistic children experience Intensive Interaction: An Interpretive Phenomenological Analysis.

Ethics Review ID: ER6420051

Workflow Status: Approved with Advisory Comments

Type of Ethics Review Template: All other research with human participants

Primary Researcher / Principal Investigator

Amanda Willcox
(Faculty of Social Sciences and Humanities)

Converis Project Application::

Q1. Is this project: ii) Doctoral research

Director of Studies

Penelope Furness
(Faculty of Social Sciences and Humanities)

Thesis chapter(s)	Research study	Ethics review reference	Approval date
3,4	How parents of autistic children experience Intensive Interaction: An Interpretive Phenomenological Analysis.	ER6420051	31/7/2018

Appendix 4: Section of transcription

Georgia: Gerry looks at us sometimes in like that desperation of like, “Come on, work out what I want.” You know, really intense look. Then when you get it their eyes just light up. That’s been nice to have those times where you’re just in their world with them and you’re understanding and you’re getting what it is that Gerry wants. You can just see sometimes they just, “Yes (sigh) you’ve got it.” Just like that relax. That stress of trying to get you to understand what it is and then suddenly you’re there with them.

It can be like seconds, minutes. I wouldn’t say it’s any longer than minutes. Minutes probably being the maximum. (Laughs) Yes, it’s nice. It’s nice(1) to relate. It’s nice to have that relationship with your child.

As I said, when Gerry was diagnosed with autism and they were two and a half, so they were very young, you start to sort of think, “What is it we’re not going to have? What have we lost?” Not lost, but, “What is it we’re going to miss out on?” Doing those things that we used to do with [sibling]; they just didn’t come with Gerry. You just don’t do them.

Actually, those times you do interact with them and get that time when Gerry’s totally with you are really precious actually. They don’t come along very often.

Interviewer: It sounds like you’re threading it through Gerry’s day in a natural way.

Georgia: Yes, because I think we can do that at home. At school it's a lot more structured, isn't it? There's some days that Gerry will come home and you can see they just doesn't want to be involved with anything. They just wants to be left alone. Then there's other days Gerry will come, they'll hold your arm and they'll look up you and they'll be laughing at you as though to say, "Come on. You know what I want."

Yeah so it has, also, you know, we've got [sibling] so it's not as easy as just saying, "This time we'll do this." [sibling] is still only [age] so they come home, we've got to do homework with them and then they'll want their tea. [Sibling] wants to talk. It is a bit trying to balance it out a little bit.

Appendix 5: Participant Information Sheet

Sheffield Hallam University

PARTICIPANT INFORMATION SHEET

How do parents/carers of autistic children experience Intensive Interaction?

Dear Parent/Carer,

You have been invited to take part in a study to share your experiences of using Intensive Interaction with your child.

I am a parent of an autistic child and currently studying part-time for a PhD at Sheffield Hallam University.

Within the research literature there are lots of opinions from professionals using Intensive Interaction and I am interested in adding the underrepresented parents' voice to this. I use Intensive Interaction with my own autistic son and also work in a school using Intensive Interaction, and I am keen to hear the views of other parents. If you decide to take part, your involvement will help bring the parents' voice to the existing research literature on Intensive Interaction, giving parents' opinions and experiences the same platform as other professionals who work with our children.

Participation involves two conversations (informal interviews) with me, taking place a few months apart. The conversations can take place in a venue of your choice, for example, at the University, your home or somewhere else of your choosing. However, it will need to be somewhere private and relatively quiet, because I would like to record the conversation.

I expect the conversations to last between 60-90 minutes. In the first conversation I will ask you to talk about your reasons for and experiences of using Intensive Interaction with your child. The second conversation will be an opportunity to revisit things discussed in the initial conversation and clarify any points. The questions will be very open-ended to allow you to talk about whatever experiences you are comfortable to share. However, if any question makes you feel uncomfortable, you can choose not to answer it. You can also take a break during the conversation or even stop it early, if you wish.

This is not a funded project so unfortunately, I will not be able to pay you for your time. However, travel expenses for travelling to the University or other venue of your choosing will be reimbursed.

The conversations will be recorded and saved on an audio file available to only myself at Sheffield Hallam University. They will be transcribed and anonymised. Only I and my supervisors will have access to these files. The files will be stored securely on a password protected Sheffield Hallam University archive for up to 10 years. The data will be reported in my PhD thesis, but I hope to publish aspects of the study in relevant academic journals and present at conferences. In all reports of this research the data will be anonymised, and I will not use your real name or any other identifying information.

If you would like to have a copy of the transcript of your interviews, I can provide this for you to keep. Also, you will be offered a short summary of the findings from the study as a whole once completed.

Participation is completely voluntary. You do not have to take part in this study. If you do decide to take part, you can still change your mind later. You will have the right to withdraw your contribution within one week of the conversation taking place. I will contact you to arrange the second conversation and you will have the right to decline to take part if you wish.

If you have any questions about the research, please feel free to contact me on the details provided below. Alternatively, if you prefer, you can contact my supervisors.

Thank you for your time.

Best Wishes

Amanda Willcox

Email: Amanda.L.Willcox@student.shu.ac.uk

Address: Dept of Psychology, Sociology and Politics

Sheffield Hallam University

[redacted]

Collegiate Crescent

Sheffield, S10 2BQ

Supervisors:

Penny Furness, email: P.J.Furness@shu.ac.uk

Nick Hodge, email [redacted]

The University undertakes research as part of its function for the community under its legal status. Data protection allows us to use personal data for research with appropriate safeguards in place under the legal basis of public tasks that are in the public interest. A full statement of your rights can be found at https://www.shu.ac.uk/about-this-website/privacy-policy/privacy-notices/privacy-notice-for-research. However, all University research is reviewed to ensure that participants are treated appropriately and their rights respected. This study was approved by UREC with Converis number ER6420051. Further information at https://www.shu.ac.uk/research/ethics-integrity-and-practice.

You should contact the Data Protection Officer if:	**You should contact the Head of Research Ethics (Professor Ann Macaskill) if**
• you have a query about how your data is used by the University • you would like to report a data security breach (e.g. if you think your personal data has been lost or disclosed inappropriately) • you would like to complain about how the University has used your personal data DPO@shu.ac.uk	• you have concerns with how the research was undertaken or how you were treated a.macaskill@shu.ac.uk
Postal address: Sheffield Hallam University, Howard Street, Sheffield S1 1WBT Telephone: [redacted]	

Appendix 6: Consent Form

Sheffield Hallam University

PARTICIPANT CONSENT FORM

TITLE OF RESEARCH STUDY: How do parents/carers of autistic children experience Intensive Interaction.

Please answer the following questions by ticking the response that applies

	YES	NO
1. I have read the Information Sheet for this study and have had details of the study explained to me.	☐	☐
2. My questions about the study have been answered to my satisfaction and I understand that I may ask further questions at any point.	☐	☐
3. I understand that I am free to withdraw from the study within the time limits outlined in the Information Sheet, without giving a reason for my withdrawal or to decline to answer any particular questions in the study without any consequences to my future treatment by the researcher.	☐	☐
4. I agree to provide information to the researchers under the conditions of confidentiality set out in the Information Sheet.	☐	☐
5. I wish to participate in the study under the conditions set out in the Information Sheet.	☐	☐
6. I consent to the information collected for the purposes of this research study, once anonymised (so that I cannot be identified), to be used for any other research purposes.	☐	☐

Participant's Signature: _____ Date: _____

Participant's Name (Printed): _____

Contact details:

_____

_____

_____

Researcher's Name (Printed): _____

Researcher's Signature: _____

Researcher's contact details:
Amanda Willcox
Dept of Psychology, Sociology and Politics
Sheffield Hallam University
[redacted]
Collegiate Crescent,
S10 2BQ

Please keep your copy of the consent form and the information sheet together.