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More-than-verbal dialogues:

Exploring communication in families of young people on the autism spectrum.

H. Driver

PhD 2019

More-than-verbal dialogues: Exploring communication in families of young people on the autism spectrum.

HELEN DRIVER

A thesis submitted in partial fulfilment of the
requirements of the University of Northumbria at
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Table of Contents

Figures:

Abstract

Within a social, political and educational narrative of stigma and exclusion relating to autism, this study engaged an autoethnographic participatory action research (APAR) approach to explore communication in families of young people on the autism spectrum. By engaging in collaborative learning within and between five families, the research process centred autistic young people in their families as co-researchers. Through communicative action and enaction, families explored what communication looked like in their family. Mothers established a collaborative learning group. Across a 10-month period they met and discussed communication, reflecting on their family communication interactions. These meetings and reflective journals, which held artefacts from young people and stories and reflections on family communication interaction, provided our data. Through this research assemblage of words, bodies, families and homes we recognised the more-than-verbal dialogues of embodied and enmeshed communication interactions.

Analysis exposed the importance of communicative space as a catalyst to the inclusion of embodiment, connections and self-narrative of autistic young people in communicative enaction. Homes provided liminal spaces of mutual becoming through enacting collaborative learning.

Acknowledgements

Firstly, I would like to thank the families who joined this study and shared their heartfelt thoughts, reflections and experiences of communication, with a very special thank you to the creative young people centred in this research.

I have had the honour to work with an amazing supervision team who have shared this journey with me, and I thank them for their thoughtful and wise support which has steered me through some ‘messy turns’; and for their detailed and patient attention to my work.

And to all of my family, who have both supported me and played a vital part in this study, I am grateful to them always for their ‘helpathy’, our new word, thanks boys!

Declaration

I declare that the work contained in this thesis has not been submitted for any other award and that it is all my own work. I also confirm that this work fully acknowledges opinions, ideas and contributions from the work of others.

Any ethical clearance for the research presented in this thesis has been approved. Approval has been sought and granted by the Faculty Ethics Committee on 11th November 2016.

I declare that the Word Count of this Thesis is 84,895 words

Name: Helen Driver

Signature:

Date: 1.10.19

“…we will never know what is inside another person’s mind, that there is, as it were, an infinity of possibility that lies on the other side of that skin”

(Antony Gormley, 2015)

Chapter 1 - Introduction

“I’m Charlie, just Charlie!” No other title, prefix, pet name, surname or label will be tolerated. Charlie is my son. Now he is 13. He likes to colour in, he likes to swing, he likes to watch Peppa Pig and he *loves* his big brother Matty.

Amongst other things, I am a mother to two boys and partner to my husband. In 2009 a new concept appeared in our family; I was parent to a 3-year-old called Charlie who was now diagnosed as autistic. What did this mean for my parenting and my family, and what did it mean for Charlie?

Societal perceptions of autism and Autism Spectrum Disorder (ASD) are informed as much by media portrayals of autism as they are by authentic experience, research and understanding. Recent campaigns to raise awareness and to increase understanding of autism have been driven by campaigners within the autistic community and charities such as The National Autistic Society. These campaigns have begun to challenge the myths surrounding autism but for the most part are only reaching those with a particular interest in the condition. A recent depiction of autism on British television in the drama The A Word (Bowker, 2016), a children’s animated series, Pablo (Brenner, 2017) as well as the presenter Chris Packham’s willingness to share his experience of Asperger’s through a documentary (Packham, 2017), demonstrate the increasing dialogue around this condition. Autistic people are more present in literature and speaking publicly about what it means for them to be autistic (Milton, 2016, Higashida, 2017, Grandin, 2014, May, 2019b). Yet autism still remains a mystery in many ways; its cause, and the myriad of presentations continue to present a challenge, one which society finds difficult to understand and therefore accept or respond to in any adequate form. And whilst publicly we become more aware of autism, it is often awareness driven by hear-say, myth and, too often, misunderstanding. Recent publicity of the systematic abuse of adults with autism and learning disabilities in Whorlton Hall and Winterbourne View provides a stark reminder of the potential vulnerability and isolation of the autistic community (BBC, 2019, Care Quality Commission, 2019). Violent and abusive practices are still common in such units, reflecting a culture that exposes the distance we need to travel before we become an inclusive society. In a condition so complex it is difficult to know and understand autism. Yet, is it so difficult to get to know and understand an autistic person?

Inclusion/exclusion

Schools continue to fail in meeting the needs of children with autism and their families, and school exclusions remain high, with many of these exclusions continuing to be based on behaviour resulting from disability (Autism and education in England, 2017). With an estimated 1 in 100 UK children being diagnosed with autism (Baird et al., 2006, National Autistic Society, 2019), the increased educational, social and medical support results in autism being constructed as a costly business (Knapp et al., 2009, Le Couteur, 2010). In a society driven by statistics, audits and austerity, the autistic community becomes commodified and is vulnerable to the perceptions of a neoliberal society which problematises autism and depicts social cost as a burden to the state (Waltz, 2013). Similarly, the quest for charity funding has the potential to create a victim culture where families and children are objectified or medicalised (Runswick–Cole, Mallet & Timimi, 2016).

The othering of autism; the constructs of difference, challenging behaviour and burden reach into the social world where our children and young people should be included to develop relationships, skills and friendships. A child would rarely be denied access to an open and fun dance class by nature of their race, religion or sexuality, yet, we are turned away, and seemingly it is still acceptable to deny access to an autistic child. This PhD study grew from my own personal experience as the parent of a growing child with autism and my position within the community of families of young people diagnosed as autistic. In order to illustrate the evolution of this study, and the experience I bring to the research, I will provide, in this introduction, an insight to my lived experience as an educator, a parent and a researcher. This background sets the study in context, outlining aspects of my life and experience that became a catalyst to the development of this research.

An educator

Only with hindsight do I realise how much I learned from my twenty-two years as a lecturer and manager in visual arts further education. I had worked with many students who were diagnosed with additional learning needs including autism. I believe I always held an intuitive respect for all of my students but I became increasingly aware of the need for individualised and responsive curricula which allowed them to connect with teachers and activity to find meaning for them. What I also became highly aware of was, so often, the need to develop an individual’s confidence (both student and staff member) to enable them to fully engage and participate and demonstrate their abilities. My experience of working with adult learners, particularly those who had very negative or abandoned experiences of education, made me realise how much the investment in their confidence could allow them to self-motivate, to self-learn and discover an enthusiasm for learning they had never experienced before. For many of these students, getting through the door into the college and studios had been almost insurmountable. Yet they were there, and they needed to feel valued and, even at the age of 28 or 42 they needed to be nurtured and their previous experiences acknowledged. Coupled with this, I witnessed an apparent increase in the number of younger students who arrived at college with learning or social difficulties and/or mental health issues which impacted on their ability to engage. Many required support to enable them to participate, and we were privileged to have a highly skilled, approachable and proactive mentor aligned to our department who was a huge support to many and worked seamlessly with the staff team. We had a number of support staff who came and went, some were hugely effective and others had less impact, even a negative impact on the learner's interaction. I managed this with as much integrity as I had knowledge, experience and human concern to offer. Anecdotally and statistically we had positive student feedback and a proactive approach to inclusion.

A parent

In December 2003 I became a parent for the first time, I was 36. I was married. We both had a sense of trepidation! What on earth could I/we offer a baby/child/teenager/adult? Why on earth would he want me as a mum/dad? My first son arrived, and strangely enough I seemed to be able to work out what to do. Even though I had absolutely no experience I seemed to be able to work out when he was hungry, when he needed changing, how to make him gurgle and smile. I was no child development expert but this small human and I seemed to be getting on rather well and going happily in the right direction. We were a pretty decent team. In March 2006 our second son arrived. Two little boys, I was amazed by these vibrant little humans. I seemed like a reasonably competent parent, sometimes a little frayed at the edges through tiredness but generally not bad! In 2009 my youngest son was diagnosed with autism, was it a surprise? No! Our boy was showing typical communication methods associated with autism. The need to understand how to communicate with my autistic son in our family is the catalyst for this research study. My experience as a parent collaborating within my family and with other families to engage in research and understanding forms the substance of this thesis. Drawing on my community positioning, this thesis engages the lived experience of communication in five families where a young person aged 9-14 is diagnosed as autistic.

A researcher

In 2009 I was searching for a way of furthering my professional qualifications. I began the process of applying to study a Master’s degree in Education when I discovered the Masters in Autism (MA Autism). My experience of developing inclusive curricula resources and learning experience for students, as well as my personal circumstances, drew me to this qualification. This would be a very personal journey, more so than I could have expected at the beginning of the process. I believed it would offer a chance to gain an objective view of my professional practice as an educator and my emerging role as the mother of a child with autism. I could review the literature and identify the most effective strategies and current knowledge and understanding of this condition. I hoped I would be able to respond more effectively to my students and my son’s needs and be able to better engage with education and service providers. It would allow me to increase my knowledge of the educational strategies and resources which would support more effective curriculum delivery and engagement of students with an autism diagnosis. What emerged was a highly personal, subjective journey through an autoethnographic study where I and my family engaged in an immersive research process. This experience challenged my knowledge, understanding and values, not only relating to communication and autism but to methodology, disability, childhood and family: My world view.

Policy

The diagnosis of autism or autism spectrum disorder (ASD) is based on diagnostic criteria identified in the DSM-5 (APA, 2013). Summarising the communication symptomatology, this describes; Persistent deficits in social communication and social interaction across multiple contexts. Deficits in social-emotional reciprocity. Deficits in nonverbal communicative behaviours used for social interaction. Deficits in developing, maintaining, and understanding relationships.

Also identified are specific behavioural symptoms: restricted, repetitive patterns of behaviour, interests, or activities, stereotyped or repetitive motor movements, use of objects, or speech. Insistence on sameness, inflexible adherence to routines, or ritualised patterns of verbal or nonverbal behaviour. Hyper or hypo-reactivity to sensory input or unusual interest in sensory aspects of the environment.

Many people may have met a person with autism, within their family, through their or their child's schooling or other social settings. However, the condition presents in such a complex and varying range of characteristics and unique profiling that each individual will present in their own unique way, which results in autism being recognised as a spectrum condition. This complex presentation challenges teachers, schools, and health and social provision to understand our young people and to meet their needs. Yet, this cannot and must not excuse the continuing exclusion of children and young people from accessing an equal and valuable school and social experience. As children and young adults, their parents and families, our primary route of support is through our education system and practitioners. Yet, the Autism and education in England (APPGA 2017) report indicates that fewer than half of teachers say they are confident to support a child/young person with autism, and also highlights that 3 years after reforms were instigated "children on the autism spectrum are still being let down by the education system" (APPGA 2017 p. 4). This system forms a key component of the education, health and care planning that is also tasked to co-ordinate and provide support for families to develop their knowledge of autism and how to engage their child.

The UNICEF report; The State of the World's Children 2013: children with disabilities (UNICEF, 2013); identified the significant challenges to inclusion that children experience

> "Concern for inclusion is rooted in the recognition that all children are full members of society: that each child is a unique individual who is entitled to be respected and consulted, who has skills and aspirations worth nurturing and needs that demand fulfilment and whose contributions are to be valued and encouraged. Inclusion requires society to make physical infrastructure, information and the means of communication accessible so all can use them, to eliminate discrimination so none is forced to suffer it and to provide protection, support and services so every child with a disability is able to enjoy her or his rights as do others" (p. 3).

This report goes further to assert that to address the significant challenges to inclusion, children with disabilities should, wherever possible, grow up in a family environment and, that the families of children and adolescents with disabilities must be adequately supported to provide the best possible environment and quality of life for their children. This would suggest, that where a child is identified as autistic through core difficulties in communication and social interaction, that these areas would be supported in families to enable communication and support children and young people to thrive.

In 2016 Dame Christine Lenehan, Director of the Council for Disabled Children, was commissioned by the Department of Health to carry out a review into the care of children with learning disabilities. The aim was to offer a strategic overview at government level and identify recommendations and actions to better co-ordinate care, support and treatment for children and young people with complex needs (and behaviour that challenges) involving mental health problems and learning disabilities and/or autism. Published in January 2017 the findings drew the following conclusion;

> “While I do not wish to paint a picture that is worse than it is, it’s important to remember that many of our group of children remain denied the basic rights of childhood, a loving family environment, a full education, and a right to develop and move towards adulthood within a community, whatever the right community looks like for them. Tackling this denial of rights should be fundamental to our thinking and tested against what action we decide. Otherwise we quickly retreat into deciding a new ‘normal’, where a different set of values apply, where what is expected for all children is not available for our children, because they are not seen as children anymore but as patients, or problems to be solved. This view has to be challenged. We must meet our obligations under the United Nations Convention on the Rights of the Child which obligate us to ensure that the best interests of the child are a top priority in all decisions and actions, that every child has the right to the best possible health, and that they develop to their full potential” (Lenehan, 2017 p. 10).

The report speaks of the inequalities and *othering* that is inherent in our systems, an othering that constructs the autistic child or young person through a deficit and deviant perspective driven by a normative agenda which serves to exclude and diminish. This report also serves as a reminder of the vulnerability of our children and young people where systems do not meet their needs, as well as the ethical and moral duty of care we have to support them to achieve fulfilled lives. Dame Lenehan acknowledges that this is not a new issue and cites the report; Don’t Forget Us, Children with Learning Disabilities and Severe Challenging Behaviour (Russell, 1997), this report too provided a clear overview of the problems and failures to meet the needs of these children, and emphasised the need for children to be recognised as children first. Now over 20 years on, our children are still exposed to systematic failure which can result in autistic young people being removed from their families to enter Assessment and Treatment Units with no clear pathway or treatment available; "… [these units] are not being used for assessment or treatment but for warehousing, they act as the long stay hospitals that I thought we had left behind" (Lenehan 2017, p. 4).

The stark contrast between the UNICEF report for children with disabilities and their families and the reality in UK practice described in the Lenehan report is troubling for our society, but for a parent, this reality can be little short of terrifying. The failure to meet even basic levels of support for families, drives an increased vulnerability and in the case of autism leaves a family and its members vulnerable to the communication barriers, which sit at the core of autism.

Autism and family

It is generally acknowledged that family relationships are an integral part of adolescents' "social, emotional and behavioural well-being" (Harper and Cooley, 2007) . It is therefore unsurprising that for children with autism, positive family communication and interaction suggests improved long term outcomes (Shire et al., 2015, Roberts and Kaiser, 2011, Weiss and Burnham Riosa, 2015). Yet, as for many parents, I was faced with a situation where my understanding of communication and my intuition in how to respond to my child were challenged. What was the best way to meet the communication needs of my son in the heart of our family, a child labelled with a condition which intimated aloneness;

reduced capacity to socialise, to bond, engage, and reciprocate? A condition which was identified by deficits and barriers to communication. My son, whilst unique in his expressions, seemingly erratic and often difficult to interpret; was warm, cuddly and bursting with energy and fun, yet, despite the love and care we offered there was potential for a reduced childhood experience resulting from barriers we experienced in communication and our ability to understand his expressions (Parsi, 2012). Recognising that my son accessed and engaged with his world in a fundamentally different way from the rest of his family, and as a result may be denied the same interaction and access to family communication, engagement, bonding and security is the driver for this research. As previously indicated in the Unicef report, all children have the right to inclusion in their community and this community includes home. Accessible communication is fundamental to inclusion, yet the often profound communication differences experienced in families of autistic children and young people can present pervasive and profound barriers to communication. Current UK services demonstrate lack of capacity, poor understanding and stigma, and little knowledge and support is available for families to understand communication. Barriers to communication can result in isolation within the family, despite loving and caring family members. Communication, verbal and non-verbal, is the means by which we engage with and within our worlds. This is where I looked to develop my knowledge and skill to include Charlie, but not just Charlie, to include us all in our family. This PhD thesis suggests that research driven by families offers potential to develop knowledge and leadership in challenging the barriers and boundaries to our children's communication experience. I am neither therapist nor teacher. I am mum, parent and a member of the community of families with autistic children and young people, it is from this situated position that this thesis is developed.

To understand the methodological context and development of this PhD study, I refer to the experience of researching and generating my Masters in Autism dissertation; an analytical autoethnographic study (Anderson, 2006). This form of self-narrative “places the self within a social context” (Reed-Danahay, 1997). As an autoethnographer I committed to reflexivity and accepted the struggle I engaged in to self-consciously recognise my position as researcher-self in the production of knowledge (Butz in DeLyser, 2009). I have previously referred to the diagnosis of my younger son with autism spectrum disorder in 2009; it was in the same year I began my Masters in Autism. I initially saw this qualification as providing opportunity to further my understanding of autism, supporting me to develop inclusive practice in my professional capacity as an educator and, not least, to provide knowledge that could inform my parenting practice to better support my young son. ‘Struggling’ and ‘fighting’ seemed to be terms that sat alongside additional needs in education and health, and drove me to seek knowledge to negotiate the system, and understanding to become the advocate I realised I would need to become; to recognise and meet the needs of my young son. I am mother to my son, and his diagnosis of autism placed an unknown in my path to parenting him and his brother and being a mother in my family. This was my family and I didn’t have all the knowledge I needed to do my job properly, this had the potential to diminish my role. I knew only one way to approach this and, for me, that was to access training and education to increase my knowledge and understanding of autism, and what it meant within our family.

Whilst the focus of my Masters study was on including our autistic son, the collaborative approach we engaged in by working together as a family through my autoethnographic approach, allowed us to recognise the importance of inclusion across the family and our family community response. We had begun to invest in a culture of inclusion in our home. I began to question the preconceptions I had held, not only relating to autism and the concept of inclusion, but also and not least, about the research process. I realised that this was an opportunity to grow understanding and meaning from *our* journey as a family and to begin to find sense and direction in *our* lives. The growing awareness of the issues driven by the insider/outsider view allowed this subjective methodology to increase my objectivity of the landscape of my family life and, gave me purpose and direction. This constant juxtaposing of self and context is inherent in autoethnographic research (Chang et al., 2016). Autoethnography allows the researcher to raise the consciousness of self. I became aware of my positionality. I am a parent, a mother, a wife, a researcher, an educator, and more. Raising my consciousness enabled me to develop my parenting praxis, to acknowledge my child with autism in our communication environment and to recognise the vital role that communication plays in the inclusion of *all* members in our family. I felt more empowered, more resilient and more able to support my family. We, as a family, engaged in dialogue and problem solving which included, as far as we could facilitate, all of our perspectives. I had found my positioning and it held meaning and purpose; and evidence indicated it made a positive impact on the wellbeing of our family. Not only did it promote the inclusion of all family members, it also revealed an apparent agency of our young children who, through engagement and play demonstrated creative, inclusive and responsive dialogue. There was an emergent resilience and mutual understanding within my family. Engaging in the research process early after my son's diagnosis has allowed us to continue reflective dialogue and increase our understanding of autism within our family. Storying, remembering and persistently reflecting, continue to underpin each of our lives and helps each of us to generate meaning in our everyday encounters. Ellis highlights the personal benefits of the autoethnographic process;

> "Of course, there are rewards too -for example, you may come to understand yourself in deeper ways. And with understanding yourself comes understanding

> others. Autoethnography provides an avenue for doing something meaningful for yourself and the world” (Ellis, 1999 p. xviii).

It is this prior journey that has informed the structure and the purpose of this thesis. Recognising the importance of inclusive communication and a collaborative approach to research in my own family is the catalyst for engaging other families in this process. My sons are older and in middle childhood/early adolescence, and the need to continue to invest in inclusive communication continues. As we develop my sons’ needs change and the challenges that we experience change. Through my MA study I had grown to understand the significance of inclusive communication, as such, this PhD study seeks to invest further in this approach by engaging multiple families in the process of exploring communication within and between families, where a young family member is diagnosed with autism.

The Thesis

As parents we are provided with little or no training to support our understanding of autism. Where children grow older and reach early puberty, a time of change and increased tension, we meet new challenges to our communication. Literature suggests there is little, if any, research on how the inherent communication difference that drives the diagnostic features of autism impacts our families’ capacity to communicate and maintain mutual understanding and connectivity. It is in this context that I introduce this thesis and the need to explore communication within families of young people who are diagnosed as autistic. In our families, where a child needs to belong and feel safe and valued, we as parents have a journey to make, to understand how to include the altered perception of our autistic children and young people. It is important to consider how, as families, we can support communication practices to counter a societal culture of exclusion. Investing in family communication which includes and connects our young people can support them to thrive during a challenging time in their development, supporting communication and interactions that continue to connect all family members. This study explores this situated experience of five families, including my family, working together to explore our communication and how we can engage an inclusive communication practice in our families where our autistic children are in middle childhood and early adolescence.

As such, this study aims to:

Through collaborative learning;

- explore an insider view of communication interaction in families where a young person has autism.
- explore opportunities and methods to support inclusion in family communication.

The study takes an Autoethnographic Participatory Action Research (APAR) approach to exploring this lived experience of communication within five families where a young person (aged 9 – 14) is diagnosed as autistic. We established a Collaborative Learning Group (CLG) where gatekeeper parents (in this study, mothers) met and kept reflective journals across a 10-month period. We explored communicative action in our homes. Through journaling and reflections, mothers contributed autoethnographic accounts to our CLG discussions, where we explored our family’s communicative encounters, centred on our autistic child. The action reflection/self-reflection cycle of an Autoethnographic Participatory Action Research approach allowed us to consider our communicative encounters and develop a reflexivity in our interactions. The APAR methodology enabled the inclusion of our autistic child or young person through parents’ narratives and stories, and through artefacts that were contributed by our children as part of their communicative encounters. Whilst this study centres on our children who are autistic, it does not seek to objectify them and allows their contribution through lived, authentic family communication encounters. Young people, both verbal and non-verbal, have been able to contribute and, most importantly, *teach us* what matters in our family communication encounters. APAR facilitates an action-reflection cycle both within and between families, allowing us to learn from one another across our full group of family members.

Chapter Structure

This section will provide a brief outline of the subsequent chapters of this thesis to allow an overview of content and structure.

Chapter 2 - Literature review
Providing a narrative review of the literature which takes a historical approach to understanding the development of research in autism focussing on families, communication and middle childhood/early adolescence. This review aims to provide an understanding of the narrative that surrounds autism from a family perspective, and the framing of autistic young people and their families from a normative perspective. Acknowledging communication as a core feature of autism, literature provides both a medicalisation and treatment focussed approach as well as beginning to offer a countering narrative of increasing critical perspective, driven by autistic authors, advocates and families. This review aims to position the PhD study, presenting knowledge, perceptions and practices relating to communication and exploring current and future directions in research relating to this thesis.

Chapter 3 - Methodology

This study engages an Autoethnographic Participatory Action Research (APAR) methodological approach to research and data generation. This chapter will provide an overview of the two methodologies of Autoethnography and Participatory Action Research (PAR) which fuse to form this situated, critical approach which foregrounds personal experience and collaborative learning. APAR responds to situated ethical practices and reflexivity which will be discussed within this chapter.

APAR engages theory, process and practice and drives the analytical framework. This chapter discusses the move to consider our research as an assemblage, facilitated through the APAR approach to research which is centred in social justice and community action. This democratic approach to research and data generation became a catalyst to a critical and inclusive approach to communicative action, which moves away from a hierarchical understanding of linguistics and data. The engagement of the philosophies of Deleuze and Guattari (1987) and complementary posthuman positioning will be discussed in relation to the process and understanding of this research study. Analysis is discussed as a two part process beginning with a rhizomatic (Deleuze and Guattari, 1987) response by parents involved in the study, which is then explored through a slow and detailed thematic analysis (Braun and Clarke, 2006).

Chapter 4 - Methods

This chapter provides a practical understanding of the methods that were employed within this study. Methods were established through a collaborative approach by gaining feedback through the consent process, allowing family members to accept or reject certain approaches to data generation. Focus remained on the situated and authentic interactions between family members. As such, our methods primarily focussed on making time for 1:1 interaction within the family to engage our autistic young person(s).

Chapter 5 – Tracings

Part I: Time and space as catalysts to inclusion

This first part of the outcomes of analysis traces the effect of our action reflection process and practice in the context of communication in our homes and with our young people. Time and space reveal themselves as significant in understanding and engaging communication which includes and empowers our young people.

Part II: Tracing communication interaction

This second section of outcomes trace the visceral and embodied, material and affective expressions within our communication that were seen, felt, and experienced in communication encounters in families. These methods and modes of communication were carried in the parents' reflections and discussions within our CLG and in the artefacts that our young people contributed to data. By acknowledging our communication experiences and findings as part of an assemblage of research and communication, the Trace of communication provides a reading of what surfaced in our data beyond which lies a vital sub-terrain of the young person's experience. This ontological positioning suggests the concept of the assemblage also described by Braidotti as a cartography (Braidotti 2018, and in Van Der Tuin and Dolphijn, 2012): A spatio-temporal geography of communication of body-place-space-affect, through which we trace our experiences. I also consider the wider impact of communication practice on the forming identity of our autistic young people and a continuing need to understand and establish inclusion to include and support the becoming adult.

Chapter 6 – Discussion

This chapter positions the outcomes and discussion of this PhD study in the wider social and political discourse of autism and suggests of the relevance of our findings of this study and their potential to inform practice.

Chapter 7 – Conclusion

This chapter provides a summary of the research and its findings, and considers the impact within the family and implications of the findings on practice and our current conceptualisation of communication in autism

Terminology

In this PhD study process we moved between terms of *autistic* and *with autism.* Whilst many in the autistic community advocate for the use of a prefix of autistic, thereby acknowledging autism as inherent to their identity, some of our young people are not yet acceptant of such labelling or could not directly express their opinion on this. Whilst I will prioritise the prefix of autistic as preferred by many in the autistic community, I will also use the term ‘with autism’ where it feels more appropriate relevant to our young people and family narratives.

This study engages children/young people with autism aged 9 - 14 with our focus on exploring communication in this adolescent phase and move to adulthood. Adolescence is defined by the World Health Organisation (WHO) as between 10 and 19 years. Young people, refers to the 10–24-year-old age group, also referred to as adolescents and young adults. I will generally use the term young people to acknowledge this and respect their evolving maturity. I am also aware that whilst some may see themselves as young adults and wish to be referred to as young people, others are more comfortable being referred to as children. I will strive to refer to children when referencing them in relation to their parents and families and will make reference to young person in other contexts and young people as a collective. I will also more frequently simply refer to the ‘young person’ or ‘young people’ meaning the autistic individuals within the study; and other children and young people in the family as siblings, brother or sister. This is in no way to diminish the sibling as secondary to their brother or sister but allows me to centre the autistic young person and not always have to affix a label. My intention is to be sensitive to the preferences of all in the autistic and youth community, but I centre my use of terms on the families engaged herein. Above all else I will heed my son’s mantra, ‘I’m Charlie, just Charlie!’

Chapter 2 - Literature review

This chapter provides a narrative literature review, (Ferrari, 2015, Collins and Fauser, 2005, Haddaway et al., 2015) taking a historical perspective of autism knowledge and research that informs a contemporary understanding of autism. This narrative approach allowed a broad consideration of the perceptions around autism which influence knowledge and practice relating to communication and family experience. By taking a historical perspective I acknowledge the impact of research approaches and framing of autism and how this influences current perceptions and drives advocacy. This enabled an understanding of the prevailing discourse and how autistic young people and their families are constructed in this narrative. The inclusion of grey literature allows the acknowledgement of autistic perspectives that may fall outside of normative research practice and presentation. This inclusion enabled a capture of current social, political and cultural perceptions and the evolving construction of autism as a condition. In reviewing research and constructs of autism since it was identified and labelled in the 1940s I discuss developing knowledge as well as perceptions and myths that surround the condition; influencing understanding and intervention and impacting autistic individuals and their families. This review explored the changing narrative and construction of the condition and the evolving discourse and implications for communication experienced by autistic people, with a focus on early adolescence and family.

By reviewing the current literature on autism through medicalised, critical disability and autistic perspectives, I aimed to explore the implications for family communication. The review of current interventions provides an understanding of UK practice which is aimed at supporting families to develop communication. Reviewing research and support in this age group exposes a paucity of literature which addresses communication differences within families focussed on middle childhood and early adolescence. Critical disability and autism studies challenge traditional approaches to understanding autism and engage autistic perspectives.

Autism – a historical perspective

The first papers recording the condition of autism were presented almost simultaneously, from Leo Kanner in America in 1943, and Hans Asperger in Austria in 1944. Leo Kanner's widely referenced paper, Autistic Disturbances of Affective Contact (Kanner, 1943) provides an observation of 11 children who present with atypical behaviour and development in social engagement and communication. This research also initiated the differentiation of autism from schizophrenia. Kanner observed that the children in his study were, from birth, unable to relate to people and situations in a typical way. This differs from schizophrenia where there is a departure from the initially formed relationships and participation. Kanner noted that in the cases of autism he studied, parents described a deficit in relational development and participation from birth. The paper records the presentation of the children in 11 case studies, offering detailed descriptions of the atypical behaviour of the children, the paper also focuses heavily on the parent-child relationships, with particular focus on the mother. Kanner records that most of the children did not adjust their body or posture in response to being picked up, and writes in one observation of this interaction between mother and child, "it was the mother who had to do all the adjusting" (Kanner, 1943 p. 243). Particular observations of the children's parents included descriptions of; "…parental coldness, obsessiveness, and a mechanical type of attention to material needs only" (Kanner, 1949, p. 425).

The article makes difficult reading in places conveying the lack of understanding and acceptance of children with atypical development and behaviour at the time of writing. There is an acknowledgement that the children are not “feebleminded”, and that they demonstrate “purposeful and intelligent relation to objects” and “phenomenal memory” (Kanner 1943 p. 249). Yet, there is little interest in understanding the “nonsense” patterns or utterances of the children. It is important to recognise the influence this paper has had in subsequent perspectives on autism. Kanner, in later years, denied any intention to implicate parents as the cause of their child’s autism and indeed, he recorded his acceptance that autism is present from birth (Bettelheim, 1967), however this paper has had marked impact in the field of autism across the years since its publication and has negatively influenced perceptions and constructs of autistic children and their parents (Waltz, 2013).

At this early stage of the journey of autism research, Kanner makes it clear that there was significant further research still needed to identify and understand the underlying aetiology, with clear suggestion that further research was needed to focus on the concept of an innate condition. Despite this awareness, he continued to implicate parents in causation;

> “In the whole group, there are very few really warm hearted fathers and mothers…The question arises, whether or to what extent this fact has contributed to the condition of the children” (Kanner, 1943, p. 250).

In the years following the publication of Kanner’s paper, child psychologists focussed on his observations that many of the children came from these cold, aloof and highly intelligent families. This perspective is reinforced in *The Empty Fortress: Infantile autism and the birth of the self* (Bettelheim, 1967), and with it the initiation of the term “Refrigerator Mother”. A term that pervaded the field of autism and child psychology for many years. Indeed, Bettelheim directly argues against Kanner’s suggestion of an innate or organic cause (Bettelheim, 1967). Bettelheim's perception of inadequate and unresponsive parenting being inherent in the cause of autism did not stand-alone but reflected the thinking in child developmental psychology in the mid-20th Century. Winnicott, a highly influential child psychologist also reflects the perception that autism results from inadequate and cold parenting, stating that;

> "If in the treatment of an autistic child, something can be done to make up for what the mother failed to do at the critical moment, then the child can reach to a place from which it makes sense for him or her to be angry about the failure. From this position he can go on to rediscover his capacity to love" (Winnicott, 1966, p. 123).

Asperger, in his parallel research study in Austria in 1944 (in Frith, 1991) presented a paper which, in contrast to Kanner's study, observed and considered very high levels of functioning in certain domains of understanding, interest and performance in the autistic young people in his study. He also recognised that which became acknowledged as the spectrum of the condition, manifesting very differently in individuals from severe, nonverbal to highly articulate and academically able. To a greater extent than Kanner, Asperger responded with an acceptance of the individuals' strengths and capacity to engage when their attributes and interests were acknowledged and nurtured. His awareness of both the pervasive difficulties but also the unique abilities allowed him to recognise the need for continued investment, nurture and support;

> "This knowledge determines our attitude towards complicated individuals of this and other types. It also gives us the right and the duty to speak out for these children with the whole force of our personality. We believe that only the absolutely dedicated and loving educator can achieve success with difficult individuals" (Asperger in Frith, 1991, p. 90).

It is interesting to note both Asperger and Kanner record the atypical presentation of some parents; however, these observations appear to be interpreted differently. Asperger believed from this early stage that the condition he saw suggested inherited characteristics and is recorded as sympathising with parents who he felt understood their children and that they were doing their best to raise them. It is interesting that Asperger's paper, Autistic Psychopathy in Childhood (1944), was not translated from German until instigated by Uta Frith and published in 1991, despite the suggestion that Kanner was aware of and potentially influenced by this work (Silberman, 2015). The delayed translation and access to this paper also denied the acknowledgement and awareness of capacity in individuals with autism suggesting a missed opportunity to encourage a more accepting perspective from an earlier stage in the developing narrative of autism; which arguably may have countered a prevailing discourse of blame, stigma and objectification of children and families.

Emerging treatments

Whilst highly significant in the evolving understanding of autism, this early research would have little impact on individuals and families where children were born autistic. The nature of the disability and severity determined whether a child would remain at home, in typical society and school, or sent to a hospital or institution for the perceived benefit to them and their parents. Large, sterile institutions housed generations of children with autism and other disabilities in crude and often abusive conditions. With little or no investment in education or training, these children were dismissed and constructed as feebleminded or retarded, and lacking the capacity to learn (DeMyer et al., 1973, DeMyer et al., 1981, Thompson, 2013). Despite Kanner's clear separation of the conditions, children with autism would continue to be classed and treated as if they had schizophrenia (Rutter, 1974). Ward (1972) identifies attitudes to young adolescents with schizophrenia which would have included those now diagnosed with Autism Spectrum Disorder (ASD), he writes;

> "Thus, the schizophrenic adolescent is described as an incompetent, incomplete human being, who has only fragmented bits of behaviour available to him" (Ward, 1972 p. 46).

In a review of the literature in 1970, Ward considers the various treatments available for children diagnosed with autism, known then as Early Infantile Autism (Ward, 1970). Whilst one must challenge his contemporary perspective which cited the "…combination of a constitutionally 'thick' barrier and an insensitive and unresponsive mother" (Ward, 1970 p. 352) as causing autism, it is interesting to read the analysis of the polarised treatments proposed at the time. Ward discussed Lovaas's behaviourist approach as a treatment which relied on punishment and reward to reinforce behaviour, a treatment which made no effort to offer a pleasant experience for the child. Ward determined that this intrusive and time-consuming approach was deemed to have little empirical evidence to support outcomes and regarded it as a questionable form of treatment. Ward goes on to suggest that the treatments which showed greatest efficacy were those by Pollan and Spencer (1959, in Ward, 1970) which noted the importance of 'warm human relationships'; O'Gorman (1967, in Ward, 1970) taught the children 'how to live' and Waal (1955, in Ward, 1970) emphasised 'acceptance, empathy and soothing physical engagement with the child' (in Ward, 1970). Ward's discussion concludes that the approaches that attained any progress were those that were active and intrusive in a pleasant and structured environment; interventions that relied on acceptance and human engagement to support the child to learn. This early recognition of the need for human engagement and response is an important consideration in the literature and challenged the prevailing narrative of his contemporaries such as Lovaas and Bettelheim (Ward, 1970). Whilst this review early in the development of autism intervention identified the positive impact of warm human interactions, this approach was not pursued, and developing treatments favoured a coercive behaviourist approach. It is noteworthy that although relational warmth was seen as holding positive impact, it was not felt that parents, in particular mothers, had the capacity to offer this. Ward continued to ascribe the cause of autism as the result of emotional distance, anger and rigidity in parents who were deemed insensitive to the feelings of their children, and unable to express their own feelings to their children (Ward, 1970).

In America, Lovaas (1973, 1987) continued to develop intervention based on behavioural modification. He established a reward/punishment approach to develop social skills and language and to modify behaviours that were often referred to as *aberrant* or *challenging*; meaning behaviours which deviated from normative expectations or that presented a challenge to those engaging with an autistic person, including self-harming behaviours. This intensive behavioural intervention evolved to become more naturalistic, identifying three factors which had most impact in improving outcomes for a child with autism; intensive treatment, family involvement, and the age of the child. Lovaas's ultimate focus on home-based treatment ran counter to the prevailing opinion that a child was better away from and protected from the negative impact of the family. The influential position of Lovaas in the field of autism research reframed the family to become a focus as part of the solution rather than the cause. In this context parents became regarded as co-therapists and trained to deliver behaviourist interventions to maximise treatment time and exposure, often including coercive treatment approaches and intense intervention of 40hrs teaching (Lovaas et al., 1973, Smith and Eikeseth, 2011). Whilst this engagement of parents began to erode a culture of parent blame it also became an invasive and medicalised intervention which was highly intrusive in families (Waltz, 2013). Many autistic advocates continue to challenge the principles of Lovaas's approach of behavioural modification also known as

Applied Behavioural Analysis (ABA) insisting that it disempowers autistics and espouses a normative agenda that denies autistic behaviours that are intrinsic to identity (Milton, 2012, Sequenzia, 2016). In 1974, Rutter published a review of the development of infantile autism which confirmed a cognitive difference was, without dispute, the underlying cause in infantile autism. This paper also acknowledged the emerging evidence to support homebased early intervention and educational methods as most effective treatments (Rutter, 1974). Whilst there is still some distance to go before fully identifying the specific neurological development which results in autism (as later discussed), read with our contemporary knowledge the recognition of an innate developmental condition sheds a different light on Kanner's observations of parent behaviours. It is likely that these presentations were indicative of a genetic component of the aetiology of autism rather than a coldness and assumed deficit parenting. Despite Rutter's clear and respected vindication of parents as implicit in the cause of autism, the legacy of assumptions of deficit parenting and deviant child behaviour have continued to pervade the lived experience of autistic individuals and families in the following decades (Waltz, 2013).

Parent advocacy

Autism remained a little-known condition for many years. The lack of understanding and appropriate treatment available, following the identification of the condition, led parents to initiate and drive research in the field, providing resources and interventions that supported the development and education of their children. In the UK, parents of children diagnosed with autism began the fight to keep their children from institutionalisation, initiating campaigning and activism to increase knowledge and awareness of autism, and to develop clinical and diagnostic awareness and treatment to improve outcomes for their children. During the late 1950's Lorna and John Wing, doctors working in the UK, identified their child as autistic and, together with other parent advocates, they ultimately formed the National Autistic Society (NAS, 2019). This charity continues to be a leading resource for autistic people, parents and professionals in the UK. Parents, still typically perceived as instrumental in causing their child’s autism, were now taking a lead in beginning to dispel the myths surrounding the condition.

Parents such as Lorna Wing and Bernard Rimland became more than parent advocates and their research made a significant contribution to forming a new perspective on autism (Wing, 1997, Fletcher-Watson and Happé, 2019, Rimland, 1964) which established a biological and genetic understanding of autism. The acknowledgement that autism has a biological basis (Rutter 1974) which impacts social development and social communication, has informed research. Literature has focussed around autism, its aetiology and appropriate intervention based on an understanding of neurological difference (Dawson, 2002, Rutter, 2013, Volkmar, 2010, Thompson, 2013). Whilst parents have driven a powerful agenda for advocacy and inclusion of autism (Solomon, 2008, Ortega, 2009) there is also a continuing tension in the role that parents can take. Some groups that include parents, still focus on treatment and an agenda driven by medicalised perspectives, with parents engaged in actively seeking to eradicate the autistic expressions and behaviours in their young people (Chamak, 2008, Chamak et al. 2008, Ortega, 2009, Saunders, 2018, O’Dell at al., 2016). Critics of some parent led organisations and those which do not engage the direct voice or participation of autistic people suggest a potential for conflict in the actions and agenda of parents and autistics (Ortega, 2009, Bertilsdotter Rosqvist et al., 2015). Where parents may be driven by a concept of inclusion that seeks to minimise autistic expressions and difference in behaviour with the aim of minimising exclusion, autistic authors and activists suggest that much of this expression and behaviour is intrinsic to individual autistic identity and communication and should be accepted as it is (Williams, 1998, Sinclair, 1992, Yergeau, 2018).

Theories of causation

As science evolves, research is increasingly able to examine neural processes which are implicated as underlying and causing autism (Happé and Frith,1996, 2006). Researchers have looked to cognitive frameworks to begin to explain biological and behavioural features of autism. Executive Functioning controls the cognitive functions engaged in planning, working memory, integration across space and time, impulse control, inhibition, and shifting attention, as well as the initiation and monitoring of action (Pennington and Ozonoff, 1996, Fletcher-Watson and Happé, 2019). Neural differences in frontal lobe activity are widely suggested to cause autistics to experience reduced control over executive functioning, impacting their attention and actions in these areas. This theory suggests an explanation for an uninhibited presentation, and the need for structure and routine, and argues that the repetitive movements and interests result from this reduced capacity to control function at a cognitive level (Demetriou et al., 2018, Frith, 2003, Happé and Frith, 2006).

Theory of Mind (ToM) involves understanding another person's intentions and emotions and using that understanding to navigate social situations. Colle et al. (2007) proposed that the differences in autism can be explained by a lack of theory of mind. The Theory of Mind hypothesis in autism describes a lack of understanding that other people hold a different perspective on the world. Baron-Cohen (1997, see also Colle et al., 2007 and Lombardo and Baron-Cohen, 2011) is a lead proponent of the concept of lack of ToM in autism and the well-established term “mindblindness” used to describe this concept in the autistic aetiology. Mindblindness is suggested to prevent an autistic person from implicitly understanding what another person is thinking or experiencing. It proposes that this lack of ability to consider a different perspective from one's own has a significant impact on communication, social interaction and reciprocity. It strongly implies a lack of empathy in autistics; suggesting that without the ability to consider another person's perspective then their own capacity to empathise is therefore significantly diminished or lost. Fletcher-Watson and Happé (2019) suggest it is not a lack of empathy per se, but an inability to express empathy in narrow and normative or expected ways that can result in an autistic expression of empathy being interpreted as lacking or inappropriate. Autistic researchers and authors are more recently challenging such theories and concepts, drawing a new level to our understanding of autism (Milton, 2012, 2016). Yergeau (2013) references the construct of lack and deficit that is so frequently inherent to theory in autism, referencing Baron-Cohen's suggestion that ToM is "…one of the quintessential abilities that makes us human" (Baron-Cohen, 1997 in Yergeau, 2013). Authors such as Yergeau (2018) and Duffy and Dorner (2011) highlight that the construct of autistics being *mindblind* (Baron-Cohen, 1997) suggests a lack of this quintessentially human characteristic and therefore positions autistics outside of the bounds of what makes us human. Thus, this deficit focussed construct serves to dehumanise a person with autism (Yergeau, 2013). Duffy and Dorner (2011) also critique the ToM concept as dehumanising the autistic mind, referencing the narrative that is built to articulate this impaired cognitive functioning. They focus on the negative positioning of lack and deficit which they argue, suggests a less than human positioning of the autistic child.

Milton (2012) too challenges the concept of mindblindness, suggesting a "double empathy problem" asserting that social situations are constructed through the reciprocal interaction between participants. As such, it is impossible for one person to hold the deficit position as the failure to engage in a social interaction is a mutual responsibility. Savarese and Zunshine (2014) also suggest that by recognising mindblindness as an actual descriptor of autism rather than a metaphor, we serve to dehumanise the autistic mind. This framing of autism as a deficit driven and impaired condition which narrates a less than human or sub-human affect, informs contemporary understanding and perceptions of autism. Such highly regarded theories as mindblindness and associated ToM in autism literature are well referenced and form the cornerstone of contemporary understandings of autism and autistics. Yet, these theories also can be read as positioning our autistic young people as not wholly human (Taylor, 2013), establishing perceptions of incapacity, serving to disempower and marginalise autistics and their families (Chamak, 2008, Ryan and Runswick-Cole 2008, 2009, Davidson and Orsini, 2013); resulting in the *othering* of autistics (Ortega, 2009, Yergeau, 2013 Milton, 2012 Milton, 2016, Yergeau and Heubner, 2017, Taylor, 2013). Furthermore, the intense scrutiny and focus on neurology has served to disembody autism and consider brain function without acknowledgement of the physical and embodied experience of living an autistic life. Autistic behaviour and communication as described by autistic authors and researchers is very much related to physical and emotional embodied states (Baggs, 2007, Williams, 1998).

Vermeulen (2015) draws upon the Theory of Mind hypothesis, building on this hypothesis to explore the concept of context blindness in autism. Acknowledging the use of context to create meaning, this hypothesis suggests that context blindness can explain some of the core behavioural characteristics in autism. Vermeulen suggests that context is used at two levels to make sense of the world. Context that makes meaning of the local or immediate environment, and global context that fits this local meaning into a broader social and expansive meaning. Being able to interpret the world relies on drawing meaning from our direct engagement with our environment; understanding language and recognising social cues. We experience this engagement as affect; sensation and movement within our bodies, known as interoception. These embodied experiences and interpretations of environmental stimuli are reported to be experienced differently by autistic people, suggesting that internal reception is not providing discernible cues to environmental or embodied stimuli (Price and Hooven, 2018). This potentially contributes to the complexity and difficulty of understanding context (Courchesne and Pierce, 2005, Westby, 2017, Vermeulen, 2015). Vermeulen suggests this may also affect sensory sensitivity reducing the capacity to differentiate incoming stimuli causing;

> "…difficulties in the spontaneous use of context to activate mind reading and to make contextually appropriate inferences about other people's mental states" (Vermeulen 2015, p. 187).

Whilst the messages of this interoception may not be decipherable and therefore not support understanding of experience or context, Schauder et al. (2015) suggest that children with autism may give increased attention to interoception, effectively being distracted by their internal experience. As such, attention competes between internal and external sensory cues in children with autism (Schauder et al., 2015), further contributing to the difficulties autistic children have in accessing and sustaining attention to external interactions. By drawing these concepts relating to context blindness together we begin to see an increasing complexity of three stages of contextual processing. Firstly, internal deciphering of affective, physical, sensory and tactile experiences; secondly, the means by which these experiences support contextualisation in the immediate environments; thirdly, the relationship of internal and local experiences to understanding wider social and world contexts. This restricted ability to contextualise results in difficulties in understanding the wider picture and contributes to a sense of dislocation. The increasing accounts from autistic authors suggest of the importance of the physical body, movement and sensation in contextualising both locally and globally (Higashida, 2017, Lawson, 2013). These perspectives allow increased understanding of the lived experience of differences and challenges in contextualising.

Contemporary theories have begun to acknowledge cognitive processes not as an isolated process but an embodied neural activity, exploring how mind/body are interrelated and should be considered so in any theoretical hypothesis aimed at understanding autism. Sheets-Johnstone (1981), advocates that the body is in constant dynamic interaction with its environment, inherently embodied and modulated by experience in its response to stimuli at the physical and cognitive level, from which the self-organising subject draws meaning. Acknowledging this mind/body integration, De Jaegher (2013) suggests an understanding of autism through *enaction* theory; an embodied and psychobiological understanding that recognises autism as a situated embodied concept of atypical sensory-motor and emotional disruption, which affects the interaction between communication partners. This theory draws on the "mutually supporting concepts of autonomy, sense-making, embodiment, emergence, experience and participatory sense-making" (p.5). De Jaegher asserts that in simple terms, "we make sense of the world by moving around in it and with it (sense-making is thoroughly embodied)" (p. 6). It is interesting to consider this hypothesis in relation to some autistic advocates' suggestion that oppressing natural autistic movements and behaviours may reduce the capacity for communication. For example, autistic advocate, essay writer, and poet, Amy Sequenzia describes how self-stimulatory movements actually allow her to write;

> "About communication: everyone communicates and behavior is communication. As a non-speaking Autistic, I can say that you can now understand my writings BECAUSE I wasn't having ABA when I learned how to type. I need to stim as I type and ABA would make me stop the stimming, therefore preventing my learning" (Sequenzia, 2016).

Jaswel and Akhtar (2019) highlight that some influential research into autism is built upon the assumption that the behaviours seen in autism evidence a lack of social interest. They specifically acknowledge that this contradicts the testimonies from autistic individuals themselves. Jaswel and Akhtar further state any theory built on lack of social interest also;

> "…misconstrues social motivation as residing within an individual when it is more appropriately understood as arising from a dynamic interaction between the individual and how others perceive and react to that individual" (p. 2).

Jaswal and Akhtar argue that, to understand and be able to support persons with autism, future research needs to contest such assumptions of lack of social interest, take the perspective of those with autism seriously, and include an embodied perspective in research.

Delafield-Butt and Trevarthen (2015) argue that it is not the motivation for social interaction that is disrupted in autism, but the ability to coordinate and activate primary sensory and motor information that enable self-expressions through body movement. The authors advocate for the increased appreciation of social meaning in embodied, non-verbal expression and to consider 'vitality dynamics' of the embodied self to socially interact, rather than over reliance on linguistic communication. Therefore, the ability to process and activate movements is altered from that which might be described as typical communicative experience. In early childhood this impedes timing and control of autonomic functions resulting in difficulty in developing the typical movements which allow engagement with the environment, including speech. Trevarthen notes that people with autism find difficulty in ordering and timing their movement, in the feeling experienced in their body and in emotional control (Trevarthen, 2013). This positioning resonates with the account of an autistic blogger who expresses the inability when pre-verbal to be able to action her thoughts;

> "My brain: "Come on, just say 'Dad, I'm hungry.' He's right over there".
>
> Me: ….
>
> My brain: "Come on, that's it, walk up to him".
>
> Me: "Aaaaaaruuuaaaa!" *Falls in front of dad and begins to scream".*
>
> (Savidge, 2018).

This short vignette suggests of the disrupted motive and motor systems theorised by Trevarthen. It also gives an insight to the frustration of preverbal communication where meaning and understanding are processed but action to execute verbal communication is not accessible. Furthermore Trevarthen (2013) proposes that:

> "…shared health and meaning are created in human awareness by primary processes of joint agency and emotional sympathy between the movements of human bodies" (p. 2).

Thus, the same neural system that perceives of a person's own possibilities for action is also that which recognises the possibilities of action in others. Atypical development in these systems is suggested to delay and disorganise the ability to react typically to stimuli, it also impacts on understanding of the social, affective, gestural stimuli presented by others. Hobson too, suggests differences in the way in which people with autism are able to attend to the emotions that allow an understanding of another person's actions (Hobson et al., 2016, Hobson, 1995). Both De Jaegher (2013) and Delafield-Butt and Trevarthen (2015) advocate for an intense interaction drawing on rhythmic and mirrored practice to acknowledge the embodiment of autism, and to be able to connect through nonverbal embodied interactions. Yergeau (2013), an autistic author, emphasises the need to re-embody the autistic mind, asserting that the body is significant in autistic experience and intrinsic to the rhetoric or self-narrative of an autistic person.

Communication

For families to understand and respond appropriately to their young person's unique abilities and approach to communication is a complex challenge, and the levels of stress amongst families in part reflects this challenge to communicate (Hastings, 2002, Schaaf et al., 2011, Ben-Sasson et al., 2013). Acknowledging the barriers to functional and social communication and interaction within the complex flow and flux, change and tensions of family life, suggests a complex communication landscape where a young person with autism may struggle to engage. To understand the current knowledge and approaches to supporting and developing social communication and interaction in families, it is necessary to consider literature relating to communication development in autism and intervention and training. By focussing on UK practice relevant to the aims of this PhD study we begin to acknowledge social and cultural understanding of communication and development in autism relevant to the context of the PhD study and the families within. This literature is typically authored from a clinical and medicalised perspective. It provides some awareness of different perceptual positioning of autistic children and young people and offers interventions to support communication and social interaction. Yet, it is when we move to listen to the narrative of autistic authors, we begin to hear authentic accounts of the experience of communication difference.

Communication as diagnostic criteria

Social communication and interaction impairments are identified as a core diagnostic feature of autism (APA, 2013), this characteristic of autism suggests of the significant barriers to communication often experienced by autistic individuals where often-profound barriers in language and social interaction are experienced. Communication typically develops in early infancy with mutual gaze and shared positive affect (Van Hecke et al., 2007), further social engagement and parental scaffolding (Pettygrove et al., 2013, Adamson et al., 2014), and joint attention, pointing and gesturing (Crais et al., 2009), emerge within the first 12 months of life. It is in the second year of infancy that we typically see significant development of spoken language (Heymann et al., 2018). No single mechanism or process can account for the development of language. Research exploring the difficulties in language development and difference in children with autism confirms atypical neurological processes and transmission, but is far from fully explaining the profound differences and associated barriers in language development (Tager-Flusberg, 2015). Neuro-imaging evidences differences between children with autism and their non-autistic developing peers in processing of auditory and language input, and non-verbal social interaction such as joint attention, (Kovelman et al., 2015, Hodge et al., 2010, Eigsti et al., 2011, Eigsti and Schuh, 2008). Unsurprisingly, where children have language processing difficulties or no verbal communication they encounter profound barriers to functional and social communication which is shown to negatively impact their long-term outcomes in terms of wellbeing and thriving (Rutter, 1970). Restricted language or an absence of spoken language in autism is traditionally assumed to be associated with reduced cognitive capacity (Dawson et al., 2007, Barbeau et al., 2013). Where typical language trajectories emerge autistic features continue to show a difference in social communication behaviours which frequently result in barriers to social interaction and engagement (Fletcher-Watson and Happé, 2019). This difference in social communication and interaction is typically understood as impaired social interest and incapacity in social interaction and communication suggesting that autistics are inherently asocial (Biklen and Attfield, 2005). Our growing access to autobiographical accounts of communication from autistic advocates and authors serves to challenge many of these perceptions and assumptions opening new narratives and understanding of communication in autism. Such critical positioning begins to challenge long held assumptions of communication and capacity in autism (Yergeau, 2013, 2018, Baggs, 2007) traditionally driven by diagnostic categorisations.

Early intervention in communication

Research into understanding and facilitating communication development in autism typically targets the period in child development between birth and 18 months. Here increased brain plasticity and formative social interaction and developmental learning offers, what is determined as, a critical time to target and address the social and communication differences in autism (Sullivan et al., 2014, Akshoomoff and Stahmer, 2006, Bradshaw et al., 2015, McConachie and Diggle, 2007, Howlin, 1998, Volkmar, 2010). As children at this stage of development are typically infants and preschool, attention has focussed on the potential of the parent-child dyad and the impact and influence of this interaction in formative social development (Green et al., 2010, McConachie and Diggle, 2007, Girolametto et al., 2007, Sussman, 1999). In essence, prevailing early intervention capitalises on the parent-child interactions to be able to maximise normative social communication and is also targeted to minimise behaviour which is deemed inappropriate.

Historically, in a western context, high profile interventions were based on behavioural approaches led by Applied Behaviour Analysis (ABA) (Lovaas, 1987), resulting in highly structured programmes of behavioural modification (Skinner, 1976). Such interventions continue to build on behaviourist approaches evident in programmes such as Early Start Denver Model (Dawson et al., 2010), and Pivotal Response Treatment (PRT); (Koegel et al., 2010), Enhanced Milieu Teaching (Shreibman et al., 2015). Such approaches are still relied upon extensively in the US and have formed a high-profile industry of treatment and intervention; these practices are increasingly influencing UK based interventions through educational practice (Denne et al., 2017, ABA 4 ALL, 2020). Increasing narrative from autistic communities has provided a critique of such intervention. Many autistic authors decry the behaviourist approaches as coercive and derogatory, seeking to cure, fix and suppress the authentic autistic expression and modify behaviours to conform to normative standards (Yergeau, 2018, Milton, 2012, 2016, Sequenzia, 2016, Williams, 1998). Yet autistic author Sue Rubin also describes her need for such training and intervention suggesting this offers her a level of control, enabling her to access communication and engagement which may otherwise remain beyond her reach (Rubin, 2018), this is also echoed in Temple Grandin’s assertion that autistic children require intense intervention (Grandin, 2014).

UK based research and intervention typically diverged from US models to establish an approach based on social interactionist theories (Vygotsky, 1978, Bruner, 2006), a theory that language development is established through the reciprocal adult-child interaction and the child’s evolving construction of their social world. Such approaches recognised and invested in the parent-child home interaction to enhance and focus on areas of social reciprocity and attention engagement, encouraging parents to be more attuned to their child’s communication overtures. This theoretical approach is evident in interventions such as PACT (Pre-school Autism Communication Therapy) (Aldred et al., 2004, Pickles et al., 2016), TEACCH (Treatment and education of autistic and communication handicapped children) (Mesibov and Shea, 2010), EarlyBird (Shields, 2001a) and Play Therapy (Jordan, 2003). Where spoken language is absent, interventions such as PECS (Picture Exchange Communication System) (Bondy and Frost, 1998, 2011, Mesibov et al., 2010) are often delivered alongside social intervention. Interventions such as PECS (Bondy and Frost,

2011) provide a method of developing functional communicative skills through exchange of visual symbols as requests. Such interventions to support functional communication are often integrated alongside developing social interaction skills. Maintaining the focus on early infancy and the opportunity this provides for developmental intervention, UK researchers advocate adopting interventions appropriately adapted to each individual child's pattern of strengths and areas of need (Howlin, 1987, Fletcher-Watson and Happé, 2019). This form of communication intervention targets support early after diagnosis and has become a focus for UK policy (House of Commons Library, 2016, National Initiative for Autism et al., 2003). EarlyBird (Shields, 2001a) is an intervention which is used widely across the UK to provide training to parents of children recently diagnosed with Autism Spectrum Condition (ASC) (Stevens, 2013). This intervention aims to increase parent-child reciprocity through initiating turn taking and being sensitive to the child’s interests and subtle overtures; to maximise naturally occurring opportunities to engage in play and interaction. Families participate in a three-month programme, with weekly group training sessions where parents learn to understand autism, build social communication, and analyse and use structure. The use of video and the group dynamic amongst families are important components of the programme. This intervention suggests positive outcomes in establishing and increasing social interaction (Aldred et al., 2004, Shields, 2001b, Cutress and Muncer, 2014, Stevens, 2013). The programme builds on the concept that the enhanced responsiveness of the adult as communication partner increases social engagement while the associated language, in turn, stimulates language and vocabulary acquisition in the child (Bonvillian, 1990). The emphasis on building social communication and focussed interaction is also aimed at preventing inappropriate behaviours such as distressed and aggressive outbursts by reducing frustration and misunderstanding.

McConachie and Diggle (2007) provide a systematic review of literature including 12 studies of parent implemented early intervention for children with autism (McConachie and Diggle, 2007). The search criteria includes children age 1 to 6 years, yet two of the reviewed studies in Pivotal Response Training (Koegel et al., 1996) extended to children aged 9 years and 12 years. The review confirmed there is sufficient evidence to indicate that parent training can, and in many cases does, work to offer improvements in children's social communication and parent knowledge, and indicates the need for parents to be attuned and responsive to their child's overtures. Findings of the review indicate that parents need, not only early intervention training, but also continuing support as their child grows, to meet the developing needs presented by their children and young people, and the needs of families. The review called for clarity as to what interventions work and why. It also indicated an improvement in reciprocity and in mood for many parents who experience success through intervention, and that parents felt empowered, potentially resulting from the increased reciprocity and positive feedback from their child which provides encouragement and reinforcement to parents. Hobson et al. (2016) suggest that caregivers of more able autistic children tend to engage in increased reciprocal play and positive feedback, however, where children have poor attention and restricted expressive communication there was more emphasis on containing children and keeping them on task. Clinical research supports early intervention, with wide agreement that early intervention can positively influence outcomes for children and families of autistic children. This is reflected in UK government guidelines that advocate early diagnosis and support for families. Yet, contrary to this prevailing narrative, it would appear that the age of initial diagnosis of autism has not decreased between 2004 and 2014 (Brett et al., 2016) and many parents do not receive training or intervention in response to their child's diagnosis.

This research in early intervention has moved to acknowledge the importance and potential of the mother-child dyadic interaction as a way of intervening and supporting increased social interaction and engagement. This substantial and pervasive move to recognise the value and validity of parents in the formative social and communicative development, accepts the importance of positive maternal and parental affect in this early phase of development of children on the autism spectrum. This importance of mother-child dyad is argued to be an example of the continued presentation of the culpable mother, whilst from a research perspective, no longer accused of causing autism, mothers now need to watch and monitor their child for any deviance and delay in development (Douglas, 2013). Douglas highlights the expectation that parents will seek diagnosis and respond with early intervention to encourage 'habilitation' and 'normalisation' continues to echo the narrative of parental/maternal responsibility which has followed autism. The parent role, in particular the maternal role, continues to be scrutinised beyond that of parents of non-autistic young people and constructs parents as co-therapists. The parent role is harnessed to administer intervention and co-therapy to provide intervention. Whilst training and support has potential to increase reciprocity and communication between parent and child the relationship between parents and their autistic child is also open to scrutiny and stigma, with parents frequently appropriated as the situated adult who can and should provide intervention prescribed by clinical and education institutions (Runswick-Cole and Ryan, 2019, Runswick-Cole, Curran and Liddiard, 2018, Douglas, 2013).

Whilst emphasis on parent-child dyadic interaction offers many positive aspects of time together, positive affect and increased reciprocity, the emphasis on minimising restrictive and repetitive behaviours and developing language skills becomes a strong agenda in parent-child interventions. This adult focussed agenda suggests of the constant monitoring which draws increasing challenge from contemporary researchers who question the power differences in issues relating to childhood and disability, (McLaughlin, 2016, Coleman-Fountain and Mclaughlin, 2013). This positions power in the medical and educational services and systems which intervene and monitor child development (Foucault, 1995, 1998, McKenzie and Macleod, 2012), imposing a discourse of normativity and positioning parents as co-therapist and intervention agents. As a child grows and begins to explore their world in playful encounters, this omnipresent monitoring and narrative permeates their development. Play is widely recognised as fundamental to learning (Griffin and Cole, 1984, Holzman, 2009, Nicolopoulou et al., 2009), primarily in childhood. Social play becomes an opportunity for teaching appropriate social interaction. This perspective of the need for intervention and constant teaching and modifying of social behaviours through play becomes a pervasive narrative and dominates the agenda in young children's playful encounters, seeking to teach children to play properly (Phillips, 2012). This normative agenda has potential to appropriate play for an adult driven agenda (Barron et al., 2017); disempowering children. Barron et al. suggest that;

> "Where the 'play-as-progress' rhetoric becomes too dominant, there is a risk of the child's right to play for the sake of play, for recreation, diversion or pleasure, being in effect denied or undervalued" (P. 4).

Yergeau (2018) suggests that autistic children are presumed to be unable to play voluntarily because their disability precludes them from prosocial forms of pretence, as a result whatever inference or social engagement emerges is assumed to be achieved through compliance to clinical intervention (Phillips, 2012).

UK based intervention beyond early years

It is suggested that 25% to 30% of children with autism will not develop any functional spoken language, or will remain minimally verbal (Brignell et al., 2018, Tager-Fusberg and Kasari, 2013). Language difficulties in children with autism are suggested to be linked with behavioural difficulties (Green et al., 2005) and higher levels of aggression (Hartley et al., 2008). Some autistics will continue life with no verbal communication, some may use Augmented Alternative Communication (AAC) systems involving visual, gestural or digital methods, where accessible (van der Meer et al., 2012). Where autistics have profoundly complex communication difficulties and without adequate and appropriate support and understanding, such systems may not be accessible. Consistent minimal language can result in reduced social engagement and withdrawal during adolescence (Lord, 2010). Research strongly indicates that self-injury seems to be an easily observable symptom of communicative deficits (Baghdadli et al., 2003). Restricted verbal communication and lack of understanding in communication partners can leave individuals experiencing both a limited ability to communicate even basic needs to others, as well as struggling to access social interaction, which can result in profound isolation (Caldwell 2012, 2007).

From the focus on social communication and interaction in early intervention, when children move to middle childhood and early adolescence, research shifts to a focus on education (Wright et al., 2016), emotional and anxiety driven behaviours (Rodgers et al., 2012, Wigham et al., 2015a, Joyce et al., 2017) and family experience, suggesting chaos and stress in families (Karst et al., 2015, Schiltz et al., 2018). With this, emphasis moves to behavioural management and research reflects a deficit model of analysing and treating autism in early adolescence. Middle childhood and early adolescence (around 9-14 years) is therefore not heavily researched in terms of communication, particularly within a home context (Pillay et al., 2011, Todd and Ioannou, 2011). As children grow, their needs naturally change and their autistic profile, sensory needs, interests and behaviours will evolve as will their awareness of their world and self. There are limited interventions which engage families in developing understanding and supporting autistic young people. The EarlyBird Plus programme, extends from EarlyBird, to support parents of children aged 5-8 and is developed to address the changing need of growing children. A study exploring the views of 120 parents who attended the EarlyBird Plus course in the North East of England suggests favourable outcomes (Cutress and Muncer, 2014). Parents reported increased understanding of autism and improvements in communication with their child. They also reported a greater awareness of how to understand and respond to their child's behaviours and felt more confident that they could meet their child's needs, resulting in a general, positive impact on family life. The study notes an additional key outcome as parents realised that it was they that needed to change rather than the child, this reflects the increasing recognition of the impact of a child's environment and the resulting social and physical stimulus. Cutress and Muncer also acknowledge the positive impact of parents working together but also the scarcity of interventions available to families with an older child (see also Pillay et al., 2011, Todd and Ioannou, 2011, Dekker et al., 2016).

The Cygnet parenting support programme aimed at children 7-18 and ASCEND (Autism Spectrum Condition Enhancing and Nurturing Development) for school-aged children, build on similar principles as the EarlyBird and EarlyBird Plus programmes but further tailors the strategies to older children. Stuttard et al. (2016) provide a pre-post intervention measure of the impact of the Cygnet programme for parents and children, a programme aimed at understanding and managing behaviour. Parents reported feeling more effective in their parenting following the intervention, they reported improvements in children's behaviour and suggested increased awareness and understanding of their young persons' needs (Stuttard et al., 2016). The programme extends beyond the EarlyBird Plus by introducing interventions such as visual supports, social stories and comic strips (Gray 2003) to increase communication and address behavioural concerns. ASCEND (Pillay et al., 2011) also provides a programme aimed at parent training, offering an overview of the autism spectrum condition supporting understanding of behaviour and communication, and introducing strategies aimed at managing behaviours of concern. The Cygnet, EarlyBird Plus and ASCEND interventions have evolved from early communication intervention programmes aiming to increase knowledge and understanding in parents and carers. The strategies within these interventions focus on functional aspects of communication alongside behavioural management, with a focus on teaching appropriate social behaviours and communication.

Social Stories (Gray and Garand, 1993) and the derivative, Comic Strip Conversations, (Gray, 1994) are a tool used widely by professionals working internationally as a means of supporting communication and understanding for an autistic child or young person. Social Stories as developed by Gray and Garand (1993) provide a "social learning tool that supports the safe and meaningful exchange of information between parents, professionals, and people with autism of all ages" (Gray, 2017, Gray, 2014). The Social Story is intended to be '*patient, respectful, and unassuming'* providing a;

> "learning experience that is descriptive, meaningful, and physically, socially and emotionally safe for the child or adolescent with autism" (Gray, 2017).

This strategy offers a means of communicating through more tangible and fixed methods of visuals and/or text rather than through verbal exchange; with a person able to continue to revisit the story to develop understanding. A social situation can be broken down to deal with more tangible, focussed aspects of the scenario to provide building blocks of understanding resulting in a fuller awareness of a complex social concept. The Social Story intervention is not designed as a behaviour management tool but as a method of investing in shared understanding, offering a communication tool that can be generalised in a home context. A systematic review by Qi et al (2015) indicates that Social Stories are an effective intervention for people with autism, and specifically effective at reducing behaviours which are deemed challenging or cause concern, with positive increases in social communication and positive behaviour (Qi et al., 2015). Social Stories have been used to teach social interaction and communication in a number of studies (Adams et al., 2004, Scattone et al., 2006, Styles, 2011) including use by parents within the home (Olçay-Gül and Tekin-Iftar, 2016, Acar et al., 2017). Yet, despite the emphasis that Social Stories should not be used as a behavioural management tool the method is also frequently used to reduce problem behaviours such as in the study by Pane et al. (2015). Here Pain et al. engaged the Social Stories approach to manage problem behaviours. Through functional analysis the study identified the target problem behaviour of ‘facial grimacing’ and ‘non-contextual smiling/laughter’, was most likely to occur after an academic demand (Pane et al., 2015). In this context the Social Story is used within a behaviourist ABA approach to replace these target behaviours, whilst the staff and researchers understood the problem behaviours were a response to difficult academic tasks, the communicative content of the behaviours was dismissed. This use of Social Stories as a social behavioural intervention is also challenged by Yergeau (2018) who sees this as a coercive tool similar to the use of ABA. This may be suggestive of the application of the Social Stories method in a US context. Whereas, typical use of Social Stories in the UK is aimed at supporting understanding of social situations and skills and preparing children and young people for transition or change to remove uncertainty.

Relationship Development Intervention (RDI) aims to offer a lifelong intervention, which provides training for parents on communication, co-regulation and interaction, also focussing on family stress, emotional regulation, parent mindfulness and decision-making

(Gutstein et al., 2007). Hobson et al. (2016) provides a pre/post-test of the ability levels of autism and parent responsiveness where children are involved in a study of parent delivered RDI, suggesting of positive effects. This intervention is focussed more on family interaction and moves to recognise the need to address a number of aspects of family life and experience.

A systematic review of interventions in autism by Mills and Marchant (2011) suggested that whilst widely used interventions such as EarlyBird and PECs may indeed have some positive impact for improving wellbeing and outcomes for those with autism, the evidence even for the more widely researched interventions remains weak. The authors assert the need to move forward with well-designed research studies, also acknowledging the important role of autistic advocates who have challenged and brought critical awareness to approaches. This research advocates for person-centred evidence-based practice to support people with approaches designed around the individual and their caregivers and incorporating a variety of validated techniques dependent on their abilities and preferences. Milton (2014) suggests there is little, if any, robust research evidence to support the interventions currently offered and that this may remain the case, given the complexity of conducting such research, as well as competing professional, parent and autistic views.

The prevailing narrative in autism research and intervention focuses on deficit and deviance in normative communication, and is driven from non-autistic perspective. Such positioning gives little or no insight into language and social communication that *is* present beyond our current understanding or presumptions of typical communicative styles and processes (Heilker and Yergeau, 2011, Milton, 2014, Biklen and Attfield, 2005). This draws further attention to the issues raised by Milton (2014) that acknowledge that interventions are typically driven by those with limited experience of autism and without the collaborative engagement of autistics, suggesting a bias towards normative non-autistic perspectives which lack the insight of lived experience and critical awareness (see also Jordan and Jones, 1998, Parsons et al, 2009 in Milton, 2014). Autistics who are nonverbal are highly likely to understand receptive language but be unable to respond with expressive verbal language (Fleischmann, 2017, Rubin, 2018, Higashida, 2017). Where children have strong verbal skills and highly developed vocabulary, society struggles to recognise and accept the difficulties young people may experience in social communication, resulting in people misreading communication overtures. Indeed the ‘gold standard’ Autism Diagnostic Interview-Revised (Lord et al., 1994) refers to the act of a child taking the hand of another person, to direct them to something they want, as a; ”lack of social-emotional reciprocity” (Gernsbacher et al., 2016), yet this simple gesture could also speak of a subtle and quiet request for help. The profile of language use is vastly different in autistic individuals and this in turn presents significant barriers to the broader understanding of what it means to be autistic, how life is experienced, and what is understood as communication from an autistic perspective. Whilst an autistic person may have a strong interest in developing relationships with others, their non-autistic communication partner may misunderstand social initiations and feel uneasy with behaviour which challenges their established, recognised norms. Milton (2012) describes this as the “double empathy problem”, the inability of a non-autistic to empathise with the presented autistic communication. Equally, there may also be individuals who appear to be disinterested and intolerant of others and often seen playing alone, which can be perceived as a rejection of, or aversion to, social engagement with others (Biklen and Attfield, 2005).

We often consider communication to be the back and forth of information, separate individual word-objects that we “volley back and forth like a tennis ball“ Lipari (2014, p. 508). This perception of communication denies the complexity and fluidity of the lived communication experience. Communication is infused with non-linear interactions and thoughts, feelings, presumptions, interpretations and misinterpretations, it is loaded with experience. Heidegger (1924) suggests “Communication means to bring others, and oneself together with others, into such being-in-the-world and to dwell in it” (Heidegger, 1924/2011, p. 23). It is the tacit acceptance of communication as the mere transmission of ideas and information that has contributed to the marginalisation of autistic individuals, the perceived back and forth, the linear exchange of symbolic language to establish verbal communication is often a process which excludes individuals with communication differences associated with autism (Milton, 2013). To enable inclusion in an autistic context we must consider communication beyond traditional perception and methods.

Autistic people who share their experience of social communication and interaction provide a powerful insight into their autistic perspective (Baggs, 2007, Higashida, 2017, Fleischmann, 2017, Beadle, 2017, Yergeau, 2018), often speaking of the difficulties they have in engaging with others, the need for patience and understanding and the need to re-evaluate our assumptions of what it is to be human and what is communication. It is broadly assumed that autistics are cognitively impaired (Dawson, 2007, Barbeau, 2013), this influences literature, public opinion, policy and practice (Yergeau, 2018, Davidson and Orsini, 2013). This perception is particularly entrenched where language is not accessible or is restricted. Dawson (2007) suggests that whilst there is evidence of atypical cognitive processing in autism, intelligence is not impaired as is currently understood. By employing an alternative test which focuses on fluid intelligence, Dawson challenges current perceptions of autism, suggesting capacity and intelligence despite language and communication differences. Whilst Dawson does not suggest that no individuals with autism have cognitive impairment, the paper concludes that typical assessment tools underestimated intelligence in many autistics. This concept is expanded through the narrative of autistic co-authors in Biklen and Attfield (2005) who describe different perceptions relating to communication.

Communication and behaviour

Autistic young adolescents are open to stigma and blame for behavioural expressions (NAS, 2018, Penketh, 2014, Mogensen and Mason, 2015), yet there continues to be limited research exploring the relationship between communication and behaviour and how this impacts an autistic young person. In contrast to the focus of *training* an autistic person to functionally communicate through behaviour modification and symbolic language intervention, if we consider research presented by Caldwell (2012) and narratives from autistic authors, some of whom do not use verbal communication (Fleischmann, 2017, Higashida, 2017, Yergeau, 2018), we begin to recognise that many behaviours are a means of communication which is overlooked or misinterpreted. Caldwell (2012) observes the behaviour of a non-verbal young man with severe autism and significant behavioural difficulties that forms a barrier to social communicative interaction and engagement. She observes the repeated behaviour of flicking a piece of string and *assumes the importance* of this action. After careful observation she recognises that what holds relevance for this young man is not the visual or physical motion of the string but the subtle contact the string makes with his left hand, she then begins to communicate through a rhythmic interaction, responding to this rhythm and touch, which offers familiarity and meaning for him. Caldwell uses Intensive Interaction (II) (Ephraim, 1998, Caldwell, 2012, Hewett, 2007), to facilitate this engagement, recognising the autistic person's behavioural presentation as communication and an opportunity for a shared non-verbal dialogue. Intensive Interaction recognises the body language and rhythm of a person as holding potential for communication engagement and *conversation* (Caldwell, 2007, 2012). This approach echoes research by Trevarthen and Delafield-Butt (2013) and De Jaegher (2013) who, as discussed earlier in this chapter, acknowledge an embodied and enactive understanding of autism. Caldwell's method of interaction and non-verbal dialogue offers a respectful, empathetic and intuitive intervention where there are significant and pervasive barriers to communication; an intervention that assumes competence and valid expression in the autistic communication partner. Observation and attunement allows intense focus on the behaviours and interaction that is available that can be accessed and can be recognised as an authentic and social communicative exchange. Caldwell suggests the need to drop one's own agenda and be led by the communication partner. It is in this intuitive and relational approach to being together, and learning to be together, that we can recognise warmth, trust and intimacy fundamental to familial communication and relational engagement. This approach offers a model of engagement which supports access to inclusive interactions and communicative engagement and learning that moves away from a medicalised, normative agenda. Intensive Interaction is typically used to develop interaction with individuals who have severe and pervasive communication and behavioural difficulties which can prevent carers from engaging (Ephraim, 1998, Caldwell, 2012, Hewett, 2007).

Programmes that support communication and interaction in early adolescence are still far from being available throughout the UK. Authorities offer little or no support or intervention relating to social communication for children in early adolescence and their families. particularly where children are older and almost no ongoing training beyond initial diagnosis (Wallace et al., 2013). Profound barriers pervade family communication where differences in communication can involve complex and often unrecognisable behaviours. This can challenge understanding and ability to respond appropriately to communication expressions, and yet, there is little research which explores how to understand and respond to behaviour and expression to engage and enhance communication, connectedness and inclusion in early adolescence within the home context. Whilst the focus of communication intervention remains on typical social and functional communication, driven through a non-autistic lens, there continues to be a limited understanding of what behaviour means in the context of communication leaving the potential for missed understanding and opportunity for interactions.

Family communication and interaction in adolescence.

In research into typical parent-child dynamics, Bronfenbrenner (1979) identifies parent-child shared time continues as an important factor in adolescent development. Research suggests that whilst there is a decrease in general social interaction of typical early teens with their parents over time, it appears that 1:1 dyadic time with parents shows some increase in early and middle adolescence. Thus, indicating that typical adolescents continue to rely upon their parents for closeness and support which allows them to maintain a connectedness whilst also developing independence and autonomy (Lam et al., 2012, Larson et al., 1996). Zimmermann (2016) emphasises the importance of good parent-child communication in supporting the adolescent transition from childhood to adulthood, it is also indicated that challenges in communication can impact this positive dynamic (Steinberg, 2001, Harper and Cooley, 2007, Shire et al., 2015). Situated within the flux and dynamic of family life, communication can become difficult for the autistic child or sibling to access. Bessette et al. (2016) studied severe childhood autism and family experience. Through questionnaires, interviews, observations and fieldnotes; one of six themes identified suggested that profound communication deficits resulted in families feeling disconnected or isolated from their child. The study described children, aged 4-13, who avoided family attempts to hug, and parents who tried to play with their child and, where the child did not engage, the parents become tired and frustrated and “…finally give up”. The research found families facing profound communication challenges, as children had few words and; “...most preferred to generally isolate themselves from others”. The authors concluded that the families experienced “isolation from the child” (Bessette et al. 2016 p. 589).

Shire et al. (2015) acknowledge that parents are in the unique position to influence their autistic children over decades where others (teachers, therapists, peers) will likely come and go (Shire et al., 2015). Woodman et al (2015) provide an analysis of the role of positive family relationships where a young person/adult has autism suggesting the positive outcomes this can offer for the young person. The study advocates that future research should consider experimental designs to evaluate interventions aimed at improving parent-child relationships and increasing positivity in their relationships (Woodman et al., 2015). Furthermore, Woodman et al. (2015) acknowledge that general literature indicates positive maternal affect and quality of parent-child interaction levels are predictive of child functioning, and support adjustment into young adulthood. Their study considers the impact of higher levels of maternal praise (based on maternal speech samples) and higher quality mother-child relationships on adolescents and adults with autism. Positive aspects of the family environment are linked with positive change in autism symptoms and behaviours in families with adolescents and adults with autism. The authors suggest that family behaviours will influence the functioning of individuals with autism from early toddlerhood through to adulthood.

There is clear acknowledgement that the family communication environment is a vital aspect of positive support for early adolescent development. Yet, despite the awareness of the core features of autism specifying a difference in communication and social interaction and the difficulties and challenges which appear to pervade family interactions, there is little research into the wider social and communicative environment of the family. Therefore, families are offered little access to information and understanding in how to support and maintain communication and connectedness through this important phase in a young person's development. It is in the small-scale studies that we find interest in the intimate and unique social interactions and communications in the family. Acknowledging the context of family life and engagement, Kuo et al. (2015) provide evidence that adolescents with autism who watched television with parents reported more positive parent–child relationships, where parents and young people shared this social time. This is an example of long-term, situated, lived family context providing opportunity to support social communication and development.

Cullen and Barlow (2002) in their study 'Kiss, Cuddle, Squeeze…' acknowledge that family communication is not solely a matter of verbal communication and that touch, body language and facial expression are forms of communication which have significant importance within the family relationships (Cullen and Barlow, 2002). This paper explores the impact of a Touch Therapy Programme for parents of children aged 3 - 13 years with autism. In pre-post interviews, parents reported feeling closer, understanding their child better and being able to find a closeness which allowed them to support their child to relax, and in some cases to be able to use non-verbal messages to ask for massage to help them reduce anxiety. Cullen and Barlow stress at many points, and from the parent narrative, that successful physical communication interaction must be on the child's terms. This awareness of the child as a partner in the interaction reflects the principles of Intensive Interaction; previously discussed (Ephraim, 1998, Caldwell, 2012, Hewett, 2007). This aligns with previously discussed theories of understanding autism as embodiment (Trevarthen, 2013) and enaction (De Jaegher, 2013). The use of non-verbal and tactile engagement in Cullen and Barlow’s intervention draws on such approaches to facilitate connection and interaction. Cullen and Barlow’s small study provides only limited evidence from a small sample, yet the authors indicate that further studies of parent–child dyads are warranted. Indeed, there is limited research which explores this family interaction as young people reach middle childhood and early adolescence and to support family members to offer appropriate and tolerable interactions appropriate to the child’s emotional and physical states.

What is continuously evident in the literature relating to communication, intervention and family social interaction and engagement is the limited contribution and perspectives from autistic authors and advocates (Milton, 2013). Perspectives of what communication is and what it means for an autistic and how this plays out in family interactions remains a little researched area. Principle diagnostic markers identify pervasive differences and difficulties in communication yet there continues to be a marked gap in the research which asks autistics to contribute to understanding of communication, what holds meaning for them, and how this impacts communication within families. Yergeau, (2018), Baggs, (2007) and Milton (2013) describe their social and non-verbal communicative approaches and behaviours which are often dismissed and rejected as empty or chaotic. Rather than exploring communication from an objective, medicalised position which assumes incapacity, there is a critical need to engage the situated experience of families who live with autistic communication. In so doing we can begin to understand the relevance of previously dismissed and rejected behaviours in family communication. As previously indicated, family communication is vital in supporting development and transition to adulthood (Bronfenbrenner, 1979, Larson et al., 1996, Lam et al., 2012, Zimmermann 2016) yet the altered communication landscape in families of autistic young people can result in barriers and misunderstanding and potentially severe isolation. Decades of previous research has undermined the vital role that parents and families play in supporting growth, development and wellbeing in their autistic young people (Waltz, 2013, Ryan and Runswick-Cole, 2008, 2009, Runswick-Cole and Ryan, 2019) demonstrating the need to invest in research which values and invests in family communication.

Factors confounding communication

As previously indicated, the diagnostic criteria for Autism Spectrum Disorder (ASD) describes social and communication deficits in autism and the presence of restricted, repetitive patterns of behaviour, interests, or activities; also acknowledging the hyper or hypo-reactivity to sensory input or unusual interests in sensory aspects of the environment (APA, 2013). For each autistic person the profile of communication, social interaction and behaviours will differ, as will the underlying sensory and emotional experiences; thus, defining autism as a spectrum of varying abilities, needs and severity, specific to an individual (Autistica, 2019). Whilst communication and interaction is the focus of this PhD study, restricted and repetitive behaviours, interests, or activities (RRBIs), and sensory processing differences are intrinsic to autistic experience and, as such, will impact communication (APA, 2013). It is therefore necessary to understand these factors further in order to recognise the implications for social communication and interaction. These features of autism should be considered from different perspectives when considering their relationship with communication. Firstly, RRBIs and sensory differences can present as a barrier to communication, disrupting and confounding processing of language and social interactions. Secondly, however, it is also necessary to acknowledge the increasing rhetoric from autistic authors such as Yergeau (2018) and Sequenzia (2016) who speak of these features of autism as also influencing communication in a positive way, by allowing them to manage dysregulation and therefore be more able to access communicative interactions, and further Baggs (2007) describes these sensory interactions as conversations in themselves.

Sensory processing

As acknowledged in the diagnostic criteria, autistic individuals will experience some level of sensory processing difference from that which is perceived as typical, with a suggestion that adverse sensory reactions occur in at least 65-80% (Tavassoli et al., 2016). It is now widely accepted that an autistic individual may move between *hyper*-sensitive (over-stimulation) and *hypo*-sensitive (under-stimulation) responses to environmental stimuli (Tavassoli et al., 2014, Bogdashina, 2016), this can affect all senses; visual, auditory, taste, smell and touch. This altered sensory processing also involves vestibular systems, controlling balance and eye movement, and proprioceptive sensation that allows awareness of the position and movement of the body (Cermak et al., 2010, Green and Ben-Sasson, 2010, Wigham et al., 2015a, Haigh, 2017). An individual with such sensory processing features is likely to struggle to filter and modulate incoming stimuli, resulting in atypical physical experience and sensory perception. The profile of sensory distortion or different attunement will differ for each autistic individual (Baranek et al., 2014, Kirby et al., 2015, Dawson and Watling, 2000, Schaaf et al., 2011). The picture of children covering their ears has become synonymous with autism (NAS, 2019); autistics may be unable to tolerate sounds such as loud voices, traffic noise or radios in social environments including home (Stewart et al., 2016). Visual sensitivity may result in the need for sunglasses or baseball style caps to avoid bright lights. An autistic person may recoil from touch or alternatively present sensory seeking behaviours, frequently resulting in autistic children and young people being intolerant of hugs, biting and chewing objects and avoiding certain food textures. Altered proprioceptive and vestibular feedback affects gross and fine motor skills, influencing the ability to engage in physical activity; movement can become more erratic or awkward, making access to some physical play and sport more challenging (Nazarali et al., 2009, Kurtz, 2008). Autistics may also find it difficult to feel their body in space resulting in disorientation and seeking movement or deep pressure to regulate their body. Autistic authors speak of the inability to filter or prioritise incoming stimuli resulting in competing sensory sensations (Gerland, 2012, Bestbier and Williams, 2017, Grandin, 2017, Grandin, 2014).

The difficulty in processing and coping with sensory stimulus results in a number of behaviours which may significantly impact family life (Schaaf et al., 2011), and not least, have the potential to cause significant distress to an autistic young person, this in turn may contribute to stress and tensions in family engagement (Hastings, 2002, Schaaf et al., 2011, Ben-Sasson et al., 2013). Schaaf et al. (2011) provide a qualitative phenomenological study including four families of children aged 8-12 with autism. Acknowledging high rates of sensory-related behaviours, the study explores the impact in these four families. There is a strong indication of the pervasive impact of the sensory processing difficulties in how families both experience and manage their lives around these behaviours. Whilst families demonstrate respect and an understanding of the resulting restrictive and repetitive behaviours, they also provide a strong sense of the impact within and beyond home environments. The increased and unpredictable stimuli of the social environment and the physical world can be so overwhelming for autistic children that this can have a marked impact on parents and siblings and their ability to engage in shared activities. Parents described numerous strategies they had developed to begin to address these behaviours, all of which would require long-term consistency, patience and perseverance (Schaaf et al., 2011). Acknowledging the neurological aetiology of these sensory processing difficulties reminds us that children with autism experience their world differently to their non-autistic peers. Research has increasingly recognised the strong relationship between sensory and social features of ASD (Thye et al., 2018). Autistic co-author Lucy Blackman (in Biklen and Attfield, 2005) asks; “If one hears the subtle sounds of speech out of order, which I do, how does one process language?” (p. 146).

The atypical cortical structure in the autistic brain is suggested to result in monotropic processing (Murray et al., 2005) this is the ability to only process one sphere of attention or stimulation at a time. In a typical environment there will be multiple and competing sensory stimuli, where an autistic person is unable to filter this stimuli, the result is frequently an assault on the senses which can overwhelm a person’s processing capacity (Caldwell, 2014). Frugone (in Biklen and Attfield, 2005 p. 266) describes that he “…becomes wooden immediately upon thinking about the act of touching something; it is as if the thought of the action renders him a statue” other individuals have described how the need to focus on processing receptive or expressive language can render other processing inert (Murray et al., 2005, Biklen and Attfield, 2005, Higashida, 2017). Caldwell (2014) and Goldschmidt (2017) also observe the heightened sensitivity which can result not only in discomfort and intolerance of the offending stimuli, but also in pain. May (2019a) suggests that many autistic people experience the sensory sensitivities noted in the DSM-5 *as* pain, hence the ‘extreme distress’. Growing awareness and research around sensory differences and a young person’s sensory experience of the physical world, informs our understanding of the challenges they face and many of the behaviours they present and the implications for communicative interactions (Wigham et al., 2015a, Stewart et al., 2016, Liss et al., 2008, Liss et al., 2006).

Autistic authors more recently have shared their sensory experiences and highlighted the importance of this sensory interaction with their environment as a meaningful communicative interaction; a communicative interaction at a non-verbal sensory level. Baggs (2007) and Rubin (2018) both provide a personal insight to their interactions with the tactile environment through sensory interaction with the flow of water. They explain that the rhythm and sensations they experience within their sensory interactions with water offer stimulus and feedback, therefore creating a dialogue of sensory interaction. These authors present as non-verbal, as such societal perception is that they are lacking in communicative ability; that they are asocial. However, these subtle glimpses into their sensation driven interactions that they share with us in their writing, speak of other dialogues than those that would be typically perceived as communicative. Considering Yergeau's perspective (2018), it could be argued that the rich and complex narrative that both Baggs and Rubin offer through augmented communication troubles or 'queers' our understanding of what is communication, suggesting "a sociality of things" (Yergeau, 2018, p.37) and experienced through sensory engagement. This concept of *things* being engaged in our communitive encounters begins to suggest of the part that non-human factors and the physical environment play in our communicative interactions and that meaningful communicative or dyadic interactions are not exclusively human to human but also engage material-non-human other, an internal or *intra-active* sensory communication experience (Barad, 2007). Such increasing awareness of the central role of sensory stimulation and engagement in autistic experience draws new questions relating to typical understanding of communication, challenging the narrow perspectives by which traditional research and literature understands and explores communication in autism (Davidson and Orsini, 2013, Milton, 2014, Baggs, 2007).

Restricted and repetitive behaviour

As with differences in communication and social interaction, restricted and repetitive behaviours, interests, or activities (RRBIs) are also a core diagnostic feature in autism. Research increasingly demonstrates that sensory processing difficulties and anxiety underlie many of the restrictive and repetitive behaviours expressed by an autistic person (Rodgers et al., 2012). Research into sensory processing differences and how they affect an autistic child has enabled increased understanding and interpretation of RRBIs, which were once perceived as meaningless behaviours (Nijhof et al., 1998). Research confirms that restrictive, repetitive and ritualistic behaviours including self-stimulatory behaviour can have very definite purposes for an individual. Evidence indicates that repetitive behaviours can serve to assert control over the environment, to establish familiarity and predictability and reduce anxiety resulting from uncertainty (Rodgers et al., 2012, Wigham et al. 2015a, Joyce et al., 2017). Liss et al. (2006) suggest that restrictive and repetitive behaviours are better described as ‘self-soothing’ rather than ‘stimulation seeking’. Such behaviours may also serve to offer interesting activity to engage in, which provides enjoyment; they are often referred to as self-stimulatory behaviour, or stimming (Besterman and Hendren, 2015), and are argued to provide intense focus, serving to block out overwhelming and unpredictable sensory overstimulation (Wigham et al., 2015b, Boulter et al., 2014). Repetitive movements or interests are highly evident in autistic young people, and can present in various ways and can appear to interrupt typical or normative social and communicative interaction. Repeating sections of script taken from films or television, books or adverts (known as echolalia) (Sterponi and Shankey, 2014, Neely et al., 2016, Yergeau, 2018) or talking extensively and exclusively about one topic of interest can dominate dialogue (Grandin, 2014). Establishing rigid patterns of behaviour when playing with toys, can divert typical play behaviour. Similarly, children may be highly rigid around eating and other family routines and activities. Once established such activities can become highly engrained and any attempt to interrupt these patterns can result in highly distressed behavioural responses (Wigham et al., 2015a). Research indicates that the familiarity and predictability of repeated behaviour, dialogue, interaction, interests and movements may serve to reduce the confusion in a world that feels complex, overwhelming and even painful or terrifying (Rodgers et al., 2012, Joyce et al., 2017, Boulter et al., 2014). Behavioural interventions such as ABA (Lovaas, 1987) place a strong focus on modifying and minimising self-stimulatory or stimming behaviours. However, as we increasingly have access to the perspective and narrative of autistic authors, we gain increased insight to the lived experience of minds and bodies that behave in restrictive or repetitive ways, and challenge such coercive behaviourist approaches. Through such narratives we begin to hear of the experience and relevance of stimming, the personal lived experience of a body that stims (Yergeau 2018);

> “I have stimmy hands, hands that wave, and flap, and tussle rubber bands. …My hands story and proclaim, denounce and congratulate. …Sometimes I am the only person who knows what my hands are meaning. Sometimes even I don’t know what my hands mean-but why must I always cherish or privilege meaning? Description cannot contain my hands. And yet, my former neuropsychologist described my movement as autistic stereotypy. My therapist described my movement as self-stimulatory gesticulation. In all of their describing, I find that little about me is described. Instead my body is reduced. Erased. Medicated” (Yergeau 2018, p.13).

Kawohl and Podoll (in Yergeau, 2018) consider their echoing (verbal, bodily, traced or drawing) as “environment driven responses … imitations of external stimuli” (p. 193) they describe this as a wavelike or embodied rhythmic response to environmental stimuli. This also suggests of the tactile and rhythmic interactions that Baggs (2007) and Rubin (2018) described of their interests in the rhythm of running water or movement of leaves in swaying trees. Yergeau (2017) expresses her understanding of echolalia; "…echolalia's meanings lie more in affect or anxiety than they do in the bounds of syntactic units" (p. 195). These insights describe the embodiment of echolalia and other echoed expressions, where affect drives the echoed response; a need to feel the rhythm or wave, to enjoy, to capture; to control, minimise or to internalise the reaction to environmental input (Kawohl and Podoll, 2008). Whilst the significance and personal experience of RRBIs remain elusive, this aspect of the autistic identity speaks strongly of a relevant and meaningful other-than-verbal embodied interaction with the environment.

Emotional regulation/dysregulation

Differences in sensory processing and difficulties in social and functional communication often result in autistics finding typical environments overwhelming. Increasingly, research acknowledges the prevalence of anxiety in the autistic population where frequent reference is made to the tendency to have a negative emotional and behavioural response to uncertain or unpredictable situations (Wigham et al., 2015b, South et al., 2017). Simonoff et al. (2008) indicate that 30–42% of adolescents with autism have an anxiety disorder. Research also suggests that 84% of children have sub-clinical symptoms of anxiety which cause significant negative experience (White et al., 2009). Further, research indicates increased anxiety, depression, and risks for suicidal behaviour in young adults with autism which has a significant negative impact on wellbeing (Skokauskas and Gallagher, 2012, Reaven, 2011, Hallett et al., 2013). Clearly, young people with autism struggle daily with increased anxiety, this can frequently become overwhelming, potentially causing damaging behavioural expressions and aggression, which can become a barrier to social and communication engagement (Baghdadli et al., 2012, Baghdadli et al., 2003).

For families with an autistic child this anxiety and intolerance of uncertainty (South and Rodgers, 2017, Maskey et al., 2013) can dominate family life and make new experience and any change almost unbearable for a young person. In the report One in One Hundred (Wallace et al., 2013), parents speak of the increased demand that the need for awareness and planning for their child places on the family;

> “It controls every breath of your day, from the second you wake up to the second you go to sleep; you have to think about the preparation, the consequences, the rest of the family…” (Wallace et al., 2013, p. 13).

Research indicates there are two dimensions to Intolerance of Uncertainty; the need for predictability, and uncertainty paralysis which can result in a sense of being cognitively or behaviourally stuck when faced with uncertainty (Birrell et al., 2011, Boulter et al., 2014). Emotional regulation relies on a person being able to identify their emotions, to employ strategies to manage their emotions by relaxing or self-soothing when emotionally over stimulated and to be able to stabilise emotions to allow them to continue with their expression or activity (Gratz and Roemer, 2004, Cole et al., 2004). It is widely acknowledged that children with autism struggle to regulate their emotions (Samson et al., 2015). Growing evidence suggests that this emotional dysregulation is indicative of social and behavioural problems over time and give strong indication that emotional dysregulation underlies many of the behavioural responses individuals with autism experience (Berkovits et al., 2017, White et al., 2014). Berkovits (2017) also found that levels of emotion regulation were unrelated to cognitive or language abilities, suggesting that these difficulties were consistent across ability profiles of autistic individuals (Berkovits et al., 2017).

Research also indicates that children with autism are likely to experience more negative and less positive emotion than typical peers (Mazefsky, 2015, Samson et al., 2015). White et al. (2014) describes emotional regulation as a broad, multilevel process, involving inter-related systems such as, attention, physiology and neurological processes. Further research is needed to fully understand what this means to an autistic person and how they can be supported to cope with and manage this pervasive anxiety and demanding emotional experience (Rodgers et al., 2012, Joyce et al., 2017). Difficulties in understanding and labelling emotions (*alexithymia*), although suggested to be a co-morbidity, may arise in part from atypical sensory function and can lead to confusion and uncertainty about how to respond to social and emotional situations. There is a growing consensus that emotional dysregulation has a major impact on the individual and their family in terms of quality of life and wellbeing (Maskey et al., 2013, Samson et al., 2015). Research indicates that emotional regulation is transactional with many parents of autistic children reporting that their own emotions effect their child's emotions and behaviours, referred to as 'emotional transmission' (Zhou and Yi, 2014, Ting and Weiss, 2017). Ryan and Runswick-Cole (2009) suggest that mother and child emotions are often enmeshed and as a result there is a complex and inter-related engagement in emotional experience. Whilst this concept of mother-child emotional transmission is generally accepted in typical development of children, the impact of this has increased significance when considered in relation to the specific concerns relating to anxiety across families where a young person has autism. These difficulties are coupled with the significant barriers to communicating and understanding such behaviour to enable support. There is clear evidence that emotional regulation difficulties are a serious concern for autistic young people and can impact across a family and life course (Berkovits et al., 2017, Richey et al., 2015, Maskey et al., 2013).

It is difficult to understand why many situations will cause intense anxiety, as such, it is important not to impose non-autistic perceptions of why a situation may trigger anxiety simply to fill a gap in understanding. As Biklen (Biklen and Attfield, 2005) suggests, when trying to understand his student Tito Mukhopadhyay's severe anxiety around travelling in a car "…hypothesizing on my part about what Tito experienced or felt would be just that: hypothesizing" (p. 13). In time Tito is able to explain his anxiety;

> "…when traffic flowed from the opposite direction, at a rapid rate of speed, his sense of depth perception failed him; also, he said that the rushing sound of air from outside the car bothered him" (p.13).

It is unlikely that a non-autistic communication partner would recognise the cause of anxiety in a situation such as this. It is important to consider how communication may be adversely affected by high levels of anxiety and how positive communication approaches and strategies may support reduced anxieties. Biklen and Attfield's (2005) ethnographic account of Sue Rubin describes her assessment at age 12 years and 10 months, indicating that she had a 'mental age' between 1 year 4 months and 2 years 6 months, and aggressive behaviours. Soon after this time Sue began to learn to type. Once a method of communication became accessible, she was able to engage in academic classes at high school and publish editorials in the Los Angeles Times. Anxiety continued to affect Sue however, she reports that prior to developing a means of typed communication she expressed aggressive and self-injurious behaviours. Autistic author, Jamie Burke describes; "Anxiety comes as a regular visitor, just as breathing. …One thing that sent me overboard was being asked a question when I felt stressed over the voices asking it. …Sadly, you are expected to respond, but you truly feel as a bird trapped" (Burke in Biklen and Attfield, 2005, p.252-253). Autistic research participants and their families have indicated that anxiety is an important focus for further understanding in research (Autistica, 2019), to support improved outcomes and to reduce the pervasive impact.

Research and autistic authorship continues to assert that rather than being diminished, autistic communication takes different forms; potentially engaging environment, movement, sensory experience and other behaviours (Baggs, 2007, Rubin in Biklen and Attfield, 2005). Yet, the different perceptual positioning of autistic and non-autistic communication partners frequently result in the barriers to communication being significant and pervasive. In research and social contexts, misunderstanding and narratives of deficit and incapacity driven by non-autistic perspectives dominate the communicative landscape. If we shift to a position where we assume capacity (Biklen, 2000, Biklen and Attfield, 2005), then to establish communication between autistic and non-autistic partners, we need to move to understand communicative encounters as a transactional process where we can begin to access and learn a common language built on respect and inclusion. This also has potential to increase understanding and recognition of the adverse effects of social, emotional and environmental barriers.

Autistic sensory and behavioural differences may indeed confound communication and result in barriers and misunderstanding. Such behaviours are typically assumed to sit exclusively within the individual as self-determined expressions and behavioural responses driven by deficits. However, it is essential to recognise that behaviour and communication are enmeshed responses to external and internal stimuli, stimuli that may result in intolerable and painful physical and emotional experiences. As discussed, the means and methods of communication and behaviour are unique to an individual yet their response is heavily influenced; moderated, exacerbated and intensified by interactions with environment both human and physical (Caldwell, 2014, Bogdashina, 2016, Murray, 2005). Negative medicalised and social perceptions have constructed autistic young people as chaotic and lacking capacity to comply to normative standards of social and behavioural communicative expression and interaction. Such positioning negates the disabling, dysregulating, distressing impact of social and physical environmental challenges. Critical disability and autism theorists challenge this position as ableist, (Thomas, 2007, Davidson and Orsini, 2013, Goodley, 2013, 2014, Goodley, Liddiard and Runswick-Cole, 2018) where disability is determined by the individual’s perceived deficits and assumed incapacity and incompetence. Goodley (2016) acknowledges that whilst critical disability studies might start with disability they never end with it: “remaining ever vigilant of political, ontological and theoretical complexity” (Goodley, 2016, p. 234). As with race, class and gender, disability is subject to stigma and potential violence and has resulted in constructs of cognitive disability as a position of incapacity (Taylor, 2013, Biklen and Attfield, 2005). In order to categorise, there must be an established normative standard set to be compared against. Murray (2013) describes the use of clinical, deficit driven language in the diagnostic manuals of the DSM-IV and the WHO (ICD 2000) as pointing to “the instrumental use of a deficit model that constructs the condition continually as a problem” (Murray, in Davidson and Orsini, 2013, p. 57). This problematised positioning informs perceptions and perspectives on autism and predetermines attitudes to autistic individuals and communities.

Where research seeks to increase understanding, it has primarily been applied to develop intervention and treatment to support an agenda focused on eradication and minimization of autistic presentation in young people. This drive to normalise suggests of the prevailing will to expunge human differences in human expression, “to ignore the messiness and non-uniformity of nature, and to control, shape, and regulate bodies” (Garland-Thomson, 2006, p. 262). Difference in sensory, behavioural and emotional experience and perception may indeed result in communicative and social interaction which defies normative categorisation, yet to dismiss this expression as incompetent, meaningless or chaotic disempowers and disables each autistic young person and their communities. How the non-autistic community acknowledges and responds to behaviours expressed by autistics is a matter for scrutiny and further understanding. To extend understanding, to value behaviours and expressions as meaningful, includes autistic communities, restores dignity and enables fundamental rights to self-expression. Baggs (2007) describes ‘communicating in hir (preferred non-binary pronoun) own language’ when interacting with tactile, auditory and environmental sensory stimulants such as running water, humming or the movement of leaves in the wind. Not the symbolic language of the typical volleying back and forth of words previously described by Lipari (2014) but a meaningful and intelligent interaction which Baggs describes as being “in a constant conversation with every aspect of my environment” (Baggs, 2007). To begin to understand authentic autistic communication and capacity non-autistic research and communities need to suspend prescribed and exclusive understandings of communication and acknowledge autistic communication from autistic perspectives.

Family experience

Despite long term acknowledgement that parent involvement in implementing strategies supports an autistic child’s development (Lovaas, 1987, Howlin, 1981, Goldson, 2016, Schreibman et al., 2015), there continues to be a paucity of research that explores communication and social interaction in young adolescents in their home context, in particular where a child has minimal or no verbal communication (Tager-Fusberg and Kasari, 2013, Shire et al., 2015). It is evident from the literature that young adolescents with autism experience significant challenges. Coping with the heightened complexity and differences in perceptual experience often manifests as behaviours that concern and challenge the understanding of those who live and care for them (Bessette Gorlin et al., 2016, Schiltz et al., 2018). As previously discussed, behaviours may present as distressed behavioural outbursts and screaming, aggression or violence towards others, (Hodgetts et al., 2013) self-harm, repetitive and restrictive behaviours, or perceived rudeness (Rodgers et al., 2012, Maskey et al., 2013, Samson et al., 2015, Koshy and McConachie, 2015). Families of young people with autism report markedly increased levels of stress not only in comparison to families of typically developing children, but also compared to families with children with other cognitive disabilities (Hastings, 2002, Weiss et al., 2015, Zaidman-Zait et al., 2014). Parents frequently report the negative impact of behaviours that can disrupt family routines and create tension in their family relationships and stress and stigma in social contexts (Bilgin and Kucuk, 2010, DePape and Lindsay, 2015, Dillenburger et al., 2014). Aggression in autistic children and adolescents is reported to be the greatest predictor of stress in families (Hodgetts et al., 2013). In a Canadian based study, Hodgetts et al. (2013) agree the definition of aggressive behaviour as "…perception of causing intentional distress or harm". Through interviews with parents of young people who engaged in severe aggressive behaviours, Hodgetts et al. indicated the pervasive impact this had on all family members. They spoke of family isolation, fear and extreme exhaustion, also indicating that professionals could provide very little guidance and almost no treatment to manage this behaviour. Autistic authors and advocates challenge the concept of aggressive behaviour expressed by autistic young people as intending to cause harm. Caldwell (2014) explores aggressive and concerning behaviours and asserts that rather than such behaviours being intended to harm they are driven by sensory, communicative or emotional reactions and serve a purpose for a young person. Such expressions may serve to communicate pain, fear or distress where language is not available or not accessible due to sensory overload. Internal sensation, emotional frustration or feeling overwhelmed by social or sensory challenges may trigger explosive responses yet autistic authors describe their own distress at behaviours which cause upset or harm to others (Bradley and Caldwell, 2013, Caldwell, 2014, Bogdashina, 2016, Biklen and Attfield, 2005). Furthermore, research indicates that stress in parents is likely to result in parental behaviour that can exacerbate and reinforce aggressive behaviour in a child (Hastings, 2002). O’Nions et al (2018) explore how parents manage irritability, challenging behaviour, non-compliance and anxiety in children with autism spectrum disorders, with results suggesting complex parenting demands where their children are diagnosed with autism (O’Nions et al., 2018). Walmsley et al. (2017) acknowledge the increased advocacy role of parents in more challenging times, referring to the increased action in response to current austerity measures.

Parsi and Elster (2012) provide a narrative enquiry on the challenges and opportunities of parenting young people with autism. As parent and stepparent of a child with autism they offer a perspective from a life where “simple communication is a constant challenge” (p. 207). This study provides a powerful insight into the experiences of parents struggling to make sense of their circumstance and, in parts, come to terms with their own difficulties in accepting or adjusting to their children. The succinct study identifies the themes of lost hopes, conflicting emotions and barriers which are present in many narratives from parents (DePape and Lindsay, 2015, Bilgin and Kucuk, 2010). Terms such as embarrassment, misunderstanding, self-hatred and their own ableism provide a powerful narrative insight to experience. Whilst there is a tangible sense of the challenges and struggle that these families experience there is also an indication of the potential and capacity to cope, and ultimately to develop understanding and learn from these experiences. This study captures negative narratives around mother’s experiences of advocacy as exemplifying “sacrifice, dashed hopes, and even heartbreak” (p. 207). This contrasts with the identification of parent empowerment in the thematic synthesis by DePape and Lindsay (2015) which provides subthemes of super parents and coping strategies. Similarly, Woodgate et al. (2008), through a hermeneutic phenomenological study explore “a different kind of normal” that parents establish when faced with bringing up a child with autism. This research suggests similar feelings of social isolation reported by other studies but with an increased sense of adjustment and acceptance. Similar to McConachie and Diggle (2007) the authors suggest that parents gain strength from valuing the accomplishments that their child achieves. Woodgate et al. (2008) recruited this group of parents from a support group for children with autism which provided access to support from families in similar circumstances, focussed on encouraging them to become advocates for their children. This contrasting narrative between the studies may indicate the benefits of parents working together as was the case in Woodgate et al. (2008) and previously suggested by Cutress and Muncer (2014) in relation to the group approach to implementing the EarlyBird Plus programme. Research engaging families to work together to implement a mindfulness-based programme for carers of adults with learning disabilities and behaviours that challenge also reported highly positive feedback from parents/carers (Cook et al., 2019). Despite the importance of the family environment there is a paucity of research which explores the communication and relational dynamics to support increased inclusion and connectedness. Policy, training and practice focus on challenging behaviours, behaviours of concern and stress. Whilst parents seek the knowledge and guidance to develop understanding and meet the needs of their young person, as previously identified, they frequently meet with limited support and stigmatisation from services.

Parent peer engagement

Driven by the need for knowledge and understanding of autism, parents often seek out and establish peer to peer networks to fill gaps in services and the provision of information and to offer mutual support (Boyd, 2002, Whitehead et al., 2015, Zaidman-Zait et al., 2018). This can provide an action focused approach which can respond to the challenges with a means of turning “negative emotions into positive outcomes” (Boshoff et al., 2018). Contemporary research recognises the potential for empowerment that an action orientated approach brings (Boshoff et al., 2016, 2018). Where access to knowledge and training is scarce parents often take up the challenge of understanding their children and family situation through independent research, often accessing social and community groups to share knowledge and strategies; aiming to meet the altered and situated response needed by them and their families to understand and support improved outcomes (Henderson, 2009, Ryan and Runswick-Cole, 2009, Rhodes, 2011, Banach et al., 2010).

Whilst parents may assume the role of advocate in day to day life, the narrative from Parsi and Elster (2012) raises a cautionary note; whilst there is acknowledgement of “steely determination” within some of the parent’s narratives, there is also self-doubt, anxiety and guilt. Parents refer to “the burden” of having a child with autism and their need to shield them from exposure to bullying, stigma and ridicule through home-schooling. Within a prevailing narrative of burden and stigma the capacity to advocate and sustain becomes challenging, with parents indicating that much of the stress they encounter is from the challenges they meet in dealing with services and stigma (Crane et al., 2016, Crane et al., 2018, Ryan, 2010). A report from the All Party Parliamentary Group on Autism reveals an autism diagnosis crisis with stark regional variation and long waits for autism diagnosis (APPGA ,2017). The Autism and Education in England 2017 report (APPGA, 2017) reflects the challenges and stigma that young people and families face when trying to access appropriate education and support. Families experiencing such challenges are unsurprisingly engaged in continuing battles and exchanges to ensure access to support and education. Stigmatising attitudes from schools and services can construct families and their young people as challenging and burdensome to services reflecting ableist attitudes to autistic young people (Davidson and Orsini, 2013). These experiences often position parents as needing to actively problematise their children to be able to access services in education and health. Indeed, Douglas (2013) raises a cautionary note, suggesting that the identity as ‘autism mother’ has the potential to enact an advocacy that seeks to fight for a cure and normative outcome for their child, reinforcing values that ultimately serve to create disabling barriers. Whilst mothers are increasingly acknowledged for their role as advocate seeking to challenge the disablement of their child and responding through activism and affirmation, there is a continued need for reflexivity and caution in how they approach these roles to prevent the reinforcement of disabling narratives (Seligman, 2007, Ryan and Runswick-Cole, 2008, Ryan and Runswick-Cole, 2009, Douglas, 2013, Runswick-Cole and Ryan, 2019).

Sibling experience

Sibling relationships play a central role in family life and are the first most intense and influential peer relationship that the child experiences (Powell, 1993). Indeed, Ben-Itzchak et al. (2016) reported better social communication skills in children with autism who had older siblings. Unsurprisingly, the social communication, behavioural and perceptual differences inherent in living with a brother or sister with autism, will influence the sibling dynamic (Ward, 2016). Research indicates the unique stresses and challenges that can result (Petalas et al., 2015), including greater emotional problems and symptoms relating to depression in siblings (Lovell and Wetherell, 2016). There is also strong reference to the positive aspects of the sibling relationships, speaking of increased resilience and sensitivity to others (Kaminsky and Dewey, 2001). Laghi et al. (2018) report increased disruption in sibling dynamics in early adolescence, suggesting that the level of satisfaction and fulfilment family members feel with each other (a measure whose definition includes cohesion, flexibility and communication) can positively or negatively impact the way siblings engage with one another. Petalas et al (2015) acknowledges "…admiration, support and warmth coexist with conflict and hostility" experienced by adolescents in families where a young person has autism (Petalas et al. 2015). Kaminsky and Dewey (2001) explore the difference in sibling relationships between typical siblings, compared to groups who have siblings with Down syndrome and with autism. The findings indicated that prosocial and intimate behaviours may be restricted by the social and communication differences in siblings with autism, such communication differences inhibiting shared thoughts and feelings. Furthermore, siblings with autism also were less likely to seek out a sibling to initiate play or to seek comfort or affection (Kaminsky and Dewey 2001). Kaminsky and Dewey concur with Knott et al. (1995), who suggests that autistic siblings are less likely to initiate interaction and both autistic and non-autistic siblings are less likely to respond to initiation between one another (Knott et al., 1995). Whilst research considers the impact of difference there is little research exploring communication between young people and their autistic siblings within the family context and how this can be understood and supported in the familial communication context. Sibling relationships provide a sustained and significant social interaction, as such the implications of the differing dynamics in social communication and interaction and their impact on the sibling relationships where a young person has autism warrant further understanding to support families to promote inclusion.

The home environment

Despite the sensory and behavioural differences, little research considers the influence of the physical environment of the home on the communication and interactions of autistic adolescents and their families. Whilst attention is given to the home environment in facilitating participation in communication in younger children there is little research that considers the impact of home environment on participation in early adolescence. Research by Pengelly et al. (2009) provides a small-scale collaborative project which explores the importance of a space at home for 3 families with a child with autism (Pengelly et al., 2009). The study reflects the importance of the environment and the potential impact of the physical environment on a young person with autism and their interaction with their family. The study found that a busy home with people, noise, smells, pictures, screens and potentially negative or misunderstood responses from others may cause sensory or emotional overload and raise anxiety levels. As previously exemplified this complexity can confound communication. Having a dedicated space to have timeout for young people to use for quiet time or homework and for parents to use to pursue their own interests or deal with aggressive or behaviours of concern, was seen as critical in contributing to their own and their families' wellbeing. Whilst creating space that supported families to include each person's needs suggested benefits for the families, there are also subtle references that suggest a space is used to remove a child from family engagement. The child is encouraged to 'use their room' because the rest of the family feel they are on guard or a child is involved in repetitive behaviours or obsessive interests, they suggest of the families' need to control or cope with behaviours. The suggestion held in this study is that this room becomes an escape from one another and has potential to isolate, yet the authors of the study do not note caution in response to these narratives. The potentially positive space could also serve to isolate a child from family engagement. This is a limited study as only the mother's narrative is included, further studies should, through appropriate methods, explore meaning from the perspective of the individual with autism. Whilst this study draws attention to the consideration of the physical environment it offers little insight into the apparent experience of the home environment that causes the need to offer this space. Nagib and Williams (2018) consider the impact of adjusting the environment of the home at many levels where children aged 3-16 were autistic. Primarily focussing on safety, control and containment they discussed how physical adjustments to create a safer environment could reduce family stress. The study suggested opportunity for family engagement and inclusion increased when they did not feel constantly on guard. Adjustments made to the environment which allowed space for their autistic young person to display their painting, engage in activity or isolate themselves if visitors came, also was suggested to offer increased inclusion.

Positive Behavioural Support (Centre for the Advancement of Positive Behaviour Support, 2016) is becoming recognised as an intervention that has potential to support families and carers (Lee et al., 2019, Saville et al., 2016, Denne et al., 2013). This approach to managing behaviour recognises that the physical and social environment will impact on the behaviour of a young person and impact communication. Mindfulness is also gaining interest with literature exploring both the effectiveness of children engaging in mindfulness strategies to manage their own behaviours (Singh et al., 2018, Singh et al., 2011, Hwang et al., 2015), and for parents to use as a tool for managing their response to their child’s behavioural expressions, which is known to then have a positive effect on child behaviours (Cachia et al., 2016, Bazzano et al., 2015). Despite the intense focus on the demands and challenges associated with parenting a young person with autism, research also illuminates some of the positive aspects to this experience. Research indicates ‘silver linings’ (Bultas and Pohlman, 2014), such as increased resilience (Bayat, 2007, Kapp and Brown, 2011), positive growth (Waizbard-Bartov et al., 2019) increased awareness and understanding of the needs of others (Bultas and Pohlman, 2014, Phelps et al., 2009) and acceptance, respect and appreciation of their child's unique abilities (Bessette Gorlin et al., 2016).

Whilst such interventions may offer holistic and inclusive approaches to improve positive behaviour management, for families there continues to be lack of coherence and agreement as to the most appropriate interventions and strategies for support. There is also a lack of coherence and agreement across services, training and information to support parents to understand how to establish and support positive communication and social interaction where autistic young people reach early adolescence (Crane et al., 2016, Siklos and Kerns, 2006). Whilst there is significant research which explores the challenges, stresses and anxieties that such family's experience, communication and social interaction in early adolescence is under-represented in literature, despite this being a core diagnostic feature of autism. This gap in literature demands the need to further explore social communication and interaction in a home and family context. Cridland (2014, 2016) takes a family systems approach to research in families of young people with autism and asserts the need for research into autism which embraces flexible and inclusive approaches to researching families. Furthermore, Cridland (2014) indicates the need to further explore periods of transition in families of autistic young people to begin to understand the impact of adolescence or school transitions on the wider family. Reflecting the more general move in NHS policy (INVOLVE, 2017), families and autistic individuals are increasingly engaged to actively shape research (Autistica, 2019, NAS, 2019, Wallace et al., 2013). Parents are in a position of tension, needing diagnosis and treatment whilst often trying to resist medical model limitations by seeking and embracing positive futures and respect for the unique identity of their child. Waizbard-Bartov et al. (2019) indicate that for some parents, the focus regarding the parenting of their child with autism should be shifted from adjustment to growth, the authors also describes a 'profound intimacy' which results from the 'special and powerful bond' that can develop between parents and their autistic children. Autistic authors discuss the need to understand the innate communication of autistic young people, Higashida (2017) for example provides an insider account of his communication within home and family which gives unique insight into the familial dialogue from an autistic perspective.

Towards inclusion

Reviewing literature which informs contemporary understandings of autism evidences a narrative rooted in constructs of deviant development and deficits in normative communication and behaviour. Kanner's early observations established autism as a condition of autistic aloneness and positioned a medicalised and deficit driven conceptualisation (Kanner, 1943, 1949) which has held influence across subsequent decades, despite advancing knowledge of causation and autistic advocacy (Davidson and Orsini, 2013, Silberman, 2015, Waltz, 2013). Such positioning has broadly and systematically neglected the need to recognise capacity in autistics and to respond by investing in loving and warm human relationships as identified and advocated by Asperger (1944) and Ward (1970). Evolving narratives have continued to expose perceptions of ineffective or damaging parenting and incapacity and deviance in autistic young people (APPGA, 2017, Lenehan, 2017, KidsRights, 2020). Despite literature and policy which unequivocally advocates for support for parents and families to better understand and engage their young people, services and educational provision continues to fail families and provides inadequate knowledge and training for professionals (APPGA, 2017) and underfunded and patchy support for families (APPGA, 2017, Lenehan, 2017). Whilst the importance of positive parent and family relationships is identified as supporting communication, interaction and wellbeing, parents and parent-child relationships have for the most part been explored in relation to the capacity to provide intervention and treatment. These interventions typically serve to underpin agendas of conformity and normativity in communication and behaviour rather than focus on the situated family communication and interaction and the needs therein (Barron et al., 2017).

As discussed, health, social and educational practices evidence a continued marginalization and neoliberal perception of burden, blame, intolerance and abuse of many in the autistic community (NAS, 2018, BBC, 2019, Buescher, 2014, Timpson, 2019, APPGA, 2017). Oliver and Zard (1989), write that dependency is;

> “created amongst disabled people, not because of the effects of the functional limitations on their capacities for self-care, but because their lives are shaped by a variety of economic, political, and social forces which produces this dependency” (p. 17).

This social, biological and political discourse produces and reproduces perceptions and constructs of the lives and capacities of young people with autism (Goodley and Runswick-Cole, 2016, Goodley et al., 2018, Goodley, 2001, Milton, 2016, Runswick-Cole et al., 2018). Autistic young adolescents are open to stigma and blame for behavioural expressions (NAS, 2018, Penketh, 2014, Mogensen and Mason, 2015), and subject to increased monitoring, scrutiny and governance in behaviour and development (Foucault, 1989, 1995, Milton, 2017, Coleman-Fountain and McLaughlin, 2013).

Traditionally, research in autism has been driven from a positivist paradigm which predefines children by their deficits, without giving due concern to individuality, relatedness, identity and diversity (Glynne-Owen, 2010). Such medicalization and fragmentation has potential to reinforce the othering of young people through positioning them as deviant or deficit; too often focussing on normalization and conformity of isolated aspects of communication or interactional behaviour (Lovaas et al., 1973, Pane et al., 2015, Pluquailec, 2018). This concept of othering leaves space to position autistic young people beyond that which is determined entirely human (Taylor, 2013) as exemplified by the concept of lacking Theory of Mind; mindblindness (Baron-Cohen, 1997, Colle et al., 2007 and Lombardo and Baron-Cohen, 2011, See also Yergeau, 2013**).**

Privileged normative conceptualisation serves to diminish our young people, constructing them as lacking communicative and behavioural abilities which are construed to define aspects of humanity (Baggs, 2007, Yergeau, 2017, Milton, 2012, 2013, 2014). These deficit laden narratives have the potential to infiltrate family dynamics and communications, challenging parents' innate responses and appropriating communicative interactions where parents feel pressured to address normative agendas (O'Dell et al., 2016).

Little research considers the experiences of families and surfaces the communicative interactions that *do* exist, those which may fall beyond the communicative norms that traditional research approaches seek to define and explore. It is important to consider what methods of communication autistic young people are engaged in within a home context. Such an approach to research holds potential to explore how communication and interaction *are* enacted in families of autistic young people and how the inherent characteristics of autism can confound and challenge communication and interactions and impact family dynamics. Such a shift in focus could hold the potential to offer a counter narrative and allow better understanding and support of communication as it is expressed. To recognise and acknowledge the methods of communication that autistic young people engage in within families provides a means of equalizing experience and mitigating for the vulnerabilities that they and their families (Taylor, 2013).

Forming identity in adolescence

Early adolescence is a notorious period of social, emotional and attitudinal development and change (Garrod, 2012). Summarising early adolescent psychological and emotional development in relation to health and wellbeing, The Lancet report by Patton et al. (2016) highlights the importance of adolescence in development. The report suggests that;

> "…parents and peers are both important reference points for the adolescent in learning how to respond to more intense experiences of sadness, anxiety, and anger. The extent to which parents are able to express and respond to emotions is likely to have a major effect on this capacity in their adolescent children" (Patton et al., 2016 p. 2432).

Where young people are diagnosed as autistic, this brings increased challenges which are exacerbated by the marginalised positioning that autistic young people may inhabit. Where narrative is a function of the forming self and identity (Bamberg, 2011) the need to engage in dialogue as a developing young person is fundamental in the complex process of becoming adult. Literature acknowledges autobiographical memories and self-narrative as processes by which we construct our identity and sense of self (Singer et al., 2013, Miller and Sperry, 1988, Nelson, 2004, Zaman and Fivush, 2013, Vieira and Henriques, 2014). As such, our method of understanding self is situated in narrative and life stories (McAdams and McLean, 2013). Habermas and Bluck (2000) suggest that the life story develops in adolescence. The situated self, telling stories to others and hearing stories about ourselves supports the developing of self (Singer, 1995, Pasupathi and Hoyt, 2009). Pasupathi and Hoyt (2009) confirm the continuing need to be listened to, to support the forming identity (Pasupathi and Hoyt, 2009, see also Bavelas et al., 2000). Where communication is altered and language may be absent, the ability to express one's life story and be listened to is challenged. Mitigation for this difference demands a move away from perceptions of communication deficit to understand that autistics *speak* but are often not heard (Milton, 2013).

Goldman and DeNigris (2015) examine the conversation styles used in parent-child recollection of shared past events, aiming to address a gap in the literature where little is known about such verbal exchanges between parents and autistic children. Whilst this is a small study, it draws attention to an important concept. With research typically emphasising functional communication and reducing problematic or inappropriate behaviours, little attention is given to how we support children with autism to engage in relational dialogue specific to the familial context, acknowledging memories, shared experiences and what supports belongingness and connectivity in families. Goldman and DeNigris (2015) advocate that it is through language and communication that children's experiences are transformed into meaningful personal memories.

Nelson (2002) questions how we conceive of and conceptualise selfhood and how we can acknowledge the selfhood without active narrative and engagement within and beyond the self. Speaking of a nonverbal sibling with limited engagement Nelson questions;

> "If personhood involves the construction of a narrative identity…how can her life have any narrative when she is unable to write one?" (Nelson, 2002, p. 29).

Such research indicates that communication is a foundational process in the development of selfhood and identity, with particular emphasis on adolescence. Yet, we have little understanding of how the difference in communication and interaction difficulties, inherent in autism, may impact the inclusion of the developing adolescent in familial dialogue fundamental to the developing self (Brown et al., 2012).

James and Prout (2015) argued for a re-appraisal of childhood, challenging images of children as ‘passive’ and re-conceptualising children as agents who are active in constructing their own narrative and identity, within their social worlds. This is particularly pertinent to young people on the autism spectrum and who are growing and developing and seeking a sense of self and identity against an imposed social construct of deficit and lack. The KidsRights index (2020) report confirms that the UK was judged harshly in its ranking of respecting the rights of children and young people because of the;

> “discrimination and stigmatization of certain groups of children (such as Roma, gypsy and traveller children, children of other ethnic minorities, children with disabilities, children in care, migrant and asylum-seeking children and LGBTI children). Also, the fiscal policies disproportionately affected children and the enjoyment of their rights” (p. 15).

This positioning, discrimination and political violence (Taylor, 2013) towards our children and young people denies voice and contribution from the cognitively (dis)abled young people that are at the centre of this PhD study. Research suggests that social stigma has the potential to effect the sense of identity and self (Goffman, 1986). Pluquailac (2018) calls for a new ethics in research with disabled children where both theory and practice affirm the humanity of a claim to childhood whilst also challenging the ableist, exclusive boundaries, advocating the shift from conceptualising children labelled autistic as disorganised and disembodied.

Towards inclusive approaches to research

Our young people are diagnosed as autistic through their categorisation as differing from normative standards of communication and behaviour (APA, 2013). The theoretical basis of these arguments is especially apparent in the wealth of literature that analyses disability from a Foucauldian perspective, showing that the social and political forces that individualise and categorise people according to particular social norms effectively produce individuals as particular kinds of people (Foucault, 1989, Foucault et al. 2001). This results in grouping according to these conceptualised standards measured against ideals of cognitive ability and compulsory able-bodiedness (Taylor, 2013, Siebers, 2009). Goodley and Lawthom, (2019) assert that there is, without doubt, a preferred citizen lying at the heart of policymaking and political discourse. Such disempowering and dehumanising medicalised models of disability have served to separate disability and impairment, thus situating disablement in an individual and denying the societal role of barriers and stigmatisation in creating disabling cultures and environments (Barnes et al., 1999, Oliver, 1990). The emerging disability movement has increasingly challenged this positioning, advancing a social model of disability (Barnes et al., 1999) which determines that disability results from exclusionary social and political practices and environments and advocates the “realignment between body, self and society” (Bendalow and Williams, 1995 in Becket p. 94). By advancing the concept of societal barriers and exclusionary practices, disability movements have challenged prevailing notions of disabled persons as disadvantaged victims, lacking capacity and dependant on family, friends and a welfare state (Barnes at al., 1999). Progress made by the disability movement has challenged traditional approaches to research where research is done to rather than with disabled individuals and communities and has pressed the need to engage the experiences of disabled individuals and communities in understanding experiences and developing inclusive approaches to inform research and policy. The social disability movement has made significant progress in challenging exclusion in communities and has laid the groundwork for further theoretical expansion and challenge to ableism; not least supporting the emergence of the neurodiversity movement.

Building on the social model of disability, critical disability scholars (Goodley, 2013, Davidson and Orsini, 2013, Goodley et al., 2018, Goodley and Lawthom, 2019) challenge the judging of autistics against narrow, normative standards of communicative and behavioural presentation. Such exclusive standards may not be wholly meaningful for this community of individuals, who experience different perceptual positioning and diversity in their expressive and receptive communication (Milton, 2013, 2016, Yergeau, 2018). Such narrow standards and practices serve to actively disable autistic young people who experience a persistent measurement against normative standards of communication and behaviour; an omnipresent judgement and governance (Foucault, 1989, 1995, Foucault et al. 2001). In these formative years this stigma has potential to influence the emerging self-narrative and potentially diminish the forming selfhood (Goffman, 1986).

The well-documented objectification and exclusion of people and groups judged to be inferior in certain domains establishes an *ableism*; reinforcing the persistent assumption that disability precludes human well-being and capacity and exposes a vulnerability in the human condition (Garland-Thomson, 2006, Taylor, 2013, Davidson and Orsini, 2013). Despite some progress, this ableist perspective still informs all of the major institutions of society (Kliewer et al. 2015, Siebers, 2009, Taylor, 2013). Taylor (2013) suggests this judgment tends toward violence; the violent erasure of that which is not normatively intelligible, not known within the cultural frames of personhood or "the human." Article 12 of the Convention on the Rights of the Child (1992) articulates the right of children to form and express their own views and that these views should be given due weight. Nonetheless, in most countries respect for the views of the child is still not self-evident (KidsRights, 2020), and where young adolescents experience restricted language and pervasive barriers to communication they experience increased challenges in expressing their views and having their views acknowledged. Popular rhetoric and political discourse continues to call into question the worth of a life lived with intellectual disability (Taylor, 2013). This discourse and positioning plays out in the lives of autistic young people. Far beyond the typical adolescent, their capacity to engage in dialogue and discourse relating to their lived experience is questioned. Taylor (2013) and Carlson and Kittay (2010) make clear, the view of intellectual disability as "other" denies any recognition that cognitive disability is a feature of the human (Carlson and Kittay, 2010) and often depends on assumptions about individuals with intellectual disabilities that are wrongful and uninformed (Carlson and Kittay, 2010; Stubblefield, 2011). Investing in research that explores the experience and discomfort that people with disabilities, parents of children with disabilities, as well as advocates and theorists of disability have about normative theories of moral status, we should reframe the question of moral personhood to address the social conditions under which the qualifying conditions for moral status and human belonging arise, in addition to asking what the qualifying conditions for moral status or human belonging are. Where we reinvest in value based judgements that espouse justice and inclusion we open to the possibility of alternative lives and alternative modes of being human. Thus, Butler calls for an "ethical posture" towards the other, a posture that "suspends judgment in order to apprehend the other" (Butler, 2005 p.44).

Goodley and Runswick-Cole (2016) ask us to consider when we think of the goals of capitalism, science, medicine and citizenship, what assumptions are these huge societal practices based upon, and in what ways does disability disrupt these assumptions (dis/capitalism, dis/science, dis/medicine and dis/citizenship)? Here, autistic children challenge and trouble and disrupt normative and narrow constructs of what defines human, offering a point for thinking again about humanness (Goodley and Lawthom, 2019). Acknowledging a critical disability positioning (Runswick-Cole et al., 2018, Goodley et al., 2018), Pluquailac (2018) advocates for an ethics which understands and values the lived experience of children and families. Literature that questions the exclusion of disabled children, challenges researchers to recognise that enacting different forms of expression and communication does not mean that disabled children have nothing to say (Beresford, 2012, Stalker et al., 2012, Milton, 2013, Higashida, 2017, 2013). In turning to a more critical conceptualisation of participation, traditional ableist, normative markers of autonomy, agency and voice can be disrupted. Kittay (2011) describes the ways in which those with 'severe cognitive impairments' have often been consigned to the category of 'human nonpersons' excluded from discussions about social justice because they are deemed to lack 'capacity' and 'autonomy' and are denied full personhood (Kittay 2011). Investing in an ethics of care (Kittay, 2011) within and beyond families to establish a value based system which acknowledges capacity and human dignity of all citizens is the only way forward to understand and support autistics and families. To fully engage with such ethical positioning this requires the engagement and collaborations of autistics in research and knowledge production (Freire, 1982, Charlton, 1998).

Without normative communication ability participation in research is denied or restricted (Kittay, 1999, 2011). Whilst young adolescents with language restrictions may not access an independent language in normative terms, they nonetheless must be accepted as having full personhood and the right to contribution in their own way and with support or collaboration to do so (Kittay, 2011). Kittay (2011) suggests there is much that is problematic in an approach that extols independence as the route to a dignified life and advocates for the need to offer support to the extent that enables participation. Many autistics require support or intervention to communicate and research approaches need to move beyond the traditional and normative linguistic approaches to enable participation, collaboration and to seek social justice. To enact an inclusive approach to research and knowledge generation we need to suspend perceptions of how and what can be contributed (Kittay 2011, O'Dell et al., 2016) and move to accept autistic participation in whatever form of communication is authentic to an individual. In many cases autistic participation may require novel methods or support from enabling others. O'Dell et al. (2016) asserts the need to engage autistics in the process of research and to acknowledge the power differences and ableism that challenge the coproduction of knowledge. Kittay (2011) asserts that we see ourselves as always selves-in-relation, we understand that our own sense of well-being is tied to the adequate care and well-being of another, suggesting the reciprocal nature of communication and care which enable access.

Critical autism studies resist the concept and construct of a non-autistic normative positioning of autism and the associated disempowering and vulnerability that this construct espouses (O'Dell et al., 2016). Critical autism scholars and authors demand the need to engage autistic people in this narrative and produce knowledge through autistic or collaborative epistemologies (Davidson and Orsini, 2013, Yergeau, 2018). Contemporary critical perspectives advocate research practices that enlist creative and novel ways of engaging those whose views have typically been excluded from research, and to recognise the young autistic person as competent and capable of contribution (Goodley and Runswick-Cole, 2011, Frigerio et al., 2018b, Douglas et al., 2019, Curran and Runswick-Cole, 2013, Coleman-Fountain and McLaughlin, 2013, Davis et al., 2017). Autistic authors and co-researchers who engage augmented and facilitated methods of communication are increasingly demonstrating the importance of working collaboratively to enable expression (Rubin, 2018, Biklen and Attfield, 2005, Kliewer et al., 2015) and where verbal communication continues to be inaccessible, to recognise and explore the communication methods that *are* engaged (Baggs 2007).

O’Dell et al. (2016) advocate a shift in epistemic dialogues to counter the hegemonic perspective. In so doing we move to a position of affirmation and empowerment (Braidotti, 2010). Critical theory calls for a recognition of the everyday humanity and potentialities of bodies and minds beyond ableist or limiting descriptions of disorder or impairment (Milton, 2017, Mallett, 2015, Frigerio et al., 2018a, Douglas et al., 2019) Critical autism studies (Davidson & Orsini, 2010, 2013) challenges the dominant understanding of autism as neurological deficit, instead calling for a recognition of autism as an identity that is “materially and discursively produced” (O’Dell et al., 2016, p. 167). Through a shift to a critical perspective we have the opportunity to acknowledge and invest in the lived experience of the communication landscape of autistic young people in and with their families (O’Dell et al., 2016). Autistic young people, their parents and siblings are the experts in their own communication skills and capacities; and collectively, in their own family communications. As such, this PhD study seeks to explore communication in autism not from the pathologised perspective of the outside view, but by injecting the situated ‘voices’ in their own language to reconsider communication and autism from within the family (Hoogsteen and Woodgate, 2013).

Chapter 3 – Methodology: theory as practice

Methodology

Contemporary autistic and critical disability perspectives bring a new positioning to the narrative of autism and demand a turn to research approaches which are inclusive of young people diagnosed with autism and their families (Goodley, 2001, Silberman, 2015, Milton, 2014, O'Dell et al., 2016). Critical autism studies (Milton, 2014, Goodley et al., 2018, Goodley, 2013, Davidson and Orsini, 2010, 2013), as well as global (United nations convention on the rights of people with disabilities, from 2006), and national (INVOLVE, 2017, Autisica, 2019) research directives, advocate the need to engage those within the autism community in the research process. This shift is beginning to allow the dominant positivist and medicalised narratives to be countered and balanced. Research methodology comprises the process, principles and positioning that drive a research study. As such, in the context of this study, the methodological approach must carry this inclusive positioning into the practical methods of participation and data generation. This chapter outlines the development of the methodological approach which structures this PhD research, enabling an inclusive approach to both process and practice of the research to allow data generation within and between participating families.

Current literature identifies a gap in understanding of communication in the autistic early adolescent and the complex communication interaction within and across their family. This thesis engages an Autoethnographic Participatory Action Research (APAR) approach to understanding communication in the group of five families participating in this PhD research. This meshing of *autoethnography* and *participatory action research* (PAR) provides a methodology specific for researching with parents to include the participation of family members on their own terms, in particular their child diagnosed with autism. To understand the development and relevance of this methodological approach, I will explore participatory action research and autoethnography, describing the principles of each and how they fuse to allow a collaborative approach to research from inside our family experiences. I will describe how this approach enabled us, as parents, to take a lead on research and explore family communication experience. This engaged parent stories and reflections, artefacts which our young people contributed to the data and, not least, the situated communicative interactions we engaged in with our family members as co-researchers. This approach allowed parents to learn from their autistic young person, through direct communicative interaction, and from each other between the participating families.

Participatory Action Research – an emancipatory approach to knowledge production.

Participatory Action Research (PAR) approaches place knowledge production in the hands of those who are affected by the issues relevant to research. It engages individuals through their communities and lived experience to contribute to the production of knowledge through collaborative learning and co-production (Kemmis, 2006, 2009, Banks et al., 2019). The current scarcity of research into communication in families of autistic early adolescents and the lack of services and support available to families, drove an activist approach to learning and doing as a research process which underpins this thesis. Similarly, as a group of parents, our need to act to support positive outcomes for our children moved us to explore the communication and interaction in our families; to understand how to include our children with autism within family interactions.

The origins of PAR are located in the work of South American activists, (Freire, 1982 , Fals-Borda, 1987), and UK-American proponents (McTaggart, 1994, Lewin, 1946, Hall, 1981). Through their work PAR has become established as a means of engaging marginalised and excluded communities in research, knowledge production and action. These early pioneers of participatory approaches responded to the needs of oppressed communities and established PAR as a global movement driven by the need to act in the face of oppression. PAR grew as an approach to knowledge generation which challenged the position of power that had long dominated traditional positivist research approaches (Reason and Bradbury, 2013). A position which had denied or marginalised the voice of ordinary citizens, deeming their perspective to be ignorant and the opinions of those who struggle to articulate their views, invalid. The collaborative approach of PAR does not privilege the researcher perspective, as in more traditional approaches to research design; instead demanding the involvement, participation and research membership of those affected by research. As such, PAR not only serves the agenda of academic research but also invests heavily in the innate knowledge of those with lived experience; to both contribute to knowledge about them, and also, to invest in their own growth in knowledge (Kindon et al., 2007). Freire (1998) describes PAR as an emancipatory approach to knowledge production that allows us to not only study the world, but also to transform the world, driven by a collaborative, reflection and action approach to learning. Freire observes; “In doing research …I am educating and being educated with the people” (Freire, 1982 p. 30). The participatory action research movement recognises the powerful alternative offered by a paradigm shift which challenges the oppression and marginalisation of communities, instead drawing in their situated experience and knowledge as co-researchers with capacity to educate and be educated through the iterative process of situated research (Kindon et al., 2007, Kemmis, 2006, Banks et al., 2019, Cargo and Mercer, 2008, Cook et al., 2018).

The principles of PAR also informed the work of early disability activists (Oliver and Barnes, 2010, Oliver, 1992). The well-referenced “Nothing about us without us” (Charlton, 1998) advocated by disability activists and the drive by critical autism theorists have challenged dominant and exclusive traditional approaches to research (O’Dell et al., 2016). The increasing narratives from autistic authors have provided an insight to the altered perception and perspective of their lived experience. This rhetoric highlights the need to include autistic perspectives in research to enable an authentic understanding of what it is to be autistic (Yergeau, 2018, Yergeau and Huebner, 2017, Milton, 2014). A shift towards participatory action research can not only engage the autistic community of individuals and their families in research but offers opportunity to co-construct and engage in the full research process. The radical epistemology of PAR, offers an orientation to the world built on a commitment to principles of equality, participation and social engagement and brings to bear the concept of inclusion (Adelman, 1993, Snyder, 2009, Brydon-Miller, 1997, Banks et al., 2019, Banks and Brydon-Miller, 2019), principles which also define this PhD study. The position of parents as advocates is not without tension and holds potential for parents to assume a dominant position and voice (Bertilsdotter Rosqvist et al., 2015). For our families the participatory action research approach allowed us to learn together and from one another, a process which is intrinsic to our study.

Mothers of five families, including my own, came together to explore communication in their family through their communicative interactions within the family and through reflections and shared dialogue. The process of knowledge generation therefore facilitates engagement, reflection, learning and evolving praxis within and between our families, and driven by their situated experience. As Freire (1982) suggests, we are educating one another through communicative action which is authentic and situated. Valuing this active, lived experience offers a unique insight into the communication context of home life.

Participatory action research as process and practice

PAR provides a qualitative research approach which differs from other qualitative methodological approaches in that it positions participants not as the subject of research, but rather, as active contributors to research, encouraged to participate in all phases of the research process (Chandler and Torbert, 2003, Kelly, 2005). It is the active involvement of participants as co-researchers throughout the PAR process that defines this approach within the qualitative research paradigm (Reason and Bradbury, 2013, Silverman, 2018, Ollerton and Horstall, 2013). Participatory action research recognises and values that people are social beings, within political, economic, and social contexts (McTaggart, 1994; Bergold & Thomas, 2012). It is built upon a strong value orientation which seeks to address significant issues identified by people, their communities, and their wider social and physical geographies (Reason & Bradbury, 2013). As such participants are encouraged to engage in the full research process from identifying the research area and question through to analysis and dissemination.

The methods used to generate data in a PAR study are driven by the context, community and participants; a situated approach to defining appropriate methods and therefore forms of data (Banks et al., 2019). The PAR process invests in collaboration throughout, engaging participants in determining and shaping a study to identify methods and engage in the data generation process. Cook (2012) highlights this collaborative approach when describing "The methods *chosen* by the group for *their* research” (p. 9, emphasis added).

Whilst PAR draws upon traditional methods of qualitative enquiry such as focus groups and interviews, it can also engage photography, walking methods, diaries or artefacts as ways of generating data (Chevalier, 2013), but all driven by a situated means of facilitating and engaging in dialogue. PAR invests in the capacity of individuals “to be creative actors on the world” through active participation as co-researchers (Maguire, 1987). Fundamental to PAR is mutual learning; together and from one another through the process of communicative action. PAR authors emphasise how important it is that the research process opens up spaces that facilitate this communication (Cook, 2012, Dentith et al., 2012).

Fundamental to this learning process and communicative action is a “non-linear process of joint learning” (Abma et al., 2017) or an action-reflection cycle (see figure 1). Lewin (1946) described the process of action reflection as a ‘spiral of steps’, each of which is composed of planning, action, observation and the evaluation of the result of the action. This description of ‘the spiral’ provides an accessible understanding of the process yet should not oversimplify and allow the under-representation of the potential impact of the participatory action research process.

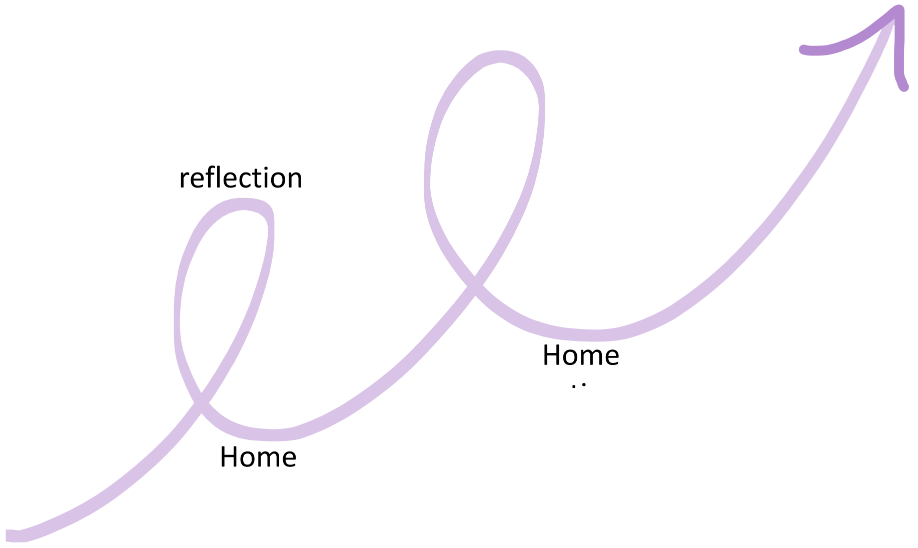


Figure 1: The action-reflection cycle within this research study

The action-reflection cycle allows individuals to both learn from the research process and to action their forming understanding. Whilst this cyclical approach allows theory to inform practice, PAR goes beyond this to a recognition that theory can indeed be generated through practice. By developing new knowledge through the reflective process, individuals are positioned to challenge their existing assumptions and to develop an increased reflexivity, this leads to a critical understanding of practice and an evolving praxis (Brydon-Miller et al., 2003). PAR is an iterative, indeed re-iterative process of action research, within an action-reflection cycle which actively accepts and accommodates flexibility, responding to the emergent understanding and meaning making by participants within a specific located community. It is this investment in communicative action through a cyclical process of action-reflection (Habermas, 1984, Erikson, 2003, Freire, 1982) which facilitates the collaborative learning inherent in PAR and enables an emergent reflexivity and praxis. Brydon-Miller (1997) draws attention to the relevance of the PAR communication-action-reflection process in evolving a praxis orientated approach;

> “Critically informed inquiry generates a form of knowledge that results in and grows out of the liberation of those generating the knowledge; it is simultaneously knowledge based in action and action based in knowledge. It is only through this dialectical process of action and reflection that the praxis of critical theory …can be achieved” (Brydon-Miller, 1997, p. 660).

Research with individuals who have significant communication and perceptual differences can present a challenge to communicative engagement in the PAR process. Ollerton (2012) suggests that inclusive research approaches and accessible research tools can enable individuals with learning difficulties, to engage as co-researchers. To facilitate engagement, it is necessary to accept and include authentic communication on the terms of participants engaged within a study process. Ollerton (2012) explores the potential of

Inclusive Participatory Action Research (IPAR) (Walmsley, 2003) to offer a practical alternative process which can inform disability research design. Rather than relying on potentially exclusive text and seemingly abstract concepts which can restrict access to engagement in the research process, Ollerton (2012) describes the methods employed to facilitate inclusive research practice;

> “The creative methods used included: role-play to teach research ethics; photography to develop pictorial texts for institutional ethnographic examination; metaphor to assist people in articulating meaning within their photographs; poetry to analyse and make meaning from data; photovoice as a data collection, analysis and dissemination tool; and colour-coding using patchwork as a means of evaluating the inclusivity of the IPAR process” (p. 7).

In the context of Ollerton’s study the IPAR approach acknowledged the authentic communication methods and perceptual positioning of the individual labelled as having learning difficulties and accepts their authentic form of contribution as co-researchers. This approach allows and recognises a valid contribution “through whatever capacity they have” (Ollerton, 2012 p. 4), and further, to acknowledge these co-researchers as experts on the experience of living with their (dis)ability (Walmsley, 2001; Walmsley and Johnson, 2003). Ollerton’s research concludes that inclusive research methodologies disrupt notions of who can or cannot conduct disability research, challenging stereotypes and allowing us to access new forms of knowledge. Ollerton speaks of her recognition that people labelled with learning difficulties had the right to “name the world as they saw it” and should be provided with the support to do this, citing Freire and Macedo (1987). Researchers committed to PAR and working with individuals with learning difficulties and/or language and communication differences often employ visual methodologies to document and reflect the reality of situated experiences.

Similarly, accessing the authentic views of children is an area of continued exploration. Hart (1992 In Shamrova and Cummings, 2017) suggests that engaging children's views in research can be tokenistic, engaged simply to give an impression of the involvement of the child's view. Yet, where PAR is utilised as a form of knowledge production it has the potential to engage voices from within isolated or marginalised communities. Children's views have traditionally been absent in research. Critics of this absence suggest that adult's views do not represent those of children and that where children's views have been engaged this continues to be interpreted though an adult lens (Alderson, 2004). Shamrova and Cummings (2017) suggest that an adult driven agenda and a tokenistic approach to PAR can reinforce existing stereotypes about children and prevent their voices from being heard. PAR has the potential to engage the voices of children and youth directly from their lived experience and perspective, identifying what holds significance to them (Dold and Chapman, 2012, Dutta, 2017).

Photovoice (Wang and Burris, 1997) is an established visual method which allows participants and co-researchers to use photographic methods to generate data and support communication experiences (Kroeger et al., 2012, Wang and Burris, 1997, Wang and Redwood-Jones, 2001). Whilst PAR and Photovoice are independent entities, the widespread use of Photovoice in PAR demonstrates the emphasis on using innovative and inclusive approaches to seek an authentic emic perspective of situated knowledge (Palibroda et al., 2009).

Cook and Hess (2007) use photographic data generation to engage the child's perspective and advocate the need to look beyond traditional assumptions of engagement to enable a more holistic understanding of a situation, by "...recognizing children as collaborators in building understandings about interaction where adult and child spaces meet" (p. 30).

Whilst McLaughlin and Coleman-Fountain (2019) acknowledge the importance of creative methods to support the participation of disabled young people they also suggest the authenticity of Photovoice as a method may be moderated by social influences which inform young people’s perspectives. Young people may seek to counter prevailing narratives in their selection of images. In the context of this PhD study, Photovoice inspired our choice to generate photos, not as a core method of the study process but as a means of promoting opportunities for expression and dialogue and sharing what held significance to our young people. Photos offered a means of communicating beyond words.

Participatory action research in the context of this study

In the context of this PhD thesis, the altered perceptions inherent in autism presented barriers to communication within the family. The flexibility and openness of PAR enabled the contributions from our young autistic family members through their own methods of communicative action. McTaggart (1997) refers to the ‘authentic participation’ that can be achieved through ownership and “responsible agency in the production of knowledge and improvement of practice” (p.29). Sinclair (1992), pioneer in the autism rights movement advocates, “Question your assumptions. Define your terms. Work with me to build more bridges between us” (Sinclair, 1992, p. 302). By allowing our autistic young people to engage in their typical communications we were able to engage their situated and authentic communication methods, allowing us to learn from their communicative actions in a safe communication space of the family home environment. Fundamental to the PAR process is reflecting *in* action *on* action (Schön, 1990), and as such the research process promoted self-realisation and learning within families through situated, lived experience.

Collaborative action-reflection, also fundamental to PAR, encouraged contribution across the community of families engaged in this research process.

Our understanding of autism is typically driven by a clinical and educational perspective. This study sought the insider view of communication in families with autistic young people. PAR enabled us to learn from the interaction and dialogue between our family members and through the communicative action between families. This approach held the potential to involve all family members as co-researchers engaged in discussion and growing understanding. This community action approach runs counter to the prevailing research narrative in autism. Zuber-Skerritt and Farquhar (2002) advocate for the need to challenge dominant approaches to research and not leave a paradigm unchallenged simply because of its majority status.

In the context of this PhD study, PAR provided a powerful process which enabled us to explore our communication interaction *through* communicative action, both within our homes and our collaborative learning group. For our autistic young people verbal communication was either not available or restricted as a form of expression, as such this situated and authentic communicative action expanded to acknowledge and engage communicative approaches beyond traditional linguistics and inclusive of individual communication overtures enacted in our homes. A practice orientation of learning through doing (Kemmis, 2009) allowed us to learn from one another inclusive of all family members, and to act upon this communication landscape seeking transformation. In practice, it was the mothers who selected to engage in the formal group learning process establishing a Collaborative Learning Group (CLG), allowing us to share the learning experience *between* families. The structure of this study established an action reflection cycle within and between families, as such, communication moved through and between families allowing co-learning and multiple perspectives to inform one another. The nonlinear approach and the parent led exploration offered potential to enable the inclusion of the *silenced* voice of the unique perspective of the family communication interaction where a young person has autism and furthermore, also held potential to engage the *silent* expression of the non-verbal young person through mutual learning in their own unique language and form of expression (Caldwell 2007, 2012). It is within the autoethnographic data generated by parents that we were able to surface these authentic communication interactions.

Autoethnography

Autoethnography provided an approach to research that acknowledged both my insider view as PhD researcher and the autoethnographic insider accounts of the family members as co-researchers engaged in the research process. Mothers as co-researchers provided autoethnographic data through reflective and storied accounts focussed on the communicative interaction with their young person with autism and within their family. These accounts served to carry the narratives of their autistic family member through nuanced artefact and interactions. Through these accounts we were able to recognise the varied methods and processes of family communication a where a young person has a different and unique way of communicating, including those who are minimally verbal and non-verbal. Our stories and shared dialogue with other parents allowed us to reflect upon the ways that we engage with our young people and how we can understand our communications to identify inclusive approaches. Autoethnography became the methodological conduit for the communicative interactions in families; both methodological approach and method which generated data and provided reflective accounts.

Contemporary autoethnography is a methodology evolved from historic ethnographic practice. Such ethnographies were typically carried out through objective methods of observing other cultures. Whilst contemporary ethnography has become a more situated immersive engagement with a culture, autoethnography provides the voice from inside a cultural narrative offering rich and illuminating accounts that are difficult to access through other methodologies (Denzin, 2006, Denzin and Lincoln, 2018).

Geertz (1973) describes culture as;

> “historically transmitted patterns embodied in symbols, a system of inherited conceptions expressed in symbolic forms by means of which [people] communicate, perpetuate, and develop their knowledge about and attitudes toward life” (p. 89).

Geertz’ perception of culture as reliant upon symbolic forms of communication troubles the cultural integration of a non-verbal autistic presence. The reliance on symbolic representation of language suggests exclusion from the cultural context of home where this form of communication is not accessible. Without verbal communication or where our young people do not engage typical forms of symbolic body language such as eye contact or facing their partner, social engagement may be reliant upon very different forms of expressions and interaction: Expressions which may be missed or misread. Yet communicative interaction remains rich and the cultural identity of home is unique to a family. The concept of culture as reliant on this symbolic representation must therefore be challenged to enable inclusion of the non-verbal autistic presence. In effect, we may not rely on historically transmitted patterns to draw on as in typical social interactions, but may need to develop our own unique histories and methods of shared meaning.

Autoethnography offers the complete insider account of a full member researcher (Anderson 2006), this approach allowing us to immerse ourselves and gain critical awareness of situated family communication. This situated positioning combines the principles and techniques of autobiography and ethnography, providing a first-hand narrative of a situated and personal cultural experience. It is therefore well placed to draw in the authentic cultural narrative of homes that engage more than verbal and symbolic communication. Autoethnography ranges from the social-science based Analytical Autoethnography of Anderson (Anderson, 2006) through to Evocative Autoethnography (Ellis, 1999, 2004). Manning and Adams (2015) acknowledge the various forms of autoethnographic writing which emphasise different aspects of “the social research-life writing continuum” (Manning and Adams, 2015). This continuum expresses the differing forms of autoethnography, which exist in between evocative and analytical approaches. These varied forms include critical autoethnography (Holman-Jones, 2016), collaborative autoethnography, (Chang et al., 2016) and community autoethnographies (Toyosaki, 2011). Le Roux (2017) considers that between the polarities of evocative and analytical there are many ways of approaching, and forms of writing autoethnography which carry the affective, yet apply an analytical interpretive approach. As such, research may take very different forms. Beyond more traditional written reports; performance, dance, monologue, song, film or photography may all form methods or outcomes of an autoethnographic research study yet will share the common heritage and core characteristics of critical reflection and reflexivity.

The autoethnographer uses ‘thick description’ (Geertz, 1973) of the cultural experience to develop an understanding and critique of the cultural life. This reflexive account encourages the reader to engage with the narrative and to challenge and question the norms and preconceptions. Adams et al (2014) acknowledge that autoethnography is not fixed and encourage the creative evolution of this methodology suggesting; “As you create your own autoethnographic representations, we encourage you to reimagine and extend these categories and forms” (Adams et al., 2014, p. 89). There continue to be differing perspectives on the varying application and validity of autoethnography. Wall (2016) argues for a moderate autoethnography that takes the middle ground, offering opportunity for evocative narrative but within an analytical framework. In a similar vein, the evocative form has been criticised as prioritising the therapeutic over analytical importance (Anderson, 2006). Autoethnography in all forms demands, and must engage, reflexivity, and requires the researcher to question their assumptions about objectivity, meaning and truth (Williams and Jauhari bin Zaini, 2016).

Autoethnography as critical lens

Autoethnography is in itself a critical approach to research process and method. As a methodology all forms of autoethnography should also provide a critical insight and make a sociological contribution (Wall 2016). It is the autoethnographic approach in this PhD study that allows us to record and reflect upon our communication encounters with our autistic young person and develop a reflexive and critical understanding, driven by our self-reflection and collaborative dialogue within and between families. Within this process our theories and our reflections are interwoven and inter-related, threaded through our stories as we collaborate in the generation of understanding and action. Adams and Holman-Jones suggests that autoethnography provides a process through which;

> “telling our stories is a way for us to be present to each other, provides a space for us to create a relationship embodied in the performance of writing and reading that is reflective, critical, loving, and chosen in solidarity” (Adams et al., 2014, p. 5).

Adams et al. (2014) assert that it is not the form that the story takes but the commitment to foregrounding personal experience and to intentionally drawing on personal experience to create “nuanced, complex and comprehensive accounts of cultural norms, experiences, and practices” (Adams et al., 2014) that determines an autoethnographic text. In the context of this PhD study autoethnography provided a critical approach that was fitting of the community and driven by the affective encounters of family experience.

Respecting the situated positioning of this study, the autoethnographic account draws on the shared narratives and the multiple storying that is offered through verbal and written data to include visual and embodied interaction, allowing us to do theory and think story as "living bodies of thought" (Pollock, 2006 see also in Holman-Jones, 2016). Della Pollock speaks of theory in the context of performance; "Performance won't stand still long enough for theory to wrap it up nicely. It moves in time and space through restless bodies" (Pollock p. 1). It is this fluid and changing performative, lived encounter of difference in communication that demands the autoethnographic account. This account highlights the lived communication experience of our young people; verbal, other-than-verbal, moving, feeling, seeing, engaging in communications that are beyond the obvious and are so easily dismissed as dis-organised bodies (Goodley, 2013).

Autoethnography in family research

Adams and Manning (2015) consider the strengths of autoethnography for doing family research through insider accounts. They suggest that sharing highly personal reflections, and theorising together, allows unique situated questions to be raised that would not necessarily be identified through other research methods. They acknowledge the potential of this methodology to study everyday experiences as families encounter unique and often difficult events, often providing more accessible texts with the potential to engage non-academic audiences (Adams and Manning, 2015). Autoethnography helps researchers "achieve an understanding of their lives and their circumstances" (Bochner and Ellis, 2006, p. 111).

Zibricky (2014) explores the personal experience of motherhood through an autoethnographic lens. She considers the marginalised position she inhabits as a mother raising a disabled child. In discussing her experience in America, a similar social context to our UK experience, she captures the narrow understanding of autism in the social and educational institution that she is supposed to rely upon for support and direction. She describes the institutional response to a challenging situation which demonstrates the failure of professionals to recognise the fundamental characteristics of autism, exposing a disregard for the regulations which protect her son. She is dismissed and ridiculed at her suggestion of the need for training in the school. Through this autoethnographic account she captures and reflects the embodied and felt experience of the power imbalance as she attempts to challenge the system. She also provides intimate insight to her struggles as she feels the fear of the future for her child. Her account is of motherhood and autism, one that cannot be disclosed without her unique insider positionality (Zibricky, 2014). The commitment to one another inherent in family relationships cannot be felt from an outsider view of the research process and experience. The shared history and knowledge of each other and their long-term commitment to each other can only be felt through embodied experience.

In emphasising personal experience that is particular to the culture of an individual situated experience (Adams and Manning, 2015), autoethnography provided an approach which enabled the families in this PhD study to contribute data which is described by Ellis as a heartfelt (Ellis, 1999) experience of parenting and growing together in a family with specific communication challenges. It enabled a contribution from each of our families which supported growing reflexivity, purpose and insight to the communication engagement with the autistic young people within our families. Valuing research that foregrounded our familial relationships, we engaged deep and careful self-reflection to understand the authentic communication encounters and what and how these informed inclusive approaches to communication (Adams et al., 2014).

Chang et al. (2016) endorse collaboration in autoethnography, advocating that this approach allows shared storying and reflections, with participants taking varying roles and levels of involvement in the full process of research. The approach offers multiple perspectives on an experiential area of research suggesting that;

> “Collaborative work has potential to engender a deeper understanding of self and others in the social and cultural context than is possible from a solo analysis …in the process of dialogically engaging with each other’s stories, collaborators interrogate others’ experiences intimately and deeply” (Chang et al., 2016).

Collaboration within autoethnographic methodology (Chang et al., 2016) allowed a collective approach to understanding the communication context and culture in our homes through multiple storied perspectives. We engaged from within our families, as our situated selves responding to the difference that autistic communication presents within our families. This methodology enabled us to provide the “complex, contradictory, structuring, and structured…. the view from a body” (Haraway, 1988).

I again draw attention back to a core characteristic of autism and the central drive of this study; communicative differences. Our children were encouraged to contribute data as and how they could. Holman-Jones (2016) suggests that stories are our means of theorising and our ‘way in’ to understanding ourselves in the context of our lived experiences. Stories also allow us a way in to acknowledge the experience of others in particular those who are different from us; “In this way, stories are windows—and doors—to understanding…” (p.230). Poulos (2009) suggests the nuances of reflections and stories that can carry what is significant to the communication in communities, our way of understanding what is significant to us. In this respect autoethnography offered a sympathetic tool for data generation within the PAR approach

Autoethnographic Participatory Action Research

Establishing an Autoethnographic Participatory Action Research (APAR) approach in the context of this PhD study fuses the collaborative learning of the PAR approach with the storying and narrative approach of autoethnography. Together this APAR methodology generates a collaborative, self-reflective approach to learning through an action-reflection cycle providing an inclusive methodological approach that engaged theory, process and practice. This positions APAR as both methodology and epistemology (Holman-Jones, 2016, Brydon-Miller et al, 2003). It provides the methods of data generation but also activates a situated epistemic knowledge driven by a situated and active community ethics. The fusion of APAR therefore becomes an ethico-onto-epistem-ology (Barad, 2007). Ethics and methods of knowledge production are situated in the hands of those that matter in this exploration of communication; the families and young people situated in the lived experience. This engagement within and between families establishes ethical practice driven by their situated needs. Furthermore, it generates knowledge through the iterative and critical communicative of action within these families, situating knowledge production in the hands of those that matter in this research and that drive this research. This approach allowed this group of families to centre the young person with autism within their family and to engage their communicative interactions in the collaborative and iterative learning process. It is the establishment of this ethico-onto-epistem-ology of engaging theory and methods in practice and production, which enabled a contribution from our young people through their own situated methods of communication, and which drove the study approach and design.

Autoethnographic Participatory Action Research in practice

In order to action our APAR approach in this study, we established a Collaborative Learning Group (CLG). It was the mothers from each family who came together as gatekeeper parents and formed this group. This approach draws upon the principles of the “Community of Practice” (Wenger, 2000) which established a collaborative space for mutual learning facilitated by the APAR approach. Our group of mothers became autoethnographers within their family research process. Through shared experience, we began to explore communication from within our family community experience. Mothers’ reflections were recorded in the discussion group and reflective journals. Whilst PAR grounded our research in community action and structured our collaborative and iterative engagement across the family members, in the context of this study, autoethnography became the methodological conduit to data generation and an active narrative process that illuminated and carried the unique communication experience from within each of our families (see figure 2).

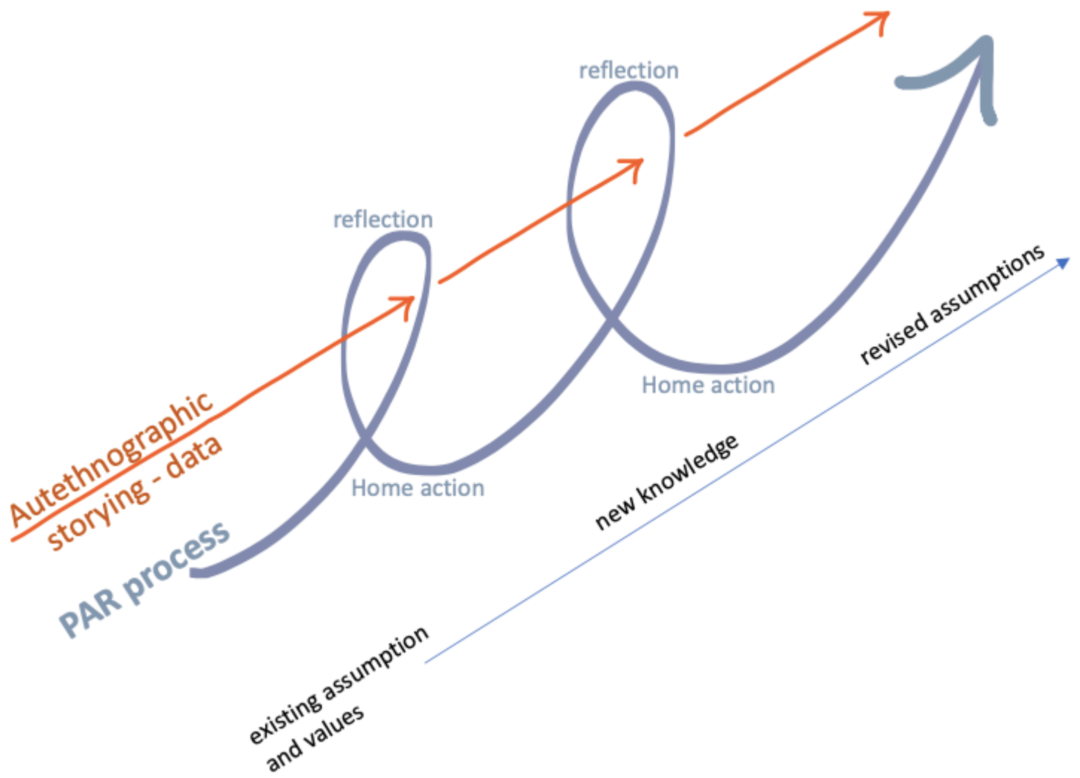


Figure 2: APAR cycle of knowledge production

Through the reflective process we, as mothers, drew on personal experience to illustrate facets of cultural experience (Ellis et al., 2011) allowing us to expose and explore the varying communication strategies and approaches of each of our individual families as they revealed themselves through the active process of communication interaction. This approach allowed mothers as autoethnographers, to contribute to knowledge in the field of autism, driven by personal experience and culture; the ideas, customs, and social behaviour of our family communication geographies. APAR became a metaphorical learning tool (Butz in DeLyser, 2009). Where the deductive, positivist research paradigms aim to minimise the subjective storying, intuition and unique situated worldview; APAR valued and foregrounded the lived experience of families engaged in this research practice, recognising that situated research is complex and meaningful and can centre the moral and ethical (Ellis, 2004). The APAR approach enabled a collective and collaborative experience of surfacing the communication stories which carried the rich and authentic language of movement, voice, touch, emotion. The marginalisation of our community of families drove an APAR approach to better understand and further include our young people. The presence of our young people with different communication demanded an innovative approach to data generation facilitated through the APAR. Caldwell (2012) argues that in order to be included in communicative interaction we must begin to recognise the authentic communications of our communication partner. The collaborative APAR framework offered the flexibility to seek the direct and indirect contributions of our young people, including our non-verbal young people.

Through encounter and interaction (Caldwell, 2012) and the artefacts from our young people, parents and family members as a research team began to surface, expose, make present the authentic contribution from our children in their unique language of expression and communication. Short describes the potential of engaging the first-person position of marginalised communities to engage in autoethnographies that;

> "help give a voice to the voiceless, the invisible to become visible and to make the differences noticeable" (Short et al., 2013, p. xi).

The complexity of applying this APAR approach to data generation within our own families charted new territories for us as parents. This was not an easy and straightforward process, the complexity of multiple perspectives, differing agenda and perceptions became a complex and entangled research experience and data set, a complexity described by Cook (1998) as a ‘messy turn’ of disparate views and complex and nuanced data. Yet, allowing the mess also brings forth a richness and authenticity. This self-reflective APAR methodology gives safe space to explore our unique ways of thinking, feeling and sensing as an extended way of seeking knowledge and generating meaning within the research process. It is in this process of reflection and self-reflections and the need to explore inclusion that we have looked to our young people as experts in their own communications and have turned to notice their unique contribution through more-than-verbal methods.

Situated communication

APAR entrusted gatekeeper parents with an active role as co-researcher of inclusive communication *in* and *with* their own family, allowing their young person to express themselves in their own authentic and situated way, within their family communication environment. Through the mutual learning process, they too became co-researchers through communicative action situated as both the *focus of* and *process of* this PhD study. This process demanded that parents opened themselves to their young person’s ways of communicating; needing to turn to face their autistic young person and explore authentic communication situated within their own family culture through a shared dialogue within the family. Parent’s records, observations and reflections on these interactions were recorded in reflective journaling and in the parents Collaborative Learning Group meetings where stories and reflections were shared. Figure 3 describes the process of APAR, where the full research process flows through families.

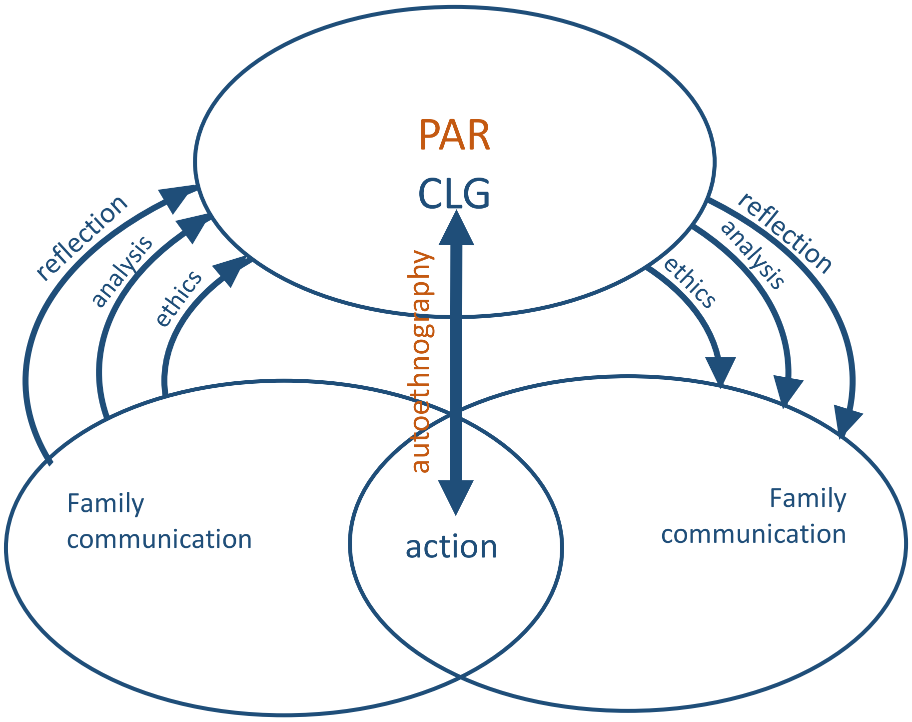


Figure 3: Collaborative learning cycle within APAR

Our young people, labelled as autistic, communicated differently from their parents and family members. It was therefore essential to explore what were their forms of communication in this context, and how we could better understand this to support inclusion. Where autism interrupted the normative verbal communication in the families engaged in this PhD study, the iterative, critical process of APAR enabled parents to work with their young person to understand the process and practices of their daily communications through their active communication. Self-reflection as a key aspect of APAR allowed parents to revisit and to further understand the authentic communication of their autistic child in order to support and facilitate inclusive communication (Caldwell, 2012, Ephraim, 1998). The critical theory and process approach of the APAR research experience enabled the holistic and inclusive exploration of situated knowledge; allowing the authentic communications to be seen and spoken, felt and moved in any language and, through reflection, surfaced what was significant in our family communicative encounters. Holman-Jones suggests;

> “The “critical” in critical autoethnography reminds us that theory is not a body of knowledge a given, static and autonomous set of ideas, objects, or practices. Instead, theorizing is an ongoing, movement-driven process that links the concrete and abstract, thinking and acting, aesthetics and criticism…” (Holman-Jones, 2016).

Where the autistic young person chose to contribute artefacts in the form of photos, notes or drawings these were included in the family reflective journal (see discussion of methods). These accounts captured the authentic expression of the young person and began to reveal what held significance for them. Through storying and reflections parents were able to experience and record situated communication encounters which captured the sensory, emotional, relational and physical nature of our children’s communications (Pink, 2015, Holman-Jones, 2016, Curran and Runswick-Cole, 2013).

As a mother involved in this study, the process has *felt* challenging. I have been surprised by the intensity of emotion and sensitivity of families exploring intimate communication encounters. I have experienced the tension in my dual role as researcher and family participant, sensitive to my responsibility to each of the family members in the study. Seeking to explore inclusive communication has opened my eyes, ears and heart to the challenges of our families and children in the study, and not least, recognised the complexity of my own family communications, a process which is both empowering but also challenging (Summerson Carr, 2003). The research process drew on personal experience and enabled increased empathy with those different from ourselves both within and beyond each family, this personal situated affective and enmeshed view helped us as parents to turn to notice communication engagement within our families.

Situated ethics

Ethical concerns in this thesis remained *a priori* throughout. This ethical concern ran through the group and challenged and informed our interaction and activity at all levels, directly engaging the situated ethics of the ethico-onto-epistem-ology positioning (Barad, 2007). I have *felt* a moral and ethical responsibility to the families engaged in this PhD study, including my own family; and carried their trust. I asked that the families in this study contributed personal insight from inside their family, their unique and intimate stories with the associated challenges and dilemmas. Whilst the red tape and time-consuming protocol of ethical approval processes in academic and clinical research can be seen as frustrating, researchers nevertheless, must celebrate the scrutiny of the ethics process and procedures that protect those involved in research from physical and emotional harm (Docket et al,. 2009). With particularly violent practices being exposed in Assessment and Treatment units in recent headlines, the ethical concerns around research in the context of vulnerable populations is stark and vital. Such troubling narratives also demand a critical view of ethical practice. Ethics is not solely driven by the process and procedure of university or clinical codes of practice; it must demand a commitment to ethical values (Gustafson and Brunger, 2014, Kittay, 2011, 2013, Brydon-Miller and Coghlan, 2018).

Mothers as gatekeeper parents attended the collaborative learning group meetings in a local and accessible venue. The venue was based in a user-led, voluntary organisation working with and for disabled people and families in the North East of England. This organisation works to support and advocate for the inclusion of disabled people in their community. As a place where parent advocates typically meet, this was identified as a suitable community venue for this study. The facilitators of the organisation agreed that, should any parent become distressed during the collaborative learning group meetings, organisation staff would be available to offer a quiet space away from the data collection activity. This user-led organisation also had parents who offered community support and were available to provide support beyond the collaborative learning group meetings if any families felt distressed by the process of their research engagement. However, this support was not required during the study.

Each family was provided with a pack of information for further specific organisations and named individuals who could provide support and guidance in the event of any negative or distressing consequences of the study. These organisations included contact details of the ASD Family Support Coordinators, of two local organisations which support families with disabled children. I had discussed the study with the named individuals from these groups prior to commencing data generation to ensure they were available and understood the nature of the family's engagement in the study, to enable relevant support if needed. None of the families, to my knowledge, required additional support from these organisations.

A full process of informed consent was conducted within this PhD study. Information sheets and consent forms were given to all family members via the mothers as gatekeepers in their family, and as co-researchers. It is they that discussed the study with all family members. All family members were given access to the information sheet; different versions were developed for parents and for young people to cater for reading ages, learning needs and abilities (see appendix 1). These were read through and explained to the young people being invited to take part in the study process. Mothers also subsequently elicited consent from their family members. Instruction was given to mothers that their autistic young people and all family members should be given the choice whether to engage in the study or not.

Whilst aware of the challenge to gain reliable consent this was actively sought from our non-verbal participants. Engaging in training and discussion through the Durham University Centre for Social Justice and Community Action (Centre for Social Justice and Community Action, 2012) and ethical dilemma café at Action Research Network of the Americas conference (ARNA, 2017) allowed me to gain critical feedback on the position of our autistic young people in this study. The challenge of not being able to access the views of our non-verbal and minimally verbal family members to reliably seek consent is a tension I have felt throughout the study (Alderson, 2004). The nature of communication barriers as a core feature of autism becomes a barrier to reliably informing the individual young person and gaining their consent. Two of the autistic young people within one family were unable to access the information regarding the study and express their consent, the young people being nonverbal and minimally verbal and did not access visual communication methods such as symbols or picture exchange methods. In this circumstance I looked to parent consent as in traditional research practices.

Family members of each of the mother-researchers all agreed for their family to engage in the study, however, two older siblings in one family did not want to engage in active data generation through specific discussions or personal data generation. Similarly one father in a family gave consent for the family to be engaged in the study and for his communication interactions to be included in the mother's reflective data however, due to personal difficulties, he did not feel able to actively contribute to data generation through direct discussions or generating his own reflective data. Each of these inactive participants gave consent for discussions relating to their family communication interactions to be carried in the mother's reflective data. This inactive participation is exemplified in that these family members did not complete the values sheet (see methods chapter) or engage in any family discussions specifically driven by involvement in the research process.

We as mother-researchers discussed different methods of data generation that we could use within our families' exploration of communication, both in meeting 1 and then at later meetings. We then offered these different data collection methods to our families for their consent. Therefore, we included in our own family only those methods the family felt comfortable to use. Initially we co-researchers had identified audio and video recording of family interactions as potential data collection methods, however, many family members decided against these methods. The number of family members who made explicit their rejection of the use of video indicates that this process of consent to methods of data collection allowed choice within the families and gave family members the autonomy to consent and provide feedback to the process. McGuire asked for caution where parents or advocates research with those living with disability, suggesting the need to be mindful of the power a parent may exert when advocating or speaking on behalf of their child (McGuire, 2010). Pluquailec (2018) encounters a similar tension in needing to 'trust' the parents in her study to speak for and of their young people. The approach through our APAR methodology allowed the consent process to inform the development of the study with regard to involvement and methods, drawing in a situated ethics.

The ethical dilemma pervaded my experience of this PhD study; how to sensitively and respectfully include autistic family members, yet without coercion or assumption of participation and, significantly, how to facilitate participation. Participatory action research "is done with, rather than on, the participants—as is often stated. Ideally, the participants become equal partners and co-researchers" (Dick and Greenwood, 2015 p. 195). Where our young people were non-verbal or minimally-verbal we looked to the young people that were able to provide direct feedback to guide our approach. In practice this led to our dismissing the concept of video as a method of data generation, as this was rejected by our young people who could express this directly. The collective perspectives provided a guidance and collective responsibility to ethical concerns. Facilitated through a participatory action research epistemological approach which drew in both theory and method (Dick and Greenwood, 2015), collectively, our young people, along with all family members, were able to show or tell us what they would accept as methods of data generation. This allowed us to engage in the research process without emotional pressures of video, interview questions or the direct focus of attention that can be overwhelming to our autistic young people.

Pluquailac (2018) calls for a new ethics in research with disabled children that shifts from conceptualising children labelled autistic as disorganised and disembodied, advocating for an ethics which understands and values the lived experience of children and families and accepts their contribution through enacting their different form of expression and communication (see also Beresford et al., 2004, Rabiee et al., 2005). I also refer to Freire, and the need to include the marginalised voice in research practices which impact their lives;

> “The silenced are not just incidental to the curiosity of the researcher, but are the masters of inquiry into the underlying causes of the events in their world. In this context research becomes a means of moving them beyond silence into a quest to proclaim the world” (Freire, 1982, p. 30).

Without this active and enacted engagement research continues to exclude those who hold an authentic position of knowing what it means to communicate as an autistic young person in their family.

The participatory paradigm which was fundamental to this study was seated in a search for social justice. Indeed, the Durham Centre for Social Justice and Community Action became a critical reference for the development of the study, in terms of theory, design, and in practice. Central to the participatory approach was the deep concern for ethical principles and practice, this became the situated ethics demanded by the critical APAR paradigm. These ethical principles must be *a priori* in research with children who have restricted ability to articulate their thoughts, wishes and perceptions (Alderson et al., 2005). The guide to ethical principles and practice provided by Durham Centre for Social Justice and Community Action were developed through workshops and consultation with stakeholders across the UK, who welcomed the establishment of guidelines to support ethical practice in Community Based Participatory Research (CBPR). The guidelines are explicitly designed to be used;

> "in conjunction with, and regarded as complementary to, subject specific ethical principles and codes of conduct, institutional research ethics guidance and research governance frameworks developed by research councils and research funders" (Centre for Social Justice and Community Action, 2012).

There was no intention for these guidelines to replace the vital pre-existing university ethical process and protocol. As this PhD research started with community practice, the need to grow ethical awareness and adherence within the research group was necessary and the guidelines provided by the Durham centre supported the establishment of ethical practice in research design and process.

Ethical challenges of working with children and young people are significant, in particular with disabled young people who have atypical language and communication (Glynne-Owen, 2010). The structure of this PhD study invested in ethical practice as a value base which not only served as a means of gaining consent (where possible) but also invested in the awareness and critique of ethical concerns through the action/reflective process and the multiple views. As previously considered in chapter 2, Curran and Runswick-Cole (2013) recognise that mothers and children's emotional states become enmeshed. As parents, revisiting and reflecting on our engagement, we also explored our values as they played out in the lived engagement with others. In doing so we were able to critique our interactions and reactions. This reflective process served to increase reflexivity which carried the ethical into our praxis. Beyond seeking ethical guidance and clearance through the university ethics committee we sought ethical practice through the research design and engagement, constantly checking our process and practice (Cocks, 2006). By seeking inclusive communication practice, we continued to challenge our perceptions through the action-reflection cycles.

Values sheets

Before the first collaborative learning group meeting, participating family members were each provided with Values Sheets. These were inspired by the Durham University Centre for Social Justice and Community Action guide to ethical principles and practice, and the ethical awareness facilitated at their doctoral training event. These Values Sheets set out a list of words that described different ‘values’ and asked participants to select which of these words/values they felt best described what they felt was important to them in the research process; to help us to understand what research meant to them and to recognise each of the individuals involved. Whilst I was aware that not all children may be able to access the process, I prepared three sheets for participants to choose from (see appendix 2). I consulted with my children as I prepared the reduced word sheet and the sheet with visuals to be given to the participating children and young people in the study. We mothers discussed the response from families in our first meeting and the difficulties some of the children had in interpreting and accessing the concept and purpose of the sheet. This was something that I had expected, and had sent the values sheets clearly saying that there was no pressure for these sheets to be completed by all participants and that feedback was not essential. The sheets were intended to be completed where individuals were able to access this form of feedback and chose to engage with it.

Both of my sons engaged in the process of filling in the values sheets, I share the following vignette not to prioritise the experience or views of my own family but to provide an insight to the engagement between me and my sons in this process, and my engagement and intention to include my autistic son’s views on the values we should hold in our research study. I made all value sheets available and asked which they wanted to use, my elder son chose the sheet with words only and my younger son the sheet with images and words, our attempt at describing the abstract values listed. My elder son questioned the word ‘strong’ and what it meant in this context. I turned the question back to him and asked what he felt. He confirmed that he felt that being strong was important as it made us more resilient and this was important to him. My younger son with autism used the sheet with visuals, yet I made all sheets available on the table. I talked through the words and he pointed at happy, funny and playful, he then paused, I asked if there was anything else, he said safe. I asked if there was anything else and he began to compare the 2 sheets of words. He noticed the word honest on the second sheet and indicated that it wasn’t on the sheet he had. I asked if he wanted to include this and he said yes. I talked to him after the process and asked if things were happy, funny and playful did he feel safe, he replied, ‘Yes’ and then left. I drew on my learned communication strategies, but am fully aware of the inevitable partiality that results from my engagement in the process. Whilst he was able to select the words, I am not wholly clear of his level of understanding both of the concept of the research study nor of the descriptive words and abstract concepts. I am also aware that my push to understand further results in my interpretation of his words, which may be inaccurate. Despite these challenges, all children had opportunity to be involved in the process and offer their personal response, and these words stayed with me through our study process.

Consent for recruitment to the study and values sheets were completed prior to the first (unrecorded) meeting of the CLG allowing these processes to inform our first discussion. This first meeting was unrecorded to allow parents to meet one another and to ensure everyone felt comfortable to ask questions of the process and discuss any concerns they held about the study process. This meeting became a discussion which focussed on the nonverbal children present in the study, and the difficulty their mother had in trying to engage with the consent and values process. The thoughts from one mum whose children were not-verbal struck a chord early in the process. Her children were unable to access the consent and values sheets discussion and processes. Nudging the sheets away and not engaging with them. She described feeling saddened that she had tried to pursue their input as she had already understood they would not be able to access these sheets but had still wanted to offer the opportunity. This resulted in our first meeting focussing on the nature of communication in each of our children and how it could be so easily assumed that a young person with good language skills could understand and access verbal communication, yet those without verbal communication and who also perceived the world in a very different way would be denied this ability to communicate and remained isolated from this process. Whilst this session touched very sensitive emotional areas it focussed our understanding of the ethical and communicative challenges inherent in this PhD thesis. This initial experience clarified the need to step with care and sensitivity, aware of our young people and their vulnerability, and collectively as parent gatekeepers and co-researchers to protecting their interests. However, rather than protecting by avoiding their inclusion, the nature of the research demanded that we look to ways of including our children by explore communicative interaction. Central to this study is the young adolescent with autism in their family. This brings forth the primary ethical tension which runs through the study, which is the need to remain sensitive to the position of those family members with limited or no verbal communication. Recognising any potential or actual adverse effects which could be attributed to their or their family's participation in this study remained vital throughout the process of study design, data generation, analysis, writing and dissemination. Families were aware of the differing presentation of our children, this concern for sensitivity and need for empathy was tangible from this first meeting. It felt as though we had established a community responsibility for ethical practice. As parents, our learning had already begun, informed by the position of difference that our children inhabited.

Reflexivity

Critical to both methodological approaches fused in APAR is the commitment to trustworthiness in the research. Lather (1986) describes a catalytic validity, a validity which is acknowledged through the impact of the research; did it result in positive change? By exploring inclusive communication in our homes, we supported the emancipatory framework through the APAR process and research which aimed to acknowledge and develop the agenda of the situated autistic young person (Mercieca and Mercieca, 2010). As part of the PhD research process I kept a reflective research journal detailing my personal journey through this research project. As I moved through the active research process, working together with other families, this and my reflective family communication journal (as kept by all mothers) began to replicate and reflect each other until they became one. The autoethnographic positionality became even more evident; I was unable to separate the researcher from the participant (Callary et al., 2012). Haraway (1998) suggests that feminist objectivity means simply *situated knowledges*, and this highlights the critical reflexivity that drove my evolving praxis. The iterative, cyclical and multiple perspectives took me on a difficult journey that caused me to question my assumptions as parent and advocate to my son and family. Ackoff's 'Messes' (1999) describes the "complex, multi-dimensional, intractable, dynamic problems that can only be partially addressed and partially resolved" (in Brydon-Miller et al., 2003). Cook describes the mess in participatory action research;

> "The 'messy area' itself is unsettling, worrying, exciting and challenging. It is disruptive of habit and custom. The purpose of entering this mess is to enable and allow new directions to emerge; to enable diversity and multiplicity to work together to challenge the given, to recognise the nearly known and to support the creation of trustworthy, transformational knowing" (Cook, 2009, p. 17)

I faced the knowledge and strength in the mothers who I met and talked with, and read their intimate reflections of complex family relations, love and nurture, fear and pain. As PhD researcher, I felt humbled by their knowledge and ability to engage and articulate their heartfelt stories. At the same time this process empowered me as a parent. I felt the growth in knowledge and understanding from our discussions. Yet, what followed me; in my thoughts and actions was the stories of interaction, communication, fear and strength from our young people. When I was at home within my family, I felt more able to understand my autistic son, I became more attuned to his internal frustrations and dialogue and grew strength from this. When he behaved in certain ways another young person came to mind, that had been spoken of at the CLG when he was lost in a fit of giggles or affronted by a tumbling in of upsetting thoughts without warning or when he was upset and shouting I was reminded of another child from our participating families and recognised the need to be patient and empathise. The tension I had felt for the ethical and moral responsibility to the families and in particular the children, dissipated when I began to experience the powerful learning that was taking place, driven by my connection with other mothers but more significantly the undoubted presence and teaching that came from our autistic children through their difference(s) in communicating and interacting.

> "The highlights when we find new dialogue and strategies that include and support closeness, fun and positive engagement. The times of sadness, of change, of growing families and their emergent independence. But at all times this trust challenges my position, my dual role, my bias and my ability. In essence, is this study trustworthy? I have a duty to continually invest in reflexivity to best serve all participants. I note down events, initial ideas-themes-thoughts. I revisit the data; I listen to the recordings and then we meet in our group" (Helen reflective research journal).

In the early stages of data generation, I was aware of my position as parent and researcher and felt a tension in these positions. The responsibility and emotional commitment were challenging, yet as the meetings took place and the discussion flowed, I felt a shift, a move to become part of the assembled voices contributing to data. I was conscious of the insider/outsider perspectives (Dwyer and Buckle, 2009), and aware of the need for reflexivity to prevent my own interpretations and emotional responses from clouding the other family member perspectives. I was conscious of the intrinsic analytical process which was carried in the APAR process and in our research experience. The experience as PhD researcher in this study caused me to question the analytical framework but in practice allowed a more critical understanding of both data and analysis. The eruptions and connections that sprang from the research process confirmed that analysis is not a linear process, it is recursive with movement back and forth and in-between, resisting and accommodating (Pickering, 1993). Analysis emerged and erupted from our research process through the mothers as researchers seeking to understand what communication meant for their family. This experience and the different perspective it facilitated opened my eyes further to the process of analysis as a fluid process of resistance and accommodation, of events and intensities where new experience erupts. Deleuze speaks of the assemblage, an assemblage of forces which flow through all things human and non-human in a constant dynamic. Intensities form as forces intersect and Intra-act (Deleuze and Guattari, 1987; De Landa, 2016). This concept of an assemblage provided a description and conceptualisation of the diversity and multiplicity which challenged my/our researcher preconceptions. As a group of mums with different children and different ways of communicating this perspective offered the multiple perspectives and experiences which demanded researcher/parent reflexivity and praxis.

I/WE - participatory methodology in PhD research.

This APAR research project is a co-produced exploration engaging five families of autistic young people producing knowledge through action-reflection and storying. As a co-researcher I engaged in this process with our five families where *we* explored communication and co-produced knowledge. As the PhD candidate who initiated and produced this PhD thesis, *I* drew upon the findings of the co-produced research and developed the thesis as a product of this research, by further analysing and critically responding to the body of data generated by *we* mothers and family members.

There exists, no doubt, a tension between the I-WE of a PhD study that engages co-production as a methodological approach. As an insider researcher (Anderson, 2006, Gair, 2012) my critical awareness and reflexivity remained central to the research process and the production of the thesis. The values of inclusive and emancipatory research practice, which drove the initiation of this thesis, were central to acknowledging what was co-produced and what was then further developed by me to produce the thesis. The iterative and reiterative approach to data generation and reflective practice enabled a live and situated analysis driven by parents (see Rhizomatic Analysis in the following section) which enabled themes to surface and generate new knowledge. This process resulted from the active research exploring our communications within and between families. We as researchers shaped the methods, generated data and initiated analysis, this and member checking ensured a collaborative engagement in the generation and initial analysis of data. As the meetings developed I initiated a thematic analysis which responded to the body of data and the emerging themes. By identifying initial themes and engaging in member checking and discussion of these themes we as the collaborative learning group members, further developed these themes as part of the data analysis process. Therefore, whilst I am conscious that the thematic analysis which captured the findings of our family communicative encounters was ultimately authored by my singular view point, this analysis builds upon member checking and continued reflection and revisiting of the words and stories, actions and enactions of the members of our research group, central to this study. This iterative process of analysis contributed to trustworthiness and credibility of the data analysis. Dick and Greenwood (2015) assert that participatory action research should be done with rather than to people, this concept is central to the co-production of the research that *we* as family members generated but moves to *I* in both the initiation and production of the PhD thesis.

Analytical framework

The analytical framework developed organically through the Autoethnographic Participatory Action Research (APAR) approach. The positioning of the lived and situated experience of participants, and the active communicative experiences in the families engaged in this study, positions the study within posthuman theories and literature. In response to the observations, storied and enacted narratives from within the families, the central concepts of the theories of Deleuze and Guattari (1987) began to be engaged. The authentic and non-verbal communicative presence of the young people at the heart of this study became a catalyst to our use of key concepts from Deleuze and Guattari in order to understand the dynamic and embodied enaction of our communicative encounters, Therefore, although not an exclusively Deleuzian-Guattarian study, I suggest that the Autoethnographic Participatory Action Research (APAR) approach to research and data generation facilitated an ontological shift to recognising a monistic (Spinoza, 1992) or *flat* ontology (Deleuze and Guattari, 1987) responding directly to the more than verbal communication exchanges expressed and enacted by our young people.

As the active research process in this PhD study began, the collaborative learning group discussions moved quickly to focus on the non-verbal communications of our autistic young people. It was this turn to notice our non-verbal communications that deprivileged language. In so doing the philosophies of Deleuze and Guattari (1987) became fundamental to understanding the study experience and emerging data. PAR draws on social constructivist understanding and is activated through communicative action (Habermas, 2015), more specifically discursive action. Throughout the study design and initial research process I was troubled by the question of how we identify an inclusive approach. If discursive action allowed the construction of meaning then those without a voice or with restricted language and communication are denied the capacity to actively produce meaning. The first meeting of our collaborative learning group met this tension head on. The more-than-verbal, other-than-verbal young people in our study established their presence and influence with immediate effect. Our discussion was focused on the positioning of our children and their situated and embodied means of communication.

Communicative action in family exploration of communication moved from a discursive process to an embodied and interactive encounter of bodies and their physical spaces. This direct challenge to a linguistic approach and understanding of communication decentred a linguistic language and an interpretive approach. Deleuze and Guattari (1987) provided a monistic or flat ontological positioning, a lens through which the innate and authentic communicative presence and process of our young people could be both present and active in the research process. This Deleuze-Guattarian (1987) *flat* ontological positioning which gives rise to concepts of *The Rhizome, events* and the *assemblage* are not only complementary but also foundational to the critical posthuman (Braidotti, 2013, 2018, Barad, 2007) and disability theories (Davidson and Orsini, 2013, Goodley, 2013) central to this research study. This theoretical position is a direct response to the more-than-verbal interactions we experienced and enacted in the research process.

In order to develop this position I will describe and discuss the concept of the assemblage (Deleuze and Guattari, 1993, 2001, De Landa, 2016) and propose that the APAR approach established a research assemblage (Fox & Alldred, 2015) through which we as mothers were able to better understand our communications with our young people and the potential for further inclusion. This shift to recognise the process and experience of this PhD study as a research assemblage was driven by two influences. Primarily, the APAR approach denies a hierarchy and indeed, demands a flattening through an emancipatory and democratic mutual learning process, this became apparent in the analytical process which began to emerge organically from the APAR action reflection cycle and mother's evolving reflexivity. Secondly, as we engaged in the active research stage with family members, the more-than-verbal presence of our young people demanded a decentring of linguistics. As such it forced the flattening and de-privileging of language in our communicative interactions and in our research process.

Research as assemblage

Fox and Alldred (2015) describe the ‘research-assemblage’ as comprising researcher-participants-data-methods-contexts and all multiple components, or *multiplicities,* of the research process interconnected in a single flat plane. Deleuze (1991, 1993, 2001) introduces the concept of the assemblage as forces in constant flux within and beyond entities. To further understand the assemblage, I refer to the concept of monism introduced by Spinoza in the 1600s (1992) the plane of immanence (Deleuze & Guattari, 1987) or flat ontology (De Landa, 2016). Each of these terms reference a shared concept that reduces traditional hierarchical perceptions of the world to a single flat ontology. Where traditional ontological positioning separated mind/body, nature/culture; the concept of the assemblage denies any such duality, hierarchy and privilege and moves to draw all things as multiplicities in an assemblage, and in constant dynamic tension. This concept challenges established polarised positioning of research approaches to knowledge production, where the natural sciences and social sciences frequently became oppositional perspectives and served to dislocate nature from culture; matter from cognition and; body from mind (Braidotti, 2013). A shift to understanding a different philosophical perspective through a monistic conceptualisation therefore considers mind-matter-culture-nature-body-environment and all things as relationally entangled in the flat ontological plane of the assemblage. Deleuze (1993) speaks of the assemblage as a set of forces in continuous flow, material and relational forces folding and unfolding, and all on a continuous plane. In this constant dynamic, these forces resist and accommodate (Pickering, 1993) the flow of energies between, but also within, all things human-nonhuman and material (Barad, 2007; De Frietas, 2017, Bennett, 2010).

In echoing Nietzsche’s criticisms of our emphasis on language and grammar in how we shape or determine our understanding of the world, Barad (2003) suggests that language has been granted too much power. Language has become the primary means by which we engage in the communication processes which inform knowledge production and our understanding of the world. In privileging language, we have privileged ‘man’ as the centre and the measure of all things (Braidotti, 2010). In our narrowing of perceptions of what matters to this singular point of reference, we have situated ourselves in a position where our understanding of the world is driven from this singular and narrow perceptual position. If our traditional European *man measure* of all things has also been centred in white, male, Anglo-American, non-disabled, typically developed, heterosexual body/mind/attitude then our understanding of all things is measured by this narrow standard. This striated or entrenched perceptual position has influenced traditional approaches to knowledge accordingly (De Landa, 2016, Braidotti, 1994). This perspective underpins and informs dominant research perspectives and practices of knowledge production to include autism and young people and their families. It relies upon a way of understanding the world from a single exclusive perspective and denies the perceptual experiences of those outside of the normative culture of ‘man’. Feminist, disabled, queer communities, and those who sit outside of this narrow normative cultural perspective have been marginalised and voiceless as a result of this exclusive perceptual field. From this ontological positioning, research became a privileged cognitive human-centric process, dislocating knowledge from where it is generated in a material, spatial and temporal connectivity. This othering and exclusion has been a catalyst in the active emergence of counter culture philosophy that challenges this perceptual man-human-centric positioning (Lather and St. Pierre, 2013, Saur and Sidorkin, 2018). This positioning is referred to as posthuman ontology (Campbell et al., 2010, Braidotti, 2006), a way of understanding the world outside this narrow perceptual position. In relation to this study, I will also make reference to *post-linguistic* to directly acknowledge an increasing move to understand the world beyond the exclusive construct of the traditional approaches which have relied on linguistics (de Freitas and Curinga, 2015).

In relation to this PhD study, the APAR approach, arguably, acknowledges and facilitates the notion of an assemblage of data. Viewed through the conceptualisation of the research assemblage the research process of this PhD study becomes an entanglement of communication as family-action-environment-body-word-data-reflections (Fox and Alldred, 2015; Denshire and Lee, 2013). This concept of the assemblage served to acknowledge and indeed respond to the situated position of families as *they* articulate the research process (Wadsworth 2001). It responded to the complex web of interconnected forces, driven by the ebb and flow of family lives and environments in constant communication, interaction and movement. The concept of a research assemblage offered opportunity to rethink and re-engage with research that connects, family-youth-autism-home-communication. It acknowledged the multiple positioning of unique family members in this research study, each bringing their own communication dynamics (Yergeau, 2018). By recognising and acknowledging communication beyond words, communication becomes inclusive of the autistic family member's authentic methods of communication as it is enacted within their family.

Analysis within this research assemblage happened in two stages. Initially, mothers responded to the cyclical APAR process, revisiting and reflecting on the communication experiences in their families and in the discussions held within the Collaborative Learning Group (CLG). Our analysis began through a spontaneous response to the lived interactions experienced by the mother-researchers engaged in the reflective and discussion processes. This initial stage happened as a spontaneous, situated, analytical response as part of the CLG discussions and mothers' reflections, surfacing what mattered to them, what felt and appeared significant (Maclure and Koro-Ljungberg, 2013, Mazzei and Jackson, 2017; Hofsess et al., 2013). This analysis became evident when mothers began to identify similar issues and thoughts and revisit these in the CLG meetings and within the parent reflective journals. As such, the analysis was an inherent part of the APAR methodology. Through the assemblage of the cyclical, the entangling, the difference, the affective, the developing reflexivity, parents began to identify what was significant to them within their family. This spontaneous *rhizoanalysis* (Masny 2014; Deleuze & Guattari 1987, Deleuze 1993, 2001) emerged from the research assemblage facilitated by the APAR approach. The concept of the assemblage and The Rhizome will be further discussed in relation to the analytical framework. The second stage of analysis engaged a Thematic Analysis (Braun and Clarke, 2006) which enabled a slow, detailed and thoughtful exploration of data. I will discuss how this thematic analysis drew upon rhizomatic response to further explore themes through written and storied data of mother-researchers, and young people who contributed to these narratives through their situated and authentic communication interactions.

The Rhizome - Difference and vitality within the assemblage

Whilst the assemblage is understood as a single plane or monism this is not to suggest it is a static and unchanging homogenous whole. Indeed, it is in the flux, the resistance and accommodation of the forces in constant flow within and between self, space, time and object that we experience difference (Deleuze and Guattari,1987). Whilst all things are entangled in and of a monistic flat ontology, it is not intended that all things hold equal force or agency. Intensities coalesce in the constant flow of forces, differentiating and affecting: *events* in the assemblage. Deleuze suggests that where there is difference, there is action and reaction; ruptures in the connectivity which result in new ways of experiencing and doing. When blocked, a force or flow may rupture creating an event which spurs new becoming (Deleuze and Guattari, 1987), where our family members meet challenges in their communications such events reshape ways of doing or thinking, a constant process of emergence or becoming through events. Deleuze and Guattari (1987) liken the entanglement and connectivity of the assemblage to a rhizome; a continuous, responsive, and rupturing force which intra-acts and communicates with the earth as it moves and creeps. For mother-researchers we responded to one another's' reflections and thoughts, reacted to our family encounters and between these experiences we were affected. New ideas and ways of seeing, feeling and reacting emerged from these events responding and rupturing. Masny describes these rhizomatic events within an assemblage;

> "consisting of multiple heterogeneous non-hierarchical trajectories of experiences, some that rupture unpredictably and others that don't and that connect with each other in an assemblage" (Masny, 2014).

We can begin to perceive of the human as part of the assemblage of flux and flow, blockage and interruption. It is here that we see difference. Intensities coalesce where flow intersects, is disrupted or blocked. Braidotti (2014) paraphrases Haraway, suggesting that some differences are 'playful and some are pillars of historical systems of domination'. It is in this vitality of forces that difference occurs, as a continuous process of becoming (Deleuze, 2001, Biehl and Locke, 2010). Our preconceptions are challenged, our assumed ways of communicating are disrupted. Knowledge production is no longer perceived as being generated through linguistics but through difference, resistance and accommodation within the assemblage (Pickering, 1993).

To understand the relevance of this conceptualisation in the context of this PhD study, I refer to the individual families as forming an assemblage of communication events of home-space-siblings-parents-young person-autism-reflections-communicative action.

Connected by our experience, the multiple assemblages of the Collaborative Learning Group of mothers-reflections-discussions journals-words; the PhD researcher-university-supervision-community-thesis, generate multiple events spurring new becomings. In the context of this PhD study this is reflected in the communicative events within the home environment. Events activate change; they actuate conceptual and material connectivity, relationships, path-ways and environments (Beck and Gleyzon, 2016). For Deleuze, events begin with affect and are actualised in spatial expressions. Through the intra-action of affect within and beyond the material, events not only manifest in space, but also change and reconfigure material reality (Deleuze, 1993 see also Barad, 2007). Davies describes the human entity as a series of interconnected flows (Davies, 2014). Our young people feel communication events as embodied affect, visceral communication which reacts and flows, or intra-acts, in relation to the social and material environment. Conceptualising our communication in and of the assemblage not only deprivileges language but also acknowledges the spatial, embodied and material stimulus of the communicative events.

Voice in the research assemblage

Central to APAR as a methodological approach is the concept of communicative action rooted in the linguistic turn; a turn to consider language as central to the construct of knowledge (Habermas, 2015). Having previously discussed the need to deprivilege language in the construction of knowledge, this engagement with the linguistic through APAR appears to run counter to the posthuman ontological positioning that seeks to decentre and challenge the privileging of language. Similar to APAR, theory as praxis is a concept shared by the posthuman/ post-linguistic philosophies which highlight the importance of situated knowledge and the need to respond to specific social, cultural, historical and local contexts (Harley, 2013). Traditional research methods served to exclude the participation of the non-verbal or restricted-verbal autistic young people in traditional research process and practice (Saur and Sidorkin, 2018); a lack of verbal capacity often being perceived as a lack of intelligence (Dawson et al., 2007). This assumption serves to deny autistic young people a place in the communicative action that can engage them as active participants and co-producers of knowledge through the research process (McAdams and McLean, 2013). Privileging language in itself becomes a disabling factor in communication; and denies access to communicative engagement in research and knowledge production. Our autistic young people are disabled by the narrow perceptions that cognitive capacity can only be demonstrated through communicative action in traditional language. Rather than being a barrier to inclusion, this PhD study demonstrates that an ontological shift to acknowledge a posthuman and therefore, post-linguistic positioning allows us to build on and be informed by critical insights driven by the linguistic turn (Spyrou, 2019). APAR provides a value driven methodological approach which extends the reach of research to move beyond a conceptualisation of lack and incapacity, and engages the communicative capacity of our more-than-verbal family members *as it is* in family communication. This approach demands that this PhD study theorises the research process as an assemblage of communication events (Braidotti, 2006, Fox and Alldred, 2015, Abrams, 2017, Saur and Sidorkin, 2018). As such, whilst this study continues to centre the theory and practice of communicative action it allows a deprivileging of language and an expansion of what is recognised and understood as communicative engagement. Through APAR, in the context of this PhD research, our communicative *action* moves to become a communicative *enaction*. As such we acknowledge the many verbal, non-verbal, visceral and behavioural embodied events as valued communicative enactions. This positioning enabled us to see, acknowledge and value the authentic communication of our young people beyond verbal dialogue, to accept and recognise the embodied and enacted communication of behaviour, touch, movement, vocalisation, rhythm as suggested by De Jaegher (2013), Trevarthen and Delafield-Butt, (2013) and Caldwell, 2007, 2012). The exploration of communication through communicative action/enaction demanded that parents engaged in communication with their young person as it was in their homes. Through this engagement and focus on communication the action-reflection process served as an enabler in communicative encounters between family members; enabling the recognition of one another's situated communicative enactions as they were encountered between family members. This also increased awareness of parents own communicative enactions and the need to recognise and engage in forms of communication other than language. APAR, the situated action - reflection of authentic communication enacted by families in this study became a powerful process of enablement for young people and parents allowing better understanding and attunement to communication as it was within their homes.

Whilst communication drives this PhD thesis as theory, process and practice of the research, I remained concerned at the capacity of the research process to engage the authentic communication abilities of our young people (Saur and Sidorkin, 2018). Whilst I had built trust in the research approach, it was this shift to acknowledge the theories of Deleuze and Guattari (1987) that began to offer a resolution to this ethical and conceptual tension. Yergeau warns against the appropriation of neurodiverse experience by neurotypical agendas (2010). I am conscious of the fact that I as PhD researcher and, we as mothers, are non-autistic and our understanding of our communicative encounters with our autistic young people will always be from these differing positions. In the context of this study this drives our need to better understand, to be able to support inclusive communication. I do not propose that we can perceive of the world as our children do, nor fully understand and experience their processing and sensory experiences and challenges. By nature of the communicative difference in autism, autistic young people (in particular those who cannot access verbal expression) have been denied a ‘voice’ in research (Davidson & Orsini; 2010, 2013; Saunders, 2018). Exposing the space between us (Dwyer and Buckle, 2009) within families and within our research community began to expose that which was hitherto not noticed, APAR provided space to learn through difference (Deleuze, 2001; Braidotti, 2018, Freire, 1998).

Mazzei and Jackson (2017) suggest this posthuman and therefore post-linguistic shift demands new ways of engaging in research, de-centring and de-privileging previous standard research practices such as interviewing. This ontological shift recognises Braidotti’s (2010) critical feminist/posthuman positioning that challenges the dominant male perspective. Bennett (2010) and Barad (2007) take this ontological flattening further to engage human, non-human/environment as implicated in the event. Thus the events enables becoming which engages the continuous flow and flux of time-space-form-energy-human-nonhuman in a perpetual and interconnected flow. This positioning places the human in a relational entanglement with the human, non-human, the environment (Barad, 2003, 2007; Price-Robertson & Duff, 2016). Mazzei (2013) and Mazzei and Jackson (2017) suggest of the voice without organs (VwO) as a means of describing and understanding the concept of voice in the assemblage, decentring and deprivileging voice as it has traditionally been understood. By moving beyond linguistics, we acknowledge the call from critical autism scholars to challenge the assumptions of knowledge production and seek to find epistemic communities that can be driven by principles of meaningful involvement and from an autistic position of knowing (O’Dell et al., 2016) and entangled in the assemblage.

By centring our young people in their families and their typical communication environments, the opportunity to gain reflexivity and forming praxis supported a critical awareness and shift towards a flat non-hierarchical system of knowing. It allowed us to consider the mother's written and verbal reflections and young person's artefacts, but also the authentic more-than-verbal communication expressions and encounters, as forming the research assemblage (Yergeau, 2018; Ollerton, 2012). These situated in-family dialogues as communicative events are not directly evidenced through observation or interview (see methods chapter) but carried in family reflections in the reflective journal and into the collaborative learning group through mother-researchers storying. These recorded CLG discussions allowed the family perspectives and interactions to be present and to surface in our data (Stewart 2007). APAR data, generated through an iterative and reflective experiential engagement, carried the active interactions of the direct family communication and dialogue; feeling, touch, intuition, object or image events. By considering emotional affect, sensory engaged behaviour, more-than-verbal interactions and the embodied interaction, we have the potential to engage with our young person's communications as they are expressed at their unique developmental position (Somerville and Powell, 2019, MacRae et al., 2018). By turning to notice our vibrant child/young person we are more able to see, feel, hear, sense, their engagement in communicative events.

By decentring language as the privileged form and process of knowledge production we in turn decentre the human and in so doing, we move to recognise a more-than-human geographies of the assemblage (Panelli, 2010). We are opened to concepts of communication beyond linguistics and can consider the more-than-verbal expressions as intrinsic to communication interactions between family members and also forming our understanding and knowledge production. A multiple belonging of bodies-space-language-movement-journal-reflection-discussion-echo-touch in the complex non-representational entangled politics of our place and situation. Within this assemblage we also engage the material and matter as intrinsic to this discourse (Barad, 2007, Bennet, 2010) bringing bodies and spaces into the narrative:

> "The full range of contexts in which language appears is material in that speakers are alive, functioning, changing, and interacting. There is no sense that language is meaningful outside the situations of its use" (Bleich, 2001 p. 120).

APAR places the research process in the hands of those who are the subject of research; it answers Braidotti's (2014) call to 'speak from where you are', a radical immanence that challenges us to account for a situated position and a politics of location. In entrusting the research process to situated family members in this PhD study, data generated was through authentic and situated communication events. These communications engaged methods driven by the capacity and presentation of individuals present in the communicative events and the cultural context of the home in which they live and where their communications have grown. Whilst as mothers our sharing of the stories and reflections in our journals and discussions was through a linguistic form. This data carried the narrative of intimate communication interactions from each of the families in the stories, memories and reflections of more-than verbal communicative interaction with our autistic family members and included nuanced artefacts of notes and drawings that they shared. It is in these intimate and situated dialogic events that we must acknowledge the varied and situated forms of communication of our autistic people who rely on a wider assemblage of communication methods to express their communications and rhetoric (Yergeau, 2018). This relational and situated communication was carried in mothers' data. Mothers spoke of behavioural, affective, visceral communicative expressions and encounters. The accounts of our situated communication interactions surface in our reflective data but beneath this surface lies internal affective dialogue (intra-action) and communicative encounters (interactions) of our lived communication experiences, a vibrant and visceral communicative sub-terrain of our communication interactions (Chalari, 2016). Our young people's *voices* are more-than-words, and through the intimate events of mother-child-family we can begin to carry these expressions and encounters into the research assemblage.

It is here that I introduce the concept of a trace. For whilst it is possible to interpret the linguistic stories, reflection and discussions of the parents, this offers the *live surface* (Stewart et al.,, 2013) of the affective and embodied communication experiences of our young people in time and space. As such, I discuss the communicative expressions and experiences of our young people as a trace that is carried in the mother's data. A mapping of the surface of young person's authentic communication as we, as parents/mothers, see, feel and record these communication events. We need to understand that beneath this surface lies a complex non-verbal cartography of intensities and lived experience of communication suggested by the more-than-human geographies or assemblage (Braidotti, 2011, De Landa, 2016; Deleuze and Guattari, 1980). Braidotti (2013) suggests that;

> "The collapse of the nature-culture divide requires that we need to devise a new vocabulary, with new figurations to refer to the elements of our posthuman embodied and embedded subjectivity" (p. 82).

Whilst we continue to engage voice and written word as data, we are open to the situated emergence of these words from within the research and communication assemblage that consists of the live and lived experiences of matter and all things. A methodological approach that is situated and draws in that which is beyond the voice, that seeks action and interaction and captures the cultural and physical interactions, enables a holistic understanding of the assemblage and forces of human and non-human in an agential play of affect.

Rhizomatic analysis

As previously suggested, analysis was immanent in the research process of this study. There was a live and spontaneous analysis as we mothers involved in the research process; met and discussed, returned home to interact, see, feel and reflect. We were all immersed and we were all seeking themes and sharing these themes as we went through the data generation process (Somerville and Powell, 2019, Hackett and Somerville, 2017). Themes emerged through our dialogue and reflections and our young people contributed to this emergence. Through our family-based communication encounters they showed us what mattered, they guided and contributed not only to the generation of data but also to the analysis positioned within and of the family through an iterative and reflexive communicative inter-action.

Voice, written and spoken, moves from being the data to becoming a ‘the live surface’ (Stewart 2007 p.4) of data, beyond which is a shifting and moving rich and thick suggestion of our communications beyond words. Here we become aware of the post-linguistic entanglement and the interrelatedness of the situated communication events which lie within and beyond words; the assemblage of situated familial communication. Our analysis started when we captured the initial responses to our interactions within our family. Maclure suggests, what ‘glows’ (2010, 2013) attracts our attention. What feels important, what affects us, draws us; these experiences stick to us; “sticky data’ sticks out, sticks to and often gets stuck in our thoughts, feelings, in our throat, on the page, in fieldnotes, camera lens or memory” (MacRae et al ,2018 p. 503).

And in our events our children's repetitions showed us what mattered to them what *sticks* to them and to us. Analytical ideas and suggestions started to spontaneously emerge from the research process when parents began to revisit topics and to repeat phrases or experiences in an attempt to draw meaning. Starting within our first CLG meeting there was a keen contribution, a recognition by mothers of each other's accounts and an acknowledgement and valuing of each contribution. As we progressed through the meetings, I received questions for the CLG group, email links, an academic paper and training resources, these contributions were linked to previous discussions which the parents were recalling and connecting with. As discussions flowed, we began to expose patterns and repetitions. I became aware of themes emerging as they surfaced from the discussions. Starting in our first recorded meeting, a parent sent some questions for the group and this formed the basis of our next discussion. This collaborative and iterative approach allowed participants to identify themes that were apparent and valued by them at each stage, and the reflections and further iterations allowed them to revisit and re-evaluate them. Then we met and our reflections, dialogue and exploration of what had become an important idea for one family was mirrored in another person's reflections; they too had explored a similar idea and considered it in their practice. Where difference or tension arose, parents were able to reflect, and challenge or reinforce their own position.

This suggested the meetings and reflective process appeared useful and encouraged reflection for the mothers who formed the CLG; it also surprised me. Inherent in APAR is the involvement of participants in the process of analysis, however, I had anticipated that this would be something that I, as the PhD researcher, initiated or triggered in some definable way. In practice there was a fluid and organic emergence of this process. From an early stage we were all engaged in reflection from and of our discussion and experiences; we were analysing from our first meeting, responding to what sticks out, sticks to and gets stuck (MacRea et al., 2018). The iterative approach allowed us to revisit and reconnect to begin to expose communication events that spurred new ways of doing (Deleuze and Guattari, 1987). Our growing awareness of the child-parent in the communication assemblage encouraged an iterative approach to data generation and analysis. APAR gives equal value to all contributions to the data. The commitment to our democratic ethico-onto-epistem-ology (Barad, 2007) acknowledges the capacity of each of the family members in this research study, as researchers. This invested in a freedom to enable a spontaneous self-reflective, participatory analysis or Rhizoanalysis (Masny, 2014).

These connections and the family member analysis decentred me as the PhD researcher, a sense of deterritorialising (Deleuze 1997), new perspectives and altered perceptions surfaced from our shared and connected experiences. I felt my territory shifting and the deteritorrialisation suggested by Deleuze and Guattari (1987) was tangible (Masny, 2014). And then, a parent would recount an observation of, or interaction with their child and we are turned again to face the research from a different perspective, an encounter carried in our reflections of one of our young people who sees, feels and interacts from their unique autistic perspective and again, I felt a shift in my understanding. A jolt from outside my experience which again served to challenge my perceptions and place. The capacity within the parent research group to bring theoretical suggestions to the table served to deterritorialise my position as *the* researcher (Deleuze et al., 2004, Deleuze and Guattari, 1987). Braun and Clarke (2006, 2017) describe thematic analysis as an organic analytical tool. As *themes* erupt in our community practice, sticking to us and sticking in our thoughts, they assembled in our discussions, there was a sense of the organic, the ruptures reminiscent of the rhizome (Deleuze an Guattari, 1987). In this process we experienced the events described by Deleuze and Guattari (1987) which spurred new ways of doing, understanding and interacting within our communication encounters. Masny

(2014) engages a rhizoanalysis as a non-hierarchical and non-linear perspective to conducting qualitative research. This spontaneous responsive analytical process provided a significant situated analytical response that offered an inclusive precursor, a way-in to the subsequent thematic analysis. I include an extract from my reflective research journal that I kept as an academic tool to support my reflexivity through the research process, which captures my awareness and experience of this process;

> A parent presents a theory, we discuss this in relation to our children. We discuss the needs and implications. Later, I go back, I sit and listen to and read the data we have generated to date. This suggested theory indeed connects to ideas and experience that we discuss and revisit throughout our dialogue. I begin to harvest the words and repetitions. Themes seem to surface and then disappear below ground. Later I begin the next step of reflection and engagement. An email comes through from a parent participant from the CLG, with a message along the lines of…'this looked relevant to the thing we were discussing (the idea)'. I read it, it is relevant and links me to another paper. Then, I go back to my autistic son and we play. We are at an inclusive and interactive movement and dance event. I swing him upside down on my arm, then watch him harnessed and walking up a wall. Words from our meeting echo back to me. The theme rises from the ground and meets me again. I bump into a parent from the study, 'you see this is what we were talking about, and in the paper I sent you' …"Yes, I sent one back which links to movement and interaction". We move away, the theme disappears back underground. The Rhizome - these rhizomatic eruptions offer the discovery of initial ideas" (Reflective research journal).

St. Pierre (2017) offers an alternative to conceptualisation of coding data suggesting that Rhizoanalysis was a way to work with transgressive data; emotional data, storied data, loving data, (St Pierre, 1997, p. 175), that erupts spontaneously from the research assemblage. St Pierre proposes that "Data is not read in the traditional way as evidence, but rather as nonrepresentational, transgressive" (1997, p. 174). It disrupts the concept of methodological thinking by establishing that there is no beginning and no ending to her project. Rhizoanalysis is an assemblage (participants, researchers, research settings, families etc.) that disrupts or deterritorialises *in situ*, "something that allows time to take off on a new path" (Colebrook, 2006, p. 57).

Hofsess et al. (2013) suggest a revision of how qualitative data is understood to move "-away from data conceptualised as stable, knowable and collectable" and instead to conceive of data as "*words at play in theory*" (emphasis in original, p. 299). Rhizoanalysis (Masny, 2014) accepts the transcription as text, it is a "sense event in which sense emerges" (p.7). Initially transcribing the data, I was re-immersed in the dialogue and the emotion of the engagement, the search to reach and secure our children who struggle to find their 'voice' and place in the world, the tensions, anxieties, preconceptions, challenges to communicate and understand. I was diligent in my transcription. At some points I felt saddened, concerned at the pressure or distress that some of our family members were experiencing. At other times I was lifted by the care, love and commitment; the humour, engagement and initiative that came through in the dialogue. At all times, humbled by the knowledge, intelligence and capacity demonstrated through the discussion, throughout the families. I heard parents reflect on their engagement and their interaction seeking understanding, what did it mean? How could they have responded more effectively? What did they miss? We listened to each other, and together sought ways of understanding. We referred to our conversations and experiences with other family members, the tensions as our children grow and sought their space, place and independence. This initial encounter with the data as a transcribed text allowed me to experience the corpus of data but also to revisit and re-experience the emotion of the discussion and events. The rhizoanalysis established an initial trace of affective data analysis to then follow through a process of thematic coding and analysis. As Deleuze suggests;

> “More generally, it’s not beginnings and ends that count. Things and thoughts advance or grow out from the middle, and that’s where you have to get to work, that’s where everything unfolds” (Deleuze, 1993, p. 161).

As I later describe in the findings and discussion of this thesis, I will refer to the findings as a trace. That which remains elusive, a liminal space of communicative entanglement that suggests and traces, rather than finds and interprets, what is significant from the communicative expressions and enactions of our young people in communicative interaction. We follow the trace carried in words and data generated by the study but also acknowledge the whole assemblage in which this data is entangled.

Thematic Analysis

The second stage of analysis built upon the initial and spontaneous rhizomatic response from mothers and engaged a re-reading and coding of the full corpus of data, through a thematic analysis. This second phase allowed the themes that had begun to surface to be explored and critiqued, followed and expanded, providing an analysis of what we experienced in our communication events. Advocating ‘the mangling of practices’ (Pickering, 1993, Jackson, 2013, Hekman, 2010), Pickering offers an onto-epistemological process of qualitative data analysis in a posthuman paradigm;

> “human and material agencies [are] reciprocally engaged in the play of resistance and accommodation. …This reciprocal play of resistance and accommodation is the mangle” (Pickering, 1993, p. 567).

This approach suggests that the need to code and establish a thematic categorisation denies the human *and* non-human agency in the play of resistance and accommodation. In exploring posthuman data analysis Jackson (2013) advocates mangling practices, explicating the complex interrelationship of human and non-human in scientific research and practice. It is important to consider a broader social and physical environment when exploring data and seeking theoretical understanding. Hekman (2010) asserts that the concept of the mangle is useful for social science inquiry and practice, particularly as it locates agency in the material, thus decentring the human individual (Hekman, 2010). The consideration of forces inherent in Pickering's mangling of practice is an important reminder of the need to consider the intra-action of material forces in the research assemblage, particularly when faced with what is in essence a collection of *voices* in written and recorded form.

If our autistic young people experience the environment through altered social and sensory perceptions, then it is essential to conceptualise through a broad and reflexive lens. The mangling of practice challenges my preconceptions of meaning and my capacity to translate data into new knowledge without considering the altered perceptual positionality of the children in our study. Yet, rather than precluding the thematic analytical framework as suggested by Pickering, I recognise the need to increase my openness to material agency (Barad, 2007) within our Thematic Analysis and interpretation and re-interpretation. This challenges Jackson's (2013) suggestion that traditional qualitative (thematic) analysis cannot stretch to include this world view. I would suggest that it is the traditional methods of data collection and preconceptions, which inform analytical conceptualisation and deny the inclusion of material or non-human agency. However, if we acknowledge the assemblage of forces in resistance and accommodation, we become aware of their impact as events within and of the data;

> "Discourse and matter are understood to be mutually constituted in the production of knowing in a flow of continuous differentiation" (Lens-Taguchi 2012 p. 268).

If we acknowledge this situated and entangled approach, then thematic/coded analysis has the flexibility to form part of the analytical assemblage of our communication events. Maclure speaks of her need to go through the slow intensity of coding (MacLure and Koro-Ljungberg, 2013). I engage a thematic analysis not to establish a *better* analysis but to be able to revisit and explore the collective data, to read and explore the words, stories, events and artefacts of the assemblage reflexively – to not prioritise my own perspective. Revisiting the text allows rereading and reliving the emotion, the tensions and affect of the data assemblage; the words, actions, observations, absence/presence, notes, images and stories, which must be searched deeply and respectfully (Lenz Taguchi, 2013).

The textual and visual data generated through our CLG includes the discussions, reflective journals in varied and responsive methods which include artefacts from some of our children. Themes as defined by Braun and Clarke (2006) capture something important about the data relative to the research question and provide a pattern through which a collective meaning can be derived. Coding describes the process of examining the data, to recognise and note those aspects that relate to your research question. Whilst thematic analysis and coding are used broadly in most qualitative methodological approaches, its application in autoethnography is contested (Bochner, 2000). Similarly, coding seemingly runs counter to the positioning of a Deleuze-Guattarian assemblage in which objects, people, emotions, vocalisations, states of bodies, combinations of bodies, are all part of the assemblage in an "unholy mixture" (Deleuze and Guattari ,1987), rather than an ordered hierarchy. In the research assemblage the linguistic, textual data becomes only a part of the assemblage of things and other regimes of signs. The data carries affective events (Grosz, 1994) that give rise to both the emotional expressions and the problem of responsibility. Applying a thematic analysis to the data I am deterritorialised, yet with an awareness of the danger of being reterritorialised in the traditional analytical practices and habitual ways of reading data. “Representational thinking categorises the world and establishes hierarchical relationship” (Maclure and Koro-Ljungberg, 2013). The rhizoanalysis as a lived analytical experience complements the detailed, focussed analytical process following the affective trace through a detailed search. Whilst the situated, affective and fragile data is allowed a fluid emergence and analysis through a rhizomatic approach, the thematic approach allows me to take a different viewpoint to decentre my immersed position. I am also conscious of the rigour requested by others in our values discussion explored in the initial meeting. The values sheets asked family members to consider what was important in the family research process. This vignette was captured by a mother to include in her reflective journal;

> Dad: I picked accuracy, compassion, empathy, integrity, openness.
> Mum: why did you pick accuracy?
> Dad: cos.. erm, I’d like it to be an accurate measure of …(child interrupts) results.
> Mum: How would you measure that accuracy?
> Dad: Just by being thorough.

This thoroughness suggests to me a need to work through this body of data slowly, methodically. The values selected by the parents in this study form a value base from the participants that have driven the research. This body of data feels very precious not just from the perspective of confidentiality and university protocol. Words, an image or note, drawing or photograph are nuanced artefacts and stories: carrying important information from within families where communication is precious. It falls to me to open and explore these gentle thoughts and words that carry the care and nurture of loving homes, of intimate relationships and dynamic or emotional events. It feels almost too precious to touch and I realise that this is in part because my family is also situated within this data. I have already felt the emotional impact of being the insider/outsider researcher and the need to revisit and reflect and critique my presence in this research process. Far from rejecting the evocative and heartfelt (Ellis, 1999) this process feels more like curating, giving space and time to these precious artefacts and words. Family members within this study cannot speak, name or describe their feelings, or engage in complex dialogue about their views or perceptions and as such the process of seeking understanding through thematic analysis must be carried out with a sensitivity and thoroughness but also a multiple lens and reflexivity which acknowledges the posthuman/post-linguistic condition. As described by Mazzei's (2013) 'Voice without organs', our data 'speaks' from multiple viewpoints. Implicit in the data is the non-verbal presence, in the gaps, the silences, the stories, the objects and ephemera. Subtle, personal, nuanced, material, affective and storied. There is a non-verbal/altered perceptual participation in the data and through an iterative repetition, in the analysis.

The findings and tracing of this study are presented in two sections. The first considers the broader concepts of space and time as facilitators for the communication, and catalysts to inclusion. The second section traces the intra-actions and intensities, the differences and repetitions; a more-than-human communication of child-young-person-adult-family.

Chapter 4 – Methods: the research practice

Five families, including my own, were recruited to engage in research to explore inclusive communication within their family. Family members engaged in the typical dialogue and interaction that they would usually engage in with their autistic young people within the family. This allowed parents to begin to reflect and further understand their young person's expressions and communicative abilities, and how they interact within their family. Reflections and discussion in the CLG enabled parents to explore their communicative interactions and to identify methods and approaches, needs and interests, to inform further communicative engagement. Each family was asked to elect a representative to attend meetings and take on the role of generating a reflective journal. This person or persons would act as gatekeeper (Lavrakas, 2008) for their family and would attend our Collaborative Learning Group (CLG) to interact through discussion and reflection with gatekeepers from the other families in the group. We became 5 families engaged in researching our situated communication with our young person(s) on the autism spectrum within our families. APAR allowed us all as active co-researchers to contribute to the process of communicative action through whatever form of communication was authentic to the person. The action reflection carried in reflective journals and CLG discussion, provided an iterative process of action-reflection and collaborative learning within and between families in our communication-research assemblage. (see figure 4 for structure).

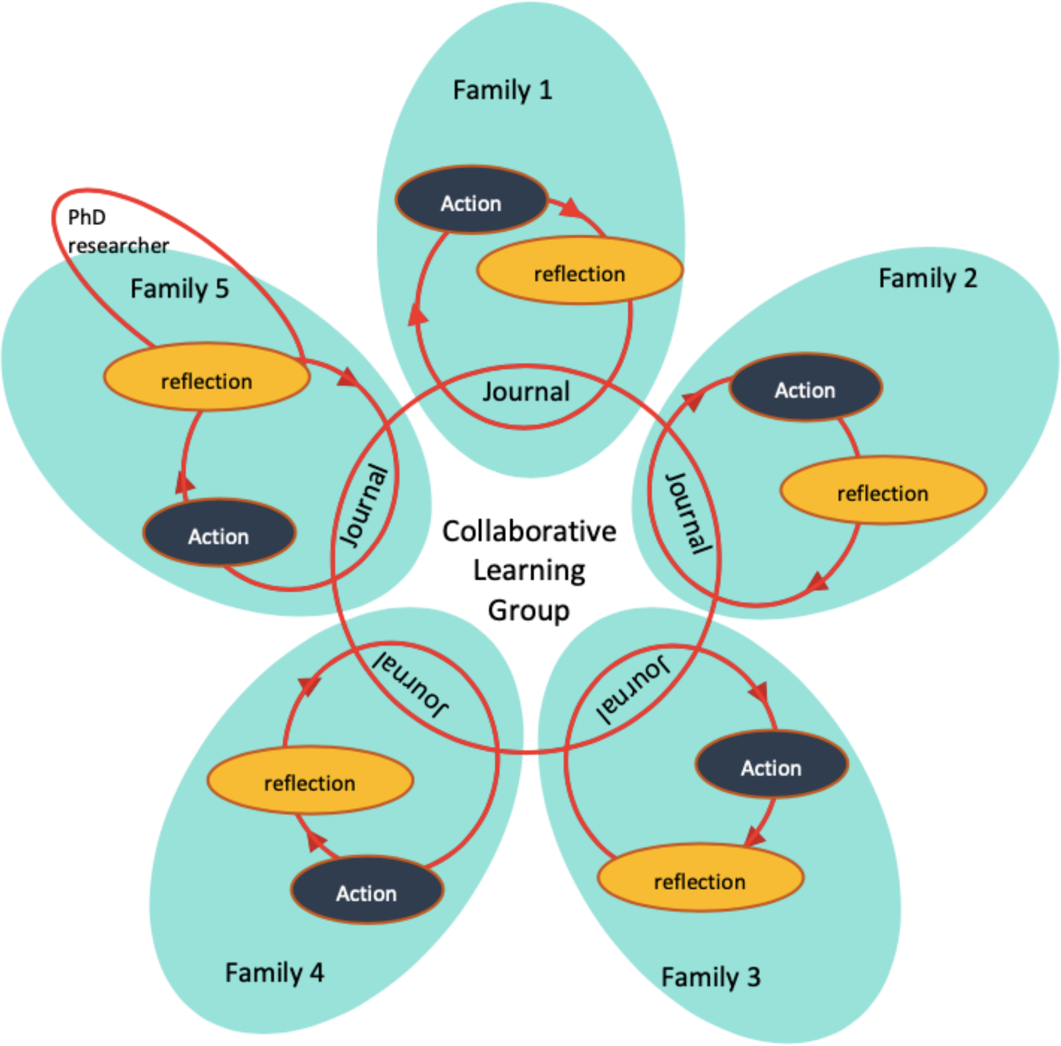


Figure 4: Collaborative learning group and research structure

In practice it became the mother from each of the families that chose to engage in the CLG. This dialogue enabled the sharing of insights, issues and challenges, exposing each of us to alternative perspectives, new ideas and ways of doing/being. Across a period of 10 months we held an initial meeting and then 6 audio-recorded meetings. Gatekeeper mothers in each family kept a reflective journal, generated within each family and including artefacts from their young people, where they chose to contribute. The meeting transcripts and journal provided data for analysis to understand the lived experience as we endeavoured to explore our family communication and consider inclusion in this context.

communication in the connect of our families. Our Collaborative Learning Group interaction and the reflective journal provided opportunity to understand the links between feeling, thinking and doing; how we feel affecting how we think and subsequently what we do (Ghaye and Ghaye, 2010). Ghaye and Ghaye (2010) describe a practice of ‘positive, purposeful action’, with the purpose of ‘bettering or improving something’. This active approach to understanding our lived experience to affect positive change seeks not only to explore inclusion in communication, but to actively engage our young people as active in the research practice as experts in their communication.

Recruitment

To understand the nature of recruitment and how our research community was formed, I will describe how the families participating in this study came to be involved. This exposes not only the process which brought the families together but also alludes to the community context of conversations which informed the research design and study aims.

Family 1
In nursery our son diagnosed as autistic went to school on the transport provided so we rarely met other parents. We sporadically met families through the network of parents and events linked to our children’s diagnosis. I regularly encountered a family whose child was in nursery class with my son, we often chatted about our experiences. Several years later they became family one. This family consisted of Mum (Maddy), Dad (now separated), Will, aged 9 and Rosie, aged 12. Will and Rosie are on the autism spectrum. Will is nonverbal and Rosie has minimal verbal communication.

Family 2

A member of the team I worked with in an educational setting was negotiating her way through the family experience which led to her son's diagnosis of autism. She knew that my family had been through a similar experience. We met for coffee and chats on a number of occasions and talked about approaches, shared stories and listened to each other's experience. After I left work to pursue this research study this colleague was aware that the research was around inclusive communication, families and autism; we kept in touch and the family expressed an interest in the study. A year or two later, family two: Mum (Josie) and Dad (now separated). Josh aged 9 is diagnosed with autism and has a younger sister.

Family 3

My son participated in a small number of research studies, through involvement as a parent representative I met another mother of a boy with autism. We had a few brief conversations over time relating to this proposed research study. This mother expressed an interest. Several months later this family became family three: Mum (Kate), Dad, Dan aged 14 and diagnosed with autism. He has an older brother and sister.

Family 4

I had set up a small group for young people my son knew, to engage in a movement and relaxation session. We had space for another child and the therapist delivering the session invited a child she knew to join this session. This was around the time I was recruiting to this PhD study and the therapist described my research as she understood it. The family expressed an interest in participating in the research, a few weeks later, family four: Mum (Jen), Dad and Ollie aged 13 who is diagnosed with autism and has an older and a younger brother.

Family 5

My family; building on the positive experience we had in our Masters' research study we felt that the opportunity to explore communication further as our son was older was a positive continuation. The action-reflection cycle had continued since the previous study and we were keen to reinvest in this process. My involvement as a researcher participant provided a unique and embodied perspective on the study engagement, one that would allow an immersive experience of the research process and personal investment and impact, family five: I as Mum, Dad, Charlie aged 12 and diagnosed with autism and his older brother.

These families are self-selecting in that each of them asked for information on hearing about the study and chose to participate. Keiding and Louis (2016) acknowledge the bias that this self-selecting approach brings in on-line study participation in health care. In survey study data this is likely to have a marked effect on study findings. In the context of this APAR study it this self-selection which drives the study, family members are specifically asked to bring their situated experiences to the research process. Through discussion they enquired about the study, requested further information and expressed an interest in joining. And so began the process of full informed consent (see appendix 1 for Participant Information Sheet and consent forms). I was previously acquainted with three of the four participating mothers and this allowed me to talk about the development of the study through community engagement. The fourth family was recruited through discussion with a third party, the relaxation and movement therapist. Whilst I recruited through the community of parents of young people with autism, I made no direct requests for these families to join the study recognising that we are acquainted, and people may have felt pressured to engage. This community relationship is highly likely to have influenced the family’s choice to participate in the study. I am conscious of the subjective nature of this study and the bias that is carried in the small sample and the narrow social profile of the families who chose to engage with the study. Whilst this does not provide a broad understanding of social and cultural differences in families and how this impacts the communication interactions, this is not the focus of this study.

What this research does engage is a breadth in the autistic communicative profile of young people. The six young people on the autism spectrum in this study have very different abilities in social and functional communication and as such, provided a dynamic and deep experiential narrative of what it is to be autistic. Our aim as parents was to explore our family communication, learning with our autistic young people to better understand our communication and how to support inclusion.

Through the initial stages of the recruitment process I discussed the study in more depth with the mother from each family and the time and commitment that would be required, particularly from the gatekeeper parent. Each of the mothers talked of their family’s efforts to support their child(ren). They understood that communication was important for them and felt it was important to understand how they might respond more effectively and how they could support the broader family to interact. Three of the parents also expressed a concern relating to the levels of anxiety that their children were experiencing and hoped that investing in communication might also help them to understand and support their child’s anxiety. Critical feminist philosopher, Rosi Braidotti describes this grounded need to act;

> “…the pursuit of practices of hope, rooted in the ordinary micro-practices of everyday life, is a simple strategy to hold, sustain and map out sustainable transformations. The motivation for the social construction of hope is grounded in a

> profound sense of responsibility and accountability" (Braidotti in Van Der Tuin and Dolphijn, 2012, p. 22).

Parents in the study came from a range of educational backgrounds and attainment. Much of the literature in autism looks to explore the deficits, difficulties and difference in order to develop understanding. As previously discussed, literature on families with children with autism tells us, as families, that we experience increased stress and vulnerability, that we regularly make adjustments to meet the needs of our children and that we are challenged to engage in typical family activities. Whilst there are no-doubt significant challenges and tensions facing our families each day, there are also significant positives to share and learn from. Families chose to participate in this study, mothers expressed an interest in working together to better understand their family communication looking to include their young person with autism. In a similar vein, Biklen refers to the ”optimistic approach” (Kliewer et a., 2015, Biklen et al., 2015, in Biklen and Attfield, 2005). Biklen actively chooses to look at situations which can be described as successful and learn from them. The families in this PhD research study are actively seeking new approaches through their involvement in this study and committing to the effort and work involved in the process. By actively seeking inclusive practice our families could be described as valuing communication and assuming the engagement of their young person and therefore engaging in an optimistic approach. Rather than asking '*can* our children be included?' they are actively seeking to explore and understand communication and asking themselves, '*How* can our children be included in our family communication?' This study establishes a community of practice which has emerged through natural processes of the lived experience. It draws together families who are seeking to find *inclusive* ways of interacting relevant to their particular situation and therefore, families that have this optimistic approach in common. The APAR positioning of this study and the associated subjectivity has strong influence on the recruitment process and the resulting participant profiles. As a member of the community of parents of children with autism this study draws on my/our personal situated experience.

In the emergent CLG it was the natural affinity with others which drew individuals together and determined the participation of families and the membership of the CLG. Whilst our social demographics may not be diverse, the common experiences in our communications with our children held the potential to inform practices across all families with young people with autism. Family social and political circumstances will differ across the wider community of families with young people on the autism spectrum. The challenges of social and political forces acting upon our communication encounters will impact in different ways, amplified or mediated relevant to individual family circumstances. The challenges and situations may differ within and beyond our small group of families. However, the presence of our autistic children and their ways of engaging in communication held commonality and enabled us to understand and contribute knowledge of the lived experience of communication engagement in our community. Far from being exclusive to our small group of five families, the findings from this participatory, community driven research have potential to inform our understanding of the experience of the many families who live with such altered communication environments and encounters, and to seek answers, direction and ways of communicating.

Sample

Mothers as gatekeepers

Each participating family selected their gatekeeper parent, who came together to form the CLG. Each family selected the mother as their gatekeeper parent. The position of mothers as gatekeeper parent may have been attributed to a number of factors specific to this particular study. My position as researcher was no doubt an influence on this selection in that I recruited to this study through my situated position as a parent in this community. This drew in many threads of gender roles, power, feminist and critical family discourses, which could all have been explored in response to this occurrence but were beyond the bounds of this study. I am aware that the recruitment through community connections would have influenced the choice of mothers to become the gatekeeper parent. The emergence of this study from my lived experience shaped the study design and methodology and reflected the current culture in the UK relating to gender and childcare roles, where women continue to manage the primary responsibility for childcare (Lyonette et al., 2011). Ryan and Runswick-Cole (2009) suggest that it is likely that more mothers of disabled children will take on the caring role than in other families (Ryan and Runswick-Cole, 2009).

This study did not actively seek to explore gender roles, however, where concepts relating to parent gender roles converged with the purpose of this research study, this was explored appropriate to the context of exploring communication. I acknowledge that the dialogue, findings and subsequent discussion would be influenced by this gendered positioning. It locates Braidotti’s (2014) humble call to do something from the places where we are. The choice of mother as attendee is a choice within each family, and was reflective of the gender roles associated with these particular families. This is who we are and how we came together and is, as such, accepted and built upon as it was presented. This is the design of the study as it has emerged from an APAR perspective, and it was for the dialogue within and between families and through the reflective process to expose concerns relating to this concept of parent roles and gender in family communication and any issues which emerge relevant to the study aims. The allocation of mother as gatekeeper was the choice of each family. This was the lived experience in which we sought to explore communication.

Our young autistic people

The families recruited to this study each had a child/young person or, in the case of one family, two young persons with a diagnosis of autism. Our children were in a period of childhood described as middle-childhood or early puberty, aged between 9 and 14 years of age. Other siblings in the families ranged from 4 to 16.

The six children diagnosed with autism participating in the study had varying use of verbal communication and each a unique profile of abilities. One child was non-verbal with no spoken words, two children had very limited or restricted communication, and currently or previously used extensive echolalia. Two children had vocabulary typical or beyond their age yet struggled to access this in conversation or when pressured or anxious. As such, the children in this study accessed the wide range of spoken language skills typically associated with autism. I make explicit this range of spoken language use or accessibility, not to define or suggest levels of ability, functioning or capacity but to describe the availability of spoken language available to our children. This was an area of potential tension for me as the instigator of this process. The differing skills or abilities of our children could have left parents feeling an increased sensitivity to the pressures or worries of having a child with no verbal communication and had potential to cause distress. The distance between the presentation of a child with no verbal expression and a child with strong vocabulary could also have had a negative impact on the ability of the parents to empathise and connect, and to be able to draw meaning from their discussion and engagement. However, this difference and space between experiences became an important aspect of our learning (as alluded to in the discussion on methodology and further explored in the discussion chapter). I was aware of this tension and also remained mindful of this potential for distress through the course of the meetings and interaction. My tension around this area decreased as the CLG almost immediately began to refer to this topic, this provided opportunity for discussion and sharing of perspectives around the differences of communication abilities of our young people. This range of unique skills in our children was typical of the families I regularly meet through the various social opportunities and encounters. Recruitment reflected the typical encounters and networking of families and the range of skills and abilities our community of children typically have.

Where children with autism were non-verbal or used few spoken words, and could not explicitly acknowledge understanding or give consent, we inevitably looked to the ethical considerations of the study. Whilst we sought consent from all young people involved in the study, we were not able to establish consent or assent from the children who were unable to communicate through spoken, written or visual language. Whilst I attempted to provide materials in relevant form, this was a tension in the study as discussed in the ethics section within the previous chapter. As previously suggested, it was the engagement through the APAR approach that aimed to enable the contribution of our young people as they communicated and through a process of learning from them through their situated interactions. Whilst this engaged the authentic contribution of our young people in the process of families exploring communication, it did not offer a solution to our ability to gain consent from all of our young people. Similarly, the inclusion of the whole family and the child within the family aimed to take a holistic look at the communication environment, and as such, we did not problematise our autistic child. Where children were unable to articulate their consent, we looked to their behaviour as a means of describing any distress or negative effects of the study and used the collective response of the children and young people to guide our perceptions and understanding of what was appropriate, relevant and acceptable to them in terms of methods of engagement in the study process.

Consent

The majority of participants provided consent to full participation in the research process. The exception being two of the young people where their mothers were unable to reliably communicate the nature of the study and where the young people did not have the established communication abilities to engage in the consent process. It was explained throughout the recruitment process that consent would be at each individual family member's discretion. Three family members chose to not actively engage but were happy that the family would be involved, and their presence and participation would be acknowledged and represented in the data generated. This position was particularly relevant to older siblings of one of the autistic young people, one father in the study also adopted this participatory position, comfortable with the family involvement but not in a position, due to personal circumstances, to actively or proactively contribute to data generation.

Our consent forms asked if family members would be willing to be photographed and/or videoed as part of the data generation for the study. With the exception of one family who were all willing to be videoed there was a general rejection of the notion of video from the children and many parents. Whilst this had been a very useful tool in my interaction with my son in my previous Masters study, the children in this PhD study were older, and the message from many of the children who could reliably say no, was no! This reluctance across most families also suggested the level of discomfort in other family members. This provided a clear and effective message that we would not be using video. It also suggests that such a method whilst highly useful for reviewing interaction with non-verbal communicators may not be a method that we can assume they are comfortable with, as such it is something that should be used with care and consent should be sought through relevant and appropriate actions where researchers choose this approach.

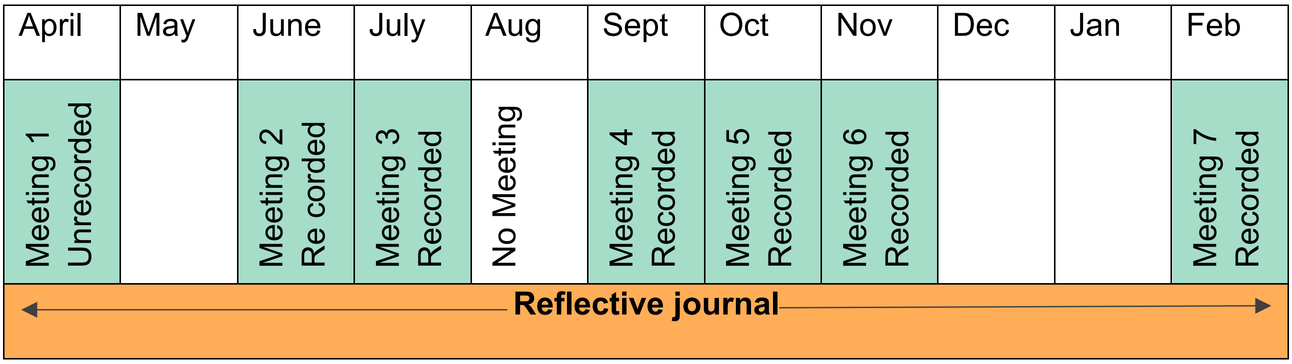
Methods

Data Generation

Data was generated through the following methods over a period of 10 months:

- Mothers as gatekeeper kept a **reflective journal**, which included some contributions from the young people and other family members reflecting family discussions, interaction and included artefacts provided by our children.
- The **Collaborative Learning Group** of mothers at gatekeepers met a total of 7 times to discuss communication; the first meeting was unrecorded, where the study methods were discussed and agreed. Six recorded meetings then took place; five

of these were monthly, with the final follow-up meeting taking place after a 3-month period, as illustrated in figure 5.



April	May	June	July	Aug	Sept	Oct	Nov	Dec	Jan	Feb
Meeting 1 Unrecorded		Meeting 2 Re corded	Meeting 3 Recorded	No Meeting	Meeting 4 Recorded	Meeting 5 Recorded	Meeting 6 Recorded			Meeting 7 Recorded
← **Reflective journal** →										

Figure 5: timeline of meetings.

Collaborative Learning Group

As part of the APAR methodology, we, as mothers and gatekeepers, established a Collaborative Learning Group (CLG), building on the concept of the Community of Practice (Wenger 2000). The community of practice is typically formed by people with a shared interest in developing their situated knowledge through collaborative learning. In our research, regular meetings and shared experience allowed a reflective approach to learning. Mothers attended the meetings and moved between their family (itself a Community of Practice) and the CLG Community of Practice establishing an action-reflection cycle that moved between in-family communicative engagement and the discussion of the CLG (as previously described in figure 1). In-family interaction was captured in the family's reflective journal and shared within the CLG discussion group. Cook (2004) suggests that the process of members expressing their thoughts appears to be a first step to recognise ways of making changes, as well as beginning to acknowledge that they could affect change. She quotes Heaney:

> “What is articulated, strengthens itself, and what is not articulated tends towards not being” (Heaney 1999 in Cook, 2004, p. 87).

This PhD study design identified 6 meetings held on a monthly basis, and a 7th final meeting, held after 3 months to allow us to see if reflective practice continued and to member check formative thematic analysis. Our CLG meetings were set up to allow open discussion around in-family communication and to share experience and reflections of communication interaction in family life. Crucial to this process was the trust in and between the gatekeeper parents and the wider family members, across the families. To further support the process of establishing trust I held the first of our meetings unrecorded. This offered a less intrusive start to the process, a chance for mothers to meet one another and to ask any further questions before committing to the recording of data. From the first meeting I was aware of the richness of the data, the personal perspectives and insights to family engagement and also the sensitivity and the living ethical practice that underpinned the stories and discussion. The initial meeting allowed us to discuss the process. We discussed the open structure of the meetings which allowed for dialogue around the experience of communication and enabled the parents and families to influence our direction. Prior to our first recorded meeting, a parent sent some questions that she had been pondering, these were well received, and parents suggested and agreed that if anyone had specific questions these could be shared prior to the next meeting to allow others to reflect and contribute on these topics. I provided a reminder of date and time via email prior to each meeting and included any questions that had been sent by other parents allowing time to reflect and consider contributions informed by responses to these questions.

I have previously mentioned the thoughts and discussion around the process of seeking consent from the child and young people who were non-verbal. These thoughts and reflections formed much of our discussion in the first unrecorded meeting and became an important aspect of shaping the study and reflections in the rest of the study process. Prompted by this experience and the discussion and thoughts we explored, I received the following questions from a participant mother and raised these at our second meeting. Generated by Maddy through her reflective journal, the following questions were shared early in the first recorded meeting, and stimulated the discussion that unfolded;

“I'd really appreciate learning what other people think about these things…

- How do you talk to your kids about their own and others' behaviour if you don't know if/what they understand about the language we use when discussing behaviour?
- If ‘talking about your feelings' isn't really an option – how do you help a child process a difficult experience?
- How do we, as parents, get better at listening to behaviour?

The group found these a very useful prompt for thought and reflection. We agreed it would be beneficial, should they choose to, for parents to send any questions to the group in advance of the next meeting. Where someone had a specific question, this could be used to support reflection but also offer a potential focus for discussion. These questions were not always forthcoming, however other things followed such as links to training or news articles, which served a similar purpose, as a catalyst for reflection. As the meetings progressed the recognition and shared interest and engagement provided rich dialogue, and interaction felt more comfortable and connected. There was a continuing investment in our community and our practice. Our discussions, although introducing difficulties and challenging situations and emotions, were positive, supportive and respectful of each other and our families. All meetings were transcribed verbatim straight after each meeting to ensure the nuances and experience of the encounter was still fresh. These were checked again for accuracy. I transcribed the meetings as I felt this would be an important process, enabling immersion in the data.

Ghaye and Ghaye suggest that when thinking about improving what you do with others and for others, thinking and conversations can often get stuck with vocabularies of human deficit, failing to engage the creative potential and problem solving of people involved (Ghaye and Ghaye, 2010). They further suggest, that by asking ourselves positive questions we can engage a different type of conversation- “one that brings with it the opportunity for positive action” (Ghaye and Ghaye, 2010). Our aim of actively exploring communication established a positive focus from the beginning; meetings and reflections were purposeful around this focal point of understanding and supporting inclusive communication.

Reflective journal

Gatekeeper parents (myself included) took a lead in generating a Reflective Journal, to capture the parent’s thoughts and the dialogue and engagement within the family. This allowed us to capture reflection *in* action and *on* action (Schön, 1990). As Schön states, professionals have become essential to the very functioning of our society. For many families of autistic children, these professionals have become the source of knowledge with regard to our children. Yet, arguably, as parents increase their knowledge and understanding of autism and engage with their children, the process of action-reflection can enable us to increase the reflexivity which supports us to action our knowledge and learn from our action, not as professionals, but from a situated parental positioning. As Schon describes;

> “reflection in action is where we may reflect in the midst of action without interupting it. Our thinking serves to reshape what we are doing while we are doing it” (Schön, 1987, p. 26).

Specific to each family and child, some children have contributed drawings and notes and through these artefacts and the engagement and enmeshed emotional interaction (Ryan and Runswick-Cole, 2009) and young person’s personal narrative (Chalari, 2016) we are given glimpses into the communication interactions of the young people as they are lived. Sanger suggests;

> “The argument as to which forms of data are authentic comes down to the degree to which data are indicators of life as lived” (Sanger, 1994, p. 74).

Mothers were given notebooks and folders to use if they chose to keep a handwritten journal or to collect artefacts or notes. They swiftly adjusted to use a range of methods of recording their reflections. Emailed journals, word processed documents, a handwritten notebook and in one case a closed video extract. Some were extensive narratives, some focussed and with bullet points. Each provided rich descriptions of family communication engagements or succinct responses. In practice it was the mother from each family that kept the journal. Whilst children and fathers did not directly write into the journals the journals captured family discussion carried in the mothers’ reflections in their journal entries. These also included letters, notes, drawings and photos which were contributed by our young people and in some cases siblings. Some of these notes were artefact were generated in direct response to the study process, such as the photographs, others such as the drawings and notes were spontaneously generated through typical family communications.

Family 1

Maddy kept the journal for her family and presented this as word documents and a video which shared via secure link. Whilst Maddy was very interested in the potential to use video and took a camera, Will and Rosie did not engage with this. Maddy felt that this was something that would need to be introduced over time and did not have the resources to do this at the time.

Family 2

Josie kept the journal for her family and provided this in a number of formats. She audio recorded her family talking about the values sheets and brought her sons' sketchbook to meetings although this work remained personal to Josh and whilst he was happy to share in the meetings did not want to directly enter this as visual or written data. Josie took a camera to see if the children wanted to use this to record things that were importance to them, whist they showed some interest this was not fully engaged with.

Family 3

Kate provided a very succinct and highly insightful account of her experience of the study with particular focus on giving time for communication. This was summarised as a word documenting and gave a very clear account of her experience and the benefits she felt from the study. Her journal reflects the interaction and engagement with other family members.

Family 4

Jen kept a handwritten journal for her family and included drawings from Ollie that his younger brother had also worked onto, she provided photocopied pages from the journal as data. Ollie was particularly interested in using the camera and adopted this to use to show images that held significance for him. The family each took photos and shared these with each other, Jen thought was interested in continuing the use of photos as a reflective tool beyond the study.

Family 5

I kept a journal in my family and added notes, drawings and thoughts from family members. I often found that I was revisiting, and analysing others comments in relation to my own family communication experiences, this journal ultimately merged with the reflexive journal that I kept as a PhD researcher. I introduced the instant camera to see if the family wanted to use it. The children provided images for the journal.

Methods of in-family engagement

The initial method for engaging in communication and interaction to generate data was to observe and engage in typical family dialogue, and to specifically give time for 1:1 interaction between mother as gatekeeper and their young person(s). I introduced the suggestion of the method of giving 1:1 time, building on the findings form my previous MA study. Our family had found this to be of benefit in exploring our communication and promoting inclusive practices. This was discussed as being an accessible and appropriate starting point with mothers in this first meeting. This method of spending some 1:1 time with our young person(s) initiated the research process of exploring communication within families, in practice this gave time to surface the young person's communication expressions, interactions and interests. From an early stage there was an indication that parent discussion and reflection was beginning to influence how parents engaged with their children; action-reflection *in action*. Whilst we recognised that activity initiated by the child or young person was important and likely to lead to more responsive and engaged interaction, we also considered what methods we could introduce to initiate further interaction.

Aware of the communication challenges inherent in the study group, I suggested offering cameras to family members inspired by Photo Voice (Carnahan et al., 2006). This was suggested as a method of engaging children’s perspectives in the communication and data process. This method could potentially allow further insight into what held significance, what was of interest or importance to them. Providing additional consent, where appropriate, (see appendix 1) to ensure all participants felt comfortable with this specific visual method, the individual families determined whether this became a tool or method to try or adopt. This method was of interest to 4 families and practically explored by 3 families. Where 1 family showed an interest but did not engage this method this was due to the challenge of time and limited capacity in the family. Whilst the mother-researcher was interested, she was not practically able to introduce and support he children to use the method, as such the children who did not use verbal communication or used very limited verbal communication did not engage in this method. The young people who used the is method were simply asked to photograph things that were important to them. The subsequent photographs became part of the family reflective journaling and also provided opportunity for a different perspective in parents’ reflections (see tracing chapter). By looking to new approaches to data generation we were able to reflect on our communication interactions and engaged a different lens for exploring these interactions. Beyond this specific method, we continued to engage in our family interactions and gave time for 1:1 engagement, responding to feedback from the young person, family and CLG discussions in a continuing spiral of action and reflection, trial and error, joy and tension. The reflections and thoughts formed the Reflective Journal and CLG discussion. In the context of this PhD study, there was a need to hold back from imposing a parent driven agenda, instead allowing the 1:1 interaction to enable us to take a lead from our young people.

In order to explore communication in families, particularly the development of inclusive communication, the methods for data generation and analysis have needed to be fluid and responsive rather than fixed and predetermined. As discussed in the Methodology Chapter, our young people generated and contributed data through their own expressions and interactions and we captured aspects of this, through story and object;

> "...a form of self-narrative that places the self within a social context. It is both a method and a text, as in the case of ethnography" (Reed-Danahay, 1997, p.9).

And in the case of our children 'text' extends further to object, action or behaviour.
My previous experience through my Masters research, subsequent family reflections and continuing dialogue contributed to my experience of the process of engaging my family in discussions, and capturing thoughts in the reflective journal. In our CLG meetings I advocated for investing in this collaborative family community approach of reflective discussions within the family. Whilst this happened sporadically across the families providing insights from fathers or siblings, it continued for the most part to be the mother/child dialogue from this closely enmeshed relationship which became the body of reflective practice. Whilst all family members agreed to participation and were involved through family interactions within the data (with only 3 family members taking a non-active role as previously described) it continued to be primarily the mother-child interaction that led the narrative that was captured in the narrative and shared in the CLG. I suggest that over a longer period of time the action-reflection spiral could have moved through the family, facilitated by mother/gatekeepers to further engage fathers and siblings. We see subtle glimpses of this process beginning in father and sibling engagements. This was very much specific to each family and reflected some of the tensions and dynamics within

each family. For some, the older siblings were less involved in family life as they inevitably looked outwards to developing friendships and establishing their independent identities. The data generated provides the experience relevant and appropriate to the dynamic of each family and continues to invest in the communication environment as it is lived in each of the families. The reflective (family) journal is flexible to accommodate the novel and situated data of each family.

Practical challenges

We held 4 meetings where all 5 mothers as members of the group attended, the other meetings did not have full attendance. Of the remaining 3 meetings, 2 had four members in attendance and 1 had 3 members. This was anticipated in advance, recognising that parents have family commitments and needs. Non-attendances were due to illness of the mother or their child or family commitments, on one occasion a work commitment prevented attendance. In order to continue the involvement and keep the flow of ideas and engagement, I provided a summary of our discussions and, where possible, met with those who couldn't attend a meeting to share reflections and thoughts. Whilst this restricted the full experience that engaging in the group would have offered and only provided a summary experience of other's reflections it allowed dialogue to continue and offered a catalyst for new reflections and thoughts.

As was demonstrated during the summer holidays, the capacity for parents to attend sessions when children are not in school presented significant challenges and disrupted our planned meeting for reasons of lack of childcare, family holidays, planned appointments for additional therapies and difficulties in organising care. This only highlights the complexity and significantly increased difficulty that parents of disabled children can face in trying to access care or cover in school holidays and the additional stress that this can place on working parents. As a result, the meeting scheduled for August proved too challenging and became too difficult to bring the parents together. To accommodate this, mothers agreed to capitalise on this time with our families and focus our attention on the 1:1 engagement with our young people with autism, taking this opportunity to action our learning through our interaction.

Emotional challenges

Whilst I had recognised and anticipated many of the practical hurdles, what struck me as a significant challenge was the emotional intensity of the process of meetings, reflection and reflexivity. Whilst this was a challenging emotional investment for me, it felt necessary. As the PhD researcher I felt the pressure of the responsibility, having initiated the study for my Doctoral study, I felt a need to manage the process to be aware of the potential impact on other participants and the emotional demands the process placed on us. I could share in this experience; I could feel the emotional impact as we explored the challenges, tensions, worry, joy and sadness that formed the content of our discussions. This position as insider researcher provided a *felt* presence in the data generation process and allowed me to monitor the emotional demands of the parent researcher position for all mothers in the group. I was also aware of the emotional intensity in other mothers as we engaged in the meetings. Our earlier meetings felt more challenging as we discussed the worries of changing sibling dynamics, the mental health of some of the children involved in the study, the fear for the future or the frustration of exclusive practices in education or services. Later meetings were more positive with mothers feeding back on positive experiences. This may have been a tangible response to a positive impact of the study process, but also suggested of the group members getting to know one another and feeling more comfortable in their discussions. Ellis acknowledges the emotional commitment that is inherent in the process of autoethnography;

> “Believe me, honest autoethnographic exploration generates a lot of fears and self-doubts—and emotional pain. Just when you think you can’t stand the pain anymore, well that’s when the real work has only begun. Then there’s the vulnerability of revealing yourself, not being able to take back what you’ve written or having any control over how readers interpret it. It’s hard not to feel your life is being critiqued as well as your work. It can be humiliating” (Ellis, 1999, p. 671).

Analysis in practice

I have previously described the two phases of analysis that were engaged in this study. The initial Rhizomatic response of mothers from within the process and the subsequent Thematic Analysis. During the course of the CLG meetings, the themes that began to surface through a rhizomatic response were captured by researcher mothers and shared with the CLG. This reflective cycle of APAR ensured that what was significant to each of the families and their understanding of our discussions was identified as emerging themes.

The transcriptions of CLG meetings and the reflective journals which included some artefacts from our young people became the full corpus of data generated through the study process. These words and objects carried the communicative actions and enactions. The transcripts and journals were read and re-read to allow me to familiarise myself with the data. I began to code the transcripts to identify repetitions and patterns that suggested of the themes that were significant in our data.

As part of the APAR methodology, the CLG meetings, held monthly, facilitated recursive and iterative action-reflection and theorising. In preparation for the fourth meeting I listened to and read through all of the meetings recorded to date and revisited each of the journals provided by the members of the group. As I heard patterns form, I noted in the margins, I kept writing and noting. I started coding. There was repetition, duplication of thoughts and ideas. Themes formed and formative analysis became a visual, as I tried to draw all of the key thoughts/themes that were assembling. I emailed these formative themes to the group prior to our meeting and asked that the parents considered and reflected on these for discussion or thoughts in the meeting, and potentially in their reflective journal. My summary of the formative analysis was recognised by all and prompted new discussion. This iterative and reiterative approach and continual member checking (Marshall, 1989) provided formative summary of themes as they evolved. Member checking became participatory and embedded. Having concluded our initial 6 meetings, we built in a 3-month space to allow for continued reflections, to recognise if the reflective practice could continue in this period and to seek thoughts on the impact of the study participation. This period provided opportunity to *Generate Initial Coding (phase 2)* and begin *searching for themes (phase 3);* phases identified by Braun and Clarke (2006). During this period, I was able to revisit and explore the data through this different analytical lens. The final meeting of the CLG allowed me to take back the initial response to the thematic analysis and share the themes with parents. This triggered further discussion which served to revisit and reinforce the themes.

Critical to this analytical approach was the need to immerse oneself in the data, beginning in our involvement in the CLG meetings, and for me not only as a researcher but also as an active participant. As a full member researcher, (Anderson, 2006) my investment in the analysis process was immersive, not only in listening to the discussion of the meetings but also an affective involvement and relatedness to the content of discussion. The subsequent Findings Chapter presents the key themes identified through the Rhizomatic and Thematic Analyses; the Tracing of data that surfaced what mattered to our families (Barad, 2007).

Chapter 5: Tracings

Tracing

In the 2 parts of this chapter I ask that the findings from this study be considered as *A Trace* (Deleuze and Guattari, 1987). This move describes the need to recognise that whilst this study explored communication in the families of autistic young people, much of what we experienced and recorded as our communication encounters can only touch the surface of the deep, rich and complex familial communication in a more-than-verbal assemblage. As Deleuze and Guattari (1987) suggest, we can take a tracing through the complex and interwoven cartography of an assemblage yet, to prevent a reductionist return to traditional understanding; "*the tracing should always be put back on the map"* (Deleuze and Guattari ,1987, p. 13). I argue that this conceptualisation is particularly pertinent when exploring familial communication in the context of families where a member has communication difference. Whilst this study led us to new knowledge in our family communication interactions and the unique and situated methods of communication our young people engage in, these communications were explored and interpreted through the experience of the parent. It is here that we must make a distinction to draw attention to the autistic positioning of our young people. They bring to this research a different perceptual positioning, one that suggests of a different interaction with the world both human and material. Whilst we as parents seek to analyse and interpret this data, we must respect that there will be a difference in the perceptual positioning between our young people and I/we as mothers and non-autistics. Beyond our trace there lies an infinity of possibility of communicative experience of our young people that we will not fully understand and have yet to notice. To acknowledge the entangled and affective assemblage of communication, the Trace reminds us that we must place our findings back on the map to acknowledge that which is not yet fully understood and lies beyond our ability to fully explore and access.

Part I: Time and space as catalysts to inclusion

Part I of our findings from the study process explores the themes which relate to Time and Space. These were continuously revisited and repeated by parents and deemed vital to the family's communication engagement and ultimately became recognised as a catalyst to enable inclusive communication.

Time

As a method introduced as part of the study process, we, as mothers who formed the collaborative learning group, engaged in 1:1 focussed time with our young person, this became a catalyst for increased communication. In early Collaborative Learning Group (CLG) discussions and journal reflections, mothers referred to the increasing awareness of the need to give time for communication interaction with their young person and the positive implications of this process. As the meetings and study progressed, we began to hear mothers referring to space rather than time, extending the concept of giving time. Parents identified that making space for communication enabled young people to express themselves, to anticipate communication interactions and to recognise the parent as an available communication partner. This opening of space served to increase trust between parent and child and in so doing empowered young people to initiate communication.

One to one time- just giving him time to speak

Throughout the data set there was significant reference made to time as an enabler in communication. Where time was made or given, we mothers talked of increased opportunity for our young people to communicate; to express themselves, and process communication;

> "And I think with a lot of children with autism they don't make their needs known …whereas another child might say, 'you're not listening to me' or, you know …. they don't necessarily make their needs known, so you almost have to overcompensate for that; by giving them the more focussed time, to let them have their say" (Kate CLG discussion June 2017).

Kate's son has vocabulary that is typical of a thirteen-year-old boy, yet he has great difficulty accessing his language and expressing himself verbally. Kate and her husband focussed on one to one time with her son, Dan, a method initiated as part of this study. Kate refers to the positive impact of investing in one to one time and how this allowed her son to express thoughts that he would not typically share;

> "He doesn't readily share information through language and he needs a bit of time and coaxing to articulate what he feels, so unless he is given the one to one time, we often don't get to hear what is on his mind" (Kate reflective journal 2017).

Kate acknowledged it was easy to forget that her son needs extra time to process communication as he had well developed vocabulary. She felt the reminder to give more time was important. Kate believed this conscious effort to give increased time for communication allowed her son to both access his language and have the time to think of what he wanted to say. Kate refers to the way her son was able to talk to her about his approaching school transition in their shared communication time, allowing his views to inform the school review process;

> "But I think what's interesting is that because we've been doing this project, normally when it comes to the student's views about it to feed into the [school] statement review we get very little out of him, and school get very little out of him

> and it’s kind of 1 word answers and things. But we actually got quite a lot out of him this time about what he’s feeling about it, it was really lovely..….and I honestly think it’s because we’ve been spending more time, just 1 on 1 time, just giving him time to speak…” (Kate CLG discussion October 2017).

Similarly, for the young people involved in the study who had minimal or no verbal communication, making time for one to one engagement enabled opportunity to communicate and be together, with a focus on playful interaction and shared experience. Maddy spoke of the positive time she had spent in the summer holidays with her two children; Will who had no verbal communication and Rosie who was minimally verbal. She acknowledged how very tiring this period was but spoke of the joy she experienced in their shared play and communication engagement, facilitated through giving time for one to one interaction;

> “Because it was summer holidays we’ve had more time with the children and so we were able to have more one to one and to reflect a bit more on our communication, which has been lovely…..it was really lovely to give the kids the full attention and spend some time, let the other stuff go and say right this is what I’m going to do and give you my full attention and that really paid dividends as well” (Maddy reflective journal September 2017).

Maddy reflected that the experience of this one to one and the attention this gave the children through focussed play and engagement allowed her to top-up or secure the children to make her less in demand at later points when both children were seeking her attention;

> “And it meant that at other times if I couldn’t give them my full attention because they both wanted me at the same time, it was ok, we could find ways to share that attention, in a bit of a tickle and a cuddle here and a bit of a tickle and a cuddle

> there, you know, we could all share the same space and that felt easier…enjoyable, so I think it was like, giving them more attention, kind of topping up that need, they were then better able to share my time and attention when the time came which is something I'll absolutely take away from it all I think" (Maddy reflective journal September 2017).

Maddy speaks of an increased awareness of the benefits of 1:1 playful interaction which she believes allows her children to feel *topped up* with her attention. This allowed a sustained connection beyond the direct 1:1 time and made the children more able to share her attention at later points in time when she couldn't offer a 1:1 focus.

Anticipated Time – "that pattern of knowing"

During the study, as we parents invested in and reflected on one to one engagement, we became aware of patterns that had begun to establish where time was made for communication. Where parent and child regularly came together for communication, children began to anticipate these interactions. Mothers spoke of communication both through language and non-verbal interaction. Children anticipated this time as a point where they would have a specific opportunity to communicate;

> "I'm doing the one to one time with him and we just sit on my bed and he just cuddles in and we just talk erm, and so I think he'd got into that pattern of knowing that he's going to have time to speak" (Kate CLG discussion October 2017).

In Kate's discussion around the bedtime routine they had established, she referred to the "pattern of knowing". This awareness of an anticipated communication time is reflected by four of our five mothers, who speak of bedtime as a particular time in the day where parent and child come together. When parents offered time to be together for one to one engagement and interaction, our children came to anticipate this interaction. Whilst the anticipated communication that Kate speaks of evolved as a result of the one to one time established as part of the study process, The reflective process made Josie more aware of the importance of this space and the opportunity it gave her son to express himself and share his thoughts or worries;

> "…. now, it's almost like he waits sometimes [until bedtime], and I walk in the room and he'll turn round and say, 'right!' he dumps on me, but it's, he knows that's just like a little quiet space…" (Josie CLG discussion October 2017).

Bedtime was acknowledged as a particularly relevant and important point of contact by the mothers of the young people who used verbal communication. Their children in particular seem more able, indeed keen, to express themselves at this point in the day. Parents of the children who used more established spoken language for communication suggested that this regular time at the end of the day allowed opportunity for their young person to communicate thoughts, concerns or issues that were on their mind.

For Charlie, whose verbal communication is restricted, bedtime was focussed on shared interaction around his books. This is an established and important shared reading time. Whilst it offered opportunity for dialogue it was also a source of narrative and storying, something that he drew upon to inform and structure his communication, these stories became a strong, shared reference for dialogue at other points in the day;

> "Reading books at bedtime this evening and Charlie asked for the little red train, "can I look at the little red train to the rescue?" He then proceeded to tell me the story, looking at the pages and explaining and asking questions, "What happened to the animals mum, they got onto the track, then what happened? They had to go back into the farmyard. The ducks are on the ice and the cows in the field". He talked me through the book and asked me questions. Teased me when I called the

> junction a branch line…"is this the signal box and this the junction?" "No' Charlie, that's the junction cheeky, is mum silly getting it wrong?" …we read together and can therefore relate to the narrative and use this to support shared understanding and dialogue" (Helen reflective journal September 2017).

For Maddy and her children there is less emphasis on a specific time in the day, yet she actively seeks to establish patterns of positive communication interactions. By investing in this positive interaction, she aims to build an expectation of playful and pleasant experience. Maddy also talks of the way she establishes phrases that her children become familiar with to be able to share her appreciation of them and reassure them when they face more difficult situations, or they are feeling less happy;

> "And I suppose on a related point, I'm just also making the effort to make our interactions as positive as they can be, yes by being very playful, but also just by remembering to show my appreciation of them and how lovely they are and stopping and making sure I'm giving them a kiss and a cuddle and things like that and again, just that little bit all the time works for us. You know, if they're not feeling good and stuff I can say, ohh, where's my lovely girl and, or, where's my lovely boy or you know, mummy loves you or just do more of that stuff. More telling them I love them, more of telling them I think they're great, more of appreciating what they're doing and then why. Wow look at you! You know, sitting so beautifully and so patient and just, I just, you know, trying to be a lot more positive makes me happy, makes them happy. And it means that when things are difficult and somethings stressful, Rosie can be a bit up and down, a bit hormonal, I can use the same positive phrasing, and use phrases that I know she recognises and she likes and she finds reassuring and they are more successful because they are against a backdrop of us having been getting on well and of her, I think, feeling quite

> validated, and her getting a lot of positive attention from me" (Maddy reflective journal October 2017).

Maddy speaks of the way Rosie asks for familiar routines that she has established with mum to provide a familiar, predictable space for reassurance, returning to these familiar routines to secure and comfort her;

> "…I just think there's so much going on sometimes she just thinks, do you know what, just do what I know, just give me a little bit of just what I know to make me feel safe. So that's what we do, so you know, it's just joining her in that, and then she's kind of like, yeah, I know this! So, when she wants reassurance, she wants for example for me to hide under the covers with her "mummy covers" and for us to pretend to be Peppa [Pig] and Suzy [Sheep] when they are in the tent together" (Maddy CLG discussion July 2017).

Increasing trust

Mothers began to talk of the development of trust through giving more time for communication. Jen referred to Ollie's bedtime as a time when her son was able to calmly ask questions. Ollie had less fluent verbal skill and, at the time of the study, struggled with severe anxiety. Yet, Jen acknowledged that they had managed to establish and maintain strong communication during this challenging period, she referred to the trust that this had allowed them to build. Unable to attend one of the meetings, Jen sent a summary to the group to update them on her thoughts. She asked for this to be read out to the group and confirmed that she and Ollie were managing to communicate well despite his severe anxiety, and she felt this had allowed him to trust her through this very difficult period;

> “…rather surprisingly our communication has been tremendous. ...every night when I go in to switch Ollie's light off, he has started to calmly ask me a question or want to tell me about something that has happened in his day, I think this is major progress and I feel he feels he can trust me” (Jen journal reflection/CLG discussion 2017).

Kate too, described the benefit of increased trust that her and her husband’s investment in time with their son appeared to be offering;

> “Through this more focussed time together we find that Dan is more open to trying new things, for example, going to social occasions, coming to the table for dinner when we have visitors he doesn’t know. It’s like he’s feeling more listened to and therefore trusts us to manage the social situation he is going in to. There is generally a greater compliance when we suggest doing things” (Kate reflective journal 2017).

Through increased opportunity to communicate in a one to one or familiar engagement our children/young people were more able to trust parents as communication partners.

Space

As our meetings progressed there was a shift to parents increasingly using the term space; building and expanding on the concept of giving time. Mothers talked about giving the space to communicate and engage, also acknowledging that this space reduced the emotional pressure of communication expectation for their young people. We spoke of the difficulty our young people have when they are pressured to communicate, where anxiety, frustration or emotional complexity inhibited communication. For example, when asked direct questions Charlie would reject the direct questioning by using the phrase ‘I don’t want to ask that question!’ The pressure of direct questioning served to close down any opportunity to for him to engage. For Dan and Josh who both attended mainstream schools, there are ongoing difficulties in dealing with the complexities of the school environment. Both mothers recognised the challenges these environments create for their young person and the impact this has on their communication when they feel pressured to speak;

> “...Dan’s communication, his receptive language is very, very good and he’s following GCSE level courses, but his expressive language is way below, and people don’t get that so when they’re questioning him about incidences, he’ll just say yes, or no, to get it over with. …So, communication is, is a really big thing, so although he’s verbal it’s still a really big thing. Because he’s not able to articulate, he’s not able to express. Or he’s not sure what his response should be he just shuts down” (Kate CLG Nov 2017 P. 18).

Josh finds the intensity of school highly demanding and takes time to regulate himself afterwards;

> “We always leave him alone for as long as we can after school, it’s basically when he comes out and starts jumping on the trampoline, that’s when it’s kind of safe to talk” (Josie CLG discussion July 2017).

In our meetings we discussed that in family communication and interaction, we are often busy or there are numerous voices and activities competing and where this extends to include others, the lack of space to join in can result in our young person becoming excluded from communication interactions. For Charlie, close family members are able to make adjustments to create space, yet where other people enter the communication interactions it becomes difficult for him to access and join in the communications;

> “What I have realised more than anything is when it’s just the close family Charlie can access language a lot of the time and we sometimes summarise a more complex conversation. Or we slow to allow him time to join in the chat. As soon as another kid or other family join in he loses the ability to engage in the conversation, it’s too quick and complex. I try to build space for Charlie to get in but it’s not easy” (Helen reflective journal 2017).

Parents recognised that offering increased space for communication allowed children and young people more opportunity to join in, to contribute their thoughts and express themselves. Through reflective practice, Josie found that by holding back from offering her thoughts and solutions, Josh was more able to process his own opinions and have space to work things out for himself;

> “I think one major thing I’ve learned is to stop talking … And I think one of the biggest lessons I’ve learned, with Josh is to just shut that off, to just stop it, and sometimes it’s still racing in my head, because he’s still, oh there might be a problem or how am I going to deal with this and immediately I’ve got 10 answers but I don’t say them anymore. I just kind of wait, I pause, I give the space” (Josie February CLG discussion 2018).

Kate found particular benefit in her increased awareness of space as a catalyst to enable Dan to express himself. She and Dan’s Dad worked together to establish increased space, allowing Dan the opportunity to process language but also to manage his emotions to be able to access and express his own thoughts and feelings;

> “…it’s just letting him have that space and I think it’s a lot of what this project is about isn’t it, be more focussed and aware of those, opportunities” (Kate 1:1 discussion July 2017)

> "…I've just become aware of the times where we don't give him enough space to go through that frustration of trying to find the right words to say, …and I've become more aware of needing to slow down and just, when he can't find the right words or just gets angry, or that, just kind of let him have space to, to say that …He'll, he often used to say 'I don't know, I don't know', but now he won't say that, now he'll try and come up with an answer erm, and again I think it's that he knows we're going to give him a bit of space rather than say I don't know what you mean…d'you know what I mean in busy family life, sometimes kids'll say something and it's like 'what was that?' and then he just kind of retreats, but now he's got that bit of space where we're going to listen, its lovely. And it's having a knock-on effect because, because he's able to express this we then know what he wants and then can tell school, so…" (Kate CLG discussion October 2017).

This study happened during a period of time when Dan was preparing for school transition and the increased time given for communication also allowed Kate to access and include Dan's views in the transition process.

Available communication partner

Jen started to say "I'm listening" to support Ollie to recognise he was actively being listened to. Her clear and explicit acknowledgement of his communication ensured that he was aware that she was available and listening properly to him. Jen is making it clear that Ollie has the space to express himself and be listened to;

> "I've actually started using the words, "I'm listening!" … And things have gone so much better since I've done that and I've, he's actually stopped ...escalating to a 4 or a 5 if we've had these kinds of chats. And we've been able to have these conversations, but I keep reinforcing, 'yes, I'm listening', and sometimes he

> struggles to get words out, not like a stutter but his brain's obviously working faster than the words will come out of his mouth and he's struggling to find the words and he'll repeat the first word quite a few times before it forms a sentence. And I just keep saying, 'I'm listening', because he gets really frustrated if he can't …like he was when he was, you know when he was non-verbal and he couldn't speak and I could see the frustration, he's now getting the frustration when he is speaking to us, but I sometimes think he thinks that we're not listening …and we don't understand. And a lot of it, you know, is quite abstract and it is quite hard to understand so I've started to put this strategy in place and it's great, it's really great" (Jen CLG discussion October 2017 P.4)

This confirmation that Jen was listening seemed to encourage increased communication from Ollie who was then able to talk more about how he felt and why he had behaved in a particular way;

> "So I was sitting him down and I started to say , 'I'm listening, what's happened?' erm and he was able to tell me and he said, "and, and I felt, I felt like running away because," and then he was able to say he felt like running away because when he came back things would be so much better and we'd be so pleased to see him" (Jen CLG discussion October 2017).

As mothers we acknowledged in our discussion that we often take for granted that our young people know we are listening. We reflected that being explicit about our availability ensures that our child knows we are listening, and they have our attention and are being given the space and opportunity to express themselves.

Empowering

As mothers we discussed the importance of setting aside our own agenda and leaving space for the child's interest or initiative. By making ourselves available we saw that we actively open the space for more inclusive communication. Maddy was explicit in her awareness of letting go of any other agenda or *stuff*;

> "….*let the other stuff go* and say right this is what I'm going to do and give you my full attention …I suppose I go in very much in a playful way, kind of, come on, let's play (fun expressive voice) but not really making any demands of them, but I'm going to do something I know you'll enjoy, what are you going to do? You know, and then letting them take the lead, so hopefully there's not too much challenge there, they don't seem to find much challenge in it" (Maddy reflective journal 2017).

We discovered that by creating space for communication, young people had more time to process receptive communications and language, and also to initiate and bring their own thoughts or needs to the communication interactions. This allowed young people to be included as more equal partners in communication; to involve their feelings, needs and expressions, in turn empowering them as communication partners;

> "I don't know if it's the work we are doing in this study or whether it is him getting older but he seems generally more able to discern what and why he finds things difficult …It's a great opportunity that these thoughts are coming from him because it gives opportunities for us to offer help (which he tends to refuse normally). So, we can say we can work with you so you feel less uncomfortable in certain situations, or work with you so you can practice what to say. Because the needs have been identified by him, he is more willing to work with us towards solutions" (Kate reflective journal 2017).

With increased opportunity and space to enable young people to engage in more inclusive communication, parents recognised the potential for empowerment of their young people. We discovered that this leads to our young people initiating more communication and social engagement with us. Kate talked about a shared interaction where she, Dan and his older sister shared their choices in music. The following day, Dan had spontaneously suggested more shared social time;

> …."but what was lovely was the next day on the Sunday at lunch time I was making Dan some lunch and he said, cos he never asks me to do things with him, he said 'could you and I watch a video this afternoon while [sister's] out and that was, I think that was a direct result of the…..but, because it was, because of the night before we were about an hour and a half of us sitting in a trio doing that, and we were all enjoying it, I was enjoying it but it led to the next thing which is, and it's just encouraging this interaction and [him] finding it can be enjoyable…" (Kate CLG June 2017).

With this increased time and space to interact and communicate our children seemed more confident to express themselves and initiate communication. Maddy acknowledged Will's intentional communication as he actively tried to engage the playful response from his mum;

> "Will is spontaneously approaching in a more playful way and coming and smiling cheekily, and maybe running off a bit, and turning around and looking and smiling and being cheeky" (Maddy reflective journal October 2017).

Maddy's summary of her interaction with her children expresses her increased awareness of the positive effect of giving time and space to make herself available for communication. She speaks of the way she and her children became more aware of each other and became partners in an evolving dialogue within their communicative space;

“I found that simply by increasing the frequency with which I was trying to interact with them made them realise I think that I was more available, not so busy and so they would come and initiate for more interaction ...we just sort of came together quite nicely in that way, which was lovely. My conclusion is simply, that for better communication, just do it more, do it more often and as we were doing it more often we were finding other ways that we enjoyed interacting with each other and communicating with each other, some other little games we could play, songs that we could sing or …it was more that we began to recognise stuff in other people. So, I was recognising more what their overtures might be, and they were with me, and then of course they become familiar and much less threatening and so just kind of a virtual circle keeps going, and you extend your repertoire of ways to interact with each other. So, I would just say in conclusion, more is better! The more you do it, the more they want to do it, at least in my experience and the nicer it is! So, it’s just been lovely really, lovely” (Maddy June 2017 reflective journal).

Part II: Tracing communication interaction

Part II of the Trace focuses on the communicative action and enaction of our young people as agential communicators. Initially considering the methods and modes of communication that our young people engage and the importance of their emotional and embodied state in the process of communication. The environment also shows to be significant in their communicative expressions and provides material and accessible forms of expression for our young people as developing communicators.

Secondly our findings will describe relational communication, the ways we as parents and family members engage and how this too draws in emotions and embodied communications, and also describing the strategies that parents develop to support communication. Siblings and family connections are referred to as important aspects of home communication.

The final section of the findings considers communication relating to developing sense of self of our young people. Parents spoke of the changes and challenges their young people encountered as they moved into adolescence and how communication was important to this process.

Young person as agential communicator

The APAR process allowed Mothers to story and reflect on their communication encounters with their children and young people. These reflections and increased time and space to communicate enabled parents to turn to notice their young people. Mothers discussed how their young people expressed themselves and how they, as parents, responded and facilitated communication interaction. Central to this communication was the embodied young person as an agential communicator drawing in body and environment to express themselves. The initial section traces the expressions and novel methods that children used to express emotion or begin to structure communication interaction and language. This explores the ways our children actively communicated through more-than-verbal methods, expressing themselves through their behaviour and their interests. Beyond this we trace the parent-child and familial communications recognising how this is influenced by the more-than-verbal interactions of other family members. Increased awareness of the communication landscape of the family enabled parents to understand the unique expressions of their young people and the family, it also exposed tensions and connections. This awareness informed parents as to how they might support increased inclusion in communication.

Material dialogues: communication using different mediums

In our study we found that children who have developing verbal communication used different methods to structure and express themselves verbally. Josh, Ollie and Charlie demonstrated the use of visual and written methods and Dan engages in dialogue facilitated by his interest in music. Ollie and Charlie in particular have used language learned and borrowed from a number of sources to structure their communication and developing language;

> Jen: “Ollie used to repeat the adverts and it was the catchy ones you know, they weren’t very long you know, Cillit Bang, Domestos, ‘Domestos kills all known germs dead’ were his very first words in a sentence ever, and that was because he saw the bottle and pointed to it and he was getting very angry, and it wasn’t till I said the

> word ‘Domestos’ that it let him, it opened the gate for the whole sentence to come out …that was another ground breaking moment, but he got so much enjoyment out of it. The Cillit Bang, we were in a supermarket and he was with us cos I didn’t take him to the supermarket very often cos it was such a nightmare and we were …I took him along and he spotted the Cillit Bang and he was in raptures and started to pick up the whole like thing, and put them in and I was like, we only need one, but it was his enjoyment ...so like you said..”
>
> Helen: “…and that’s such an opportunity for interaction isn’t, you know even if you don’t buy Cillit Bang, you do now!”
>
> Jen: “We did that day!” (CLG discussion February 2018).

Jen and I went on to recall the importance of this borrowed language; words and script that clearly affected our children and became part of their repertoire of acquired captions or script which they seemingly used for enjoyment, familiarity and also to structure their verbal expression and communication;

> “I remember walking along when Charlie was tiny, and he would just repeat scripts of Iggle Piggle you know and then he would do the ‘whoop’ and fall over like Iggle Piggle you know. And at the time there would be no eye contact, and he was a little tot, but I would think, no it’s important to him, he’s making sense of the world with it, because that’s his only thing he can access, cos the rest’s so complex, so even if he’s using it in a very internal way, to make some meaning, it’s important!” (Helen CLG discussion February 2018)

Jen recalls how Ollie was able to use his extract from a Peppa Pig episode for interaction;

> “… he would recite the whole Peppa Pig, even from the point of ‘episode 4’ ...and I can remember exactly where I was the first time he ever used the right episode in context. We were on a beach and there was a thunderstorm coming, and it started

> to rain, and I was packing up the things but I couldn't do it fast enough, and the kids were running around and this old couple came up and they started speaking to Ollie and he launched straight into the Peppa Pig thunderstorm episode. Now he didn't deviate from the episode, I can't remember which lines they were, but he would pause …and they would say something and he would go back with the next line from the Peppa Pig thing and they walked on and they were none the wiser and he had just done the whole thing but he kept pausing, in between the things. Yes, and, and I've got goose bumps now, because I can remember that day and I stood there in the rain with the thunderstorm cos I just thought oh my god, I can't believe he's used that in context …and from then quite rapidly he did progress with is language, I mean you know, it still has issues and it's still hard but that was the moment, that was the breakthrough moment that I'll never forget …and I wouldn't say that was empty language, it really helped him you know, this old couple bless them didn't have a clue …" (Jen CLG discussion Feb 2018).

We discussed the ways in which this borrowed language was an important aspect of communication for our children who had restricted spontaneous language. It demonstrated their early and continuing efforts to structure and develop their own verbal communication. As this verbal language and understanding developed they seemed increasingly able to express themselves.

In our group discussions and reflective journals, we noticed the ways in which our young people continued to engage images, script and other forms of expression to support and scaffold their own communication;

> "I really love the different ways Ollie has been trying to communicate with different mediums not just with speech" (Jen reflective journal November 2017).

As a suggested method of the study process we considered the use of cameras (see discussion in methods). These were made available and offered to our young people and families, at the discretion of the mothers and family members. Ollie and Charlie in particular seemed to enjoy using this as a method of recording and expressing. Ollie struggled with anxiety and frequently talked about his family and his fears of losing his mum or his family breaking up. His family took an instant camera as part of the study process to take photos of what was important to them, Ollie took photos of the “Inappropriate Families” he saw in television programmes such as The Simpsons that he liked to watch. Ollie’s mum included these in her reflective journal and expressed how these connected to his current focus on these shows and families.

Figure 6: Ollie’s photos

Ollie also used his camera to photograph His Bionicles (Lego figures) and asked if he could send his photos to a friend. His mum facilitated this, and Ollie began a photo swap with his friend who reciprocated, moving from using the camera as a record of something significant to him to becoming a tool for social communication.

Charlie was distressed by his brother’s move from their shared bedroom, taking his x-box into his new bedroom, something that was in their living room and they used to watch and choose episodes of a television programme together, a regular part of their social routine. Charlie is offered a camera; he photographs each of their bedrooms and their toys and the x-box;

> “I asked Charlie if he wanted to take some photos to show us what was important to him. He photographed rooms around the house and then later went back to photograph his toys. I asked him to choose some. He chose photos of [Brother’s] and Charlie’s rooms and of his toys. I asked if he wanted to name the photos, he said, ‘bedroom’ and ‘bedroom’. …These were not surprising as images but gave food for thought. They seemed to show how much this was at the front of his mind. His stress over the rooms and his brother growing and moving out has left Charlie very upset repeating the question for his brother to come back in to share a room numerous times a day, “When is [brother] going to share a room again?” (Helen Reflective journal 2017)

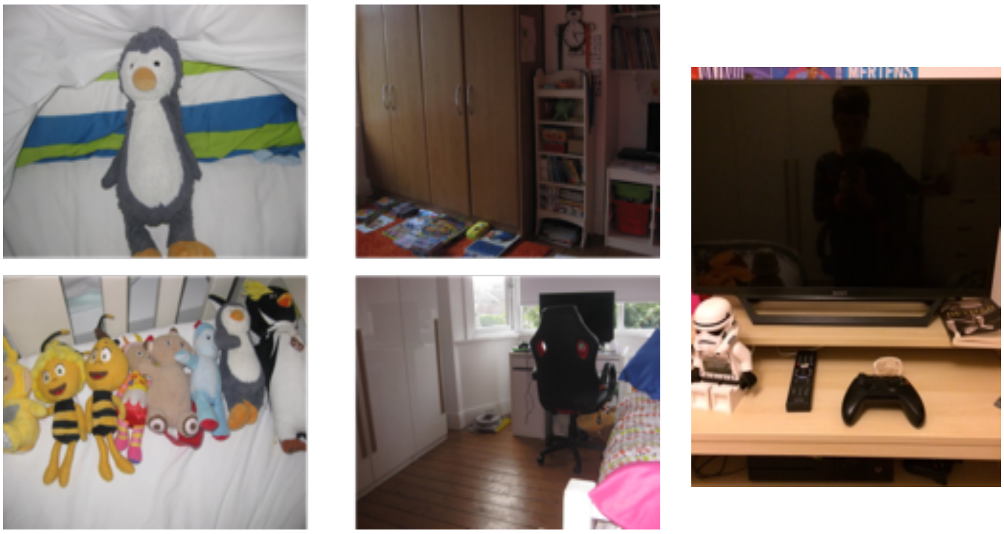


Figure 7: Charlie’s photos

It is his older brother that notes;

> “[Charlie’s brother] suggested that the photos had helped Charlie to calm down about the bedroom and that he had stopped asking so much for him to move back in. He thought the photos had helped Charlie” (Helen reflective journal 2017).

We discussed at the CLG that the photos allowed Charlie to express something that held significance for him, and that he could not articulate through language other than through distressed repetition. By expressing this through images he seemed more able to begin to accept the change.

Jen provides drawings that Ollie had done to express his frustration at his hair which was getting in his eyes;

> “It is only recently that Ollie has been able to express more than happy and sad and, you know, he’s been able to say that he was being grumpy …(Jen introduces Ollie’s drawing), yes, because they’d cut his hair and they’d left his fringe too long and it was getting in his eyes and it was bothering him and his senses were bothering him and it was ‘*can I get my hair cut!”* (Jen CLG discussion July 2017)

Jen also describes how Ollie used these images to communicate the silliness of his younger brother which at times he found frustrating and isolating as he couldn’t access the nuances of the humour his brothers shared;

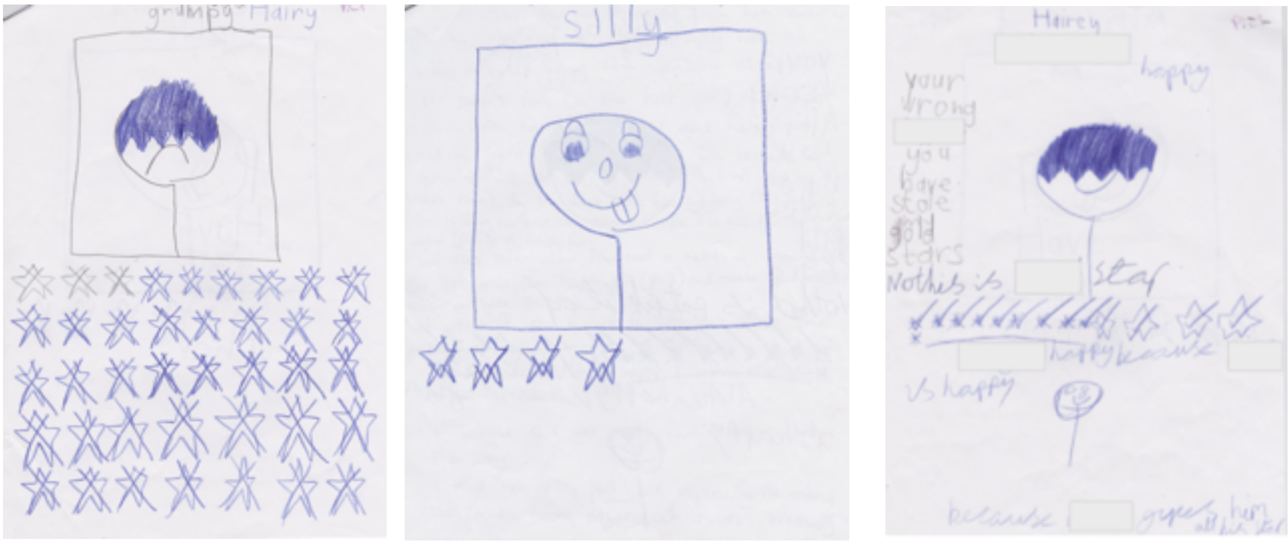
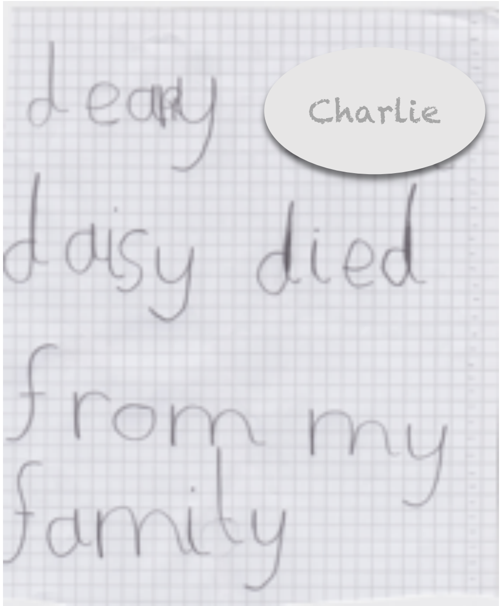


Figure 8: Ollie's drawings

When Charlie's Guinea Pig died, he spontaneously asks for paper to write a letter. Charlie has never spontaneously written anything before. He announced", "*I need paper; I need to write a letter!"*



Charlie

dear
daisy died
from my
family

Figure 9: Charlie's letter

The family quickly recognise Piglet's letter in a bottle from a Winnie the Pooh story. Charlie often uses narrative from stories in books or television/films to find a vehicle for his expression or emotional processing, Charlie's dad, suggests,

> "It's because it's concrete, it's a big deal and it's made it important because the message in a bottle was important" (Helen reflective journal 2017).

Of course, we do not know for sure what this process meant for Charlie, what was central was that he was able to draw on his own resources, he echoed not just the script but the actions and perhaps emotions found in his books.

Josie told us what interests and motivates Josh;

> "He's prolific, he writes and draws all the time, it's all he does, in his room he writes and draws" (Josie CLG discussion June 2017).

She told us how this writing allowed Josh to express strong emotions about things that bother him, "*4 points he'd like to take to the headmistress about why you should sack these different members of staff"* for example. His drawing is very skilled for his age, this is very important to him and something that he needs taken seriously. Josie went further to discuss the way she and her son communicate through notes, capturing the difference this displaced emotion can have. By expressing the anger on paper, it not only allowed her son to express himself and express his emotion it also seemed to diffuse her reactions, the emotion having been filtered through the process;

> "Josh, quite often will leave notes, we will exchange notes quite a bit if there's been a thing, erm, and in the past there's been an awful lot of notes going backwards and forwards, but he finds it incredibly useful, and I think when you're having a conversation, … then if you're writing it and your emotions are there erm... the fact that you're wobbling a bit, or you're a bit teary, a bit angry, isn't in the words on the paper it's the, in your person, in your being. So, so that makes that bit of paper

> who’s less angry and horrible to me to think ok, let’s work with that and I’m not as, and it just seems a bit easier because erm, none of the feelings are in there, or if they are they’re kind of expressed beautifully! …I came home to a note on Josh’s floor, saying he was sorry, and trying to explain his upset... I left one for him for when he got up to say thank you for his note, that I always loved him, even when there was upset, and that there was never an issue we couldn’t resolve” (Josie reflective journal October 2017).

Kate shared her concern that her son Dan seemed not to have a specific interest that motivated him. Her realisation that he had a new interest in music surprised her and, whilst she was aware that it would be counterproductive to place direct focus on this interest and that Dan did not want to talk about it, it also began to offer a less direct opportunity for interaction and sharing;

> “My Dan’s the same age (as Ollie), he just wants to be in his room the whole time on his iPad and its really difficult to get him out, he’s thirteen in September …and [daughter] and [older son], my other 2 had noticed he’d started listening to music on the iPad, you know like Justin Bieber and Iona Grande and all this sort, …this is just something so, kind of age typical, it, it’s quite surprising, but if you ask him about it, no, I’m not listening to music, I’m not listening to music…” (Kate CLG discussion June 17)

Whilst Dan did not directly use music to communicate, an interaction drawing on his music interest provided a less direct or overwhelming way of engaging. Similar to Josie’s comment about notes being less emotional than direct conversation, the spontaneity and focus on the music seemed to take away the pressure of direct interaction for Dan;

> “…unusually my daughter was in on the Saturday night and we ended up the 3 of us, me her and Dan sitting on Dan’s bed and we took it in turns to play music off of

> YouTube so each person had to like choose a song, so I chose one from my generation, [my daughter] the tune that she likes and then Dan got to choose one, and he absolutely loved it……we just did it, because if I’d asked, he’d have said no…so we just did it… ” (Kate CLG discussion June 2017)

For the children with developing language or able to access vocabulary typical of their age, each of them struggled to engage in verbal communication and deal with the emotional intensity. These various methods of engaging different mediums to scaffold their communication allowed increased expression and a means of communicating which was driven and structured by them, engaging novel and personal ways of communicating and also serving to dissipate some of the anxiety or emotional intensity of more direct communication encounters.

Embodied expression

Where language is restricted or unavailable our young people communicated through their behaviour. Will and Rosie in particular relied on behaviour as a means of self-expression. Our reflections exposed the ways our children found to express their fear, anxiety, anger or frustrations. This exploration of our young peoples embodied, behavioural communications also served to increase our awareness of our own embodied expressions and increased our sensitivity to our nonverbal communicative processes.

Maddy’s reflections of her engagement with the children shared the depth of their non-verbal communication and interaction but also the importance of the embodied state. Maddy provides a key observation, if our children were struggling to regulate themselves physiologically, how would they then be receptive to any form of communication?

> “And I know that! ...But it’s just good to keep remembering that if somebody physically and from a sensory perspective is feeling a bit all over the place then they aren’t going to be feeling particularly secure or they aren’t going to be feeling particularly safe …Cos my understanding is that it’s very difficult to meet the higher order needs and the hierarchy if those needs have not been met, so if you have say, sensory processing disorder and you often feel, quite alarmed just by the world, and then that’s quite difficult for you …it is going to be so much more difficult to deal with the other stuff. And of course, you are not going to be as focussed on, or driven by, or motivated by, stuff to do with relationships and communication and that belongingness and love needs are not going to be as important to you in that moment as that basic trying to feel ok from a physiological point of view…” (Maddy CLG discussion September 2017).

Behavioural communication was a strong focus of discussion and journal reflection for Maddy. Will relies entirely on non-linguistic expressive communication, and Rosie uses minimal verbal expression. In revisiting the importance of embodied nonverbal expression in her interactions, Maddy clearly acknowledged that this was her children’s primary means of communication and that this communication was in their behaviour, in “what they do”;

> “…my 2, I mean, Will doesn’t use any words at all and Rosie uses some words and, I suppose the way they communicate with me the most, and in the most powerful way is by what they do, not what they say” (Maddy CLG discussion June 2017).

With restricted or no available means of articulating emotional states we discussed the ways our children communicated through more-than-verbal, behavioural expressions;

> “With Will not using words to communicate it becomes all about behaviour and when I think more about it, our communication about abstract concepts is all rooted in behaviour” (Maddy reflective journal June 2017).

Whilst Ollie and Josh have developing or established language skill, each of them also expressed themselves through their behaviour;

> “…he’s started to try and run away … but I almost think it’s more of a, it’s not a definite oh I want to run away and get out of the house, it’s more of make a point” (Jen CLG discussion September 2017).

> “Now he wasn’t running…to get away, I could tell that from how he was running, cos I thought well I’m out of breath but I’m managing to catch up, you’re not gone, gone, you’re just angry erm and he stopped on a sand dune and I just went up to him grabbed him, squeezed him really hard, didn’t say anything …erm, and then he calmed down” (Josie CLG discussion September 2017).

Maddy demonstrates a strong understanding of her children’s expression. She empathises with their need to express the complex and abstract emotions that the children experience, and how behaviour is a key to understanding the children’s feelings and emotions. She acknowledges that their current response to a more unsettled environment is evident in their behaviour;

> “Both kids have suddenly, recently become aggressive – this is very new, but I think it is their way of communicating the fact that they are frightened and confused by lots of things [happening] at home. As the kids don’t talk about their feelings, other than Rosie saying “is sad” sometimes, the only way they communicate how they feel is by doing what feels appropriate to them at that time. If that means punching,

> biting, scratching, then I feel fairly confident to conclude that they are feeling really bad. I can’t imagine that it’s happiness that is causing them to behave in this way” (Maddy reflective journal 2017).

Our discussions in the CLG meetings were always supportive and positive with a focus on understanding communication. We engage differently with our children and each of us was respectful of these different approaches. When discussing behaviour, we encountered a more polarised difference around the response to what is frequently referred to as challenging behaviour. Maddy expressed her concern that her son Will has been demonstrating behaviour that she described as aggressive; she was aware that he had recently been frightened and struggling, and saw this behaviour as a manifestation of his distress rather than an act of aggression;

> “If my Will pulls my hair when he’s really upset. I don’t think he thinks it hurts me, I don’t think that’s his intention, I think he’s just lost” (Maddy CLG discussion June 2017).

Similarly, Dan struggles to express himself and communicate when directly questioned or if there is too much attention on him. Despite having well-developed vocabulary demonstrated in his able academic profile, when feeling anxious or emotionally distressed he had begun to lash out. Kate speaks of how she took a clear no tolerance approach to this behaviour;

> “[I] drew the line at physical aggression towards me …you know, loss of privileges the minute there was anything physical to me… And in a way I think …you know your children best but almost like the pulling hair, loss of privileges, it’s almost, you don’t give an explanation, you just cut that behaviour like right away” (Kate CLG June 2017).

Maddy reinforces the concept that whilst her son is displaying aggressive behaviour this is more than an angry outburst but a child struggling to cope and communicate their distress;

> "But, I suppose, what comes into my head as well is that if you have no words, if you use no symbols, if the only way you can explain how bad you feel is through your behaviour, how do you show when you are feeling really, really bad? How do you tell the person that is probably the person you trust the most and who you're closest to, how do you then do that? ….and if you're also lost and angry and sad and completely beside yourself…. if they have literally no way to tell you, if they can't say I'm sad, if they can't choose a sad symbol, if they can't do any of that then I think if you're panicking, if you're like uuuuhhh [vocalises and motioning as if searching for help], help me! How do you ask for help?" (Maddy CLG discussion June 2017).

The differing responses to the behaviour reflected the different ways the mothers perceived and responded to aggressive behaviours. Whilst Kate may be able to reprimand Dan for his behaviour through loss of privileges it is likely that Dan can recognise the concept of withdrawal of privileges in response to his behaviour. For Maddy and Will, where the world is less accessible and such conversations cannot reliably take place then Maddy becomes more focussed on and responds to the embodied distress as communicative expression.

As mothers our understanding of non-verbal communication was heightened, Kate's increased awareness of her son's non-verbal expression caused her to consider what lay behind it;

> "I was able to see that he has quite a lot of anxiety when flying – I've started to look more to body language since the [CLG] which I think has been one of the benefits

> of working with other parents of less verbal children and hearing what they do – and we experienced turbulence and he held onto my hand and was physically shaking after it …It's got me thinking about the underlying anxiety he might have even when he doesn't verbalise it or particularly show it in any way" (Kate reflective journal 2017).

This increased awareness of non-verbal, behavioural expression allowed mothers involved in the CLG to look for and recognise different ways of communicating, beyond verbal communication, in our young people. We increasingly became conscious of the behavioural expressions and this gave us an opportunity to consider how we acknowledge and respond to these expressions.

Bumping into memories

This sub-theme builds on our reflections around embodied expression. In our CLG meetings, we discussed times where language is not available as a means of expression for our young people, then there is no way for them to verbally articulate or share memories. Maddy recounted the emotional encounter that Rosie seemed to have when she remembered something that strongly affected her. Without the language available to share this troubling memory she was unable to express what had upset her or, occasionally, made her laugh. These *rememberings* seemed to come back with raw and intense emotion as if they had just happened "As if they've been transported back into the middle of it" (Maddy July p.24). The sense of injustice or distress seemed as intense as when it first happened, and without the verbal skill or ability to recognise and name the emotion there was no way of sharing the memory or talking about it. Maddy described this as her daughter bumping into something in her head, something which Josie and I also recognised.

> Maddy: "… often with Rosie she will be absolutely fine, absolutely fine, absolutely fine and we'll be hanging out or whatever and, and then will burst into tears or then will scream, and it will be out of nowhere, and you spend so much time thinking did I miss it, did I miss the thing? …And it's as if in her head she's just bumped into something that upsets her, in her head"
>
> Josie: That's a really good way of putting it!
>
> Maddy: "With Rosie it always seems to be a sad memory, although saying that, sometimes she will just laugh out of nowhere... she says, 'very funny'" (CLG discussion November 2017).

Josie relays her experience of her son's aggressive response to memories;

> "…like Josh can quite easily punch through doors and break tables when he's in that rage and that could have been sparked off by something off God knows how long ago" (Josie CLG discussion November 2017).

Similarly, Charlie would giggle out of nowhere, or became distressed by an event from the past. Whilst these events made him laugh or upset, he had previously been unable to express what affected him. With developing language, he was more able to express what was disturbing or humouring him;

> "…emotions flood back and we hear both the triggers of years ago when he was unable to verbalise these events and I realise that not only are there the upsets but also the giggling fits which sporadically happened and he couldn't share the joke ...now he can tell me how funny it was (when he remembers his plays) "was I a sheep and Matty was a goat…was it funny?" (Helen reflective journal 2018).

Charlie's emerging language allowed him to share the things that he has been bumping into in his head. For Charlie, Rosie and Josh the memories seemed to be re-encountered with an undiminished emotional impact. Maddy referred to a rear-end collision in her car to try to explain this carried memory;

> “And in my head I didn’t actually feel scared, I didn’t find it a frightening experience, I didn’t find it an enjoyable experience, but it didn’t scare me, but it’s funny on some level it’s like it scared my body even though it didn’t scare my head. And I also think with a lot of these big emotions and stuff as well, with Rosie it’s a lot of, I don’t know how all that factors in, d’you know what I mean? Cos, even if you’ve processed it in your head your body hasn’t quite caught up yet has it?” (Maddy CLG discussion July 2017).

Further, Josie adds “…and if you can’t consciously process it, how can you subconsciously process it?” (CLG July 2017). When this experience results in distress and without the ability to explain, it is almost impossible to recognise the cause of distress, yet we assume that these memories hold significance for our young people.

Developing emotional recognition and language

Through discussion we acknowledged that our young people with developing or established language found difficulty in using emotional language. They were often unable to understand and articulate their emotional distress and, they too, reacted through their behaviour. Whilst they clearly experienced a range of emotions, they struggled to identify, label and communicate about these emotions. Emotional language needed to be on our young person’s terms, relevant to their level of development, understanding and acceptance. Early in our meetings Kate asked the question;

> “…everybody’s touched on their children feeling strong emotions but not being able to kind of articulate them, what might be anger or aggression or whatever…can they

> learn that, can we teach them that, or can they just not process it? I just wonder if we're trying to teach them something that they'll never be able to manage." (Kate CLG discussion June 2017).

Whilst Kate questioned whether our young people simply cannot recognise the emotions that they encounter, Ollie and Charlie demonstrated their increasing ability to both recognise and verbally articulate their emotions. Ollie and Charlie had developing verbal language. Typically, "Charlie will only use happy or sad" to describe his positive or negative emotional state and not tolerate other emotional language, becoming agitated if other terms were used. Yet, when Charlie's brother moved his bedroom downstairs Charlie was bereft, first screaming and crying, but then able to express "I'm lonely, I'm all alone, I need [brother] with me" (Helen CLG discussion September 2017).These are words that he had not used before, he was clearly very upset and able to articulate this distress and apply new emotional language to be able to express this.

Similarly, Ollie's developing verbal communication allowed him to express more complex emotional language, Ollie and his mum's established communication space supporting him to ask questions and clarify aspects of this emerging language;

> "just in the last 3 months he's using words like, you've made me feel so embarrassed…he can recognise that feeling, whereas this time last year it was happy or sad. …A week or two weeks later, he came to me at night time when we're having our little night, night, questions, and he said to me, can you describe lonely? …But he realised that being alone and being lonely are two different things, but he'd never experienced being, feeling lonely…what did it feel like?" (Jen CLG discussion Feb 2018).

Charlie and Ollie are able to demonstrate their evolving emotional recognition and, as their language develops, verbal expression. Having space for communication Ollie is able to question his mum about his emotional feelings and understanding as it develops.

Similarly, Kate reflects on the increased time and space Dan has had, and the opportunity to express himself. Dan is more empowered to be able to express his thoughts. Whilst he has not articulated a specific emotion, he is able to express that he will miss the presence and company of his Learning Support Assistant as he transitions to his next school. Kate shares her acknowledgement of the increased recognition of their son’s sensitivity and awareness of his emotions;

> “He’s starting to use words like, I’ll miss her, which he would never have used those emotional connections before. And he said, like, I see her more than I see you, which is absolutely true, but he’s reflecting and thinking, I’m missing her *because* I see her …more than I see family even" (Kate CLG discussion October 2017).

Ollie and Charlie’s developing language skills show that they are increasingly able to recognise, label and communicate these emotions. Whilst they are maturing and their language is developing, each of the children is also given the space to work through emotions that might impede language and given time to ask questions, allowing the space to be able to express themselves. Dan’s increased communication space allows him to begin to articulate some of the emotions he is feeling.

Time, space and growing trust allow Dan increased awareness of his own emotional state. Led by Dan’s articulation of his feelings, Kate becomes more aware of how to support her son’s social anxiety within home, family and daily events, supporting him to understand his discomfort and tackle difficult situations.

> “He sat for a meal in our house with some of [his sisters] teenage friends. We felt he was ready to do this. He coped very well but one of the things he does is go into the kitchen (from the dining room) to get a drink repeatedly even though he has a drink on the table. It’s his way of escaping. We gave him lots of praise for managing the meal but the next day we talked about why he was doing this and that it was

> because he felt uncomfortable but that was ok and the discomfort would get less the more he tried it. He seemed to identify more with this expression of discomfort rather than ‘admitting’ he had anxiety. He needs quite a lot of help in recognising and connecting with emotions which is one of the things we have learnt through the study. …He actually thinks quite deeply about things but often needs help to express these things” (Kate reflective journal 2017).

When unable to articulate emotional distress, Josh and Ollie expressed their emotions through dramatic actions. Ollie had been running away from home and Josh had talked of suicide. Whilst both parents were seeking help and believed their children were trying to express their feelings and would not follow through with these actions, they were both, of course, highly concerned and upset about the risk behaviour and potential consequences of the threat of running away or self-harming;

> “…he was essentially saying, I feel really strongly about this, look how strongly I feel about this, and that was terrifying! ...It wasn’t that he was going to do any of the dangerous things, it’s that he had these other emotions, that he couldn’t say I’m really angry about this or I’m really stressed about this” (Josie CLG discussion September 2017).

Through sustained investment in giving space for communication, Ollie and Josh are increasingly able to understand and express the emotional dysregulation and distress they experienced. Jen’s reflections suggested that Ollie was increasingly able to employ strategies to try to manage his own emotional state. When given time and the support he told her that he had tried to regulate himself when he was feeling angry and was now able to express that he was feeling the same as he did in the summer when he was running away. He had been given tools to help him to reduce his anxiety and had tried each of them to no avail. Not only was he able to recognise his emotional state and the cause, he was also able to draw the connection between his anxiety and the feelings he had during the summer when he was running away;

> "…well I've tried the trampoline and I've the calming down, I've tried to think about nice things. I've tried the breathing and it's still not working; I still don't want you to go out. And then he said, it's just like the summer. So all the, the running away we had in the summer, and I was like 'I'm listening!" and it was and, and he said, well I don't understand why you have to go out, it's making me very anxious, and so then I was able to have the conversation" (Jen CLG discussion October 2017).

Josie describes the way her son Josh is able to communicate his building tension and the way he felt before he expresses his frustration by saying 'shut up' when in school. His words are written in a note (Josh did not want to include the note in data and be directly quoted, but was happy for us to paraphrase) which allows him to explain his feelings and reaction;

> "and he said he felt like there was spiking in his brain and then he wanted to cry… it was like the tension's building up and building, and building, and building…and he said shut up, but now he's been told off but you can read that he's actually in pain before then, it's too much overload. He now felt like the anger had spiked in his brain and was making him more angry in general in life/at school. He felt like he couldn't control/keep in the hate as much" (Josie CLG discussion November 2017).

Having this insight to the emotional and physical dysregulation helped Josie to understand Josh's perspective and experience of his emotional outburst. She was aware that he was feeling overloaded, similar to Maddy's earlier observation of the impact of Will's physiological dysregulation, Josie talked of how Josh’s emotional tension and anger dysregulated him and impeded his ability to communicate.

Whilst parents recognised the difficulty and barriers their young people experienced in recognising and labelling emotional experiences, the reflective process allowed us to recognise the need to give space for this emotional expression and to allow our young people the opportunity to try to articulate these feelings. Where emotion was expressed through behaviour, parents developed increased awareness of the emotional capacity and authenticity of these behaviours. Recognising what drove behavioural expression allowed parents to better understand the emotional experiences of their young people and to give time and space to support their young person to express these emotions.

Relational communication

As parents increased their awareness and recognition of more-than-verbal expression, we began to acknowledge the reciprocal aspect of this form of communication, how we engaged with these expressions, and the potential impact of our own non-verbal expressions. Parents also expressed the concerns of changing relational dynamics as their families, children and young people grew up and faced the inevitable challenges of adolescence. Whilst this had direct impact on communication through the tension and dysregulation it caused in their young people, it also suggested the longer-term implications of communication on their young person’s evolving sense of self.

Embodied communication between family members

The importance of non-verbal communication and the awareness of their nonverbal dialogue through embodied communication was richly acknowledged by Maddy in her early journal reflections and discussions, indeed, Will and Rosie's other-than-verbal presence was a catalyst for all mothers to turn to notice more than verbal communication in their own young people. Will and Rosie's reliance upon other-than-verbal methods to express themselves enabled Maddy to have a strong awareness of non-verbal communication, including her own nonverbal expressions. As previously mentioned, Maddy was aware of the physiological dysregulation her son experienced and the need for appropriate feedback to support him to regulate. She explains here how she responds to her son when he seeks this feedback;

> "We were focussing quite a lot on the kids being regulated, and from that I've taken very much that Will, he really needs a lot more proprioceptive input, which I knew. He's been requesting just a lot more just full on squishes under cushions and pillows and things and I've been doing that a lot more. …now I'm being proactive thinking about, d'you know, if you're distressed, I'm going to non-verbally, offer him a lot more kind of squishing and stuff …and I think if I offer that more, that's what he needs right now, to help him feel settled from a physiological point of view, then he may be more available and *care* more about that whole communication and relationship thing, and I'll just shut up! And not focus on communication at all other than showing him that I can squish him if he wants" (Maddy Reflective Journal September 2017).

Maddy was able to understand Will's behavioural expressions and his need and request for physiological feedback. She was therefore able to acknowledge this request and offer an appropriate response by providing the proprioceptive feedback he needed through a deliberate and tangible nonverbal response. Josie too found that her son benefitted from the deep pressure when he was feeling dysregulated;

> “When Josh’s really stressed, I’ll physically grab his chest or [squeeze him] him….and then that will relax him a bit” (Josie CLG discussion June 2017).

As parents we became increasingly aware of the non-verbal atmosphere of home communication environments. Our young people recognised and were affected by the nonverbal expressions of their parents. Ollie demonstrated an increasing ability to recognise and respond directly to nonverbal messages from mum, his mum also increased her awareness of the messages she sent and how her son interpreted these subtle communications, celebrating his increasing ability to recognise and respond to communication;

> “cos he walked past me into the house, I gave him a look, I don’t know what look it was, I didn’t realise I was doing it…erm, and he stopped, and he looked at me and he said what! And immediately I thought, what, what am I doing, what’s my body doing, cos I haven’t said anything, what’s my body doing, what’s my look doing, and he said…have I disappointed you? ….and at that point I just wanted to throw my arms around him and shout…yeah!” (Jen CLG discussion February 2018 Pg. 2)

Maddy and Josie recognised that their own emotional state was communicated to their children through their nonverbal expressions. They became more aware of their own nonverbal communications and their understanding of what they were communicating through these expressions and how this affected their children. From this they began to recognise that their nonverbal expression could contradict what they were saying verbally, betraying their attempts to cover up anxiety or tension;

> “Words seem to have a very limited impact in helping them to calm down and so I respond to them mainly nonverbally. Will in particular is very skilled at recognising

> what my body is telling him – he only feels safe and calm if my nonverbal communication says that I am also feeling safe and calm” (Maddy Reflective Journal June 2017).
>
> “We go over the day, he says he feels really bad and hasn’t been able to work at home tonight thinking about it. I apologised to Josh for anything which I might have said or done, which made him feel bad, I realise that my own emotions and trying to deal with two very different children, and onlookers seeing Josh’s distress etc, made me quite tense. …At this point of talking I understood that had I explained my own feelings to Josh this morning, he may not have spent the day feeling as bad” (Josie reflective journal June 2017).

These reflections establish the importance of the nonverbal expressions from us as communication partners.

Maddy explained her heightened awareness of the use of and recognition of her body language and behaviour as an intrinsic aspect of their communication when she was trying to support Will when he was upset;

> “Then I became aware of how incredibly tense my whole body was. Life is stressful and quite often with the kids I initially fake calmness to soothe them. As we sit together, the breathing and the peace usually makes me feel genuinely calm. This has been ok so far, but this week I wasn’t doing a very good job of faking it as I was so worried about the kids. Whilst I was making all the right noises, I was still feeling stressed and I think Will was picking up on that, probably from the tension in my body. I could be wrong, but when I made the effort to relax my body, he seemed to settle better and as this then reassured me that I could help him, so it helped me genuinely relax” (Maddy reflective journal May 2017).

> "….Will communicates with me non-verbally but what he's getting most from me is my non-verbal stuff, not my verbal stuff and although I knew that in my head, I wasn't really getting that because the reason why I wasn't able to calm him down, I then concluded was, I can say the right things and I can [say ahh and gentle calming words] and just sit there. And my body…I was tense, and with Will I've realised, not just with me but with everybody, it's really hard to lie to that boy, because it's everything about you, it's if you're holding any tension in your body" (Maddy CLG discussion June 2017).

These intimate reflections increased our awareness of our non-verbal communications. Will felt and responded to Maddy's embodied expression of tension and stress, once reduced this had an impact on his ability to calm. She describes how she engages with her children to support them to calm down;

> "..usually if he's upset I can calm him down and I do that just by sort of hanging out with him and ...you know I sort of model how to be calm and I breathe deeply and I'm just it, it's like …in a way ...and this is no disrespect to Will or to Rosie, it's the way that I soothed them when they were babies ...and it's just continued to me, a sort of very physical thing …and it wasn't working for me" (Maddy CLG discussion June 2017).

In her journal she described this process;

> ""Little by little we usually get in sync and they start to snuggle in, their breathing gets calmer and we just exist in the same space together. The communication is mainly non-verbal as I don't want to burden them with processing language from me on top of trying to regulate themselves. I might rock or sway and cuddle them in to do the same if it feels right. To be honest, it's hard to say what I do as I just do

> whatever feels right to me, and gauge their reaction” (Maddy reflective journal May 2017)

Similarly, Kate used physical interaction to help Dan to understand what it felt like to be relaxed through massage;

> “I would massage his back, …he loves it. And you say, so that’s what it’s like to feel really relaxed, cos I think somebody else did some work with him and said that he’s probably so tense all of the time that he doesn’t recognise it as anxiety, just, normal, so you know, it’s trying to teach him about relaxation so he recognises when the tension’s there” (Kate CLG discussion November 2017).

Josie also spoke of how she stroked Josh’s feet to help him to relax at bedtime;

> “And I’d sit on the quilt, feet, and I’ll just be stroking his feet until he went to sleep. Like over the weekend cos he just needed a bit of, and he’s happy with that, because he’s obviously just tense” (Josie CLG discussion November 2017)

Our discussions allowed us to become more aware of the nonverbal connections we make. Kate identifies through the APAR process that whilst her son would not actively request a cuddle he still prefers the physical closeness of cuddling in to his parents;

> “We have also learnt that he particularly favours shared activities that involve a cuddle! So, for example he still (despite being nearly 13) loves to read with me but we also have a cuddle while we are doing it. Equally he loves watching a film with another adult and he usually snuggles up under a blanket while we are watching it. But he would never request a cuddle” (Kate reflective journal 2017).

Having reflected on nonverbal communication Jen became more aware of the nonverbal interactions between family members when she returned home from the CLG discussion;

> “…and then I just stepped back and watched him interact with everybody else in the house and I thought actually that is their main way of communicating. Sometimes they actually don’t know what to say but the 16 year old …will go up to him and just, you know, walk in the room and just put his arms round him and then they don’t say anything…and then I noticed his dad does the same although his Dad’ll sometimes announce it or while he’s doing it say, give me a cuddle or you know that kind of, …and the younger, the younger one, he’s a bit more like me, so like on the sofa, maybe would like maybe would lean in and stroke arms or tickle feet or something, [younger sibling’s] a bit more like that and I thought actually it is more physical their communication, when I thought about it” (Jen CLG discussion October 2017).

Jen’s reflections and observation in her home allowed her to recognise the non-verbal interaction which was an important aspect of the communications between Ollie and his dad and siblings. She was able to recognise the way they interacted with one another, and this supported Jen to recognise the subtle and intimate connections Ollie has with others in the family.

Charlie likes to use his non-linguistic vocalisations to initiate a reciprocal communication;

> “He does a little squeaky noise or various other vocalisations and I started repeating it again, like mirroring it back, like I did years ago and he was just loving it, “do this one” and doing noises and I had to repeat them, and I got into this funny little conversation thing” (Helen CLG discussion September 2017).

Through the APAR process parents developed increased awareness of embodied, other-than-verbal expression and dialogue as an important means of recognising children’s communication expressions. Importantly, parents as communication partners also became more sensitive to the nonverbal messages they were expressing and how these affect the young person. We, as parents became significantly more aware of the need to be sensitive to nonverbal communication and dialogue between us as communication partners and the impact nonverbal (mis)communication could have.

Strategies to support communication: making it tangible

Parents had developed a range of strategies to support communication engagement, providing more tangible communication processes that made communication more accessible. Kate and her husband were working around emotions with their son Dan, trying to support his emotional awareness/expression. They ask Dan to provide a list of things that made him happy and then asked him to rank them on a scale of 0 to 6, the resulting list surprised mum and dad and also gave an insight into other likes, dislikes and more complex emotional experiences. The process of capturing the expression on paper but also ranking the thoughts, supported Dan's ability to express what made him happy but also enabled expansion to explore his likes or dislikes;

> "So, we've been doing some work around emotions with Dan and we were looking at happy and we were, [Dad] and I were getting him to list all the things that made him happy, well I was doing the writing cos he doesn't like writing. And, there were all kinds of things came out, going on holiday, birthdays, you know, all different things came out. But then we got him to scale them on 0-6 …You know, 0 just makes you a little bit happy, 6 makes you really, really happy, and that's where it became really interesting because he classified things completely differently to the way you thought, the way we thought he would. And lots of things came out of that. So one of the things he said was that when we go out for a family meal and [sister] is with us, so my oldest daughter …and as we were talking to him it became clear that he's really missing her because she's out with her boyfriend a lot. …And it became clear that he's really missing that and through all of this scaling that he did

> and things like as well, I used to think he was really, really excited to go, when we flew abroad, but he’s actually rated much higher going to a holiday camp we go to in Ayr and [Dad] and I were like….so he rated the flying abroad a 2 and the holiday camp in [Scotland] a 5 and he said, I really don’t like the heat, and we kind of knew he didn’t really like the heat but that must be what he’s thinking before we go” (Kate CLG discussion October 2017).

Creating a list with his mum and Dad gave Dan the opportunity to express what made him happy. Further, the process of scaling the items on the list provided the catalyst for discussion around these points. The process of structuring the communication increasing Dan’s ability to communicate some very important information and feelings which allow his parents a better understanding of Dan’s experiences and perspective.

Maddy shared the new developments in her son’s communication and his emerging use of signing and Picture Exchange Communication System (PECS). This visual and tangible communication method is also enhanced by the very focussed, available and therefore tangible communication partner.

> “so he’s obviously discovering something about his hands and communication and so I was saying, I mean it’s “Mummy” (signs mummy) you know “Mum, Mum…Mum, Mum (signing)” and he was really looking, and then he was like..(claps the sign) which is pretty close …I was like “Yeees!! Mum, Mum!” …and his little face again, he’s sooooo pleased which obviously breaks my heart as well because …so much joy because he can communicate 1 word. I mean he’s 9 bless him but how fabulous though. So, it is a really, a really positive thing, so I’m now thinking, …just agree on some sign that we’re going to use really consistently. Because something is happening, and I think a lot of it is about the change in school, erm …I mean he probably sees the speech therapist every day. …Cos there’s a lot of the kids in that unit have more communication than Will. So I imagine he’s quite a priority …and he

> has one to one constantly …so just that, there's somebody listening to him…so yeah" (Maddy CLG discussion November 2017).

Maddy used the term 'self-talk' to describe the way she exposed and made explicit her thinking by articulating her actions or thought processes, making these abstract processes more tangible and therefore accessible;

> "…I've been questioning how the kids and I communicate about abstract concepts. Is it effective? I don't believe I know what the kids think/believe about many words I use regularly to describe important concepts in our shared life. At present I try to make these concepts more easily understandable by linking them to concrete examples which are familiar and hopefully understandable to the children. I try to communicate things with my behaviour (or spotlighting other people's behaviour) and attaching a commentary. …When we read stories, or watch TV or listen to songs I now realise that I'm constantly passing comment (judgement!!!!) on what people are doing/saying – 'that's not kind of Peppa to say George can't play – it makes George sad' …is this how kids start to build their internalised view of what a concept is – they have lots of examples pointed out to them and they somehow draw out the commonality and begin to get a feel for what something means?" (Maddy reflective journal April 2017).

Maddy expands on the concept of making explicit what is happening around her children.

> "I suppose I feel two things, one thing is, erm, if you struggle to understand what's going on in someone's head, then people making that more explicit for you surely is helpful and if that enables you to recognise that other people maybe feel the things that you feel sometimes, then surely that can help, but also, help you feel less isolated, and I think the world must be a scary place if people are going around

> doing things and you don't understand why! You don't understand what's going on with them" (Maddy CLG discussion July 2017).

This discussion on the use of narrative as a tool resonates with my own reflections:

> "I almost narrate the world in Social Stories format. Building on the early use of social stories, I began to use this structure as a way of informing my language with Charlie. I think that was a real help for him just hearing that all the time …I knew he was taking on everything and I think it helps develop that broader contextual understanding as well ...you know when you can't join in a conversation in the world and you can't really access the context of things, I think that narrative must be really helpful, and must be quite securing" (Helen CLG discussion July 2017).

Josh is an articulate boy who is more able to understand complex language, yet he struggles to express more complex emotional situations. When struggling to cope with a new event, and the emotional challenge this brings Josie believes that 'self-talk' or narration of the situation would have enabled him to access and understand her emotional reaction and prevented him from harbouring his own negative emotions and "feeling bad" throughout the day. Her subsequent discussion with her son demonstrates the way she would typically make tangible her thinking and acknowledges she was not able to explain her thinking at the time of the event due to current distractions;

> " …but usually I would have, would have planned for it or told him in advance or something but I just missed and just said to him I'm really sorry but with dad moving out there's just another big list of things for me and dad to do, never mind any emotions or anybody's feelings, and usually son I would have given you warning or discussed it with you or, you know this would have been a lot better and I have to hold my hands up and its completely my fault but its cos my brain hasn't got space

> to do everything and I'm trying to do this bit instead at the minute. He, he listened to that, I would say" (Josie CLG discussion February 2018).

Maddy talks of the way she is trying to use this narration of actions and explaining behaviours to try to mitigate for the negative situations the children have recently been exposed to. As considered in the previous sub-theme of embodied communication between family members, she is aware that her children are having to witness negative emotional and behavioural expression in others causing contradiction and confusion. She tries to be explicit in narrating this experience to help the children to better understand and work through this;

> "There is a lot of 'an adult behaving in a way and then criticising a child for behaving in the same way' going on which is incredibly confusing and frustrating. The aggression must surely be linked to this! And just being a way of communicating all the sadness and fear that the kids must be feeling. …I talk with the kids about positive things they do and I will discuss negative things they've seen e.g. 'it's not ok to throw things as you might hurt someone' but if you're seeing an adult behave in a certain way consistently it must be very confusing to understand if it's ok. Particularly if it's a parent" (Maddy Reflective journal).

Both Josie and Maddy recognise the tension in their current home circumstances and try to explain the confusion. By narrating the behaviours, the children witness, and making tangible the reasons and impact of these behaviours, the mothers aim to support the children to better understand and contextualise these behaviours, hoping to reduce the confusion of contradictory messages they are receiving. By narrating events or other people's emotions, mothers aim to expose that which is hidden, complex and influx. This approach seeks to include our children in emotional and contextual understanding and reduce confusion and isolation that can result from complex family dynamics.

Siblings

Our young people with autism experienced relational changes as they and their siblings were reaching puberty. As parents, this process of change felt challenging and distressing. Mothers with older children spoke of the tensions, isolation and sadness as our children's interactions changed. This shift in sibling dynamics had the potential to leave their autistic young person feeling isolated. For Jen and Kate in particular, sibling dynamics was a current and challenging experience in their families. Both having an older autistic child and they having older siblings, both parents spoke of their appreciation of the opportunity to share these experiences and shared their thoughts;

> "…it's really, as a mum its hard, because before we all used to go out, …I'd take the 3 of them out and we'd go off for days out and things like that, but the older ones are not interested now and there's that distant relationship …the kids are going their different ways as they're getting older, they haven't got that bond with him anymore and they'll just ignore him, they'll ignore him for days on end…" (Kate CLG discussion September 2017).

> "…like the family change and as they get older, which, is something that I just never, ever, thought about, I thought I had every, you know, box ticked and everything, I would be prepared, and this one I wasn't. Really!" (Jen CLG discussion February 2018).

Jen knows that Ollie's shared space with his brother is timing out and it will no longer be appropriate to share a bath as her sons will need to seek privacy. This has been a particularly important time where the boys played together, Ollie calling it 'Bro time";

> "Erm, but it's still, he still has that connection with [younger brother], so we have that issue of well, your bodies changed now Ollie, bath time with [younger brother's] probably not going to be any more, well that was just devastation, …because what

> the bath time did with him and [younger brother], and I used to listen, was his role play kind of, it was just free flowing and it was just his imagination and we'll kind of get this truck and this shark and we'll do this with them, and it was the only time Ollie could do that kind of play free style not copied from a film or a movie, and to take that away from him.." (Jen CLG discussion February 2018)

Kate also recognises the lost connections that her son experiences;

> "[sister] used to have quite a mothering relationship with him and they did, bake cakes with him and everything but she's off with her boyfriend now and with her friends, and she just doesn't really interact with him" (Kate CLG discussion September 2017).

In these excerpts, both mothers lament the loss of the playful space that their young people enjoyed with siblings as they see these spaces closing down and the connections being lost.

As the children become more distant and spend less shared time together the connections are challenged. Ollie has become used to being without his older brother around, establishing a new pattern of interaction, and when his brother joins them this disrupts his new pattern of engagement. Jen reflects that Ollie's difficulty in accessing the silliness and playful engagement of his two brothers causes him to acknowledge his difference from them, and the isolation he can feel;

> "He said to me he felt left out, and I think it's because [his brothers'] relationship, for all (Ollie's) closer to the youngest one, [his brothers'] relationship's just so much more natural" (Jen reflective journal 2017).

This difficulty in engaging in the typical family interaction and understanding the nuanced interaction can leave Ollie isolated and upset. Jen recounts the stress that was felt during their school holidays and the impact that behaviour and tension had on Ollie's siblings. She spoke of the sadness and upset her other children felt as a result of the increased stress as Ollie struggled to cope with change and emotions during the summer holidays;

> "Ermmm, there's been some fantastic ups and some fantastic highlights and we've laughed all the way through the majority of the time but, stress wise the effect on my other 2 sons, has just, it's never hit them as much or as hard, even in the early days you know, when we had the first diagnosis and meltdowns in, you know, public places…" (Jen CLG discussion September 2017).

Responding to this difficult experience Jen brought the rest of the family together (without Ollie) and shared that Ollie's felt left out. She recorded in her journal that his older brother said;

> "…this just made him sad"

She followed this with journal entries;

> "[brother has really tried to include Ollie in things, listen to him, joke with him on subjects Ollie likes …I've seen an improvement …still an improvement" (Jen reflective journal 2017).

Similarly, Charlie's older brother finds a way of building a new space and interaction that the family can join in, by printing off the cover of Charlies favourite DVD the family joins in by each choosing an episode;

> "So, thanks to [older brother] we have a little thing now where we each choose our favourite episode of Ivor the Engine, but then Charlie will spend time leading up to it going' what's your favourite episode, which one are you going to watch?' So, and there's a lovely dialogue around it" (Helen reflective journal).

Kate echoes this increased stress in families as the children grow;

> “They used to cope with the meltdowns when he was younger, you know it was just fine, but now they just haven’t got the time for it or the willingness to deal with it, and so it’s quite hard isn’t it. Because you want your family to be like a unit” (Kate CLG discussion September 2017).

Yet, despite this acknowledgement of the difficulties, our discussion and reflections also acknowledge the positive dynamic and influence our children have in supporting and enabling their autistic sibling, and also, the love and bonding that they share.

> “…but when you focus on the good stuff and the beauty of the boys’ relationship and acceptance of each other and their intuitive inclusive perspective and Charlie’s no inhibition stance in our world then I am filled with awe and pride. These boys lead the way for us as parents ...they show us what it means to genuinely accept, to include, to see the world as equal and not see disability, just people…” (Helen reflective Journal 2016)

> “Oh, last night even though she was feeling awful, I said do you want to say night night to Will and they were both on the landing and so I said Will, do you want to say, night night to Rosie and he kind of wandered over and she grabbed him quite, quite intensely and gave him a big smacker on the lips and, which she’s never done and his little face, he looked kind of shocked and then he got this big smile …and I was like oh, you got a kiss from Rosie, she loves you…” (Maddy CLG discussion February 2018).

Staying connect

Our reflections expose the importance of our family connections and maintaining connection to support a sense of belonging and inclusion in the family as social partners. With minimal reliance on language, Maddy is aware of the importance of playful interaction and how this can offer an inclusive and mutual way of connecting;

> "…communication that was about sharing the contents of your head with them or them with you, and that, for my children, that isn't going to happen with using words necessarily, but it doesn't mean that it doesn't happen, and I thought well, those times when I feel really connected with the kids, it's usually about a shared experience. The shared experience might be that I'm tickling them and they're looking and we're laughing and we're both; but it's that shared experience isn't it?" (Maddy CLG discussion July 2017)
>
> "That play you have with your child is very bonding, it's, I don't want to say getting down to the child's level, because that, that I feel is, a negative way of putting it. However it's connecting with your child in a way that isn't so much about power and one person having all of the power and one person having less power, it's much more equal I would say in terms of balance of power, and by doing that and saying let's relate to each other in a way that isn't 'I'm the grown up and you're the child' it is showing respect for your child and it encourages that sort of bonding and that connection…" (Maddy reflective journal October 2017).

We talk about the evolving relationships as all of our children grow and where new opportunities to stay connected emerge. Kate describes the way she builds on her experience of listening to music with her son and daughter to then engage all her family in an activity whilst on a long car trip;

> "He's into pop music at the minute, so it's videos on You Tube, and things so …that's one way we've got the others interacting a bit, not a lot but, there, I was saying we had to go up to Edinburgh one day in the summer, I was driving, [Dad] wasn't there. So, I was doing the whole journey up and down in a day. And, we just took turns putting music on, on the phone, what everybody liked, and he was fully joining in with that and everybody interacting" (Kate CLG discussion September 2017).

Kate further refers to this event in her reflective journal acknowledging how the study process has enabled her to facilitate these opportunities to sustain inclusive family connections;

> "Dan loved being part of this [family activity] and playing an equal part in something. I wouldn't have necessarily thought to make these activities interactive between the siblings if I wasn't in the study" (Kate reflective journal 2017).

Jen too, recognises new ways Ollie is trying to engage and emulate his older brother, whilst she sees the spark of a new shared interest she is also mindful of the need to manage this relevant to Ollie's age and development;

> "Unfortunately, the thing that we're, what they do have in common is that Ollie's desperate to watch something that's 15. …And I think that if [older brother] and him were to watch it together that would bring a great bond but I can't let that happen, do you know what I mean? Because he's like [brother] do you think this is and what about this and [brother]'s like what about this and I can see the sparks flying. So I do think it will come back but it's just …" (Jen CLG discussion September 2017).

Whilst the changes that occur as children grow can disrupt communication and engagement between siblings and result in tension, conflict and feeling isolated from sibling and family inclusion. Our reflections make us more aware of the new connections that can form when opportunities show themselves. Whilst mothers agreed that there was no point in trying to impose these opportunities, the investment in communicative spaces gave more opportunity for these communicative connections to emerge, and when they occurred naturally we could recognise and “fuel them”.

Whilst Jen is grateful for Ollie’s increasing ability to express himself, she questions how she can use communication to invest in their connections and relationships to reassure and support Ollie through his period of severe anxiety;

> ”The one positive, actually at the moment is the communication because he’s able to express himself, it’s just in the times where, …..I want to be able to help him and the times where he is feeling bad and helping, because he is telling me, ‘ I want to annihilate their friendship and he’s telling me how I want to be, for us to be able to communicate with him so he doesn’t feel like that, that’s going to be a tall order because we don’t know whether we can, whether there’s ever going to feel like that but we can at least build the relationships we’ve got with him better…” (Jen CLG discussion June 2017).

Josie recognises her son is also starting to seek independence and talks of their relationships as foundations and hopes that this will endure and they will continue to return to family interactions;

> “cos each child has to be independent, whatever age we’re at, each child has to find their own way and then, if you’ve laid the foundations of, you know, everybody being together, and we all do this, or you’re welcome for this, that they know that’s there and they come” (Josie, CLG September 2017).

A developing sense of self

As well as their siblings growing and changing, our autistic young people too are between 9 and 14 and as such, are maturing and reaching puberty. They show different levels of development and awareness of their world and themselves as they grow up. This is a time of complex changes in young bodies and minds as they experience both the physical changes of puberty and their growing awareness of themselves as individuals. Mothers recognise that this is a crucial time to invest in and sustain communication to support their young person to feel included and connected in the family. Jen's recollections of her son Ollie's worry about growing up reflect the challenges of this period;

> "It's like he's been in this bubble so far, stuff has filtered in but it's like it's starting to crack and the world is breaking in unfiltered, it's just appeared and he's seeing like his whole life and he's just wondering where he fits into it, just like any teenager does really but it's almost like, he's, it's become so much more intense. …Last week he actually, Ollie actually said to me, I don't want to grow up! I want to stay, why can't I stay a kid, I don't want to grow up, why do I have to stop having baths with [brother]" (Jen catch up discussion December 2017).

We had discussed that the concept of change can be very challenging for a young person with autism and the fear of his body changing had distressed Ollie;

> "Well he didn't want his body to change he wanted to stay a young boy, why does my body have to change, I, I don't want anything to change, and [as] we were discussing before, the thought of the change, so when it actually happened it was a relief …Oh, I'm just exactly the same…" (Jen CLG discussion February 2018).

> "Yes, it's really affected him …you know one day he, he, he's more acceptant of how his body's changed and the next he's begging to go back to being younger

> because its, it was so much easier and then on the one aspect he wants to be alone and doesn't want to speak to anyone and the latest one is he'…I'll just tattoo my face, I'll just tattoo my whole face and then people will leave me alone …but then in the next breath he worries about, well but I've got to meet a wife because I want to have 2 children" (Jen CLG discussion February 2018).

Ollie is able to express some of his worries and fears of his changing body and of the increasing awareness of the future. Against a backdrop of Ollie's anxiety Jen is aware of the importance of their communication space and trust in supporting Ollie to work through these fears and worries (see sub-theme on Increasing Trust). Yet, as Josie expresses, it is sometimes difficult to sustain the level of energy and input that the repeated or evolving questions demand. She also acknowledges the need to be constantly mindful of Josh's age and developmental and communication abilities to be able to respond appropriately to these complex questions;

> "My Josh doesn't stop talking and it, and its deep and it's probing and it's questioning and your brain's tired when you've finished with him. …. but my head actually needs a rest now, because I've got into this big conversation that you might or might not have understood, so as well as the conversation we might have had about x, I've also had to work with your abilities or your understandings to try and explain x, and that's every time“ (Josie CLG discussion September 2017)

Growing self-awareness is evident in our younger children too yet demonstrated in ways appropriate to their language and developmental stage. Maddy believes that Will's increased self-awareness is also linked to his new and increased ability to communicate through signs;

> "I don't know if this is purely, I think this is linked to his communication in that he's really, really kind of, I won't say woken up because that's doing him a disservice, he

> seems to be seeing himself as somebody who is more capable than he saw himself in the past so he's really wanting to do stuff, like he's suddenly got massively into cooking …so he really seems to be thinking; no, I'm going to do this and I'm going to do that and I'm going to do the other! … and also, I can do this, yeah…I can do this, oh you've got the whisk out, that must be my job. I'm going to come and whisk. So, and I wonder if that's cos his communication seems to be really coming on, I think because of school he is, at home we get a lot of (claps) 'more' erm signing and at school he's also doing, there are 4 signs they're really going to focus on with him, he's got a sense of his own agency in a way, that he can ask for stuff and get the stuff that he's asked for and make demands and have those needs met, and so this is what I'm thinking might be behind it, but it's good" (Maddy CLG discussion February 2018).

Our young people's independence is also demonstrated in their behaviours, how they express their interests and what amuses them.

> "but even for me yesterday he was trying to have a little go but the smile on his face is so cheeky it is just something he's trying on, but I like that I like that kind of thinking, oh, I'll give this a go and I'll give that a go and he's not only going to choose the nice things like mopping the floor he's going to choose the other stuff as well, so I just feel he seems, there's a bit more self-determination or something, which is great, yeah it's great…" (Maddy CLG discussion February 2018 Pg. 32)

> "And in testing the boundaries and trying cheeky tricks learned from other kids there's a sense of agency a sense of the emerging teenager…" (Helen CLG discussion February 2018).

Kate reflects on Dan's challenging behaviour in school recognising it as his communication of indignation and injustice and the value it holds in providing a way for him to express himself. Whilst Kate acknowledges Dan needs support to communicate this more effectively, she sees value in his agency and capacity to make his presence and feelings known;

> I often think that these anger outbursts which can be so distressing when you get the call from the school, but in my mind I think well no one’s going to push over Dan, no one’s going to walk over him, you know, the school bullies are not going to walk over him because he will come back at them and he’ll get angry, and he’ll have to manage it and we’ll have to teach him how to use it appropriately and all that sort of stuff, but I think the children who are more quiet and don’t have that sense of righteousness can get walked over in mainstream school” (Kate CLG Discussion November 2017).

Our discussions explored that as our young people are growing, developing and becoming adults, they experience change, physical change, emotional and relational change, and the many challenges that puberty and growing up involve. Their different perspective and way of interacting with the world makes these challenges more significant and demanding. We see that the reliance on sameness and familiarity are disrupted by the changes of becoming adults; family dynamics, relationships, experiences and self-awareness conflict with the need for stability and cause increased tensions and anxiety. Yet, despite the challenges, the need to assert individual identity is apparent.

In addition to the typical challenges of growing up, Josie acknowledges the tension in her son as he acknowledges himself as an autistic young man, but also as wanting to be the same as everyone else;

> “on the one hand he wants to be the same as everybody else and not made any fuss of, hidden completely, same as everybody else, no fuss, I’m just the same as the person I’m sat next to and on the other hand he wants all of the exceptions to

> be made because he struggles with this or that or the other. And it’s constantly that battle of where do they fit in? Where do they…what do they perceive of themselves. Like Josh knows he has autism but sometimes he wants to forget it” (Josie CLG discussion September 2017).

Ollie too is becoming more aware of difference and is struggling with his diagnosis of Autism.

> “Ollie’s getting more realisation of how different he is but he’s not accepting that he has autism. ...And then in the holidays, he just, out of the blue, the therapist who took him was called Sue, and he said “I’m gonna prove Sue wrong!” And I said ooh really, well, what do you mean, and he said “I’m gonna prove her wrong, she’s wrong about me, I’m not the same as the child, he said, I’m not autistic! So, I think he’s got the understanding but he hasn’t got the acceptance, and at the moment he’s desperate to be in the older brother’s category, do you know what I mean?“ (Jen CLG discussion September 2017).

Jen expresses the difficulties in knowing how to approach Ollie’s diagnosis of autism with him and within her family;

> “But it just didn’t, I just didn’t want to, want him to have a label. Not that I didn’t want to, not recognise it, because we did, and I discussed it with my other 2 sons, very early on, they knew all about it very early on, which perhaps was a bit unfair. But it was just, I wanted to be open with them and when they had questions, they asked. Ollie didn’t ask any questions!” (Jen CLG discussion September 2017).

Kate reflects on her son’s inherent communication barriers which prevent him from expressing himself, she is aware that he experiences a lot of anger and confusion because he cannot express himself. Kate believes it is important to invest in her son's ability to express himself to reduce his frustration and be able to express the emotional challenges he experiences in order to support his developing sense of self;

> "So, the, but what that, the questions about communication came through this week (from the other families) and I thought well, that is something that's going through my mind is how going forward going into moving into High School and becoming an adult and becoming independent how do we make sure that Dan's got a greater ability to communicate and what are we not cap …like what are we, are, that's why I'm asking are all those thoughts in his head and he can't get them out? …all that confusion in his head and he can't get them out. It all comes out as anger, even though there's a lot more going on he'll say I never feel anxious" (Kate CLG discussion November 2017).

Josie too, recognises the need to invest in communication as her son is developing. She is aware that, that while Josh may struggle to cope with the direct focus of praise, it is important to give positive feedback to her son. She shares his friends' comments as well as her own appreciation of the effort she knows it takes for him to communicate whist managing his emotions;

> "I asked if he understood why I'd acted the way I did, after a while he nodded. I said how proud I was of him and his achievements, how happy I was that he was able to talk to me about his feelings and how much I loved him. I also told him what [friend] had said about him as I dropped him off 'I think Josh is really brave, he's one of my favourite friends, he's fun and creative" (Josie reflective journal June 2017)

Chapter 6 - Discussion

This chapter will discuss the research findings in relation to the study aims, and consider the contribution to current knowledge in autism studies. The aims of this study were;

Through collaborative learning;

- explore an insider view of communication interaction in families where a young person has autism.
- explore opportunities and methods to support inclusion in family communication.

The initial section of this discussion will consider the importance of building upon an inclusive methodology to engage family members as co-researchers: This is a significant aspect of the study design and enabled an insider view of communication in families with a young person with autism, rather than the typical exploration driven by external researchers. This inclusive methodological approach engaged the silent and silenced 'voices' of our young people as collaborative learners. This research approach provided space for diverse communications. It is this communicative space that reached into families. Giving time and opening space for communicative action between mother and child, and beginning to include other family members, enabled parents to acknowledge the importance of being available for communication and supporting young people to demonstrate their authentic communication. It is through this collaborative approach to learning that our children were able to teach us what matters to them in communication.

Secondly, I consider the embodied and material communications that our young people expressed as modes and methods of communication interaction, through which they demonstrate their capacity to engage with their material and social worlds. This exposed the complex entangled and affective communication encounters that, through reflection, enabled parents to recognise and learn from their young person, to understand how they communicated and what was significant to them. This increased awareness of the young person as an active and enactive communicator allowed parents to be more open to understanding the authentic communication of the young person and what was significant to them.

The final section of this discussion draws attention to the unique dialogue of the family as a social and physical space that was found to be a significant, indeed vital, aspect of the young person‘s becoming. Drawing on philosophies of Deleuze, (1987) and Braidotti (2013), *becoming* speaks of the complex and inter-related forces at play in the assemblage through which we are in constant dialogue and emergence. For our young people they are becoming adult, becoming communicator, becoming social. Self-narrative is central to this becoming and is supported by the connections and authentic dialogue of the communicative environment of home and family. Space, empowerment, memories, emotions and playful intra-interactions facilitated a mutual narrative that invested in connections. Family connections were found to be an important factor in supporting inclusive communication which in turn facilitated an emerging self-narrative entangled in the family narrative of mutual becoming. The need to invest in and sustain the connections became an important part of creating trusted communicative relationships, which enabled the young person to be included in their families’ forming narrative and their own reciprocal self-narrative and becoming.

Whilst some of the messages are nuanced and subtle within our findings, I draw again to the concept of a tracing of time, space and communication interactions. Our children contribute through action, word, vocalisation, image and touch. It is in this nuanced and subtle contribution, carried in family reflections, stories and memories that we can learn what it is to communicate and how we can include one another in this dialogue;

> "If we had a keen vision and feeling of all ordinary human life, it would be like hearing the grass grow and the squirrel's heartbeat, and we should die of that roar which lies on the other side of silence" (Eliot in Middlemarch, 1871 p. 194).

Building on Deleuze-Guattarian theories I draw primarily on the philosophies of Braidotti (2010, 2013, 2018), Barad (2003, 2007) and Bennet (2010) to understand the outcomes of the research that underpins this thesis. Their critical and new-materialist ontology draws matter, body and subjectivity into our understanding of the world. We are located in space, time, body, mind and material entanglement; in perpetual intra-action with and beyond self through which we are continually becoming as subjects. It is this politics of location that supports our understanding of the findings of this research study.

Time and space for communication

Themes of time and space were significant throughout our findings. Introducing the apparently simple concept of spending one-to-one time with our children asked that we, as parents, gave time for communication; in so doing we needed to slow and look for opportunities to join our young person in communicative action. As discussed in the methodological approach to this study the APAR process engages communicative spaces as a means of active research which engages democratic principles of knowledge production. As a research process APAR also responds to the needs of the young person to have communication space opened and accessible to them. The process of engaging in and reflecting on our communications as part of the study process demanded a turn to face our young people. In looking to our communicative action mothers gave time and recognised the importance of space; both time and space revealed their significance as catalysts to more inclusive communication.

Cluttered communication space

Whilst the wider social and political discourse will continue to permeate family experience and influence perceptions and actions, this research study actively turned inward to within family communication interactions. Turning our gaze inwards as families working together to understand and promote inclusion, revealed the often-simple politics of located and situated family lives. Our families began to recognise and express these situated micro-politics as lack of time to engage in communication and lack of time to reflect. Through discussions and reflections, mothers identified difficulty in finding time and making time, and spoke of the busy family environment which could mean missing our young person's attempts to communicate or lack of space for the young person to express themselves. We spoke of being busy and distracted, of being anxious or stressed and as such not focussed on or available to the subtle communications from our young people. Differences in our ways of expressing and experiencing communication resulted in barriers to shared language and shared conceptual understanding. Mothers questioned whether their children could recognise and understand their own emotional experience, and how we as parents should react to behaviours that challenged our own understanding and knowledge of how to respond. Mothers recognised the attempts to communicate that were often missed or times when children were not clear that their parent or family member was available and listening. Tensions in family circumstances which caused anxiety and disruption also contributed to the cluttered spaces that our families experienced, clutter of emotion, multiple voices, multiple and competing agendas, presumptions and lack of time which served to disable communicative overtures. The move to recognise communication as part of the research assemblage and the wider communication events of families and family members, brought with it the movement of forces in resistance and accommodation as suggested by Pickering (1993). Pickering draws attention to this resistance and accommodation of forces in the assemblage and of the blockages and flow of these forces as they intra-act in events, in the context of this discussion, communicative events in home and family. Our cluttered family communication spaces had potential to interrupt the nuanced interactions, divert communication overtures and could exclude our young people with autism; our child's communications were easily, blocked, diverted, perhaps missed or not acknowledged.

The process of the research underpinning this thesis demanded time. It asked parents (in our instance mothers) to invest 10 months of reflection and attend 7 meetings. Through participation in this study parents were asked to give time to reflect on communication and inclusion within their family, and with their family. In the process of exploring these communication interactions to identify events to reflect on and to record and share, parents needed to focus on their communication interactions. In so doing, we turned to notice the communicative interactions between our autistic young people and us as mothers, and other family members and as a result, became more aware of the nuances and the opportunities open to us, and more sensitive to our communication partner, our autistic child, and *their* communication.

Where we gave time for one-to-one communication, we swiftly recognised the benefits. This shared and focussed time allowed mother and child to come together and become more familiar with one another as communication partners. Mothers spoke of our children getting used to being heard, waiting for the time when they then express worries or thoughts. In this communication we became more aware of our children's communication abilities and agency. Attention through one-to-one time and anticipated spaces held potential to secure the children with benefits stretching beyond the one-to-one or focussed time. These spaces suggest a confidence and trust in their communication space and partner; as parents recognised the significance of giving space they invested in these spaces and actively made themselves available and included simple strategies to increase their availability. Saying “I’m listening” allowed Jen to make evident her attention and availability for her son. Maddy actively invests in making her time with Will and Rosie more playful and recognises how this *tops up* and sustains the children by establishing a culture of affirmation and anticipated positive engagement. APAR authors emphasise how important it is that the research process opens up spaces that facilitate this communication (Cook, 2012, Dentith et al., 2012). Through opening these spaces to our young people we enabled their communicative action in whatever form they needed to express themselves; they were given time and space to enact their communication. As our children expressed themselves mothers began to recognise and learn more what communication was and what mattered to our young people we were educating one another through communicative action which is authentic and situated Freire (1982). By increasing reflexivity, we as mothers were able to increase our awareness of communication beyond the normative expectations that disabled communicative events. This iterative and reiterative communicative enaction not only enabled our young people but also enabled mothers to understand and support communication.

Patterns of knowing

In their reflections on giving time for communication, parents began to recognise patterns that had become established. Bedtime was a particular reference, specifically for those children who had established and developing spoken language. Here bedtime became a strong point of reference where mothers in particular met and gave time for their young person to be able to express themselves. When a time was regularly given over to communication children began to anticipate that they would have opportunity to express themselves. For two of our young people, they already regularly used bedtime as a point where their mother helped them to calm down and where they talked about the concerns that were on their mind; this was a regular time when mother and child came together, yet the reflective action of the study process allowed mums to recognise the importance of this time and further invest in their availability. As a result of the study process Kate actively made time for her son for communication and found that cuddling up on her bed as a regular slot where she and her son came together, became an anticipated time when they communicated.

Where expressive verbal language was more restricted, bedtime became an anticipated time for shared reading. Books were a strong feature in the echoing and narrative that underpinned much of Charlie's expressed language. Whilst restricted language prevented Charlie from spontaneously questioning or sharing things on his mind, this bedtime was an important point of reference for him to share and absorb stories and narratives from books. These shared narratives were used by Charlie at other points in time to connect to events such as his guinea pig dying or to share a narrative. The shared familiarity provided by the habitual meeting established a strong connection and familiar narrative from his books. Similarly, coming together in a shared familiar space under the bedcovers and re-enacting the Susie-Sheep and Peppa-Pig scene provided familiar and shared engagement and interaction for Rosie. Parents found that anticipated times also offered familiar points of reference at other points in the day, particularly for young people with highly restricted verbal expression. Book or story narratives allowed Charlie and Rosie to revisit familiar and established narratives that created the familiar and recognisable in the flux of family and life dynamics, providing a safe shared reference to engage parents. Shared sibling time had offered a significant, familiar and anticipated space for Ollie, Dan and Charlie to engage with their brothers and sister, Ollie enjoyed shared TV time and talked about episodes from TV as well as sharing his Mashup pictures, Ollie also had a shared bath time with his younger brother that was an important connection time for them, Dan had an established time where he used to bake with his sister, Charlie had shared the room with his brother when his brother used to play his x-box. Anticipation of familiar shared space was generally acknowledged as important to offer security and predictability to our autistic young people, this supports a comfort and trust in familiar and anticipated spaces and communication partners. This recognition of the importance of anticipated time reflects literature on autism that demonstrates the increased importance of routine and familiarity for our young people. Boulter et al. (2014) and Joyce et al. (2017) highlight the difficulty autistic young people have in dealing with uncertainty, seeking routine and familiarity to counter this. For our young people, regular and trusted spaces for communication provide a space and time that is available and recognisable. Where they come to know this space, know their role in this space and know their partner is available pressure releases and communication is enabled.

Empowering

Whilst the concept of giving time and making space for communication seems so simple, our findings showed that these concepts and actions carried significant potential to enable inclusive communication. Where we mothers gave our children space, we too experienced this space. As mothers we also became more aware of our presence in the communication interaction and the power we held to control or manage the communication space. Literature confirms the monitoring and governance of families has potential to influence the parent and family perceptions. Rose (1998) considers the influence of the normative and 'natural' parent bond of mother and child, natural in the sense that anything that deviates from the typical and prescribed behavioural patterns is identified as 'unnatural' (Rose 1998). Behaviours that describe difference such as repetitive movement, restrictive interests, echoed speech, distressed expressions, describe difference and atypical development. For parents whose young people do not meet the typical developmental markers or demonstrate normative social interaction, this creates a tension between the presumptions we hold driven by wider society and the intimate understanding of our young people from a parent perspective. Foucault’s (1989, 1995) recognition of the omnipresent governance which prescribes hierarchical systems serves to enforce a hierarchy and can influence parental perceptions and practices. In homes, as parents, we are expected to discipline and reinforce appropriate behaviours. These constructs of deviance of child behaviours, or dominance of the parent position, can challenge intuition and roles in parenting, and hold the potential to enforce and inform a parental agenda in communication interactions. Frigerio et al. (2018) discuss the implications of diagnosis, expected normative behaviours and the tensions where development deviates from expected. In their account of a mother’s account of her child’s diagnosis, the child’s special interest in numbers and symbols become the projection and embodiment of her autism and, as such, are shut down. Her interests, objects of focus and engagement are removed. The parents-professional perception and dominance removes that which is central to the child’s self-narrative. In practice our preconceptions of what communicative should be as a dialogic interaction can dominate and disable authentic expression. For parents engaged in this research study, increasing awareness through reflective practice supported a developing reflexivity. Our reflections suggested a shift in the dynamic of our interactions, we became more aware of ourselves as communication partners and our influence on the communication encounter. As mothers we spoke of dropping our agenda, learning to stop talking and giving our young person the space to go through their emotions or frustration. Particularly in families, communication goes far beyond the functional communication that is so often the focus of interventions in autism. Young (1997) advocates a standpoint of moral humility and ‘wonder’ in the face of the other

(Young, 1997 in Milton, 2016). In referencing Young's' work Milton highlights that one cannot see or experience the social world from the perspective of another person and therefore we must wait and learn, through listening and engaging, to be able to gain an understanding of another's perspective and perceptions. Indeed, making ourselves more available to communication and giving the space for our young people to go through their emotions, to find their words or to ask for a squish under a cushion, exposed the capacity of our young people to be able to articulate their depth and richness of communication, both in words and actions; and through this expression we, as parents were able to wait and learn. Becoming more attuned to the space for communication and aware of their communication partner, parents referred to the reduction in pressure on their young person and also that they, as parents, learned to be quiet or to allow their young person to lead on conversation or play. Giving space to our young person reduced pressure on them to communicate and gave more time to access language but also to dissipate the emotional intensities of communication. Mothers relinquished and released control, whether real or perceived, on the communication interaction: Whilst Jen was confident she was listening to Ollie and not preoccupied, by actively acknowledging 'I'm listening' she created a tangible space for Ollie to express himself. Staying quiet enabled Josh to find the words he needed to work through his own emotional expression and find solutions to his upset. Similarly, by giving Dan increased space he was able to work through his anger, anxiety or frustration to be able to more readily express himself.

By giving time and space, parents were able to wait, listen and engage, learning directly from our young people, our findings indicated that we recognised them as a more equal and capable communication partner. Maddy very specifically, articulated her awareness of the balance of power within her interactions with the children, others reflected on the increased trust and confidence and capacity they began to see in their young people supported by this rebalancing of power. Saur and Sidorkin (2018), in researching dialogue in the context of people with learning disabilities, refer to Buber's suggestion that the situation of power imbalance itself prevents dialogical relation from unfolding. Where communication partners allowed the young person to take a lead in dialogue there was a shift in power, an acceptance of the capability of the non-verbal communication partner, but also a recognition of the 'adult' as available and open to listening. This investment in shifting the power balance is evident in the Intensive Interaction of Ephraim (1998) and Caldwell (2007, 2012). Brief references to the children's (often prepubescent) playful interactions with siblings suggests too of this equal engagement, bath time and shared video time being important fluid and creative spaces. Early interventions such as EarlyBird (Shields, 2001) and PACT (Green et al. 2010) build upon the parent as teacher approach or the capable adult, establishing the adult as the knowing other who demonstrates appropriate social skills to support learning in their child. Within interventions targeted at adolescents, whilst there is a move to understand the young person's expressions, there continues to be an emphasis on teaching new social skill to replicate normative engagement. Yet, what is evident in the communicative spaces that we explored within our families was not only the capacity of parents to facilitate communication by giving and making space, we also experienced the capacity of our young people as agential communicators. This interaction also provided an opportunity for mutual learning, thus challenging the hierarchical positioning of the parent and shifting our understanding to recognise the mutual and reciprocal learning between parents-child-siblings.

This deprivileging of the parent perspective and the increased space for the young person to engage their voice and presence re-engages the concept of the assemblage as a flat ontology a flat plane of events in a constant dynamic play of resistance and accommodation. By opening space, we unblock and allow our young person's communications to be engaged in its authentic form. In this decentring of parent and the relinquishing of power we served to empower our young person. Maddy’s playfulness is reciprocated and Will begins to initiate playful interaction, Dan is able to engage in new activity, and further to feel confident to request activity beyond this, and Charlie creatively engages his family in playful interaction, leading and instructing. Where power is more balanced, parents as communication partners are more open and available. By facing our young person, seeking communication opportunities and making space for their initiation we learned to be quiet, to just stop talking or to let our young person work through processing, frustration or emotion. We dropped other agenda, we increased openness reducing the pressure on our children to perform. Our children were more able to explore and try, to practice and engage in communicative enaction on more equal terms, they too learned new ways of engaging and became more available listeners. Caldwell (2007, 2012) argues that when our communication partner is our focus and we are in authentic communication engagement, we are learning from our communication partner. Intensive Interaction (Caldwell 2007, 2012, Nind and Hewett, 1994) provide an intervention which is typically drawn upon to engage with individuals with very severe communication and behavioural barriers that can result in severe isolation. Yet this approach offers a model closest to our findings as parents whether young people were verbal or used other forms of communication. It was in the turn to notice our young people that we also let go of our agendas and became authentic communication partners, available and with them in that communicative encounter for the purpose of communication. As Freire (1982, 1998) also advocated, we were learning together and from one another as experts in our own situated knowledge. We found that our increased openness and availability for communication secured our children and allowed them to get to know us as we got to know them, as equal communication partners.

Where we referred to ‘giving the space’ we acknowledged that this offered our young person the increased time to process and access language, the space to calm and to try to find words, to express their distress, or to respond to reciprocal playful interactions. Mothers referred to the fact that their young person might just give up trying when they couldn’t access the family conversations but by giving them space they were more able to engage, mothers also referred to the fact that their young person had more to say than they had anticipated and were surprised by the depth of thinking when they established a space together. We began to know one another better. In this shift, we served to empower our children. Without space Charlie struggled to engage his voice in family interactions, Dan was unable to join the family for mealtimes, Josh exploded with anger and frustration, Will struggled to regulate his body, and Ollie was challenged by fear and anxiety. Where we offered space, availability and listened, our children were more able to find ways of expressing and seeking the appropriate response to answer their needs. We as parents became more sensitive to the need for space for our young people to express their emotions and have their expressions validated. By opening up spaces to communication we moved from a dominant and disabling understanding of communicative action to recognise communicative *enaction* which enabled both young person and parent to engage more fully in authentic dialogue.

Contrary to the metaphors which portray autistic young people as asocial, and measured against a ‘non-humanness’ (Waltz 2008 p. 14) our young people demonstrated keen social engagement, when given the time and space to engage in communication and to access and recognise their available communication partner they demonstrated their capability as communication partners. James and Prout (1997) challenge the concept of children being passive in their social, cognitive and emotional development and as social capital being transferred from older experts to younger novices. Our findings confirmed the need for an available communication partner and reciprocity, which is advocated by interventions in autism such as the Cygnet programme, developed by Barnados in partnership with parents. Whilst Cygnet and similar interventions increased parents understanding of autism and ways to manage behaviours, the focus on communication was primarily in terms of functional commination, using visual supports and schedules to support these processes. I draw attention back to the children in our study, Rosie and Ollie, who actively rejected visual supports and picture communication systems. Furthermore, where our young people had more significant communication barriers we found the need to learn from our young people what held meaning for them in their communication, without assuming methods of communication, trusting and empowering them to teach us. As such, our findings more closely align with the child led approach of Caldwell's Intensive Interaction, importantly, aligned to the developmental stage of our individual young person. Our findings showed that given the time and space to engage in communication and to access and recognise their available social partner the children demonstrated their active capacity as a communication partner. The need to establish trust and learn from our communication partner is also echoed in the narrative of autistic authors such as Yergeau (2018), Higashida (2017) and Milton (2013, 2016). Yergeau (2018) asserts that we need to listen to autistic narratives, "the interbodily potentials, desires and moments that structure an autistic life, or any other life" (p. 4).

Playful encounters

Our findings began to expose the space between as suggested by Dwyer and Buckle (2009); space that exposed difference that enabled learning events. These authors consider their insider/outsider positions as researchers. Where researchers can empathise with the participants they are engaging in research they can learn from the space between their experience and the difference in their positioning. Where an insider view is taken, empathy can allow an affective experience of shared enquiry. Braidotti (2013) provides a similar acknowledgement of the spaces we traverse, and the events where difference can serve to inform our becoming. For us as parents, our situated exploration exposes spaces. Space between us, within our families, allowed us to acknowledge difference in our perceptions, positioning and understanding of our situation. For our families this space between at times suggested a gulf between us, where emotional pressure or language inhibited typical communication, a space we struggled to understand and to bridge. Early in our discussions, Maddy spoke of her concern that her children were different to others and did not use spoken language. She expressed her concern that this could impede our ability to learn from one another as it was often easier to learn from similar or shared experience. She also spoke of being unsure as to what her children experienced and understood by emotional language and expressions of terms such as kindness, this exposed space between us and our children and our families, the space between us as non-autistic and our autistic children, the space between us as verbal communicators and those who are not; or who engage and rely upon a much wider range of communicative methods. Our findings reflected the space between us as parents and between our children and others. Parents reflected upon the difference between their children as verbal or nonverbal communicators, discussing the difference in understanding and expressing emotion that could prevent us from communicating where we expected our young people to communicate emotional experience through spoken word. Whilst this space initially presented as a potential barrier to our communication, engagement and learning, Freire (1998) refers to difference as offering a place for differentiation which facilitates learning. Saur and Sidorkin (2018) in their exploration of new interpretation of dialogue in the posthuman era, considers the position of people with learning disabilities who may be unable to verbalise their thoughts and wishes in a language that can be shared with others. In their study they suggest “the fullness of human life occupies the space between individuals” in contrast to the idea of existence within “an isolated self”. Indeed, the presence of Will and Rosie as almost exclusively other than verbal communicators became an early catalyst to understanding situated and authentic communication methods. Parents recognised different ways of communicating, or ways of responding to expressions, we were reminded of alternative ways of doing through difference. Difference demanded that we question and/or reinforce our values and ways of including and communicating. We experienced the space between not as a polarised difference but as a space to learn from our children, from one another, from the difference between each of us. This echoes the call from autistic authors to learn from our communication partners (Sinclair, 1992, Yergeau, 2018). Braidotti (in Dolphijn and van der Tuin, 2012) describes that “otherness” and “sameness” interact in dynamic and non-symmetrical power relations. A vitalism of processes, dynamic interaction and fluid boundaries; events which enable a becoming through difference.

Barron et al. (2017) advocate for the need to respect and retain a playfulness with children that is not appropriated for adult or normative agendas and reinforcing reductive narratives. Where the “play-as-progress” agenda dominates playfulness in childhood, communication interaction in adolescence can too become laden and appropriated for the need to shape social skills and normative social behaviours. Our study found that by decentring parents from their position as the transmitter of knowledge and values and accepting the mutual and iterative engagement of young people in the communicative interaction through their authentic form of communication, we were able to engage in playful encounters that allowed mutual learning, as advocated by (Biklen and Attfield, 2005). Caldwell describes the ‘delicious conversations’ that she is able to engage in with her communication partner when other agenda are dropped and a mutual and reciprocal engagement is established. Both partners and young people engaged in their communication spaces with a creative and open willingness to engage one another and learn from one another.

Whilst play is typically assigned to the world of children, the process by which we explore the world and develop, a concept closely aligned to childhood and child development, in the context of this study, play suggests of our openness to new methods and creative ways of engaging in a manner that is equally exploratory for child and parent. Play in which we engage on equal terms and through which we can learn as children, young adults and parents. Whilst our children are aged between 9 and 14 their need to continually engage in exploratory interactions continues, as does ours as parents. Our findings show the importance in engaging in extended play which gave opportunity to learn and to develop through communicative and dialogic interactions.

We reflected on 'productive uncertainty', establishing a familiar routine and then subtly changing and expanding the routine. For Maddy such an encounter drew her and her son into a communicative engagement, safe, familiar and subtly nudging the boundaries to offer difference and a playful interaction. Mother and son focussed, present and waiting to respond to one another's reactions, what next? Vygotsky discusses the zone of proximal development (1978, see also Ferholt and Lecusay R. 2009, Chak, 2001, Zuckerman, 2007), a developmental position just beyond the stage that a child is currently experiencing, and typically social interaction enables the adult to draw the child into this space. Within our study playful encounters allowed the sustained connection, new connections and creative opportunities for growth and becoming within our young person's tolerance. Building on this concept we expand to engage a bidirectional development between adult and child where we can draw one another into an iterative dialogue of playful interaction. Yet beyond this we also recognise the agency of our young people to not only access the social interaction of a teacher/parent/adult communication partner, but also witness them creatively engaging other environmental and available resources to self-scaffold their own learning and move into their zone of proximal development, a bi-directional human-non-human learning process. Ferholt and Lecusay (2010) indicate that a zone of proximal development has the potential to foster development in both adult and child. The authors assert that we can not only see the unidirectional development of the child but also “the simultaneous development experienced by adults participating in the zone with the child” (p. 59). Espousing this theory, Ferholt and Lecusay (2010) quote Griffin and Cole (1984) who describe this zone of proximal development as a “dialogue between the child and his future; it is not a dialogue between the child and an adult’s past” (Griffin and Cole, 1984 p. 62 in Ferholt and Lecusay). Research with our young people suggests that this zone or spatiotemporal interaction between partners can allow a mutual learning of how we communicate and how we can learn from one another. This positioning also suggests of the events which spur becoming, previously described in the analytical framework of this study relating to the assemblage. Braidotti (2010, 2013) discussed the concept of the self always becoming through intra-action within the assemblage. A playful intra-interaction. Our young person’s development may be in more subtle steps relevant to their ages and developmental stages yet the nudging of the boundaries through connecting and sharing communication interactions allows our young people to engage and develop their communications, but also engaged the parent as a creative/playful learner, where we each anticipate out partner’s next move.

Where power shifted and parents became more available as social partners; we found that there was also the potential to become more open to playful interaction; play as a process of openness, of exploration and curiosity as suggested by Barron et al. (2017). An interaction that holds no other agenda than an equal inclusive communicative encounter. Play becomes a relevant term beyond its familiar use in childhood. Where we as parents were able to release our agenda, we became more interesting and available communication partners, playfully engaged in our parent-child becoming. It is this aspect of play as a means of engagement where we learn from and with one-another in a mutual becoming. A coproduction through the mutual engagement in playful dialogue.

Embodied communication

Literature in early childhood (Hackett and Somerville, 2017, Somerville and Powell, 2019, Myers, et al., 2015) is increasingly turning to recognise the material and posthuman child, this shift in perspective acknowledges that children engage with the world through their full range of senses embodied and intra-acting with environment, this echoes Jaswel and Akhtar's (2019) call to include an embodied perspective in research. Braidotti (2010, 2013, 2018) discusses the knowing subject, located both geographically and materially, embodied and agential. This move to recognise the relevance of the material world and how we engage with the world beyond traditional understandings of social construction, language and social interaction begins to open new ways of understanding autistic communication. Frigerio et al. (2018) and Douglas et al. (2019) consider autism and youth through a posthuman ontology; challenging perceptions of autism and childhood as disorganised and incomplete. The findings of the research underpinning this thesis demonstrated the need to consider communication as agential, embodied and material throughout childhood, adolescence and also in parent interaction. With altered sensory perception widely acknowledged to be intrinsic to autistic experience, this recognition of material as embodied, vital and agential holds particular significance.

At this juncture, I wish to acknowledge the use of the term *agency.* This term does not typically comply with theories of Deleuze and Guattari. Agency suggests that the capacity to exert power sits within an individual as opposed to the result of a dynamic relationship to others and the material environment. In contrast, Davies describes the human entity as a series of interconnected flows (Davies, 2014) reflecting Deleuze and Guattari’s concept of capacity of an individual activated through the intra-action with external forces, rather than the internally situated and driven dynamic suggested by agency. Such interconnections described by Davies exist within and beyond the human and as such deny the concept of an internally driven, independent agency. However, I have elected to continue the use of the term agency for the following reason. Whilst society speaks of capacity in relation to our young people it is too often understood as a latent capacity (social) or negative capacity (behaviour). Autistic young people have been denied their capacity to influence and inform their socio-political environments. I make this decision to use the term agency as young people with cognitive disabilities are frequently denied active capacity and capability, a capacity that is too often not granted the space or acceptance to be enacted. I suggest that the term agency has potential to reflect the common use of the word: It suggests of an active engagement, an intelligent and thinking engagement that has purpose, rather than the disorganised mind that is so often associated with autism. Braidotti too, whilst building her posthuman positioning on Deleuzian theory (Braidotti, 2010, 2013, 2018) discusses the knowing subject as located and agential, acknowledging the capacity to affect through enacted capacity. Strom (2018) resists the potential exclusivity of “high theory”. She argues that by employing accessible language and engagement with “Deleuzian/Deleuzoguattarian thought” we may interrupt the linear, status quo thinking and more widely challenge oppressive assumptions (Strom, 2018). Our common use of the term agency suggests that a person acts to produce a particular result and espouses a purposeful and intelligent enaction, also suggested by Trevarthen (2013), challenging the chaotic behaviour so often suggested of autistics.

Affective expression

This section of the discussion considers the affective expressions of the young people involved in this research study. Without words or unable to articulate and express their experiences and emotions our young people demonstrated a visceral and innate reaction to affect in response to internal physiological states or environmental reactions. The shift to recognising communication as being in and of an assemblage and a flat and non-hierarchical ontology demanded a shift away from the privileging of linguistics. This shift in understanding of our communication processes came in response to our reflections and discussion in the process of the study. In so doing this ontological positioning engaged a turn to matter within the entangled events of our communication. For our children their experience of the world was likely to be more complex, unpredictable and, often frightening. Fear and anxiety frequently challenged our children, an experience familiar to autistic authors including Higashida (2017) Rubin and Burke (In Biklen and Attfield 2005). Along with these intense emotions our children experienced frustrations, anger, injustice and humour. In this PhD study, our findings move us from perceiving communicative action as the traditionally understood passing of information between people through words and symbols, to a communicative *enaction* which engages mind-body-material in and of communication events. In recognising the body and embodied in communication we draw through the concepts driven by De Jaegher (2013) and Delafield-Butt et al. (2019) which locates difference in autism within movement, embodiment and enaction (De Jaegher, 2013). As previously discussed in the review of literature Delafield-Butt and Trevarthen (2013) advocate for the appreciation of social meaning in the embodied expressions of autistic movement and behaviours, describing this as the ‘vital dynamics’ of the embodied self to socially interact. Netto (2007) also considers language beyond the spoken word and symbolic interaction as situated in a special and temporal embodiment asserting that;

> “The bodily is a form of experience that relates directly to communication in a diversity of forms, and may also be an extraordinarily rich form of communication quite distinct from the possibilities of language” (Netto, 2007 p.240).

Netto also considers the importance of the physical space in which we communicate as a fixed and visual reference point that can serve to locate our bodies within the communicative encounter, in contrast to the fluidity of social and human movement. Yergeau (2018) describes autistic movements of echo, tic, stim and rhythmic movement as representing “linguistic and cultural motions that pose possibilities for autistics” (p. 181), indicating autistic embodied communication has potential to challenge what we know and understand about rhetoricity and therefore the forming self-narrative. This echoes Baggs (2007) narrative of rhythmic, playful intra-action with the material environment engaging multiple senses and absorbing embodied rhythmic affect. Hermansson (2017) describes affect is that which is felt before it is thought; it has visceral impact on the body before it is ascribed subjective or emotive meaning. Different from emotion in that it is a subjective bodily response to an encounter before it is coded and labelled as emotional: Emotion comes later when we are able to recognise, classify or stratify this affect. Our study findings showed that our children experienced and responded to powerful affective forces that disrupted and moved their bodies emotionally and physically. Well known autistic author, Temple Grandin, spoke of thinking in pictures, and our findings indicate that our children also think in embodied affect. Will and Rosie, in our first meeting, provided a point of entry to the complex, entangled communication assemblage; through their more-than verbal dialogue, location and affect, we as parents, as researchers, as communication partners, were decentred. This first meeting challenged parents, in particular those whose young people had well developed vocabulary, drawing their attention to our over-reliance on verbal communication. Whilst their affective experience may not be described in words, we as parents, saw and felt this visceral and affective expression in our young people. Carried in Maddy's words we heard of Will's embodied expressions, fear, anxiety, dysregulation, playfulness communicated through embodied expressions. Will in particular had no verbal communication, and in his other-than-verbal expressions he was able to communicate complex concepts through his behaviour. Braidotti (2011) acknowledges the mind-body continuum that we are able to engage when we no longer privilege linguistic and cognitive processes, Will demonstrated that his entire body thinks. Whilst some of our young people could not fully recognise, name or articulate this affect through spoken language, their bodies were moved by this affective force. Ollie struggled to cope with his feelings of anxiety, Will scratched and pulled at his mum, Dan lashed out, Rosie bumped into memories with raw and intense emotional response, Josh could punch through a door and needed mum to squeeze him to help to regulate him and Charlie laughed uncontrollably at sensations from years past. Serres (2008) draws our attention to the bodily experience through sensory interaction before language. Bodies that move, feel and interact with their environment engage in the whole person communicative encounter; To abstract means to tear the body to pieces rather than merely to leave it behind..." (2008 p. 28). This suggests that when we isolate aspects of communication, such as spoken language, it becomes dislocated and removed from whole and embodied experience of communication. Where we interact with our young people they draw on our whole embodied expression to interpret what we are communication, I draw on Josie's concern that she had communicated her anxiety to her son who had then harboured this through the day, whilst she had verbally explained herself she had communicated a different message through her embodied state.

This affect could not be named by our young people, but the affect was visible, present and authentic. It may have been difficult or impossible for parents to find out what had triggered this affect, and what physiological state or emotional category it would fit, but it was present, felt and it moved our young people. Where we as parents were available, listening, watching our children we became more sensitive to their affect and other-than-verbal communication and we were more able to recognise the intra-actions of our child and how they reacted to internal or external stimuli, present, distant or historic. Our children's bodies demonstrated the tangible and affective experience of intra-action within themselves, responding to sensation triggered by their internal proprioceptive state and their responses to their environment, understood through a new-materialist ontology where, as described by Braidotti, (2013) the entire body thinks. Our findings suggest that the entire body also communicates.

Behaviour is typically perceived as deviant or challenging in young people with autism. Through our reflections we found and acknowledged the importance of recognising our child's embodied expression through body language, mood or behaviour. How to respond and show empathy and concern was the stuff of parenting but inherent to this response was the need to acknowledge a genuine and intense embodied experience that needed to be expressed and needed to be supported in a way that helped our young person to cope. Maddy's reflections on Will's need for proprioceptive feedback reminded her to stay quiet whilst responding in the only way relevant to Will, by squishing him under a cushion. Her belief in the authenticity and communicative nature of behaviour that she found challenging, supported her to remain calm and open to provide an embodied and connected reply.

Where spoken language was more developed, our young people sustained the need to refer to only happy or sad as emotional/affective states, with emerging use of more complex expressions of loneliness, discomfort or disappointment. Parents' openness to the varied expressions and ways in which the children communicated made them more able to recognise expressions of fear, panic, anxiety or anger. Recognition of these expressions allowed parents to explicitly acknowledge these affective states and to make themselves more overtly available to listen and validate these expressions. Parents were more able to demonstrate their young person was heard and, whilst the cause of distress may not have been evident, such as in Rosie's bumping into memories, her raw emotion and distress was acknowledged and her mum empathised and supported her to cope with the distress. By recognising authentic expression, parents also recognised the need to be available and able to respond appropriate to their young person's need. In doing so they offered a valid answer to their child's overtures. Josie and Maddy told of how they often replied to their sons with deep pressure squeezes to help them to regulate physiologically. Josie and Kate rubbed feet or massaged backs to help to calm their sons. Kate reflected that, as a result pf the reflective process, she was more attuned to her son's anxiety when they were flying. Kate was moved by her son's emotional awareness when he began to talk about his impending school transition and the relationship with his Teaching Assistant and how he would miss her. Kate came to realise that he actually thought quite deeply about things but needed the space and support to be able to access and process his emotions and language to be able to articulate this. Their one-to-one time connected them and established a communication that allowed his mum to become more attuned to his other-than-verbal communications.

Each of the children in this study is unique. Their ways of experiencing and interacting with the world an evolving and experiential interplay of the many complex and entangled forces through which each of us are continually in communication and intra-action. Bergson (1911, p.24) suggests “There is no perception which is not full of memories.” Our children’s internal narratives draw heavily on their embodied experiences. Rosie opens us to the intensity of her internal narrative, the sudden and powerful memories she bumps into, which distress her, or occasionally cause humour, it is carried and returns when triggered by a similar affective experience or tangible references. Most importantly it is authentic emotional reaction which holds meaning and resonates with raw intensity: It is important. As Maddy suggests, it scared her body, the emotion seems to affect our children bodily and is retained and communicated through behavioural expression.

Material dialogues - what matters in communication

I begin this consideration of material dialogue in our findings by opening with a quote from Bronwyn Davies in which she references Rinaldi;

> “Opening up the not-yet-known through dialogue, and through the careful listening that is involved in keeping meaning open, relies, …on recognition of the “one hundred languages” that we share with children. “it is a declaration of the equal dignity and importance of *all* languages, not only writing, reading and counting . . . for the construction of knowledge” (Rinaldi, 2006: 175 in Davies, 2014 p.12)

The new-materialist ontological positioning recognises our autistic young people who did not, may not, or cannot, privilege verbal communication, who did not always privilege human interactions, who experienced the sensory and material more intensely and who could be stilled to silence in the face of overwhelming, embodied processing demands.

Their world, far from a fragmented collective of disparate entities and objects was an assemblage of interwoven and interrelated events in which humans and things “slip-slide into each other” (Bennett, 2010, p.4). Not only a whole-body communication but a whole body entangled within a material and human dialogic assemblage. Bennett speaks of the vitality of matter, that matter is not inert as it is traditionally perceived, but that matter is able to block and or impede the actions of humans, she also describes a vibrant materiality that runs alongside and through humans as a material force that has an agency, a capacity to affect the human through intra-action. In this context our physical body and environment has potential to affect.

Fox and Alldred (2015 p.11) argue that emotions are only a part of a more generalised affective flow that links human bodies to their physical and social environment, and as such contribute to the production of many aspects of the social world and human history, including subjectivity. Posthuman concepts of environment recognise humans as fully integral to the social *and* physical world. Massumi (2002) suggests affect links human bodies and brains to their environments in ways not reducible to language and reason, challenging long held views about consciousness and human intentionality. Exploring communication through a new materialist onto-epistemology we challenge what communication *is* relevant to the focus and process of this study. The shift to notice matter (Barad, 2007) and to recognise vitality (Bennett, 2010) in the material moves beyond a poststructuralist understanding of affect being carried in language. We therefore begin to understand matter as active within discourse and therefore directly engaged in dialogue. Our young people, recognise more than we that “the space of agency is not restricted to the possibilities for human action” (Barad, 2007, p. 178). We draw back to Bennett’s (2010) concept of vitality in matter. Not only does human interaction have the capacity to affect the human self but the environment and the physical body form part of the communication assemblage, we are in dialogue with the material other. In this ontology there is radical shift to decentre the human, this forces us to consider how the material world intra-acts with us in ways that do not necessarily ‘pass through language’ in the manner that we suppose and presume (Barad, 2007).

Barad’s (2007) concept of intra-action discusses the force within an individual or object, an agency that is present in both human and non-human. We are in constant dialogue and exchange with human and non-human agency through which we are constantly engaging in a dialogue within and beyond self. All things are constantly becoming through the interplay, resistance and accommodation of these forces within and between all things. Agency is therefore both cognitive and material, it engages mind-body-thing in a constant dynamic of becoming (Barad, 2007; de Freitas, 2017). Past narratives have perceived autistic people as presenting behaviour and movement that has been dismissed as chaotic and meaningless, and behavioural interventions have focussed on minimising and eradicating self-stimulatory movements and gestures. Yet, our children reflect the increasing narrative from the autistic community which describes meaningful intra-action with bodily movement and material other. Baggs (2007) describes hir intra-actions with the non-human environment, feeling the movement of water flowing, reacting to the rhythms of trees, water, light as ways of engaging and communicating in her environment. Movement or vocalisation, tactile and rhythmic engagement, memories, echoing and personal interests all form the internal-external narrative, the intra-action which inform our young person’s authentic language and their evolving selfhood. In our turn to matter and the acknowledgement of the agentic events we as parents were able to recognise the body as self-organising and responsive, with the agency of enacted capacity to move and respond to stimuli and affect.

Drawing, moving, touching, tickling, feeling your body in space, the proprioceptive feedback of a hug or the rhythm of music and mirroring of echoed vocalising or scripts were part of the landscape of our children's unique and embodied language, suggesting of the dialogue beyond our typical understanding of communication and demonstrating the young person's intra-action with bodily enaction and material other. Where verbal language is not accessible, children drew upon creative self-driven methods to express themselves, they turned to body and turned to matter; book-words, actions, notes, letters, drawings, photos, running, touching, creating familiar spaces, became forms of expression and communicative enaction. Whilst the difference and depth of this atypical language may challenge us as parents to fully understand their communication, Davies reminds us that "listening is about being open to being affected" (Davies, 2014, p. XI).

Shotter (2011) describes the need to see ourselves as essentially living within "dialogical and hermeneutical, back-and-forth relations with the others and othernesses around us" (p. 592). Innumerable causal factors engaging in our actions that only become tangible or reified once they are realised through our communicative enactions both within the self and beyond. Shotter suggests this material dynamic offers a developmental continuity, that our material and embodied entanglement is intrinsic to our forming self-narrative. Building from the raw reactions of affect, our young people engaged the bodily and material in communications. What mattered to our young person was what allowed them to engage and develop, an agential embodied and playful intra-action with internal, external, material and human. The behaviours we saw were the authentic expressions of this conversation through a material and human dialogue, connecting to what is available and accessible to them at their stage of development and in their situated communicative environment. The young person accessed and engaged with what could be tolerated and understood. Ollie and Charlie drew on book and DVD scripts and narrative, Will sought feedback to regulate his physiological state and began to engage in coded communication through the use of signs and symbols, through both methods he demonstrates his capacity as a communicator; he shows through bodily agency what response he needs and what the external pressure can answer in his needs. Parents recognised in Will's actions an agential communication, he initiated playful interaction through his behaviour, running away and looking back at mum, he joined the activities in his home with expectation and purpose as a social partner in whisking and cooking, he engaged the material force of a cushion and his mum as a feedback to his bodily proprioceptive requests. Our young people, through their movements and embodied expressions showed and taught parents what mattered in their intra-actions, parents learned from their young people what held significance, what was accessible and what mattered to them. What was accessible to a body/mind at that point in their young person's development.

Josh, Ollie and Charlie engaged the use of notes and drawing to filter and express emotions, Rosie brought mum into her familiar space of Peppa and Suzie's tent/blanket, Dan sought the physicality of a cuddle in on mum's bed establishing a safe, connected and familiar communication space. Our children found ways of engaging the physical environment in their shared dialogue of comfort, security and rhythmic mutual dialogue. Our young people's embodied communication suggested an increased sensitivity to material interaction, responding to the affect of the material intra-actions in which they engaged. The physical space, the material comfort, the shared reference of bedtime, books, the physical feedback of a squish, provided material feedback. Whilst Josh had the language skill to explain his distress or frustration, the physical note on paper allowed him to filter the emotion and, as such enabled his expression of anger or frustration, that may otherwise have erupted as an aggressive outburst. Similarly, Ollie was more able to communicate through a text rather than face-to-face or written note as it enabled him to make corrections without trace, and again filtering emotion through the material production. Such interactions shared from the perspective of a more-than-verbal and heightened sensory perception offer rich and articulate communicative encounters of more-than-verbal dialogues.

Predictability and familiarity provided vital intra-actions which provided securing feedback. Our children relied heavily upon familiar scripts or echoed phrases, to begin to access, support and structure spoken language. Rosie had minimal language and was able to request the familiar shared narrative of Peppa and Suzie under the covers, “mummy cover” and experience the familiar and safe revisiting of the narrative. Where language was emerging Ollie and Charlie developed strong connections with film and book narratives. Echoing scripts, soundbites and stories found in books and television, adverts and DVD’s informed their intra-actions. This accessibility of the material-words effectively slowed language, they could be repeated, revisited and scripts learned. These forms of dialogue were more static more accessible than the flux of busy family dialogue. When ready and relevant to them they begin to use and apply their stored words, sentences and scenarios. Peppa Pig and Piglet, through books and television, offered a way into language. Our children drew in the material dialogues, the book-words and the television-story to be able to connect and express their inner narratives. The use of books and scripts, DVD’s and book narrative, drawing, notes, letters photos of objects offer more stable accessible words and forms of dialogue or narrative.

Ollie’s thunderstorm narrative, “Domestos kills all known germs” and Cillit Bang”, where weather and detergent bottles were catalysts to access an inner narrative and a means of initially communicating in the linguistic world. Charlie’s books and stories became an available and accessible narrative shared in bedtime stories and revisited at other points to provide or to construct communication. The young people in our study demonstrated agential and creative methods of applying their stored stories, their remembered and repeated scripts and their unique and creative means of engaging in dialogue.

Netto, (2007) considers “space as referential to communication” disclosing a “material referentiality” (p. 195) at the heart of our communication practice, this acknowledges the entangled communication of both language, and space, and suggests the possibility of material space as a more tangible counterpart to the elusiveness of fluid communication. Space is therefore more stable, relevant to the motion and fluidity of human to human interaction. Engaging their spatial, material environment, through images, notes, spaces, lists and messages, echoed phrases and personal recollections our children engaged in a material dialogue. Letters, notes, drawings and photos enabled a less direct encounter and carried less emotional intensity and reduced the need to process language, they can serve to diffuse our emotions and offer a more fixed and therefore accessible form of communication.

Serres (2008, see also Tucker, 2011) draws our attention to the whole physical body as integrated and integral to our dialogue within ourselves and with our social and material environment; “Dancing, the music of the body, reigns before language” (2016 p.323). Our children’s interests and behaviours are a major source of debate in social and academic discourse. Restrictive and repetitive behaviours, vocalising, highly focussed interests are seen to form barriers to communication interactions. Yet these interests and ways of enacting mattered to our young people. They not only influenced and informed the communication assemblage but provided communication in its foundational and accessible form, driven by an innate and situated intra-action where dialogue engaged both human and non-human actants, bodies, minds and objects. By taking a turn to matter, we can consider the behaviours of the young person as offering a powerful expression from our child and what matters to them through the “unboundedness of both the human and nonhuman actants” (Stirling & Hackett, 2017). Our young people found their way into language and communication through innovative methods and means that were accessible and held meaning to them.

Between family members

Parents’ reflections, discussion and enacted communication with our young person allowed a growing awareness of our own impact on communicative encounters. A forming reflexivity enabled us to recognise how we influenced communication both by empowering our young person through giving space, and being available, but also how our affective expression was communicated to, and felt by, our young person.

Zimmermann (2016) emphasises the importance of good parent-child communication in supporting the adolescent transition from childhood to adulthood, this literature also indicated that challenges in communication can impact this positive dynamic (Steinberg, 2001, Harper and Coley, 2007, Shire et al., 2015). As parents we found, through our reflective practice, that we were more aware of our young people’s affective and embodied expressions and what mattered to them in communications. When Jen reflected on the changing family dynamics as her children grow and mature, she was saddened by these changes and the impact they had on all of her children, and the heightened anxiety and distress that is experienced by Ollie in this changing landscape. She maintains a strong communication with Ollie in which she is moved by his anxiety and fear of family change, he talks about dysfunctional families and expresses his fear that his family will separate. She was grateful for and continued to invest heavily in her own communicative connection with Ollie, seeing this as a way to support him to cope with his anxiety. Through reflection she was also able to recognise how other members of the family communicated and interacted, this allowed her to encourage and support further interaction between other family members and Ollie. Jen's elder son expresses his sadness when they met to discuss the difficulties they faced in trying to support Ollie as the children grow. Whilst this was a difficult emotional time for Jen and her family, her opportunity to reflect on the challenges of their family communication also enabled her to recognise ways that her family members engaged with Ollie, beyond words, this enabled her to invest in supporting Ollie within the family.

As parents we found that by being more aware of the embodied and affective communication of our young person we also became more aware of our family, and more specifically, our own embodied communication and how this impacted our young people. Maddy in particular felt the panic, fear and confusion her children sometimes faced without typical language. She responded bodily and in expressing empathy, I hear-feel-sense your panic-fear-distress. Beyond words, Maddy attuned to her children's nonverbal expressions and was able to recognise their affect through their behaviour and emotional expression. "The body is a surface of intensities and an affective field in interaction with others" (Braidotti, 2011 p.34). It was through embodied response that Maddy was able to tune into her children to try to ease their distress through familiarity, empathy and just being there, modelling calm through her own embodied enactions. We experienced in ourselves the vitality of bodies intra-acting with one-another in a more-than-verbal dialogue. Daniel et al. (2017) consider the importance of rhythm in our communication with those diagnosed with autism, drawing on the methods and innate communicative interactions observed in infants. I return to Kawohl and Podoll, (2008), as discussed in the review of literature, and their description of a wavelike or embodied rhythmic response to environmental stimuli. This also draws on Caldwell's (2012) use of rhythmic interactions to engage in more-than-verbal dialogue. Through observing, waiting, listening and opening up to rhythm of vocalisation, breathing, touch and body movement, Caldwell is able to open diverse and accessible conversation spaces that allow severely isolated partners to enter and find familiar rhythm to locate themselves. Autistic co-author Blackburn (in Biklen and Attfield, 2005) says that certain environments are not predictable and may not emit sounds to which she can easily orientate herself. Our findings suggests that our young people also respond to the familiarity of shared and established rhythmic interaction. Reading one another's embodied state, we recognised the potential of communicating through other-than-verbal methods, and became more aware of our capacity to respond to our child's needs without relying on language. We connected with the rhythms or sensations, through modelling calm, sharing our breathing, massaging, or even the reciprocal vocalisation that was shared between Charlie and I, we shared in interaction which could not be accessed through language. Focussed and intense, seeking meaningful body rhythms and movements that could be echoed and reflected in meaningful dialogue. Charlie and I engaged in a happy conversation of repeating vocalisations, Maddy synchronises her breathing with Rosie and Will, even in the shared narrative of bedtime when Ollie relaxes into his rhythm of breathing and talking with mum, when Dan has his back massaged to begin to experience calm and Josh getting his feet stroked, our children seek the nonverbal embodied feedback of rhythm and synchrony that is easily overlooked.

This increased awareness and reflective approach allowed parents to understand the impact of their own embodied communication intra-interactions with their young person, and how their own emotional state and more-than-verbal expressions affected their child. Our increased reflexivity allowed us, as parents, to recognise our own embodied expressions and their potential to affect our children; to regulate or dysregulate our children. We acknowledge there is a clear communication of our anxieties or frustration through our embodied expression. Maddy and Josie know that their bodies will communicate their emotions; the stress, anxiety, frustration. And that their embodied communication will betray any attempt to lie about their emotional state. We become more aware of the communications we express and how this can support regulation or feed dysregulation in our young person. Maddy spoke of her worry when she could not support Will to calm in the usual way; by sitting and using her own body to model calm. In recognising that she too was stressed and anxious, she realised that her attempts to project a calm exterior meant nothing and that her body was expressing her anxiety, she realised she couldn’t lie to Will. Mothers began to recognise their own more-than-verbal expressions and the messages they sent to their young person and the need to be conscious of this in their communications. By recognising the importance of our own more-than-verbal expressions we became more able to include our young person by explicitly explaining or managing our own expressions.

Tangible communication to support inclusion

Building on previous knowledge and training, parents talked about different strategies they used to try to support, structure and include their young person in communication. Parents implemented practical strategies aimed at making aspects of life more accessible to their young person; providing augmented or more tangible ways of communicating, sharing thoughts or explicating context or concept. Informed by a CLG discussion, Kate encouraged her son to share what was important to him by writing a list, she then supported him to order the things which he identified, allowing her to understand his thoughts better. This simple strategy scaffolded a wider discussion around the different things that Dan had identified and a growing awareness of Dan’s perspective and interests.

Prompted by progress triggered by Will's change in school, Maddy recognised her son's use of signing was starting to emerge, she swiftly responded to reinforce this by engaging a focussed and controlled engagement of these signs with family members and personal assistants who worked with him, celebrating and recognising his acquisition of this developing form of communication, validating and affirming his efforts. I spoke of the simple adjustments we made in family to slow our conversations or to make space for Charlie to contribute. We concluded that reflections on everyday encounters allowed parents to recognise their young person's experience more readily and include simple interventions or adjustments to improve access to communication. Our responses to the needs of our children shared through reflections and used to develop our praxis.

Our reflections allow us to explore the methods we used to connect and to support our children to understand aspects of our contextual and conceptual communications within our families. As described in the review of literature, context blindness (Vermeulen, 2015) suggest narrow perceptual positioning, where immediate detailing may be highly focussed for our young people yet wider context may be obscure. Similarly, complexity and fluidity of family interactions my alienate our young people who experience social communication differently. Without being able to establish wider contextual awareness our young people were more vulnerable to change and flux often resulting in unpredictability, anxiety and intolerance of uncertainty (Joyce et al., 2017). We found that building a contextual narrative both verbal and embodied, offered support to make sense of some of the complexity and nuanced communications. Maddy and Josie refer to self-talk and I used a running narrative, like a running Social Story, to make explicit what's going on around us and in parent's heads. We used these techniques to expose and make explicit our thinking as well as to explain our responses and experiences when engaging with our young people. Maddy connected this to her training in Relational Development Intervention (RDI)

(Gutstein 2009) and I refer to speaking in Social Stories (Gray, 2017) each of us is confident that this exposure of our thinking supports our children to access and begin to understand the complexity of our thinking and also builds context to our lived experiences. Sinclair (1992) describes his experience of understanding emotions and feelings, where it was assumed that he would have the same understanding, no one thought to explain;

> “And through all this condescending concern about feelings and emotional issues, no one ever bothered to explain to me what the words meant! No one ever told me that they expected to see feelings on my face, or that it confused them when I used words without showing corresponding expressions. No one explained what the signals were or how to use them. They simply assumed that if they could not see my feelings, I could not feel them. I think this shows a serious lack of perspective-taking!” (Sinclair, 1992, no page no.).

Josie too has devised and engaged this process over time to explain complex emotions and situations to Josh, driven by her respect for his need to be included and access contexts and concepts. Whilst Social Stories aim to structure and teach appropriate social skills, our application of this narrative in our findings is more driven by the process of self-talk. Maddy would comment on the way people behaved and whether that was ok, and how it might make other people feel. She was aware of behaviours that the children might see and not be able to understand if these were positive or not. Josie spoke of the way she used this technique to explain her own emotions to help her son to understand why she might feel anxious or stressed and that it was ok, she was ok, and it was not his fault. We discussed where we know our children struggle in certain areas of their lives and how we began to build a narrative around this to support understanding. This related to our emotional states and how we, or others might cope with these, accessing new activities or social situations or coping with things that caused general anxiety. Our children who were verbal engaged with coping strategies, explaining they could not cope although they could not fully understand why, they sought support and tried to learn coping strategies.

It is in the embodied and nuanced communication between family members where we more overtly recognise the parent-child-family communication. I return to the concept of bidirectional development between adult and child, playful encounters which can serve their own agenda of mutual learning and becoming. Our children's creative and able narrative identities can be supported and developed; driven by their capacity and agency rather than being trained or prescribed by the coercive interventions that are driven by a normative agenda in many cultural contexts. In our findings we acknowledged the enmeshed and entangled, affective communication assemblage, our reflections and increasing reflexivity served to lead us to what was important and worked for our child in our communication encounters specific to our family. These methods and processes differ relevant to each child and their needs and tolerances. It is in this nuanced augmentation, an increased sensitivity to affect, embodiment and matter in parent-child-family dialogue that we see an overt parenting, an approach we rely upon to understand and to respond to our specific child. We observed and recognised only some of our child's intra-actions, we may have only glimpsed the emotions, memories and anxieties. Through an increasing awareness and reflexivity we became more available to the affect of our child and more open to listening and hearing their authentic expressions, what moved us mattered and what mattered is where we looked to understand and support. Where our children expressed affect and emotion we were moved to understand this mattered to them; and what mattered may be experienced through human or material interactions. Whilst we may not fully understand, if we listen to their affect, we can learn what matters and respond. I'm listening, I hear your memory, your fear, your story, your need for comfort, your need to be alone, your sense of injustice. It is this opening of space and emotional availability of the social partner, the noticing and responding to embodied communication, that created inclusion in our family communication. Maddy spoke of the way she will respond to her children as she did when they were babies, not to patronise but to watch and to see, to learn from their expressions. Our findings suggested that this open and intensive approach to interaction has relevance throughout childhood and in all of our communication interactions to enable inclusion. It drew us as communication partners into a space of mutual and reciprocal inclusive dialogue.

Family communication as a liminal space of becoming

Connecting

As previously discussed in the literature review, Lam et al. (2012) and Larson et al. (1996) suggest that young people continue to seek 1:1 interaction with their parents during adolescence; with positive interactions having the capacity to improve well-being and outcomes for young people. Patton et al. (2016) acknowledge adolescence as a period of identity formation where the contexts of family and school environments are critical to social development during this period.

Lam et al., (2012) further describe adolescents seeking one-to-one dyadic relationship with parents to maintain connections during their adolescence, indicating that this dyadic interaction shows an increase against the broader familial social interaction during adolescence. Findings in our family research indicated that this dyadic connection is important, not only between parent and young person but also to be supported and maintained between siblings. Dunn (2005) considers the entangled positive and negative influence of sibling relationships within the complex and entangled social environment of the family, suggesting that adolescents are heavily influenced by these relational dynamics in terms of social and mental health and wellbeing. Our findings indicate that the unique and vital relationship between parent and child, and child and sibling has potential to offer security bonding, love and trust. Similarly, the intensity of our relational interaction also served to dysregulate our children, the directness of questions or interactions, the change in dynamics and the nuanced and fluid familial communications proving too intense, exacerbating difference and becoming emotionally charged.

The young people with autism engaged in our study were in middle childhood and early adolescence, a time of growth, physical and emotional change and of increasing awareness of their developing self and the wider world beyond home. Becoming teenagers and moving towards adolescence brought new tensions and change. Our young people sought and anticipated the familiar activities, spaces and interactions in their family communications. Bath time, TV time, simple and familiar routines with siblings and family offered inclusive spaces, connection and belonging. Growing up brought disruption and change, both to themselves as young adolescents and their relationships with their growing siblings.

In families the challenges of nurturing an emerging adult who is autistic, were evident and felt. Jen notes the difficulties over summer when the stress and anxiety had hit her family, in particular her other children. Kate and Maddy referred to the aggression which they encountered when their children were distressed, angry or frightened. Josie speaks of her son's abilities to punch through doors and we heard of the potential of self-harm and risk behaviours of Josh and Ollie. Ongoing anxiety was experienced by our young people and in our families, articulated most profoundly by Ollie who was approaching 14, and was struggling with change of his body, his feelings, his relationships with his brothers and his understanding of difference and autism. Family lives were charged and often stressful and volatile. With an increased space between parents, family members and their autistic young person as communicators, the need to invest in and connect through communication was fundamental to providing the familial support our young people needed. Jen is confident that her strong communication with Ollie had supported him to manage this very difficult time in his life. Bedtime space, “I’m listening” and recognising Ollies’ interests and methods of communication helped Jen to sustain their communication connections, focussed on enabling Ollie’s expression and dialogue. Ollie used drawing, photographs and mashups to connect with family and friends. He referred to the inappropriate families of the programmes he enjoyed, perhaps to express his worries over his family changing and falling apart. His mum was able to continually reassure him that the gang (family) was still together. Dan too, found the process of his siblings growing up and looking outwards to friends and relationships difficult, he missed the companionship and felt isolated. By recognising this and supporting Dan to express this, Kate was more able to invest in shared time and use Dan’s interest to seize opportunities to engage the siblings as a group in a shared engagement around music, she also felt the benefits when he felt more confident to ask her to join him to watch a video. Charlie also felt the beginnings of these shifts as his brother moved his room and disrupted their shared space and routine. Yet, his brother stepped in, setting up a new and shared activity of each choosing episodes from Charlie’s DVD.

Investing in parent-child-sibling connections through inclusive communicative approaches supported our young people to develop trust in their communication partner and to feel more confident to engage more readily with parents, and also siblings. Giving space to support this process was an important way of sustaining and nurturing these connections. Where siblings grew apart, our young people felt left-out or isolated, missing their siblings and feeling lonely. Being able to verbalise these emotions offered significant progress in being able to support our young people to manage these difficult times. Where language was more restricted, not available or accessible our young people expressed negative emotions, fear and worry though their behaviours. Parents recognised the need to support and nurture one to one connections to ensure that their young person continued to feel connected to them and supported siblings to find new spaces to communicate and engage. For Dan this allowed him to re-join family activities such as coming for dinner with family and others. Will initiated playful engagement and Ollie's older brother actively tried to engage Ollie in new interactions. Our findings indicated that maintaining communication and therefore social connectivity between family members was an important aspect of including our autistic child/young person within their family. Where communication is difficult, complex, fluid, fast and nuanced our young people can easily feel isolated. Investing in one-to-one engagement but also nurturing opportunities for family interactions to include siblings invested in connections between family members building trust between family members and also supporting confidence in our young person to interact within their family. This is also supported by the findings from The Lancet report on adolescent health and wellbeing (Patton et al. 2016). This extensive report indicated that adolescence is a time of identity formation and the social contexts of family, and school, are critical during this period. The report indicated that these contexts support the young person to be able to learn how to respond to more intense emotional experiences of sadness, anxiety and anger that are associated with this period of their development.

Narrative identity

Graci and Fivush (2017) suggest that "we are the stories we tell about ourselves", our self-narrative shaping and supporting our becoming. Adolescence is an important period in establishing self-narrative. Histories, connections, relationships, emotions and experiences contribute to this narrative identity. Singer et al. (2013) describe narrative identity as providing individuals with an overall sense of “unity and purpose” in their lives. Singer (2004, 2012) proposes that the key components of narrative identity are autobiographical memories, narrative scripts, and life stories. Habermas and de Silveira (2008) indicate that adolescence is a critical phase in this developing narrative identity and a time that can heavily influence a well-formed narrative identity. Fivush, Bohanek and Zaman (2011) discuss the importance of family in co-constructing the narrative identity. Identity formation is not an isolated process but a process of continual reciprocal dialogue and co-narrative. Whilst Pasupathi and Hoyt (2009) confirm that the developing self relies on being listened to as well as expressing the forming narrative. Our findings reflected the significance of this adolescent period in young people becoming more aware of themselves as becoming independent and more aware of themselves and their own narrative. Yet our findings also suggest of the increased vulnerability of our young people to the changes and challenges inherent in adolescence. This coupled with the challenges to communicative engagement in family dialogue held potential to isolate autistic young adults within their families.

This need to recognise language and dialogue in the forming self is echoed in Braidotti’s (2013) suggestion that we are speaking beings, that language is a mediator that constructs the self and makes us fundamentally not one but a result of our dyadic interactions. Yet, where spoken language is not present or is restricted to deny spontaneous sharing and reciprocity, our young person continued to share the fundamental need to develop their self-narrative in its own unique form. I previously quoted in the literature review, Nelson (2002) who questioned her sisters’ capacity to establish a personhood where she was unable to write her narrative, her sister had no communitive interaction with others. Whilst young people in our study may not have used verbal communication or could not access their language to converse spontaneously, they demonstrated creativity and capacity to establish their own self-narrative through methods and modes accessible to their understanding and developmental ability, finding creative ways to express themselves and scaffold emerging spoken language. Their language may be unique, echoed, storied, behavioural, written, or needing support to access it, yet it is their own innate and authentic language. Our young people remembered, felt, and were affected by their histories and evolving narratives in their unique form. We were able to trace this in the surface that we saw, the movement, anger, fear, loneliness, humour and playful encounters. The innate language that is so eloquently expressed and shared by Baggs (2007) draws attention to a language beyond words; the material dialogue and gives purpose and meaning to the embodied expressions of our children, their language to be acknowledged and to be valued. The vocalisations and embodied expressions, the echoing of scripts, the need to feel pressure, the hidden and often distressing memories, all part of the events of our young person's developing narrative identity. Parents increasingly acknowledged, listened to and responded. "I'm listening" I hear your expressions, I recognise your memories and bumping into memories as affect and emotion which speaks of self, of things important, unsettling, funny, unresolved. Your story. As parents we were mutually affected by this emotional journey and evolving narrative. Whilst, it belongs to our young people and it is through their authentic affective, embodied more-than-verbal narrative they become adults, we are ever present in this evolving narrative and are co-authors to a greater or lesser extent to this narrative identity. Pasupathi and Hoyt (2009) confirm our role as listeners, through which we serve to co-narrate this narrative-becoming. If we shift in our understanding of communication to include an embodied enactment of communication, we also shift to understand listening to be an embodied process and a human-non-human listening. Affirmation comes from all things through a playful intra-action, enacted in dialogue with self-matter-other. Where we de-privilege linguistics and take turn to matter we are able to recognise the more-then-verbal intra-action which contributes to this narrative and gives us opportunity to better understand, accept, contribute to and support this forming narrative and where necessary to steer dysregulating or damaging behaviours and intra-action such as self-harming and running away. These in themselves are part of this forming narrative, important and authentic, needing to be expressed, given space, time and to be listened to and responded to with care and empathy.

Playful becoming

Garrod (2012) defines early adolescence as a notorious period of social, emotional and attitudinal development and change. Bergson (1911, p. p. 88) describes the continual becoming, ever changing self, always on the boundary of something that is forming. “But already we may speak of the body as an ever-advancing boundary between the future and the past, as a pointed end, which our past is continually driving forward into our future” (p. 88). Where family social and communicative enaction and dialogue informed the narrative identity of our young person, we recognised our young people as interacting with family members, but also intra-acting with stories, objects and alternative mediums of communication to support, mitigate or mediate communication and dialogue; to self-structure and self-organise their commutative enactions. This continues to inform their evolving narrative. Our young people evidenced their capacity as creative and agential communicators in their narrative self and advancing boundary of past and future. Future that is built on Rosie’s memories and familiar spaces, Ollie’s reflections and need for assurance, Dan’s immersive time with family members which establishes new patterns of knowing, Josh’s drawing, writing and sense of justice/injustice, Will’s vital and embodied expression and engagement of his world, and for Charlie an awareness of closing spaces but an increasing confidence to negotiate the new, using found narratives to help him with this negotiation. Rosie kisses her younger brother goodnight; sometimes communications show subtle, gentle and new connections yet full with love and affection or challenged by fear and dislocation. By establishing inclusive communication, we are not only able to connect and offer more accessible family interaction, we are also better able to support our children through the complexity of growing up and seeking new ways of engaging with their world, we can provide a more inclusive co-author in this mutual becoming. Our findings indicated the challenges that changing family dynamics presented, siblings growing up, changing their familiar routines and looking outwards from the family resulted in a sense of loss, isolation or disorientation for their autistic sibling. These challenges brought anxiety, tensions, stress and upset. Yet out of these changing dynamics parents began to see, find or even stimulate new shared spaces and ways of connecting. Whilst perhaps felt and experienced differently, our young people experience their forming of narrative identity and require the dialogue and communicative interaction that supports this forming narrative. Whether our young people are able to articulate their narrative identity or not and whether we fully understand their expressions, or not, family will continue to play an inexorable role in their forming self-narrative and identity.

When safe, connected, and able to communicate and express themselves, the boundaries continue to move and the young person moves into this space – playful dialogue, self-narrative and communication between self and other allows the playful learning through dialogue. Biklen and Attfield, (2005), in summarising the narratives of the autistic co-authors of his book, refers to each author speaking of the give and take relationship with a parent or others that led to the autistic persons' advances, also referring to a high degree of self-reflection and self-direction at each turn. Furthermore, Biklen and Attfield, (2005) references Goode's (1992 in Biklen and Attfield, 2005) idea of the *etic* and *emic* relationship. Etic describes the dismissal of any behaviours which deviate from the norm, whereas the emic frame emphasises value and creativity in 'deviant' behaviours. Vital to the emic positioning, the observer must learn to listen and to hear. Biklen indicates that a this may require a shift of perspective, particularly an awareness of one's own location. As communication partners, parents therefore have opportunity to learn from the difference, the space between themselves and their young person. The embodied and material, spoken and enacted communication events become an experiential dialogue between self and other which enables the continuous becoming. Lipari (2014) emphasises the need to understand communication as an entangled process as described by the assemblage and, as such, should not be read as a process that reinforces the binary of self and other. Communication is often regarded as the passing of word-objects back and forth, often understood as individuals engaging in an exterior language which travels through a space to another located individual (Lipari 2014). Space in our findings identified a spatial and temporal opening where parent-child came together becoming a catalyst to include communication partners in a more equal process of mutual learning. Whilst young people favoured familiarity and repetition to secure them, and anticipated communicative interactions and spaces, each of these encounters brought something new, something different from their partner. Subtle or more challenging differences that continued to engage their becoming self, becoming communicators, becoming social. In opening communicative space with our young people, we opened to their engagement, to learn from one another in a nonlinear temporal process of becoming together; a playful intra-action that enabled a mutual becoming of young person and parent. The spaces that we established in our communicative encounters and enactions in our study provided a safe communication space in which our children can nudge boundaries and build from the safe and secure; initiating playful encounters.

Mulcahy (2017) describes learning through the *in-between.* Learning that is liminal and as located in a liminal space, always on the brink of becoming within our spaces, through difference of spaces between us as communication partners and our environment and experience. It is in the liminal space in which difference emerges through which we become as knowing subjects (Braidotti 2018). Too radical a difference and we run the danger of "wildly destratifying" (Deleuze and Guattari, 1987 p.160-61), dysregulating and disorientating our children beyond their capacity.

Our experience exposed the liminal spaces of communicative enaction in which we were becoming together. Where we came together in communication, we brought difference. Where we gave time and made space for communication we turned away from other agenda and became available to the communication interactions of our young person. In our dyadic interactions we encountered one another in playful engagement. At times this was play that would be associated with early childhood development of playful tickling, chasing and fun. At other times a playful interaction of serious and open engagement of dialogue described in the intensive interaction described by Caldwell (2007, 2012) and Nind and Hewett (1994). An augmented parenting where being together in the moment brought an intensive authentic communicative encounter that supported and enabled our young people to try, to express and be listened to. In return we as parents learned and felt and thought in our own becoming. In the context of this study home revealed itself as a situated, "materialist temporal and spatial site of co-production of the subject" (Braidotti 2010 p. 199). Young person-parent-sibling-environment-interests in a constant becoming through their dialogue with both human and material other. Learning through our difference and the spaces between us and other allows a perpetual learning through whatever communicative means we engage in. Space and time, awareness and availability support this perpetual becoming through the differentiated space between us as communication partners and the wider communication assemblage. Where we explore these spaces through playful/open interactions we are able to learn. All things in the communicative assemblage of child-adolescent-parent-sibling-space-object-word-image forming the continuing narrative as part of the young person's becoming in our liminal space and place.

> "Observe on the surface of the skin, the changing, shimmering, fleeting soul, the blazing, striated, tinted, streaked, striped, many-coloured, mottles, cloud, star-studded, bedizened, variegated, torrential, swirling soul "(Serres, 2008 p. 23).
> …and "an infinity of possibility that lies on the other side of that skin" (Gormley, 2015).

Chapter 7: Conclusion

Responding to the paucity of research exploring communication in families of young people on the autism spectrum, this study engaged 5 families through Autoethnographic Participatory Action Research to co-research communication in their families. As discussed in the methodological chapter, parents self-selected to engage in this study, suggesting of an ‘optimistic approach’ (Biklen and Attfield, 2005); open to the research process and looking to invest in communication. In practice this optimistic approach may have contributed to the positive and empowering experience of their involvement in the research, that Kate described as “not a moaning shop”. In practice the discussions in the Collaborative Learning Groups were positive, highly supportive of one another, and productive. This attitude was evident both in the discussions and in the mothers’ data and journals, including where challenges and emotional tensions were high and families were struggling to manage competing agendas.

What mattered in our research

Through collaborative engagement between families and within our families we were able to learn from one another what was significant in our family communications. Key findings indicated the importance of collaborative learning which included our young people through their own unique methods of engagement. Giving time and space for communication was critical in enabling our young people to demonstrate their agency and capacity as communication partners; and for us as parents to learn from these interactions. Opening space became a catalyst for inclusion where power shifted and our young people increased confidence and trust in their communication partners and in their spaces. Situated in our home environments we found a located and vital engagement with the space and place of home. It contained the young person's interests, familiar places spaces and routines through which they were able to scaffold and self-organise their forming self-narrative.

Reflexivity and forming praxis enabled parents to become aware of the entangled communication of familial relationships. Connections and belonging were seen as vital aspects of family communication. Investing and reinvesting in these connections supported our young people to feel connected and themselves, to be more available to engage within the family.

The findings from this study indicate a need to further explore the situated dynamic and experience of young people within their family communication environments. As autistic young people encounter changes, and emotional challenges of adolescence, our study described the increased need for strong communication and connections in families. The increased vulnerability that communication barriers create, have marked impact on our family communications and can cause isolation at this crucial stage in development.

Impact

Seeking to write this conclusion I looked to my family and asked them what they felt about the research that we had engaged in over the period of the study. This simple action drew my attention to what mattered in the study and how the reflective and situated process had informed our home communication. This study started with my family, the need to act, to respond to our situated and ethical dilemma; how to create a home that could mitigate for the differences in our communication. How to keep us talking and connected when words failed. In foregrounding lived experience we have looked deep into our homes and shared stories of fear and love, joy and tension. A powerful message of respect is carried in the reflections from our families; a respect for difference. And in this difference, we found the space between us, which became a powerful space to learn.

In talking to my family about the impact of the study I recognised also the vital role that all of the children engaged in this study offered. When my son Charlie struggles to control his emotions when something goes wrong, when he is stimming to cope with the demands of his anxiety or when we snuggle up in his bed at bedtime I am drawn back to the stories of bumping into memories, self-talk, squishing and sharing music. There is a sense of responsibility to the young people who engaged in this study through their parents. An ethical call to respond to Charlie as they would want it, patient, waiting, calm and ready to listen. I am not always there to hear, to feel, to notice. I am not always patient. Sometimes I am sad, or happy. At times I get it horribly 'wrong' and escalate anxiety and distress in my son. Yet, my increased awareness driven by our agential, intelligent and vital young co-researchers deep in their families, continues to resonate and teach me. Our young people teach me what communication can be and how I can learn and engage. They teach me what matters: Diverse and accessible communications that speak their language of inappropriate families or Piglet and Winnie the Pooh; trust in family members as communication partners that keeps them located and connected in their families. They teach me the importance and powerful affirmation of difference, a difference of creative alternatives.

Parents and siblings are not therapists, service providers or natural intervention agent but mums, dads, brothers, sisters. Where services fail to meet needs and social pressures stigmatise and problematise our families, where school budgets and support are cut, where our young people are labelled difficult, challenging and unteachable, parents and families become absorbed in a culture of stress and fighting for access to services, support and respect. Supportive networks are an important aspect of the community of families of young people with autism, yet tensions and challenges in services have potential to absorb the focus and energy of these community peer support opportunities. Talking out tensions, lack of services and seeking support or training to fill gaps in services may be supportive to parents, but it can also absorb energy and infiltrate families, drawing attention away from one another and our communication interactions.

Families play a vital role in supporting adolescents through emotional and developmental transition to adulthood. The difference in perspectives, experience and not least communicative processes creates significant barriers to engaging in communication inclusive of our autistic communication which also underpins our young people’s forming narrative identity.

Braidotti (2018) speaks of the joyful affirmation of powerful alternatives. Our interactions exposed power both as entrapment (potestas) and as empowerment (potential) (Braidotti 2018), both in our communicative encounters with our young people but also in our engagement as a community of learners. Powers that served to diminish and disempower through stigma and blame, that interrupted and disable our communications through pressures and life events, yet also powers that yield and shift and expose creativity and opportunity, love and nurture; that enable through communicative enaction. The deceptively simple process of giving time and space to communication allowed us to generate purposeful, situated knowledge that changed the dynamics of our homes and allowed us to include our young people and support their continuing becoming.

And our message to inform practice and policy; accept our difference, learn *from* our difference and through communicative enaction, *with* our difference. Participatory approaches to knowledge production allow the silenced voice to inform research practice and policy if we can give space to engage the authentic and situated voice and respect its message.

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Appendix

Appendix 1(b)

Project Title: - Exploring communication in families of young people on the autism spectrum.
Young person information sheet.

My name is **Helen Driver**

I am a researcher at Northumbria University.

What is research?

Research is a way to understand things better.

I am trying to understand how we talk and play in our families and how we make sure everyone gets the chance to talk and be listened to.

Why have I asked your family to join my research study?

Your parents thought you would all like to join in the study and think it might help you all to understand each other better and what you like to do together.

Do I have to take part?

No. You don't have to take part.

You should only take part if you want to.

What will I have to do?

I would like your family to take photos or record videos of you playing and talking and doing the things you usually do. Only your family will look at the photos or videos.

I would like you to talk with your family about what you like to do together and how you like to talk together in your family. Your Mum, Dad or carer will keep a diary and you can add some thoughts and ideas to this by talking with your family.

Who will know I am helping with the research?

Only the other families in the research study and me will know that you're joining in with the research.

What if I don't want to do it anymore?

If you decide you don't want to go on with the study you can tell Mum, Dad or your carer and you can stop. It's ok if you choose to stop. No one will mind if you want to stop.

Remember…… if you get worried or have any questions about taking part you can ask your mum dad or carer and they can ask me any questions.

Thank you!

Appendix 1(a)

Project Title: Exploring communication in families of young people on the autism spectrum.
Young person consent

My name is **Helen Driver**.

I am a researcher at Northumbria University.
I would like your family to help me with my study about how we talk and play together in our families.
I will ask you to **talk with your family about what you like to do in the family and think about ways you communicate and listen to each other.**
Tick or point at the boxes to let your mum, dad or carer know if you are happy to join in the study.
I agree to join in the study:

Yes ☐

No ☐

I would like your family to take photos or record videos of you doing the things you usually do. Only your family will look at the photos and videos.
Tick or point at the box to tell your mum, dad or carer if you agree to joining in taking photos and videos of you and your family to use as part of this study:

☐ Yes ☐ No

You and your mum, dad or carer can sign here if you have agreed to join the study.

Your name: ____

Adult signature: ____

If you decide you do not want to do the study you can tell Mum, Dad or your carer and you can stop. It's ok to choose to stop. No one will mind if you want to stop.

Thank you!

Faculty of Health & Life Sciences

Study Title: Exploring communication in families of young people on the autism spectrum.
Investigator: Helen Driver

Participant Information Sheet

You are being invited to take part in this research study. Before you decide, it is important for you to read this leaflet so you understand why the study is being carried out and what it will involve.

Reading this leaflet, discussing it with others or asking any questions you might have will help you decide whether or not you would like to take part.

What is the Purpose of the Study?

The purpose of this study is to explore the lived experience of enabling inclusive communication in a home environment in a family where a child has autism. Families may or may not receive training and guidance to support their communication at home and there is little research to understand the 'lived experience' of communication in our family lives. My aim is that through collaboration as a group of families we can consider the insider view of how we try to enable communication and explore what works and what barriers we encounter. The study will ask the whole family to reflect on how they communicate and how they can work together to develop their communication to include all members of the family.

Why have I been invited?

You have been invited to join this study as you are the parent or carer in a family where a child has an autism spectrum diagnosis and is between the ages of 8 and 12. You live in Newcastle or the surrounding area. You have expressed an interest in the study and engaging with the collaborative group to explore and share your experience.

Do I have to take part?

No, you do not have to take part. You should only take part if you are happy to meet with other parents and you and your family are happy to share your thoughts and experiences with the researcher and the collaborative group. This is a collaborative study and as such I will ask for you to discuss and agree the methods of data generation before we start. This may result in us refining the methods of data generation to better meet the needs of the participants.
You can choose to withdraw from the study at any time, just let me know. You don't need to tell me why.

If you decide to take part, I will ask for consent/assent from the members of your family to make sure that everyone is happy to share their experiences with the researcher and the collaborative group and that their experience will contribute to the final study which may be published.
Across a 6 month period:
You will be asked to meet with the collaborative group on 6 occasions.
You will be asked to dedicate time in the family to interact and play and to meet in your family and discuss communication.
You will be asked to share your thoughts in a collaborative learning group and what you feel works in family communication and what barriers you encounter.

The study is asking you to reflect on your family interactions and be able to look at how you might positively develop these interactions. It may be stressful to look so closely at your family dynamics and this may cause you some anxiety but the emphasis will be on problem solving and promoting positive interaction.
The data generation will take some commitment of time which is always precious. Some of this is part of family life but the meetings with the group will ask more of your time.

<u>What are the possible benefits of taking part?</u>

This study is developed out of my MA (autism) study where I went through this reflective process with my own family. I found it helped me to understand how we communicated with my son with autism. It also helped me to understand how I might do things differently to improve communication. I also found that it made me and the family understand how we could include our son with autism better in family communication and engagement. You may also find similar benefits.

<u>Will my taking part in this study be kept confidential and anonymous?</u>

You will meet with me (the PhD researcher) and the other members of the collaborative learning group. Outside of these people you will remain anonymous and any data you contribute will be kept confidential.
I will give pseudonyms to all participants so that you and the family will not be identifiable in any published material.

The only exception to this confidentiality is if the researcher feels that you or others may be harmed if information is not shared.

<u>How will my data be stored?</u>

Data in a digital form will be kept in a password protected file and accessible only to the researcher. All paper data, including journal information, transcripts and your consent forms will be kept in locked storage. All data will be stored in accordance with University guidelines and the Data Protection Act

What will happen to the results of the study?

We will analyse all data generated during the study. The results will contribute to my PhD study, I intend publishing a paper from the study which will appear in a peer reviewed journal. You will not be identifiable in the study or any published paper as all participants will be anonymous. I hope that the narrative data presented will help to inform services and organisations who work with families and individuals with autism and ASD.

Who is Organising and Funding the Study?

The research is funded by Northumbria University, Faculty of Health and Life Sciences. There are no other organisations involved in the study. I initiated the study as I feel this is an area of research that has not been explored and that the experience of our families in this context is not always understood.

Who has reviewed this study?

The study has been reviewed by my supervisory team, Dr Joanna Reynolds and Dr Tina Cook. Also, the Initial Approval Panel: Dr Colin Cameron and Dr Se Kwang Hwang and the Northumbria University Ethics Review Committee.

Contact for further information:

Researcher email: h.driver@northumbria.ac.uk
Supervisor email: joanna2.reynolds@northumbria.ac.uk

Appendix 1(c)

northumbria
UNIVERSITY NEWCASTLE

Project Title: **Exploring communication in families of young people on the autism spectrum.**

Consent form

Principal Investigator: Helen Driver

please tick or initial
where applicable

I have carefully read and understood the Participant Information Sheet.	☐
I have had an opportunity to ask questions and discuss this study and I have received satisfactory answers.	☐
I understand I am free to withdraw from the study at any time, without having to give a reason for withdrawing, and without prejudice.	☐
I agree to take part in this study.	☐
I understand that by taking part in this study I may be exposed to situations that may generate some psychological distress that may become apparent during and/or after the study has finished. I accept the small risk of experiencing psychological distress as part of this research	☐

Signature of participant.. Date.........................

(NAME IN BLOCK LETTERS)..

Signature of researcher.. Date.........................

(NAME IN BLOCK LETTERS)..

Consent for video and audio recordings to be taken

Project title: Exploring communication in families of young people on the autism spectrum.

Principal Investigator: Helen Driver

I hereby confirm that I give consent for the following recordings to be made and used by my family:

Recording	Purpose	Consent
Photos or Video of family – taken by family members	For review within the family to stimulate reflection and discussion.	
Voice recordings	To capture the discussion within the collaborative learning groups for transcription and analysis.	

Clause A: Participants will be asked to review photos or videos of family interaction within the family. It is not intended that these photos or videos will be shared outside of the immediate family.

For ethical purposes I agree that I will not share the photos or video used within the study with other's outside of the family during the period of the study.

Tick or initial the box to indicate your consent to Clause A ☐

Clause B: I understand that the voice recording(s) may also be used for research purposes within the context of this study. My name or other personal information will never be associated with the recording(s).

Tick or initial the box to indicate your consent to Clause B ☐

Signature of participant.. Date........................

Signature of researcher.. Date........................

northumbria
UNIVERSITY NEWCASTLE
Faculty of Health & Life Sciences

Consent for photographs to recordings to be taken as part of the study.

Project title: Exploring communication in families of young people on the autism spectrum.

Principal Investigator: Helen Driver

I hereby confirm that I give consent for photographs to be taken by and of my family and used as follows:

Recording	Purpose	Consent
Photos of family and home – taken by family members	For review **within the family to stimulate reflection and discussion**.	
Photos of family and home – taken by family members	To be viewed and discussed in the **Collaborative Learning Group**	

Any photos used for the purpose of discussion will be viewed only within the family OR within the family AND the Collaborative Learning Group and not for any other purpose.

Signature of participant.. Date.......................

Signature of researcher.. Date.......................

Thank you

northumbria
UNIVERSITY NEWCASTLE
Faculty of Health & Life Sciences

Project Title: Exploring communication in families of young people on the autism spectrum.

Hello. We are continuing the study about communication and how we talk and play together in our families.

In our parent group meeting we thought it would be a good idea to use something called **Photo-voice**. This means that you could use a camera to **photograph what is important to you**. You can give the photos a title if you choose to.

I would then like you to **pick the photos you want to share and show them to your family so that you can talk about the photos. It is up to you to decide who gets to talk about the photographs and if you want them to be shown to the other parents in our group.**

Tick or point at the boxes to let your mum, dad or carer know if you are happy for photographs to be taken and **shared in your family** as part of this study:

👍 👎

☐ **Yes** ☐ **No**

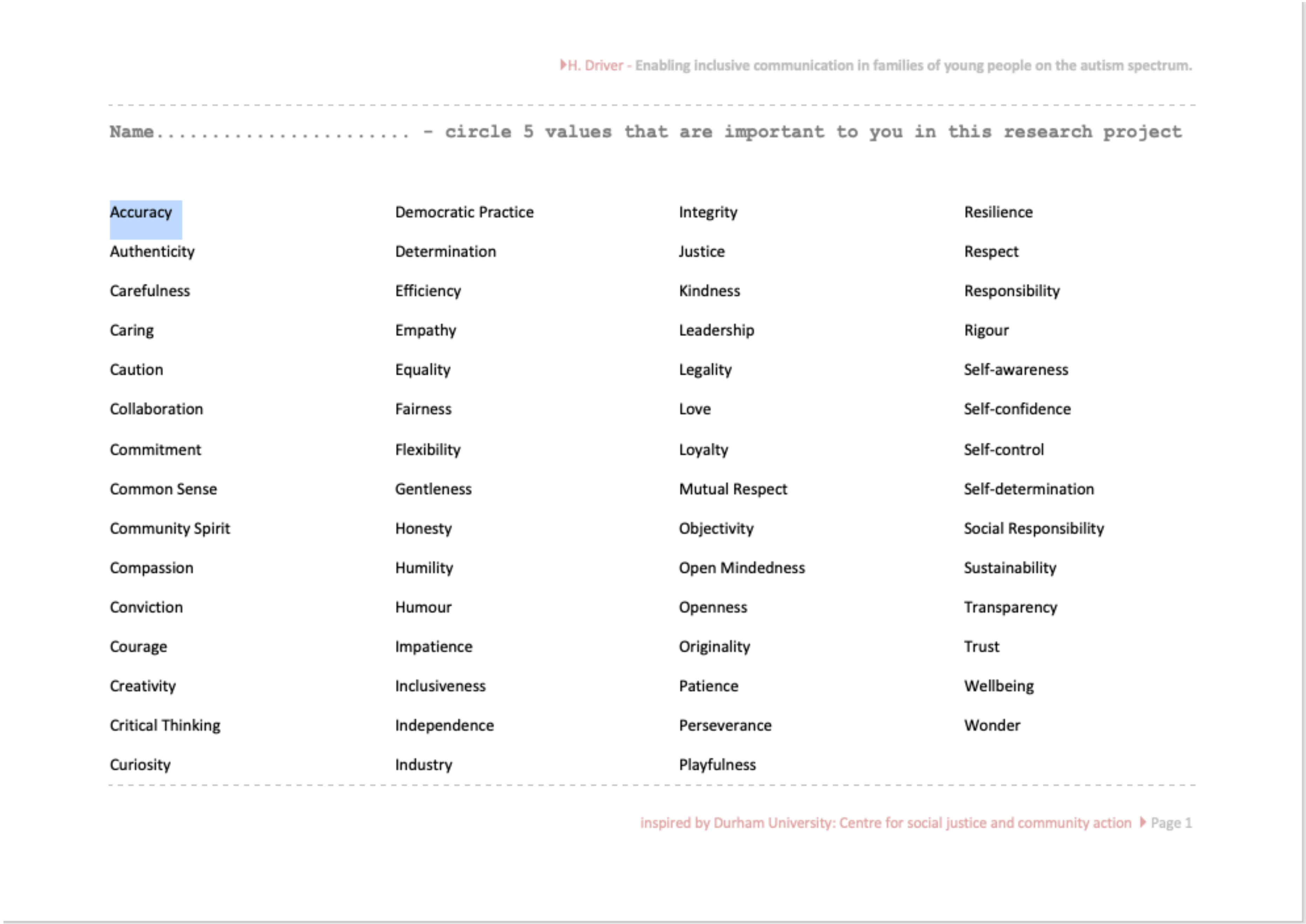
I agree to let the photographs I take be shared with the **other parents** in the group::

👍 👎

☐ **Yes** ☐ **No**

Thank you!

Appendix 2(a)



▸H. Driver - Enabling inclusive communication in families of young people on the autism spectrum.

`Name....................... - circle 5 values that are important to you in this research project`

Accuracy
Authenticity
Carefulness
Caring
Caution
Collaboration
Commitment
Common Sense
Community Spirit
Compassion
Conviction
Courage
Creativity
Critical Thinking
Curiosity

Democratic Practice
Determination
Efficiency
Empathy
Equality
Fairness
Flexibility
Gentleness
Honesty
Humility
Humour
Impatience
Inclusiveness
Independence
Industry

Integrity
Justice
Kindness
Leadership
Legality
Love
Loyalty
Mutual Respect
Objectivity
Open Mindedness
Openness
Originality
Patience
Perseverance
Playfulness

Resilience
Respect
Responsibility
Rigour
Self-awareness
Self-confidence
Self-control
Self-determination
Social Responsibility
Sustainability
Transparency
Trust
Wellbeing
Wonder

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Appendix 2(b)

Name.. What do you feel is important to you in research?
Circle 3 or more if you wish! This study should be…

Happy

Funny

Kind

Gentle

Fair

Playful

Safe

Important

Honest

Strong

Loyal

Respectful

Brave

Caring

Appendix 2(b)

What do you think is important in this research study?

happy		**respectful**	
playful		**brave**	
funny		**kind**	
serious		**safe**	
fair		**You choose....................**	

Tick 3 (or more) Name...