# The Talking, Being and Becoming of Autism, Childhood and Dis/ability

# Abstract

This thesis is a piece of Creative Analytic Practice which uses auto/ethnographic storytelling to dis/orientate autism, childhood, and dis/ability. Dis/orientation is a theoretical tool I develop through, and with, the thesis borrowing from Critical Disability Studies’ dis/humanism and Ahmed’s orientation in queer phenomenology. Dis/humanism both desires the human and rejects it at the same time; the vital and giddy experience of dis/orientation is both to be drawn towards a comfortable orientation and at once to reject its seductive temptation as a final resting place or single direction when encountering lives lived as ‘autistic’ and ‘child’. All orientations to autism, childhood and dis/ability are the effects of repeated and often concealed actions over time which I argue are temporary and changeable, given time and dis/orientating labour. Herein lies the hopeful call of dis/orientation throughout this thesis.

I use a tool of dis/orientation to explore the terrains of lives labelled and lived as both ‘child’ and ‘autistic’ through ethnographic fieldwork with children and families living with/in autism. Stories are told as both method of inquiry and analytical tool; three analysis chapters explore the ‘talking’, ‘being’ and ‘becoming’ of autism, childhood, and dis/ability. I argue that through talk, autism becomes rhizomatic in families lives and is shaped by, and shaping of collective identity work, emotional labour, and the neuro governance of everyday life in neoliberal, commodified times. I argue that some orientations make some beings and becomings of childhoods labelled autistic more im/possible than others. Most significantly, I claim that a turn to embodiment outside of Cartesianism is valuable to theory, policy, practice and research in recognising the potential ‘becomings’ of disabled children’s childhoods in which they exceed subjectivation as ‘autistic’ or ‘child’ with, and through, their bodies in everyday life.

## Acknowledgements & Dedication:

## #JusticeforLB #Justiceforallthedudes

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## Project & Thesis Overview: Process and Product

This thesis acts as a piece of Creative Analytic Practice (CAP) (Richardson, 1999; 2000) of my auto/ethnographic PhD project. It is a landscape of the terrains of autism, childhood and dis/ability over and in which I have wandered with children, families and allies. It bears the hallmarks of a thesis, though perhaps on less conventional terms due to its CAP conception as both process and product (ibid). Lincoln and Guba (2005) explained CAP as:

Texts that seek to break the binary between science and literature, to portray the contradiction and truth of human experience, to break the rules in the service of showing, even partially, how real human beings cope with both the eternal verities of human existence and the daily irritations and tragedies of living that existence. (p. 211)

The thesis contains an exploration of literature, an underpinning of theory, a methodological justification, data, analysis and discussion, though each is storied in a non-conventional guise which argues for research in the everyday lives of disabled children. Chapter 5 explores the features of a CAP as both methodological design and analytic framework. The project began as an ethnographic exploration of the everyday lives of children labelled with autism. It spawned into something inherently auto/ethnographic and the writing of the thesis product itself became part of the research process and analysis. In a blurring of the boundaries of representation in social sciences, I write to create a sense of place (Sikes, 2005) and invite the readers into the experience of both the research process and the thesis product explicitly (Richardson, 2000). CAP encourages a turn away from ‘doing’ qualitative research, to qualitative research premised on social, political and critical purposes (Denzin, 2000). I tell a series of stories with and through the thesis, of the children and families that participated in the project. There are children and families that feature briefly but our main focus is on five families, which included thirteen children, ten of which have a label of autism. Chapter 5 begins with an introductory overview of these families and the methods employed in working with them (see Figure 1 and Figure 2). The central focus of the project was to spend time with children and their families exploring their experience of everyday life, which I did through talking and being with parents and children at homes, in public spaces, at schools, nurseries and a very muddy allotment. The fieldwork took place between July 2013 and February 2015, over the course of which I spent time with children and families on anywhere between half a dozen and several dozen occasions. The ‘data’ of the project is a series of stories that I wrote as a result of the time I spent talking and being with them in these spaces. The writing of these stories, rather than a representation of field notes, is a Creative Analytic Practice, in which writing *is* inquiry and *is* analytical (Richardson, 2000; 1999; 1994). In chapter 5 I describe these stories and the thesis, as both process and product; as ‘becoming’. The project was conceived as threefold, ‘Talking’ ‘Being’ and ‘Becoming’, which did not occur discretely despite employing distinct methods. The methodological ‘talking’, ‘being’ and ‘becoming’ were the everyday encounters of this auto/ethnographic process with children and their siblings and parents (see Figure 2). ‘Talking’ was largely conceived as being with parents and ‘Being’ as time spent with children, though neither was exclusive. These methodological phases were also analytic tools, as can be seen in the three analysis chapters; ‘Chapter 7: Talking’, ‘Chapter 8: Being’ and ‘Chapter 9: Becoming’.

Having outlined the structure of the project and its resultant thesis, I begin with the first piece of auto/ethnographic data, the first story written during my PhD journey, which has become the thesis’ Preface.

## Preface: The talking, being and becoming of an embodied PhD

*This was the first story I wrote during the PhD process. It came to be in a coffee shop one morning, after my supervisor had seemingly goaded me into writing in a way that I felt at ease with that I had not at considered, until this point, to be appropriate for academia.*

This is me putting my research methodology into practice, on myself. This is the sensory ethnographic storied version of my place in my research written one year into my PhD. I’m using it as a tool to explore the techniques of presenting an embodied experience of my research life and how to do this in a narrativised way. In an effort to create a sense of shared experience, of embodiment, there should be some good music playing and a really decent cup of coffee sitting alongside the reading. I’m starting to think about creating senses of place and this is something that’s playing on my mind as I write this. My PhD life is very lived, sensorial. It’s very bodily. From the sights and sounds I surround myself with whilst I read and write, to the battles I have with my body’s chronic illness, which wills me to listen to my body, to separate it very distinctly from my mind and what my mind wants to do. My body shouts at me over the top of my PhD life of books and words, demanding my attention and breaking my concentration. So my desire to work on the body and the ‘being’ of it is a strong one. I’m trying to work out how to make the experience of reading my writing a more bodily, sensory experience and at this point in time all I can think of is the enhancements I am drawn to daily in the becoming of this PhD; a good background tune, some of Sheffield’s finest coffee, and a cosy corner of a cafe.

I’d like to take you on a journey through the journey I am experiencing, from musings in coffee shops dripping in the sweet scent of caffeine and the dulcet tones of Radiohead, to cold sweats of blind panic whilst laying in bed unpicking whether a PhD really is the meaning of life.

I’ve been reading about the ‘potential of paying attention’ and how Cichosz (2013) relates this to the affective experience of a metaphorical trip, the ‘trip’ of psychedelic drug use. She talks of how, by paying attention to the affective nature of our experience (the trip), we can learn something of how we relate to the world. I feel like this is a beautiful parallel for me to explore when thinking about the ‘journey’ or the ‘trip’ of my PhD. Perhaps the discomfort and confusion I feel is the very site of the potential for change that Cichosz speaks of coming out the other side of an affective trip.

I think here of Sarah Pink (2007) and sensory ethnography and how I’ve used this idea in the past to make an attempt to ‘share’ “empathetic and sensory embodied understanding of another's experience” (p.250). I want to work towards a level of writing about my research journey beyond the descriptive and towards the ‘being’ and ‘becoming’ I am trying to unravel and give resonance to in my work with children. This is new to me too.

The Trip

I could start with an analysis of why I’m driven to do what I do, or a linear, coherent description of my research positionality. But I don’t *think* I live a linear, coherent, or particularly cohesive life. I could postulate my desire to be a ‘decent’ person, a moral citizen, to change the world...But that would all start and end very quickly once I admit that the performative demands of ‘being’ such a person is something I can’t quite keep up. Instead, I need to come clean and acknowledge that I still don’t have a profound, justifiable, cohesive philosophical understanding of why I feel I must do these things, but I must all the same. And so the contradictions and messiness of the experience begins; as contradictory and messy as any of our everyday lives.

What it does come down to is a tiny handful of relationships with children living in spaces of autism; short-lived, unconventional, perhaps entirely one-sided, that imprinted something on that very ‘being’ of me and draws me into feeling ‘I HAVE TO DO SOMETHING!’ Perhaps that something - sitting around thinking about, reading about, writing about, and talking about autistic children and their lives - isn’t the most productive something I could be doing. I’m no activist stomping the streets outside parliament despite my daydreaming. I’m a thinker, a chatter and a muser and I’ve always been able to put pen to paper (or fingers to keyboard). Perhaps a little poignantly, it is from the very fruit of ableist achievement - continual praise for an essay, a paper, a dissertation - that my ‘doing’ something became an academic pursuit. Stick to what you’re good at kid, as my mum would say. And so begins my battle with whether this academic pursuit is really ‘doing something’ at all.

My *being* in my research starts with me *doing* something. Before starting this PhD I was a full time personal tutor at a local college for the ESOL (English for Speakers of Other Languages) department. I was responsible for the pastoral care of around 130 students under the age of 19. All of the students were recent arrivals to the UK from across the globe, from economic migrants, asylum seekers, refugees, to those who didn’t have the language yet to explain how or why they had ended up here in Sheffield. I reduced my personal tutor contract down to 0.5 and attended every lecture, workshop, seminar, guilt-diminishing session I could to make me feel like I was doing something other than abandoning the very real, embodied needs of my students at college. The lived experience of my students, sometimes living outside, homeless, in a foreign country, had an emotional pull that I found hard to switch off. The lived experience I shared with them negotiating Britain, negotiating social care, and negotiating the dangerous and painful plains of their life as a homeless, foreign young male in Sheffield S2. The insides of my stomach churned as I sat ‘doing something’ in the warm, cosy, stuffy comfort of The University of Sheffield whilst they sat alone, in steely silence in the corridors of another Local Authority building trying to persuade a civil servant to give them somewhere to stay that night. My affective experience spilled into my body and over the edges. Coming back to read this story nearly two years later, to edit it as the preface of my thesis, it still does.

And so began my desire to do my doctoral work well, for the sake of lessening the guilt I had for doing my personal tutoring considerably less well. At first this pushed me into hectic schedules and the ‘doings’ of university life, but eventually forced me to stop ignoring the less practical, more theoretical reading about my field and to become immersed in the very politics that my work was steeped in. For the first time my thinking was about justice, social justice, politics and philosophy; the injustice I was watching, observing and sharing with my Somali student, that emotional, gut reaction I felt, paralleled the sentiment of my work with autistic children. This took me from the realm of having to ‘do’ something with children - to observe their communication, to drag them into my research and call it participatory - to spending time thinking about the bigger picture of what I was working in and whose goals I was serving. No longer was I setting up camp within the new sociology of childhood and multimodal analysis, carving out niches for autism and childhood that I had carefully articulated in my PhD proposal. I was learning about neo-liberalism and the foundations of the society I lived within and heralding critical disability studies like no one had ever heard of it. Social justice, hello people! Holier than thou, as my mother would have said. And she would have been right. It felt like an epiphany; like I was connecting the dots for the first time, like everything I knew about autism didn’t really matter, that the children I worked with were not living with autism but living with society and politics, marginalisation and injustice, just like my Somali student. After an inordinate amount of time spent getting caught up in these debates and ignoring children, I recognised that my flighty PhD bubble was in need of popping. I felt really lucky to have worked outside of the university throughout the year, as I felt it stopped me getting so self-involved with my doctoral work and disappearing into a world of self-imposed stressful indulgence.

I spent less and less time in the university itself ‘being/doing/performing’ as a doctoral student and more time working from public spaces; cafes and the local Winter Gardens being my venues of choice. The chatter and noise of passing buses and life-in-practice were where I wanted to be. They lived in the conversations I overheard of parents comparing notes on their children over coffee, they breathed with the grandparents tearing through the winter gardens on the tail of a fearless toddler. Engaging with my subject became more and more about everyday life and the people living merrily (or not) within systems of ideology, and less and less about the ‘subject’ of autism. And that felt exciting.

Why did autism matter after all? What was so fascinating about autistic children’s lives. ‘So what, autism?’ This ‘so what’ was the response of a parent of an autistic child when she heard me speak at the Theorising Normalcy and the Mundane 2013 conference about how I wanted to write about the everyday, mundane, boring stuff that autistic children and their families do and live with. ‘So what’ hit the nail on the head. What was so special about these stories? Nothing. And that felt like it summed up what I was striving for. Perhaps autistic lives are as boring, everyday, messy and ugly as the rest of ours. Perhaps an autistic life is a human life. A normal childhood. Perhaps not being normal is pretty normal in itself. I read a story of living with blindness recently by Deborah Kent. In reflecting on her childhood she said, ‘I wasn’t *like* a normal child - I *was* a normal child (Kent, p.243). This was the plight I wanted the world of research to recognise. That the stuff of ‘so what’ that’s accepted elsewhere in our world could be a ‘so what’ for autistic children too.

But here was an impasse.

I’d put Autism in the corner.

So autism as a subject of study seemed to matter less to me at this point. The stuff of socio-political everyday life was where I was at. But there I was being pulled back to my project. Did I think I could recruit families with autistic children and then not talk about autism? Not deal with autism? Not talk about cognitive theories, intervention, Applied Behaviour Analysis...Put autism in the corner and enter theoretical debates with parents about the meaning of their children’s humanity and how we needed research that shouted from the hilltops about this? Fool. I had to come back to autism and recruit people, inevitably through autism networks. Interestingly, as I go on to discuss in ‘Recruitment’ in Chapter 6, my adverts through autism-specific networks resulted in responses internationally from researchers, journalists and the odd parent (Sri Lanka, Uganda, Canada....), but very few in South Yorkshire. Oops. So drawing on my resource as an employee of an organisation with 1,000+ employees, I sent an email to all staff and was inundated within the hour. Interesting? Yes. This was the stuff of everyday life again. It wasn’t people actively consuming autism and seeking it out (through networks, activism, research centres etc.), it was employees coming to work and living with autism mundanely, in the background, at home. Some wanted to ‘do me a favour’, some wanted to tell me what to do and one in particular was simply just interested. This mum, of a young boy, Nathan, who had received a diagnosis within the last year was not actively consuming autism or being consumed by it. Her, her partner and her son had had autism thrust upon them, the local nursery having pushed for a diagnostic assessment. They had not sought it out, they had been living their lives and were now living with autism. A brief foray into this world of autism just after his diagnosis had been somewhat devastating for the mother; through the horrors of Google this family had resigned themselves to it being ‘better not to know’ and to get on with their lives, raising their child. A psychologist had asked if he had had a birthday party for his 4th birthday. The mum pulled a funny face at this in hindsight but at the time had said no and moved on to the next question. A psychologist had told him that, despite his love for Buddy Holly, they were probably better off trying to get him to like music that his peers like, that was more suitable for a boy his age.

He had recently started school and to their delight was loving it and receiving the attention and support that helped him to thrive. The school had been excellent and in that sense his diagnosis was no longer scary but helpful. This mum wanted to be part of my project so that other families didn’t have to experience the shock and fear they had when autism was unexpectedly thrust upon them. Her son was a happy little boy she said, and that was good. His teacher had told them that after hearing him sing a Buddy Holly song, she found it on YouTube and the class spent the afternoon dancing to the song and learning the words. He had loved it. His classmates loved it.

And so we come to the new academic year. A year in which autism has been plucked out of the corner of my mind, dusted off and firmly cemented back in the picture. My new role teaching about all-things-autism, as a ‘Lecturer in Autism’ at a local university, has pulled my thinking back to my beginnings with autism as an academic subject. Autism’s back; I am bathed in it. I’d forgotten that I understood cognitive theories of autism - that I could and inevitably was, applying ideas of sensory processing to what I saw and the lives of children I met. I had forgotten that I too, in my second year of my undergraduate degree, had wanted to know what to do to make my experiences with autistic children less overwhelming and scary and unpredictable. I’d forgotten that I too had wanted answers, not endless reams of questions. And so here I was, being pinned down for answers, by students. Because I should know. Because I’m a lecturer. Because what is the point in learning about autism if it’s not to get answers? I’d got to a point of assuming that anyone working with autistic children would see what I see and do what I did; that that wasn’t based on anything I had learned to do, or from mistakes I’d made, but that was just what anyone would do. Silly. I spend my time now talking to students about those short-lived, unconventional relationships with autistic children who wouldn’t know me from Adam now. And I still have those relationships imprinted on the very fibre of why I do this. And not because I did something good or because I was any different to those children than anyone else they’ll come across in their lives, but because they were part of broadening my understanding of other people. They opened up spaces for me to think. To think about them. To think about myself. To think about how we do and don’t treat other people well. To think about our dependence on others. And how that’s ok. That these children have been told by professionals that they haven’t got life right. They’re impaired, different, labelled, marked, abnormal, deviant. And yet they’re still living it in everyday, mundane ways regardless. With their parents living in their everyday, mundane ways. With autism being everyday. Mundane.

Perhaps such mundanity is quite creative. It’s most certainly quite political. It involves thinking outside the box on how to deal with school, and supermarkets, and birthday parties.

That’s living outside of the box, not necessarily through choice, and that feels important to explore and to challenge. After all, we all live outside of some kind of box, but for most of us that life doesn’t have a name, a label, a diagnosis. It’s just called life and it’s expected that it’s messy and complicated and that we contradict ourselves and don’t produce this linear being but that it isn’t open to scrutiny or correction, it’s just being a person. That it’s probably boring a lot of the time. That it doesn’t have some melodramatic resolution, the Hollywood narrative that Connelly and Clandinin (1990) speak of. These fragmented beings are ok for some of us and not for others within research. We don’t hear about these lives in research, about disabled children; we just hear about their impairments, or their development, or their failings and interventions. So perhaps there’s space for us to bring autism and childhood in from the cold. It’s ok not to become a contained, linear, cohesive human. Because who are we kidding, right?

Leaving that story to settle for a while, I introduce my research questions here, which, despite being conceived in a very different way to the Preface story, are reflective of the sentiments I explored in it.

1. *How is autism spoken about and how else might we talk of autism?*
2. *How might we consider being autistic as part of being a child?*
3. *What does autism make im/possible for a child to be and become?*
4. *What does autism do to/for/in education?*
5. *How can autism research broaden its understanding of the everyday?*

## The Gaze and Dis/orientation in the thesis

Two themes are drawn upon continually throughout this thesis, which are in need of some definition or, at least, conceptual framing from the outset; ‘the gaze’ and ‘dis/orientation’.

## The Gaze

**The gaze**, a philosophical concept adopted by many, is used in this project in the Foucauldian sense; that is, the ‘clinical gaze’ or the ‘observing gaze’ (Foucault, 1973). The theoretical unpacking of Foucauldian thinking comes in Chapter 2 but the tenets of ‘the gaze’ are introduced here. Foucault, in *The Birth of the Clinic,* explored how the rise of medicine and its tools of surveillance, observation and testing, had allowed for a new form of power and knowledge to manifest in individuals’ lives; the truth of medicine. The means by which this technology became enacted was through the observation, seemingly neutral and most importantly truthful, provided by the clinician's gaze.

Just a gaze. An inspecting gaze which each individual under its weight will end by interiorizing to the point that he is his own overseer, each individual thus exercising this surveillance over, and against, himself. A superb formula: power exercised continuously and for what turns out to be minimal cost. (Foucault, 1980, p.155)

Such a gaze is omnipresent in the lives of disabled children by the very virtue of their being known as an individual, and as disabled. Again, the theoretical meat to these bones is to be added later in Chapters 1 and 2. This gaze of Foucault haunts the thesis, reminding us that we are all being made and remade, and are all bound in producing and reproducing ourselves and others as subjects. So, I ask of this project that it draws us to ‘gaze upon autism and childhood in new ways’ rather than suggesting that we do away with the gaze entirely. This is not a call to a gaze of truth that the clinical gaze offers. I am not suggesting replacing one gaze upon autism and childhood with another but rather that keeping ‘the gaze’ in mind, in any form, is a helpful tool in relating to the stories, analysis and conclusions of this project. Injecting a phenomenological turn to the gaze, much in the way as I inject phenomenological sentiments throughout, is to recognise the gaze not simply as a nexus of power/knowledge but as a social encounter (Heron, 1970). The phenomenological gaze is where we encounter each other; a meeting ground. It includes both the physical act of looking and the psychological experience of looking upon and being looked upon. It is mutually constitutive and comes into being in a shared moment, that which ‘quietly breaks through the other’s eyes’ (Heron, 1970, p.236). It is in bringing together the Foucauldian gaze with a certain embodied, phenomenological encounter that I situate ‘the gaze’ and act of ‘gazing’ upon autism and childhood in this project.

## Dis/orientation

I use a theme of **dis/orientation** as a theoretical sensation throughout this thesis. I get travelsick easily so, in the travel that this thesis asks us to take, it is not difficult for me to envisage the sensation of being or feeling disorientated. It is an invitation to an experience that is both conceptual and embodied; a sensation which I have experienced continually in the thinking and doing of this project. The conceptual notion of dis/orientation came from my encounter with two foundational sets of thinking through which much of this project is grounded; dis/humanism (Goodley & Runswick-Cole, 2014) and Ahmed’s (2006) notion of orientation in queer phenomenology. Both will be introduced within their wider disciplines, Critical Disability Studies and phenomenology, in Chapters 3 and 4 respectively. In the meantime, the important features of both concepts can be laid out here to provide a sense of how I developed the notion of dis/orientation to be used and experienced throughout.

Dis/ability, a Critical Disability Studies turn that spawned dis/humanism, first offered a critical turn to ‘...the meaning making of either side of the disability-ability binary and the messy stuff in the middle. Dis/ability is also a moment of contemplation: to think again what it means to be dis/abled and what it means to be human’ (Goodley, 2014, x). Where dis/ability in its slashed form enters, we are invited at once to the *ability* complex of dis/*ability* and to question its form and power. Dis/humanism, as dis/ability, also takes the prefix ‘dis’ from dis/ability and from the colloquial verb ‘to dis’ as in to dis-respect (Goodley & Runswick-Cole, 2014). *Dis/*humanism, in this sense, is ambivalent to the modernist conception of the human, independent, rational and contained, as it so often is incongruent or exclusive of those who experience dis/ability (ibid). In bringing in the ‘dis’ to humanism, Goodley and Runswick-Cole (2014) ask that whenever we speak of the human, we recognise the inherent need to speak of disability politics. Whenever we stalk the human, a politics of dis/ability should not be far behind. A key premise of this, and CDS more broadly, is put forward by Shildrick, who asks, ‘what would it mean, ontologically and ethically, to reimagine dis/ability as the very condition of human becoming?’ (p.3)

It is in the dis/humanist form then, that I bring the ‘dis/’ to dis/orientation, to recognise that, throughout this thesis, whenever we are called to orientate towards or away from something, we recognise it as a disorientating sensation that is always mindful of the dis/orientating experience; where dis/ability is every present and its politics recognised. Dis/ability is disorientating. Ahmed (2006), in thinking through phenomenology from a queer perspective, brings in the notion of ‘orientation’ as a pertinent undertone of queer experience. ‘What difference does it make’, she asks, ‘which way we are orientated?’ (p.1)

To be orientated is...to be turned towards certain objects, those that help us find our way. These are the objects we recognize, so that when we face them we know which way we are facing. They might be landmarks or other familiar signs that give us our anchoring points. They gather on the ground, and they create a ground upon which we can gather. And yet, objects gather quite differently, creating different grounds. (Ahmed, 2006, p.1)

I introduce, and problematise a number of orientations throughout this thesis that are pertinent to the everyday lives of children labelled with autism, beginning in Chapter 1 ‘Contextualising the Terrains’. Landmarks of developmental psychology, schooling, family life, the canon of autism and childhood are all familiar signs that offer anchoring points that both gather ground and create ground upon which disabled children live their lives. Ahmed (2006a; 2006b) goes on to explore how orientation requires work to become familiar, and that it brings some worlds into being and hides others from view. When we face one way, we have our back to another. The phenomenological turn here is in recognising the repeated moves that direct attention most readily towards ‘what is already at hand’ and the work that does in shaping bodies and worlds (ibid). The well-worn lines that make some orientations more possible than others conceal the work of making those lines worn. In the landscape of this project, those orientations which bring a world into being are the grand narratives of autism, dis/ability and childhood that allow their study, allow them to be apprehended as ‘objects’. However, recognising orientations as starting points in the phenomenological sense, as the beginnings of perception, is an opportunity to attend to the labour that brings ‘autism’ and ‘childhood’ into view in their dominantly narrated ways; as states of disordered childhood. Orientations take time to become established (Ahmed, 2006b); this thesis has the luxury of time in exposing and exploring the work of orientation towards, and away from, autism, dis/ability and childhood. We will hear about some particularly dominant orientations throughout Chapters 1 and 2 and explore how their histories have come to be viewed as natural and neutral orientations. We will stop to consider how it has come to be that ‘what is already at hand’, what is within reach, has served to produce particular orientations towards autism and childhood that create conditions of disorder, deficit, and lack, and what they go on to make im/possible for a child to be and become. We will then be reminded of the potential of, and for, dis/orientation.

Ahmed (2006a; 2006b) goes on to encourage embracing disorientation as an experience that disrupts orientation; spaces in which we seek out new, less travelled lines, to bring new worlds into view, to explore other possibilities. Though the sensation of being disorientated is an unpleasant one, she encourages, ‘...if we stay with such moments then we might achieve a different orientation toward them; such moments may be the source of vitality as well as giddiness. We might even find joy and excitement in the horror’ (Ahmed, 2006a, p.4). Adding the slash to dis/orientation brings the dis/human complex into the mix. In much the same way as dis/humanism both desires the human and rejects it at the same time, the vital and giddy experience of dis/orientation is both to be drawn towards a comfortable orientation and at once to reject its seductive temptation as a final resting place or single direction. If all orientations are the effects of repeated and often concealed actions over time, (ibid) they are temporary and changeable, given time and dis/orientating labour. Herein lies the hopeful call of dis/orientation throughout this thesis. Within a queer phenomenology of orientation, there is always a toward, ahead of us, just out of reach and calling for apprehension. If the knowable autistic child comes to be through the labour of particular orientations, an attention to dis/orientation allows us to get in between that work and potentially carve out new paths. Particularly strong orientations would have us follow paths of developmental psychology, disorder and autism theories, concealing the labour of these orientating lines and the worlds these lines both bring into view and obscure. Instead, in recognising this process as temporal, as always yet-to-become, we can embrace dis/orientation; the drawing towards knowing and apprehending the objects of autism and childhood, ‘the autistic child’, whilst asking questions of its lines and demanding the tracing out of new ones.

Perhaps returning briefly to one of the stories from the Preface would be helpful in fleshing out such a theme. We heard about Nathan, his love of Buddy Holly, his psychologist’s disapproval and his teacher’s classroom practice. The normative social conventions that the psychologist draws upon, are particular orientations and dominant ones at that; children of Nathan’s age, in 2013, do not listen to 1950s rock and roll music, and will face social exclusion as a result. Such orientations direct (and also come out of) other lines of travel, ones in which Nathan’s love of Buddy Holly can be understood as a result of his impairment characteristics. Diagnostic descriptions of autism tell us that the disorder is characterised by special areas of interest and an inability to recognise or take part in social conventions (American Psychological Association, 2013, B.3). There are consequences of these lines, that is, more lines to be followed through such an orientation, one in which Nathan’s future experience of social relationships will be affected by such failure to adhere to normative social conventions. The psychologist draws on these orientations in her reading of Buddy Holly and of the future direction of travel necessary, that is, a return to the straight and narrow lines in which Nathan begins to listen to music that is more socially acceptable for a child of his age in 2013. Where Nathan had been read through orientations of autism as a developmental disorder, with specific impairments, he was read as queering the pathways of childhood. His teacher, by comparison, perhaps seeks out a moment of dis/orientation in which this project rests and explores. The teacher gazed upon Nathan’s love of Buddy Holly along different, or perhaps *additional,* lines to those orientations of the psychologist. She was drawn to the orientating opportunity of Nathan’s love of Buddy Holly to forge a learning activity for both Nathan and his classmates. This chimes as a familiar orientation in childhood, perhaps reminiscent of developmental psychology orientations; a desire to see childhood as synonymous with learning and development, one that is ever-more pervasive in disabled children’s childhoods (Goodley & Runswick-Cole, 2010). At the same time, we can be drawn towards the ‘dis’ of the dis/orientating embrace that the afternoon spent singing along to Buddy Holly as a class offered; the *dis/*orientation in which the teacher sought to disrupt the limiting descriptions of an impaired child who was unable to engage in normative social conventions and was marked with, and by, difference from his peers. Here, the disavowing of dis/orientation allowed for new pathways through the lived experience of autism and childhood to be carved out, even temporarily, and explored.

So, it is the bringing together of Ahmed’s thinking on orientation and disorientation, with a dis/human call to keep disability central to our commitments, that I invite you into the experience of dis/orientation, both sensational and political, throughout this thesis.

## Summary of Chapters

Section 1: Contextualising the Terrains

*Chapter 1: Contextualising the Terrains*

This chapter takes the form of two on-going routes of travel around literature related to autism and childhood. Neither route is finished or necessarily the only route to take; both have the central focus of contextualising the terrains of autism and childhood. Instead, we scroll through the options on our sat nav hovering between two options; 1. the quickest route from A to B, avoiding traffic and toll roads, 2. the scenic route, frustrating the lady inside the sat nav who gently encourages us to take a U-turn to return to the route from A to B at the earliest opportunity.

*Chapter 2: Introducing a theoretical travel guide*

This chapter introduces a Foucauldian travel guide to our routes through the literature of autism and childhood. It revisits the whistle-stop tour of the terrains of autism and childhood in Chapter 1 and instead recognises the discursive powers embedded within this route around autism and childhood. It introduces notions of biopower in research about lives labelled autistic and interrogates how these discourses have come to be socially, politically and culturally through the history of autism, childhood and family life. It introduces Rose’s (1990) work on neuro-governance as a technology of the self and considers how such governance has been put to work through powerful discourses of neuroscientism.

*Chapter 3: From Disability Studies to Dis/ability Studies*

This chapter introduces prominent work in and around disability studies and Critical Disability Studies I briefly explore the history of the field, its situation in parallel to political agendas and advocacy, and the emerging space for work done outside of the traditional boundaries. I return here to Rose (1990) to consider how the marrying of Goodley’s (2014) dis/ability studies and Rose’s unpacking of familial self-governance provides one of many starting points for families living with autism. I begin to formulate the foundations of what a project situated in dis/humanism would mean theoretically and methodologically.

Section 2: Researching Childhood, Researching Disability

*Chapter 4: Orientating Theory, Theorising Dis/orientation*

This chapter asks, what would the theoretical underbelly of a project that embraced the terrains that I have mapped, in their junctures and divergence, look like? I ask if it is possible to queer the dominant orientations of each of these terrains’ gaze on childhood, autism and disability? To orientate is to turn towards, and turning one way is to turn away from another. The queer(y)ing orientation described in this chapter may be the means by which the dis/orientation of the attention afforded to the lives of children labelled autistic becomes possible. Away from the gaze of developmentalism, medicalisation, pathologisation, normalisation. I argue that when attention is afforded to everyday lives, to lived experiences, a queer(y)ing phenomenology coupled with dis/humanism, which I term ‘dis/orientation’, that digs around the borders and boundaries of such an experience, may disrupt the dominant stories pervasive in children’s and families’ worlds.

*Chapter 5: An auto/ethnographic story of methodology and Chapter 6: The ethics of advocacy and consent*

Chapter 5 & 6 turn to research methodology and ethics. Turning away from the dominant methods of autism research in its disembodied, positivist form, I ask that we adopt dis/human methods of researching the everyday lives children labelled autistic. I tell an auto/ethnographic story of how both the research methodology and methods came to be through the projects’ three phases in turn ‘method/ology of talking’, ‘method/ology of being’, and ‘methodology of becoming’. This develops towards Chapter 6 in which I explore ethical issues as process and product of both methodology and analysis.

Section 3: Findings and Analysis

*Chapter 7: Talking*

This chapter dis/orientates our gaze on the dominant talk of autism and considers the rhizomes that come to be through parents speaking of lives labelled both child and autistic. It draws in the dis/orientating and productive experience of the rhizome and the im/possible ‘beings and becomings’ of autism that reside when particular ways of knowing and coming to know autism and childhood are mobilised. It responds to the question,

*‘How is autism spoken about and how else might we talk of autism?’*

*Chapter 8: Being with/in Bodies*

Chapter 8 ‘Being’ dis/orientates our gaze towards the body and its queerness in research around autism. invites dis/orientation to ‘being’ an autistic child, or living in spaces labelled child, autistic, disabled. ‘8.1 Being in education’ uses a turn to the dis/child (Goodley and Runswick-Cole, 2014) as tool of dis/orientating education for children labelled with autism. Here, the orientation gazed upon is that of the neoliberal school child who is desired through academic achievement. Dis/orientating, by means of a dis/child analysis allows the ableism embedded within dominant orientations to education to be exposed and explored. Using a story of The Goodwin siblings, each with labels but with very different relationships to desirability in education, we move back and forth between the slippery experience of striving for academic achievement whilst resisting its exclusive, ableist grasp; we dis/orientate.8.2 Being and Ways of Knowing considers the well-worn lines of particularly dominant orientations towards autism and childhood and asks what happens when we wander away from those lines and begin to dis/orientate. It is framed by embodiment and valuing embodied ways of knowing and being known. It navigates the questions,

*‘2. How might we consider being autistic as part of being a child?’*

*‘3. What does autism make im/possible for a child to be and become?’*

*‘4. What does autism do to/for/in education?’*

*Chapter 9: Becoming Between Bodies*

This chapter carves out our dis/orientated gaze on childhood, dis/ability and autism; bringing together the becoming of what is done *to* childhood’s labelled autistic and what is done *by* children labelled with autism. It asks that we adopt further theoretical fuel to our orientations, a turn to the becoming of emotions. I use a turn to emotions suggesting that some dis/orientations offer the means to navigate new becomings for our relation to autism, childhood and dis/ability. This is by no means a resolved orientation, an end point, but the final line of flight for this thesis. It is in the smooth space of becoming that I wish to leave our thinking and relating to autism, childhood and dis/ability open to a dis/orientation that continues way beyond the pages of the thesis or the bounds of this project.

*Chapter 10: Discussion and Conclusions*

This chapter brings together responses to the research questions and makes suggestions for future research and implications for both theory and practice in the everyday lives of disabled children. I do so through a series of Take Home Messages. It ends upon our newly dis/orientated terrain; Neitherherenorthere. I finish by sending a series of postcards from this dis/orientated terrain to some important people; children and families living in spaces of autism, professionals, autism researchers, and theory.

# Section 1

# Contextualising the Terrains

# Chapter 1

# Contextualising the Terrains

On Linton’s (2008, p.520) advice I use these chapters to find and contextualise ‘...a location from which to comment’. It would be divisive to suggest such contextualising could ever be done from a single location. Instead, I use these coming chapters to map the terrains of this project from several locations, and will always veer off across multiple terrains. Those terrains are foregrounded and shelved at various points of the thesis depending on the priority of that particular piece of writing. In mapping this terrain, I call the reader into the experience of dis/orientation to autism, childhood and dis/ability.

The map fosters connections between fields...The map is open and connectable in all of its dimensions; it is detachable, reversible, susceptible to constant modification. It can be torn, revised, adapted to any kind of mounting, reworded by an individual, group or social formation. It can be drawn on a wall, conceived of as a work of art, constructed as political action....(it) has multiple entryways as opposed to the tracing, which always goes back ‘to the same. (Deleuze & Guattari, 1980, pp.13-14)

These contextualising chapters are the map of my project’s terrain. They foster the connections between autism, childhood and dis/ability from multiple entryways and are constructed as a form of political action, as well as a thesis. The thesis is conceived as a piece of Creative Analytic Practice (Richardson, 1994) through its literary-driven stories, with a desire to disrupt the grand narrative tracings of autistic children’s childhoods which always go back to the same.

## 1.1 A guide for traversing the terrains

The journey metaphor is perhaps overused in the writing of a thesis but it does not mean it need be defunct. Instead of a journey metaphor suggesting a predefined start, middle, and end destination, I structure this thesis in terms of travel and movement, of turning and dis/orientating our gaze. This following chapter, Contextualising the Terrains, takes the form of two on-going routes of travel. Neither route is finished or necessarily the only route to take; both have the central focus of contextualising the terrains of autism and childhood. Instead, scrolling through the options on our sat nav, we hover between two options; 1. *The Quickest Route* from A to B, avoiding traffic and toll roads or 2. *The Scenic Route*, frustrating the lady inside the sat nav who gently encourages us to make a U-turn to return to *The Quickest Route* at the earliest opportunity.

*Route A-to-B* is the linear journey, the quickest route with the fewest distractions from one point to the next. It is a chapter in which the story of childhood and autism are told in their most grand narratives. This route is the meta-narrative of autism which the DSM-5 tells us is a pervasive developmental disorder affecting social interaction and communication (American Psychological Association, 2013). It takes the positivist highway from autism’s discovery towards the horizon of its treatment and eventual cure, barely slowing down at critical junctions or hindered by inconvenient ethical or socio-political traffic. It is a route of straight roads, wide motorways and heavy-loads. Our destination is a child with a medically diagnosed neurodevelopmental disorder. This child, in its abnormal development, is prescribed interventions specific to those with autism; diagnoses that bring the child back towards the makers of normal development.

On re-taking *The Scenic Route,* we slow down to give due attention to those junctions and traffic. This chapter meanders away from the linear route and instead explores an alternative. It takes back roads, side roads, dirt tracks and bridges to experience the sensation of wandering. It questions the sat nav’s obsession with a single route when, in fact, through meandering we discover there are many. This chapter takes the literature from *A-to-B* and pauses at its junctions. It skips red lights to see what happens and occasionally stops off for coffee to explore who and what rests along its route. Here, the story of childhood and autism are neither linear nor neutral but instead exposed as constructed and lived, as moments of the political, cultural and social. It is in this route that the terrains of this project take root.

I begin with Route A-to-B as the means of mapping a landscape on which to skate our new, scenic, and alternative route.

## 1.2 Route A-to-B: The History of Autism and Childhood

Historically, the child began as a biological, universal product of nature. Be it the early modern child of Rousseau’s Emile, pure in its unspoiled form, or Locke’s tabula rasa of the curious child’s mind, childhood was a natural, biological state and, more importantly, a state of development. The natural sciences in its study of the infant object had an opportunity to ‘uncover’ the child, its biological make up, its predisposition, its evolution and its development (Walkerdine, 1993). Through the emergence of developmental psychology it became possible not only to map biological features of childhood but also the psychological features of the developing child (Burman, 2008). In the 1950s and 1960s, prominent psychologists (Vygotsky, 1962; Piaget, 1962) offered the positivist disciplines the means to systematically study children’s developments to inform educational and child rearing practices. These truths of normal child development additionally offered the means to measure and systematically study where development was abnormal. Markers of development in language, play and social interaction were sequentially passed through from childhood to adulthood (ibid). The normally developing child showed their progress towards adulthood through the demonstration of ever-more sophisticated markers of socialisation; the psychological processes of such socialisation becoming ever-more complex until adulthood was achieved. This linear progression coincided with physical maturity, the adult body aligned with an adult mind; rational, socialised, and cognitively competent (Walkerdine, 1984). Where deviance from this path towards adulthood was identified through psychological development, the measurement of such deviance became the means to identify abnormality; psychological disorder.

Prior to developmental psychology, abnormality had been the mainstay of psychiatry. Leo Kanner (1943) pioneered the study of such deviance in children that became diagnosed as ‘autistic’. Kanner studied children who had been previously diagnosed as either schizophrenic or feeble-minded through psychiatric observation (Fombonne, 2003). His observations suggested some children held psychiatric characteristics not best described by such diagnosis but instead rooted in disturbances of affective contact (Kanner, 1943). Parents were also part of these longitudinal studies as the bearers of such affective disturbance, characteristics which Bruno Bettelheim (1950) went on to term ‘refrigerator methods’. The refrigerator reference was made in relation to the ‘cold, isolating, unloving’ disposition of parents’ relations with their child, which lay at the heart of these children’s disturbance.

From its psychiatric origins, the discipline of psychology saw the demise of psychodynamic theories of autism as scientific, psychological testing became commonplace (Fombonne, 2003). With the means to test for symptomatic criteria through the application of scientific, psychological measurement, autism became firmly rooted as distinctly, specifically and scientifically diagnosable. The cause and effect model of disturbed or dysfunctional parenting practices proved experimentally invalid (McKeever et al., 2004) which situated the origins of autism within the individual child's disordered cognition. With the site of the problem now established as internal to a child at a psychological level, there became the means of progress. The cognitive interventions that followed to address psychological deviance were progressive. Previously subjected to institutionalisation as commonplace and an ‘incurable handicapped life’ (Fombonne, 2003, p.504), the promise of interventions and the pursuit of a cure for this psychological disorder was now possible. In the 1980s, Lovaas published his seminal work on Applied Behaviour Analysis (ABA) (1987). This was a systematic, scientific intervention that worked on Skinnerian theory of behaviour modification through conditioning. Children with autism diagnoses within Lovaas’ study received long term, intensive one-to-one ABA therapy, which corrected deviant behaviours through a system of reward and punishment. Behaviours that were identified as being ‘symptomatic of autistic psychosis’ were punished, with the child’s demonstration of more appropriate behaviour rewarded (p.8). Lovaas (1987) heralded a cure for autism through the removal of autism’s symptomatic characteristics. Such interventions remain popular in western contexts, with ABA intervention now federally mandated as covered by Medicaid in the USA (Department of Health and Human Services, 2014).

Alongside psychology’s interest and intervention in autism, biomedical narratives were traversing somewhat similar terrains, albeit on different terms. Within these disciplines, autism is again the product of disordered internal processes but not purely of disordered cognition. Public consciousness of autism’s biomedical origins was first drawn in the 1990s by Andrew Wakefield’s paper linking the MMR vaccination to the onset of autism symptomology (Wakefield et al., 1998). Wakefield’s research has since been proven invalid, the findings fraudulent (Deer, 2011), the paper retracted (Lancet, 2010) and his licence to practise medicine revoked (General Medical Council, 2010). Wakefield was not alone in the pursuit of autism’s biomedical origins. Research within the broad biomedical disciplines offered a vast number of possible understandings of autism, from its causes to its symptomology, including studies of; associations with vaccinations, associations with gene-environment risk factors, epigenetic origins (including the mapping biomarkers), comorbid health conditions, the study neuropathology, and neural systems, to provide a brief overview (IACC, 2012).

Identifying a biomedical cause and symptomatology of autism offered the means to pursue a new avenue for its cure beyond the individual child’s disordered psychology. The psychological and biomedical theories of autism now stand alongside one another as powerful meta-narratives. A report of the autism research landscape in the UK showed that of the £20.8 million of funding between 2007 and 2011, £11.6 million (56%) was spent on research within ‘Biology, Brain and Cognition’, a further £3.8 million on ‘Treatments and Interventions’ and £3.1 million on ‘Causes’ (Pellicano et al., 2013). Of these studies, 72% focused specifically on children and adolescents, despite the majority of the population living with autism in the UK being of adult age (ibid).

## 1.3 Returning to the start and taking the scenic route

Within this A-to-B route of the history of autism I have introduced an objectivist chronology of its origins, symptomatology, and its cure. This is *The Quickest Route* from A-to-B of autism. It offers little in the way of distraction and provides a narrative that can be digested and productive for a particular cause; the championing of intervention educationally, medically, psychologically, and socially to cure a disordered individual (Goldstein, 2002; Koegel, 2000; Lovaas, 1987; Carr et al., 1985). However, perhaps this route is so digestible precisely because of its simplicity. It is those narratives that appear so natural, so simple, so easy to digest that are in the greatest need of problematising (Walkerdine, 1993; Rose, 1990; Foucault, 1979).

It is with that in mind that we come back to our sat nav, to the moment that we hover over the decision between *The Quickest Route* and *The Scenic Route*. The highway that is described previously is now avoided, we select the ‘via’ option and set off along a new route, ready and willing to get lost, become disorientated, and begin to explore the multiple possibilities of a journey with no singular beginning, destination or route in between. The desire for this route, in its scenic venturing, is one that draws us to ask different questions of our encounters with childhoods that are known as autistic.

Childhoods that are diagnosed as autistic childhoods pose a problem in need of a solution; a disorder in need of intervention (McGuire & Michalko, 2010). As we have seen, there are a number of disciplines offering solutions to this problem of autism, saviours to the restoration of childhood. What happens though if we veer from the highway of the problem posed by autism’s residence in children’s bodies and minds towards the disorientating experience of autism not as an interior disorder, but as a site of the social, political and cultural imaginary in neoliberal times?

## 1.4 Why wander? Through a Politics of Wonder

Along the roadside here we spot a landmark for the first time; disability. It’s always been there, somewhere on a distant horizon, but it is only now that it comes into view. This will become a familiar landmark that will appear at every turn we make in this journey, whether we’re expecting to see it or not. It’s like the vast fields of bright, pungent rapeseed that can be seen (and smelt) at every turn of a journey in springtime. The smell of it lingers long after you’ve passed it, the vibrant crop of colour sits on the horizon in every direction at certain times of the year. So pervasive is the landmark of disability in its theoretical offerings to this project that it guides the very way in which we take *The Scenic Route,* the places we return to and the experiences we will have of them. I introduce the first of our disability perspectives; Titchkosky’s (2011) ‘Politics of Wonder’.

Titchkosky encouraged us to engage in a ‘politics of wonder’; the act of attending to, in wonder, the politics that we adopt in responding to disability. A wondering of our casting and ‘recasting’ (Diprose, 2002, p.126 cited in Titchkosky, 2011, p.133) of the problem (of disability) is both disruptive and imaginative as it challenges us to go beyond the *why* of ‘why things are the way they are’ and towards the *how* of such things. This, Titchkosky reminds us, ‘is not disruption for the sake of disruption...but a disruption for the sake of the possibility of forging new lives together’ (p.133). Here is a space to wonder if ‘there might not be some better, more lively and imaginative ways to conceive of a collective’s version of problems, as well as its version of answers and solutions’, because simply attending to *why ‘*things are as they are’ may leave us with ‘diminished or unimaginative’ responses to the lives of disabled people (ibid). There is resonance between this politic and the casting and re-casting, or dis/orientating, of our gaze on the study of autistic children, labelled with autism which this next route offers. Why, indeed, not spend some time wandering through the politics of *how* grand narratives of autism and childhood came to be?

## 1.5 The Scenic Route: A wondering and wandering through the terrains of autism and childhood

I begin with a moment in the sociological imagination in which the terrain of childhood shifted and remains forever unchanged; the becoming social of childhood (James & Prout, 1997). It was Aries in the 1970s who first brought to attention the idea that childhood was not in fact a constant, universal experience but indeed a modern, social phenomena (1973). Drawing on representations of children and childhood prior to the fifteenth century, he suggested that historically, childhood had not always existed. He suggested that it was in fact with the dawning of schooling that the child as distinct and recognisable as not-adult came into being. Critics such as DeMause (1976) claimed Aries’ work to be partisan, instead suggesting that it was child-rearing practices that had changed, not ‘childhood’ per se. He believed that it was through primitive parenting practices that modern childhood was unrecognisable. Pollock (1983) argued that simply because western, modern depictions were not recognisable that that alone was not enough to suggest society held no such concept. Despite his critics, Aries remains an influential reference point for the emergence of the study of childhood as distinct, non-universal and social.

Perhaps the most helpful contribution offered by the sociology of childhood in this unfolding meandering, is the opportunity to veer away from psychology’s neutral projection of the universal, normally developing child, and instead turn towards another orientation in which childhood is a site of the social, political and cultural. Within the new study of childhood, children were now ‘no longer regarded as simply the passive subjects of structural determinations’ (James & Prout, 1997, p.4) but actively involved in their own cultural and social constructions of their world. Where children and their development stage – childhood - had been the objects of the natural sciences, ‘environmentally vulnerable travellers on a biologically determined road to adult status’ (Priestley, p.208), James and Prout (1997) proposed childhood not as a period of preparation of ‘becoming-adult’ but a distinct and valuable social construct. With an emerging attitude towards the construction of childhood, issues of identity, rights and social justice came to the fore. This paradigm shift brought with it research and policy aimed at increasing the participation of children in their childhood (McNaughton, 2005). Traditional representations of the child as ‘....unreliable and developmentally incomplete’ (Mayall, 2008, p.110) were replaced. This progressive research agenda strove for the recognition of the diversity and non-universal experience of childhood and was undoubtedly hugely successful in redressing the positivist imbalance. However, as participatory methods with children developed, it became apparent that disabled children (in their diversity), who may enact their agency and autonomy in ways that were not normatively visible, remained at the margins of such research (Watson, 2012). The beginnings of participatory methods were often framed around ableist conceptualisations of ‘participation’; the autonomous child’s ‘voice’ being predetermined by a literal voice or observable social competencies (Davis et al., 2008). Disabled children, particularly those who didn’t use spoken language as their primary mode of communication, remained marginal to, or excluded from, research aiming to recognise and value the diversity of childhood experience. Those critical of such exclusion of disabled children challenged researchers to recognise that enacting ‘voice’ in non-normative ways did not equate to not having anything to say (Beresford, 1997). In turning to a more critical conceptualisation of participation, the centring of ableist, normative markers of autonomy, agency and voice can be destabilised (Davis et al., 2008; Curran & Runswick-Cole, 2014; Watson 2012). Even Prout (2005), himself one of the founders of the new sociology of childhood, suggests that perhaps the study of childhood needs to move towards a more critical era. No longer, he suggests, is it necessary to present the study of childhood as dependent on a set of narrow dichotomies (e.g. biological determinism versus social constructionism). His argument is that these claims, whilst necessary to carve the niche to emancipate the study of childhood from biological determinism, now serve to divert attention from the complex spaces between such dichotomies (2005, p.68). The future of the sociological study of childhood then, requires the recognition of the complex spaces of childhood and, as such, literatures, theory and methodologies which themselves allow for complexity and emergence to be central.

This wandering towards and around the sociology of childhood offers a gaze upon childhoods labelled autistic that our first route ignored; a centring of childhood. The shift in perspective offers the potential of a new terrain in the research agenda, an opportunity to dis/orientate both autism research and childhood research. The turn to the sociology of childhood disrupted the grand narrative of childhood as a biological, universal experience, which, with the critical turn that Prout (2005) calls for, could destabilise the grand narrative of autism. The emergence of disabled children’s childhood studies is the grounds upon which this turn is beginning to gather (Curran & Runswick-Cole, 2013). As Curran (2013) reminds us, research about disabled children’s impairments is not research about their childhoods. The premise of disabled children’s childhood studies is not additive, a call for inclusion into either childhood studies or disability studies, as it requires different starting points and different approaches to research design and ethics that neither discipline alone can offer (Curran & Runswick-Cole, 2013). Instead, the different starting point that disabled children’s childhood studies could offer is one in which disabled children do not simply have problems or cause problems, but have childhoods (Curran & Runswick-Cole, 2014). In introducing the potential of a critical turn to childhood and the literatures, theory and methodologies it could offer, I ask, ‘2. How might being autistic be considered part of being a child?’, and ‘5. How can autism research broaden its understanding of the everyday?’

I find it helpful now that we have set off in this new direction to stop for some theoretical fuel. This is where I pull over and grab a cup of coffee to focus the mind ready to employ the theoretical means to continue on my navigation. Along with my caffeine, I tuck a copy of a petrol station Foucauldian travel guide under my arm to delve into when my sat nav fails to offer me much-needed theoretical orientation.

# Chapter 2

# Introducing a theoretical travel guide

Subtly ignored by the whistle-stop tour of the autism and childhood grand narratives was the recognition that ‘normality’, which was both observed and developed (along with its deviance, abnormality), was not simply an observation, but a valuation (Rose, 1990). This valuation, in its presentation as a neutral, observable object, serves to produce a vision of normality (and its deviance, abnormality) so blinding that it is difficult to see any way to navigate it otherwise (Burman, 2008). Enter our Foucauldian travel guide.

Here I traverse some of the same landmarks as our previous route but, instead of mapping them through the gaze of objectivism, I re-map them with a little help from Foucault, or perhaps more broadly, Foucauldian thinkers. Foucault’s genealogical process is a means by which the limits and constraints of particular ways in which individuals become constructed as subjects (the autistic child) can take account for the political and economic imperatives implicit within such discourses. The power/knowledge regimes that have come to be such a blindingly dominant discourse can be interrogated as having a particular political, economic, and social history that have led to particular ‘technologies of the self’, self-governing individuals (Foucault, 1979). If Foucault is to frame our re-interrogation and re-routing of our travels through autism and childhood, I must first trace out some of his landmarks - history, power, knowledge and the subject - that line our route.

‘In a Foucauldian frame, history is understood not as the march of progress, but as marked by improvisational borrowing in the face of new and pressing demands’ (Youdell, 2006, p.35). Where historians have criticised Foucault’s ‘fast and loose’ approach to historical data, there has been a counter-call that accusing him of historical inaccuracy is to miss the very point of his work; Foucault, Megill (1985) tells us, is ‘best treated as an animator - not as an authority’ (cited in Allen, 1996, p.229). So instead, we recognise history itself as ideological and adopt the sentiment of Foucault’s (1984) genealogical approach. Discourse here is the tangled web of knowledge and power in which some things, and bodies, become produced and reproduced as commonsensical and others as nonsensical (Youdell, 2006). Knowledge here is neither neutral nor reflective of any objective truth, as mapped in our *Route A-to-B*, but is constructed and interwoven, contingent on its intimacy with power. It is the circulation and reproduction of power/knowledge discourses, which creates the circumstances in which the subject comes to be known and reproduced (Foucault, 1979; Butler, 1997). This is not a unidirectional enactment by the powerful upon the powerless but a *process*, no longer of punishment but *discipline,* both structural and practical, between individuals called in to self-govern (Rose, 1990; Foucault, 1975). It is within this process that power becomes productive; the means by which a person becomes subjectivated as both *acted upon* and *activated* as subject (Butler, 1997, pp.83-84).

We’re a little lost now. We can see the highway on the horizon and are tempted to cut across the expanse of fields back to its familiarity and convenience. Look at it, with its allure of speed and linearity, mocking us as we swerve and turn on small side roads seemingly getting nowhere. I almost wish I hadn’t picked up that Foucauldian Travel Guide, reading in the car always makes me feel queasy. As Chapter 4 will navigate, however, a sense of discomfort, queasiness and disorientation could be just what our terrains of autism and childhood need. So we plough on, turning down an even smaller road signposted ‘biopower’.

Particularly pertinent within this re-mapping of familiar terrain of autism and childhood is the technology of biopower (Foucault, 1979). A particular technology of power, biopower reaches into the interior of individuals and makes them known, and knowable (ibid). Biopower here is the productive circulation of discursive power that makes some subjects possible and others impossible through the authority of certain disciplines of the body; medicine, biology, psychology. Foucault’s guide here asks us to interrogate not an end point of ‘why’ certain discursive power renders some subjects more possible than others, but to recognise the ongoing process of ‘how’ this particular formation was reached as opposed to others. *How* do some bodies become so readily known as child and read as providing residence to autism? No discourse, we are told, is guaranteed (Foucault, 1990). Whilst some dominate at this particular point in the social and political conscience, there is always potential for disruption and unsettling of such dominance (ibid). With this in mind, I now re-map our Route A-to-B through a more scenic Foucauldian terrain in which the technologies that made our first route possible and problem-free are open to disruption and unsettling. As Shumway encourages us, in the deployment of Foucauldian framework, ‘add Foucault and stir’ (1993, p.161).

In the vein of post-structuralism, language constructs knowledge and as such, *is* power, which inscribes itself on bodies. As Nietzsche said, ‘to name something is to determine its essence’ (in Paterson & Hughes, 1997, p.335). Foucault (1980) talks of the power of these very processes, ‘(it) reaches into the very grain of individuals, touches their bodies and inserts itself into their actions and attitudes, their discourses, learning processes and everyday lives’ (p.39). In this sense, it becomes possible to see the interplay of language, power and medicine in controlling and inscribing what is understood as disorder, abnormality and impairment. Medicine is the god of disorder by virtue of its power to name, diagnose and label. This in turn produces, reproduces, iterates, and reiterates a corpus of knowledge about that child, which becomes known as autistic through discursive practices. A poststructuralist approach removes this notion of disorder from the land of the medical and psychological, in which the experience of being autistic is a biological given, and drops it within a new land as a discursive practice in need of analysis and interrogation. The aim here is to replace the modern ‘truth’ of science with discourse and, further, to leave said discourse open to scrutiny (Goodley, 2011).

Taking forward these ideas, Rose (1990) explores the extension and scope of the technologies of self-governance. In ‘Governing the Soul’, Rose invites us to consider a central theme of governmentality in relation to subjects that are ‘obliged to be free’ (p.217). Children and childhood play a core ‘idea and target’ in this governance, as the ‘most intensively governed sector of personal existence’ (p.123). The ‘pedagogic machine’ he goes on to describe is operated to ‘not only impart knowledge but to instruct in conduct and to supervise, evaluate, and rectify childhood pathologies’ (p.124). Here we come to the making of the child and its ab/normality through the technology of schooling.

2.2 The making of the child through the technology of schooling

The British industrial revolution saw Christian philanthropists acting out of moral obligation to protect and nurture the young of their society by driving forward schooling for the masses (Walkerdine, 1993). Interwoven within this new system of educating, moralising and socialising children was the rise of the natural sciences’ interest in the child. Mass education was to be the solution to two problems of the industrial turn: crime and pauperism (Jones & Williamson, 1979). Schooling would be the opportunity to teach the poor to read, to read the Bible more specifically, and, as a consequence, live a moral life. The social product of poverty here, crime, was to be eliminated, not by improved material wealth or social conditions, but with the instilling of moral qualities of virtue (Jenrick, 1990; Jones & Williamson, 1979). The schooling of the era, monitorial in its ethos, soon saw that instilling moral habits fell short of producing the social good the Christian curriculum professed (ibid). It was the interior *nature* of children that was to hold the key to the means of educating the masses (Walkerdine, 2009). It was ‘happy accident’, Rose (1985) tells us, that psychology had just the tools to hand to condition virtuous habits of reason and responsibility into the individual children of the paupers (cited in Walkerdine, 2009). We rest in our scenic wandering, by the side of the road at a moment in historical, social and political imagination; at a Foucauldian ‘condition of possibility’ (1970).

It was in the psychologising of schooling that the means by which the technologies of how an individual became ‘made’ was most readily enacted for children (Foucault, 1979). Psychologisation, that is, ‘to make something psychological’, is the process we have been exploring in which the moral, social and political become understood as residing in the psychological (Madsen & Brinkmann, 2011, p.180). De Vos (2008, p.1) describes it as ‘...the phenomenon of how the psy-sciences became a hegemonic discourse, delivering particular signifiers and discursive schemes for looking upon oneself and upon the world’. By gathering people en masse Foucault explains, it became possible to observe and delineate the commonalities and differences that created an ordered sense of knowledge, and a knowable individual (ibid). As we have seen, the natural sciences took these observations and mapped normality and abnormality as a matrix by which the behaviours of an individual were measured and became known (Burman, 2008). Through the rise of psychology’s interest in a child’s interior was a process of biopower, ‘difference was no longer marking itself unambiguously on the surface of the individual; it was receding into the interiority of the soul. It would have to be made legible’ (Rose, 1990, p.14). These ‘inscriptions’ on/of individual children made the invisible visible, through the means of ‘making’ a person; categories, labels, markers of normality and abnormality gave life to the pathologisation of autistic childhood. A seminal technology of the ‘making’ of such pathology was Binet’s IQ test, which systematically delineated the individual’s internal features, offering the means to map normality and its deviance. The ‘making’ of a child was made possible, Rose (1999) tells us, through the ‘gaze of the psychologist’ (p.135). ‘The child here is caught up within a complicated arrangement that transforms it into a visible, observable and analysable object, within a particular rational scientific discourse (developmental psychology) making a particular kind of claim upon our attention, a claim to truth’ (p.147). Where deviance had previously been mapped through moral criteria, the turn to psychology, legitimised as aligned with medicine, allowed for the classification of normality and abnormality to be delineated; through normalising development it was possible to identify abnormality (Burman, 2008, p.20). The psychologist’s gaze (Rose, 1990) that used standardised testing, such as the IQ test, allowed for the moral judgements implicit in such classification of a child’s normality or deviance to be presented as neutrally scientific, a claim to truth (ibid), both ‘invisible and incontrovertible’ through the apparatus of statistical norms of impartiality (Burman, 2008, p.25). This was the technology of pathologisation.

## 2.3 Pathologisation and Familisation

How then, Foucault would ask us, did this pathologisation and psychologisation of bodies and minds take hold, become produced and reproduced as, and in, everyday discourse? A key site of self-governance is the family. The technologies deployed in the ‘familization’ (ibid) of the 19th century were to subtly weave the imperatives of an economically productive state with the moral desire of individuals for secure and ‘free’ family life (Rose, 1989). This, Rose tells us, was the foundation of a social institution built on supporting economic production but disguised as a moral duty. No longer subjects at the hands of landowners and Lords, the autonomous family could rear its children free from surveillance; a new gaze would be necessary, the self-governing gaze of pathologisation.

The family, in its familised form, is a key site of the production and reproduction of childhood pathologisation (Rose, 1990). Through the alignment of developmental psychology and schooling, assessment and professional intervention in childhood deviance, developmental norms permeated the walls of the family home. Mother-child relationships became a particular source of scrutiny (Burman, 2008) and a means by which to render a child’s maternal attachment normal or disordered, and as predictor of future successful developmental milestones being met (see, for example, Bowlby’s 1969 attachment theory). Parents were positioned as both the ‘apprentice psychologists’ observing and measuring their children’s development achievements and the root cause of any deviance from the norm, simultaneously (Rose, 1990). This public permeation of private family relationships fuelled families to maintain, regulate and discipline in their own pursuit of normality through the bodies and minds of their children. ‘...the almost inevitable misalignment between expectation and realisation, fantasy and actuality, fuels the search for help and guidance in the difficult task of producing normality, and powers the constant familial demand for the assistance of expertise (Rose, 1999, p.132)

This cycle of pursuit towards a narrow, elusive, developmentally normal child, coupled with failure of children and families to meet it, was perhaps no better exemplified by early descriptions of autism as a disorder of affective disturbance (Kanner, 1943) and a cold, unloving maternal relationship, which was coined by Bettelheim (1950) as the ‘refrigerator mother’. Here, the imperative of the dysfunctional parent-child relationship becomes not an objectivist truth but a site of biopolitics; where the technologies to surveil and categorise children becomes material in families’ lives. Such narratives of psychology's claim to child pathologies has been somewhat superseded in recent times by a new turn; the gaze of neuroscientific narratives (Furedi, 2001).

## 2.4 Neo-liberal Technology of Self-governance: Neuroscientism

Traditionally, the state was reluctant to appear as overtly concerned with the perceived ‘private’ sphere of the family regardless of the discursive practices that implicitly circulated through, around, and in homes. However, a recent undercurrent of particular attention to parenting practices has drawn focus in both policy and public consciousness back to the centrality of parenting. ‘The relationship between parent and child is thus constructed as both naturally foundational to society but also too risky and important to be left to the unseen vagaries of the private realm’ (Macvarish et al., 2015, p.252). Though many of the original psychological theories of attachment (Rutter, 1972; Emerson & Schafer, 1964; Bowlby, 1969) have since come under criticism, a discourse of legitimate intervention based on a new kind of ‘evidence’ has implicated parenting practice in a child’s ab/normal development; a discourse of neuroscience. Such a discourse disseminates a return to the threat of parents; to brain-claiming and parent-blaming.

Neuroscientific claims to the neurobiological root of pathologies have been adopted in the social policy mainstream and hold pertinent powers to surveil and regulate children and families’ lives (Macvarish et al., 2015; Wastell & White, 2012; Furedi, 2001; Bruer, 1999). Despite the discipline of neuroscience itself recognising its embryonic stages in understanding the brain (cf Steven Rose in Royal Society policy paper, 2011), the mainstreaming of those technologies, which surveilled children through psychology, has spread to self-governance by neuroscience. Nowhere is this more apparent than the UK social policy sphere, where ‘evidence-based practice’ is now the mainstay undergirding the development of family policy and resultant intervention (Wastell & White, 2012). A particularly influential government commissioned report (Allen, 2011a; 2011b) presented a review of neuroscientific studies calling for early intervention in disadvantaged children’s lives, using bleak images of neglected brains as its flagship argument. In a paper exploring the data and extrapolations that Allen had made, Wastell and White (2012) challenge the presentation of neuroscience as ‘powerful “trump card” in what is actually very contentious terrain’, which fuels contemporary policy landscape as ‘the latest in modernity’s juggernauts reifying human relations into “technical objects” to be fixed by the state’ (p.399). Bruer (1999), taking a similar contention to the United States ‘decade of the brain’ (George W. Bush, 1990), wrote of the power of such a narrative. The power of such a myth is its dissolution of social ills as the product of brain development, but it is this extrapolation, oversimplification and misinterpretation that serves to return to a damaging perpetuation of parent blaming (ibid). This misappropriation of legitimate neuroscience has been reviewed by Macvarish et al. (2015) in Anglo-American contexts and termed ‘neuroscienticism’ (p.254). The danger of using neuroscientific understandings distorted in social rhetoric is ‘its crushing of the debate we need to have as a human society about where and how the state should tread and its limits’ (Wastell & White, 2012, p.409).

It is not enough to dismiss the power of such narratives, as Youdell (2015, n.p.) reminds us, ‘this is in the room, in families lives, so we must hold off the hate’. Instead, turning to the interrogation of the technology of such a narrative, along with the adoption of neuroscientific literature that is clear about its scope and reach, allows an exploration of the discursive power at work in families’ lives (Rose & Abi-Rached, 2013). This is a return to Rose’s (1990) thinking about how parents are called to recognise their (and their children’s) failings and their need for state intervention (termed ‘support’ in current rhetoric); this is self-governance in action. Parents are called to orientate to their children through such powerful psychologising discourses. ‘We can see’, Burman (2008, p.26) tells us, that through these processes ‘the modelling of an ideal typical citizen-subject who is knowable, known, docile and productive’, the need for technologies that identify, govern and produce the ideal, adult, neoliberal subject. In calling the family (and parent-child relationship) to centre stage in policy, they are simultaneously pushed to the margins as responsible for their child’s *need* for support (Macvarish et al., 2015). Individual parents are ‘foolish gods’, simultaneously to be praised and blamed, as ‘architects’ of their child’s development and perpetrators of their child’s ills (Furedi, 2008). This leads me to formulate the questions, ‘1. How do we speak of autism and how else might we talk of autism?, and ‘3. What does autism make im/possible for a child to be and become?’ These are Foucauldian questions, asking that we interrogate how particular discourses of autism and childhood have come to be so pervasive in the western neo-liberal conscience. I ask what these discourses have made im/possible for a child to be and become.

## 2.5 Conclusions: Invoking autism, childhood and the autistic child

The two routes that we have so far journeyed have invoked versions of autism, childhood and the autistic child. The quick, convenient *Route A-to-B* gives us the biological, individual child that can be known and measured in terms of its compliance or deviance from markers of developmental normality. Through the measurement of psychological features of development using standardised testing, a neurodevelopmental disorder, autism, can be diagnosed and known. On knowing the internal disorder, medical professionals are able to prescribe appropriate intervention. These interventions, developed out of theories of autism’s disordered cognitive features, allow the child to be brought back as closely as possible to the developmental markers of normality.

Our second, *The Scenic Route,* which takes pit stops and wonders on the neutrality of the *Route A-to-B,* invokes a different version of autism, childhood and the autistic child. In exposing pathologisation, such as autism diagnoses as a technology of biopower, the vision of this disordered autistic child becomes inherently problematic. No longer does a neurodevelopmental disorder reside in the individual child’s interior. Instead, we are drawn to the discourses at work above, around and on the modern child in the institutions of family, school and state. The markers of development and their resultant interventions are unpacked as themselves a form of governance to manage and discipline those children and childhood’s that do not readily meld to the image of the neoliberal child becoming a neoliberal, adult citizen. If we stay with this vision of a childhood labelled as autistic, we are drawn to question and problematise its construction and the materiality of its manifestation in everyday life. It is staying with this imagined child that I ask,

1. How is autism spoken about and how else might we talk of autism?
2. How might we consider autism as part of being a child?
3. What does autism make im/possible for a child to be and become?
4. What does autism do to/for/in education?
5. How can autism research broaden its understanding of the everyday?

## 2.6 Language

I take a pit stop here to discuss my choices of terminology throughout this thesis. Perhaps more traditionally these ‘definitions’ would have come at the very start to provide a clear and definitive position and a means of orientating the reader to the text to follow. However, without some meat on the bones, those definitions may have provided a comfortable sense of resolution and coherence that would jar with the politics of what was to follow. Problematising the language used by myself, others, the academy, parents, and so on, is a permanent feature of this thesis, which makes the writing of it ever more problematic because, at some point, linguistic choices and politicised language positions must be taken. So here I unpick some of the (ir)rationale for why certain terminology is at times favoured, and at others, cast out.

For the majority of this thesis I choose ‘childhood labelled autistic’ or ‘children labelled with autism’, rather than ‘autistic child’ or ‘child with autism’. This choice is not accidental or ambivalent, but neither do I argue fervently that it is necessarily the right or only choice. It is a choice that I would sooner not make, as I fear it perpetuates limiting notions of autism that are neither helpful nor productive but that appear static and resolved. I would like to get in between the language that surrounds autism and hold it in tension. In tension, we are drawn to suspense; the possibility of a number of orientations allowing us to explore notions of ‘autism’ in less fixed and reductive ways, to remain dis/orientated. Choosing the phraseology ‘child labelled autistic’ allows us to be ever-mindful of the biopolitical process at work in such a labelling; the bodies I speak of become knowable in the particular ways that are short-handed by biopolitical labels. I share now some of the specific ways that autism language is storied in order to demonstrate a number of dominant positions.

Self-advocacy movements predominantly in the UK and USA, which consider autism to be a neurodiversity (a different but equally valuable form of neurological functioning), claim that the language of ‘autistic person’ and ‘autistic child’ draws on identity politics in parallel to, for example, sex and race (see Ortega, 2009 for a detailed debate). They reject ‘child with autism’, as person-first language suggests that a child with autism could equally be a child without autism; it is read as a denial of identity (Sinclair, 2013). There is a potential contradiction in such language that could serve to perpetuate the essentialism of a ‘thing’ of autism present within a child’s body, which draws on pseudo-medical language of neurological functioning. I would ask if this language offers enough distance from the oppressive, medicalising discourses of autism; that once autism becomes fixed as a question of biological functioning, it slips back into the ownership of medicine and the dominant biopolitical tale of autism as disorder. It may draw attention away from the discursive power of autism constructed above and around the child. I pay heed to Goodley (2007), who cautions that any identity politics is inherently problematic, as it suggests a finished, complete being; the definite autistic-child-subject. In theorising such a choice, it sits more comfortably with me on the page. In the lived world beyond this page, however, I am left troubled by such a politic. Such a problematising of the potential reductionism of identity politics did not, and does not, seem to bear weight in the everyday lives of the children and families I work with, the everyday contact that I have with them and others who would be considered to be labelled with/by autism. Aside from not tripping off the tongue, ‘child labelled with autism’ seems to lack resonance in everyday life. People I meet, more often than not choose to refer to themselves as autistic, and parents too to their ‘autistic child’. With that in mind, I respect individuals choices in line with the American Psychological Association’s (2001) recommendation to, ‘...respect people's preferences; call people what they prefer to be called’ (p.63) within my everyday encounters and generally use ‘autistic child’ (and its various derivatives). So it is within the spoken world, in everyday practice, that I find myself heeding the call of the neurodiversity movement’s preference for ‘autistic person’. Here is a juncture between the theorising of autism and its lived manifestation; what I will go on to suggest is part of treading the slash of dis/ability.

There is potential, when understandings of autism are held in tension and the space and friction of these tensions is explored, which is expanded on in the coming call to ‘dis/ability’ (Goodley, 2011). Titchkosky (2011, p.232) encourages us to delve into the ‘betweenness’ of the language we use in relation to disability and be continually surprised by the new and unexpected possibilities it offers us.

I ask here that you bear with me and take me at my word that the inevitable sense of frustration at gaps in explanation and a wanting of clarity is a moment of suspense that will dissipate with your patience to keep reading. If you’re feeling a certain amount of frustration and discomfort then I am in some ways pleased. It means my desire to story a multiple and complex route through the literature of this project is working. The need to juggle a number of conceptual and disciplinary balls at the same time needs a call for patience. In Chapter 3, I bring in Disability Studies and Dis/ability Studies to begin that sense-making and meaning-making process (though without the promise of any singular, comfortable resolution). These disciplines are the linchpins of this project and help the fractured side roads of this route to hang together, forging new bonds, and connecting the literature explored so far in new ways. This, perhaps, is our hitchhiker, who is brought into our road trip to begin a dis/orientating gaze upon autism and childhood. First though, we stray into the land of socio-cultural autism. It’s part of our journey on a toll road for, as we will hear, the loudest discourses of autism certainly come with a toll. The glossy, expensive toll road masks potholes and road works of lived experience This is a land, perhaps quite far removed from the literature, that has come so far and from the turn to disability that we’re on the cusp of making. It provides us with the discursive terrain of children’s and families’ everyday lives that resonates through what a label such as ‘autism’ means.

## 2.7 Socio-cultural Autism: Autism Advocacy in The United States

Until now there has been little reference to geographical location, though a sense of the UK-centric terrains has been mapped through particular historical reference points. We briefly hop over the pond now to the United States to explore the culturally specific ways in which autism is being mapped transatlantically. Though I am not aiming to map autism internationally, its position in the Western neoliberal imaginary involves terrains beyond UK waters. The US provides a pertinent source of autism discourse, a powerful one at that, and as such offers our foray into international terrains. Much of the global rhetoric of the increasing prevalence of autism comes from US data; where autism is considered to be identifiable in around 1 in 100 of the UK population, US estimates put diagnosis at 1 in 68 children (Centre for Disease Control, 2010) with some national surveys claiming prevalence as high as 1 in 45 children between the ages of 3-17 (National Health Interview, 2014). The higher estimates of prevalence are coupled with much higher research expenditure in research terms. In 2010, it was estimated that £2.6 million was spent on autism research in the UK, with 89 times more, that is, $357 million (£234 million) spent in the USA in the same year (Pellicano et al., 2013). A research and public agenda of such scale is a worthy site of exploration in our mapping of the terrain of autism.

The USA may at first appear to be a relatively similar landscape to the UK in relation to autism. However, the dominant dealings with autism in the USA are quite different to the dominant UK context, which suggests that a broad sweeping, neoliberal terrain is not the only governing backdrop to autism discourse. The dominant public voices of autism in the UK define it as a ‘neurodevelopmental disorder’ and a ‘lifelong disability’ (National Autistic Society, 2015). Though firmly within the domain of individual pathology, the biomedical narrative is somewhat of a murmur. The dominant discourse of autism in the USA is of autism as an ‘epidemic - a public health emergency’ (Autism Speaks, 2015) in which lives are ruined, lives both threatened and lost, by the pathology of autism residing in individual’s bodies (McGuire, 2011). The response to such threat to health posed by biomedical autism comes from a well-funded body of advocacy organisations that seek to mobilise the public in the ‘war against autism’ (McGuire, 2015). Autism advocacy within the United States remains very much within the domain of medicalised models of health-related disability. I concentrate my attention here on the most powerful (in a number of senses; most notably in terms of economics and public reach), Autism Speaks, which is the merged organisation of Autism Speaks and Cure Autism Now (2007) and another organisation with a particularly powerful, war-like public campaign, The New York University (NYU) Child Studies Centre. The NYU Child Studies Centre Ransom Note Campaign (2007) Autism Speaks, ‘I Am Autism’ campaign (2009), and more recently ‘Light it up blue’ (Autism Speaks, 2015), were each designed to ‘raise awareness’ of autism. The two former campaigns presented autism in personified form, the first Autism as a hostage taker of children and the latter Autism as a horror film monster. ‘I am Autism...’, we hear as an ominous voice-over accompanying stills of children with a sinister soundtrack, ‘... I know where you live..I live there too...I work faster than pediatric AIDS, cancer and diabetes combined... And if you are happily married, I will make sure that your marriage fails.’ (Mann & Cuaron, 2009). Autism as hostage taker and monster weaves a sophisticated imperative; the clear divide between autism and the child as two distinct entities, autism the unwelcome, monstrous guest colonising the child’s body and mind. As distinct, other, monster, autism in these awareness campaigns becomes removable by virtue of its separateness from the child (McGuire, 2011; 2015) The separating out of autism and child has not gone unnoticed by autistic self-advocates, who claim autism as integral to their humanity, personhood and identity, an ethic far removed from mainstream autism advocacy. Jim Sinclair, an autistic advocate, who was at the forefront of claiming autistic difference back from its construction as pathological, turns such rhetoric back to the advocates of autism awareness. Writing before many of these national and international organisations came into existence, his message to those, parents included, who wish to proliferate discourses of autism as a biomedical appendage, is clear,

Autism isn't something a person *has*, or a "shell" that a person is trapped inside. There's no normal child hidden behind the autism. Autism is a way of being. It is *pervasive*; it colors every experience, every sensation, perception, thought, emotion, and encounter, every aspect of existence. It is not possible to separate the autism from the person--and if it were possible, the person you'd have left would not be the same person you started with.

This is important, so take a moment to consider it: Autism is a way of being. It is not possible to separate the person from the autism.

Therefore, when parents say,

I wish my child did not have autism,

what they're really saying is,

I wish the autistic child I have did not exist, and I had a different (non-autistic) child instead.

Read that again. This is what we hear when you mourn over our existence. This is what we hear when you pray for a cure. This is what we know, when you tell us of your fondest hopes and dreams for us: that your greatest wish is that one day we will cease to be, and strangers you can love will move in behind our faces. (Sinclair, 1993, n.p.)

The ‘I Am Autism’ campaign received a huge number of complaints about the tone of ‘fear and pity’ it invoked (Ne’eman, 2009, n.p). The Autism Speaks Executive Vice President, Peter Bell, responded by citing the praise the film had received, but also recognised that it ‘hurt a certain segment of the population’ (Wallis, 2009, n.p.). Both this campaign and The Ransom Note Campaign received such a number of complaints that they were retracted. Autism Speaks’ most recent campaign, ‘Light It Up blue’ (2010-15), adopts the United Nations World Autism Awareness Day (WAAD) as an opportunity to, ‘...shine a bright light on autism as a growing global health crisis’ (Autism Speaks, 2015). In the run up and aftermath of WAAD, the social media hashtag, #ActuallyAutistic, trended responses to the Light It Up Blue campaign from autistic individuals, families, and allies. As autistic blogger Matt Carey (2015) wrote, Autism Speaks is ‘corporate autism’. Whilst recognising its visible power, Carey and the #ActuallyAutistic hashtag highlight an autistic community (though I use such term with caution) site of resistance (see, for example, one of many Storifys of the #ActuallyAutistic hastag: <https://storify.com/SFdirewolf/autistic-people-speaking-loud-and-clear-autismspea>). Autism Speaks, along with many North American advocacy organisations (Age of Autism, Autism Media Channel, Talk About Curing Autism), cling tightly to biomedical understandings of autism, which strive for answers to both cause and cure. They do not have any board members, or senior organisational members, who identify as autistic, a key premise of disability rights movements which support disabled people being at the heart of decisions that affect their and their community’s lives. As Gernsbacher et al. (2005) challenge in their article, ‘Three reasons not to believe the autism epidemic’, using the term ‘epidemic’ to describe the increased numbers of people with autism diagnosis connotates danger, a pandemic, a scourge. What, they ask, does such a message send to those children and adults receiving diagnosis? The rhetoric of such danger serves to perpetuate the pursuit of biomedical cure, which is then capitalised on by the same such advocacy organisations that seek to raise autism awareness (McGuire, 2009).

If this is the material of public discourse dominant in the USA and indeed present as a low murmur in a UK context, what and how does this feed into everyday discourses of those living immediately with autism? It leads me to ask, ‘*1. How do we speak of autism? and how else mightHow else might we talk of autism?’, ‘2. What does autism make im/possible for a child to be and become?’* One terrain of those everyday discourses is the wealth of published literature written by parents of children with autism labels. .

## 2. 8 Parents’ literature: a specific terrain

Alongside autism advocacy in the USA, parents in the UK and elsewhere are contributing to socio-cultural autism discourse. Publications written by parents are a huge market, a quick search of ‘Google Shopping’ using the terms ‘autism+parent+biography’ offering no less than seven pages of books titles. Titchkosky (2007) sees texts as social actions that ‘make up the meaning of people’ (McGuire, 2011, pp.61-2), those social actions contributing to the talking, being and becoming of children’s and families’ lives.

Texts appear to people, and with real consequences, texts enter our lives. In the context of our lives, texts come to life. This life reflects, if only in a flash, the meaning of the being of that which the text speaks... (Titchkosky, 2007, p.26)

The texts that parents of autistic, disabled children write and read have real consequences, reflecting, ‘if only in a flash’, the meaning of being a parent or child in spaces of autism. Those real consequences, born out of writing about the experience of autism and parenting are of interest to a project asking for dis/orientations to childhoods labelled autistic. I ask, *‘1. How is autism spoken about and how else might we talk of autism?’* and ‘*3. What does autism make im/possible for a child to be and become?’* I now briefly explore a rich and complex body of literature that narrates lived experience; parents’ literary works. I consider several of these texts here to explore the specificities and tensions of parenting a disabled (and more specifically, labelled autistic) child in literature.

Broderick and Ne'eman (2008), in an article titled 'Autism as Metaphor', explore how representations of autism in popular, western culture have led to a construction of the phenomenon, which has created a cultural narrative dominating how society diagnoses, labels, educates and views children and adults with labels of autism. Alongside the advocacy organisations we have seen, much of this representation has come from work written by parents narrating their experience of raising child with an autism label. What is interesting to consider in this body of literature is its diversity. If autism were static, an autistic childhood homogenous, then one might expect a trope of similar substance in parent’s writing. The very existence of such diverse literature surely speaks to a multiple autism, which can be understood from multiple entryways.

Murray and Penman (1996) collated parents of disabled children's poetry in a collection titled, ‘Let Our Children Be’,

Disabled children are often not accepted as the individuals they are. They are often denied their human rights. We want all our children to belong in their local communities and to have ordinary lives. This is a collection of stories from disabled families who want to be valued exactly as they are. (Murray & Penman, 1996)

The poems that follow speak to a politicised experience of disabled families that seeks to resist medicalisation, pathologisation and marginalisation of their children’s lives.

When You Look at My Child

What do you see

When you look at my child?

How does he make you feel?

Your words confirm what I see in your eyes

Confident words, so secure

In the assumptions that you make

Which child are you speaking about?

What do you see

When you look at me?

How do I make you feel?

Your manners suggests the response you expect

So sure of your words, taking

For granted that role that you choose.

Are you really talking to me?

When did I tell you I wanted him changed

That I would prefer him different

From as he is?

When did I tell you I wanted your help

To change him?

I longed for my child for such a long time

I met him and chose him

And held my breath for a while.

I was very lucky.

He decided I belonged to him too.

Why would I change him?

Don’t you realise that I can feel

Your need to change him

Your need for him to be other than he is

To be “improved”

To be more or less or whatever

You are disturbed by?

Don’t you understand that

The comments you make about my child

Tell about yourself

And not about him?

And the needs we discuss

Are yours

And not his.

When you look at my child. (Penman, 1996, pp.3-4)

Literature written within a human rights discourse sits alongside, and rubs up against, socio-cultural representations of autism harking back to its historical origins, in which the child is 'trapped' by autism, otherworldly, and not akin to an ordinary or indeed, human, childhood (see Sainsbury’s ‘Martian in the Playground, (2009); O’Neill’s ‘Through the Eyes of Aliens, (1998)). Within this body of literature we hear of parent’s pursuit and discovery of cure, for example, McCarthy’s (2007) ‘Louder than Words: A Mother’s Journey in Healing Autism’; and Khodabandehloo’s (2011) ‘Lonely Girl, Gracious God: A Mother's Story of Autism's Devastation and God's Promise of Enduring Love’. How then, I ask, is autism spoken about and how else might we talk of autism?

## 2.9 Blogging and autism

There has been a relatively recent abundance of academic attention given to online worlds, communities, spaces etc. and one in particular that is worthy of note in this collection; the contested ‘Mummy Blogging/Mummy Blogger’. The blogosphere was not an intended ‘object’ of study in this project but became so through the evolution of networks, browsing, curiosity. What became apparent was that these virtual and metaphorical sites couldn’t be ignored in a project about everyday life, autism and childhood. The contested nature of the term, field and space as ‘Mommy Blogging’ has an air of the self-indulgent and a pejorative tone Friedman and Calixte (2009) remind us. I would argue that what is apparent in the blogging of mums (and occasionally) dads of disabled children should be cautious of such tarnish. These blogs are productive spaces in which we, as researchers should be looking to learn from the insight, reflection and expertise of parents *doing* difference, *doing* resistance, shaping and creating autism discourse through socio-cultural material. Morrison’s (2010) definition of the term is that a central posit of ‘Mommy Blogging’ is the everyday. So perhaps this is an opportunity to open up the definition of ‘Mummy Blogging’ to be something politically active and resistant, see for example Bamberger (2011). I would align my readings (and there will be alternatives) of these blogs with Wilkins (2009), who claims that they are challenging hegemonic conceptualisation of mothering and motherhood. Mauthner and Doucet (2012), writing on the subject, return to the work of Ruddick to articulate the potential power of mothering discourse and its evolution, ‘maternal thinking is a “revolutionary discourse” that has been marginal and peripheral but that, as a central discourse, could transform dominant, so-called normal ways of thinking’ (Ruddick, 1995, p.268 in Mauthner & Doucet, 2012, p.103).

My interest here lies in how these different framings of autism challenge or perpetuate a particular discourse of what it means to be a disabled child and more, how they potentially expand narrow understandings of what it means to be a valued human. Autism, within this body of literature, is incompatible with childhood and an impossible version of the human (McCarthy, 2007; Khodabandehloo, 2011) whilst at once a valued life and an everyday messy relation between parent, child and marginalising society (My Daft Life; My Son’s Not Rainman; BleuJane; JaneYouell; A Bit Missing; Penman and Murray, 1996).

In turning to how parents talk and write of autism, we can explore the practices of dis/humanism (Goodley & Runswick-Cole, 2014) envisaged in such storying; a critical disability studies line of thinking that troubles conceptualisations of the human, which I will now introduce in Chapter 3 ‘From Disability Studies to Dis/ability Studies’. If Penman’s poem talks of resistance to the dehumanising practices pervasive in disabled children’s lives and McCarthy’s the dehumanising of autism, what can become of such parental literary discourse? What can we understand of autism, childhood and conceptualisations of the human by attending to such talk? I take these questions forward in asking;

*1. How is autism spoken about and how else might we talk of autism?*

*3. What does autism make im/possible for a child to be and become?*

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# Chapter 3

# From Disability Studies to Dis/ability Studies

I now move on to work done in and around disability studies, in order to introduce dis/ability studies and its offspring dis/humanism. I explore the history of the field, its situation in parallel to political agendas and advocacy, and the emerging space for work done outside of the traditional boundaries.

## 3.1 The British Social Model of Disability

Historically, disability was the concern of medicine, an individual problem and a ‘personal tragedy’ (Barnes, 2012, p.12). Those afflicted with impairments were at best unfortunate and pitiable and at worst deserving of their impairment through moral wrongdoing.

The ambiguous moral status of disabled people in the Christian Middle Ages (Stiker, 1999; Wheatley, 2010) vindicates both giving and maltreatment simultaneously. Disabled people walk a tightrope between a position in which they are objects of charitable intention and a theological discourse that reduces impairment to wicked sinfulness. (Hughes, 2015, p.996)

In the UK, attention to disability as anything other than tragic and pitiful first came not through the academy but through activism; the Union of the Physically Impaired Against Segregation in the 1970s (1974), an organisation initially formed in response to the economic disadvantage experienced by those with impairments. It quickly evolved to develop the foundations of a movement, which saw disability as a form of social oppression and exclusion, positioning disability not as the result of impairment, but as a socio-political force at work around and above those with impairment. From these beginnings, the academy became concerned with the confrontation between sociology and the medical model of disability that brought the biggest paradigmatic shift towards the social model, alongside the disability rights movement of the 1980s (Oliver, 1983). The social model of disability in its early forms concentrated on barriers created by society and largely drew on materialist principles in relation to access, work and equality of opportunity. It was hugely successful in drawing attention away from individual impairments and towards the social structures that positioned disabled people at the peripheries of society. Developing a social movement, which emancipates and liberates disabled people from the shackles of the medical, individual model, was monumental progress. However, the social model in its ‘strong’ form (Shakespeare & Watson, 2001) has, in its simplicity, become a site for critique and, perhaps ironically, exclusion. Acknowledging the parallels with the feminist movement, in which to recognise bodily difference is to open the floodgates to further oppression, French (1993) wrote of the materiality of impairments, bringing the much ignored body in the social model to the front and centre. Following on from this, Crow (1996) and Thomas (1999) both addressed the experience and limitations of pain and, from a new materialist perspective, the effects of impairment respectively. Shakespeare and Watson (2001) drew on such critiques of the social model’s absence of impairment to suggest the need, not to continue its evolution or develop its inadequacies, but to call for its disposal in British disability studies. They made the following proposal,

For us, disability is the quintessential post-modern concept, because it is so complex, so variable, so contingent, so situated. It sits at the intersection of biology and society and of agency and structure. Disability cannot be reduced to a singular identity: it is a multiplicity, a plurality. (Shakespeare & Watson, 2001, p.19)

Meekosha and Shuttleworth (2009) urge caution of the dilution of impairment-disability identities as fluid and multiple. In blurring hierarchies of difference, they fear the significance of the social model in disabled people’s lived experience is underplayed and its power as a political tool lost. Instead, they call for an on-going dialogue of impairment and disability, in which the social becomes neither universal nor dissolved.

Swain and French (2000) took the social model towards a model of affirmation, which aimed to redress the imbalance of negative focus in and around disability. This model aimed to promote notions of positive identity in association with disability and to recognise the development of disability culture that were emerging through the arts. They identified that current models, associated with the ‘personal tragedy’ of disability, had undertones that, ‘disabled people want to be other than as they are, even though this would mean a rejection of identity and self’ (p.576). This was not to deny that disability, or more specifically impairment, can be difficult, but that there are also practices within the community, socially and individually, that assert optimism, celebration and cultural value. The affirmation model draws on cultural practices celebrating elements of disability that people value, identify with, and draw on in their daily lives (Swain & French, 2000).

## 3.2 Learning Disabilities/Difficulties

The social model neglected those with learning difficulties (Chappell et al., 2001; Goodley, 2001; Aspis, 2000), or at best saw them tagged on as an afterthought (Goodley, 2000). The seminal social model framework of Oliver (1990) makes little mention of people with learning difficulties (Aspis, 2000). Aspis (1997) commented that, where the lives of people with learning difficulties had been brought into play, it had largely been in relation to service evaluation and improvement rather than more politicised agendas of the Disabled People’s Movement. Those with learning disabilities are, in fact, ‘othered’ within disability studies (Dowse, 2001; Roets et al., 2004; Docherty et al., 2010). In no other sphere of disability has terminology changed so rapidly and frequently; the two most prominent terms in the UK being learning disability and learning difficulty, whilst in the USA intellectual disability is currently in favour. Self-advocacy organisations tended to favour ‘learning difficulty’, as it situated the issue as context dependent, with the push for self-definition actualised in People First’s (1974) motto ‘label jars not people’. The language of learning disability has been repeatedly adopted in cultural mainstreams, in derogatory slang (idiot, moron, retard, handicapped) requiring new terminology to be adopted with fewer negative connotations attached (Wehmeyer, 2013). Perhaps this is reflective of the processes at work that continue to ‘other’ those with cognitive impairments as a category of non-human, by virtue of qualities required by modernist humanism; rationality, competence, autonomy at times, being deemed as lacking in those with labels of learning difficulties. The philosopher Peter Singer (2011; 1993) is perhaps the most infamous voice in the debate on the qualities needed to be considered human; rationality, competency and self-consciousness being the borderlands of humanity, a position strongly contested by those claiming the rights to humanity for those with severe cognitive impairments (see Kittay, 2010). With such extremes set aside, even within the DPM, a hierarchy of impairments can be seen in which those with learning disabilities or mental distress were seen as the ‘doormat of disability’ (Docherty et al., year, p. 438).

Chappell (1998) suggests a number of possible reasons for this exclusion, or neglect, from disability studies. Where the feminist critique was of the body as absent in the social model (French, 1993; Crow, 1996), Chappell suggests that there is, in fact, a pervasive concentration on the body through the dominance of understanding ‘impairment’ in tightly constrained, physical terms. This has served to marginalise any interest in learning disabled people, through the misconception that their ‘able-bodiedness’ left them free from the material barriers experienced by those with physical impairments or that those experiences were less worthy of attention. Goodley (2001) takes this further, asserting that it is not enough to bring those with learning disabilities sensitively into the fold with purist social model thinking in which ‘impairment’ is naturalised, but that the impairment that learning disability speaks of (i.e. impairment of intellect) is also of social construction. If the second wave social modelists had begun to attend for impairment and its experience, the impaired mind needed to be approached with equal caution, at risk of becoming naturalised or biologically given (ibid). Here, the chimes of our Foucauldian interrogation about how biopower comes to name and know the bodies and minds of children labelled with autism can be heard. There is nothing neutral or natural about the conceptualisation of people with learning disabilities; they are made in those disciplinary processes that delineate normality and carve out categorisations, autism and learning disability. They are made in these familiar orientations which seem to bring into being a knowable impairment. An important note here is the requirement of a Cartesian dualism inherent in this debate. As I will go on to discuss, the body, as I see it, is no more natural than the mind and vice versa. Neither is one experienced without the other. It is in bringing in the body through a disability politic that we open up a new field of enquiry for those labelled with labels of cognitive impairment, the means of exploring the body (inclusive of its mind) as lived.

I have briefly outlined the history (or lack thereof) of learning disability in mainstream disability studies, with particular attention to the dominant force in the UK, the social model. It has sketched out some of the epistemic issues that the theorising of learning disabled people’s experience has faced, under the guise of their experience of disability being somehow removed by those with physical or sensory impairments. A subtle, yet pervasive undertone of Cartesianism haunts the individualising of this group of people’s experience as somehow beyond the realm of social; the mind as the final frontier of the natural.

So where does autism come into this? Learning disability or difficulty, depending on one’s preference and epistemic position, is most commonly associated with impaired intelligence (Valuing People, 2001; WHO ICD-10). This does not equate to autism, which does not, by diagnostic standards, include reference to a person’s intelligence (APA, 2013), though it is considered the most common ‘comorbid condition’ with estimates of between 40-67% of children and 20-30% of adults with autism diagnoses also being categorised as having a learning disability (Emerson & Baines, 2010).

However, if we have learnt anything so far through our travels, it is that narrowly defined, biopolitically-shaped categories are neither natural nor neutral. Instead, I have used literature around learning disabilities to broaden our understandings of the context of Disability Studies, which, in turn, I consider to be a fundamental orientating landmark to this project. It is not enough to delineate tight boundaries between and around either autism or learning disability, as some advocates would. As I will reiterate time and again through this project, the social, political and cultural understandings of children living in labelled spaces speaks to something broader than a contribution to knowledge about any single impairment category. If disability is socially conceived, as is learning difficulty, then autism too comes into this fold. From this socio-political standing, children labelled with autism *are* learning disabled by the current social, educational, and cultural practices that recognise their ability, inability, or difference to learn in normative ways as disordered. The Cartesian spectre present in research, writing, and socio-cultural thinking about learning disability is all too apparent in our development of understanding autism; psychologisation and pathologisation of a disembodied disordered mind dominates the research agenda. I ask that the privileging of impairment categories, in which hierarchies of desirability create grounds for further exclusion and oppression, be set aside for the remainder of this thesis.

## 3.3 Disability and The Human

To consider disability a stable, static subject outside of the political, social and cultural is dangerous. As Leaman (1981) said of the danger of de-politicising the issue, disability is not something individuals possess, but something society possesses. To be societal is to be political and here lies the socio-political requirement of disability; to explore why the disabled ‘other’ and ‘otherness’ is situated firmly in the western historical conscience.

Humanist logic reifies the need for the ‘other’ through the fundamental assertion that prerequisites of what it is to be ‘human’ lie in traits of rationality, competency and autonomy (Erevelles, 2002). The body houses such traits as its able, controlled self (Thomson, 1997). The *dis*abled body, therefore, is viewed as the ‘unruly body’ (Erevelles, 2002), disrupting humanist rationale. From this, neoliberal individualism can be seen to draw on notions of the disabled, ‘defective’ body to reify humanist rationality, autonomy and competence (Silvers, 1997). Modern western liberalism *needs* the ‘other’ as justification for the very foundations of society; full participation therein requiring the demonstration of humanist hegemony. The rational body is a being which produces the maximum benefit to society and is of minimum cost; a linchpin of capitalism, the ideology of the ‘free individual’ merged with the ‘free market’ (Soldatic & Meekosha, 2012, p.197). To situate the rational body within socio-political framing is to prioritise the abled body and objectify the ‘other’ through a gaze of humanist normalisation (Young, 1990). This, Campbell (2009) tells us, is ableism. To have a body incapable of being fully socially and economically productive is to disrupt ideas of capitalist cost-benefit. Thus, the disabled body becomes positioned as ‘other’ by default and disablism is born.

Traditional materialist disability studies, such as the British social model as has been shown, failed to give the body, and its agency, just attention and understandably so. Disability studies, in its social model form, needed to get out of the body in order to re-train the gaze towards social oppression rather than individual impairments. The risk here, as it has unravelled, is that it left the notion of impairment open to reification as biological and universal. Without a critique of the very conceptualisations of impairment being invoked in disability, the body and the experience of it, embodiment, is left out in the cold. Where the body has been brought in, it has been ‘without much sense of bodiliness as if the body were little more than flesh and bones’ (Paterson & Hughes, 1999, p.600). Within the emergent field of Critical Disability Studies (McRuer, 2003; Davis, 2006b) (herein CDS), which has drawn on critical race studies, feminist studies and queer studies, rather than incorporating ideas of the body by explicitly ignoring it, the Cartesian body/mind dualism is disrupted. A CDS position signifies new terms of engagement in disability, ‘...the struggle for social justice and diversity continues but on another plane of development — one that is not simply social, economic and political, but also psychological, cultural, discursive and carnal (Meekosha & Shuttleworth, 2009, p.50).

The compulsory ableism (McRuer, 2006) of rational humanist discourse needs to ignore the body due to its unruly nature. Ableism is far removed from an empirical, lived body, instead circulating as a normative discourse of an ideal, sanitised, invulnerable, aspirational body (Kumari-Campbell, 2012). ‘It is what we are supposed to aspire to, to learn to be but can never become...It is a body aghast at the messiness of existence’ (Hughes, 2012, p.22). It ‘...provides just the right amount of temperature and nutrients for disablism to grow’ (Goodley, 2014, x). In response, CDS incorporates the body as a site not to be feared, but as the site in which discourse and the social are in need of discussion and consideration. It invites an analytical interrogation of ableism, indeed, what does it mean to be able (ibid)? When the limitations of Cartesian ideas are interrogated and the myth of the natural body uncovered (Butler, 1993), it becomes equally feasible to ‘denaturalise impairment’ (Donaldson, 2002, p.112). This re-thinking of bodies allows us to re-think how we talk about bodies in all their un/natural forms.

## 3.4 Towards Dis/ability Studies

Taking CDS forward, Goodley (2014) adopts the term dis/ability, deliberately split and slashed to explore how disablism and ableism always exist simultaneously, always play off one another, relying on one another for existence (xiii). This offers a critical turn to ‘...the meaning making of either side of the disability-ability binary and the messy stuff in the middle. Dis/ability is also a moment of contemplation: to think again what it means to be dis/abled and what it means to be human.’ (ibid, x).

I return here to Rose (1999) to consider how the marrying of Goodley’s dis/abilty studies and Rose’s unpacking of familial self-governance provides one of many starting points for families living with autism. Rose reminds us how families are called and cast-out simultaneously by the need to regulate and strive for normality within their parenting practices and their children’s development. The elusive statistically normally developing child remains just that, ever-elusive and is a moment at the ‘slash’ of dis/ability. This tightrope walk that parents negotiate between interventions for their children, underpinned by normative developmental demands, is lived in everyday, mundane ways. McLaughlin and Goodley (2008) honed in on those everyday moments with families of disabled children and theorised how families lived in a balance (often equally unweighted) between rejecting and accepting certainty in theirs and their children's lives; at once desiring and clinging to notions of normality whilst simultaneously rejecting its usefulness in their lives. The everyday complexities of dis/ability are the site of this project; the sophistication by which families and children live this complexity, embodying its tension, contradiction and disruption, are its very foundations.

## 3.5 A turn to the dis/human

Perhaps then, a turn to the dis/human is necessary to flesh out those foundations. Dis/humanism, first discussed by Goodley and Runswick-Cole (2014) as somewhat of a heuristic of dis/ability, invites complexity, invites relationships and invites humanity, to a commitment of dis/ability politics. Dis/humanist studies is '...ambivalent about the human because too often it represents only a minority and bypasses the empirical human world' (ibid, p.10). Instead of, as Titchkosky suggests is the case, 'detaching disability from what it means to be human, dis/ability and the dis/human, allows us a way in to renegotiate humanism to consider ...how we value the human and what kinds of society are worth fighting for' (Goodley & Runswick-Cole, p.4). It allows for the moment of reflection on the human and disability, at once desiring of the norm and at the same disrupting its narrow boundaries. ‘Disability is...ambiguity incarnate, a rupture in the clarity and unquestioned flow of daily life, and thus almost a “natural” starting place for thinking about the workings of culture’ (Titchkosky & Michalko, 2012, p.141).

There is time now to pause on the most significant critique offered to critical disability studies by Vehmas and Watson (2013). In ever ‘stalking ableism’ (Kumari-Campbell, 2012) as oppressive, what (or who) is being denied? They question the validity of ableist ideals being invariably oppressive and call for a hiatus in the pursuit of ableism’s demise. Is a desire for normality in one's life, one's health, one's relationship and employment status always a failing of resistance to ableism? Or is there, as Boxall (2013, n.p.) said, ‘a lot to be said for wanting to feel normal’.

Again, I return to thinking about parents and families; to considering the lived mundanity of that dis/ability complex. It is easy for me to sit at my desk (childless) and profess the call of dis/ability studies and resistance to ableism. But equally, I sit here with an imagined future of parenting a child bearing all the hallmarks of ableism’s ghostly spectre. I guiltily bask in ableist, normative desires. So I hear Vehmas and Watson’s call loud and clear but I am also wary of it. I do not think it helpful to set up camp in opposition to one dichotomy by replacing it with another. That is not to dismiss the cosy, seductive appeal of some of ableisms more stealthy desires, but to wobble along the ‘slash’ of dis/ability in constant dialogue; why is it that in our stalking of ableism we are still continually drawn to it, what of its power and how do we get in between it? This wobbling that Vehmas and Watson (2013) fear is missing need not be; here is an inroad in this project, to consider how children and families speak of and live between these spaces. I ask, ‘1. How is autism spoken about and how else might we talk of autism?’ and 3. What does autism make im/possible for a child to be and become?’.

So then, the *dis* of dis/ability studies and dis/human comes to the fore of this project’s concern. ‘The prefix *dis* indicates negation, lack or deprivation: to deprive something of its power’ (Goodley & Runswick-Cole, 2014, p.5); it is to *trouble* (ibid). To sit with dis/*ability* is to desire the normative aspirations of ability, whilst to *dis/*ability is to negate it and trouble its power (ibid). I take forward one of the author’s troubled/troubling binaries as the particular theoretical fuel of choice for this part of our travels; the dis/child. The dis/child asks us what of contemporary childhood do we wish to discard? And what do we claim? It troubles the normalising hold of particular forms of governance in childhood; schooling, developmentalism, pathologisation, whilst recognising much of their desirable allure; ability, achievement, normality. In problematising the how, and why, of children and childhood’s particular ways of being known in the world, it asks that we tread the slash of the dis/child to explore the messiness of the everyday politics in between disability and childhood. So I ask,

*‘1. How is autism spoken about and how else might we talk of autism?’*

*‘2. How might we consider autism as part of being a child?’*

*‘3. What does autism make im/possible for a child to be and become?’*

*‘4. What does autism do to/for/in education?’*

## 3.6 A Story to Introduce the Dis/child

I take forward the first story from my fieldwork to exemplify the challenging complex of the dis/child. This is not to suggest that the dis/child is an empirical child but that the dis/child politic lives in classrooms and homes across the land. It is a moment that had somewhat plagued me at the time. Why, I asked myself, was I continually drawn back to narrow, ableist desires? Why did I find myself back on route A-to-B before I even recognised it? It felt at the time like a failing of disability politics on my part, a continuation of the oppressive fallacy of normalcy and ableism that I so desired to challenge. I recognise it now as a moment of the dis/child complex and an opportunity to problematise the stealthy desires of ableism, to de-centre its power and to consider what visions of, and for, childhood, are worth clinging onto.

*It’s the end of the morning at the inclusive nursery. The ‘community’ children are all collected by parents and the remaining children, those with identified Special Educational Needs, are gathered in a small room at the side of the nursery for an extra half an hour. All the staff are part of this session, far outnumbering the four children. Samuel entertains himself with a toy that was intended for another child. He lies across the floor sprawled out, concentrating on a car he wheels back and forth. ‘Sit up then’, a staff member encourages. He doesn’t. A photo of him is now thrust in front of his face, his attention seemingly elsewhere. ‘What’s that?’ he says to a straw now in his hand. ‘Bye straw’, he says as he’s asked to return it to a box. He’s speaking! These are the first words I’ve heard him say despite it not being the first time I’ve met him. I find myself smiling and excited. He takes his photo out of the box in front of him and looks at it intently. ‘My name is Samuel Connor’, he announces clearly and loudly to the photograph. Joy fills the room as the staff praise his ‘good talking’. It’s the first time that there’s a sense of anything other than going-through-the-motions from the staff and I find myself joining in with their sharing of delight and congratulations. It’s the first time anyone has really noticed Samuel; he appears too placid and easy going to really warrant much attention. I can’t help being happy but what or who am I happy for? I’m thrilled that he’s achieved a target yet cynical about the targets ableist intent. I grin at the thought of hearing him speak again, to marvel at his progress. I’ve absolutely bought into the joy of his rote repetition whilst damning its tyrannical normalcy. I’m disappointed at my lack of conviction. Simultaneously, I beam a wide smile straight at Samuel, I’m overjoyed.*

What then, in hearing the story of Samuel, can we learn about, and from, the dis/child in everyday life? *What then, does autism make im/possible for a child to be and become? What does autism do to/for/in education? How can those of us engaging in autism research broaden its understanding of its everyday?* The complexity of these dis/child, dis/human tensions, will be returned to through the analysis chapters of the thesis.

I now take these questions forward in contextualising the theoretical attitudes helpful in designing a dis/human approach to research in the next chapter, Chapter 4: ‘Theorising Orientation, Dis/orientating Theory’.

## 3.7 An Aside

First, an aside. The thesis so far, though perhaps not written in the most conventional form, has done quite conventional things; outlining and positioning key literature, contextualising the academic terrains to develop research questions. It has, hopefully, begun to carve the niche of the project’s research space and hinted towards the contribution it will make to this field in its broadest sense. What it hasn’t done perhaps, aside from the *Preface,* is offer the social and political carving of a niche in everyday life; why such a project needs to exist. So before I move onto the next academic turn, the introduction and development of theoretical orientations, I take the thesis outside of the sphere of a piece of academic writing and into its lived version; Mum’s on July 3rd.

## Mum’s on July 3rd

*I write this on July 3rd 2014, which we now know to be the eve of the anniversary of the death a young man, loved by his family, who happened to have a label of, amongst other things, autism. His family have, through their grief, spent the last year (and arguably, long before), fighting for justice for their son, known online by his mother as Laughing Boy. LB spent the last 107 days of his life in an Assessment and Treatment Unit where, having been left unsupervised, he died as a result of drowning in the bath.*

*It seems fitting then, to spend some time thinking about families, parents, and more specifically mothers on this day. I want to write in praise of mothers that I’ve met in my time working with disabled children, as I am continually (as not-a-mother) in awe of their grit, determination, and love, and saddened by the necessity of grit and determination to fight for other people to respect their child’s childhood and personhood. To consider the motherhoods that are all too readily deemed different (that tragic difference, the one none of us really wants) by virtue of the experience of raising a disabled child, that assumes that bad difference comes from the child’s impairments rather than the people, places, and systems that they are continually forced to occupy, resist and demand. I use the language of protest here quite deliberately. Because out there, out there in the stories the mums in my project tell, out there on the internet are sites of resistance, physical, virtual and metaphorical. I was at a conference recently and was very much looking forward to a paper about the stories of mothers with disabled children. The paper was being given by a researcher at a similar stage in her work to me. We’ll have so much to talk about! Or so I thought. However, the paper that followed was not the paper I had envisaged from its title. It was a paper that positioned the disabled child as a burden, a problem, and an inherently negative drain on the mothers’ lives. In fact, the children themselves were ghosts to the paper - they didn’t exist, they weren’t part of the project. The literature base was of similar reference - stress, depression, exhaustion, breakdowns rang through. Each word chosen was steeped in the inherent doom that mother’s inevitably experienced as a result of raising a child with impairments. This was an individual problem, or rather, two individuals problems; the child and the mum’s and a harrowing fate. Everyone else, and everything else, didn’t exist. Rarely at the end of conference papers do I have something to say, more often than not, I’m impressed and too busy thinking about the application to my own work.... But this was different. I asked, tentatively, nervously, and cautiously, if the researcher was worried that she was perpetuating a discourse in which a disabled child is inherently burdensome, and why the ‘different experiences’ parents had with a disabled child could be uncritically assumed as negative. The researcher glazed over and responded coldly with the answer - ‘but that’s what the literature says’.*

*There were others in the room who chimed in about Critical Disability Studies, about Sara Ryan’s writing, about different experiences that weren’t negative, or at the very least weren’t the child’s fault. As I left the talk, I was surprised how surprised I was - I, clearly completely naively, had assumed that this type of research was becoming more and more a dim and distant past. That is perhaps why I’m not always that convinced that I’ve got all that much new to say. But if this research is still being done, being funded, being disseminated and presented as an unproblematic truth and reality for the mothers of disabled children, then perhaps there is still a lot to be said. And perhaps the language of protest, resistance and change is still needed.*

*Nowhere in this do I want to unproblematise the problem, to get out the chocolate box house and the picket fence. My case as I see it, is to carve away at that niche in which we, as-the-privileged-researcher, don’t stomp all over valuable lives and relationships with our uncritical assumptions that a child’s difference has to be something all families would sooner live without. Where disabled children are not unproblematically positioned as an emotional and psychological drain on their parents. So I write back to that researcher, to that literature and to that dangerous discourse that undervalues and damages a disabled child’s life, their relationship with their mum and positions them as less-than-human. I do so with stories from the parents in my project, mostly with mothers about their messy, complicated relationship with both autism and their children.*

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# Section 2

# Researching Childhood, Researching Disability

# Chapter 4: Orientating Theory, Theorising Dis/orientation

What does it mean to be orientated? To be orientated is...to be turned towards certain objects, those that help us find our way. These are the objects we recognize, so that when we face them we know which way we are facing. They might be landmarks or other familiar signs that give us our anchoring points. They gather on the ground, and they create a ground upon which we can gather. And yet, objects gather quite differently, creating different grounds. What difference does it make “what” way we are orientated? (Ahmed, 2006, p.1)

## 4.1 Introducing Theoretical Attitudes to Research

I move now to discuss how the theoretical orientations touched upon in ‘Chapter 1: Contextualising the Terrains’ have guided and informed my turn to the project’s design; from research questions to methodology to analytical framing. What would the theoretical underbelly of a project that embraced the terrains that I have mapped, in their junctures and divergence, look like? We’ve already heard how a politics of wonder allows us to wander the literature of autism, dis/ability and childhood and how deploying a Foucauldian travel guide is useful in doing so. This chapter then, adds meat to those theoretical bones by building on a dis/humanist approach, which begins with dis/ability studies, CDS and introduces a coupling of queer theory.

It explores how responses to the research questions I ask require a queer(y)ing of research design, methodology and ultimately direction. To queer is to trouble and disrupt the norm, in methodological and theoretical terms; to act as scavenger to bring those marginalised to the front and centre (Halberstam, 1998). Gibson-Graham (1999) sees queer(y)ing in research as an act to seek out change and new possibilities.

I take such queer(y)ing to phenomenology to ask, how can dis/ability dis/orientate our gaze on childhood, autism and dis/ability? To orientate is to turn towards, and in turning one way, to turn away from another. It invokes a body, movement and change. ‘What difference’, Ahmed asks us, ‘does it make “what” way we are orientated?’ (2006, p.1). A queer orientation may be the means by which thedis/orientation of attention, afforded to the lives of children labelled autistic, becomes possible; away from the gaze of developmentalism, medicalisation, pathologisation, and normalisation that stalked our first route A-to-B and was exposed by the scenic route. This dis/orientation has already begun with our turn to dis/ability and, further, to dis/humanism. Such a dis/orientation offers new landmarks, new anchoring points and new grounds on which to gather our gaze on autism, childhood and dis/ability. In recognising how the disabled child queers the neoliberal vision of the human, we need to consider the theoretical work in and around such a queer(y)ing orientation. Such is a dis/humanism ambivalence to the straight and narrow discourses at work in and around disabled children’s everyday lives. Turning to the theoretical offering of dis/humanism can queer(y) our starting points and,

...allow us to claim normativity in childhood (play, development, family, relationships) while simultaneously drawing on disability to trouble, re-shape and re-fashion narrow, neoliberal models of childhood as time of preparing citizens of the future ready to contribute to the global markets. (Goodley et al, 2015, p.7)

## 4.2 Transdisciplinarity in CDS Theory → Dis/humanism ↔ Queer →

An underpinning of Critical Disability Studies, the lifeblood of a dis/humanist ethic, is its embrace of transdisciplinarity in its theoretical orientations; its welcoming of plunderous theoretical engagement (Hughes et al., 2012). It has evolved out of engagement with a broad range of theoretical resources, which have been woven with disability politics; gender, sexuality, race and their offspring, queer theories, critical race theories and feminist theories (Goodley, 2011). Within each of these rich and varied disciplines, theoretical engagement has been a call to problematise a host of political, social and cultural sites that marginalise and oppress. In disrupting the naturalised realms of public/private, social/biological, identity politics, difference and deviance, queer theory, in particular, shares much of the epistemological underpinnings as politicised spheres of disability studies (Sherry, 2004). In bringing together queer theory and disability studies, it is important to emphasise that the call is not to an identity politics of queer disabled people, but to *queer* understandings of disability; a transgressive, resistant space that speaks back to social, political and cultural marginalisation. Queer, as Sherry (2004, p.771) reminds us, is not simply an identity, but more a *signifier* of a critical relationship to heteronormativity. By extension, CDS can be seen as not merely identity politics of disability but as a critical relationship to ableist normalcy. As Davis (1995) said of the purpose of disability studies, it is a means by which ‘to help “normal” people to see the quotation marks around their assumed state’ (xii). McRuer (2006) brings together the queerness and queering of disability in crip theory; a challenge to compulsory ableism.

What follows is not an attempt to over-theorise for theory’s sake but an attempt to respond to lived experience of disabled children through a turn to the theoretical (Goodley et al., 2015). It is an adoption of theory with a postmodern (or perhaps more aptly, post*human*) sentiment, recognising that its deployment and understanding will always be made, remade and undone by its user. It is informed within and around a number of approaches favoured by dis/humanism; Deleuze (1976; 1980), queer phenomenology (Ahmed, 2006), and as we’ve heard, an underpinning of Foucault (1979; 1980). Dis/humanist approaches borrow from phenomenological and poststructuralist theories amongst others to ‘dispute the ‘given-ness’ or ‘already there’ of any body’ (Goodley & Runswick-Cole, 2012, p.5). Each of these theoretical resources are used as just that, resources rather than scripture, as Hughes et al. (2012, p.316) profess, as a plunder of theory or ‘plunder as method’. In plundering a range of theory, I rest with Hughes et al. that ‘any intellectual system or social theory is fair game when it comes to building a case for emancipation or for sharpening the tools that are of value in opposing discrimination, exclusion and oppression’ (pp.315-316).

Where theoretical friction might arise, for example the call to both discourse *and* the lived body, I suggest there is an opportunity for creativity in theory (or as Deleuze would have us believe, joy!); to bring together seemingly divergent logic, which recognises the theoretical complexity of the material world in people’s mundane realities. I am reassured by Ahmed’s recognition of the validity and celebration of ‘non-proper’ theoretical engagement; ‘Such an approach is informed by my engagement with phenomenology, though it is not ‘properly’ phenomenological; and indeed, I suspect that a queer phenomenology might rather enjoy this failure to be proper’ (2006, p.2). Indeed, in my failure to mobilise theory ‘properly’, I further pedal this thesis’ causes; to disrupt dominant ways of orientating and gazing on the lives of children labelled with autism and to imagine dis/orientations to our understandings of these lives. To queer normative notions of childhood and autism by bringing attention to what dis/ability, in its dis/humanist form, can offer. The project of CDS is to embrace this potentially queer, non-proper theorisation,

Speaking of disability in theoretical terms, then, must both respond to, and critique, the power and simplicity of binary thinking...the question of difference that entails a radical shift from the modernist privileging of an autonomous and stable self to the postmodernist contention that the self is always embodied, dependent on its others, unsettled, and always in process. To mobilize such a critique signifies not the search for some successor theory, but a way of holding open theoretical conjunctions that are potentially contradictory in meaning and original intentions. (Shildrick, 2012, p.33 & p.37)

It is with this in mind that I ask, *‘5. How can autism research broaden its understanding of the everyday?’*

I begin here with a dis/orientation, which takes forward some of the work carried out in The Scenic Route; considering how denaturalising the disordered body/mind of a child labelled with autism can shift our gaze.

## 4.3 Talking of bodies

We began our first of many theoretical dis/orientations when we introduced our Foucauldian travel guide. Such theoretical adoption asks that we interrogate the dominant discursive gaze upon childhood and autism (of Route A-to-B) to attend to the power that is being produced and reproduced within and around such a gaze (The Scenic Route). This is the opportunity to explore *‘1. How is autism spoken and how else might we talk of autism?’* and, to an extent, *‘3.What does autism make im/possible for a child to be and become?’,* both of which will be addressed in Chapter 7 ‘Talking’ through a discursive framing. Discursive attention is useful and vital in denaturalising childhood and autism and recognising the work done on and around children’s bodies; an attention to biopolitics. The body here is read as a ‘problematic text, that is as a fleshy discourse within which the power relations in society can be both interpreted and sustained’ (Turner, 1996, p.27). Such a poststructuralist gaze on the body, constructed as both child and autistic, can be thought of through Butler’s (1993) notion of performativity in which the subject is formed by the continued performative constitution as a subject. The work of the social can be read through its performance of the subject. As Youdell reminds us that the practices of performative politics and the discursive agents within them ‘...amount to a politics that insists nobody is necessarily anything’, and by my extension, ‘what it means to be’ an autistic child, ‘...might be opened up to radical rethinking’ (Youdell, 2006, p.519). This is our biopolitical reminder that even the most subjectivated bodies are also sites of resistance. This gaze focuses on what is *done to* the body, potentially at the expense of a consideration of what is *done by* the body (Turner, 1996, p.33). So this is where our turn to phenomenology begins.

## 4.4 Being with/in bodies

What discursive practice alone cannot offer is an attention to the body in its lived form, as experienced and experiencing; as embodied. Much like the social model of disability, the body in its lived form is problematic and therefore much ignored. In isolation, discursive practice becomes somewhat of an obsession with language, which in turn leads to a new kind of essentialism. ‘...the body and the sensate – in effect – disappear into language discourse, and lose their organic constitution in the pervasive sovereignty of the symbol’ (Hughes & Paterson, 1997, p.334). An attention to embodiment ‘...more adequately captures the notions of making and doing the work of bodies - of becoming a body in social space’ (Turner, 1996, p.xiii). Hickey Moody argues ‘....for an understanding of corporeality that medical and sociological discourses of intellectual disability are not able to realise’ (2006, p.xviii). ‘Bodies with intellectual disability need to be known in terms of what they produce, rather than by reference to what they are not’ (ibid., p.2). The biopolitical narrative of children labelled with autism is one in which they are recognised and known as inherently lacking, which in turns feeds a discursive focus on the ever-elusive ‘normal’ child. This is fed by modernist narratives of Cartesianism, which leaves the mind marked as lacking and, as such, a discourse of those labelled with intellectual disability as somehow lacking the characteristics of what it means to be human. Disrupting the Cartesian dualism of mind/body is to get in-between discourses that trap intellectually disabled lives in a cycle of the disordered, disembodied mind. It is an opportunity to dis/orientate our gaze away from ‘what they are not’ towards recognising ‘what they produce’ (ibid). As Youdell (2015) reminds us, there is a tendency within traditional tropes of research about children, and more so, disabled children to leave the body notably absent. Studies of development, neuroscience, health and education centre around particular conceptualisations of the human child with little or no reference to their bodies as lived; as embodied. So in an effort to dis/orientate our discursive gaze, it is helpful to bring in the body as lived, as its very presence queers research in and around autism, dis/ability and childhood. In bringing in the body I address, *‘5. How can autism research broaden its understanding of the everyday?’* and *‘2. How might we consider autism as part of being a child?’* This gaze is attended to within Chapter 8 ‘Being’, to address those questions with a framing of embodiment.

In a dis/orientating turn, in which multiple resources can be usefully brought together, phenomenology speaks of the capacity of the body itself to be a 'source of self and society' (Goodley, 2011, p.56). By moving away from the Cartesian dualism in modernism in which the body is a passive, pre- cultural object, phenomenology allows us to talk about 'being and becoming'; the 'experienced and experiencing body' of lived experience (Paterson & Hughes, 1999, p.600). It offers the opportunity to ‘graft on qualities of sentience and sensibility to notions of oppression and exclusion’ (p.598) and allows a move beyond the potential disembodiment of poststructuralism or material disability studies.

Unlike the English language, German has more than one word for the body; the 'leib' describes a body of feeling, sensing and bodily experience (Crossley, 1995), and ‘korper’ the exterior, objective body (Bendelow & Williams, 1995). When the body is constituted as the ‘leib’ as oppose to the dominantly storied ‘korper’, it becomes possible to think about bodies that are lived in both childhood and autism as sites of embodiment, which if considered as a body 'worth living in', can give us the opportunity to revise how bodies *can* be lived in. The experience of being in one’s body is ‘always a mediated “it”’, Titchkosky (2012, n.p.), suggests; 'people are never alone in their bodies'. A turn to embodiment allows for a turn to exploring sites not of individual bodies, but to mediated sites of the social, of discourse and of shared lived experience. Rejecting accounts of the body as deficit allows for the reframing of the body as a site of becoming, reflection and production (Overboe, 2007).

Bringing together phenomenological attention to embodiment with dis/ability brings those that are othered by humanist accounts of the body into the fold. No longer is the body a house of biological impairment, the mind a disembodied entity dictating bodily action. Neither is it solely a site of governance and subjectivation; of inscription of biopolitics. In a phenomenological consideration of embodiment, the ‘other’ body is a worthy site of knowledge because it speaks of lived experience, which in phenomenological premise, *is* knowledge (Schutz, 1972).

For post-structuralists, the body is 'the body', an abstract, singular, intrinsically self-existing and socially unconnected individual; the social behaviour, personal identity and cultural meaning of this entity are passively determined by (disembodied) authoritative discourses of power. For the new political movements of personal-social, cultural-environment resistance, by contrast, 'the body' consists essentially in processes of self-productive activity, at once subjective and objective, meaningful and material, personal and social, an agent that produces discourses as well as receiving them. (Turner, 1994, p.46)

Bringing in the bodies of children labelled autistic as the phenomenological body, the embodied, living, corporeal body, is a site to queer the space between personal-social, cultural-environmental, the individual autonomous human. It is an opportunity to dis/orientate our gaze on the lives of those living in spaces of childhood and autism (and their families) and ask what such a dis/orientation can offer. ‘*3. What’*, I ask by turning to embodiment, ‘*does autism make im/possible for a child to be and become?’*

## 4.5 Dis/orientating Phenomenology

So what does the bringing together of dis/ability and phenomenology do in its queerness and queer(y)ing? It is its very call to the experience of dis/orientation; dis/ability’s disruption of what it means to be a modernist, neoliberal human, as first outlined at the start of the thesis. A queer phenomenology explores what is queer of phenomenology and uses that queerness to make rather different points (Ahmed, 2006, p.4). Taking a phenomenological perspective on disability, Titchkosky and Michalko (2012) ruminate on, and around, the framing of disability as ‘always-already a problem’ (p.133). In making disability identical, difference is absorbed into the social whole just *like* everyone else but not *as*; to be disabled is just one of our many taken-for-granted always-already a problem phenomena, but always one of the least desirable kind (ibid, p.134). The phenomenon of ‘problems’ is subtle yet pervasive in the lives of disabled children; when disability is always-already a problem, within the inevitability that all people have problems, not everyone *is* a problem (ibid). Titchkosky and Michalko engage W. E. B. DuBois’ (1903) ‘double consciousness’ to exemplify an phenomenological understanding of such an experience,

Within the contemporary biomedical ideological paradigm, disabled people do experience their disabilities as a problem, as the body, mind, senses or emotions gone wrong. This is one way and, a dominant one at that, for us (disabled people) to experience our disabilities. Then, there is another way; disabled people experience the ways non-disabled others experience us. We experience their experience, or better, we experience ourselves through their experience of us. Through the contemporary frame of disability-as-problem, we experience ourselves as having a problem and we also have the ‘strange experience’ of being a problem to and for others. (p.135)

The dis/orientating effects of dis/ability are touched upon by Michalko (2010) who suggests in relation to blindness, that it is through encountering blindness that sight sees itself. Blindness therefore, and dis/ability, can be understood in an experience of dis/orientation. Sight is orientating, it is disorientated by blindness; the encounter is a moment of dis/orientation. In its reflection, ability comes to know itself. In the experience of dis/orientation, the desire to orientate oneself pulls hard, to return to the familiar, to seek order in dis/order (McGuire, 2010). We have a desire to resolve and reorientate at the earliest moment, to make the queerness of disorientation and its nausea dissipate. ‘But if we stay with such moments then we might achieve a different orientation toward them; such moments may be the source of vitality as well as giddiness. We might even find joy and excitement in the horror’ (Ahmed, 2006, p.4). Perhaps then, I suggest, to be dis/orientated is to tread and work the slash of dis/ability. To trouble the push and pull of humanist desires for the neoliberal, able, productive human (Goodley, 2014); to desire and push back at both normativity and difference in autism and childhood. In turning to dis/ability we are confronted with dis/orientation and come to colliding crossroads in which we decide how to proceed. My suggestion is that the turn to embrace the vitality and giddiness of encountering lives lived as both autistic and child might contain potential to dis/orientate our gaze on both childhood and autism in more productive and less reductive ways.

## 4.6 Becoming between bodies

Ahmed gestures towards Althusser’s ‘turn’ suggesting, ‘Depending on which way one turns, different worlds might even come into view. If such turns are repeated over time, then bodies acquire the very shape of such direction’ (Ahmed, 2006, p.15). Here is the coming together, the *becoming,* of attention to both what is done *to* bodies and what is done *by* bodies (chapter 9: Becoming). Here is our ‘autistic child’ that is known and knowable by virtue of discourses of both autism and childhood. It is the repeated turns, in their particular hailings of ideology (Althusser, 1970 cited in Ahmed, 2006) that bring the autistic child into being in the familiar ways of our original *Route A-to-B*. These well worn turns, that traverse over well-worn lines, constrain what is possible to know, and what is possible to be and become in life labelled child and autistic.

Lines are both created by being followed and are followed by being created. The lines that direct us, as lines of thought as well as lines of motion, are in this way performative: they depend on the repetition of norms and conventions, of routes and paths taken, but that are also created as an effect of this repetition. To say that lines are performative is to say that we find our way and we know which direction we face only as an effect of work, which is often hidden from view. So in following the directions, I arrive, as if by magic. (Ahmed, 2006, p.17)

Unpicking and unpacking the magical arrival of how lives come to be known and understood as both child and autistic is a moment of dis/orientation, in which I ask if there are not some less-well worn paths that can be trodden in addressing, *‘1. How do we speak of autism? and how else mightwe talk of autism?’, ‘2. How might we consider autism as part of being a child?’, ‘4. What does autism do in/for/to education?’,* and *‘3. What does autism make im/possible for a child to be and become?’*

## 4.7 Bringing in Deleuze & Guattari: staying with dis/orientation

In all of our turning, gazing, and orientating, becoming dis/orientated and turning again, there comes a desire to stabilise, to sit down, set up shop, find our camp and lay our hat. The giddiness that Ahmed (2006a; 2006b) invites us to embrace is somewhat tiresome, particularly in a thesis that should offer at least some sense of direction and resolution. So I pause here to catch a breath and justify why we should continue with our giddy embrace of continual dis/orientation. Such a dis/orientating sensation keeps us mindful of the need to be ever critical of any resolution or single orientation towards childhood, autism, and dis/ability, any sense of an orientation that is final It keeps us on our toes in complicitly coming to know or understand these phenomena and the experience of them in singular and inevitably reductive ways. A plunder of Deleuzoguattarian logic here offers us the means to bear with the inevitable discomfort that comes with persistent turning and dis/orientating; a turn to ‘becoming’. I take dis/orientation to be an act of becoming. Deleuze and Guattari (1980) ask us to dispel any notion of the singular, complete sovereign self. Children do not ‘become’ adults, and ‘become’ complete, they are ever-becoming, ever-fluid, ever-on the move. Bodies do not ‘become’ autistic and knowable as autistic. Becoming does not end, it is without final orientation, final resting point. It is a helpful sensation for us to keep with us then in dis/orientation; in this embrace of turning and gazing in new ways. It offers us the means to remain optimistic that we’re on the right track; a track that is multiple and always, always more; an assemblage. It recognises that any orientation we might draw towards is only ever temporary and will always be unmade as it continues its becoming; we must continue to dis/orientate.

In thinking through research questions, design, and methodology, is a recognition that much of our ways of ‘knowing’ or ‘understanding’ childhood, autism, and dis/ability is about what is *impossible*. There are assemblages in the stories we hear of disabled children’s lives that are blocked, lines in assemblages that run deep and are stuck in striation (Youdell & Armstrong, 2011). Lines that never quite seem to converge. Many of the ways of coming to know and understand here are about the ‘really deep lines’ (Youdell, 2015) and what they make possible and impossible for a child’s being and becoming. To profess such temporal and incomplete understanding is not to suggest that the assemblage or the becoming within, without or between, assemblages are unrestrained or anarchistic.

Deleuze and Guattari’s (1987) thinking on smooth and striated spaces can be helpful to move this argument forward, as can Butler’s (2004) writing on subjectivation. Butler suggests that, in order for the subject to be performatively formed (in this case, the ‘autistic child’), discourses need to be produced in recognisable ways (2004, p.5); the knowable autistic child who *appears* as both autistic and child. This is the child who demonstrates, through their behaviour, the discursive hallmarks of autism, those perhaps most readily recognisable through the DSM5 (APA, 2013), a difficulty in social communication, for example. Deleuzoguattarian smooth and striated spaces, however, take this subject beyond the individual and a singular space and into an assemblage (Deleuze and Guattari, 1987). The striated spaces space here are the processes of diagnosis that quantify and qualify certain ways of being in the world as classifiable, knowable as ‘autistic’; the visible reading of social communication difficulties in a child’s behaviour. If striated spaces are the disciplined spaces of hierarchy, binaries and normative meanings (Youdell & Armstrong, 2011), in which a body can be known and subjectivated as both child and autistic, smooth spaces, then, are the spaces in between such biopolitical governance. Lines of flight are the means by which these striations are disrupted, they ‘...allow us to trip out of the striations in which we are caught and skate on the smooth plateaus between, even if in doing so we slip into or begin to grind out yet another striation’ (ibid, p.145). The line of flight is the moment of unknowing, or becoming unknowable, in which the striated, diagnostic certainties of knowable autism are disrupted. These moments, taking us towards smooth spaces, move beyond the child that is knowable as autistic, through their behaviour that tells us so, and instead produce a smooth space of becoming. Becoming, in this case and in is this project, is taken to be an ever-moving, always productive space of potential. Becoming in smooth spaces rejects the reference points of striation, the diagnostic understandings of the knowable subject, either ‘autistic’, ‘child’ or ‘autistic child’. These smooth spaces are spaces of becoming because they go beyond the knowable and appearing subjectivated autistic child and into spaces of exploring the potential of what a body can do (Deleuze & Guattari, 1987). This style of logic allows the body to be invoked in smooth and striated spaces, offering the potential to explore what the body *can* do in such spaces beyond the governed, performatively formed subject (that which is *done to* bodies.) In following the lines of flight we can consider what they make both impossible and possible. It allows us to recognise the ways in which children use their bodies to subvert despite the limits of the biopolitical descriptions of their everyday lives; how they speak back to what is done to their bodies, with their bodies. I ask Deleuze and Guattari with their smooth and striated spaces to help me relate to the question, 3. *What does autism make im/possible for a child to be and become?*

## 4.8 Dis/orientation still to come

From methodology to analysis, each chapter that follows asks for a different orientation and continual dis/orientation towards childhood, dis/ability and autism. Each, in turning and gazing in different ways allows for different versions of the world to come into being. The plunderous approach to theoretical engagement adopted throughout the thesis calls for differing theoretical fuel for different analytic purposes. This means that the particular theoretical orientations of each methodological and analytic chapter are necessarily contained within that chapter, that is, they are privileged and shelved as needed. *Chapter 5 and 6* turn to research methodology and ethics. Turning away from take dis/orientation to a queer(y)ing orientation to research methodology and ethics. By dis/orientating the dominant methods of autism research in its disembodied, positivist form, I ask that we orientate to dis/human methods of researching children labelled autistic’s everyday lives asking,

*1. How is autism spoken about and how else might we talk of autism?*

*2. How might we consider being autistic as part of being a child?*

*3. What does autism make im/possible for a child to be and become?*

*4. What does autism do to/for/in education?*

*5. How can autism research broaden its understanding of the everyday?*

*Chapter 7* ‘Talking’ dis/orientates our gaze on the dominant talk of autism and considers the rhizomes that come to be through the discourses of parents and professionals speaking of lives labelled both child and autistic. It draws in the dis/orientating experience of the rhizome and the im/possible ‘beings and becomings’ of autism that reside when particular ways of knowing and coming to know autism and childhood are mobilised. It responds to the question,

*‘1. How is autism spoken about and how else might we talk of autism?’*

*Chapter 8* ‘Being’ dis/orientates our gaze towards the body and its queerness in research around autism. It considers the well-worn lines of particularly dominant orientations towards autism and childhood and asks what happens when we wander away from those lines and begin to dis/orientate. It is framed by embodiment and valuing embodied ways of knowing and being known. It navigates the questions,

*‘2. How might we consider being autistic as part of being a child?’*

*‘3. What does autism make im/possible for a child to be and become?’*

*‘4. What does autism do to/for/in education?’*

*Chapter 9* ‘Becoming’ carves out our reimagined, and dis/orientated gaze on childhood, dis/ability and autism; bringing together the becoming of what is done *to* childhood’s labelled autistic and what is done *by* children labelled with autism. It asks that we adopt further theoretical fuel to our dis/orientations, a turn to the becoming of emotions. I use a turn to emotions, suggesting that some dis/orientations offer the means to navigate new becomings for our relation to autism, childhood and dis/ability. This is by no means a resolved orientation, an end point, but the final line of flight for this thesis. It is the smooth space of becoming that I wish to leave our thinking and relating to autism, childhood and dis/ability open to a dis/orientation that continues way beyond the pages of the thesis or the bounds of this project.

I briefly introduce the turn to emotions brought in the final chapter, 9 ‘Becoming’, as a taster of our final resting place; the terrain of Neitherherenorthere. ‘Emotions’ here are not an individualised, internal psychology but understood through a socio-spatial lens to attend to the palpable affect that becomes between bodies when considering the everyday lives of children labelled autistic. They are understood as a ‘...socio-spatial mediation and articulation rather than as an entirely interiorised subjective mental state’ (Bondi et al., 2005, p.3) which are located in bodies and places and relationally between them. Discourses embedded within childhood and disability exert power over possible becomings that make some possible and others impossible. In attending to how emotions work to make this power productive, I explore what or who it is possible for children labelled autistic to be and become. It allows for an analysis, which considers the dynamic between emotion and power and the influences of the structures of institutions, such as family, schooling and state (Procter, 2013, p.497) and, as such, the questions, *‘4. What does autism do to/for/in education?’* and *‘3. What does autism make im/possible for a child to be and become?’*. Such a turn to emotion explores the affective economies at work; how emotional capital is afforded to some and denied for others (Ahmed, 2004). That is not to say that the deployment of emotional capital results in fixed subjects, rather that it makes some becomings more possible than others. As Roche (1999) reminds us, ‘children have to make their own space in spaces not of their making’. We look here to what is becoming between bodies; both what is done by bodies and what is done to them.

As Ahmed (2004) sees it, Marx’s model of capital can be applied to the accumulation of emotional capital, as an affective economy. This is a recognition not of emotions’ residence in the individual’s interior but of the becoming of emotions through bodies, boundaries and surfaces. ‘Affect does not reside in object or sign, but as an effect of circulation between objects and signs (= accumulation of affect over time)’ (p.121). Certain signs accumulate more and more affect as they circulate, to the point that they become recognised as ‘containing’ affect. Taking this further in relating ‘feelings’ to Marx’s ‘commodity fetish’, Ahmed explains how feelings become to *look* like objects, or have residence *in* objects only through the concealment of their social, historical exchange and accumulation. This allows for certain feelings, or emotions, to gather more weight than others and seemingly look like objects; to become sticky. What then, are the particularly ‘sticky’ economies of affect that are at work above and around childhoods labelled autistic and how do they become stuck to certain bodies? This is part of the labour of orientations; how the well-worn lines seem to appear as if by magic, concealing their affective economies. As we have learnt, orientations, however well-worn, do have the potential for change; they are temporary and open to dis/orientation. In such an analysis, we are given the means to read and relate to the everyday lives of these children through a lens of becoming, as always on the move and always in re-production; we can begin to imagine otherwise for the becoming of autism, childhood and dis/ability.

## 4.9 Concluding, moving forward

I have used the chapters ‘Contextualising the Terrains’ and ‘Orientating Theory, Theorising Dis/orientation’ to reflect on the multiple terrains at work on, in, and around the lives of children labelled autistic and their families. I have used this discussion to formulate a series of research questions, which encompass the aims of my work and give focus to the project. I now move on to methodological considerations of these questions and the methods of my project aimed at addressing them.

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# Chapter 5

# An auto/ethnographic story of working through method/ology

Knowing does not come from standing at a distance and representing but rather from a direct material engagement with the world. (Barad, 2007, p.49)

As Mauthner and Doucet (2003) remind us, all methodologies have philosophical roots, as Kohli writes, ‘One’s ‘location’ is not unrelated to one’s political and philosophical positions’ (1998, p.512). With this in mind, I draw forward the theoretical orientations of the previous chapter. Silverman (2000), writing about research strategy, suggests that 'methods are techniques which take on a specific meaning according to the specific methodology in which they are used' and are 'not neutral and depend upon an implied model of how social reality works' (pp.110 & 112). It is therefore important for me to unpick the epistemological underpinnings of my theories and the implications they have on my methodological approach and methods employed. We spent time in the previous chapter experiencing the dis/orientating turn to autism, childhood and dis/ability in its queer(y)ing of the neoliberal child. I take forward such a sensation now with the methodology and tools of this project as the particular terrain.

Reviewing methodological literature of research around autism makes the dominant stories of autism as medicalised, pathologised and psychologised all the more apparent. Prevalence of positivist methods of measurement, identification and labelling, becomes impossible to ignore. This is where my methodological considerations began. This chapter addresses the methodological research question I ask, *‘5. How can autism research broaden its understanding of the everyday?’*

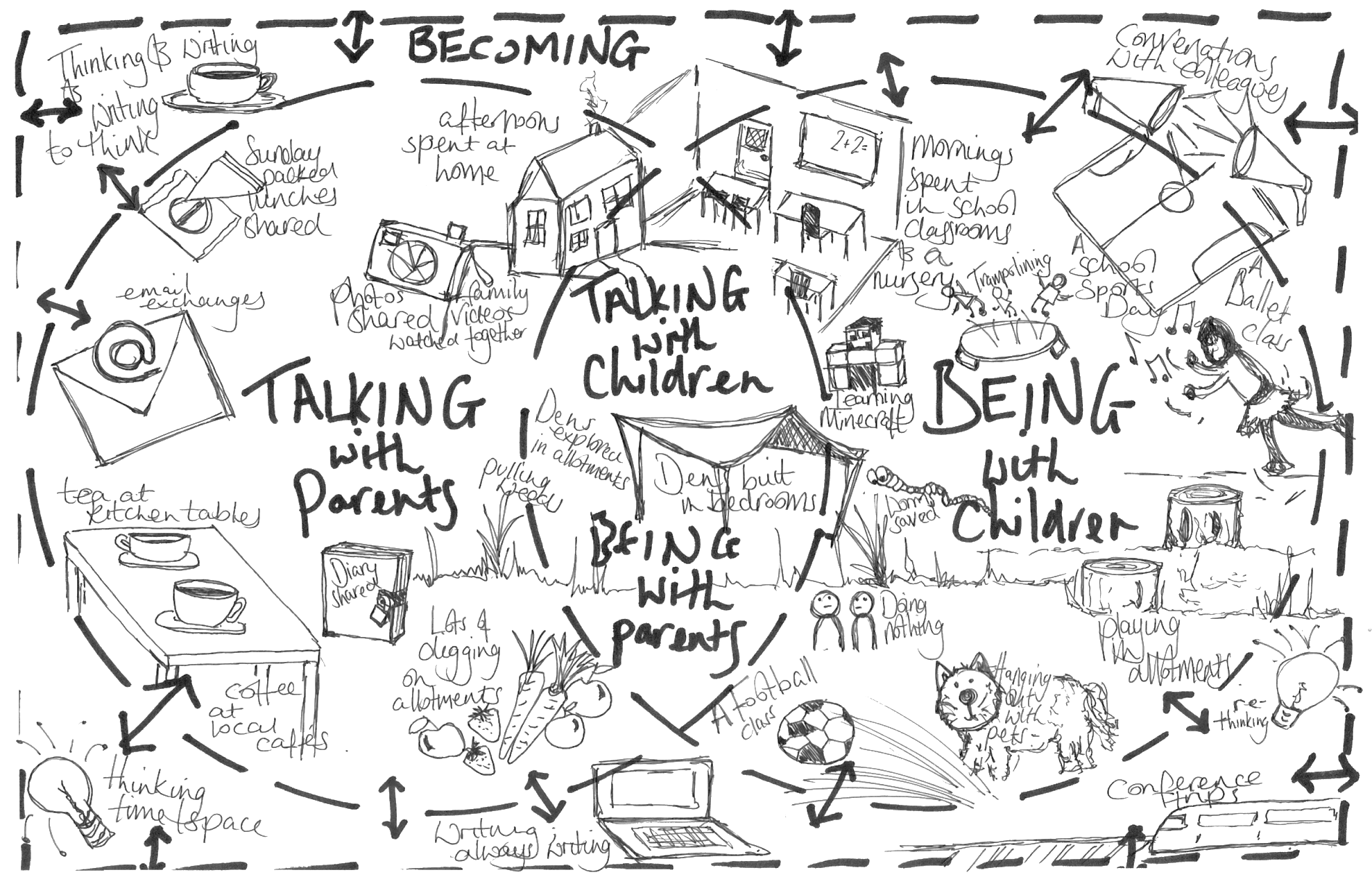
In keeping with the epistemological motivations of the project, of experience, of stories, I considered methodologies and practices that would speak to such an ethic and invoke narratives. In problematising the disembodied dominance of disabled children’s research, in which attention is far more readily afforded to that which is impossible rather than possible (Youdell, 2015), a familiar orientation of lack or deficit, I also came to question if my project should have a single impairment (autism) focus. In a similar vein to my hesitations around the neurodiversity movement’s risky alignment with pseudo-medicalised language, there is methodological tension for me in setting up a project around a single impairment category, ‘autism’. Priestley, in an agenda checking and setting papers for disabled children’s research, once again cautioned about the friction accidental or otherwise, of falling foul of biomedical agendas that ‘divide and rule our understanding of disabled children’s social lives’ (Priestley, 1998, p.209). ‘Suffice to say’, Priestley warns, ‘that it has become common practice in social research with disabled children to pick your impairment first and ask questions later’. It is this call that brings me back to a dis/human theorising of the potential of a project such as this, to ask, ‘*2. How might we consider being autistic as part of being a child?’.* The desire here isn’t to know autism, know childhoods in, or for, empirical terms. A dis/humanist framing asks again what a troubling of the current orientations towards autism and childhood can ask of our current orientations towards the neoliberal human, and child (Goodley & Runswick-Cole, 2015). So, though this project sits ‘within’ autism, and the children and families in the project live ‘with’ autism, I also ask that we heed a broader call to what the problematisation of such positions, labels, and beings can offer to our understandings of childhood, being with/in bodies and becoming as humans. Beginning with this dis/orientation of autism, I introduce the methodological design of the project with that in mind.

I decided on an ethnographic process in three phases that would allow me to explore, reflect and craft the project with the children and their families. In order to give a sense of specificity and structure to the phases, I labelled them; ‘Talking’, ‘Being’ and ‘Becoming’, which themselves draw on the theoretical framings of the previous chapter: ‘Talking of bodies’, ‘Being with/in bodies’, ‘Becoming between bodies’, the explanations for which will now be discussed. Figure 2 provides an overview of the project methods of ‘Talking’, ‘Being’ and ‘Becoming’, in which the priorities were talking with parents and being with children, though notably, as can be seen, neither happened in isolation. The diagram in Figure 2 maps the data collection sites to give a sense of where and how fieldwork took place. ‘Talking’ included data, that is, stories written after the very first meetings with parents, so fieldwork is considered to have taken place from July 2013 and periodically with children and families through to February 2015. This was not a continuous period of fieldwork and the timelines and number of occasions we met varied from one family to the next, an issue addressed as I introduce the families later in this chapter.

Figure 1 maps the recruitment process and the access to participants chronologically and gives a sense of when different points in the project took place. Together they provide a visual overview to contextualise how, where, and when the project took form.

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Figure 1: recruitment process and meeting families

Figure 2: Fieldwork sites

5.2 Methodology and methods of ‘talking’

This phase of the project was designed to respond to the research questions, *‘1 How is autism spoken about and how else might we talk of autism*?’

Storying the everyday lives of children and families in this project is itself an act of resistance from the prevailing unproblematised medicalised narratives that dominate research around autism and childhood. Framing these experiences within the realm of dis/ability’s ‘disruptive potential’ (Goodley & Runswick-Cole, 2014, p.1), where dis/ability is recognised as a biopolitical category as opposed to a biological given, is to re-orientate our gaze on autism, childhood and dis/ability as sites of sociological and cultural critique (Runswick-Cole & Goodley, 2015, p.2). This alternative starting point for the study of these lives needs to be situated within an alternative body of literature; the socio-cultural analysis of dis/ability, or perhaps more pertinently, autism.

I begin with Mallett and Runswick-Cole’s (2012) socio-cultural critique of the commodification and festishation of autism. There is a warning within their work of the prevalence of the single impairment category ‘autism’ gaining a disproportionate amount of attention in public, and more notably, academic arenas. Mallet and Runswick-Cole (2012) explore how autism has come to ‘be’ a ‘thing’ through a process of abstraction. Through the abstraction of experience through diagnostic criteria, individuals’ heterogeneous lives become clumped into a homogenous object of autism (albeit masked in heterogeneity through the language of ‘spectrum’). This is biopower in action. In the marketised neo-liberal west, the ‘thing’ of autism becomes commodified as a set of experiences that it becomes possible to ‘know’ (and label) in a person and through further abstraction and commodification, possible to research, amongst other things. This is a very particular narrative centring around a casting of a very particular impairment category, autism, which is so unique that it warrants bracketing off from wider disability studies to become a field of study in its own right. So unique is the autism narrative, that it warrants a commodity fetish in which its consumers long for more knowledge, more consumption, more autism. McGuire and Michalko (2011) highlight the socio-cultural framing of autism as the ultimate puzzle in need of a solution of western contemporary times. When framed as a puzzle, it becomes possible to festishise, and marketise, a solution; education, intervention, a knowing of autistic subjectivity. Runswick-Cole elsewhere suggests, when considered within the market system, ‘autism itself is, then, perhaps the quintessential neoliberal subject’ (2014, p.1126).

If a socio-cultural narrative of autism is one of production and consumption, of solving a mysterious puzzle, what is the material of such commodification? And what of its effects? Debate within the medical humanities exists around the ever-evolving concept, and material, of ‘autistic narrative’ and the part that this plays in shaping and transforming what it means to speak of autism and to live as autistic. The work of Ian Hacking around the ‘making up of autism’ (2013; 2009) invites us to reflect on the very foundations of what it means to *be*autistic and what part the material narratives surrounding autism play in such being. As Hacking (2009) sees it, with the naming of autism came the means of a new way of grouping people as a new form of ‘human kinds’ that in turn generates knowledge about what it means to be one of those human kinds. His use of ‘human kinds’, a phrase ‘(so) ugly….no one else would ever want to use it’ (p.351) is deliberate in its ring of the inhumane, focusing on the idea of ‘kinds’ as a system of classification rather than speaking of people. He uses this expression to conjure categories of people who can be known, about whom we can create such systematic and accurate knowledge that we can formulate generalisable truths; ‘ generalisations sufficiently strong that they seem like laws about people, their actions and their sentiments’ (p.252). This evolves into a ‘looping effect’, in which norms become established that produce and reproduce what it means to be, for example, autistic. Hacking sees the narrativisation of the subjective experience of autism (through auto-biography, works of fiction, the arts etc.) as contributing to the shaping of autism, which he considers to be ‘in flux’ and which has not yet ‘settled down’ (2013, n.p.). Take, he suggests for example, the many and varied directions autism is taking; from neurodiversity movements, to the celebration of artistic achievement of fictional works around autism (e.g. Mark Haddon’s The Curious Incident of the Dog in the Nighttime), to the genome mapping programs of the genetic industry, to behavioural interventionists. There are many and varied ways that are in the evolution and flux of what it means to identify with, live alongside, and narrativise our cultural understandings of autism. ‘Autistic narratives’ are, Hacking (2010, pp.262-263) tells us, ‘....a new language game, one that is being created before our eyes and ears. This speech is, in turn, creating or extending a way for very unusual people - namely, autistic ones - to be, to exist, to live’. Traditional cognitive theorists would contest the credibility of such effects (particularly in relation to self-reports and autobiographies) primarily on the basis of cognitive understandings of the central deficits of autism; to write about one’s subjective experience is to reflect on mental phenomenon, a core feature of an autistic individual’s impairment (Frith & Happe, 1999). McGeer (2009) reflects on this tension in relation to Hacking’s writing on the Kohler phenomenon. The Kohler phenomenon, as Hacking (2010) sees it, is the way in which we do not simply *infer* the internal states of others, but that we *see* it through their behaviours. Their expressions, movement, gestures, outwardly express their internal experience; the child who wants to touch a dog, but doesn’t (ibid.). For Hacking, because we do not *see* the internal state of autistic individuals’ minds through our interpretation of their outward behaviour, we naively assume that such subjectivity does not exist; we see a ‘thin’ person. To be seen as a ‘thick’ person, that is to be minded, McGeer (2009) extrapolates, is to be co-minded; to have entered into the shared scaffolding practices with another, which allow us to negotiate complex social interactions automatically and interpret others’ internal states. We learn to behave in recognisably social ways and herein become seen as ‘thick’ individuals with rich subjective experiences of the world. It is this difference that McGeer sees as being what sets autistic individuals free from the pervasive effects of looping human kinds. She suggests that without the social dimensions of norms and norming (which Hacking suggests are emerging within autistic communities through looping), their influence remains insignificant. Without the desire to grasp and reproduce such norms, they do not take hold, become looped, and form and reform what it means to *be* autistic. Perhaps, she suggests, that precisely because of this seeming disinterest in the Kohler phenomenon in which people become understood and ‘seen’ in the social dimensions of the world, what it means to be autistic will forever remain multiple and idiosyncratic (p.529).

Having explored a master narrative of autism through a sociocultural lens, and the proposed effects of the material narratives of an analysis, I now situate the narratives used in this project. Bamburg (2006) wrote of ‘big stories and little stories’, the little stories being those of the everyday, the small moments that actually serve to speak to bigger stories. It is those small stories of the everyday mundanity of children and families lives that I introduce through this thesis.

Drawing on both Mallet and Runswick-Cole (2012) and Fine et al. (1996), the stories told throughout this thesis are of the everyday and the mundane. In an attempt to follow Mallet and Runswick-Cole’s call to de-festishise public and academic interest in the ‘autistic child’, the stories that I write of my time spent with children and families work to resist conclusive, linear portrayals of life as either ‘disordered’ or in some way ‘unique’, i.e. beyond the ordinary and into the realm of extra-ordinary. It is from these two disparate positions that the majority of stories in the public domain present autism and indeed dis/ability in general. Young (1995, p.59) talks of the ‘consumption of diversity’ as a current cultural fascination. Society, Rogers (2011, p.992) tells us, no longer ‘...recoil(s) at difference, they recast it as commodity’. In order for alife to be worthy of attention, there is a need to demonstrate abilities above and beyond that of other children, non-labelled children, to be extraordinary; to fit the ‘celebrated diverse’ (Rogers, 2011, p.993), to embody the ‘supercrip’ (Barnes, 1992). This mythical, magical depiction of autism (and the autistic individual) can be seen through dominant cultural narratives spanning the last three decades and beyond (Waltz, 2013; 2012).

I would suggest that stories of the extra-ordinary autistic child are no more productive than those of the disordered child. Both genres encourage the reduction of experience into knowable literary (and medical) discourses. Both hone in on the individual as central, which serves to disguise the structures within children’s lives being lived. To be extra-ordinary is preferable to being disordered it seems. But such stories leave the everyday lives of everyday children with autism labels wanting. They leave parents, families, practitioners and academics wanting. They hide behind a guise of compulsory ableism (McRuer, 2006) that deem a disabled life to only become worthy once dis/ability is overcome by the individual striving to normalise their being (Liddiard, 2014). They mask the oppressive tactics of normalcy’s elusive ghost within the realm of Berlant’s (2011) ‘cruel optimism’. The spectre of cruel optimism is the kin of the ghost of normalcy. It is the promise that is so near, yet so far. The allure of cruel optimism is the ‘autistic child’ who may have some hidden special ability, who might be able to ‘show their full potential’, given the means. These means are an individual's, or a family's self-determination, as we see in the headline stories of the ‘extra-ordinary’ child achieving in spite of autism; ‘Determined Beauty Queen doesn’t let autism get in her way’ (ABC News, 2013), ‘Non-verbal autistic child finds his voice through Disney songs’ (Autism Speaks, 2014), ‘The amazing painting talent of autistic Iris, aged 3’ (Huffington Post, 2014).

So it is in an attempt to de-festishise the dominant stories of childhoods marked by autism in both the academy and wider public discourse (Runswick-Cole & Mallett, 2012) that I situate the stories I tell with the families in this project. Having introduced the context, the methodological justification for the use of stories will now be discussed; I begin with the resonant words of Thomas King, ‘The truth about stories is that that is all we are’ (2003, p.2).

## 5.3 Narratives & stories

A broad-sweeping criticism of using narrative inquiry in research is the vagueness of its origins, intentions and practices. Here, therefore, I attempt to outline an argument for my use of stories to work with children and families in my project. ‘Stories are a model of narrative coherence - but the genre is not socially or politically neutral – it’s a way of prioritising, privileging and silencing’ (Goodson, 1995, p.90). Goodson’s quote could be used to argue the case both ways for my use of stories and narratives. On the one hand, the one that I feel justifies their use, I seek to use stories to counter those that are predominantly told of autism and children’s lives; the biopolitical tale of pathologised disorder. I aim to redress the silence and privileging, by providing space for alternative stories of these lives to be told by those living them. On the other hand, it could be argued that, without caution, I will have inevitably prioritised certain stories over others, those that best support my research intent. Troyna (1994) speaks of the relative danger of research with emancipatory aims; a mis-handled narrative can further silence the marginalised when a reader doesn’t identify with the story being told. I take up this issue during the ‘Talking’ chapter, where I story a number of disparate experiences of parenting. Were I to present any of those stories as representative of parents’ talk of autism, it would serve only to marginalise and disable children and families further.

Cary (1999) talks of her experience of narrative research in which the personal motivations of the participants was such that it ended up jeopardising the project aims. This is an inherent danger in research aiming to give ‘voice’; how to balance, prioritise, manage and present these voices. The issue of ‘voice’ within disability studies research is hugely contentious, not least due to the ableist trap of ‘voice’ itself. As has been highlighted already, there has been a paradigm shift in childhood studies, in which the child became agentive as a social actor contributing to reach in an active voice (Christensen, 2003; Prout, 2000; James, 1997). Such a shift does not seem to have extended to children that do not, or cannot, participate in normative ways (Runswick-Cole & Curran, 2014; Watson, 2012; Davis et al., 2003). Disabled children within research are still commonly ignored, marginalised or ‘spoken’ for. These issues will be returned to again in the ‘Ethics’ chapter, in relation to consent and advocacy. They will also be drawn into the methodological discussion of ‘Being’ as a means of exploring children’s lived experience that doesn’t rely on normative conceptualisations of ‘voice’ or participation.

In resolving, or at least making peace with the fine line of negotiating whose ‘voice’ is heard in research, Elbaz-Luwisch (2010) argues the case that I found most productive to my cause; the need to not become risk-averse at the expense of the opportunity to build a collaborative research relationship with those we work with. As will be seen in my discussion of recruitment and meeting parents, the establishing and maintaining of research relationships has been a difficult and negotiated practice. Returning to Elbaz-Luwich’s call, I always aimed to air on the side of building collaborative relationships with the parents and children in whatever form that may have evolved. Cortazzi (1993) sees these relationships as being the key premise to the success of research working with narratives and stories. I feel this to be a central drive to my work, as the result of my experience in my MA[[1]](#footnote-2); the relationships of mutual trust and collaboration are the cornerstone for meaningful stories to be told (Smith, 2011). We are reminded by Sikes (2004) that individuals taking part in projects have to see, and feel, that they are gaining something (tangible or not) from their participation. I hope that in building collaborative relationships with the families, they felt that their interests were being served by the project and that the work is beneficial, in a wider sense, to their experience of their lives with autism.

We often find it easier to identify with the personal rather than the general (Clandinin & Connelly, 2000) and storytelling offers this means. Connelly and Clandinin (1990) suggested that it is important to consider a narrative as a whole not just the telling of a story; the relationship, process, analysis and retelling need to be understood, considered and reflected on to avoid simply telling the ‘neatest’ story (Goodson & Sikes, 2001). As will be seen, the recruitment, meeting, maintaining and re-negotiating of the relationships with the people in my research has been problematised to reflect the ever-changing and fluid nature of the process of hearing, crafting and re-presenting families’ stories.

Sikes (2004) regards the listening, recording and analysing of stories to be inherently a shared and collaborative experience. Schwandt (2004) considers this to be the ‘taking ourselves along’ (p.36) in an effort to make sense of and understand the stories we are being told. Farrant (2014) takes the criticism of research ‘contamination’ (the inclusion of the researcher as influential in the research process) as, if inverted, a positive opportunity to engage more fully with those we are researching with. This is far removed from a dis-interested positivist methodological application but something that Walker (2001) feels should be celebrated by storytelling approaches; subjectivity and experience are recognised here as powerful and compelling. After all, Barad (2007) reminds us, ‘knowing does not come from standing at a distance and representing but rather from a direct material engagement with the world’ (p.49).

I also aimed not to use or develop narratives that simply offer clean demonstration of my position (Cary, 1999). It is not enough for me to claim to want to listen or capture stories (Sikes, 2004) but to accept that everyday lives and their stories are ‘never finished products. They are constantly “in the making” and, therefore, incomplete and incompletable’ (Craig, 2009, p.112). If my research data (the stories) had resulted in some clean and definitive narrative of ‘the autistic childhood’, I would not only have somehow been unfaithful to the method of narratives, I would have betrayed the heart of my project; to offer space for the talk of autism to be troubled and the messiness of lives to be allowed into this talk. I therefore took the advice of Goodson and Sikes (2001) not to overextend the span of the stories I re-tell, and to be explicit about my reflection on these in relation to my project and personal position. The stories, in some senses, are written in collaboration with the families, they would never have been written without them. In a practical sense, they were written by me. It was my fingers that tapped at the keyboard and re-told, re-cast and re-presented whatever it was that we happened to do together that day. I did not tell stories in the ‘voices’ of children or their families because I did not intend to disguise my hand. I did not wish to feign such a voice, I narrate collective stories of my ethnographic work; what Roets and Goedgeluck (2007) define as ‘tagging along with each other’ (p.85). Connelly and Clandinin’s (1990) notion of the ‘Hollywood narrative’ has been a pertinent cautionary tale throughout this project; avoiding the temptation to tell a counter-narrative with undertones of something extraordinary, a blockbuster so to speak. This is precisely what I hoped to avoid and presents the dichotomy I hope to unpick. I wanted to use the strength of storying approaches to acknowledge the complex, fragmented nature of life and the stories we tell of it, whilst recognising the social, cultural, political, personal and interpersonal nature of it (Walker, 2001; Clough, 2002; Goodson, 1992; Connelly & Clandinin, 1990), which is often neglected from the stories told about and around autism and childhood. As Clough (2002, p.83) said of the experiential power of stories, ‘perhaps “messiness” will one day become a “respectable” form of understanding’.

## 5.4 Methods of Recruitment and Access to Participants

Figure 2 provides a visual timeline of the recruitment process and access to children and families. As can be seen, the formal recruitment process began in June 2013, with the first parents being met in July 2013 and the first children in October 2013, with the final fieldwork visit taking place in February 2015.

Recruitment was a challenging process for a number of reasons. The time of reflection that endured throughout - from frustration, to panic, to confusion and despair - was, I feel, a reflection of some of the complex facets at work in and around arenas such as autism and childhood. I share here some of the material, logistical and philosophical quandaries that this phase highlighted. I do not consider these stories to be simple issues of sampling but fundamental issues of ethics in research. The application of arbitrary bounding around participant requirements felt uneasy to me but, as may be seen in the following section, could perhaps be argued to have been necessary. I am pleased that I avoided the temptation to tidy up my sample with requirements of age or diagnosis for the most part, but yet I somehow justified those boundaries in other ways. Why did I make those boundaries and, ultimately, were they mine to draw? Was I guilty of the cautionary tale of Troyna (1994) in claiming emancipatory research that simply served to further exclude the excluded? I hope not but neither can I claim with certainty that I was not.

My initial recruitment was a blog post that had an audience of those interested in autism in its broadest sense; academics, students, parents, individuals who identified with autism, interested professionals, to name a few. The post was an informal introduction to my project intentions with some brief contact details (see appendix 1) It was an invitation for parents of children with an autism label to contact me if they were interested in taking part in a research project about their children’s everyday lives. I wasn’t overrun with responses. It became apparent that despite my deliberate lack of boundaries (age restrictions being the one at the forefront of my thinking), I had also accidently lacked some more pragmatic boundaries. I received emails from a parent in Canada and other people interested in India and Zimbabwe but little in the way of responses from closer to home. Acknowledging the need to include perhaps slightly more in the way of participant requirements, I re-drafted the project advert for a more local (or at the very least, within-travelling-distance) audience.

I still felt that I didn’t have ‘enough’ participants, although I wasn’t entirely sure when ‘enough would be enough’ in this case. What limits was I going to set for the number of children and families in my project? Could I afford to start turning families down and what would be my justification for doing so? In an effort to satisfy this still yet unknown quantity of participants I sent a cross-university email with some brief information about my project and my contact details (see appendix 2). Within the first morning I had had nineteen emails from a huge range of people. Once again, my deliberate and accidental boundary settings were brought to bear. I had made quite a deliberate lack of age restrictions, choosing simply (or so I wrongly thought) terms like ‘parent/carer’ and ‘child’. More than one email was from a parent who had a child with a label of autism who was in their 20s or 30s. I had naively forgotten that parents have children beyond the arbitrary age of 18, and that despite through an external, societal view, that ‘child’ becoming known as an ‘adult’, they forever remain the child of their parents.

This was a point of return to the concepts under investigation within my project. I was in fact exploring the conceptualisation of ‘childhood’ rather than ‘children’ and this served as my justification as to the age boundaries of the people in my project. Indeed, perhaps the arbitrary age of 18 was not the right one, as ‘childhood’ being predetermined by such a legalistic bound is contestable but it felt like the only means at that time of justifying having any such age restriction at all. Having neglected to set up such boundaries in the recruitment advert, I had these conversations with parents via email. Parents with adult-children and those who contacted me from geographical locations considered too far (by myself and them) for regular travel was excluded from the project. This amounted to five different interested parents. I discussed this via email with each of these parents, thanking them for their interest.

I had more than one email from people telling me that they had a child with a label of autism and they were too busy to take part in my project. I wondered what motivations they had in contacting me in the first place? It seemed as if there was a desire to be known (or else why send the email?) but also a desire to be distanced (by being too busy to take part). I spent a lot of time thinking about the intentions of those few individuals. Since the beginning of my PhD I have had a huge range of responses from people I’ve encountered in my everyday life when they learn what my project is about; ‘autism’. Upon entering into the discussion of ‘what is your PhD about?’ I am far more often than not, bombarded with information about autism; newspaper articles, documentaries watched, theories about its origins and cures, stories about a neighbour’s child or a child in their child's class. The list is endless. The overwhelming theme of these responses seems to be a desire to share knowledge about autism. Having spoken to many other PhD students, I don’t think that this desire is one of polite conversation of being (or pretending to be) interested in your PhD study. It seems to be quite specific to dominant social discourses around autism. This seems to be Mallett and Runswick-Cole’s (2012) autism fetish in action.

5.5 Introducing the families

Here I refer back to Figure 1 and begin to introduce the main families involved in my project. Important to mention though, is that these were not the only families to have been part of the project at some point, in some capacity. There were parents (three mums) who I met and discussed the project with, then consented for them and their children to be part of the project but I never saw them again. There are those relationships that progressed a little further to meeting the child, Gabriella, but then their involvement also ceased. This, as I understand from what I have been told, or have learnt, was not in any of the cases an active ‘withdrawal’ in terms of the traditional research ethics procedural consent, i.e. them deciding that they didn’t want to be involved in the project for any reason directly related to the project (its ethics, commitment and so on and so forth). In all cases it was far more complex and lived for the individuals involved. In one case there was a family breakdown, in another a difficult and complicated deterioration in the child’s mental health, and in a third family, after a number of rescheduled meetings, I do not know for sure. At times this has been a moment of Early Career Researcher crisis; my failure to establish and maintain the firm, clear boundaries of the research project, its expectations and commitments, and to see that research relationship through in its entirety. At other times, it has been a moment of the postmodern research project; an acknowledgement that the complexities of people’s everyday lives, compounded by the negotiation of ableist education, health, social (and research) systems, writ large in children’s and families’ lives. I’ve seen the looks of horror and confusion on colleagues’ faces when I told them of the months that would often pass between communication with a family. ‘Are you going to have enough data?!’, their first concern, and ‘Will you finish on time?’ often their second.

What if, though, this failing of fieldwork, this void of data (with some families), was in fact a pertinent *source* of data or a methodological resource? Email exchanges and quick cups of coffee through parents’ exhaustion bore testament to the ‘between-spaces’ that children and families in this project were living in, negotiating, subverting and subsuming to/with. I think here of Farrant’s (2008) writing about those who are present in a piece of research (or writing), through their absence. One of the emails I received in response to my recruitment advert simply read,

‘Dear Jill

I have an autistic child. I’m too busy to take part in your project.’

As a methodological resource, the transient participation of children and parents is a reminder of designing and conducting research with enough flexibility and creativity to recognise, work with and through the demands of busy and complicated family lives. This appears to amount to emotional labour, a theme I explore through the talk of one parent in particular in Chapter 7. Such, I am reminded here, is everyday life as disabled child, parent, family unit.

The Connors

I met Rachel, the mum of The Connors, in September 2013 and first met the children a few weeks later in October. The Connors are a family of four, mum and dad and their two children both of whom have an autism diagnosis. Sophie was 4 when I first met her and Samuel 3. They live in a semi-rural location and the children attend educational placements some distance from their home; Sophie travelling daily to a large special school now having previously attended a more local inclusive nursery, which her brother Samuel now attends. Upon first meeting Rachel she described her children as any parent, with a close and intimate knowing that I always find privileged to be allowed into, as is often the case when doing research with parents about their children. Both of the children, when their involvement in the project began, did not readily use complex language primarily for communication but were verbal in a broader sense. They both use more language now. I was quickly invited to meet the children at their home, crossing paths with their dad on his way out to his weekday work elsewhere in the country. The house smelt of freshly baked muffins, which I, Rachel and Sophie wholeheartedly indulged in. The children played alongside us in the living room, as the adults circulated around autism and schools, and everyday life. I played Twinkle Twinkle on the piano as I left which seemed to put me in good favour with Sophie. Beyond that day, despite our mutual agreement, I didn’t go back to the Connor’s family home. Our paths met more regularly elsewhere in their everyday lives; I visited both children at school/nursery as more than one of the stories in this thesis tells. I met them elsewhere over weekends at a local museum, a dance class, and a football lesson. As we met, Rachel was just about to begin her PhD, which itself began with autism as a central interest. As the project has developed, so too has Rachel’s work, so interspersed throughout have been conversations, musings, reflections and a shared experience (both similar and different) of the PhD experience. The fieldwork with the family came to an end in February 2015 with a visit to Sophie’s school, though I have emailed and seen Rachel intermittently since.

The Goodwins

I met Kate, the mum of the Goodwins, not through the recruitment process but through a chance, work-related network. We had met, had coffee and chatted several times before we discussed the possibility of her and her children being part of the project in February 2014. The Goodwins are a family of 7 (in strictly human terms, though the children add that up to 18 at the last count if all family members are included; cats, dog, and an array of other domestic pets). The mum and dad, Kate and Craig, are parents to five children; Lilac 4, Max 7, Ruby 10, Joe 12 and Amelia 15. Upon first meeting them, all but Lilac had a diagnosis of autism or Asperger's. Recently, Lilac too received a diagnosis and, around a similar time, after a long wait, their dad Craig also received a diagnosis. The children attend a whole host of schools across the area, Ruby being the only one to change schools during the project (transitioning from local mainstream primary to small, local, public secondary). Amelia, the oldest, attends a local secondary, Joe the same public secondary as Ruby (they both receive fees scholarships for high educational achievement) and Max and Lilac the local mainstream primary, in juniors and infants respectively. Education, at this point in its loosest, most encompassing sense, was quite central to my interactions with the Goodwins, play, play and more play coming a close second. Interestingly, unlike other families, all but one occasion of spending time with the children was within the family home. The family professed to spending most of their time at home in a leafy suburb. The children were, I would suggest, both siblings and friends. Health, its presence, absence and precarity was also ever present for this family, more often than not for more than one of its members at a time. As their involvement in the project began, Craig was undergoing surgery and had been not-working for a number of months for various health reasons. Kate was caring for all the family in their various forms full-time, whilst part-time studying for an MA in Autism. Since starting the project, Kate, like Rachel, has also begun a PhD centred around autism. I met with Kate throughout this project period in local cafes and lost many hours over coffee developing shared understandings of hers and her children’s everyday lives.

The Collective

The third family are actually three families but for the purposes of this thesis are discussed as one ‘unit’, I would suggest, a collective. The reason for this is not to deny the three distinct, unique and diverse families themselves but to recognise their productive collective, which I came to know; Producing Autism. Producing Autism is the charity that these families set up on a local community allotment in early 2014 to offer a space for families ‘touched by autism’ (Producing Autism, 2014). A proper introduction to Producing Autism is storied later but, for the sake of family portraits, there are three sets of mums and dads, each with a son of similar age (around 6 when we first met) with an autism diagnosis and a gaggle of other younger siblings from one to five years old. Each family lived and worked across different areas of Sheffield, their children all attending different primary schools. They are mum and dad, Paul and Lisa, their son Fran and his younger siblings David and Jodi. Mum and dad, Helen and Jacob, their son Ben and his younger sister Emma, and mum and dad, Mags and Dan, and their son Tom. Fran and Ben’s families spent the most time on the allotment site, living much closer and having more time available to be there at weekends. Helen and Paul were seemingly the most active of the group, Helen taking on the task of finding money to keep them afloat and Paul leading on a campaign with BBC Radio Sheffield to promote the charity’s development. They committed their free time and energy to the project as and when they could, and, as and when the weather permitted. These families weren’t afraid of hard work, a bit of mud or the prospect of opening the allotments to families of autistic children across the whole city, that was their dream. Paul, in his excitement and enthusiasm, had a master plan of allotments of this kind across the city, providing a network of safe and welcoming places for families like his to spend their free time. I spent time with these families exclusively on their allotment site over a series of weekends and school holidays interspersed over around 18 months. I arrived in their world not long after Producing Autism’s conception, so have been lucky enough to have seen them bloom from overgrown, overwhelming community garden, to shared, productive (and still often, over-grown) family space.

## 5.6 Methods of meeting and talking with parents

I had expressions of interest from academics working within the autism field who also had children with autism labels. What if we didn’t agree? What if I ended up in this really messy place and I was wrong and they were right? I feared Cary’s (1999) experience of a project hijacked by participants’ specific motivations. Instead, I drew on Elbaz-Lusiwch (2010) and I was to embrace this tension and use it as part of my research; to analyse my experience and discuss the discourses being played out in front of me, which I was part of. This can be seen in the excerpt of my writing about meeting academic parents for the first time.

*The pesky internal push and pull:*

*“Ooo this is nice, someone that I can talk to about my research who understands!*

*But wait, they don’t understand at all, what do they think I’m actually doing here?!*

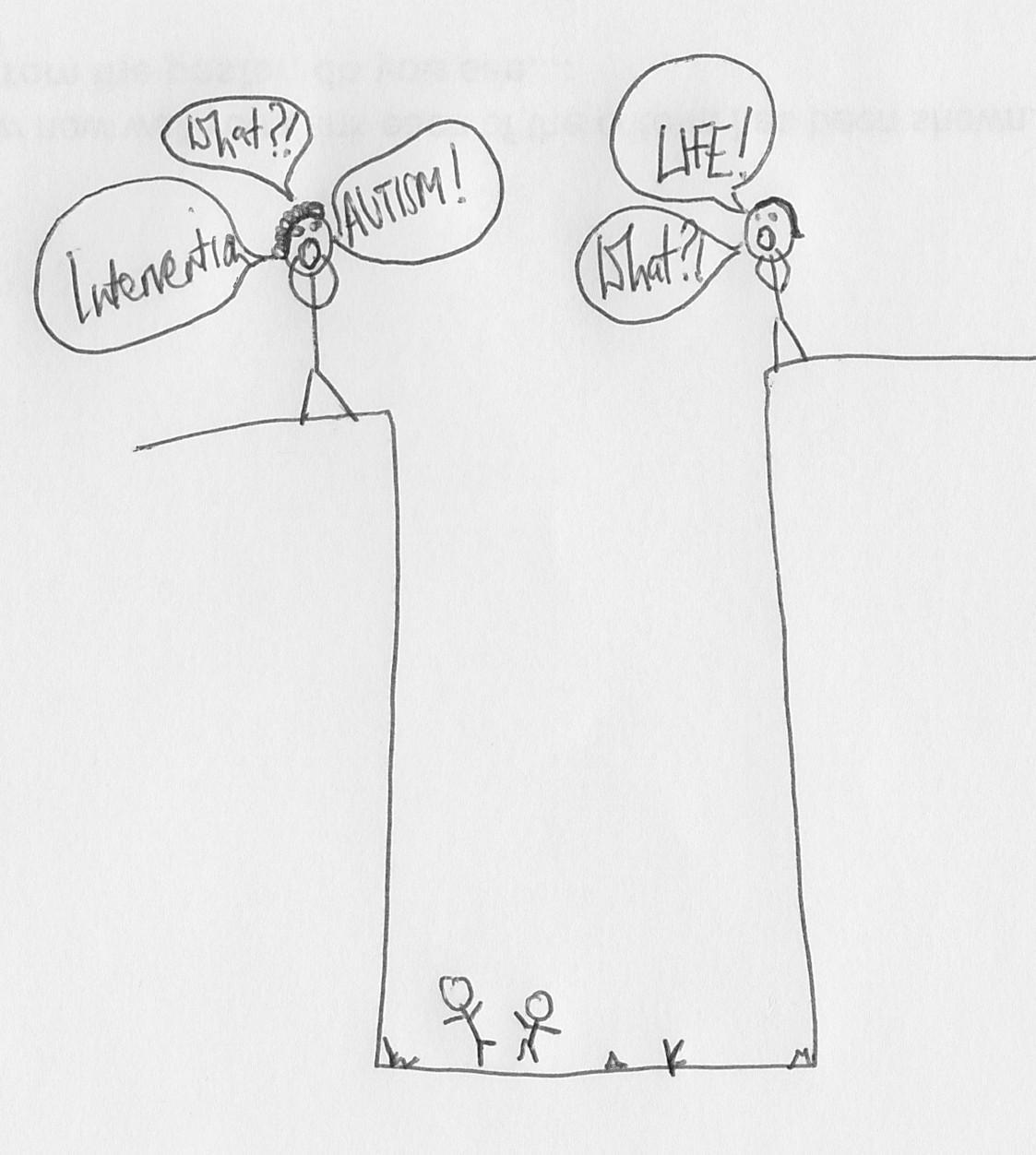
*But you don’t have much choice, who else is going to take part? You should be grateful that anyone is willing to give up their time.*

*Wow, she really sounds sure about this stuff, perhaps I don’t know much about anything at all, after all, she does have an autistic child.*

*Ooo but isn’t this nice.*

*Oh dear. You either don’t understand what I’m doing and haven’t realised that you hate it yet. Or, you’re trying to persuade me to be on your side. Argh.*

*It’ll be great to meet some kids. I’ll breathe easier when I meet the kids. I haven’t been near a child in ages, what am I going to do with them?”* (Taken from my research diary, September 2013).

So I needed to work out what to do about this tension and conflict. I expected and welcomed challenge and change as part of the process but I wasn’t quite sure what to *do* with it. It got me thinking about embodied knowledge and knowledge production between myself and another; the intersubjective nature of that knowledge and how it was being re-produced, re-formed, shot apart. I turned to vanStapele’s (2013) work about narrating ‘self’ and ‘other’. What parts of my knowledge were being watered-down, compromised, devalued in this intersubjective site of production? What kind of knowledge ‘truths’ were being missed in what felt less like a dialogical process and more like a void (see my drawing from my research diary).

I should have had more faith.

Schrivers (1991) talks about the respect and valuing of the other in these dialogical exchanges, in which knowledge is created, formed, unformed; and this is where my faith needed to lie. At the heart of coffees, cakes and awkward moments was a site of productive and exciting tension, but ultimately one of respect, and an opportunity to engage in self-reflexion meaningfully. Standing on the edge of our respective cliffs trying to bridge our knowledge and understanding could be good. This move beyond dichotomous stand-off is in fact, where Prout (2005) would suggest our research with children needs to develop. Working the hyphen (Fine, 1994) of our researcher-researched relationship and considering this to be a positive contribution to the knowledge production within my project encouraged me to loosen my tight grasp. Standing on my cliff-edge, I worked on that discomfort and tension to avoid complacent analysis and to challenge both mine and said-parents way of seeing and way of coming to know.

## 5.7 Trying again: refining the method with a new parent

Here follows a story of meeting another parent for the first time[[2]](#footnote-3). Each interested parent was invited to meet with me to discuss their and their child’s involvement in the project before they made any further commitment. I prepared myself for the cliff-edge moments of bridging and building knowledge with the parent but moved forward with a greater sense that this collaboration was an opportunity in itself.

*It’s a Monday afternoon in a well-known chain of coffee shops and I’ve just met a new parent who is going to take part in my project. I’m feeling pleased with the way that I approached today’s coffee, it felt less bumbling and vague than in the past and I think I’ve found a new way to go about introducing myself and my work; asking first about parents’ expectations and hopes for their involvement. Doing this seemed to instantly set a tone of ownership in a way I had not given credence to in the past. I worried that asking, ‘why are you interested in my work and what do you want from it?’ would sound flaky and awkward, that I should be the one bringing something to the table, metaphorically (and in hot drinks). What I actually found was that it was incredibly helpful in giving me time to sit back and think through what I was and wasn’t able to offer and it was an opportunity for Carole to be clear too.*

*‘I work at the university so I always want to help people out with their studies if possible, and because I have an autistic son, yours is interesting to me.’*

*This bit scared me, perhaps I hadn’t been clear. I always feel like I’m asking parents for a bigger commitment than ‘help’ and panic that I haven’t been clear enough about this.*

*‘And I would like to think that you could help me, you know, with some tips’.*

*This pushes the expertise button that I seem to be backed into a corner of wrestling with time and time again in this project. I can’t and won’t claim any expertise in children’s lives and parents’ lives, I explain.*

*‘Don’t worry, I know there’s no magical solution’, Carole offers reassurance. Equally, I am starting to recognise that people, parents, may inevitably expect a certain ‘expertise’, a particular amount of knowledge - I am after all doing a doctorate about autism. My temptation is always to downplay expertise and some kind of powerful knowledge but I’m beginning to realise and accept that this positioning is a part and parcel default of being a researcher, of doing a doctorate. We talk on this point and offer clarification and reassurances on both sides that we have an understanding of each other’s expectations and how they can be matched on both sides.*

This story has been told to explore how the recruitment process unfolded and evolved from meeting one parent to the next. It showed the complexity of negotiating participation with potential participants as one in which shared understanding needs to be developed *with* participants about what, and how they will participate based on their expectations. Some of this complexity and its unfolding is explored now in the exploration of ‘methodology and methods of ‘Being’ in which I introduce the auto/ethnographic approach of the project and what this meant for how the project was shaped and formed in the social, *with* participants.

## 5.8 Methodology and methods of ‘Being’

## 5.9 The Turn to Auto/ethnography

The storying methodology was originally intended for the ‘Talking’ phase with parents. It was to be a distinct chapter that narrativised the conversations with parents, the reasons for which were justified above. The ethnographic phase, ‘Being’ with children exploring embodiment, space, and everyday life, was not intended to be re-presented through story. However, here was a stumbling block. How *was* this ethnography going to be re-presented? I had mixed expectations and experience of ethnographic writing and feared the traditional anthropological pedestal of ethnographer-in-the-field and how that, in turn, would become writing and analysis.

I found myself reluctant to auto/ethnography. Why? Because in my naive understanding, the explicit prioritising of the self (auto) felt like it would detract from the ethnography of children’s and families’ lives. It felt like this was a methodological privilege and would be the means by which the stories of my ethnographic experience would somehow become more significant than the stories of those in my project. I heard echoes of Lal’s (1996) caution that too much of the researcher’s subjectivity drowns out the participants. This would be, as I saw it, the perpetuation of the silencing of certain voices in the research process and would be counter to the ethos of the project. I feared an uncritical ‘othering’ dominating my writing; this is *my* writing about *your* life. However, the journeying from start to finish of this project, from proposal, to families, to thesis, has taught me otherwise. This project has been inherently auto/ethnographic. ‘The ethnographic life...’ Richardson (2000) tells us, ‘is not separable from the self. Who we are and what we can be - what we can study, how we can write about that which we study - is tied to how a discipline disciplines itself and its members, its methods for claiming authority over both the subject matter and its members’ (p.235).

My original reluctance was, I realise now, one of methodological (and epistemological) naivety. In exploring the tenets of auto/ethnographic philosophies, I came to a critical understanding of it as at once epistemological position, methodological tool and analytic process.

Perhaps….auto/ethnography only signifies a greater tolerance now for the diverse goals of ethnography and a better understanding of the fallibility and indeterminacy of language and concepts. (Ellis & Bochner, 2000, pp.642-743)

Ellis in Ellis and Bochner (2000) pauses on the continuum of auto/ethnographies, in which researchers engage to a greater or lesser extent with the self (auto), culture (ethno) and the research process (graphy). Reflecting on this continuum in itself has been a helpful means of situating my project and its stories methodologically. This has given me the means to position the ‘I’ of my written stories with a greater degree of criticality and sensitivity than I originally thought auto/ethnography afforded. Whilst I choose to write my stories in the first person (me), it is not intended that ‘I’ am the central character of each story. I choose this first-person position in an effort to avoid disguising my hand in the story-telling, rather than privileging my perspective within the story. This is why I choose auto/ethnography as a term over autoethnography. The slash delineates a critical recognition of the entanglement of myself with others in the storying of the ethnographic process rather than a singular ‘my’ story (Ellis, 2007). It has at times felt like a tight-rope walk to negotiate the explicit position of these stories as collective and shared re-tellings and the over-emphasis of my subjectivity that Lal (1996) cautioned against. Who was being ‘othered’ by my stories, who was the ‘us’ and ‘them’ I was inscribing and how could I be mindful of and attentive to this? This teetering work takes place on Fine’s (1994) ‘hyphen’. This hyphen, Fine tells us, is the work between self-other, researcher-researched that serves to,

limit what we feel free to say, expand our minds and constrict our mouths, engage us in intimacy and seduce us in to complicity, make us quick to interpret and hesitant to write. Working the hyphen means creating occasions for research and informants to discuss what is, and what is not, “happening between”, within the negotiated relations of whose story is being told, why, to whom, with what interpretation, and whose story is being shadowed, why, for whom, and with what consequence. (p.72)

I found Fine’s (1994) writing on ‘working the hyphen’ of researcher-researched, to be of great comfort and challenge during this time. Borland (1991) questions if attempting to displace differences (between researcher-researched) can ever go beyond the artificial but Fine and her colleagues (Weis, Wessen & Wong, 2003) suggest there is the means to do this if we move beyond the simplistic temptation of hyphen (researcher-researched). They remind us of the potential risks (as researcher) of walking into a research project with constructions of the ‘other’ (the researched), which serve to do little more than perpetuate damaging and oppressive representations. Compounding such risks is the temptation to seek out the ‘great stories’ (ibid, p.117) of clear and coherent resistance, the ‘alluring fictions’ (Clifford, 1986) that fool us into believing individuals enact linear and cohesive means to resist their oppression; that the researcher is simply there to hear. In negotiating the re-presentation of the stories of those so dominantly silenced in policy and literature (in Fine et al.’s (1994) case, black men and women in New Jersey), Fine et al. suggest that those researching with such populations tread a fine line of responsibility between the falsehoods of ‘great stories’ of resistance and of perpetuating oppressive ‘othering’. They suggest that part of this responsibility of countering such oppression is, in fact, to avoid re-presenting the stories of dominant representations (in my case, the child as disordered or the child as extra-ordinary).

Instead of sanitised versions of these lives that traditional research tropes would support, the postmodern turn draws us to problematising both the collecting and reporting of ‘data’ (Richardson, 2000). This crisis of representation has provided those driving what has become known as ‘alternative ethnographies’ with much in the way of food for thought. The authority of realist ideology pulls hard towards a need to be ‘true’ to the original story or experience of the individuals we study with (Clough, 1992). I indeed felt that authoritative and tempting pull before, and during my fieldwork and had much anxiety about appearing as a ‘real researcher’ (Wolcott, 1999). After a morning spent in the field (that is, a visit to Samuel’s nursery), and trying to ‘record’ the ‘data’ I had ‘observed’, I found myself in conversation with my supervisor uttering the words, ‘but nothing happened’. Looking back, I find that I had drawn such a conclusion both baffling and troubling but reflective of that desire (and fear) to remain true to the realist ideology of recording the events of that morning. I couldn’t do it, I couldn’t turn that morning into recognisable data that would meet modernist, realist standards of objectivity, validity and rigour. That morning had left an impression on me, an affective one. It had stayed with me and I’d been thinking about it a lot but I wasn’t able to process that impression by research standards. I’d hated it, I told my supervisor. I’d hated the experience, the stuffy room, the military-style schedule, the children’s simultaneous obsession and disinterest with my presence. I’d been uncomfortable with the staff and their words, felt useless in my observers corner, observing. But this wasn’t the story that *should* be told in research, and recorded from fieldwork.

Bochner (2000) would no doubt recognise my reluctance as a preoccupation with rigour, with a neglect of imagination. ‘I wonder...’, he asks, ‘...what it is we are not talking about when we are talking about criteria? Instead of asking, how can this be true? we could ask, what if this were true? What then?’ (p.267). Spending time considering what criteria I was indeed measuring my experience and lack of ‘record’ against, left me reflecting on the wider theoretical framing of my project. I was drawn to Butler’s (1990) work on performativity and began to think about the performance that I was negotiating between enacting and resisting the ‘real’ researcher (Fontana & Wolcott, 1999) during that morning and in my reluctance to write about it afterwards. Once I began to recognise and unpick the embodied, performative demands I was pushing and pulling against - the desire to record the real experience of a child in a nursery versus the emotion-drenched, frenzied complexity of a confusing morning in a highly disciplined room - I began to be able to blur the line between what was and wasn’t an acceptable story to tell of that day.

Placing myself back in that nursery room, back in that morning steeped in noise, and stuffy air, performing staff and riotous children, allowed me to explore the experience through a new lens, a lens through which my writing about the emotional, evocative morning was afforded the position of ‘true’ research ‘data’. I allowed myself, and that morning, to be measured by new criteria, in which my writing itself became inquiry (Richardson, 1994), story-became-scholarship (Sparkes, 2000) and analysis happened *within* the story (Ellis, 2000). My writing became less about recording the data I had collected and more about creating a sense of place (Sikes, 2005) into which to invite my reader. The criteria of alternative ethnographies became my yardstick. Did my reflections (writing a story of that morning) promote dialogue (Ellis & Bochner, 2000)? Did it express a reality - embodying a fleshed out, embodied sense of lived-experience (Richardson, 2000)? Did it seek to nurture the imagination not kill it (Bochner, 2000)? Was I providing a view that complexified the phenomenon (of autism and child, of nursery-life and Early Years staff) that had enough literary substance to provide a readable balance of chaos (Ellis, 2000)? Did it read, as Denzin (2000) hopes, as a moral text, that brings the world into play, presenting specific problems and ‘anchoring them in their historical, cultural, and biographical contexts’ (p.261)? In imposing my story here, I recognised its utopian facets, its saturation that can never be beyond representation and its aesthetic desire to articulate a ‘politics of hope’ (Denzin, 2000, p.262). This was a crystallising turn in my project, and particularly my fieldwork. I began to write against these new criteria and use my writing as inquiry, as an analytic tool to think *with,* not just *about,* the stories I was telling(Ellis & Bochner, 2000). Situating my fieldwork within auto/ethnographic frames based on ‘movement, complexity, knowing and not knowing, and being and not being exposed (Wall, 2008, p.41) took my subsequent writing from being a ‘record’ of fieldwork towards a continuation of fieldwork (Tedlock, 2000).

This period of grappling had somewhat surprised me. I *thought* I was already resisting scientific, positivist research paradigms in my research and had chosen ethnographic methodology. I *thought* I was already measuring myself and my fieldwork against postmodern criteria and it was only at this stalemate of bringing together fieldwork and writing that it became apparent how deeply embedded discourses of traditional research methodology, analysis, and writing were for me. Even in finding space to resist these standards by applying new alternative ethnographic framings, I am reminded of Bochner’s (2000) caution of the allure of ‘criteria’ in general. Even ‘alternative’ criteria have an inherent subtext, masked as somehow ‘natural’ and not socially produced and always a means by which to measure certain representations of knowledge as somehow more or less legitimate or authoritative (p.269). The conclusion Bochner (2000) draws is taken forward within my subsequent story and analysis chapters; not to get distracted by the desire to conform to re-written criteria but rather to maintain dialogue so that we can imagine better ways of living together.

The story of that morning in a nursery sits within the ‘Being’ chapter, it is told within the phase of ‘being with’ the children and analysed through a turn to ‘being with/in bodies’. Now, I move on to describe the extrapolation from auto/ethnographic methodology towards the development and refinement of the practical, logistical methods of meeting, talking to, and being with children.

## 5.10 Methods of Being with/in bodies

The ‘Being’ phase of the project was the time I spent with children and families to explore the questions, *‘2. How might we consider autism as part of being a child?’, ‘4. What does autism do in/to/for education?’* and, *‘3. What does autism make im/possible for a child to be and become?’*

It was a time of embodied participation on mine and the children’s parts; it was time to ‘be with’ children as the data collection sites visualise in Figure 1. From a phenomenological perspective, it felt important to work towards a methodology which moved away from disembodied exploration of subject and object and towards exploring embodied (lived) experiences of children and their families. Adopting the methods of ‘talking’ with children would be to undervalue the role of multimodal communication and risk the over-privileging of the spoken word as communicative method. The hierarchy of communicative currency prefers the back and forth of verbal fluency in child development (Flewitt, 2006). Flattening this hierarchy felt particularly pertinent in a project with children labelled with autism, who are often deemed communicatively incompetent as measured by their linguistic or verbal competency (see DSM-5 criteria). Whilst ‘being with’ children did not discount ‘talking’, it felt important not to prioritise this particular form of communication in our interactions. In valuing experience of life as mediated through our bodies (Shilling, 2003, p.7), it felt important to adopt an approach to exploring the everyday through a methodology which afforded attention to embodiment in meaning-making and coming to know the world (Hackett, 2014; Pink, 2009; Christensen, 2003). I took forward the approach of my MA project, sensory ethnography, as a means of framing my entry into the field; that is, my time with children.

Drawing on notions of embodiment, sensory ethnography brings the sensate to the fore and, as such, brings in methods which acknowledge the experience and perception of the sensory experience (Pink, 2007). Sensory ethnography is not a unified technique, or practice, but more a broad umbrella of engaging the sensory within the research process, with varying degrees of theoretical engagement. It provides an opportunity to stop and pay attention to the affective, sensory experiences on and through the body, which are shared in the research process. It is a critical methodology that has its basis in being a reflexive and experiential process, through which understanding and knowledge is produced (Pink, 2009). As Benedix (2000) purports, this is a profound kind of knowledge, as it speaks of human experience and the phenomenological world; it would be wrong to equate this to a data collection method, it is a shared, fluid, reflexive process.

The critical element in my pursuing of sensory ethnographic aims was that my adoption of such objectives sat with the phenomenological underpinnings of my theoretical background (see Chapter 4: Orientating Theories, Theorising Dis/orientation). Early forms of sensory experience research separated the body and mind as natural and constructed respectively (Tuan, 1993, p.165). A word of caution in this vein comes from Ingold (2002); the danger of identifying sensory experience as merely a ‘vehicle...to carry the semantic load projected by society’ (p.156). This caution rings true with phenomenological critique, in which the body is separated from the mind in a object/subject dichotomy. The danger here is that through introducing embodied experience as removed from ‘constructed mind’, neither are seen as agentive but merely products of societies’ projections. If we return to the notion of the ‘leib’ (Crossley, 1995) then we are able to consider sensory ethnography with a phenomenological gaze, that in which the body and mind interweave to interpret and produce the lived experience of the world, not merely as a mirror of the social. As Ingold (2002) argues, we need to recognise the individual sensory experience as being agentive in the social world. By introducing notions of embodiment, it becomes possible to resolve the divide; the body becomes both the source and the site of agency and not an entity in need of rationalising by the mind and, in turn, society (Csordas, 1993). This felt like a key premise underpinning my theoretical and methodological embrace of embodiment, as it refocuses the gaze on autism and children’s lives away from a disordered, disembodied mind/body dualism. Such a premise is developed further in Chapter 9 ‘Becoming’.

In practice, this meant a highly flexible, responsive period of the project, led, in essence, by the children. The form that it took varied by family, child, setting and day. With the Connors children, I spent time around them in relatively structured environments, both within their respective education settings and then in planned activities; a trip to a local museum, a football class and a dance class. This guided the form that the ethnographic work took, as I was predominantly outside of the children’s immediate experience; alongside them in school activities, chatting to their parents as they wandered the museum. The ‘back-seat’ nature of this felt at times to jar with a desire to disrupt the researcher gaze; the children at times slipping into the observed objects of study as I perched on a chair in the corner of a classroom. What was key in disrupting this potential slip was the framing of the ‘gaze’ that I took in maintaining the principles of a sensory ethnographic approach and a CDS ethic. Where my ethnographic work became observatory, I clung tightly to the potential that an auto/ethnographic ‘stepping-in’ offered.

With the other children in the project, The Goodwins and The Collective children, the time I spent with them took place in less formal spaces; family homes and allotments. As a result of the less-structured nature of these times, the children very much led what we did or didn’t do, how much I did or didn’t share in an experience with them. Doing research in people’s family homes is a moment of working-the-hyphen, in which I was both a guest in someone’s home, with a set of socio-cultural negotiations (‘How do you take your coffee? Are you hungry? Don’t worry about taking your shoes off, sorry about the mess, mind the dog’), and also a researcher collecting ‘data’. Perhaps it was the very complexity of the socio-cultural experience of being a guest that led what came to be the fieldwork in these settings. Having played with various members of the family for an afternoon one day, Max, who had wandered away from his siblings and I, came back into the room and asked wryly, ‘Jill, I’m going to watch TV downstairs, do you want to come and watch me watching The Simpsons?’. Seemingly, my desire for the children to lead what we did and when did not slip Max’s keen eye as a moment of ‘double consciousness’ (DuBois, 1903), in which he experienced himself through my gaze as a researcher (no matter how deft my Lego and den-building skills were). Here, Max was demonstrating how he was experiencing my experience of him; the double consciousness, in which he read his own experience through mine. This felt like more than just him understanding what research was, and why I was there, which he skilfully recognised. This was his experience of my experience of him, permeating his doing and being in his family home. We laughed together as Lilac declared the prospect to be nothing short of boring.

## Methodology and Methods of Becoming: A Creative Analytic Practice of Auto/ethnography

Having borrowed a sensation of becoming from Deleuzoguattarian thinking theoretically in Chapter 4, I now explain how I put this sensation to work methodologically. Though characterised as three ‘phases’ of a project, the ‘becoming phase’ was not distinct in chronological terms or separate in practical terms. Drawing from my theoretical borrowing when I spoke of ‘becoming between bodies’, in methodological terms it was conceived as the writing time of the project, that is, the times and spaces in which the fieldwork became the stories of the thesis. As Figure 2 shows, it was the time ‘around’ the talking and being with children and parents. It was the time to digest and use writing to do so, it was a time for the becoming of ideas through and with the stories I wrote. It was often the epitome of dis/orientation in which I grappled with the pull of the familiar, comfortable orientations to the moments before me whilst I simultaneously drew towards the ‘dis/’ of the experience in which I sought dis/ability politics, complexity and a productive reimagining.

For Deleuze, the very nature of becoming reverts back to a need, a desire, to move onward (even if not in a forward direction) but always to be productive, to evade any possibility of being static; this is the becoming of this project. Though in the written word of this thesis and its stories there is a risk of losing such mobility, such a sensation of always becoming, I encourage a reading of it, and a feeling of it, embodied in a sense of urgency to always desire more, and ask more than that which makes it to the pages between thesis thesis’ covers and this project’s timeframe. In the closing days of my PhD candidacy and beyond, the lives being lived by the children and families of this project continue to become, refusing to be pinned down by the temporality of the stories written as this inquiry. The children I write of continue to become, not just through a passage of time, through a chronology of age, but in their becoming between bodies, in the social, in their everyday encounters of always becoming more.

So to take a sentiment, a methodology, of becoming to a project and a thesis is no mean feat. I am not the only one to grapple with Deleuzian thinking tools as at once enlivening and difficult, entire editions have been written about the desire to think with Deleuze coupled with the frustration and terror of doing so (see The International Journal of Qualitative Inquiry Special Edition ‘Thinking with Deleuze in Qualitative Research’, 2010). Deleuze and his philosophical partner Guattari, have a tendency to seem intimidating at times as they invite you in to their whirlwind of concepts, figurations and thinking tools, especially as a fledgling academic. As I psyche myself up to sit down with an original text, I prepare myself to be baffled, enliven, intimidated and giddy. Something of their ideas draws me in, pulls me to the page whilst washing over me seemingly without comprehension. I return to snippets time and again, each time finding a different understanding than the last, the nuance changing and the ‘real’ meaning seemingly evading my capture and remaining illusive, somewhere over there, just beyond reach. Just as I grasp on to the ‘aha!’ moment, I turn the page and become undone. So perhaps with such a fleeting and unstable understanding of such figurations and thinking tools, I should avoid bringing them to a thesis for fear of doing so improperly or impurely. But perhaps this sensation, giddy and fleeting, is precisely what Deleuze has in mind for the generation of ideas, always becoming, fluxing and changing, moving and weaving. And perhaps this becoming is the giddiness and vitality offered by dis/orientation as productive potential.

In ‘using’ Deleuze, and particularly ‘becoming’ as methodological, I risk the criticism of simply adopting such concepts as no more than metaphor. Becoming as metaphorical for the evolution and writing of a PhD project is certainly a helpful capturing of a ‘process’ but I suggest it is far more than that, far more than a simply literary device or a playing with words. ‘Instead’, Mazzei and McCoy (2010, p.505) encourage, ‘such use of Deleuze attempts a thinking with the vocabularies that provide new means of description and that encourage different understandings or engagements that confront the very image of thought that guides us.’ It is the using of becoming to think with Deleuze that I bring to the project in both a theoretical turn in Chapter 4 ‘becoming between bodies’, here in a methodological turn in ‘writing as becoming’ and in Chapter 9 analytically, in becoming: towards a critical analysis of childhood, autism and dis/ability. Becoming is not only metaphorical, despite its usefulness as such, it is sentimental, it is embodied, vital and living with/in the encounters of children, families, fieldwork and writing; it is becoming between bodies.

To come back down to earth a little, amidst the risk of a line of flight too far removed from the practicalities and mundanities of research methodology, I turn to some of the methodological offerings that I feel best embody a becoming approach in this project; Creative Analytic Practice (Richardson, 1999) and writing as analysis (Richardson, 1994). Neither of these approaches were designed as Deleuzian but I suggest illuminated in these approaches which invite complexity, fluidity and creativity into qualitative research is the very essence of becoming.

## 5.12 Creative Analytic Practice

Creative Analytic Practice (CAP) is an active move away from potentially pejorative terms such ‘alternative’ or ‘experimental’ ethnography which serve to reify modernist, traditional ethnographies as the right or proper form (Richardson 1999). Framing my auto/ethnographic as a CAP is to reify the methodological justifications of auto/ethnography explored earlier in this chapter. The troubling of the research relationship, authorship, and representation that I have demonstrated are fundamental to a piece, and process of CAP (Denzin and Lincoln, 2005).It opens space to considering how all involved in the ethnography, myself, the children, and the family play agentive roles in the research. Richardson plays with the origin of the word ‘cap’ to explicate on CAPs potential,

Cap, comes from the Latin for head, caput. Using the head for ethnographic work breaks with tradition and also breaks down body/mind. The head is both, and more. CAP ethnographers are using their heads, the products mediated through headwork and through the body.... (1994, 929) They display the process and the product as deeply intertwined; both are privileged. The product cannot be separated from the producer or the mode of production or the method of knowing’ (1999, 661).

This cannot be separated from me as producer, or the thesis writing as mode of production, all of which are interwoven I am interested here in MacLure et al’s (2007) writing on that which resists analysis as time and again, as first discussed in the auto/ethnography section, it felt like the ethnographic experience resisted analysis, resisted becoming ‘data’. Using writing as analysis was the first step in recognising experience as ‘data’. The way that I wrote had to attend to experience as lived and embodied, hence the turn to storying rather than traditional ethnographic fieldnotes that perpetuated an objectivist reality. The process of storying allowed for the sensation of a sense of place to be invoked (Sikes, 2004) and the tentative narration to be recognised as a state of ‘becoming’ in a way I didn’t feel other methods of writing offered. In thinking about Max’s discrepancies of what was and wasn’t a story, I was heartened by his suspicion about the ‘reality’ of stories. The call of CAP allowed for the space of writing as itself analytic, in which the stories became a blurring of self and others and a recognition of both a process and product that would in some senses always remain unfinished; as becoming.

In centring writing as itself an analytic process it felt important to let the stories speak to those moments within an experience that at first may have seemed to have exceeded and preceded capture by language. It was often the smallest of acts, the tiniest of moments from an experience that sat within my remembering of a morning spent with a child or a family. As Blaise (2013, p.189) reminds of the potential of the micropolitical, ‘just because a movement, action or encounter is small, does not make it insignificant’. In a project which centres around the ‘Talking, Being and Becoming’ of autism, childhood and dis/ability, an analysis which explored the becoming between bodies needed to attend to the work done between those bodies. These were often those small, micropolitical moments that Blaise encourages close attention to. Here is our affective, or emotional frame of reference introduced through Ahmed’s affective economies in Chapter 4.

In place of the cerebral comforts of ideas and concepts, or as well as these, we could acknowledge those uncomfortable affects that swarm among our supposedly rational arguments - moments of nausea, complaceny, disgust, embarrassment, guilt, fear and fascination, that threaten to undo our certainty and self certainty, by, again, allowing bodily intensities to surge up into thought and decision making. The gut feelings point to the existence of embodied connections with other people, things and thoughts, that are far more complex than the static connections of coding’ (MacLure, 2013, p.172).

I address Jones and Holmes’ (2015, n.p.) call to resist ‘the suspicion of a creative analysis’ (of affect and embodiment), manufacturing a ‘sedated response’ and instead to ‘touch the gut of the affect’. Reading, writing about, or perhaps most significantly, experiencing, ‘touching the gut’ of the times I spent with children, in classrooms and allotments, demanded an attention to that which emanated from, but exceeded the assembling of the bodies (ibid). The sedated response would be a singular explanation or exploration with a tidy and coherent coding of objects (emotions, behaviours, causes, effects). The creative analysis instead brings us back to assemblage (always multiple) and lines of flight (always moving, always becoming). Such a centring of multiplicity and becoming is a reminder of the number of ways of relating to the ethnographic experience which will always be an excess. In recognising that these experiences and the storying of them will always be an excess, of emotion, embodiment, and becoming, I ask what lines of flight are possible, what becomings can weave away around the blockages of striation towards a plateau of smooth space in which we can come to a dis/orientation of autism, childhood and dis/ability.

## 5.13 Moving forward: between methodology and ethics

This chapter has shown the methodological considerations embedded within the project in a way that demonstrates a commitment to epistemological and theoretical underpinnings that respond to my research questions. It has outlined methodology and methods that were developed, deployed, re-developed and re-deployed as the project evolved with the children and families that took part; how the project was a process and product of ‘becoming’. I have shown how an assemblage of methods were necessary to attend to the differing requirements of each research question.

Next I turn to the ethical considerations that permeated the project from conception to the writing of the thesis (and beyond). This acts as an analytic chapter as much as a methodological one and so is presented discretely. Thinking, feeling, writing and analysing critically about ethics throughout the duration of this project was a constant dis/orientation. It was by far the most troubling auto/ethnographic blurring of researcher-researched. As I go on show, the familiar orientations of ethics within a research project; the planning of an ethical consent procedure, the clear and concise information for participation about their involvements were undone, remade, problematised and developed continuously. The uncertain moments in which those familiar orientations to ethical procedures needed to flex and change, were the pull of the ‘dis/’ of dis/orientation; those times in which ethical considerations of what it means to be part of a research project as child, parent, family member, researcher demands more than a university ethical protocol could account for, demanded a recognition of the inherent unfolding of ethical moments in social encounters. Negotiating this ethical dis/orientation in terms of consent, advocacy and risk now follows.

A CAP framing of this project allows for the drawing together of the body and mind and subjectivities between them. The process of doing and writing this thesis is deeply intertwined with the finished product. with what it was possible for me to *know* in doing the project and the means by which that knowing came to be, and was explored, through analysis. The stories I wrote were both process *and* product of CAP. This is how I frame the *process* and *product* of this project as ‘becoming’. Each set of stories in the chapters ‘Talking’, ‘Being’ and ‘Becoming’ demanded a different analytical resource to respond to a different research question. Where attention needed to be drawn to discursive practice in one instance, it needed to be pulled towards embodied ways of knowing in another.

# Chapter 6

# The ethics of advocacy and consent

This chapter, though short, is presented discretely between the end of the methodology chapter and before the analytical chapters because it is both methodological and analytical. It explores ethical issues, particularly in relation to advocacy and consent, which are necessary in developing, delivering and writing an ethical project. At the heart of the project is a queer(y)ing of normative conceptualisations of children labelled autistic, which, as has already been discussed, requires a queer(y)ing of traditional theoretical and methodological orientations. Where we were first introduced to the child invoked by our *Route A-to-B* terrain of autism and childhood, we dis/orientated towards a conceptualisation of childhood that became biopolitically understood as produced, reproduced and disrupted by the label of autism. I suggest that such an orientation in itself is an inherently ethical one. Traditional conceptualisations of the disordered childhood in its natural, disembodied form ruminate on a particular ghostly spectre of ableism, as we have seen. Such a conceptualisation of this child does not see an ethical imperative to understand, know or relate to said childhood beyond the sum of its parts; its disordered cognition and the neoliberal call to a child as productive adult-in-the-making. In a dis/orientating gaze upon a childhood labelled by autism is an ethical commitment to dis/humanism. It is to claim and carve out new lines, new grounds and new ways of orientating (Ahmed, 2006) to autism and childhood, which are committed to a politics of dis/ability which disrupts, and contributes, to what it means to be a valued child and a valued human (Goodley & Runswick-Cole, 2015; Goodley et al., 2015). So ethics, in this sense, is not merely procedural, an adherence to social research or university ethical *codes*, it is a commitment to ethical *values* (Homan, 1992), which are embedded in the very formulation of the research project (see University Ethical Approval letter in Appendix 3). Such a commitment is an ethical one, which is embedded in the sentiment of my research questions,

*1. How is autism spoken about and how else might we talk of autism*

*2. How might we consider being autistic as part of being a child?*

*3. What does autism make im/possible for a child to be and become?*

*4. What does autism do to/for/in education?*

*5. How can autism research broaden its understanding of the everyday?*

The ethical challenge here is to provide spaces for dis/orientating our thinking, knowing, and relating to childhoods labelled autistic through talking, being and becoming. Ethical here means understanding and valuing the everyday lived experiences of children and their families as valuable in and of themselves; to queer the dominant orientations of medicalisation, pathologisation and psychologisation, to value and speak to their childhoods and their humanity, to trouble discourses and practices that do otherwise. The working through of ethics has been so pivotal to the being and becoming of this project that the very research questions themselves can all be considered to make reference to ethical imperatives,

*How ethically is autism spoken about?*

*How else can we ethically talk of autism?*

*How might we ethically* *consider autism as part of being a child?*

*What does autism do for/to/in education ethically?*

*What does autism do for/to/in an ethical education?*

*What* are *the ethical implications of what autism makes im/possible for a child to be and become?*

*How might autism research ethically broaden its understanding of the everyday?*

To be ethical is to interrogate the moral implications both implicit and explicit in the designing and doing of a project; the risks and potentialities of such issues. ‘Ethics’ do not exist in a vacuum and take place in the social (Bulmer, 2008), that is, the commitment to ethical research takes place *with* the participants, not simply before or around them. It therefore felt important to consider the ethical dimensions of this project, not just from a methodological standpoint but analytically too, through the data that was being gathered and produced with parents and families. It is with this ethical gaze that I now turn to some of the most pertinent considerations embedded within this project’s conception and undertaking; consent, valuing embodiment and advocacy.

## 6.2 Consent and Advocacy

Billington (2006, p.8) asks us, as professionals working with children, to question ‘how do we speak of children?’ I extend this to myself as researcher and to the parents in my project; how do we speak of these children? Taking on board the earlier critique of auto/ethnography, in relation to the telling of our stories and others’ stories, I take this critique forward into the ethics of parents giving consent for their children and the advocacy they share in their conversations with me. It became apparent very early in meeting each of the parents that advocating on behalf of their children was a familiar and well-worn path. I was to be one of many ‘professionals’ that had come before, and would come again, into their family lives in the complex relation to disability and their child. I write about the complexity of the ethical process in a formal sense of gaining informed consent from both the parents and the children, and the enmeshment of advocacy woven throughout parents’ conversations with me throughout the process. Parents, in their talk of their lives, children, autism and dis/ability, narrated the stories of other lives too, their other children, their partners, teachers and more. In recognising how stories seep into one another, spreading from one life to another, I consider some of the ethical possibilities inherent in such leakage. ‘The familial relation is not a simple one; it is an embodied relation and as such it is a messy, tangled nexus of love, hope, grief, anger, disappointment, joy and, always, always more’ (McGuire, 2010, p.1).

I originally developed an extended period of consent to be undertaken with the children in my project. This was to include a period of discussion with the parents, including the sharing of ideas and materials (photographs, favourite TV characters, music, areas of interests) to be developed into a personalised consent form, in the form of a Prezi on an iPad (see example: http://prezi.com/nzrm-kai0wof/?utm\_campaign=share&utm\_medium=copy)[[3]](#footnote-4). This was designed to explain the purpose of my being introduced to the children in a way that recognised the need to make such a process personal and meaningful for the child.

However, for a number of implicit and explicit reasons, this digital process of personalised consent didn’t happen with any of the families. Instead, parents gave written consent and the consent with children was established verbally and on a moment-by-moment basis. I turn here to the conversation I had with one mum about how I should be introduced to her son and what I would or should mean to him and him to me.

*We had an interesting conversation about how Kate should ‘pitch’ me to Max. However she pitches me will effect whatever experience I am able to share with him and that I needed to know what that was manufacturing. Am I Kate's friend who is interested in stuff to do with autism? Am I a researcher? Or am I someone that likes to play with Lego? I very much wanted Kate to take the lead on this and talked about how I was never quite sure of how comfortable I or the families were with how much they had to give to be part of the research.*

*I won't film with Max because Kate said he thinks he is ugly. That’s massive isn’t it? Funny how most of us will have rarely, if ever, been filmed when we were kids but the rise of the iPhone has entered a world of conscious, instant image capture. Must be tough! What can we do together, share, make? I need to brush up on my Lego construction skills…. We talked about consent and the assumptions and potential for overdoing it. I want to be 100% about these things but the rest of the real-world doesn’t seem to be as neurotic as me. I explained my plans for the super-personalised digital consent and had to concede that, knowing Max as she does, Kate was probably right in suggesting I could just talk to him instead. She laughed as she said she didn’t have a problem consenting for him, she does it all the time anyway. Perhaps it's because we as parents think we have ownership over our children - Kate reflects. Her one reservation was about how much time I spent with Max and how he might become attached and then distressed after I stopped the research. We need to talk about this more.*

This story had all the hallmarks of each of the conversations I had with the parents about consent for their child’s participation in the project. Each, in one way or another, as Kate reflected, seemed happy to claim ‘ownership’ over their child that if they said something was fine, the child would accept it was fine (or have to accept it). This varied from ‘oh there’s no point trying to explain it to them, they won’t get it anyway’ or ‘he’ll let you know if he doesn’t want you around, trust me!’ From experience, these responses to the consent process aren’t unique to this project or specifically about parents referring to their child’s communication or comprehension skills in particular but more a common discourse around parent-child decision-making. Within Childhood Studies there has been an active move to counter the discourse, which reifies children as passive in an adult-led world, submitting (or being without) agency in their decision-making because of their lack of adult competency. Developing research projects, with children’s active participation in the ethical consent process, has been front and centre of such a move (James et al., 1998; Danby, 2002; Christensen & O’Brien, 2003; Christensen & James, 2008). I would suggest, as have others (Watson, 2012; Davis et al., 2012; Curran & Runswick-Cole, 2014) that the participatory research agenda has somewhat sidestepped or bypassed disabled children in an overly homogeneous conceptualisation of childhood agency and participation, which doesn’t account for differing embodiments or communicative modes. In drawing together an ethic of disabled children’s childhood studies, which recognises overly ableist approaches to conceptualising participation, I spent time considering how best to recognise agency and value communicative intent for the potential children I envisaged taking part in my project. I felt at times that I was becoming over-reliant on narrow cognitive conceptualisations of competencies associated with autism and communication that were pushing me towards a deficit-approach, reifying children’s passivity in the process; how to compensate for children who didn’t use language. In drawing back from such a slippery slope, I returned to the sociology of childhood’s framing of agency, whilst resisting its normative stance. This conceptualisation of agency, as we’ve heard earlier in Chapter 1 ‘Contextualising the Terrains’, recognises children as competent participants in their social lives and as active contributors to research; no longer were children to be viewed as passive objects of study who lacked the rationality or agency to consent and contribute to decisions about their lives (James & Prout, 1997; Christensen, 2003). As was acknowledged in Chapter 1, however, the normative markers of what constituted competency and participation, i.e. a literal active voice, risked excluded disabled children who enacted their participation through non-normative modes e.g. without spoken language (Curran & Runswick-Cole, 2014; Watson, 2012; Davis et al., 2008; Beresford, 1997). In de-prioritising spoken language, I turned my attention to a more visual and personalised presentation of what my project could mean to the children participating. This drew loosely on communicative strategies supported by autism theory, such as the Picture Exchange Communication System (PECS), which recognises the value of personalised, visual information. Where I would caution against the homogenisation latent within such assumptions about autism and communicative preferences, the adoption of techniques that offer creative inroads to the complex process of consent were welcomed.

It was within this move that I had gone to such lengths to develop a creative consent procedure for the children, which I felt drew on notions that recognise their ability to communicate intent and make decisions. I stand by such an intent but also recognise how the imposition of this process, which I acknowledge now as far too time-consuming, was in tension with the parents’ sentiments of ‘knowing what’s best’ for their child. In a similar quandary, Davis et al. (2008) wrote of their ethnographic study with disabled children at school, in which the children were homogeneously positioned as incapable of understanding the consent process, with the power to ‘access’ remaining firmly in the staff’s hands. It seems possible that, perhaps not knowingly on either side, I was becoming re-socialised by the parents and their constructions of their children by changing my original plans for consent. How was I to value the parents’ expertise about their children (a central call of the project) whilst simultaneously remaining mindful of what/who is conceived when parents advocate for their disabled child (McGuire, 2010)?

I reminded here of the ever-pertinent words of Titchkosky (2007, p.3) who advises us to ‘read our readings and watch our watchings’ of how we come to speak of disability in particular ways. Building on this, McGuire (2010) cautions that we need to be mindful of the ‘we’ being conceived, when ‘we’ (parents and allies) seek to speak of ‘living with’ the disability of another (in this case the child). Taking Butler’s (2004) notion of ‘unknowingness’, the distance between you and I is at once what binds and separates us (McGuire, 2010, p.5); it is not a natural space but a negotiated one that happens at once between parent and child, researcher and family. McGuire contests the ‘we’ of those ‘living with’ disability and reminds us to be ever-mindful of the seamless leaps often presented as natural when describing our interpretation of another’s life. The temptation to gloss over the power exerted when a parent speaks of their child is not a site for moralising parents’ knowing of their child but a site to interrogate how the ‘other’ is always already being reconstituted through such a storying. ‘To ‘live with’ the other, to speak the ‘we’, is always to be at risk of relation to the other violently (ibid). However, this risky space may also be an opportunity to ‘re-enter the story that ‘we’ are telling and to tell it differently’ (ibid, p.14).

The ethics of such a power imbalance and its complex facets were at the heart of this project and remained a cautionary tale in my research with families, my writing of the stories and the analysis of the ‘we’ (the child, parents, and I) that I speak of. As I saw it, for this project to be ethically grounded, it had to be done with a commitment not to prioritise the parents over the children; to continually problematise the ‘we’ that was being conceived by myself in interactions with parents and children. Without problematising this ‘we’, the project risked further perpetuating the dominance of research carried out around disabled children’s lives that is actually exclusive of their experience and focuses only on the experience of their parents.

If there were a ‘crisis point’ of my project this was it; was the project becoming more about the parents at the expense of the experience of the children? I felt quite strongly that the process I had developed was conceived recognising the children’s participation actively in the consent process. I had spent a long time during my MA project considering how to develop an understanding of when a child who didn’t use language was and wasn’t happy for me to be around and be actively part of my research. In this particular project, I was video recording and using multimodal analysis to understand her embodiment of participation and refusal. This took time. I had the added benefit of already having spent a lot of time with this child, as a weekly volunteer in the family home, for quite some months before I began my project. This inevitably aided my ability to interpret her enactment of participation and an understanding of her nuanced actions. I didn’t have this luxury in meeting the children for this project, I was going in cold, I needed consent from the outset. And so, despite my reservations, I had to take trust in each of the parent’s advocacy of their child’s consent in the first instance, and work on a range of verbal and embodied sharing of my project’s intentions and the children’s consent as I met them. This is not by any means to suggest that, once the formal consent had been handed over by the parents, I assumed the children’s participation. This was a differentiated process with each child, which I felt more capable of deploying as time passed.

## 6.3 Consent as embodied and ongoing

In hindsight, the *procedure* I developed was not as embedded in the theoretical thrust of the project's intent, in which children’s *embodiment* was taken seriously and valued in the sharing of meaning-making. As I have explained, I began by relying on relatively traditional tenets of ethical codes in a procedural sense, with a consent ‘form’ that perhaps was still overly reliant on markers favouring normative participation, spoken words and active agency demonstrated through a literal ‘voice’. In *practice*, the process of consent was very much embodied and enacted in a shared moment-by-moment becoming of participation. It was undoubtedly ‘assent’ that I sought rather than informed consent. This was not because I believed the children’s consent to be unimportant or that I believed them to lack the agency or competency to give consent, rather that I problematise the ableism of the individualising concepts themselves. I feel it would be problematic to suggest the children participated in something that could be called informed consent by traditional definition; (1) presentation of information, (2) understanding, followed by (3) a response where consent is either given or withheld (Morris, 1998). This was not exclusive to the children but I think speaks to a more general issue around truly informed consent in research. I spent many hours conversing with parents about my project, its everyday workings, its potential outcomes, and would still contend that many did not give fully informed consent relating to either their understanding or my presentation of information. On one occasion, long after the formal consent process and several visits with the family, one of the dads of Producing Autism said, ‘Are you still wanting to do your study? When are you going to start?’ Somewhat taken aback, I realised that despite information sheets, consent forms and conversations explaining what the project would ‘look’ like, there was still an expectation somewhere that I would be *doing* some kind of formal *studying* of the children. There I was, digging away at some weeds chatting to a parent about school, the children pottering around the allotment site, *doing* my research, or so I had thought. The dad, however, was seemingly still waiting for me to *do* something with his children. Research, in this ethnographic, was problematic for participants as well as me, I was not the only one having to negotiate Fine’s (1994) hyphen of researcher-researched. The parents here were having to enter into the space of what was and wasn’t part of the research process and when I was or wasn’t just another volunteer on the allotment site.

So, instead of somewhat unreflexively assuming informed consent, I sought to understand children’s assent to my presence. This valued embodiment as a way of knowing and a process of meaning-making (Hackett, 2014). With the children at the allotments, this was often just a ‘checking in’ as I arrived at the site, a wave from a distance, a crouch to say hello or a shared plot of soil to dig alongside, without the need for any direct interaction. I was never the only ‘stranger’ at the site and the children seemed as indifferent to my presence as to any other adult who pottered and dug around their play. Interestingly, I also wasn’t the only ‘stranger’ publishing work about the children and allotments; BBC Radio producers were visiting the site as part of a feature on this new Sheffield charity. The children had the space to be far removed and out of site from my, or anyone else's, ‘gaze’ as much as they pleased and I made a conscious effort not to spend any time with them that wasn’t initiated by them. This meant that, for the most part, my time at the allotments was spent chatting to the parents and other adults and various siblings scattered across the site. Over time, as I became more familiar, Ben in particular began to initiate interaction with me, firstly in the hunt for dock leaves after he got a particularly distressing nettle sting.

*I’m pottering away weeding the seamlessly endless knots of weeds around the raspberries, chatting away to one of the mums about schools and classrooms and difficulties with friends in playgrounds. Ben is brought to my attention with a sharp scream before I catch sight of him in my periphery. He yelped, whooped and sobbed and dragged me by the arm through the site to an area where he’d previously found the helpful leaf. I turned back to his mum to check she didn’t want to intervene. She looked a little shocked and mouthed quietly, ‘let’s see what happens, he always comes running to me, it’s good that he’s not’. I scrambled for a leaf, with a vague panic that my choice wouldn’t be a medicinal leaf but something poisonous and assisted in the ritual rubbing of the nettle sting until his sobs subsided. Subdued, red in the face and a little snotty, Ben leaned into me and then carried on his merry way.*

On a different occasion, Max brought home the slippery task of truly informed consent and the difficulty in clearly articulating exactly what involvement in the project meant.

*When I asked Max to write a story with me, about whatever he wanted, something that told me about himself, he was at first reluctant, then nervous, and eventually refused. Once he felt comfortable enough to share his objections, it was clear that his unwillingness to participate was a caution that I should heed. His understanding of a story was something made-up. If the story was going to be about him then it wasn’t made-up, because he was real and, ergo, whatever we did together wasn’t a story. Perhaps, he suggested, what I was actually asking him to do was write an article, like in a newspaper. That told people real things about him. To Max, if he were to share with me his ‘truth’ then why dress it up as a ‘story’?*

Max’s caution is a reminder of the need for clarity and an extended, negotiated process of consent. After all, our versions of what constituted a story were of course different for a number of reasons, not least because I consider myself a storytelling researcher. I love writing and Max hates writing. It would be easiest to equate these crossed wires to a child/adult binary and to suggest that an adult would have understood what I had intended by the use of a singular word, ‘story’. That somehow discredits Max’s knowledge and overstates my explicitness. It has been helpful food for thought when considering the legitimacy of any process of consent, as every being truly achieved within the procedure rather than a shared negotiated relationship between myself and the children and families. Joe, Max’s older brother, challenged the legitimacy of ethics procedures, which are designed to protect and safeguard participants in research further in the following story.

## 6.4 Joe’s reminder of risk

*Coming towards the end of a visit to the Goodwins, I come down to the kitchen after a stint of serious den-building and am greeted by a chuckling Kate and Joe, who eyes me with caution and humour. ‘Joe has something he wants to ask you, Jill’ Kate smiles, flitting her attention between me and Joe’s grin. Joe returned his gaze to his computer screen seemingly presenting as nonchalant. ‘He wanted to know if you were a paedophile. He asked me how I knew you weren’t a paedophile and I realised I couldn’t say for sure, that I suppose I just assumed you weren’t. I asked him why he thought you might be - why else would an adult want to play with children, he thinks it's weird. I told him you weren’t a paedophile and that I trusted you. If I didn’t then I wouldn’t let you spend all this time with my kids would I? But then he asked if I’d be ok with you going up to my children’s bedrooms and playing if you were a man and I realised that I wouldn’t be - so my son’s just pointed out that I’m sexist too!’ All the while Joe gives half of his attention to the conversation and to mine and Kate’s light-hearted dismissal of his light-hearted accusation. We spend some time chatting through his astute recognition of such questionable consensual ethical agreements between myself and parents. Kate conceded that my university branding had given me de facto access to her children and de facto status as trustworthy and non-threatening. She admitted that her willingness to take part in my project and continually to consent to my time spent with the children was somewhat reliant on my being a woman and a small, bubbly, young one at that. That if I’d been a man she’d have been suspicious - which she recognised as equally shaky but true nevertheless. Joe had recently been in trouble for having a ‘voice chat’ with someone he didn’t know on the Internet. He’d been chastised for talking to strangers, which was explicitly against the clear and defined rules of his access to computers. He’d been trading something complicated (the understanding of which fails me) and the voice transaction had made it easier and quicker. Debates around safety, predatory adults, strangers, and paedophiles was a hot-topic between Joe and his mum at the moment and he’d spotted inconsistencies in his mum’s line of argument by her agreement to let a relative stranger spend time alone with her children, something he considered far more risky than a virtual conversation.*

As light-heartedly as Joe and his mum negotiated a serious and, within the family context, legitimate concern, it was a pertinent reminder of the powerful discursive foundations, which are brandished, often unwittingly, through my own and the parents’ clandestine advocacy on the behalf of their children in this project. It is a reminder that the will of the children in this project is always somewhat subjugated by that of their parents’ willingness to invite me into their homes, schools’ willingness to open their classroom doors without question or hesitation. I am pleased that I am not asked if I’m a paedophile on a regular basis, that it is assumed that my intentions are legitimate rather than sinister but I am also troubled by it. Without any sinister intent, it perhaps shouldn’t be so readily assumed that my status as a university researcher makes me devoid of fault or the potential to harm (despite ethics procedures designed to formalise such a commitment). There is inherent risk in research with people and children that, at some point or another, my presence or actions can cause distress. Or that in the writing of this project ethical integrity also becomes problematic. In storying the lives of others, there is the potential for violence, as McGuire (2010) cautions.

## 6.5 Advocating Otherwise

This section draws on the overlap between the advocacy of parents consenting on behalf of their children, talking of their children within the storying of their lives, and the advocacy I rely on in my story telling. Many of the critiques of auto/ethnography could equally be applied to the processes that happen when parents speak about their children, or *for* their children. As I have suggested earlier, as much as this project is not an auto/ethnography in a biographical sense, the more that I am implicated and entangled in the stories the more I am able to write about the children and families I have met. Equally, parents tread a line of ‘auto’ whenever they speak of their children, as the storying of their lives as parents and the storying of their children’s everyday lives are wholly enmeshed. As Tollich (2010) reminds us, even when we think we are speaking of ‘ourself’, we are implicating others, ‘the self is porous, leaking to the others (p.1608), which he fears is often without due ethical consideration of such blurring. Such leaking, Chang (2008) would argue, is fundamental to our lives as social beings, others are always visible and invisible in our storying of it, we do not live in a vacuum, which Connelly and Clandinin (2000) then ask, if we tell a story, do we own it? I ask these questions of the stories I write in this thesis and the conversations I have with parents about their children. I take these questions forward in the next chapter ‘Talking’, when I turn to the idea of the rhizome (Deleuze & Guattari, 1987). My negotiation of the ethical rub of storying others’ lives is to consider Denzin’s suggestion that ‘telling does not subtract from other tellings; telling is not a zero-sum game (Denzin, 1996, p.47). This is a reminder of the ever-multiple becoming of storying as always incomplete and contingent on teller, listener, time, place, and a whole host of other factors (Davis et al., 2004). What must be remembered here is that these stories, as parents, as stories of their children, forever remain unfinished, forever remain complex, incoherent, changing, moving, are stories told in one context, with one researcher, with several cups of coffee, are told more often than not without the other parent being involved, shaping, changing, developing a shared story. I draw here on Pulsford’s (2014) claim to story-as-rhizomatic; they will forever reach in multiple directions, morphing as they come into contact with other stories, creating, disrupting and blurring assemblages.

## 6.6 Stories left untold

It is worth a brief aside here to acknowledge another specific ethical mire of this project in relation to the sharing of stories; the conversations I had with parents that I felt could not (or should not) be written. The reasons for such hesitancy in writing up certain conversations into the storying of this thesis range from the blurring of the ethical integrity of telling others’ stories (for example of children and families not part of the project) or a much debated issue of storying aspects of lives that the participants hadn’t explicitly consented to being part of the project. Ellis (2007), a much revered auto/ethnographer, has also come under criticism for a number of controversial pieces written that have been deemed by some as exploiting the participants’ consent, as the people within her work had never given actual consent to be part of the research. As much as I recognise that, within an ethnographic process, there are unexpected moments that could never be planned and prepared for, the only solace I could find within literature, justifying either side of this coin, was in Medford’s (2006) call only ever to include material that you would be happy for participants to read. I don’t expect that my participants will read my thesis but have used such a tool as my yardstick for when to take fingers to keyboard and when to leave encounters unwritten. There were conversations I had with parents that were no doubt influential to the storying of theirs and their children's everyday experiences around autism, which nevertheless felt too intimate for a thesis. Stories of days spent with families about which I felt unable to write without drawing in aspects of their lives I had never intended to be part of the project and they hadn’t ever thought would be included. Such is everyday life and a project based around it. These stories, though never written, have nonetheless inevitably permeated this thesis as they permeated my ongoing relationships with the families; they coloured my knowing and understanding of them and framed what it was possible to know and understand beyond it. It may seem somewhat of a teaser to speak of untold stories but it is an acknowledgement of the limitations of any thesis, and any project, to always be bounded and to recognise that any story told is never the only story possible.

Some of the stories I have written have already been read by parents. Kate for example, curious to get a better sense of what my project was about and what the stories would actually ‘look’ like, read the story I wrote after we first met. Rachel was contacted towards the end of the project to ask if she would consent to the inclusion of some of the email conversations we’d had that had seemed relevant in hindsight. Having recognised that our initial discussion about the project and its data hadn’t included emails, I shared with her the extracts I was wanting to use to check she was comfortable with this. On her agreement to these extracts, and after a similar discussion with Kate, email data has been included.

The following is a story of meeting Gabriella, which speaks to many of the ethical issues around advocacy, consent and embodied assent that I have explored so far. We met first at the family home and then ventured out on a shopping expedition to buy presents for a series of friends’ birthday parties coming up.

*Within seconds Gabriella is presenting her mum with various objects, each of which she simply must have, she pleads. ‘I knew this would happen’ Alison says lightly rolling her eyes.* *‘Ok. You can have three things so you have to pick carefully. But we are here for your friends presents remember?’ Gabriella is off well before the end of the sentence, digging around the recesses of shelves of different bits and pieces. As we wind through the aisles we chat about the different toys and how much fun they are, how flimsy they look and how much junk kids acquire. Gabriella entertains herself with her quest to find her three new, precious objects that hold her attention for as long as it takes for her to get them in her hand. The casual strolling goes from aimless to purposeful as we step up the search for ‘toys for little boys’. Gabriella reaches for my hand and takes it in hers as if we have known each other forever, seemingly at ease with my existence in her world of a small aisle in a cluttered shop full of treasure and junk. I feel a sense of gratitude that she doesn’t mind me being around and take her offering of her hand as demonstrative of it. I breathe a silent sigh of relief, take comfort in the offer she has given. The power of a 5 year old’s tiny hand!*

*Before I met Gabriella, I had met with her mum Alison for coffee to talk through my project, learn about Gabriella and generally see if this was going to work for them. Amongst the hour or so we spent talking, one conversation lingered with me prior to meeting Gabriella that afternoon; it hung over me and fluttered in my stomach. Alison had offered both caution and reassurance that Gabriella could, and probably would, go from loving to hating me, and vice versa, in the blink of an eye. Her moods were very volatile and when things went wrong for her, they did so quickly and with a surge of emotion. These meltdowns (Alison’s term) were really hard and weren’t personal, that much she wanted me to remember. Often, Alison said, after a particularly bad episode, Gabriella wouldn’t actually remember a thing of what had happened. The majority of the time though, such outbursts of hatred were followed by remorse, an apology and a return to the good stuff. I completely understood (which of course I didn’t really) and would take it all as it comes, hey, if she doesn’t want me around, I’ll go away. I’m kind of glad that she’ll make it quite clear. We talked about consent here and that this was perhaps a helpful part of it. Alison asked me if I wanted to be around if things were ba, as, as we both recognised, this was very much part of their everyday life too. Again, we talked about this as being very much led by Gabriella, and Alison. That due to such unpredictability I was more than happy to follow what felt best for Alison in those situations - if we’d planned to meet and they were having a really bad day and Alison felt I would only add to it, she could cancel at the very last minute. Equally, if while I was around things started to go wrong and Alison wanted me to stay and help out, then of course I would.*

*The mire of ethics, in a procedural and a personal sense, of these situations are ones that I have dealt with situationally in the past and given much thought to in the meantime (see Smith, 2011). However, in the recent history of my project I’ve had very little cause to draw on it. The complexity of it in a conversation, with a mum about her child, reminded me of the possibility of this project being demanding, of being hard, and the bit that concerned me most of all and turned over in my stomach the morning before I met Gabriella was the thought that my presence could be hard on Gabriella, her mum, and their everyday lives.*

*As the uncertainty of mine and Gabriella’s fledgling relationship began to unfold that Saturday afternoon in the fluorescent light of a stuffy pound shop, Gabriella’s hand offered me more comfort than she could have possibly been getting in return.*

In a pertinent conclusion to a chapter about the ethical mires around consent, advocacy and participation, I didn’t see Gabriella and her mum again after that day.

## 6.7 Moving forward: Ethics in analysis/ethical analysis

The stories written for each of the analytic chapters that now follow were steeped in an ethical commitment to particular orientations and lines; the moments where I was pulled towards deployment of a certain conceptualisation of ethics and away from others. The discussion of the evolving consent process showed this tension being played out. These orientations and lines were situated firmly within a dis/human ethic of valuing what childhoods labelled autistic disrupt and contribute to our valuing of humanity (Goodley & Runswick-Cole, 2015). I was cautious and mindful to attend to the implicit discourses embedded in reductive or representational leaps of storying the experiences I shared with children and their families. I remained watchful and mindful of MacLure’s (2013) suspicion of the ‘sedate analysis’ and to a CDS imperative to expose and problematise ableism stalking the stories I told and the analyses I went on to make. McGuire’s (2010) cautionary tales of the risk and violence of advocacy bled into the experience of storying, and relating to the experience of narrating these children’s and families’ everyday lives. Coupled with an auto/ethnographic commitment to Creative Analytic Practice, and the criteria of such methodological approaches outlined in Chapter 5, I used these tools as yardsticks to evaluate the more slippery ethical dimensions of what should and shouldn’t be written and how it should (or could) be analysed as part of a thesis. This was perhaps a process of dis/orientation, the danger was always to slip into analytic practices that served no more of a productive purpose than the dominant discursive conceptualisations of children labelled with autism I sought to dis/orientate. The potential and possibility of advocating otherwise (McGuire, 2010) is to stay with dis/orientation, to recognise that a single orientation in ethics would be unethical; the conception and deployment of ethical procedures always needs to be situated, problematised and take place *with* participants. The *dis/* of orientations in ethics is to problematise methods of participation, as I have shown in the development of a consent process which challenges normative markers of agency that would exclude disabled children as less valuable contributors or unable to contribute (Curran & Runswick-Cole, 2014). It is the dis/human turn to claim (active participation) and reject narrow definitions (normative modes of participation) of what it means to be a valuable and valued child in everyday life (Goodley & Runswick-Cole, 2014). The responses to my research questions and their ethical imperatives directed each of the coming chapters, ‘Talking’ ‘Being’ and ‘Becoming’.

# Section 3

# Findings and Analysis

# Chapter 7

# Talking

# The rhizomes of everyday autism

Chapter 7 ‘Talking’ dis/orientates our gaze on the dominant discourses of autism and considers the rhizomes that come to be through the talk of autism. It draws in the dis/orientating experience of the rhizome with multiple entryways, and the im/possible ‘beings and becomings’ of autism that reside when particular ways of knowing and coming to know autism and childhood are mobilised. The dis/orientation worked through in this chapter circulates around talk of autism. The dominant orientation in the talk of autism follows the grand narrative of developmental disorder with an equally static counter orientation of autism as neurodiversity. We are drawn to those orientations through the discourses exploring in Chapter 1, orientations which conceal the labour involved in creating those well worn lines that allow their existence to appear as natural, as if by magic. A dis/orientating turn demands that we recognise that maintaining such singular orientation towards autism, through talking of autism, is regularly undone. I work through the dis/orientating experience of talking of autism as always more than a singular orientation; as rhizomatic. The thinking tool of the rhizome is used as a tool to embrace dis/orientation; the push and pull between orientating towards autism, through talking in a singular, resolved way, coupled with the continual need to draw on it as always multiple, always more.

It responds to the questions, *‘1. How is autism spoken about and how else might we talk of autism?’ and ‘3. What does autism make im/possible for a child to be and become?’*

I do so by telling some stories of my encounters with the parents in this project and considering the discourses at work in and around the conversations we had. I take snippets from email exchanges where these conversations have been extended, when one or both of us has gone away from a conversation and had something else to say. As we considered earlier, in the wealth of literature written by parents about autism, the stories parents tell of autism, both publically and in everyday life, are significant. They are significant in producing, reproducing and resisting how autism is constituted, in contributing what is known and is possible to know about what autism means, and how it is lived collectively. Hacking (2009) would have us believe that such talk evolves autism’s ‘looping effect’, Rose (1990) that it biopolitically shapes parents’ and children’s sense of selves and Goodley and Runswick-Cole (2014) that it is an opportunity to think about the dis/human qualities of what we value in our conception of childhood and the human. I take forward each of their calls in thinking about the personal and political dimensions of the selves being created when these families speak of an ever-elusive ‘autism’.

## More than a single orientation, a rhizome

If any of the ways of relating to or talking of autism explored below were the only ways, the bind of autism would be untenable, unliveable. Instead, I story multiple ways of coming to talk of autism that call for less rigid and more fluid ways of relating to autism, allowing a multiplicity of living with autism; of being and becoming with autism. In talking of autism, it becomes possible to think about what ways of ‘being autistic’ and ‘becoming with/in autism’ are lived; interrogating the phenomenon of the lived experience of autism (Hacking, 2009). A singular, bounded, knowable way of relating to and living with autism is disempowering. As has been alluded to earlier, even the most emancipatory neurodiversity movement relies on the familiarity of some of the most well-worn biopolitical lines of autism’s medicalisation. As will be seen, the talk of autism that enabled *some* parents was disabling to others; it forged particular assemblages that were unliveable for some and full of potential becomings for others; autism-brain-centred-personhood, autism-celebrated-diversity, autism-lifelong-impairment, autism-distress-exclusion. This is a recognition of the ‘else’ in ‘how ‘else’ can we talk about autistic children’s lives?’ Leaving room for possibility and potential, the ‘else’ leaves room to manoeuvre around the boundaries of singular, certain ways of talking about autism and lived experience. The talk of parents I encountered, constituted stories of the self, of on-going identity work for both themselves and their families; a self which did not reside in the interior but that was made and shaped in the social (Davies et al., 2004). This talk permeated the boundaries of their children’s individualised selves and seeped into their own, to their siblings, to teachers and professionals; they were always already connected. As connected, they were always already being remade and undone in the moments they were articulated. This is a moment in which autism talk can be considered dis/orientating; parents switched between talk of autism, childhood, family life and more to demonstrating the many, and often competing, orientations in their lives. These were not individual’s stories but spoke to a wider discourse of parents constructing a way of sharing their experiences and lives around autism, family life and parenting (see Ryan, 2010; Ryan & Runswick-Cole, 2009; 2008). Their talk spoke of the untenable discourses of autism in their lives and their negotiation around its blockages, always enmeshed in the broader storying of self that we share in relating to an other.

In thinking about ways of talking about autism, therefore, we need to consider ways of talking of selves; of narrating the self. In recognising that a story told over a cup of coffee is always multiple in an assemblage of others, we can turn to the rhizome of stories or stories-as-rhizomatic (Pulsford, 2014; Sermijn et al., 2008). A Deleuzoguattarian logic, the rhizome invokes a multiple, spreading, weaving, horizontal complex that always remains incomplete, which is read in new ways dependent on entry way and always an excess, always more (Deleuze & Guattari, 1987).

A rhizome has no beginning or end; it is always in the middle, between things, interbeing, intermezzo. The tree is filiation, but the rhizome is alliance, uniquely alliance. The tree imposes the verb ‘to be’, but the fabric of the rhizome is the conjunction, ‘and … and … and …’. This conjunction carries enough force to shake and uproot the verb ‘to be’ …. (Deleuze & Guattari, 1987, pp.27–28)

Sermijn et al. (2008) adopt the rhizome as a metaphoric thinking experiment (rather than method or analytical tool) in relation to the talk of self. To think of the self not as a noun but a verb is to adopt a rhizomatic sentiment; the self coming to be anew time and again each time we speak (Davies et al., 2004). Indeed, if we are to recognise stories as always in the making and entry into the rhizome as entering into connection, then I am implicated in talking with parents about theirs and their children’s lives; I become part of the rhizomatic telling of autism, as connected (Sermijn et al., 2008).

What follows now is a chapter of rhizomes of everyday autism, several parents involved in several moments of talking and writing of autism and family life, each connected to another in this thesis, spreading and weaving a new rhizome of autism’s talk. Within each parent's storying are further rhizomes that amalgamate, branch off, become blocked and weave around one another. In envisaging the rhizome, I invite you to take one of many entryways into the talk of autism to explore how we may come to relate and talk of autism otherwise; how dis/orientating our talk of autism may be possible and how staying with dis/orientation might be helpful.

## Kate: Writing talk of autism

Early in our research relationship Kate sent me a document she’d written three years earlier called ‘Diagnosis Story’, as a material example of how she storied autism in her and her children’s lives. At the point of writing this story, two of the five Goodwin children had autism diagnoses. It is included here in a much shortened version, though the text itself not edited. My interest in including Kate’s written story here is twofold; 1. its temporality in demonstrating how a storying of lives is rhizomatic; incomplete and ever-evolving, and 2. as a material piece of narrative data which serves a different purpose (and tells a different story(ies)) to those stories that are told in everyday life and shared over cups of coffee. It is from these starting points that the story is considered.

*‘To discover that my child, who looks and seems so perfect, might be different on the inside, has come as a shock. That the hopes and dreams I had invented for her future, (probably before she was even born), may be more difficult if not impossible for her to achieve; that her life may be less happy; our relationship less deep; all of these things fill my head. And yet she is the same as she has always been. Nothing has changed.* (from my diary)

*My two children have been diagnosed at 11 and 4 years of age. My eldest child is quite subtly different. She is different in her thinking and understanding, her processing of information and her emotional reactions to people and situations. Her differences are not immediately obvious - you have to know her well, spend time with her and listen to her to understand what they are. She presents as a reasonably typical, loud, cheeky pre-teen, who is perhaps a bit immature and lacking in social confidence. She is capable of many things and has always attended mainstream school without being identified as having any special needs. She is considered a high achiever and has been described as a "model pupil". It is only by listening to her understanding (or more often misunderstanding) of situations, her interpretation of what has been said, of other people's intentions towards her, that you can have insight into her world. Her behaviour is so well modelled on that of her peers that, to a casual observer, she doesn't stand out. The social world of ten year old girls carries on in playgrounds and bedrooms, out of sight and earshot of monitoring adults. It is possible for a child to be confused and lost within that world without anyone knowing. It wasn't until her unhappiness began to manifest in unpleasant behaviour and she chose to disclose her difficulties, that we discovered the levels of stress, and distress, she was struggling with, day in day out.*

*On starting school she appeared to make friendships successfully, although it was noted that she was unusually attached to particular people - she would follow them to the toilet and physically hold on to them - as a result she was described by teachers as fiercely loyal. She was clumsy and sometimes hurt other children unintentionally by running into them in the playground or hitting them too hard when playing games such as tig - her teachers felt that she was boisterous but without any negative motivation. She was very clear about school rules and would tell on her peers if she observed rules being broken - her teachers described her as honest and reliable. She started copying her friends' drawings and handwriting, rather than maintaining her own more advanced style. I felt disappointed that she didn't show her teachers what she was capable of, and sometimes worried that it might indicate poor self-esteem and a lack of confidence to be herself, but reassured myself that she was probably making a quite normal attempt to blend in. I was told at parents' evening that she seemed overly concerned with the tiniest of scratches or bumps but, as this coincided with her father's treatment for cancer, I thought she was probably reacting quite appropriately to worries about health. Another teacher informed us that he thought she had a processing difficulty. He had noticed that she would read an instruction to do something, which he knew she was capable of, but then wait for the child sitting next to her to begin before following her lead, as if she couldn't understand the written instruction for herself. I interpreted this behaviour as another example of her anxieties - that she didn't want to make mistakes. Unfortunately it seems that he understood her better than I, but he left the school soon after and his concerns were never acted upon. I was completely unaware that her profile of abilities and behaviour reflected anything other than her personality and intelligence together with my style of parenting. I knew nothing more about AS than what I had seen portrayed in films like Rainman.*

*I kept looking for answers - how could a child I had made such efforts to bring up to be sensitive, polite, generous, respectful, thoughtful and well mannered, have become so "brattish"? Much of her behaviour seemed to stem from unhappiness relating to poor self-confidence, so I wondered if perhaps I had been too critical a parent, or too strict, or her behaviour was a product of her life experiences. Or perhaps she was affected by changing hormones, or she had too many siblings to compete with, or too few friends to play with. But none of these explanations – even in combination – seemed satisfactory – especially as her younger siblings, with the same parenting and experiences, displayed no such difficult behaviours. I often criticised her behaviour, trying to make her see how unreasonable she was, resenting the effect her behaviour was having on the family. She would refuse to listen or see my point of view. I really felt that I was losing her and, with adolescence looming, was fearful of what was to come and dreaded the possibility of a complete breakdown in our relationship.*

*A chance conversation with a friend was the turning point for us. I was talking about my daughter following a particularly fraught weekend. My friend, who teaches in a specialist inclusion unit for children with an ASC, said she was reminded of a boy who had a diagnosis of Asperger's. I recognised many of my daughter's behaviours in my friend's description of this boy, and she helped me to understand the reasons for his behaviour. It was fascinating and I spent the rest of the day finding out as much as I could. The effect of this conversation on me was immediate. That it was possible that neither my daughter nor I were to blame for her behaviour came as a revelation. My attitude towards her changed that day, and my recognition that there might be something different about her was all it took to shift the downward spiral. I made a conscious decision to change my reactions to her behaviour. If she had Asperger's, or another condition, which made her behave as she did, she would need support not criticism. With no further intervention than new insight, I was able to be more accepting and more loving. To realise that her tantrums might not be about her trying to get her own way, but a reflection of her distress, that they were not something I had to control, but rather something I needed to contain, made all the difference. With this new realisation I could hold her, love her, support her and accept her. Such a small shift in my thinking (that she might not be able to help it and it wasn’t a reflection of me as a parent or her as a brat), dissolved the stalemate we had come to and brought back understanding.’*

## Entering a story of a lived rhizome

As well as being beautifully written by Kate, this story is beautifully crafted to present a plotline of narrative coherence that achieves many of the goals of traditional narrative inquiry itself (Connelly & Clandinin, 1990). Kate narrates in such a way that we are drawn to the affective dimensions of a troubled relationship with a child, the trials and tribulations of parenting, and to the sense of relief and resolution that the autism explanation offers us. The storying of a life, or in this case, a mother and daughter as central characters, offers the means to make sense of the social world and its unfolding and unpredictability. The narrative coherence Kate offers, allows us the benefit of hindsight and has provided a point of reflection for Kate and a sense of reassurance reframing what was lived at the time as being a worrying and distressing period of their family lives. We share re-presented lives in literary form, in a vein similar to many of the auto-biographical accounts explored earlier in the thesis. Journeying, struggle, discovery, and acceptance are all implicated here through sophisticated literary devices.

Storytelling prowess aside, I want to dig around some of the discourses at work within such devices and explore the implications they have for how lives are being lived around autism and crafted in the rhizome beyond a single story.

We begin and end in somewhat of the same place; being troubled by the implications of lives lived with autism, whilst being called to recognise autism as an ontologically valid way of being in the world. At the start of the story, the brief Preface taken from her diary, Kate tells us of her imagined future for her child that has now been taken away, coupled with a pertinent reminder, ‘And yet she is the same as she has always been. Nothing has changed’. Where we begin with this insight to Kate’s sense of conflict, we are drawn back to it again at the end as the means by which a troubled relationship became rebuilt, as a call to hope,

With this new realisation I could hold her, love her, support her and accept her. Such a small shift in my thinking (that she might not be able to help it and it wasn’t a reflection of me as a parent or her as a brat), dissolved the stalemate we had come to and brought back understanding.

How was it encountering a single word, ‘autism’, offered such a transformative moment in the storied version of Kate and her family's lives? In the extended version of the story, we hear in detail about the everyday successes and failings Kate describes of her parenting. She continually calls into question her sense of self as a parent, recounting the strategies she actively chose and avoided in her child rearing.

Her now formal knowledge of autism cognitive theories reframed her understandings of her child’s behaviour, both those interpreted as positive (her high achiever status at school), and negative (her unusual interactions and unreasonable behaviour). Without explicitly naming cognitive theories of autism, Kate subtly weaves their explanations of behaviour through the narrative of Amelia’s development, hinting to a reader with prior knowledge of autism as an explanatory tool. When read through a lens of autism theory, Kate’s story reads as a comprehensive Autism 101 guide to identifying autism in childhood. By the end of the story, we learn how in the blink of an eye, for Kate, ‘autism’ provided emancipation,

*The effect of this conversation on me was immediate. That it was possible that neither my daughter nor I were to blame for her behaviour came as a revelation. My attitude towards her changed that day, and my recognition that there might be something different about her was all it took to shift the downward spiral. I made a conscious decision to change my reactions to her behaviour. If she had Asperger's, or another condition, which made her behave as she did, she would need support not criticism. With no further intervention than new insight, I was able to be more accepting and more loving.*

So dis/orientating is the breaking down of her relationship with her daughter that it appears to constitute a loss of self for Kate, or selves for the family. The disjuncture between Kate’s understanding of Amelia’s subjectivity is being called into question by a child she feels less and less able to know and understand; ‘I really felt like I was losing her’. We hear how Kate’s understanding of herself is tied inextricably to her daughter, and how the destabilisation of this is inherently social; Kate and Amelia come into being through their embodied entanglement of life,

It is not as if an ‘I’ exists independently over here and then simply loses a ‘you’ over there, especially if the attachment to ‘you’ is part of what composes who ‘I’ am. If I lose you under these conditions, then I not only mourn the loss, but I become inscrutable to myself. Who ‘am’ I, without you? (Butler, 2004, p.22)

McGuire (2010) contemplates that, faced with a sense of disorientation or loss, there is a ‘seductive temptation to quickly return to the former state of order; to ‘look for answers’....to give order to (a) disorder’. Kate narrates such a quest in searching for meaning in Anna’s actions, to resolve the vulnerability of uncertainty in her family's everyday lives, a resolution storied by the answer of autism as explanatory tool. Kate recognises the contradiction of such powerful explanations, ‘*And yet she is the same as she has always been. Nothing has changed.’*

This story in its written and lived form has provided a powerful discourse for Kate and her family. Being able to situate her experience within an ontological framework of autism has reframed what came before, what is lived now, and her expectations of her family’s futures. This is a productive entryway into the rhizome of their family life. In valuing the power and stability that is offered by this autism story, it frames how I have come to understand and relate to the Goodwins in this project, in being invited to enter through at the same point of the rhizome, here was my entry to connection.

We are left with a storied sense of living happily ever after; I met Kate and the Goodwins three years after this particular story’s ending. Three years later and four more (including dad, Craig) autism diagnoses. I wonder what the written storying of autism would look like if penned by Kate now, if it would be entered at the same point and narrated with the same commitment to coherence and the same talk of autism. Without this to rely on, I move forward with the storying I have made having met the Goodwins and spent many hours ruminating on the subject of ‘autism’ with Kate. I focus on an aspect of my time spent with Kate that is implicated within her diagnosis story but never explicated. Perhaps this framing isn’t one that Kate drew on at the time, although I hear it reflected back in the story as a result of our conversations; a turn to brain-centred personhood.

## Talking of autism as brain-centred personhood

Kate’s story speaks to a politics of neurodiversity, in which the claim to a different (but importantly not deficit) functioning of the brain lies at the centre of calls to identity (Blume, 1998; Singer, 1999). This is a narrative introduced earlier of the child constituted by neuroscientism, who is subjectivated through discourses of brain metaphors. Neuroscience has extended beyond brain imaging in laboratories into schools, homes, assessment centres and public discourse (Rose & Abi-Rached, 2013). It is not surprising that ‘brain-claiming’ was a familiar plot line in more than one parent’s story of their children. Ortega’s (2009) ‘cerebral subject’, described as an ‘‘anthropological figure’ that has no reality prior to its performative embodiment’, is a subject that I want to explore in relation to the parents in this project. Here, the ontological foundations of subjectification require an interrogation of the ways the self (or in Kate’s storying of her children) is constituted in cerebral terms (ibid).

The discourses of identity that Kate drew on in particular were very strong and seemingly consistent through our conversations. The cerebral subject narrative was threaded through much of our coffee and email exchanges.

*We talked about bodies and difference. Our own and autistic bodies. Kate sees that there is a big difference between having a different body and a different brain because we will probably have had fewer negative experiences come out of having a different body. She says autistic bodies are different and definitely that autistic brains are different. (10th March 2014)*

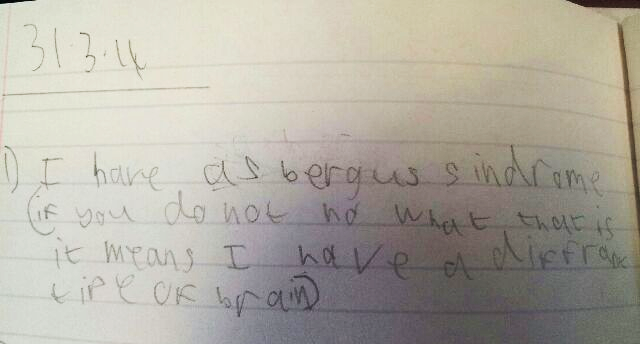
From email exchange after the initial conversation:

*From: Kate*

*To: Me*

*13/03/2014*

*Can’t remember what I said about disabled body vs brain experiences but I do think having a different brain which is invisible to others makes eliciting support more difficult than if you had an obvious body issue....No one would tell a wheelchair bound child that getting up the steps into school was just a pain barrier they had to push through would they? But if the steps are threatening, the wrong colour, the doorway to hell etc but your legs work you can be dragged up them kicking and screaming... You have to “get over it”... Right? That’s how it is for lots of autistic kids :(* (Personal correspondence, 13th March 2014)

I wondered how much of this liberation diffused into the children’s sense of selves, in relation to their label. Each of the children seemed to actively identify with the label of autism positively and as Kate reminded me, would introduce themselves as ‘autistic’ rather than ‘having autism’. Max certainly claimed his brain narrative as part of his school identity,  *‘I have asbergus sindrome (if you do not no what that is it means I have a differant tipe of brain)* (photo sent to me by Kate from Max’s school work, 31st March 2014)

In making autism cerebral, of the brain, Max and his mum tap into neurodiversity politics, which, often considered to exist in somewhat of an a-theoretical vacuum, can actually be explored in a broader context of brain-centred personhood (Ortega, 2009) and the neuro-self (Rose, 1990). The double-edged sword of brain claiming, in relation to autism, lies in both its emancipatory potential and its reduction of subjective experience. Luhrmann (2000) shows how a process of biologising that which was previously considered pathological can be positive, since to cite difference within the body,or the brain is liberatory, as ‘the body is always morally innocent’. Pertinent here is how body, brain, and mind slip into one another, not in a collapsing of Cartesianism into embodiment but rather in the reification of a disembodied mind. The brain here is considered an organ of the body and, therefore, without moral association. At the same time, this bodily organ constitutes a claim to personhood, an autistic brain that *makes* an autistic person.

This circulates around to the previously explored discourse of neuro-parenting. In a similar vein to the distance created between individual and difference by brain claiming, the distance between parenting and difference seemed to be a helpful one for Kate. At the start of the project, Kate had four children with autism diagnosis, by the end, she had five children and a husband all with a diagnosis. The outside world needed an explanation as to how a household becomes so full of autism and Kate needed a solid foundation for her family's narratives. I’ve been with Kate as she reveals the diagnostic labels of her children to other people, I’ve watched their faces. On more than one occasion Kate chuckled and rolled her eyes in recounting tales of people’s responses to finding out about the glut of autism diagnoses within their family. It would not be enough to let people wander around the rhizome of the family’s lives without a directed entryway. This involved a commitment to a stable, coherent narrative. The situating of this narrative around the brain clearly offered that as the means to ‘escape the omnipresent spectre of blame’ (Runswick-Cole, 2014, p.1124) that so often stalks parents’ narratives. Having a different brain was emancipatory for Kate and her children, in its cerebral form, the label of autism metamorphosised from stigma to a tool of liberation (Ortega, 2009, p.434). It allowed a nod towards the legitimising and legitimised theories of autism’s genetic etiology, whilst sophisticatedly avoiding the reification of brain dysfunction. Kate, and her children, embody to a greater or lesser degree autism pride; the bedrock of a neurodiverse persuasion. A different brain in their family was branded as central to identity claims and fervently against any deficit-discourse of brain functioning.

In a family of an autistic majority, this was complicated. On learning of his dad’s new autism diagnosis, one of the children poked fun at Kate, ‘We don’t need you now, you’re not part of our club. You wish you were autistic!’ he prodded. She laughed about it forlornly over coffee soon after. The irony was not lost on her. Craig’s recent diagnosis was not happenstance. Kate had long had a hunch and for quite some time prior to that had informally started using autism as an explanatory tool for hers and Craig’s relationship. During the course of this project, she wrote a book chapter reflecting on her relationship history through a new lens of autism and had clearly found a lot of comfort and explanation in re-reading their lives through claiming autism. ‘If he’s autistic then he’s not a twat’, she joked with me one day, whilst they were waiting for a diagnostic assessment. In the time running up to Craig’s assessment, Kate tells me he voiced his anxiety, ‘What if I’m not autistic and I am just a twat?’ Autism in this family was a de-burdening and a source of potential identity development; an invitation to remap the rhizome of their family lives. To claim autism, in its neurodiversity branding, in cerebral form, was emancipatory in the walls of that family home and in the family’s storying of their lives beyond it.

Here is a moment of the rhizome of autism’s talk. Kate and her family weren’t oblivious to the difficulties that came along with their everyday lives, as a family of autism. She expressed tinges of doubt for her neurodiversity-as-liberation narrative when reading the pitying look on people’s faces as they heard of her many children’s many diagnoses. She leaned towards normative, neoliberal understandings of the ‘ability’ side of the dis/ability complex in these moments. The rhizome contained slippage and movement as the narrative was challenged or temporarily disrupted. Maintaining and managing the rhizome of this particular entryway to autism was burdensome, convincing the outside world that her family weren’t in need of pity, but rather resources and support, required work. So here I turn to the broader strokes of what a neurodiversity politics makes possible and impossible in people’s lives.

The cautionary tale of those concentrating efforts on theorising neurodiversity warns,

If, on the one hand, seeing oneself as a cerebral subject bolsters one’s sense of identity and helps erase the social stigma often associated with mental pathology, it may, on the other hand, somewhat solipsistically narrow the notion of what it is to be a person. (Ortega, 2009, p.331)

Describing her children in metaphors of the brain was by no means a reduction of their subjective experiences on Kate’s part but a powerful narrative function in the family’s call for understanding and support from the outside world. It maintained the borders of the rhizome and controlled who could and couldn’t enter. I suspect neither Kate, Max, nor Craig and the other children, would wish to be confined to a self defined by the brain. Yet the claiming of the brain was necessary, a valid marking of difference required in order to seek out and maintain the support of services for her children’s everyday lives that Kate so often feared would be removed. As Runswick-Cole (2014) cautioned, in a critique of neurodiversity politics, such a politics does not exist in a vacuum but within neoliberal times and, even more pertinently, austerity. The hesitancy she holds for a neurodiverse politics, based on claiming an identity in which one is treated the ‘same but different’, is down to the danger of perpetuating a great binary divide of ‘us’ and ‘them’, which is helpful neither to ‘us’ nor ‘them’. The neoliberal call to identity is a call to be one of ‘us’, the ideal, able, economically productive self (Goodley, 2014). ‘Them’, the ‘Other’, are the undesirable, marginalised, who must be kept at bay through either intervention to integrate ‘them’ into ‘us’ or a demonstration of status as a ‘worthy them’, the impoverished, handicapped, vulnerable members of society that a paternalistic state can protect (Runswick-Cole & Goodley, 2015). Enacting a ‘worthy them’ status, in which impairment is recognised and made visible, is a necessary performance in the neoliberal agenda to gain access to support, be that financial, educational, or health related. Claiming a ‘same but different’ politics, Runswick-Cole (2014) highlights, is a risky move; where difference becomes too far removed from being understood as impairment, the risk of state support (in all its forms) rolling back becomes magnified in times of austerity. Without an autism-as-impairment narrative, Kate’s family would have their ‘passport to resources’ (Mallett & Runswick-Cole, 2012) revoked.

So here we return to the sophistication of the lived experience of families’ autism narratives, in which identity politics are negotiated, woven and flexible across time and space. The narration of family life was subtly rhizomatic (weaving and becoming), whilst also disciplined in its maintenance (structured and patrolled). Kate maintained a tight grip on a number of ways of talking of autism, which could be mobilised differently depending on her prediction of the most enabling narrative. The claiming of a different brain was a highly interpersonal narrative within her storying of her relationships with her children and husband and provided the means by which the family evolved individual and collective identities. Almost simultaneously, Kate could close her palms around the claim of ‘same but different’ in another context and open her other hand to neoliberal impairment narratives in order to access the educational support her children required.

*I am currently battling the LA\* to get him (Max) an EHCP\*\* to protect his educational support which is in danger of being withdrawn due to the sheer number of ‘Special’ children attending his school. Got Ed psych coming to meet him tomorrow - although he says he’s not going to talk to her! (*Email correspondence with Kate, 27th July 2015)

\* Local Authority \*\*Education, Health and Care Plan

Here are several branches of the rhizome of everyday autism in action; 1. The reification of autism as impairment in neoliberal times of austerity, 2. The ‘fight’ that parents of disabled children engage in to access support for their children, 3. The resistance of children to be subjectivated by professional practice, 4. The subtle resistance and negotiation of these rhizomatic branches by Kate.

I return to the implications of the rhizomes at work here in Chapter 8 ‘Being’, in relation to Max’s (un)desirability as a neoliberal school child.

## Talking of autism as emotional labour

Here is another rhizomatic departure for autism, another entryway, another way of knowing and relating. What follows is some of Rachel’s talk of autism in her and her family’s lives.

*So, there I was several months into my second year of the project and in need of more families and children. Having done the formal network routes I decided that a friends and family approach might be more productive. I started with an email to one of the mum’s in my research project already. With two children at a nursery and a special school I felt confident that they would have playground acquaintances that might be interested. So I penned a quick email asking if she could just ‘pass my details on to anyone you think might be interested’. My general experience of the world of autism is one of such networks and support that this seemed like an obvious option. The reply I got surprised me but was one that I brushed off and moved on from with little thought until now.*

*‘Asking the wrong person, I avoid other autism parents where possible!’*

*I was initially struck how this was unlike the vast majority of ‘autism parents’ I had come across in the past, like I say, being part of support groups and networks seemed to be common place. I also had a little chuckle at the turn of phrase ‘autism parents’. Kate had another turn of phrase for her and her gaggle of parents-with-autistic-children, ‘special parents’. This had been a running joke in the playground after the headteacher at one of her children’s schools had said they were, ‘very interested in and committed to the special children’. (Notes from April 1st, 2014)*

Katherine Runswick-Cole’s (2013) chapter considers the emotional labour that resides in the everyday lives of disabled children’s families. Hochschild’s (1983) study of the emotional labour of those in the service industry spoke of the investment of being ‘nicer than natural’, in order to suppress one’s own emotions so as to produce and/or regulate those of another. The very idea that the performance of a particular emotion serves to perpetuate the norm in a particular context, Steinberg and Figart (1999) and Runswick-Cole tell us, goes as far as to define this act as a cultural performance.

I am drawn to Rachel’s avoidance of other ‘autism parents’ as a moment in which I feel emotional labour is at work. I do wonder if Rachel considers this an avoidance of having to manage a particular norm of what it means to be an ‘autism parent’, with which she doesn’t share an allegiance. To make a conscious effort to avoid engagement with these ‘peers’ would possibly suggest this. I wonder what she feels is going on within the exchanges she has, or has had, with other ‘autism parents’ that has led her to the decision that she’s better off without them.The next time we meet, I ask Rachel specifically why she avoids other ‘autism parents’ and how this had struck me as unusual, compared to the highly-networked parents I was used to coming across. She told me she had become disenchanted by the promise of ‘support’ from either parent networks and/or the ‘autism community’. Upon Sophie’s diagnosis, she had attended a National Autistic Society parent meeting and been so put off she chose to actively avoid such networks again. She recounted how it had been a collective sharing of horror stories and woes that she had found neither helpful nor comforting. Since then, she had taken up what she called an ‘information based’ approach to her contact with the world of autism, relying on her own abilities to seek out relevant advice as and when it became needed. She made it quite clear that she didn’t find talking to other parents useful for her or her children. ‘A very autistic approach to autism, I suppose!’ she joked. I remember Rachel sharing stories of family and friends’ well-meaning offerings of autism cures, remedies and smoothies when Sophie was diagnosed and how tiresome it felt. She had a similar bone to pick with the ‘autism community’, which she recognised as being exclusionary for her daughter and, at times, offensive.

‘The autism community doesn’t speak for my daughter,’ she told me. She also professed to no longer talking about ‘autism’ and not ‘using the A word’ with people any more because of the endless intrigue, lists, advice and chatter people wanted to have as soon as they learned her children’s diagnosis. For now she was using ‘learning disability’ instead, as this seemed to invite far less from people in conversation.

*I do think the people with more negative stories are silenced and ostracised within the 'community' though. When I told a fellow participant at an autism event that I could not think of a single advantage of ........ having autism she was horrified at me and after casting around desperately for some stories of special savant abilities or the like (yawn) told me that it MUST be a blessing in some way, maybe it has made me a better person to have a disabled daughter? This was just the most woeful attempt to make a real family story fit an ideology, however awkwardly. However I rather suspect the lady in question was an Aspie self-advocate and had her own personal/emotional investment in the blessing/neurodiversity discourse - which I understand up to a point until it is imposed on me... (email exchange with Rachel, 1st May 2014)*

Rachel sounds to be enacting emotional labour here. In this email she was, and always is, polite and smiling even through occasionally, seemingly gritted, worn out, teeth. It seemed a real conflict for her to be confronted so often with a claim of autism identity for her children that she didn’t identify with. The material reality of Rachel and her children’s lives was not about the formulation of their subjectivities as autistic but the everyday practices and challenges of mundanity. Her ‘real family story’ did not neatly fit with a neurodiversity narrative, which seemed to butt heads ideologically with their lives. This wasn’t a devaluing of her children’s identity in any way, rather that the neurodiversity movement only served to further marginalise her children’s and family’s experience. Though perhaps well-intended, this narrative created a blockage in the rhizome, it drew towards an orientation that closed down options and became problematic. It drew towards the ‘dis’ of dis/ability at the expense of Rachel’s claim to hopes of some salience of normative development for her children and discounted the material difficulties her and her children faced as a result of their impairments. Instead, Rachel set up shop *within* the dis/ability complex and maintained dis/orientation; both rejecting at times narrow ableist claims that excluded her children whilst also needing to reject neurodiversity claims that were also marginalising for her children and their experience.

It may have been noted that so far our rhizomatic talk of autism has circled around and been guided by mums rather than dads. I am mindful that this is neither accidental nor neutral but reflective of the wider feminist call to the role of mothering practices, particularly in relation to raising a disabled child (Ryan & Runswick-Cole, 2008). I’m reluctant to fall into the trap of ‘gender blind’ research (Traustadottir, 1991) by over-using the term ‘parents’, when in fact, up to this point, our attention has solely been focused on, and directed by, mothers. Dads do enter our rhizome through a different entryway, in the community collective at the allotment, so I do not want to over-essentialise the point. For now, it is with a keen eye on feminism that the rhizome of autism as emotional labour is framed.

Notwithstanding the complex debate of ‘care’ between feminist theories and the Disabled People’s movement (see Hughes et al., 2005 and Watson et al., 2004), I orientate our gaze upon this Saturday morning Football Class through a feminist framing of care and emotional labour. The tiredness I read into Rachel that morning was more than the sum of psychological and emotional stress reported by parents raising a disabled child though, interestingly, such literature claims parents of children with an autism diagnosis experience higher levels of stress than parents of children with other disabilities (Hayes & Watson, 2013; Dunn et al., 2001). Rachel was not just worn-out by the experience of parenting her children and accommodating their needs on a daily basis, but also, as I would see it, through a different entryway in the rhizome; the care and labour of mothering a disabled child. Discourses of idealised mothering have long haunted the experience of parenting premised on the unspoken and naturalised socio-economic imperative of women to undertake the bulk of child rearing and unpaid caring (Burman, 2008). As we heard in the literature of familization, that idealised parent and family life, which produces the normatively developing child, is a powerful discourse. It’s premised on the ghostly spectre of ableism, the idealised child who is the picture of the ideal, sanitised, invulnerable, aspirational body (Kumari-Campbell, 2012). It is perhaps no surprise then, that in ‘...the almost inevitable misalignment between expectation and realisation, fantasy and actuality’ (Rose, 1999, p.132), parents of disabled children, as heard in Rachel’s story, contain emotional labour. Rachel was never *just* a mother bringing her child to a Football Class, she was a mother containing and negotiating the caring complexes of fighting for resources for her children, for respite for their family, for managing and maintaining their family’s relationships with professionals and the outside world. Singing and dancing along to ‘Here we go round the mulberry bush’ was perhaps the epitome of the ‘delight and drudgery’ of care from a feminist perspective (Benn, 1998 cited in Watson et al., 2004).

Ryan and Runswick-Cole (2008) offer a perspective on the labour of mothers of disabled children in the move from ‘advocate to activist’ (p. 43). Such a shift from advocate to activist was not part of a collective identity, formulated around ‘support groups’ for Rachel, but a micropolitical engagement in everyday interactions, in which she sought to resist conceptualisations of her children’s experiences and their family life that she found disempowering or exclusionary. This took the form of ‘internal activism’ (ibid) rather than the far end of the ‘activism continuum’, ‘external activism’, in which mothers’ campaign for broader social change for disabled children (ibid). Rachel was polite, energetic and stoic in every conversation we had and in every email exchanged. She was working hard to maintain ways of relating to autism and learning disability that could be understood by the outside world, whilst remaining faithful to hers and her family’s experience of everyday life. She negotiated dis/orientation daily in the micropolitical interactions we’ve heard; drawing towards and pulling away from orientations that opened up and closed down her claims for both her children’s *dis*/ability and dis/*ability.*

I return to some of the threads of this labouring process in Chapter 8 ‘Being’, in relation to the rhetoric of parent/professional partnerships in education policy.

## A (temporary) new entryway to rhizome: intervention

In re-presenting the positioning and storying each family told about their relationship with/to autism, it has become somewhat inevitably oversimplified. Each of the parents, even those like Kate with a great investment in a specific storying of autism, did not solely narrate it in such a tidy way unremittingly; the rhizomes always managed to spread and spill over the edges, despite border patrol. Having watched a BBC documentary about autism and Applied Behaviour Analysis (Lovaas, 1987), in which a boy was given intensive ABA therapy to broaden his diet, Kate reflected on a fleeting attraction to the therapy, despite her usually staunch view that ABA violates autistic identity - in keeping with a neurodiversity narrative. At the moment she shops and cooks for at least four different meals, per family meal, per day, to meet each of her children’s food preferences and requirements. What if ABA was the means to an end that could see this routine changed and her family able to go out to eat at a restaurant? It was clear through the conversation that she wasn’t by any means going to go out and adopt ABA into their lives but she conceded briefly that a removal of, what ABA would term, ‘autistic traits’ could lead to an improved family life. As micro as this may seem, it is a glimpse of the necessity in parents’ lives to call on a number of resources in crafting their stories with autism, which at times conflict with the identity positions they work hard to develop in their relationship with it.

Rachel, perhaps by having younger children, perhaps influenced by her background as a teacher and her PhD subject, had a keen interest in intervention, the details of which can be saved for her thesis rather than mine! However, the brief mention of ABA is worth some attention due to its dominant narrative in mainstream autism intervention discourse spanning the last three decades. ABA was the first intervention Rachel tried with her first child, Sophie, which she spoke about with mixed feelings. In some senses it had been invaluable; previously, Sophie had little safety awareness and would run into traffic. ABA intervention stopped this, for which Rachel was grateful. Beyond fundamentals of survival and safety, the intervention had left Rachel wanting as she no longer found any benefit for her or Sophie. In an email exchange about play, Rachel voiced her feelings on the intervention,

*We started out with a very normative, narrow idea of play partly because the first intervention we tried was ABA therapy - the idea being our children weren't playing 'properly' because children of that age 'ought to' be doing pretend play, dressing up like princesses, etc. One of the exercises we had to do in ABA therapy was to teach Sophie to do a teddy bears' picnic and pretend to pour and drink imaginary tea. She saw no point in it and neither did I really, but the ABA therapist assured us she had to learn to play properly. That's one of the reasons I'm so positive about Intensive Interaction - it has a much wider concept of play - i.e. watch what amuses your child, join in, have fun and laugh together, establish a connection and that is good play. We've had a lot more fun since we became more flexible about what constitutes 'play'! In fact in Sophie's PECS book the symbol we use for her to request Intensive Interaction is 'play' - they're pretty much interchangeable concepts to me. I.I. has been the only way into joint play for us, the alternative being solitary play by Sophie (which she continues to enjoy also).*

Within an intervention rhizome here, crafted for this thesis, two parents are brought together in dialogue about the purpose and usefulness of particular discourses of autism in their children’s lives. Both cannot rely on static discourses, for their lived experience is far more slippery than a singular relation allows. Where Kate usually presented a singular coherent narrative of neurodiversity, in which ABA would be vehemently opposed as damaging to her children’s autistic identity, she concedes, even temporarily, that there is appeal in the intervention for its potential to improve the quality of their family's everyday life, or at least reduce her shopping list. There is a desire for the normative abilities, the ability side of the dis/ability complex that surround family life, food and a varied diet. Rachel had woven her narrative of interventions like ABA around an even more subtle acceptance and rejection of its usefulness to her and her children. Both parents had to draw on multiple ways of relating to, and talking about, autism and their children. McLaughlin and Goodley (2008) speak of the ways in which parents of disabled children accept and reject certainty in the children’s lives at different times, for different purposes. In much the way Kate mobilised particular conceptualisations of autism and her children’s lives, dependent on the most enabling outcome, Kate and Rachel’s interaction with interventions such as ABA relies on a similar negotiation. Rachel desired much of the normative developmental trajectory for her child that ABA could at least initially, offer. She had to negotiate the slash of the desirable yet exclusionary ‘ability’ of the dis/ability complex in relation to ABA as time went on. The ‘abilities’ ABA was aiming to develop became recognised as less desirable over time; Rachel brought the ‘dis’ to dis/ability as she dis/orientated narrow conceptualisations of play. I continue to weave through the negotiation of acceptance and rejection of certainty from another entryway now, the collective talk of the community group; this is a rhizome of biosocial autism.

## Collective talk of autism

My final turn to the talk of autism is in and around the project’s collective, Producing Autism. In thinking about the talk of three families and how autism is constituted between them, I want to consider the biosocial work at play in its formulation and evolution in this group of families and how it has come to be, through a collective bid, both for and against certainty in their lives at different points. I begin with my serendipitous meeting of one of the Producing Autism parents and wander through a story in which autism is talked of, and lived, in a muddy, overgrown allotment.

## Meeting Producing Autism

*Sitting in my office, lecturer hat firmly in place, an electrician comes in to check the lights.*

*‘Do you have any research projects going on here?’ He asks. ‘With kids?’*

*‘No, not that I know of,’ shoving my lecturer hat into the bottom drawer, ‘but I’m doing a research project at the other university for my PhD. With autistic kids and their families.’*

*‘Oh, right.’ he says. ‘My kid’s autistic. I’d sooner rather he was normal though.’ he smiles.*

*‘Oh.’ I say.*

*‘I just don’t think he’s as happy as his sister, you know. Ah, I don’t know.’*

*I offer to share the parent information with him and scramble about through my hard drive looking for it. We continue our autism chit chat and niceties. His son doesn’t have friends, he’s conscious that that might bother them, as parents, more than it does him. As I bash the printer politely to kick it into gear he hands me a business card.*

*‘We’re setting up a charity, me and my wife and some other parents with autistic kids. We all met at the diagnosis place. We’ve all got kids the same age.’*

*I look down at the professional looking card, there are carrots strewn underneath the words, ‘Producing Autism’. I chuckle.*

*‘We’ve been given four plots up at the allotments, you know it? We’re trying to get funding at the moment, BBC Radio Sheffield are doing a thing on us. We’re going up on a Sunday with the kids, it’s mostly just clearing out at the moment, it’s completely overgrown. We’ve been going about five weeks. But the kids seem to love it, being outside I mean. You know a lot of them aren’t very good with food so we’re going to teach them about it and perhaps if they plant it and see it grow and understand where it comes from then they’ll eat it, you know.’*

*He looks down to the information sheet I’ve handed him. ‘We’d love to take part.’ he says. ‘We just need help, we don’t know about autism other than our kids. So we just need help.’*

*‘I’m not an expert,’ I say. ‘You’ll know a lot more about autism from your children.’*

*‘Yeah yeah, we’ve been on some of those courses up at the centre, but you know. We’re having a friends and family day on Sunday. You’re welcome to come down and meet everyone.’*

*‘I’d love to. I’ve grown a couple of tomatoes in my time.’ I boast.*

*Sunday 6th April*

*10am. It looks cold. And like it’s going to be rain all day. I totter out of the door in my best outdoorsy, I-ain’t-scared-of-mud attire and worry that my floral notebook might get damp.*

*I wind up the side streets of Sheffield’s hills and arrive at the dirt track end of the allotments, which leads to the Producing Autism plot. Another of the dads, Paul, meets me at the gates, picks up my out-of-Sheffield-accent immediately and we break the ice with geographical chit chat. We reach the plot and I’m bowled over. It’s huge. It’s green and twiggy and muddy and HUGE. Pockets of adults chatting and digging and pulling and snipping are dotted in every direction. I’m met by the electrician, who goes by the name of Jacob and am quickly chauffeured in the direction of ‘our autistic kids’.*

*‘The two little gingers are mine.’ Jacob chuckles. ‘Ben is the autistic one. Jill, let me show you this that he’s done. I kept it aside to show you.’ He hurries to a colouring book and produces reams and reams of paper with different coloured felt tipped numbers written in rows and columns.*

*‘Look.’ Jacob says. ‘He loves numbers. Writing from 1 to 1000andwhatever. It’s all he does. Home from school and numbers. He loves them.’*

*It’s impressive. There’re a lot. I’m not entirely sure what to say. I feel like there’s a pause in the air for my ‘expertise’ to step in.*

*‘Wow. He clearly loves it doesn’t he? Cool.’ They’ll be dead impressed with that Jill.*

*I take the grand tour meeting people and children along the way. The site extends in every direction with raised beds, orchards, bird-watching dens and big, big plans. Jacob demonstrates the height and volume of plants and mass that had come before them and makes it clear that they’ve already achieved a huge amount in a short time. Grandparents potter by in gardening gloves reminding us that perhaps some planting needs to happen some time soon. Like now. Throughout the morning there are continual chirps of ‘none of us are gardeners you know’. We chuckle together as we stumble across another sprouting green, unsure of its origins or its future. There’s some hacking at what is a suspected artichoke. But it smells a lot like celery. Is it celeriac? Maybe. No idea. Collective conclusion. No idea. Let’s take a photo and Google it.*

*Weaving in and out of the beds, the cuttings and the overgrowth are clumps of children. Mostly small and in ones and twos. There’s little supervision and guidance and the children are free to be in all their forms; Spiderman, Iron Man and countless worm-samaritans.*

*There’s a brief flurry of chaos as calls across the plot of ‘has anyone seen Fran?’ are met with grumbles, sighs and uncertainty. The kids are hollered, ‘Is Fran with you?’ they barely look up from their muddy adventures, but no, Fran isn’t with them. Having surveyed the open spaces up and down the plot, it is apparent that Fran is not there. Calls turn to louder shouts and casual glances turn to thorough scouting, in bushes over fences and deep into the thick overgrowth at the back of the plot. Fran’s parents pick up their pace and the tone of the calls has a heightened sense of concern. From what seems like a long distance off, ‘got him’ echoes back to the main plot.*

*‘Got him.’*

*‘Got him.’*

*‘Got him!’ reverberates over the fence to those that had been looking further afield.*

*Paul trudges out of the overgrown peripheries with Fran over his shoulder, plank-like and indifferent.*

*‘He was all the way back in the middle of the thorns!’ they exclaim. ‘Right in the middle just sitting there!’*

*Sighs of relief and light-hearted joking are shared amongst those of us still digging and we move on to sharing stories of childhood nettle stings and bramble prickles.*

*I’m called to the decked area to meet others and tell them about my project. I’ve already been introduced to each of the parents with autistic children over spades and nettles. The formality seems to detract from that. Fortunately, those from Radio Sheffield override this pretence with their formalities and start discussions about a day over the school holidays to get the ball rolling. There’s a brief flurry of talk about post-diagnosis experiences from parents. A relief. Frightening. Sighs. An individual, diverse, but collective experience. The three children here were all diagnosed at the same time. That was how the parents found each other and the group started. Paul explains how and why they feel their collective is so important, ‘I have friends who haven't got children with autism they don't understand it. They try, but they're not on the same page as what we are, but as a group, you defend each other, and you know everyone's going through the different ups and downs of autism. We get together, and we support each other through good times and bad times. But there's only us who know. That's why we've, sort of, bonded together really well.’ There’s a lull.*

*‘Are autistic children’s brains like the brains of people with dementia?’ Paul asks, turning to me. He had seen pictures of dementia patients’ brains on a training course at work.*

*‘They looked similar. Are they similar do you know?’ he wondered, in my direction.*

*‘I have absolutely no idea.’ I said.*

## Autism as Biosocial

In the ever-evolving UK Disabled People’s Movement, there was cause for pause on the emergence in the late 1960s of what has been variously termed ‘biological citizenship’, ‘the citizen patient’ ‘biosociality’ (Rabinow, 1996) and their associated communities of ‘condition based consumer groups’ and the ‘social movement in health’ (Hughes, 2009). This biosocial movement in health draws on the notion of ‘community’ developing out of biological similarity and an ethic, which bears similarity to the neurodiversity movement. Such biological citizenship affords newly empowered citizen patients ownership of, and in, their health-related lives; it is a movement which embraces both political orientations and medical expertise with individuals (and their collective identities) as central facets. Hughes (2009) sees such communities of shared identities as evolving ‘condition-based consumer groups’ who are contributing to, and shaping new pathways in medicalised and political arenas for individuals with particular diagnoses. Diagnosis, he tells us, becomes a ‘calling card that is central to their claims of identity’ (p.679). Again, the parallels with the neurodiversity movement are apparent. To be diagnosed as autistic is to claim citizenship within the particular identity politics of such a group.

Such a politics was one that parents often drew on for themselves and their families. Groups and networks were part and parcel of all but one parent in the project. The diagnosis of their children had given them a ‘calling card’ of parent-of-an-autistic-child, which had led them to seek out, or be thrust into, certain formal and informal condition-based consumer groups. One parent was an active member of no less than five different groups associated with parenting a disabled child. Hughes (2009) suggests that such groups ‘...provide for members some existential and emotional anchorage in a world infused with biological precariousness’ (p.682). It is noteworthy to stop and consider membership of such groups from the perspective that it is not in fact the parents themselves who have been afforded such biological citizenship but their children. Here is the slippery ethics of advocacy that McGuire (2010) cautions in how one speaks of living with disability. Again, however, in recognising the weaving of such processes as always already connected in the rhizomatic becoming-of-autism, then this bleeding of boundaries between parent and child is simply another resting point.

Where both Rachel and Kate seemed relatively confident in their talk of autism - ideas and opinions formulated, texts digested, support deployed - the same didn’t seem to be apparent with the parents of Producing Autism. The rhizomes of Kate and Rachel’s talk moved more slowly, having gathered weight over time, and were more likely to return to familiar entry ways and rehearsed paths. The parents of Producing Autism were in the early stages of spreading and weaving their multiple, collective, connected becomings-of-autism. They were all in the relatively early stages after diagnosis and were keen to remind me, and others, of their lack of knowledge about autism beyond their child. Their calls to expertise and humility in their own expertise can be read through the story of my first coming into contact with the group and my first visit to the allotments. They sought out connection, actively extending their rhizome outward and rapidly; their enthusiasm for expertise, the BBC campaign, the invitations to family members, all of which took place in/on a public, social platform; an allotment.

Part of this spreading rhizome, the distribution and collecting of autism knowledges, is resonant with McLaughlin and Goodley’s (2008) seeking and rejecting of certainty. There seemed to be a shedding of the desire for ‘normal’ over time that dispersed its way through the group, from shared stories, experiences and spending time on the allotment site, through to a grasping of it at times in which it provided some semblance of certainty. The experience of having met one another, during each of their son’s respective diagnostic processes, had been an experience of individual families and collective identities seeking out and being given certainty; an autism diagnosis. The call to medical knowledge as a call to certainty is shown by Paul in his quest for autism knowledge when he asked me about brain imaging, as can Jacob’s sharing of Ben’s number writing, specially set aside for my attention. From this seeking of certainty through a desire for expertise and particular forms of knowledge of autism, the collective began to negotiate a far more nuanced corpus of autism knowledges than the certainty of medical (or otherwise) expertise afforded them in their early rhizomes of autism talk.

Jacob had first introduced himself to me with, ‘My kid’s autistic. I’d sooner rather he was normal though’. During a chat with Paul on another sunny Sunday at the allotment, we talked about the families’ hopes for what the allotments would offer their children. The seeds were sown for the idea of the allotment between the families when Paul realised his son Fran wouldn’t cope with environments he’d envisaged for his childhood, like Scouts. Encountering uncertainty here, which McLaughlin and Goodley (2008) would see as an opportunity for creativity and critical agency, the families pushed outside of the potentially marginalising positions of excluded children and families; they got themselves an allotment and registered as a charity. Within the same conversation, Paul teetered along the dis/human slash of dis/ability and was drawn back to the complexity of desiring normality in his and his child’s lives. When talking about the charity’s plans he used the word ‘normal’ but quickly retracted it, ‘I don't like saying normal - a straightforward lifestyle as we can give them, you know, encourage them to have a pretty steady-going lifestyle’. For the most part, the families seem to have conceded that ‘normal’ wasn’t the best description for their families, Paul seeming to spend time thinking about, and questioning, his own relationship to normal with both sophistication and his dry-wit; ‘there’s nothing that normal about any of us here’. It was perhaps this recognition that had brought them together in the first place, the desire to create a space in which ‘normal’ wasn’t so highly prized and the pressure to strive for it relieved.

## Rhizomatic knowledges of autism

There was a relative nervousness in the group’s talk of autism, and a continued to turn to me as ‘the expert’; Paul’s curiosity about the autistic brain and his turn to my knowledge of it, Jacob’s plea for knowledge about Ben’s desire for numbers. The transition of expertise distributed between us has changed over time and there seems to be a greater recognition of the parents’ expertise now through their achievements over the last year. Their confidence in ‘knowing’ autism and speaking of it has spread as quickly as the weeds that continue to rampage through the allotment. This knowledge hasn’t been gained through academic texts but through the community, through their Producing Autism. Through spending time digging on an allotment and tracking how and where their children do and don’t enjoy playing, their talk of autism has moved from shaky to collective. This knowledge has grown through the production of produce; through growing gluts of apples and the making of apple crumbles. It epitomises the rhizome. This speaks to an embodied way of knowing and coming to know the world. It goes beyond discursive talk and into shared experiences. In coming to understand the children’s love of the allotment plot, the parents talked to each other and learned from sharing embodied experiences with their children on the site; from scooping them up when they fell, from sharing their delight at another saved worm. They watched from a distance as Fran toddled off into small secluded spaces, respected Ben’s desire to entertain himself and revelled in the freedom to roam that this plot offered Tom and all of the children. Here was a site of new knowledges; to share and come to know children and autism that was more than discourse, it was embodied, tacit, muddy and unruly. The knowledge that courses for parents of diagnosed children had given them was enmeshed and superseded by this development of an embodied sharing of experience.

*I find myself gravitating towards a jingling that I hear coming from the ‘sensory area’. The parents had been chipping away at this small corner of the plot, a small clearing amongst the trees, as a designated space for all that was sensory. Some new visitors (volunteers) had spent the previous Sunday gathering, crafting and installing contraptions that appealed to the senses. Ahead of me I catch the glint of a newly hung mobile hanging on a branch sculpted out of dessert spoons dangling from string. Entering the space the light changes under the dense cover of the trees seeming far removed from the vast expanses of the plot behind us. It’s quiet and somewhat mesmerizing. The improvised cutlery wind chimes tinkle and clink providing a soundtrack to Fran who is circling the upstanding tree trunks arranged in the enclosed space. He hops from one to the next rhythmically and systematically becoming occasionally stopped in his tracks by Stephanie, one of the younger siblings, who cautiously stretches her tiny legs from one stump to the next. There’s an old candelabra atop a fencepost that teeters and occasionally clatters against a child’s body toppling from a tree stump. The metallic sounds perforate the gentle breeze through the trees and twittering of birds, the shiny surfaces in amongst the greenery creating dancing patterns of light across tree trunks.*

The sensory area was an amalgamation of several different autism knowledges; those *given* to parents by professionals, those sought out from each other and those developed by and with their children on the allotment site. The resultant physical space speaks to the potential of rhizomatic autism talk; how embracing many possible versions of autism discourse, of multiple knowledges, can be productive in the everyday lives of children. It is the epitome of the value of multiplicities in autism knowledge; social theory, developmental psychology interventions and the sophistication with which parents of disabled children meld and break the complex rhizomes of knowledge in their material, mundane everyday lives.

It is at this juncture of the talk and embodiment of autism, that I move towards the ‘Being’ chapters.

## 

## A Striation

Chapter 7 ‘Talking’ has made the case for considering the talk of autism as rhizomatic, as ever-becoming, weaving and spreading outwards in multiple directions. In staying with Deleuzoguattarian thinking tools, we come here to a blockage in the rhizome, a striation. Where the knowledges and talk of autism that were spreading and becoming throughout Chapter 7, in this next story, our route is blocked. We butt up against this space (or lack of) of striation in which autism talk, and knowledges, become singular, reductive and fixed. I include this story here as representative of a common experience that I have as a researcher interested in autism but not particularly interested in positivism and occasionally troubled by neurodiversity politics. It highlights the temporality of any rhizome, always at risk of blockage and striation, and problematises some of the ways in which that comes to be and what can be done to negotiate those blockages and work around their edges to new lines of flight.

# Chapter 8

# Being

This chapter invites a dis/orientation to ‘being’ a disabled child or living as child, autistic, disabled. It takes the form of two sections, 1. Being in Education and 2. Being and ways of knowing. ‘1. Being in Education’ stories the un/desirability of labelled children in schooling. It takes a dis/child framing to interrogate what we desire and resist in the production and reproduction of the neoliberal school child. ‘2. Being and ways of knowing’ considers the well-worn lines of particularly dominant orientations towards autism and childhood and asks what happens when we wander away from those lines and begin to dis/orientate. It is framed by embodiment and valuing embodied ways of knowing and being known. The two sections come together to navigate the questions,

*‘2. How might we consider being autistic as part of being a child?’*

*‘3. What does autism make im/possible for a child to be and become?’*

*‘4. What does autism do to/for/in education?’*

‘8.1 Being in education’ uses a turn to the dis/child (Goodley and Runswick-Cole, 2014) as tool of dis/orientating education for children labelled with autism. Here, the orientation gazed upon is that of neoliberal school child who is desired through academic achievement. Dis/orientating, by means of a dis/child analysis allows the ableism embedded within dominant orientations to education to be exposed and explored. Using a story of The Goodwin siblings, each with labels but with very different relationships to desirability in education, we move back and forth between the slippery experience of striving for academic achievement whilst resisting its exclusive, ableist grasp; we dis/orientate.

‘8.2 Being and ways of knowing’ works through the potential of a dis/orientating gaze upon play, development and everyday family life. The orientation of development in the play and everyday lives of autism is so deeply embedded within the gaze upon childhoods labelled with autism, the routes that have been trodden time and again to arrive at such an orientation seem to almost maintain themselves. The turn here, to embodiment within a wider framing of the sociology of childhood allows for the problematising of the labour at hand in creating and maintaining this dominant orientation in which the play and everyday life of children is developmentally disordered and in need of intervention. Using attention to embodied experience as a dis/orientating tool allows us to embrace the potential of Titchkosky’s (2011) politics of wonder. Titchkosky’s (2007, p.3) thinking encourages a sentiment of dis/orientation, of always coming to ‘watch our watchings’ and ‘read our readings’ of our relating to the politics and lived experience of being disabled.

# Being in Education

Here I respond to my research question, *‘What does autism do to/for/in education?’.* Unsurprisingly, a lot of time spent talking with parents centred around education for their children, and of their children. This seemed to be a topic where the talk of autism became vital (in all senses). I bridge these stories and their potential (always multiple) analyses from the chapter of ‘Talking’ to ‘Being’, as I incorporate the talk of parents and the time I spent in a number of educational settings that some of the children attended. As McLaren (1988) cautioned, those in the theorising of education must attend to the production and reproduction of subjectivities through discursive practices that ‘penetrate the level of the body’ (p.69). Erevelles (2000) pointedly notes that where attention has been afforded to marginalised bodies through race, gender and sexuality, in critical education, disabled bodies have been omitted by and through the historical educational agenda of separating out disabled learners. It seems, as Erevelles makes the case, that even for critical pedagogy, disability is ‘...the boundary condition that resides just on the other side of hope...the condition that one must escape rather than improve’ (Ferguson, 1987, p.55 cited in Erevelles, 2000, p.37).

This chapter begins in the ‘talk’ of autism and moves towards ‘being’ contributing further to the questions, ‘*How is autism spoken about and how else might we talk of autism*?’ and developing a discussion of ‘What does autism do to/for/in education?’ Beyond this, it turns to dis/orientate our thinking around the question, ‘How might we consider autism as part of being a child?’ ending with ‘What does autism make im/possible for a child to be and become?’ It ends with a move towards a space of becoming which takes us to the final analytic chapter.

I start with a story of Max and his experience of education. This story is shared by his mum, Kate, and is interwoven with stories of his other siblings’ experiences of education. I use it to explore the dis/orientation of education that dis/ability, specifically autism, brings, and to consider how the dis/child can dis/orientate our understandings of what it means to be a child living in spaces of autism and schooling.

*We talk about the fact that Max is very well liked. He's likeable. He wants relationships but frustrates the school as he is uncooperative. An incident in which he refused to write a letter to his mum to tell her some facts about Neil Armstrong is something we stop to consider from Max's point of view. Kate has thought about and unpicked this after talking to Max about why he wouldn't do it. Kate metaphorically crouches down to try to consider the (lack of) purpose of the task from Max’s point of view and, with him, has drawn these conclusions.*

* *Why would he write his mum a letter when he could go home and tell her?*
* *His mum already knows about Neil Armstrong.*
* *His understanding of a ‘fact’ was new information that other people didn't know. He didn't know anything about Neil Armstrong that other people didn't already know.*

*Perhaps if the teacher had shared the goal, the real purpose of the activity, (we assume to demonstrate understanding of the information they had been learning about Neil Armstrong), that wasn't dressed up in pedagogic creativity then Max could have done the task, Kate says.*

*Kate tells me early on after we first meet that he's not happy in school, a mainstream where he is in year one.**That he'll struggle the most of all the children with mainstream secondary. That unlike two of his older siblings, he won't be given a scholarship to a private school based on an exceptional academic profile. Those siblings were often described as quirky, witty, and bright. But that more than any of his siblings he needed the small class sizes that they, in private school, were afforded. At parents’ evening last night, school expressed their frustration that he ‘didn't show them what he was capable of’, that they were well aware of his abilities but couldn't assess him at those levels because of his lack of cooperation. That he's definitely a mainstream child. Kate wants to know what’s so different about him compared to his siblings. Imagine being different at being different?! Doing difference differently. That must be pretty hard work.*

*On the rainbow chart, a behaviour monitoring tool, Max had begun moving his name to the red stripe of the rainbow. Red meant a child had behaved exceptionally badly and that their parents would be called and the child sent home. Kate saw this as Max's means of communicating how bad he felt and how desperately he wanted to go home. The teacher saw this as something to be ignored. If my heart had strings they would be pulling for Max at this point.*

*There was a lot of outwitting and manipulation going on between Max and school. He would often be conned into compliance -*

*Can you write three sentences for me? No?*

*Two? No?*

*One? OK.*

*(We only wanted one anyway)…..*

## The Dis/Child in Education

This story speaks to a dis/child framing of education, policy, and practice. If dis/humanism asks us to consider the aspects of a modernist conception of the human that we seek to desire and resist (Goodley & Runswick-Cole, 2014), the dis/child in education asks the same questions of childhood and pedagogy. In this story, we learn how ableism and resistance rub up against one another and seem to come into being almost in the same breath. A linchpin of neoliberal ableist childhood, academic achievement, is a site of this friction. Max’s older siblings, in achieving high academic standards, have been recognised by the neoliberal school system as both desirable and deserving and have thus been given access to a schooling context that better meets their needs; small class sizes. They are able to shake off their labels as disordered or impaired and instead are greeted with descriptions of a more desirable kind; quirky, witty, bright. The small class sizes of their public school are desirable for Kate’s imagining of Max’s current, and future, school experiences; he currently struggles the most with the size and busyness of school life and would stand to benefit from smaller, more controlled classroom environments. However, Max does not demonstrate the qualities (high academic achievement) that would grant him such access. In not meeting, or resisting, those normative, ableist standards, Max troubles his educators as ‘non-compliant’. His non-compliance challenges the pedagogic creativity of teaching activities, as can be seen in his understanding (or not) of the Neil Armstrong activity. His means of reasoning in this situation was unacceptable due to this alternative understanding of the activity’s intent. I suspect that had one of his older siblings articulated the same rationale for such an understanding of the activity they would be recognised as challenging in a desirable way; as ‘quirky’, a description that Kate tells me has often been assigned to the two eldest children. Max’s ‘quirkiness’ was framed as non-compliant, as he isn’t understood as having the academic capital (high achievement) available that would afford him the virtue of being desirably challenging. Instead, Max’s experience of schooling is one of being liked but frustrating, loved but dismissed. His siblings’ ableist achievements hark to narratives of autistic difference that is celebrated as being associated with high IQ and exceptional ability. The desirability for this version of autism, that which can be read as a ‘celebrated diversity’ (Rogers, 2011, p.993), is evident in the positioning of Max in relation to his siblings. Joe and Ruby were read as treading a different tension of the dis/child continuum. As their labels of autism slipped away, as trumped by their academic capital, they were potentially caught in a new bind. Both were subject to a desiring of their quirkiness and their academic achievement that left little room for their autism label. When autism reared its head, it came with an added weight of expectation; surely such a bright, quirky young man could not find such a trivial issue so difficult. Having to be re-read as autistic disrupted and challenged the flow of Joe and Ruby’s academic capital at times when their differing needs were apparent. Their desirability as the gifted, neoliberal school child was precarious, they were drawn in and cast out almost simultaneously; they lived the complex of the dis/child.

Children in the same family, with the same labels, were having very different experiences of school due to that rub of the dis/child; what we desire and resist in childhood and education. Desirability here is the promise of future economic production; the child becoming an independent adult contributing through labour. Max inhabits a risky space of resistance, one in which his potential for imagined future dependence (through non-compliance with normative educational achievement) leaves him open to marginalisation as less desirable than his siblings (Erevelles, 2000). High academic achievement would allow Max capital and access to a school that could better meet his needs; arguably a need of his impairment, his mum would suggest. In desiring this ableist accolade, Max also disrupts and brings into question pedagogic practice, which has to manipulate him into compliance.

In thinking about *how* desirability comes to be and gather weight in education, I now take a step back from classroom interaction to broader educational discourses; policy and partnership.

## Policy and The Dis/child

We need to continue to remind educators, at all levels, that people do not ‘have’ special educational needs. People may experience impairment but their educational needs are made special as a result of the ways in which we conceptualise and organise our education systems. (Penketh, 2014, p.1486)

Under the recent UK Coalition government rhetoric of ‘Broken Britain’ (Cameron, 2010), Michael Gove propelled a discourse of an equally broken education system. Education policy, specifically with disabled children in mind, drove the 2014 SEN Code of Practice (CoP) coming out of the Children and Families Act (2014). Ball (2013) reminds us of the ever-alluring modernist promise of policy as a means of progress; from an inadequate present to a bright future. Education policy for disabled children then, perhaps, is neoliberal ideology writ large. The discourse of participation, voice, collaboration and reparation (Penketh, 2014) to enact a brighter future for individual children, in which the adult, autonomous, labouring self is actualised, is nowhere more apparent than in the SEN Code of Practice (2014). In a return to the medicalisation of abnormalities (Ball, 2013), disabled children’s education becomes ‘special’ through ‘identification’ of support needs defined in health and, inevitably, medical terms. Disability and education here become driven not by pedagogy but pathology (Penketh, 2014, p.1488) and, in turn, to the service of market production; as can be read through the varying degrees of desirability, in relation to The Goodwin children’s status as autistic.

The conflation of education with the labour market is a broad concern (Erevelles, 2000; Bowles & Gintis, 1976) but is well-exemplified by the continual conflation of education and a child’s right to progress to meaningful employment and independence (DfE & DoH, 2013, p.49). Cruel optimism hangs in the air (Berlant, 2011). The recipe of the CoP discourse; mix the right support, with a pinch of valued participation and a smattering of parental partnership and, by the end of the CoP’s remit at age 25, the disabled child will have had the means to self-actualise into the economically productive, independent adult. Having high aspirations for disabled children has no doubt been lacking in education policy and practice historically but its individualised, market-driven repackaging certainly errs on the side of cruelly optimistic. Max was reminded of this in being storied as nothing short of very likeable, but frustrating and problematic. He resisted the bounds of the desirable school child, as his way of being, knowing, and learning did not readily meld with the assessment of those educational policy objectives that measure his progress towards adult economic productivity. Ruby and Joe, on the other hand, were, for the most part, as desirable as school children could be, as they could engage in the exchange that educational policy so desires, the being, knowing and learning, that meets and exceeds the markers of progress towards the idealised neoliberal adult. Such desirabilities, though mobilised in policy, were experienced through, and with, the Goodwin children’s everyday lives in schools. Max was left in the untenable bind of the dis/child in his classroom and interactions with staff and, as a result, hated the experience of going to school each day. Ruby and Joe recognised their desirability only too well; they experienced the everyday pressure of it in the pursuit of perfection in their work and the anxiety of maintaining the highest possible marks. Kate would often greet me with stories of the latest scramble of trying to pick one of them up from the depths of their very lived anxieties, having come second in the class in a recent test. So, though the mechanics of this neoliberal desire take place through educational policy discourse, the materiality, the lived experience of it, takes place very much within the bodies and minds of children every day, in and out of classrooms.

Partnership

As The Goodwin’s story suggests, and earlier in *Chapter 7 ‘Talking’* as Rachel’s storying suggested, parents are often right at the heart of the policies coming to bear on their children’s lives. As I will now briefly explore, parents are often situated as ‘partners’ alongside professionals, whether willingly or not. The rhetoric of ‘partnership’ is professionalised and families and children are brought into narrow, restricted, terms of participation in theirs and their child’s education (Rogers, 2011). The ‘joined up working’ of education and healthcare have been brought together in disabled children’s lives through such policy. Pausing on the rhetoric of ‘partnership’ between parents and professionals, Rogers (2011) explores the disharmony of such a discourse, pointing to its continued status as central to a disabled child’s education for at least the last three decades (Tomlinson, 1982) and, as Penketh (2014) notes, still going strong in the prominent CoP (2014) today. Within this rhetoric, there is a heady mix of Rose’s (1990) narrative of the surveillance and governance of the family, combined with the neuroscienticism discourse of family social policy. Parents’ experiences of the professional partnership relationship seem to be central to children’s education (and their experiences of it). Take, for example, Kate’s nod in *Chapter 7 ‘Talking’* to her negotiation of accessing a new Education, Health and Care Plan for Max. Here she entered into partnership by engaging with the formal process of appointments with school and educational psychologists, whilst seeking to protect Max from the potential distress of such surveillance, ‘*Got Ed psych coming to meet him tomorrow - although he says he’s not going to talk to her!’ (Email correspondence with Kate, 27th July 2015).* Here, Kate was brought into the professionalising of parental expertise, in which she had to tread a careful line, through the negotiation of her rhizomatic talk of autism and her child, between gaining access to resources for Max and resisting the practices that reproduced discourses positioning him as the undesirable school child. Interestingly, McLaughlin (2008) highlighted how the void between parents and professionals, common between form-filling bureaucracy and a lack of interest in parental expertise, is often only overcome by parents themselves performing either heroism or compliance. The same can be seen in the pedagogic options available to Max; comply or ‘overcome’ your impairment. The complex negotiation of parent-professional relationships was a pervasive undercurrent in parents’ everyday lives across time; prior experience, current issues and future expectations.

## Neuroscienticism in Policy

This perhaps speaks back to the discourse of neuroscienticism that is embedded in the social and policy landscape far beyond political persuasion. As introduced *within Chapter 1 ‘Contextualising the Terrains’*, the centring of neuroscientific explanations of child development, interwoven with parenting, serves a particular form of governance in children’s and families’ lives. Rhetoric of partnership is well-suited to such narratives, in which the parents, more specifically mothers, can be both called in as responsible for, and cast out as to blame, for their child’s brain-based development (Blum, 2015; Runswick-Cole, 2015). Blum (2015) sees the bringing in of mothers as an evolved, complex of parent-blaming that has become ‘so expansive, yet so indirect’ (p.240), where older discourses about ‘not-normal’ children have faded, they are not forgotten (p.5); no longer subject to psychodynamic theories of dysfunctional relationships but, instead, seen as the bearers and managers of their child’s em-brained disorder (p.6). Blum takes ‘em-brained’ from the sociologist Pitts-Taylor, in much the way that Ortega (2009) takes the cerebral subject on which we ruminated earlier. The suggestion here is that mothers are called to navigate, embrace and manage their children’s em-brained disorder; the brain as an embodied object of the individual, which can be managed, developed, maintained and put to work for neo-liberal productivity (Blum, 2015). In the narratives of parent/professional partnership, parents must juggle discourses of em-brained neuroscientism alongside the intricacies of educational policy, disability law and health and social care systems (ibid), as can be read in the rhizomatic ways in which parents in the ‘Talking’ chapter weaved and negotiated the complex of autism.

I now bring together a view of policy and education that considers ‘4. What does autism do to/for/in education?’, in relation to what it means to be a child living in spaces of autism and schooling. The experience of autism as a Special Educational Need has become a neoliberal site of desire, in which hierarchies of difference are more or less valued through frames of compliance. Butler (2004) invited us to expand the norms of which lives are liveable, which I suggest have been expanded, by exploring ‘what does autism do to/for/in education?’ through a lens of desirability. Where Max’s siblings could be read more easily as docile in their compliance to ableist standards of academic achievement, Max’s embodiment was read as unruly, pushing at the boundaries of what was and wasn’t valued in neoliberal education. I have briefly explored the experiences of Max, Ruby and Joe as an exemplar of the dis/child complex; their very being in school spaces desires and resists normative understandings of education, pedagogy and childhood. Such desires themselves have been shown to speak to broader neoliberal policy discourses. In interrogating education and experiences of schooling through the dis/child and desirability, we can begin to expand the norms of which lives are liveable for the schooled neoliberal child.

In the next section, ‘Being and ways of knowing’, I move outside of education and into broader spaces of everyday life. Whilst education is and was central to much of the children’s and families’ everyday lives, I suggest that there is a greater contribution to be made to understandings of disabled children’s childhoods outside of school spaces. So it is towards ‘being’ in the everyday that I now turn. These stories continue to expand the norms of liveable lives through an attention to liveable childhoods.

# 2. Being and ways of knowing

This chapter navigates around the sensory ethnographic moments of my project, valuing embodied ‘being’; ways of coming to know, make meaning and sharing the world of the children in a number of settings. It responds to the questions,

*2. How might we consider being autistic as part of being a child?*

*3. What does autism make im/possible for a child to be and become?*

*5. How can autism research broaden its understanding of the everyday?*

It shifts our attention from how we come to know children’s worlds through ‘talking’, to how children come to know and share their worlds through embodied ‘being’. The everyday is the site of analysis, in which ‘being’ is not subject to interrogation as a transition to becoming adult or as a series of developmental milestones (Hackett et al., 2015; James & Prout, 1997). A becoming-adult analysis, as we have seen earlier, leaves little room for manoeuvre for children labelled with autism and perpetuates deficit-laiden understandings of their disordered being. Such a version of ‘being’ sits within a Cartesian formulation of what it means to be human; the development of a competent mind ruling over a subservient body. If such bounds of human competency are the only valuable, and valued, way of being, knowing, and making meaning in the world, the children in this project can be found wanting time and again. So instead, in valuing ways of knowing and being known through the body, with the body, in embodiment and the tacit, we can dis/orientate our understandings of these childhoods. It is in the centring of embodiment as a way of knowing, meaning-making and sharing that this chapter is situated within the sociological study of childhood (Hackett, 2015; Hackett et al., 2015; Procter, 2014; Prout, 2005; Christensen, 2003; James & Prout, 1997).

So is this ‘being’ at all? Does ‘being’ not invoke a standing still, a fixed state, a present moment of certainty? There is a risk that ‘being’ begins to sound like an orientation, or an attempt to know and be known. It all sounds very static. But if our journey of dis/orientation has taught us anything so far, it is that we are always on the move. This knowing or knowable ‘being’ is not the vision of ‘being’ that this thesis, its methodology and analysis takes, however. Whilst ‘being’ is taken as not-becoming-adult it is open to Deleuzoguattarian sentiment of ‘becoming’. The ‘being’ deployed in this analysis is embodied *and* becoming; it is not about childhood as an age, stage, developmental period or ‘growing up’ but is recognised with the temporality, possibility, potential and excess of ‘becoming’.

As introduced in Chapter 5, Pink (2009) suggests that we come to know the world through the experience of embodiment. Meaning-making of ourselves, each other, and our worlds, can happen through the sharing of embodied experiences (Pink, 2007). The academic study of children with a label of autism is largely disembodied (Youdell, 2015), or with a Cartesian sense of a body that only comes into existence through the mind. Where references to experience of the sensate exist, it is largely in relation to individual pathology; disordered sensory integration or processing (see Jacob et al., 2011; Lane et al., 2009; Hilton et al., 2007; Tomchek et al., 2007; Kern, 2006). First-hand accounts by autistic self-advocates speak to an experience of embodiment that centres around the sensory (Price-Hughes, 2007; Mor, 2007; Tammet, 2006; Birch, 2003; Willey, 1999; Grandin 1995; Williams, 1992). Accounts of a highly sensorial experience of the world, including differing perceptions of sensory information and differing emotional resonance with the senses, suggest there is value in sociological attention to exploring embodied, sensorial meaning-making and knowing of the world in better relating to labelled children’s everyday lives (Conn, 2015).

I begin with an example to help demonstrate the disjuncture between the academic study of the everyday being of children with a label of autism’s and the discursive power this brings to bear on their lives and our understandings of them; a turn to play. Play has been appropriated by most disciplines that have any interest in the child or childhood, as will be seen. By exploring this appropriation, I dis/orientate to lesser used framings of play, those with a Childhood Studies perspective, to show how attending to children’s ways of knowing and making their worlds with and through their bodies is an opportunity to think of autism and childhood beyond deficit or difference discourses.

## Disembodied Play

Play was a big feature of spending time with and around the children in this project. From the outset that might be challenged by some, as dominant narratives of autism would have us believe that autistic children with autism labelsoften do not play, that abnormal play, or no play, is itself a ‘symptom’ of autism (Conn, 2015; Goodley & Runswick-Cole, 2010). Through exploring brief moments of play, I unravel some of the well-worn biopolitical stories at work in these children’s lives, which position their play as signifier of a/typical cognitive development, rather than an embodied way of coming to know and make-meaning.

Within the realm of autism, play and diagnosis are quite tightly woven (Conn, 2015). The recently updated Diagnostic and Statistical Manual (DSM-5) states, within its diagnostic criteria for autism, ‘Deficits in developing, maintaining, and understanding relationships, ranging, for example, difficulties in sharing imaginative play or in making friends’ (American Psychiatric Association, 2013). Here, within a key process of biopower (diagnosis), your play becomes a tool with which to measure your successes and failings of social interaction and imagination. A particular conceptualisation of play is being drawn upon, which perpetuates the biopolitical story of a child labelled with autism as being disordered. Play here is no longer part of your being-as-a-child but now *belongs* to the realm of autism, the diagnosable and the neurodevelopmentally disordered. Your play, in its now pathologised difference, is used to mark your body and mind as different or, more specifically, deficit. But what if we draw in a sociological perspective as the means to understand this play otherwise; as moments of the embodied knowing that are free and unproductive (Callois, 2001; 1990)?

## A playful interlude of play?

*It’s a warm(ish) Sunday afternoon on the allotments and as usual there is a flurry of activity in every direction. There are new faces and new donations every time I arrive and the latest is a large wooden sun house that has been erected in one corner of the site. I volunteer to spend the afternoon giving it a fresh lick of paint with one of the mum’s, Mags, who I’ve not spent a lot of time with until now. We while away an hour or two, paint brushes in hand, as she recounts stories of her son and his school experiences. Play time is tricky but he’s got his friends. One of the other children has just been moved to a special school after a long, difficult period so this is a regular comparison point between her child’s experience. Ben has been pottering away at the periphery for some time, pacing the length of the external fence. He’s quiet in his demeanour. Watching him from a distance gives the impression that whatever he’s doing, it’s highly satisfying. He’s surveilling something as he potters along. Another while passes until our attention is drawn back to Ben, Mags turning to him with a loud burst of laughter. He’s still at the site’s periphery, but now with a fresh coat of paint on most of his clothes and most notably on the large, old apple tree trunk his paintbrush is negotiating. There’s a collective roar of laughter as people start to turn towards the now ‘water and weatherproof for a guaranteed 10 years’ apple tree and its thick, glossy new look. With no-one offering much in the way of objection, Ben continues on his merry way, humming a quiet tune as he takes his brush back to trunk.*

Beyond diagnosis, play is often situated at the heart of intervention; education and socialisation strategies to repatriate, or move towards, normative child development. Historically, this has meant children have been the subject of controversial, corrective and educational interventions targeting how they do or do not play. Vygotskian (1962) ideas of learning through play have been somewhat hijacked by those with normalising ideals. A discourse of ‘proper’, ‘normal’, ‘age appropriate’ play dominates such interventions to a far greater extent than elsewhere; normative notions of play are pervasive in the lives of children labelled autistic (Goodley & Runswick-Cole, 2010).

This narrow conceptualisation of play as instrumental (Powell, 2009) leaves little opportunity to consider play as the cultural artefact a sociological study could offer; part of being in childhood (though not exclusive to it). Pervasive through autism and play literature are; play as developmental marker (Rodman & et al., 2010), play as developmental tool (Murdock & Hobbs, 2011), play as educative means (Dupere et al., 2013; Luckett et al., 2007), but little in the way of play that bears resemblance to the play that is being conceptualised in wider Childhood Studies literature; play as embodied moment of meaning-making and way of knowing (Hackett, 2015). I turn to the French sociologist Caillois (2001), who offers a definition of play that is often drawn upon in wider childhood/play research; play as (amongst other things) free, uncertain and unproductive. It is not my intention to replace one conceptualisation of play with another but to suggest that an opening up of the debate around play within autism is a necessary step. Conceptualisations of the intrinsically valuable play of Caillois (2001) are noticeably absent from the prevalent autism/play literature.

As the earlier brief selection of literature highlights, play as a subject of autism research is huge; huge in a whole host of disciplines, from psychology to biomedicine, from education to psychotherapy, but distinctly disembodied, measurable, abnormal, and in need of normative developmental intervention. Children here become the subjects of ‘the psychologist’s gaze’ (Rose, 2008, p.212) as soon as they begin (or not) to play. Take, for example, the paper by Luckett et al. (2007), ‘*Do behavioural approaches teach children with autism to play or are they pretending?*’ Goodley and Runswick-Cole (2010) offer critique of this paper. Not only, they tell us, is the child’s play measurable (and deficit) but, in intervening and teaching the child to play, the child is left still unable to win. Having learnt to play the play taught to them, this play still does not meet the required standard to be accepted; they have not *really* learnt to play properly, they are just *pretending* to play properly. After all, if you teach play, it’s not play. Or so this paper suggests. What is a child to do? Why is it, Goodley and Runswick-Cole ask, that children without disability labels escape such analysis of their play? Such analyses are dressed in a guise that ignores that much of the play of children sitting within normative bounds involves teaching and learning, pretending and imitation (Mastrangelo, 2009). In rejecting or not meeting developmental play standards deemed normative enough, the child labelled by autism has their play taken away from them. They are pushed to the margins of play, either as ‘not play’, ‘not quite good enough play’ or ‘good enough but no longer actually play’.

Research about the everyday lives of children without labels and their embodied experiences is already commonplace. However, there appears to be little in the way of research that crosses the void between those interested exclusively in ‘autism’ and those explicitly interested in ‘childhood’ and, I would argue, very little in the way of recognising one another’s existence. Runswick-Cole and Curran edited a collection in 2013, ‘Disabled Children’s Childhood Studies’, in an attempt to begin bridging this divide. Curran (2013) pointedly notes that studies about disabled children’s impairments or development are not studies of their childhood. Here, I make the claim for the same stake in Childhood Studies for childhood's labelled with autism. There is value to be gained from taking play seriously. If we take the play of children labelled autistic seriously as play with a Childhood Studies framing, rather than reproducing narrow biopolitical stories, which pathologise, medicalise and normalise, we can begin to dis/orientate our understandings of children’s lives. If we have moved away from ‘othering’ childhood as the absence of adulthood, perhaps (James & Prout, 1997; Jenks, 1998) the same principles can be applied in order to move away from ‘othering’ the play of children labelled by autism as the absence of proper, normal, appropriate play. In applying these same principles to play and autism, the play of the labelled child is no longer a space steeped in disallowing or correcting certain types of play or working towards transitioning play to more normative standards. Here, it becomes an opportunity to turn our attention to embodied ways of coming to know and make-meaning in the world; as a valuable moment of being in childhood.

This is a story of an afternoon I spent with the Goodwin children at their home. I tell it as a moment of being in childhood.

## Embodied Play: Den building

*Lilac bounces at my shoulder asking if we’re going to make the den yet - Kate tells me they’ve planned to play this when I come round. We troop off upstairs and the barrage of instructions and details begins. Ruby opens her notebook where she has been writing down everything we needed to know to build the den correctly. She continues to amend and add, asking me if I would like to join them in a different name especially for the game. The kids have long-held names so I choose the same one I had last time, in keeping with tradition. A dozen soft toys are lined up and separated into their groups of responsibilities. Each of the dozen or so toys has a name, character traits, their own tools, special skills, roles and specific personality. These too are long-held and each of the children recounts various tales of the ridiculous antics that the toys have each got up to at one time or another. The chatter and explanations go on for such a long time that Ruby occasionally struggles to keep her team on-task. Lilac has spent this entire time sitting various teddies on my head to see if they stay balanced. I’m amazed by their level of occupation within their play - they’re endlessly entertained with and entertaining for each other. Any bickering is settled with maturity and reason - ‘Max, you always have the space under the desk, perhaps it would be very kind if this time you would swap with me’ Lilac negotiates.*

*Recognising the reason in her argument Max fairly concedes.*

*Amidst this, Max and Lilac beg me to bury them. I agree whilst quickly trying to be safety conscious about the chances of them suffocating under a mound of duvets. New blanket, duvets and pillows are offered as the two children pin themselves like boards to the floor insisting on the positioning of various pillows on their feet, different layers for their heads and a need for each to be receiving exactly the same burial. They giggle and roar as the layers pile on, begging for a deeper burial and more pressure over the entirety of their bodies. As a very claustrophobic person, this would be a living hell for me, the children, on the other hand, appear completely content. They lie still and quiet, interspersed with my anxious checks that they’re ok. They’re fine they remind me, and, if there were more duvets in this house, they’d ask for more. I can’t see fingers or toes under the rise of several feet of bedding. Max pops his head out and offers Lilac more pressure and enclosure by bouncing on her. She excitedly and happily obliges. This is the point that will definitely end in tears I think. I try to reign in Max’s enthusiasm but Lilac wants more. Just as I make my insistence that he’s careful with his knees, there’s silence from under the mound and a whimper perforates the room of giggling. I quickly exhume Lilac and her crumpled face has tears rolling down it. I prop her up offering comfort and reassurance. Max nervously crawls towards her, visibly upset by the experience and close to tears himself. He offers his big brother comfort and wraps his arms around her. He looks unsure what to say but like he knows that the hug is probably doing a better job than his words anyway. I stop myself from asking him to say sorry to Lilac. He’s got a much more appreciated approach. He reminds Lilac (who is still sobbing) of the time she accidentally kicked him in the head in the middle of an equally risky game and before we know it a wry smile appears on her face and the tears subside, replaced by high-pitched giggling as they recall previous traumas.*

*All the while, on the other side of the bedroom Ruby has been working away. She’s light-heartedly frustrated by the lack of concentration on the den construction so has been plugging away with structurally engineering blankets held up by pegs on her own. She’s created something quite impressive though none of the kids, Ruby included, seem particularly impressed - they’ve done better. Ruby invites me to inspect her work and we crawl into the den under the low ceiling of blankets. The light is translucent and compared to the normally raucous atmosphere, it’s peaceful and quiet. She looks content and relaxed tucked away in the furthest corner of the den under the desk, usually reserved for Max.*

## Dis/orientating Play

There are dozens of analyses I could make of the stories. Instead of presenting a single analysis, I highlight how the shifting of analytical lenses dramatically changes how these embodiments can be understood; it gives space to dis/orientate and imagine otherwise.

We could analyse the children’s planning of games, the dictation of rules, the obsession with regulation and repetition in the naming and ordering of the written den-building procedure. Such analyses could fit neatly into diagnostic understandings of autism and play; an apparent lack of imagination in their repetition of previously played games. The most commonly used diagnostic tool, ADOS-G (Lord et al., 2000), would likely map these behaviours in such a way. We could comment on the lack of spontaneity and consider interventions to encourage spontaneous, imaginative play (Wolfberg, 1999). Or, through a politics of wonder (Titchkosky, 2011), which interrogates how such behaviours and ways of being have been cast as a problem, we could speak of the becomings of brothers and sisters playing together in bedrooms, exploring and creating spaces, taking our analyses in new directions that are less concerned with narrow normative notions.

The burial of Max and Lilac could be analysed as demonstrative of the children’s abnormal sensory desires, their abnormal love of pressure and small spaces. Or, through wonder, it could be explored as a moment of collective joy in a shared embodied experience of the sensory world. Dense and rich in its embodied squashed, enclosed, intense space, a space in which the children’s sense of play and enjoyment, in-between autism-child-play, an opportunity to disrupt the certainties of their beings as autistic-child from their moorings as sensorialy abnormal.

The ensuing end in tears and Max’s response could show a lack of empathy on his part, taken from our understanding of autism as a deficit in ‘Theory of Mind’ (Baron-Cohen et al., 1985), his inability to appreciate the pain of his sister and to take that experience seriously. Or, when we dis/orientate, as the inscribed embodiment of pain and empathy on two children, it is the brotherly hug when words would be far less effective. It is the becoming of emotion between two siblings. Max appears not only to understand his sister’s pain but to feel it too. A moment of shared embodied emotion. It is the sophistication of a brother to redirect his sister’s pain through humour and the shared remembering of another embodied moment in their family play history.

## Continuing to Dis/orientate

What is far more interesting than these reductive or potentially dichotomous analyses is the potential to open up our imaginings of play, autism and child, to possibilities - the becoming, fluid, complex and ever-changing understandings we can explore of childhoods labelled by autism. The potential to explore children’s uses of space, crafting of their embodied worlds, engagements in their sibling relationships, their experience of family life at home. All of which are commonplace for those without labels of autism but far less common for those of us working within autism. The aim here has not been to demonise play-as-instrumental but to redress an imbalance in the focus of such interventions in lives of children labelled by autism and the autism research agenda. It is to embrace the potential dis/orientation of play; negotiating the balance between the normative *ability* of dis/ability in which play indeed is a developmental tool and learning opportunity, with a sociological conceptualisation of play open to those without labels; play as free, unproductive and uncertain (Callois, 2001). It has drawn on inter-disciplinary debates on the biopolitical construction of play, childhood and autism and made a case for a coming-together of Childhood Studies principles, as a place for exploring, discussing and contesting each of these spaces. Taking analytic framing from a politics of wonder (Titchkosky, 2011), I have explored an afternoon that de-prioritises normative notions of play in relation to autism. It refocuses our gaze from pathologisation and towards alternative; dis/orientating analyses of potential and possibility. With these dis/orientations, I would suggest, we can bring childhoods labelled by autism (and their play) in from the cold and begin to re-set a research agenda, which has already been mapped out in other disciplines drawing on Childhood Studies. We can begin to take disabled children's play seriously outside of developmental framings, as a site to explore their everyday lives and their embodied stakes in their worlds.

So now that we’re taking play seriously beyond its casting as signifier of development, we can continue to dis/orientate towards stories of everyday life. We can begin to re-frame and re-read how children come to know their world in the everyday. With that turn in our attention, the next story is steeped in the embodiment of family life, of being and becoming a sibling, of crafting of everyday lives in the family home. This is a story of an afternoon spent with the Goodwin’s at home that centres around those very features of everyday life.

## Embodied knowing, sharing, & meaning-making

*Lilac’s big smile and tiny body bounce at the window as I walk up to the house. She tears around the living room door and greets me at the doorway presenting the fidgety kitten to me with glee. Her toes touching mine, she looks up at me expectantly and scurries and bounces her way in the kitchen to show me to her mum. As Kate offers coffee and chats away telling stories of family and calamity, Lilac clambers to my knee pressing her nose against my face as we talk, all the time chattering happily in my ear. ‘Excuse my daughter, she has no idea about personal space it seems!’ We all chuckle and Lilac continues to use my body as a climbing frame seemingly aware and enjoying her status as the ‘family pesterer’ (her older sister declares her).*

*Max skulks in the kitchen nervously curling himself into a round ball and squinting his eyes on the kitchen bench. ‘Happy birthday Max!’, I wish him.*

*‘How did you know?’ he asks suspiciously.*

*‘I guessed from the cards’, I said, pointing to the flurry of 8th birthday cards around the kitchen’s perimeter. Kate produces her screensaver of Max’s cake on her phone.*

*‘Oh I love cake!’ I exclaim. The kitchen giggles. Blazoned across Kate’s phone is Max’s cake, only it’s not made of cake. It’s a circle of stacked Party Rings and Jaffa Cakes, with a satsuma in the middle holding a protruding burning candle.*

*‘Max doesn’t do cake’. We all giggle at the unexpected cake with Lilac exclaiming that she wanted to eat the satsuma but wasn’t allowed because it was Max’s birthday cake. Max smiles, turning his head down. Three of the children gather around me all with various things to share and tell and show. Ruby brings me her entry for the 500 words story competition.*

*‘Guess how many words it is?’ Kate chuckles expectantly.*

*‘500!’ The children chorus, rolling their collective eyes at their mum’s suggestion that it would be anything more or less.*

*Climbing my arm, Lilac asks me to read it aloud. The children’s ears prick up and they lean in with expectation despite already having read the story themselves. Ruby beams at my shoulder, swinging her arms behind her back with pride. And proud she should be, the story is wonderful and it’s a hit with the family. With finesse, eloquence and great detail, we are told the story of Doodleboy, a stick man drawn by the story’s narrator to fend-off the school bully. It’s a story of creativity, surprise, tension, anticipation and triumph. By the end of the story, the narrator no longer needs Doodleboy’s help having used his stick-friend’s advice to stand up to the bully. As the story ends, everyone cheers and congratulates Ruby on a fantastic story. Max’s eyes swell and fill with emotion.*

*‘I cried a lot when I read it first’, Max whimpers quietly, his lips starting to puff out and his eyes brimming.*

*‘He did!’ Ruby says, without malice or mocking.*

*‘Why?’ Kate asks.*

*‘Because Doodleboy left’, he says with a real depth of sorrow in his voice.*

*‘But that’s a good thing!’ We all chirp at various points.*

*‘He left because everything was ok now and he had to go and help someone else that needed him’, Kate explains.*

*Max nods, seems to get it, but wishes he didn’t have to. He draws in a sharp, tearful breath.*

*‘Do you want to cry this time?’ Kate cuddles into him.*

*He shakes his head and pulls his best brave-face.*

*‘Well Ruby told me maybe there’d be a Doodleboy 2!’ He looks up starting to perk up. Suggestions fly around the kitchen about Doodleboy’s next act of heroism as Kate begins to sketch Doodleboy in the notebook next to Max. The mood quickly returns to giggles and ideas, the melancholy at the loss of Doodleboy has passed.*

*The other children have been shooed upstairs and it’s just me, Kate and Max in the kitchen now as Max shows us his new birthday Lego and explains who the Teenage Mutant Ninja Turtles are. I’ll admit, I was struggling with the Lord of the Rings bunch but I’m on familiar ground with Michelangelo and the gang. He lets me fiddle with various bits and pieces and ask questions about who’s who as I go. We have a spate of Lego and chat and storytelling of the Lord of the Rings variety. There’s a hush as we each slap different characters around the table, Max’s with a greater sense of purpose than mine.*

*‘Do you have any questions?’ Max asks me.*

*‘Erm. Well, you know how I’m writing about play and what people like to play with?’*

*He nods.*

*‘I know you love Lego but I don’t know why. Can you tell me?’*

*He explains that Lego is brilliant because of the bobbles on it, which make everything stick. Because otherwise everything would fall over and it would be a disaster. He giggles as he shows me examples and uses his feet slapping on the bench to show me how the people would fall through floors and destroy things if it weren’t for the bobbles. He acts out a tumble from the bench, complete with sound effects.*

*We briefly talk about school and how you don’t play when you go to older school, that it’s all reading and writing. We talk about if his school friends play Lego and he deftly reminds me, ‘I don’t know any of the other children’s personalities so I don’t know if they like Lego. I’ve only been to one of my friend’s houses and he had some Lego. He has his own cosy corner! It’s like a blanket in the room that’s just his and it just has all of his things to play with on it!’*

*This seems to be really exciting for Max, and he searches his mind to describe it to me more. His face is animated and his eyes as wide as they’ll open. Max doesn’t have a cosy corner of private space like his school friend but he does have two drawers, he explains. He quietens and slowly traces the edges of the drawers with imaginary lines to show me how big they are and how they are positioned. He explains their content and how they’re only for his Lego and no-one else’s things. The other drawer of three, he explains, is the house’s, so it’s one that everybody shares. We wind through the hallway and into the living room to see the real thing. His mum and dad are in the living room and explain that I’ve come to see Max’s drawers because I’m excited to see what’s in them. We chat about what Max’s cosy space would be like and how he’d like to have one. He sways his body, always on the move. Then I’m invited to rummage through the drawers of Max’s Lego, his treasure, personal stash and tiny cosy corner of his Lego-based world. What a privilege.*

## Sharing through embodiment

It was in this shared afternoon that I began to relate to the Goodwin children’s individual and collective ways of being (coming to know and coming to make) in their worlds. Lilac’s climbing of my body, her desire for proximity, seemed to be central to how she was coming to know me, and for my getting to know her. Her closeness allowed her to peer at the contours of my face, to touch my hair and manipulate my arm to bring her closer. I never asked her why she had such a penchant for physical closeness, a desire that she was certainly used to having pointed out by her siblings; her position as the ‘family pesterer’. I didn’t mind being used as a climbing frame for the most part. The occasional hand in the face in the middle of a conversation with her mum, though distracting, offered a sense of familiarity.

Max also used his body to come to know and share his experience of his family life. Despite being very verbally articulate and seemingly comfortable with the back and forth of conversation, he was at times frustrated by my endless questions and desire to have things explained to me in words. His directing of my attention to the details of his Lego characters and their movement offered the explanation he was after. Showing me the mechanics of the objects he loved was far more effective; he shared tacit knowledge through the manipulation of the Lego characters’ features. Where objects weren’t at hand, he used his hand to draw me to his imagined space, his friend’s ‘cosy corner’, in an effort to share that which wasn’t materially present. As his fingers traced imagined edges, his voice drew in to a hush as a narrator drawing in his audience. I found myself leaning closer as I was pulled into his outpouring of enthusiasm of a space he could not show me but nevertheless wanted me to know. His sharing of experience continued as he offered further substance to help me to know what he knew, how he knew it. Taking me to his best equivalent ‘cosy corner’ (though notably inferior in his opinion), his drawer, added a material dimension to his embodied description of this imagined space. Here the coupling of his description, with words and body, was brought together in physical space. These spaces, imagined and material, were valuable in Max’s everyday life and he used a variety of modes to share the experiences of these spaces with me to best effect. In a busy family home, these spaces were clearly important to Max, a ‘corner’ of privacy and ownership; a rarity amongst shared spaces and objects amongst five siblings.

Here I have briefly explored a shared moment of Max’s everyday life. His way of knowing the world and sharing it with me have been shown to be embodied and experiential and as a sociological site of research about everyday life. Such a centring of embodiment keeps us mindful to an orientation away from psychologisation or pathologisation that so pervades the research of children labelled with autism. It is within such sociological sites that we can come to a less reductive, more productive and imaginative means of a research agenda about, and for, disabled children’s childhoods.

## A Nursery Trip: slipping back to disembodiment

If the previous stories were the potential of coming to know the world through embodiment, what follows now is its blockage. It is a story that is read most easily as a disembodied, disordered mind resulting in unacceptable bodily actions. However, by re-centring embodiment as a way of coming to be and know the world, I suggest there is room to manoeuvre and dis/orientate our gaze. This is a story of a morning I spent in an inclusive nursery in Derbyshire with Samuel. It takes place mainly in the large open room where all the children, around 25 ‘community children’ and 5 with ‘special educational needs’, and the staff congregate. I spent much of the morning on a tiny, tiny chair feeling like a giant and being mobbed by the masses. There were children everywhere. It was hot, stiflingly hot, and loud, endlessly loud.

*How was I to reflect on the experience that I walked away describing somewhat sweepingly, naively, as ‘scary’? Had not my doctoral training and MA in research methods taught me more than this? Shouldn’t I walk away with insight, knowledge, data ripe for the picking? Shouldn’t I be too old and too sensible to be scared of a nursery?* (From my notes at the end of the morning)

This is the morning, and its written form, the story that I introduced in the methodology chapter. After spending time amongst the doubt and confusion of what felt like a very vapid experience, I was drawn back to Cichosz’s (2013) idea of tripping and realised that within that morning I had taken a trip in/with/through the nursery. ‘“Tripping” Cichosz describes as ‘an affectively-amplified part of a continuum of consciousness that can teach us something about how we relate to the world’ (p.3). In paying attention to this trip, as Cichosz recommends, I want to consider the ‘ethical potential’ of such attention and how I can take the affect I experienced, the palpable sense of discomfort that coursed through my body, and consider it a site of possibility to dis/orientate; ‘Change depends upon the fostering, tending to, and strategic actualization of the potential found in affect’ (ibid, p.3).

## Window Licking

*There is a moment within free-play that Samuel spends with the big, floor-to-ceiling window of the nursery. I sit at a distance, behind him to his right as he pushes the side of his face against what I imagine to be the cold, refreshing glass, his brow-bone and cheek-bone flattened to its surface. He pushes his tongue, wide and flat against the window whilst gazing through it to the play area outside. Condensation drips down the pane, glistening seductively in the fluorescent light which refracts through to the puddles outside. It trickles down his cheek. He is peaceful, relaxed and seems to enjoy the moment he’s experiencing. Behind him, the gaggle of other children continue their riotous play and once again swarm to my knees to share pictures and toys with the stranger in the corner. It is loud, chaotic (in a highly organised fashion) and stuffily hot. I shift my attention back to Samuel and his window-haven. I imagine the satisfaction of the cold condensation of the window on my tongue and the hypnotic experience of zoning out of the chaos and spending time with a window. I smile and feel that Samuel has given me something in that moment; something peaceful and reassuring amongst the regulation of chaos around us both.*

*Later in the morning as Mary shows me Samuel’s dense folder of paperwork she recalls having observed me observing Samuel during the window licking. ‘You’ll have noticed he licked the window a few times’; I am reminded of my observation and recall it with fondness,*

*‘yeah, do you wonder if there was some kind of sensory satisfaction going on there, you know, with the cold surface, it’s smooth…..’*

*I am cut off.*

*‘‘It’s bad habits. He needs to stop it and we are getting there. He’s doing it less than he used to, we just need to keep on top of it and stop him when he does it’. [[4]](#footnote-5)*

I stop at this point to return to my trip of attention. I am struck by a number of things here, which I will now attempt to discuss discretely. However, my affective relationships to the scene interweave and the experience itself was complex and nonlinear, which may make the distinction tricky.

## Challenging behaviours and imagined futures

Samuel stopped being a child in the classroom, playing and enjoying himself and his time with the cool, wet, smooth window and was positioned as trouble, a problem, and inherently in need of remedy by professionals. Here, Mary began to draw on a discourse that commonly crops up for children with autism labels in relation to professional descriptions of their actions, in descriptions of their being - ‘challenging behaviour’. Challenging behaviour has traditionally been defined most commonly as,

culturally abnormal behaviour of such an intensity, frequency or duration that the physical safety of the person or others is likely to be placed in serious jeopardy, or behaviour which is likely to seriously limit use of, or result in the person being denied access to, ordinary community facilities. (Emerson, 2001)

Challenging behaviour discourse pervaded the act of Samuel licking the window as symptomatic of autism. Mary drew on this conceptualisation, one in which autism limited what would be acceptable in the nursery room, and pushed Samuel’s actions to the margin, as non-normative and merely a ‘bad habit’. Images of a future-Samuel were invoked - the bad habit needed to be stopped now, so that older, future-Samuel wasn’t licking windows in his later life. Do we assume that all three-year-old children will be engaging in the same play in their adult life? We don’t. However, what Samuel was doing that morning was not able to be considered as a small act, perhaps a part of play, transient and temporary, but as something that, unless stopped, he would inevitably continue to engage in in the future. When positioned as such, his actions became part of the challenging behaviour discourse in which, due to its social inappropriateness, could and would be stopped through professional intervention and replaced with something more acceptable, i.e. not licking a window.

An affective orientation to Samuel’s experience was driven by my imagined sensory, affective satisfaction of a body in contact with a surface. Samuel seems to have a penchant for contact, for touch, for pressure on his skin. Bogdashina (2003) would consider this part of his personal ‘sensory profile’; his preferences for particular sensory stimulation. As a result of seeing this in action in his everyday world, I took his interaction with the window as working at a bodily, sensory level, in which something was satisfied by the sensation of his tongue on the glass. He certainly seemed satisfied. His body, in ‘showing’ his autism, offered him satisfaction. His body, in showing others ‘bad habits’ frustrated and pushed at Mary. Why?

Her raising of the moment with me felt like re-direction, like censorship of my interpretation.

*You know what you think you saw, well you didn’t. Let me tell you what you* ***did*** *see*.

So why did Mary feel this needed to be done? She clearly didn’t like or believe in my meaning-making of the senses. A turn to critical discourse is helpful here in unpacking how Mary’s interpretation can perhaps be initially read as the most ‘natural’ reaction to Samuel’s window-licking.

## A Turn to Critical Discourse

Nunkoosing and Haydon-Laurelut’s (2012) Critical Discourse Analysis of challenging behaviour encourages an adoption of Foucault and Goffman in our understandings of ‘the trouble with being a problem is the problem that other people have’ (Michalko, 2009, cited in Nonkoosing & Haydon-Laurelut, p.198). Utilising Foucault and Goffman offers a means of ‘stripping away the layers of the social making up of intellectual disability’ in which Foucault can offer the *why* and Goffman the *how* (ibid, p.208). In framing Samuel within this scene, discourses of autism, learning disability and challenging behaviour are circulating in the air and become real, written on Samuel’s body through Mary’s words (Foucault, 1979). At work here, behind the scene, is the production and reproduction of a particular regime of power-knowledge (ibid, 1979) of autism, of which ‘challenging behaviour’ is itself a product (or byproduct) of this particular power-knowledge system, which has seeped into everyday language of speaking of children with labels. Goffman’s performance of identities can be read through Mary’s enactment of professional expertise and sharing of her knowledge of Samuel’s behaviour. She worked to regulate and re-interpret my understanding of the scene, dispersing her expertise through the staff-room and the tour of the nursery facilities, all the while producing, and reproducing, a performance of ‘care’ for Samuel and the other children within her professional remit.

## Dis/orientating window-licking

My interest in this scene is in the potential for it to be understood otherwise, with a glimmer of hope that a Goffmanesque or Foucauldian analysis would perhaps not seem to lend itself to. Both do, however, offer potential and possibility in their theorising, as power ‘...is in all relationships at all moments and this is what makes power changeable’ (Nonkoosing & Hayden-Laurelet, 2012, p.209). Where there is power, which is both pervasive and oppressive in its scene, there is always resistance (Foucault, 1988). A dis/orientating of this scene, from the perspective of Samuel and his embodied being in the world, allows for a reading of resistance to his subject position as autistic child demonstrating challenging behaviour. Bringing attention back to the body to explore this re-reading offers the potential to dis/orientate understandings of Samuel and his behaviour.

The body does not appear outside of the social world within which it is made manifest. Just as the meaning of the text resides as much between its words and between read and text, so too the meaning of the body resides between bodies, between those who live through them, in them, and those who bring them to mind. (Titchkosky, 2005, p.664)

The body being brought to mind by Mary that morning was a body of disorder and challenging behaviour. It was a body in need of intervention. It was predominantly a body enacting the disorder of its mind, which was invoked as an impossible way of being a child in an inclusive nursery. By reimagining the meaning of Samuel’s actions as residing between himself and that window, we are able to unpick the discursive positioning that subjectivate him as the autistic child. Taking forward what is offered by this attention to embodiment, I move towards the ‘Becoming’ chapter, in which I bring together the stories of ‘Talking’ and ‘Being’ with new stories offering critical analyses of autism, childhood and dis/ability as opportunities to imagine otherwise.

# Chapter 9

# Becoming: Towards a Critical Analysis of Autism, Childhood and Dis/ability

This chapter carves out our space for a dis/orientated gaze on childhood, dis/ability and autism; bringing together the becoming of what is done *to* childhood’s labelled autistic and what is done *by* children labelled with autism. It asks that we adopt further theoretical fuel to our dis/orientations, a turn to the becoming of emotions. This is by no means a resolved orientation, an end point, but the final analytical line of flight for this thesis; the call to stay with dis/orientation. It ends with the smooth space of becoming, in which I wish to leave our thinking and relating to autism, childhood and dis/ability open to a dis/orientation that continues way beyond the pages of the thesis or the bounds of this project. It responds to the questions,

1. How is autism spoken about and how else might we talk of autism?

2. How might we consider being autistic as part of being a child?

3. What does autism make im/possible for a child to be and become?

4. What does autism do to/for/in education

5. How can autism research broaden its understanding of the everyday?

The call to dis/orientation in this chapter begins with dis/orientating challenging behaviour and ends with dis/orientating cartesianism. The orientation gazed upon here is one of emotions framed by challenging behaviour. Where historical discourses of the badly behaved child have been replaced with newer narratives of autism as developmental disability, this has come along with a particularly strong set of orientations towards the behaviour of children labelled autistic; behaviour as symptomatic of autism pathology or behaviour as responses to a disabling environment. Through turning to Ahmed’s affective economies (2006c), I suggest we are able to bring in a dis/orientating experience that explore the labour implicit in dominant orientations to the behaviour of children labelled autistic. This tool of dis/orientation works towards an analysis of the micropolitical acts taking place in everyday interactions between children labelled with autism and professionals in a classroom. Such a dis/orientation takes our relation to these micropolitical acts as exemplars of the productive potential of turning to the becoming of autism, childhood and dis/ability.

Titchkosky (2003) asks us to consider what happens ‘between’ the language that we use to speak of dis/ability. She reminds us that we are inclined to resolve contradictions by privileging one position over another, when in fact we should be concentrating our efforts on that unresolvable space between things, between words, between bodies and minds.

*In the middle* of all these words and the things that they produce, disabled people find themselves marginalized, embodying a plethora of conceptualisations that are packed full of contradictory meanings. Yet, living in the midst of all these concepts means that every disabled person represents the possibility of combining these words, these concepts, in a new way and thereby forging some reconciliation with the world. (Titchkosky, 2003, p.219, italics in original)

It is in those spaces of what I would consider to be dis/orientation, ‘in between words, bodies and minds’ of autism and childhood, that I situate this final analytical chapter. Methodologically and analytically getting in between such things was no mean feat. It required a particular orientation to the telling of the stories that follow, and the gaze through which they were analysed; a gaze I have framed through emotions, affect and embodiment. This is a response to the question, ‘5. How can autism research broaden its understanding of the everyday?’

What follows are two stories about Sophie, both of which I suggest dis/orientate us towards a critical gaze upon autism, childhood and dis/ability. They are stories of two very different experiences for both Sophie and myself. By considering both as stories of Sophie’s being and becoming, we can explore how the subjectivation of children labelled with autism is a becoming *between* bodies; that which is done by bodies and to bodies. I use the stories to respond to the ‘else’ of the research question ‘1. How else can we talk about autistic children’s lives?’ The most pertinent contribution threaded through each story and their subsequent analysis is, ‘3. What does autism make im/possible for a child to be and become?’

A Turn to Theories of Emotion

There are a number of ways of reading, or feeling this first story, ‘Biting’, some of which I explore. Some of those ways of knowing or relating to the story complement one another, feed into one another, bleed into the next. Others are incompatible, requiring an ontology of autism that rubs up against another, unable to exist simultaneously. I begin the analysis of this story by introducing its terms; the theoretical framings deployed in relation to its telling. In coming to relate to this story, I turn to the work of emotions. ‘Emotions’ here are not an individualised, internal psychology but understood through a socio-spatial lens to attend to the palpable affect of that morning and those involved in its constitution. Discourses embedded within school spaces exert power over possible becomings for children such as Sophie. In attending to how emotions work to make this power productive, I explore what or who it is possible for Sophie to be or become. From this perspective, emotions are a ‘....socio-spatial mediation and articulation rather than as entirely interiorised subjective mental states’ (Bondi et al., 2005, p.3), which are located in bodies and places and relationally between them. It allows for an analysis that considers the dynamic between emotion and power and the influences of the structures of schooling (Procter, 2013, p.497). Such a turn to emotion explores the affective economies at work; how emotional capital is afforded to some and denied others (Ahmed, 2004). That is not to say that the deployment of emotional capital results in fixed subjects, rather that it makes some becomings of emotions more possible than others. As Roche (1999) reminds us, ‘children have to make their own space in spaces not of their making’.

## Creating Analysis of Emotion

An attention to emotions requires the analytic means to do so. I am interested here in MacLure et al.’s (2007) writing on *that which resists analysis,* as this story has for many of the preceding months felt like just one of those moments. Finding an analytical hook for these particular stories *had* to attend to emotional work because, in returning to them time and again, I recognised them as steeped in emotion for Sophie, myself, and all involved. I needed an analysis that explored such a relation. I was drawn to Stewart’s (2007) work on affect as the means to let the meaning-making from that morning ‘sit’ before jumping to its representation. Attending to affect ‘...tries to slow the quick jump to representational thinking and evaluative critique long enough to find ways of approaching the complex and uncertain objects that fascinate because they literally hit us or exert a pull on us’ (Stewart, 2007, p.4). MacLure (2013) cautions against the leap to representation, in which things become frozen in an allotted place, within a rigid structure, to render them comprehensible as failing to take hold of that which ‘exceeds and precedes “capture” by language, such as bodily, asignifying, disrupting (and connecting) intensities of affect’ (p.170).

In an analysis that centres on the productive power of emotions, the deployment of affective economies and the embodiment of becoming in a classroom, I attempt to analyse that which seemingly resists analysis and so, instead, to slow down the leap to representation.

In place of the cerebral comforts of ideas and concepts, or as well as these, we could acknowledge those uncomfortable affects that swarm among our supposedly rational arguments - moments of nausea, complacency, disgust, embarrassment, guilt, fear and fascination, that threaten to undo our certainty and self certainty, by, again, allowing bodily intensities to surge up into thought and decision making. The gut feelings point to the existence of embodied connections with other people, things and thoughts, that are far more complex than the static connections of coding. (MacLure, 2013, p.172)

I begin with a story called ‘Biting’. This is a story of a morning I spent in an Early Years classroom in a special school with Sophie. Reading, writing about, or perhaps most significantly, experiencing, ‘touching the gut’ of that morning demands an attention to that which emanated from, but exceeded, the assembling of the bodies in that room (ibid); the affective economies that hung in the air.

I address Jones and Holmes’ (2015) call to resist ‘the suspicion of a creative analysis’ (of affect and embodiment), manufacturing a ‘sedated response’ and instead to ‘touch the gut of the affect’. The sedated response would be a singular explanation or exploration with a tidy and coherent coding of objects (emotions, behaviours, causes, effects). The creative analysis instead brings us back to assemblage (always multiple) and lines of flight (always moving, always becoming). Such a centring of multiplicity and becoming is a reminder of the number of ways of relating to the morning, which will always be an excess. In recognising that this morning will always be an excess, of emotion, embodiment, and becoming, I ask what lines of flight are possible, what rhizomatic becomings can weave away around the blockages of striation towards a plateau of smooth space, in which we can come to relate to Sophie’s embodiment of autism and childhood otherwise.

Returning to Deleuze and Guattari’s (1987) thinking on smooth and striated spaces can be helpful to introduce our frame of reference for this chapter. As we have heard earlier, Butler suggests that, in order for the subject to be performatively formed (in this case, the ‘autistic child’), discourses need to be produced in recognisable ways (2004, p.5); the knowable autistic child who *appears* as both autistic and child. However, a turn to Deleuzoguattarian smooth and striated spaces takes this subject beyond the individual and a singular space and into an assemblage (Deleuze & Guattari, 1987). If striated spaces are the disciplined spaces of hierarchy, binaries and normative meanings (Youdell & Armstrong, 2011), in which a body can be known and subjectivated as both child and autistic, smooth spaces, then, are the spaces in between such biopolitical governance. Lines of flight are the means by which these striations are disrupted, they ‘...allow us to trip out of the striations in which we are caught and skate on the smooth plateaus between, even if in doing so we slip into or begin to grind out yet another striation’ (ibid, p.145). These smooth spaces are spaces of becoming because they go beyond the knowable and appearing subjectivated autistic child and into spaces of exploring the potential of what a body can do (Deleuze & Guattari, 1987). This style of logic allows the body to be invoked in smooth and striated spaces, offering the potential to explore what the body *can* do in such spaces beyond the governed, performatively formed subject; that which is *done to* bodies. In following the lines of flight, we can consider what they make both impossible and possible. It allows us to recognise the ways in which children, in this case Sophie in a school classroom and a ballet class, use their bodies to subvert, despite the limits of the biopolitical descriptions of their everyday lives. We read through these two stories how Sophie speaks back to what is done to her body, with her body. The two stories of this chapter, when read as articulations of striated and smooth spaces, sketch out the im/possible beings and becomings of children living autistic childhoods. The first story that follows now is of a morning spent in Sophie’s school classroom. A morning which centres around a bite. An analysis of the affective economies of that morning which created particular orientations to Sophie, a child labelled with autism, follows.

## Biting in the classroom

*I arrive in the school’s one-way parking system just before the morning bell behind a convoy of battered and bruised local authority buses. Children of all shapes and sizes are disembarking with assistants in tow. This is quite the operation; taxis drop older children closer to the path and school staff ferry the children, their bodies and various equipment towards the entrance. I get to reception at the same time as the straggling students who are collected and deposited in classrooms along the corridor ahead of me. I’m asked to take a seat while the teacher gets the children settled and stop to look at the staff photo board - I scan at least 150 staff members sprawling the reception wall.*

*I’m greeted by a smiling teacher who directs me back to her classroom with pace and enthusiasm. We sweep through the locked, heavy door and into the classroom. It’s tiny and packed to the rafters with bodies, adults and children alike. I perch on a spare chair in the corner and spot Sophie in the opposite corner just as I tune in to her ghettoblaster playing Disney hits.*

*‘Oooh it’s nice to have a change of CD today Sophie!’ The teacher calls out over her head. None of the other five children have music playing, I wonder if they like Sophie’s taste.*

*The room has the all hallmarks of TEACCH, each child with their own designated workspace, partitioned from their neighbour and facing outwards to the wall. Anna seems very focused, scanning the room of children. Each child is doing something different, self-directed and self-directing. The teaching assistants mill around singing nursery rhymes vaguely in the direction of one child or another whilst busying themselves with chatter between themselves.*

*‘What’s Rhett’s Syndrome?’ says one, flipping through a child’s individual ‘passport’ and passing it to another assistant.*

*Sophie’s workspace has a visual timetable pinned to the wall, her CD player blasting Disney classics, a PECS book and a box labelled ‘finished’. She sits back, crossing her legs. She looks a lot older than the last time I saw her. She wears a uniform and thick glasses now. She leans into one of the assistant’s body and drapes herself over the staff member’s arm, leaning into her lap. Her attention seems to be firmly directed towards her music. ‘No climbing Sophie, you’ll fall’, a different assistant directs across the room. Sophie pulls her body back to sit on her chair.*

*There’s rarely a moment when everyone’s in the room. Two new children appear through the door, one lead by the hand whimpering. ‘It wasn’t that bad!’ Anna assures with a chipper smile crouching down to the body. She sits him at his workspace. He wails.*

*It’s circle time. A door I hadn’t noticed has been unlocked and we’re led into an even smaller space that is dark and stuffily hot. An interactive whiteboard fills the entirety of one wall and a collection of tiny chairs is crammed in front of it. The children are directed towards previously assigned seats, each with an assistant sitting between them and the next child. I clamber over big and small bodies to the darkest, smallest corner of the room in order to take up as little space as possible. Anna sweeps into the room with the air of enthusiastic purpose and authority that seems to command both the children and staff’s attention. The squirming bodies are reorganised and reseated when they wander. There’s nowhere to go anyway as Anna has her chair directly in front of the door. Swathes of internet-based videos take us through short, focussed bursts of attention; the Good Morning song, the Thursday song, the Name Game, Gym Time. It’s a seemingly endless barrage of open browser tabs. During the Hello Song, accompanied by Makaton from the adults, Sophie springs to her feet, hurling herself the two meters across the room towards the screen, whooping and bashing the wrong photo assigned for her name on the screen. There’s a flurry of chaos as she hits someone else's name and throws off the sequence of the activity. A quick redirection; ‘It’s Gym Time!’ Anna enthuses switching browser tabs. Oh wait, it’s a youtube clip of finger exercises. Not quite what I was expecting. Before I know it a cartoon insect is blaring ‘Wind the Bobbin Up’, booming through the small space.*

*Sophie’s largely left alone when she’s passive in her chair, attention instead being directed towards other receptive or unruly children. Some of the children have constant physical touch from a staff member seemingly to encourage them to stay seated. This varies from tight, comforting brushing of the children’s arms, which seems relaxing, to an arm across the lap for wriggling bodies.*

*The youtube videos stream on. Anna looks down to some paperwork, the assistants communicating in eye glances and smiles between themselves above the children’s small, seated selves. A Fifty Shades of Grey advert perforates the Early Years atmosphere abruptly. Sophie becomes loud and agitated. There’s a sharp intake of breath and a high-pitched squeal from one of the assistants next to Sophie and a wet mouth-shaped ring on the arm of her t-shirt. ‘Did she bite you?!’ exclaims one of the other assistants, followed by another.*

*‘Did she?! The little....!’ They’re furious.*

*Anna takes Sophie by the hand and out of room in one fell swoop. The background videos demand attention amidst the newly tense and chaotic air. The assistant that has been bitten is supply, shipped in from another class for the day whilst the regular staff member is off. She half smiles, playing it down, whilst commenting that it’s quite painful and rubbing her arm vigorously. The other staff hurry to her aid with a barrage of instructions and advice; they send her out of the room to clean her arm and check if it’s bleeding, all the while suggesting she goes to the hospital. I take the opportunity to leave the flurry of emotions too and go back to the classroom where Anna is sitting closely opposite Sophie working quietly on a maths task. ‘Sophie likes things just ready’, she turns to say to me, ‘It was Mr Grey that did it!’ she half-chuckles nervously turning her body back towards Sophie. She leans in close now, holding her arm and her gaze, ‘What are we going to do with you Sophie Connor?’ she exhales.*

*I go back into the circle time room, which still seems unsettled and tense. Without Anna in the room, the other staff seem nervous and the children are watching youtube or entertaining themselves. The bitten-supply-assistant has more energy than the others and tries to engage the child next to her with the video on the screen. Each time an advert comes on the outside world sneaks in for 20 seconds. Sophie’s been returned to the room in the interim and takes her seat next to the supply she had bitten ten minutes earlier. The mood seems less hurried now and Sophie turns to lie across the supply’s body. ‘I felt her tummy rumble!’ she laughs.*

*‘Ooooh she likes her food,’ each of the assistants comments in turn.*

*Anna comes back, taking her seat in front of the door seemingly stressed and flustered.*

*‘I can smell one of them’ sniffs an assistant. Others sniff in turn.*

*‘I get used to it’ they laugh collectively.*

*‘Would you call it physical bullying?’, Anna looks up from the form in front of her. ‘I have to do an Assault Form. Is it physical bullying?’ she looks to the assistants.*

*‘I definitely wouldn’t say it was,’ offers the supply, ‘she was happy before. It wasn’t working that’s what triggered it.’*

*‘She was angry,’ another assistant tuts across the room. The other assistants mumble seemingly in agreement.*

*‘Autistic kids don’t like things to change’.*

*‘She’s not in after-school today, I’ll write it in her diary to her mum’, Anna concludes.*

*There’s an obvious division of worlds now, the staff chatting over the children’s heads and the children’s world of the huge screen lighting up the room.*

## Affective Economies

What follows is an exploration of this story in relation to the affective economies that were at work around Sophie in the classroom that morning. As Ahmed (2004) sees it, Marx’s model of capital can be applied to the accumulation of emotional capital, as an affective economy. This is a recognition, not of emotions’ residence in the individual’s interior, but of the becoming of emotions through bodies, boundaries and surfaces. ‘Affect does not reside in object or sign, but as an affect of circulation between objects and signs (= accumulation of affect over time)’ (p.121). Certain signs accumulate more and more affect as they circulate, to the point that they become recognised as ‘containing’ affect. Taking this further in relating ‘feelings’ to Marx’s ‘commodity fetish’, Ahmed explains how feelings become to *look* like objects, or have residence *in* objects, only through the concealment of their social, historical exchange and accumulation. What were those particularly ‘sticky’ emotions building to in terms of possible ways of knowing Sophie? How did they come to be and what would they become? What did they make im/possible for Sophie to be and become?

## Collapsing emotion into behaviour: autism and challenging behaviour

It is interesting to think through why there may be such a great wealth of attention to ‘behaviour’ in the pathologisation of children over ‘emotion’. Briefly, it comes back to the conceptualisation of ‘emotions’ and what productive power can be brought to bear. If emotions are understood as somehow ‘lower’, corporeal, pre-intentional, then there is little that intervention could offer. Conceptualisations of ‘challenging behaviour’ understood as an individual responding to their world in a way that is challenging to others (Emerson 2001; Clements & Zarkowska, 1997) is a common and pervasive discourse in autism practice and education. It is founded on a premise of learned behaviour theory, which affords intentionality that an individualised, naturalised conceptualisation of emotion does not. If behaviours are learnt (and emotions somehow natural), then behaviours are a site for intervention and discipline.

Challenging behaviour discourse is about the dynamics of a relation; it, the behaviour or the person displaying it, *becomes* challenging when it exerts itself on an other. Challenging behaviour only comes into being in relation to an other. The emotional response of the other has been well documented (Hastings & Brown, 2002; Horne, Rose & Hastings, 2004; Hastings, 1995). This exertion is often itself framed within embodied emotional terms; causing harm, distress, hurting another, shouting, hitting, losing control. Such behaviours have been shown within research to be associated with negative emotions and very rarely with positive feelings from the point of view of that other ([Bromley](http://onlinelibrary.wiley.com.eresources.shef.ac.uk/doi/10.1046/j.1365-2788.2002.00378.x/full#b2) [& Emerson, 1995](http://onlinelibrary.wiley.com.eresources.shef.ac.uk/doi/10.1046/j.1365-2788.2002.00378.x/full#b2); Hastings, 1995; Hastings & Remington, 1995; Chavira *et al.,* 2000). Within such a discourse, behaviour is a manifestation of an emotional state, most commonly understood as an excess of a negative (undesirable) emotion; distress, anxiety, confusion, frustration, anger. Behaviour, in these terms, is an externalising of an internal emotional state. These behaviours, which represent internal emotional states, are understood through an emotional recognition as ‘challenging’, that is, negative or undesirable. Choosing such a psychological (or pathological) understanding of emotions over socio-spatial conceptualisations is needed to maintain the asymmetry of power between the individual and the other (Procter, 2014). Those that do *not* display such behaviours are afforded the emotional capital in such a relation; they are recognised as controlled, rational, competent, and thus, powerful. Capital is revoked from individuals unable to contain the external manifestation of their internal states through positioning their emotions as ‘lower’; attributes of a body (rather than mind), pre-intentionational, an impaired body (with impaired emotional competence). At best these behaviours, read as rubbing up against emotions, are understood as an attempt to communicate. By revoking emotional capital, the individual becomes a site for intervention; how to develop emotions that are valuable, and valued as ‘higher’; that which can be re-presented as an attribute of intelligence (Ahmed, 2004). Within challenging behaviour discourse, this is the strategic intervention to develop ‘functional communication’ (Carr & Durand, 1985); where emotions that are recognised as legitimate and valued are rewarded through the recognition of their communicative intent. The valuing of functional communication is the commodity fetish of emotions in action; the concealment of its historical value as a ‘tool for the project of life’ (Ahmed, 2004, p.4). Children who develop functional communication, which removes the requirement for bringing challenging emotional work, can gain the status of neoliberal human; rational, contained, individual and productive (Runswick-Cole & Goodley, 2014).

## Dis/orientating Emotion through Autism

The affective economies associated with pathologisation are no coincidence. Where diagnostic labels such as autism now exist, once sat descriptions of the naughty, difficult, problem child. Brain-claiming discourses provide the distance between the cerebral subject and the troublesome subject in theory but a turn to emotion explores otherwise. Pathologisation has a long history with the problem child. In work around how children ‘become a problem’ in education, MacLure et al. (2012) explored the ‘complex interplay of discipline and learning’ that lead to children acquiring a reputation as a problem; a particularly sticky set of emotions that seem at times to be somewhat collapsed into diagnostic labels. When the practice of Early Years pedagogy, which fluxes between discipline and learning, care and control (Burman, 2008), works alongside (on?) a pathologised body, what (or who?) is it possible to be or become?

What churns through my own gut and re-tellings and re-readings of that morning of ‘biting’ is Rogers’ poignant reminder; within education settings, ‘it’s ok to be different, just not difficult’. What happens when one does not only *have* problems but *is* a problem (Michalko, 2009)? These are the sticky emotions of an affective economy at work on a micro-political scale between adults and children in Sophie’s school world. In a classroom of difference, in a special school of inclusion, the staff (I can only assume) were fully signed-up to an ethos of inclusive difference. They seemed to be, given their interactions with the more docile children in the classroom, the ones that embodied their difference in less physical, more malleable, more desirable ways. This is not to suggest that the pathologised child is a trapped, deterministic subject; subjectivity is, as Butler reminds us, malleable, it is ‘a practice of improvisation within a scene of constraint’ (2004, p.1).

So here lies our hopeful analysis; an analysis of becoming, or possibility of improvisation, that rubs up against, and perforates through, the affective economies circulating around Sophie’s body, her education, and her everyday life. If Sophie’s subjectivity in the classroom is ‘neither wholly pre-determined nor fully self-actualising’ (MacLure et al., 2012) then there is room for manoeuvre, and manoeuvre she does, in a complex weaving of embodiment and affect from spaces of deep striation and towards the smooth spaces of otherwise.

## Autism marking bodies

I turn here to how a narrative of ‘autism theory’, in which emotions are individual psychology, might interpret the bite, which would no doubt herein be known as ‘the incident’.

The bitten-supply-assistant drew on autism-challenging-behaviour and its associated ‘good practice’ in identifying a ‘trigger’ to the bite; the ‘behaviour’. Such a behaviour analysis is the means by which challenging behaviour interventions strategise a response to, and an understanding of, an individual's actions (Clements & Zarkowska, 2000). A ‘bite’ within this framing is constituted as a challenging behaviour and understood to have communicative intent. It follows a linear, causal model, in which the Settings, Triggers, Actions and Responses (ibid) of a situation and its resultant behaviour are analysed and interpretation of the behaviours communicative function hypothesised. The aim of such an analysis is to offer explanation and solutions to prevent future occurrence of such challenging behaviour and instead provide an intervention, which offers the individual a more functional behaviour to achieve the same communicative ends. In this situation, Sophie’s behaviour was deemed a consequence of her environment; the ‘Mr Grey’ advert ‘triggering’ her challenging response. The discursive understandings of autism acted as a founding undertone through the interpretation of both trigger and consequence, which seemed to put the staff both at ease, and slightly redirect the finger of blame from Sophie. She *needed* to bite in order to have her distress at the disruption understood by the staff; to communicate. The biting itself was somewhat of an inevitable outcome of an environmental trigger. The distress experienced by the disruption was a symptom of her impairment; autism. Autistic children don’t like change.

But here was an impasse. Simultaneously, it seemed, the staff both legitimised and demonised the understanding of her impairment as they saw it. ‘It’, the bite, was both *within* Sophie and *without* her. ‘She’ that is, an *intentioned* she, wasn’t to blame for causing harm yet was seamlessly chastised for its consequence. ‘Forgive the sinner, not the sin’?

The bite, and its associated biter were cast into Neitherherenorthere The act was both accepted and condemned in the same breath. *We’re* to blame for the trigger but she must accept its consequence because her choice of communicative mode was unacceptable. She was both with and without intention. It was bordering on acceptable that she *had* to bite (beyond/without intention) but that she still *shouldn’t* have bitten (returning to intention).

If the biting was to be tolerated (though punished), it needed to be understood as constituting part of autism symptomatology; it needed to be an inevitable response to the triggering of her impairments; autistic children don’t like change. Her desire to bite had to either be pre-intentional or part of autism pathology. These were the only option for forgiveness. The discourse of challenging behaviour had to trump any other.

The sensory experiences of those labelled with autism are beginning to be taken seriously. This began within autobiographical accounts of the embodied experiences of the senses (Grandin, 1992; Williams, 1992) and has been taken up in the academy by a turn of attention to sensory processing and sensory integration (Bogdashina, 2003). Within traditional autism theory this appears to be somewhat of a progressive turn, which recognises the importance of differing sensory experiences. Does a turn to a sensory interpretation of biting offer an inroad? If we take sensory understandings of autistic embodiment seriously, then that allows for a new discourse to emerge, one in which biting is not about anger and pain but something else. Within this corpus of autism knowledge, Sophie is afforded a different understanding of sensation and pain. Here, she is understood not to understand pain normatively. If she herself doesn’t understand or feel pain in the same way as non-autistic others, then she wasn’t to know that biting would hurt another and, ergo, was wrong. But what does that do to intentionality? It removes it from within her remit; she *couldn’t* know better. Here she becomes abnormal, here she is sensorially deficit. Autism discourse, of a different kind but ever-stealthily normative and ableist, once again, trumps.

Through the affective economy of concealment (Ahmed, 2006), Sophie’s bite *appears* to generate emotional responses that are both natural and necessary. Biting (in and of itself) appears without a history of moralisation as wrong and unacceptable; as if it weren’t a sign, rather, an object (ibid). The staff’s shock and condemnation only appear through the concealment of such moralising. Here the accumulation of emotional capital is afforded to Sophie in its negative; the circulation of affective exchange in which Sophie is associated with emotions of fear, disappointment, pity, anger, is so rich that its history is negated. The culmination of micro-political acts, a bite, a thrown object, a broken rule, has been steeped in affective relations that lead to the seemingly naturalised emotional response that came to be between Sophie and the staff members in that room.

The bite, its aftermath and the emotions that come to be around it neither begin *nor* end there. In the fluidity of always already being and always already becoming constituted as a subject, the emotions that glide over and stick to understandings of Sophie and her body are also always fluid and becoming. It is in *moving* that these emotions gather weight, that some become stickier than others (Ahmed, 2004). It is in the emotions that seem to stick to ways of knowing Sophie that make some becomings more possible than others. Those sticky emotions that fail to glide over Sophie do so not in a vacuum but within a wider framing of pathologisation; the economies at work in that room rely not just on affective histories and becomings between individuals but alongside diagnostic understandings of her label as autistic.

## Inhuman Emotions (Impossible emotions)

It was a time of emotion, of intense affect. Therefore, I now move from what was happening in the words (both said and unsaid) to attend to the circulating and permeating emotions in the room. It appears easy to implicate emotions in and around the bite. Contained, rational humans don’t bite each other, children often do. Part of the socialisation of children involves the moralising of biting one another as wrong. When a child understands something is wrong they stop (or eventually stop) doing it. Or so normative developmental psychology would tell us (Murray-Law, 2011; Claffery et al., 1994; Goldstein, 1979). In moralising the act of biting, Sophie became inhuman. If it was driven by emotion (as opposed to autism in one guise or another), it was wrong. It cannot be possible that Sophie wanted to bite the supply, because this is not possible in school, it is an impossible emotion (Youdell, 2011). It disrupts the normative developmental trajectory of a child of her age that appears to haunt the classroom of this special school. To bite is to harm and to harm is wrong. To be a proper school child is to be a moral child who understands the unwavering virtues of right and wrong.

The master translation of the affective economies at work in classrooms with labelled children, such as Sophie, has been to pathologise the dynamic becomings of such emotional relations through a particular discourse that sticks to autism; challenging behaviour. Discourses of behaviour, in relation to children with autism diagnosis, are powerful and legitimised by, and with, bodily practices in education (see for example Team-Teach, 2010). Research tells us, in fact, that children with a label of special educational needs are far more likely to be touched, or restrained, than those without (Allen, 1996). Why then is physical contact deemed legitimate in the lives of these children (Hodge, 2014) amongst a wider discourse of ‘safeguarding’, in which school staff are often guided by policy that explicitly forbids physical contact with a child (Piper and Smith, 2003)? Piper et al. (2006) suggest that within Early Years settings in particular, touch is a marker of both developmental and behavioural status. They suggest that children must be seen to demonstrate an appropriate developmental and behavioural stage in order to ‘earn’ exemption from unsolicited touch. Sophie is unable to gain such status, by virtue of the accumulated and concealed signs of her subjectivation as both fearsome and a child living in spaces labelled by disorder.

The contact between adult/child bodies in that morning tread the line of care and control with a fluctuating mix of sophistication, aplomb, fear and uncertainty. Children were quite explicitly deemed to be more manageable when sitting in a chair and physical contact deemed acceptable to meet such ends. The performance of a ‘proper’ school child, one that sits in its assigned chair, and directs its body towards the adult, was as prized within this setting (which theoretically recognised children’s differing embodiments and accommodated them) as it was within mainstream discourses of the school child ready and eager to learn, by being *recognised* as such through the positioning of their bodies. The pursuit of the seated child, appearing ready and eager to learn, appeared high on the agenda throughout the morning. This wavered from a comforting rubbing of a child’s arm to the restriction of a child’s whole body with an adult arm over its lap. The blurring of when these contacts were care or control was interplayed with uncertainty about their intention and how they were received on the part of both the child and adult involved. Early in the morning, as Sophie draped her body across one of the assistants, the interaction between their bodies appeared mutual and, at worst, indifferent. It was interpreted by another adult as a site of control, and an opportunity to regulate; ‘no climbing Sophie, you’ll fall’. Here, Sophie’s initiation of physical contact was deemed inappropriate, the observing adult interpreting her intentions in the complex of discipline and the opportunity for developmental learning. Later, physical contact was in fact heralded as an intervention of good autism practice; offering ‘deep pressure’ in the firm rubbing of a child’s arms during a moment of distress (Edelson et al., 1999).

There seemed to be a nervousness around encounters with Sophie from the assistants in general, with the exception of the newest member of staff. Perhaps this assistant’s lack of experience of Sophie on a daily basis was what freed her from responding to her with such apprehension. Perhaps it’s what got her bitten. Where, in general, the other children encountered all adults in the room, contact with Sophie was largely left to Anna. Throughout the morning, I watched Sophie being watched by one of the assistants through sideways glances that continuously checked what she was doing, how she was moving, surveilling for unpredictability. Over the heads of the children, nervous glances were shared between the adults at signs of Sophie’s unpredictability, a whoop, a quick unwieldy spin, each the potential sign of a ‘trigger’ of another ‘incident’. These small acts, slight movements, were as Jonet et al. (2010, p.?) remind us, ‘...calibrated against powerful definitions, overt and tacit, of what counts as ‘normal’ development, orderly conduct and the ‘proper’ child’; marking Sophie as not-quite human or not-yet-human.

The bite is an exemplar, it *does* something. It established, and maintains a distance (both physical and emotional) between Sophie and other bodies, as fear, nervousness and unpredictability is read as difference off the surface of her body (Ahmed, 2004). These emotions themselves were *doing* things, aligning the staff in their ‘natural’ collective response to her biting. Sophie is read as a child to be avoided, a body to be feared. She becomes fearsome through the circulation of signs of fear, such as the bite, as discrete acts accumulate emotional resonance over time. Such a coming into being of emotions served to have material effects on the room, on Sophie’s body, in which their reading resulted in her segregation to another room and to the justification of unsolicited touch. She is kept at a distance as proximity then becomes imagined as potential future harm (ibid). An assault form is completed to document this. The exemplar of the bite stood for something bigger (Renold & Mellor, 2013), as the reification of Sophie’s biopolitical labels as disordered and challenging. As she becomes fearsome, she becomes inhuman. The responses of the staff members become justified; she can be treated as non-human because she is non-human, her actions tell us so.

## Anna: personal and political emotions, impossible feelings

A particularly tricky and sticky circulation of emotions surrounded the teacher that morning, who, through micro-political actions, negotiated power complexes at both an interpersonal and institutional level. Assistants looked to Anna for guidance, seemingly comforted by her presence and troubled by her absence. The affective atmosphere shifted in Anna’s absence, the tone of the room changing, the air tensing, the formal pedagogy left hanging, frozen in time and space until she returned. In her presence, Anna commanded the attention of both children and staff through the enactment of differing emotional tactics. Assistants received quick, sideways smiles that seemingly conveyed authority and reassurance, simultaneously interspersed by intense attention to the children and their bodies with a chirpy, instructional voice and a strong, unwielding smile. This was a performance that appeared both demanding and skilled, and served particular purposes in regulating the emotions that circulated and rubbed up against one another that morning. Anna was quick to attend to the individual children’s shifting and changing emotional embodiments, in scooping children into her arms when they appeared distressed and redirecting their attention when they appeared overwhelmed. Nowhere was this more apparent than amidst the bite and its aftermath. The swell of emotions that overflowed in those moments was still within Anna’s remit of control it seemed; a remit, which she seemed herself to find somewhat overwhelming. The surge of responses saw Anna flustered and an effort to contain the situation, she was to contain the *emotions* of the situation. She swept in and removed Sophie from the room, creating spatial boundaries which separated the becomings of emotions between the staff’s responses and Sophie’s. Having seen what appeared as swift and decisive discipline from Anna, which was quickly removed from my sight, when I joined them outside of the room not long after I was met by quite a different scene. The breathless fluster of Anna’s initial response was nowhere to be seen and Sophie’s unruly body appeared calm and without distress in its attention to the maths task being undertaken. Anna’s embodiment appeared tense and alert coupled with her chirpy, enthusiastic focus on Sophie’s task and her achievement of it. There seemed to be a disjuncture between Anna’s psychic emotional response and her political one. As the two prepared to return to the class, Anna put her arm around Sophie and cuddled into her saying softly with a sigh, ‘what will we do with you Sophie Connor?’ Here seemed a moment of emotional disjuncture for Anna; the constitution of Sophie and her impossible emotions drew Anna into a space of interpersonal and institutional quandary; her personal care for her, coupled with her professional, imagined future, in which Sophie would continue to be subjectivated in such ways if she continued to fail to ‘pass’ as the proper school child (Burman, 2008).

Within the blink of an eye, the deployment of emotions that may have been constituted between Sophie and Anna was subject to a new framing; of bureaucratic care, the Assault Form. Allan (1996) suggests that the gaze of surveillance children experience in school spaces is extended further upon those with Special Education Needs to include the documenting of their behaviour and their emotions. In completing the form, Anna understood the situation in a new light, ‘would you call it physical bullying?’ Where moments before Anna had shared affection and (a particular kind of) care for Sophie, here Sophie became gazed upon in ways that invoked criminal behaviour; assault. The short but significant negotiation between Anna and her staff of how best to describe the bite, within the disciplinary remit of the assault form, required the legitimising and delegitimising of emotions that were and weren’t possible in that setting. Situating the bite within individual, pathological understandings was the only possibility within the form’s small boxes and multiple choices.

## Dis/orientating: Biting Otherwise

Reading, or feeling, the morning and the biting through affective economies, gives us a way to relate to Sophie and the micropolitics becoming between her and the staff in a different way. It allows for the recognition of her subjectivity and her subjectivation as always incomplete and, in an assemblage of constitution weaving around and up against the striation of her school experience as always becoming. It allows for an exploration of how small acts are read as ‘“standing for” a bigger problem; while the status of the bigger problem is consolidated through the iterations of the acts that exemplify it’ (MacLure et al., 2012 p.455). When the emotion work of that morning is framed as being mediated by, through, and *between* bodies, it becomes possible to reject the moralising of Sophie’s biting and to interrogate the concealment of it as a sign; as the impossible school child, as the non-human. If Sophie’s bite is freed from discourses of challenging behaviour, good practice and individualised, naturalised emotions, then it becomes possible to recognise Sophie’s resistance to the ‘conditions of possibility’ (Renold & Mellor, 2013, p.26) in Early Years education, in which the proper, contained, docile school child is the *only* possibility. It may be that children, individuals, are always coming to be and be known within a ‘scene of constraint’ (Butler, 2004) but as Sophie’s bite reminds us, where there is power, there is always resistance (Foucault, 1979) and this itself is always on the move, always becoming and always dis/orientating.

A story between and beyond autism and child

Leaving ‘Biting’ and the notion of becoming between bodies hanging, to gather around those sticky emotions, I move on to tell another story of Sophie. It centres on an analysis of ‘3. What does autism makes im/possible for a child to be and become?’ by exploring the lines of flight that can come to be in smooth spaces, one of which I suggest is a physical space, a ballet class. Where ‘Biting’ focussed on an analysis of what was done *to* bodies, this second story takes a more optimistic gaze upon what is done *by* bodies, the lines of flight. The lines of flight of this second story offer us a final dis/orientation to autistic childhoods allowing us to, ‘...trip out of the striations in which we are caught and skate on the smooth plateaus between, even if in doing so we slip into or begin to grind out yet another striation’ (ibid, p.145). This story takes us into a smooth space of becoming - beyond the knowable and appearing subjectivated autistic child and into spaces of exploring the potential of what a body *can* do (Deleuze & Guattari, 1987).

Sophie’s mum suggested that I visit Sophie’s ballet class. This was a class in a village on a Saturday morning in a dance school. It was for children Sophie’s age. Sophie was the only child in the class living in a labelled space (other than child) as far as I knew. Sophie’s mum said that Sophie really loved the class and that the staff were brilliant with her. She’d recently been in the dance school show. The story is told now and followed by an analysis of what is done *by* bodies to contest ideas of knowable bodies.

## Saturday Morning Ballet Class

*It’s early on a Saturday morning with crisp, bright sunshine and a thick layer of ice on my windscreen. I’m going to be late. I scrape furiously. The bitter air whips under my scarf as I get into the car and my frozen hands stick to the steering wheel. Sat nav at the ready I set off along out of the lazy, deserted roads of Sheffield and into the wilderness of unknown Derbyshire villages. In 150 yards, I bear left.*

*I arrive at the dance school in the nick of time and tentatively introduce myself to the first smiling face I see, in the hope that they have remembered I’m coming. I’m in luck, it’s Anna, the Dance School owner. I’m quickly ferried into a vast dance studio that has such a chill I see my breath. I’m offered the seat next to the burning hot electric heater, which I need to enjoy while it lasts; it’s switched off once the children arrive to stop prying fingers meeting a blistered fate.*

*In the distance from the changing rooms, I hear the hum and giggles of small voices and parents wrestling with tutus. I play with my notebook and realise I have no idea what’s coming next. How exciting. I wonder if Sophie is already here, if her mum was having a fight with a tutu and if Sophie is going to be having a ‘good day or a bad day, we never know’ like the dance teacher foretold. She tells me the new music hasn’t been going down too well with Sophie and that the prop teddy bear had been dropkicked in recent weeks.*

*Quite out of the blue I’m pulled back into the room by a hush and a stilling of the distant scurrying feet. From a nostalgic ghetto blaster, a Disney classic (Aladdin!) rises from the depths. The room of the studio door is opened and three teenage girls corral and direct each girl, no older than 4, a vision of pink, lycra and bounce, to their assigned seat on the floor in front of Anna. Seamless. They’re reminded of ‘tidy toes and big smiles’ and follow instructions keenly and adeptly. I sing along (word for word) in my head.*

*Sophie is brought in last, guided by one of the older girls and led with enthusiasm and gusto to her spot on the floor. She watches Anna cautiously, through sideways glances whilst seeming thoroughly enthralled by the experience. The music is loud. It’s consuming, filling the large space with its boom and invitation to get lost in the Disneyfication of it all and Sophie’s bought into it as much as I have. The music continues to crescendo and Sophie gets to her feet and whoops and shouts. This isn’t the instruction she should be following but the teenage helper, acting as her shadow, and Anna too, seamlessly reorganise her space and she finds a new way to express her engagement with the experience, waving her hands and shaking her head.*

*A new girl, thinner and even smaller than the others, arrives late and scurries to sit herself down next to Sophie. A sideways glance from Anna is all it takes for her to know this might make Sophie uncomfortable. ‘We’re a bit squashed here’, Anna casually ushers, ‘let’s move to here’ gesturing to the other side of the room. This feels thoughtful, and easy, and allows Sophie and the new girl their space to be in the way they need to be. It’s seamless.*

*As the music continues, Sophie’s helper becomes occasionally overwhelmed by her body as it bolts across the room or spins quickly and unsteadily, flopping to the floor. Again, without fuss, Anna casually steps in, sweeping with the music across to Sophie’s space. She seems to be at ease with Anna’s presence, her body, and allows Anna to dance along with her, supporting and twirling her floppy body in a mutually acceptable way.*

*Somewhere amongst this musical whirlwind wands have appeared and are used to direct the next phase of the girls performance. They’re each given the opportunity to solo in front of the mirror, ‘sway, sway, sway and tuuuuuuuuuurn’, tiny feet teetering and stumbling with a vague resemblance to 360 degrees; Sophie accepts the direction of her body and the regulation of her movement happily, she’s not bothered. She’s too busy loving it.*

*The rest of the class passes in a blur of Disney and a haze of pink. Adults (or teenagers) are always at hand for Sophie, for the other girls, to make sure she can join in where she wants and roam free when she chooses.*

## What is done *by* bodies

Following on from Althusser’s ‘turn’, ‘Depending on which way one turns, different worlds might even come into view. If such turns are repeated over time, then bodies acquire the very shape of such direction’ (Ahmed, 2006, p.15). Here is the coming together, the *becoming,* of attention to both what is done *to* bodies and what is done *by* bodies. Here is our autistic child that is known and knowable by virtue of discourses of autism, challenging behaviour, normative development and childhood. It is the repeated turns, in their particular hailings of ideology (Althusser, 1970 in Ahmed, 2006), that bring the autistic child into being in the familiar ways first explored in the literature of *Route A-to-B,* then heard echoing through Mary’s interpretation of Samuel’s window-licking and the staff’s reading of Sophie’s ‘bite’. These well worn turns, that traverse over well-worn lines, constrain what is possible to know and what is possible to be and become in a life labelled child and autistic.

Lines are both created by being followed and are followed by being created. The lines that direct us, as lines of thought as well as lines of motion, are in this way performative: they depend on the repetition of norms and conventions, of routes and paths taken, but that are also created as an effect of this repetition. To say that lines are performative is to say that we find our way and we know which direction we face only as an effect of work, which is often hidden from view. So in following the directions, I arrive, as if by magic. (Ahmed, 2006, p.17)

Unpicking and unpacking the magical arrival of how lives come to be known and understood as both child and autistic is a moment of dis/orientation, as we have seen through our turn to an affective economies analysis. I have asked if there are not some less-well worn paths that can be trodden in contesting a knowable autistic-child-body. Sophie’s dance class offers us a final turn down a less-well worn path, in which our focus is the possible side of im/possible, how a turn to embodiment can be a dis/orientating linchpin in turning towards a critical analysis of autism, childhood and dis/ability.

Dis/orientations: Contesting a knowable body

I draw here on the corpus of autism theory to demonstrate how this story can contest the descriptions of a body that is knowable as disordered. Within understandings of sensory processing complexities commonly associated with autism is the notion of proprioception; the sense of where one’s body is in relation to other bodies and objects. There is a nod towards the importance of the body in relation to research around autism but it seems to stop there, at a vague acknowledgement of sensorial abnormality or deficiency. The body as a sensory being can be a tricky one if you live in spaces labelled with autism because, through the discourses that provide legitimate knowledge of what it means to be autistic (biomedicine), that sensory being becomes knowable. Most significantly, that being becomes knowable as sensorialy abnormal and in turn governable. The experiences of the body in relation to autism within the dominant discourse are accounted for by brain function, regulating or failing to regulate sensory experiences. The body is tied up by the brain and is owned by it. This is a sticking point because it dictates that the embodiment of autism is bound up in the realm of all things cognitive. These domains leave little room for anything very ‘experienced’ at all and are far more concerned with the process of brain function and its consequences of subservient bodily function. We are haunted here by what the body is and is not, and what the mind is and is not, by the Cartesian call of disembodiment. If we draw boundaries around and between the body and mind whilst insisting on a body that is ultimately dictated by the mind, then an ‘autistic body’, labelled by an ‘autistic mind’, leaves little room for manoeuvre. Hickey-Moody (2009, p.3) speaks of this marginalisation of the body as a product of Descartes’ pushing of corporeality as ‘exterior to the realm of pure thought’. As such, the body is not a site of knowledge; it is without thought and is limited and undervalued by virtue of its mind’s ‘intellectual disability’. Braidotti (1996, p.55 as quoted in Hickey-Moody, 2009) imagines the body, its flesh, as the ‘silent other’, which Spinoza (2001) would argue is, in silence or deliberate silencing, not less powerful but less well understood. Spinoza has us believe that our ‘minds are the idea of our bodies’ (Hickey-Moody 2009, p.5). This alternative leads us towards the ‘thinking body’ (2009, p.6); a body is neither able nor disabled but is a process of becoming. When the limitations of Cartesian ideas are interrogated and the myth of the natural body uncovered (Butler 1993), it becomes equally feasible to ‘denaturalise impairment’ (Donaldson 2002, p.112). No longer is Sophie’s body a knowable entity of sensory abnormality, of cognitive disorder, but a being which produces and pushes at Cartesian ideas of what it means to know and live at the collision of autism and childhood. Within this becoming, we are offered potential from the story of the Saturday morning ballet class and from the knowledge that Sophie and her body were producing in that smooth space. Sophie and her body subverted the limitations of the descriptions by which she was bound. Let us return to the ballet class to consider the sites in between the body and mind dualism that allow us the space to explore this potential. From a layperson’s perspective, ballet could perhaps be understood as a discipline – by which I mean a regulated, controlled form, in which one learns techniques, movements and processes for and with the body. It is very much a realm (again, understood as a layperson) of something at which one can be ‘good’ or ‘bad’. I think back to the harking ‘tidy toes’ that were spattered throughout that Saturday morning. Ballet requires discipline in order to produce freedom; the body regulated as a means to an end, the body’s formalisation and precision allowing eventual expression, I would theorise. In this sense, then, Sophie could have been very easily bound up within the unruly realms of not being very good at ballet; her body did not conform to the discipline set out for it. I had previously listened to practitioners from her inclusive nursery setting describing Sophie and her body, their descriptions encapsulating her being as ‘challenging’. Narratives of professional expertise spoke of a child with ‘challenging behaviour’ (Emerson 2001). Those echoes rang dim on this Saturday morning. Should not her unruly body be invoked in much the same way by the ballet teacher here? Her body could surely be considered far more ‘challenging’ in this space because of its disregard for the discipline that is ballet. But for some reason it was not. For some reason, within a space that should, in theory, place much greater value on bodily conformity, compared with an inclusive nursery promoting free-flow-play, Sophie and her body existed with far less regulation and discipline. This space - without an ‘inclusive’ branding or ‘autism specialist’. Here, Sophie and her body were less well known (through a lens of autism and childhood) and instead were producing knowledge, were becoming. Hickey-Moody (2007, p.87) considers ‘how does one create a space with an atmosphere that positively transforms the way in which bodies can be thought?’ One might be more inclined to believe that an inclusive nursery would be more likely to achieve such an atmosphere than a Saturday morning dance class. However, it would seem that this dance class was a space that far more readily embodied transformative understandings of the body. This methodological approach, with a focus on embodiment as a place of knowledge production and experience, offers us a means of going beyond the traditional limits and boundaries of empirical methodologies, which know and measure Sophie not by her body’s production, but through her mind’s disorder. In this dance class, the mind was not privileged over the body, neither autism nor child was privileged over the embodied experience of space; this was a space of becoming, of autism and child. By introducing notions of embodiment it becomes possible to get in between the divide; the body becomes both the source and the site of agency and not an entity in need of rationalising by the mind and, in turn, society (Csordas, 1993). Through engaging in ethnographic practices such as this, the stories that we tell of bodies, of autism and childhood, can maintain a phenomenological gaze through affording attention to descriptions of collective, sensorial, embodied encounters. By bringing together embodiment through ethnography and storytelling, there is the possibility to create a space of becoming and potential; a becoming beyond the subjectivation of autism and childhood. I have explored the beginnings of these possibilities here and reflected on the potential for our understandings of the collision of autism and childhood through a methodology of storytelling. That storytelling has been used to experiment with a line of flight from the disembodied autistic-child-research assemblage into dis/orientated and dis/orientating new spaces, where the becomings of bodies within the collision of autism and childhood can be celebrated.

We now draw towards the final call of the thesis, a call to remain open to the potential of living within permanent, or perhaps more aptly, ever-becoming dis/orientation with autism, childhood and dis/ability. Though theoretical, dis/orientation is also embodied it is a way of life. This way of life is discussed and concluded in Chapter 10: Take Home Messages and signed off with a series of Postcards from Neitherherenorthere to parents, professionals, autism researchers and theory.

# Chapter 10

# Discussion & Conclusions

# Take home messages from a dis/orientated terrain

Our traversing of the terrains of autism, childhood and dis/ability were not a journey from start to finish. This is, however, the end of the thesis journey and, as such, brings together the findings of the project as Take Home Messages. These take home messages are our willing embrace of a permanent, ever-becoming dis/orientated gaze upon childhoods labelled autistic. Where a true embrace of ‘becoming’ would be reliant on remaining ever-nomadic (Braidotti, 2002), the multiplicities of possible becomings in a thesis need to be brought together to address their implications and suggest future directions for research across these dis/orientated terrains. As you take these messages home and they find residence in those familiar, comfortable places; the cosy chair with the good book and a glass of wine, I ask that you stay ever-mindful of letting the sensation of dis/orientation that this thesis invoked remain. I ask that you remain faithful to Ahmed’s call that I have used at this thesis’ foundation; ‘...if we stay with such moments then we might achieve a different orientation toward them; such moments may be the source of vitality as well as giddiness. We might even find joy and excitement in the horror’ (Ahmed, 2006a, p.4). What I risk here, in drawing the thesis to a close, is carving out such defined, restrictive new lines in our orientations to autism and childhood that they become as constraining and problematic as those original lines, the grand narrative of disordered childhoods. Alan Prout (2005), in predicting the future of Childhood Studies, asked that we resist replacing one dichotomy with another, which I suggest is possible in the dis/orientating experiences of the stories in this thesis. With the theoretical fuel taken from Foucault, Ahmed and dis/humanism, we must remain cautious of the ableism stalking any gaze upon autism and childhood and the discourses of power/knowledge being produced. We must remain on the lookout for those dis/orientating opportunities in and beyond these Take Home Messages.

The begins with a story that ends the auto/ethnography. I then turn to the Take Home Messages and a summary table of the implications of these for policy, practice and research. I spend the rest of the chapter unpacking those implications before ending with some postcards from our dis/orientated terrain; Neitherherenorthere.

## Ending the auto/ethnography

*The designing of and doing of this PhD, the conceiving and writing of this thesis, have been the becoming of me as a researcher and, at this end point, an academic working for an institution with autism branding. It has been, and will remain, the very embodiment of a rhizome both personally and academically. Pinning down the fluxing and competing narratives of my daily life so heavily steeped in autism, its commodification, its materiality, its theorising and its sociality has, at times, been most unbecoming. It has carved out certain ‘really deep lines’ (Youdell, 2015) at particular points; that stealthy desire to find a single orientation. It’s occasionally been full of a desire to decomplexify the entire experience of being, doing and becoming a researcher at the peripheries of both CDS and any semblance of ‘autism studies’. Were I to rest my head amongst the familiar well-worn lines of autism as impairment, neurodiversity, social construction or otherwise, I would experience far fewer quandaries and critical encounters professionally and academically. Designing teaching materials and autism modules, contributing to course reviews and strategic plans would be far less problematic had I a clearer more static relationship to the slippery subject of autism and its spectre - autistic childhood. However, I find solace in the rhizome and its becoming that I have explored through this project. I have made my peace with autism as rhizomatic and with an inherent need for dis/orientation and will spend many hours trying to convince others of its potential for more productive understandings of childhoods labelled with autism. As I sit three years on and think of my becoming as a researcher writing her first story (that now makes up the Preface of this thesis) to where I sit now, I am heartened by the potential becomings I have weaved in and through the experience of this PhD project. I’ve met hilarious and feisty children, who push and pull at the world, fraying its edges and demanding more of it. I’ve lost (no,* gained*) countless hours of conversations with parents over coffee and veg patches in snippets of their rhizomatic relationship to autism, their children, to research and theorising of childhoods labelled with autism. I’ve been prodded and shoved into uncomfortable spaces by strangers, students and colleagues, who demand more of my autism knowledge than I dare commit. I’ve been challenged by their intrigue in my motivations and pushed to articulate the becoming of autism in ways I find no more productive to the cause of understanding or relation to autistic childhoods than the reductive or oppressive discourses of yesteryear. I’ve tangled myself in an organisation that is firmly with/in commodified autism. And I love my job. Such is an acceptance and embrace of dis/orientation.*

*I also come to think about the beauty of hindsight as I prepare to undertake my doctoral supervisor training for the coming academic year; what would I want my future students to know about the experience of doing a PhD and what would I have done differently given my time again. I’d love to do it all again! The project that came to be, and the writing of it, wasn’t, thinking back, what I had imagined, or proposed in applying for PhD funding. That’s testament to the rhizomatic becoming of selves that comes out of meeting my supervisor, the CDS colleagues I’ve stumbled across on the way, the academic post I took up in my second year, and the pesky ageing process that’s added on three years to the youthful twentysomething who wrote the PhD proposal. The project became through those meetings, my knowledge shaped and disrupted by others, and most importantly, by the children and families in the project. The project never could, or never should, have come to be in the way it was proposed; it had to become with the people, spaces and places that entered it and shaped it.*

*Logistically, I would have done some things differently as some of the trials and tribulations of recruitment in Chapter 5 describe. I found the process of meeting and negotiating the bounds of the project with parents particularly difficult. I think this partly came out of a feeling that I was asking clearly busy people to give of their time, and their children’s. Children who already had dozens of strangers and professionals in their lives, who could perhaps do without another ‘interested’ person. Where I was able to explain, and parents were fully on board, this really worked. Where parents clearly needed a greater degree of structure and sense of me ‘doing’ some research with their children was a slippery and tricky interpersonal negotiation that I didn’t always get right (again, see stories from Chapter 5 and 6). Chapter 6 explored the ethical dimensions of the project in a procedural sense, which I feel was the greatest quandary of the project. The consent (assent) procedure that became in the project, I feel, is in tension with its ethos, which values the embodied participation of children front and centre. Though I do not think there is a definitive solution to this, in future, I would spend much more time with parents discussing the importance of negotiating and building meaningful consent with the children themselves. That being said, I think one of the greatest improvements that could be made to a project like this* is *more time being spent with the children themselves. As the ‘methods of being’ in Chapter 5 discuss, there were times where I felt I slipped into the position of ‘observer’, that I again felt rubbed up against the notion of becoming between bodies and sharing through embodiment I had hoped for. Hindsight is a wonderful thing. I end with gratitude to the children and parents in this project, those who were there start to finish and those who appeared fleetingly; they pushed and pulled the bounds of this project in new directions and to new ends in wonderful, mundane, resistant, embodied, everyday, and dis/orientating ways.*

## Summary of Research Questions, Take Home Messages and Implications

The research questions were explored through three analytical chapters*; Chapter 7 Talking*, *Chapter 8 Becoming*, and *Chapter 9 Becoming*. I include the research questions here before introducing the Take Home Messages that act as a summary of responses to those questions. Each is expanded through implications for research, policy and practice and built upon through this concluding chapter.

1. *How is autism spoken about and how else might we talk of autism?*
2. *How might we consider being autistic as part of being a child?*
3. *What does autism make im/possible for a child to be and become?*
4. *What does autism do to/for/in education?*
5. *How can autism research broaden its understanding of the everyday?*

I start by discussing the ways these dis/orientations responded to my research questions. I do so through a series of ‘Take Home Messages’ which have been drawn from each of the analytical turns in ‘Talking’, ‘Being’ and ‘Becoming. I describe what has become so far, with implications for theory, policy and practice and finish with a series of postcards from Neitherherenorthere, the terrain of dis/orientation, to some important people; children and families, professionals, autism researchers and theorists. The take home messages of this thesis and the implications for practice, research and policy, are;

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| What dis/orientation can offer **Talking**  1. Critical Disability Studies can broaden autism research’s understanding of everyday life  2. Storytelling can provide counter discourse to grand narratives of autism and what it means to talk of, and to be and become, an ‘autistic child’  3. Autism is rhizomatic in the talk of parents. It is shaped by, and shaping of, collective identity work, emotional labour, neuro-governance and the commodification of autism  **Being**  4. Children labelled with autism experience education through the lens of the desirable neoliberal school child  5. Considering autism as part of childhood theoretically, methodologically and practically is vital in understanding everyday life for children labelled with autism  **Becoming**  6a. There is value in paying attention to what is done to bodies and by bodies; in valuing embodiment outside of Cartesianism  6b. Children labelled with autism exceed their subjectivation as ‘autistic child’ with and through their bodies in everyday life |

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| Implications for practice and policy  * Autism research needs to be open to dis/orientation. This means new disciplinary grounds, a reconceptualisation of the terrain; not of the disordered, disembodied mind but the embodied, lived and everyday. * Methodologies of Creative Analytic Practice, including storytelling, can provide new criteria for a research agenda for the everyday lives of disabled children’s childhoods.      * Professionals, autism educators, practitioners working within commodified autism need to defetishise. This means a close critical eye to that which we desire and resist in our conceptualisation of autism and our practice with children. Rather than desiring individual subjectivities we must work to recognise the broad social processes at work in and around the lives of labelled childhoods. * Practitioners and policy makers must recognise the framing of the ideal neoliberal citizen that permeates disabled children’s experience of education. Our practice and policies must recognise the nexus of the dis/child at work here; the negotiation children, families and practitioners are brought in to in desiring and resisting the narrow boundaries of the neoliberal school child positioned as becoming ideal neoliberal citizen. * Research, policy and practice needs to be open to dis/orientation; away from developmentalism, neuroscienticism, psychologisation, and pathologisation. Children’s childhoods, rather than impairments, need to be front and centre. The sociology of childhood, in its most critical form, can be helpful in this dis/orientation; where everyday life and the sociological study of childhood is centred. * Research needs to bring in the body, as lived, knowledge producing and valuable. Beyond this, our theoretical work needs to embrace the potential of dis/orientation. In practice, this means remaining ever watchful of our orientations towards (and away from) autism, childhood and dis/ability and the children living those childhoods. Embracing dis/orientation keeps the subjectivating work of single orientations at bay, remembering that children always exceed their subjectivation as ‘child’ and ‘autistic’, with and through their bodies, in their everyday lives. |

## 1. Critical Disability Studies can broaden autism research’s understanding of everyday life

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| *Implications for research, policy and practice:*  Autism research needs to be open to dis/orientation. This means new disciplinary grounds, a reconceptualisation of the terrain; not of the disordered, disembodied mind but the embodied, lived and everyday. |

In this thesis I have made a case for situating research about autism and childhood in new disciplinary grounds, Critical Disability Studies. This is a response to research question 5, *‘How can autism research broaden its understanding of the everyday?’* This, in itself, is a new terrain upon which to explore autism and childhood that has recently emerged as a new body of literature and a research agenda, disabled children’s childhood studies (Curran & Runswick-Cole 2014; Runswick-Cole 2015; Curran; 2015). CDS offers the theoretical, methodological and analytical means to navigate the dis/orientating experience autism and childhood in new and progressive ways. Autism research takes place predominantly in disciplines that are positivist, disembodied and situate the experience of impairment within broad tragedy narratives. More progressive work that brings lived experience front and centre, coming from the neurodiversity movement, has provided narratives countering the oppressive medicalised discourses of autism. The neurodiversity movement alone does not offer the theoretical means of taking these accounts further than the individual. What is missing from such work is the socio-political landscape in which this research takes place. I have suggested that a turn to theory and the theoretical offerings of CDS have been helpful. This thesis has contributed to the growing body of work situated in disabled children’s childhood studies with a particular focus on autism.

Dis/orientating with CDS can offer the means by which,

...the struggle for social justice and diversity continues but on another plane of development — one that is not simply social, economic and political, but also psychological, cultural, discursive and carnal. (Meekosha & Shuttleworth, 2009, p.50)

In this thesis I have made the claim that the disabled childhood queers the neoliberal version of childhood, as can be read in the stories of Chapter 8 Being and Chapter 9 Becoming.  Such a queer(y)ing requires research agendas for autistic children’s childhoods to traverse different terrains. Turning to the theoretical offering of dis/humanism can queer(y) our starting points and dis/orientate to,

...allow us to claim normativity in childhood (play, development, family, relationships) while simultaneously drawing on disability to trouble, re-shape and re-fashion narrow, neoliberal models of childhood as time of preparing citizens of the future ready to contribute to the global markets. (Goodley et al., 2015, p.7)

The methodological evolution of an auto/ethnographic project, in which everyday practices were led by children and families, allowed me to write stories that could be navigated by a CDS and, more specifically, dis/humanist analysis. The stories of the children - Max in his risky relationship with neoliberal desirability in school, Sophie in her biting and ballet dancing, and Samuel in his window-licking, taught us that a dis/humanist approach is a moment of reflection on the human, childhood, and dis/ability, at once desiring of the norm and disrupting its narrow boundaries. Titchkosky and Michalko (2012) ruminate on, and around, the framing of disability as ‘always-already a problem’ (p.133). In making disability identical, difference is absorbed into the social whole as just *like* everyone else but not *as*; to be disabled is just one of our many taken-for-granted always-already a problem phenomena, but always one of the least desirable kind (ibid, p.134). The phenomenon of ‘problems’ is subtle yet pervasive in the lives of disabled children; when disability is always-already a problem, within the inevitability that all people have problems, not everyone *is* a problem (p.134). At points in the thesis, we have heard stories that bring children and their families into that complex of being cast as always already a problem; Sophie in the reputational discourse that circulated her bodily actions in some contexts, but importantly not others, and The Collectives back and forth with the seeking and rejecting of normality. It is with a turn away from dis/ability as always already a problem, that stories such as the Saturday Morning Ballet Class offer, that I have suggested the autism research agenda can broaden its understanding of the everyday lives of children labelled autistic. Storying the everyday lives of children labelled autistic, which dis/orientates our gaze on autism and childhood, I have claimed, allows us to develop a research agenda that does just that.

## 2. Storytelling can provide counter discourse to grand narratives of autism and what it means to be an ‘autistic child’

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| *Implications for research, policy, and practice:*  Methodologies of Creative Analytic Practice, including storytelling, can provide new criteria for a research agenda for the everyday lives of disabled children’s childhoods. |

This Take Home Message gathers together findings of more than one of the research questions and was a central call of the thesis as far back as Chapter 1, where we first recognised the number of ways of traversing, or storying, autism and childhood through our two routes. This storying theme continued through to the methodological design of the project in Chapter 5 and 6 and produced the stories told throughout Chapter 7 Talking, Chapter 8 Being, and Chapter 9 Becoming. The theme of storytelling as counter discursive responds to the questions, *‘1 How is autism spoken about and how else might we talk of autism?’,* and *‘5. How might autism research broaden its understanding of the everyday?’* The stories themselves were used to provide analytic substance to the questions, ‘*2. How might we consider being autistic as part of being a child?’, ‘3. What does autism make im/possible for a child to be and become?’* and ‘*4. What does autism do to/for/in education?’*

I turn here to the implications of storytelling as methodological means to design and dis/orientate research about children’s everyday lives. Reviewing methodological literature of research around autism made the dominant stories of autism as medicalised, pathologised and psychologised all the more apparent (see chapter 5). Chapter 1 and 2 had already shown us that we claim a lot of knowledge about children labelled with autism, in relation to impairments. What autism research knows less of is everyday life; the lived experience of autism in children’s and families’ everyday lives. The desire of this project has not been to know autism, know autistic childhoods in, or for, empirical terms.  A dis/orientation of autism and childhood, taken from dis/humanism, offers a troubling of our current orientations towards the ideal neoliberal human, and child (Goodley & Runswick-Cole, 2015).

### 2.1 Dis/orientating methods

I have made a case that storytelling offered the means to counter grand narratives of autism and childhood and that the writing of them gave the analytical means of exploring my research questions. Writing, as a form of CAP, became inquiry (Richardson, 1994) and analysis happened *within* the stories (Ellis, 2000). This approach allowed us to dis/orientate our gaze on the everyday lives of children and families away from their pathologisation as disordered or through the festishised lens of autism. Setting criteria of CAP ethnographies became my yardstick and, I argue, a helpful yardstick by which to develop our research agendas and projects around the everyday lives of disabled children. Reflection promoted dialogue (Ellis & Bochner, 2000). It expressed a reality - embodying a fleshed out, embodied sense of lived experience (Richardson, 2000). I sought to nurture the imagination not kill it (Bochner, 2000). I provided a view that complexifies the phenomenon (of autism and childhood) that has enough literary substance to provide a readable balance of chaos (Ellis, 2000). It read, as Denzin (2000) hopes, as a moral text, that bring the world into play, presenting specific problems and ‘anchoring them in their historical, cultural, and biographical contexts’ (p.261). Such methodological and analytical concerns have not, until now, been at the front and centre of autism research.

### 2.2 Implications of dis/orientations: Theory and Practice

The contribution to an autism research agenda centred around everyday life has now been summarised. A key implication for the practice of this research agenda is an ethical one. The ethical orientations of this project were situated firmly within a dis/human ethic of valuing what childhoods labelled autistic disrupt and contribute to our valuing of humanity (Goodley & Runswick-Cole, 2015). This is an ethic that the emerging disabled children’s childhood studies is growing out of (Curran & Runswick-Cole, 2013). McGuire’s (2010) cautionary tales of the risk and violence of advocacy bled into the experience of storying and relating to the experience of narrating these children’s and families’ everyday lives. Coupled with an auto/ethnographic commitment to Creative Analytic Practice, and the criteria of such methodological approaches outlined in Chapter 5, I used these tools to evaluate the more slippery ethical dimensions of what should and shouldn’t be written and how it should (or could) be analysed as part of a thesis. The danger was always to slip into analytic practices that served no more of a productive purpose than the dominant discursive conceptualisations of children labelled with autism I sought to dis/orientate. The potential and possibility of advocating otherwise (McGuire, 2010), to claim and reject narrow definitions of what it means to be a valuable and valued child in everyday life (Goodley & Runswick-Cole, 2014), guided my practice with the children and their families. I argue that such a practice in the making and doing of a research project is essential to progressive research around disabled children’s childhoods.

## 3. Autism is rhizomatic in the talk of parents

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| *Implications for research, policy, and practice:*  Professionals, autism educators, practitioners working within commodified autism need to defetishise. This means a close critical eye to that which we desire and resist in our conceptualisation of autism and our practice with children. Rather than desiring individual subjectivities we must work to recognise the broad social processes at work in and around the lives of labelled childhoods. |

Autism is rhizomatic in the talk of parents. It is shaped by, and shaping of, collective identity work, emotional labour, neuro-governance and the commodification of autism. This message came out of the findings of Chapter 7 Talking, in which I responded to the question ‘*1. How is autism spoken about and how else might we talk of autism?’* I began the thesis in Chapter 1 Contextualising the Terrains by mapping the terrains of autism, childhood and dis/ability through two routes, The Quickest Route A-to-B and The Scenic Route. The travelling of this terrain offered us the opportunity to traverse some of the most well-worn lines in the history of autism and childhood. By orientating towards a CDS framing of dis/ability and the sociology of childhood, we were able to expose that quick, convenient route as a dominant discourse in need of further exploration. We gathered some Foucauldian fuel and re-took our route via the scenic option; stopping off at junctures and taking side roads to interrogate the terrains from a different orientation, that of biopower.

Chapter 7 ‘Talking’ carried us through stories of the dis/orientating experience of living with, and alongside, autism. It dis/orientated our gaze on the dominant talk of autism and considered the rhizomes that come to be through parents and professionals speaking of lives labelled both child and autistic. It drew in the dis/orientating experience of the rhizome with multiple entryways, and the im/possible ‘beings and becomings’ of autism that reside when particular ways of knowing and coming to know autism and childhood are mobilised. It evidenced how parents and children are already living their everyday lives amongst the giddy experience of dis/orientation in their encounters. They draw towards and away from particular orientations of dis/ability, autism and childhood, as their talk of autism spreads and negotiates the complexity of everyday life. I now move on to the messages that were found within these dis/orientations and consider the implications for research, policy and practice with a particular focus on those working with/in commodified autism.

### 3.1 Messages from dis/orientations

Through the rhizomatic exploration of a number of ways parents spoke of their relation to autism, their family lives and their children, we took a number of entryways to that slippery rhizome. A single way of talking, relating to, or knowing autism proved untenable in the lived experiences for these parents. Kate found a claiming of autism, in its neurodiverse, cerebral form, to be a source of liberation and identity formation in the relationships of both her and her family. She wove a narrative of brain-centred personhood through her storying of her relationship with her oldest daughter and provided examples of Max claiming a similar cerebral identity for himself. The situating of this narrative around the brain clearly offered that as the means to ‘escape the omnipresent spectre of blame’ (Runswick-Cole, 2014, p.1124) that so often stalks parents’ narratives. Having a different brain was emancipatory for Kate and her children, in its cerebral form, the label of autism metamorphosised from stigma to a tool of liberation (Ortega, 2009, p.434). Where Ortega (2009) cautions the risks of such a centring of personhood in brain-claiming plains, Kate’s deployment of this narrative was far more nuanced; she continually dis/orientated autism, childhood, difference and dis/ability. In neoliberal times of austerity, claiming difference as too far removed from a broader narrative of impairment, the claim of a worthy ‘same but different’, risks access to resources being withdrawn (Runswick-Cole, 2014), a reality all too familiar for Kate. This is the sophistication by which parents of disabled children work and live amongst dis/orientation in their lives; Kate readily storying her children as both same but different *and* impaired, depending on the most enabling outcome for her children. This was demonstrative of the fluid orientation to autism’s talk in their family life, the rhizome of autism spreading and weaving in action. Where one ‘talk’ of autism would lead to a blockage, Kate weaved around its edges in a new direction.

As we carried on through our rhizome, we came to new branches and blockages that allowed and prevented new beings and becomings of the talk of autism to take form. Rachel drew attention to the disempowering experiences of particular claims of neurodiversity as exclusionary for both her and her children. Rachel’s talk of autism was read as a great source of emotional labour in the maintenance and containment she enacted in managing other people’s responses to her children and their needs. She pushed the edges of an autism-as-difference narrative in articulating the clash of ideology with her family’s material experience and often sought out the ability side of the dis/ability complex. As a response to this blockage in the talk of autism she encountered, she had branched towards more enabling terms, one being the choice not to use ‘the A word’ anymore when speaking about her children. In negating autism, in removing it from her everyday vocabulary, she was resisting the discourses she was finding unhelpful to her and her children, blocking the reproduction of its power in her interactions with others. For Kate, the use of the word autism was a powerful trump card, a de-moralising of her families’ experiences and a passport to resources for her children. For Rachel, the use of the word autism was producing particular discourses of knowledge about her children that she didn’t recognise as part of her ‘real family story’. The talk of autism in these families’ lives was complex, enabling and disabling depending on the entryway into its rhizome.

The talk of autism in The Collectives lives had brought the families together in a diagnostic centre waiting room. Its talk had become material in the setting up of a charity, the growing of vegetables and the baking of apple crumbles. Autism talk, here, had certainly been productive. Such a disjuncture between the different mobilisations of autism need not be feared, in the multiplicity of the rhizome there must be a multiplicity of relations. For The Collective, the allotment site was the material amalgamation of several different autism knowledges; those *given* to parents by professionals, those sought out from each other and those developed by and with their children on the allotment site. The resultant physical space speaks to the potential of rhizomatic autism talk; how embracing many possible versions of autism discourse, of multiple knowledges can be productive in the everyday lives of children. It is the epitome of the value of multiplicities in autism knowledge; social theory, developmental psychology interventions and the sophistication with which parents of disabled children meld and break the complex rhizomes of knowledge in their material, mundane everyday lives.

The implications of this are both theoretical and practical, both within and without the academy.

### 3.2 Implications of dis/orientations for those working with/in commodified autism

Recognising the power of particular orientations to autism, childhood and dis/ability is a key place to start for practitioners, autism educators, researchers and theorists working with/in commodified autism. Childhoods labelled autistic are always ready to dis/orientate and are always already dis/orientating. As the stories of these families have shown us, there isn’t a single way of talking, relating to, or knowing autism; autism is always rhizomatic in people’s lives. I have argued that families negotiate the complexity of autism with nuance and sophistication and are required to deploy different narrative orientations of autism in relation to their child’s needs in different contexts. This is a great source of labour for families, who have to manage and contain others’ understandings of autism and relationships with their children, to avoid the spectre of blame that haunts autistic children’s parents’ narratives (Runswick-Cole, 2014). This meant claiming and resisting particular discourses of autism, and the knowledge produced around it, at some times and not at others. It meant living in dis/orientation. At times, the medicalisation of autism was a vital passport to resources for families who needed the certainty of diagnosis and accepted it fully. At other times, this meant a negotiation of such certainties’ limitations when in tension with their lived experience. McLaughlin and Goodley’s (2008) analysis of parents’ acceptance and rejection of certainty provided a helpful framework for exploring some of these nuanced negotiations in parents’ talk of autism.

As I explored in ‘Chapter 5 Methodology’, autism is now a successful and powerful neoliberal commodity (Mallett & Runswick-Cole, 2012; Runswick-Cole, 2014; Timimi, 2013). We learnt about the materiality of this from ‘Chapter 7 Talking’, in which we heard about the ways in which parents negotiate the commodification of autism in their children’s lives. The interventions Kate and Rachel had been ‘sold’ as educational tools and normalising methods for their children’s development, the diagnostic centre courses that The Collective met at, all speak to neoliberal, marketised discourses of autism. Those of us, myself included, who work with/in the commodified autism must pay attention to the broader socio-cultural messages coming out of the stories of the parents in this project’s negotiation with autism. As educators of this product, this brand of autism, which we exchange with education practitioners, health professionals and a social care market, we can either contribute to an individualising discourse of festishising behaviours and symptomologies, inventions and solutions, or we can use them to develop tools of defetishisation theoretically and in our practice.

I have called, in *Chapter 7 Talking,* for a pause on the many rhizomatic ways autism is functioning; the production and reproduction of autism discourse.  Dis/orientating the commodification of autism is a vital analytic tool for professionals in interrogating autism discourse in children’s and families’ lives. Professionals must take a critical view of the part they are playing in the commodification of autism and children’s experiences; how they are contributing to, or disrupting, enabling and disabling autism discourse in their practice. How, we must ask, are we orientating to autism, childhood and dis/ability and what are the risks of any single orientation? What, we must ask, is the potential of dis/orientating autism, childhood and dis/ability? As we have seen, the commodification of autism, within the academy and broadly across society with our neoliberal brain-claiming of childhood and parenting, bears down on parents’ and children’s material experiences. Parents are offered and asked to consume autism through courses, training, literature and parenting classes (see Runswick-Cole’s 2016 recent response to the government's announcement of parenting classes). Practitioners are brought into this process by training and qualifications allowing them to develop their knowledge of autism and skills of working with autistic people. The imparting of knowledge from autism educator to practitioner brings with it a risk of perpetuating the psychologisation of individuals or, at the very least, the clumping of subjectivities under the guise of the ‘autism spectrum’. Autism educators, at an individual, institutional and collective level, must work to defestishise such an exchange (Mallett & Runswick-Cole, 2012). It is not enough to individualise each of the families in this thesis to personal narratives, unique and subjective, as if they don’t speak to a broader experience of families living with autism in the UK at this point in the social imaginary. Brain-claiming liberated Kate and her children from the moral spectre of blame through discourses of the neuro-self, in which identity is formed and maintained in a subject's interior. What Rachel and The Collectives stories showed us was that such creation and maintenance of personhood, of identity, takes place in the social and is always dis/orientating. That neoliberal social imaginary is centred around a desire to know autism, to quantify and qualify the subjectivities of being autistic. Professionals need to defestishise such desire of the individual, interior subjectivities, in recognising the social processes at work in such commodification of a single impairment category, autism. We must disrupt the socio-cultural proliferation of autism as a fascinating mystery to be solved, as the quintessential puzzle of our contemporary times (McGuire & Michalko, 2011) in our talk, education, intervention and research in people’s lives. As the rhizome of ‘Chapter 7’ demonstrated, knowledges of autism are multiple, spreading and fluid and, as The Collective taught us, they are most enabling in their form when they are grown by those who contribute to such knowledge through lived experience. The call for my ‘expertise’ as ‘Lecturer in Autism’, which has been sought out and shelved at various points in the thesis depending on when and where my ‘autism branding’ was valued or not (that is, when it held biopolitical currency), speaks to the risks of commodifying impairments both socially and academically. The Collective have evidenced this in their growing of fruit, veg, and autism knowledge, all of which came to be as the result of the lived experience of a biopolitical act, autism diagnosis, in action, producing produce. It is recognising the ways in which lived experience goes beyond personal experience of the interior, or psychologisation of subjectivity, that those bound with/in commodified autism can dis/orientate and work the slash of dis/ability. This is the very push and pull of that slash in neoliberal times.

One area for future work coming out of this thesis that has already begun is the development of teaching resources for those working with/in autism. During the writing of this thesis, I developed an instructional week for The University of Sheffield MOOC (Massive Open Online Course) ‘Exploring Play: The importance of play in everyday life’ called ‘Disability and Play’ (Smith and Goodley, 2014). I used some of the stories written as part of this project to develop resources, which asked practitioners to dis/orientate their gaze on the play of children labelled with autism. Rather than fuelling a festishised gaze upon the developmental ab/normalities of children's play, I invited practitioners to interrogate the stories through a lens *outside* of autism, challenging behaviour or developmental discourses; through a lens of the intrinsic value of play. Alongside these resources were the contributions made by The Collective. This dissemination through the MOOC queer(y)ed research and teaching in autism. Though still branded as ‘within’ the academy, by virtue of being run by, and under, the university, the nature of MOOCs is such that they are often considered as taking place ‘outside’ of traditional academic spaces (see Wintrup et al., 2015). The Collective’s contribution blurred the boundaries of academic knowledge, parenting, and activism. Here, students (practitioners) working with/in autism were invited into the creation of knowledge about autism produced by parents. This is the rhizome of autism talk and knowledge in practice and is a vital tool in dis/orientating away from the psychologisation or fetishisation of autism and towards attention to lived experience and everyday life.

Autism, as a commodity is of great value, from its educational good practice, its branded interventions its enormous literature base, to its socio-cultural artefacts. As Runswick-Cole (2014, p.1126) perhaps tauntingly reminded us, ‘autism itself is, then, perhaps the quintessential neoliberal subject’. It is what is done to, and with, this broad social process, commodification, that this thesis asks us to be mindful of. How *else* can we talk of autism? I asked. Some starting points have been outlined here. Implications for the talk of autism and its many possibilities continue through the responses to my other research questions now. This is by no means a resolution or a call to give up on autism in its commodified form. Titchkosky (2003) asks us to consider what happens ‘between’ the language that we use to speak of disability. She reminds us that we are inclined to resolve contradictions by privileging one position over another, when, in fact, we should be concentrating our efforts on that unresolvable space between things, between words, between bodies and minds.

## 4. Autistic children experience education through the lens of the desirable neoliberal school child

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| *Implications for research, policy, and practice:*  Practitioners and policy makers must recognise the framing of the ideal neoliberal citizen that permeates disabled children’s experience of education. Our practice and policies must recognise the nexus of the dis/child at work here; the negotiation children, families and practitioners are brought in to in desiring and resisting the narrow boundaries of the neoliberal school child positioned as becoming ideal neoliberal citizen. |

The stories of Chapter 8 Being responded to the question ‘*4. What does autism do to/for/in education?*’, which led to a discussion of the experience of schooling as an experience of the un/desirability of the neoliberal school child. As McLaren (1988) highlighted, those in the theorising of education must attend to the production and reproduction of subjectivities through discursive practices that ‘penetrate the level of the body’ (p.69). Erevelles (2000) pointedly notes that where attention has been afforded to marginalised bodies through race, gender and sexuality, disabled bodies have been omitted by and through the historical educational agenda of separating out disabled learners. The stories in this thesis which centred around school spaces, have contributed to our understanding of how disabled children are marginalised through a lens of desirability.

### 4.1 Messages from dis/orientations

The story of Max’s (un)desirability in education and the interpretation of Samuel’s window-licking at nursery speak to the discourses at work in the childhoods of those labelled autistic that leave little room for manoeuvre. Both Max and Samuel, I claim, use the little room for manoeuvre that they have in their subjectification as autistic as a site of resistance; as wiggle room. This wiggle room is an exemplar of the dis/child; an ambivalence to the neoliberal version of childhood that has long since left children like Max and Samuel out in the cold. Max’s experience of desirability in school, compared to his siblings, is a moment of the dis/child in education, policy and practice. If dis/humanism asks us to consider the aspects of a modernist conception of the human that we seek to desire and resist (Goodley & Runswick-Cole, 2014), the dis/child in education asks the same questions of childhood and pedagogy. In this story we learnt how ableism and resistance rubbed up against one another and seemed to come into being almost in the same breath. A linchpin of neoliberal ableist childhood - academic achievement - was the site of this friction. Children in the same family, with the same labels, were having very different experiences of school due to that rub of the dis/child; what we desire and resist in childhood and education. Desirability, here, is the promise of future economic production; the child becoming an independent adult contributing through labour. Max inhabited a risky space of resistance, one in which his potential for imagined future dependence (through non-compliance with normative educational achievement) left him open to marginalisation as less desirable than his siblings, in spite of their matching labels (Erevelles, 2000).

### I have shown how the experience of autism as a Special Educational Need has become a neoliberal site of desire, in which hierarchies of difference are more or less valued through frames of compliance. Where Ruby and Joe could be read as docile in their compliance to ableist standards of academic achievement, Max’s embodiment was read as unruly, pushing at the boundaries of what was and wasn’t valued in neoliberal education. Butler (2004) invited us to expand the norms of which lives are liveable, which to an extent has been the bedrock of inclusion agendas.

### 4.2 Implications for Policy

In attending to policy in education, it might be expected that this thesis makes recommendations for policy makers. This is a risky business and a dilemma I often feel drawn into as both a researcher and lecturer, perhaps for my fear of contributing to the neoliberal commodification of autism, childhood and, in this case, education, that I’ve addressed earlier. As Oliver and Barnes articulate for me,

....to get too close to the government is to risk incorporation and end up carrying out their proposals rather than ours. To move too far away is to risk marginalisation and eventual demise. (Oliver & Barnes, 2006, n.p.)

In those moments of dilemma, I am drawn back to a dis/humanist call, which I suggest asks that progress can only be found by engaging in that push and pull exemplified by Oliver and Barnes. As the ironically neoliberal National Lottery catchphrase goes, ‘you’ve got to be in it to win it’ (Dale Winton, 2012). Towards the end of this project, I embraced such a call to engage with the neoliberal policy agenda in a brief stint working in central government policy analysis (though not education). The process of being ‘in it’, and the everyday experience of resisting ‘it’, proved untenable, to put it politely and lightly. I remain unresolved on whether I should, or could, as a researcher and lecturer, make recommendations to policy makers, having seen and been part of the turning cogs of central government policy. Policy is, for me, a risky business that produces and reproduces a web of knowledge and governance over children’s lives. Greenstein (2013) asks that we ‘think global - act local’ as a progressive means of engaging and resisting the governance in disabled children’s education. This is, she tells us, ‘a dual approach of building localised and self-organised alternatives, while continually resisting oppressive structures and practicing global solidarity’ (p. 320). This approach was embodied by the work of The Collective, in which they were carving and growing their alternatives in an overgrown corner of Sheffield, expanding out to other families across the city. Their concerns and actions took place amongst weeds and in vegetable patches, whilst their work, the talk amongst families and the solidarity growing between them, bled into the parent-teacher meetings, fights for EHC Plans and school placements, far beyond their allotment borders. This suggests that it is not in becoming happy bed-fellows with policy makers that the everyday lives of children and their families are improved but that the resistance and collective solidarity, which chips away at ‘the global’, is a fruitful endeavour.

My dis/human imperative requires recommendations to be made all the same (as, no doubt, does the requirement of a thesis). Broadly speaking, policy makers involved in the mechanics that govern disabled children’s lives need to reconceptualise the vision and versions of autism, childhood and dis/ability that permeate the neoliberal arena. Situating autistic children’s subjectivities in a disordered mind, or discourses of neuroscienticism, perpetuates a paternalistic policy field, in which children, as Max, Samuel, and Sophie have shown us, become known and knowable as lacking, unruly and undesirable. Through their unruliness and undesirability, they are positioned as in need of neoliberal tools of educational intervention; professional partnerships with families and ECH Plans being the most recent.  The stories of this thesis call for a dis/orientating of this conceptualisation, a gaze in which the everyday lives of children are recognised as being beyond the neoliberal bounds of autism and childhood and are always becoming and always more.

## 5. Autism as childhood. Considering autism as part of childhood, theoretically, methodologically and practically, is vital in understanding what it means to be an autistic child

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| *Implications for research, policy, and practice:*  Research, policy and practice needs to be open to dis/orientation; away from developmentalism, neuroscienticism, psychologisation, and pathologisation. Children’s childhoods, rather than impairments, need to be front and centre. The sociology of childhood, in its most critical form, can be helpful in this dis/orientation; where everyday life and the sociological study of childhood is centred. |

Having offered a response to the question ‘*4. What does autism do to/for/in education?*’ I now move more broadly to those stories experienced and told in the children’s and families’ everyday lives. Education, though a big feature of this project, only accounted for part of it. I have argued, along with Curran (2014), that research about disabled children’s impairments is not research about their lives. As I have shown, educational experiences of disabled children are predicated on surveillance, management and support of their impairments through the discourses of Special Educational Needs and Disabilities (SEND) policy. To respond to the question ‘*2. How might we consider being autistic as part of being a child?*’, we needed an orientation centred around experiences of childhood and everyday life, rather than experiences of impairment. *Chapter 8 Being* drew on the contributions of the sociology of childhood to experience a moment of dis/orientation; where autistic childhoods were part of childhood. It used literature from childhood studies to frame the way the lives of the children in the project would be viewed and told stories in such a vein. It was the site in which the methodological design of ‘Being’ took place, formulating methods of engaging and sharing in everyday experiences of children. Importantly, it took a breath in our dis/orientating to autism, childhood and disability, which centred the experiences of the children not as becoming-adult (James & Prout, 1997) but as valuable moments of the sociological study of children’s lives. In a novel dis/orientation away from traditional autism research with children, it centred embodiment. In that sense, I was also responding to the question ‘*5. How might autism research broaden its understanding of the everyday?*’ As Youdell (2015) reminded us, research with children so often neglects the body or considers it a site, an object of study, rather than a phenomenological turn to embodiment. It was with such a turn to the body as lived through sensory ethnography, that this project contributed something new to autism research; research that is embodied, lived, and values the sharing of meaning-making of children.

### 5.1 Messages from dis/orientations

An attention to embodiment ‘...more adequately captures the notions of making and doing the work of bodies - of becoming a body in social space’ (Turner, 1996, p.xiii). Hickey Moody argues ‘....for an understanding of corporeality that medical and sociological discourses of intellectual disability are not able to realise’ (2006, p.xviii). ‘Bodies with intellectual disability need to be known in terms of what they produce, rather than by reference to what they are not’ (p.2). The biopolitical narrative of children labelled with autism is one in which they are recognised and known as inherently lacking, which in turns feeds a discursive focus on the ever-elusive ‘normal’ child. This is fed by modernist narratives of Cartesianism, which leave the mind marked as lacking and, as such, a discourse of those labelled with intellectual disability as somehow lacking the characteristics of what it means to be human. The stories told throughout this thesis disrupted dualism’s centrality. Disrupting the Cartesian dualism of mind/body is to get in-between discourses that trap intellectually disabled lives in a cycle of the disordered, disembodied mind. It is an opportunity to dis/orientate our gaze away from ‘what they are not’ towards recognising ‘what they produce’ (ibid). If we look back to the stories of Sophie, particularly The Saturday Morning Dance Class and The Bite, we can see push and pull of dis/humanism at work above, and through, both stories. The Ballet Class, a space in which Sophie was known in terms of what she produced, beyond Cartesianism which would leave her positioned as lacking. Here, she was not subjectivated as the knowable autistic child, the neoliberal disordered child, but a body of becoming, of potential and possibility. This story rubs up against the vision of Sophie produced in the affective economies of The Bite. Here, sticky emotions of fear and disruption subjectivated Sophie and her body as the unruly school child with a disordered mind. She was caught in a nexus, which constrained what it was possible for her to be and become.

Max and The Goodwins taught us a lot about the everyday lives of children labelled with autism. They also taught us a lot about childhood. The implications for this sit mainly within a theorising of autism and a progressive autism research agenda that centres the embodied, lived experience of children at the heart of our endeavours, to better relate to the sociological experience of being an autistic child. The story of den-building and Max’s sharing of his cosy-corner were examples by which we are able to dis/orientate our attention in research away from pathologised or psychologised versions of children’s experience and towards an agenda in which everyday life, as a valuable site of sociological enquiry, is foregrounded.

### 5.2 Implications of dis/orientations: theory and practice

Such a reframing of the debate - autism as part of childhood - opens up our thinking to possibilities; the becoming, fluid, complex and ever-changing understandings we can explore of childhoods labelled by autism. The potential to explore children’s uses of space, crafting of their embodied worlds, engagements in their sibling relationships, their experience of family life at home (see Chapter 8 Being); all of which are commonplace for those without labels of autism but far less common for those of us working within the field of autism. The stories of den-building and playing in family homes dis/orientates normative developmental orientations that would leave descriptions of these children’s childhoods as abnormal. It refocused our gaze from pathologisation and towards alternative analyses of potential and possibility. With these dis/orientations, we can bring childhoods labelled by autism in from the cold and begin to progress a research agenda. We can begin to take disabled children's everyday lives seriously - their play, sibling relationships and experiences at home - outside of ableist developmental framings, as a site to explore their everyday lives and their embodied stakes in their worlds.

## 6. There is value in paying attention to what is done to bodies and by bodies; in valuing embodiment outside of Cartesianism because children labelled with autism always dis/orientate; they exceed their subjectivation as ‘autistic child’ with and through their bodies in everyday life

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| --- |
| *Implications for research, policy, and practice:*  Research needs to bring in the body, as lived, knowledge producing and valuable.  Beyond this, our theoretical work needs to embrace the potential of dis/orientation.  In practice, this means remaining ever watchful of our orientations towards (and away from) autism, childhood and dis/ability and the children living those childhoods. Embracing dis/orientation keeps the subjectivating work of single orientations at bay, remembering that children always exceed their subjectivation as ‘child’ and ‘autistic’, with and through their bodies, in their everyday lives. |

Building on the message that calls for disabled children’s everyday lives to be taken seriously as sites of embodied experience, leads to our final dis/orientation of the project; the value in paying attention to what is done to bodies, and by bodies. This is the becoming between bodies that we first explored in Chapter 4; through the dis/orientating experience of what is done *to* childhoods labelled autistic and what is done *by* children labelled with autism. Our final analytic chapter 9 ‘Becoming’ brought our thinking towards a critical analysis of autism, childhood and dis/ability, in which the potential of resistance and smooth spaces of becoming were explored. This was done through two stories, which focussed on the lived body of Sophie, how it was subjectivated through affective economies, how she resisted such subjectivation, and how she was always becoming, always an excess of biopolitical inscriptions given to her. The concluding story of the ballet class was a final productive turn of potential and possibility; the smooth space of becoming that is possible beyond the bounds of her subjectivation, as the knowable autistic child with a knowable autistic body and mind.

The body does not appear outside of the social world within which it is made manifest. Just as the meaning of the text resides as much between its words and between read and text, so too the meaning of the body resides between bodies, between those who live through them, in them, and those who bring them to mind. (Titchkosky, 2005, p.664)

Sophie’s body was, from metanarratives of autism and childhood, the same body in both the school classroom and the ballet class. But, as Titchkosky reminds us here, her body was given meaning differently in those two stories through that which resided ‘between bodies, between those who live through them...and those who bring them to mind’. The Saturday Morning Ballet Class was a story that spoke to a version of disabled children’s childhoods beyond autism and childhood. Hickey-Moody (2009) asks ‘how does one create a space with an atmosphere that positively transforms the way in which bodies can be thought?’ Sophie, in that dance class, offered a response, which I argue is the smooth space of becoming towards which this project has dis/orientated. A focus on embodiment as a space of knowledge production and experience offers us a means of going beyond the traditional limits and boundaries claiming knowledge of autism or subjectivating a knowable ‘autistic child’. In this morning, the mind was not privileged over the body, neither autism nor child were privileged over the embodied experience of space; this was a space of becoming, of autism and child.

By introducing notions of embodiment, it becomes possible to get in between the divide; the body becomes both the source and the site of agency, not an entity in need of rationalising by the mind and, in turn, society (Csordas, 1993). As Sophie’s stories showed us, as did Samuel in his licking of a window, children labelled with autism exceed their subjectivation as ‘autistic child’ with and through their bodies in everyday life.In future research, by bringing together embodiment through ethnography and story-telling and not solely focussing on discursive practice, there is the possibility to create smooth spaces of becoming; a potential becoming beyond the subjectivation of autism and child. I have explored the beginnings of these possibilities in the stories of the dance class, Sophie’s bite and Samuel’s window licking, and reflected on the potential for our understandings of disabled children’s childhoods on these new terrains of autism and childhood, with our gaze dis/orientated. This thesis has been used to experiment with a line of flight from the autistic-child-research assemblage into new spaces, where the becomings of bodies within the dis/orientation of autism and child can be celebrated (Smith, 2016).

# The End

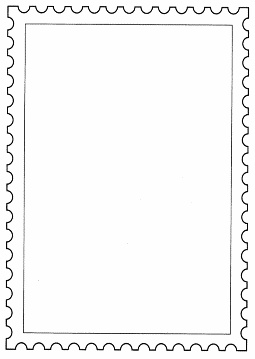
So here we end. We began with a ‘gaze’ and were called into the experience of ‘dis/orientation’. Being ever mindful of the way disabled children with labels of autism are gazed upon has been a theme carried from start to finish; attending to orientations, what they drew us towards, turned us away from, and hid from view. More importantly, exploring the work of those well-worn lines of orientation that make some appear more readily than others. Dis/orientation, I have suggested, offers us the means to interrogate how those well-worn lines of the talking, being and becoming of autism have come to be and the potential beyond them. Through an auto/ethnographic project and a Creative Analytic Practice, both in the doing and writing of this thesis through stories, I have made a case for dis/orientating critically to the talking, being and becoming of autism, childhood and dis/ability. I began by showing how children have long been cast as subjects (Rose, 1990) and none more so than the disabled child, who has been produced and reproduced by discourses in education and the socio-cultural imaginary as always already a problem (Titchkosky & Michalko, 2012). I have called to dis/orientate that gaze on childhoods labelled with autism through a turn to dis/humanist approaches (Goodley et al., 2014), Ahmed’s (2006a; 2006b) thinking on orientations and methods of storytelling in Creative Analytic Practice (Richardson, 1994). I have argued that, in order to dis/orientate our understandings of children’s everyday lives, we need to value bodies and embodiment beyond the tight subjectivating boundaries of Cartesian dualism. Stories have been told to illuminate the enabling and disabling consequences within and without such dualism. Beyond Cartesianism, through a dis/orientation to embodiment, children labelled autistic are no longer knowable as disordered and lacking but recognised as producing knowledge with and through their subjective embodiment, which resists the micropolitical acts that position them (Hickey-Moody, 2006). The relational process between bodies is the means by which children become knowable and known, a process of subjectivation, which children, and their bodies, always exceed (Butler, 2004; Hickey-Moody, 2006; McGuire, 2012). It is through such a dis/orientation that we have embraced the notion of ‘becoming’ (Deleuze, 1980), in which the potential and possibility of children labelled autistic is recognised and celebrated (Smith, 2016). The future of our relationship to the rhizomatic discourses of autism and the subjectivated beings and becomings they produce, lies in a research agenda that challenges and disrupts any notion of the pre-given autistic child subject and asks what dis/orientation can offer to our (always becoming) understandings of children’s and families’ everyday lives.

So here we part ways. But where, upon the terrains of autism, childhood and dis/ability have we ended up? Well, as I began the thesis I set the scene to take us on a journey, a journey that I suggested was most productive if it was wandered through, with no sense of an end point or final destination with a willingness to experience getting lost and the giddy sensation this brings with it. This experience in itself is disorientating and my call for dis/orientation has given theoretical navigation to this giddy and occasionally overwhelming sensation. What would a terrain of dis/orientation, one in which autism, childhood and dis/ability were gazed upon in new and productive ways of becoming look like? Look up. Look around you. We’re there - Neitherherenorthere. Neitherherenorthere is the terrain of dis/orientation, the place that this thesis now calls home. Each way you turn new worlds come in to view, when you turn back to look at where you’ve come from, the view has changed again and is not quite what you left behind. You wander towards the horizon and it continues to stretch out before you with distance objects becoming closer and fluxing and changing as you get nearer. Just as you think you’ve arrived, you turn a corner and a whole new landscape stretches out before you. It’s a vivid place with landmarks you don’t recognise but that have a tinge of nostalgia that you can’t quite put your finger on. Don’t worry, you’re not lost, this is exactly where you’re supposed to be, in that giddy place of dis/orientation that is Neitherherenorthere. We better get writing some postcards, people will wonder where we’ve been all this time...

# Postcards from Neitherherenorthere

Dear children and families labelled with autism,

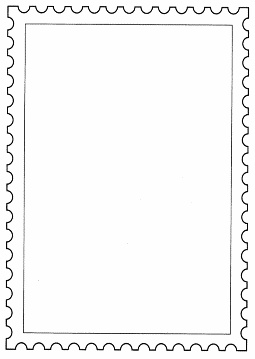
It’s been a pleasure and a privilege to meet some of you over these last three years, I’m writing this to you and friends, other children and families labelled with autism. Ending up here in Neitherherenorthere has taught me much about the experiences you encounter in everyday life with your labels of autism. Living out here and navigating its dis/orientating landscape must feel like old news to you all. Talking and being amongst your families has shown me the ways you negotiate the complexity of a social, political and cultural world that sometimes finds you difficult, sometimes makes you difficult and often doesn’t seem too interested in your everyday lives, only your branding of autism and its associated impairments and interventions. Parents have shown us the sophisticated ways you accept and reject this depending on how enabling you feel this will be for your children. Kids, you’ve shown me time and again how you refuse to be pinned down and known by anyone as ‘only’ a child or ‘only’ autistic, you’ve pushed and pulled at people and places and forced them to recognise that you are always more than that and you will continue to become more than that in your everyday lives. You’ve also been a whole lot of fun. The ways in which you’ve made me look again at what everyday life can look like and how full-of-life objects and spaces can be just by sharing those things in my presence has been nothing short of delightful. Kids, you and your parents are doing wonderful things to these things that we want to call and know as autism and childhood, you’re living and doing some very clever work to disrupt any ideas that you’re somehow lacking or that your way of being is broken and in need of fixing. I hope that you never stop becoming together, as children and families, and parents and kids, in a space that is always more than any single orientation of autism and childhood - I look forward to hearing about it! Jill x



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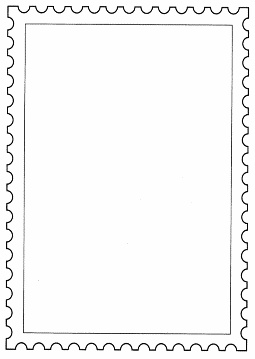
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Dear Professionals,  
Come with me, come to Neitherherenorthere the weather’s great and the water’s fine. This place, Neitherherenorthere is a wonderful place to be for you and I, interested in autism and childhood. It’s a safe place even though it’s dis/orientating; you spend a lot of the time feeling lost and a little dizzy, but hey, that’s all part of the fun! It’s safer than a lot of the other spaces you might be tempted to visit and set up camp, those places where you feel most comfortable that you can see autism, almost touch it within a child and that you somehow feel drawn towards knowing. That orientated place might feel comfortable and safe to you, and me at times, but the journey we have taken over these terrains has shown us that it’s not a place that is too safe for children and their families. It’s no picnic for these children and families to see you over there, watching them and knowing them. See that place, for those children and families, has bleak horizons and few routes of travel. There aren’t spaces for the children to play and to be, there’s no room, there aren’t spaces for families to resist the routes you map out for them. But guess what? If you look over there, you’ll see that the parents look confused by your map and are muttering things under their breath - you can barely see the kids in the distance who have wandered away from the route you’ve set for them regardless of your insistence on the need to follow well-travelled roads. They look like they’re having fun, don’t they? So, join me, in rethinking the map of travelling towards those safe spaces. Instead, join me in Neitherherenorthere and embrace that giddy sensation that you get as you’re about to set off on a journey that might be really fun, even if a little scary, that you might come back home from feeling changed and renewed. You never know, that vigour might just translate into your everyday encounters with those children and families that you work alongside. It might just help you to join them in that feeling of dis/orientation, confusing and enlivening, that they spend much of their everyday lives feeling and experiencing. And that might just be productive. Jill x



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Dear Autism Researchers  
I didn’t know if you’d want a postcard or if you’d rather I just disappeared off in the distance and kept myself to myself, but then again, even though it might make us all feel a bit uncomfortable and resistant at times, I am one of you too. We don’t know each other well enough, I suspect. I’ll admit, at times, I’m not great company, I always have a bone to pick and a go on and on about everyday life, as if that is nothing to do with what you spend your huge research grant money on. I suppose, if you ever wanted to come and visit me here, in Neitherherenorthere, we should talk this through, whether my rants and your grants are really that helpful to children and families living with labels of autism. We need to clear the air.   
I suppose I should just come out and say it, after I’ve danced around it for this long; these children, that you diagnose and prod and poke for symptoms and interventions, behavioural markers and cures, they deserve better. They are, after all, your equals and I think this sometimes gets lost whilst you’re measuring them; they’re more than the sum of those measurements, targets and outcomes. They’re not containers of disorder or receptacles for your devised interventions, they have everyday lives that are as messy, complicated and vital (in all senses), as yours. If we spent a little more of our time, and money, us autism researchers, talking to and being with children and their families, we’d know a lot less about autism, and childhood, we’d be continually surprised. It would, I admit, be dis/orientating and unnerving as what we thought we knew would be undone as we saw the ways in which children use their bodies to resist and disrupt all that is done to them in classrooms, public spaces and everyday life. They’ll exceed everything, everyday, and will continue to do so no matter how much you want to know and want to discover and uncover. But what of it? What if we wander through Neitherherenorthere with these children and their families, alongside them, listening to and sharing in their discoveries? What if, that was really productive to the cause of understanding the very becoming of autism and childhood as something always more and full of potential? Have a think about it and let me know if you want me to book a ticket.



We can work it out, promise. Jill x



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# Appendices

## Appendix 1

## Blog post for recruitment

Available at: <https://theautismcentre.wordpress.com/2013/06/04/university-of-sheffield-phd-student-is-seeking-research-participants-families-of-children-with-autism/>

## **[University of Sheffield PhD student is seeking research participants (families of children with autism)](https://theautismcentre.wordpress.com/2013/06/04/university-of-sheffield-phd-student-is-seeking-research-participants-families-of-children-with-autism/)**

Posted on [June 4, 2013](https://theautismcentre.wordpress.com/2013/06/04/university-of-sheffield-phd-student-is-seeking-research-participants-families-of-children-with-autism/)by [The Autism Centre, Sheffield Hallam University](https://theautismcentre.wordpress.com/author/autismcentre/)

Request from a research student from the University of Sheffield for interest in a PhD project:

Hello

I’m in the market for some families to collaborate with me in my PhD research project at Sheffield University. I’m coming towards my second year of study now and looking for parents and children who would be willing to share their experiences with me.

The project aims to explore the ways in which families talk about autism and their children, and how others around them speak about their child and autism too. I am hoping to broaden my understanding of the ways families involved in ‘autism’ perceive wider discussions of what autism means for their child and their lives.

I feel it would be useful to share a little of my background and motivations for undertaking this PhD to help you understand the direction I’m coming from and to help you decide if you would like to work with me.

My academic interest in this area is both personal and practical beginning in 2006 during a voluntary placement at …… as part of my undergraduate study. Having no prior experience of working with autistic children this time proved exciting, engaging and challenging. Returning to the academic world to see what ‘autism was all about’ I found myself troubled by how little I felt the written world of autism reflected the everyday world of working with autistic children that I experienced. I found it almost impossible to find anything written about the real, the personal, the everyday lives and relationships of autistic children and their families. I was overcome, and disappointed by what seemed to be the dominance of pessimism that seemed to cloud study after study.

I have continued to work with autistic children and their families throughout including summer play­schemes and work within family homes. I feel that we need to listen more, explore more, and talk more about the lives of autistic children; their happiness, their relationships and their futures outside of the worlds of medicine and psychology, which is what brought me to my PhD studies.

It is with these motivations that I am hoping you would be interested in taking part in this project.

My aim is to work with you towards promoting new ways of talking about autism, autistic childhoods and the everyday value within their relationships and daily lives.

I’m looking for families that are willing to share their experiences and their time. I am hoping to spend time with you informally to talk through my project and to hear your stories about your children. I’d like to spend time with your child too and get to know you all in as relaxed and informal way as possible – I don’t want my research to become a burden or a further obligation in yours or your child’s lives. If you’d like to meet for a chat about what I’m doing and/or taking part that would be brilliant – or we can do it via email etc.

Thank you all in advance for taking the time and the interest to read this – I look forward to hearing from, and meeting some of you soon, I hope!

Jill

Jill Smith, University of Sheffield PhD student

JCSmith1@sheffield.ac.uk

## Appendix 2

## Cross-university recruitment email

Sent March 27th 2014

**Families and children living with autism**

Are you the parent or carer of a child living with autism?

I am looking for children and families to take part in my PhD research project about autism and everyday life.

If you would like more information please feel free to contact me

Thanks in advance

Jill Smith

JCSmith1@sheffield.ac.uk

PhD Candidate

School of Education

\*This project has been approved by the University of Sheffield School of Education ethics review procedure. It is supervised by Prof Dan Goodley.

## Appendix 3

## Ethical Approval Letter

Received 25th March 2013

1. My MA dissertation was a case study exploring the methods and ethics of researching autism as a diversity of childhood in a family home. The relationship of trust and collaboration built between myself and the parents was a pertinent source of data with the parents themselves acting as ‘data collectors’ with their child. [↑](#footnote-ref-2)
2. This parent consented to her and her family taking part in the study after meeting me, though after she cancelled a number of dates to meet the child, our contact stopped. From what I knew, this withdrawal from the project was due to broader family issues that made a commitment such as this problematic, though I cannot know for sure. [↑](#footnote-ref-3)
3. The link is included rather than a screenshot as this is a ‘live’ document that is navigated interactively by the user. [↑](#footnote-ref-4)
4. This story has been used to develop teaching materials for The University of Sheffield MOOC: Exploring Play. The story and parts of its subsequent analysis are now covered by copyright: © University of Sheffield ‘Research stories: play or challenging behaviour?’ by The University of Sheffield is licensed under a: [Creative Commons Attribution-NonCommercial-NoDerivatives 4.0 International License](http://creativecommons.org/licenses/by-nc-nd/4.0/). [↑](#footnote-ref-5)