**Reconstructing the Dominant Discourse of an Empathy Deficit in Autism:**

**Adopting a Foucauldian Perspective towards ‘Insider’ Accounts**

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# Abstract

Despite a heterogeneous quantitative research base, individuals on the autistic spectrum are often constructed as being socially debilitated: unable to perceive the minds of others and almost entirely devoid of the emotional expression necessary to sustain what we might consider ‘normal’ human interaction. In other words, they have an *empathy deficit*.  This is an understanding based on the diagnostic and medical model discourses that have traditionally dominated the field of autism and is necessarily based on an etic (‘outsider’) perspective.  I argue that this kind of understanding not only serves as an injustice to autistic individuals and the emotional insights of which they are capable, but moreover engenders wholly negative and pessimistic terms in which to speak of them.  In recent years, however, there has been considerable agentic resistance from within the autistic community and an ever-growing body of literature attempting to understand autism from an emic (‘insider’) perspective.  This may be described as the “emergent counter-narrative” of autism (Broderick and Ne’eman, 2008).  Using focus groups with young people (aged 12-17) diagnosed as being on the autistic spectrum, and analysing this data using a critical Foucauldian-inflected discourse analysis, I seek to build upon this. I do not attempt to refute or replace medical models of autism, but rather suggest that our understanding of autism may benefit from the counter-cultural critique offered by insider accounts and, further, that this can make available new ways of talking of, and ultimately thinking about, those diagnosed as being on the autistic spectrum.

I argue that, through their active participation in the focus groups, and the subsequent opportunity to critique my analysis, participants are offered a level of empowerment and emancipation, and are able to demonstrate a wide range of emotional insights.  While there is evidence of participants drawing upon traditional discourses of deficit and ‘lack’ (and adopting the according subject positions that have been forged for them), there is also evidence of participants beginning to defy the restrictions enforced by these discursive locations, and drawing upon more alternative and subversive discourses. In so doing, I argue, the participants build upon a wider narrative that helps us to deconstruct (and reconstruct) the notion of an empathy deficit, and the wider discourses in which this concept is bound.  Questions are raised around the concept of ‘normal’, and there is a strong emphasis on the idea of a *difference* rather than a deficit in empathy. Moreover, I argue, there is a need for us (as professionals and ‘neurotypicals’ generally) to accept this difference, and reflect upon our own empathy deficit and the ways in which we can adjust our own communication to meet the social reality of autistic individuals.  Latterly, the emphasis of my writing shifts towards the wider implications for professional practice and the implications this may have for autistic role identity and subjective experience.

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# Prologue

Without a full grounding in relevant literature to provide a necessary contextual background, it would be difficult to fully explicate my positionality within this study. For this reason I begin by providing an overview of the concept of empathy and its evolution over time. This is then discussed in relation to autistic spectrum conditions (ASC), and a review of the empirical evidence (upon which the dominant discourse of an empathy deficit is based) is given. The dominant discourses of autism are then explored, and juxtaposed with the counter-dominant discourses – arising primarily from emic, or ‘insider’, accounts of autism – along with a consideration of the transformatory potential that these may hold. It is at this point that the present study, and my own personal investment within it, is fully explained.

 What I can do at the outset is say that my research is certainly driven by my past experience working with young people with a diagnosis of ASC, as well as some of my core values, such as the empowerment and emancipation of young people with learning difficulties (and more specifically those with a diagnosis of ASC). The participatory nature of my research is reflective of my belief in inclusion in all its forms, and the importance of giving a voice to those most alienated and marginalised within society. What I can also do at this point is define some of the key terminology used within this thesis, and justify my specific use of language, which is central to the design of the research.

For example, when I refer to those on the autistic spectrum, I am referring to those who have received a diagnosis based on the criteria within the *Diagnostic Statistical Manual* (DSM-5, American Psychiatric Association, 2013). This is a categorisation, I would argue, that is based on a very specific understanding of autism, demarcated by the medical and the deficit-model discourses that have come to be dominant within the field. The usefulness of this kind of categorisation is something my research questions but, rather than mentioning this each time the term arises, I mention it here so the reader can assume that it always comes with this caveat.

Another convention to which I subscribe when talking about those with a diagnosis of autism is the use of person-first language. Autistic self-advocates who view autism as central to identity (see, for example, Robertson, 2010) tend to prefer identity-first terms (such as “autistic individual” or “ASC individual”) rather than the person-first language (such “individual with autism”) typically employed by the research community (Orsini & Smith, 2010). American self-advocate Jim Sinclair explains this position: “Autism is a way of being. It is not possible to separate the autism from the person – and if it were possible, the person you would have left would not be the same person you started with” (Sinclair, 1993, p. 1).

Finally, I refer on a number of occasions to ‘neurotypicals’, or those without a diagnosis of autism. I then accompany this with the use of pronouns such as ‘we’ and ‘our’, possibly implying that the readers themselves are neurotypical. This may give the impression that I am assuming that ASC individuals will not read this research, when in fact I hope the reverse is true. Rather, my decision to employ this use of language is based on my acknowledgement that I myself am part of the neurotypical population to which I refer, and therefore the implications for professional practice are directly reflexive and relevant to me.

#

# Introduction

*“You never really understand another person until you consider things from his point of view – until you climb inside of his skin and walk around in it.”*

To Kill a Mockingbird (Harper Lee, 1960)

## The Concept of Empathy

The origins of the concept of empathy can be traced back to Robert Vischer, a German philosopher who, in 1873, coined the term *Einfühlung*, literally meaning ‘feeling into’. It was popularised by another German philosopher, Theodor Lipps, who used it as a concept within philosophical aesthetics to refer to our ability to ‘feel into’ works of art; that is to have an emotional rather than a rational response to them (Lipps, 1883). In 1909, American psychologist Edward Titchener wished to have an English equivalent of the word, and so introduced the term *empathy* (deriving from the Greek *empatheia*, literally meaning ‘in-suffering’). Psychologists initially described empathy as a form of ‘social mimicry’ (see Allport, 1937), or a natural proclivity to mirror that which is observed. However, such descriptions soon gave way to a more complex, dualistic definition of empathy, encompassing both a *cognitive* and an *affective* component.

 Cognitive theories of empathy have tended to hold perspective-taking (Mead, 1934) and an understanding of another’s emotions (Kohler, 1929) as the key constituents. An influential early study into the cognitive component of empathy was The Three Mountains Task, carried out by Piaget (1948). In the original experiment, children were presented with a three-dimensional model of a mountain scene and asked to describe what a doll would see as it was moved into different positions around it. Children aged under four tended to choose their own perspective, which Piaget interpreted as them having yet to acquire the ability to taken another’s point of view.

More recent terminology tends to describe the cognitive component of empathy in terms of ‘theory of mind’ (ToM). ToM refers to one’s ability to ‘mindread’: to understand that another person has a mind that is different to one’s own and to attribute mental states to ‘self’ and ‘other’ (Frith, 2001). However, there remains considerable inconsistency in concept definition, with some authors deeming ToM as simply demonstrative of the cognitive aspect of empathy (e.g. Wheelwright & Baron-Cohen, 2011), others believing it encompasses a more general emotion recognition ability (e.g. Rutherford et al., 2002), and still others seeing ToM and emotional processing as two entirely separate constructs (e.g. Bird et al., 2010). A full discussion of the construct of ToM lies beyond the scope of the present review, and indeed whole books have been written on such an issue (e.g. Doherty, 2008). For the purposes of my discussion, I will adopt Frith’s account of ToM as my working definition.

In addition to this inferential perspective-taking process, cognitive empathy also implies the ability to *predict* another’s behaviour based on the perceived mental state (Dennet, 1987). A classic demonstration of this is the Sally-Ann Task (see *Figure 1*) originally described by Wimmer and Perner (1983). It is expected that children aged 4 and above will be able to predict Sally’s behaviour, understanding that she would look in her own basket for the ball as this is the last place she saw it. In so doing, they have not only correctly ascribed Sally’s mental state, but also inferred the action in which she will engage as a result.



 ***Figure 1: The Sally-Ann Task (Wimmer & Perner, 1983)***

Affective theories of empathy, by contrast, describe empathy as a shared emotional experience involving the appropriate emotional response to the affective state of another (Krznaric, 2014). Of course, defining what is appropriate in terms of an emotional response is not always straightforward, and in many instances there will be two or more different responses that are equally fitting. Ultimately, the cognitive and the affective components strands of empathy are closely intertwined and not readily disentangled. There is now relative consensus that a full account of empathy must necessarily entail a dual-definition which takes into account both the ability to *understand* another’s emotions (the cognitive component) and the ability to *respond* appropriately (the affective component) (Omdahl, 2014).

A common misconception associated with empathy, that ought to be clarified at this stage, is that it is synonymous with the concept of sympathy. Early definitions of sympathy do indeed bear a striking resemblance to our current understandings of empathy. For example, consider the account offered by moral philosopher Adam Smith in the 18th century: “changing places in fancy with the sufferer” (1759, p. 35). As Olinick (2014, p. 137) writes, “empathy is becoming a buzz word, signifying what formerly was the domain of sympathy”. Even contemporary definitions of sympathy – which generally maintain the idea of acknowledging another person’s hardships and a desire to take action to alleviate their suffering (Lishner et al., 2011) – are not dissimilar to the affective component of empathy. Indeed, Baron-Cohen and Wheelwright (2004, p. 163) argue that sympathy is merely a “special subset” of empathy, and the two terms are still commonly used interchangeably. However, whereas a sympathetic response is generally confined to feelings of pity and the desire to comfort, empathy can include a myriad of different emotional responses. Moreover, a full definition of empathy (i.e. one that includes a cognitive component as well as an affective one) implies that the observer has understood things from another’s perspective. In other words, a person’s response is a direct consequence of perceiving another’s emotion, and so in that way the emotional experience is *shared* (Batson, 1991). No technical definition of sympathy infers such perspective-taking or recognition of emotion. The contrast is elegantly depicted by Krznaric (empathylibrary.com, retrieved November 2015):

*If you see a homeless person living under a bridge you may feel sorry for him and give him some money as you pass by. That is pity or sympathy, not empathy. If, on the other hand, you make an effort to look at the world through his eyes, to consider what life is really like for him, and perhaps have a conversation that transforms him from a faceless stranger into a unique individual, then you are empathising.*

## Autism and the ‘Empathy Deficit’

It has long been understood that human beings have a natural propensity for understanding and expressing emotions (Darwin, 1872). Newborns are responsive to others’ emotions, and are biologically predisposed to recognise and express emotional states (Cheng et al., 2012). Current evidence indicates that, rather than perceiving a “great blooming, buzzing confusion” (James, 1890, p. 462), children enter the world well prepared to make sense of their physical and social environment. However, it is often reported that children with ASC have inherent ‘deficits’ in their ability to recognise and respond to emotions (Uljarevic & Hamilton, 2012).

Evidence typically cited in support of this assumption is comparative developmental data from children with a diagnosis of ASC and those without. For example, it is reported that the ‘typical’ (note the use of inverted commas) 24-month-old engages in pretend play, understanding that the children with whom they are interacting are merely play-acting (Leslie, 1987). Children with ASC seem to engage less in pretend play, or at least their interactions are restricted to more rule-based formats (Baron-Cohen, 1987). The ‘typical’ three-year-old is able to pass the ‘seeing leads to knowing’ test – understanding that touching a box is not sufficient to know what is inside – whereas children with ASC are generally delayed in this (Baron-Cohen & Goodhart, 1994). The ‘typical’ four-year-old passes the False Belief test (of which the Sally-Ann Task is one example) recognising when someone has a mistaken belief about the world, whereas children with ASC tend to struggle with this task (Baron-Cohen, 2007). Finally, the typical nine-year-old can interpret another person’s expressions from their eyes, whereas children (and adults) with ASC find this far more difficult (Baron-Cohen et al., 2001).

While many researchers (e.g. Bowman et al., 2004) subscribe to this idea of an *empathy deficit* in autism, many others (e.g. Back et al., 2007; Vivanti et al., 2011) have sought to challenge it. Due to the nature of contemporary quantitative research findings, it is a subject that has provoked considerable debate. While quantitative research is not the direct focus of my study, it is important to acknowledge the nature of the evidence upon which this debate centres, and upon which the dominant discourse of an empathy deficit is based.

A major barrier to establishing any kind of universality in relation to an empathy deficit in ASC is that most existing studies focus on group differences rather than individual performance. For example, it has often been claimed (see, for example, Platek et al., 2003) that contagious yawning directly relates to one’s capacity for empathy. In a classic study, Senju et al. (2007) found that a group of children with ASC yawned significantly less than a group of non-ASC children in response to a video of an adult yawning, but no reference to individual scores was provided. Those studies which do provide individual data (e.g. Bird et al., 2010) tend to show significant variability in terms of reduced empathy in ASC individuals, which have been variously explained with reference to verbal abilities (e.g. Quintin et al., 2011), non-verbal cognitive abilities (Humphreys et al., 2007), IQ (Dissanayake et al., 2011), ASC symptom severity (Philip et al., 2010), and age (Law Smith et al., 2007). Significant deficits in aspects of cognitive empathy, such as recognition of emotions from facial expressions, are generally only demonstrated in studies involving the recognition of subtle emotions (Greimel et al., 2010), complex emotions (Baron-Cohen et al., 1997), emotions presented in only part of the face (Wallace et al., 2008), and emotions presented for short durations (Kliemann et al., 2010).

Many studies have found that children with ASC show less concern and look less at a ‘distressed’ experimenter than typically developing children (Charman et al., 1997). However, children with ASC still appear to display more concern for a person exhibiting distress than they would for a person exhibiting neutral affect, and are less atypical in their responses to fearful expressions of people with whom they are familiar (Nuske et al., 2013). Using physiological reactivity of ASC children in response to observing distress in others, studies have found normative responses (Sigman et al., 2003) and even hypo-responsiveness (Corona et al., 1998). Data of this kind would seem to suggest that their affective empathy is firmly intact, and perhaps even heightened.

Indeed, Rogers et al. (2007) suggest that the sometimes aloof and seemingly uncaring manner of ASC individuals arises from a specific difficulty in perspective-taking, and if information is presented in a way they are able to understand, they show as much concern as typically-developing individuals. Jones et al. (2010) reiterate this and argue that, when emotional information is presented explicitly, and thus the cognitive component of empathy is circumvented – as in, “you forgot your mother’s birthday and made her feel sad” – we are presented with a snapshot of ASC individuals’ capacity for affective empathy. Similarly, Heerey et al. (2003) found that when ToM is controlled for, ASC individuals score normatively on the recognition of emotions, and a number of other studies (e.g. Shamay-Tsoory, 2007) have found a similar association. Other studies have found a dissociation between the performance of ASC individuals on tasks of ToM and tasks of empathy (see, for example, Ponnet et al., 2004), although these differences may be explained by inconsistency in ToM concept definition.

So, based on heterogeneous performance across individuals and across tasks, it appears that, while some ASC individuals show impairments in relation to empathic responding, the supposed empathy deficit in ASC is not universal. However, normative behavioural performance alone does not exclude the possibility of atypical neurocognitive processing that may be masked through compensatory strategies. It is therefore important to consider the neurophysiological data.

Again, the majority of studies provide only group level data, most of which indicates abnormalities in ASC populations (e.g. Pelphrey et al., 2007). For example, a number of studies identify atypicalities of neural activity in regions thought to be related to facial emotion recognition, such as the fusiform gyrus (e.g. Hubl et al., 2003) and the amygdala (Wang et al., 2004), as well as those responsible for conscious awareness of internal physiological states, such as the insula (Silani et al., 2008). Atypical neural activation has also been reported in regions associated with social processing – such as the superior temporal sulcus (e.g. Spencer et al., 2011) and the inferior frontal gyrus (Eigsti et al., 2012) – which, though not a direct component of classic empathy, is likely to affect an individual’s empathic responding in everyday life. In contrast to this data, however, there have also been studies which report no atypicalities in brain activation patterns for ASC individuals during emotion recognition tasks (e.g. Bird et al., 2010), and some which report greater activity in visual processing areas during explicit emotion recognition (e.g. Loveland et al., 2008) and imitation of emotional expression (Dapretto et al., 2006).

It should be noted that this area of research is a burgeoning one, and clearly additional neurophysiological studies are required. However, once again, while there is some evidence for an empathy deficit within ASC, the heterogeneity of experimental data seems to refute claims of universality. The empathic responding of ASC individuals should not, then, be considered an ‘all-or-nothing’ phenomenon, but one that is highly task and context-dependent. In everyday life, ASC individuals naturally struggle as the processing of emotions is embedded within a complex framework involving dynamic social, communicative and cognitive factors. It seems, then, that rather than being ‘emotionally detached’, ASC individuals simply send and receive emotional signals in *different* ways to non-ASC individuals. If empathy is conceived as a broader neurocognitive or superordinate construct, then vulnerabilities in subordinate parts of the system such as attention (see, for example, Klin et al., 2009) and motivation (see, for example, Joseph, 2011) – as well as the more general atypicalities in social processing – are likely to impact upon empathic responding. As such, when emotions need to be recognised and expressed in complex, rapidly-changing social environments, weaknesses in the component processes are more likely to be exposed, and an empathy deficit becomes more apparent (Nuske et al., 2013).

## Dominant Discourses

Historically, learning disabilities have been constructed as biological truths that only legitimated agents (i.e. health and medical professionals) are capable of discovering, naming and treating (Lester & Paulus, 2012). Autism has been no different. Since its initial construction in the 1940s (see Kanner, 1943), the prevailing methods of investigation have been firmly situated within deficit and medical models of representation (Glynne-Owen, 2010), with a clear emphasis on cause location, behaviour modification, and ‘cure’ searching. Following the cognitive revolution, and with the ever-increasing import of cognitive and biogenetic sciences (Farrugia, 2009), it is these paradigms that form the basis of most contemporary autism research, and that have yielded the quantitative findings described in the previous section. It is often assumed, despite the apparent heterogeneity of this research evidence, that autism has a specific biogenetic aetiology and is a specific kind of information processing deficit related to brain structure. A focus on these (assumed) deficits, as well as associated aetiology and treatment, has yielded a broadly essentialist understanding of autism, and an enduring rhetoric of scientific evidence-based discourse (Post et al., in Mills et al., 2012). This may be described as the “culturally dominant metaphor of autism as a disease” (Broderick and Ne’eman, 2008, p. 459). However, Nadesan (2005) argues that this culturally-dominant paradigm involves an uncritical reduction of mind to biology and a reification of ‘normal’ rationality, construing those on the autistic spectrum as being of some dehumanised autistic subjectivity.

Furthermore, this paradigm implies a certain way of speaking about those on the autistic spectrum. For example, while there is now a shift towards talking of autistic spectrum *condition*, it is still regularly spoken of in terms of a ‘disorder’ from which the individual ‘suffers’. In addition to this, terms such as ‘impairment’ and ‘deviance’ are still commonly employed. Schulte-Rüther et al. (2008) use “healthy” (p. 402) to refer to non-ASC control participants, inviting the question: as opposed to what, ‘unhealthy’? Similarly, Frith (2001) compares ASC individuals to “normal people” (p. 969), and, incidentally, in the same article talks of ASC as a “*devastating* deficit in human social insight [italics added]” (p. 969). I noted earlier the use of ‘typical’ to describe non-ASC individuals – as though ASC individuals are categorically distinct from those without a diagnosis – and this implication is endemic in much ‘expert’ autism literature. Clearly there are questions here about what we mean by ‘typical’ and ‘normal’, and indeed Michel Foucault (1977) – whose theories are central to the design of this research, and will be explored in more detail later – suggests that society is organised and regulated according to what is deemed normal, and that the social sciences have played a part in this by studying people closely, and thus defining the boundaries of normal and abnormal behaviour. This is a discussion to which I will return later, and indeed the concept of normalcy forms a recurrent theme in much of my analysis.

These ways of speaking are reinforced by existing authority such as the Diagnostic and Statistical Manual, the most recent of which describes ASC as:

*A neurodevelopmental disorder characterised by (a) persistent difficulties in social communication and social interaction across contexts, not accounted for by general developmental delays, and (b) restricted, repetitive patterns of behaviour, interests or activities* (DSM-5, American Psychiatric Association, 2013, p. 50).

So medical and diagnostic models of representation direct and produce dominant discourses, which then reinforce the use of the very diagnostic and personal-deficit models that produced them. As such, this becomes a cyclical process where certain patterns of thinking create certain patterns of speaking, and vice versa. Or, put another way, “if thought corrupts language, language can also corrupt thought” (Orwell, 1946, p. 4). Ultimately, these discourses construct autistic individuals in a way that is individualistic and pessimistic, and is suffused with the notion of inferiority. Moreover, and with particular significance to the focus of my own research, these discourses construct autistic individuals as being socially debilitated: unable to perceive the minds of others and almost entirely devoid of the emotional expression necessary to sustain what we might consider ‘normal’ human interaction.

Furthermore, these discourses are, necessarily, based on an etic or ‘outsider’ perspective. For reasons largely rooted in a scientific elitism and social closure (not specific to ASC) which influence the degree of social value attached to various levels of expertise, the voice of autistic individuals within autism discourse has traditionally been overlooked (Rose, 1999). While specialist expertise (i.e. from qualified professionals) within the autistic community is generally acknowledged (e.g. Lawson, 2010), the more common ubiquitous expertise – i.e. ‘non-expert’ accounts of the experiential world of the autistic individual – is often neglected in favour of non-autistic ‘specialists’. This tendency is then exacerbated by the supposed empathy deficit, and the widely-held assumption that ASC individuals are somehow ‘machine-like’, lacking the socialisation and emotional literacy required for effective communication of their views (Milton & Bracher, 2013). Milton (2012) describes the ‘double empathy’ problem that then ensues where each group struggles to relate to the other. A “negative spiral” (Milton, 2014, p. 7) of psycho-emotional disablement then occurs (Milton & Moon, 2012) where, due to an awareness of the narrow ways in which they have often been constructed, ASC individuals have become distrustful of researchers and their aims and often distance themselves from the process of knowledge production (Ashby & Causton-Theoharis, 2009). Mukhopadhyay, for example, (2000, p. 65) talks of himself as being “disqualified in the human race” by virtue of his “different form of mind”.

## ‘Insider’ Accounts

Despite this, in recent years, a platform upon which autistic individuals are able to stand and express their views is gradually being constructed. There is an ever-growing body of literature attempting to understand autism from an emic (‘insider’) perspective which challenges the pessimistic teleology of the medical narrative and highlights considerable agentic resistance and negotiation from within the autistic community (Chamak, 2008). These accounts seem to suggest that, far from being emotionally-detached, ASC individuals are able (albeit idiosyncratically) to display marked insights and awareness into their own emotional experience and the emotions of those around them. Perhaps the most renowned insider author is Donna Williams (e.g. 1992, 1995), who is able to talk at great length and with extraordinary linguistic dexterity of her emotional experiences of autism: “Trish cuddled me…I was terrified…it seemed tears were welling up from a part of me long buried and forgotten…I always paid for closeness with fear” (Williams, 1992, p. 72). Billington (2006) argues that such reference to one’s own emotional and expressive life has little in common with traditional descriptions of autism, or the argument for ‘zero degrees of empathy’ (described by Baron-Cohen, 2012) typically used to marginalise insider accounts. It is through the lens of these insider accounts where a *difference*, rather than a deficit, in empathy begins to seem a more accurate representation. This line of thought may be described as the “emergent counter-narrative of autism” (Broderick and Ne’eman, 2008, p. 459).

Smith (1999) contends that, because discourses of (dis)ability centres around positivist professionalised science, counter-narratives in this field inevitably inhabit “marginalized territories” (p. 124). Dominant discourses become imposed and inscribed upon people in social interaction and through institutional culture, and become so entrenched as to seem immune to challenge (Holland, 1997). However, the counter-narrative of autism is increasingly challenging the culturally-dominant rhetoric of autism as a form of ‘illness’ or ‘disease’, and in recent years there have been steadily increasing efforts towards a cross-cultural collaboration between the so-called ‘expert’ and ‘non-expert insider’ groups. This being said, there generally remains a stark juxtaposition between these accounts and the more common diagnostic accounts (note, for example, the contrast between Donna Williams’ description of autism and that presented within the most recent DSM). Milton and Bracher (2013, p. 64) refer to the “glass subheading” where autistic participant contributions are treated as empirical data for analysis by non-autistic researchers, rather than material upon which to mutually reflect and explore. Indeed it remains doubtful as to whether true ‘interactional expertise’ – that is, where one is able to engage and interact with the language and communities of a specific sub-group (Milton, 2014) – has been achieved. This, then, raises a question: is a phenomenological understanding of the lived experience of being autistic even possible, or will something always be lost in translation?

Both Wittgenstein (1953) and Nagel (1974) conducted thought experiments from which they concluded that it is not possible to move beyond one’s own *somatic affordance* (the limitations of one’s inherent physiology), to conceive of a distinct ‘other’. On this basis, it may then be argued that an ‘autistic bodily state’ is a necessary condition for expertise regarding autistic subjectivity. By this reasoning, it would follow that authentic interactional expertise between the autistic and non-autistic communities is unattainable. One must remember, however, that despite the recurrent narrative of autistic individuals being from a different community, or inhabiting a ‘different world’ – and indeed the use of such rhetoric in itself often serves to perpetuate the perceived divide – these individuals are still human, and they are still social (albeit idiosyncratically so). For this reason, a continued appreciation of insider accounts of ASC seems a more than worthwhile venture.

 Indeed as Hacking (2009a) points out, autobiographical reports are but one thread in a much larger tapestry of what he calls the “autistic narrative” (p. 1467). An alternative way of promoting interactional expertise and developing a language with which to talk about ASC, he proposes, is through ‘autism fiction’. The most well-known autism novel is The Curious Incident of the Dog in the Night-Time (Haddon, 2003), which, argues Draaisma (2008), has created a model in terms of which neurotypicals can think about an autistic adolescent. It is true that, within autism fiction generally, the autistic characters tend to be portrayed as people who are intrinsically unique and interesting in their own right, with the characters surrounding them generally acting as role models (or, indeed, anti-role models) for family and caregivers, demonstrating how to accept and to love these individuals exactly as they are. Some autism fiction has been criticised for giving a false sense of what autism is really like, downplaying the depth and difficulty of the condition, or perpetuating common-held myths about the ‘powers’ that ASC individuals possess (and arguably perpetuating the image of, for example, Dustin Hoffman’s character, Raymond Babbitt, in Rain Man (1988)). However, one would hope, notwithstanding these reservations, that, as people begin to notice shadows of themselves within the autistic characters portrayed, the line between ‘the autistic’ and ‘the neurotypical’ will become blurred.

What seems clear is that, be it through autobiographical account, autism fiction, qualitative research, or otherwise (increasingly, internet forums and social media provide an outlet for autistic self-advocacy, and this something to which I return later), the ‘autistic narrative’ gives the non-autistic reader a unique insight into what it is to be autistic. From this, asserts Hacking (2009b, p. 501), is being created:

*An entire mode of discourse, cementing ways in which we have recently begun to talk, and will talk, about autism. It is a developing language, or, if you will, a new language game, one that is being created before our eyes and ears.*

The “emergent counter-narrative” described by Broderick and Ne’eman (2008) is quite contradictory to many traditional discourses, and challenges many of our deep-seated assumptions about the condition. This is not to say that insider literature has completely dismantled the concept of autism, but it certainly allows us to view the condition through a different lens. As Williams (1996, p. viii) points out: “Having sat around with ‘autistic’ people who have more empathy, curiosity imagination or ingenuity than most so called ‘normal’ people, I think it is time that the myths that hover over these people were not just uncovered but unravelled”. Indeed McGeer (2009) speculates that, in enriching our understanding of the autistic experience, the autistic self-narrative has the power to not just inform but to *transform* how the autistic spectrum is constituted, both for those who inhabit it and for those who do not. The ‘translation’ of the dominant discourses surrounding autism into new discourses produces and promises alternative and free ways of being, becoming and living, and, as such, has the potential to transform what it is to be autistic.

# Methodology

## The Present Study

It is the “emergent counter-narrative” described by Broderick and Ne’eman (2008) on which I will focus and – by using focus groups to elicit the views of young people diagnosed as being on the autistic spectrum – seek to build upon. Using a broadly critical Foucauldian perspective, the present study aims to explore these insider accounts of autism in an attempt to reconstruct the notion of an empathy deficit, and the dominant discourse that surrounds it. A Foucauldian perspective is concerned with the way in which phenomena come to be understood based on the discourses available within society, and how these discourses are dictated by various institutional structures and systems of power (Foucault, 1994). Certain discourses, Foucault argues, emerge as dominant or as constitutive of a “regime of truth” (Foucault, 1980, p. 131), while others become subjugated and excluded. However, counter-dominant discourses can and do emerge, as is in evidence in the recent proliferation of literature attempting to understand the autistic narrative, and offer new ways in which phenomena may be understood.

It seems appropriate, at this point, to make explicit my own personal investment in this area of study. I have spent a number of years working closely with autistic individuals, of a range of different ages and abilities, and in a variety of different settings. While I do not attempt to encapsulate all my reflections on this experience, I feel that those which are most abiding can generally be captured within the same bracket. Not only did these individuals seem to be inherently interesting and unique, they seemed to demonstrate great sensitivity in the way they processed their social environment and great subtleties in their communications and interactions with it. Moreover, this observation was brought into focus when juxtaposed with the ways in which people talked of these individuals, and I was unable (and continue to be unable) to reconcile myself with these common descriptions of ASC individuals and my feeling (albeit subjective) that I had a wealth of anecdotal evidence to the contrary.

However, while I feel strongly about the inadequacy of the term ‘empathy deficit’ as a label to describe the emotional processing abilities of those on the autistic spectrum, my aim is not to try to demonstrate that these individuals *possess* empathy (however we choose to define it). Rather, I wish to explore the extent to which an adherence to the label of an empathy deficit (and to the wider discourses in which it is bound) constructs these individuals in a particular way, and makes available certain ways of talking of, and ultimately thinking about, those diagnosed as being on the autistic spectrum. Furthermore, I wish to explore how the emergence of counter-dominant discourses from within the autistic community makes available new ways of thinking about these individuals. As Goodley and Roets (2008, p. 244) suggest, “the dominant disability discourse of ‘impairment’ as functional deficit, personal tragedy and lack, rooted in arborescent, hierarchical (but social) networks (Bayliss, 2006), undergoes a critical deconstruction within dynamic and reflexive networks of social engagement and activity”.

Tacit within this will be a reflexive component in which I consider the extent to which dominant discourses have made available certain ways of interacting and being with those on the autistic spectrum, and again how emergent discourses may offer new ways of thinking about the social environments they inhabit and about wider implications for practice. As part of this, I wish to consider the notion that the empathy deficit “goes both ways” (Dant, 2015, p. 55), and how the dominant discourse may in fact be perpetuated by our own empathy deficits as professionals (and non-ASC individuals generally). As McGeer (2009) argues, we (as professionals) do not directly perceive the subjective experience of ASC individuals any more than they perceive ours. In other words, if they are ‘blind’ to our minds, then we too are blind to theirs.

## Ontology and Epistemology

My research adopts a social constructionist approach to epistemology: I argue that our understanding of autism has been constructed based on the discourses available within society, and equally that it can be re-constructed with the emergence of alternative discourses. In other words, I take autism as being inseparable from the cultural models that define it. Furthermore, my data will itself be socially constructed through the dynamics and interactions within the focus groups, and this is something I aim to unpick within my analysis. I also reflect upon the constructivist nature of my data. Clearly my own values and lived experience cannot be divorced from this construction of knowledge and from my research process in general, and I acknowledge that the way in which I analyse and interpret the information produced within the focus groups is based upon my own unique ‘system of knowing’ (Piaget, 1950). In this sense, it is not only about the words the participants speak, but how those words in turn speak to me. It is for this reason that the subsequent chapter is titled *Analysis and Interpretations* rather than ‘Results’.

Given that I intend there to be a considerable reflexive element to this research, where I consider our own empathy deficit (as professionals and practitioners), I not only accept this inevitable positionality but actively embrace it. In being reflexive, it is important for me to acknowledge the ways in which my actions may inadvertently marginalise or exclude certain participants, and how this may feed into wider organisational practices and institutionalised power imbalances (something I discuss in more detail in the *Setting up the Focus Groups* section). In the same way that, through this research, I encourage readers to stand back from their existing beliefs and value systems, their habitual ways of thinking and relating to ASC individuals, and their structures of understanding themselves in relation to these individuals, so I must impose these rigours upon my own thinking and upon the process of knowledge production within this research. In so doing, I acknowledge my own central position in the construction of knowledge, aware that “the knower is part of the matrix of what is known” (DuBois, 1983, p. 63).

My epistemological stance infers an ontology that moves away from *realist* understandings of autism: autism as a single axiomatic truth independent of our conceptual schemes, perceptions, and linguistic practices (Miller, 1994); or *essentialist* understandings: autism as having a set of attributes (a triad, or now dyad, of impairments) that are necessary for its identity (Cartwright, 1968). Rather, I take a *relativist* perspective where autism as a concept has no absolute [truth](http://en.wikipedia.org/wiki/Truth) or [validity](http://en.wikipedia.org/wiki/Validity), but rather has only relative, subjective value according to differences in perception and consideration. As noted, central to this stance is the stipulation that, through my research, I do not attempt to disprove or refute diagnostic models of autism. Rather, I propose that these models – and the implied universality of an empathy deficit – do not do justice to the nuances and complexities of emotional processing in ASC individuals. I propose that it is reductionist, pessimistic and not reflective of the heterogeneity of the qualitative (nor indeed the quantitative) literature, and that our understandings may benefit from a significant counter-cultural critique.

In classic Foucauldian tradition, my aim is not to replace one “regime of truth” with another, but rather explore the “battle about the status of truth” (Foucault, 1980, p. 133). As with any Foucauldian discourse analyst, I do not seek to understand the ‘true nature’ of psychological phenomena, but rather the ways in which particular versions of these phenomena have been constructed through language (Willig, 2008). As Vakirtzi and Bayliss (2013, p. 365) propose, “this new type of conceptualization of autism does not intend to challenge medical theories on autism, but instead examines the environments in which they emerged”. From this position, it is no longer a question of whether or not autistic individuals possess empathy (however we choose to define it), but rather how a new conceptualisation of the ‘empathy deficit’ may be constructed, and how in turn this provides a more adequate representation of the diversity of the autistic experience.

## Foucauldian Discourse Analysis (FDA)

Discourse analysis, more generally, emerged from the ‘turn to language’ in the 1970s and 80s and the emergence of social constructionism (Georgaca and Avdi, 2012). Discourse analysis is a broad and diverse field that includes a variety of different approaches, but each is based on the assumption that language – rather than providing a set of unambiguous signs with which to label external states – is *productive*; that is, it constructs versions of social reality and is used to achieve social objectives (Willig, 2008). In this sense, discourse analysis is less a research method and more a critique of mainstream psychology, offering an alternative understanding of the nature of psychological phenomena (Billig, 1997).

 There is great pluralism within the discursive methodologies, and while Wetherell (2001) identifies as many as six different ways of conducting discourse analysis, two major versions have tended to dominate the literature. The first – inspired by conversation analysis and rhetorical work in psychology – is *discursive psychology*, an approach concerned primarily with the performative quality of everyday language, and the role it plays in constructing meaning, reality, identity and responsibility (Wiggins & Potter, 2008). The second – which draws upon post-structuralist thinkers such as Foucault, as well as others such as Barthes and Derrida – is Foucauldian discourse analysis (FDA). While a number of authors (see, for example, Burr, 2003) highlight the distinction between the two approaches, Potter and Wetherell (1995) suggest that the distinction “should not be painted too sharply” (p. 81). As such, while FDA forms the basis of my methodology, I also draw upon aspects of a more traditional discursive analytic approach. I will outline the specific procedural guidelines for my analysis later in this chapter.

FDA focusses upon the availability of discursive resources within a culture, how these construct various object and subject positions, and how these constructions in turn make available certain versions of reality (Harré and Van Langenhove, 1999). From a Foucauldian perspective, discourses – defined as “sets of statements that construct objects and an array of subject positions” (Parker, 1994, p. 245) – facilitate and limit, enable and constrain, what can be said, by whom, where and when (Parker, 1992). FDA goes beyond the immediate context within which language may be used and seeks to describe and critique the discursive worlds people inhabit, and explore the implications this has for subjectivity and experience (Willig, 2008). Accordingly, a Foucauldian approach dictates that there is no definitive ‘truth’, but rather meaning-making and knowledge is constructed through discourse and, as such, multiple possibilities for what can be known exist.

Crucially, FDA attempts to locate discourses within a broader socio-cultural context, and understand their role within wider processes of legitimation and power. In exploring the ‘systems of power’ which ‘produce and sustain’ truth, the Foucauldian task becomes one of analysing the performativity of discursive practice. Within this, issues of historicity and genealogy are central. As Powers (2007, p. 26) asserts, “Discourse cannot be analysed only in the present, because the power components and the historical components create such a tangled knot of shifting meanings, definitions and interested parties over periods of time”.

As noted, in a Foucauldian sense, dominant discourses are said to legitimate and reinforce existing social and institutional structures, and in turn are further supported and validated by them. One may argue, then, that the dominant discourse of an empathy deficit in autism is self-perpetuating. However, in understanding why certain discourses emerge as dominant or as constitutive of a “regime of truth” (Foucault, 1980, p. 131), one must also consider those which are subjugated or excluded. While there is growing body of literature attempting to understand the experiences of those diagnosed with autism through the analysis of discourse, there is often the assumption that “autism organises discourse” (Ochs and Solomon, 2004) – or, in other words, that the talk of autistic individuals is taken to be indicative of certain features of ASC – rather than examining ways in which the discourse itself constructs our understanding. Indeed relatively little research has applied a critical Foucauldian orientation to the construct of learning disabilities, and this is something I wish to address.

That being said, there have been some attempts to approach autism from a Foucauldian standpoint. Vakirtzi and Bayliss (2013, p. 377) propose approaching the phenomenon of autism in general from a Foucauldian methodological platform which, they argue:

*…entails the notions of agency, resistance, self-constitution and freedom, and makes a shift from the medicalised body as a starting point both in autism research as well as in educational approaches and interventions*.

A number of other papers have used Foucauldian approaches to address more specific issues. For example, though her direct reference to Foucault is minimal, Bagatell (2007) infers aspects of Foucauldian thinking in her discussion of the complex negotiation of the individual identity construction of ASC individuals in the faces of dominant discourses and inscribed institutional culture. Broderick and Ne’eman (2008) used a Foucauldian approach to explore the significance of metaphor and dominant cultural narratives in autism discourse, and share Foucault’s concern with explicating the “political economy of truth” (Foucault, 1980, p. 131). Farrugia (2009) used aspects of a Foucauldian methodology in exploring the stigmatisation of parents of children diagnosed with autism and in critically interrogating the concept of stigma generally. Lester and Paulus (2012) also used aspects of a Foucauldian methodology in exploring the meanings of autism through the talk of parents of children diagnosed with autism.

Though all these studies bear some similarities to my own, none use a focus group methodology in the collection of data, and while they imply issues of emotional recognition and understanding, there are none, to my knowledge, that use ‘empathy’ as the named discursive object.

## Participants

Ethical approval from a university-based institutional review board was obtained prior to recruitment of participants (see *Appendices, Appendix 1*), all of whom attend a specialist educational provision in a city in the north of England. My only criteria for involvement in the study were that the young person be aged between 11 and 19 (as it turned out, all were aged between 12 and 17), that they have a diagnosis of ASC, and have some level of verbal ability. The designated age range was intended to maintain a level of homogeneity within the sample (though I address issues of the heterogeneity of the sample in the *Conclusions* chapter). The diagnosis of ASC was necessary to ensure that the accounts provided by participants are 'insider' accounts as specified within the research title. Some level of verbal ability was required in order that participants were able to respond to the questions within the focus groups.

## Focus Group Rationale

In justifying my decision to use focus groups – and in considering the associated ethical concerns – a key potential advantage was the establishing of a ‘group dynamic’ (see Gibbs, 2012). I hoped that participants would feel strongly about the subject of their emotional experience and may actually enjoy discussing it with others who share similar views. Equally, focus groups typically allow participants to talk about potentially sensitive issues that in a different context, such as an individual interview, they may find difficult to discuss. It was my hope that participants would take confidence from the group setting and engage in a mutual, if subconscious, drive to be more open and discursive.

 This being said, it is often the case when conducting a focus group that there will be problems in managing group interaction, potentially resulting in a chaotic or disorganised dynamic where the focus group loses the very focus that defines it (Krueger & Casey, 2008). Without wishing to perpetuate the discourse my research aims to challenge, it remained important to acknowledge the *different* emotional needs my participants may have, and acknowledge that this dynamic was likely to be more pronounced with the client group involved. This is particularly the case if the mediator (in this case, myself) is inexperienced (which, relatively speaking, I am). As I discuss in the *Analysis and* *Interpretations* chapter, the pilot study was valuable in providing information about how to locate and navigate developing group dynamics, and in reflecting upon and improving my own mediatory practice. The use of ground rules was also important, and ensuring these were framed in a clear and concise manner seemed be critical to the smooth running of the focus groups, and the consequent well-being of the participants.

In addition to this, a focus group, particularly one that is in any sense disorganised, has the potential to marginalise or discourage the participation of certain group members (Hopkins, 2007). While a ‘group dynamic’ may serve to increase confidence and encourage participation, the converse argument is that, if an individual is not especially loquacious or articulate, or does not feel comfortable discussing certain issues in front of their peers, then their views may well be lost. I had to be aware that it may be anxiety-provoking for these individuals to participate within the focus groups, particularly when discussing personal and potentially quite sensitive issues relating to their 'condition'. This would be very much at odds with the emancipatory and inclusionary aims of my research and it was something I needed to be mindful of. Again, the pilot study was of vital importance in locating and navigating these developing dynamics, and highlighted the necessity of a dissemination of results that allowed for *genuine* critique and challenge of my analysis (discussed further in the *Ethical Bottom-Line* section).

 Halcomb et al. (2007) identify another advantage of a focus group as being that it allows the discovering of a ‘collective perspective’. While focus groups allow for individual views to be expressed, they also encourage a synthesis and group validation of ideas. One might reasonably suggest then, that, provided that potentially harmful or divisive dynamics were circumvented, participants may achieve more detailed and considered perspectives, and ultimately provide a more nuanced and profound indication of their collective views. Furthermore, in using focus groups, I hoped to reflect the move away from individual voices articulating the emerging counter-narrative from within the autistic community, and mirror the broader and more collective nature of the response to the dominant scientific hegemony.

 A further advantage of using focus groups (as identified by Gibbs, 2012) is their ‘restorative’ nature. As alluded to above, in the establishing and maintaining of a strong group dynamic, creating an environment in which the main principles of Restorative Practice are promoted (e.g. openness, honesty, listening to other people’s perspectives) tends to be vital. In the case of the present research, and based on the potentially vulnerable group of participants with whom I was to be working, it was of particular importance. As will be highlighted further when discussing the dissemination of results, the research is intended to be empowering and emancipatory, and to this end, a methodological set-up that not only acknowledges the participants emotional *differences* but actively addresses them throughout the research process seems, to me, fundamental. Indeed this is ratified by the BPS Code of Ethics and Conduct (2009, p. 10): “psychologists should value the dignity and worth of all persons, with sensitivity to the dynamics of perceived authority and influence over clients”.

 While I felt that the advantages of using a focus group methodology for my data collection were numerous, it is important to consider one final potential drawback: namely, the difficulty often experienced in analysing the resulting data. It has been argued that, because focus groups can sometimes produce an array of complex verbal and non-verbal responses from the participants, the subsequent analysis and interpretation of the data can be an arduous task. It is true that the process of analysis and interpretation was a complex one and there is little doubt that data produced from individual interviews would be quicker and easier to analyse. However, ultimately I felt that the advantages of using focus groups far outweighed this (and the other potential drawbacks), and that in terms of validity, reliability and ethicality, it was the most appropriate form of data collection. I reflect on the extent to which this feeling was upheld having actually carried out the focus groups in the *Analysis and* *Interpretations* chapter.

## Setting up the Focus Groups

My focus groups were semi-structured and based around the questions outlined below. These provided only a guiding framework, however, and by no means did I adhere to them rigidly. Indeed it was my intention to maintain as authentic and naturalistic an environment as was possible. Constructionist research of any type demands that the researcher is ‘present’ throughout the collection of data, maintaining an emphasis on research *with* as opposed to *on* the participants. By adopting this kind of position (as opposed to that of a formal researcher reciting a prescribed list of questions), it invites the participants themselves to adopt an alternative position, and in so doing creates a symbolic space wherefrom (one would hope) they begin to feel more empowered and more able to express their views. Furthermore, while adopting such a position may feel less safe or less comfortable for the researcher, it provides greater scope for personal and professional reflection and growth.

## Focus Groups Questions

* If you crash-landed on a desert island with a plane full of passengers, and you were put in charge, what 3 rules would you make in order for everyone to live together and be happy?
* If someone mentioned “feelings”, what do you think they would be talking about?
* Do you find it easy to describe how you are feeling?
* Do you find it easy to understand how other people are feeling?
* Are there times/places where this is easier?
* If you saw your friend crying in the playground what would you do?
* If your friend had some good news what would you do?
* How do you think your mum/dad might feel if you got them something nice?
* What about if you forgot their birthday?
* Can you remember a time when you have made someone feel good?/Can you remember a time when someone has made you feel good?
* Can you remember a time when someone has hurt your feelings?/Can you remember a time when you have hurt someone else’s feelings?
* How do you think it makes teachers feel if when you work really hard/misbehave?
* Do you think teachers understand you?
* Do you think being diagnosed as autistic makes a difference [to understanding emotions]?

There were various iterations of this schedule but, ultimately, the questions were designed to encompass both the cognitive (*perspective-taking*) and affective (*shared emotional response*) components of empathy; to be both hypothetical (asking the participants to ‘speculate’) and authentic (asking the participants to reflect upon previous experience); and to include affirmative questions alongside those that assume a level of difficulty or impairment. In a broader sense, they are designed to be open-ended and to promote a wider discussion around emotional understanding and expression. In this way I sought to tread a fine line: *allowing* counter-discourses to be produced, without actively creating or directing them. While the questions used in my focus group were intended to be unobtrusive and relatively simple, the pilot was also used to highlight whether there were any particular questions where the participants felt uncomfortable or found difficult to answer.

The first question is intended to act as an ‘ice-breaker’: an ostensibly creative and enjoyable activity that allows everyone an opportunity to practice saying something in the group, encourages participants to feel relaxed, and establishes an environment in which sharing and listening are valued (Gibson, 2007). It is also a question where the participants’ responses may begin to uncover aspects of their empathic understanding, without being based on learnt social rules. Burman (1994) argues that, particularly in social scientific research of this kind, ice-breaker questions can be problematic in that they serve to blur power dynamics that exist. In other words, the researcher (intentionally or otherwise) is masking the position of authority they inevitably hold, and as such may be seen as dishonest or disingenuous. While I acknowledge this as a critique of my use of an ice-breaker, and indeed of my use of focus groups in general, I argue that its primary function is in fostering a sense of ease and well-being amongst the participants, and in fact emphasising their position as equal and active agents within the research process. My next question (regarding their understanding of the word “feelings”) further seeks to redress any power imbalance that exists and establishes a template for an interaction based on the participants’ own understandings. Coupled with my more general efforts to maintain a naturalistic and authentic environment, I do not see the ice-breaker as disingenuous, but rather part of my wider attempt to create a focus group that is predicated on equality.

In general terms, the literature I aim to reflect (and build upon) is that in which autistic individuals discuss their experiences (often in relation to emotional recognition and expression), and as such my questions seek to elicit comparable reflective discussion. While the questions do not generally refer to ‘autism’ or ‘empathy’ – instead aiming to uncover the participants understanding of their meaning more indirectly – I felt that the final question may elicit some reflective and reflexive insight into the effects of being the bearer of an autism label.

## The Ethical Bottom-Line – Beyond Malfeasance

Ethical considerations within my research have largely been addressed (and outlined in the previous sections) through my recruitment of participants, justification for using focus groups as my method of data collection, and through the way in which the focus groups were set up. A broader ethical concern not yet addressed relates to the issue of informed consent.

When working with a potentially vulnerable client group, it is often necessary to include additional information within the initial information sheets and consent forms (which I did, see *Appendices, Appendix 2*). I also met with participants prior to the conducting of my focus groups to ensure that they were fully aware of the nature of the focus groups and were *genuinely* consenting to their involvement. In addition to this, it was important to consider the obtaining of consent as an on-going process as opposed to an isolated event (see HCPC’s Guidance on Conduct and Ethics for Students, 2009). Regardless of the amount of forethought given and preparation carried out, participants may have been exposed to what, for them, was an unforeseen circumstance. It was important that they felt able, at any time, to raise doubts or queries they may have, and felt sufficiently comfortable and confident to exercise their right to opt out. Such a philosophy can be promoted by maintaining a relaxed and informal atmosphere, but it was also necessary to have an additional ‘check-in’ at an approximate mid-way point. I also felt it was important to conduct a thorough de-briefing after the focus groups, in which I reminded participants of the basic aims of the research and how the data from the focus groups was going to be used. Furthermore, this provided an opportunity to consider the potential emotional effects the topics of discussion may have had, and to answer any further questions. In this way, I took a range of appropriate steps to safeguard against harm being caused (Arnold & Hughes, 1999), i.e. *non-malfeasance*.

Ultimately, however, I felt that it was not enough for my research to be non-malfeasant; rather, I felt that it must *beneficent*, i.e. actively ‘do good’ (see Israel & Hay, 2006). As such, a major part of the follow-up is the dissemination of my interpretations back to participants, where I wished to give them a genuine opportunity to critique and challenge my analysis. There is a strong link here to *action research*, an approach that promotes change based on the perceptions and aspirations of the individuals most affected by such change (Lewin, 1946). Action research emphasises group decision-making and the resolving of issues of inequality, particularly within marginalised or minority groups (Adleman, 1993), such as the autistic community (see, for example, Nicolaidis et al., 2011). So, through participation in the focus groups, and subsequent critique of my analysis, the participants become active agents within the research process and, through their collective voice, begin to defy the restrictions and assumptions made about them within their discursive location (Townsend, 2010). It may also contribute towards the growing trend towards agency and enablement within the autistic community, and the emergence of a collective voice challenging dominant cultural assumptions. My hope, then, is that my research will have both immediate benefit (i.e. for the participants involved, through their participation in the focus groups) and a benefit that is more far-reaching (i.e. reflecting and adding to the wider discourse of agency and enablement from within the autistic community). While I do not claim to be conducting a piece of action research as such, the participatory principles seem eminently relevant.

## Procedural Guidelines for Analysis

There are a variety of ways in which Foucauldian-inflected discourse analysis may be conducted. Parker (1992) provides a detailed guide to analysing and comparing discourses and positioning them within their historical and socio-cultural context, but this is based upon a protracted 20-step process. Kendall and Wickham (1999) propose a guide that relies on fewer steps but presupposes a highly advanced conceptual understanding of Foucault’s method. While conceptual considerations are of interest, my main concern is with *pragmatism* (see Rennie, 2007), and producing research that has utility for the participants and for the wider autistic community. On this basis, all methodological preferences that maximise welfare can be seen as equally valid (Shaw, 1999). The procedural guidelines I use for my analysis are based on the six-stage process presented in Willig (2008) and the similar process presented in Georgaca and Avdi (2012), both of which adopt an overall critical Foucauldian perspective, while utilising the analytic tools of discursive psychology. This does not represent a ‘pure’ version of FDA because, while I acknowledge issues of historicity, I do not explicitly address the evolution of discourses over time. However, my procedural guidelines provide a practical and efficient method that satisfies my concerns around pragmatism and utility, and are designed to achieve my twin aims of:

1. Exploring the degree to which dominant (‘expert’) and emergent (‘insider’) discourses open up and constrain opportunities for talk, thought and practice;
2. Examining the more immediate group dynamics and minutiae of social interaction (both participant–participant, and participant–researcher).

***Stage 1: Discourses (Language as ‘constructive’)***

This involves the highlighting of all references, both implicit and explicit, to the discursive object. The discursive object in this instance may be said to be empathy. However, this may be taken to include all references to recognition of and responding to emotions, and, given that I wish to explore the alternative ways in which empathy may be conceptualised and understood, empathy may be seen as the start-point for a broader discussion around the superordinate construct. The different ways in which the participants construct this will then be examined. Willig (2008) suggests that when the researcher is attempting to explore the relationship between public or expert discourses and the way in which society takes up this meaning (as I am), they must analyse the transcripts with reference to a variety of texts including documents, published papers and official publications (as I do). This will involve direct reference to the wider discourses upon which they draw.

***Stage 2: Rhetorical Strategies (Language as ‘functional’)***

At this stage of analysis, the dynamics of interaction are examined and the ways in which the participants’ use of language serves an interpersonal function is explored (see Georgaca and Avdi, 2012). One attempts to understand utterances in relation to the discursive contexts in which they are produced and the effect that this has on the unfolding interaction. This may be referred to as the participants’ *discursive agenda*. A related concept is that of *action orientation*, which refers to the possible functions of the speakers’ utterances in the context of the interaction. While my primary focus is on the wider discourses upon which participants draw, it remains imperative that I acknowledge the intricacies of group interaction, and appreciate the ways in which participants’ talk may be used (deliberately or otherwise) to achieve certain interpersonal goals. In attempting to do this, I also draw upon psychodynamic theorist Wilfred Bion (1961) and his work on the functioning of groups.

***Stage 3: Positionings***

A position, or *subject position*, within a discourse identifies “a location for persons within the structure of rights and duties for those who use that repertoire” (Davies and Harré, 1999, p. 35). So at this stage I will explore the ways in which the ‘subjects’ (participants) have been constructed within the dominant discourse, and how this has created a discursive location from which to speak and act. For example, from within the diagnostic and personal-deficit discourse of autism, the autistic individual may have traditionally adopted the *subject position* of being ‘deficient’, ‘damaged’ or somehow ‘less than human’, locating them as one in need of ‘categorisation’ and ‘cure’. However, one could equally speculate that participants may begin to show resistance to these and, as they draw upon alternative counter-dominant discourses, begin to forge and embrace new subject positions of ‘difference’, ‘diversity’ and ‘individuality’. As they adopt these positions, participants may be offered new and more positive ways to speak about themselves and others.

***Stage 4: Practice***

Here, I will explore the ways in which the discursive constructions and subject positions legitimate (or illegitimate) certain forms of action. This may relate to the ways in which an assumed empathy deficit has reduced the participants’ opportunities to reflect upon and communicate their social and emotional experiences, or negatively affected how they have been treated within educational and social settings generally. If such practice has been legitimated by the dominant discourse, then it follows that resistance to this, and the propagation of a counter-dominant discourses, may have implications for enriching the social environments of individuals on the autistic spectrum, and for developing the ways in which we support and interact with them, both individually and on a systemic level.

***Stage 5: Subjectivity***

This final stage is concerned with the subjective experience of the participants. In other words, it relates to what can be felt, thought and experienced from the various subject positions the participants have taken up, and how this might be transformed if new subject positions were constructed? Again, this may links to the ideas in the previous section and may involve a consideration of the phenomenological concept of *intersubjectivity* based on a shared experience. Naturally, this stage of analysis is the most speculative, but equally it may be the one that holds the most transformatory potential for what it is to be autistic.

## Interpretive Choices

It is important to consider that, in a Foucauldian sense, the guidelines for any discourse analysis are themselves constructed on a foundation of discourses that have come to be accepted as dominant in the field, and, as such, I do not see the above guidelines as a strict set of rules. However, in terms of the process by which I coded my transcripts, the guidelines do denote the broad structure used for my analysis, which involved three close readings of the transcripts.

My initial reading of the transcripts involved the first part of Stage 1, namely: highlighting all references, both implicit and explicit, to the discursive object (of empathy), and how the participants were constructing this. Examples of this stage of coding may be seen in Focus Group 1, ‘F1’ (see *Appendices, Appendix 3*), line 117, as well as Focus Group 2, ‘F2’ (see *Appendices, Appendix 4)*, lines 80-81.

A second reading of the transcripts involved the second part of Stage 1 (i.e. directly referencing the wider discourses upon which participants draw) and Stage 2 (examining the rhetorical strategies used, and the ways in which the participants’ use of language serves an interpersonal function. The referencing to wider discourses can only be achieved with a full understanding of those that are available, which I have been able to develop both through my literature review, and previous in-depth reading within the area of insider literature. Examples of this stage of analysis may be seen in F1, line 168, and F2, line 399. My understanding of rhetorical strategies has been developed through reading around the area of discursive psychology, and supplemented, as noted, with reference to the work of Bion. Examples of this may be seen in F1, line 204, and F2, line 38.

While my referencing of wider discourses (during my second reading of the transcripts) necessarily dealt with some aspects of the later stages of analysis, my third and final reading of the transcripts involved a particular focus of these stages. Examples of Stage 3 (identifying the way in which participants have, or could be, positioned), may be seen in F1, line 368, and F2, line 196. Examples of Stage 4 (exploring the ways in which discursive constructions and subject positions legitimate, or illegitimate, certain forms of action) may be seen in F1, line 316, and F2, line 307. Finally, examples of Stage 5 (exploring the implications of previous stages on subjectivity) may be seen in F1, line 241, and F2, lines 172-173.

So, while my analysis has a clear grounding in the philosophical assumptions of critical and Foucauldian discourse analyses, I have used the procedural guidelines as a supporting framework as opposed to a rigid set of rules. As Manning and Cullum-Swan (1994) argue, using pre-defined rules for coding limits the possibilities for subtle, imaginative, context-sensitive and elaborate interpretation.

Indeed, in the presentation of my results (*Analysis and Interpretations*), rather than laying out the information according to the procedural steps, I attempt to thematise meaning in search of a greater level of clarity and profundity that I hope will be evident. This involved a gradual process of taking the annotations from my transcripts and beginning to group these into broad sets of meaning, using certain quotes to structure my thinking. This process is more subjective and less easily replicable than the process by which I coded and analysed my transcripts. One may liken it to the process by which someone writing a discussion an essay would organise and structure their ideas, which we would assume had been done to maximise clarity and impact of message, but would not expect them to state this explicitly. It is also important to note that certain aspects of my analysis – such as Stage 4 (*Practice*) and Stage 5 (*Subjectivity*), or at least parts thereof – seem to fit more neatly in the *Implications* chapter alongside potential implications for research and practice.

So, if not on its adherence to a prescribed set of rules, on what criteria is my analysis (and the thematic presentation of this analysis) to be judged? Traditional quantitative criteria of reliability and replicability, as with most qualitative research, would be inappropriate and relatively meaningless; yet there still needs to be some means by which to evaluate quality. Yardley (2000) suggests four criteria for good qualitative research, namely: *sensitivity to context*, *commitment and rigour*, *transparency and coherence*, and *impact and importance*. Alternatively, Parker (2005, p. 147-148) suggests four criteria as being *reversal* (“…against the author, the discipline, the will to truth”), *exteriority* (“conditions of possibility”), *specificity* (“a violence which we do to things”), and *discontinuity* (“questioning the pervasive reductionism”). Georgaca and Avdi (2012) present evaluative criteria that are similar to Yardley’s (2000), but are specifically relevant to the epistemological assumptions and methods of discourse analysts, and, as such, it is these to which I will refer in my analysis:

1. *Internal coherence* in accounting for the data;
2. *Rigour* in accounting for deviance and inconsistency, and in providing a richness of detail;
3. The analysis should be *transparent and situated* so that the reader can judge (through explication of the stages of the research process) the quality of findings and (through grounding of the analysis in the extracts) the context of their generation;
4. *Reflexivity* through the researcher’s attention to their role in the generation of data;
5. *Usefulness* in terms of providing new insights, enhancing existing research and having real-world applicability.

Other criteria are available, and indeed the ways in which particular studies fulfil these criteria (or not) will tend to vary considerably (Secker et al., 1995). I return to the criteria at various points – through a series of *Reflective Boxes* – which allow me to step back from my analysis and reflect upon the extent to which I have fulfilled these criteria, and furthermore the extent to which the thematic presentation of my interpretations is conducive to clarity, coherence and rigour, and allows my research to be truly exploratory.

# Analysis and Interpretations

## A Successful Pilot Study

*“I’ve got absolutely no idea”* (Pilot Study, not transcribed)

In the sense that a malfunctioning pilot study is useful in highlighting areas that may be improved upon, my pilot focus group was a resounding success. Due to a restricted number of participants, my pilot focus group consisted of only two young people (one of whom was largely unwilling to speak), and, on reflection, this was likely to have been a primary reason for the difficulties encountered. However, I also felt there were some more underlying process issues that needed to be addressed. Whilst there were no specific questions that the participants seemed to find particularly difficult (or uncomfortable) to answer, the general way in which I presented them may have been somewhat problematic. Although I attempted to present the questions conversationally, I felt that at times they perhaps came across – whether due to lack of confidence or lack of practice on my part – more as though they were being recited. As a response to this, I made a conscious effort in the subsequent focus groups to adopt the kind of narrative approaches espoused by, for example, Hollway and Jefferson (2000), where ‘stories’ are elicited by staying close to the meanings created by the participants and, perhaps most importantly, using pertinent follow-up questions that match their meaning and phrasing (Whiting, 2009). In this way, I hoped to shift from “the highly visible asker of questions to the almost invisible facilitating catalyst to their stories” (Hollway and Jefferson, 2000).

With this, and with the additional assurance this brought, I felt I was able to remain more present in the focus groups and create a ‘space’ in which meaning was created together. Again, the words of Hollway and Jefferson (2000, p. 4) provided a useful heuristic: “The research subject cannot be known except through another subject; in this case, the researcher”. Perhaps less interestingly, the pilot focus group took place in a relatively small, somewhat dimly lit room, and so for the subsequent focus groups I requested that the location be changed. In this way I was able to make available a physical space that was commensurate with the metaphorical space described above, and would further support participants to express themselves.

During the focus groups themselves, it was certainly my perception that the participants seemed to be at ease (note, for example, the interaction in F1, line 326). The proposed ice-breaker question (which was in fact relatively successful in the pilot focus group) was kept in, and generally (particularly in F2) seemed to achieve its intended purpose (encouraging participants to talk, cultivating positive group dynamics, and so on). I also introduced a set of ground-rules; not in a formal sense, but rather a brief introduction in which I highlighted the importance of listening to each other, valuing people’s opinions and treating one another with respect. In the first focus group there were a couple of requests to leave and return to class (see, for example, F1, line 216), though these were towards the end of the session and, I sensed, motivated more by impatience than an underlying discomfort or unease. There also remained some confusion over the questions (see, for example, F2, line 152), but this was rare, and possibly reflective of the heterogeneity of the sample (something I address as a potential limitation in the *Conclusions* chapter).

**Reflective Box**

Though in some ways this first section is intended to be a precursor to the discourse analysis itself, there is a link here to Stage 2 of my procedural guidelines (*Rhetorical Strategies*) in that I attempt to understand utterances in the discursive contexts in which they are produced, and consider the effect that this has on the unfolding interaction. This also links back to the ‘dual aims’ of my analysis in that, as I was clear to point out, not only do I seek to explore the ways in which discourses (and the associated subject positions) have constrained (and opened up) various opportunities for thought (and practice), but also the more immediate group dynamics and minutiae of social interaction.

## The Focus Group as a Social Event – A Bion-esque Group Analysis

In 1961, Wilfred Bion published *Experiences in Groups*, “a landmark in thought and conceptualization of the unconscious functioning of human beings in groups” (Lawrence et al., 1996, p. 28). By no means do I propose to produce a detailed analysis of this here. Rather, I aim to transpose Bion’s theoretical framework in reflecting upon my focus groups, in order to capture the immediacy of the group dynamics therein, and provide comment upon its potential status as a ‘social event’. Bion proposes that groups fundamentally operate in two contrasting ways, namely through *work-group* mentality and *basic-assumption* mentality. Work-group mentality describes the “disposition and dynamics that characterise the life of a group, to the extent that its members are able to manage their shared tensions, anxieties and relationships, in order to function effectively” (French, 2007, p. 2). Basic-assumption mentality, by contrast, describes the state of a group that is taken over by strong emotions – fear, anxiety, guilt, love, hope – and has, as a result, lost touch with its purpose, and become caught up in an “unconscious group collusion” (Eisold, 2005, p. 359). I argue there was evidence of both during the focus groups.

 First, there was certainly some evidence of basic-assumption mentality within the focus groups. For example, on a number of occasions (see F1, lines 97-100; also F1 lines, 196-199), one participant’s line of inquiry was closed down by an interjection from another participant, apparently motivated by a strong need to communicate their point of view. Partly as a consequence of this, and as I had suspected may be the case when considering the rationale for using focus groups, there were occasions when certain group members were somewhat marginalised and actively needed to be drawn into the conversation, as in, “What about you ‘T’ what do you think?” (F1, line 202). There were also occasions when participants seemed to be ‘taken over’ (in Bionian term) by strong emotions. For example, in F1 (lines 296-297), when describing a (generic) pupil becoming increasingly angry as (s)he is reprimanded by a teacher, a participant seems almost to experience the emotion (of anger) himself.

 Perhaps the clearest indication of work-group mentality was through the intentional use of humour. There were numerous examples of this, particularly in the second focus group: “The first rule of desert island is don’t talk about desert island” (F2, line 28); “Or alternatively you could throw [him] in the water” (F2, line 36). These seemed to me both an indication of, and a subconscious attempt to maintain, the smooth running of the groups. With arguably the same purpose and cause, there were numerous examples of one peer attempting to supplement or interpret the meaning of another. For example, in F1 (lines 203-204), one participant states: “erm […] you would feel like […] I don’t know”, to which another replies, “confused maybe?”. In a separate example, one participant suggests that one way in which people’s feelings could be hurt would be through two people “grabbing each other” (F1, lines 269-270). Another participant quickly jumps to the other’s aid and assures me: “he’s never grabbed anyone”. Again, it could be argued that both examples are reflective and supportive of a strong group dynamic. Positive social interactions of this kind were not uncommon, and co-operation and reciprocity were in abundance: “What is bad temper?”…”It means like if you’re so angry and you can’t control yourself” (F1, lines 276-277). Indeed this reciprocity and co-operation was not limited to inter-participant interactions; there was also a seeming concern for my own feelings: “I’m not going to spoil the ending for you” (F2, lines 262-263). These interactions seem to represent quite a feat for individuals with a “devastating deficit in human social insight” (Frith, 2001, p. 969). One could argue that this is not demonstrative of empathy, *per se*, but I would counter by questioning why one would even seek to try and categorise it in these terms, and what would be the benefit of doing so.

 Equally, and as alluded to in the previous section, the way in which participants took to the ice-breaker question was arguably quite revealing. Contrary to my expectations, the content of their answers did not necessarily uncover anything about their appreciation of the emotions of others (as in their fictional co-passengers on the airplane), but the form of their answers, I would argue, certainly did. While they were quite literal in some of their answers (something typically associated with ASC individuals) – see, for example, “set up a tent” (F2, line 24) – they also worked collaboratively as a group, made positive and thoughtful contributions, and, perhaps most noticeably, showed great imagination. These are not qualities, I think it would be reasonable to say, that are typically associated with ASC individuals. This could, then, be taken as presenting some form of challenge to traditional medical and deficit models of autism. Alternatively, and from a more critical discourse analytic perspective, it may be said that, by taking an interest in them as individuals, and not assuming that they would not be able to complete the task – and adopting the Rogerian therapeutic conditions of congruence, unconditional positive regard, and, of course, empathy (Rogers, 1957) – an alternative discursive location was created (albeit temporarily), offering the participants the opportunity to explore new ways to speak and act.

**Reflective Box**

In part, this section aims to capture some of the nuances of social interaction within the focus groups, and so in this sense is a continuation of the first section’s attempt to address Stage 2 of my procedural guidelines (*Rhetorical Strategies*). Furthermore, this section of analysis is perhaps the one that is grounded most firmly within the interview transcripts – compared to other parts of my analysis which are necessarily more inductive – and goes some way to satisfying point 3 in Georgaca and Avdi’s (2012) criteria for high quality discourse analysis: that it must be *transparent and situated*.

At the end of the first part of *Experiences in Groups*, Bion emphasises that his interpretations “seem to be concerned with matters of no importance to anyone but myself” (1961, p. 320). For the reader’s sake, I hope this is not the case with my own. Regardless, as Yardley (2000, p. 220) suggests, “the social context of the relationship between the investigators and the participants in [qualitative] research can be crucial”. So, if nothing else, these reflections should provide a useful precursor to the more ‘formal’ aspects of the discourse analysis that follow.

## An Invitation for Creativity and Wittgensteinian Language Games

*“I think it’s like the Sahara magic that does it really”* (F1, line 27)

A notable theme arising from the focus groups was the inherently interesting and intriguing descriptive means that the participants seemed to have at their disposal. Some of these related to more generic concepts – as with the quote: “I think it’s like the Sahara magic that does it really” (F1, line 27) – whereas others related more specifically to emotion: “disinflamed” (F1, line 117). Though some of the words used were arguably ‘non-word’ (as with “disinflamed”), the logic was generally clear (as in ‘inflamed’ meaning angry, and the prefix ‘dis-‘ meaning less). There was use of metaphor in the description of emotion when, for example, a participant talked of another child “breaking into bits” (F1, line 297) when being told off by a teacher. There were also interesting alternative interpretations of the word ‘feeling’, where it was represented as a physical sensation rather than an emotional state: “Is sense of voice vibration […] is that a feeling?” (F1, line 122). Even in their ambiguities – for example, one participant suggesting that his parents might feel “nervous” if he forgot their birthday (F2, line 139) – there is an inherent intrigue.

 As Davidson (2008) notes, the autistic community (particularly online) are beginning to create distinctive styles of communication, or “Wittgensteinian language games” (p. 793), and, much like the deaf community, are beginning to forge a communication style that is all their own. Even before we address the potential insights into empathic (and related) processes that insider accounts may provide, and the potential challenge they offer to the notion of an empathy deficit (and the surrounding discourse), the sheer originality and linguistic dexterity with which they are able to reflect on their experience surely adds to the narrative of autism. I contend that the impact of these contributions may even extend to qualitative disability research more generally. Parker (2005) argues that every qualitative research report is an invitation to creative writing and an opportunity to consider aspects of research not often valued by psychology. If we accept this, then it provides a strong claim for the active contribution of ASC individuals within the broader qualitative research agenda (regardless of whether the research is oriented towards autism).

## Restrictive Discursive Locations

*“I don’t know that’s harder”* (F2, line 128)

There certainly appears to be evidence – through the apparent discursive locations, or subject positions, taken up by the participants – of the narrow ways in which ASC individuals (and more particularly the nature of their emotional processing abilities) may have been constructed. For example, in the first focus group, when asked “…what does that mean ‘how you’re feeling’?” (F1, line 49), there was a long and palpably uneasy silence within the group. One interpretation of this is that ASC individuals struggle to express, or at least to talk about, their emotions. A different interpretation is that, in their silence, participants are adopting subject positions created by traditional discourses of deficit and lack, and that within this “network of meaning” (Willig, 2008, p. 116), certain discursive locations have been made available for the speakers to take up. Put another way, it may have been assumed in the past that these individuals would not be able (and would certainly not value the opportunity) to express their emotional state, and therefore opportunities to do so may have been limited.

Similarly, in the second focus group, as a follow-up to the question, “if you saw your friend crying in the playground or in the quad what would you do?” (F2, line 108), I asked, “what if you saw your friend and they were really happy?” (F2, lines 126-127). To this, one participant immediately responded, “I don’t know that’s harder” (F2, line 128). While participants did go on to answer this somewhat more fully, this initial response may be read as an indication that there are fewer available discourses, or interpretive repertoires, that relate to a shared experience of positive interactions. In both these example, it may be argued that participants are adopting the traditional subject positions that have been forged for them, in which opportunities for emotional expression (particularly in a positive context) have been, if not actively constrained, then certainly not encouraged.

**Reflective Box**

This section of analysis arguably includes recourse to Stages 1 (*Discourses*), 3 (*Positionings*) and 4 (*Practice*) of my procedural guidelines. This should give some indication as to why I felt it more appropriate to structure my analysis thematically rather than in a series of disjointed analytic stages.

## Defying Restrictions and Re-framing the Deficit

*“I know how I’m feeling as a person but my face doesn’t know all the moves”* (F1, line 97)

The previous section notwithstanding, there does seem to be evidence, perhaps through their active participation in the focus groups, of participants beginning to defy the restrictions enforced by the discursive locations described above. For example, participants are certainly capable of insightful and articulate reflection on their own emotional experience: “That story’s quite mood-swaying as well ‘cause you get like sad at certain parts of it and you can get like happy at certain parts (…) it’s quite emotional sometimes” (F2, lines 256-258). When one girl ponders, “I know how I’m feeling as a person but my face doesn’t know all the moves” (F1, line 97), it is highlighted that, while she may struggle in physically communicating her emotions (the *affective* component of empathy, one might say), her cognitive processing of the emotion is very much intact. What is more, she is able to express this concept with great eloquence and clarity. Indeed, there are numerous examples within my transcripts of at least a base-level appreciation of the emotions of others; for example, “they get upset and […] you know […] a bit tensed” (F1, lines 81-82). There is also evidence of a more nuanced understanding of emotions, including a level of predictive ability, i.e. inferring the internal emotional state based on the external presentation; for example, “that means angry maybe or furious maybe” (F1, line 85). This would seem to suggest an intact faculty of the cognitive component of empathy.

In other examples, even when the participants seem to be struggling to demonstrate an empathic connection – “most of the time he just comes up to people and forces you to play with him and if you don’t he starts crying” (F2, lines 405-406) – or when the participants’ talk may not always be indicative of an appropriate empathic response – “a cheeky boy threw a gingerbread man at one of my old friends and I had to barge in and stop them really” (F1, lines 154-155) – it at least demonstrates a thoughtfulness and consideration of others and their situation. Furthermore, the participants show themselves to be highly inquisitive and curious – “But why would any child forget someone they loved’s birthday?” (F1, line 194) – actively searching for meaning in their experiences. Whether successful in this process of meaning-making, and of empathising with others, their intent and willingness to engage is clear: “I hope I can do it perfect for [him]” (F1, line 177). Again, there are different ways in which these data may be interpreted. One way would be to say they are demonstrative of the participants’ abilities to display a form of empathic awareness. However, from a more critical Foucauldian perspective, my interpretation is that, despite the restrictions that may be enforced within society, when ASC individuals are given the opportunity (as are the participants in this research), new discursive locations from which to speak (and act) can and do exist.

**Reflective Box**

There is a clear reference here to my attention to my role in the generation of data (see point 4 in Georgaca and Avdi’s criteria). I acknowledge that there are alternative ways in which the transcripts may be interpreted, and am clear that the way in which I have interpreted the transcripts is based on the methodological paradigm in which I have chosen to position myself. In this way, I acknowledge the constructivist nature of my interpretations, and am able to demonstrate the imposition of reflexive rigours upon my own thinking and upon the process of knowledge production within this research.

The above examples also begin to build on a wider discourse that may play a valuable role in re-framing the ‘difficulties’ experienced by ASC individuals. For example, it highlights that their difficulties are not universal and all-consuming, but rather embedded within a complex framework of alternative strengths and abilities. In the second focus group, a participant states, “Sometimes it’s really hard [to say how you’re feeling], sometimes it’s really easy” (F2, line, 98). In so doing, he inadvertently elucidates the perhaps common-sensical, but often unexplored construct that emotions are not all-or-nothing concepts, but rather are highly task and context-dependent. Furthermore, this indicates that a difficulty in *explaining* feelings is not the same as having a difficulty in feeling itself. This kind of discourse may offer a new way to view those on the autistic spectrum, where no longer must we see them as ‘unfeeling’, but rather as being delineated by a somatic affordance (the limitations of one’s inherent physiology) that does not conform to cultural and societal expectations.

## The Looping Effect and the Impact of an Autism Label

*“Some people have worse autism than others”* (F2, line 399)

As indicated in my methodology, the final question in my focus group schedule – “Do you think being diagnosed as autistic makes a difference [in understanding emotions]?” – was designed to elicit reflective and reflexive insight into the effects of being the bearer of an autism label. There has been much written about the impact of an autism label on those upon whom it is imposed. Draaisma (2008, p. 1476) suggests that “the very act of labelling initiates a complex interaction between the label and the perception and understanding of the person so labelled”. Hacking (1999) introduced the concept of *interactive kinds* to refer to any concept or discourse that interacts with the individual that carries it by “shaping its mode of behaviour, its identity, and consequently its subjectivity” (Vakirtzi & Bayliss, 2013, p. 365). If we take autism to be an interactive kind (as Hacking did), then those with a diagnosis of autism may be thought of as *moving targets*, who, as a result of their diagnostic label, are changed, and so “are not quite the same kind of people as before” (Hacking, 2007, p. 293). This is termed the *looping effect* and presents a useful framework within which to understand the participants’ perceptions of their autism diagnosis.

It would appear that, for some participants, their autism diagnosis is not a defining narrative in their construction of self: “I don’t know ‘cause I’ve never heard of it” (F1, line 368). However, in the second focus group, when two participants answer immediately in the affirmative to the question of whether being diagnosed as autistic makes a difference to understanding emotions (see F2, lines 394-395), it appears they not only relate closely to the identity role of being autistic, but draw on the associated discourse that this affects emotional processing. In qualifying his response, one participant offers the caveat: “Depending on how severe it is” (F2, line 397). On the one hand this quote may be couched in positive terms and taken to indicate that the participant is drawing on a discourse of neurodiversity and displaying a genuine understanding of the broad variance of need that exists across the autistic spectrum. Indeed a follow-up comment: “…like they react differently if you say something or do something” (line 399-400) would, in many ways, seem to corroborate this. However, in more negative terms, it could be said that the word “severe” connotes quite pessimistic, deficit-based discourses. Indeed in the same exchange a participant suggests that: “some people have *worse* autism than others” (F2, line 399), and there is some indication that their understandings of emotions generally seem to be based upon related medical and neurophysiological discourses: “parts of your mind that trigger when certain things happen” (F2, line 80-81).

**Reflective Box**

Here I attempt to account for ‘inconsistency’ within the data, thereby providing a richness of detail (see point 2 of Georgaca and Avdi’s criteria). I explain that there are participants for whom an autism diagnosis does seem to be a defining narrative in their construction of self, and those for whom it does not. Furthermore, even within the group where an autism diagnosis does seem to be a defining narrative, there are different ways in which this may be understood.

In their understandings of autism, participants draw upon the dominant medical discourses associated with a diagnosis, to which, as a result of their diagnosis, they are likely to have been exposed. In so doing, they seem to be identifying as the medicalised beings that this discourse creates, and inadvertently colluding with the associated narrative that those with an autism label (and ergo they themselves) have deficits in their ability to process emotions. In this sense, rather than being passive bearers of their autism label, the label fundamentally changes the way in which their self-identity is shaped. One may extrapolate that the way in which they understand themselves is likely to have influenced the way in which others understand them – and the pedagogical, educational and interactional practices to which they have been exposed – thus reinforcing the subject position they have come to adopt.

## Neurodiversity and Echoes of Higashida

*“Sometimes when I’m excited my head shakes a little bit but mum said don’t shake it too much or else you’ll get a headache”* (F1, line 168)

In relation to the above quote, a discourse upon which we can draw, which is in many ways antithetical to the discourses associated with ‘labelling’, is that of *neurodiversity*. The neurodiversity discourse dictates that the “the paradigm of acceptance extended towards racial, religious and other similar differences should apply to neurology as well” (Broderick and Ne’eman, 2008, p. 470). It is a construct that challenges the positioning of autism within solely medical and disease-oriented language and practices, and instead positions autism within social, cultural and political discourse. The neurodiversity movement, which arose primarily through online groups, celebrates autism as an inseparable aspect of identity and seeks to provide a culture in which autistic people feel pride in their minority group membership and may provide each other mutual support in self-advocacy as a community (Jaarsma & Welin, 2012). From within this discourse, autistic individuals may adopt a position not of being damaged or deficient, but rather exhibiting a natural form of human variation. As John Elder Robinson, diagnosed with autism in adulthood, and now a prominent online blogger, states: “Asserting that I am different – not defective – is a much healthier position to take” (Autism Speaks website, retrieved October 2015).

What struck me most about the above quote – “Sometimes when I’m excited my head shakes a little bit but mum said don’t shake it too much or else you’ll get a headache” (F1, line 168) – was the utterly casual manner in which it was presented. The boy simply highlights a behaviour (head-shaking) and then identifies the emotional cause (excitement). While the speaker was not intentionally drawing on the discourse of neurodiversity, in so doing, he highlights an alternative conceptual framework into which the construct of autism may fit. For those who have read *The Reason I Jump: One Boy’s Voice from the Silence of Autism* (Higashida, 2013), memories will be invoked of how 13-year-old author Naoki skilfully demystifies much of the ‘unusual’ behaviour observed in ASC individuals (such as jumping up and down on the spot, hence the title). Positioned within a discourse of neurodiversity, this behaviour is no longer ‘bizarre’, ‘odd’ or ‘peculiar’, but rather a given individual’s very natural (albeit idiosyncratic) physical reaction to a specific internal state.

If this explanation permits us a different way to *view* some of the atypicalities in behaviour, the second part of the quote – “…mum said don’t shake it too much or else you’ll get a headache” – perhaps implies something about the way in which we respond to this behaviour. An autism discourse that is oriented towards medical and deficit models has made available certain ways of responding to these kinds of behaviours, and a tendency to attempt to normalise rather than accommodate them (encapsulated by the mother’s response to her son’s shaking of his head). The most commonly used – and most often studied – specific intervention for children with ASC is Applied Behaviour Analysis (ABA), and while there is a considerable body of empirical evidence suggesting its efficacy (Matson & Smith, 2008), it has been heavily criticised for its narrow focus on forceful normalisation for its own sake, and the acquisition of skills that are mechanistic and rigid, and not necessarily generalisable to novel (particularly social) situations (Baker, 2011). The discourse arising from advocates of neurodiversity, first, promotes subjective well-being and adaptive rather than typical functioning (such as reliable, but not necessarily spoken, communication) (Savarese et al., 2010). Furthermore, it tends to oppose interventions that aim to eliminate unusual but harmless behaviour, such as avoiding eye contact or repetitive body movements (Kapp et al., 2012). As Bogdashina (2001) posits, ASC individuals’ well-being relates to their being able to experience ways of being that are compatible with their dispositions, without being forced to mimic non-autistic behaviours that can be confusing or bewildering to them. The alternative ways of responding are not directly implied within this but it is something to which I will return and indeed forms a theme throughout the remainder of my analysis.

The discourse of neurodiversity is so pertinent to the present study because, as noted earlier, I do not aim to *disprove* the notion of an empathy deficit in ASC. Rather, I suggest that, if we locate ourselves within a different kind of discourse, such as that of neurodiversity, we create alternative ways of thinking and speaking about *differences* in emotional processing (both within and across the spectrum), where said differences are not only accepted, but embraced as an integral and indispensable part of the self. From this position, the term *empathy difference* seems significantly more apt.

**Reflective Box**

Again, even within the space of a few paragraphs, there are clear links to Stages 1 (*Discourses*), 3 (*Positionings*) and 4 (*Practice*) of my procedural guidelines. It is clear, then, that within the context of my write-up, these strands are inextricably linked, and are best presented as such. The same also holds true in the following section.

## Phenomenology and ‘Radical Empathy’

*“Depends who asks the question”* (F2, line 99)

Thus far, discussion has centred primarily around how the participants’ discursive constructions are reflective, and augmentative, of emergent counter-dominant discourses from within the autistic community, and how, by drawing upon these discourses, alternative ways in which to speak of, and think of, those on the autistic spectrum are offered. The focus now shifts towards *Practice* (Stage 4 within my procedural guidelines). This has already been addressed to some extent, when considering how discursive constructions and subject positions may have legitimated (or illegitimated) certain forms of action, for example, and how an assumed empathy deficit may have reduced the participants’ opportunities to reflect upon and communicate their social and emotional experiences. However, the emphasis is now placed upon the alternative forms of action, or practice, that may be opened up. (This is not intended to preclude a discussion of the study’s wider implications for professional practice, which comes in the *Implications* chapter.)

 The participants make numerous references to the importance of the quality of the interaction offered by a significant other. For example, when asked, “…do you find it easy to describe how you’re feeling?” (F2, lines 95-96), one participant responds, “depends who asks the question” (F2, line 99). Presumably this implies that the way in which the question is asked, and, moreover, the way in which people communicate and interact with him generally, can differ significantly, and that this is likely to affect his emotional response. When participants were talking in positive terms about the staff with whom they engage, themes of familiarity and the need for some form of ‘empathy’ (on the part of the adult) were ever-present, “Cause they know me and I understand them” (F1, line 305-308). Similarly, participants seemed to intimate that if this quality of interaction is absent then it is likely to invoke a negative interaction, “some teachers really don’t understand me and it annoys me” (F2, line 327). This follows on from the previous discussion around the idea that an apparent lack of empathic understanding between ASC and non-ASC individuals “goes both ways” (Dant, 2015, p. 55), and the importance of professionals reflecting upon this. But what are the forms of action mapped by these discursive constructions of the participants?

 On a number of occasions, participants construct positive interactions as being achieved through some form of *shared experience* or mutual enjoyment of an activity: “someone who does your own enjoyment” (F1, line 241). Moreover, participants seem to construct this notion of shared interest as the foundation for both sibling relationships (“ [my brother] was so happy ‘cause I taught him Sonic” (F2, lines 172)) and their closest friendships (“Yeah but [computer games] are how we all came together as friends really” (F2, lines 265-266)). One approach that may be implicated from this is what Ratcliffe (2012) calls *radical empathy*. Drawing upon theories of phenomenology and intersubjectivity, Ratcliffe proposes that a ‘connection’ can still be made despite apparent variations in subjective experiences of their life-world. It involves “suspending, to varying degrees, a world of norms, roles, artefact functions and various other artefact functions” (Ratcliffe, 2012, p. 478); or, in other words, learning by conscious effort, to accept the world as others see it. Arguably, this is what many autistic people already do as they attempt to ‘get by’ in complex and rapidly-changing social environments.

This is in contrast to traditional theories of cognitive empathy and ToM as a prerequisite for empathy, as it does not presuppose that it is a necessity for one person’s mind to directly compute the mind of another. Whilst there is a considerable degree of apperception and embodied co-experience between people with autism and those without (Dant, 2015), it is unlikely that sufficient common ground will be found for the different orientations of mind to become appresent, and for a traditional empathic connection to be achieved. Indeed, Wittgenstein (1953) and Nagel (1974) both concluded that it is not possible to move beyond one’s own somatic affordance to understand the lived experience of being autistic. Radical empathy, then, may be said to offer a genuine alternative to this philosophical dilemma.

 It may also provide the basis for an alternative approach to ASC interventions generally which, it has been argued (see, for example, Jordan et al., 1998), may appear to superficially address the needs of autistic individuals, but can often be ‘unfeeling’ or lack sensitivity. Billington (2006) warns against strategies that are devoid of meaning, and surrounding individuals with mere “lifeless artefacts” (p. 10). Indeed, one wonders if such a strict reliance on behavioural approaches could ever do justice to the subtle nuances and complexities of the emotional processing of those with ASC. Furthermore, one must wonder whether they provide the individual with skills that are transferrable to ‘real-world’ social situations, or allow for any sense of spontaneity, individuality, creativity or originality. Perhaps, if we are able to adopt a broader stance of radical empathy, we will have the opportunity to develop the ways in which we support and interact with ASC individuals and, ultimately, enrich the social environments they inhabit.

## Enriching Social Environments

On the basis of the previous discussion, it may be argued that the apparent ‘emotional detachment’ exhibited by ASC individuals is not an inherent *symptom* of autism, but rather the *consequence* of an environment ill-equipped to address their needs. Returning directly to the focus group transcripts, there is some evidence of participants constructing their environment, and the strategies to which they have been exposed, in a way that draws upon traditional behaviourist discourses associated with ABA. For example, a participant seems to be referring to the firm boundaries that are likely to be in place in an environment that employs a system of ABA (which their school does) when he states, “no-one pushes in the line here” (F1, line 316). Similarly, a participant makes direct reference to the associated system of rewards and sanctions, “that’s like free time (…) and say if you have some bad marks you don’t get it at the end of the lesson” (F2, line 319-320). However, there is once again evidence, as we see below, of participants defying their subject positions and drawing upon alternative discourses that may implicate alternative ways to respond to and support those on the autistic spectrum. Again, the question here is about the forms of action that are mapped by the participants’ discursive constructions and, moreover, what can be thought and experienced from the various subject positions the participants have taken up.

**Reflective Box**

While, as discussed, I do not work through the stages of my procedural guidelines for analysis sequentially, these final stages are concerned primarily with *Practice* (Stage 4) and, latterly, *Subjectivity* (Stage 5). In this sense, the overall ‘flow’ of my analysis remains true to traditional formats. Furthermore, while I do pay some attention here to the utility and real-world applicability of my findings (see point 5 of Georgaca and Avdi’s criteria), as noted, parts of this discussion fit more neatly within the *Interpretations* chapter.

It is interesting to note that, in many instances, there is no complex inference required to understand the ways in which participants may wish for us to ‘enrich’ their social environments; rather, they are able to tell us quite directly. Take this quote, for example: “cause he can’t talk at all so he needs to use like a touch screen really to ask him what he wants really […] he’s good at understanding though […] but he’s not good at talking though” (F1, lines 103-105). It seems to suggest not only the importance of visual (and electronic) equipment in accessing the autistic voice, but also, and perhaps more pertinently, that simply because participants are unable to communicate their views verbally, it does not necessarily imply that their understanding is any less. Equally, another participant explains that “there’s some teachers that really don’t understand me and it annoys me” (F2, line 327), and then elaborates on this by saying “like if I don’t understand a piece of work (…) like they won’t explain it to me they’ll just force me to do it” (F2, line 331-332). Again, there seems to be a fairly clear implication that attunement, understanding and nurture are likely to be more beneficial, at least from the participants’ point of view, than “normalization for its own sake” (Kapp et al., 2012).

 This gives some indication as to how the social environments of ASC individuals may be enriched, but, as noted, this will be explored in more detail in the *Implications* chapter. So what, then, can be felt and experienced by ASC individuals when positioned in this way? Initial indications from the focus group transcripts would seem to suggest that participants see such approaces as promoting a sense of general well-being, “you make someone feel good if you make friends with them” (F1, line 228). Again, they seem to construct having a shared interest with another person as the necessary and sufficient conditions for a healthy relationship, “I can tell you that one thing I really like is my computing teacher… She looovves computers” (F2, lines 346-348). Furthermore, they seem to place an inherent emphasis on ‘fun’ and ‘light-heartedness’: “he didn’t make frequent jokes but he kind of had a sense of humour about him” (F2, lines 358-359). Yet the fact that that there was relatively limited discussion regarding positive interactions fits with earlier parts of my analysis where I suggested that participants seemed to have fewer available discourses or interpretive repertoires in this regard.

# Summary of Interpretations and Critique of Analysis

The decision to feed back my interpretations to participants necessitated their abridgement into a more simplistic form. In the headings below (in bold) I outline an approximation of what I said to the participants in the follow-up groups. Ultimately, I aimed to capture the key meaning contained within the preceding chapter, while attempting to avoid being convoluted or confusing in any way. Under each heading, I provide a brief exposition regarding the inclusion of each comment, which also acts as a précis of my interpretations for the reader.

**“Can you remember the focus groups we did a few months ago – how do you feel about them now and how did you feel about them then?”**

Initially, I wanted to open up a space for participants to reflect upon their experiences of the focus groups, without the imposition of my own biases.

**“I think you worked really well as a group, and I was really impressed by how you listened to one another, valued each other’s opinions and treated everyone with respect.”**

This comment is intended to reflect the positive (and, perhaps for some, surprising) way in which participants took to the focus groups in general. There is no intimation here to the content of their answers, but rather the focus is on the rich *social* content of the groups themselves. I allude, with a level of simplicity I felt was appropriate, to the co-operation and reciprocity that appeared to be in evidence, and, in reference to my Bion-esque analysis, I also allude to the group’s potential status as a ‘social event’.

**“I think you gave really interesting, creative and unusual answers, not only with the ice-breaker question, but throughout.”**

This is a general comment on the inherently interesting and intriguing content of the participants’ answers. In my interpretations I suggest that these distinctive communication styles, or “Wittgensteinian language games”, provide a strong argument for the active inclusion of autistic individuals within the autism research agenda, and indeed within qualitative disability research more generally.

**“Have you had many opportunities to talk about feelings in this way before? Would you like more opportunities to do this?”**

In my interpretations I make the assumption that certain discursive locations have been made available for participants where opportunities for emotional expression may have been, if not actively constrained, then certainly not encouraged. Rather than stating this outright in my feedback to participants, I frame it as a question in order to explore the extent to which participants identify with this viewpoint. In the second question I prompt participants to reflect upon the extent to which they would value the opportunity to do more of this, and to defy the typically exclusionary research agenda referenced in the previous comment.

**“I feel, from what you said, you usually know how you’re feeling inside, but sometimes it’s difficult to show people or to tell them.”**

This comment aims to pick up on statements such as: “I know how I’m feeling as a person but my face doesn’t know all the moves”, which seem to imply that while participants may struggle in physically communicating their emotions (the *affective* component of empathy), the cognitive processing of the emotion is very much intact. In other words, a difficulty in explaining or communicating feelings is not the same as having a difficulty in experiencing feeling.

**“I think maybe when I asked whether you find it easy to understand how other people are feeling, or to tell others how you are feeling, it was a bit of a silly question because, from what you guys said, it seems that it totally depends on the person you’re speaking to, how familiar you are with them, the situation you are in, and so on.”**

This comment aims to pick up on statements such as: “Sometimes it’s really hard [to say how you’re feeling] sometimes it’s really easy”, which highlight that emotions are not all-or-nothing concepts but rather are highly task and context-dependent, and that difficulties in emotional understanding are not universal and all-consuming but rather embedded within a complex framework of alternative strengths and abilities.

**“I think the way you were able to talk maybe showed a lot of grown-ups that it’s them that need to work on their communication skills, not you.”**

Here I pick up on a broad theme form the transcripts, relating to Dant’s (2015) assertion that the empathy deficit “goes both ways” (p. 55). More specifically, I was interested to elicit participants’ views on the idea that, rather than attempting to normalise the behaviour of ASC individuals and demanding they behave in a way that we consider appropriate, the onus is perhaps on us as professionals (and non-ASC individuals generally) to reflect upon our own empathy deficit and consider the ways in which we can modify our interactions in order to meet the social reality of ASC individuals.

**“I got the impression that rather than grown-ups telling you what they want you to do, you’d prefer them to join in with what you’re doing already.”**

This comment has a similar justification to the previous one and prompts participants to further reflect on the ways in which adults respond to them. Furthermore, it prompts them to reflect upon the alternative forms of action that may be available, perhaps where the adult attempts to ‘meet’ the autistic young person in their world by sharing in their experiences, and where idiosyncrasies in behaviour are promoted rather than suppressed.

**“What do you think of the behaviour charts you have in school?”**

This comment is intended to reflect the social environment to which the participants are currently exposed in school (i.e. one dominated by ABA) and is designed to promote wider discussion on the ways in which their social environments may be enriched.

**“I think you had a really good understanding of autism and how it might affect people’s ability to understand emotions. I’m curious, do you think this label affects how you see yourself?” (Question specific to F2 because, by the time I had asked the question regarding an ASC diagnosis in the first focus group there was only one participant left, and he said he had never heard of autism.)**

Finally, I wanted to draw attention to the significance of an autism label, or at least the participants’ perceptions thereof, in the processing of emotions. Furthermore, and though it was not addressed within the participants’ responses, I wanted to explore the perceived significance of an autism label in the formation of ‘self’. In this way, participants are prompted to reflect upon the extent to which the dominant discourse of an empathy deficit “shapes [their] mode of behaviour, [their] identity, and consequently [their] subjectivity” (Vakirtzi & Bayliss, 2013, p. 365), and as a result, a layer of participant reflexivity is introduced.

 **\* \* \* \***

## Participant Responses

I have not transcribed the follow-up focus groups but, with considerable use of direct quotations, I aim to reflect the participants’ words as authentically as possible. While there were apparent differences in the abilities of participants in the two focus groups to fully understand and be able to respond to my feedback, I present their responses here as a cohesive whole. I was wary of categorising the two groups as those who ‘got it’ and those who did not. Furthermore, despite the natural heterogeneity of my sample (which I have noted), I felt it was important to promote, as I have attempted to throughout, the idea that the voices of my participants reflect the collective nature of the emergent counter-narrative from within the autistic community.

As noted, although there were some difficulties in responding to the feedback I offered (more so in the ‘F1’ group) and while there were instances in which I feel I could have communicated my meaning more clearly, my general perception was that participants were generally able to attune to my comments and, moreover, valued the opportunity to comment upon and critique my analysis. Furthermore, even when participants diverged from the original question or comment I had made (as they did quite regularly), or there was something of a ‘breakdown’ in communication – such as when I asked how they were “finding” their new school site (to which they had moved in between the first and follow-up focus groups) and one participant responded, “well I get on the bus and the driver knows where he’s going so that’s how I find it” – I did not necessarily view this as a problem, but rather as adding to the richness and authenticity of the participants’ feedback.

I summarise the participants’ responses under the questions I asked:

**“Can you remember the focus groups we did a few months ago – how do you feel about them now and how did you feel about them then?”**

Participants’ perceptions of the focus groups appeared to be broadly positive: “I liked them, they were alright. 9 out of 10.” There was specific feedback on the positive atmosphere I had attempted to create, such as, “I enjoyed talking about being happy”. Participants also seemed to respond well to the relatively relaxed and informal environment, and the unobtrusive nature of the questions I asked. The following quote encapsulates this quite elegantly: “You didn’t ask too many questions which I found good. You asked me a few questions but you didn’t go overboard with it – you didn’t get too personal.”

**“I think you worked really well as a group, and I was really impressed by how you listened to one another, valued each other’s opinions and treated everyone with respect.”**

Participants generally seemed to identify with this statement, although found it somewhat difficult to comment further. That being said, participants were able to explain that at least part of the reason they acted in this way was to do with the existing relationships they already had: “Well we are kind of friends, aren’t we?” Furthermore, they were able to recognise the importance of such skills in maintaining these kinds of relationships: “If I didn’t treat him the right way, how he understands, he wouldn’t be my friend.” Indeed it was interesting to note that, even in having this discussion, participants again demonstrated the ability to listen to and value one another’s opinions, and showed genuine mutual respect, just as they had in the original focus groups.

**“I think you gave really interesting, creative and unusual answers, not only with the ice-breaker question, but throughout.”**

There was some acknowledgement of the interesting and unusual answers that they had given: “Yeah I remember laughing at a lot at the things you [one of the other participants] said”. However, the participants again seemed to find it somewhat difficult to respond to this, perhaps because it was more of a general comment than a direct question. In actuality, the participants were just keen to talk further about the desert island scenario and, though I do not have the space to include it here, their originality and creativity again shone through.

**“Have you had many opportunities to talk about feelings in this way before? Would you like more opportunities to do this?”**

There was something of a variance in opinion amongst participants as to whether they had had many opportunities to talk about feelings in this way before, with answers ranging from, “In the middle probably – 5 out of 10 I’d say”, to, “I’d say 9 out of 10.” There was some reference to the speech and language therapy sessions they have in school, which apparently involve a similar set-up in terms of sitting down as a group and discussing various topics. However, the participants’ perceptions of the topics discussed in these sessions were not altogether positive: “We just do unnecessary questions.” Indeed it seemed that the issues discussed within the sessions were fairly limited – “they just ask you what makes a good friend and stuff, but I haven’t spoken about feelings with people before” – perhaps adding some weight to my claim that it is often assumed that ASC individuals would not be able (and would certainly not value the opportunity) to express their emotional state, and that opportunities to do so have therefore been limited. When I asked if they would like more opportunities to do this, they generally answered in the affirmative, albeit some (“oh yes”) with more enthusiasm than others (“yeah I don’t mind having another session”).

**“I feel, from what you said, you usually know how you’re feeling inside, but sometimes it’s difficult to show people or to tell them.”**

The idea that having a difficulty in explaining or communicating feelings is not the same as having a difficulty in experiencing feeling is something that seemed to resonate strongly with participants. They were able to talk articulately about some of the emotions they experience in daily life, and indeed were able to label these appropriately, as in “embarrassed” and “self-conscious”. However, when I questioned them further about the meaning of these words, participants found it somewhat more difficult – “I don’t really know all about lots of feelings really” – suggesting that, when the emotion is abstracted from actual experience, they find it much more difficult to explain. Indeed, participants found it much more difficult to explain feelings based on complex emotional concepts, as opposed to those based on physical manifestations within the body: “It’s easy to explain an upset tummy – that’s something that’s easy for me to understand.”

**“I think maybe when I asked whether you find it easy to understand how other people are feeling, or to tell others how you are feeling, it was a bit of a silly question because, from what you guys said, it seems that it totally depends on the person you’re speaking to, how familiar you are with them, the situation you are in, and so on.”**

Again, this seemed to strike something of a chord with participants, and they engaged in detailed discussions about the reading of others’ emotions. First, they acknowledged that a person’s outward display of emotion is not necessarily reflective of their affective internal state: “Yeah, ‘cause like one person could be stressed but they wouldn’t really be showing it. Like one person could be sad but they could be looking really happy on the outside. So it just depends how like you mask it.” This point was elaborated upon and they discussed how even apparently unequivocal feelings, such as an “upset stomach”, can sometimes prove to be more ambiguous, “It can be food poisoning but it can also be like a worried tummy”. They also went on to talk about how, for this reason, they themselves often have to make assumptions about how others are feeling: “I just usually think everyone might just feel embarrassed…because they feel self-conscious.” While on the one hand this reflects the difficulties ASC individuals may experience when attempting to process emotions in complex and rapidly-changing social environments, it also serves to illustrate that any difficulties they do have are embedded within a framework of alternative strengths and abilities, such as the ability for in-depth self-reflection displayed here.

**“I think the way you were able to talk maybe showed a lot of grown-ups that it’s them that need to work on their communication skills, not you.”**

There was certainly some agreement with this statement and an expression of a desire for teachers to be more considered in their styles of communication: “Sometimes, yeah, ‘cause there’s a teacher, she’s like really strict and it’s really hard to understand what she means, and it’s just like, can you be a bit clearer ‘cause I don’t know what you want me to do. You’ve given me 2 strict options, you’ve given me no leeway here.” However, participants were able to acknowledge the difficulties teachers may experience in this regard – “it’s kind of tricky ‘cause you have to kind of work round everyone’s needs and wants” – and that their own styles of communication were liable to fluctuate: “It depends, ‘cause I can be like talking to you now but I’ve been known to use the wrong tone of voice”. Though I have attempted to keep this section free from references to the literature, there seems to me an unavoidable link here to Ratcliffe’s (2012) concept of *radical empathy*, where a ‘connection’ can still be made despite apparent variations in subjective experiences of their life-world. Ultimately, participants came to the wholly balanced and reasoned conclusion that, “I think it’s a little bit of everyone really [that needs to work on their communication].”

**“I got the impression that rather than grown-ups telling you what they want you to do, you’d prefer them to join in with what you’re doing already.”**

Participants seemed to identify with this statement and responded with characteristic insight and humour, “Yeah ‘cause like we don’t live in a dictatorship so we should be given a degree of freedom. Yeah we should be told what to do but not how to do it.” However, for a number of participants, this idea of sharing in experience seemed rather alien, “I don’t have anyone that talks like that.” Conversation quickly moved onto friendships, and the importance of shared interests and experiences in maintaining them. As ever, the participants were considered in their responses, suggesting that having shared interests in this way is not always necessary, “Yeah ‘cause it’s just like we all have similar interests and we all have our different interests too.” They went on, “There’s a person in our group who doesn’t really know much about comics but we don’t force it upon him to learn about comics like he doesn’t force it upon us to learn about lizards and dinosaurs and stuff.” Again, they summed up effortlessly: “I’d just prefer people to be themselves really” (presumably as they would like to be allowed to be themselves as well).

**“What do you think of the behaviour charts you have in school?”**

Perceptions of the behaviour charts used in school seemed to be somewhat mixed. While there were some negative perceptions – “They’re a bit childish really” – the participants did acknowledge their efficacy for certain young people: “Again it depends on your needs and wants ‘cause like me and him don’t really need a behaviour chart, but we’ve got kids in school who’ve got like no sense of danger so they have like a red green yellow thing. So it just kind of depends what works for you.” Indeed the participants noted that the behaviour charts are generally adapted to meet each individual’s needs: “I have something called a stress dial that I sometimes use when I’m a bit stressed which helps me calm down and show other people how I’m feeling”. However, it did appear from what the participants said that this differentiation in approach was largely dictated by staff: “Everyone has a different system really, but if you don’t get on well with your own system then the teachers will decide if you can change it or not.” Ultimately, participant responses seemed to represent a commonly-held stance regarding ABA-type approaches: that there is value to them in certain contexts, but that it also tends to result in the recipient of said intervention ceding a level of individuality and autonomy.

**“I think you had a really good understanding of autism and how it might affect people’s ability to understand emotions. I’m curious, do you think this label affects how you see yourself?” (Question specific to F2 because, by the time I had asked the question regarding an ASC diagnosis in the first focus group there was only one participant left, and he said he had never heard of autism.)**

Participants began by elaborating upon how they feel autism affects an individual’s ability to process emotions, and again seemed to display a good awareness of the broad variance across the spectrum: “We have students here with additional needs and some are stressed like 100% of the time but you can’t see it…and then you’ve got other people who are totally emotionless.” Participants did find it difficult to answer specifically how an autism *label* (as opposed to an essentialist understanding of autism as a biological ‘truth’) affects their own formation of self, and indeed it is a difficult question to answer. I switched the focus somewhat and asked whether it would make a difference if they had never heard of autism or if autism wasn’t even a ‘thing’ that people talked about. They thought that it would make a difference and suggested it would not only affect the way they saw themselves but the way that others viewed them as well: “You’d act different and people would just think you’re a strange person…if there wasn’t such a label they’d just think you’re weird and then it’d give them an even better excuse to bully you.”

Many of the participants’ responses seemed to reflect the meaning I had attempted to communicate, but with arguably a greater level of profundity and insight than I was able to achieve. A level of insight, perhaps, that can only be achieved by a true insider.

While at times the participants found it difficult to fully relate to, or at least respond to, some of my feedback, as I have noted, I did not see this as an inherent problem, but rather as adding to the richness and authenticity of the participants’ responses. Furthermore, and though it is clearly subjective, it was my perception that participants genuinely valued the opportunity to comment upon and critique my analysis. In this sense, it was less about the specific responses the participants gave, and more about the process of feedback itself. I was able to continue the process I had aimed to initiate in the original focus groups, where, through their active participation in the research, the participants were offered alternative discursive locations (albeit temporarily), and as such were given the opportunity to explore new ways to speak and act. The process also goes some way to addressing my broader research aims, such as maintaining an emphasis on research *with* as opposed to *on* participants, and aiming to remove the “glass subheading”, described by Milton and Bracher (2013, p. 64), where autistic participant contributions to autism research are often treated as data to be analysed by non-autistic researchers, rather than material upon which to mutually reflect and explore.

# Implications

As with any FDA, my *Analysis and Interpretations* chapter contains considerable reference to research literature, akin to the Discussion section of a more traditional qualitative research study. This chapter will further develop some of the ideas raised within the *Analysis and Interpretations* chapter, with a particular emphasis on role identity and subjectivity, and the wider implications for professional practice.

## Reflexivity

Although I have been clear throughout that my aim is not to try and replace medical models of autism, if we support the idea of accepting autistic difference as described in the previous chapter, then we need also to question the modes of discourse that have tended to inhibit such thinking. It certainly seems that a simplistic understanding of autism as a triad, or now dyad, of impairments (see, for example, Wing, 1996) and a rigid adherence to positivist, personal-deficit models of autism cannot possibly do justice to the depth, variety, complexity and profundity of the autistic experience as displayed within insider accounts. As well as fundamentally reframing the way in which we think of autistic individuals, and the way in which we talk *to* them and *of* them, it again prompts us to reflect upon our own empathy deficits as professionals (and non-ASC individuals generally).

 While discourses of neurodiversity, and of accepting autistic difference, are central to my analysis, it is not contradictory to say that my analysis also begins to build upon a wider discourse that does not position ASC individuals as ‘distinct others’, but rather as individuals who share a great many cognitive and emotional similarities to those without a diagnosis. One way to conceptualise this would be to think not of an *autistic* spectrum, but rather of a spectrum upon which every human being falls, one end of which is categorised as ‘the autistic part’. As noted in the introduction, Hacking (2009a) suggests that the genre of autism fiction plays a crucial role in this blurring of the line between ‘the autistic’ and ‘the neurotypical’, and in developing a new language with which to talk of (and think of) those on the autistic spectrum. The great irony is that, when readers fail to appreciate the cognitive parallels between themselves and the autistic characters, it is not due to the deficits or impairments of the characters portrayed, but a rather those of the reader. So why, then, should the onus be placed solely upon the autistic individual?

 If someone fails to make a ‘connection’ with an autistic individual, then they have been unable to empathise just as much as the other way round. As McGeer (2009) argues, we (as professionals) do not directly perceive the subjective experience of ASC individuals any more than they perceive ours. In other words, if they are ‘blind’ to our minds, then we, too, are blind to theirs. In ‘*The Reason I Jump: One Boy’s Voice from the Silence of Autism’* (Higashida, 2013), 13-year-old author Naoki summarises this with an almost effortless elegance, as he posits, “one of the biggest misunderstandings you have about us is your belief that our feelings aren’t as subtle and complex as yours”. Not only does he highlight our own inherent preconceptions when relating to those on the autistic spectrum, but in so doing, displays (possibly inadvertently) a remarkable level of insight and understanding (and empathy?) of his own. As David Mitchell – renowned author and himself a father to an autistic son – writes in the foreword, “[Naoki] unwittingly discredits the doomiest item of received wisdom about autism”.

 There have long been calls from within the autistic community for such a change in perspective amongst professionals and researchers. One notable example is a piece written by Jim Sinclair (1993), entitled *‘Don’t Mourn for Us’*. In it, he talks of the great ‘tragedy’ that neurotypicals perceive autism to be, and the grief felt by parents as they come to realise that their child will never be quite as they had expected or hoped for. He suggests, however, that the problem lies not with the autistic individual but with the world in which they come to find themselves, and the inability of those around them to attune to their social reality and to accept them as they are. Perhaps, then, the onus is now with us (as professionals and as ‘outsiders’) to reflect upon our own social limitations in order that we may be able to better tolerate our own insecurities and respond more appropriately to the social and emotional reality of the autistic individual, and the identities they forge.

## Identity

There has been much discussion throughout this research regarding the re-positioning of an *empathy deficit* in the more neurodiverse terms of an *empathy difference*. Indeed (as discussed in the *Analysis and Interpretations* chapter), from within a discourse of neurodiversity, autism itself may be regarded as a difference to be respected as opposed to a deficiency to be repaired or counteracted (Silberman, 2010). I previously suggested that the categorisation and labelling of autistic individuals is based on a very specific understanding of autism, defined by the medical and the deficit-model discourses that have come to be dominant within the field. While I stand by this, it seems to be the view of most prominent autistic self-advocates that it is not the diagnosis itself that is the issue, but rather the negative perceptions this diagnosis tends to connote (Owren & Stenhammer, 2013). As Sinclair (1993) writes, “it is only when a characteristic is deemed as negative that someone would wish to separate themselves from it – but autism is not negative”.

 Indeed, for many autistic self-advocates, autism is not something a person *has* but something they *are*: they wear their label as a “badge of honour” and see it as the thing that makes them unique (Moore, 2008). They reject society’s rhetoric of “how do we make people with autism behave more normally?” and indeed have no desire to become ‘less’ autistic (Silberman, 2010). There are those who take a different stance and prefer not see autism as an inseparable part of the self, but rather one small part of their make-up, which can be controlled: “I can fight autism” (Williams, 1995). However, regardless of the stance taken towards their label, the constant theme is the desire not to be defined solely in those terms. While this may be seen as somewhat incompatible with the idea of wearing autism as a ‘badge of honour’, I would argue that – as with membership to any group, be it social, ethnic, religious, or otherwise – one is likely to hold the apparently incongruous views of, on the one hand, pride at one’s membership to that group and, on the other, the desire not to be defined solely in those terms. As Timimi et al. (2011) argue, to open up a constructive approach to those who attract the autism label, unless it is found that this diagnosis has any clinical value, we must first remove the artificial distraction created by such a limiting approach to these people’s lives.

One caveat to this discussion is the acknowledgement of the broad variance of need across the spectrum, something about which, as noted, the participants themselves seemed to be highly aware. The neurodiversity movement has previously been criticised for being of relevance only to the ‘high-functioning’ end of the spectrum, and has drawn controversy in the past on the grounds that some of its high-functioning proponents seem to oppose the amelioration of deficits (Tincani et al., 2009). While there may be some validity to this claim, I would argue that this is a largely subjective interpretation of a culture that celebrates autism and opposes efforts to attempt to eliminate it. While discourses of neurodiversity do tend to oppose interventions that aim to eliminate unusual but harmless behaviour, such as avoiding eye contact or repetitive body movements (Kapp et al., 2012), they certainly do not preclude the remediation of certain vulnerabilities. This may involve, for example, employing behaviourist-inspired approaches but, rather than incorporating them into an all-encompassing system of ABA, using them more selectively to, for example, teach certain skills, or reduce self-injurious behaviour (e.g. Tiger et al., 2009). Certainly most emerging literature suggests that leaders of the neurodiversity movement do acknowledge the vulnerabilities of ASC individuals and support some interventions to accommodate the individual affected (Savarese & Savarese, 2010).

 Regardless of where an individual may be positioned on the spectrum (or what might be termed *symptom severity*), the traditional medical model view – that, as a result of these differences/deficits, the reduction in opportunities for participation and inclusion is an unfortunate but unavoidable result of autism – seems highly untenable. The UN’s Convention on the Rights of Persons with Disabilities (2006) distinguishes between ‘impairment’ (though this would not be my choice of language) and ‘disability’, stating that disability results from the interaction between those with an impairment, and attitudinal and environmental barriers imposed upon them. In other words, participation may be improved just as effectively by the reduction of environmental barriers as by the amelioration of one’s ‘deficits’. This social model of disability implies a principle of ‘universal design’, and while it may be implausible to think we can entirely modify the social structures that turn some impairments into disabilities (Barclay, 2010), we should strive towards creating a physical environment that, in so far as is possible, is equally accessible to all.

## Environment

While universal design for those with a physical disability is likely to focus upon increased access, the emphasis for ASC individuals is likely to be on accommodating for certain hyper- and hypo-sensitivities (Bogdashina, 2010). First-hand accounts of autism give us very powerful illustrations of the atypical and, at times, bewildering experiences of sensory stimuli. For example, a number of studies involving the active participation of ASC individuals identify sensory factors such as crying children, mobile phones and the smell of perfume as potential barriers to accessing public transport and, as such, to the equal participation of autistic individuals within society (Ryan & Räisänen, 2008; Madriaga, 2010). Similarly, autistic author Gunilla Gerland recalls a time when she was at school and a teacher asked her to use an electric saw. She perceived the saw as deafening and dangerous, and talks of how it hurt her inside, and made her lose all sense of direction (Gerland, 2003). Stephen Shore, who has written at length about the idea of hyper- and hypo-sensitivity, highlights the idea that, while many autistic individuals experience a sensory overload, others receive such negligible sensory input for it to be almost imperceptible (Shore, 2003). Williams (2005) describes a sensory difficulty where – while most people are able to “use all of their senses simultaneously” (p. 96) – she feels that she is only able to experience them ‘singly’, which causes her great difficulty in making sense of her sensory and social world. Lawson (1998, p. 1) suggest that: “One of the best ways of understanding what Asperger’s Syndrome is like is to imagine yourself as a perpetual onlooker. Much of the time life is like a video, a moving film I can observe but cannot reach.”

These accounts provide a vital, and otherwise unattainable, insight into the sensory processes of ASC individuals, and imply that society functions in an indirectly discriminatory manner towards its autistic citizens. However, an arguably greater obstacle than physical (or sensory) factors within the environment is posed by the prospect of interactions with ‘neurotypicals’. In a study by Beardon and Edmonds (2007), 83% of participants (all of whom had a diagnosis of autism) stated that they felt ‘strongly’ or ‘very strongly’ that many of the problems they faced were as a result of neurotypicals failing to understand their needs. This may be described as an attitudinal barrier to participation of autistic individuals within society and, again, prompts the neurotypical to question how we understand and respond to the behaviours with which ASC individuals present. Insider accounts invite neurotypicals to explore our own limitations and our seeming inability to accept naturally-occurring difference. Perhaps, then, a useful categorisation of neurotypicals would be the one suggested by an autistic participant in a study by Hurlbutt and Chalmers (2002), who states: “One of my friends divides neurotypicals into two categories: high functioning, such as yourself, and low functioning, who do not understand us”.

 There are clear messages here, not only for professionals and practitioners, but for every neurotypical who has, or ever will, come into direct contact with an autistic individual. Perhaps most pertinent is the suggestion that the seemingly unusual movements and behaviour of ASC individuals are not merely perfunctory rituals, but rather an individual’s very natural (albeit idiosyncratic) physical reaction to a specific internal state, representing anything from a cathartic act aimed at normalising an overwhelming sensory overload, to a joyous connection between the individual and their physical and social world. Viewed through this lens, such behaviours can be seen as a vital part of an ASC individual’s communicative repertoire, rather than being dismissed as mere ‘obsessions’. This begins to draw attention to the “unexceptional normality of doing things differently” (Hansen and Philo, 2007, p. 502), and it is my view that we must begin to value these ‘different forms of mind’ and see creating inclusive contexts for competencies as an integral part of our job. ASC individuals should be encouraged to pursue their own personal interests, and should be provided with sensitive and flexible support that meets their basic needs, but at the same time enhances their autonomy and independence. Part of this involves dispensing with our own personal experiences and understandings, which serve us well in our own lives, but in the context of interactions with ASC individuals, represent an uncritical use of neurotypical standards. In so doing, we recalibrate our attitudinal stance and thereby begin to deconstruct the attitudinal barriers to participation. Clearly this is a challenge, but it is necessary if we are to be truly non-discriminatory in our interactions with ASC individuals, and in the services we create to support them.

## Practice

If we favour interventions that celebrate difference and aim to promote idiosyncrasies in behaviour rather than remediate them – and, furthermore, acknowledge the inherent ‘uniqueness’ of each autistic individual – then it suggests that we should take an eclectic approach to practice. While there are consistent positive elements to interventions, such as intervening early and actively involving parents (Jordan et al., 1998), Schreibman (2004) concluded that, “there is no ‘one-size-fits-all’ treatment for children with autism...different children may benefit from different approaches” (p. 375). It follows, then, that irrespective of a diagnosis, intervention approaches must consider the specific profile of need of the individual, their cognitive strengths and difficulties, and the environments in which they are operating (Hulme & Snowling, 2009).

 One intervention that seems to provide a good framework around which to construct such an approach is TEACCH (Treatment and Education of Autistic and Communication-Handicapped Children) (Schopler, 1994). Despite the questionable nomenclature, this is a well-established global approach for young people that promotes the formation of a structured learning environment (rather than using specifically-structured learning tasks), is based on close collaboration between parents and professionals, and uses both organisational and visual supports to help the student with autism compensate for their difficulties in organisation, memory, auditory processing and managing change (Homewood, 2004).It generally involves physical organisation of the classroom into recognisable parts; a high level of scheduling to help students understand sequences of events and manage the concept of time; and predictable routines that make it easier for students with autism to process and manage their environment (Potter & Whittaker, 2001).

 There is no reason that, within this framework, aspects of, for example, ABA could not be incorporated. As Callahan et al. (2010) write, while ABA and TEACCH have different conceptual emphases, they are not theoretically opposed and therefore need not necessarily be used exclusively from one another. This is particularly true if one subscribes to broader definitions of ABA, which view it not merely as a system of ‘discrete trial’ training, but as an approach that incorporates a strong emphasis on functional communication, developed through approaches such as *PECS* (Picture Exchange Communication System) which emphasise the use of reinforcement, prompting, shaping, error correction, and other features of a behavioural orientation (Bondy, 2011). Again, there is no clear conceptual basis that would preclude, within an eclectic package of support, the inclusion of alternative approaches to developing communication. One such alternative is *Intensive Interaction* (Hewett and Nind, 1988), a form of communication based, initially, on a mirroring of the individual’s behaviour, from which the neurotypical is then able to develop a non-verbal dialogue based on the individual’s preferred styles of communication. It is an approach that accepts that we each have a unique way of interpreting our social world and suggests that we may be able to meet the autistic individual in their world by sharing in their experiences. It attempts to understand the ‘autistic world’ and promote rather than suppress idiosyncrasies of behaviour.

 A related approach here is *SMILE* (Seach, 2007) which, in essence, aims to develop **S**ocial skills and **M**otivation by allowing the child to **I**nitiate **L**earning so that they **E**njoy interaction with others. It recognises the importance of play in developing spontaneity, creativity and flexibility of thought (and suggests it should be encouraged and supported in all its forms), and asserts that an empathic relationship does not depend solely on a child learning to recognise the emotional states of others. Both SMILE and Intensive Interaction deviate from cognitive theories of empathy and ToM as a pre-requisite for interaction and, in keeping with the principles of ‘radical empathy’, promote mutual enjoyment through shared experience. They fit with emerging discourses of neurodiversity in that they embrace differences rather than attempting to categorise or curb them, and, rather than seeing ‘obsessive’ behaviours as a barrier to learning, see them as an opportunity to nurture interests and encourage interaction. With these kinds of approaches (and the underlying theory) as our dominant discourse, we might say that it is not that ASC individuals do not have ‘empathy’, but rather that, without interaction, they have no means of expressing it (Williams, 1998).

 In 1926, Lev Vygotsky wrote: “People with great passions, people who accomplish great deeds, people who possess strong feelings, even people with great minds and a strong personality, rarely come out of good little boys and girls” (p. 27). Ultimately, if we value producing autistic individuals who are more than “good little boys and girls”, but rather ones who are not only social, but unique and individual, and indeed have “great minds and a strong personality”, then we surely cannot rely upon rigid behavioural approaches alone. We must continue to seek interventions that are sensitive to interactionist possibilities and are less isolating to the individual (Billington, 2006), placing responsibilities for behavioural change not solely upon the autistic individual but upon ourselves. This is not to say that we cannot remediate certain vulnerabilities and use approaches that provide individuals with practical skills that allow them to function within their day-to-day environments. Rather, it is to say that it is not contradictory, and in fact highly logical, to also provide these individuals with support that accepts their difference and celebrates their uniqueness. Perhaps, then, the task of good clinical care is to take each individual’s and their family’s narratives into account, and find creative possibilities for change and for more hopeful potential stories that can emerge, instead of the stigmatising lifelong disability script a diagnosis can lead to (Timimi, et al., 2011). So our interventions must be multi-faceted and bespoke – comprising social and cognitive approaches alongside more behavioural ones – and must be tailored specifically to the needs of the individual. In other words, our approaches must be as subtle and as nuanced as are the individuals themselves.

## Subjectivity

What, then, are the wider implications of this for exploring autistic subjectivity? I have already addressed, at least to some extent, what can be felt and experienced by participants through the subject positions they adopt. But how may insider accounts and autistic self-advocacy also operate as a ‘technology of the self’ (Foucault, 1983)? In much the same way that ASC individuals have traditionally been portrayed as asocial, it is also typically assumed, presumably because they are often bereft of words, that they are bereft of subjective worldviews. The autistic self-narrative already interrupts dominant notions of competence and disability, and challenges our assumptions about difference and deviance from the norm. Sirota (2010), however, argues that these personal life narratives do something more:

*…they imbue human lives with culturally consonant order, contour, and form, linking remembered pasts and imagined futures, personal experience and social action, anticipated moments and bewildering uncertainties through a lens of collectively comprehensible mores and logic.* (p. 95)

Similarly, Polkinghorne (1988, p. 13) talks of narrative as constituting a “fundamental scheme for linking individual human actions and events into interrelated aspects of an understandable composite”, while Bruner and Feldman (1993) suggest that narrative structures scaffold thinking such as to allow meaning to be successfully linked to shared topics in discourse. Particularly in his later work, FoucauIt (e.g. 1994) emphasised that such narratives are formulated and shaped in the social context in which they are produced, and therefore operate in tandem with institutionally mediated systems of regulation. Perhaps, then, self-narratives offer autistic individuals not only a means for mere self-presentation, but a vehicle for the very expression of their highly subjective life worlds and, moreover, of their intersubjective attunement within their physical and social environment.

 Becoming the subject of one’s own biographical narrative may indeed be considered a quintessential tool for attaining a successful and well-adjusted life. Sirota (2010) argues that they allow us to order life events, recount past occurrences and anticipate imagined futures, to formulate and express a point of view, and to render experiences meaningful through a shared vocabulary of stances, motives and affective hues. Similarly, Frank (1995) suggests that giving voice to stories is a basic obligation that accompanies each and every life. From this vantage point, narratives of disability not only have the potential to disenfranchise, expand, and replace existing narratives with a broad set of alternative possibilities and choices, but also make visible the dynamic intersubjective practices that contribute to human subjectivity. They may act as a reflexive tool that affords the user epistemic authority as a social actor who is entitled to formulate and express definitive standpoints on life events. With reference to Foucault’s conception of subjectivity as a relationally mediated process, this viewpoint permits a broader consideration of the social and interpersonal matrices that produce, sustain and challenge attributions regarding impairment and divergence. Moreover, it facilitates robust portrayals of ASC individuals as they are regarded as subjects capable of holding meaningful and coherent portrayals of themselves and their lives. As Braidotti (1994, p. 141) asserts, “it is only when subjects have gained the right to speak or find a language to express their ontological desire to posit potential that they are able to discover a multiplicity of versions of the self, an alternative distribution of being”.

# Conclusions

In this final chapter, I begin by acknowledging some of the potential limitations of my study, and make suggestions as to how these have been addressed and mitigated. Following this, there is a discussion of potential implications for future research (implications for practice have already been explored in the previous chapter). I conclude with some final thoughts regarding the research project as a whole.

## Potential Limitations

One potential limitation of my study, which I have referred to throughout, is the heterogeneity of my subject sample and the differing abilities of my participants, particularly in the area of language understanding and processing. The nature of my study dictated the involvement of participants with some level of verbal ability, but I was non-specific as to the level this needed to be, and indeed there was great variance across the participant group. As noted, this resulted in a somewhat varied understanding of the questions, but certainly not to the point that it was disruptive to participation in the study. In part, I believe the designated age range of participants helped to maintain a level of homogeneity within the sample, and a sense of cohesion within the focus groups generally. This was supported by the general ethos and atmosphere of the focus groups, and the open and nurturing environment I aimed to create. Furthermore, the focus group questions (and indeed the feedback in the follow-up groups) were presented with a simplicity and succinctness such that they could be accessed by all participants, and so despite differing levels of understanding, they were able to engage with the material on at least some level.

 There is a potential counter to this in the sense that, even if it is accepted that the set-up of my study was not discriminatory towards the participants (or, at least, that I took a range of appropriate steps to guard against this), it may be said that the discourses to which I allude in my analysis, and the conclusions I draw from these, are only relevant to a specific sub-group of the autistic population, and that my research is therefore covertly discriminatory. As noted in the previous chapter, a number of researchers (e.g. Jaarsma & Welin, 2012) claim that many of the counter-dominant discourses prevalent within insider literature, such as the claims of the neurodiversity movement, are relevant only to ‘high-functioning’ ASC individuals. However, other researchers (e.g. Owren & Stenhammer, 2013) have sought to challenge this, and indeed the classification between high and low-functioning generally. For example, autistic self-advocate Amanda Baggs, often classed as low-functioning due to her idiosyncrasies in physical movement and the fact that she rarely speaks, is able, with the use of appropriate technology, to communicate her experiences quite eloquently (see Baggs, 2007). Similarly, Tito Mukhopadhyay, Indian poet and author, diagnosed in early childhood with severe or low functioning non-verbal [autism](https://en.wikipedia.org/wiki/Autism), has been able to convey, through the medium of poetry, profound and at times startling insights into his sensory reality. While clearly such self-expression is not going to be possible for all those on the autistic spectrum, it seems that, given the appropriate forum (as I hope the participants in this study were), and provided we are prepared to listen (as I feel I did), ASC individuals tend to find a way to communicate their views. Perhaps, then, the challenge for professionals and practitioners is to develop more innovative means through which ASC individuals can clearly and consistently express their views, regardless of verbal ability or ‘level of functioning’. In this context, the afore-mentioned discourses, such as those of neurodiversity, come to hold a more widespread significance.

Even if one accepts that my research has relevance to individuals across the spectrum, there is likely to remain questions around the *generalisability* of my results, and their direct applicability to the wider autistic population. Generalisability of results (or a lack thereof) is a common criticism of qualitative research studies, usually from those who are positioned within a different theoretical and methodological paradigm. Indeed most qualitative researchers aim to produce results that provide richness and depth, rather than direct generalisability to wider populations, and as such they would reject lack of generalisability as a valid criticism. I believe that the nature of my own research invalidates this criticism even further in that the data produced from my focus groups were supposed to reflect, and indeed add to, the emergent counter-narrative from within the autistic community. Any criticism that my research is overly-specific or lacks generalisability would be erroneous, since each contribution to this counter-narrative is necessarily unique to the individual who contributes it, each of whom are themselves unique, and with their own distinctive view of the world. So, while the results of my research may not be directly generalisable, they do add a significant increment to the body of related work which, in aggregate, provides great insight into the autistic experience.

I suggest that, using the qualitative research criterion of ‘transferability’ (see Robson, 2002), the reader themselves may judge what potential links might be sensitively made to other contexts and the extent to which constructs may be consistent with other populations. Since I, as the researcher, know only the “sending context”, and not the “receiving context” (Shenton, 2004, p.70), it is not possible for me to make transferability inferences. However, provided I have given sufficient contextual background to the generation of my interpretations, and drawn these in ‘thick’ descriptive terms (Geertz, 1973), the reader may decide the extent to which they believe their situation(s) to be similar to those described in the study, and, as such, how the findings relate to their own positions. Even if the reader does not find the interpretations directly relatable, it does not imply that either position is more or less valid. Rather, it may simply reflect that there are multiple realities of the phenomena in question, and, if an appreciation can be gained of the reasonsfor the variations, this understanding may prove as useful to the reader as the findings themselves.

A further potential limitation of my research centres around the tension between an inductive and deductive approach to the analysis and interpretation of my data. As is typical in qualitative studies, I aimed to take an *inductive* approach to enquiry: that is, beginning with specific observations, and gradually moving towards more generalised conclusions, thereby generating new ideas and understandings. One concern, or at least reflection, I had during the process of my analysis was the possibility that I was being more deductive and imposing my own preconceived schema onto the data, i.e. having certain ideas in mind of what I expected or indeed hoped to see, and then reading the data in such a way that these were borne out in my analysis. Again this is something that needs to be taken into account in almost all qualitative research, particularly when the researcher has a close personal investment in the area under investigation (as clearly in this case I do). With regards to this tension, I reiterate the position that I have emphasised in my methodology and throughout, which is that my background, beliefs and values are the very thing that drive my research, and are what makes it (I hope) a textured, meaningful, and ultimately individual piece of work. My interpretations are inescapably personal to me and so, as noted, it was not only about the words the participants spoke, but how those words in turn spoke to me. For this reason, I not only accept my inevitable positionality, but actively embrace it, and see my subjectivity as integral to the process of analysis. With the imposition of the appropriate reflective and reflexive rigours upon my own thinking, and upon the process of knowledge production within this research (which I hope I have demonstrated), I am then able to adopt a position where “the knower is part of the matrix of what is known” (DuBois, 1983, p. 63).

 Though I do not have the space to discuss it in detail here, my enquiry may be said to adopt the theoretical middle-ground of *abduction*, where categories of analysis are developed in accordance with the research question, and the researcher oscillates between theory and data in retroductive ways (Wodak & Meyer, 2009). In this middle-ground, one is able to draw informed conclusions based on a set of observations and the pre-existing information one has available, generating new ideas and knowledge that can then be further tested and explored. My analysis thus remains grounded in the transcripts, without representing absolute comprehensive coverage. Indeed it was never my aim to achieve the theoretical saturation of, say, a grounded theory methodology, in which the transcripts are analysed and re-analysed until no further meaning can be drawn from them. On the contrary, I openly accept that another person’s perspective may have been very different from my own and would certainly welcome further inspection and analysis of my transcripts. Indeed, I believe that discussion around the issues raised, and the understandings of the counter-narrative to which I refer, would be all the richer for it.

## Future Directions

This final point represents one potential future direction with regards to this research in the sense that, in the same way that my transcripts could be re-read and re-analysed (and, from this, new understandings and insights created), so new research may be undertaken. From a personal perspective, it would be interesting to carry out follow-up with the same participant group. My research was necessarily a ‘snapshot’ from a particular moment in time, and attempting to understand how participant responses may vary across different stages in their development strikes me as a more than worthwhile venture. Other researchers carrying out research with a similar foundation and orientation may wish to adopt a different methodological set-up and alternative forms of data collection. Equally, future research could involve a different area of focus as a start-point. My own research used empathy, and more specifically the concept of an empathy deficit, as an initial platform, and from this built towards a wider set of interpretations and conclusions. It would be interesting to explore how, by beginning from a slightly different start-point (say, for example, the emphasis placed on eye contact, or the apparent lack thereof, in ASC individuals), the direction of the study would be changed, and consequently new opportunities opened up for different meanings to be uncovered.

If one were to retain empathy (or the empathy deficit) as a start-point, then perhaps an alternative question to focus on would be: why does empathy, as a concept, hold so much currency in today’s society? It is a word that people (including myself) bandy around quite freely, and one that is often presented as the pinnacle of personal virtues to which we should all aspire. However, as we have seen, there is no single definition of empathy and it is often used as a catch-all term to refer to a range of different attributes. It is unlikely, then, that when we talk of empathy we are actually talking about exactly the same thing. Furthermore, and as I hope my research has gone some way to illustrate, for certain sub-groups (such as the autistic population), traditional definitions of empathy seem rather inadequate. In these cases it seems appropriate to dispense with such a term, and indeed in doing so, I would argue, we are provided with a much richer description of an individual’s emotional world.

What, then, is the future for empathy? Krznaric (2014), while extolling the virtues of empathy, and of a society in which it is in plentiful supply, suggests approaching it with a degree of caution:

*Let’s not, however, be naïve. Empathy is not a universal panacea for all the world’s problems, nor for all the struggles we face in our own lives. It’s important to be realistic about what empathy can and cannot achieve.* (p. 28)

It seems, then, that while empathy is a powerful concept, and one that carries great weight within society, there may be benefit to imposing a greater level of criticality and problematisation within research. It may also be beneficial to approach this research cross-culturally and explore the extent to which empathy is exhibited differently cross-culturally. Indeed, if we accept that autism is itself a discrete culture, then such research may provide a model for understanding the empathy differences exhibited in autism.

Furthermore – though for my own research I feel a Foucauldian-inflected discourse analysis was apt, and have justified this throughout – alternativee forms of data analysis are available. For example, approaches derived specifically from Narrative Thinking (White, 1995) may help us to further support ASC individuals to voice the rich stories of their lives – thickening accounts of success and strength, while diminishing stories of lack – and allow us to further recognise, acknowledge, and utilise, in more creative and explicit ways, the expertise that they can bring (Wagner, 2008). Indeed, I drew upon this kind of approach in asking my focus group questions where, as discussed, I attempted to be the “almost invisible facilitating catalyst to their stories” (Hollway and Jefferson, 2000). Alternatively, an Interpretive Phenomenological Analysis (IPA) may allow us to tap in more directly to the moment-by-moment experience of ASC individuals, and further explore associated subjective and intersubjective processes. Indeed, the primary aim of IPA, according to Conrad (1987), is to explore the participant’s view and to adopt, as far as possible, an ‘insider’s’ perspective.

This provides only an indication of the alternative avenues of research that may be trodden, and it is by no means intended to be prescriptive. Indeed it may be appropriate in future research to take a *bricolage* approach to methodology that involves “taking research strategies from a variety of scholarly disciplines as they are needed in the unfolding context of the research situation” (Steinberg, 2006, p. 119). This would allow researchers to borrow from a variety of toolboxes in the search for rich meaning, much as I have borrowed from Foucault’s toolbox, without conducting a strict FDA. Furthermore, and again as was my own intention, this would disrupt the dominance and authority of methodology in research (Curt, 1994) in favour of relevance and utility.

 It should also be noted that future research need not be limited to qualitative enquiry alone. The area of neurophysiological research, for example, is a burgeoning one, and one that clearly requires further study. Indeed research of this kind, and the production of empirical data generally, should help to consolidate (or indeed challenge) the medical and biological grounds upon which dominant discourses in autism tend to be based. It may also help to elucidate certain anomalies or conflicts that arise within the literature. For example, some research (e.g. Sigman et al., 2003) has previously indicated that affective empathy in ASC may be heightened as compared to cognitive empathy; whereas in my own study, there was a strong emergent theme of the reverse: participants intrinsically understanding feelings but struggling to understand how to explain or respond to these. Though my research has taken an exclusively qualitative approach to enquiry, I certainly recognise the value of quantitative research and believe that, ultimately, each paradigm is likely to feed into and complement the other.

Ultimately, what does seem clear is that there is a strong claim for the active contribution of ASC individuals within autism research and indeed within qualitative disability research generally. There is a prevalence of exclusion of ASC individuals in contemporary research, and the agenda of most autism research continues to be centred around cause location, behaviour modification, and ‘cure’ searching, all within a rhetoric of scientific evidence-based discourse (Post et al., in Mills et al., 2012). However, examples of participatory action research and good inclusionary practice do exist (Milton and Bracher, 2013). For example, self-advocacy organisations (such as *Autism Speaks*) and research bodies (such as AASPIRE, *Autism Asperger Partnership in Research and Education*) are leading the drive to support research that is relevant to the needs of adults on the spectrum (Nicolaidis et al., 2012). Milton and Bracher (2013) suggest that the “inclusion of autistic people as *equal participants* [italics added] can help to enrich the research process and guard against deterministic designs and interpretations” (Milton and Bracher, 2013, p. 63). Furthermore, if autism research is to be less offensive to the autistic community, and less alienating to them in the process of knowledge production, there needs to be a greater level of attunement, understanding (and empathy?), and a significant shift from tokenistic practices to meaningful involvement of autistic people in understanding autism.

 It may also be apposite, moving forward, to consider the alternative streams through which data (in their broadest sense) may be gathered. Increasingly, members of the autistic community are taking to internet forums and social media to express their views and talk about their experiences of autism. Davidson (2008) suggests that, through online communication, ASC individuals are “freed from constraints of neurotypical timing, neurotypical ways of interpreting body language, free from the information overwhelm of eye contact, and the energy demands of managing body language” (p. 801). Online environments are only one way of facilitating communication, and indeed one should be wary of colluding with the dominant discourses that perpetuate subject positions where ASC individuals are assumed capable only of inhabiting, and communicating through, detached ‘computer-game’ worlds. However, they do provide a hub of mutual support, group bonding, and even the creation of an autistic culture, and indeed were reported to be the foundation of the friendship of the participants in the second focus group (see p. 45). As such, online communities must surely be seen as a vital resource for understanding the autistic experience, and one that cannot be left untapped.

Indeed other forms of media, such as TV and film, are increasingly proving to be a vital platform for more accurately depicting the autistic experience, and indeed communicating this to a wider audience. Be they characters who are explicitly acknowledged as autistic (see, for example, Asa Butterfield’s character in the film *X+Y*), or those who are not, but seem to display autistic traits (see, for example, Saga Noren in *The Bridge*), there is a growing array of sensitive and well-rounded portrayals available to us. While there is no suggestion of side-stepping the associated difficulties they encounter, there is some sense that these are embedded within a framework of alternative strengths and abilities. There seems to be scope for analysis, here, into the extent to which such depictions are, for example, able to destigmatise autism, debunk societal misconceptions, and propagate more accurate understandings of the broad variance of need across the spectrum. It may also be a worthwhile venture to analyse audience (and specifically insider) responses to these depictions, and the emancipatory potential that these depictions may hold (see, for example, “*How The Bridge's heroine became a role model for women with autism*”, BBC website). More speculatively, one may attempt retrospective analyses of well-known characters from fiction and film who seem to display traits of autism, such as *Sherlock Holmes*, or Mr. Darcy from *Pride and Prejudice* (autism-help.org), or comparative analyses of the way in which these characters were perceived and understood, between then (before the concept of autism existed) and now.

## Concluding Comments

*“Words are but the vague shadows of the volumes we mean.”*

Sister Carrie (Theodore Dreiser, 1900)

The primary thought that strikes me as I write these final words is whether, in the preceding pages, I have truly been able to capture the full extent of the meaning I have sought to convey, or, and perhaps more importantly, whether I have been able to fully reflect the wealth of meaning that the participants sought to communicate to me. That being said, I do feel that there is a great deal I have achieved in this research.

 For example, I have taken on the not insignificant task of tackling autism, a highly-disputed territory within which a broad and disparate array of discourses are available. I have attempted to navigate this territory with fairness and balance and, in so doing, make clear the foundation on which my research is based. However, particularly as the research has progressed, I have been clear about my positionality within this, and made clear my belief that our understanding of autism may benefit from a counter-cultural critique. I have produced a piece of research that is reflective of some of my core values and is faithful to the principles that guide my own practice. It is also a piece of research that stays true to my ideals of inclusion, empowerment and emancipation, and one that, I feel, is reflective and augmentative of the agentic resistance from within the community in the way I set out to achieve.

The research also reflects a personal journey on my part, and I can genuinely say that it will better me as a researcher, a practitioner and as a person. I have learned a great deal about research methodologies and about the importance of ethical practice, and was able to design, organise and facilitate focus groups which, in themselves, represent a great personal achievement for me. Furthermore, I learnt a great deal about autism as a construct and how I understand it, and though I had a good idea as to the direction my research would take, there was a great deal that was unexpected for me, as is the nature of true exploratory research.

To try and then capture all of this within a highly-structured written format is by no means straightforward. It is my hope that some of the non-traditional ways in which I have chosen to present my research (such as the structure of my analysis and interpretations) goes some way to addressing this, and indeed I hope that the justification for making these decisions has been clear throughout. This being said, I have still presented the research in a way that adheres to the conventions of good practice. I have been honest about my process and clear that my research has not always proceeded in a simple linear fashion. I have been transparent about the decisions I have made and the reasons for doing so, and aimed to provide consistent reflective and reflexive insight. I have also (I hope) been coherent in my writing and ensured that the inter-connectivity of the various strands of my research has been maintained. Furthermore, and perhaps most importantly, I have rigorously and consistently sought to answer the all-important “so what?” question of my research.

Ultimately, perhaps it is the case that my words are “vague shadows of the volumes” that I (and my participants) sought to convey. However, I feel I can also say that I have achieved a great deal, not only in deconstructing (and reconstructing) the notion of an empathy deficit and challenging some of the dominant discourses within autism generally, but in providing an authentic representation of the autistic voice and, in so doing, beginning to offer alternative (more emancipatory) terms in which to speak of, and ultimately think about, those on the autistic spectrum. I hope this is a feeling that is shared by the autistic individuals for whom this research is written.

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# Appendices

## Appendix 1 – Ethical Approval



## Appendix 2 – Information Sheets



**Pupil Information Sheet**

Hi,

My name is Rob Begon and I am a student at the University of Sheffield. I am doing some research about the feelings of young people who have a diagnosis of autism. I would like to invite you take part in this research project, but before you decide please read the following information carefully, and talk to a teacher or your parents about it if you like.

I am going to use two small groups (3-4 people in each) and I will ask some simple questions about your day-to-day life. If there are too many people who want to take part I will have to choose randomly. I will record the sessions using a voice recorder but I will be the only one to listen to the recordings and they will be deleted once I have written it all down. I won’t use anybody’s names when I write things up so no-one will know who said what. I would like to meet up again when I am writing up my results so you can let me know what you think. Once my research has finished, I will let you and your parents know where to find it.

It is completely up to you whether you would like to take part in this research but your parents will have to sign to say that it is ok. You should speak to them about it before you both decide. I know it might feel awkward to talk about things in front of you friends, but I hope it will be a really enjoyable and interesting experience. Even if you agree to take part, you can change your mind at any time and you don’t have to give a reason. I will be coming into school soon so we can talk about this research and so you can ask any questions that you might have. If you need any more information you should speak to your parents and ask them to contact me.

Thanks,

Rob.



**Parental Information Sheet**

Dear Sir/Madam

My name is Rob Begon and I am a 2nd Year Doctoral student of Educational and Child Psychology at the University of Sheffield. I am currently undertaking a research project that aims to look at ‘insider’ accounts of autism (that is, individuals with a diagnosis of autism talking about their own experience) to provide a new perspective on the idea that autistic individuals struggle to recognise and respond to emotions.

I would like to invite your son/daughter take part in this research project. Before you decide, please take some to read the following information which will give some additional information about what the research will involve.

It is often assumed that individuals with autism are somehow emotionally-detached; that they have what is known as an *empathy deficit*. However, I have seen many examples (as I am sure you have) where people with autism area able to demonstrate great levels of emotional understanding and sensitivity. While they may process emotions *differently*, and may at times struggle with complex and rapidly-changing social environments, using the term ‘deficit’ implies something negative. Should their uniqueness not be celebrated? Furthermore, why should the onus be placed solely upon them? If someone fails to make a ‘connection’ with an autistic individual, then they have been unable to ‘empathise’ just as much as the other way round.

I am planning to conduct two small focus groups (3-4 individuals in each) with young people (aged 11-19) diagnosed as being on the autistic spectrum. I will ask questions relating to their everyday emotional experience (such as, "Do you find it easy to understand how other people are feeling?) and ask them to speculate on some hypothetical everyday scenarios (such as, "How do you feel your mum/dad would feel if you got them something nice for their birthday?"). If there are an excess of individuals who wish to take part then participants will be selected at random from the completed consent forms (please see attached).

I will record the sessions using a voice-recorder, but I will be the only one to listen the recordings and they will be deleted once they have been transcribed. All information will be completely anonymous and confidential, unless there are concerns about a situation where a child may be at risk of harm. There is also a possibility that anonymised information will be used in a published article based on the research. I hope to meet up with participants during the analysis of my focus group transcripts to get their feedback on my interpretations. Once the research has been completed, all participants and parents will be notified as to how they can access it.

Both yourself and your son/daughter will need to give consent if you wish for them to be involved. Taking part in this research is entirely voluntary and it will be important to discuss this with your son/daughter (who will receive a similar information sheet) before deciding. I certainly understand that it may be difficult for your son/daughter to talk about their experiences. Every effort will be made to ensure that they feel as safe and comfortable as possible, and it will be made clear that they can withdraw at any point without giving a reason. My hope is that taking part may in fact be an enjoyable and empowering experience for them. Furthermore, the results may have implications for how we talk of, support and, ultimately, think of individuals on the autistic spectrum. I will be coming into school to give you an opportunity to discuss this research further, and to answer any questions or queries you may have before signing the consent.

This research project has been ethically reviewed by the Education Department’s ethics review procedure at the University of Sheffield. If you require any further information, please do not hesitate to contact either myself (rbegon1@sheffield.ac.uk) or my research supervisor (t.billington@sheffield.ac.uk).

Many Thanks,

Rob Begon.



**Staff Information Sheet**

Hi,

My name is Rob Begon and I am a 2nd Year Doctoral student of Educational and Child Psychology at the University of Sheffield. I am currently undertaking a research project that aims to look at ‘insider’ accounts of autism (that is, individuals with a diagnosis of autism talking about their own experience) to provide a new perspective on the idea that autistic individuals struggle to recognise and respond to emotions.

I would like to invite the pupils at your school to take part in this research project. Before you decide, please take some to read the following information which will give some additional information about what the research will involve.

It is often assumed that individuals with autism are somehow emotionally-detached; that they have what is known as an *empathy deficit*. However, I have seen many examples (as I am sure you have) where people with autism area able to demonstrate great levels of emotional understanding and sensitivity. While they may process emotions *differently*, and may at times struggle with complex and rapidly-changing social environments, using the term ‘deficit’ implies something negative. Should their uniqueness not be celebrated? Furthermore, why should the onus be placed solely upon them? If someone fails to make a ‘connection’ with an autistic individual, then they have been unable to ‘empathise’ just as much as the other way round.

I am planning to conduct two small focus groups (3-4 individuals in each) with young people (aged 11-19) diagnosed as being on the autistic spectrum. I will ask questions relating to their everyday emotional experience (such as, "Do you find it easy to understand how other people are feeling?) and ask them to speculate on some hypothetical everyday scenarios (such as, "How do you think your mu/dad would feel if you got them something nice for their birthday?"). If there are an excess of individuals who wish to take part then participants will be selected at random from the completed consent forms (please see attached). I am also hoping to conduct a pilot focus group and again participants will be selected at random from those remaining after the initial selection.

I will record the sessions using a voice-recorder, but I will be the only one to listen the recordings and they will be deleted once they have been transcribed. All information will be completely anonymous and confidential, unless there are concerns about a situation where a child may be at risk of harm. There is also a possibility that anonymised information will be used in a published article based on the research. I hope to meet up with participants during the analysis of my focus group transcripts to get their feedback on my interpretations. Once the research has been completed, all participants and parents, as well as yourself, will be notified as to how they can access it.

Taking part in this research is entirely voluntary and will only go ahead with signed consent forms from parents and pupils. I certainly understand that it may be difficult for your pupils to talk about their experiences. Every effort will be made to ensure that they feel as safe and comfortable as possible, and it will be made clear that they can withdraw at any point without giving a reason. My hope is that taking part may in fact be an enjoyable and empowering experience for them. Furthermore, the results may have implications for how we talk of, support and, ultimately, think of individuals on the autistic spectrum. I was hoping to come into school on to give parents and pupils an opportunity to discuss this research further, and to answer any questions or queries you may have before they sign the consent.

This research project has been ethically reviewed by the Education Department’s ethics review procedure at the University of Sheffield. If you require any further information, please do not hesitate to contact either myself (rbegon1@sheffield.ac.uk) or my research supervisor (t.billington@sheffield.ac.uk).

Many Thanks,

Rob Begon.

**Pupil Consent Form**

Name of Researcher: Rob Begon

Institution: The University of Sheffield

Course: Doctorate of Education and Child Psychology

Please initial box

1. I confirm that I have read and understood the information sheet provided and

 have had the opportunity to ask questions.

1. I understand that my participation is voluntary and that I can withdraw at any time

 without giving a reason.

1. I understand that the focus groups will be recorded, transcribed anonymously and

Included within the research.

1. I understand that there is a possibility that anonymised information will be used a

 published article based on the research.

1. I agree to take part in the research project.

…………………………………………………… ……………………… …………………………………………

Name of Participant Date Signature

……………………………………………….. ……………………… …………………………………………

Name of Researcher Date Signature

**Parental Consent Form**

Name of Researcher: Rob Begon

Institution: The University of Sheffield

Course: Doctorate of Education and Child Psychology

Please initial box

1. I confirm that I have read and understood the information sheet provided and

 have had the opportunity to ask questions.

1. I understand that my son/daughter’s participation is voluntary and that I/they

 can withdraw at any time without giving a reason.

1. I understand that the focus groups will be recorded, transcribed anonymously and

Included within the research.

1. I understand that there is a possibility that anonymised information will be used in a

 published article based on the research.

1. I agree for my son/daughter to take part in the research project.

…………………………………………………… ……………………… …………………………………………

Name of Parent/Guardian Date Signature

……………………………………………….. ……………………… …………………………………………

Name of Researcher Date Signature

## Appendix 3 - Focus Group 1 Transcript

R: Facilitator (me)

J: Participant 1

T: Participant 2

I: Participant 3

\*Before the recording was started I introduced myself and briefly explained that, as part of my course, I needed to do some research, and that I had chosen to do it about “feelings”, both one’s own feelings and other people’s.

R: So first of all I wanted to try a bit of an activity as a group […] so the question is: if you crash-landed in a jungle, and you guys were put in charge, what rules would you come up with to make sure everyone could live together and be happy?

J: Never panic

R: That’s a really good one isn’t it. So everyone should stay calm and not panic

J: Yeah

T: Try and protect yourself

R: Yeah that’s a really good one as well

T: And don’t complain while crashing land

R: Yeah I like those, yeah

J: And make sure you’ve packed the right stuff even though you were heading to a hot place too, not like a sightseeing place really

I: But there are things to see on a desert island

R: Oh yeah there’d be lots of nice things

I: Like what?

R: Oh erm […] well palm trees and waterfalls and beaches

J: sounds like a paradise!

R: Yeah, there might not be too much water to drink, that could be a problem

J: Yeah or it might just be an oasis maybe or you might come across a mirage

R: So maybe some people in the group would have to go and search for food and water

J: Yes and if you bump into them really then they disappear like magic

I: I hope there’s no-one that eats people

R: Oh yeah me too

J: That might be a mirage maybe

R: So what’s a mirage, is that where […]

J: Well if you bump into something […] if you feel […] when you think you see something and when you get closer it disappears […] I think it’s like the Sahara magic that does it really

R: Ok great. So what were our three rules, we said […]

J: Never panic

R: Never panic

[group pause]

R: What else do we think? […] hmm [looking towards T] don’t complain?

T: Don’t complain, that’s right

J: Remember you’ve packed the right stuff maybe in case you’re going to a sightseeing place and it was wrong

R: Ok, are we happy with that guys as the third rule?

T: Yeah

R: Cool, well I think they’re three really good rules, I think everyone would be really happy with those […] Ok so we’ll crack on with some of the questions about feelings now […] so the first thing is, if someone mentioned feelings, what would you think that meant?

[group pause]

I: Say it

R: What would you think they meant if they said feelings, what would

I: Can you say it?

R: Do you want me to ask you the qu-

I: I want you to say the word

R: Feelings?

J: Or maybe they’d want you to explain how theyr- you’re feeling maybe […]

R: And what does that mean, “how you’re feeling”?

[long group pause]

R: It’s quite a tough one isn’t it […] are there different kinds of feelings? […] What kinds of feelings can you have?

I: Happy

J: Furious

I: Sad

R: Furious, happy, sad (…) they’re really good ones

T: And […]

R: How might you feel (…)

T: [whispering] Angry

J: Disappointed

R: Wow yeah these are really good ones

I: Scared

J: Amazed

R: Wow yeah brilliant […] anything else? It seems like you’re on a bit of a roll now!

J: Moaning

I: Well moaning is something you do more than a feeling

J: Yeah could be

T: Complaining

R: Yeah I suppose you could feel a bit moany and complainy you’re right

J: And you might go sad a little bit maybe

R: Yeah they’re some really good words I like those […] and do you guys find it easy to describe how you’re feeling […] if someone says “how are you feeling” do you find it easy to tell them?

J: [shakes head]

R: You’re shaking you’re head […] so you don’t find it easy to tell people how you’re feeling?

J: [continues to shake head]

R: Why’s that

J: [long pause]

R: So if I said how are you feeling right now, what would you say to me?

J: [long pause, looking away with arms folded, suggesting he wasn’t keen to speak]

R: What about you guys, if someone said how are you feeling […]

T: Yeah you know when (…) when the school children are having a difficult time they can […] they get upset and […] you know […] a bit tensed […]

R: Yeah

T: Is tensed a […] is tensed […] is that a

J: That means angry maybe or furious maybe […]

R: Yeah tensed is definitely a feeling […] when you’re feeling all a bit anxious and

T: What does anxious mean?

R: Erm […] it just kind of means tense or feeling a bit scared maybe […]. [To I] What about you, do you find it easy-

[interrupted by walkie talkie going off in the room]

R: So do you find it easy to understand how other people are feeling?

J: Yeah

R: Are there times when it’s easier to understand how people are feeling do you think?

J: Sometimes maybe […]

R: So do you think if you went into a classroom now you’d be able to tell how people were feeling?

I: I know how I’m, I know how I’m feeling […] as a person […] but my face doesn’t know all the moves

R: Ok that’s interesting

J: It might be hard to describe [mentions another girl in school] because she doesn’t talk at all that much

R: Ok so it’s harder to tell how people are feeling if they can’t talk and tell you

J: Yes but some of the people in school have a like a little iPhone really just to talk really like their voice like [mentions boy in school] ‘cause he can’t talk at all so he needs to use like a touch screen really to ask him what he wants really […] he’s good at understanding though […] but he’s not good at talking though […]

R: Ok so he needs something to help him tell people how he’s feeling and what he wants

J: Yeah

T: Do you know something?

R: Go on

T: [Not entirely clear] Is sense of voice “feelings”?

R: Sorry could you say that again?

T: Is sense of voice vibration […] is that a feeling?

R: Oh that’s a good question […] well you might express your feelings by talking mightn’t you […] like we’re doing now […] yeah […] but that’s a really interesting question though

T: Is disenflamed?

R: Disenflamed? Wow, where have you heard that one?

T: Disenflamed means when you’re […] when you do this [seemed to mime the action of going from tense to relaxed]

R: Ah ok well that’s a good one, that’s new to me

T: That’s a very new feeling isn’t it

R: Yeah no that’s a really good one I’ll have to remember that […] And [to I] you said something before that was really interesting about […] you know how you’re feeling but sometimes your face doesn’t show it did you say?

I: Yeah

R: Can you tell me a bit more about that?

I: I can […] like […] my heart can tell […] like if I’m scared […] but my face doesn’t know when to smile or when to cry […]

R: Oh right […]

I: Or when to shout […] or when to be […] to show movements […]

R: Yeah

I: Another thing, and I don’t know if this counts as feelings but [long pause] but [long pause] I can’t acclimatise

R: You can’t acclimatise, ok […] so what do you mean by that?

I: I don’t know if I’m hot or cold […] my body will still react to it but I won’t be able to feel it

R: Ok

I: Say for example if I went outside in the snow on a really cold day with no clothes on […]

R: You wouldn’t know that you felt cold? […]

I: But I would still get frostbite and my body will still react to it but I won’t […] well I’ll know I’m getting poorly by it because you do know when you’re poorly […]

R: Yeah you do don’t you […] ok […] so that must be good for you at the minute with the hot weather, does that mean you don’t feel it?

I: Yeah but my body will still react

R: Yeah so you’d still get sweaty and need a drink […] ok well thank you for that, that was a really good description I liked that […] ok so here’s another question for you guys: if you saw your friend crying in the playground, what would you do?

J: We don’t really have […] we have two really […] just call it playground and the quad really

R: Ok so if you saw your friend crying in the playground or the quad what would you do?

I: I would ask why […]

R: Ok so you might ask them why they’re crying?

I: Yeah

R: That’s really nice yeah […] is there anything else you might do

[long pause]

J: Well once when I was at [names old school] a cheeky boy threw a gingerbread man at one of my old friends and I had to barge in and stop them really […]

R: Ok so you kind of looked after your friend?

J: Yes ‘cause he’s always picking on my old best friend really […] he was always picking on her

R: So you were looking after and protecting her?

J: Yeah ‘cause when he threw the gingerbread man I had to just jump on it and it blocked it then […]

R: Ah that’s really nice […] so there’s a couple of things you could do, you could go and look after them and protect them […] as ‘I’ said you could go and ask them what’s wrong

J: Well mostly […] the first time I had to run and get a tennis racket ‘cause he was really in a hurry when he just ran so I had to just throw the tennis racket and then the gingerbread man broke and then that teached him

R: Ok […] and what about if you’re friend had had some really good news, what might you do then?

J: Shake a little bit

R: Yeah, get excited

J: Sometimes when I’m excited my head shakes a little bit but mum said don’t shake it too much or else you’ll get a headache

R: [Laughs] Yeah [To T and I] and what about you guys, if you knew your friend had had some really good news and they came into school what might

T: They came to visit school you mean

R: Yeah they came to visit school and you knew they’d had some really good news, what might you do or say

J: Well like if a new student

T: You might do greetings […] meet together

J: I hope I can do it perfect for [mentions boy’s name] because he’s coming and he’s from my old Primary School really […]

R: Ok so there’s a new boy coming to school?

J: Yes

R: And what will you do when he gets here?

J: I don’t know really ‘cause it’s very hard to talk to Aaron

R: Is it?

J: Yeah

R: But are you gonna look after him?

J: Maybe […] ‘cause he might have some new changes maybe

R: Well yeah it’ll be a big change to come to a new school won’t it

J: Yeah

R: Ok […] so we’ll try a bit of a different question now […] so how do you think your mum and dad might feel if you forgot their birthday?

I: Sad

J: Friendless

R: Ah that’s a nice word yeah […] [to I] you said sad?

I: But why would any child forget someone they loved’s birthday?

R: Well some people

I: Have you ever forgot […] do you live with anyone

R: I do yeah

J: Well ‘I’ it’s like if someone invited everyone except for one person left that might make you feel a bit friendless maybe

R: Yeah […] so would you never forget anyone’s birthday

J: I never forget anyone’s birthday ‘cause I always know the dates really

R: What about you ‘T’ what do you think?

T: Erm […] you would feel like “I don’t know” […]

J: Confused maybe

R: They might be confused why you’d forgotten

J: No we might be confused

R: Oh ok you’d be confused […]

J: Or they might be confused why we didn’t turn up

R: Ok […] and what about if you remembered their birthday and bought them something really nice?

J: And forgot to give it to them?

R: No this is a different thing so imagine you bought them a present, you gave it to them, how do you think they’d feel then

J: I don’t know ‘cause I wouldn’t know if they’d like it or not

R: Yeah […] and what do you think ‘I’ ‘cause you said you’d never forget your mum or dad’s birthday […] so how do they feel when you get them something really nice for their birthday?

I: I don’t know […] I’d like to go back to class and do computing

R: Are we ok just to ask a few more questions? Is that ok?

I: Yes

R: Is that alright, and we’ll try and be as quick as possible?

J: I’m not bothered really

R: ‘Cause you guys are doing really well and I love some of the answers you’re giving and you’re thinking really well so that’s great […] especially for a Monday morning […] Ok so can you remember a time that you have made someone feel good?

I: No

J: Only when I stopped the bully from throwing the gingerbread man at my friend

I: Yeah that was a good one […] and what about you ‘T’, can you remember a time you’ve done something nice for someone or made someone feel good?

T: You make someone feel good if you make friends with them

R: Yeah

J: I hope it’ll be easy to make friends with [mentions boy he talked about earlier who is soon to start at the school]

R: So you’ll make him feel good by making friends with him?

J: It might […] well it might […] I don’t know if it’ll be easy making friends with him though […]

R: But you’re gonna try?

J: Yeah

R: Ok, and can you remember a time when someone has made you feel good […] someone’s done something nice for you?

[long pause]

R: What do you think guys […] can you remember a time when someone’s made you feel good

T: When you’re having you know when you’re having self-development and your future enjoyment and your consideration with someone who does your own enjoyment

R: Ok, so when someone enjoys the same things as you?

T: Yeah […] what do you think ‘I’ […] can you remember a time when someone’s made you feel good about something?

J: Sometimes if she gets a bit fed up she mostly has a bit of time out sometimes if she doesn’t want to join in that much

I: Back to class

R: You want to go back to class?

[‘I’ nods]

R: Ok that’s fine but thanks for coming that was great

I: Ok [‘I’ leaves]

R: Ok so […] can you remember a time when someone has hurt your feelings

T: You know something […] on your phone if you have a pass code and you don’t know it then if it’s disabled and broke apart you might get cross and like your mum and dad tells you off

R: Yeah definitely

J: If someone told your friends and they were flaming what was going on on me and they all turn up at me like […] they guys flaming me really

R: Ok could you tell me a bit more about that?

J: Like flaming means you know like someone’s pretending really to get someone else in trouble […] it’s like that really […] but there’s no flamers here though

T: Can I go back to class please?

R: Can we just do 3 more minutes?

T: Yeah

R: Ah thank you […] so can you remember a time when you’ve hurt someone else’s feelings

J: Never […]

R: Ah that’s really nice so you wouldn’t hurt someone’s feelings?

J: No

R: What about you ‘T’?

T: Someone grabbing each other

J: But he’s never grabbed anyone

T: You know the other day when I first blew ‘I’’s candles he grabbed me on the shoulder

R: Who grabbed you?

T: ‘I’ grabbed me on the shoulder and it made me cross

R: Oh ok […] and why do you think she grabbed you on the shoulder?

J: Well that’s how ‘I’ behaves really ‘cause she sometimes has a bit of bad temper

T: What is bad temper?

J: It means like if you’re so angry and you can’t control yourself

R: That’s a really good description I like that, well done ‘J’ […] so do you think when you blew ‘I’s candles out maybe that hurt her feelings and then she went like that and then that hurt your feelings?

T: Yeah

R: Ok […] so how do you think it makes your teachers feel when you do some really good work?

T: It makes them feel happy

J: Amazed!

T: Also impressed

R: Yeah that’s a really good word […] and what about if you’re messing around in class, how do you think that makes teachers feel?

[J turns away with arms folded]

R: Are you ok ‘J’? What’s up? […] Can you tell us how you’re feeling?

[long pause]

R: Are you just gonna have a quick breather? Yeah, that’s ok. […] So if you mess around in class or you misbehave, how do you think that makes teachers feel?

T: What does misbehaved mean?

R: It means you’re messing about […] being silly […] behaving in a way that teachers don’t like

T: I believe that is when teachers get […] you know […] teachers get erm […] get angry and then tell them to stop and then […] tell them 100 times which is a lot and that makes them EXTREMELY EXTREMELY angry […] and they break into bits […] and it makes students so angry

R: Yeah […] that’s a really good description I like that […] ok […] and do you think your teachers understand you

T: Yeah

R: ‘J’ are you going to listen to this ‘cause I really want to hear what you’ve got to say as well? […] Do you think your teachers understand you at school?

J: [Now smiling, indicates ‘maybe’ with his hand]

R: Ok so ‘T’ says yes, ‘J’ says maybe maybe […] Why did you say yes ‘T’?

T: ‘Cause they know me and I understand them because you know the other day […] erm […] when I first done Maths […] you know I hate getting them wrong and I hate mistakes […] I think they make me think ‘Do I have to ruin my work’ or do I have to […] you know […] tear my work apart […] that makes my teachers feel angry

J: I think that’s what ‘I’ does sometimes when she’s grumpy, she tears it apart […] and she sometimes comes in here to

T: You know something […] the other day […] on drama […] with that visitor who came around […] when ‘I’ turned paper she threw into another boy’s head

R: Oh no

J: And now we all know he used to be a bully did this boy

R: Oh right […] did he? What did he do?

J: He used to push in the line even if he was at the back […] no-one pushes in the line here

T: No-one pushes in the line […] it’s ok to be 1st or 2nd or 3rd or last

R: Yeah it doesn’t really matter does it

J: Well mostly when I’m sad it makes me wanna go to the back sometimes […] yeah it makes me feel like being at the back

R: Ok […] and I was just interested what you said before ‘J’ ‘cause when I said do you think teachers understand you you went [makes appropriate hand gesture] […] so do you think there’s times when they do understand you and times when they don’t?

J: Maybe I don’t really know

R: That’s ok

T: [rubs hair on my arm] One day mines gonna be like that

R: Yeah? When you get older?

T: Yeah

R: Right […] well […] I think you’ve done really well today guys […] I really like the way you’ve talked […] we’ve talked a lot about our feelings and about other people’s feelings […] and jus the last think I wanna ask before we go

J: I don’t wanna go I’ll stay with you longer

R: Ah do you? That’s nice […] erm […] do you think it

J: We don’t really have a pass code on the school iPads really ‘cause we don’t want everyone to forget it really […] ‘cause there is a password to get onto the internet but most of the teachers do it for us really

T: You know something […] at homes, iPads and iPhones […] some mums and das have their pass code on their own phones and iPad

R: Why do you think they do that?

J: They probably think it’s private to them

T: They probably think it too because I think it’s like you know a secret when you keep it to yourself and not share with others it’s like when you’re not going to be able to tell them and stuff like that

R: Yeah so you’ve got stuff on there that you don’t want other people to see? So maybe if you had like a diary or something on there […]

T: A diary, yeah

J: Yeah and you might think it’s private to yourself […] or you might be a bit selfish maybe

R: So ‘J’ could you tell me […] I’m still really interested about what you said about your teachers […] and remember no-ones going to hear this

T: I think I should go back to class

R: Yeah?

T: Ok see ya later

R: Ok it was very nice to meet you and thank you for answering all those questions so well

T: Thank you

R: Ok have a nice day

T: Have a nice day, you too

[T leaves]

R: Are you ok for a couple of minutes ‘J’ you said you wanted to stay here?

J: [nods]

R: Excellent […] so did you want to tell me about your teachers or?

J: [sighs] They always get me

R: They always get you? Ok and have they always got you?

J: Mostly yeah

R: Ah that’s nice […] so they understand you and how you’re feeling

J: Yeah

R: Ah good […] ok […] so like I say the last question I was going to ask was […] because we’ve been talking a lot about feelings today […] and I was wondering whether you think does autism make a difference?

J: I don’t know ‘cause I’ve never heard of it

R: Oh you’ve never heard of autism? Ok […] that’s fine […] erm so do you have any questions for me or anything you’d like to tell me about anything really

[long pause]

J: [sighs deeply]

R: How are you feeling right now?

J: Don’t know

R: Ok […] would you like to stay here or go back to class?

J: Stay here

R: Ok that’s fine

J: Sometimes at the end they give us a little bit of time before we move onto the next bit maybe

R: Ok so do you want a few minutes just to chill before you go back to class

J: Mhm

R: Yeah that’s fine […] shall we stop the recording?

J: Yes

\*End of recording\*

## Appendix 4 – Focus Group 2 Transcript

R: Facilitator (me)

1: Participant 1

2: Participant 2

3: Participant 3

4: Participant 4

\*Again, before the recording was started I introduced myself and briefly explained that, as part of my course, I needed to do some research, and that I had chosen to do it about “feelings”, both one’s own feelings and other people’s.

R: So the first one’s a bit of an activity to do as a group and the question is this so if you crash-landed on a desert island (…) so if you’re on a plane and you crash-landed on a desert island and you guys were put in charge, what 3 rules would you come up with so everyone could live together and be happy?

1: Supplies!

2: What’s a desert island?

R: So like if you crash-landed in the middle of nowhere (…)

1: An archaeologist

3: That’s not a rule (…) it’d be like if someone swears you can slap them in the face

1: That is my archaeologist

3: No it’s rules

4: I would put like some kind of rationing in place ‘cause if it’s an island there’s not going to be much food

R: Ok good idea

4: And also like if there was a group of us I’d keep someone on night watch every night ‘cause if it’s a desert island you might get attacked

3: By pirates

4: [sarcastically] Yes ‘3’ I’m sure there’d be pirates

1: Oh there’s also an oasis somewhere

R: There might be yeah

4: And I can’t think of a 3rd one

R: Ok can anyone else think of third one (…) what other rule could we have for everyone to live together and be happy?

1: Set up a tent

R: Yeah that would be a good start wouldn’t it

3: Never tell anyone about the rules

4: Wouldn’t that cause total anarchy

3: The first rule of desert island is don’t talk about desert island

4: I was thinking that

R: Is that like Fight Club?

3: Yeah

4: There could be a rule where erm (…) each person goes out to the sea to see if they can see a ship (…) yeah ‘cause you don’t want to be stranded on a desert island all your life

3: I do

R: So ‘4’ you’re thinking you might have a rule to try and get off the desert island?

4: Yeah (…) or you could alternatively throw ‘3’ in the water

R: [laughing] I’m not sure ‘3’ would agree to that though would he

4: And then he causes a massive tidal wave and then we can walk under the water

3: If you threw me into the water it would still come back down wouldn’t it genius

4: Good point (…) we’ll just use you as a platform

3: You do?

4: I said we’ll just *use* you

3: But I’m not 5000 feet tall

4: Ok good point

1: Ok quit stop changing the subject

3: What?

4: Alright yeah I’ll stop

R: [laughing] Ok (…) did you want to say something ‘2’?

2: We’re going to have to escape because we can’t populate the island ‘cause we’re all boys

R: Ok yeah (…) but if there was a whole plane full of people though?

4: I’ve got (…) there could be like a rule where like we split up into smaller groups and then we set up each of our own camps

3: And then we could look for food

4: Yeah and everyone each gets their own job to do (…) ‘cause then you could like make the island

2: Can I tend to the cats

4: Yes you can tend to the cats

3: Why would there be cats on the plane

R: There might be (…) people might be taking their cats on holiday

4: You might crash land into Cat Island

1: There’s no such thing as Cat Island

3: There is, it’s in Japan

1: What there is?

3: There’s like 28 people and 200 something cats

1: By the way, what if you bring cats to the desert, they’d surely die instantly?

3: It’s a desert island

R: Yeah it might be a bit hot for them

3: It’s a desert island though

R: Yeah so there’d be trees and water and things as well

1: Yeah the oasis

R: Yeah there’d hopefully be an oasis (…) well well done guys, I think if you guys were in charge then I’d be happy

3: I’d be in charge because I’m the coolest

R: [laughing] Ok so you know today we said we were going to talk about feelings (…) I’m just wondering what you guys (…) what do you think feelings means?

1: The emotions

4: Yeah that’s what I was going to say

1: I read your mind

R: Is there anything else?

4: Emotions are like erm (…) aren’t they bits of (…) parts of your mind that trigger when certain things happen?

R: Yeah that’s a really good description yeah

4: I can’t really describe emotions it’s kind of hard

R: It is hard isn’t it (…) are there different kinds of emotions (…) what sort of emotions

3: happy, angry, sad (…)

1: Its like when you leave it makes me sad

3: It depends where you leave (…) what if you leave school?

[pause]

R: Yeah so angry, happy, sad (…) how are you guys feeling right now?

1: Kinda bored

R: Oh sorry about that

4: Don’t know (…) kinda neutral

[long discussion about a cast that one of the participants had on their arm – quite off-topic and difficult to transcribe as there was lots of talking over one another]

R: Alright guys are we ok to get back to (…) so we were talking about feelings (…) so do you find it easy to describe how you’re feeling (…) so if someone said how are you feeling like I just did

3: Sometimes

4: Sometimes it’s really hard, sometimes it’s really easy

3: Depends who asks the question

R: Are there times when it’s harder or easier to say how you’re feeling

4: I don’t really know (…) erm (…) yeah I don’t really know

R: But sometimes it’s easy and sometimes it’s hard yeah?

4: Yeah

R: Ok (…) and do you find it easy to understand how other people are feeling?

3: Sometimes (…) it depends if you know the person well or not

R: Yeah definitely (…) definitely helps if you know them doesn’t it

[long pause]

R: Ok so if you saw your friend crying in the playground or in the quad what would you do?

3: Laugh

1: We would never laugh

4: I don’t know

1: We would warn the teacher

3: I’d laugh

1: ‘3’!

4: I don’t know what I’d do (…) it would depend what friend

R: Ok can you tell me a bit more about that?

4: If they were really good friends I would go and help them but if like I don’t really know them I’ll just go and tell the teacher

R: Ok so you said if they were really good friends you’d go and help them (…) what would you do (…) how would you help them

4: I’ll just see what’s wrong with them (…)

R: Yeah (…) what about you ‘2’?

2: I don’t know

1: You should know

2: I’ve never seen that happen

R: That’s ok (…) that’s fine (…) ok what about this (…) what if you saw your friend and they were really happy (…) you know like if they’d had some good news when they came into school?

4: I don’t know, that’s harder

1: Say “what are you so happy about?”

R: Yeah so you could ask them why they’re happy, what their news was about (…) anything else?

1: I have a feeling that ‘4’ might have an idea

4: What sorry I was lost

R: Did you have an idea?

4: I don’t know

R: You’re not sure about that one

4: No

R: Alright let’s try a different one then (…) so how do you think your mum and dad might feel if you forgot their birthday?

1: Might feel quite nervous

4: They’re used to it

3: Disappointed

4: Mine are used to it, I just don’t really bother with birthdays (…) unless they’re mine!

1: Except if it’s mine too ‘cause I go bowling

R: Yeah (…) so how do you think it makes your mum and dad feel if

3: Depressed (…) let down

1: Depressed

R: Yeah (…) and how do you think they’d feel if you got them something really nice for their birthday?

3: Thankful

4: Yeah (…) thankful

3: Happy (…) they’d buy you lots of things

1: Forgiveful

3: Why would they feel forgiveful?

R: Go on you tell me what you mean by that ‘1’?

4: Yeah that makes no sense

R: So if it was your mum or dad’s birthday ‘1’ and you got them something really nice how would they feel?

1: Uh (…)

R: You said happy before didn’t you?

1: Yeah (…) no wait that was ‘3’

R: Oh was it (…) what did you say I can’t remember

1: I forgot

R: You forgot, ok (…) and what did you think ‘2’?

2: I don’t usually remember their birthdays (…) I think they’ve past (…) I think their birthdays have passed

R: Oh they’ve passed this year (…) did you get them anything?

2: Err no (…) I didn’t know it was her birthday (…) and I probably wouldn’t have because (…) I wouldn’t [unclear]

R: Ok thank you (…) so (…) can you remember a time when you’ve made someone feel good?

1: My brother

R: Ok, how did you make your brother feel good?

1: My brother lives at my dad’s and (…) he was so happy ‘cause I taught him Sonic (…) I showed him how to play Sonic

R: Ah cool (…) is your brother older or younger than you?

1: He’s five years old now

R: Oh so he’s younger than you

1: Well he was three when I first taught him

R: Oh wow that’s really young (…) is he any good at it?

1: Yep

R: He is (…) so that’s a nice one (…) so you taught your brother to play Sonic and that

1: He knows the basics

R: He know the basics (…) but he’s not as good as you

1: He is never going to be as good as me (…) ‘cause I’m the best!

R: Ok (…) so what about anyone else?

3: I can’t think of any

4: No, I don’t know

R: Can you think of a time when someone’s made you feel good?

1: Speaking of time what time is it?

R: It’s 25 to 11

4: I erm (…) no I cant sorry

R: That’s ok (…) what about maybe if you had a surprise of someone

3: I don’t like surprises

4: I’d probably feel happy if it was a surprise (…) erm (…) but it depends if it’s a good surprise or a bad one ‘cause I don’t like being surprised often

R: Ok (…) so what would be a good surprise?

4: If someone got me a present or something (…) or if they took me out somewhere

R: Ok (…) and what would be a bad surprise?

4: If someone jumps out on me (…) especially when you’re in the toilet (…) when someone jumps out on you as soon as you shut the cubicle door ‘3’!

1: Like that game I was playing [unclear]

4: Yes that’s a jumpy game

3: But it’s not scary

4: It’s not scary

1: But the sounds make the game look really creepy

3: How can sounds make the game *look* really creepy?

4: But yeah (…) it just depends what kind of surprise it is

R: Ok cool (…) so this is a bit different (…) so can you remember a time when someone has hurt your feelings

4: I don’t know

3: No not really

1: I remember the time that [another boy in school] beat the crap out of me

3: Did he?

R: Do you want to tell me about that?

1: No

3: When?

4: I can’t remember that

3: Neither can I

2: Was that before I came to this school?

4: I have no idea

R: When was it ‘1’?

1: It was a few years ago

3 and 4: You’ve only been here one year

2: He’s been here two years

1: Well almost two

4: Good point actually

3: Was it a different one or the same as this school?

1: Same one

4: [Looking at 3] I can remember when a certain friend unfriended me online on PlayStation network and it was like that for a whole week and then he added me back

R: Could this certain friend be ‘3’ by any chance?

4: Yeah he’s done it twice now

3: I did it again

4: No you didn’t I checked this morning (…) but erm yeah (…) I can also remember when someone took away my laptop from me

R: Oh right (…) why did they do that?

4: ‘Cause it was broken

3: You’re in love with your laptop

[unclear exchange]

4: I was just really bored and (…) it just made me sad ‘cause I didn’t have a lot to do

R: Ok (…) so are there people in school (…) ‘cause I guess we get on better with some people than others don’t we so are there people in school that maybe annoy you or make you angry at all?

4: There was but they’re not any more (…) [pointing at ‘2’ and ‘3’] both of these two annoy me as well but I can deal with them

R: But they’re still your friends

4: Yeah

R: So why do you think you guys are friends?

3: ‘Cause we came to school at the same time

4: Yeah (…) well I came a little bit before you two (…) erm (…) we just (…) I was friends with another person and then we just (…) ‘3’ decided to come to us one time and he’s erm (…) not went away since (…) and then ‘2’ just kind of drifted towards us (…) I have no idea (…) I don’t know why (…)

R: Have you got similar interests then?

4: Yeah I like to play certain games and so does ‘2’ and ‘3’

R: Ok (…) what sort of games do you play?

4: I play mainly like fighting games but I also like games that are story-driven (…) so like I quite like to play these games (…) they’re by a company called Tell Tale but (…) they like release them in episodes but like every action you do is the story (…) and that story’s quite mood-swaying as well ‘cause you get like sad at certain parts of it and you can get like happy at certain parts (…) it’s quite emotional sometimes

R: Ok can you tell me a bit more about that

4: Yeah so there’s one called the Walking Dead which is based off the TV series and erm (…) you play this guy and at first it’s a normal story and then it gets like deeper and deeper and like (…) you slowly become attached to these certain characters and then one by one they just die and then like (…) I’m not going to spoil the ending for you but it’s just really sad

1: Yeah and all the blood and guts!

4: Yeah I guess that can be sad for some people (…) but yeah but that’s how we all came together as friends really

R: Ok cool (…) and do you kind of like help each other out in school and look after each other or?

4: I try to but (…) yeah (…)

R: What sorts of things do you do?

4: I try to be helpful but (…) and then he decides to sing Viva Las Vegas while kicking me in tune

1: Wait, doing what?

4: He kicked me in tune to Viva Las Vegas (…) and yeah (…)

R: Ok (…) so we were talking then about someone hurting your feelings (…) can you think of a time when you might’ve hurt someone else’s feelings?

3: Never ever ever ever

4: No I can’t think of a time

1: [unclear]…but when I leave he cries

4: Who’s that ‘1’?

1: My little brother

4: Oh right (…) I have a little brother

R: Do you (…) how old is he?

4: 14

1: Maybe your brother and I could be friends

[long pause]

R: Do you ever hurt your brother’s feelings do you think?

4: I think there might be some times yeah (…) like when I shouted at him (…) a few years ago we were at this seaside and I took this doughnut out of his hand and ate it

1: That’s cruel

4: I know

[unclear exchange]

1: You guys are bonkers

R: Ok guys so we’ve only got a few more questions (…) and this ones about teachers actually (…) and remember you can say whatever you want (…)

3: They’re stupid

R: Yeah if that’s what you think that’s fine (…) and so what I wanted to ask was (…) how do you think it makes your teachers feel when you do some really good work?

3: Pleased

4: It makes them feel pleased

R: What do you think ‘2’?

2: I forgot

R: That’s ok (…) and what about if you mess around in class (…) how do you think

3: “Uhhhh ‘3’”

R: Is that what they say to you?

3: Yeah

R: Is that one teacher in particular?

4: Yeah well they all say it (…) I can’t actually think of one teacher that hasn’t said it to him

3: “Uhhh ‘3’ don’t do that …”

1: What the hell are you talking about ‘3’?

R: Why would they say that to you (…) what kinds of things would you be doing for them to say that to you?

3: I don’t know (…) different things

R: And what do you think they’re thinking when they say that to you?

4: It could make them feel really annoyed

R: Does it annoy you when they shout at you?

3: It makes me laugh (…) when people shout at me it makes me laugh for some reason

R: Ok (…) so do you get like punishments at school (…) do you get time outs and things or?

1: Yeah I had to miss [unclear]

R: You had to miss what?

4: That’s like free time (…) and say if you have some bad marks you don’t get it at the end of the lesson

R: And do you think your teachers understand you?

4: Sometimes

3: Some teachers do (…) because you have key workers [unclear]

4: Mine’s myself

[long pause]

R: So some teachers understand you and some don’t?

4: Yeah there’s some teachers that really don’t understand me and it annoys me

3: Like who? The new people?

4: No I’d rather not give any names out

R: That’s ok

4: Yeah it’s just (…) say like if I don’t understand a piece of work (…) like they won’t explain it to me they’ll just force me to do it

R: That’s not really helpful is it (…) and someone that does understand you, what would they do instead?

4: Like talk me through it (…)

R: Yeah so listen to you, see what the problem is and explain things to you (…)

4: Yeah

R: What do you think ‘1’?

1: Well there is one teacher that really annoys me

R: Ok and what annoys you about them?

1: Everything

3: What teacher

1: You know who ‘4’

4: Oh yeah

R: Can you tell me a bit more about them ‘1’ I’m interested?

1: No but I can tell you that one thing I really like is my computing teacher

R: Ok (…) what is it you like about them?

1: She looovves computers

R: Ok so you’ve both got the same interests

1: Yeah

3: She introduced me to programming

4: I remember that one time there was this teacher (…) he doesn’t work here anymore but (…) he was a good teacher (…) he was one of my favourite teachers

1: Yeah mine to

R: Ok (…) can you tell me what was good about him (…) because I’m interested to find out what makes a good teacher?

1: Well he showed us a film

4: He made jokes (…) like he didn’t make frequent jokes but he kind of had a sense of humour about him (…) and say like if you didn’t understand something he helped you (…) and he was just quite (…) he didn’t like (…) if you didn’t do a certain he thing he would help you look that bit up (…) say like it was English he usually taught and like (…) sometimes I put capital letters inside my words by accident and he just kind of helped me stop that

R: And are you guys gonna have the same teachers when you move to your new place?

4: I think so yeah (…) I know I’ve got my same teacher

3: I think I’m going to be with someone else

R: Are you looking forward to moving ‘cause you’re moving to a new building in September aren’t ya?

1: Yeah we are

4: Yeah

R: How are you feeling about that?

1: Nice

4: Yeah it’s good

3: No more silly little children

1: And there’s going to be advanced coding

R: Advanced…?

1: Coding

R: I’m sorry I don’t know what that is

4: It’s kind of like a little bit stressful for when I move ‘cause I live quite far away from the school

1: You get buses

4: Yeah I have to get two buses so it kind of like adds half an hour extra to the journey

1: So you have to get up pretty early too

4: That’s cool

R: But I bet the building’ll be really nice (…) you’ll probably have more space than you’ve got here won’t you I guess

4: Yeah we’ve only got like a strip of corridor

2: It’s because this school is poor (…) poor like peasants

1: Shall we go now?

R: Well I think I’m pretty much done guys (…) so have you guys get any questions for me or anything else you wanted to tell me

1 and 4: I haven’t

R: Ok well I’ve just got one last question actually (…) so today we’ve been talk a lot today about feelings (…) our feelings and other people’s feeling (…) and I was just wondering if you thought autism makes a difference?

3: Yes

4: Yeah

R: Ok so both said yes straight away

3: Depending on how severe it is

R: Ok could you tell me a bit more about that?

3: Some people have worse autism than others (…) like they react differently if you say something or do something

4: Oh yeah

3: [shouts boys name]

R: Ok so do you think he finds it harder to understand feelings?

3: Yep all of them

4: Yeah because most of the time he just comes up to people and forces you to play with him and if you don’t he starts crying so I don’t think he really understands emotions that much

1: Yeah I really hate him too!

4: I don’t hate him I just think he doesn’t know a lot about feelings

[member of staff walks in to say that it is almost time for break]

4: So yeah like (…)

R: So you said it makes a difference having autism?

4: Yeah like it just depends on how (…) if you’ve got high-functioning or low-functioning (…) it just depends really

R: Excellent (…) alright guys well thanks for coming today it’s been really helpful (…) and I’ll let you go to break now