A Qualitative Exploration of Autism and Transition into Further and Higher Education

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Abstract

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Keywords: Autism, education, FHE, transition, university, college, disability, self-presentation, support, self-regulation.

In this thesis, I explore 42 autistic individuals' transitions into further and higher education (FHE) in England, drawing on personal experience as well as interview data. I was diagnosed with Asperger's Syndrome in 1998 at the age of 13. At the age of 15, my mother introduced the topic to me, and autism soon became the foundation of my socio-political identity. The discussion is divided into three themes; stigma and perception management strategies, formal and informal support networks and the interplay of autism with institutional factors. I draw upon Tringo's (1970) work on the hierarchy of impairment and Goffman's (1963) work on stigma. Tringo's (1970) hierarchy of impairment led me to my intra-communal hierarchy of impairment (perpetuated *by* autistic individuals *against* autistic individuals) and Goffman's (1963) work on stigma led me to my four degrees of openness; autistic individuals can be indiscriminately open, or indiscriminately reticent, but openness if relevant, and openness if necessary, are more common strategies. UPIAS' (1976) work on the social model of disability laid the foundation for my socio-political identity *and* this thesis. I argue autism has been largely absent from the political arena. I outline how there are four ideals; the ideals of self-regulation, normalcy, ability and independence. Eager to conform to these ideals, eager to self-present as 'independent', 'self-regulating', 'normal' or 'capable', some autistic students are reluctant to request support and accommodations, complicating the transition to FHE.

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Dedications

For those longing for ‘home’ (whether home or your *alma mater*). For those told your future is bleak and expectations are low. For those whose differences are so profound it seems no one dares associate with you.

Contents

Chapter 1: An introduction

1.1 Rationale and context: a personal story

I was 13 years old when I was diagnosed with Asperger’s Syndrome. I was too ‘young’ to manage and process the complexities of a diagnosis of autism, my parents withheld information about my diagnosis until I was 15 years old. Transitioning from a pupil referral unit to a college in 2001, at the age of 16, I struggled to adapt to the mainstream setting. With a class size of 10, taught in a shared music technology suite, a full-time daily schedule, no tutors to usher us to classes, a performance-based system of progression and withdrawal for ‘poor’ behaviour a constant threat, I was not in my comfort zone. With appropriate support, I flourished, but *only* after my mother had advocated for me in a crisis meeting. In 2010, at the age of 25, I transferred to my second university from my *alma mater* (where I had been registered for five years). It was there that I failed an assignment. It was there that support worker Steve was invited to represent my interests in two crisis meetings in semester one, and there was some talk of downgrading to a postgraduate certificate. It was there that, when I submitted my thesis, my examiners invited me to revise and resubmit.

In 2016, at the age of 31, I was a student representative at an eight-day sociology conference. By then, autism was the foundation of my socio-political identity. By then, I was a PhD student, with a ‘shared’ but disused office. There was never any cause to cover (Goffman, 1963). Covering is where a person with a stigmatised identity is happy to disclose information about the stigma to others but minimises their stigmatised differences. In this context, I was covering when I felt comfortable in identifying myself as autistic to neurologically typical or non-autistic others but self-presented as near-neurologically typical to avoid negative attention. Covering for eight days contravened my Autistic self-identity, the ordeal physically and emotionally exhausted me and for the first time in eight years, I saw autism as ‘lesser’. But I was determined that I should not damage my career prospects, I was in the company of, who I considered to be, published, esteemed sociologists.

These three moments in time laid the very personal foundations of this thesis. I have an ‘ideal’ vantage point and an ‘insider-outsider’ researcher status. Using auto/biography (Rogers, 2020; Simmons, 2020) and writing as an autistic woman, I share auto/biographical vignettes to illustrate how autistic behaviours can be interpreted. Auto/Biographical vignettes will offer an illustrative, personal and authentic insight into Asperger’s Syndrome, unrestricted by a desire to self-present as ‘high-functioning’ or neurologically typical. My status as an insider-outsider researcher facilitates the use of auto/biographical vignettes and auto/biography (chapter 2), and a meaningful connection to my research participants.

Furthermore, I carried out in-depth interviews with 42 autistic, self-recruiting research participants in the West Midlands, the East Midlands, Tyne and Wear and Yorkshire, to understand how autistic people experience their transition into further and higher education (FHE). By analysing interview data and reflecting on some of my personal experiences, I address the following research questions:

- What are autistic students’ experiences of transition in FHE?
- What perception management strategies (if any) do autistic students employ in FHE settings?
- What support is currently available to autistic students in FHE?

Statistical analysis by Taylor et al. (2013) significantly indicates the diagnosis rate for autism began to increase in the 1990s, with annual incidence and prevalence rates (new cases) in eight-year-old children plateauing in 2004, and subsequently increasing incrementally over a six-year period. These statistics are only indicative of *diagnosis rates* and only cover individuals who were eight years old at diagnosis, but, those eight-year-old children are now young adults registered on FHE programmes of study. Whilst *my* study is not statistically relevant, I understand that these statistics tell a story of social patterns, while I am going to tell a story of social processes (Mills, 1959).

Research into autism and transition into FHE is *crucial* at a time when colleges and universities are ‘confronting’ an influx of autistic learners. Autistic individuals have had the right to access FHE for almost two decades. In 2001, the UK government passed the Special Educational Needs and Disability Act (SENDA, 2001) updating the Disability Discrimination Act (DDA, 1995) to secure rights for disabled individuals in compulsory education and FHE, including reasonable and anticipatory adjustments. A reasonable adjustment might be a British Sign Language (BSL) interpreter, or lift access, or signage in Braille, or a non-medical helper. It would, however, be unreasonable to eliminate the use of fire alarms for a student with auditory hypersensitivity, or to ban the sale of bananas, for a student with an aversion to, or phobia of, bananas. Lift access and signage in Braille are anticipatory adjustments, BSL interpreters and non-medical helpers are not (it is not standard practice for a BSL interpreter to interpret lectures, if there are no Deaf students present, but a wheelchair user would not need to request a lift, or ramps, in advance).

Disabled Students’ Allowances[1] (DSAs) fund non-medical helpers for autistic learners (Student Finance England, 2019a). DSAs increase annually (for example, in 2017, a full-time undergraduate student could receive a maximum of £21,305. In 2018, it was £21,987) (GOV.UK, 2019b). When a person applies for DSAs, they might be invited to attend a needs assessment. I was asked to attend two needs assessments, once in 2005 (at the beginning of my degree) and once in 2010 (as I transferred to another university). The person carrying out the needs assessment determines the number of contact hours to be allocated to the applicant, and it is at their discretion whether to allocate additional contact hours on the student’s request:

> DSAs will not pay for hours of support where this is more than that shown on the DSA2 letter. However, a student can get further recommendations for additional hours if required. The SLC will monitor the weekly and yearly amounts of NMH support recommended and

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[1] This is a non-repayable grant, not linked to income or eligibility for help with everyday living costs, for example Personal Independence Payment.

> drawn-down for individual students, and will challenge any which appear excessive (Student Finance England, 2018: 41).

It is against this backdrop of well-established rights and diligently monitored contact hours with support workers that increasing numbers of autistic learners are beginning FHE. Research into autism and transition in FHE is timely, relevant, even essential under these circumstances.

Autism is an umbrella term, covering a range of distinct but interlinked conditions: autism, pervasive developmental disorder not otherwise specified (PDD-NOS), and Asperger's syndrome (AS). A person receives a diagnosis of PDD-NOS when there is *some* indication of autism, but they do not fulfil the criteria for autism. Autism is more profound than PDD-NOS or AS, but all 'autistic spectrum conditions' can be profound, moderate or mild. Autism manifests itself in several, sometimes contradictory ways (for example, the autistic person might exhibit sensory hypersensitivity and/or sensory hyposensitivity). For a diagnosis of Asperger's Syndrome to be confirmed, the patient must present with a minimum of nine, of 20, indicators identified by Gillberg and Gillberg (1989), which are divided into six criteria (difficulties with reciprocal interaction, all-consuming interests, the need to impose routines and interests on others, issues with speech and language, problems with non-verbal communication and motor co-ordination difficulties). All six criteria must be met, but AS could be confirmed in any two individuals, with only two overlapping indicators (motor co-ordination difficulties must be present in all cases, and three, of five, speech and language problems must also be observed) (Gillberg and Gillberg, 1989).

1.2 On knowledge and power

Researchers have the power to determine what constitutes knowledge (Stubblefield, 2013). Stubblefield (2013) had been referring to researchers who design, and test, new variants of the Sally-Anne experiment (Baron-Cohen et al., 1985), but the same can be said of social researchers. The Sally-

Anne test was designed to test the theory of mind hypothesis, which ‘refers to the notion that many autistic individuals do not understand that other people have their own plans, thoughts, and points of view’ (Edelson, 2019: n.p.). Autistic children, children with Down’s Syndrome, and typically developing children were shown a short story. The premise of the story is that two children (Sally and Anne) are together in a room. Sally has a marble and a basket and Anne has a box. Sally places her marble in the basket and leaves the room. When Sally has left the room, Anne places Sally’s marble in her box. Sally returns, and participants are asked ‘where will Sally look for her marble?’ Children ‘pass’ the test if they attribute false belief to Sally (‘Sally will look in the basket’), and ‘fail’ the test if they answer, ‘Sally will look in the box’. Framing the outcome of the test as a ‘pass’ or a ‘fail’ stigmatises the participants.

Similarly, there are parallels to the discourse which is used to describe deafness. Bauman and Murray (2014) applied frame theory to question the use of the word ‘loss’ in deafness discourse. In using the word ‘loss’ (in ‘hearing loss’), clinicians frame deafness as ‘less than’. The use of the word ‘fail’ when reporting the findings of these experiments frames autism as ‘less than’. Some researchers (for example, Klin et al., 2003) seem attached to the idea of theory of mind and developed several subsequent ‘tests’ of increasing complexity, no longer to test a hypothesis but to ‘prove’ the theory, whenever the previous test began to produce any evidence which might disprove it (i.e. when autistic participants began to ‘pass’) (Rajendran and Mitchell, 2007; Stubblefield, 2013). It is within this context, in which the ‘autism as less than’ narrative is pervasive and persuasive, and effects how society, autistic individuals included, views autism, that my research is critical.

1.3 Autism as a foundation of socio-political identity

For people who self-identify as Autistic (‘Auties’ and ‘Aspies’), autism is the foundation of their socio-political identity (Robertson and Ne’eman, 2008). ‘Auties’ and ‘Aspies’ see autism as a positive, a ‘gift’ (The Silent Wave, 2016), and the neurodiversity movement has built up over time (Robertson and

Ne’eman, 2008). ‘Autistic’ is not a proper noun, but the use of a capital letter, like ‘Deafies’[2], and ‘Dwarfs’, connotes belongingness to a culture. There is no direct comparison to Deaf culture as Autistic culture is less established, and does not have a separate linguistic system, but the principles are similar (Davidson, 2008). Members of the neurodiversity movement object to therapies and interventions designed to manage autism, and research into a ‘cure’ for autism (for example, amniocentesis screening) (Bagatell, 2010). To Autistic people, autism is ‘different, not less’ (Grandin, 2012). For Autistic self-advocates, the locus of the ‘problem’ is the privileging of some neurotypes over others, and the reluctance of neurologically typical people to accommodate, tolerate and welcome autistic ways of being (Bev, 2009).

Several factors have contributed to the rise of Autistic culture (Straus, 2013). The diagnostic criteria for autism have been widened, and individuals who do not present with global learning delays (GLDs) and individuals who are articulate, can now be diagnosed as autistic. The number of individuals who have been diagnosed with autism, or those who have self-diagnosed, has been increasing significantly over recent years. The growth of social media, disability studies and the neurodiversity movement have all contributed to a burgeoning Autistic culture. Autistic individuals who do not present with GLDs, and are relatively articulate, can communicate the aims of the movement effectively, finding support amongst increasing numbers of newly diagnosed or self-diagnosed autistic people. The widespread use of social media introduces these narratives to a larger audience.

1.4 Autism: a historical context

The word ‘autism’ originates in the work of Bleuler (1950), a psychiatrist specialising in schizophrenia. He used the word to describe socially withdrawn

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[2] ‘In deaf culture, there are two separate spellings of the word "deaf." They are the "big D" Deaf in which a person identifies as a member of the deaf community and "small d" deaf in a person is deaf but doesn’t identify as such’ (Berke, 2019: n.p.).

schizophrenic patients, in work published in 1911[3]. Victor the ‘wild boy of Aveyron’, who lived feral in a French woodland until the estimated age of 12, over a century earlier, is now thought to have been autistic. Kanner (1943) published an article about the case history and familial relationships of 11 children, exhibiting what he named ‘early infantile autism’. Although he used Bleuler’s (1950) concept ‘autism’, he did not agree that what he was observing was schizophrenia. In 1944, Asperger (1991)[4] published a paper on ‘autistic psychopathy’ in four boys, describing the boys as ‘little professors’. Asperger’s (1991) ‘optimistic’ view of the condition contrasts with the pessimism of Kanner’s (1943) work. Asperger (1991) was less complimentary about profoundly autistic individuals but his focus was on children who, today, would be diagnosed with Asperger’s Syndrome. Asperger’s (1991) research paper attracted little attention until 1981, when psychiatrist Wing (1981) recognised the described ‘symptoms’ in patients referred to her clinic, and named the condition Asperger’s Syndrome, 37 years after Asperger proposed it. Gillberg and Gillberg (1989) published the first diagnostic criteria for Asperger’s Syndrome in 1989, and the condition was added to the DSM[5]-IV (American Psychiatric Association, 1994), before it was removed from the DSM-V (American Psychiatric Association, 2013) after 19 years. The DSM-V (American Psychiatric Association, 2013) also simplified Wing and Gould’s (1979) triad of impairments, from a triad to a dyad.

The triad of impairments is impairment of social interaction, social communication, and social imagination (Wing et al., 2011). Impairment of social interaction is ‘the marked reduction of non-verbal signs of interest in and pleasure from being with another person’ (Wing et al., 2011: 768). Impairment of social communication is ‘the decreased ability to ‘‘converse’’ non-verbally and verbally with another person, sharing ideas and interests or to negotiate in a positive friendly way’ (Wing et al., 2011: 769). Impairment of social imagination is ‘the decreased capacity to think about and predict the

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[3] The work was translated into English and published in 1950.
[4] The work was translated into English and published in 1991.
[5] The Diagnostic and Statistical Manual of Mental Disorders.

consequences of one's own actions for oneself and for other people' (Wing et al, 2011: 769). Thus, while Kanner (1943) recognised the children who he was describing were not 'feebleminded' (the terminology of that time used to refer to a person with GLDs), the cases were more profound than many of those Asperger (1991) had been describing.

Research suggests Asperger's (1991) observations would have been affected by the political context at the time of writing (Baron-Cohen, 2018; Czech, 2018; Sheffer, 2018). Complying with government policy, Asperger referred profoundly autistic children to the *Am Spiegelgrund* ('at the bottom') clinic in Vienna (where many were euthanised) although other children who fulfilled the criteria for admittance to the *Am Spiegelgrund* were spared (Czech, 2018). The contrast between how Asperger (1991) described 'high-functioning' and profound cases is inextricably linked to the historical context. Potentially, this contributed to the intra-communal hierarchy of impairment, as Asperger's Syndrome is privileged, relative to autism. With both Asperger (1991) and Kanner (1944) distancing their 'preferred' cases from GLDs, this might also have led autistic individuals to perpetuate the idea of GLDs as 'less than'.[6]

1.5 On language

There is no consensus on how best to describe autism, or people who have been diagnosed with autism (Kenny et al., 2015). I distinguish here between person first and identity first language. Used deliberately, 'a person with autism' and 'an autistic person' convey quite disparate beliefs about autism and how it relates to the self. To describe a person as 'with autism' or as 'having autism' is to see autism as an annexe. The person's identity is not

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[6] Arguably, it is essential for researchers in this area to pay due diligence to the triad of impairment, when designing a research project, and to 'get a full picture' of how autism might shape an autistic person's educational trajectory. If autistic individuals exhibit no pleasure in being in the company of others, and they are not able to communicate with others verbally, the researcher would be well advised not to rely on face to face interviews. Difficulties negotiating with others in a positive and friendly way and predicting the consequences of their actions for themselves and others *potentially* effects the extent to which the autistic learner is included in, or excluded from, educational and social life.

defined by autism (Liebowitz, 2015). ‘A person with autism’ is person first language. The appeal of person first language is how it relegates autism to an ‘aside’. To consciously use ‘autistic person’ is to see autism as a defining feature of the person’s identity. It is favoured by members of the neurodiversity movement. ‘Autistic person’ is identity first language (Liebowitz, 2015). I will use identity first language here, but I am guided, wherever possible, by the meaning my participants attach to their own actions.

Individuals not on the autistic spectrum have been referred to variously as neurologically typical, neurotypical, typically developing, allistic, and non-autistic (Silvertant, 2018). ‘Non-autistic’ and ‘allistic’ are sometimes used interchangeably with ‘neurotypical’, ‘typically developing’ and ‘neurologically typical’ but this is misnomer. A schizophrenic person might be described as allistic, or non-autistic if there is no diagnosis of autism, but they are not neurologically typical, typically developing or neurotypical (Silvertant, 2018). ‘Allistic’, and ‘neurotypical’ are currently neologisms (Brusie, 2017). I will use non-autistic, typically developing and neurologically typical (or NT) where appropriate.

Functioning labels, ‘high-functioning’ and ‘low-functioning’ are divisive, arbitrary and contentious. To describe a person as ‘low-functioning’ is to perpetuate a hierarchy of impairment, the idea that the person with GLDs is ‘less than’ (Rogers, 2007). To privilege ‘high-functioning’ autism promotes the practice of passing (deception) or covering (minimisation), and the idea that ‘less is more’. There is a stigma attached to the label ‘low-functioning’, and Flynn (2018) proposed ‘high support needs’ as an alternative to ‘low-functioning’. I will revisit this several times in this thesis. ‘High-functioning’ autistic individuals are those who ‘can’ mimic NT behaviours (Flynn, 2018). I will be using inverted commas to challenge functioning labels or using ‘profoundly[7] autistic’ to refer to those identified as ‘low-functioning’.

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[7] ‘Profound’ can be used reverentially (e.g. profoundly Deaf).

Challenging, not contributing to, the hierarchy of impairment, is key to this work.

1.6 Thesis outline

Chapter 2 explores and utilises auto/biography as an innovative method, which recognises the self as a source of data. There is nothing to be gained from omitting my Autistic Self from this analysis. I outline my stance on claims to 'objectivity' in research in chapter 4 (in brief, here, there is some subjectivity underlying *any* research, whether it is declared or not) and I have mentioned my position as an insider-outsider researcher above. As I mentioned at the beginning of this chapter, I self-presented as near-neurologically typical at an eight-day sociology conference in April 2016. The consequences for my self-concept and mental well-being were mercifully temporary but devastating. In chapter 2 I detail and reflect on the events of days one, four, six, seven and eight of the conference, covering self-isolation, self-presentation, self-regulation, Self-sacrifice and self-concept. I explore what motivated *me*, an Autistic woman, to mask the condition which is the foundation of my socio-political identity. Chapter 2 is about a 'choice', under duress, to forego my self-integrity in the interests of protecting my career prospects and how this sat uncomfortably with me. This chapter reconciles my Autistic Self and my identity as a social researcher, using my position as a social researcher to confront the injustice of 'fake it or you will not make it', and challenge the idea that autism is 'less than'.

In chapter 3, I outline seven areas of research interest, each of which is central to my study. I will begin with an exploration of work on the stigma of autism. Grounded in Goffman's (1963) work on stigma, the opening section of the literature review identifies autism as a stigmatised identity and how enhanced awareness, of the condition overall and an autistic individual's diagnosis, can minimise stigma, with an overview of work by Goffman (1963), Chambres et al. (2008) and Gardiner and Iarocci (2014). In the second section of the literature review, I familiarise readers with the social model of disability (Oliver, 1983; UPIAS, 1976) and the care ethics model of disability (Rogers, 2016a). The social model of disability was effective, but it excludes profoundly autistic individuals and others who *cannot* be independent.

In the third section, I introduce four ‘ideals’ to which some autistic students are unable to conform. These ideals, the ideal of self-regulation (Foucault, 1976), normalcy and ability (Davis, 1997) and independence (French, 1991; Kittay, 2011) are socially constructed but deeply embedded in the collective imagination, and it is difficult to extricate oneself from these ideals. This compels some autistic students to forego necessary support and services, to seem to conform to these ideals, but, as I propose in the fourth section of the literature review, supports are valuable to the autistic learner and contribute significantly to autistic students’ academic outcomes (Anderson and Stephenson, 2017; Taylor et al., 2008).

In the fifth section of the literature review, I explore the ideas of self-presentation (Goffman, 1956; 1963) and self-regulation when under observation (Allan, 1999; Foucault, 1975), and the effects on the autistic individual’s emotional well-being. In the sixth section, I outline some of the key literature on the hierarchy of impairment, which ranks disabilities in order of preference, the order of which is consistent for the public (Tringo, 1970), close relatives of disabled individuals (Rogers, 2007) and *within* some impairment groups (autistic individuals included). The seventh section is concerned with current literature on colleges’ and universities’ transition policies which have alleviated some of the stress of transition for autistic students (Adreon and Durocher, 2007; Willey, 2000), grounding my study not only in theory but in current practice. My research explores the interplay of my participants’ autism with all seven areas, in the context of FHE, and introduces autism to the socio-political arena, from which it has been largely absent.

In chapter 4, I outline my research decisions. The chapter begins with a brief introduction to the study (the 'what', 'when', 'where', 'why', 'how' and 'who' questions). The focus shifts to the research process, and the underlying ideas which shaped my decisions. I will articulate my research philosophy and its influence on my methodology. I introduce the participants (their pseudonym, age, region, nationality and programme of study). I used four types of interviews: face to face interviews, Skype interviews, telephone interviews and email 'interviews', I will underline the benefits of each type of interview, with a focus on autistic research participants and researchers. I will reflect on data analysis, justify my use of thematic analysis and separate the themes of the research into three levels of analysis (themes 'emerging' from the interview schedule, close reading of the transcripts and abstraction). I identify critical ethical issues in social research and how I ensured my conduct complied with prescribed ethical standards. I reflect on my position as an 'insider-outsider' researcher and how this facilitates the use of auto/biography and auto/biographical vignettes. I outline several types of research bias and the action taken to avoid them. I conclude by acknowledging some limitations of my study, in the interests of promoting further research.

In chapter 5 (the first of three data chapters), I introduce 'distancing' or the intra-communal hierarchy of impairment, my contribution to the current body of work on the stigma of autism. Distancing is an embarrassed disassociation from profoundly autistic individuals, for example 'her autism is *worse than* mine,' or 'I'm autistic, but not as *bad* as him'. Distancing is grounded in the hierarchy of impairment (Tringo, 1970). I identify how most participants were willing to identify themselves as autistic to neurologically typical and non-autistic others, to some extent, under some circumstances (for example, if autism is relevant to the conversation, or to explicate 'challenging' or socially awkward behaviours). I describe this as my four degrees of openness, which is key to my thesis. In accord with Kanuha (1999) and Olney and Brockelman (2010), in many cases, non-disclosure does not indicate self-stigma or a fear of stigma. It is not always appropriate to self-disclose in the early stages of a working relationship or a friendship, or where it is unconnected to the topic of conversation.

Oliver (1990a) identified a tendency to over-medicalise disability, not *every* decision a disabled individual makes or problem the disabled person confronts can be attributed to their disability. Similarly, I propose, not *every* decision a stigmatised individual makes or problem the stigmatised individual confronts can be attributed to their stigmatised identity. My focus then turns to expectations (met and unmet) of stigma, and how the stigma of a *diagnosis* of autism might have lessened, but the stigma of *autism*, the stigma of its quirks, intricacies and sensitivities has not. Neurologically typical individuals, non-autistic individuals and autistic individuals alike seem willing to tolerate, even celebrate autism, on the condition of its minimisation. Profoundly autistic individuals are left to languish at the bottom of the hierarchy of impairment, and ‘high-functioning’ autistic individuals are left to camouflage, for a higher position in the hierarchy, and the privileges this affords. I conclude by using the social model of disability to re-frame ‘deficits in social interaction’ as hostility against autistic individuals.

Chapter 6 is about support and relationships, formal support networks (for example non-medical helpers, counsellors, note-takers or ‘study buddies’) and informal support networks (friends, relatives and romantic partners). In one case, university student Vanessa overcame a difficult period of self-harm with support from her boyfriend and speculated she might have taken her own life had her boyfriend not intervened. Some participants had enrolled in autistic students’ societies, or disabled students’ societies, for companionship. Others were more cautious and sceptical of autistic students’ societies, choosing other foundations on which to build their friendships. I concede in this chapter that no support currently available is universally useful, or appropriate for all autistic students, no support currently available will completely compensate for the inherent challenges of autism. But the value of these measures cannot be overstated, many autistic students *do* benefit greatly from these supports.

From academic staff to non-academic staff (including janitorial and administrative staff), from autistic students to non-autistic and neurologically typical students, from disability services to the students' unions, every member of the university, in any capacity, can create a more supportive learning environment for autistic students.

Chapter 7 explores the interplay of autism and the built environment, institutional forces and the autistic person's social world. This chapter is about how tutors and lecturers simultaneously presume competence and incompetence, how autistic individuals who request supports can be perceived, or *expect* to be perceived and how the absence of accommodations (for example, extenuating circumstances policies) can exclude the autistic person from FHE. My focus also returns to autistic students' societies and disabled students' societies, and the question of agency. This chapter is, equally, about sensory hypersensitivity, and how this is manifested in FHE settings (for example, in on-campus facilities and during freshers' week). It is here that I explore the possibility of segregated spaces for autistic students, and the criticism of autism-specific spaces, introducing researchers who propose segregated spaces will contribute to the ghettoisation of autism (Madriaga, 2010).

The conclusion is a 'call to arms', as I present, for the final time, my intra-communal hierarchy of impairment, the theories in which the concept is grounded, why the hierarchy of impairment and the intra-communal hierarchy of impairment *should* be challenged, and the action necessary to challenge them. The hierarchy of impairment excludes some profoundly autistic individuals from social life and the socio-political sphere, and in some cases, where it leads autistic students to forego necessary supports (from pastoral staff or teaching staff), it can exclude 'high-functioning' autistic students from education, or else make the transition a more fraught process. I propose clinical interventions cannot be exempt from social analysis (focusing on applied behaviour analysis, ABA). I also revisit my four degrees of openness and its significance for autistic students in the transition to FHE, and their inclusion in, or exclusion from, academic and social life. It is in chapter 8 that I propose future research. Research can produce more questions than answers, but it is in proposing future research that we open other fields of inquiry and produce new knowledge.

Chapter 2: Auto/Biographical sociology: it depends on the window you look through

2.1 Introduction

This chapter is about Autism as the foundation of my socio-political identity, how Autism is valued, and simultaneously it is given no value whatsoever (see also, Simmons, 2020). Autism has value for me *personally*, it is my Self, and when I give expression to my Autistic Self, I circumvent the emotional and physical exhaustion of covering, and its attendant potential to compromise a person's self-concept. In some settings (in the story I share here, at a high-profile, eight-day sociology conference), Autism 'as is' has no value whatsoever. I was a heavily supported Autistic delegate; I did not have permission to be my Autistic Self. Autism 'as is' is 'less than' (Gurbuz et al., 2019). Meltdowns[8] are 'less than'. Self-stimulatory behaviour is 'less than'. I overrode my instincts to *be* Autistic. Autism has no place in amongst 'esteemed' sociologists[9]. This chapter explores the consequences of self-presenting as neurologically typical for an Autistic person; me, an Autistic person not ordinarily inclined towards pretence, and the consequences for my self-concept and emotional well-being.

Between 1 April 2016 and 8 April 2016 inclusive, towards the beginning of my PhD, I was a delegate at three consecutive sociology conferences, which my *alma mater* and then-university was chosen to host. Between 1 April and 4 April, I also acted as a student representative; my duties included welcoming and orientating international delegates. I was also a source of local knowledge, living in the surrounding area and knowing the university well (I had studied at the university from 2005 to 2010, and from 2014 onwards). Throughout this eight-day period, I 'covered' my autism. I chose to position myself as autistic in conversation, but downplayed my 'difficult differences' (Rogers, 2007) and decided to mask my meltdowns. There is no universal experience of a meltdown, mine are felt as a rush of adrenaline, and a subsequent brief period of intense distress or anger. I supressed self-stimulatory behaviour, for

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[8] Meltdowns are 'intense responses to overwhelming situations' (Ryan, 2010: 871).

[9] I am reflecting on my feelings during the conference here.

example, plaiting small strands of my hair absent-mindedly, until I was no longer under the watch of my non-medical helper. The objective was to be autistic only in name, not in action.

In April 2016, I was midway through the data collection phase of my research project. I chose my research topic and decided to use auto/biography in 2014. I was confident in my decision to use auto/biography and how it would contribute to the thesis. The turbulent transition from my *alma mater* to another university, which I described at the beginning of this thesis, had to be put to *some* use. I was awarded an MPhil, a level seven qualification, at the 'journey's end'. I had also been awarded an MRes, a level seven qualification from my *alma mater* towards the beginning of the 'journey'. On reflection, in four years, I had made no progress, in my opinion, in my educational trajectory. I had graduated from university with little more than a new pastime. There *had* to be some use for those four fraught years. I made some 'fieldnotes' shortly after the conferences in a retrospective 'essay' to reflect on the event and analyse my experiences. I took other 'fieldnotes' at the time, some of these 'fieldnotes' were 'notes to self' and others were memoranda, to come prepared with earphones, for example, because a fire alarm test had been scheduled for that Friday. I had to dull the offending noise, to skirt sensory overload and its attendant meltdown, but I had to be *incognito.*

In spring 2016, I was wholly unfamiliar with Goffman's (1963) concept of covering. Even in secondary school, when there is great pressure on *all* young people to 'blend in' (Humphrey and Lewis, 2008), I never chose to downplay my differentness; I never chose to mask, to 'play normal' to win friends. I resented my unpopularity, but it did not occur to me to 'change' or pretend. A PhD is a solitary undertaking, there are very limited opportunities to interact with others. I worked in a large but mostly deserted shared office, on some days I worked from home, and I had no cause to attend any taught courses for several months (the last taught course had been a low-stakes level two evening class in British Sign Language, there was never just cause to self-present as NT)[10]. Covering as defined by Goffman (1963), and my interpretation of it, was a breach of my principles, my self-integrity. Covering demanded a skilled performance for which I had not rehearsed, but supported and monitored ably by Steve, I obligingly covered, self-presenting as an autistic-NT hybrid (Ahmed, 1999; Sion, 2013). The hybrid's stigmatised identity is always known. In some contexts, this visibility might work in the hybrid's best interests, for example, there are several careers where 'insider' knowledge of the 'outsider' group is an advantage. But a hybrid will downplay and minimise their differentness to present themselves in ways which the majority find acceptable in any social situation (Sion, 2013).

This chapter is about my (mercifully temporary) Self-sacrifice, this is about the loss of *my* Self. Yet crucially, other autistic individuals are strongly advised to cover, to circumnavigate stigma and negative attention (Gensic, 2015). I am not the only autistic person to Self-sacrifice, for the arbitrary label 'high-functioning' and the privileges accompanying a higher position in the hierarchy of impairment (Tringo, 1970). The story may be mine to tell. The deeply personal experiences described here may be mine alone. My data indicates the experiences of covering and Self-sacrifice, and the lowered self-esteem which often results, are not (Hendrickx et al., 2016).

Writing an auto/biographical account of this eight-day conference was a worthwhile activity. The conference was an opportunity to experience what my participants had experienced: the chance to be 'new' to some extent (and thus re-experience the beginning of the transition phase), when I had not been 'new' since 2010[11]. It was an opportunity to spend several hours, each day, surrounded by unfamiliar others, as undergraduate students (the bulk of the sample) spend several hours per working day surrounded by largely unfamiliar faces. Participating in the conference, too, was a chance to experience the

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[10] In April 2016, not at the time of writing.

[11] I had reregistered with my *alma mater* two years prior, but I was not 'new' *per se*.

pressure to pass for neurologically typical, when ordinarily I work in a private space, and I am familiar with those with whom I have contact.

My story is one detail in a bigger picture. Yet, my story contributes to our understanding of that 'bigger picture'. My reflections on this eight-day conference add a social dimension to what would ordinarily be viewed through a solely medical lens (Poulson, 2009). Self-presenting as neurologically typical and emotional self-regulation would typically be understood to be symptom management (medical), but in this analysis, the compulsion to self-present as neurologically typical is grounded in the ideal of normalcy (Davis, 1997). The narrative, and my analysis of that narrative, demonstrates how easily an Autistic person, for whom autism is the foundation of their socio-political identity, will perpetuate and endorse the intra-communal hierarchy of impairment. It also demonstrates how willing the Autistic person is to comply with the demands of this act, when confronted with an equally unattractive, but sometimes longer-term alternative, for example, reprimand, a damaged working relationship, or the forfeiture of career opportunities.

In this chapter, using auto/biographical sociology (Coffey, 2004; Parsons and Chappell, 2020; Rogers, 2020; Simmons, 2020; Stanley, 1995) and auto/ethnography (Ellis, 2004)[12], I reflect on and analyse my experiences of covering for that eight-day period, at those three consecutive conferences (although I will only focus on the first and final conferences here). Used to its full effect, auto/ethnography, and auto/biographical sociology can be methodologically sound analytical tools, which have great potential to make a significant contribution to sociology (Allen-Collinson and Hockey, 2008). Far from being self-indulgent and 'navel-gazing', auto/biographers will usually revisit some difficult, often painful memories (Ellis, 2004). Rogers' (2020) concept of socio-political death is a macabre but useful metaphor for the

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[12] '[A]utoethnography is a mode of self-reflective or introspective writing that connects personal autobiography and experience with broader social, cultural meanings and contexts' (Drabble, 2018: n.p.).

myriad ways in which stories too harrowing to be told are filtered out, and stories ‘not worth hearing’ from voices ‘not worth listening to’ are erased from the published work. Autistic voices, the voices of people with GLDs, or mental ill health, are often silenced. This chapter demonstrates my socio-political survival and in sharing the stories of other autistic individuals in this thesis, I am facilitating *their* socio-political survival[13].

The use of auto/biographical writing in a PhD thesis is an innovative and ‘risky’ decision (Doloriert and Sambrook, 2011; Flood et al., 2013; Stephens Griffin and Griffin, 2019). Stephens Griffin and Griffin (2019) note auto/biography has been labelled ‘lazy’ (Delamont, 2009) and ‘narcissistic’ (Fine, 1999). Stephens Griffin and Griffin (2019) propose narratives which misidentify auto/biography as ‘narcissistic’ ‘deny the potential of autoethnography, which positions researchers within the research, and utilises personal experiences, knowledge, and position to study a topic or situation reflexively, rather than the researchers themselves’ (Stephens Griffin and Griffin, 2019: para. 33) and contest the accusation that auto/biography is ‘lazy’, asking ‘Is it more difficult to think about other people than oneself?’ (Stephens Griffin and Griffin, 2019: para. 23).

With a focus on the use of auto/biography in PhD research, Doloriert and Sambrook (2011) identified how some thesis examiners can judge the quality of the dissertation to be poorer in cases where the dissertation includes the candidate’s auto/biography. The research traditions of the awarding university and how the student’s supervisory team and examiners interpret the marking criteria (i.e. whether supervisors and examiners perceive auto/biography to be in discord or accord with the brief) will affect the outcome of the examiners’ decision (Doloriert and Sambrook, 2011). The use of auto/biography in *my* thesis, alongside interview research, does not contradict the brief. Flood et al. (2013) identified how early career researchers are subjected to hostility from established academics who interpret ‘activism’, including auto/biography (Gale

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[13] Sections of this chapter appear in Simmons (2020).

and Wyatt, 2018) as ‘nonconformist’. But I am in a supportive, forward-thinking learning environment, and auto/biography has much to contribute to the study.

2.2 My experience of the three conferences

Friday 1 April 2016

I am 31 years old and I am a student representative at my *alma mater*. Today marks the beginning of an eight-day international sociology conference. Today also marks the beginning of autism awareness month. It is an irony that for the first eight days of autism awareness month, I will be self-presenting as neurologically typical, or ‘covering’ (Goffman, 1963), the function of which is unawareness. Autism is the foundation of my socio-political identity. I defiantly display my autism as is. Pretence contravenes my instincts and principles. But acting on the advice of non-medical helper Steve, I will be covering for this ‘brief’ period. I will be in the company of hundreds of high-profile sociologists. Potential employers. To exhibit autism ‘as is’ would jeopardise my intended career.

I don the ‘mask’ under duress and prepare to compromise my well-being and self-concept, for the sake of my working relationship with Steve, and to win favour with high-ranking professionals in my field. I am temporarily sacrificing my Self, my Autistic Self, to pursue a career in sociology. Statistics indicate 68% of autistic adults are unemployed (National Autistic Society, 2016b). If I am to be one of the 32%, I must demonstrate perfect behavioural and emotional self-regulation, perfect social literacy, and excellence in networking. With 68% of all working age autistic individuals in the UK not in full or part time paid employment (National Autistic Society, 2016b), my worries were reflected in my sample. University student Hudayfa was anxious about his future. He was in the final year of his degree and wondered whether he would have the opportunity to gain meaningful employment, post-graduation. College student Michael, too, was apprehensive about his prospects.

Today is April Fools' Day. April Fools' Day is a tradition originating in France, 1582, with the introduction of the Gregorian calendar, replacing the Julian calendar, the 'fools' were those who celebrated the new year on 1 April. Not every delegate would observe the tradition (which is celebrated with hoaxes and practical jokes). For some, the day of tomfoolery falls on 28 December (the Day of the Holy Innocents), for others, there is no designated day of fooling. But I am *en garde*. Whenever I am the fool, I 'meltdown':

> A meltdown is 'an intense response to overwhelming situations'. It happens when someone becomes completely overwhelmed by their current situation and temporarily loses behavioural control. This loss of control can be expressed verbally […], physically […] or in both ways (National Autistic Society, 2016c: n.p.).

A meltdown is a sensation of 'shock'. A meltdown is the sudden onset of giddiness, quickened breathing, penetrating anger. A meltdown is a cascade of expletives, queasiness. Meltdowns render the 'invisible' visible. And not once have I managed to disguise a meltdown. It seems prudent to 'take everything with a pinch of salt'.

Julian, the conference facilitator, welcomes us warmly. His housekeeping is interrupted by the late arrival of Samara, a student representative, 'sorry I'm late,' the dishevelled latecomer apologises, 'my car wouldn't start!' 'That's quite alright! Have a seat!' I 'smell a rat' and smile broadly, is this an elaborate April Fool? In hindsight, it would have been wholly inappropriate to disrupt a conference for a 'joke'. In hindsight, my 'knowing' smile could have been misconstrued as untimely mirth, a 'laugh' at the expense of Samara's misfortune. I fear meltdowns. I fear the loss of control. My fear has intensified three-fold. Exhibiting my Self so explicitly is a failure, if the objective is to cover (Goffman, 1963). Steve is observing me meticulously and I will be reprimanded, if I am seen not to self-regulate (Allan, 1999; Foucault, 1975). And if autism was not so heavily stigmatised, April Fools jokes would be, if not a nonissue, less of a cause for concern (Oliver, 1983; UPIAS, 1976).

Julian seems to be concluding his opening remarks. There is a knot in my stomach, and butterflies are flitting about it. I fretfully entertain two scenarios. Would Julian have organised a game? Not all ice-breaker games are competitive. Some are brainstorming or ‘getting to know you’ games, some require creativity and/or lateral thinking. But some games are competitive. ‘Ha!’ asks players to lie, sardine-like, in a row. The objective of ‘Ha!’ is to eliminate other players by crying ‘ha!’ while pressing your neighbour’s stomach. The game has a ‘you laugh, you lose’ format. I might fare well; I would be wholly unamused by the game. But I am wont to be a ‘sore loser’. Losing, and especially elimination, is highly likely to lead to a meltdown in me. The second scenario is a comparative techniques question.

Comparative techniques questions are popular in focus group settings and in market research to gauge public opinion. The question challenges participants to compare a product or political figure to an inanimate object (for example, a pizza topping or a make of car) or another species (for example, a farm animal, insect or flower). In training sessions, comparative techniques questions might be used as a ‘getting to know you’ exercise; participants are challenged to compare themselves to an inanimate object or another species. The phrasing is usually, ‘if you were a [object or species], what would you be?’ Using anthropomorphism, the participant identifies human characteristics (characteristics central to their sense of Self) in non-human life forms or inanimate objects. Confronted with a comparative techniques question, I will offer a considered response. A meltdown is highly unlikely. But I will be uncomfortable. I will be humiliated. The prospect of ‘being’ an inanimate object is discomforting. The prospect of ‘being’ an inanimate object has contributed to my anxiety. The prospect of ‘being’ neurologically typical is daunting but I would sooner ‘be’ neurologically typical than a foodstuff.

But Julian does not ask this of me. I am not asked to compare myself to an inanimate object or another species, but as other delegates introduce their research, I make comparisons, I begin to compare myself unfavourably to ‘them’. It is an imagined ‘them’. My gaze lingers on Kimberley. I invent her life history. I invent her Self. I imagine she is organised and mature, I imagine she was relaxed as she boarded her flight to England, alone, independent, well-travelled. She would have travelled by taxi from the airport, to the inner-city hotel where Julian had booked several triple rooms, her ‘home’ for nine days. She would have met her ‘roommates’, charming them with light conversation and she would have unpacked in a timely fashion. This is imagination. If this, in whole or in part, is factual, it is by coincidence. Kimberley is Irish, she is a lecturer in a Scottish university, she is researching student satisfaction surveys. This is the only information she has volunteered, but I know ‘imagined-Kimberley’ well. The category of ‘non-stigmatised person’ is the default, and upon meeting someone unknown to us, it is usual to make a series of assumptions about them, often unconsciously, these assumptions only come to light when we are presented with evidence which contradicts them (Goffman, 1963). Kimberley was a ‘non-stigmatised person’ by default. All delegates were ‘non-stigmatised people’ by default. My paper was accepted by default. I am a student representative, my paper has not been subjected to the same rigorous application process; if it had, would I have been invited to speak?

I am apprehensive as the delegates introduce themselves. My ‘turn’ nears. Will my voice abandon me? Should I self-present as a detached third party to my research or is it best to make some passing reference to my diagnosis in a rationale? My ‘neighbour’, Hulya, introduces herself. Hulya is a Turkish sociologist, her research focus is on gentrification in Ankara. I inhale deeply and ‘gabble’, stricken with ‘stage fright’, ‘hi, my name’s Amy Simmons, and I’m looking at autistic students’ transitions in further and higher education, and I go here, I’m from round here,’ my distinctive, relatively broad accent would ordinarily render this redundant information but this is an international conference, regional accents might not be so easily identifiable to non-native English speakers, I reason.

I ponder, briefly, how sociology can be so wide-ranging. Until recently, when I read Hulya’s paper, the term ‘gentrification’ was not in my vocabulary. The concept was alien to me. But Hulya specialises in gentrification. Imagined-Hulya has organised counter-movements to resist gentrification in Ankara. She is heavily involved in anti-gentrification social media campaigns and regularly protests peacefully in public spaces. It is imagined-Hulya’s prerogative. I cannot navigate social life independently, nor can I navigate the physical environment without proper guidance. My social media accounts are diligently monitored, I would be reprimanded for any involvement in social media campaigns (‘rants’) and the likelihood of obtaining parental consent to attend a demonstration is remote. I am, to repurpose Rogers’ (2020) terminology, socio-politically dead (or in a socio-political limbo). But this is imagination. Hulya is an unknown.

‘Hello, I’m Hilda! Oh, I’m sorry, I didn’t see you there!’ Hilda apologises to Steve, who has been overseeing events from a distance. ‘That’s quite alright, I’m not here!’ But Hilda insists, I wonder if she has misconstrued ‘I’m not here’ as some passive-aggressive ‘joke’, ‘no, don’t be silly, you go ahead’ she invites him to introduce himself. ‘I’m Steve, and I’m actually a specialist disability support worker, looking after this young lady here,’ he gestures to me, ‘can I tell them what I do?’ I choose not to shroud myself in secrecy. There is some reference to my diagnosis in my paper. There is the possibility that some delegates are wholly unfamiliar with Asperger’s, it might be best to be ‘matter of fact’, it might be best for this not to be ‘my big secret’. Left to the imagination, a ‘big secret’ can evolve into a ‘far bigger secret’. But I would sooner ‘come out’ on my own terms, and I ‘gabble’, ‘what it is, my research is semi-auto/ethnographic, so I’m using interviews and my own experiences, I’ve got this thing called Asperger’s Syndrome, I’m autistic, so, Steve’s my support worker,' Steve delivers his standard 'she's an axe murderer' joke with impeccable timing. Now 'out', my beats per minute fall to a manageable level. I replay and dissect my cringe-worthy 'big reveal', how the adrenaline had somehow been tangible in my voice, how I had been relatively inarticulate.

It is mid-afternoon. Ian, an Australian sociologist whose work centres on anti-immigration rhetoric in Australia, is delivering his presentation. I smile what I would hope is a warm smile, and stare at the bridge of his nose, nodding periodically, at what I would like to think are opportune moments. Preoccupied with self-presenting as 'asymptomatic', I have no surplus energy to devote to Ian, covering requires my undivided attention. To be 'NT', I must concentrate on the performance, I have always fared best in FHE (and in adult education) when I am not 'in character'. It may be no coincidence that in 2010, when I transferred to another university and covered (unconvincingly) until semester three, I failed my semester one assignment, and I can recall very little of the content of the taught element (a two-part course, delivered once weekly in two-hour seminars, for 22 weeks in total). Exhibiting autism 'as is' increases the risk of withdrawal on grounds of misconduct, managing autism 'as is' increases the risk of withdrawal on grounds of failure to work at the required standard. As Ian hastily draws his presentation to a close (he has miscalculated the timings by quite some margin), I applaud, and the panel (Julian, Hilda and Kalina, a high-ranking trustee in the organising body) and several delegates enthusiastically contribute their considered opinions and questions.

I watch the clock, longing for the tea break, hoping for biscuits. I am in no position to contribute to the discussion. If Ian has comprehensively addressed my 'question' (asked for effect, not information) in his presentation, if I repeat an earlier question, I will make my inattention quite plain. But I also uphold a self-imposed isolation in my silence, as stigmatised individuals are wont to do (Audet et al. 2013; Cairns, 2013; Corrigan and Rao, 2012). My solitude is a sanctuary. If I do not speak, I do not risk opening the 'closet' door inadvertently. I will say nothing atypical, or confusing, if I say nothing. Research participant

John isolated himself from his flatmates, choosing not to socialise with others in his student accommodation, opting to socialise with other autistic students living in another flat. John had an active social life, but I interpreted his ‘relationship’ with his flatmates as self-isolation. I occupy a liminal space, neither ‘in’ nor ‘out of the closet’, there is no deliverance in confession, as Foucault (1976) identified. Volunteering stigmatising information can liberate a stigmatised person from the burden of secrecy, but confession perpetuates the cyclical relationship of knowledge and power.

Monday 4 April 2016

It is midday. Julian distributes a generous sum of money to the international delegates, to cover their evening meals. Steve, Samara and I live locally, commuting daily, but we have been treated to our evening meals, nonetheless. It is in these informal settings that I am comfortable, it is in these contexts that conversation flows most easily between myself and others. I demonstrate regional variation in BSL, much to the good-natured amusement of Julian, I ‘mingle’, I am Amy ‘as is’. I am bubbly, self-assured, I am delighted to welcome delegates from so far afield to one of my nearest cities, my ‘second home’. I am socially awkward, but I am content. I am on an even footing with other delegates. In the seminar room, I retreat into my ‘shell’. Julian announces a pioneering, thought-provoking exhibition, documenting xenophobia, in a nearby university (‘post-1992 university’). I am semi-familiar with ‘post-1992 university’. My youngest cousin Beth is an undergraduate student at the university, I had interviewed a participant at the university, I pass it on my commute.

‘Is it far to [post-1992 university]?’ Kimberley asks, ‘no,’ I respond, flinching, I am startled, ‘it’s not far,’ I continue, bolstered, the ice is broken, ‘just a couple of streets away,’ I hesitate, ‘I can show you if you like?’ I contemplate the directions; it would be a complicated affair. ‘We’ll reconvene after lunch, when we’ll have Amy and Kimberley,’ Julian restores some order to the proceedings. ‘Show time’. It is difficult not to reflect on a conference paper I delivered in

Nottingham in January. I had not slept. I was ill with fear. My mouth was bone dry, I gasped for breath and sipped water to buy time, before an audience of seven, including the chair, Steve, two other presenters, and three vaguely interested parties. But the post-lunch slot is perfect for a nervous presenter. There is time for Bach Rescue Remedy (an herbal remedy to ease the nerves). There is time to retreat to the toilets to immerse myself in music, written to inspire, and uplift the listener, but there is no time to 'overthink'. My presentation runs to time, as rehearsed, and by my standards, I am 'calm'. The anticipated panic attack does not materialise. The discussants and delegates are not critical but curious. I listen actively. Julian has designed the group discussions to meet *my* needs as a presenter. I was not 'singled out'. There was no announcement (i.e. 'group discussions will follow a 'question-answer' format to accommodate Amy's needs as a presenter living with a processing delay'). From the outset, the group discussions have had a 'question-answer' structure. A 'questions-answers' format demands auditory processing skills I do not have, a working memory I do not have. A 'questions-answers' format expects the panellist to commit to memory *all* questions, process *all* questions and give a considered response to *all* questions. The questions are successive. There are fewer demands on the working memory in a 'question-answer' panel discussion. The perfect slot, the perfect panel discussion format.

Wednesday 6 April 2016

On the evening of Wednesday 6 April, the delegates congregate for a drinks reception, organised by my department to launch a new publication and mark the opening of the third conference. There are several renowned sociologists in attendance. By 'the delegates', I no longer refer exclusively to the 20 international guests but to approximately 450[14] sociologists (comprised of the 20 international guests and 430 other interested parties). Under the guise of 'reading the posters' on display, I circulate the room alone. I am a 'cared for' student. Ordinarily, the toilet is my space to process social life, and my inner

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[14] Plenaries were delivered in a hall with a seating capacity of 450.

world. It is the one space where I ought not be accompanied (Steve is a *non*-medical helper). But circulating this room alone is an opportunity to process the enormity of the eight-day conference, the enormity of using my home as a ‘base’ (I live in my parental home, we are a family of dog owners, but I have seen very little of my mother, my father or my dog), the enormity of self-presenting as near-neurologically typical, the loss, or disguise, of my Self. Autism is the foundation of my socio-political identity. And in this context, my Autistic Self is ‘not good enough’. In this context, should I exhibit my Autistic Self, I will *fail*. Steve is a warm and compassionate man, but I will be disciplined if I cannot ‘manage’ my Asperger’s. I dare not disappoint him. I run my fingers through my hair. I reposition my child-size spectacles on my nose. My right hand protectively grips my left. Am I stimming? Or am I medicalising?

In one case, outlined in Oliver (1983), a man attended an appointment with a social worker. He was in the process of completing a form, and there was a point of ambiguity. But the social worker made no effort to elucidate the form, advising him on how best to ‘come to terms with’ his clinical condition. Whilst the man had stated the purpose of his appointment, the social worker had been insistent. Oliver (1983) identified the social worker’s behaviour as ‘medicalisation’. A non-disabled person might have made these enquiries. His queries were wholly unrelated to his disability, but the social worker groundlessly attributed his decision to book an appointment to his medical complaint. It is possible that I am repositioning my spectacles on my nose because the fit is not perfect, and the nosepiece is lower than is comfortable for me. It is possible that my long and unruly hair is brushing against my face and irking me. It may be a nervous habit. But diagnosed with Asperger’s, ‘ordinary’ behaviours can be misidentified as a stim, and to stim is to fail.

My eyes skim the text of a research poster. I absorb no information, I am ‘reading’ for show. Processing the information would be time consuming. I forego comprehension to disguise my dyslexia, lest the presenter should identify me as ‘different’. Be it a conference paper, a lecture or a poster presentation, I cannot concentrate on, or process, the content, if I am to self-present as neurologically typical. The international delegates cheerily greet me as our paths cross. With some sadness, I see the bond developing between the international delegates. I am a ‘hello friend’. The international delegates are living in close quarters. I commute, I have barely contributed to group discussions. I should not be surprised. But there is still some longing for more than ‘hello’, more than Facebook contacts I will likely not contact. I am ‘the local’.

It is not my first brush with this ache. In 2009, I had a close-knit circle of friends. One woman, Michelle, lived in Milton Keynes, but she was Ghanaian and emigrated to Ghana shortly after graduation. Anastasija had immigrated from Latvia and emigrated to Belgium, Matylda had immigrated from Poland and emigrated to Sweden, Maciej too had immigrated from Poland. He had settled in the area for a time but with no roots to ground him to the city, he eventually embarked on an extended tour of Asia. ‘The local’ will forever be the one ‘left behind’. Overwhelmed by the sheer volume of delegates, I meander towards Steve. I accept a complementary orange juice with a ‘thank you’. I direct my attention towards a senior lecturer in my department, who is preparing to deliver a speech. He appeals for silence. I sip my orange juice, the ‘epitome of sophistication’. I choke, gasping for a breath! I contemplate fleeing to the toilets to right this, the orange juice is restricting my airways, but fortunately the incident passes unnoticed, and shaken, but no worse for wear I ‘listen’ to the speaker as he welcomes guests and promotes the publication. I spot a familiar face, a friendly face. Steve reprimands me, ‘stop staring!’ Obediently I redirect my gaze to the speaker, but my attention is drawn towards her all the more. Be it self-stimulation, using ‘filler language’ or staring at a colleague, I want what is ‘out of bounds’.

The speaker concludes his welcome remarks and the delegates disperse, I chance another glance at the woman, she is relaxed, sharing a joke with a colleague, sipping a glass of wine. ‘Amy! Stop staring at her!’ When a non-medical helper offers advice, the ‘cared for’ student would do well to take heed. I am almost morally obliged to override my instincts, in the event of a conflict with his, I am almost morally obliged not to contravene social norms. The loss of privacy, the loss of freedom, the impermanent loss of my Self, all sacrifices I willingly make, for a prospective opportunity, a quality of life. Providentially, I am distracted by a woman in a vibrant orange outfit; her appearance is striking, her dress, her shoes, her accessories, her wheelchair, all vibrant orange. I noticed her at registration this morning, and again in a paper session. With somewhat similar research interests (the disability studies branch of sociology), our paths cross in Frontiers sessions. She is well-spoken, and I resolve to initiate a conversation with the woman, Joanne, before close of play on Friday evening. I am ‘drawn’ to Joanne. Is there some greater purpose for it? I contemplate our respective privilege. Should I choose to self-present as NT, should I choose to withhold information about my diagnosis from others, should I hone my NT ‘act’ and perform it with conviction, I might circumvent the ableism to which I would otherwise be subjected.

Joanne cannot self-present as non-disabled. Her disability is visible, mine has the potential to be rendered invisible. But there is no expectation that she will ‘pass’. It is commonplace for a delegate to be conscious of their self-presentation at a conference (Ford, 2013). This is not exclusive to autistic individuals. But her behaviour is not monitored, she will not be reprimanded if she ‘messes up’ (to borrow terminology from Goffman, 1961). Imagined-Joanne will not bore other delegates. Imagined-Joanne self-regulates with ease. When I imagine Kimberley, or Hulya, or Joanne, when I invent their Self and life history, I am processing my ‘inadequacies’, imagined-Kimberley is a point of comparison, ‘she’ is mature, I have a developmental delay. Imagined-Joanne is well-liked, charming, I am socially awkward. My imaginings are about *me*, *my* insecurities, *my* supposed inadequacies.

Thursday 7 April 2016

It is midday. The remnants of a mushroom stroganoff are scattered about my plate. The caterers do not provide knives. I am relatively content to make do, but Steve is bolder, and has approached a server. ‘This is fucking stupid!’ He reports, ‘he said they’re not giving people knives in case someone gets violent with them!’ I smile, but briefly entertain the possibility that I am a ‘threat’, autism is a developmental delay, but social, emotional and behavioural difficulties can be comorbid. ‘I said to him, I could hurt you with this fork if I wanted to. I could hurt you with a plate if I wanted to! He went,’ (Steve demonstrates a mock-nervous expression), ‘yeah!’ The elongated ‘yeah’ indicated some degree of satisfaction with the response his ‘threat’ had elicited. I persevere with the stroganoff.

I retrieve my already well-thumbed conference book from my complementary tote bag. I choose a Frontiers paper session (two Frontiers paper sessions are running concurrently), and, shouldering my tote bag, I stroll sleepily to the conference room, Steve in tow. None of the presentations are wholly pertinent to my thesis, but I am reluctant to waste the opportunity. The conference room door is unlocked, but Steve and I are the sole occupants of the room. ‘Steve, can you pass my conference bingo card, please?’ Conference bingo is a joke. It is to be ‘taken with a pinch of salt’. There will be no winner, likely most delegates will have discarded their card, seasoned delegates might have smiled, reading the ‘bingo card’ as a guide to ‘conference clichés’. But it has been presented as a game, and I can be competitive to a fault. Steve dutifully hands me my conference bingo card and a pen. I sigh and check the clock; 1:05. I lift the lid of the pen to check the ‘a presentation is cancelled’ box. *Click*! *Creak*!

The session chair and three young presenters with an aura of nervous energy enter the ‘scene’ in a rabble. ‘Is that alright then? Louise, you’re going first, then we’ll have Natalie, and we’ll finish off with Victoria,’ the chair confidently syncs the computer and projector, the image of the desktop, projected onto the whiteboard, updates in real-time. Louise, Natalie and Victoria upload their files, none of the presentations have familiar titles. ‘We’re in the wrong room!’ Steve whispers, ‘oh well!’ I aim to affect nonchalant airs. ‘This is a round table,’ the chair warns me. This communicates little to me, ‘that’s okay, we’ll stay anyway!’ ‘We’ll go,’ Steve has made an executive decision. Immediately, I stand, and take my leave, hypothetical tail hanging between my legs. I am compliant. I override my instinct, to support Louise, Natalie and Victoria, three young women who might have prepared for this paper session for months, designing and rehearsing a PowerPoint presentation, making travel arrangements, perhaps managing performance anxiety. Now, there would be no interested parties to ‘perform’ to. But this is the lot of the ‘cared for’ student. The non-medical helper’s better judgement overrides the client’s instinct.

I shake with adrenaline as we near the lounge (it might be a bar area, a refectory, its function is ambiguous). I prepare to cross-reference the room number of the paper session with that of the pre-lunch paper session, prepare to ‘confess’ my mistake to Steve. I anticipate his anger, his frustration, he has supported me since 2003. My mistakes are his own, if I ‘fail’ it reflects badly on his mentoring skills. I fare best with shock and discipline, but shock and discipline are disquieting. But the room numbers coincide. ‘Probably because we didn’t go to the plenary this morning,’ I reason. ‘More than likely, Aim’. But I tearfully ‘turn the air blue’. At home, I do not use expletives. ‘Fart’ is a standard colloquialism for ‘flatulence’ or else it is used as a mock insult, ‘you old fart,’ but I was not to use it in the company of my parents. My upbringing was reinforced at school, with an old wives’ tale (upon a person’s death, an oversized foot would tread with force on whomsoever swore in life). But in the throes of penetrating distress (the shock, the humiliation, and the hormones), I lose all control, free to use a barrage of expletives, Steve curses regularly. Steve intervenes, mortified, ‘remember where you are’. ‘Remember where you are’ is his warning, ‘your behaviour, in this context, is inappropriate’. ‘Where I am’ is a conference centre, in a university, my *alma mater*, and whilst there are no delegates in earshot, there is still a possibility, however remote, that a ‘straggler’ might be exposed to this spectacle, and I might cross paths with this ‘straggler’, in a job interview, or in a *viva voce*.

It is possible that I might be overheard by a senior member of staff in my department, and my ‘bad’ (autistic) behaviour could be reported to my personal tutor; he is an affable man, but could he forgive me if I damaged the reputation of the university? ‘I *suggest* we go up to the office for a bit,’ Steve interjects, ‘it’s too late to go to one of the other ones now,’ and I agree. The alternative is to laze in the lounge/bar/refectory ‘twiddling our thumbs’ for an hour. I would sooner salvage *something* from this scenario, which calls to mind an embarrassing event in my youth. Dishevelled and panic-stricken, with no circle of friends in my form and poor wayfinding skills, I interrupted my French lesson at the age of 11. The teacher scolded me and queried my tardiness. In a false French accent (I was a ‘loser’, I thought I may as well cement that reputation), I drawled, ‘I got, how you say? Lost!’ I was not lost earlier, but I was, quite accidentally, and very noticeably, in the wrong room. Under ordinary circumstances, in an ordinary paper session, the oversight, the error, or my sheer misfortune would have gone unnoticed, it would have passed without incident. I would be a ‘face in the crowd’, it would, perhaps, have been an opportunity to discover an area of sociology I had not yet considered, or else, I would have feigned interest. But fortune was not in my favour. And ‘you turn up to the wrong paper session’ is not an item on my conference bingo card!

Fresh air, or what qualifies for fresh air in a city centre; the delegates are elsewhere, in the conference centre, mid-paper session, I could sing! Literally. I am wont to express myself in song, I am wont to use musical theatre and fantasy to process social life. For context, in the Disney animated musical Frozen, two princesses prepare for the elder sister’s coronation, the younger princess, Anna, is elated, but her sister Elsa fretfully prepares for her public engagement. For much of her life, Elsa has lived in solitude, and she has been warned by her superiors to manage a ‘difficult difference’ which, if exhibited to her subjects at this public event, could have widespread consequences. For the most part, I work in an office. The office is largely disused (others may use the office, but it is rare I have company). But this is a well-attended conference, and I must manage my ‘difficult difference’, on the recommendation of my non-medical helper; the consequences of ‘failing’ to self-present as neurologically typical could be far-reaching and dire. I begin to sing *For the First Time in Forever*, ‘Don’t let them in, don’t let them see, be the good girl you always have to be, conceal, don’t feel, put on a show, make one wrong move and everyone will know’ (Anderson-Lopez and Lopez, 2013a). ‘Remember where you are!’ Steve interrupts my ‘number’. He does not approve of my musical interludes. He especially disapproves of my musical interludes at public events.

He has issued his second warning in two minutes. Child-like, I protest, ‘I didn’t think it mattered out here, I thought you meant when I was in the conference!’ ‘But someone’s bound to overhear you and say something, you know what they’re like!’ Singing might not be a disciplinary offence, but it is unprofessional. I concede defeat and fall silent. But Elsa does not fall silent. It is a blissful earworm, which evolves into *Let it Go*, a song which reflects my need for emotional release; I ‘can’t hold it back anymore’ (Anderson-Lopez and Lopez, 2013b).

I am storm-like, I crash through sets of heavy double doors and round the many corners in this ‘warren’ of a floor (there is no possibility of a wrong turning, but it can be disorientating). The office promises sanctuary. It promises solitude, a release, the possibility of music. And it is a promise that is unfulfilled. Murphy’s Law! Priya is at her desk. She is kind, warm, and ordinarily I would delight in her company. But these are no ordinary circumstances. Research participant Vanessa, a university student, reflected on her need to be alone after a difficult day, too, and how at times this was not possible. I key in the passcode. ‘Hey, how are you?’ *Broken, humiliated,* *confused, tired of masking, in need of a release,* ‘not bad thanks, you?’ There is an unwritten rule, governing communication; in most contexts, the ‘question’ ‘how are you?’ is not a question *per se*. It is a ‘question’ to convey sociability. ‘How are you?’ requires a positive statement, in the happiest, or most dire of circumstances. ‘Not bad, thanks’ is the standard below which no one must fall.

Malinowski (1923) identified this as ‘phatic’ language. It is small talk; sociability requires the use of figurative language, and the correct interpretation thereof. It is a social rule of which I had little knowledge until the age of 16. A ‘friendship’ had developed between me and Hayley, a year my senior. Hayley tolerated me, she was kind, but I was clingy. Using ‘see you later’ as a parting statement, Hayley inadvertently confused me. I would wonder where, and at what time. ‘Hedging my bets’, I would wait patiently in the refectory. I would watch her, confident my ‘later’ would come. My behaviour caused Hayley some discomfort; limpet-like, I had ‘latched’ onto her, and she reported me to pastoral care. I might have been withdrawn from my programme, had my mother not defended me in a crisis meeting, my first of four in FHE. She had advocated for me in previous crisis meetings, but never had I risked withdrawal until that hearing in November 2001.

Hayley had used phatic language. I recall my conversations with a second young woman at this time, Shellie, a pleasant performing arts student of my age. ‘How are you?’ I would enquire after Shellie’s well-being; ‘not bad!’ Was her physical and emotional well-being not subject to change? Was her life so monotonous that she never had cause for delight, for fear or self-doubt, excitement, anger or pain? Shellie had been using phatic language, which might not, at times, have reflected her emotional state. It is ‘ordinary’, ‘everyday’ language, but to a somewhat literal thinker with little concept of social communication, ‘not bad’ was something of an enigma. I sit at my desk, my bracelet slightly ‘digging into’ my left wrist, the edge of the desk slightly ‘digging into’ my right. I perfect a conference application; the conference will be a day-long department-wide event for PhD students and faculty members. *All* papers will be accepted. Inwardly I sigh, I cannot ‘let it go’ for over 24 hours. But after 149 hours, the ‘finish line’ is in my sights.

Friday 8 April 2016

In an hour, I will be ‘homeward bound’. I am hormonal and wanting for something more than ‘nibbles’. I feign interest in a display, to give the impression that I have cause to be there, ‘I want cake’ does not seem *quite* legitimate! The vendor smiles, ‘are you looking for something in particular?’ ‘No, I’m just browsing, thanks’, I reply in haste. I am reminded of a brief interaction at the foot of an escalator in a department store, I am passing through, hurriedly. I have an informal interview at my *alma mater*. ‘Hi, how are you today?’ ‘I’m really good thanks, how are you?’ Is this cheerful young woman an old friend? It has been four years since my registration with my *alma mater* expired. Is this an old friend greeting me, a ‘welcome home’? The woman is surprised, ‘I’m okay, thanks, first of all can I just say thank you for stopping to talk to me today, most people just ignore me! What it is, we’re looking for people to donate to the RNIB,’ (Royal National Institute for the Blind) ‘right, yeah,’ I am uncomfortable, ‘well, I’m in a bit of a rush at the moment, but, er, I’ll take a leaflet,’ I snatch *her* leaflet, ‘we don’t have any leaflets, sorry, that one’s mine,’ I sheepishly return her leaflet, Steve intervenes, guiding me to the exit, ‘sorry, we’ve got to go, we’ve got a meeting at the university!’ I am a ‘sucker’. I contemplate the peculiarities of these interactions; interactions with the warmth of a friendship, but it is an affected and artificial warmth.

In my compromised emotional state, I ponder, ‘is this the closest to friendship I will come?’ I *do* have friends, but I *feel* lonely. I spot a caterer, outside the bar/lounge/refectory, row upon row of cupcakes have been arranged on a buffet table. I choose a cake, ‘rewarding myself’ for a week of managing my emotions, my Asperger’s Syndrome, my Self. Kimberley is in the bar/lounge/refectory. I attract her attention, I have not been limpet-like, but she and Joanne were the two delegates I had been most ‘drawn to’. ‘Erm,’ I am hesitant, ‘just so you know, not all autistic people are like me, just in case I’ve been a bit, you know, weird or whatever,’ my conduct largely conforms to the Asperger’s stereotype, I am socially illiterate, the ‘best’ advocates for autistic individuals are those who do not conform to the stereotype. I am an ‘embarrassment’ to autism, but Kimberley is quick to reassure me, ‘my little cousin is autistic, so, you haven’t done badly, but even if you had, I wouldn’t think that you were all the same!’

Two hours on from my brief exchange with Kimberley, I am home. David, my brother, three years my junior, hugs me and bids me goodbye, leaving our house for his own home, which he shares with his fiancée Rachel. He is visiting *me*, and I appreciate his efforts. He and Rachel live ‘close by’ (within eight miles of our village) but he has had a 25-minute drive. Our parents have been invited to a wedding reception, guests of the bride Sarah, a one-time friend of mine, the elder daughter of friends of the family. Linda and Carl, Caroline and Spencer, Angela and Rob, Fiona and Bryan, and my parents Ellen and Clive are ‘the gang’ (Linda, Caroline, Angela, Fiona and my mother are ‘the women’ and Carl, Spencer, Rob, Bryan and my father are ‘the men’, two separate units for the most part). Sarah is the elder daughter of Linda and Carl.

‘The women’ bonded at a mother and toddler group; Sarah, Fiona and Bryan’s daughter Kelly and I are the same age, Sarah’s sister Lauren is the same age as Caroline and Spencer’s son George, and Angela and Rob’s eldest son James. Sarah, Lauren, Kelly, George, James and his two brothers, Christian and Hugh, were a ‘ready-made’ circle of friends. Reflecting on my childhood, I was not *lonely*. I had ‘friends’ by default, I was ‘Ellen and Clive’s daughter’. I had no incentive to mask. It mattered not that on a long weekend in Derbyshire, I sobbed because one child, Tommy (the younger of two Welsh boys, whose family[15] have since immigrated to Portugal), playfully hurled a water balloon in my direction. It mattered not that in a game of rounders or cricket, I would, with some force, throw down my bat in a ‘temper tantrum’, or, if I felt ‘sporting’, I might congratulate the bowler with an acerbic handshake.

It mattered not that on Sunday 31 May 1998, in a state of shock, I downed my Sony Walkman, overwhelmed by adrenaline, and solemnly announced to the nonplussed women ‘I can now confirm that Geri Halliwell has quit the Spice Girls’[16] or that, at lunch, I had interrogated Sarah, who was enjoying a hard-boiled egg, ‘I don’t know how you can eat that!’ The aversion to boiled eggs is not particular to autism (David lives with the same aversion and he is neurologically typical), but I could not appreciate that the aversion might not be universal. But now, I realise, as I insert my Frozen DVD into my ageing laptop, which whirs with the effort of reading the disc, I am left behind. Left behind as my parents celebrate Sarah’s wedding. Left behind as the one-time delegates board their respective flights home. Left behind as one-time friends become parents, live independently, marry, progress in their chosen careers, drive; and I am spending Friday evening with only a dog for company and an animated Disney film for entertainment.

I imagine ‘the delegates’ parting company, set to *Vuelie* (Fjellheim and Beck, 2013), the opening number in the musical, these images have more resonance (the piece is a chant with no direct translation, but in this moment, the sounds move me). I sob. The emotional release is needed. Either I lose my composure, or I lose that which I can ill afford to lose, Amy. In the subsequent weeks, on the surface, I regress, I ‘struggle to manage’ my Asperger’s Syndrome. Steve warns me, ‘come on, this is getting stupid! This is almost back in [college] mode!’ Panic-stricken, I consent to monitoring my behaviour,

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[15] The older of the two, Edward, and I are the same age. The composition of ‘the gang’ is relatively stable but subject to fluctuation, and I excluded Anita, Richard, Edward and Tommy from my earlier description on these grounds.

[16] I include this narrative here to reflect the absence of theory of mind; this news item was not of universal interest, but I did not appreciate this and behaved inappropriately.

my emotions, my Autistic Self. I consent to ‘making progress’. But ‘progress’ is a betrayal, to ‘recover’ is to concede that to be autistic is ‘less than’. This ‘regression’ is the release of a meltdown, deferred for several days.

Research participant Neil, a college student, reflected on deferred meltdowns (Attwood, 2015), how he tolerated sensory overload in public but, once in the family home, in the company of his supportive parents, his difficult feelings were given expression. For one so unused to covering, for one so uncomfortable with pretence, eight days of covering, of pretence, of denying the Self its right to exist or to be given expression, can be wearing, detrimental to a person’s well-being:

> [A]ttempts to normalise people through behaviourist means or any other, would send them into disequilibrium and a state of personal anomie and possibly rather than leading someone away from a state of mental ill-health, be actually leading someone toward it’ (Milton and Moon, 2012: 2).

Milton and Moon (2012) described the case of a woman with Asperger’s Syndrome, who took her own life, an effect of normalising. I might choose to *defer* a meltdown if I am covering, but once in ‘safe’ company, or alone, I give expression to these difficult feelings. I willingly ‘risk’ a ‘low functioning’ reputation, I knowingly give the impression of ‘regressing’. A meltdown, in me, is not self-limiting. It can be supressed, temporarily. It can be silenced, so I seem to be ‘coping well’ but within a 24-hour period, unprovoked, there will be some ‘random’ outburst. If I ‘coped well’ outwardly, I fear I would cope badly inwardly. I am seemingly regressing but I am conserving my emotional well-being. ‘Safe’ company is crucial. For Neil, deferring meltdowns until in ‘safe’ company is a release. Likewise, participant Stacey, a university student, listed several parties, teaching staff, disability support co-ordinators, her friends and her mother, who had supported her during her transition to university.

2.3 Normalisation

In light of the above auto/biographical narrative/auto/ethnography I am able to reconcile Autism, the positive self-identity, with autism, a catalogue of social, emotional, behavioural and sensory difficulties. I am Autistic, but I cannot overlook the realities of autism as a clinical condition. Kapp et al. (2012) identified how ‘Neurodiversity advocates, while often emphasizing social barriers, have acknowledged this interrelationship between internal and social challenges’ (Kapp et al., 2012: 10).

Clinical, psychological and social forces are at play, and there is interplay between the three. The Autistic person can challenge the misconception that autism is ‘less than’, but to survive, Autistic individuals *must* meet the challenges of autism. ‘Survive’ is no hyperbole for Autistic individuals in ‘no-man’s land’, ‘not autistic enough’ to qualify for state benefits, ‘too autistic’ to be considered for a job. But the high value which was being placed on ‘normalcy’ and normalisation (Davis, 2014; Wolfensberger, 1972), did not sit easily with my Autistic self-identity. Normalisation makes ‘available to all people with disabilities patterns of life and conditions of everyday living which are as close as possible to the regular circumstances and ways of life or society’ (Nirje, 1985: 67). It is difficult to oppose this principle, proposed when individuals with profound GLDs were confined to institutions and *fully* excluded from social life (for example, residents were barred from observing public holidays, and there was no separation of the working week from the weekend) (Nirje, 1994).

By covering (Goffman, 1963) and normalising, I had been hoping to achieve a ‘regular’ way of life, a fulfilling career, a living wage and a good quality of life. The *principle* of normalisation was ground-breaking and re-integrated disabled individuals into social life, but the *process* of normalisation can have devastating consequences for the autistic individual’s self-perspective and emotional well-being (Milton and Moon, 2012). Other thinkers have expressed *their* reservations about normalisation. Parents are advised to register their autistic children in therapy for ‘early intervention’ to mould the child’s behaviour at an age when behaviour is relatively pliable; applied behavioural analysis (ABA) is one of the most popular, yet controversial therapies available to normalise autistic children (Devita-Raeburn, 2016).

ABA practitioners build a profile of the autistic client (identifying the child’s interests and areas of ‘weakness’) to develop a personalised programme. When an autistic child exhibits behaviour appropriate for a child of their age (for example, maintaining eye contact), the therapist will reward them (for instance, they might be rewarded with a brief time playing with a favourite toy, or a piece of their favourite chocolate). Should an autistic child *not* exhibit the desired behaviour, or if the child exhibits ‘inappropriate’ (autistic) behaviours, the therapist will temporarily withhold a privilege. But some of the principles underlying ABA, and some of the unintended consequences of ABA are troubling to many Autistic social commentators, and the parents of autistic children. Citing Pellicano (2013), Lambert (2013) identified how:

> Although therapists wouldn't say that they're trying to normalise children with autism, that is the underlying ideology of ABA – to make them indistinguishable from their peers […] Being told there's something wrong with you is going to potentially make you more anxious and more depressed, which is already highly prevalent in people with autism (Lambert, 2013: n.p.).

I have never been enrolled in therapy. ABA *is* suitable for adults, but the therapy was not recommended for me. My parents are uncomfortable with ABA. Television personality Chris Packham’s documentary Asperger’s and Me (Russell, 2017) featured an ABA session; ‘Clive? Clive!’ my mother woke my father, ‘I don’t think I can watch any more of this!’

But Pellicano’s (2013) ideas are consistent with my (mercifully brief) experiences of normalisation, and the (happily temporary) consequences for my emotional well-being. Although Neil had been developing an Autistic socio-political identity, he recognised the importance of conforming to socially prescribed norms, to move forward in education, which Myers et al. (2011) identified as the bicultural stage of the autistic individual's identity formation. I am marginally bicultural, I have good interpersonal relationships with neurologically typical others, but I am not quite bicultural, I am not quite 'mainstream'. I conformed to socially prescribed norms, but under duress. For eight days, I overrode my socio-political identity, unable to reconcile my need for Autism with Steve's advice to adhere to social norms. What I have been describing in this chapter is biculturalism *before* becoming bicultural.

Normalisation reinforces to autistic individuals that they are broken, flawed, and damaged, it reinforces the dangerous idea that self-integrity is tantamount to failure, the damaging idea that the person is 'not good enough', or that there is something inherently *wrong* with autism 'as is'. Pellicano (2013) and Lambert's (2013) critiques of ABA also emphasise how the therapists are not at fault here, similarly, Steve cannot be held accountable for how I responded to those eight days of normalisation. The source of the problem is not the aims, objectives and personal values of therapists or support workers. The source of the problem is a society which undervalues, and is unwilling to accommodate, difference, a society which stigmatises those who are identified, in some way, as different, 'Unfortunately, rather than leverage those differences to our collective benefit, we often allow our differences to impede progress and innovation. When confronted with someone who looks or acts differently, many of us tend to recoil' (Page, 2007: xiv).

The downplaying of difference, the observation and mimicry of NT behaviours to give the impression of 'doing well' is Self-sacrifice. For the *possibility* of an 'ordinary' standard of living, for the opportunity[17] to build a career as a sociologist, I temporarily sacrificed my Self. Normalisation and/or covering appears to resign profoundly autistic individuals to the bottom of a hierarchy

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[17] This can only ever be an *opportunity*, a *possibility*. Self-presenting as NT is no guarantee of a job.

of impairment (Tringo, 1970), the ‘less autistic’ the autistic person appears to be, the ‘more human’ they are perceived to be. Normalisation, as a process, not ‘only’ has the potential to damage an autistic individual’s emotional well-being, it is a gross social injustice to individuals on the other, more heavily stigmatised end of the arbitrary autistic spectrum. Davis (2014) observed ‘while diversity is the regnant ideology, the older concept of normal still holds sway, but only when it comes to disability’ (Davis, 2014: 6).

Autism ‘as is’, its peculiarities (for example, expertise in an obscure topic, an aversion to, or phobia of, an everyday product or situation) also languishes at the bottom of (what I will refer to as) a ‘hierarchy of weirdness’. It is not uncommon for neurologically typical individuals to *deliberately* deviate from socially prescribed norms, to be ‘quirky’ and ‘individual’, but only ever within the confines of social acceptability, and only ever fleetingly (Waldschmidt, 2005). Disabled identities permanently lie outside the boundaries of ‘socially acceptable’ difference. Davis (1997) claimed the ‘“problem” is not the person with disabilities; the problem is the way that normalcy is constructed to create the “problem” of the disabled person’ (Davis, 1997: 9). The ‘problem’ is created concurrently with ‘normalcy’, the ‘problem’ of autism is, to some degree, created when society privileges NT behaviours above autistic behaviours. All that is autistic has been defined in relation to all that is neurologically typical, and mostly unfavourably.

It is not uncommon for a person to manage their self-presentation in everyday life (Goffman, 1956), or at a conference (Ford, 2013). It is not unusual for a person to (consciously or unconsciously) manage how others perceive them. But the stigma attached to autism added a second dimension to everyday perception management strategies, and ordinary conference behaviour and insecurities. Non-stigmatised individuals are not expected to pass, camouflage, mask, cover or compensate. Livingstone and Happé (2017) defined compensation as ‘the processes contributing to improved behavioural presentation of a neurodevelopmental disorder, despite persisting core deficit(s) at cognitive and/or neurobiological levels' (Livingstone and Happé, 2017: 731). When, at the beginning of the conference, I prepared for a possible elimination game, my hope was to compensate. There were ongoing issues with low-grade[18] kakorrhaphiophobia (a disproportionate fear of losing or failure), my objective was to behave in an age-appropriate way, to behave in ways which Steve would approve. Similarly, when I prepared for the possibility of a joke to celebrate April Fools' Day, my aim was to compensate. There were ongoing issues with this branch of humour, but my intention was to behave in a way which gave the (false) impression of 'improvement'.

Hull et al. (2017) identified the physical and emotional consequences of autistic individuals' use of camouflaging, 'In the short term, camouflaging results in extreme exhaustion and anxiety; although the aims of camouflaging are often achieved, in the long term there are also severe negative consequences affecting individuals' mental health, self-perception' (Hull et al., 2017: 2532). The deterioration in my emotional well-being and my self-concept, which I described above, raises the question of causality. Shame can cause individuals with a stigmatised identity to cover (i.e. if the person is ashamed of their stigmatised identity, there is a stronger likelihood of that person passing or *at a minimum* covering), but equally, covering can cause the person who is covering to feel ashamed (i.e. if the person has been advised to cover a stigmatised identity, some will question *why* this is necessary, falsely locating 'the problem' in the identity, not in others).

None of this is mutually exclusive, but for me, it was the latter, covering instilled a sense of a shame in me. I chose to cover to protect my job prospects, aware of how few job opportunities are ordinarily available to autistic individuals. I chose to cover under Steve's surveillance, regulated because I cannot self-regulate (Foucault, 1975), in common with many other autistic individuals (Whitman, 2004). Steve is gentle and patient, but I will be reprimanded for

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[18] Kakorrhaphiophobia at its most debilitating, can prevent a person from pursuing FHE or adult education.

undesirable behaviour. I did not choose to cover in shame. I am not ashamed of my Asperger's Syndrome, although 'Stigma […] is intimately bound up with shame. In moments of stigma, Goffman famously noted, 'shame becomes a central possibility'' (Lyons and Dolezal, 2017: 208). Individuals with stigmatised identities cover for reasons besides internalised stigma, most often to circumnavigate the unwanted consequences of social stigma (Kanuha, 1999; Olney and Brockelman, 2010). The decline in my mental well-being began *as the conference progressed*, worsened by unremitting covering, for a prolonged period (this is relative; to one who is not accustomed to masking, to one who is Autistic, eight days is a prolonged period). Eastman (2015), an autistic woman who *chooses to* pass, as an act of self-preservation, wrote 'Passing undermines who we are. Passing causes irreparable damage to our psyche, because we know that unless we put on an act, who we really are will not be accepted by the vast majority of people' (Eastman, 2015: n.p.).

There is no freedom for the person who chooses to cover. Downplaying difference necessitates almost as much concentration and energy as masking (Goffman, 1963). I would like to use the analogy of a tightrope walk here. The autistic person is expected to 'perform' before an audience, cautiously treading a 'high wire', on which there is little to no room for manoeuvre or error. Covering gives the autistic individual a safety net to fall back on, covering gives the autistic person a legitimate 'excuse' for their atypical behaviours (where the autism is known to others, the autistic 'tightrope walker' can apologise and 'blame' their behaviours on autism, but they have 'fallen', they have 'failed', and there is no freedom even in 'failure', only humiliation, and a lower self-opinion). If a person 'fails' while covering, it is not *carte blanche* to be their Autistic Self. In the event of a second, *identical* 'triggering incident', one who covers is expected to 'improve' on their previous 'performance'. The show must go on.

Covering however, would be quite unnecessary if there was no stigma attached to 'difficult differences' (for example, mental ill health, GLDs and

SEBDs). The most up-to-date statistics in several areas of interest, including the number of homeless individuals with possible or confirmed autism, the under-employment of autistic adults, hate crime figures and public responses to filicides[19] resulting in the death of an autistic child can be harrowing reading. 73% of people with GLDs and autistic individuals have reported hate crime, and the incidence rate is likely to be much higher, as not all occurrences of hate crime will be reported (Dimensions, 2018). The National Autistic Society (2016b) reported that just 16% of working age autistic adults are in *full-time*, paid employment. This figure has remained static for a decade, despite government initiatives, for example, the Equality Act (Equality Act, 2010) to improve these employment rates. A disproportionate number of autistic individuals, or individuals with *possible but undiagnosed* autism are homeless (Churchard et al., 2018), relative to the number of autistic individuals as a percentage of the UK population. Willingham (2013) questioned the public outpouring of sympathy and support for the perpetrator(s) in the wake of most incidents of filicide involving the death of an autistic child, undermining the value of autistic lives. The life of the autistic child and their parents is a life deemed ‘not worth living’ (Morris, 1991), and filicide is seen as reasonable, compassionate and humane under these circumstances.

These are seemingly disparate statistics, but their inclusion here is justifiable; what these statistics indicate is autism is still a heavily stigmatised, desperately misunderstood condition. It would be a gross disservice to the other delegates if I implied that I had been stigmatised during the conferences. For the most part, my interactions with the other delegates were very positive, and there was no reason to imagine that autism was at play in any ‘difficult’ interactions. But mediated stigma and vicariously experienced stigma (Essed, 1991), social exclusion experienced via mass and social media or others (for example, autistic acquaintances) respectively, meant I was conscious of the stigma which is still attached to autism, leading me to self-present in ways which were not authentic, and ways which did not sit easily with my Autistic Self.

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[19] Filicide describes the murder of a child perpetrated by their parent(s) or caregiver(s).

Gray (2002) proposed that autistic people ‘are people with a disability who must deal with the social world as if they were not disabled. The implications of this for problematic social interaction are considerable. One of the problems they experience through social interaction is stigma’ (Gray, 2002: 735). Some non-autistic and neurologically typical others are prepared to make allowances for autistic individuals. It would be an unjust generalisation to make any implication to the contrary. Some such individuals have insider knowledge of the condition. Familiarity with, and close emotional proximity to, a stigmatised person often lessens the possibility that a non-stigmatised person will stigmatise others with the same stigmatised identity (Goffman, 1963), evidenced by my conversation with Kimberley (above).

Kimberley had some familiarity with autism. She was willing to make allowances for me, but other delegates might not have been willing to make those allowances for me, or other autistic individuals. There is no failproof way for the autistic person to *know* from the outset of a social interaction who will, and who will not, accommodate their ‘difficult differences’. In public spaces, autistic individuals are under relentless pressure to conduct themselves as though they were not disabled, never certain whether the next person they have some cause to interact with will, or will not, be willing to accommodate them.

Whilst there is no direct comparison, for me, it called to mind Foucault’s (1975) work on the panopticon. Bentham designed his panopticon prisons to allow a single guard, who was stationed in a central watchtower, to observe inmates without them knowing who was being surveyed at any one time (with the use of Venetian blinds, a one-way mirror of the time). The guard could only observe one inmate at a time, but none of the inmates could know which cell was under observation, and when. The prisoners would then behave as though they were *constantly* under surveillance, bringing about behavioural reform. I felt as though I ought to behave as though I was NT for similar reasons, never knowing who is watching. On the surface, this contradicts current thinking on the audience effect (i.e. autistic individuals are less susceptible to the audience effect, less prone to behaving in particular ways to give a favourable impression to the observer) (Chevallier et al., 2015; Hamilton and Lind, 2016). Yet my experiences *support* these findings. Behaving, or ‘acting’ for an audience is unnatural to me. This behaviour is an uncomfortable experience for me. This is consistent with Chavallier et al. (2015) and Hamilton and Lind’s (2016) research. I acted to comply with Steve’s advice, and in fear of hindering my prospects.

2.4 Conclusion

This chapter is concerned with my Autistic identity, and the consequences of covering for an Autistic individual’s emotional well-being (in particular, an Autistic individual with little prior experience of covering) (Russo, 2018). Potentially, to ‘be yourself’ is a privilege afforded to the NT. The autistic individual can, quite literally, not afford to be themselves (Bev, 2009). To achieve a decent quality of life, for the slim possibility of an income, and meaningful employment, the autistic person *must* cover, an emotionally and physically exhausting task, which can damage their self-concept and mental well-being (Russo, 2018). I described above how feelings of shame were a *consequence*, and not a *cause* of covering (Goffman, 1963). The feelings I described above were temporary, I no longer feel ‘less than’, for the most part, to be who I am no longer feels like failure (these feelings are becoming more prominent now, as I prepare to make the transition from FHE to paid employment).

But these experiences were cause for me to contemplate the well-being of the autistic person who covers and camouflages on a regular, perhaps daily basis, over a prolonged period, maybe a lifetime (Eastman, 2015). These experiences led me to ponder the position of the autistic individual for whom there is no freedom, no release, from masking, whether in public or at home.

Some autistic individuals have an opportunity to release their difficult feelings in the home (Attwood, 2015; Ives and Munro, 2002; Myers, 2015) but not all autistic individuals have supportive parents or carers (Bonello, 2016). This chapter has been concerned with Self-sacrifice. It should never be necessary to sacrifice the Self in order to gain access to the opportunities NT others take for granted (Bev, 2009).

Using auto/biographical reflection improved the ease with which I could relate to my participants' experiences. Auto/Biographical writing is especially useful for autistic researchers who are not otherwise able to empathise with others, 'to empathize with another person, one must have the cognitive and emotional experience to relate personally to another's feelings. People with autism […] may simply lack the experience necessary to empathize—even if they are quite capable of sympathizing' (Rudy, 2019a: n.p.). I developed my ideas *after* I had collected the data. I did not have the opportunity to explore these ideas at interview. My use of auto/biographical writing was thus also an opportunity to produce data which explores these ideas more explicitly. Self-presentation at an academic conference is a legitimate focus for an auto/biography. Stephens Griffin (2015) who has a history of mental ill health, reflected on a panic attack during an academic conference in his PhD thesis, an account which parallels my own in many ways, Stephens Griffin (2015):

> [D]iscussed a panic attack he had experienced at an academic conference, his feelings of embarrassment and humiliation, worries about his reputation, that other professionals would perceive him as mentally unequipped for an academic career and that it would impair his future employment prospects (Stephens Griffin and Griffin, 2019: para. 35).

I never felt humiliated. I was motivated by the fear of reprimand, but I too feared for my prospects.

This thesis explores the themes of stigma, support, self-presentation and the interplay of autism and institutional factors. In the wider context of this research, there is a stigma attached to the symptomatology of autism (my data supports this) which led my NMH, Steve, to advise me to self-present as neurologically typical as other autistic students do unprompted (for example, Neil). Steve monitored my behaviour meticulously (Allan, 1999; Foucault, 1975) and I self-regulated my emotions (Foucault, 1975) and covered (Goffman, 1963), identifying myself as autistic without there being any indication of this in my conduct, although on the afternoon of 7 April, a ‘trigger incident’ would have compromised this ‘high-functioning’ image, had I been in company. For those eight days, I internalised a hierarchy of impairment (Rogers, 2007; Tringo, 1970). Institutional factors, including the possibility of reprimand for behaving inappropriately and damaging the reputation of the university, whether from Steve or staff in my department, and the potential loss of already slim career prospects (National Autistic Society, 2016b) compelled me to self-present as neurologically typical, and to forego my Autistic socio-political identity. It was with support from my parents, David, Steve, my supervisors and good friends of mine that I was able to recover from the events of that week, some congratulating me on my achievement, others breaking the ‘meltdown cycle’ with stern words and discipline, and some reassuring me that ‘Amy’ is ‘good enough’. My attention now turns to the ways in which this auto/biographical chapter contributes to the aims and objectives of my study.

To reiterate, my research questions were: what are autistic students’ experiences of transition in FHE? What perception management strategies (if any) do autistic students employ in further and higher education (FHE) settings? What support is currently available to autistic students in FHE? Using auto/biography to begin to address my research questions, it can be difficult to concentrate on learning, to focus on the content of seminars and lectures, if the autistic learner is preoccupied with self-presenting as neurologically typical (I quickly lost focus on the delegate presentations and subsequent group discussions, and remember very little of the content of *any* presentations, I was preoccupied with self-presenting as neurologically typical).

As the semester progresses, peers develop friendships, and this can be distressing for the autistic student who is keen to connect with others but finds it difficult. By Wednesday 6 April, the delegates were bonding, and I was a ‘hello friend’. I had been a commuter whereas the other delegates were guests in the same inner-city hotel. For autistic students who choose to commute (as I do), without the independent living skills to function in halls of residence, friendships are harder to come by. Some students will be tempted to self-present as neurologically typical, to manage their first impressions, but this can increase the risk of internalising the hierarchy of impairment in the process. While the conference *was* hosted by my *alma mater*, most of the building was unfamiliar to me and the unfamiliar learning environment, and unfamiliar people, can intensify the symptomology of autism for autistic students.

I covered, by self-presenting as neurologically typical, but sharing information about my diagnosis with others, often from the outset of a conversation. When Hilda invited Steve to introduce himself, at the beginning of the conference, I identified myself as autistic, but this was not a blank cheque to *be* autistic. My refusal to speak in that setting until day *four* of the conference, my plan to use the toilet as a refuge in the event of an elimination game and the plan to avoid the fire alarm test by arriving late on the final day of the conference, all of these actions and plans indicate self-isolation. Initially in the conference centre on Thursday 7 April and subsequently in my office, I deferred a meltdown, as other autistic students do, until I was alone, on the evening of Friday 8 April. Deferring meltdowns exacerbates ‘difficult’ behaviours in some autistic students (such as when I seemed to have ‘regressed’ and Steve intervened).

Steve was integral to my ‘performance’. I have very limited social awareness but with support, I had a clear indication of when to mask and when my behaviour was inappropriate. My experiences indicate widespread provision of NMHs (to monitor the student’s behaviour, encourage emotion work, effectively manage the transition and liaise with others on the student’s behalf) is beneficial for some students. However, the transition to FHE (especially to *postgraduate* education, for students pursuing an academic career trajectory) is *best* facilitated by attitudinal shifts *within* academia. Stephens Griffin (2015) and I both acted out of concern for our career prospects, but neither autism nor mental ill health are incompatible with a career in academia.

Chapter 3: Contextualising autistic students' transitions to FHE: stigma, support and self-presentation

3.1 Introduction

I will cover several interrelated topics in this chapter. I begin by positioning autism as a stigmatised identity. The stigma attached to autism leads some autistic students to self-present in ways which are not authentic, to mask the condition, and to demarcate themselves in opposition to profoundly autistic individuals. Goffman's work on stigma (Goffman, 1963), and his work on the presentation of self (Goffman, 1956) are central texts which analyse the management of stigmatised identities[20]. Equally the social model of disability (Oliver, 1983; UPIAS, 1976) introduced disability and disabled individuals' lives to the socio-political sphere, from which autism has largely been absent. I propose autism can be included in the socio-political sphere, and outline Rogers' (2016a) work on the care ethics model, which redefines the relationship between the carer and the cared for and reclaims (inter)dependence. For supported students or students with higher support needs, it is critical to explore (inter)dependence from the ideal of independence against which it is judged.

I will introduce four ideals, including independence (French, 1991), self-regulation (Foucault, 1976), ability and normalcy (Davis, 1997). To be seen to conform to these ideals, some autistic students 'choose' not to request support or approach tutors or lecturers for advice. Choice is a contested concept. A person's 'choices' may seem to be an exercise of free-will, but they can be determined or constrained by *prior* events, limiting the extent to which the person can exercise true free-will (Strawson, 1994). An autistic student may 'choose' not to access services or, conversely, an autistic student may 'choose' to access services but for some, this 'choice' has been influenced by the ideal of independence (for example, the person has received positive reinforcement to promote their independence), or the ideal of normalcy, and previous events which led them to adopt these values. This has unwanted

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[20] The focus of *this* section is *autism* as a stigmatised identity.

consequences for some autistic learners as some will not reach their full academic potential without support. With support, students with higher support needs *can* be included in academic and social life, and, I propose, *thrive* in FHE. The focus then shifts to covering. Covering is ‘admitting to the stigmatised feature or attribute, but working hard to minimise its significance,’ (Thomas, 2007: 23) and ‘Persons who are ready to admit possession of a stigma […] may nonetheless make a great effort to keep the stigma from looming large’ (Goffman, 1963: 103).

In covering (to reiterate, in sharing information about the diagnosis with others but self-presenting as though neurologically typical), the autistic person is complicit in the hierarchy of impairment, what I describe as the intra-communal hierarchy of impairment (the autistic person perpetuates the hierarchy of impairment, denigrating more profoundly autistic ‘others’). The hierarchy of impairment (Tringo, 1970) ‘ranks’ groups of disabled individuals (for example, individuals with sensory impairments are ‘preferable’ to individuals who live with GLDs). To preserve a preferential position in the hierarchy of impairment, the autistic student self-presents as near-neurologically typical, choosing not to request necessary supports and perpetuating the hierarchy of impairment. Finally, I present literature on autistic students’ transitions to FHE, which will underline the need for high quality transition programmes. I conclude by making explicit how all these areas of interest are interconnected.

3.2 Autism as a stigmatised identity

There is some evidence of ongoing discomfort with autism and perhaps a reluctance to interact with autistic individuals on an ‘intimate’ level (Gardiner and Iarocci, 2014; Gillespie-Lynch et al., 2015). Gardiner and Iarocci (2014) surveyed 202 undergraduate students. Participants read a description of a character, ‘Jamie’, who exhibited a high autism quotient (AQ). Overall, their findings indicated widespread acceptance of ‘Jamie’:

> Most indicated that Jamie did not make them feel afraid (89%), he was probably as smart as them (60.2%), they would not mind him living in the same hallway or apartment building (94.1%), felt comfortable around him (66.1%), and would like him as a person (80.6%) (Gardiner and Iarocci, 2014: 1013).

But under half of those surveyed indicated a willingness to socialise with ‘Jamie’. Under half of those surveyed indicated a willingness to volunteer with autistic individuals. Research indicates the transition to university for any student is easier if the student integrates into a group of friends (Centre for Excellence in Learning and Teaching, 2018). Notably, if students are reluctant to socialise with autistic peers, the transition will be more difficult for the autistic student (Buote et al., 2007).

One of the most frequently used measures of stigma is the extent to which the participant is prepared to engage with a stigmatised person, on a distant or intimate level (Bogardus, 1933), leading Gillespie-Lynch et al. (2015) to conclude that this was indicative of stigma. Gillespie-Lynch et al. (2015) adapted Bogardus’ (1933) social distance scale for their research with college students, administering a pre-test and identical post-test questionnaire and comparing the findings. The questionnaires were comprised of a ‘social distance’ component and a ‘knowledge’ component. Their findings were consistent with Gardiner and Iarocci’s (2014) work, the closer the proposed social relationship (the closest proposed social relationship listed in the Gillespie-Lynch et al. (2015) study being marriage to an autistic person), the greater the social distance (level of discomfort).

Upon completion of the programme, Gillespie-Lynch et al. (2015) reported, scores on the social distance component decreased, and scores on the knowledge component increased, with an inverse relationship between the two. Yet there is scope for improvement. The participants:

> [E]xhibited fairly high knowledge of autism and low stigma towards people with autism. They also recognized that people with autism are often independent and integrated members of society. However, they frequently confused autism with other disabilities and were relatively unwilling to engage romantically with people with autism (Gillespie-Lynch et al., 2015: 64).

Public awareness campaigns have augmented rudimentary knowledge of autism, but to some degree, there is a stigma attached to autism, conditional on social distance, conditional on the level of intimacy the relationship demands. Conditionality characterises the autistic learner's educational trajectory, their life course, self-presentation and self-concept. Conditionality is a thread, woven through autistic individuals' social life. The research outlined above (Gardiner and Iarocci, 2014; Gillespie-Lynch et al., 2015) indicates that neurologically typical and non-autistic students would most likely feel comfortable sitting in close proximity to an autistic peer (for example, in a lecture theatre), and that a non-intimate relationship with an autistic peer (for example, collaborating with the autistic person on a group project) would be acceptable to most neurologically typical and non-autistic students. But friendships (i.e. inclusion in social life) are less likely and as I outlined above, this can negatively affect the autistic learner's transition to FHE (Centre for Excellence in Learning and Teaching, 2018).

Not 'only' does stigma exclude autistic individuals from social life, stigma precludes participation in FHE, where students 'choose' not to share information about their diagnosis with the relevant parties (i.e. disability services and lecturers). These students waive *essential* services and adjustments, and some do not meet the required academic standard (Anderson and Stephenson, 2017; Martin, 2010). The outcome of this *anticipated* stigma is, in some cases, withdrawal from the programme of study, in the event of 'misbehaviour' or failed resubmissions (I will return to this in chapter 7).

Changes, including the transition to FHE, sometimes result in behavioural difficulties, ‘The person may become irritable, demanding, threatening or abusive, less able to cope with everyday demands’ (Clements and Zarkowska, 2000: 55). This depends on the constitution of the person, and the presence or absence of other ‘arousal’ triggers, but in cases where the autistic person *does* respond to arousal with ‘inappropriate’ behaviours, or *is* relatively less able to manage the demands of FHE (Clements and Zarkowska, 2000), for example, poor time-management skills, then the student risks withdrawal from the programme of study. Anticipated stigma has a detrimental effect on a stigmatised person’s emotional well-being (Quinn and Chaudoir, 2009) but it can also have consequences for the autistic learner’s academic outcomes, where the student ‘chooses’ not to apply for necessary supports and services and withholds information about their diagnosis from disability services and lecturers. In managing their self-presentation (Goffman, 1956), autistic students in FHE (especially those living with SEBDs) are confronted with a difficult choice. Human help is a visible indicator of difference, but in the absence of a non-medical helper, there is a greater ‘risk’ of behaving in a way which might draw negative attention.

The problem of anticipated stigma originates not in colleges and universities, but in early childhood (Chambres et al., 2008), i.e. *prior to enrolment*. Autism is necessarily manifested pre-diagnosis (the behaviours *lead to* the diagnosis), and these behaviours are often misinterpreted in childhood as ‘bad’ behaviour; ‘it is because deviant behaviors of children with autism are associated with the lack of a physical stigma (as in Down’s syndrome or a motor impairment) that they are judged so severely’ (Chambres et al., 2008: 1321). From a young age, the autistic person associates autism with ‘bad behaviour’ and reprimand, and neurologically typical behaviours with ‘good behaviour’ and rewards. Autistic individuals recover with relative difficulty from spates of bullying (Tantam, 2000), which confounds the issue, increasing the risk of anticipated stigma, and the concurrent issues for the autistic learner outlined above, as the autistic student anticipates negative attention in an FHE context and uses non-disclosure as an avoidance strategy.

There is evidence to suggest the stigma of autism lessens where the diagnosis is *known*. The findings of several studies (Chambres et al., 2008; Matthews et al., 2014; Sasson and Morrison, 2017) indicate others are more likely to be willing to include autistic individuals in social life if there is a 'legitimate' explanation for their behaviour. In the studies listed above, participants were introduced to a person, or several individuals, exhibiting behaviours characteristic of autism. Some characters were known to be autistic, but in other scenarios, the characters were not known to be autistic. Participants were asked to evaluate the character's behaviour or give their first impressions of the person. Behaviours were rated higher and first impressions were more favourable when the character was known from the outset to be autistic (Chambres et al., 2008; Matthews et al., 2014; Sasson and Morrison, 2017).

Arguably, disclosing information about the diagnosis benefits autistic students twofold. In sharing information with disability services, support can be arranged (Anderson and Stephenson, 2017), reducing the risk of exclusion from academic life and in sharing information about the diagnosis with other students and teaching staff, the likelihood of stigma is lessened, and initial impressions are more likely to be favourable (Chambres et al., 2008; Matthews et al., 2014; Sasson and Morrison, 2017). By the same token, the autistic person who 'chooses' not to disclose information about their diagnosis to others is more likely to be subjected to stigma (Sasson and Morrison, 2017), increasing the risk of *anticipated* stigma, and decreasing the likelihood that the person will share that information with others, which continues a vicious circle (Franz et al., 2010; Lee et al., 2005; Quinn and Chaudoir, 2009; Vogel et al., 2006; Yebei et al., 2008). The relationship between stigma and passing which Goffman (1963) observed is not linear but cyclical.

3.3 Models of disability

Prejudice[21], and exclusion from social life and the built environment are central to the social model of disability (Oliver, 1983; UPIAS, 1976). The clinical presentation of autism is still central to public and professional understandings of autistic individuals' social exclusion, still central to some autistic individuals' understandings of their own social exclusion. To some degree, what Shakespeare (2014) described as the 'barrier free utopia' (Shakespeare, 2014: 219) which UPIAS (1976) and Oliver (1983) proposed is relatively inconceivable for individuals living with GLDs or autistic people:

> [P]hysical and sensory impairments are in many senses the easiest to accommodate […] What about people on the autistic spectrum, who may find social contact difficult to cope with: a barrier free utopia might be a place where they did not have to meet, communicate with, or have to interpret other people (Shakespeare, 2014: 219).

The social model of disability as it was originally proposed is not, thus, wholly meaningful for the experiences of individuals living with profound GLDs, i.e. individuals who require 'care' (Rogers, 2016a) and it has not yet been used to its full explanatory, or socio-political potential for autistic individuals' social experiences, or autistic students' transition experiences in FHE. It is thus worth outlining the social model (Oliver, 1983; UPIAS, 1976) and the care ethics model of disability here (Rogers, 2016a).

In a consultation with the Disability Alliance, the Union of the Physically Impaired Against Segregation (UPIAS) proposed the principles of the social model of disability, identifying disability as:

> a situation, caused by social conditions, which requires for its elimination, (a) that no one aspect such as incomes, mobility or institutions is treated in isolation, (b) that disabled people should, with the advice and help of others, assume control over their own lives, and (c) that professionals, experts and others who seek to help must be

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[21] I use the word 'prejudice' in preference to stigma here, Oliver was *highly* critical of Goffman's (1963) work on stigma.

> committed to promoting such control by disabled people (UPIAS, 1976: 3).

The social model of disability (commonly abbreviated to ‘the social model’) was a departure from earlier, medical interpretations of disability. This brief statement, above, outlining the points of concordance between the Disability Alliance and UPIAS, is a springboard to further discussion, illuminating several areas of contention between the social model and individual model of disability. Defining disability as ‘a situation, caused by social conditions’ (ibid.) challenges conventional ‘wisdom’ and re-centres the ‘problem’ of disability. The problem is partially clinical, but it is *also* socio-political. I emphasise ‘also’ here to underline how UPIAS and the Disability Alliance prescribed a more comprehensive view of disability, but the original social model has been distorted, effectively seeming to omit impairment from the analysis, for which it has attracted criticism (Dewsbury et al., 2004; Morris, 1991).

In response to this ostensible omission, Crow (1992) wrote ‘As individuals, most of us simply cannot pretend with any conviction that our impairments are irrelevant because they influence every aspect of our lives’ (Crow, 1992: 7). It would be a gross injustice to overlook the physiological, emotional and academic challenges which many autistic students confront in FHE. Fabri (2016a), for instance, reported on the findings of a multinational study involving autistic students enrolled on higher education programmes in the UK, Netherlands, Poland, Spain and Finland. Autistic students reported difficulties in deciding which course to pursue, and which university best met their needs, living independently in halls of residence, navigating an unfamiliar learning environment, the assault of crowded or brightly lit spaces on their senses, unanticipated changes of routine or plan, and unpredictability, and the unwritten, unspoken rules of interacting with lecturers and peers.

The research also concluded some autistic learners have unrealistic expectations of their course, and might not appreciate how all modules are connected, to each other and to the programme of study. Some autistic students experience difficulties with following assignment briefs, a problem which is compounded by lecturers' expectations that all students will work independently, others will find it difficult to manage the disappointment of achieving lower grades than they were awarded at school and collaborative projects will also be challenging in some cases, where the autistic person contributes too much or too little to group discussions, or introduces tangential topics (Fabri, 2016a).

Oliver (1990a) confronted the over-medicalisation of everyday life, the disproportionate influence of medical staff in the disabled person's affairs, for example, 'assessing driving ability, prescribing wheelchairs, determining the allocation of financial benefits, selecting educational provision and measuring work capabilities and potential' (Oliver, 1990a: 48). Some interventions, he saw as wholly appropriate, for example, diagnostic procedures and the stabilisation of a person's condition. Other interventions, including rehabilitative measures and in some cases physiotherapy, he saw as inappropriate[22]. The over-medicalisation of autism locates the stigma of autism *outside* the socio-political sphere, i.e. the autistic person is presumed to have failed to assimilate and is attracting negative attention, leaving the ideal of normalcy (which I will outline below) and the stigma attached to autism unaddressed.

From the outset, Oliver (1983) identified the scope for incorporating the individual (clinical) *and* the social into social worker assessments, under clearly defined conditions:

> Assessments that take account of individual and social aspects of disability and the relationship between them need to be undertaken by competent and knowledgeable professionals in collaboration with

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[22] In some contexts, physiotherapy is entirely appropriate (e.g. to recover the use of a previously fractured bone).

> disabled people to ensure that they take into account the wishes, concerns and goals of their clients (Oliver, 1983: 86).

But the language in other work was relatively ambiguous; cited in Oliver (1983), Finlay (1978) wrote ‘Handicap is caused by having steps into buildings and not inability to walk’ (Finlay, 1978: app. 7). On first impressions, Finlay (1978), and Oliver (1983) by endorsement, are discounting the effect of being unable to walk. But ‘handicap’[23] is the relationship between impairment, ‘a problem in body function or structure’ (World Health Organisation, 2019: n.p.) and the restriction of activity and participation in social life.

Applying Finlay (1978) and Oliver’s (1983) work to my study, the clinical presentation of autism cannot be omitted from this analysis, but in a social and educational environment which is appropriate for the autistic person’s needs (for example, the autistic person can be confident, when disclosing information about the diagnosis to others, that they will not be alienated or infantilised), the person who is autistic is not ‘handicapped’. Perhaps restricted in some way, but the restriction is minimal. There is a workable alternative to the social model:

> The medical model and the social model are often presented as dichotomous, but disability should be viewed neither as purely medical nor as purely social: Persons with disabilities can often experience problems arising from their health condition. A balanced approach is needed, giving appropriate weight to the different aspects of disability (WHO, 2011: 4).

The World Health Organisation (2011) promoted the bio-psycho-social model of disability. The model defines disability as ‘the negative aspects of the interaction between an individual (with a health condition) and that individual’s contextual factors (environmental and personal factors)’ (WHO, 2011: 4). The bio-psycho-social model adds a third dimension to UPIAS’ (1976) model, the psychological dimension or ‘personal factors’, for example, readiness to act on

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[23] The word ‘handicap’ is no longer appropriate.

the advice of medical professionals (or readiness to act on the advice of NMHs), fulfilling UPIAS' (1976) stipulation 'that no one aspect such as incomes, mobility or institutions is treated in isolation' (UPIAS, 1976: 3).

No component of the social model of disability is incompatible with the realities of impairment, no component of my analysis is incompatible with the realities of autism, but UPIAS' (1976) model is inherently political, and the focus is on socially imposed barriers to participation in public life:

> [D]isabled people's politicisation has its roots in the assertion that "the personal is political", that our personal experiences of being denied opportunities are not to be explained by our bodily limitations (our impairments) but by the disabling social, environmental and attitudinal barriers which are a daily part of our lives (Morris, 2001: 3).

UPIAS' (1976) second condition for the abolition of disability was 'disabled people should, with the advice and help of others, assume control over their own lives' (UPIAS, 1976: 3). The power relationship between the disabled person and their carer, their support worker, their physiotherapist, their surgeon, is uneven, and professionals can be reluctant to shift the balance of power (Oliver, 1983). Some autistic learners are unwilling to enter into this uneven relationship and forego necessary services (Anderson and Stephenson, 2017).

Hunt's (1966) work on institutionalisation, and the position of profoundly disabled people, cited several examples of how this imbalance of power can be manifested in residential settings. He reflected on some carers:

> [W]ho have had people removed on slight pretexts, who try to break up ordinary friendships if they don't approve of them. There are the staff who bully those who cannot complain, who dictate what clothes people should wear, who switch the television off in the middle of a programme, and will take away 'privileges' (like getting up for the day) when they choose (Hunt, 1966: 5).

Hunt was one of four self-advocates who represented UPIAS in the consultation with the Disability Alliance of 22 November 1975, the minutes and transcript of this meeting and commentary from both parties were reproduced in UPIAS (1976). The balance of power between carers and the cared for is still uneven, as the Winterbourne View case (Plomin, 2019) exemplifies. Residents at the Winterbourne View specialist hospital have been subjected to abuse, for example, staff exposed one young woman, living with globophobia (the phobia of balloons) to balloons. Grohol (2018) notes exposure therapy is a recognised strategy which, when administered under controlled conditions, can lead to the patient's recovery from their phobia. A person living with globophobia *would* be exposed to balloons, with a view to their eventual recovery. But this must be done with the patient's consent and co-operation. The intention in the Winterbourne View case was to cause distress to the resident, who was non-consenting.

It was Hunt who presented the principles of the social model of disability, outlined above. The social model calls for professionals (for example, physiotherapists, care workers and support workers) to act in the best interests of the client, empowering disabled individuals to 'assume control over their own lives' (UPIAS, 1976: 3). 'Control' ought not to be confused with 'independence' but is. Undue emphasis on independence (the ideal of independence) can limit control; (inter)dependence (i.e. support) can be liberating, the time and energy the disabled individual is expected to commit to 'independent living skills' could be reallocated to more interesting pursuits, and more productive, supported activities (French, 1991). This would fulfil UPIAS' (1976) third stipulation 'that professionals, experts and others who seek to help must be committed to promoting such control by disabled people' (UPIAS, 1976: 3).

UPIAS' (1976) fundamental principles are thus germane to my research; autism is a clinical condition, complicated by social conditions, including (in FHE settings) fluorescent lighting, disciplinary procedures (for example, withdrawal from the programme) for ‘poor’ behaviour, and limited structured support. There is no universal, definitive autism. Autism is an amalgamation of several interrelated variables; the socio-political, the cultural, the fiscal, the clinical, the institutional, and the psychological. None of this can be considered in isolation, if a full picture of an autistic learner’s educational life is to emerge.

‘Professionals, experts and others’[24] (UPIAS, 1976: 3) have the potential to effect academic outcomes. Disability support co-ordinators, support workers, counsellors, and study facilitators, government funding bodies, support organisations, policy makers, researchers, mass media, social media users, students, educators and administrative staff, the public, relatives, friends and significant others can be instrumental in the autistic individual’s educational trajectory, self-concept, empowerment and emotional well-being (O’Connell, 2015). Should the aforementioned parties act in the best interests of the autistic person (and should ‘the best interests of the autistic person’ be defined in consultation with the autistic person), autistic learners and others stand to benefit (O’Connell, 2015), if UPIAS’ (1976) fundamental principles are to be taken as credible, and apposite to autistic individuals in FHE. But UPIAS’ (1976) principles are not *wholly* apposite to autistic individuals in FHE. Rogers’ (2016a) care ethics model of disability incorporates disabled individuals who do not conform to UPIAS’ (1976) or Oliver’s (1983) vision of the disabled person.

Rogers’ (2016a) care ethics model of disability is comprised of three spheres; ‘the *emotional sphere*, where love and care are psycho-socially questioned, the *practical sphere*, where day-to-day care is carried out relationally, and the *socio-political sphere*, where social intolerance and aversion to difficult differences are played out’ (Rogers, 2016a: 26, emphasis in original). The care ethics model of disability incorporates individuals living with GLDs into the social model of disability (Oliver, 1983; UPIAS, 1976) and is also suitable for use as a framework for understanding autistic individuals’ experiences of

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[24] These are not mutually exclusive categories.

transition in FHE. To reiterate, UPIAS (1976) stipulated ‘that disabled people should, with the advice and help of others, assume control over their own lives, and […] that professionals, experts and others who seek to help must be committed to promoting such control by disabled people (UPIAS, 1976: 3). Likewise, Oliver (1990a) cautioned ‘the medicalisation of disability [has] given doctors power and left disabled people powerless’ (Oliver, 1990a: 6). Oliver’s (1990a) work challenged the uneven power relations between the carer and the cared for. Morris (1991), too, identified a power imbalance between disabled individuals and non-disabled[25] others, reflecting on how these uneven power relations can be manifest or latent.

Morris (1991) documented several incidents of nursing staff in institutions for profoundly disabled individuals abusing the residents (manifest uneven power relations) and how, as a wheelchair user, she was obliged, for her own benefit and for the benefit of other wheelchair users, to smile and express her gratitude whenever a person held the door (latent uneven power relations). She cannot challenge the imbalance of power by confronting individuals who hold the door without her consent, because she and other wheelchair users rely on non-disabled individuals to navigate the built environment. If she refuses assistance in cases where assistance is not needed, the non-disabled person might be reluctant to assist her, or other wheelchair users, in other contexts where assistance *is* needed. But some autistic individuals in FHE *do* depend on support (Anderson and Stephenson, 2017; Mulder and Cashin, 2014; Van Bergeijk et al., 2008).

It is critical to establish that care is not about control (Rogers, 2016a), support is not about control. As I outlined above, some autistic students are reluctant to enter into a working relationship with an NMH if they misunderstand the student-NMH relationship to be about control. Individuals living with GLDs and

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[25] I refer here to *any person* (disabled or non-disabled) in a position to hold a door for a wheelchair user.

their carer(s) have an (inter)dependent relationship, depending on caregivers for survival; calling for a reduced role for caring professionals and medical professionals, the social model fails individuals with profound learning delays. ‘Without committing to a moral, political and ethical formulation of caring’ (Rogers, 2016a: 34), the social model fails individuals with profound learning delays. Calling for a reduced role for professionals (for example, NMHs), the social model (and in practice, the government) fails autistic students in FHE. Willetts (2014) was explicit in the government’s aim to reduce support and encourage independence:

> We will fund the most specialist Non-Medical Help. HEIs are expected to consider how they deliver information to students and whether strategies can be put in place to reduce the need for support workers and encourage greater independence and autonomy for their students (Willetts, 2014: n.p.).

The ideal of independence can be used to justify the withdrawal of support. In the following section, I will outline four ‘ideals’, the ideals of self-regulation, normalcy, ability, as well as independence, ideals which collectively UPIAS (1976), Oliver (1983) and Rogers (2016a) have confronted. Despite this, neither the social model of disability, nor the care ethics model of disability, have been used to their full socio-political potential. Autism is recognised to cause difficulties with social interaction (Bauminger et al., 2003; Wing et al., 2011) which obscures the stigma of autism and removes autism from the socio-political sphere. The social model of disability (Oliver, 1983; UPIAS, 1976) has great potential to empower autistic individuals, but fails to incorporate the lives of individuals with GLDs (Rogers, 2016a) and is underused as a framework for interpreting autistic individuals’ experiences of stigma, which is detrimental to our understanding of the stigma of autism.

3.4 Social and academic consequences of non-conformity, and conformity to, the ideals of self-regulation, normalcy, ability and independence

The ideal of self-regulation

The work of Foucault (1975; 1976) is useful here. To reiterate, Foucault (1975) outlined the practice of regulating prison inmates until self-regulation, and behavioural reform, had been achieved. He also introduced the concept of biopower (Foucault, 1976). In several diverse areas, including health and personal hygiene, the public are no longer coerced by the military but by the medical profession. Military power is the exercise of regulation. Medical knowledge leads to self-regulation. The public willingly conform, acting on medical advice. The medicalisation of emotion pathologises emotional dysregulation, self-regulation is the 'ideal' to which the public are compelled to conform. Non-conformity to this socially prescribed norm, observed in autistic individuals (Whitman, 2004) can cause concern. Samson et al. (2012) noted 'With respect to emotion regulation, individuals with AS/HFA used reappraisal less frequently than TD individuals and reported lower levels of reappraisal self-efficacy' (Samson et al., 2012: 1).

From infancy, a person is urged to self-regulate and develop 'emotional intelligence' (EI), to manage and recognise their emotions and those of others (Bronson, 2000). It is a potential cause for concern if a child cannot self-regulate (Southam-Gerow, 2013). Online guides have been published to advise parents and caregivers on developing a child's self-regulation, for example, Ramirez (2015) advised parents on how best to promote deferred gratification in children. She cited superior 'emotional coping skills, higher rates of educational attainment, higher SAT scores, lower BMI, lower divorce rates, [and] lower rates of addiction' (Ramirez, 2015: n.p.) as tangible benefits of deferring gratification, although these listed benefits were based on the marshmallow test[26] (Mischel and Ebbeson, 1970) which has since been discredited (Watts et al., 2018) for overlooking confounding variables (namely the participants' socio-economic background).

Alongside the benefits of self-regulation listed above, Wranik et al. (2007) proposed EI was a valuable interpersonal skill in a working environment, that it was easier to thrive in a workplace if a person managed their emotions, irrespective of a colleague or customer's behaviour, and irrespective of the industry or sector. This is a clear benefit of emotional self-regulation. Employment is a key source of income, and income significantly improves a person's quality of life. Working age autistic adults have poorer emotional self-regulation (Whitman, 2004) and consequently a lower employment rate (National Autistic Society, 2016b) relative to neurologically typical contemporaries.

Dysregulation (poor self-regulation) also intersects with gendered behaviour. Guerrero Witt and Wood (2010) described men as agentic (dominant, assertive, masterful and competitive) and women as communal (friendly, concerned with others, expressive and unselfish). 3174 young adults participated in the study, which explored self-esteem and conformity to standards of gendered behaviour. Overall, participants reported higher levels of self-esteem when conforming to gendered behaviour, a task which demanded self-regulation. Linked to dysregulation and non-conformity to gendered behaviour is sensory hypersensitivity, which is common in autism (Bogdashina, 2014). Belden (2018) who self-identified as a 'highly sensitive man' challenged the stigma of sensory hypersensitivity and perceived non-conformity to gender norms:

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[26] This is a test for deferred versus instant gratification, testing whether participants (aged three to five) will choose to eat a marshmallow immediately (instant gratification) or wait 15 minutes for a second marshmallow (deferred gratification). The child 'fails' the test if they satisfy the 'instant gratification' criteria.

> We receive and process more sensory input than most others do; consequently, we can sometimes find ourselves feeling overwhelmed in contexts that others find routine [which] frequently run[s] counter to the values and practices of [a] culture that wants more and more, faster and faster, all the time (Belden, 2018: n.p.).

As Jordan (2014) observed, infant males are also more likely to be chastised for emotional dysregulation than infant females; although children of all genders are expected to self-regulate (Ramirez, 2015), unlike males, females are also expected to express their feelings (Guerrero Witt and Wood, 2010). Self-regulation is linked to gender roles and can affect the extent to which an autistic person fulfils socially prescribed gender norms. Non-conformity to any norm carries a stigma.

The ideal of normalcy and the ideal of ability

I introduce two 'ideals' here. For Davis (1997), the ideal of *ability* is bound up in the ideal of *normalcy*. The concept of 'normal' has its history in statistics (Davis, 1997), in what Davis (1997) referred to as '*l'homme moyen*' (the average man) (Quetelet, 1842). *L'homme moyen* was the benchmark of normality; deviating 'too' far from this centre point often led to stigma. Deviating from the neurological centre point (neurologically *typical*) is still heavily stigmatised today. The ideal of 'normalcy' is a social construct and has since been challenged, in academic literature (Davis, 1997) and in media published online (Maisel, 2011; Rose, 2016). The 'norm' itself is not entirely a social construct; statistically, there is a 'norm', mathematically, there is an 'average' or 'mean', and autism has been defined in relation to this 'norm' (consider 'sensory hypersensitivity'; the hyper- prefix denotes 'sensitivity above what is average'). But it is the meaning we attach to these deviations from the centre point (i.e. that to be a 'normal' person is the ideal) which positions autism as somehow 'less than'.

Davis' (1997) work on enforcing normalcy was grounded in other challenges to the ideal of 'normal' in other areas, lessening the stigma of other variations of the human condition (e.g. race and gender). Davis (1997) observed a relative dearth of work challenging the ideal of ability. Other stigmatised identities were beginning to be reconceptualised as different but not less than, but relatively few people had disputed that it is inherently 'worse' to be disabled than non-disabled. Davis (2005) reflected on how 'In our own time, we always wonder how it was that authors like Charles Dickens, Daniel Defoe, or even Sigmund Freud could get issues like race or gender so wrong' (Davis, 2005: n.p.) and questioned whether future generations would be shocked by 'our' use of 'pejorative […] phrases like "turn a deaf ear" or "a blind eye" or references to "lame" notions or "crippled" economies' (Davis, 2005: n.p.). 'Normal' might be the standard by which all else is judged, but 'normal' is context specific (Davis, 2005) and disability is context specific (Oliver, 1983).

But unlike other identities which deviated from socially prescribed norms, disability is notable by its relative absence from the political sphere. Mollow (2004) proposed '[D]isability has been neglected as an identity category, while the concerns of other marginalized groups have been more scrupulously attended to […] disability must be understood as a social condition rather than an individual defect' (Mollow, 2004: n.p.). Other stigmatised groups have successfully mobilised against the equation of minority status with a 'lesser' identity. Mollow (2004) cites several examples of political mobilisation of this type, including the women's rights movement and the civil rights movement.

It has been more challenging to contest the ideal of ability and it has been more difficult to challenge the misconstruction that disability is less than ability (Davis, 1997). The prefix 'dis-' denotes 'the opposite of ability' but it connotes 'less than ability'. Whilst autism is a stigmatised identity (autistic behaviours and sensory sensitivities more so than the diagnosis), it is misunderstood to be a condition to 'overcome', and 'overcoming' the condition is analogous with covering (Goffman, 1963) and camouflaging (Russo, 2018). For some autistic individuals, the ends justify the means, the prospect of a lucrative career justifies the trauma of camouflaging (Russo, 2018). But if the ideal of ability (*and* the ideals of self-regulation and normalcy, in some cases) was not so compelling, camouflaging, a difficult, exhausting and ongoing act (Russo, 2018) would not be *quite* so 'necessary' for the autistic person.

The ideal of independence

As self-regulation is considered the ideal, or centre point, and emotional dysregulation is considered the 'lesser', and as ability is perceived to be the ideal, or centre point, and disability is perceived to be the 'lesser', so independence is viewed as the ideal, or centre point, and (inter)dependence is viewed as the 'lesser'. Morris (1991) described the case of a young woman who was confined to an institution almost from birth. She was dependent on carers for personal hygiene, sustenance, and sitting upright. She was non-verbal and incontinent, she was denied an education (caregivers presumed she would not benefit from an education), relying on self-teaching strategies to gain some rudimentary knowledge of mathematics (for example, she wore reusable nappies and observed how her carers folded her nappies into angles). She communicated her story of infantilisation with an assisted communication device in adulthood. With her high support needs and high (inter)dependence on carers, the woman had been treated as though a child, inappropriate for her age.

French (1991) relayed a similar story of a disabled child who was forced, daily, to dress himself, a time-consuming task which diverted his attention from more productive and rewarding activities, in the interests of independence. For the child's occupational therapists, his independence was paramount, his education was secondary to his independence. As I outlined above, the government are quite explicit, the role of the NMH is being phased out in the interests of promoting the autistic student's independence (Willetts, 2014). The student's independence is seen to be *paramount*; their educational outcomes are presumed to be *secondary*.

Kittay (2011) proposed (inter)dependence was a universal (albeit primarily temporary) state, describing non-disabled individuals as ‘temporarily abled’ (Kittay, 2011: 49). Siebers (2008) had similar ideas, in older people, (inter)dependence is quite usual, in infancy, (inter)dependence is universal, the disabled person’s (inter)dependence is continuous, but is otherwise broadly akin to the (inter)dependence of the infant or senior citizen. Kittay (2006) promoted the idea of acknowledged dependence. The idea of (inter)dependence can be used to challenge the idea of disability as ‘less than’:

> When we recognize that dependency is an aspect of what it is to be the sorts of beings we are, we […] can begin to confront our fear and loathing of dependency and with it, of disability. When we acknowledge how dependence on another saves us from isolation and provides the connections to another that makes life worthwhile, we can start the process of embracing needed dependencies (Kittay, 2006: 337).

(Inter)dependence has been conceptualised as bad, but Kittay (2006) reconceptualised (inter)dependence as a rewarding experience, accentuating how (inter)dependence can strengthen interpersonal relationships. The ideal of independence has consequences for autistic learners in FHE. Anderson and Stephenson (2017) identified how autistic students who ‘chose’ not to disclose information about their diagnosis to their university or to access supports fared less well, in their academic outcomes and in their experience of university overall, than those who did ‘choose’ to access support.

Disclosing information about the diagnosis to the university does not predict take-up of support. A report by Student Finance England (2017) indicates some students are willing to notify disability services and teaching staff of their diagnosis, and to inform the relevant parties how autism can affect their education, but not to relinquish their independence by arranging support. The stigma of (inter)dependence can influence autistic individuals’ academic outcomes; with support, the autistic student fears they will be stigmatised, but without support, some will not manage their workload or navigate their social world.

Summary

A disabled person’s disability (especially the autistic person’s autism) is popularly perceived to be the root cause of the stigma, disadvantage and discrimination to which they are subjected, ‘once a disabled individual has been categorized, the category assignments take on master status, and subsequent information about the person is dominated by the nature of this category’ (Stone and Colella, 1996: 360). ‘Overcoming’ the disability is widely understood to be a worthwhile pursuit, a pursuit more worthwhile than an education. Teachers of autistic primary school pupils are more preoccupied with the child’s behaviour and social interaction with their peers than their academic progress (Allan, 1999).

The ideal of self-regulation, the ideal of ability and the ideal of independence have seldom been challenged or used as a framework for understanding the stigma of autism, but my thesis addresses this gap. The ideals of self-regulation, normalcy, ability and independence deter some autistic students who require support from requesting it, keen to affect an impression of conforming to the ideal. In the following section, I will outline how some autistic students prosper in FHE with support.

3.5 The value of support

It is common for autistic students to need support to function in FHE (Anderson and Stephenson, 2017; Mulder and Cashin, 2014; Van Bergeijk et al., 2008). Taylor (2005) and Taylor et al. (2008) identified how autistic students, and students living with social, emotional, behavioural difficulties (SEBDs) need access to a special educational needs co-ordinator (SENCO), or NMH. In many cases, the consequences of not accessing support, as I outlined above, are devastating and avoidable (Anderson and Stephenson, 2017). To reiterate, Willetts (2014) announced changes to Disabled Students’ Allowances funding, which sought to reduce expenditure on non-medical help, with the stated aim of targeting limited resources to those with the greatest need. Universities were advised to make arrangements to negate the need for NMHs, be it providing support in-house or otherwise meeting the needs of autistic learners. But despite the availability of alternative arrangements, autistic students ‘could be affected by the withdrawal of funding for non-medical helpers, and the withdrawal of funding for specialised accommodation’ (Taylor et al., 2017: n.p.). Speaking to Hirsch and Lagnado (2010), Quinn, a senior disability officer identified ‘a catastrophic failure to provide effective targeted support to disabled students, and the people who need it most are really suffering […] Some of our students on the autistic spectrum need support in place from day one’ (Hirsch and Lagnado, 2010: n.p.).

Van Hees et al. (2015) identified the need for an NMH, crucially, during the transition *and* the programme of study, ‘Besides being granted accommodations, students experienced a need for coaching, both in the transition to, and as well as in higher education itself. Students preferred one designated person, a personal coach, to monitor and support their activities’ (Van Hees et al., 2015: 23) in three spheres; academic work, social life and independent living. Students with higher support needs *require* support to function in FHE, but some are reluctant to identify themselves as autistic (Cox et al., 2016) and require an advocate to liaise with disability services on their behalf (Adreon and Durocher, 2007). This is in conjunction with current thinking (Disability Rights UK, 2012) and research-based guides to best practice (Autism & Uni, 2014). Without support, it is difficult for autistic learners with higher support needs to succeed in FHE (Anderson and Stephenson, 2017).

This is linked to the ideal of independence, the ideal of normalcy and the ideal of ability. Independence is the *ideal* to which disabled individuals are expected to aspire (French, 1991; Kittay, 2006; Morris, 1991). To receive support is to forego independence, to receive support is to be (inter)dependent, ‘less than’.

Relative to the overall student population, a small minority of students in FHE receive support from a SENCO or NMH. Of the 2,343,095 students who were in higher education in the 2017-8 academic year (Higher Education Statistics Agency, 2019), approximately 29,000 of those students were eligible for non-medical help (Student Finance England, 2017), a figure which has remained stable over time. Further, not all those students will receive support for autism as ‘non-medical helper’ is a broader concept, covering BSL interpreters and other positions. To apply for support is to ‘confess’ to *not having the ability to* function independently in FHE, when ability is the ideal. Some students are not accessing necessary supports, to meet the socially prescribed ‘ideal’ (Anderson and Stephenson, 2017). For some students, conformity to the ideal of independence and the ideal of ability is preferable to arranging support, although it should be noted that for many students diagnosed with ‘hidden disabilities’, support from informal support networks and supportive lecturers is largely superior to ‘formal’ disability-specific arrangements (Couzens et al., 2015).

3.6 Covering or self-presenting as neurologically typical

As I narrated in chapter 2, at an eight-day conference, I self-presented as near-neurologically typical, but I was happy to disclose information about my diagnosis to other delegates (Simmons, 2020). Goffman’s (1963) definition of ‘covering’, and his work on the presentation of self (Goffman, 1956) describes my self-presentation. Autism, the diagnostic label, carries relatively less stigma than autism, the variable set of social behaviours (for example, social awkwardness and sensory processing difficulties). Covering is an ‘option’, a compromise, for autistic individuals who neither want to pass for neurologically typical, what ‘Adam’, a participant in Cox et al.’s (2016) study described as ‘faking people out’ (Cox et al., 2016: 17), nor confront the stigma attached to autism (for example, Gillespie-Lynch et al., 2015).

For Goffman (1963), stigmas which were immediately apparent to all were of little to no interest:

> [I]f a stigma were always immediately apparent to any and all Persons with whom an individual had contact, then one's interest would be limited, too, although there would be some interest in the question of how much an individual can cut himself [sic] off from contact and still be allowed to function freely in society, in the question of tact and its breakdown, and in the question of self-derogation (Goffman, 1963: 92).

Goffman (1963) had a similar view of invisible stigmas; ‘Where the stigma is nicely invisible and known only to the person who possesses it, who tells no one, then here again is a matter of minor concern in the study of passing’ (Goffman, 1963: 92). I am interested in passing (i.e. cases where the stigma is not known to others) *and* stigma (i.e. cases where the stigma, or the person’s ‘difficult differences’, are known to others). Autistic individuals whose autism is not immediately apparent (i.e. those who have an ‘invisible’ disability) must choose whether to disclose information about their autism or not. This can be a choice between compromising their mental well-being (where the person self-presents as neurologically typical) or foregoing the opportunity to participate in social life (where the person ‘chooses’ not to mask the condition) (Russo, 2018).

Autism can be visible or invisible (Seeley, 2016). The focus in this section is on ‘invisible’ autism, on autistic individuals who, if they so ‘choose’, can self-present as (or ‘pass for’) NT. On invisible disability, and the decision to ‘voluntarily’ disclose information about a condition, or not, Garland-Thompson (1997) wrote ‘A disability’s degree of visibility also affects social relations. An invisible disability, much like a homosexual identity, always presents the dilemma of whether or when to come out or pass’ (Garland-Thompson, 1997: 14). To ‘come out’ is to confront the possibility of stigma. To ‘come out’ is to forego the privileges of a non-disabled identity, to risk losing their status as a whole person (Goffman, 1963). It is to make themselves more vulnerable to abuse. But the ‘closet’[27] is a suffocating space. The closet can damage a

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[27] I refer here to a metaphorical space, within which a stigmatised person who chooses to self-present as a non-stigmatised person is confined until declaring their stigmatised identity.

person’s self-concept. It is a commitment to a performance for an indeterminate period. The decision to ‘come out’ or otherwise is personal to the individual, and it is not a decision to be taken lightly, but ‘coming out’ can bring relief and a positive identity (Bagatell, 2007).

The closet is a place of suffering, without the freedom to unburden oneself. The closet promises sanctuary from direct stigma, but it offers no protection from other stigmas, for example, mediated stigma, perpetuated in the media, and vicarious stigma, experienced via third parties (Essed, 1991) and it can result in, or intensify self-stigma (Russo, 2018). ‘Closeted’ or otherwise, all autistic individuals are subjected to collective stigma (stigma directed towards *all* autistic individuals). ‘Closeted’ or otherwise, autistic individuals will be subjected to individual stigma, their own sensitivities and peculiarities are still stigmatised, often before they receive their diagnosis, or before their diagnosis is known to others (Sarris, 2017; Sasson and Morrison, 2017). Goffman (1963) identified how ‘while the stranger is present before us, evidence can arise of his [sic] possessing an attribute that makes him [sic] different from others in the category of Persons available for him [sic] to be, and of a less desirable kind’ (Goffman, 1963: 11). This does not refer exclusively to *disclosure* but to *any* evidence, any difference which divorces the stranger from the ‘norm’, for example, an aversion or sensory hypersensitivity. Below I outline two perception management strategies autistic individuals use whilst ‘in the closet’; self-isolation and the deferred meltdown.

Some autistic individuals ‘choose’ to self-isolate (Mahjouri et al., 2012). The nature of self-isolation differs from that of social isolation. Self-isolation is the avoidance of others, by keeping one’s own company. Unlike social isolation, self-isolation is not inflicted on the autistic person by others, it is self-led. Mahjouri et al. (2012) observed 18 autistic school pupils and measured their level of loneliness and engagement with their peers and collected information about their emotional well-being. Self-reported levels of depression and anxiety were average (as expected for the age group) but their levels of loneliness were above average. The pupils were ‘choosing’ to self-isolate. Self-isolation is not always maladaptive behaviour. It might serve an important function for the autistic young person, as temporary respite from the social pressures of their learning environment, or to ‘fit in’ with the scholarly pupils, who frequent the library during unstructured times (lunchtimes and breaktimes) and choose to work alone.

The Mahjouri et al. (2012) study challenges the ‘common sense’ view of autism and apparent self-isolation. The researchers observed very little interaction between the autistic pupils and their peers. The ‘common sense’ interpretation of these observations might be ‘the autistic pupil is socially isolated’, but the researchers ask whether this isolation might be self-imposed. The ‘common sense’ understanding of self-isolation is ‘self-isolation is bad’ (neurologically typical academic pupils are choosing to self-isolate, but this behaviour is interpreted differently in autistic pupils), but the researchers do not take this for granted. Self-isolation has a purpose. Self-isolation benefits the autistic person who is overwhelmed with the inherently social nature of school (Mahjouri et al., 2012) and by extension, the autistic person is who is overwhelmed with the inherently social nature of college or university, particularly in cases where the student is living in student accommodation (Drake, 2014).

The ‘common sense’ interpretation of self-isolating behaviour is ‘the autistic person is making no effort to integrate into a social group’. But if the ‘target’ social group is the ‘academic group’, who work independently during unstructured periods, rather than socialise, the autistic person is acting in accordance with group norms (Mahjouri et al., 2012). Awkward conversations and negative attention are less likely when the autistic person ‘chooses’ to self-isolate (if social communication is an area of difficulty for an autistic person, it is sensible for them to minimise social interaction) (National Autistic Society, 2018) but there are alternatives to the deficit model of self-isolating behaviour.

This deficit model reflects individual model thinking (Oliver, 1983), the autistic student's decision to self-isolate can be interpreted as inherently 'bad' and linked to the person's autism (medicalisation), or a rational choice, which may be unconnected to the person's autism (i.e. belonging to the 'studious group'), or linked to social forces (i.e. the stigma of autism), in line with social model thinking. Not all cases of an autistic student working, or spending unstructured times, alone indicates self-isolation, any suggestion otherwise is tantamount to over-medicalisation (Oliver, 1990a) although there is currently no consensus on whether most autistic individuals *prefer* to be alone (Warland, 2015) or whether, overall, autistic individuals would, given the choice, prefer to be in company (Causton-Theoharis et al., 2009).

The second passing strategy is the deferred meltdown, which has been named variously as the Jekyll and Hyde effect (Attwood, 2015), and the delayed effect (Myers, 2015). This is the difficult process of delaying a meltdown until 'backstage' (Goffman, 1956) or in the company of one's immediate family:

> The child may be very conscious of the necessity to follow the codes of conduct in the classroom and try to be inconspicuous and behave like the other children. This pressure to conform and retain self control can lead to enormous emotional tension which […] is released when the child reaches home. Here the child is a different character, almost a Jekyll and Hyde (Attwood, 2015: 39).

This is not a reflection on the parents' ability to 'manage' their child, Attwood (2015) advises, but a feature of Asperger's Syndrome in some children. He suggests parents incorporate a relaxing, or energetic activity into the child's routine, as they return home from school, the National Autistic Society (2017b) also give this advice, and recommend teachers introduce a solitary and/or relaxing exercise for the autistic child shortly before the close of the school day. Attwood's (2015) use of the word 'character' is noteworthy. When the child is 'Hyde' (i.e. the 'bad' character) they are not in character at all. 'Hyde' is the autistic child 'as is', the *character* is 'Jekyll'.

Using the social model of disability (Oliver, 1983; UPIAS, 1976) as a framework to interpret this phenomenon, the Jekyll and Hyde effect can be understood as an effect of institutional forces (within the school) and social forces (the stigma of emotional dysregulation). The advice given, to relax the autistic child before, and immediately after, they return home from school, overlooks the stigma of autism, although as a guide for professionals and parents, this does fall outside the remit of Attwood's (2015) book. School (and education more broadly, i.e. FHE) can be distressing for the autistic person, particularly where it does not meet their needs. The advice given is remedial, not pre-emptive. Educators could plan their lessons to suit their autistic students, to minimise the distress of the school day, but instead they are advised to manage the autistic child's stress levels at the end of the day.

The social model of disability has been influential, but autism is still understood to be undesirable, ultimately malleable behaviour. Predating Asperger's Syndrome as a recognised diagnosis, the social model is yet to influence how autism (and the barriers autistic individuals confront) is popularly conceived, as I proposed above. Breakey (2006) identified how the social model of disability:

> [C]hallenges the prejudice and discrimination which autistic people experience on a daily basis and leads to a fundamental need to shift our professional focus and approach from one which seeks to normalize and teach the autistic person to 'pretend to be normal', to one which examines and addresses the barriers in the organizations in which we work, so that they become more accessible and inclusive for autistic people' (Breakey, 2006: 26).

It is the autistic person, still, who is expected to 'adapt' (or pretend to, resulting in deferred meltdowns) (Breakey, 2006). The actual well-being of the autistic individual can be secondary to how well they act 'fine', or how well they seem to be coping (Milton and Moon, 2012). Compounding these issues for school children is the observation of autistic children in the classroom, which exceeds the observation of typically developing peers (Allan, 1999). I will outline the relevance of Allan’s (1999) work for my research below.

Allan’s (1999) work on the observation of autistic children in the classroom expanded on Foucault’s (1975) ideas around the ‘means of correct training’ (observation, normalisation and examination), using these ideas as a ‘toolbox’. In primary school, all children are monitored, but if the child has not ‘slipped through the net’, if there is a diagnosis, or a possibility, of autism, their behaviours and social interactions will be continuously monitored, and meticulous records kept, any behaviour which contravenes ‘the norm’ will be ‘corrected’ (Allan, 1999). The pupil’s academic progress becomes tributary to their social skills (Allan, 1999), as I identified above. Observation (particularly regulation) leads to self-regulation (Foucault, 1975), but it is common for autistic individuals to be unable, or at least less able to self-regulate (Whitman, 2004), leading to deferred meltdowns (Attwood, 2015), where distress is not self-limiting. Foucault’s (1975) work on panopticism is valuable here, as an explanation for these patterns of behaviour in *adults* (i.e. my research participants, none of whom were minors).

Prisoners in panopticon prisons, which I described in chapter 2, would exhibit desirable behaviour consistently, to circumvent the likely ramifications of being caught misbehaving. The inmates would be given no indication of when the guard might be surveying (regulating) them, there would be no ‘safe’ time to misbehave. Over time, the desired behaviour would become routine and habitual, the prisoners would self-regulate (i.e. the behaviour would continue in the absence of guards), and they could be reintegrated into society. Irrespective of the degree of regulation to which the autistic adult is subjected, ‘self-regulation’ (or seeming to self-regulate) and its attendant deferred meltdowns is *habitual*. Deferring meltdowns is difficult (Myers, 2015; Simmons, 2020). Feigning ‘fine’, or ‘coping well’ is difficult (Russo, 2018). But until emotional regulation is no longer the ideal, until emotional dysregulation is no longer heavily stigmatised, deferring meltdowns and feigning ‘fine’ and ‘coping well’ is *necessary,* as I outlined above.

3.7 The hierarchy of impairment

The hierarchy of impairment (Tringo, 1970) is the idea that some types of conditions are inherently inferior to other types of conditions, the idea that some features of a condition are inherently inferior to other features of the same condition. This transfers to *people*, i.e. individuals living with those features are falsely believed to be ‘less than’. GLDs and SEBDs both rank low in the hierarchy of impairment, *especially* GLDs, (Rogers, 2007). The hierarchy of impairment is ‘I am autistic *but*’ with some reference to a milestone to distance oneself from GLDs, or some clarification, or some favourable comparison to others more profoundly affected by the condition. The hierarchy is seldom challenged, although its existence has been recognised for several decades (Tringo, 1970).

Tringo (1970) identified how the public perceive some disabilities more favourably than others, framing this hierarchy in the language of ‘preference towards disability groups’ (Tringo, 1970: 295). His intention was to use these findings to rehabilitate disabled people, ‘An understanding of the public’s attitudes toward various disability groups is necessary to aid us in our attempts to help the disabled adjust to normal life’ (Tringo, 1970: 295). Subsequent research (Deal, 2003; Rogers, 2007; Snow, 2005) has *challenged* the hierarchy of impairment, which 30 years on had largely endured (Thomas, 2000). Tringo (1970) used data from the general public, with a view to reintegrating disabled individuals into social life, whereas Rogers (2007) approached the subject from a different angle, analysing data from individuals closer to the source, parents of children with SEBDs and/or GLDs, not to rehabilitate disabled individuals but to challenge the pressure on mothers to produce the ‘perfect’ child, and explore parents’ emotional trajectories when the child does not conform to the socially prescribed definition of ‘perfect’.

Rogers (2007) defined the hierarchy of impairment as ‘categories of disability that parents can place their child within’ (Rogers, 2007: 140). She quoted ‘Kerry’, mother to two sons with GLDs:

> When I first walked into the school I straight away thought, “Oh my god these are physically and mentally handicapped” […] They were, to my opinion, an extreme, extreme case of problems [….] if every parent was honest with themselves and with other people, they would not want their child that only has speech problems mixing with children like that (Rogers, 2007: 139-140).

‘Kerry’ is perpetuating the hierarchy of impairment, her children ‘only’ had a language delay, a communication difficulty, her sons were not ‘like that’. Rogers’ (2007) work added a ‘care-full’ dimension to the conversation (see also Rogers, 2016a).

Rogers (2007) described ‘Kerry’s’ reaction as a defence mechanism, a coping strategy to offset the ordeal of the severity of her sons’ GLDs. ‘A need to hang on to some ‘normality’ is often graded in relation to other more severe disabilities, and then disassociated from *that* category’ (Rogers, 2007: 140). Like Rogers’ (2007) participant ‘Kerry’, who perpetuated the hierarchy of impairment while advocating for her son, Snow (2005) reflected on how disabled individuals, and their allies, perpetuate the disability hierarchy, often while advocating on behalf of other disabled people (primarily relatives). She recalled a conversation with a young woman, a delegate at a presentation she was delivering:

> “People talk about Kris like she’s not even there!” she exclaimed. “I mean, she’s not *retarded* - she just uses a chair!” The unspoken message seemed to indicate it would be acceptable for Kristina to be presumed incompetent if she *did* have a cognitive disability, but it was *not okay* since she “just” had a physical disability (Snow, 2005: 1, emphasis in original).

Rogers (2007) found parents of children diagnosed with GLDs or SEBDs were reluctant to register their child at a special educational needs school (although this might have ultimately benefited the child), due to concerns their child was ‘not as bad as’ the others in their peer group. For parents of children living with profound GLDs, this can be denial, a common defence mechanism (Rogers, 2007). The worry for other parents is the child will ‘regress’, if children with profound GLDs are their peer models, if SEN behaviours become their new normal (Independent School Parent, 2019).

One of the arguments in support of integrated classrooms is the availability of peer models (Daly, 2014). It follows that with profoundly autistic peer models, the autistic pupil will assimilate to group norms and their autistic behaviours will ‘worsen’ (in relation to the ideal of normal), although research *does* indicate imitation is weaker in autistic individuals (Williams et al. 2001). But in seeking to disassociate their profoundly or moderately autistic child from other profoundly or moderately autistic children, parents can unwittingly perpetuate the hierarchy of impairment. This is divisive, separating autistic individuals into ‘high-functioning’ and ‘low-functioning’, and autistic individuals can internalise this. This division is arbitrary and wholly unnecessary. If it was not for the ideals of normalcy and ability, ‘high-functioning’ autistic individuals and their families would not ‘need to hang on to some ‘normality’’ (Rogers, 2007: 140), or distinguish themselves from, and stigmatise, profoundly autistic individuals.

On a related note, Oliver (1990b) warned disabled people against dividing themselves into groups (as autistic individuals have been divided into groups, ‘high-functioning’ and ‘profoundly autistic’, and ‘pro-cure’ and ‘anti-cure’), for example, wheelchair users, people with visual impairments/blind people, people with hearing impairments/Deaf people, and people with chronic illness or mental health conditions. Oliver (1990b) used kerbs as an example. Wheelchair users benefit from lowered kerbs, it is both a question of comfort (easing oneself onto the road, without a steep drop) and safety (it is very difficult to manoeuvre a wheelchair over a raised kerb, a raised kerb could not be mounted at speed). But people with visual impairments benefit from raised kerbs, which is also a question of safety. It is otherwise difficult for a person with visual impairments to distinguish between the road and the pavement, which could have serious, if not fatal, consequences.

There was for a time a conflict of interest between these two groups (Oliver, 1990b). Eventually, the groups compromised, with a lowered kerb and a tactile pavement, ‘in recognition of the needs of other pedestrians, it is accepted that it is necessary to have level or ramped crossing points in certain locations. In such locations, tactile paving compensates for the absence of a kerb’ (UK Roads, 2014: 3) but the wider point here is division, ‘us versus them’, weakens the movement, and hampers progress (Oliver, 1990b; Rose, 2017). Different groups of disabled people have different needs, but every one of those groups is denied opportunities, marginalised, and either upheld as an ‘inspiration’ or pitied as a helpless vegetable (if not both simultaneously). With reference to autism and underlining the diversity of need and opinion amongst autistic individuals and caregivers, Wilson (2016) ventured ‘we are divided far too many times when a united front would serve us better’ (Wilson, 2016: n.p.). The division into ‘profound’ and ‘high-functioning’ autism stigmatises those who are profoundly autistic and some, wary of the ‘profound’ label, are deterred from arranging support at university (Anderson and Stephenson, 2017).

Labelling is influential. The effects of labelling on any child have been well documented (Becker, 1963; Willis, 1977). School pupils often behave in accordance with how they are labelled, for example, the students labelled as deviant or ‘trouble-makers’ are more likely to be devious, the students labelled as studious are more likely to be studious, but this does not reflect the teacher’s foresight. ‘Deviant’ students’ deviant behaviours and ‘studious’ students’ studious behaviours are in response to the label (Becker, 1963). School pupils respond to their teachers’, and their own, expectations. Willis’ (1977) study of schoolboys in a deprived town near the outskirts of

Birmingham (England) documented ‘the lads’’ behaviours, attitudes to school, careers and other pupils, and their social interactions with others and each other; ‘the lads’ were the ‘working-class’ in-group. ‘The lads’ expected (and were expected to) work in the manufacturing industry, ‘the lads’ made no effort to engage with learning, and their teachers made no effort to engage with them.

But students labelled with ‘special educational needs’ are also at risk of negative labelling, leading to poorer educational and career outcomes (Algraigray and Boyle, 2017):

> [L]abels and classifications created by education systems and/or the medical industry are likely to be socially developed to carry other meanings leading to the devaluation of people being so labelled […] societies and communities play a fundamental role in bringing about stigma and discrimination (Algraigray and Boyle, 2017: 79).

For Shifrer (2013) and Algraigray and Boyle (2017) it is not the label, i.e. special educational needs, but how others respond to that label which excludes individuals living with SEN from social life, education and the labour market. I have proposed above that autism has been absent from the socio-political sphere because conventional wisdom positions autism as a social deficit, i.e. stigma is ‘par for the course’. Much the same can be said of the educational and career trajectory of pupils labelled with SEN. It is expected that a child with special *educational* needs will have poorer educational outcomes than typically developing children, it is expected that an adult with GLDs will have fewer opportunities for career progression than individuals who do not live with GLDs, or autism. But Algraigray and Boyle (2017) challenge these presumptions; it is not autism or special educational needs *per se* which limits the autistic person’s prospects but how others respond to the label.

Individuals labelled ‘high-functioning’ are relatively privileged but it is the use to which that privilege is put, and the measures the ‘high-functioning’ autistic person takes to preserve that privilege which is crucial. Ferguson (2014) proposed:

> ‘You don’t need to feel guilty for having privilege because having privilege is not your fault: It’s not something you chose. But what you *can* choose is to […] use it in a way that challenges oppressive systems instead of perpetuating them’ (Ferguson, 2014: n.p.).

The challenge now is for ‘high-functioning’ autistic individuals to do whatever is necessary to champion the rights of those living with profound autism, and to promote their full and active participation in social life. There must be no autistic person left to languish, no autistic person who is ‘less than’ all others, no ‘high-functioning’ autistic person distancing themselves from profoundly autistic individuals in fear of losing the privileges of self-presenting as NT. Onaiwu (2015), for example, actively exploits her ‘high-functioning’ status and her position as a scholar and educator to advocate for profoundly autistic people. Likewise, other ‘high-functioning’ autistic individuals could exploit *their* privileged position to benefit profoundly autistic individuals.

Autistic, non-autistic and neurologically typical individuals are socialised into the hierarchy of impairment from an early age. As Meyer (2013) in her analysis of child and adolescent fiction proposes, children’s authors and writers of adolescent fiction perpetuate the hierarchy of disability. Meyer (2013) found disabled individuals are becoming increasingly well represented in children’s literature, authors are beginning to include disabled characters in their books, but they are still representing GLDs in quite problematic ways. Meyer (2013) identified three tropes in use today. The first is the physically disabled narrator and protagonist who integrates into the ‘in-group’ by demonstrating they are ‘not retarded’. The second theme is the physically disabled narrator and protagonist who distances themselves from peers with GLDs. The third type is the protagonist who *does* live with GLDs, who ultimately demonstrates intellect. None of this represents individuals with GLDs positively (none of the protagonists have GLDs proper, and it is this absence of GLDs which is their redemption). If characters are redeemed and integrated into the ‘in-group’ by virtue of *not* living with GLDs, individuals who do live with GLDs are, by implication, unworthy of inclusion in social life, or esteem, a ‘burden’, damaging the reputation of other disabled individuals.

Deal (2003) described how some groups of disabled people did not want to be associated with other groups of disabled people; most groups of disabled people, he found, do not want to be associated with people with GLDs, or people with mental health conditions. Deal (2003) gave several reasons for this, including competition for resources, stigma, and the increased likelihood of finding a sexual partner. Deal (2003) called for more research to be carried out into how disabled people view other disabled people, which could lead to a more inclusive disability movement, and although many studies have been carried out since, and many opinion pieces have been published since (Meyer, 2013; Rogers, 2007; Snow, 2005), there is still space for my own research to contribute to that body of literature.

Some autistic students are fearful of the consequences of being mistakenly labelled ‘special educational needs’ (this was a recurring theme in my research), leading to covering and reluctance to arrange support (Humphrey and Lewis, 2008). Other autistic students with ‘hidden disabilities’ ‘choose’ not to self-disclose, concerned that their disclosure will be met with scepticism (Olney and Brockelman, 2010). But as I outlined above, for some autistic individuals, covering and non-disclosure leads to poorer first impressions (Sasson and Morrison, 2017) and poorer academic outcomes (Anderson and Stephenson, 2017). My analysis explores the interplay of the hierarchy of impairment, and the resultant decision *not* to self-disclose, and the outcomes of non-disclosure for autistic students’ social and academic inclusion and emotional well-being.

I will return briefly here to Rogers (2007). There are two key differences between my research and Rogers’ (2007) work. I chose to focus exclusively on autism, Rogers (2007) had a broader focus (i.e. individuals living with GLDs) and rather than interviewing parents of children with a diagnosis, as Rogers (2007) did, I interviewed ‘high-functioning’ autistic adults. It is important to carry out research with autistic adults *and* parents of autistic children, to appreciate the full extent of the hierarchy of impairment, and the social exclusion and marginalisation which people with GLDs are subjected to. GLDs are part of profound autism, but they are less pronounced, or not present, in people identified as ‘high-functioning’ (Fader, 2019). GLDs are heavily stigmatised, people labelled ‘low-functioning’ have access to fewer opportunities, they are infantilised, and decisions are frequently made on their behalf (Snow, 2005). Autistic people identified as ‘high-functioning’ may have a vested interest in perpetuating the hierarchy of impairment, in being ‘not like *them*’, the label ‘high-functioning’ confers many privileges (a quality of life, access to social life, and educational and employment opportunities), and to continue to enjoy those privileges, ‘high-functioning’ autistic adults must work to minimise their differences, distancing themselves from profoundly autistic individuals in the process (Sarris, 2017).

3.8 Current transition programmes for autistic students in FHE

Formulating a framework for assessing, and addressing, the transition needs of autistic individuals in FHE, Adreon and Durocher (2007) advised autistic prospective students to give some thought to which type of college, or university, would be most appropriate for their needs. Smaller colleges and universities are often in a better position to offer learners individual attention, but ‘difficult differences’ can be rendered more visible. Larger colleges and universities might be prone to overcrowding, and there will be less opportunity for one-to-one attention, but there is a higher likelihood of developing friendships with others on the social periphery, as the student population is more likely to be diverse.

One autistic graduate reflected on how ‘At college I met people who appreciate me for who I was instead of making fun of what was different about me […] College was an exciting time. I could be myself’ (Shore, 2001: 77). Drake’s (2014) work on the college experiences of autistic graduates, who had successfully completed a bachelor’s degree pre-diagnosis, also supports this theory. Adreon and Durocher (2007) also encouraged prospective students to factor in the proximity to home, a campus close to home would facilitate a daily commute from the parental home, or else, support would be close by if required. Living arrangements would also need to be given some consideration, whether to request shared or private accommodation. Drake (2014) proposed autistic individuals could be offered a private dormitory, without ghettoisation. Private living quarters would be *optional*, some autistic students prefer to live with others, which will become apparent in chapter 6.

Sensory integration difficulties can have a detrimental effect on the autistic person’s independent living skills, effecting autistic students living in halls of residence (Ackles et al., 2013). Sensory difficulties can cause discomfort in cafeterias, if the autistic learner is restricted to particular brands, textures and colours of food (Adreon and Durocher, 2007; Cermak et al, 2010). Prospective students with sensory difficulties would be well advised to take heed of this. Adreon and Durocher (2007) identified the following 10 areas of deficit, prospective students were advised to give some consideration to commuting from home if they were unable to manage their personal hygiene, dressing themselves, being roused by an alarm clock, arriving at lectures and seminars punctually, shopping (whether for essentials, gifts or other products), setting, and working to, meal plans, using their student ID card, tolerating fire alarms in the early hours, locating toilets on and off campus, travelling confidently, and using public transport independently.

College students and university students are also required to draw upon problem-solving skills, Adreon and Durocher (2007) warned. Living in halls of residence, some competence is expected in managing medical emergencies, and minor ailments (when to self-treat, when to seek advice from a general practitioner and when emergency care might be more appropriate), in managing finances, and in using electronic communication. It is also important for the autistic learner to have the confidence to advocate for themselves and disclose information about their diagnosis to the relevant parties (Adreon and Durocher, 2007). Disclosing the condition to the disability team, or the funding body is advisable. In England, the student is given the opportunity to indicate a disability, and the type of disability, on their university application form, and the disability team arrange an appointment to discuss their needs, the self-advocacy required of the autistic student in this context is to indicate the diagnosis on the application form, attend the scheduled appointment and advocate for their needs. Student Finance England permit DSAs applicants to bypass disability services, funding is still available without a signature from student services. If the student would be uncomfortable with self-advocacy, parents or caregivers might do well to employ a 'go-between' to liaise with others on their 'child's' behalf (Adreon and Durocher, 2007).

Autistic learners commonly require accommodations, including 'reserved' seating in lectures and seminars, amanuenses (note-takers), permission to record lectures and seminars to Dictaphone, and to sit examinations in a separate room and with 25% additional time. Some students (those with a fear of public speaking, for example, or social anxiety) would benefit from exemption from 'group projects, group discussions, laboratory assignments and group seating arrangements' (Willey, 2000: 134). Oral examinations could be administered, replacing written examinations where appropriate (Willey, 2000), and flexible deadlines for essays to accommodate processing delays, co-morbid dyslexia, and motor co-ordination difficulties (Willey, 2000). Autistic individuals can also experience difficulties with executive function; 'planning, initiation, organization, inhibition, working memory and self-monitoring' (Adreon and Durocher, 2007: 276). The recommended supports include study skills support, a study assistant to offer guidance on organising ongoing projects (including theses), and discipline-specific tuition. An external tutor might be better equipped for this task than a tutor employed by the college or university, this would be at the discretion of the client.

Disability services could arrange a point of contact for the autistic learner, Adreon and Durocher (2007) proposed. This person would be in regular contact with their mentee, monitoring their well-being and signalling any issues which might have arisen, or any causes for concern, and advise their mentee on how best to manage, and rectify, the situation before it deteriorates (or suggest an exercise in damage limitation). This person might liaise with the learner’s parents and assist the student with the registration and enrolment/re-enrolment process, help the student select an appropriate course and optional modules, support the student at graduation, and enable the student to navigate the social world, the ‘unwritten social rules of classroom, dorm, and campus behavior’ (Jekel and Loo, 2002: 5). Peer mentoring might also be valuable for some students.

Adreon and Durocher (2007) suggested autistic prospective students ought to ‘get to know’ the campus in advance of freshers’ week. If the college or university runs a summer school, or organises an event, open to the public, before the student enrols on their course, the prospective student would be well advised to participate, or to visit the campus beforehand ‘on spec’. Visiting the college or university’s website and familiarising oneself with campus maps prior to arrival is also worthwhile, particularly for autistic prospective students who live with topographical agnosia (Copley, 2011), difficulties with wayfinding. Coulter (2003) proposed autistic students could be provided with details on how to ‘check into’ student accommodation and on orientation.

In an evidence-based guide to best practice, Sims (2015) outlined a series of recommendations for autistic individuals transitioning to university, comprised of six areas, recommendations which correlate with my findings, and the work of others. Sims’ (2015) recommendations included; clear information ought to be distributed in advance, staff should exhibit a comprehensive understanding of what it is to be autistic, there should be pre-registration events (prior to freshers' week) to introduce prospective students to campus facilities and key points of contact at the university with sensory input kept at a manageable level, accessible campus facilities and services and on-campus events, an autistic students' society (with an online presence), and *affirmative* mentoring services. Sims (2015) proposed autistic prospective students should establish contact with disability services at the earliest convenience. Ideally, there would be a broad range of supports available, flexible and tailored to the individual (MacLeod, 2010; Sims, 2015). Clear and concise information would be published on the university's website, detailing how best to disclose information about the diagnosis to disability services, and indicating the benefits of contacting disability services *prior to* enrolment.

All staff at any university (from lecturers to caterers, librarians to security services) should be given *compulsory* autism training (Sims, 2015). Staff are *offered* training, but it is not currently mandatory (Hastwell et al., 2013; Sims, 2015), which can leave a gap in collective knowledge, and in some cases compromises autistic students' well-being. Compulsory training would address this knowledge gap. Training sessions, Sims (2015) proposed, would be tailored to the attendees, to their role, to the level of contact they should expect to have with an autistic learner, but *all* staff in *any* capacity ought to be given some training. Autistic learners interact with tutors, lecturers and supervisors, who *are* offered autism training (Sims, 2015), but non-academic staff (for example, receptionists) ought not to be overlooked when planning and delivering autism training sessions. Autistic individuals interact with receptionists, library staff, catering staff, janitorial staff and security personnel, and would benefit from widespread awareness (I will return to this in chapter 6).

Affirmative mentoring would benefit autistic individuals in FHE (Sims, 2015). Mentoring is an invaluable resource for autistic learners but there is a risk that some non-medical helpers might coerce the autistic client into self-presenting as neurologically typical and manage their behaviour and self-presentation in ways which the client finds age inappropriate. If this is the explicit goal of the client, there might be a case for the support worker to offer some direction, but it is for the client to decide whether the NMH provides direction, monitoring and/or support (Sims, 2015). Speaking to Beardon and Edmonds (2007), one autistic individual was highly critical of non-medical helpers who intervene, where their intervention is unwelcome:

> People need to get over the idea that the 'neuro typical way is the right way and any other way is wrong […] People with AS don't need to be […] trained how to be 'normal'. It's the 'normal' people who […] need to be taught not to be prejudiced and discriminatory, and to accept and accommodate us for who we are (Beardon and Edmonds, 2007: 6).

Yet as I outline in Simmons (2020), the role of the NMH is more complex than this, if monitoring and behaviour management is expected to lead to the desired outcome. Russo (2018) noted autistic individuals are more likely to be offered a lucrative job if the condition is camouflaged and kept to a minimum, and if the student's stated objective is to optimise their career prospects, as in Simmons (2020), some degree of monitoring and symptom management will be necessary, irrespective of whether the student is concerned with their self-presentation.

Sims' (2015) findings lend support to pre-registration events, involving tours of key locations including the library, lecture theatres, seminar rooms and halls of residence and talks on courses and student services. She described Gardner et al.'s (2012) pre-entry event, with talks covering 'meeting people, getting involved in groups and societies, accessing support and managing coursework. [They] also provided prospective students with tours of university accommodation and the university cafeteria' (Sims, 2015: 6). Gardner et al. (2012) also recommended organisers tailor these events to the attendees' interests, intended career and any anxieties or uncertainties the participant might have. Freshers' week can instigate sensory overload (the smell of street food, jostling crowds, societies vying for new membership) (Madriaga, 2010). These pre-entry events give autistic prospective students access to essential information, whilst circumnavigating freshers' week and its attendant sensory overload. A 'quiet hour' could be scheduled for freshers' week proper, and an online freshers' fair might best meet the autistic prospective student's needs, an opportunity to participate in freshers' fair without exposing oneself to an overwhelming sensory experience.

Subjected to abusive behaviours in other settings (for example, at school) autistic individuals might be hesitant to make connections with new social groups (Sims, 2015). Sims (2015) proposed an autistic students' society or an online social group (MacLeod, 2010; Sims, 2015), which would serve a pastoral function, and a social function, but might also be a resource, an opportunity to clarify any uncertainties, 'compare notes' on the same assessment, and to update oneself on any lectures which might have been missed. It is relatively commonplace for autistic students to be absent from lectures or to play truant (Chen et al., 2015; Sims, 2015) and online social groups would mitigate the effects of these absences. Preece and Howley (2018) proposed several areas of difficulty which lead to unexcused absences in autistic learners, primarily 'difficulties regarding social interaction and communication, rigidity of thinking and sensory sensitivities [and] the heightened anxiety that many on the spectrum experience' (Preece and Howley, 2018: 468).

Evaluating a three-day residential event, the autism summer school, which had been running for several years, Lei et al. (2018) analysed feedback forms submitted by the prospective students who consented to their data being used in this way. The autism summer school was divided into three components; 'work', 'rest' and 'play'. On arrival, the participants were issued with a relatively detailed programme, an outline of the content of each talk, and hand-outs for each session. The summer school was delivered jointly by student representatives, academics in the psychology department and individuals from the disability team. The ‘work’ component was comprised of the following: disclosing information about the diagnosis to the relevant parties, accessing student services, the roles of lecturers, and an opportunity to participate in a sample lecture. The ‘rest’ strand included lectures on attending to physical and mental well-being (for example, managing anxieties and stress, the upkeep of a personal hygiene regime). Participants were given talks on students’ societies, communal meals, and the opportunities to socialise with others in the ‘play’ element of the programme.

The prospective students were also given the opportunity to listen to current autistic students, delivering presentations on their university experience. Most participants, the written feedback indicated, found the autism summer school a beneficial and informative event. The participants found the actual content of the sessions (particularly a talk on the use of autism as a strength in education), the opportunity to experience life in halls of residence and on campus, and the chance to interact with student ambassadors, and other autistic individuals who would soon be transitioning to university, or had transitioned previously, particularly useful (Lei et al., 2018). Some summer school participants reported the event had led them to confront the question: ‘is university for me?’ This is worth some deeper analysis. University is not suitable for every person, whether autistic, non-autistic or neurologically typical. Autism summer schools are not a marketing exercise; if some participants decide FHE is incompatible with their circumstances, inappropriate for their needs, or not a useful means to their end, this is not a failing of the programme but a success. Potentially, more provisions could be made for autistic individuals who decide *not to* pursue FHE, and autistic individuals with needs which cannot (currently) be met in FHE.

Finally, Lambe et al. (2018) invited autistic prospective students to envision their forthcoming transition into higher education, and reflect on their anxieties, ambitions and plans. The participants expressed concerns about independent living, time management and building positive reciprocal relationships with peers. There were five areas of concern; ‘The Social World, Academic Demands, Practicalities of University Living, Leaving the Scaffolding of Home, and Transition to Adulthood’ (Lambe et al., 2018: 1531). Their findings are an insight into autistic prospective students’ anxieties pre-transition and the issues which transition programmes could be designed to cover in advance of the students’ arrival.

3.9 Conclusions

The hierarchy of impairment can be defined as the hierarchy of preference for certain categories of disabilities (for example, physical disabilities or sensory impairments) above others (for example, SEBDs or GLDs) (Tringo, 1970) or a coping mechanism to manage one’s own diagnosis, or the diagnosis of a family member, as a consolation, i.e. ‘it could be worse’ (Rogers, 2007). The public, caregivers and autistic individuals (and other disabled individuals) are all party to the hierarchy of impairment. For the ‘high-functioning’ autistic person, the hierarchy of impairment demands an act, to cover or pass (Goffman, 1963) to preserve the privileges of a ‘high-functioning’ status. For the profoundly autistic person, the hierarchy of impairment confines them to the lower reaches of society, the disabled ‘community’ and the autistic ‘community’ and excludes them from social life and FHE.

The ideal of ability perpetuates the hierarchy of impairment and facilitates the marginalisation of individuals living with GLDs or otherwise profound autism. This compels ‘high-functioning’ autistic students in FHE to cover or pass (Goffman, 1963), manage their self-presentation (Goffman, 1956) and choose not to arrange support or request accommodations (for example, extended library loans), to circumvent the ‘risk’ of being identified as profoundly autistic. The premise of covering is relevant not only to the autistic student’s presentation of self but to how the autistic learner uses disability services. Some autistic students will disclose information about their diagnosis to the relevant parties (i.e. the disability co-ordinator, teaching staff), but will not arrange support or accommodations, to give the impression of ‘high functionality' and to minimise the visibility of their condition. But withholding information about their diagnosis, and *needs*, from others (peers, teaching staff and disability co-ordinators) can hinder the autistic student's first impressions (Sasson and Morrison, 2017) and places the autistic student at an unnecessary disadvantage if their support needs are relatively high (Anderson and Stephenson, 2017).

Some autistic students are keen to uphold the ideal of independence and, for this reason, do not opt into support or accommodations, irrespective of support needs, which for some autistic students can have unwanted consequences. Some autistic students will not manage the demands of academia without support (Anderson and Stephenson, 2017) and 'failing' to meet prescribed academic standards often leads to withdrawal from the programme of study. The government, too, are invested in the ideal of independence, and policies are in place to reduce the need for NMHs, thus, not all autistic students are eligible for NMH support. To be granted necessary supports, both the autistic learner and the funding body must reject the ideal of independence.

The ideal of self-regulation, and the ideal of normalcy, leads autistic students to work to manage their emotions on campus. Displays of difficult emotions are by default, 'inappropriate', emotional self-regulation, which is difficult for the autistic person (Whitman, 2004) is, by default, 'appropriate' behaviour. Given the widespread subscription to the ideal of self-regulation, this emotion work is 'the norm' and to conform to the ideal of normalcy, the autistic person must self-regulate (self-regulation is expected in FHE, 'failure' to comply can result in withdrawal from the course). The emotion work involved in meeting these ideals causes (in some) a decline in mental well-being and deferred meltdowns (Attwood, 2015). On emotion work, a socio-psychological act which is not particular to autism, Hochschild (1979) wrote, 'Emotion, it is argued, can be and often is subject to acts of management. The individual often works on inducing or inhibiting feelings so as to render them "appropriate" to a situation' (Hochschild, 1979: 551). The autistic student's transition experience is made unduly uncomfortable by these four, socially constructed, but deeply embedded, ideals.

Poulson (2009) explored what sociological thought can contribute to contemporary understandings of autism, identifying how sociologists usually consider clinical conditions to lie *outside* of their realm. Poulson (2009) wrote ‘A common and particularly provocative debate among people with Asperger’s and autism […] concerns the degree to which they should be forced to conform to social norms established by the “neuro-typical.”’ (Poulson, 2009: 45). I *am* a person with Asperger’s Syndrome, and I am in a position to further these important discussions. Disability, and autism particularly, has been largely absent from the socio-political sphere (Mollow, 2004; Poulson, 2009). This study introduces autism to the socio-political sphere, utilises the social model of disability, in preference to the standard social deficit model of autism as a framework and explores how *socially constructed* ideals can be destructive and disabling for autistic students in FHE. In this chapter, I have situated my research in the existing body of literature. In the next chapter, I will outline my methodological decisions, and introduce my participants. This will contextualise my data analysis and discussion, and the auto/biographical work which I presented in chapter 2.

Chapter 4: Research methods

4.1 Introduction

To reiterate briefly here, my research questions are:

- What are autistic students' experiences of transition in FHE?
- What perception management strategies (if any) do autistic students employ in further and higher education (FHE) settings?
- What support is currently available to autistic students in FHE?

Qualitative interview data is instrumental to my thesis, and it is in this chapter that I will outline the process of gathering, and analysing, that data. In this chapter, I reflect upon the decisions I made at each stage of the research process, and the rationale behind them, with a focus on the particularities of research with autistic individuals where appropriate. I justify my research approach, the methods I used, my sampling strategy, and the criteria for including participants in, and excluding other interested parties from, my study. I present pen portraits of the participants. I acknowledge the limitations of this study, towards the end of the chapter. I will also restate my positionality, as an autistic researcher, outline the process of writing an auto/biography, and challenge the value placed on 'objectivity' in research. I will reflect on the experience of producing 'insider-outsider' research. When designing a study involving autistic participants, researchers are advised to reflect on several ethical considerations, particular to autism (The Autism Research Ethics Task Force, 2019), in conjunction with standard ethical procedures, such as protecting the participant's identity and correct data handling practices. I explore these ethical dilemmas in detail below.

4.2 The essentials

What follows is a brief overview of the data collection phase of my research and my research decisions, to introduce my study 'in a nutshell'. This section will address the 'what', the 'why', the 'when', the 'where', the 'who' and the 'how' questions. Between August 2015 and May 2017, I interviewed 42 current and former students registered on various FHE programmes, in disciplines as diverse as oncology, equine management, astrophysics and performing arts. 41 participants were diagnosed with Asperger's Syndrome, Donna's diagnosis was not confirmed but the diagnostic process was ongoing, and 40 were current students (Frank and Kevin had graduated).

I interviewed some participants face to face, some over the telephone, some via Skype, and others over email. Flexible research methods meant no autistic individuals would exclude themselves from the study, for reasons of discomfort with the method (for instance, face to face interviews demand social interaction). I used auto/biography (chapter 2); the auto/biographer analyses their written account of their life history, or their account of an event (in my auto/biography, I reflected on an eight-day conference and the emotional and physical exhaustion of covering). I am an autistic PhD candidate, studying autism and transition into FHE; auto/biography utilises this vantage point to its best effect.

I also took fieldnotes, some of which are reproduced in this thesis. Taking fieldnotes gave me the opportunity to record my thoughts and feelings in real-time, not on reflection. Fieldnotes can constitute the data of a study in whole or in part, used alongside interview data (Schwandt, 2015). In this study, fieldnotes will be used as supplementary evidence, complementary but subsidiary to my interviews. There are several reasons to support the use of fieldnotes in social research. Fieldnotes:

> expose a range of emotional and practical responses to a chaotic data collection process, and more often a moment in time, a moment that perhaps is continuous and bound up with the micro-politics of a domestic environment and embedded in the sociopolitical sphere (Rogers, 2016b: 4).

Labaree (2019b) proposed the use, and simultaneous analysis of field notes promotes self-reflection and directs the researcher's attention to potential themes. For Geertz (1973), fieldnotes allow researchers to preserve a moment, an event which would otherwise have been fleeting.

England was the locus of the study; all participants were based in the West Midlands, the North East or the East Midlands. I invited all autistic university students registered with their disability department to participate via disability services' mailing lists (I approached every university in the country to circulate the invitation to participate[28]). My NMH, Steve, is an educational support assistant at a college in the West Midlands, he acted as a gatekeeper, recruiting six college students and one university student (a recent college graduate) to the study:

> Gatekeepers are individuals who can be used as an entry point to a specific community. […] Gatekeepers can also help the researcher to access the community through introductions and by establishing a relaxed or appropriate environment for the research process (Given, 2008: 2).

Participants were invited to choose their research method, and the date, time and location of their interview if applicable. Autistic individuals exhibit a strong preference for familiarity, and sensory hypersensitivity or hyposensitivity is present in some cases; to minimise discomfort to the participant, it was essential for interviews to take place in a venue which felt comfortable for them. The participants were welcome to guide the conversation, but I used semi-structured interviews, retaining some control over the direction of the conversation where necessary (i.e. where participants introduced tangential topics which could not easily be diverted back to the subject of our interview). This accommodated the participants' repetitive patterns of thought. Summarising the semi-structured approach, Galletta (2013) wrote 'The questions are open-ended in order to create space for participants to narrate

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[28] The aim was not representativeness or generalisability, but to give every autistic person in HE, who had self-disclosed to disability services, the opportunity to participate in the research.

their experiences; however, the focus of the questions is very deliberate and carefully tied to your research topic' (Galletta, 2013: 47).

Tangential topics, moreover, can be a frame of reference, giving participants the opportunity to process their thoughts and experiences (for example, for Neil, Harry Potter was a frame of reference for processing his relationship to neurologically typical others). But tangential topics can divert attention from the interview, and increase the risk of interview fatigue by prolonging the conversation (for example, when asked how her Asperger's Syndrome might have positively impacted on her interactions with her peer group, Hannah also introduced Harry Potter to the conversation, listing 'obscure' and disparate facts which did not contribute to my objectives). I used a general interview guide approach (Gall et al., 2003) to interviews.

My intentions, in using a general interview guide approach, were twofold. Reflecting on his PhD research, Turner III (2010) described how he had engaged with:

> [P]articipants in a relaxed and informal manner where I had the opportunity to learn more about the in-depth experiences of the participants through structured interviews. This informal environment allowed me the opportunity to develop rapport with the participants so that I was able to ask follow-up or probing questions based on their responses to pre-constructed questions (Turner III, 2010: 755).

I intended to develop a rapport with my research participants, with in-jokes and references to shared interests wherever possible, an inherently bubbly personality and empathy, as if we were friends, to relax my participants. This is both ethically sound (British Sociological Association, 2017) and produces higher quality data (DiCicco-Bloom and Crabtree, 2006). But this style of interviewing also begins to redress the power imbalance between the researcher and participant (Oakley, 1981).

Warmer, empathetic interviewing styles, Oakley (1981) proposed, can be preferable to colder, more clinical approaches to social research. One of my participants, Vanessa, disclosed previous self-harm and having contemplated taking her own life, for example, and another of my participants, Gregory, reflected on a previous narcissistic relationship, a detached style would have been entirely inappropriate (Moyle, 2002) and false to me. A connection with participants is not wholly desirable or possible in all circumstances, nor is it always possible or necessary to have a personal connection to the topic, although participants and colleagues expect this of social researchers (Katz-Rothman, 1996; Letherby, 2003). Furthermore, the power relationship between a researcher and a participant will *always* be complex (Letherby, 2003). But I chose to take advantage of my connection to the research participants and my personal relationship with the topic and interviewed my participants in a way which felt natural to me.

4.3 The research process

Using semi-structured interviews allowed me to cover topics of interest and ask 'follow-up' questions and permitted some degree of comparability between my participants. Semi-structured interviews do not limit the participant as structured interviews do (Turner III, 2010). It was key to give all research participants scope to interpret and process events and make sense of their feelings. I designed the research with the comfort of autistic individuals at the forefront. To reiterate, I chose to use face to face interviews, email 'interviews', telephone interviews and Skype interviews, to eliminate the *necessity* for face to face social interaction. I invited participants who chose to be interviewed face to face to choose the location of our interview, to minimise the possibility of sensory discomfort. I chose several topics of interest to cover with my research participants. I encouraged the research participants to reflect on how autism had impacted on their relationships with peers and staff, on their use of on-campus facilities and on their academic progress. The interview covered the support and services the student had received, and the adjustments which had been made, as well as their ideal transition programme, anticipated stigma, others’ reactions to their self-disclosure, and self-presentation. At the end of the interview, I invited participants to lead the conversation.

Having defined my research focus, I composed two template emails, the first was an invitation to participate in my study, the second was a request to disability services to circulate my invitation to participate. I adapted my online self-presentation to suit my intended audience. I presented myself as professional and academic in my communications with disability services, and a bubbly ‘insider’ in my emails to the potential participants. I also designed a poster advertising the study, a participant information sheet and consent form (Crombie et al., 2013), including demographic questions. In social research, it is necessary to collect demographic information (Roysircar, 2016) to explore questions of intersectionality, ‘an individual’s identity is comprised of multiple intersecting social locations derived from interacting societal structures and associated macro-level biases, informed by the power, privilege, oppression experiences, social dictates, constraints, values, strengths, and perceived deficits of those identities’ (Roysircar, 2016: 3). Some participants are uncomfortable sharing personal information with a relative stranger, or total stranger; ‘a relatively large proportion of survey participants felt uncomfortable disclosing household income (67%), sexual orientation (40%) and educational background (38%)’ (Kirst et al., 2013: n.p.). Including demographic questions as an annexe to the consent form counteracted some of this discomfort.

All interviews were initiated by the research participant, with an initial expression of interest. I thanked each potential participant for their interest. I invited all participants to decide how to participate and asked them to read the attached participant information sheet, and to return their completed consent form. Whenever the participant chose a verbal method, I invited them to choose a date and time convenient for them, and if the participant chose to be interviewed face to face, a location. Primarily, I interviewed the participants at *their* college or university, or nearby[29], Emma and Ilyas chose to travel to *me*. All interviews, irrespective of method, followed a question and answer format, although it was commonplace for the participants to also introduce tangential topics, in verbal/synchronous methods more so than nonverbal/asynchronous methods (Curasi, 2001; Meho, 2006; Meho and Tibbo, 2003; Murray, 2004; Murray and Harrison, 2004).

4.4 Research philosophy; the route to qualitative research

Empiricism

Empiricists[30] propose that while values are learned and relative, 'there are universal truths about right and wrong' (Bernard, 2013: 8). The subordination of autistic individuals who cannot or do not conform to the ideals of normalcy, self-regulation, ability or independence, and the exclusion of autistic individuals from educational and social life, is *wrong* (Department of Health and Social Care, 2018; Robertson and Ne'eman, 2008). The hierarchy of impairment (to reiterate, the hierarchy of *preference* for some disabled groups[31]) can negatively impact on autistic students' transitions to FHE, as some autistic students mask to self-present in ways which do not indicate the presence of GLDs or mental ill health, both towards the lower reaches of the hierarchy of impairment (Deal, 2006). Challenging the hierarchy of impairment and its injustices is *right*.

Lithari and Rogers (2016) wrote 'Until there are care-full education processes, marginalisation will remain, impacting on disabled children's transition to secondary school' (Lithari and Rogers, 2016: 259). Likewise, care-full education processes have a positive impact on autistic students' transitions to FHE. Care-full education processes are *right*. I occupy the 'middle ground'

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[29] In the interests of widening participation for other autistic researchers and transparency, I acknowledge Steve accompanied me to all interviews and my family shouldered all travel costs.

[30] I recognise 'empiricism' has multiple meanings.

[31] The hierarchy of impairment can also refer to the 'right' to define oneself as disabled (Reeve, 2004).

between the position that subjectivity invalidates social research and the opposing view that there is no reality. Letherby (2011) summarised this:

> ‘Theorized subjectivity’ relies on a recognition that, while there is a ‘reality’ ‘out there’, the political complexities of subjectivities, and their inevitable involvement in the research/theorizing process make a definitive/final statement impracticable. Rather what is practicable, desirable and necessary is the theorization of the subjective (which includes the research’s motivation and practice and the respondent’s expectations and behaviour) and its significance to knowledge production (Letherby, 2011: 70).

One of the central tenets of empiricism is the notion that the foundation of all knowledge is experience (Psillos and Curd, 2010). There are no truly universal experiences (experience is subject to interpretation), there are infinite possible realities (Pizzini, 2008). I anticipated that some autistic individuals would have been exposed to stigma, for instance. For these people, the stigma of autism is their reality. Other autistic individuals would not have been exposed to stigma and their truth would be very different, i.e. autism is not a heavily stigmatised condition.

It is partly for this reason that my research is concerned with my participants’ experiences (the use of qualitative interview data), not the search for an absolute truth (quantitative, generalisable findings) although this is not a ‘rejection of the need to be critical, rigorous and accurate’ (Letherby et al., 2012: 3). Methodologically sound critical analysis and subjectivity are not mutually exclusive (Letherby et al., 2012), contrary to popular misconception. From the outset of the study, I recognised autism was too broad a concept to make any claims to generalisability. Autism is a condition of ‘extremes’, for example, some autistic individuals cannot tolerate clothing labels (hypersensitivity), others will comfortably touch water at boiling point (hyposensitivity), some autistic individuals will be selective eaters, and others will live with pica (the consumption of non-edible objects) (Alli, 2018).

It is not always possible for autistic individuals to read a person's intent or social communication, especially if the statement or action is sarcastic or 'banter' (The Wirral Autistic Society, 2015). I recognised from the outset that one autistic student's experiences are not representative of other autistic students' experiences. My sample size of 42 is above average for a qualitative study (Mason, 2010), but the diverse symptomatology of autism (Alli, 2018) and how the same interaction can be interpreted differently (The Wirral Autistic Society, 2015) meant empiricism was a methodologically sound choice for me.

Humanism

Humanism influenced my approach. Quantitative research methods dominate autism research (Bölte, 2014) but humanism values qualitative research methods. The perceived superiority of quantitative research is grounded in the misconception that methods used in the natural sciences are transferable to the study of humans (Bernard, 2013). Humanism recognises the research methods commonly used in the hard sciences are inadequate and wholly inappropriate for the study of human behaviour. Humans are qualitatively different to inanimate matter. Humans are sentient, and attach meanings to objects, relationships, customs, behaviours and interactions with others (Association for Humanistic Psychology, 2014). To research human behaviour and human emotion, Dilthey (1883) proposed, some rudimentary appreciation of the meanings human beings attach to these objects, relationships, customs, behaviours and interactions with others is necessary.

Above, I identified how autistic individuals can attach different meanings to the same behaviour or statement (The Wirral Autistic Society, 2015). I also identified in chapter 3 how neurologically typical individuals attach different meanings to the same autistic behaviours, which in part depends upon whether the autistic person's diagnosis is known to them (Sasson and Morrison, 2019). Positivism demands objectivity (Dudovskiy, 2018). By contrast, Bernard (2013) proposed 'Humanism sometimes means a commitment to subjectivity – that is, to using our own feelings, values, and beliefs to achieve insight into the nature of human experience' (Bernard, 2013: 22). The best example of this in this thesis is my use of auto/biography, but my analysis is also led (in part) by my own values, beliefs and feelings as well as theory. I began the research from the position that I could make no claim to objectivity, with my emotional, and physical, proximity to the subject. Humanism repositions subjectivity as valid and instrumental to the task of the social scientist.

Humanism calls for researchers to include (indeed, embrace) in their analysis that which is unique; human experience is unique to each experiencer. By contrast, positivism calls for researchers to exclude outlying data from their analysis (Ramanathan, 2008). Günbayi and Sorm (2018) identified four paradigms and their uses in social research. The interpretive paradigm suits most qualitative research (including mine) and 'radical humanism' is a good fit for participatory action research and emancipatory action research. My research is neither participatory action research nor emancipatory action research, but the ethos is similar, the focus of this research is on autistic students and *their* diverse voices, with the long-term objective of indirectly improving other students' transitions into FHE. I also anticipate the 'butterfly effect' outcome of that (i.e. the contribution to society which some of those students will, ultimately, make). I designed my research to facilitate the participation of as many autistic students as possible, more so to accommodate, instead of silencing, as many autistic voices as possible, than to generalise from my findings.

Humanism does not expect researchers to generalise from their findings and with the inherent heterogeneity of the research population, the multitude of interpretations and misinterpretations of human behaviour and social interactions, and my qualitative methodology (in-depth interviews with a relatively small number of research participants), it was prudent to align myself with humanism. I was unconcerned with statistics (aside from some rudimentary quantitative data analysis to develop my four degrees of openness theory[32]). If only one participant recounted a given experience, or opinion, at interview, it was of no less interest to me, it was not discounted as an ‘outlier’. The concept of ‘outlying data’ is irrelevant in qualitative research (Paritosh, 2007).

Plummer’s (2015) critical humanism has much to contribute to my research. ‘It is people together who change the world and make it a better or lesser place. It is people that matter’ (Plummer, 2015: 20). My research, like any social research, is focused on people, and on the possibility of positive change. Humanistic research, therefore, begins with human beings, individuals whose day to day existence is shaped, to varying degrees, by difference from ‘the norm’, including autistic students whose daily lives are shaped, in some cases characterised, by difference, and the management of stigmatising differences. Humanism is concerned with the ‘talk, feelings, actions, bodies, vulnerabilities, creativities, moralities, sufferings, joys, and passions of people as they share communities and social worlds, create human bonds, and confront the everyday constraints of history and a material world of inequalities and exclusions’ (Plummer, 2015: 20). My research is concerned with how autistic students in FHE navigate a social world which identifies their neurology as unequal to (less than) the ‘norm’, and reprimands deviation from the ‘norm’ with exclusion.

Autism is the interplay of corporeal experiences (‘bodies’), behaviours (‘actions’), feelings, passions and vulnerabilities, which autistic individuals manage, and make sense of, in diverse ways. Humanists are also interested in dehumanisation, the social processes through which human beings (individuals living with GLDs amongst them) are made ‘less human’, seemingly objectively ‘less than’ and propose there are several, equally valid ways to be

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[32] I identified the most popular and least popular perception management strategy amongst the sample.

human, and human life is context specific, inextricable from the time and space in which it is lived.

Interpretivism

Pizam and Mansfeld (2009) identified the key differences between positivism and interpretivism. I focus here only on interpretivism, not on how interpretivism is defined in relation to positivism, in many ways its opposite. For the interpretivist, reality is socially constructed, it is not concrete or singular, interpretivism accommodates multiple realities. I identified above how my research was grounded in empiricism. Interpretivism is complementary to empiricism. Research participants' realities are shaped by their experiences (Pizzini, 2008), but 'experience' is subject to interpretation (Myers, 2008). The purpose of interpretivist research is to further the researchers' and readers' understanding of the topic through *empathetic* understanding, and it is not commonplace for the research to be led by a hypothesis (in its place are research questions).

I chose not to formulate a hypothesis, to eliminate the possibility of design bias (Smith and Nobel, 2014). Some researchers who decide to formulate a hypothesis intentionally design interviews to produce data which supports their hypothesis, others deliberately interpret, and misinterpret, their data in ways which support their hypothesis. The focus of interpretivist research is on what is particular, and what is exceptional, it is designed to generate meaning, and interpretivists are cognisant of how their findings are context specific. In common with humanists, interpretivists recognise the interplay of the historical, geographical, and cultural context, the dominant value system of the culture and their participants' personal values (Pizam and Mansfeld, 2009).

The focus here was not *solely* on what was particular, but the heterogeneous symptomatology of autism meant it was wholly appropriate for me to accommodate the particular and the exceptional. My analysis generated meaning[33], I interpreted participants' actions and thoughts, challenged taken for granted 'understandings' of autism, and recognised from the outset that the experience of autism is context specific. This is, partly, why I chose to contact every university in the country, to cover a broad range of contexts. Interpretivists are concerned with what their participants do and how they think, the issues they confront, and how, collectively or individually, they respond to, and manage, these issues (Pizam and Mansfeld, 2009). This was a focal point of my research. Researchers and participants enjoy an interactive relationship in interpretivist research, with both participating on a *relatively* even footing, 'the division between researcher and subject is blurred, and control over representation is increasingly shared' (Gergen and Gergen, 2000: 1035). I chose to position my research participants as the experts and as I outlined above, my interview technique was informal (with the use of humour and 'in-jokes', empathy and reflecting on personal experience).

My consistent use of the word 'participants', and not 'interviewees', 'subjects' or 'informants' throughout is intended to reflect a more equal partnership between the researcher and participant, to reflect a redressing of the power imbalance, and an ongoing awareness that too great a power imbalance is likely to influence the participants' responses (Edwards and Holland, 2013). To reiterate, the balance of power between a researcher and a participant cannot be equal, and a researcher cannot be an 'insider' (Letherby, 2003) but researchers can 'level the playing field' to some degree. For Plummer (1995), sharing personal stories with participants adds value to a study, for both the researcher and their participants.

In sharing personal stories with participants, to redress the power imbalance between myself as a researcher and my participants (and in accordance with my personality), I led some of my participants to greater awareness of their

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[33] Quantitative research produces no less meaningful results than qualitative research, but quantitative researchers are more concerned with correlations and relationships (Pizam and Mansfeld, 2009).

condition, and to the recognition that their ‘problems’ and ‘quirks’ were not particular to them. I seemed to have enlightened and reassured Vanessa when I mentioned, by chance, my severely impaired social imagination.[34] She confided, ‘I had no idea that was a symptom of autism, I thought I was just really bad at taking criticism. It all makes perfect sense now!!’ For Munro (1998) participation in social research has the potential to empower research participants, increasing their awareness of the impact of socio-political forces on their self-concept, and offering them a platform from which to challenge the view that *they* and their management of their condition are responsible for their social position.

Interpretivists also acknowledge the role of interpretation during the data analysis phase. The interpretation of data is fluid, subject to interpretation (this includes quantitative data[35]) (Lebied, 2018). The findings I present in this thesis are my interpretations of my interview data; other researchers, if they were to analyse *my* data for *their* purposes, would discover different themes (Braun and Clarke, 2006). Interpretivist researchers are careful not to overstate the potential outcomes of their study (Sumner et al., 2014; Tijdink et al., 2016). Although I have interpreted the participants’ realities in innovative ways, in line with interpretivism, I make no claim that this is the *only* legitimate interpretation of their realities.

There is a popular misconception that quantitative research is inherently more ‘credible’ than qualitative research (Bölte, 2014; Smith and Nobel, 2014), this underlines the need for further research in this area, my own research is qualitative (although my research still has the potential to exact change with widespread dissemination), but my findings indicate the need for change, and quantitative research is more likely than qualitative research to bring that

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[34] My social imagination is more profoundly impaired than my social communication or social interaction.

[35] ‘As many as 32% of autistic persons are in full or part time paid employment’; ‘as few as 32% of autistic persons are in full or part time paid employment’. The statistic is stable (32%) but the meaning is fluid (‘as many as’, ‘as few as’).

about. However, qualitative research was the most appropriate methodology for my research questions and my research philosophy. Qualitative research is most appropriate for research questions pertaining to experience (Rucker, 2015), including my research questions on autistic students' experiences of transition in FHE. Qualitative research is the most appropriate paradigm for interpretivist, humanist and empiricist research (Bernard, 2013).

4.5 Pen portraits

Kevin is a 28-year-old White British male. Kevin is a college graduate; his highest level of education is a BTEC qualification in acting. He attended a college in the West Midlands. I interviewed him via email.

Gregory is a 21-year-old White British male. Gregory is working towards an art degree at a university in the East Midlands. I interviewed Gregory face to face.

Frank is a 40-year-old White British male. Frank holds a university degree in equine management and is working as a team leader at a university in the West Midlands. I interviewed Frank face to face.

Katrina is a 39-year old White British woman. She is studying for a sociology degree at a university in the North East. I interviewed Katrina over the telephone.

Hannah, a White British girl, is 16 years old. She is working towards a level one qualification in art, at a college in the West Midlands. I interviewed her face to face.

Neil is a 16-year-old White British boy. He is working towards a level one qualification in art, at a college in the West Midlands (he and Hannah are enrolled on the same course). I interviewed him face to face.

Hank, a White British boy, is enrolled on the same art course as Hannah and Neil. Hank is 17 years old. I interviewed Hank face to face.

Harry is a White British boy, he is enrolled on the same art course as Hannah, Neil and Hank. He is 17 years old and I interviewed him face to face.

Ashley is a 20-year-old White British man, he is studying for a degree in chemistry, at a university in the North East. I interviewed Ashley via Skype.

Chloe is a 19-year-old White British woman. She is studying for a degree in audiology at a university in the North East, I interviewed Chloe via Skype.

Lucinda is a 23-year-old White British woman. She is studying for a BA in childhood, family studies and education studies at a university in the West Midlands. I interviewed Lucinda via email.

Vanessa is a 19-year-old White British woman, studying for a degree in physics and astrophysics. She is registered with a university in the North East and I interviewed her via email.

Robert is a 19-year-old White British man, studying for a degree in graphic design at a university in the East Midlands. I interviewed him via email.

Ilyas is a 27-year-old British South-Asian man, in a postdoctoral position in oncological technology, at a university in the East Midlands. I interviewed him face to face.

Fahim is a 20-year-old British South-Asian man, working towards a degree in geology, at a university in the East Midlands. I interviewed him via email.

Hudayfa is a 21-year-old British South-Asian man, undertaking a degree in sociology at a university in the East Midlands. I interviewed him via Skype.

Christina is an 18-year-old White British woman. She is studying at a university in the North East, she is working towards a degree in engineering. I interviewed her via email.

Ellie is a 19-year-old White British woman, who I interviewed over the telephone. She is a performing arts student at a university in the East Midlands.

Bethany is a 19-year-old White British woman. She is studying for a degree in nursing, specialising in paediatric nursing and GLDs. I interviewed her via email.

Michael is a 17-year-old White British man. He is a college student in the West Midlands, studying for a BTEC diploma in media studies. I interviewed him face to face.

Alex is a 31-year-old White British man. He is a university student, working towards a degree in intelligent systems at a university in the East Midlands. I interviewed him via email.

William is an 18-year-old White British man. He is a university student, working towards a BSc in environmental health. I interviewed William via email. He is registered with a university in the West Midlands.

Philip is a student at a university in the East Midlands, studying for a degree in palaeontology. He is 19 years old and White British. I interviewed Philip via email.

Connor is a student at a university in the East Midlands, studying for a degree in English literature and creative writing. He is 19 years old and White British. I interviewed him via email.

Joel is a student at a university in the North East, studying for a degree in fine art. He is 19 years old and White British. I interviewed Joel via email.

Donna is a student at a college in the West Midlands, working towards a level one qualification in art. She is 16 years old and I interviewed her face to face. She is White British.

Emma is a student at a university in the East Midlands, studying for a degree in psychology. She is White British. She is 18 years old and I interviewed her face to face.

Andrew is a student at a university in the West Midlands. He is studying for a degree in graphic design, he is 19 years old and I interviewed him face to face. Andrew is White British.

Lisa studies at a university in the West Midlands, she is working towards a foundation degree in health and social care. I interviewed her face to face. She is White British, and she is 20 years old.

Ferguson is a student at a university in the West Midlands. Ferguson is studying for a degree in accounting. I interviewed him via email. He is White British and 18 years old.

Melissa is studying at a university in the East Midlands. She is White British, and she is working towards a degree in mathematics. I interviewed her via Skype. She is 20 years old.

Nicholas is studying for an MA/MSc degree in multidisciplinary innovation at a university in the North East. I interviewed Nicholas via Skype. Nicholas is 22 years old and White British.

Owen is studying for a degree in chemistry at a university in the North East. He is 18 years old and I interviewed him via email. Owen is White British.

Lee is studying for a degree in business management at a university in the East Midlands. He is White British, and I interviewed him via email. He is 19 years old.

Lewis is studying for a degree in chemical engineering at a university in the North East. He is 19 years old. He is White British. I interviewed him via email.

Gareth is studying at a university in the North East, working towards a BA in Middle Eastern studies and politics. Gareth is 20 years old and I interviewed him via Skype.

Ray is a student at a university in the North East, studying for a degree in computer management. I interviewed him via Skype. Ray is 24 years old.

John is a student at a university in the East Midlands. He is studying for a degree in accounting and business management. He is 18 years old and I interviewed him face to face.

Stacey is a 24-year-old student at a university in the North East, working towards a degree in English. She is White British. I interviewed her via email.

Spencer is an 18-year-old student at a university in the West Midlands. I interviewed him face to face. He is White British. He is studying for an art degree.

Josh is a 19-year-old White British student. He is studying at a university in the North East, working towards a degree in video game design, I interviewed him via email.

Tom is a 20-year-old White British student, studying at a university in the East Midlands. I interviewed him via email, and he is working towards a degree in economics.

4.6 The advantages of the four types of interviews I used

Face to face interviews

Easwaraoorthy and Zarinpoush (2006) defined interviews as:

> [A] conversation for gathering information. A research interview involves an interviewer, who coordinates the process of the conversation and asks questions, and an interviewee, who responds to those questions. Interviews can be conducted face-to-face or over the telephone. The internet is also emerging as a tool for interviewing (Easwaraoorthy and Zarinpoush, 2006: 1).

The focus here is on the face to face interview. The face to face interview 'allows a researcher to investigate and prompt things we cannot observe. We can probe an interviewee's thoughts, values, prejudices, perceptions, views, feelings and perspectives' (Wellington and Szczerbinski, 2007: 81). I decided face to face interviews were wholly appropriate for my research, for probing autistic students' thoughts, views, perspectives, perceptions and feelings towards their transitions in FHE, in concordance with Wellington and Szczerbinski (2007) and my research questions. Face to face interviews facilitate in-depth communication between the researcher and participant (Guion et al., 2011). It was important to me to explore my research participants' experiences in depth, to access their interpretations of events, unrestricted by constraints of time or space (i.e. limited space on a postal questionnaire). In-depth interviews were the best fit for my research questions.

Interviewing research participants face to face meant non-verbal cues, for example, body language and facial expressions were clearly visible; ‘Nothing is taken for granted or overlooked for a qualitative researcher. They notice gestures, jokes, tone of voice, […] body language and a multitude of other details of their studies’ (Bogdan and Knopp Biklen, 2007: 5). Research participants’ non-verbal and verbal social cues would have indicated whether they were uncomfortable with the topic of conversation, whether they were offended, whether they had a passion for a topic, or whether they were deceiving me, there would also have been visual cues if any research participants had been anxious (Madziwa, 2016). This was especially useful when interviewing autistic individuals, for whom apparently ‘trivial’ problems can initiate a stress response (Dalmayne, 2015). None of my research participants *did* exhibit signs of distress, but this, in part, informed my decision to use face to face interviews.

Skype interviews

Skype, video-calling software, launched in 2003 (Cowling, 2018) is free to download and use (Nehls et al. 2015) and neither party in the conversation incurs travel costs (Lo Iacono et al., 2006). Skype is a cost-effective research method for a self-funding research student and students living in student accommodation, or students with no source of income. Studies are no longer limited by distance, where the participant has access to Skype (Bertrand and Bourdeau, 2010). All my research participants were living in England, but had Skype not been available, interviewing research participants in the North East would have been an expensive and time-consuming activity (I refer here to the time, and cost of travelling to interviews and, the expense of overnight accommodation for myself and my NMH[36]); the North East is a 426-mile round trip from home, approximately. Using video-calling, visual cues are available to the researcher (in common with face to face interviews) (Lo Iacono et al., 2006), without the expense and discomfort of travelling. Using public

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[36] The expense of carrying out research is greater for a supported researcher or any other researcher who is not travelling alone.

transportation is an area of difficulty for many autistic individuals (Lowery, 2017) and using Skype minimised the need for either party to travel (Hanna, 2002).

Introversion is relatively common in autistic individuals (Grimes, 2010) and many autistic individuals are anxious in social situations (National Health Service, 2019a). Seitz (2015) proposed it is easier for shy, introverted or socially anxious participants to interact with a researcher on screen than face to face. When either party is anxious or uncomfortable, the quality of the data can suffer, as the anxious party, or parties, rush through the interview, to 'escape' the situation as soon as possible, without giving much thought to the quality of their responses, or actively listening to the participant (Dicicco-Bloom and Crabtree, 2006). Addressing one of the causes of anxiety in autistic participants was in the best interests of the study.

It is impossible to make eye contact using Skype or other video-calling software. On a hand-held device, such as an iPad or other tablet, or on a laptop, the camera is installed above the screen. In a Skype conversation, users must decide where to direct their gaze. Directing the gaze towards the screen at eye level will give the impression of a downwards focus. Focusing on the camera will give the impression of eye contact, but the screen is only in the user's peripheral vision. But some research participants feel uncomfortable with eye contact (Lo Iacono et al., 2016). For some participants (and researchers), an interview without the expectation, or possibility, of making and maintaining eye contact is appealing. Autism can lead to difficulties maintaining eye contact and Skype is useful to this end for autistic researchers and participants, 'An atypical pattern of mutual gaze behaviour, or eye contact, is among the most distinguishable manifestation of the qualitative impairment in social interaction in ASD' (Senju and Johnson, 2009: 3). Skype interviews permit access to verbal and non-verbal cues, in common with face to face interviews, without demanding eye contact, in common with email 'interviews' and telephone interviews.

Telephone interviews

The benefits of telephone interviews are, by and large, comparable to the benefits of Skype interviews. Telephone calls are not free (GOV.UK, 2019a) and there are no visual social cues (Novick, 2008), but the two are otherwise broadly similar. Kegeles et al. (1969) identified how telephone interviews facilitated communication between researchers and participants who do not live in close proximity to each other. They proposed the value of telephone interviews had previously been overlooked, with earlier research focusing on interviews between parties living locally to each other. Research participants and researchers can interact, without the need for travelling. The participant will often feel more comfortable participating from home (Hanna, 2002), and autistic individuals exhibit a strong preference for familiarity (Ambitious About Autism, 2017). Telephone interviews make no demands on either party to travel to interview venues (Shuy, 2002). As I expressed above, many autistic individuals experience some difficulty with travelling (Lowery, 2017).

There is no expectation or possibility of eye contact in telephone conversations (Sweet, 2002). There is no demand, on either party, to maintain, avoid or give a false impression of eye contact, a task which can distract the autistic person from the interview (McGlensey, 2016), impairing the quality of the data. Where the autistic person self-presents as neurologically typical, concentration can be weakened, as I identified in chapter 2. Telephone interviews will be a welcome alternative to face to face interviews, where one or both parties are uncomfortable with face to face social interaction (Novick, 2008) and with social anxiety, shyness and introversion common in autistic individuals (Grimes, 2010; National Health Service, 2019a), the benefits for autistic research participants and autistic researchers living with social anxiety are self-evident. The final research method, the email ‘interview’, *minimised* the need for social interaction.

Email 'interviews'

The Skype interview and the telephone interview *lessen* the need for social interaction but there are *some* commonalities with the face to face interview, namely the availability of verbal cues, and non-verbal cues via Skype, and the expectation on both parties to interpret them correctly. There is *minimal* demand for social interaction in an email 'interview', ideal for research participants and researchers who live with social anxiety (Burnard, 1994). Without the demand for verbal interaction, non-verbal and semi-verbal researchers and research participants can carry out or participate in research (Ison, 2009). Some autistic individuals are non-verbal or semi-verbal (Rogers et al., 2006) and email 'interviews' are a viable alternative for research participants and researchers who would prefer not to communicate via a third party (i.e. a BSL interpreter[37]). Benford and Standen (2010) advocated the use of email 'interviews' when engaging with 'hard to reach' ('high-functioning' autistic) research participants. Whilst the research methods literature *only* explores the use of email 'interviews' with non-verbal or semi-verbal autistic research *participants*, the same could be said for the use of email 'interviews' with non-verbal or semi-verbal autistic *researchers*. In facilitating the non-verbal or semi-verbal autistic individual's participation in social research, the researcher facilitates their socio-political survival (Rogers, 2020). None of my research participants self-identified as non-verbal or semi-verbal, although Donna's mother spoke on her daughter's behalf, but it had been my intention to accommodate this.

In face to face interviews, participants often feel obliged to respond to the researcher immediately, to circumvent 'awkward' or 'uncomfortable' silences, to mimic the flow of a conversation (Poland and Pederson, 1998), whereas in email 'interviews', researchers and research participants share a mutual understanding that there may be a 'silence' of several days (Bampton and Cowton, 2002). Processing delays are common in autism (Bogdashina, 2003),

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[37] I have previously worked with BSL interpreters and would have asked any interpreters not to share details of the interview with third parties.

and it is crucial that participants and researchers who live with processing delays, I include myself in this, do not feel obliged to respond immediately, this will compromise the quality of the data and analysis. Email ‘interviews’ serve this function well, more so than verbal research methods. As above (i.e. Skype interviews and telephone interviews), participants and researchers can participate from home, there is no reason for either party to travel (McCoyd and Kerson, 2006) and there is no expectation or possibility of eye contact (McAuliffe, 2003). Autistic research participants and researchers who are unable to maintain eye contact without difficulty or discomfort are able to commit their attention to the interview, *not* giving the impression of eye contact.

4.7 Data analysis

It was essential for my data analysis strategy to be appropriate to the interpretivist paradigm. I used thematic analysis. Thematic analysis is appropriate for use with data from interpretivist research. As Bhattacherjee (2012) noted:

> [I]nterpretive analysis is holistic and contextual […] Interpretive interpretations tend to focus on language, signs, and meanings from the perspective of the participants involved in the social phenomenon […] Rigor in interpretive research is viewed in terms of systematic and transparent approaches for data collection and analysis rather than statistical benchmarks for construct validity or significance testing (Bhattacherjee, 2012: 104-105).

But he also noted thematic analysis was contentious. Not all interpretivists approve of efforts to codify individual experiences and perspectives into themes (Bhattacherjee, 2012). I *did* codify my participants’ responses into themes, not to identify a majority view or a ‘consensus’ but my interview schedule had been designed to examine those themes. It is contrary to my principles to exclude data which does not support the majority view, but this did not preclude codification.

Within a day or so of each interview, I would listen to the recordings and transcribe the interviews. This would usually be a two-day process. I used ‘inaudible’ where one of us had not spoken clearly into the recording device (although I would replay the unclear part of the conversation several times before I resorted to this). Sometimes I would be able to establish what was said, in the context of the conversation, at other times I would write unrelated words in parentheses to indicate ‘I could not distinguish what was said, but the words were comprised of these sounds’. I used earphones or headphones for privacy, as I was usually in company, in a shared office, during playback. Earphones or headphones are especially useful for autistic researchers supported by an NMH, to protect the research participant’s privacy. I decided against using specialist software (for example, EXMARaLDA) to transcribe my interviews, using Microsoft Word instead, without timecoding or annotation. Autistic individuals can have unusual patterns of speech (Sharda et al., 2010), with unconventional pitch, volume or repetition, so there was little to be gained from annotating the transcript to highlight linguistic features. The transcripts also contained fieldnotes, as I recorded my observations and thought processes.

Concurrently, I began the thematic analysis, again without the use of specialist software (for example, NVivo). Braun and Clarke (2006) advise researchers to avoid the language of ‘emerging themes’, as this denies the role of interpretation, and how researchers decide which data is relevant, or irrelevant, to their research questions. I analysed my interview schedule, to ascertain which topics had been covered with the participants (for example, stigma, and support). I will return to this below. Once all interviews had been transcribed, or copied across to a Word document, I printed each of the interviews in 42 separate documents. I re-read the interviews several times, highlighting quotes which pertained to each topic, using colour-coding and underlining (for example, ‘support quotes’ were highlighted in green). From the outset, I was prepared for the possibility that there would be no recurring themes in the data, I was prepared for the possibility that autism is too diverse for patterns or themes to recur, and I chose to use and analyse data which did not belong in a theme, if it only described one person's experience, but it was relevant, as discussed above; in research of this kind (empiricist, interpretivist, humanist research) the notion of outlying data has no significance.

Data had to be coded (Gibbs, 2007). I opened a new Word document and listed all topics, listing every participant (by pseudonym) below each of these headings. Returning to the electronic copies of the interviews, I copied and pasted all highlighted quotes onto the new Word document, listed under thematic subheadings beside the name of the relevant participant. These thematic subheadings included: 'Disclosing or covering, the reactions of others', 'What was helpful or would help, or didn't[38] help?' 'Feelings like meltdowns, fear, excitement', 'Their own feelings towards autism' and 'Miscellaneous notes'. I began to recognise patterns in the data. Several participants described the stigma of sensory hypersensitivity, or aversions, for instance. Detailed descriptions of events as diverse and unique as an aversion to tonal languages, a phobia of crisps and hypersensitivity to tobacco were coded as 'Stigma of sensory hypersensitivity'.

Once I had coded the data (without coding 'inconsequential' data), and I had identified key themes, I began the thematic analysis, by referring to the wider literature. For example, I read, and reflected on, Goffman's (1963) work on stigma and masking, and Olney and Brockelman's (2010) research on perception management strategies, and how these converged with, or diverged from, my research findings on the stigma of autism, and the myriad ways autistic individuals present themselves to NT, non-autistic and autistic others. The pattern of consulting the literature and analysing the data continued until I had completed the thematic analysis. I used thematic analysis to categorise all participants as either indiscriminately open, open if relevant, open if necessary or indiscriminately reticent. I used a Microsoft Excel spreadsheet, entering each participant's name in separate cells in a column, and I/O, O/R, O/N or I/R in separate cells in a row. I marked the appropriate

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[38] I am quoting verbatim, hence the contraction.

cells with a ‘YES’ with a yellow background and all other cells with a ‘NO’ with a blue background, the contrasting colours allowed me to easily identify which participants had been assigned to each category, and which was the most, and least, commonly assigned category. From this rudimentary quantitative analysis of qualitative data, I was able to develop a typology, my four degrees of openness, which I outline in chapter 5.

For Braun and Clarke (2006), the use of an interview schedule to develop themes is inappropriate, as it is wholly deductive. The use of semi-structured interviews facilitates thematic analysis on a rudimentary level. My interview schedule covered participants’ emotional responses to the transition, how autism may have affected the participant’s interactions with peers and staff, educational attainment and use of communal facilities (for example, the library and dining areas). I identified which supports had been available to the participants and which supports the participants had arranged. I asked participants for their views on how transition programmes could best meet the needs of incoming autistic learners. I also asked participants who at their college, or university, had information about their diagnosis and why they chose to self-disclose, or not to self-disclose. The following eight themes ‘emerged’ from the interview schedule: anticipated stigma, how the stigma of autism can be manifested in FHE settings, the value of formal support networks, the interplay of autism and the built environment, communicating with, and requesting clarification from, tutors and lecturers, favourable and unfavourable methods of assessment and preparing for the transition.

Jackson (2000) proposed ‘Themes might ‘emerge’ from the (analysis of the) data or more likely […], might reflect the original aims of the project and the theoretical issues that underpin the research’ (Jackson, 2000: 251). The following six themes were unanticipated, ‘emerging’ in the data analysis phase: the value of informal support networks, why, relative to compulsory education, the stigma of autism is less prevalent in FHE settings, what motivates some autistic students to forego essential supports, the limitations of support, the role of agency in students' societies and the effects of presumed competence and incompetence. These themes 'emerged' from spontaneous tangential topics, recurring themes, and experiences common to several of the participants, unanticipated at the outset. For example, informal support networks are key to the well-being of the autistic student, and Neil, Vanessa, Ashley, Lee, Chloe, Stacey and Lucinda all cited examples of support from informal support networks at interview, but there was no question in the interview schedule to facilitate this discussion.

Other themes 'emerged' from abstraction. For Jackson (2000) 'Having conducted a series of interviews or focus groups around a number of themes […] the writing up can be structured around a different set of themes at a higher level of abstraction' (Jackson, 2000: 251). The following three themes 'emerged' from abstractions: my four degrees of openness, the intra-communal hierarchy of impairment and the over-medicalisation of autism (the exclusion of autism from the socio-political sphere). This involved in-depth sociological analysis. To develop the intra-communal hierarchy of impairment, for instance, the 'surface level' data was 'several participants self-identified as 'high-functioning' or 'mildly autistic''. There were few explicit references to GLDs, or profound autism (Hannah compared herself to a profoundly autistic friend, and Lucinda and Robert reflected on their anxieties that they would be infantilised and mistakenly identified as profoundly autistic). But reading, for example, Goffman's (1963) work on covering, Tringo's (1970) work on the hierarchy of preference for disabled groups, and Rogers' (2007) work on the hierarchy of impairment, I interpreted these anxieties and comparisons, and 'mildly autistic' identities as the intra-communal hierarchy of impairment. 'High-functioning' autistic individuals were 'distancing' themselves from profoundly autistic persons, to preserve their relative privilege.

4.8 Ethical considerations

Researching with disabled individuals, I was obliged to take precautions (many of which I have outlined above) to protect the best interests of my research participants. Booth (1996) challenged the exploitation of disabled individuals in social research; it is critical to value disabled individuals as people. At that time, sociologists were exploiting disabled individuals, only valuing their contributions to their studies, leading to an upsurge in discourse on the uneven power relations between researchers and participants (Truman, 2000), and an expanding body of ethically sound research, designed with the needs of traditionally hard to reach marginalised groups, including disabled individuals, as a central concern. On the surface, there is minimal risk of a disabled researcher not valuing disabled research participants as people, but I exercised caution. Any researcher is vulnerable to undervaluing research participants, to overlooking the person behind the story, and Booth's (1996) principle equally applies where the autistic researcher perceives the research participant to be more profoundly autistic than themselves.

Walton (2008) identified the need for researchers 'to ensure that research is conducted in a way that serves interests of individuals, groups and/or society as a whole' (Walton, 2008: n.p.). With a proper dissemination strategy, engaging with the 'right' audiences and my recommendations for future research, there is potential for the study to serve the interests of autistic students individually, as a group, and, with a 'butterfly effect', society, as I outline in the final chapter of this thesis. I also served the interests of individuals at interview by not maintaining a cold and detached self-presentation. When Vanessa volunteered information about her self-harm, I was empathetic, when Christina spoke of the challenges of living independently, I complimented her on her courage (she had recently completed her first 'big shop'). I honoured the principle of non-malfeasance (Burke, 2019) by, to reiterate, offering participants a choice of communication methods, inviting participants to choose the date, time and location of their interview where appropriate, and unless the participant suggested otherwise, travelling to them. This is good ethical practice, allowing autistic individuals to participate in social research in ways which feel safe for them.

There are five recognised ways of meeting the beneficence criteria and the non-malfeasance criteria, the researcher needs to observe the principle of ‘do no harm’ (where the research includes ‘vulnerable’ participants, it is sometimes necessary to use participatory research to this end) (Hugman et al., 2011), and confirm all participants have given informed consent (Wiles et al., 2005). Social researchers must protect research participants’ confidentiality and their right to withdraw (withdrawing data from, or discontinuing participation in, the study) (Graham et al., 2007) and must not, without proper justification, deceive their participants (Behnke, 2009).

As I described above, I produced a participant information sheet, and a consent form, which included sociodemographic questions, and I included information about the study in my invitation email. Every participant was given a participant information sheet to read before the interview (mostly in advance of the date of the interview). Every participant was given a copy of the consent form to complete in advance of the interview; my intention was to induce a feeling of relative anonymity (Egan et al., 2009) and to give participants the opportunity to define their identity in my absence (as above). Participants were also welcome to ask questions for clarification. I was thereby able to obtain informed consent. I have outlined above how I minimised the risk of harm to participants; I also gave participants the option of participating in company or alone; Donna opted to participate with her mother present (this allowed her to participate in a way which felt safe for her), and their choice of seat, giving participants the opportunity to sit close to the door.

To protect the participants’ anonymity, I assigned them randomly generated pseudonyms. Much of my research approach was participant-led, giving participants ‘choice’, but I decided ‘choice’ would compromise their anonymity. When Frank chose a pseudonym by which he was known on the BDSM circuit, I realised participants could be identified by their pseudonyms. Inviting participants to choose a pseudonym can expose any research participant’s identity, but more so where the participant lives with repetitive patterns of thought (crudely, ‘obsessions’). There is a risk the participant might choose a name with which they are associated, be it the name of a relative, a stage name or alias, or the name of a fictional character. The participant’s association with their chosen pseudonym might not be apparent to the researcher (it is highly unlikely this information *will* be available to the researcher[39]).

I chose the first name I thought of, or heard, as I was naming individual transcript documents. The names ‘Fahim’ and ‘Ilyas’ were randomly generated on Behind the Name, to match the names’ country of origin, ‘Hudayfa’ was not randomly generated on Behind the Name, but I confirmed it matched the participant’s country of origin. The computer on which the data is stored is PIN protected (Center for Internet Security, 2019), and the mobile device on which the recordings were made is pattern protected; the use of different security codes to access different devices, bank accounts and other accounts is advisable (Notenboom, 2017); in the event that another person memorised my PIN or my pattern code, not all data would be compromised.

There were no deceptive strategies used. There was no reason to deceive participants; Moon (2000) identified the positive effects of self-disclosure, data is richer, participants are happier to disclose personal information in cases where the researcher has revealed personal information about themselves. I had positioned myself as an autistic researcher but some of the college students overlooked this (for example, Neil seemed to ‘other’ NTs in his interview, and prefaced this with ‘no offence’, indicating he mistakenly believed me to be neurologically typical). I self-disclosed as and when the college students falsely identified me as neurologically typical. Finally, all participants were given the right to withdraw from the study. Some potential participants expressed an initial interest in participating in the research via email but did

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[39] For the researcher to identify the use of a relative’s name as a pseudonym, there must be full knowledge of the participant’s family tree. To identify the use of a character’s name as a pseudonym, there must be full knowledge of the work and awareness that the work is of interest to the participant.

not respond to my first question, but only Lucinda withdrew from the study (justifying the use of her data, here, she did not withdraw her data from the study). The option to withdraw was open to all participants and this was made clear from the outset, although it is easier to withdraw from a study via email than face to face (Deakin and Wakefield, 2013; Janghorban et al., 2014).

I was also careful not to make any unrealistic, misleading claims about the use to which this thesis could be put. Amplifying the voices of individuals whose voices have previously been silenced is no guarantee of social change (Letherby, 2003), but there is some contribution towards that end; ‘Knowledge is not simply produced, it is also received, interpreted and, in some cases, used’ (Truman, 2000: 26). The researcher cannot control for the uses to which their research is put, but to the best of my knowledge, there is nothing written here which could be misused or misinterpreted. In light of the above, my conduct at all stages of the research process was ethically sound.

In addition to ‘standard’ ethical procedures which social researchers must adhere to, I had other issues to consider. Rogers and Ludhra (2012) maintain ‘sensitive research will pose challenges and ethical dilemmas, but it should be critically engaged with and not dismissed for ‘safer’ or easier alternatives. Such research offers valuable opportunities for representing marginalised views and young people’s interpretations’ (Rogers and Ludhra, 2012: 43). Research examining autistic learners’ experiences of transition into FHE *is* sensitive research, requiring some autistic individuals to reflect on difficult periods, on separation from family, pets and home (Connor, Vanessa), academic ‘failure’ (Alex), and severe mental ill health (Vanessa). But in engaging in the research sensitively, I was able to explore important issues without causing damage to the participants.

Rogers and Ludhra (2012) also challenged the presumption that emotional detachment from research participants is an essential component of ethical research. As I indicated above, I was not emotionally detached from my participants and in some cases emotional detachment *would* have been unethical (for example, when Vanessa divulged previously having contemplated taking her own life, and her history of self-harm). In most cases, my relationships with the participants were positive but short-lived (not continuing past the end of the interview). I chose not to respond when Owen initiated a personal relationship, but Katrina is now a Facebook contact and I have sporadic contact with Frank and Neil. In all cases, I shared information about my diagnosis, experiences, perspectives and personal life with my participants and none of this is unethical (Rogers and Ludhra, 2012).

4.9 Insider-outsider research and auto/biography

When a person adopts a role as a researcher, they forego their status as an insider (Letherby et al., 2012) but the concept of an 'insider' *does* have meaning (Costley, 2010). Being an 'insider' confers several advantages, for instance, 'Not only do you have your own insider knowledge, but you have easy access to people and information that can further enhance that knowledge' (Costley, 2010: 3). My research methods reflect this. I have my 'own insider knowledge', with which I wrote an auto/biographical piece on covering at an eight-day sociology conference (chapter 2). I also had 'easy access to people', both as a student with a diagnosis of Asperger's Syndrome and via my NMH and gatekeeper, Steve.

Barton (1999) entreated social researchers to question what right they have to research their chosen topic, and what their responsibilities to others are. To the extent that any researcher can claim the 'right' to research in this area, in any area, I have that 'right'; I received my diagnosis of Asperger's Syndrome pre-FHE (to reiterate, I was 13 years old at the point of diagnosis and 15 years old when my mother shared information about my diagnosis with me), I am familiar with the transition process (more so, I would venture, than other PhD students). I have given some thought to my privilege. It is my responsibility to challenge social injustice, for example, the intra-communal hierarchy of impairment, the exclusion of autistic individuals from educational and social life and the root cause of all of this.

A PhD thesis may be unlikely to influence policy, but I do *hope* to exact change, and there is *potential* for my research to facilitate change, my findings and experiences have influenced my thinking, and I intend to disseminate my findings, applying to present my research at conferences. I intend to engage with the public via social media, challenging the social injustice of the intra-communal hierarchy of impairment. My PhD will be available online, for any interested parties to read and my study has the potential to lead to further research, or to challenge popular misconceptions of autism and GLDs (not on a wide scale but in individual readers).

Turning my focus now to my responsibilities, it is my responsibility to my participants to protect their identity. It is my responsibility to my participants to amplify their silenced voices, facilitating socio-political living, not socio-political death (Rogers, 2020), although I make no claim to *empower* them (Rogers and Ludhra, 2012). It is my responsibility to my participants to see to it that some good comes of their involvement in the study, that some good comes of their difficult feelings, and sometimes harrowing life stories. Similarly, I would like some good to come of my own tribulations, with the publication of my auto/biography as a book chapter (Simmons, 2020). On the use of personal stories in social research, Laslett (1999), wrote, ‘Personal narratives can address several key theoretical debates in contemporary sociology: macro and micro linkages; structure, agency and their intersection; social reproduction and social change’ (Laslett, 1999: 392).

It is important for any researcher to articulate their positionality, ‘the life experience and identities of researchers are present in all that we do and that it is important to acknowledge this’ (Letherby et al., 2012: 3). I am an insider-outsider researcher (Corbin Dwyer and Buckle, 2009). For more than half a century, social researchers have been studying cultures and communities to which they belong, or individuals with whom they share one or more central sociodemographic features (Hockey, 1993; Saidin and Yaacob, 2016). I took advantage of my insider-outsider researcher status, building a rapport with my research participants, mindful of the risk of producing a polemical essay, and the need to maintain a standard of academic rigour. The need to maintain a standard of academic rigour can inhibit a researcher from fully identifying with their participants' stories, but it is worth engaging with insider research to promote the use of a caring methodology (Cooper and Rogers, 2015). My status as an 'insider' is relatively self-evident. I am an autistic student. My research participants are autistic students.

But as no researcher is an insider (Letherby et al., 2012), I am also an 'outsider', 'Crossing borders from the academic to the real lives of people is fraught with tensions and misunderstandings' (McKinley Brayboy and Dehle, 2010: 163). Some social researchers exploit their research participants (McKinley Brayboy and Dehle, 2010; Moore et al. 1998), inducing suspicion in research-fatigued research populations. I advertised my research on social media, registering with interest groups on Facebook. Initial reactions to my invitation were hostile and I was met with disbelief. When research participants are suspicious of a researcher, the conversation can be stilted (Bloor et al., 2001). My participants' troubles were not my troubles, I benefited from their difficult lives. I was not wholly an insider.

To some degree, I was 'passing through', albeit not to the extent that Alice Goffman (2015), a White young woman, in her research on Black young men in Philadelphia, has been said to have been 'passing through' (Flaherty, 2017). Insider-outsider researchers 'conduct research with their own community, workplace or social groups whilst occupying an outside position such as that of the researcher' (Crean, 2018: para. 2). My attention now turns to auto/biography, it is almost an extension of an earlier part of this chapter, which focused on research processes.

Auto/Biography is not self-indulgent (Ellis, 2004; Sparkes, 2002). ‘Social life is messy, uncertain, and emotional. If our desire is to research social life, then we must embrace a research method that, to the best of its/our ability, acknowledges and accommodates mess and chaos, uncertainty and emotion’ (Adams et al., 2015: 9). Writing an auto/biography demanded I revisit a period in my life when I temporarily lost my Self, a period in my life when all that was ‘Amy’ was all I must not be, a period in my life when loneliness overwhelmed me, my parents guests at a wedding reception, my brother on his 20-minute commute home, and some of the delegates enjoying each other’s company for another night. This is commonplace in auto/biographical writing, difficult feelings lend themselves better to auto/biography (Ellis, 2004). Writing an auto/biography required me to call to mind and reexperience the ‘butterflies’ in my stomach in anticipation of a game, in anticipation of elimination (to invoke the feeling of anticipated exposure to a phobia) and its attendant meltdown, in anticipation of the short-term and long-term implications of my involuntary actions (in the short-term, I would be reprimanded, in the long-term, I would damage my career prospects). This was not a self-indulgent activity.

Some auto/biographers rely exclusively on personal memories and recollection for their auto/biographical work (Chang, 2009), but Chang (2009) advised against this, noting other sources of information are often available. Conference proceedings were available, and I kept some fieldnotes, documenting my feelings and memoranda. In some cases, there will be no fieldnotes detailing the event (Ellis, 2004), mine were only brief. But music was also an asset to me (Krumhansl and Zupnick, 2013), an aide-memoire. Music is one of my frames of reference, a tool for processing the social world. Krumhansl and Zupnick (2013) identified how their participants’ autobiographical recall was strongest for events in their adolescence and early 20s and how music can strengthen recall. I used music to evoke similar emotions to those experienced at the time. Alone at home on 8 April, I reflected on the loss of Self, I reflected on once solid friendships, now memories. I reflected on a childhood with Sarah, Lauren, Kelly, George, James, Christian, Hugh, Tommy and Edward, once friends, now strangers. The lyrical content of

MMMBop (Hanson et al., 1997) and the memories it evokes meant the song induced the same memories, state of mind and nostalgia I experienced on the evening of 8 April. I did not listen to the song that evening, but music, Hanson et al. (1997) and other pieces, was a resource for me as an auto/biographer, consistent with Krumhansl and Zupnick's (2013) findings.

Other parties can be implicated in auto/biographical writing and authors are advised to adhere to prescribed ethical standards, including relational ethics (Ellis, 2007), when publishing work which implicates others (Chang, 2009). Steve chose to be named. His association with me is too close, too widely known, for me to protect his anonymity; 'it felt unnecessary, pointless even, to start writing about our lives using pseudonyms' (Saville, 2020: 638). Steve's role is to monitor my conduct, to correct my behaviour, to protect me from withdrawal from the programme of study. I had to be very clear that this was not manipulative behaviour, or the withdrawal of my autonomy, or a degree of attention which transcends what is appropriate; Steve was implicated in my auto/biography and I had a responsibility to him, not to damage his standing.

Independence is the 'ideal', as I described in chapter 3 (French, 1991). I was keen to frame (inter)dependence as 'the ideal' for me (Kittay, 2011), to represent Steve and our working relationship accurately. Any researcher has a responsibility to their research participants, but all researchers have responsibilities, irrespective of whether the method involves other research participants. All auto/biographers have a responsibility not to misrepresent third parties (Ellis, 2004). I will be using auto/biography throughout this thesis; Steve aside, all third parties are anonymised in my auto/biographical vignettes. Ambler (2012) noted the use of auto/biographical vignettes promotes self-knowledge and critical reflection.

The voices of insiders are important to this study. I use weblogs and other online text produced by autistic individuals, caregivers and those closest to them throughout my thesis. Traditionally, the use of non-academic sources in academic work has been discouraged, but, relatively recently, the use of weblogs has gained credibility (Powell et al., 2012). Research findings are produced by the researcher's interpretation of their data, whereas weblogs maintained by autistic individuals permit direct access to the source. My use of weblogs reflects my commitment to socio-political living (Rogers, 2020). Academic researchers choose whose voices are worth listening to, whose stories are worth telling (Moore et al., 1998), and to restrict my sources to published academic work silences the voices of those who 'choose' not to pursue a career in academia, or those without the necessary skills to do so, or those who prefer not to participate in social research, but who nonetheless have experiences and socio-political opinions which social researchers have previously overlooked, experiences and insider knowledge which contribute to my research aims.

The experience of carrying out insider research

It is best practice to set aside an indeterminate block of time for a research interview, as semi-structured in-depth interviews 'take between 30 minutes to several hours to complete' (DiCicco-Bloom and Crabtree, 2006: 315), but I was a supported researcher, which constrained the time I was able to commit to each interview. I was conscious of my NMH's schedule, but I was reluctant to restrict the participants. Hannah and Hank spontaneously self-recruited. I had only intended to interview Harry and Neil. I had allocated two hours to this, whilst Steve finished his shift. I was yet to interview Hank and little more than half an hour of the allotted two hours remained. I was in conversation with Hannah, post-interview. I chose to update Steve and I was prepared to extend my visit. But I was uncomfortable, Steve facilitates my education, and I worried my decision to be flexible would inconvenience him. This brief period of discomfort notwithstanding, I welcomed the opportunity to interview participants, to engage with others. I had very little interaction with others, in common with other PhD students. Interviewing participants was one of the most satisfying phases of the research.

Reflecting on my interview with Frank, I had an opportunity to 'validate'[40] several 'meltdown triggers', which I had previously imagined were exclusive to me (for example, apparently disproportionate responses to 'minor' inconveniences). I related a story of re-recording a video, uploaded to social media, when I noticed a minor error. The mistake had otherwise gone unnoticed, 'but you noticed! The whole thing's ruined!' Frank empathised. We reflected on our respective responses to differences of opinion (whether questions of politics or taste), Frank told me 'I consider [differences of opinion] a personal affront', which contradicts the broadly upheld philosophy of 'to each their own'. Likewise, some participants expressed their satisfaction in interacting with me, Hank, for example, was 'excited' by the prospect of engaging with another autistic person, in participating in the interview with me. Vanessa discovered more about how she responded to criticism and how these responses were linked to her autism. Christina was happier to participate in 'insider-outsider' research, 'I'm glad you as an autistic person are doing research about autistic people as I feel too many non-autistic people speak over us when the [sic] we're the topic'.

To reiterate, some participants (those enrolled on college programmes) expected that I would be neurologically typical, and others seemed to 'pre-empt' me, misinterpreting the question 'did you disclose your diagnosis to anyone at the college/university? Why or why not? To whom did you conceal it from or reveal it to?' as an active search for examples of anticipated stigma and masking. Goffman's (1963) work on stigma is illuminating. As I identified in chapter 2, until evidence to the contrary presents itself, the tendency is to presume others are 'normal', non-stigmatised individuals (Goffman, 1963). Harry, Hannah, Hank, Neil, Donna and Michael were not given advance notice of my diagnosis of Asperger's Syndrome, I was 'a PhD student'. The participants were taken aback when I divulged my 'insider-outsider' status. My background in sociology was known to all participants, and in some cases, social researchers *do* pose 'leading questions' to accept a hypothesis (Moore

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[40] Shared experience is not necessary to validate feelings or experiences.

et al., 1998), or to produce data consistent with their experience, which I will revisit below. The participants were familiar with the concepts of masking and anticipated stigma, in practice if not in theory and some (for example, Fahim) chose to distance themselves from individuals who consciously self-present as NT, opting to self-present as ‘naturally’ ‘high-functioning’.

4.10 Research bias

With my diagnosis of Asperger’s Syndrome, I cannot be expected to be free of bias (as above, I am an insider-outsider researcher). No researcher is free of bias, ‘Researchers bring to each study their experiences, ideas, prejudices and personal philosophies, which if accounted for in advance of the study, enhance the transparency of possible research bias’ (Smith and Nobel, 2014: 100). There are several types of research bias: design bias, selection bias, data collection and measurement bias and analysis bias[41] (Smith and Nobel, 2014). A poorly designed study will produce unreliable results (using quantitative research to address a qualitative research question will not produce the depth of information required, using qualitative research to address a quantitative research question will not produce statistically significant data). When a researcher designs a project to prove a ‘pet’ theory, this is also design bias (Smith and Nobel, 2014). My methodology was appropriate to the research questions and there was no ‘pet’ theory to prove. I developed my argument only once the data collection phase was complete. This is very often the case for auto/biographers too (Ellis, 2004), I did not volunteer for a position as a student representative with the intention of writing an auto/biography. 1 April 2016 to 8 April 2016 can be reinterpreted as a ‘data collection phase’, with my argument developing much later.

Selection bias exists where certain groups have been excluded from a study (for example, without access to the internet, some people are necessarily excluded from any study advertised only online) (Henderson and Page, 2007).

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[41] Other types of bias exist but I list only those relevant to my study.

Several stakeholder groups are usually invited to participate in most qualitative research, to minimise this type of bias. The scope of my study restricted me to one stakeholder group, autistic students, and I mostly used mass emails to advertise the project. All higher education students have internet access, at home or at university. Steve did exclude profoundly autistic college students from the sample, which is to be expected of gatekeepers (Moore et al., 1998), but had I been given the choice, students with higher support needs would not have been excluded from the sample. Data collection bias is the intentional or unintentional use of leading questions, betraying the researcher's own biases (Choi and Pak, 2005). To replicate the conditions of a conversation without influencing my participants, I reflected on personal experience *after* my participants had reflected on theirs.

I invited the participants to reflect on all experiences, both positive and negative, and chose not to formulate a hypothesis, to reduce the possibility of analysis bias. Hypotheses are uncommon in qualitative research. When researchers analyse their data, some discount any data which contradicts their hypotheses, life experience or values and only analyse data which complements them. Šimundić (2013) observed 'A researcher can introduce bias in data analysis by analyzing data in a way which gives preference to the conclusions in favor of research hypothesis' (Šimundić, 2013: 13). A different set of circumstances govern autistic students' experiences today than the circumstances under which I entered FHE in 2001 (for example, the hours of support available). Autism is such a diverse condition, there was some degree of overlap between my own experiences and the participants', but some of my experiences were particular to me. I was quite prepared to analyse any relevant data, including ideas and experiences which did not coincide with my own.

4.11 Limitations of the study

All research is beset by limitations (Labaree, 2019a). The limitations of my study were primarily related to my recruitment methods and I will outline these here. My reliance on gatekeepers necessarily excluded some autistic students from the study. Not all disability service teams were willing to circulate my invitation to participate. Research fatigue can affect research participants' and gatekeepers' willingness to engage in social research (Way, 2008) and some are suspicious of social research (Moore et al., 1998). Gatekeeper Steve selected 'high-functioning' students for the study, 'filtering out' students with more complex support needs (as above), mindful of *my* needs as an autistic researcher. This excluded profoundly autistic, less articulate students from the research. Similarly, Moore et al. (1998) reflected on gatekeepers who discounted certain groups from *their* studies with d/Deaf school-leavers (BSL users were excluded from the studies, only aurally trained school-leavers were permitted to participate). It would have been interesting to engage with profoundly autistic college students, and further research is needed to this end, but my research with 'high-functioning' autistic students (e.g. Hannah and Neil) offered *some* insight into how students with GLDs are perceived.

On a similar note, in using *disability services'* mailing lists, my sample was skewed towards autistic students who were prepared to share information about their diagnosis, similar to Humphrey and Lewis' (2008) work on secondary school pupils diagnosed with Asperger's Syndrome. Kevin, who was recruited via social media aside, all participants had self-disclosed to disability services. It would have been impracticable to invite research participants to the study via other channels. Advertising a study via social media requires the approval of a gatekeeper (the Facebook page administrator or Twitter account holder) and the response is often a refusal. I chose not to involve *college* disability services, I had access to autistic college students via Steve, and approaching college disability services was not time-efficient, when further education *precedes* higher education (university students were invited to reflect on their further education trajectories). With further research, and wider-reaching recruitment strategies, it would be possible to address this gap. The skew towards relatively open autistic learners was an insight into covering, however. Some participants had been willing to self-disclose to disability services, but *not* to arrange support.

It was not feasible to explore some questions of intersectionality as my sample was demographically imbalanced. This was the unfortunate outcome of the self-selection recruitment process (Mattis et al., 2008). The sample was almost exclusively White and men outnumbered women 29 to 13. Three South Asian men (Ilyas, Hudayfa and Fahim) volunteered to participate in the study, but there were no Black, Hispanic or East Asian participants, leaving several demographic groups unrepresented, although autism is more commonly diagnosed in White males (Centers for Disease Control and Prevention, 2019; National Autistic Society, 2019a). I could not approach or 'cherry pick' individual participants without access to their contact details and demographic information. 'Cherry picking' was not appropriate for the study, which sought to *maximise* the number of autistic learners who were given the opportunity to narrate their stories. Intersectionality is *always* influential in the life history and experiences of *any* individual, and there were some participants who did briefly refer to the interplay of gender, sex and autism, but this was not commonplace.

4.12 Conclusion

With a view to the creation of new knowledge and social change, I designed the research with the research participants' needs at the forefront. The intention was to represent groups of autistic students who might otherwise exclude themselves from social research, and in so doing 'plug a gap' in the field. This consideration was reflected in my research methods. My use of email 'interviews' facilitated communication with participants living with social anxiety, and (at the outset) to accommodate non-verbal or semi-verbal autistic participants who would prefer *not* to be interviewed via a third party (for instance, a BSL interpreter). I interviewed Donna in the presence of her mother (who participated on her daughter's behalf), but the option of an email 'interview' was available to her. In offering potential participants a variety of methods, including Skype interviews, telephone interviews and email 'interviews', I intended to facilitate communication with participants who do not travel independently. The focus here has been on autistic research participants, but much of this applies equally to autistic social researchers and I include myself in this, to a degree. I am fully verbal, but I do not travel independently. In engaging with the issues I have confronted, as an autistic social researcher with relatively high support needs, I hope to contribute new knowledge to the field, from which other autistic researchers can benefit.

To reiterate, a general interview guide approach (Gall et al., 2003) is the use of set topics, with open-ended questions, from which ‘offshoot’ topics can spring. The general interview guide approach permitted a level of flexibility (Turner III, 2010), promoted a *genuinely* warm interviewing style, consistent with Oakley’s (1981) proposed interview technique, and allowed me to make comparisons, from one participant to another. All of this was key to researching with autistic individuals. It was important to allow for tangential topics, to accommodate ‘obsessions’ and individual frames of reference. A warmer interviewing style was appropriate, with the highly emotive nature of the research, and the discomfort many autistic individuals experience in social interactions. Comparability was useful to identify potential themes and common experiences, particularly in light of the heterogeneity of the autistic condition.

The locus of the study was England (the logistics of travelling regularly to Scotland[42] from the West Midlands dissuaded me from widening the scope of the study to Great Britain), but within this small geographical context, 42 autistic individuals volunteered to engage with me, and no one who was eligible to participate was excluded from the research (had I interpreted the inclusion criteria stringently, Kevin, Frank and Donna would have been excluded but I chose not to overlook their contributions).

My methods were judged to be ethically sound, by the relevant parties (the ethics committee at the university I attended at the time of the data collection

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[42] I live 50 miles from Wales.

phase[43]) but, as Rogers and Ludhra (2012) note, ‘Thinking about ethics at the beginning of the research process or simply completing an ethics form does not constitute ‘critical engagement’’ (Rogers and Ludhra, 2012: 45). Ethical practice is a fluid and ongoing process and, as a social researcher with a commitment to ethically sound research, I engaged with these issues continuously. I designed my research to minimise distress and discomfort, meticulously completed my ethics form, assessed (very occasional) ethical dilemmas on a case by case basis, accurately represented my participants to the best of my knowledge and outlined my decisions here, for the benefit of other autistic social researchers and research participants. What follows is the discussion, over three chapters, beginning with stigma and perception management strategies.

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[43] I did not carry out data collection during my registration with the University of Bradford.

Chapter 5: Findings and analysis: the stigma of autism

5.1 Introduction

This chapter begins with what I have named my four degrees of openness. I build upon Goffman's (1963) work on passing, on how in most cases, stigmas are known to few, some, or most, but stigmas known to no one, or to all, are exceptional. My four degrees of openness corresponds to Goffman's (1963) observations. Most of my participants felt able to talk to others about their diagnosis in conversation, or to defuse a tense situation, in the event of confrontation, or to elucidate 'socially inappropriate' behaviours. In this chapter, and in the two subsequent data chapters (on support, and on the interplay of autism and institutional forces respectively), I explore how these four disparate perception management strategies effect autistic students' transitions in FHE. My four degrees of openness is an innovative use of the related concepts of 'coming out' of or 'staying in' the 'closet'. I then go on to refute the common misconception that people pass because of shame, or fear of stigma. Most participants expected unfavourable reactions from others and were relieved to discover how relatively little stigma the diagnosis now carries; a concealable, stigmatised identity, autism included, leads to anticipated stigma, which has a detrimental effect on the stigmatised person's emotional well-being (Quinn and Chaudoir, 2009).

I offer two potential explanations for this incongruity, between expected and actual stigma. The first is how stigma can be learned from sources other than personal stigma; mediated stigma (via mass and now social media) and vicarious stigma (via third parties). The second is how the diagnosis carries relatively little stigma now, but autistic ways of being (for example, meltdowns, aversions and sensory hypersensitivity) are still heavily stigmatised. Five interrelated but distinct frames define 'autism'. Autism is an umbrella term, for several conditions, including classic autism, pervasive developmental disorder not otherwise specified (PDD-NOS) and Asperger's Syndrome. Autism is 'classic autism', the 'default', the variant Kanner (1943) observed and identified. Autism can be the foundation of a person's socio-political identity

(Robertson and Ne’eman, 2008). I outlined this at the outset of this thesis and ‘These models are not mutually exclusive and, depending on their circumstances and needs, people draw on whichever model is of most use to them at the time’ (Royal College of Psychiatrists, 2014: 5). But much of this chapter is about the distinction between the label or diagnosis and the clinical presentation of autism, and how autistic individuals, and non-autistic and neurologically typical individuals, respond to both.

The focus then shifts to the intra-communal hierarchy of impairment, which draws on Rogers’ (2007) work on the hierarchy of impairment. People ‘higher up the spectrum’, individuals identified as ‘high-functioning’, distance themselves from profoundly autistic people. Profound autism, and its associated GLDs, languishes at the bottom of this socially constructed hierarchy (Deal, 2003; Meyer, 2013; Rogers, 2007; Snow, 2005), which is so deeply embedded in the collective conscious that it has rarely been challenged (as I identified in chapter 3). I look at the experience of stigma, and how it can affect a person’s self-concept, with narratives from Katrina, Owen, Frank, Gregory, Hannah, Hank and Neil. Each had their own story to tell about stigma; the stigma of an aversion, specific phobia, ‘age-inappropriate’ interests, sensory hypersensitivity, and sensory hyposensitivity.

To reiterate, the Jekyll and Hyde effect (Attwood, 2015) hypothesises that an autistic child will manage their ‘challenging behaviour’ at school, where there will be repercussions but, as these difficult feelings are not self-limiting, the child ‘melts down’ at home. Taking the Jekyll and Hyde effect and extending it to students in FHE, I wonder if it might be more pronounced in FHE, *post*-compulsory education, with its policy of withdrawing any student who does not meet academic standards or expected standards of behaviour; it can be difficult for the autistic person with emotional dysregulation to function in FHE (Gurbuz et al., 2019; White et al., 2016). The stakes are higher in FHE, disciplinary procedures in FHE are more severe than lines, a detention, a letter home, a ‘debit’ or the loss of a ‘credit’ or, for more serious offences, the loss of a ‘merit’ (Locke et al., 2015; Trevisan and Birmingham, 2015). ‘Faking it’ is no longer about winning favour or friendships, but about continuing in education; normalisation or conformity is a key function of education (Foucault, 1975). I end the chapter with a brief look at how individual model thinking (i.e. the idea that autistic people find it difficult to make friends) might have obscured the stigma of autism.

Briefly revisiting stigma

Stigma is ‘the situation of the individual who is disqualified from full social acceptance’ (Goffman, 1963: 9), it is ‘an attribute that makes [a person] different from others in the category of Persons available for him [sic] to be, and of a less desirable kind – in the extreme, a person who is quite thoroughly bad, or dangerous, or weak’ (Goffman, 1963: 11). Goffman defined ‘stigma’ as a ‘disgrace’ (for example, mental ill health, vagrancy, a facial difference[44] or criminality). Stigmas are fluid, in a sporadic state of flux, ‘Shifts have occurred in the kinds of disgrace that arouse concern’ (Goffman, 1963: 11). Asperger’s Syndrome did not, at one time, carry the stigma it does today. Before ‘Asperger’s Syndrome’ entered the public vocabulary, before the diagnostic criteria had been finalised, the manifestations of Asperger’s Syndrome, while broadly similar to the manifestations of Asperger’s Syndrome today, were *interpreted* differently. People with the condition were ‘day dreamers’ (O’Leary, 2014), ‘artists’ (Harris, 2016), ‘non-conformists’ or ‘gifted’ (Sarris, 2017).

Disability is also relative to context (Gleeson, 1998; Oliver, 1990b). Individuals with Asperger’s Syndrome *were* stigmatised (as people living with the condition today are stigmatised pre-diagnosis). Adams, interviewed by Harris (2016) reflected on a difficult event as a primary school pupil; he had drawn, from photographic memory, a picture of a street, local to the school. His headteacher asked to display the drawing in the entrance hall, and Adams had

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[44] Shaw (2016), who has partial facial paralysis, uses the term ‘facial differences’ to describe her distinctive appearance. Charity Changing Faces (2016) uses ‘facial disfigurement’, mirroring the terminology used in the Equality Act (2010). ‘Disfigurement’ is offensive to some and I will not use it.

agreed. Accorded praise for his artistry (a feature of his Asperger's Syndrome), he was stigmatised for his illiteracy (*also* a feature of his Asperger's Syndrome). When asked to write his name on the back of the drawing, he obliged and submitted his artwork. The teacher shredded his work immediately; the eleven-year-old had misspelled his name. The teacher announced to the assembled pupils, 'he's spelled his name wrong – he'll never be anything' (Harris, 2016: n.p.). Hulsey, interviewed by Sarris (2017), described how she had been bullied, continually, at school; on reporting this behaviour to her teachers, she was advised not to be 'weird' and scolded for 'provoking' the bullies (Sarris, 2017). She had been identified as 'gifted'.

Autistic individuals *were* subjected to stigma (bullying, humiliation) but, 'non-conformist', 'gifted', 'artist' and 'daydreamer' are not recognised stigmatised identities, for example, the Crown Prosecution Service defines hate crime on the grounds of 'disability, race, religion, sexual orientation or transgender identity' (Crown Prosecution Service, 2018: n.p.). 'Age, disability, gender reassignment, marriage and civil partnership, pregnancy and maternity, race, religion or belief, sex [and] sexual orientation' (Equality Act, 2010: n.p.) are characteristics protected under the Equality Act (2010). A person diagnosed with Asperger's Syndrome living today is more likely to be stigmatised than a person with undiagnosed Asperger's Syndrome, which might 'only' have been manifested in a gift for art or language, or only interpreted as 'daydreaming' or 'non-conformity'. Receiving the diagnosis confers many advantages, including access to necessary support, and a plausible explication for 'undesirable' behaviour, for both oneself and for others, for some it is the foundation of their socio-political identity (Robertson and Ne'eman, 2008), but there is also a stigma attached to the condition. From the point of diagnosis, the autistic person, perhaps a hitherto non-stigmatised person, must manage a stigmatised identity. It is possible for a stigmatised identity to be destigmatised (Clair et al., 2016), but for the moment, autism *is* a stigmatised identity (Butler and Gillis, 2011).

5.2 My four degrees of openness

Fig. 1: My four degrees of openness presented as a spectrum.

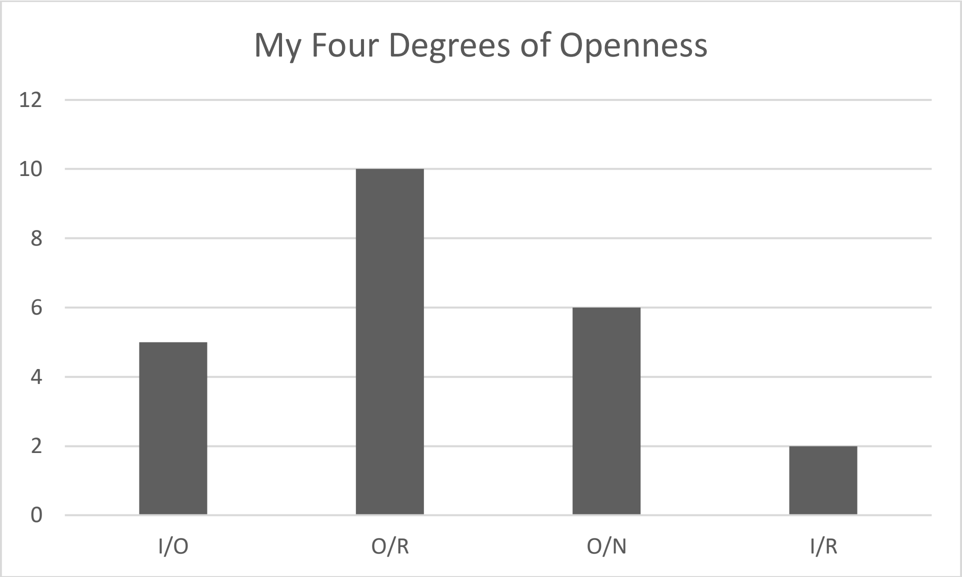

Fig. 2: Number of participants in each category.

Wherever possible, I categorised the participants as either indiscriminately open, open if relevant, open if necessary or indiscriminately reticent. Most participants seemed to occupy a liminal space between the interior, and exterior of the ‘autism closet’, neither totally out in the open nor totally silent about their diagnosis. These participants used their discretion to determine whether it would be more appropriate to ‘come out of’ or ‘stay in’ the closet, in any given context. Goffman (1963) wrote of this no man’s land ‘It is apparent […] that these two extremes, where no one knows about the stigma and where everyone knows, fail to cover a great range of cases’ (Goffman, 1963: 92). Some participants felt able to talk to their peers about their diagnosis, when the circumstances dictated, for example, Katrina disclosed information about her diagnosis to other team members working on a collaborative sociology project, following an uncomfortable conversation about pornography (detailed below).

Some of the participants were happy to weave their diagnosis into a conversation, if someone else introduced the topic, or a closely connected topic; for example, Connor recalled how ‘I didn't tell anyone else, but my friend asked if I had autism (he guessed because his brother does as well), so I told him’. Others used their diagnosis as a ‘safety net’ to fall back on, Tom made a game of it, ‘I like to see how long I can last before I have to tell someone I’m autistic’, damage limitation in the event of ‘difficult’ behaviour, for example, a meltdown, or an ‘awkward moment’. ‘Awkward moment’ is now in use in modern parlance, especially on social media, to connote a relatable scenario, causing some slight embarrassment, but I use it here to mean an uncomfortable exchange between a stigmatised person and a non-stigmatised[45] person (Goffman, 1963).

For some participants, the opportunity to ‘come out’ had never presented itself. Autism is not a staple of everyday conversation in all social circles. Ashley jokingly remarked, ‘I mean, it’s not like you’d be playing [drinking game] ‘Never Have I Ever’[46] and someone’ll go “never have I ever been diagnosed with a mental health condition”, I’ll drink to that!’ I identified Ashley as open if relevant; if autism had been introduced in conversation, he would have shared information about his diagnosis with others. I identified Katrina as open if necessary; if she deems it *necessary* to disclose information about her diagnosis to her peers, she will do so, but she seemed reluctant to volunteer this information otherwise. Katrina recalled how she had been working with a group on a collaborative project. The project was in its early stages, with the topic yet to be decided. The group bandied around ideas and Katrina decided to contribute to the conversation:

> “What about pornography and the denigration of women?” It seemed like an obvious choice to me! They all looked at me like I was some kind of pervert! So, I thought I’d better tell them I’ve got Asperger’s, and they

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[45] I am borrowing terminology from Goffman (1963), any person, on or off the ‘autistic spectrum’, might be subjected to stigma.

[46] The premise of the game is variable, but each player begins with a statement, ‘never have I ever’, finishing the sentence with a sexual, embarrassing or ‘once in a lifetime’ experience. Any players who have had this experience must drink (Howcast, 2012).

> all just sat there, just smiling, and it felt like they were just being nice, do you know what I mean?’

I asked Katrina to elaborate. She reflected on how she had felt the others seemed uncomfortable, smiling to be polite, without understanding.

Morris (1991) observed this behaviour in non-disabled individuals; non-disabled individuals exhibit ‘kindness’ towards disabled individuals but there is still the underlying assumption that the disabled person is ‘less than’. But the point here is that Katrina is willing to be open if necessary. This difficult exchange, this ‘awkward moment’, seemed to *necessitate* an explanation. This one excerpt cannot tell us whether Katrina is also happy to be open if relevant (autism might not have come up in conversation before this point) but later in our interview, she joked ‘my mum’ll just proudly say, “it’s ‘cause I’ve got autism!” and I tell her “mum, you can’t say that!” Her mock-embarrassment and warnings to her mother not to speak so casually, indiscriminately, about her own diagnosis suggests Katrina might be more guarded than Ashley (or her mother).

Other participants were on the extremities. I identified Joel as indiscriminately open. There is some evidence that autistic individuals make a more favourable first impression in cases where the autism is known to others in advance, than if the other person is not given prior notice of the diagnosis (Sasson and Morrison, 2017). Joel recalled how ‘Much like with the students/classmates on my course, only even more eagerly so, I disclosed my ASD to as many of the staff as possible’. Joel had previously been near-indiscriminately reticent, but he made the decision to ‘come out’ to as many others on his course as possible, shortly before joining the university in 2015. This was initially overwhelming for him, but it led him to feel ‘more socially comfortable with classmates, and resulted in me being able to kickstart conversations when in the studios and partake in ones started by others more easily than before starting uni’ and if ever he experienced any difficulties, he felt confident that he had given his lecturers enough information about his difficulties in advance to limit the potential complications of his actions (for example, withdrawal from his programme).

On the other end of the spectrum[47], Kevin chose not to tell anyone at the college about his diagnosis. Under SENDA (2001), Kevin could not have been treated unfavourably, his application to study acting could not have been refused on the grounds of fitness to study, but when I asked how the staff responded when eventually his diagnosis came to light, Kevin replied ‘they didn’t care, they kept me. Because I do good work’. Kevin’s fears draw the line between discrimination and prejudice, between ‘inclusive’ education and social inclusion. Rogers (2007) also draws this distinction, the classroom might be ‘integrated’ (i.e. a disabled child is *permitted* to be in the classroom) but said child is not included in social life or given an education in any meaningful sense. In one case, a child with GLDs was ‘included’ in a mainstream classroom, but he would be dismissed, and given dispensation to tend to the school grounds, whenever his teacher deemed the topic would be too complex for him.

Fahim, Connor and Ashley seemed eager to refute the idea that they were anxious about how others would perceive them. I asked, ‘to whom, if anyone, at college or university did you disclose your diagnosis, from whom, if anyone, did you conceal your diagnosis and why?’ Fahim, told me ‘I haven't mentioned having AS to peers because it hasn't come up in conversation, I don't feel like it would be a problem mentioning it to anyone but there hasn't been a moment where it could be mentioned really’. Connor said ‘I don't mind people knowing, I put it on my Facebook information, but I don't normally tell people when I meet them or if it doesn't come up’, and Ashley, likewise, ‘I’m not ashamed of it, but it’s not like it’s something you talk about with your friends every day’. This is consistent with Olney and Brockelman’s (2010) work on disabled students with visible and invisible disabilities. When Ashley, Connor and Fahim choose not to disclose information about their diagnosis to others, unless it

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[47] I refer here to my four degrees of openness; I am not referring to the ‘autistic spectrum’.

becomes relevant to the conversation, they are not ‘motivated by low self-regard or fear’ (Olney and Brockelman, 2010: 35), but by the rules of everyday conversation (i.e. the topic of conversation shifts gradually). Ashley, Connor and Fahim are stigmatised, but in these cases, it is not possible to link non-disclosure to stigma, in line with Oliver’s (1983) work on disability.

Disclosure etiquette (Goffman, 1963) dictates how a stigmatised person ‘comes out’, and Goffman’s (1963) reasoning is quite different from how my participants (for example, Fahim, Connor and Ashley) interpreted their ‘coming out’ behaviour, their motivations for ‘coming out’. Goffman (1963) defined disclosure etiquette as ‘a formula whereby the individual admits his [sic] own failing in a matter of fact way, supporting the assumption that those present are above such concerns while preventing them from trapping themselves into showing that they are not’ (Goffman, 1963: 124). This is the ‘coming out’ process which I identified as ‘openness if relevant’. It is the casual mention of the stigma in everyday conversation, without fanfare, shame or the atmosphere of a confession.

Confession is not liberating (Foucault, 1976) and can shift the power imbalance further towards the person listening to the confession, continuing the knowledge-power cycle as I described in chapter 2. The stigmatised person does not warn others of a pending shock, there is no air of apology, nothing to suggest that the stigma is ‘bad’. Thus far, ‘disclosure etiquette’ and ‘openness if relevant’ could be one and the same. But for Goffman (1963), stigmatised individuals made casual references to the stigma in conversation to preserve the non-stigmatised person’s dignity, to ‘spare them their blushes’. Goffman (1963) saw ‘coming out’ in this way as evidence of the stigmatised person acting in the non-stigmatised person’s best interests.

None of my participants who ‘came out’ in this way mentioned the other person’s interests. Having ‘come out’ in this way myself (I self-identify as open if relevant, although, in the presence of an NMH and in light of my research interests, autism *is* usually immediately relevant to the conversation), the other person's interests were never involved in my decision-making process. Fahim, Connor and Ashley (and others) 'came out' casually to contribute something relevant to the conversation. It is here we see the divergence between Goffman's (1963) work on stigma and my work on autism. Goffman was a non-stigmatised person. He quickly established himself as a 'normal', with his use of the first-person plural, for example 'The attitudes we normals have towards a person with a stigma, and the actions we take in regard to him [sic], are well known' (Goffman, 1963: 14). I may have an insider-outsider researcher status (a researcher cannot be an insider, however close to the subject matter), as I outlined in chapter 4 (Letherby et al., 2012), but I am a stigmatised person. I have 'come out', and this lived experience, combined with the interview data, gives me valuable insights. Non-disclosure is not evidence that autism is objectively 'less than', nor is it evidence that autistic individuals have internalised this view of their condition, although some *do* anticipate stigma.

5.3 Anticipating stigma

Some participants (for example, Fahim and Christina) reported largely positive reactions from others, on 'coming out', which came as a welcome relief to them. It is heartening, the stigma of the diagnosis seems to be lessening, or else there is very little open hostility towards autistic people. It is not possible to ascertain whether a diagnosis of autism carries little stigma or whether NT and non-autistic people are *tolerant* and *civil*, but the signs are promising. 'Tolerance' is little better than open hostility (Rogers, 2016a) and positions autism as 'lesser'. When I asked whether others responded as expected, or more, or less positively than expected, Christina and Fahim (and others) reported the reactions of others were better than expected, for example, Fahim identified how 'Those I have told have reacted better than I thought they would, they have all been supportive and understanding which is nice'. Christina 'was worried about telling people I was autistic and then having to hear ridiculous micro-aggressions like "You don't look it" (somebody said this to me once when I told them in conversation). However, they were understanding and welcoming'.

Overall, people were apprehensive before telling other people about their diagnosis, with some exceptions, notably from Hannah and Hank, for whom 'coming out' was a nonissue. Hannah had no expectations, 'No, don't expect' and Hank responded with 'I just tell them'. This was consistent with their overall outlook, and their responses to bullying. I will return to this point below, but suffice it to say, the reactions of others, however hostile, were inconsequential for their self-concept. Without directly experiencing stigma, some of my participants seemed to anticipate it (notably Vanessa), this is anticipated stigma (Nyblade et al. 2017; Quinn et al., 2014). There is more than one explanation for this, stigma from secondary sources (vicariously experienced stigma and mediated stigma), and conditionality.

Stigmatising messages can be shared on social media, as well as in traditional mass media (Birch, 2011), building upon Essed's (1991) typology which could only include mention of mass media (her work was published before the advent of social media in 1997). Lee identified how he had 'heard bad things from other sources in the world about autism, especially on the internet. That is what triggered me to worry when revealing the fact that I'm autistic to someone'. Essed (1991) defined this type of stigma as mediated stigma; in cases where the autistic person has no personal experience of stigma, news items detailing how autism has been stigmatised can reinforce to the autistic reader that their identity is a stigmatised identity.

Vicariously experienced stigma is experienced via third parties (Essed, 1991). Vanessa reflected on how 'I was brought up with autism in my family, so was aware of the stigma associated with it, and hence my assumption that most responses would be negative'. Vanessa's early experiences of vicarious stigma led her to *expect* stigma:

> [T]hose who didn't accept my condition were reacting as I had expected everyone would, and those that responded by being very understanding and helpful surprised me greatly. I have only told a few of my peers of my condition, and the only reaction I have gotten so far is an awkward silence, which is exactly what I expected.

This awkward silence is not unusual, for example, Katrina reported a similar reception. This might not indicate stigma or ill-feeling towards the autistic person.

If a group of people are gathered in silence, and unexpectedly, and unrelated to any previous topics, one group member volunteers an arbitrary and wholly irrelevant opinion, or if, in conversation, a group member introduces an unconnected subject, uncomfortable silence is likely to follow, however innocuous or popular that opinion might be. The conversation has been disjointed, the silence has been disrupted, and a tangential topic has been introduced; interrupting a conversation in progress and abruptly introducing a new subject can be awkward (Crouch, 2014). An awkward silence can be interpreted as context-led, not content-led (i.e. it is not what is said, but the context in which it is said). But an awkward silence can also be interpreted (or misinterpreted) as hostility, something which can cause distress to the people involved (Burrows, 2016).

It might be that this awkward silence, or these smiles, the ‘just being nice’ did reflect hostility towards, or discomfort with, autism. I offer this only as an alternative explanation. But there is a reason why Katrina and Vanessa interpreted awkward silence as hostility, ‘Being aware of the negative stereotypes associated with a stigmatized condition, affected individuals anticipate devaluation and discrimination, and adapt their behavior to avoid, challenge or otherwise cope with expected social rejection’ (Hing and Russell, 2017: n.p.). Aware of the negative stereotypes surrounding autism, and late diagnosed[48], Katrina and Vanessa *anticipated* stigma, and when their ‘confession’ was met with awkward silence, this ‘confirmed’ their fear that they would encounter hostility.

5.4 The intra-communal hierarchy of impairment

My intra-communal hierarchy of impairment, which is grounded in the concept of endorsed stigma (Bathje and Pryor, 2011; Sharp et al., 2015), refers to how some ‘high-functioning’ autistic individuals (for example, Hannah and Neil) are complicit in the hierarchy of impairment, confining profoundly autistic individuals to the lower reaches of the hierarchy. People with profound GLDs languish at the bottom of the hierarchy of impairment (Rogers, 2007). It is ‘worse’ to have a GLD than any other difficulty, including SEBDs (Deal, 2003; Meyer, 2013; Snow, 2005).

Using Tringo’s (1970) hierarchy as a springboard, to analyse some of my data, I developed the idea of distancing. Distancing can be conceptualised as an intra-communal hierarchy of impairment. Distancing perpetuates the stigma of GLDs. To reiterate, distancing is, ‘I am autistic, *but*’: ‘I am autistic, *but not like that*’. It is the language of ‘*worse than*’, ‘her autism is *worse than* his’. It is the idea that profoundly autistic individuals are ‘less than’, an embarrassment to ‘high-functioning’ autistic individuals. It is the parent who distances their child from profoundly disabled others, hoping that their child is ‘higher functioning’ than others. In Rogers’ (2007) work, for example, participant ‘Kerry’ was initially reluctant to register her son with a special education unit, in the belief (or hope) that her son’s condition was ‘better than’ those of the children in the unit.

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[48] A later age at diagnosis is a predictor of anticipated stigma (Johnson and Joshi, 2016)

The following two quotes, from Neil, and classmate Hannah respectively, are illustrative. ‘I don’t mean to brag or anything, but my autism’s really quite mild’ and:

> I have this friend, right, I don’t know if you’ve met him, Luke? Well, he’s a bit loud, he can be a bit annoying, he doesn’t have many jokes, but I feel sorry for Luke! Because up until about five, four, maybe three years ago, I was worse than he is now!

In the above quote, Hannah is exhibiting a great deal of empathy for her friend. But she uses the language of ‘worse than’ to position Luke’s autism in relation to her own. Neil is being modest, but still he positions his relatively minor autism above profound or moderate autism. Both Hannah and Neil seem to make the effort not to distance themselves from other autistic individuals, but the hierarchy of impairment permeates the collective consciousness and it is difficult to extricate oneself from this. Here, as above, and as Morris (1991) observed, there is an amalgamation of benevolence and ‘autism as less than’. Amongst disabled individuals as amongst non-disabled individuals, able is the ideal. Amongst autistic individuals, as amongst non-autistic or neurologically typical individuals, normalcy is the ideal.

Some participants (for example, Christina) seemed quite perplexed by the ‘compliment’ ‘you don’t look autistic’, ‘I was worried about telling people I was autistic and then having to hear ridiculous micro-aggressions like "You don't look it" (somebody said this to me once when I told them in conversation)’. Research indicating autistic individuals have distinctive facial features has been widely refuted. The accusation that a person might be feigning their condition, if their facial features do not conform to the expected ‘look’, the idea that the autistic person’s conscious experience is secondary to their outward appearance can be offensive, and confusing. But only Lucinda questioned the ‘compliment’ ‘I never would have guessed you were autistic if you hadn’t told me’. Lucinda reflected on her confusion whenever she was the recipient of this ‘compliment’ and wrote, ‘When I do tell people that I'm autistic, they seem shocked and they say things like they couldn't tell or I don't act like I'm autistic (not sure how an autistic is supposed to act to be honest)'.

Interpreted as a compliment, 'I never would have guessed you were autistic' perpetuates the intra-communal hierarchy of impairment. An identifying feature, or question of taste, in place of 'autistic' would sound nonsensical, especially if there are no stigmas, or preconceived ideas, or negative labels attached to it, for example, the person's name. It could never be interpreted as a compliment. But 'I never would have guessed you were autistic if you hadn't told me' can be interpreted as a compliment. I focus on interpretation here very deliberately. The focus in this section is the *intra-communal* hierarchy of impairment (distancing), on how, and why, autistic individuals readily interpret 'I never would have guessed you were autistic if you hadn't told me' as a compliment, and how in so doing, they become complicit in the hierarchy of impairment. It is the sense of satisfaction when told 'you seem NT, you manage and mask your condition well' which betrays the extent to which an autistic individual has internalised the hierarchy of impairment. Referring to how his course-mates responded well when he disclosed information about his diagnosis, Joel wrote, 'These positive comments [later in the first year] included people saying how I had nothing to be embarrassed about and many even how they would have never guessed me having the disorder without me telling them'. Joel interpreted 'I would never have guessed' as a compliment.

The autistic individual's 'success' and their 'functionality' is measured by how convincingly they self-present as NT, how faithfully they conform to prescribed norms. This is an ideal transmitted to autistic individuals, consciously or unconsciously, from NT others, therapists, medical professionals, educators, support workers, peer groups, mass and social media and relatives. Normalcy, as I have said in chapter 3, is the mathematical centre-point, but how others *respond* to 'normalcy', and crucially, how others respond to deviations from the centre-point, is destructive. Normalisation is intended to equip autistic individuals with the skills necessary to integrate into society, to make the autistic person indistinguishable from their NT peers. And some of this is quite reasonable, a person's quality of life will suffer for want of some of these skills. Rudy (2019b) described severe autism (and the absence of these skills) as 'much more debilitating and challenging than other types of autism' (Rudy, 2019b: n.p.).

Individuals with profound autism experience 'many of the same issues as anyone else on the spectrum, but to a much greater degree; and (2) people with severe autism often have major symptoms that are relatively rare in higher functioning autism' (Rudy, 2019b: n.p.). This can cause difficulties in a variety of settings, including schools, supermarkets and doctors' surgeries (Rudy, 2019b). But this can lead to an 'us versus them' mentality, and 'they' will always be viewed unfavourably, mirroring Asperger's (1991) arbitrary distinction between those children who exhibited traits of genius and originality, and those children who presented with GLDs.

Listed here are government statistics on unemployment rates of other 'out-groups' as a point of comparison. Women have an unemployment rate of 28.6% (Powell, 2019c). Individuals from BAME[49] backgrounds have an unemployment rate of 6.9% (Powell, 2019b). Disabled people have an unemployment rate of 8% (Powell, 2019a). LGBTQIA+[50] individuals have an overall unemployment rate of 20% (Government Equalities Office, 2019). The underemployment of autistic people (National Autistic Society, 2016b) tells another story for *this* research population. To achieve a standard of living, the autistic person must self-present as near-NT; 'camouflaging well can land you a lucrative job […] It helps you get through social interaction without there being a spotlight on your behaviour or a giant letter A on your chest' ('Jennifer' in Russo, 2018: n.p.).

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[49] Black and minority ethnic.

[50] Lesbian, gay, bisexual, transgender, queer, intersex, asexual.

Low employment rates alone do not perpetuate the intra-communal hierarchy of impairment. Charities, relying on public sympathy, perpetuate the idea of autism as ‘less than’; ‘the charity system uses negative images of disabled people to raise money’ (Morris, 1991: 190) and ‘charities [not disabled individuals] are seen to have legitimate ownership of the ‘cause’’ (Scott-Parker, 1989: 12). It is difficult to free oneself from the ‘autism as less than’ narrative. With employers seemingly unwilling to hire autistic applicants and the monopoly of charities, shaping the public perception of autism, the privileges of the ‘high-functioning’ label are clear (Russo, 2018).

When confronted with a diagnosis of autism, repurposing Rogers’ (2007) observations for my own research, some autistic individuals will ‘grade’ the severity of their condition, relative to profound autism, distancing or disassociating themselves from profoundly autistic individuals, to retain some degree of ‘normality’, to which some, late diagnosed, will be accustomed. At the point of diagnosis, I was not accustomed to ‘normality’, there might have been no mention of the word ‘Asperger’s’ until the age of 13, but by the age of six, I had been diagnosed with dyspraxia, and by the age of 11, I had been diagnosed with scoliosis (curvature of the spine). I was intermittently assigned to ‘the special needs table’ throughout primary school and placed in ‘the special needs form’ at secondary school. It had been a mixed ability form, but I was under no illusions. I was registered with a pupil referral unit before *I* was given a name to put to my ‘difficult differences’ at the age of 15. I did not lose ‘normality’. I was never ‘normal’.

Autism is the foundation of my socio-political identity. I am an Autistic self-advocate, 20 years post-diagnosis. Writers like Oliver (1990b) and Morris (1991), heavily politicised disabled self-advocates, shaped my self-concept. Insights like Rogers’ (2007) are essential. Rogers’ (2007) compassionate analysis is a reminder of the *human being* behind the diagnosis, a person in turmoil, a person who *is* now a part of ‘the other’. Rogers’ (2007) work grounds the hierarchy of impairment in the realities of a medical diagnosis. The difficult feelings which accompany a diagnosis of autism originate in the *social* (i.e. the ideal of normalcy, the ideal of ability) but the *emotional* must not be overlooked. Reflecting on the morning *I* was given my diagnosis, the hierarchy of impairment was *my* coping strategy. This was not a terminal diagnosis. ‘It could be worse’. This, too, had been my father’s coping mechanism, for several years he had mistakenly believed I was terminally ill (confusing motor co-ordination difficulties with motor neurone disease), autism was a wonderful relief.

5.5 How the stigma of autism is manifested in FHE settings

In this section, I explore narratives from Katrina, Owen, Neil, Frank, Hannah, Hank and Gregory, who each gave either a personal, or a third person account of stigma. Katrina experiences significant difficulty processing tonal languages, for example, Mandarin, Punjabi, and most languages spoken in sub-Saharan Africa. She was quick to distance herself from xenophobia. At interview, she became very anxious that I would misinterpret her sensory processing difficulty as discomfort with certain groups of people (for example, South Asians). Diagnosed with Asperger’s Syndrome relatively late in life, Katrina initially understood her sensory processing difficulties (issues with tonal languages and the sound of her infant son’s cries) to be a character failing and she began to self-stigmatise. The stigma surrounding her sensory processing difficulties gave her the false impression that she was ‘wicked’. Her sensory issues seemed to indicate xenophobia to some, and she had been identified as a ‘racist’, challenged, stigmatised and alienated. It is right that racism is challenged, of course, but the accusations of racism directed at Katrina were false. It is common for the autistic person’s actions to be misinterpreted as character flaws (Soraya, 2015).

Olfactory hypersensitivity meant Owen was uncomfortable with tobacco. In the following exchange, Owen had initiated a conversation with another student, but the man was a smoker and was quite unsympathetic to Owen:

> The first person I met and tried to be friends with told me to grow up, be a man, and stop being a pussy when I made comment about smoke hurting my nose because I have a higher sensitivity to things like that.

When his expectations of how Owen, as a man, ‘ought to’ behave were not met, this man alienated him. The man’s intent is not clear from the above quote, this might have been intended as a joke, but as I identified in chapter 4, the focus here is on the autistic person’s *interpretation* of events. As Paris and Murray-Slutsky (2014) observe, self-regulation demands the distinction between consequential and inconsequential stimuli. The smell of tobacco is an ‘inconsequential’ stimulus (it does not require attention). Having not made this distinction, Owen dysregulated and ‘failed’ to conform to the ideal of self-regulation to which his companion was subscribed.

Many autistic people experience aversions, a strong and disruptive dislike of something, (Mouland, 2016) or phobias, an intense and irrational fear, disproportionate to the level of threat presented (Paxton, 2012). Some phobias, for example, arachnophobia, the fear of spiders, acrophobia, the phobia of heights or ophidiophobia, the fear of snakes, are relatively common (Tracy, 2019). Other phobias are rare, for example, agyrophobia, the fear of crossing roads, porphyrophobia, the fear of the colour purple, or bibliophobia, the fear of books (Tracy, 2019) and their sufferers are more likely to be subjected to ridicule and the offending object itself (Vix, 2017). Specific phobias are common in autistic individuals (Maskey et al., 2014; Mayes et al., 2013). Neil ‘confessed’ to his phobia of crisps at interview, when asked how autism had affected his social life at the college. ‘Strange as this may sound, I don’t like crisps’. As the conversation progressed, I realised he was describing a phobia. He could not tolerate the texture, the sight, the sound or the smell of crisps, he could hardly touch a crisp packet with his bare hands. If anyone ate a bag of crisps in his company, he would gag or panic. As Neil told his story, it became clear that he had been derided about his crisp phobia, he seemed cautious, embarrassed. Normalcy is the socially prescribed ‘ideal’ (Davis, 1997) and *specific* phobias deviate ‘too’ far from the centre-point of normalcy.

Much of what is described here is sensory hypersensitivity, but sensory hyposensitivity can also be stigmatising, ‘Some people have no sense of smell and fail to notice extreme odours (this can include their own body odour)’ (National Autistic Society, 2016d: n.p.). Frank described a young man with olfactory sensory hyposensitivity (under-sensitivity to smell). Unprepared for the levels of self-care and self-regulation required to live independently in student accommodation, one student neglected his personal hygiene, and ‘he didn’t see the point in using a washing machine, and people were starting to complain about the smell’. People began to give the student a wide berth. Eventually, he was referred to Frank, who advised him to use the available laundry facilities, but by this point, he already had an unfortunate reputation, and people on his course had already begun to avoid him.

An offensive smell can lead to marginalisation; ‘The history of attitudes towards body odour […] teaches us that stigmas and revulsion are largely constructions, not inevitable, biological responses to smelly bodies’ (Thorpe, 2019: n.p.) but the problem can be ongoing for several months. It is common practice to choose to broach difficult subjects indirectly, if the subject is to be broached at all, in the interests of social acceptability (Tannen, 1987), and it might not be something the autistic person with olfactory hyposensitivity notices without explicit information; subtle cues can be difficult for the autistic person to process (Zürcher et al., 2013). ‘Offensive’ body odour is a social construct (Thorpe, 2019), but it is ‘normal’ to mask body odour and normal is the ‘ideal’, and with olfactory hyposensitivity and difficulties with self-regulation, some autistic individuals deviate from the ‘ideal’ centre-point, and are stigmatised for it.

Repetitive patterns of thought or behaviour in autism can lead to ‘special interests’ or ‘obsessions’ (Ambitious About Autism, 2017). Some special interests attract negative attention. Some of my participants reported an interest in activities and objects usually marketed to children or perceived to be ‘weird’. Hank collected plastic dinosaurs, amassing quite an extensive collection. Against the warnings of his father, who was concerned for his son’s well-being at the college, afraid he would be easy pickings for bullies, Hank brought some of his collection to college, to manage the pressures of the classroom at an already fraught time. Eventually, there were as many as 10 dinosaurs on display on his table, and he was warned this was becoming excessive. Hank’s father’s fears were realised, although Hank indicated his indifference to the bullying at interview, ‘I’ve learned to just ignore what people think’.

Hannah, too, was detached from her own situation, from ongoing hostility from others in her peer group. During Hannah’s younger years, most of her school year had bullied her, over her passionate interest in werewolves and clinical lycanthropy (a body perception disorder, resulting in the patient’s false belief that they have become a dog or wolf, or another Canidae animal). Now at college, the bullying had continued but Hannah was relaxed, relieved that the bullying had *reduced*, ‘well, it’s only three boys [bullying me], so it ain’t so bad’. Hannah was quite hardened to the bullying, almost resigned to the inevitability of her unpopularity, her outsider status. Other autistic young people seek a reputation for individuality and integrity, reconciling their differences with a desire for a positive reputation (Cage et al., 2016).

But while Hannah and Hank learned to manage these difficult experiences, for Neil in particular, it was difficult to recover. Neil reflected on how he deferred meltdowns until he was in ‘safe’ company, how he ‘chose’ not to share information about his diagnosis with his friends, how he masked in public following an extended period of bullying at school. The ideal of normalcy shapes how others respond to autistic individuals’ obsessions. Neurologically typical individuals experience obsessions, but the content of ‘normal’ obsessions differs from the content of ‘abnormal’ (and more heavily stigmatised) obsessions (Rassin et al., 2007).

Weiss and Fardella (2018) found autistic individuals were more susceptible to sexual abuse, and other acts of violence, including property damage and bullying, than neurologically typical others. Gregory reflected on an abusive relationship in his first year of college. The Wirral Autistic Society (2015) found *every person* in their sample in the 16-25 age category reported that it was difficult to differentiate between friends and those with malevolent intentions, which in some cases led to mate crime (perpetrators of mate crime 'befriend' the victim, coercing and taking advantage of the 'friend'). Landman (2014) observed the connection between independence and risk of mate crime. As the individual living with GLDs and/or autism 'achieves' independence, previous caregivers cannot assess their 'friendships' with others or the risk to the disabled person. 'Friends' are company, in the transition to independent living and in the transition to FHE and it can be difficult for the autistic person to distinguish between friendship and mate crime. Gregory was in the 16-25 age bracket, at interview and at the time of the relationship. Below is an auto/biographical vignette to illustrate mate crime. I am a mate crime survivor. The events detailed below *did* happen, but I use 'creative license' with the timescale:

> The tanning salon smells of UV, a sickly-sweet smell. I am under eight miles from home, but I am an outsider here. The ethos is different in this deprived town. 'Amy? Best friend?' Jon wheedles, jokingly, 'lend me a tenner? I'll give it you back, I need a top-up!' I retrieve £10 from my purse, giving it to Jon (I use 'giving' here deliberately, I have no expectation that Jon will reimburse me). Friendship is a solid investment. 'I said I'd meet Ginny and Ade in a bit,' a voice echoes from the cylindrical tank. 'Yeah,' I sigh silently, this is not welcome news. 'A bit' passes, and we walk steadily in the direction of Jon's terraced house. 'Dookie, sit!' Jon's family own a rottweiler, but she is not with us, and her name is Jess. *I* am 'Dookie'. I also answer to 'Sidewinder'; 'Dookie', I am told, is a term of endearment for 'someone who's a bit ditzy', 'Sidewinder' is a reference to scoliosis. Immediately I sit on the pavement. Ginny, Ade and Jon laugh. 'A bit' more passes and Jon and

> I are alone. ‘Sorry about, you know, that, bab, I’m in the closet, I’ve got to be a bit, manly around them lot!’ ‘Yeah,’ I grimace sympathetically. Sitting on command and supplementing Jon’s beauty regime? How petty, in comparison! Jon is my *one friend*. Who exposes their *best friend* to homophobia?

An autistic person, or a person living with GLDs, can be more susceptible to friendships and relationships with others who do not act in their best interests (Rogers, 2009).

University staff can have an uneasy relationship with autistic students and can be unsure how best to support autistic students’ needs, there is sometimes a conflict of opinion between students and teaching staff on a diverse range of issues including the need for disclosure and formal support networks, and how sensory hypersensitivity and the struggles of daily life can have an impact on academic outcomes (Knott and Taylor, 2014). It is difficult for the autistic person to extricate themselves from the ideal of independence and request assistance, irrespective of need, as I outlined in chapter 3.

But hostility from a tutor or lecturer during the entrance interview can exclude autistic individuals from FHE (or their intended course) before the course begins. During an entrance interview for an accountancy course, Michael was made to feel uncomfortable and unwelcome. Reflecting on this difficult experience, Michael told me, ‘I don’t know if she was just having a bad day or something, but I was just left feeling like she didn’t really want me there, I just remember feeling very, very uncomfortable about the whole thing’. Michael’s educational support assistant advised him to make enquiries at a nearby campus of the same college. She had noticed a media studies course advertised locally and Michael agreed to explore this new possibility. Michael enrolled on the media studies course and was very successful, directing a prize-winning short film about Asperger’s Syndrome. He felt settled, and welcome.

But the outcome for Michael might have been very different if, dejected after his upsetting entrance interview, he had chosen not to continue in further education. As an ‘insider-outsider’ researcher, I am able to reflect on *my* experience of discrimination. I applied for a joint honours degree in sociology and psychology. The interviewer seemed hostile and both the head of the sociology programme and the head of the psychology programme had reservations about my suitability for higher education. Ultimately, my application was unsuccessful, and I pursued my higher education at another university. This was my first interview and, had I not been so determined to continue my education, had I not been slightly ‘headstrong’, the outcome for me might have been very different. Stigma, whether felt or enacted, can disrupt, or end, an autistic person’s educational trajectory.

Other participants reported difficult interactions with lecturers and tutors, who were unsure how best to support their needs. Overall, Vanessa was satisfied with her interactions with her lecturers, but some lecturers were unclear about how autism might affect her:

> Sadly, some lecturers did not see [the effects of autism] as issues to do with my condition, more as an excuse for poor attendance when my stress levels got too much, or when my work suffered as a result of stress.

Like dyslexia (Olney and Brockelman, 2010), autism can be misinterpreted as an ‘excuse’ for inferior work, or poor attendance. Accommodations are necessary to ‘level the playing field’, but others might misinterpret these as an unfair advantage (for example, sympathetic marking, library loan extensions or non-medical helpers). Individuals with physical disabilities are also subjected to this cynicism. Siebers (2008) recalled how he was challenged to a race in his youth, on the condition that he removed his leg brace. The child who had challenged him had been worried the brace would enhance Siebers’ performance and confer his opponent an unfair advantage.

Autism is a heavily stigmatised condition (Milton, 2013). Traolach et al. (2011) concluded autism '*as is*' can be stigmatised, individuals with markers of autism, without a formal diagnosis, had fewer employment opportunities and fewer qualifications, than individuals without autism markers. Described above were only a few examples of how NT, non-autistic and autistic others can respond to autism, sensory hypersensitivity, sensory hyposensitivity, and 'age-inappropriate' interests. Meltdowns can also attract negative attention (Ryan, 2010). The life of an autistic individual is a life lived on the margins of a social world which is unwilling, and seemingly unable to tolerate 'difficult' differences, a social world which misinterprets their sensitivities, passions, aversions, their very selves, as 'wicked', 'weird', or 'stupid' (as I outline below) (Gray, 2002). The consequences of this for an autistic person's self-concept might be negligible or devastating, depending on several factors, such as whether the person has received their diagnosis (Sarris, 2017), and how they have interpreted what was said (Evans, 2018).

Pre-diagnosis, some autistic individuals self-stigmatise:

> Jennifer Scriven said she grew up believing her social difficulties were "a character flaw." […] She found her own diagnosis to be liberating. "A lot of high-functioning autistics, especially women, enjoy self-discovery at any age. It's a joy for us to know why we do some things, like stimming. It's very empowering," said Ms. Scriven (Sarris, 2017: n.p.).

Describing her self-concept, pre-diagnosis, Katrina said, 'I just thought [my processing difficulties were] because I was the Wicked Witch of the West!' I described above how, living with auditory hypersensitivity, Katrina struggled to tolerate the cries of her infant son, and process tonal languages, how she had been subjected to stigma. This led her to interpret her sensory experiences as a character flaw. Bethany described her relief when she received her diagnosis, realising she was not 'weird', that there was a clinical, 'legitimate' explanation for her behaviour, 'I was relieved that I had my diagnosis because I knew that was not weird but I had a reason why I behave the way I do'.

For both Katrina and Bethany, their sensory experiences and ways of being were stigmatised, and led to self-stigma, as they misinterpreted their indicators of autism as failings of character. Katrina and Bethany were not alone. With no other frames of reference with which he could interpret his difficulties, in a social world so unforgiving of social communication difficulties, Frank labelled himself as ‘stupid’ and ‘worthless’, ‘before I got my diagnosis, I thought I was stupid, I thought I wasn’t any good at anything, I felt worthless’. Others, for example, Stacey, resist critical interpretations of their behaviour, ‘I didn’t know what my accommodation was going to be like and hated (not for selfish reasons) the thought of having to share a kitchen and a bathroom with several other people that I’d never met before’. Stacey’s clarification here ‘not for selfish reasons’ indicates that others had misinterpreted her strong preference for private facilities for selfishness, but she had not internalised this. My four degrees of openness also indicates it is possible to resist stigma, cases of non-disclosure were not, primarily, led by self-stigma, or actual or anticipated stigma, as I identified above.

Autistic individuals (like any other individuals) interpret social interactions in different ways. Owen and Ashley interpreted very similar sentiments in quite dissimilar ways. When Owen was told to ‘be a man’ when he struggled with olfactory hypersensitivity, he became withdrawn and anxious, hesitant to approach, and initiate conversation with, other students, lest someone else mistreated him. It caused him significant distress, and a loss of self-confidence. Ashley felt comfortable with crying, ‘I mean, what’s wrong with a man crying, for fuck’s sake?’ He had been teased about this, but he took it in good humour, he had interpreted this as banter, he had a good self-concept, he was still willing to engage with others, he was still willing to express himself and his feelings. It is relatively commonplace for autistic individuals to contravene ‘feeling rules’ (Hochschild, 1983) and this is the most explicit example of this; in this case, the ‘feeling rule’ is emotional self-regulation. The derision Ashley reported is an example of a ‘rule reminder’, which is manifested as scolding or teasing (Hochschild, 1983), but he actively challenged this derision. As Hochschild (1983) observed 'We may also believe that there shouldn't be a feeling rule in a given instance' (Hochschild, 1983: 58).

As above, autistic individuals respond to bullying in different ways too; while Hank and Hannah became resilient to bullying, and were unconcerned with self-presenting as NT, Neil suffered terribly. Neil went to great lengths to mask his differences. He described how 'it can get quite tricky really! If there's a lot of noise, I can maintain it, during the day, I can maintain noise, sort of bottle it up, but when I get home, it just sort of explodes'. Managing difficult emotions in public and expressing these unwanted feelings at home has been described as the 'delayed effect' (Myers, 2015) and the 'Jekyll and Hyde effect' (Attwood, 2015) and it is closely connected to the stigma of autism and the ideal of self-regulation. To reiterate:

> Children with Asperger's syndrome can sometimes consciously suppress their feelings at school and wait until they are home to release their anguish on younger siblings and a loving parent. Such children are more confused, frustrated and stressed at school than their body language communicates, and the constrained emotions are eventually expressed and released at home (Attwood, 2015: 132).

Some autistic individuals choose not to express difficult emotions in the workplace, or in their learning environment, where autism is heavily stigmatised (Russo, 2018). The long-term consequences of expressing these upsetting emotions (suspension, expulsion, withdrawal or exclusion from the labour market) can outweigh the temporary, short-term relief. With evidence to support the idea that camouflaging in high-stakes situations is common (Russo, 2018), and results-based progression in FHE (offers for a place on college courses are conditional on GCSE results, for example) (Gardner, 2019), I venture the Jekyll and Hyde effect is even more commonplace in FHE. Displays of 'bad' (autistic) behaviour are more likely to lead to enforced withdrawal in FHE, the cost of 'misbehaving' is too great. Masking or covering here is less a question of shame, or ‘faking it’ to win friends, as Olney and Brockelman (2010) observed.

Masking or covering in this context is, for some, a question of continuing, or discontinuing, their education, it is a question of access to, or denial of, learning opportunities. Following our interviews, some of the participants were asked to withdraw from their course. Hannah’s support needs were thought to be too great, there were questions about her productivity and her behaviour. Some tutors invited students to listen to music in their classrooms (audible to all students), and Hannah did not work well under these conditions, if the song was a favourite of hers; institutional forces interplayed with her autism (i.e. not differentiating between ‘consequential’ and ‘inconsequential’ stimuli) to reduce her productivity, but her unsatisfactory work output was interpreted as a flaw of *hers*, not a flaw of the *system*. Other participants were withdrawn from their courses, for other reasons (for example, Bethany was excluded after failing two modules, I will return to this in chapter 7), but I focus on Hannah here because she was so unabashedly autistic.

The social acceptance of an autism *diagnosis* is no guarantee that there is no stigma attached to autistic *behaviours*, which carry relatively more stigma than the diagnosis (Gardiner and Iarocci, 2014) and are sometimes misinterpreted as threatening, or offensive. Joel’s case is a good example of this inconsistency in his own conduct (sharing information about his diagnosis with others, relatively indiscriminately, but interpreting ‘I never would have guessed’ as a compliment) but Hannah’s case is the clearest example of how this inconsistency plays out in college policy. Her application to read visual arts at the college had been accepted. She had stated her diagnosis on the application form, but when she behaved in ways consistent with her autism, she was withdrawn from her course. Autistic individuals might not be met with open hostility upon ‘coming out’ (i.e. disclosure on an application form) but how others perceive their behaviours, their sensory experiences, their ways of being, exposes latent prejudices and the consequences can be unwanted.

5.6 Par for the course?

These prejudices might have been easily obscured until now by the steadfastly held belief that developing and maintaining friendships is an area of difficulty for autistic individuals (Asperger, 1991; Wing, 1981). Other classic papers infer autistic individuals exhibit no interest in interacting with others, or their interactions with others are aggressive and inappropriate (Kanner, 1943). Such widespread agreement on the autistic person's apparent incapacity to form positive, reciprocal social relationships blurs the lines between social incompetence and social alienation.

This is reflected in McLeod et al.'s (2019) study of autistic students, otherwise disabled students and non-disabled controls. On several measures of well-being (social, academic, physical and mental), the non-disabled control group scored significantly higher than autistic students and otherwise disabled students. McLeod et al. (2019) concluded autistic students are affected by issues including stigma and marginalisation, in common with otherwise disabled students, which challenged the presumption that the educational and social 'failure' of the autistic student is inevitable in FHE. All that I have identified as stigma above could be interpreted by others as a difficulty in building and sustaining positive relationships with others, depending, to an extent, on which model of disability is used to frame these difficult experiences.

Owen had an uncomfortable exchange with a course-mate, who was on his cigarette break (as I described above). The social model of disability (Oliver, 1983; UPIAS, 1976) might interpret this man's behaviour as a display of ignorance, he chose not to accommodate Owen's sensory hypersensitivity. Gender differences are also at play here:

> Being a sensitive man can present unique challenges, as men are still held to a standard of masculinity that does not often include showing their feelings. Being a highly sensitive person involves struggling to cope with feeling overwhelmed by sensory and emotional information

> and the stress of modern life, and finding opportunities to express those feelings can be difficult (Ward, 2012: n.p.).

But the individual model of disability leads to a very different interpretation; Owen failed to predict the consequences of his request, and he should not have been so determined to manipulate his environment.

Bauminger and Shulman (2003) and Locke et al. (2010) proposed autistic individuals have very little, if any, experience of meaningful, enduring friendships but relatively more recent research, most of which involved some assessment of the autistic individual's quality of life, has recognised the possibility, and benefits of, friendships for the autistic person (Mazurek, 2014; Tobin et al., 2014). Not 'only' does the autistic person's quality of life improve, for the autistic student, friendships and romantic relationships can prevent a person from taking their own life (Vanessa, who had a history of mental ill-health, identified how if it had not been for her boyfriend, she might have died by taking her own life). I will return to this in the next chapter.

But there is usually thought to be some inevitability about an autistic person's social isolation, 'By definition, children with autism have poor peer relationships, despite age and ability' (Locke et al., 2010: 74). Social problems do surface before other children have clearly defined ideas about what transcends the boundaries of 'normality', and before 'normalcy' is of paramount importance (i.e. before peer relationships can be impaired), although some children self-present as neurologically typical *before* the stigma of autism threatens peer relationships; 'I've always passed as neurotypical, *even* when I was younger' (Christina, emphasis added). But still, there is space for a discussion of stigma here.

Gerhardt and Holmes (2005) and Ranson and Byrne (2014) used the language of deficit and limitation to promote peer intervention programmes. Ranson and Byrne (2014) wrote:

> Due to a fundamental limitation in the social capacity of individuals with HFA […] more efficient and effective interventions can be developed to support individuals with HFA (and their peers) by extending the 'sphere of intervention' beyond the individual themselves to include peer education (Ranson and Byrne, 2014: 7-8).

Any measures to lessen the stigma of autism (i.e. peer education programmes), any possibility of fostering a supportive learning and social environment for autistic young people is laudable, but I must move this forward, autism, as I outlined in chapter 3, is largely absent from the political arena, to the detriment of autistic individuals. The quotation above can be interpreted as 'autistic people invariably fail to assimilate, the alternative (the 'next best thing') is an intervention programme, to promote a *tolerant* social environment for the autistic young person'. I make no suggestion that to *be* autistic is to fail, that enforcing normalcy (to borrow terminology from Davis, 1997) on the autistic person is preferable to challenging the stigma of autism. To be made to assimilate is to mask the Self, to be taught to perform. To challenge the stigma of autism is to render this performance unnecessary.

5.7 Conclusions

I have introduced the concept of distancing, and the related concept of the intra-communal hierarchy of impairment, which expands on the hierarchy of impairment (Rogers, 2007; Tringo, 1970). To briefly reiterate, distancing is the language of 'I'm autistic, *but it's only mild*' or 'their autism is *worse than* mine' or 'not all autistic people are *like that*'. Distancing is the idea that profoundly autistic individuals are an embarrassment, a hindrance to the cause of autistic self-advocates, it is the disassociation from individuals perceived to be 'low-functioning'. Rogers (2007) challenges the mostly unchallenged idea that people with GLDs are 'less than', the yardstick of misfortune, the 'lowest' of all impairment groups. Likewise, Flynn (2018) called for the labels 'high-functioning' and 'low-functioning' to be replaced by 'lower support needs' and 'higher support needs', acknowledging the stigma of a 'low-functioning' status. The hierarchy of impairment is the reluctance to send a child who might benefit from special educational provision to an SEN unit, in the hope that the child is ‘not as *bad* as’ other children (Rogers, 2007).

Grounded in the work of Batje and Pryor (2011) and Sharp et al. (2015), my research unveils the *intra-communal* hierarchy of impairment; autistic individuals themselves can perpetuate the hierarchy of impairment, against profoundly autistic others. My research finds no malice in distancing or the intra-communal hierarchy of impairment. Hannah, for instance, was highly empathetic towards the profoundly autistic friend from whom she distanced herself. But the hierarchy of impairment permeates the collective conscious, until it is almost an ‘objective reality’ and disabled individuals seem no more able to extricate themselves from this hierarchy than non-disabled individuals.

The idea of autism as a spectrum is still prevalent (National Health Service, 2019b), and autism can be diagnosed later in life, when the autistic person has been socialised and the hierarchy of impairment has shaped their ideas around GLDs (Johnson and Joshi, 2016). GLDs are common in autism (Mental Health Foundation, 2019), and people on the ‘spectrum’ identified as ‘high-functioning’ could be ‘lumped in with *them*’, without careful self-presentation and perception management strategies, and without passing or covering. In other politicised disabled groups, for example, in Deaf culture (Padden and Humphries, 1988), individuals with a profound impairment enjoy a higher status, *total* and congenital impairment is the centre-point from which all other levels of impairment deviate (Padden and Humphries, 1988). Profoundly autistic individuals are not revered by ‘high-functioning’ Autistic individuals in this way; profoundly autistic individuals live with GLDs, and GLDs are at the *bottom* of the hierarchy of impairment (which some Autistic individuals, for example, Hannah, Neil and Joel, have internalised). To enjoy the privileges of a ‘high-functioning’ label (for example, employment and educational opportunities), autistic individuals pass or cover, self-present as NT or near-NT and distance themselves from those with profound or ‘low-functioning’ autism (Russo, 2018).

My four degrees of openness expands on Goffman's (1963) idea that most stigmas are known to some, but seldom to all or none. In some contexts, the most visible stigmas can be temporarily invisible, and, in other contexts, the best hidden stigmas can be temporarily visible. Most of my participants (Kevin and Frank aside) were registered with their college or university's disability service. However the autistic student might self-present, however convincingly they pass for neurologically typical, it is still necessary for them to make their diagnosis known to disability support co-ordinators, to access support. Depending on the level of support available (for example, if the autistic student is assigned a non-medical helper and their NMH is a constant presence), there may be some visual clues that the student is autistic (Humphrey and Lewis, 2008). Conversely, the unsupported autistic student, who might be (using my typology) 'open if necessary' or 'open if relevant' might be mistaken for NT or non-autistic *ad infinitum* depending on the circumstances (for example, if the topic is never introduced in conversation), without making any deliberate attempt to give the impression of being neurologically typical. Autism is heavily stigmatised, but not every case of non-disclosure can be attributed to stigma.

What this chapter tells us is autism can be understood as a diagnosis or a set of behavioural and sensory indicators (moreover, Autism is the foundation of a socio-political identity, and autism is also an umbrella term for a range of conditions *and* a specific condition). Autism, as a diagnosis, is now widely tolerated (Gardiner and Iarocci, 2014; Gillespie-Lynch et al., 2015). My use of the word 'tolerated' is deliberate. The word 'tolerate' infers a diagnosis of autism is still understood to be a misfortune, an inconvenience, as 'less than', something a person 'puts up with', in others and/or in themselves. In the interests of civility, some non-autistic and neurologically typical, and 'high-functioning' autistic others feign understanding, as Katrina identified, not openly hostile but not quite willing to challenge their idea of autism as 'less than', aware that autism exists, but unaware of what it is to be autistic (Rogers, 2016a).

As I outlined at the beginning of this thesis, some autistic individuals choose to self-identify as Autistic, the condition is the foundation of their socio-political identity. This reconceptualisation of autism is becoming increasingly popular (Robertson and Ne'eman, 2008), particularly amongst 'high-functioning' autistic individuals and people with Asperger's Syndrome ('Auties' and 'Aspies'), for example Neil; 'no offence, but you know neurotypicals, right? I call them muggles'. The usage of 'muggle'[51] in this context positions NT individuals as outsiders. But meltdowns, socially inappropriate conversation, sensory hypersensitivity or hyposensitivity, unconventional interests (including, in some cases, an 'obsession' with a peer, or a member of staff), aversions, emotional dysregulation, or boring others with 'pet' topics, none of this is easily tolerated (Gray, 2002).

For Autistic, autistic, non-autistic and NT individuals alike, however comfortable with their diagnosis, or with another person's diagnosis, they might be, however closely autism is interlinked with their socio-political identity, the clinical presentation of autism is still widely misunderstood to be 'less than' (Gray, 2002). Autism as a combination of indicators is inextricable from social convention, for example, the student who could not smell his own body odour and, Frank claimed, 'didn't see the point of using a washing machine' was alienated by other students; body odour is a social construct (Thorpe, 2019). In the next chapter, I will explore the formal, and informal support currently available to autistic students and make the case that stigma and social isolation might be common with autistic individuals, but they are not unavoidable.

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[51] The concept originates in Harry Potter and the Philosopher's Stone (Rowling, 1997) and denoted, in its original context, a non-magical person (*outsiders* in the novel and series).

Chapter 6: Findings and analysis: how autistic students evaluate their supportive formal and informal interpersonal relationships in FHE

6.1 Introduction

This chapter is about relationships and formal and informal support networks. Central to the discussion is *support*, and the parties who *provide* that support. In this chapter, I cover friends, significant others, parents and autistic students' societies or disabled students' societies (informal support networks) and support workers, counsellors, and academic support (formal support networks). Positive and reciprocal interpersonal relationships can be an integral part of the transition process for any incoming student (Centre for Excellence in Learning and Teaching, 2018), and enhance the autistic person's overall quality of life (Mazurek, 2014; Tobin et al., 2013). The following support is available to autistic students in FHE; 'disability advisors, mental health advisors, special educational needs co-ordinators, learner support and study skills support staff such as study assistants and non-medical helpers. Non-medical help [includes] note-takers, scribes, readers and lab assistants' (Taylor et al., 2017: 373). There will also be some discussion of the limitations of support and why some autistic individuals prefer to work independently and navigate social life without support, with ongoing reference to the ideal of independence.

I am a heavily supported student; I have been supported since 2001. I am supported in lectures and seminars, supervisions, unstructured study periods and when I travel to and from the university. I am entitled to extended library loans and the conditions under which I sit my *viva voce* examination can be adjusted at my request[52]. I no longer sit written examinations but when I did, I was given a separate room, and 25% additional time. I include this here to acknowledge my positionality. I *have* benefited from support, and this has necessarily influenced my outlook. There *were* participants with higher support needs who benefited from support or other arrangements (for example,

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[52] The examination was adjusted successfully.

Bethany, Alex and William), and equally, there were participants with lower support needs who ‘chose’ not to arrange support or arranged very little support (for example, Lucinda and Philip). My research supports the person-centred model of provision, with support packages available to any person disclosing a diagnosis of autism to disability services. Students then have the ‘freedom to choose’ whichever supports, and arrangements, best suit their needs.

6.2 Formal and informal support networks

I previously outlined one of the parallels between Rogers’ (2007) work on parents of children with GLDs and my work on autistic students in FHE; the hierarchy of impairment (the hierarchy of impairment perpetuated by ‘*outsiders*’) and the intra-communal hierarchy of impairment (the hierarchy of impairment perpetuated by ‘*insiders*’). But there is a second point of conjunction between our respective findings; the need for formal and informal support networks. Relatives, friends, significant others, non-medical helpers, study support, and mental health practitioners comprise an autistic learner’s support network, the composition of the support networks varied between the participants. Stacey’s account of transitioning into living independently in halls of residence is testament to the variety of support available to autistic students in FHE, and the tangible benefits of that support, ‘I very quickly adapted to university life through the support of lecturers, disability support staff, friends, and my mum who is always on the other end of the phone and only an hour’s car journey away’.

Full time undergraduate students registered for the 2019-20 academic year are allocated up to £22,603 Disabled Students’ Allowances funding *per annum* for a non-medical helper, part time undergraduate students are allocated a maximum of £16,951 *per annum* for non-medical helpers, and for a postgraduate student the maximum funding per year is £20,000 (GOV.UK, 2019b). Mentoring sessions could be arranged at once-weekly intervals, or fortnightly, or as required; this is not pre-determined, but contact hours are monitored and ‘excessive contact hours’ will be challenged (Student Finance England, 2017). Non-medical helpers:

> [P]rovide support to help students address barriers to learning, such as dealing with high levels of anxiety and stress, difficulties with concentration and managing course workload etc. (this is in addition to the support usually offered to all students, sometimes called wellbeing support) (Student Finance England, 2017: 1).

As my fieldnotes[53] evidence, for many autistic learners, appropriate support is essential (Anderson and Stephenson, 2017):

> Overheard a conversation between a support worker and an autistic student. Student worried for their future because they will not see their support after graduation, and is worried about his work prospects, thinks it isn’t acceptable in the workplace. The man is encouraging him, told them about how other people have grown and flourished, came to university nervous, timid, left confident, intelligent. Working one hour per week with this guy, then next he’s going to [another campus]. ‘Think it, but don’t say it’. Have issues at school, can’t escape it, never ending negative circle going round, around, around. All you can do is change your attitude and put it behind you. One person failed degree because there was no support available and did manual work, hated it, went back to university, years later, with support, got BSL qualification, now an interpreter. Let down by people who were supposed to be supporting her in the past, and the autistic student. It is the student’s choice if they want to see the man in a week, a couple of weeks or whenever, any problems, text him, wants to get a rapport going.

The fieldnotes give some indication of the type of support the NMH can offer the autistic university student. The NMH responded to the client’s anxieties (i.e. when the student expressed his anxieties about his career prospects), one of the roles specified by Student Finance England (2017), allaying the client’s anxieties. Anderson and Stephenson (2017) observed better outcomes

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[53] I omitted any details which might identify the university, but the fieldnotes are otherwise reproduced here verbatim.

for autistic students in FHE where they had access to support and the fieldnotes support this (both the autistic person working as a BSL interpreter and the autistic person who was ‘nervous, timid’ but graduated ‘confident, intelligent’). The fieldnotes also illustrate how there is no set interval (for example, once weekly, fortnightly) for mentoring sessions, that this is decided by the client; ‘Students have a right to be matched to academic study support workers with appropriate skills, qualifications, and experience, to deliver appropriate support at an optimal time for the student’ (National Association of Disability Practitioners, 2015: 5).

Some of the support and accommodations which were made available to my research participants included; additional time in examinations, deadline extensions and library loan extensions, simplified worksheets (to minimise information overload) and notes to lecturers to provide information in a visual way, for example, infographics during presentations (William), a study support tutor (Lucinda), and a counsellor, although counselling services are available to all students, whether autistic, non-autistic or neurologically typical (Christina, Joel, and Vanessa, reflecting on her college education), counselling services are ‘wellbeing support’ (Student Finance England, 2017: n.p.), i.e. available to all university students. Autistic students can also be assigned a note-taker at their request (Joel; Lucinda was also offered a note-taker, and other support, for example, extended library loans and additional time on assignments, but she chose not to pursue this further) and a support worker or NMH (Michael, Hannah, Neil, Harry, Donna, Hank, Ashley and Philip).

Dunbar (2016) described his experiences of studying English literature in a university; he was given once weekly one to two-hour long mentoring sessions, deadline extensions and additional time in examinations. Many of the supports listed here are available at college and at university, although the education, health and care plan (EHCP) is void once the student has graduated college. Christina and Joel arranged counselling appointments at university and Vanessa had been referred to an on-site counsellor at college.

Michael, Hannah, Neil, Harry, Donna and Hank were college students, Ashley and Philip were university students, and all had been allocated a support worker. Alex was offered a separate room for examinations at university, I sat examinations in a separate room at college, and, likewise, William was allocated additional time for examinations at university, I was allocated additional time for examinations at college (both continued at university). The same supports are available in further *and* higher education.

I draw exclusively[54] on Frank's interview in this section, which will give an indication of the support available to autistic individuals in FHE, and some of the scenarios support staff might confront. Frank successfully defended a student at a disciplinary hearing. In the throes of a meltdown, the student had damaged a table in a lecture theatre, and the university had misinterpreted their actions as vandalism. The panel took heed of Frank's explanation of the student's behaviour and acquitted them of any charges of wrongdoing filed against them. Acts of property damage contravene university policy. But this is autism '*as is'*. To *be* autistic is, for some, to exhibit behavioural dysregulation and this can include property damage in the midst of a meltdown (Colvin and Sheehan, 2012). There were no unwanted consequences for the learner involved, but they were 'at the mercy' of the panel; had Frank not advocated for the student successfully, had the panel been unwilling to listen to him, the outcome for the student would have been much worse. Frank did not indicate the student's degree of openness, but this underlines the need for *some* degree of openness, whether 'indiscriminately open', 'open if relevant' or 'open if necessary'. Had the student been 'indiscriminately reticent', the outcome would have been worse.

Frank related the story of a student who was referred to the autism team with offensive body odour; body odour is a social construct (Thorpe, 2019) but the effects on the person deemed to have offensive body odour, and, conversely individuals living with olfactory hypersensitivity who cannot tolerate offensive

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[54] Frank had an insight into these cases as a team leader and NMH.

body odour, are *real*. It was Frank's responsibility to broach the subject with the student with olfactory hyposensitivity who, as I specified in the previous chapter, had been the subject of several complaints. He 'did not see the point in using a washing machine' and could not smell the body odour on his clothing. Frank did not give 'follow-up' information on the student, but in using a washing machine and attending to his personal hygiene, which some autistic individuals find it difficult to maintain (Wrobel, 2003), the student improved his prospects of future friendships, and other positive interpersonal relationships with others. Interoception (interpreting bodily signals) is also impaired in some autistic individuals (Mahler, 2015); had Frank not intervened, one student might have died by dehydration. For three days, the student had consumed neither food nor water; he had misinterpreted the bodily signals signifying hunger and thirst as a persistent need to use the toilet. When he met Frank on the third day of his degree, it was immediately clear to Frank that the student was unwell, and he offered guidance, impressing upon the student the importance of hydration and satisfying his hunger. The focus now briefly shifts to intimacy, as I continue to describe the critical role Frank plays in autistic university students' social functioning.

Autism can cause problems with intimacy (Urbano et al., 2013); some autistic individuals are unwilling to engage in intimacy, others engage in 'inappropriate' sexual behaviours. One student Frank had been mentoring was in a relationship, but the idea of sexual intercourse (which his partner expected) was unnerving for him. It was not within Frank's remit to advise the student to pursue a sexual relationship with his partner, but he was able to give the student some indication of what the other person expected. In the following chapter I will describe in detail how a fifth autistic student, who referred themselves to the autism team, requested (and was awarded) an extension, having noticed an unspecified error while proof-reading an assignment and deleted the near-completed document in the week of a deadline. Frank negotiated with the examiners and procured an extension for the student, whose autism made them highly reactive to mistakes, relative to neurologically typical peers (Notbohm and Zysk, 2010). Without this extension, the student might have failed their assignment.

The focus here, to this point, has been on support workers. But there is another group of people who have not yet received any attention here, administrative staff, and their contribution must not be overlooked. Autistic individuals can ‘sweat the small stuff’, because that which is, by common consensus, a minor inconvenience, that which is generally agreed to be ‘the small stuff’ can be highly distressing for the autistic individual, a ‘molehill’ to one could be a ‘mountain’ to another (Summers, 2012b). If Frank misses his bus, whether this significantly delays his journey or not, he will not fully recover from this apparently ‘minor’ event for two weeks. For Owen, a strong smell is a ‘big deal’; for Neil, a packet of crisps is a ‘big deal’; for Katrina, tonal languages are a ‘big deal’. It is worth comparing the following responses to the same scenario, from Connor and Vanessa respectively):

> The reception staff are very helpful and informative in response to questions about post and in helping me get my window fixed (it has been broken by some drunk people at night when I was about to go to bed).
>
> Someone smashed my window at one point, and it took more than a week for anyone to even clean the glass up, nearly two for them to fix it, and I ended up in tears over that incident because I didn't feel safe anymore. This all ended up driving me to self-harm again.

Although both Vanessa and Connor were describing property damage, their responses were rather different, and how responsive and helpful the relevant parties (for example, student accommodation receptionists and estates) had been, influenced how easily Vanessa and Connor recovered from the damage (although this cannot be taken in isolation from their overall emotional well-being, Connor gave no indication of mental ill health, whilst Vanessa had a history of self-harm, depression and contemplating taking her own life). The parties handling Connor’s complaint were effective and worked in a timely fashion to resolve the issue. Connor was satisfied, his window had been repaired and there was no emotional damage. Vanessa was dissatisfied with how her complaint had been processed. For Vanessa, the week-long wait for the shards of broken glass to be cleared away was excessive, and the two-week wait for her window to be repaired was unacceptable. This led to self-harm and might have led to worse without the support of her boyfriend, ‘Overall, I’m quite surprised I even made it through my first year’.

The risk of a person taking their own life is lessened in cases where that person has a high quality, reliable, local social network (Pilisuk and Froland, 1978); Vanessa’s risk of death by taking her own life was reduced significantly with support from her boyfriend. Irrespective of whether she would have taken her own life, her emotional health suffered terribly as a result of the way her complaint had been managed. Possibly, there were some restrictions on the parties involved, and Vanessa’s case could not have been dealt with any more efficiently, but Vanessa’s story tells us everyone is a cog in a machine (Hancock, 2019).

A receptionist ‘Serves visitors by greeting, welcoming, and directing them appropriately; notifies company personnel of visitor arrival; maintains security and telecommunications system’ (Monster, 2019: n.p.). The role of the receptionist in the well-being of the autistic student is overlooked. A person who greets, welcomes and directs visitors and students, notifies the relevant parties of the visitor’s arrival and oversees the maintenance of electronic communication systems has no *obvious* involvement in the autistic students’ well-being. The need for receptionists to receive training in autism has recently been recognised (Department of Health and Social Care, 2019) but nothing has been actioned yet. Everyone has a role to play in the smooth-running of the autistic person’s educational life. If someone shirks their role, there could be disastrous consequences for the autistic student.

This is symptomatic of individual model thinking (Oliver, 1983). Specialist workers and pastoral staff, i.e. NMHs, are falsely presumed to be almost solely responsible for the autistic student’s well-being. In recent years, autism trainers have begun to recognise the role of academic staff, but administrative staff are falsely presumed to play little to no role in the autistic learner’s well-being. In his recent guide to best practice and reasonable adjustments, for example, Fabri (2016b) addressed policy makers in disability services, and to a lesser extent, lecturers, but made no reference to administrative staff. This underplays the role of the social (in this case, the conduct and attitudes of administrative staff), in favour of the clinical (specialists who can mitigate the effects of autism).

Support is available via official channels (non-medical helpers employed by external agencies, including Cosmic People, Key Fort and Clear Links) (DSA-QAG, 2019) but also unofficial channels, from friends (Chandler, 2015), relatives (Myers, 2015) or significant others (Slavin, 2013). The focus shifts now to support from informal support networks. Discharged from child and adolescent mental health services (CAMHS), and not eligible for any support as an adult, shortly before coming to university, Vanessa experienced ‘the worst self-harming period of my life without any support to help me, and the only reason I made it through was because I met my boyfriend at the time’. In the absence of support from the CAMHS, Vanessa might have taken her own life, had love not intervened. Autistic women without GLDs, with a history of depression, including Vanessa, are a particularly high-risk group for death by taking their own life (Mandell, 2018).

For Ashley, too, his relationship with his significant other was important. Ashley was living independently, in rented accommodation, with his NT girlfriend, and as our interview progressed, it became apparent that she contributed extensively to his emotional well-being, ‘I don’t know what I’d do without my girlfriend, I’d be lost without her!’ He mentioned his girlfriend several times during our conversation; she was a calming influence, someone to share a joke with, a person with whom he could live day to day and with whom he could share responsibility for running the household, a person who would love him *as is*, making it wholly unnecessary to self-present as near-neurologically typical in the home, something other participants (for example, Neil and Lewis) also appreciated (I will come onto this below). The supportive element in a relationship is not exclusive to relationships between autistic and neurologically typical individuals (Dadula, 2019). But to the autistic person, living independently can be much more daunting than for neurologically typical individuals. To the autistic person, with little to no experience of independent living, living with a partner can be a useful intermediate step to complete independence. As Glennon (2001), in her research on stress, and university students with Asperger's Syndrome suggests:

> Independence is challenging for the typical student, it might actually be foreign for a student with Asperger syndrome. At home, a parent would be able to monitor follow-through of household and self-care activities. At elementary and high school, a team of professionals would assure that the student attended to daily responsibilities (Glennon, 2001: 188).

The autistic person is more likely to have been protected in the parental home, with relatively few opportunities to develop in some areas, for example, cooking (Van Hees et al., 2015). Van Hees et al. (2015) interviewed several autistic students, towards the beginning of their studies, and cooking was an area of difficulty, with one of their participants surviving on uncooked pasta and uncooked rice for several months. Neurologically typical students may not cook well, cook very little (Denham, 2013), or consume food which has not been stored safely (Hein, 2019), but most adults are aware that pasta and rice ought to be served cooked, as Kaminsky (2019) observed, 'Nine and ten-year-olds are ready to cook things like pasta that require boiling water. They may be able to tackle something like boxed macaroni and cheese or spaghetti' (Kaminsky, 2019: n.p.). If the autistic individual's parents have not demonstrated how best to cook, or if the autistic young person has not been given the opportunity to prepare a meal, an apparently 'straightforward' skill like cooking pasta might not have been acquired by the time they are admitted to student halls.

It is an irony that autistic students do not acquire independent living skills when independence is the ‘ideal’. Fahim had reservations about living independently, although he also welcomed the opportunity. Until this point, his needs had been met by his parents at home, ‘I was excited at the challenges of living away from home as I would have to make everyday decisions for myself without as much help from my family, which I felt that I needed to do’. To an autistic person, independent living is not necessarily ‘straightforward’. Flatmates (Chloe) and significant others (Vanessa, Ashley) can be an invaluable source of support. I outline Chloe’s story below.

To reiterate, Neil was able to ‘maintain’ (tolerate) noise during the day. He described a deferred meltdown, ‘exploding’ once at home, sometimes in the company of his parents. This support from his parents is very valuable. For Goffman (1956), even the home, in the company of others, is ‘front stage’, but Neil can rely on the love of his parents. If one, or both, of his parents are at home, Neil can nonetheless ‘explode’, secure in their ongoing love and support (Attwood, 2015). Without this love and support, Neil’s ordeal would be prolonged (i.e. until he was alone). At the beginning of Joel’s second year, the art department reorganised the studio space, without warning. Joel would be in a separate (and unfamiliar) area of the studio to most of his peer group, he created a different style of art to his friends. This was a highly distressing event for Joel. The new arrangements made conversation with his friends only slightly less convenient, but the unanticipated change in routine was upsetting (National Health Service, 2015). The new distance between Joel and his friends resulted in:

> [A] bit of an emotional breakdown on that first night back at home. One thing that my parents did make me think of while comforting me over this was the fact that I might have felt a bit of isolation because of the

> fact it was […] fresher's week, so therefore there were obviously not going to be that many people around at all.

The art department did not give advance notice to Joel, but he found comfort in his parents. Joel was not entirely unsupported, he had ‘one or two mentoring sessions a week for me to discuss with them how things are going on my course, including what is going well and what may be concerning me as of that time’, but he did not specify when he would next be in contact with his mentor. His parents were available to comfort him *that same day*.

Lewis, too, remembered a meltdown in the car on the commute home from university at the end of his first week in student accommodation (on weekdays, he would live in halls of residence, on weekends, he would live in the parental home). His mother was chauffeuring him. University was initially overwhelming for Lewis. He was unhappy with his choice of discipline, he was struggling to cope with the complexities of applied mathematics, and ultimately, he would transfer to a chemical engineering course, which better suited his research interests. University is an opportunity to gain new independence, and many autistic young people (for example, Fahim and Christina) may have so-called ‘helicopter’ parents, ‘hovering around’, monitoring their behaviour, well-being and personal hygiene (Glennon, 2001; Hooven, 2017) but in times of distress, loving parents can be what any person needs; ‘Love, support, trust and optimism from [the adolescent’s] family make them feel safe and secure, and are powerful weapons against peer pressure, life’s challenges and disappointments’ (Reach Out Australia, 2019: n.p.).

To reiterate, recent research carried out by the Centre for Excellence in Learning and Teaching (2018) on the transition to higher education, The Here Project, reveals friendships, and a sense of belonging, can be paramount to a successful transition. Other research has recognised the possibility, and benefits of, friendships for the autistic person and for their quality of life (Mazurek, 2014; Tobin et al., 2014). My research supports this. Chloe’s case is especially illustrative here. Chloe developed a close friendship with one of the women in her halls of residence, Alison, who ‘took her under her wing’, and with others in her student accommodation. Chloe reflected on her friendship with Alison. On one occasion, in a nightclub, there was a miscommunication between the two women. Chloe and Alison were separated for a brief period by the toilets, and Alison, feeling responsible for Chloe’s well-being, panicked. In this scenario, Alison had acted to protect Chloe. She included her autistic friend in the social life of the group, but she did so with care, for a person she perceived to be ‘vulnerable’.

Protecting the most ‘vulnerable’ (or those understood to be vulnerable) is an integral part of the group dynamic. Chloe recalled how late one evening, the group noticed a nightclub bouncer[55] had posted a derogatory Tweet about one of the party, a Deaf man. The friends immediately defended their Deaf friend and challenged the bouncer. Within half an hour, the Tweet had been removed, and the bouncer had apologised to the Deaf patron. When Chloe described to other residents how autism could affect her, her friends were aghast, ‘I told [my friends] what happens when I have a meltdown, how I bang my head against the table, and they were like, “Oh Chlo[56]! What you like?”’ It is worth noting how Alison and her flatmates easily involved Chloe in their social life without foregoing their favourite activities. Chloe settled well, and she attributes this to her relationship with her flatmates.

Lucinda described her friendship with an outgoing young woman named Carly. She and Carly were both enrolled on a level one college course, and when she and Carly progressed to the same level two course, they ‘buddied up’. Empowered by Carly’s confident personality, Lucinda felt able to socialise with other students on her course, and enduring friendships began to develop. As Carly and Lucinda continued to the level three course, Lucinda’s self-confidence blossomed, and she became more comfortable when delivering

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[55] Bouncers vet nightclub patrons, refusing entry to the venue if necessary and ejecting other patrons in the event of violent behaviour.

[56] She abbreviated her name at interview, I abbreviate her pseudonym here for this reason.

presentations and working on collaborative projects (although this was still an area of significant difficulty at the time of the interview). She reached several milestones at college, including committing to a long-term relationship, socialising with others in nightclubs and bars, and obtaining her driving license. Lucinda largely credits her friendship with Carly for this relatively newfound confidence.

Fahim, Connor, Christina, Andrew and Alex all benefited from membership of an autistic students' society or a disabled students' society. Alex told me how he 'quickly fitted into a group of friends that are on about the same kind of social level as me via societies, opportunities, autism officer offering autism based socials and such'. For Alex, registering with the autistic students' society (and other societies) was an opportunity to meet other autistic individuals and integrate *quickly*[57] into a wider group of people. Andrew reflected on how he enjoyed meeting other autistic people for occasional meals out, and other leisure activities, and Connor described the autistic students' society as fulfilling and worthwhile. In registering with an autistic students' society or a disabled students' society, autistic university students become part of a support network, which is mutually beneficial for them and others. Engaging with insiders can be cathartic (Cooper and Rogers, 2015), and the 'autism closet' can be a restrictive and unsettling experience (Russo, 2018), these groups facilitate openness to some degree (the *diagnosis* will be known to others).

For Fahim, it was important for autistic students to be given a 'choice' of activities, 'I would […] try to form some sort of society or group specially for autistic students, where they got to choose things they'd like to do E.g. go on a day trip somewhere'. For Christina, joining the disabled students' society widened her social circle and she was able to participate in the political life of

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[57] The speed of this integration is key here, for a friendship to have a positive effect on a person's transition, it needs to form early in the process (Centre for Excellence in Learning and Teaching, 2018).

the university, becoming a self-advocate, and an advocate for other disabled people, once she ‘learned of the 'Disability Action Society' at my university which seeks to maintain equality and spread advocacy for disabled people by disabled people’. Depending on how disabled students’ societies and autistic students’ societies are organised, and their overall objectives, it is possible for groups of disabled or autistic students to exact real change and promote equality for other disabled or autistic students.

Autistic students (those who belonged to autistic students’ societies or disabled students’ societies and those who did not) welcomed the opportunity to interact with other autistic individuals. Hastwell et al. (2017) reflected on the successes of a social group for autistic students at the University of Cambridge, which ‘served as a social confidence booster and a safe space for some students on the autism spectrum. Students particularly valued the opportunity to spend time with peers’ (Hastwell et al., 2017: 97). To be outcast and marginalised, as so many autistic people have been outcast and marginalised, then to discover there are others on the social periphery, others with a similar experience and a similar outlook, is an affirmative experience (Drake, 2014), for instance, ‘For the first time in my life, I felt like I could be myself and that people would understand me and not judge me for being autistic. I was in good company!’ (‘Ernie’ in AASPIRE, 2019: n.p.). I outlined my own experiences of connecting with some of the participants in chapter 4.

Some students’ societies are more conducive to friendships than others, depending on how they are structured; the more heavily structured the society is, the less conducive it is to friendship (Patterson, 2017). The value of the students’ society depends on its intended use. A disabled students’ society, or an autistic students’ society, might have no (or limited) value if its intended purpose[58], its anticipated, hoped for outcome is a durable, meaningful friendship; friendships developed at university are generally temporary (Meadows-Fernandez, 2017; Morin, 2017), I will return to this below. That

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[58] By ‘intended purpose’, I am referring to the member’s intentions.

same society (i.e. at the same university) can be said to have a much higher value if the anticipated, hoped for outcome is a temporarily enhanced social life, or an introduction to other members, who might be experiencing something similar (Done and Mulvey, 2017).

Josh was sceptical of autistic students' societies and the extent to which these societies might lead to meaningful, lasting friendships with others. Josh chose to build his friendships on other grounds (such as interests in common, similar or complementary personalities, a similar sense of humour, or enjoying each other's company). For him, a shared diagnosis of autism is a superficial basis for a friendship, and these friendships are unlikely to endure much beyond graduation. A mutual diagnosis of autism might not be a solid foundation for a friendship, but it might be a springboard to a closer, more fulfilling and enduring friendship. Joint membership of a disabled students' society, or an autistic students' society might be a catalyst, a space in which to meet, and cultivate a friendship, as any two people might meet in an office, or a seminar room, and develop a friendship.

Friendships post-graduation do falter (Morin, 2017). This is true of any group of people, at any stage of education, it is not particular to autistic individuals. A lecture series, a collaborative project, shared student accommodation, or a student society might be an 'adhesive', or a 'tie that binds', but once the project is submitted, when the student is no longer in halls of residence, that 'tie' is loosened, the 'adhesive' is no longer effective, and the friendships often disintegrate (Peters, 2017). Once close friends become Twitter followers, Facebook friends, who might 'favourite' the other's Tweet, 'like' their Facebook status, and the friends might exchange birthday greetings, but there will be very little meaningful communication between them (Knight, 2017).

Some friendships *do* endure, for example, reflecting on a level two college programme, Lucinda 'slowly began to feel comfortable with everyone and gained some friends that I still have now'. But there are no guarantees of an enduring friendship, not a shared diagnosis of autism, not shared interests, and not shared living quarters. And some, but not all, autistic people do find it easier to relate to other autistic individuals, than non-autistic or NT individuals (Rudy, 2019a). John was living in student accommodation. His flatmates were all NT. He would often visit another group of flatmates living in other student accommodation on the campus, who were all autistic. John felt more comfortable in the company of other autistic individuals than his flatmates. Autistic students' societies and disabled students' societies are an opportunity, and a potential catalyst for a meaningful friendship, but they are not a *guarantee* of any friendship which can 'survive' graduation.

6.3 Why the stigma of autism is less prevalent in FHE

Gates (2019) interviewed six autistic adults, who reflected on the stigma of autism and the resulting feelings of rejection and shame. The 'Participants generally agreed that the use of stigma cloaking, or strategies to appear "normal" as a protective factor against stigma, become less urgent with age' (Gates, 2019: 112). This is consistent with my findings. For Michael, the stigma of his autism had lessened since school, he told me at interview 'We've got people here from different ethnicities, we've got people here who'm[59] gay, so it's just another difference really'. At school, differences are downplayed, and any deviation from the prescribed 'norm' is likely to lead to bullying (Humphrey and Lewis, 2008). In college, young people feel more comfortable with their differences and self-identity and begin to express their individuality. This is also consistent with the findings of Drake's (2014) study, looking at the college experiences of late diagnosed college graduates, who were diagnosed post-graduation. One of her participants, 'G. H.' reflected on how, 'My social life also blossomed in college as I was welcomed into a co-ed fraternity that was pretty much a group of geeks, misfits, and outcasts' (G. H. in Drake, 2014: 3).

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[59] 'Who'm' combines 'who' and 'am' and should be understood as 'who are'. Michael used a regional (West Midlands) dialect.

In college, different is the ‘new normal’; the ideal of normalcy enjoys *less* prestige, although on some level it is still prevalent, there is a ‘right’ and a ‘wrong’ weird (Waldschmidt, 2005). In college, and at university, autistic people develop friendships with others on the social periphery. Alex was quickly able to integrate with other ‘outsiders’; to reiterate, ‘I quickly fitted into a group of friends that are on about the same kind of social level as me’. Chloe frequented her local cinema with other autistic students, and John spent time in another flat where all residents were autistic (outlined above). The autistic person’s differences are less pronounced, because others around them are different, giving expression to these differences in immediately identifiable ways (for example, fashion). Therefore, autistic students are more likely to build positive relationships with others in FHE than at school (Drake, 2014; Humphrey and Lewis, 2008).

The meaning we attach to difference is not fixed but fluid, and context specific; it is not unusual for people to sporadically choose to be ‘quirky’, to be different within the parameters of what is socially accepted (Waldschmidt, 2005) and some of the participants (for example, Robert and Ellie), chose to self-present as ‘quirky’. Quirkiness is actively encouraged in some disciplines. Performing arts student Ellie, and her peers, were advised from the outset to be quirky:

> They told us we need to stand out, be a little bit quirky, if we want to get ahead in performing arts, they said by the end of the year, every member of staff in our department needs to know us by name.

Hank said autism made him more imaginative, more creative, valuable assets for an art student. Creative subjects like performing arts, visual arts and media studies are prepared to welcome and accommodate differentness; Michael reflected on how ‘accountancy, like, it’s just people who’m good at maths, whereas in media studies, there’s almost got to be something a bit different about you’. More autistic individuals are attracted to the ‘hard sciences’ than social sciences or arts-based subjects (Baron-Cohen et al., 2001), but autistic individuals *also* exhibit creativity and quirkiness (Best et al., 2015), traits prized in arts programmes. The concept of ‘weird’ has both positive and negative connotations, and whilst quirkiness is positive-weird, the social difficulties associated with autism are negative-weird (Macleod, 2019). As I proposed in chapter 3, although some deviations from the ‘norm’ (i.e. quirkiness) are socially acceptable and in some cases revered, other deviations from the ‘norm’ (i.e. autism) can be heavily stigmatised. O’Connell (2017) described eccentricity (quirkiness) ‘as a ‘border’ region between disability and normalcy, one that can disturb the strict and stigmatizing boundary between these artificially separate categories of identity’ (O’Connell, 2017: 352).

6.4 The ideal of independence revisited: why some autistic students ‘choose’ to forego support

To reiterate, Lucinda was offered a support package, to meet both her academic and emotional needs, but she chose not to access most of the services available to her, or request any extensions (extended library loans, additional time for examinations or extended deadlines for coursework). But whilst Lucinda had no use for these services, or accommodations, for William, this level of support was necessary. Philip, too, did not feel he needed much, if any support. He felt that support and accommodations were largely intended for the benefit of individuals with moderate or profound autism, that a ‘high-functioning’ autistic person ought not to request many, if any, support services or accommodations:

> A person on the extreme end [of the autistic spectrum] would need a lot of support but someone else on the mild end, like myself, might feel confident dealing with problems on their own and wouldn't need or want that much support if at all.

I introduced the intra-communal hierarchy of impairment in chapter 5. If ‘a person on the extreme end’ of the ‘autistic spectrum’ is expected to require support, but not ‘someone else on the mild end’, some autistic individuals who self-identify, or have been identified as ‘high-functioning’ can be deterred from seeking support, even if it is needed, whether because support is ‘not meant for them’ or because they fear it might give the impression of ‘lower functionality’.

There is a stigma attached to supported learning as the following auto/biographical vignettes will show:

> I am in a poster conference. The conference has been organised as a competition. I have not won. But I am in my *alma mater* and Steve has given a ‘warning’ tone. I tremble, I feel queasy, I give what I hope is a passable impression of a good loser. A losing scenario in a public setting; no one sees the emotion work, the preparation, the Self-sacrifice. It is April 2016, two weeks and one day after the close of an eight-day sociology conference. The mother of an autistic young person scans my poster with some interest. We engage in some uncomfortable conversation. The woman does not approve of support, ‘I’d rather Pierce maybe not get [his A level qualifications] first time than get him to depend on support, I mean, he’s been getting the bus by himself since he was 12, do you know what I mean?’ I am reeling, is this how my research, my own ‘choice’ not to navigate social life independently, my own ‘choice’ to be *safe*, is viewed?
>
> It is September 2007, I am in an unfamiliar office, off the combined studies staff room. Paul, head of combined studies, is a familiar face, the common room is a ‘safe space’, but nothing feels like ‘home’. There has been some confusion, some suggestion that Steve is tutoring me. I have a good GPA (67%) and I choose to observe the six-week holiday with a two-day working week, researching independently in the on-campus library. ‘I mean, if I was to say, Amy, go to the library and research molecular physics, not as I would! But let’s just say you were writing an essay on molecular physics; would you know where to start? Do you know how to use the library catalogue, do you know how to take books out?’ ‘Yeah, definitely,’ I am in shock. There has been no collusion, yet I feel I am the guilty party.

Academic support is not in the role descriptor of a non-medical helper, the role of the NMH is:

> Supporting students to develop their independence and autonomy in HE, for example by providing support with issues such as time keeping;

> organisational skills etc. and can be supplemented by practical support E.g. library support, workshop support etc. Supporting a disabled student during examinations (DSA-QAG, 2016: 48).

Whilst there is stigma attached to (inter)dependence (a stigma which permeates the public imagination and how autistic individuals, for example, Lucinda and Philip view their own needs), (inter)dependence can be liberating, freeing the disabled person to pursue their interests (French, 1991). (Inter)dependence (or take-up of support) was liberating for Bethany, William, Joel, Hannah, Neil, Hank, Donna and Michael, and others. It is in receiving support that these participants were free to pursue FHE. But it is difficult to liberate oneself from the ideal of independence.

6.5 The limitations of support

Autism will present the autistic person with challenges which no support arrangements, services or accommodations, or a widespread public shift in attitude could resolve (French, 1993; Oliver, 1996). In the description of the role of an NMH (DSA-QAG, 2016), there is no mention of support with sensory difficulties. In an exhaustive list of autism-specific reasonable adjustments, there is only one reference to sensory issues, 'provision of quiet room if there are sensory issues' (Disability Rights UK, 2012: n.p.), but there is still the possibility of an unexpected noise (for example, a fire alarm) interrupting the quiet. Autism can hinder social inclusion, irrespective of the intentions of others. Frank reflected on interpreting social invitations literally. 'Shall we go for a coffee?' is almost universally understood to be an invitation, with the expectation of light conversation and a non-alcoholic drink. But Frank will accept or decline the invitation, solely based on whether he does, or does not, want a coffee at any given time.

Suggesting a coffee in advance of the date, for example 'Shall we go for a coffee next Friday at 3:00?' is confusing for Frank; he will not know whether he would like a coffee a week in advance. He will frequently overlook one of the primary functions of ‘going for a coffee’, the social function, and there is no alternative to coffee in this context for a literal-thinking person; autistic individuals are prone to literal thinking (Porter, 2011). It is ‘a coffee’ which has been specified. ‘Coffee’ is interchangeable with any other drink sold in the cafeteria or café. But for Frank, there is no possibility of tea, hot chocolate, water or juice, only coffee. To give a literal-thinker a complete picture of the invitation, more details would be necessary (i.e. highlighting the expectation of a conversation, and how ‘coffee’ should be interpreted loosely, to mean ‘a drink’), which would be quite clumsy and, potentially, lead to information overload. The result is a disappointed friend, and a missed opportunity for social interaction. Frank went on to say in a follow-up email:

> [I]t is not fundamentally a societal attitude that presents me with barriers. There are some situations that, I suspect would be challenging whatever society I was living in. I feel that my autism at times limits significantly the number of social interactions I can have and that isn't a function of how society is structured but a function of how my brain is structured.

In a similar vein, Lucinda had requested a buddy for induction week at university, but no one had come forward and she was unsupported that week. On reflection, she questioned whether a buddy would have been helpful, or whether she might have been ‘anti-social’ (i.e. distant, withdrawn) with the buddy, as well as with other prospective students:

> I know my social difficulties are not really something that can be resolved as such, even if I did have a buddy I don't think it would of helped as I may have been anti-social with them as well as everybody else.

For Lucinda, as for Frank, social communication difficulties would still have affected her interactions with others, irrespective of how well supported she might have been. The ideal would be for NT others to understand how the autistic person’s social awkwardness, bluntness and apparently ‘anti-social’ ways of being are not personal, but characteristic of autism (Summers, 2012a). But without knowing the other person’s diagnosis, without knowing what it is to be autistic, the person cannot make allowances; autistic individuals make a better first impression when their autism is known to the other party (Sasson and Morrison, 2017).

Not every autistic person will want to socialise; the social motivation deficit (Chevallier et al., 2012) proposes autistic individuals are less motivated to socialise than non-autistic and neurologically typical individuals. But for autistic people who do want to develop friendships with others, autism can close doors (Hickey and Crabtree, 2018). Disability is a multi-layered, context specific experience (Morris, 1991; Oliver, 1990b; UPIAS, 1976; World Health Organisation, 2013), comprised of socio-political, economic, cultural, psychological and clinical components. Supports, adjustments and attitudinal shifts cannot compensate for *all* the clinical components of a condition (French, 1993; Oliver, 1996) but they *do* facilitate disabled individuals' participation in social life to a significant degree.

6.6. Conclusions

Rogers (2007) proposed that the parents of children living with GLDs benefit from support from both formal and informal support networks and my findings indicate autistic students also thrive with support from various sources, some formal (for example, NMHs) and others informal (for example, parents). Autistic students have at their disposal a diverse range of services and support, both human help and policies including deadline extensions and extended library loans, to meet their social, emotional and academic needs (support workers, counsellors and study skills tutors respectively). Many autistic students also have an informal support network, comprised of friends, relatives and significant others (Chandler, 2015; Myers, 2015; Slavin, 2013). Administrative staff, such as receptionists, can also contribute to how the autistic person manages some of the difficult situations which might cause some distress in student accommodation (for example, property damage). Students and staff, irrespective of position, families and caregivers, friends (and the media, and the public, as I identified in chapter 5) can, and do, all affect the autistic person's educational trajectory, both positively and negatively.

Disability services and needs assessors (Broadbent and Co., 2018), in consultation with autistic prospective students, determine which arrangements would most benefit the autistic learner, on a case by case basis, but crucially, some autistic students (for instance, Lucinda) are offered support and accommodations (i.e. it is determined that the student would benefit from support) but 'choose' not to access them, preferring to study independently. The autistic person's needs are many and varied. Some autistic individuals have a higher level of need than others (Flynn, 2018), regardless of their functioning status. Not all services, and not all accommodations, will meet all autistic individuals' needs. There will be no need for support and accommodations in all cases. But the ideal of independence (French, 1991; Kittay, 2011) and the intra-communal hierarchy of impairment, in conjunction with the expectation that a 'high-functioning' autistic person will know, intuitively, what is expected, and the stigma attached to asking for presumably 'obvious' points to be clarified (Sinclair, 1992), which I will expand upon in chapter 7, is also influential. Support *is* available, and in many cases, it is recommended, but not all students are willing to arrange it.

In this chapter, I have also outlined the destigmatisation of difference (including autism) in FHE. Stigma is context specific (Kumar et al., 2009) and the stigma of autism varies with the level of education at which the autistic learner is studying (Drake, 2014; Humphrey and Lewis, 2008). But where autistic learners *anticipate* stigma (for example, Neil, who reflected on playground bullying, which effected his perception management strategies and self-presentation in FHE), they will be reluctant to 'come out', which will limit their opportunity to access necessary services and accommodations, and to develop the supportive friendships which were a great comfort to Chloe and Stacey. In all I have discussed here, it is apparent that support is available (via informal interpersonal relationships and formal support networks), and where students ‘choose’ to access this support, educational outcomes will often be enhanced, but the stigma of autism and (inter)dependence is a barrier to accessing this support.

It is also evident that irrespective of a college or university’s transition policies and staff awareness training, or how willing peers are to include autistic students in the social life of the university, barriers to accessing formal and informal support networks are in place *external* to academia, sometimes *before* the student registers with the college or university. In the following chapter, I will explore the interplay of institutional forces, the built environment and the social life of a college or university with the autistic learner’s autism, and how this can include or exclude autistic individuals from academic and social life.

Chapter 7: Findings and analysis: the interplay of autism with the built and social environment

7.1 Introduction

In this chapter, I cover several interrelated areas of interest. I begin with the interplay of autism and the built environment of the college or university. Participants reflected on the volume of traffic in the immediate surrounding area (Harry, Neil and Hannah), the intensity of the lighting (Christina) and the noise levels in lecture theatres (Bethany). I continue the chapter with a discussion of autistic students' societies and disabled students' societies, and agency, the 'freedom of choice', and why for some autistic learners (notably Fahim) it is important to have this 'freedom of choice'. This need for 'choice' is rooted, in part, in the prior experience of infantilisation (i.e. cases where an adult is treated as though a child). This is linked to the presumption of incompetence (Lucinda, Robert) and the related presumption of competence (Lucinda). I explore these presumptions in the following section.

The presumption of competence is problematic in cases where tutors and lecturers choose student-led grouping for collaborative projects, or where the student is met with incredulity upon asking for clarification on an apparently 'clear' matter. This sometimes limits communication between teaching staff and autistic students, who are apprehensive about approaching tutors and lecturers for advice, for fear of ridicule, or who are intimidated by social interaction, as I will outline in the subsequent section. Choosing not to seek advice from lecturers and tutors to clarify a point can be detrimental to the autistic student's academic outcomes, but, as I will outline in the next section, the student's academic attainment can also be effected where the methods of assessment are unsuitable for their needs. Finally, the tone of the chapter takes a positive turn, and I will describe how some participants prepared themselves, or were prepared, for the transition to FHE.

My interview schedule was designed to cover the built environment *and* the social environment, grounded in the ideas of UPIAS (1976), Oliver (1990b) and Morris (1991). I was keen to explore how institutional forces were at play, including assessment procedures and options available to students for whom some assessment methods would be intolerable (for example, oral presentations or collaborative research projects). Many autistic individuals live with sensory hypersensitivity or hyposensitivity, including high sensitivity to light, ‘photophobia’, and auditory hypersensitivity, high sensitivity to sound (National Autistic Society, 2016d) and restrict their diet to bland foods, some have an aversion to the smell of certain foods (Attwood, 1998). I wondered how this would ‘play out’ in a cafeteria, with fluorescent lighting, the overpowering smell of food, brands the learner is unfamiliar with, the cacophony of sounds, from conversations in the immediate vicinity to a radio station, intended to be used for background noise, and the expectation to engage with servers, or share a table with others. This chapter is about institutional forces, and the built environment, and how autism interacts with the social environment of a college or university. There is some practical use to which this information can be put, for example, it contextualises some unsettled, ‘disruptive’ behaviours and it is a rationale for what might seem *irrational*. It will also underline the need for safe spaces and for giving autistic learners ownership of those spaces.

7.2 The interplay of autism and the built environment of the college or university

All participants were registered on courses which demanded the physical presence of the student. Alex had previously been a student with the Open University but at interview, he was following a taught programme. All participants had some experience of the built environment of their college or university. The built environment was not, overall, a cause for concern for the participants, but there were *some* difficulties, which warrant some exploration here. Harry, Hannah and Neil, who to reiterate had been course-mates, reflected on how it could be difficult to access the library. There are several campuses of their college. The college is in a learning quarter, an area of a city or town where a cluster of college, or university campuses have been built. This college has an independent living centre for individuals with special educational needs, a sixth form college, a specialist hospitality college, several technical schools, a sports complex and two general purpose college buildings. The newer of these two buildings is the ‘arts’ building, offering programmes in musical theatre, costume design, media studies, music, and art and design, to name but a few of the courses available there.

My NMH Steve specialises in visual arts, and until 2018, he had been the designated education support assistant for autistic art students, all of his contacts at the college who participated in my research (Harry, Hannah, Neil, Donna, Hank and Michael) were enrolled on arts-based programmes; Harry, Hannah, Neil and Hank were following the same visual arts programme, Donna had been on the same course but a year on, and Michael had been enrolled on a media studies course. The older of the two general purpose buildings offers traditional courses (‘hard’ sciences and human sciences), engineering, psychology, accountancy, sociology, and animal management (again, amongst many other programmes of study). This building houses the library. Students based in the arts building are expected to cross an A road, with a moderate flow of traffic, to access the library. For some of my participants, the prospect of crossing the road proved too daunting and this deterred them from visiting the library. Harry, Hannah and Neil had previously confronted their anxieties, crossing the A road to visit the college library, but they were reluctant to do so again. Hannah told me ‘I don’t know if you know [*name of college*] college at all, but you have to cross a busy road if you want to go to the library, and it’s quite a long way down [the road]’.

To understand the autistic person’s anxieties with navigation, it is essential to have more than rudimentary knowledge of the condition[60]. Autistic individuals perceive movement differently to non-autistic individuals. The autistic person will typically perceive movement more quickly than non-autistic individuals (Schallmo and Murray, 2016), exhibiting weak ‘normalisation’ (‘normalisation’

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[60] The field of study is sociology, but this is a disability studies project and there will necessarily be some foray into the medical.

is related to visual perception here). Autistic individuals experience difficulties with ‘switching’, ‘Transitions may be moving from place to place […] They may also involve a shift in thinking, action, perception’ (Davis, 2001: n.p.) and for autistic individuals, there is often some considerable effort involved in the process. Navigating a road with a moderate to high traffic flow demands an immediate shift in thinking, action and perception, as the pedestrian processes oncoming traffic, quickens their pace if needs be, and times the crossing to circumvent a collision. Auditory hypersensitivity, too, is likely to be a contributing factor for some autistic individuals, the average car operates at the same volume as a stereo built for home use at its highest volume (Decibelcar, 2015). With weak normalisation, difficulties with switching and auditory hypersensitivity, it is perhaps unsurprising that these young people were reluctant to use their library, restricting their resources to online sources.

The auto/biographical vignette below is an insight summarising how I experience inner-city navigation:

> It is a Friday, at 3:40 in the afternoon. Steve walks kerbside, protecting me. Steve has always been insistent that he walks kerbside in a city centre. It is the ‘gentlemanly’ thing to do, it is in keeping with tradition, but it will also protect me in the event of a terrorist attack. We near tactile paving, and a two-way road, I see the ‘green man’ vanish and the ‘red man’ replace him. My instinct is to be guided by the ‘red man-green man’ system, but I override this, tapping my foot, seemingly impatient. The movement is comforting to me, it is self-stimulatory behaviour (a ‘stim’) but it is, equally, self-regulatory behaviour (albeit not self-regulatory behaviour of which many approve). Steve extends a hand; I clutch at it.
>
> He assesses the flow of traffic from the road behind us and the road to our right, across a junction, I fix my gaze on the railings opposite, on the promise of ‘refuge’. Steve leads me to the centre, almost an island, more tactile paving, and more railings, and another crossing point. The green man is shining. With relative confidence, I cross. I veer off to my

> right, but I am off-balance now, and the abrupt stop at this third crossing point unsettles me. I clutch Steve’s hand, child-like. My urge is to scuttle. A car approaches from our right, travelling at an ordinary speed. ‘Missed me!’ I screech triumphantly. To the autistic mind, the speed is excessive. To the autistic mind, the driver accelerated.

Shifting the focus now to the physical environment of the college or university, away from the layout of the campus, the participants were, overall, comfortable in the communal areas of the university (toilets, cafeterias, the library). This is consistent with Drake’s (2014) findings, ‘The physical environment on campus also mattered to the participants. G.H. described “walking across the campus in the summer” as one of her favourite aspects of college’ (Drake, 2014: 3). Philip reported he frequented the library regularly, ‘I go to the library a lot, mostly to check my emails on one of the computers, and I have no troubles there’. Similarly, Robert reported no difficulties with the built environment, ‘Autism for me has had almost zero impact on Assessments or [my response to] the built environment around me’. Like ‘G. H.’ (Drake, 2014), some participants enthused about campus facilities. Katrina reported she was able to work for 12 consecutive hours in the library, under the right conditions (for example, if childcare could be arranged, and with a low intensity of other library users). From the range of resources in the library to the variety of catering facilities on campus and nearby food outlets, from the availability of lifts to the maintenance of the lighting, William compared the built environment of the university favourably with the built environment of his sixth form college.

However, consistent with Madriaga’s (2010) work on freshers’ fairs and sensory issues in autistic prospective students, other participants were uncomfortable with their physical environment, in halls of residence and in their learning environment. Christina mentioned ‘I could benefit from a light that I can dim down (thankfully the counselling rooms have this feature)’. Christina had been referring to the lighting in her bedroom; one evening, she had been applying make-up, the daylight was waning and the lighting in her bedroom was too intense. When I interviewed Hannah, she was wearing sunglasses to alleviate some of the discomfort of photophobia. The fluorescent lighting in use at the college was unsuitable for her needs. Auditory hypersensitivity caused Vanessa some discomfort when accessing the university facilities, she did not specify *which* facilities were overwhelming, or *why* (for example, overcrowding, the noise of the plumbing, the hum of electrical equipment) but she did identify auditory hypersensitivity as the root cause of her difficulties, 'I do find the uni facilities quite overwhelming, especially with my hearing being so sensitive […] I also find it difficult in large crowds, especially when I am stressed, as I like my own space when I've had a bad day, which isn't always possible on campus'.

Overcrowding was also a problem for other participants, some participants had the good fortune to have very little experience with overcrowding. Connor reported 'I am fine with going [in the students' union building] unless it is very crowded' and 'I am fine with [the canteen] as it is rarely crowded'. The conditionality implicit in these statements ('*unless it is*'; '*as it is*') indicates overcrowding would have affected Connor. Bethany, too, was anxious in noisy or crowded environments, 'I do not do well with loud noises so large lecture halls are not my biggest fans! Also I can find crowds quite daunting especially if I'm in a new unfamiliar place'. Bethany's anxieties around crowds is exacerbated in unfamiliar settings. Freshers' week is almost *characterised* by overcrowding and unfamiliarity (Madriaga, 2010), I will return to this below. Neil was able to 'tolerate' noise, masking his frustrations during the day, but the outcome at home was a meltdown, 'it can get quite tricky really! If there's a lot of noise, I can maintain it, during the day, I can maintain noise, sort of bottle it up, but when I get home, it just sort of explodes'. His deferred meltdowns would continue for the duration of his college programme, seemingly not effected by his familiarity, or unfamiliarity with the learning environment.

Some university libraries offer designated silent study areas; I have studied in four university libraries, all of which have designated spaces for silent study, the results of a Google search for ‘university library silent study’ indicate other university libraries also offer these facilities, which cater for the needs of students with auditory hypersensitivity. But research has explored the possibility of *other* silent or autism-friendly spaces, for example, Breakey (2006) called for segregated eating areas for autistic students. Responding to Breakey’s (2006) calls for segregated dining areas, Madriaga (2010) wrote ‘Having segregated eateries […] only reaffirms the ghettoisation of an already excluded group of people. Whether they eat in their accommodation or in a designated dining space, they are still alone and set apart from others’ (Madriaga, 2010: 48). Madriaga (2010) was concerned that separating autistic diners from others in their peer group would be a missed opportunity for them to socialise with non-autistic or NT others, and (equally) vice versa.

But research indicates autistic individuals *do* appreciate autism-specific spaces. Citing Davidson and Parr (2010), Bertilsdotter Rosqvist et al. (2013) wrote, ‘It is clear that separate spaces offer places of safety and inclusion, however they may also reproduce exclusion and marginalization’ (Bertilsdotter Rosqvist et al., 2013: 6-7). Bertilsdotter Rosqvist et al. (2013) concluded that whilst autistic individuals *wanted* segregated spaces and shared spaces, ‘In order to create and maintain neuro-shared spaces […], a take up of the principles of neurodiversity must be witnessed, which present autism as a difference rather than a deficit’ (Bertilsdotter Rosqvist et al., 2013: 24). This calls for the neurologically typical occupants of neuro-shared spaces to abandon the ideal of normalcy. Individuals who deviate from the centre-point are *different* not *deficient.*

I would like to refer here to a case, to give some indication of what is being done in an FHE setting to provide a segregated space for autistic learners. Dudley College, in the West Midlands, introduced an AS Base, a student-led initiative described as ‘a social space they are comfortable in as well as a [quiet] room for when the stress of college becomes too much and they need to ‘take a break’’ (Excellence Gateway, 2012: 2). The AS Base is a segregated space, but it is not ghettoisation, autistic individuals are not *confined* to the AS Base, but it is available if needed. On a similar theme, Drake's (2014) work highlights the need to offer single-occupancy accommodation to autistic prospective students indicating their intention to live in halls of residence.

Co-habitation (as I briefly identified in chapter 5) can be difficult for autistic individuals, it can be difficult to accommodate another's routine, to compromise and be social. There is the possibility that a person, of any neurotype, can unwittingly distress their autistic roommate (for example, if the person is averse to a smell, taste or texture), or if, in the case of 'E. F.' in Drake's (2014) study, the roommate for the most part does not give the autistic person sufficient alone time. Drake (2014) proposed 'Colleges could offer students with autism their own dorm room and accommodate this need for their own space' (Drake, 2014: 3)[61]. *Offer* is the key word here. Autistic students can 'choose' to live in shared accommodation. They can 'choose' not to use designated rooms like the AS Base. They can 'choose' not to use an autism-friendly dining area. What Drake (2014) proposes here is a 'choice'.

7.3 Students' societies and agency

Students' societies are ordinarily organised through students' unions (UCAS, 2014). Students pay an annual registration fee, which ranges from under £5 to in excess of £100 (Mock, 2016), and meet, usually once-weekly (Oxford Royale Academy, 2014) at the university or off-campus, to socialise or to open debate on topics of concern (Mock, 2016). For autistic learners, autistic students' societies or disabled students' societies, as we saw in chapter 6, can be a useful resource, a gateway to a social life and an opportunity to socialise when these opportunities do not present themselves through the 'usual' channels (for example, friendships which usually develop on a course or in student accommodation). Normalcy is the *ideal*, the centre-point, against which all other social conduct, sensory perception and perspectives are

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[61] Drake's (2014) reference to 'colleges' can be read as 'universities' for this purpose.

judged (Davis, 1997). But normalcy is context specific; what is normal in one context is abnormal in another context. The centre-point is fluid, and in the company of other autistic individuals, the centre-point shifts; the autistic person is ‘normal’ (Davis, 1997). Yet autistic students’ societies are not exempt from the ideal of ability.

Disabled people are infantilised, treated as children, irrespective of their biological age (Gardiner, 2018; Stevenson et al., 2011; Wiseman and Ferrie, 2018). Writing about disabled women, and their bodies, Wiseman and Ferrie (2018) described how ‘The infantilization of disabled women and women with learning disabilities compounds the marginalisation and low status they are afforded and the constraining of their agency and decision making’ (Wiseman and Ferrie, 2018: 5). I will return to infantilisation below, but this discussion of agency and the social life of autistic students’ societies also warrants some mention of infantilisation. To reiterate, Fahim expressed an interest in setting up an autistic students’ society:

> [W]here they got to choose things they'd like to do E.g. go on a day trip somewhere, again I think it'd help students with all different levels of autism to feel more comfortable if they were given the choice to decide things to do with one another rather than it be decided for them’.

Consultation is important for any group of disabled people, but with the attendant specific phobias and aversions, the multiplicity of interests and needs, the broad diagnostic criteria, and somewhat arbitrary categories of functionality, autism is a special case (Social Care Institute for Excellence, 2010). Autism is characterised by heterogeneity (Lenroot and Yueng, 2013). Familiarity with autism (whether the experience of autism is personal, or vicarious, or whether a person has a professional or academic interest in autism) does not guarantee that a group leader can confidently predict how group members will respond to a planned activity. Previous success with an event is no guarantee of future success with a repeat event. This is no different, in theory, to any group event. Organisers cannot guarantee their event will be a success. But with specific phobias and aversions (Maskey et al., 2014) autistic individuals are likely to have needs surplus to those of other groups of people.

Research indicates autistic individuals are prone to difficulties with decision making (Luke et al., 2012). Luke et al. (2012) compared findings from a survey administered to autistic participants with survey data from a non-autistic control group. Autistic individuals reported 'several problems in decision-making more frequently than the comparison group, and were more likely to report avoidance of decision-making, as measured using the [General Decision Making Style inventory]' (Luke et al., 2012: 612). But indecisiveness is not universal for autistic people. Some autistic individuals, for example, Fahim, would want the opportunity to choose or suggest an activity. Another autistic student would be happy for others to decide. But however well-versed in autism the group leader is, they must actively listen to autistic voices. Charlton (2000) wrote at length about the exclusion of disabled individuals from the decision-making process (for example, policymaking). These were decisions which would affect *disabled people*, policies made about them without their input. Government policymaking on behalf of disabled individuals is a high-stakes activity, quite unlike planning activities on behalf of a small group of autistic students, but in *principle*, silencing autistic voices is malpractice in this context too, in line with Charlton's (2000) work on the principle of 'nothing about us without us'.

Membership of an autistic students' society is not good value for money if the members (customers) are unable to access the activities, and the attendant opportunities for socialising with others, because the organised activities are unsuitable for their needs. Several 'ordinary' leisure activities, which are popular with other students' groups, might be difficult or unsuitable for some autistic individuals. Visiting restaurants can be difficult for autistic individuals; the autistic person must choose their food (decision-making), potentially manage disappointment (self-regulation), and exercise some degree of flexibility, if the chosen meal is unavailable, and exhibit patience while waiting for the order (Autism Speaks, 2013). Some autistic individuals will not manage the social life and sensory assault of a nightclub, as one autistic young woman described, ‘I just wanted nothing more than to escape the noise, the nasty smell of sweat mixed with various perfumes and colognes, the smoke, and the cheap beer. As soon as I got home I went to bed. I needed to de-compress. I was done’ (Elcheson, 2017: n.p.). Elcheson (2017) reflected on how she had lifted the hem of her skirt to show a tattoo on her thigh to a group of unfamiliar men, how she had left the venue with them before returning home alone. Her actions were misconstrued by the young women who had invited her to the nightclub (but fortunately not by the young men she had been associating with).

A games night might be upsetting for some autistic individuals, losing can be a distressing experience for many autistic individuals, who may struggle to acknowledge that others can also be good at a game, or experience some rigidity of thought (that it is always important to win), or may not have sufficient practice with losing with grace, if parents or caregivers have ‘let them win’ games to avoid conflict (Middletown Centre for Autism, 2019). Finally, a visit to the cinema might also be unnerving for some autistic individuals, due to the darkness of the screen room, the overwhelming volume of the soundtrack, the patience needed to sit through trailers, the urge to move, or use vocal self-stimulation to self-regulate (National Autistic Society, 2017a). These are some of the difficulties event organisers might confront when planning activities for autistic individuals.

Giving autistic individuals a ‘choice’ is important, to alleviate some of the distress of restriction and control (Simone, 2010). It is not unusual for autistic individuals to seek to control their environment and enforce routine on themselves and others, to manage the discomfort and unpredictability of social life, which can be misinterpreted as manipulative behaviour (Simone, 2010), and is sometimes referred to as pathological demand avoidance, or PDA (National Autistic Society, 2017c). For the student with PDA, the prospect of group leaders choosing an activity on their behalf is a very uncomfortable one. It *is* possible to manipulate the outcome of an innovation meeting, but group leaders are advised against giving group members a ‘token’ say, advised not to invite contributions if there is no intention of a follow-up. There is no literature pertaining to presidents of students’ societies in this area, but Costa and Oliveira (2015) advised consultants, ‘use participants’ contributions and never conduct a public consultation if you won’t change anything on the document’ (Costa and Oliveira, 2015: 2). The principle applies whether the parties involved are consultants and members of the public or group leaders and group members.

7.4 Presuming incompetence, presuming competence

Some participants were worried they would receive unfavourable treatment on the grounds of their (actual or perceived) functionality. The ideal of ability has permeated the *public* imagination but, in FHE, the ideal of intellectual ability is central. Lucinda and Robert were both reluctant to ‘come out’, for fear of being infantilised. The worry was, they would be ‘treated like’ someone with special educational needs, which is significant, individuals with special educational needs are treated unfavourably, but this has largely been absent from the socio-political sphere. The unfavourable treatment of individuals with physical disabilities or sensory impairments has received political attention (Oliver, 1983; Padden and Humphries, 1988), but the unfavourable treatment of people with GLDs has attracted less political attention, as GLDs are in the lower reaches of the hierarchy of impairment.

For Lucinda, these fears were born of previous experience, ‘As understanding as people are in today's society, I find that low academics is still associated with special needs and I know my diagnosis does not affect my academic ability, only my social interactions’. Prior to ‘coming out’ to the relevant parties at the university, for Robert, ‘One of my biggest fears is that I'd be talked down to and treated like a simpleton’ although ultimately, these fears were not realised, and he was treated with dignity. Lucinda, who had attended a special educational needs secondary school, had been mistakenly understood to live with GLDs.

In a brief but comprehensive review of the available statistics, Emmerson and Bains (2010) concluded, ‘Given the variation in prevalence rates, we have derived two estimates of the overall prevalence of learning disabilities among children with autism for use in subsequent modelling: an upper estimate of 67% and a lower estimate of 40%’ (Emmerson and Bains, 2010: 7). But statistics vary significantly depending on the source, and some sources are more widely consulted than others. Charities can shape public perceptions of autism. Charities can shape public perceptions of disability and they will usually give the ‘worst-case scenario’ to generate profits and increase donations (Morris, 1991). Charities are a useful source of information on any condition. But information from charities can be skewed. Profoundly autistic individuals with GLDs are a ‘posterchild’ for charitable organisations and their campaigns. GLDs are ‘the worst-case scenario’ (and I will not contradict the idea that profoundly autistic individuals can have fewer opportunities, more stressors and more difficulty learning than ‘high-functioning’ autistic individuals).

It is quite unsurprising that the expectation is that autistic people will present with GLDs. These expectations are grounded in the hierarchy of impairment (Tringo, 1970) and perpetuate the intra-communal hierarchy of impairment. Expectations on autistic individuals are *lower* in some cases when, with or without good reason, the non-autistic or neurologically typical person has anticipated the autistic individual lives with GLDs. This perpetuates the intra-communal hierarchy of impairment as autistic individuals self-present as ‘high-functioning’ or neurologically typical to evade unfavourable treatment.

Robert and Lucinda did not experience GLDs. Robert was not treated unfairly, none of the teaching staff with whom he had been in contact had any preconceived ideas of how autism might affect him. But 40-67% of autistic individuals *can* be identified as having GLDs. By implication, potentially 40-67% of autistic individuals *will be* treated unfavourably on the grounds of their GLDs. It would be wrong to overlook this social injustice because the label has not been applied to my participants, especially considering how little research has been carried out in this area. Robert feared he would be '*treated like a simpleton*'. The word 'simpleton' is a derogatory term for a person with GLDs. Robert was reluctant to 'come out', therefore, for fear that he would be treated like a person with GLDs. But it is a moral obligation to question why people with these difficulties are treated so unfavourably. Taken at face value, Robert's relief that he was treated with dignity might be a 'good news story'. And it is, on some level. Quite rightly, staff at the university did not belittle Robert. But dignity, and the right to be addressed in an age-appropriate fashion is contingent on whether the person is perceived to be 'high-functioning' or 'low-functioning'.

I would like to contribute to this discussion here by reflecting, again, on the hostile interview for a place on a joint honours degree, to study sociology and psychology, in 2005. I was treated unfavourably; the panel were condescending, I was 'treated like a simpleton' (to reuse the above quote), I was perceived to be quite profoundly autistic, and ultimately the application was unsuccessful. This gave me one of many insights into what it is to be perceived to be 'low-functioning' in FHE. Adults are spoken to as though they were infants; the 'public' face of autism is that of a child (Stevenson et al., 2011). It is taken for granted that people with profound autism are unworthy of respect. Respect and dignity are conditional on actual or perceived 'functionality', but this is not an inevitability, 'Accommodating the support needs of an autistic 17-year-old […] does not mean that you should treat them as though they're younger than their actual age. You can support people without condescending to them' (Gardiner, 2018: n.p.).

Some staff, by contrast, presume competence, and this equally causes problems. Lucinda recalled how, towards the beginning of semester one:

> [S]ome lecturers would […] assume that I was just as able as everybody else and would expect us to group ourselves, and as you can imagine all the social groups teamed up whilst I was left on my own, this […] caused me much anxiety and due to this I did not attend these lectures for the rest of the semester.

Some of Lucinda’s lecturers presumed social competence and expected their students to divide themselves into groups independently. But what is more disturbing was the outcome for Lucinda, which could have had devastating consequences for her progress. She chose not to attend some of her lectures. She performed well in her coursework and was satisfied with her results, but it is necessary to consider the bigger picture here. Lucinda’s grades did not suffer as a result of her poor attendance, but other students would see their GPA fall as a result of nonattendance.

Catapano (2019) identified 22 teacher-led or random strategies for grouping students. Teacher-led grouping strategies included turning the row (alternate rows of students turn to the row of students behind them and work together), grouping by interest (if the research interests of the students are known, students are grouped according to those interests), and alphabetical rotation (students are grouped in alphabetical order of surnames, or given names). Random grouping strategies include pulling names from a hat, synonym cards and ‘famous pairs’ cards (each student is given a card, they must partner the holder of the complementary card). There are alternatives to student-led grouping strategies, but Lucinda’s tutors expected students to group themselves.

7.5 Communication and clarification

In this section, I explore communication with lecturers. Both institutional and social forces are at play here. Many participants did not feel comfortable approaching lecturers for advice or clarification, linked to their fear of infantilisation. Philip described how he found it difficult to interact face-to-face, ‘I don't really ask questions during lectures or practicals because I'm not always comfortable talking with people face-to-face and prefer to work things out on my own first when I get stuck’. Connor, Joel, Fahim and Vanessa all reported similar issues. Refusing to book an appointment with a lecturer, or ask for clarifications, can have a detrimental effect on the autistic person’s educational attainment (Shives, 2015). Reflecting briefly here on personal experience, in 2011, I failed an assignment, I was given feedback, ‘it is a good idea to consult with the appropriate member of staff before submitting your coursework’. I had not consulted anyone beforehand, not because I was uncomfortable but because it had not occurred to me to do so.

I turn my attention now to the question of independence (to the *ideal* of independence), to identify possible explanations for the observed reluctance to ask tutors and lecturers for clarification. To reiterate from chapter 3, it is not possible to be entirely self-sufficient, we are all interdependent. We all rely on each other, at some stages of life more than others (i.e. during early childhood and later life), but some of us will require support with greater urgency and at a higher frequency than others (i.e. disabled people, or people with a serious illness) (Kittay, 2011). Interdependence is the norm, but there is a level of dependence, relative to age, which transcends the boundaries of what is socially accepted (French, 1991). I use ‘interdependence’ and ‘dependence’ here to distinguish between a mutually dependent relationship in which both parties contribute more or less equally, and the state of dependence on others for daily needs, for example, travelling and road safety, cooking, personal hygiene, and the imposition of a daily routine.

Many parents want their autistic child(ren) to become independent (Rudy, 2018). There are independent living skills courses for autistic adults. Independent living skills range from what might arbitrarily be identified as ‘basic’ to advanced skills. The autistic young person registered on an independent living skills course might cover life skills, for example using the toilet, functional skills, for example, travelling by bus, leisure or recreational skills, including visiting a cinema or theatre, employment skills (skills particular to the job, working with others), interpersonal skills, from managing relationships to appropriate greetings, and technological skills, the use of a mobile telephone, for example (Rudy, 2018). Unless otherwise specified (i.e. collaboration with others on group work projects), university students are expected to produce work independently. Autistic individuals can be literal thinkers (Porter, 2011), some autistic learners misinterpret this notion of independence (i.e. 'without input from tutors or lecturers') and this miscommunication interrelates with the emphasis on independence, the ideal of independence, identified above (French, 1991).

From a young age, people diagnosed with 'high-functioning' autism, including Asperger's Syndrome, learn not to request advice, clarification or help. Sinclair (1992), diagnosed with 'high-functioning' autism, realised there were:

> [G]aps between what is expected to be learned and what is assumed to be already understood. Even when I can point to the gap and ask for information about what goes there, my questions are usually ignored, treated as jokes, or met with incredulity, suspicion, or hostility (Sinclair, 1992: 295).

For the autistic person, more explicit advice is necessary in some cases, where non-autistic and neurologically typical individuals learn by observation and modelling their behaviour on others. There is sometimes no evidence of a learning delay; there might, on the contrary, be evidence to suggest the autistic person learns easily, and quickly (for example, the autistic person might be highly qualified), and however insistent the autistic individual might be that there are 'gaps' in their knowledge, the 'high-functioning' autistic person will be met with incredulity upon requesting clarification (Sinclair, 1992) or impatience upon exhibiting executive dysfunction (Cazalis and Lacroix, 2018). The gaps in the 'high-functioning' autistic person's knowledge might be what most people would consider 'the basics', but that which is not taught is often not learned (Price, 2016). It seems to be almost a paradox. The autistic person might function at the highest level, without functioning at ‘base level’. How the ‘high-functioning’ autistic person learns is often at odds with how they are expected to learn, and, crucially, with how they are *taught* (Sinclair, 1992). Typically developing young people learn by observation or instinct (Meltzoff, 1999); the need for specific, clear, detailed instructions on ‘the basics’ is more likely to be expected where the person has been identified as profoundly autistic (Jisc, 2014)[62].

The ‘high-functioning’ autistic person is in a difficult position, learning as quickly and easily as a typically developing person would, but with very particular learning needs, in common with profoundly autistic individuals (Sinclair, 1992). Many ‘high-functioning’ autistic students will be reluctant to ask lecturers for clarification and advice, if all their apparently ‘silly questions’ have been met with hostility or ridicule. There are many benefits to consulting a tutor or lecturer with specialist knowledge in the essay topic, and autism might affect the quality of written work. Dyslexia (and hyperlexia) is a co-morbid condition (National Autistic Society, 2019b). In light of what has been established above (i.e. the presence of an intense, all-pervasive interest and difficulties interpreting language) it is not inconceivable that some autistic individuals would introduce their ‘special interest’ or ‘obsession’ at every opportunity, or select an essay topic which is wholly irrelevant to the brief, solely to indulge in this interest. It is, equally, not inconceivable that the essay questions (or the core reference material) might be phrased unclearly, and open to misinterpretation. Any of this will affect the quality of the autistic individual’s written work, and in some cases, this will only become apparent when a tutor, lecturer, supervisor or a person in their support network draws their attention to the issue (for example, in the event of a failed assignment).

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[62] Jisc is the name of the organisation, it is not an acronym.

7.6 Extenuating circumstances, methods of assessment and disciplinary procedures

It is necessary to re-cover old ground here, to explore the role of extenuating (or mitigating) circumstances policies. I have previously outlined Frank's involvement in the case of a student who required a deadline extension (in chapter 6), but this case is equally relevant here. The method of assessment was unsuitable for the student. Institutional forces can work to include or exclude autistic learners from FHE. To reiterate, Frank reflected on a student who deleted a document which was in some way 'flawed', whilst proof-reading the document shortly before the advertised date of submission. This student had deleted an essay. Without extenuating circumstances procedures, the outcome might have been, ultimately, withdrawal from the programme or a lowered GPA. It is possible to produce high quality work in a brief period (Cummings, 2016), but the student had *requested* a deadline extension, indicating they would have fared badly under these circumstances.

But extenuating circumstances procedures *were* in place and Frank negotiated an extension for the student. When Hank engaged in a sexual act in a corridor, and he and his partner were reported to the course head, procedures were in place to give his status as an autistic person due consideration (his partner, Heather, lives with GLDs, and allowances were also made in her case). Had there be no extenuating circumstances policies, Hank and Heather might have been excluded (although there is no explicit reference to sexual activity in the college code of conduct, there is some reference to 'disruptive behaviour'). But these policies *were* in place and the students were permitted to continue, on the grounds of diminished responsibility.

But not all participants had the benefit of extenuating circumstances policies, Bethany especially:

> I am coming to the end of my second year at university and I have been told that my course is being terminated because I have failed two of my modules from my first year. Because of this academic failure, I am not

> able to appeal this decision as personal circumstances are not taken into account.

Bethany *did* have mitigating circumstances, but the panel chose to withdraw her from her course of study. At her university, performing ‘badly’ in assessments cannot be excused by mitigating circumstances, and an extenuating circumstances request *must* be submitted within two weeks of the deadline or examination if it is to be valid. At some universities, autism is overlooked as a mitigating circumstance, if additional support is in place, or if arrangements have been made for the student (for example, additional time on an assignment, or a separate room for examinations). In some cases, this leads to withdrawal from the programme of study. Wessel et al. (2009) reported only 53% of *all* disabled students are awarded their degree and Barnard-Brak (2010) attributed this relatively low figure to a low degree of understanding on the part of the awarding university. There is very little consistency between universities’ continuation policies. Reflecting on her son’s transition to university, Stewart (2018) described how her son, who had failed *all* first-year modules, was invited to repeat the year. The consequences of autism are context specific.

Above, I outlined how some autistic individuals can fail to meet prescribed deadlines (i.e. the student who restarted their essay shortly before the deadline). The focus now shifts away from extenuating circumstances policies towards methods of assessment, and in-class activities. Expressly, I am interested in the stress responses these activities can illicit in the autistic learner. Presentations were difficult for Lucinda, and she described the overwhelming corporeal experience of profound stage shyness:

> Presentations were […] terrifying, both group and individual, I've always had difficulty with presentation, even when I'm comfortable with the audience and my group, I stutter, hyperventilate, shake and tend to talk quite fast in order to get it over with.

This anxiety was not universal. Other participants were less anxious about delivering presentations, despite, in some cases, prior reservations. Philip expected not to be able to present well, because social communication was a weak area for him, in common with any autistic person (Wing et al., 2011). But social communication, in conversation with small groups of people, differs from presentation work. Boundless (2019) differentiated between public speaking and conversation:

> Public speaking is the process of speaking to a group of people in a structured, deliberate manner intended to inform, influence, or entertain the listeners. Conversation is a form of interactive, spontaneous communication between two or more people who are following rules of etiquette (Boundless, 2019: n.p.).

Some people feel comfortable delivering a ‘monologue’ before an audience, with little to no expectation of social interaction, but might struggle to communicate well with others in a ‘dialogue’ and conversely, many people are happy to hold a conversation, but would shy away from delivering a speech or a presentation or performing for an audience (Winter, 2015). Philip expressed his surprise at how well he performed in presentations, ‘when I came to university I thought I would really struggle in group work and presentations, both of which required good communication. But surprisingly I've been pretty strong in both cases’. Thus, not all autistic students struggle to deliver presentations; some participants welcomed the opportunity to present their findings to a group and performed well in these tasks. But for others (notably Lucinda), presenting for an audience was a terrifying ordeal. For some autistic learners, the interplay of autism and the method of assessment *is* an extenuating circumstance. Many autistic students perform better in coursework than under test conditions, or working on collaborative projects, or delivering oral presentations.

BTEC qualifications hold a certain appeal for autistic learners, these are wholly assessed by coursework, as Michael identified, ‘One of the biggest things for me about media, one of the biggest things about doing a BTEC, you know, was that it’s all coursework, no exams’. Many autistic individuals struggle under test conditions and can underperform in examinations due to exam anxiety (National Autistic Society, 2016a), and the opportunity to attain a qualification without an examination is a welcome one. At GCSE level, it is more commonplace for pupils to be assessed by means of a written examination, ‘GCSEs, AS and A levels are assessed by exam, except where there are essential skills in a subject that can only be assessed using non-exam assessment’ (Ofqual, 2017: n.p.). This is the norm for the autistic student in secondary education, but other methods are in use in FHE. Michael was not alone in his preference for coursework, nor was he alone in his discomfort under examination conditions.

Lucinda reflected on how she had been assessed at university via oral examinations, and presentations, how during her four-year college education, she had only been assessed by written coursework, and how difficult this upsetting change was to manage. I half-jokingly commented, ‘My goodness! Oral assessments, that truly could not have worked out less in your favour, from how you describe yourself and difficulties in this area!’ Lucinda had previously written to me at length about her fear of public speaking. She responded, ‘I know, there’s me thinking it would be all about assignment writing, which I believe I do quite well, based on previous results’. Standard assessment procedures are inconsistent, from one level of education to the next, and at AS/A level and in higher education, from one module to another. The individual, or individuals, responsible for designing each module choose the method of assessment. Learners who have recently graduated college, having completed a BTEC, or other coursework-based qualifications (for example, art), will be unprepared for this wide variety of assessment procedures, and for an autistic person, this is not ‘only’ a change, this change is not for the better, and that can be overwhelming.

Alex noticed discrepancies between phase tests and end-of-year examinations, ‘the end of year exams I get a separate room but the phase tests are a bit more erratically arranged so usually I have to do them in a computer lab with other people’. Possibly because phase tests are relatively minor assessments, administered outside the examination period, Alex’s lecturers did not book a separate room for Alex, and for some of his assignments, he depended on re-sits to pass. He took one test under ordinary test conditions and failed with 9%. He re-sat the examination at home and passed with 75%. Alex felt this extraordinary improvement was due in no small part to his working environment. From another candidate breathing deeply, to a bird flitting past the window, there was much to distract Alex from his examination during phase tests, and his concentration waned, which was subsequently reflected in his results.

Alex was hospitalised with abdominal pain, brought on by the stress of assignments, 'I was hospitalised with severe stomach ache and bleeding about two year [sic] ago, I never thought at the time it was due to the stress of a math based uni assignment' and phase tests, which are *formal* tests and contribute to the candidate's overall GPA, 'I get bad stomach aches/medical problems before these kinds of exams also'. If Alex is becoming ill, not with common nervous loose bowel movements but medical complaints resulting in admission to hospital, if he is failing with 9% on an examination which he could pass with 75%, phase tests are unsuitable for his needs and phase tests ought to be suitable for the candidate's additional needs (Irwin and Hepplestone, 2012). For Alex, as for Lucinda, the extenuating circumstances here were in the interplay of autism and the method of assessment.

7.7 Preparing students for the transition

Capozzi (2019) advised autistic school pupils, and their parents, to begin transition planning as early as possible, with the pupil's input and preferences given due consideration. At this 'historical moment when students with autism, with their great promise as well as their great needs, are arriving on college campuses in great numbers' (Hurewitz and Berger, 2008: 113), beginning the process early and building partnerships between schools and colleges can shape an autistic learner's educational trajectory. My findings support this; Michael reflected on how his educational support assistant, assigned to him at school, had supported him in admissions interviews and accompanied him on pre-entry campus visits.

Research indicates autistic school-leavers are not always on an even footing with NT school-leavers, which supports the call for early transition planning. NT pupils develop key social skills, including compromise and negotiation, and building social networks, by participating in extra-curricular activities (Turnbull III et al., 2003). These opportunities are relatively limited for the autistic pupil. It may be the pupil has a poor self-concept and 'chooses' to exclude themselves from these activities (Wagner, et al., 2007). Of all disabled people, Wagner et al. (2006) concluded autistic people were the least independent and research from the U.S. Department of Education (2007) indicates many autistic young people also struggle with self-advocacy, which is a key skill in the transition to FHE. Pre-entry campus visits and support with college applications are *useful* but there is a bigger picture; there are gaps in the skill sets of some autistic school-leavers, which are possible to plug.

Research indicates freshers' week can be overwhelming for autistic students and autistic prospective students need ample opportunity to familiarise themselves with the college or university campus in advance of freshers' week (Madriaga, 2010; Madriaga et al., 2008; Sims, 2015). Students are expected to memorise new names, and unfamiliar faces, and to an autistic person with prosopagnosia or 'face-blindness', this can be an almost impossible task. Prosopagnosia is not exclusive to autism, but the condition is co-morbid (Bogdashina, 2015). Students must also familiarise themselves with at least one large and unfamiliar campus, and with topographical agnosia (difficulties with wayfinding) effecting approximately 33% of individuals with Asperger's Syndrome (Copley, 2011), a new university can be disorientating. The difficulties of prosopagnosia and topographical agnosia are not particular to freshers' week (they will be present whenever the student arrives on campus), but visiting the campus in advance, as often as necessary, will be a 'head-start', 'I think what made [freshers' week] so hard for me [as an autistic student] is the fact that absolutely everything is new- the people, the places, the atmosphere, the expectations and the responsibilities' (Fantoni, 2016: n.p.).

Some autistic prospective students will also be subjected to sensory overload, particularly during freshers' fair:

> I walk into the society fair and they crammed all these societies in a little room ...I walked-in. Oh ******* hell, I got to get out of here! There was all these mad people in there. It was like students bouncing off the walls. I felt like I could hit somebody in a minute. I cannot be dealing with this! I don't like big crowds of people ['Alan' in Madriaga, 2010: 43, sic.]

Lucinda reflected on welcome week, which she was expected to navigate without support, 'During welcome week I did not have a buddy, so I attended all the activities on my own, which from my previous emails [detailing social anxiety] you can imagine was quite daunting for me'. Lucinda had specified the need for a buddy with disability services, but no support had been arranged for that week. Two institutional forces are at play here, interacting with Lucinda's Asperger's Syndrome and its attendant social anxiety; the absence of a pre-freshers' week event for autistic prospective students, and the unspecified circumstances which prevented disability services from providing a buddy as agreed.

Some autistic students will not have their support in place during freshers' week, or for several weeks afterwards. UCAS (2019) (the Universities and Colleges Admissions Service) and Student Finance England (2019b) advise prospective and continuing students to apply for Disabled Students' Allowances funding as early as possible. An application for DSAs can take up to six weeks to process, and it can take up to 14 weeks for support to be put into place (GOV.UK, 2019b). The process can be much quicker, depending on whether a needs assessment needs to be carried out, whether support is ongoing from previous years, and whether the applicant has provided all the necessary evidence. Some autistic students might not receive the support they need during those turbulent and uncertain first weeks, choosing to conserve their allocated contact hours for the second or third semester. Funding for interim support is available in some cases (if the student requires support *before* funding is approved), but the hours of interim support provided will be subtracted from the overall contact hours awarded. If a student is awarded 25 hours of support, for example, but they have used five hours of support *prior* to this award being confirmed by the funding body, they will receive *20* more hours of support.

Frank spoke of the value of giving prospective students information ahead of freshers' week, of 'giving students essential information, broken down into manageable bitesize chunks, before the absolute information overload of freshers' week'. Andrew also reflected on the information overload of freshers' week, 'they did give us a lot of information, it was a lot to take in, it helped that they spaced it out over a week'. The idea of giving autistic students access to essential information ahead of freshers' week, and the opportunity to familiarise themselves with the college or university campus in advance is not new. Sims' (2015) work on autism and transition in higher education highlighted the need for 'pre-entry orientation events', drawing on Gardner et al. (2012) and Hastwell et al. (2013). These events are an opportunity for incoming autistic students to familiarise themselves with the campus, and for the relevant staff to give autistic students all the necessary information, before most new students arrive on campus for freshers' week.

Frank also organised three-day residential visits for autistic prospective students, giving them the opportunity to experience living independently in halls of residence, in a secure environment with support and advice readily available. Student representatives and staff deliver talks, to introduce the features of the university, what will be expected of them and what they could expect from the university. Travelling in groups, prospective students are tasked with using public transport, visiting an inner-city supermarket and purchasing ingredients for a specified evening meal on a budget (subsidised by disability services). The groups of students are expected to follow a set recipe and work collaboratively to prepare a meal. These residential visits and activities are beneficial to incoming autistic students, equipping them with the social skills, and independent living skills, needed for living in halls of residence (Lei et al., 2018). But these events were not available at all universities. Lucinda, Andrew and William, for example, were not given the opportunity to participate in three-day residential visits (residential visits began in the 2019-20 academic year). Living independently can be challenging wherever a prospective student is based, and whichever university is their confirmed choice, although this will vary from person to person.

7.8 Conclusions

My findings indicate an interplay between autism and institutional forces, social life and the physical environment. Much of the focus of this chapter has been on policy, and how policy can, by its absence or its presence, exclude autistic individuals from FHE. I outlined above how mitigating circumstances policies (whether for a disciplinary offence or 'failing' to meet a prescribed deadline) can be a salvation for autistic learners, and how, in cases where autism is *not* covered by mitigating, or extenuating, circumstances policies, students can be withdrawn from their programme of study. The implementation, or non-implementation of policy (for example, organising pre-entry residential visits, or failure to provide a support assistant for an orientation event) can ease a person's educational trajectory or cause unnecessary discomfort to the autistic prospective student at what is already a fraught time. In some cases of discontinuation or involuntary withdrawal from the programme of study, the autistic person may not be fully liable for the outcome. In some cases, policies might have been implemented (or *not* implemented) which fail the autistic learner and fail to take account of the needs of the autistic person. Re-centring 'the problem', in line with the social model of disability (Oliver, 1983; UPIAS, 1976) in some cases, it is not *autism* which has led to the student's voluntary or involuntary withdrawal from their programme of study but *policy* or the lack thereof.

The built environment can be overwhelming for autistic individuals living with sensory hypersensitivity. Lighting (i.e. fluorescent lighting) can be too intense, and overcrowding is an uncomfortable experience for some autistic learners. The size of a college, and a university, relative to the size of an average secondary school, in conjunction with topographical agnosia, can impair the autistic person’s facility to navigate their physical learning environment, highlighting the need for pre-entry campus tours, residential visits and ‘unofficial’ visits, giving autistic individuals the opportunity to familiarise themselves with the layout of the campus. Some colleges and universities have launched ‘safe spaces’ for autistic students. Madriaga (2010) expressed concerns that spaces designed exclusively for autistic individuals are tantamount to ghettoisation, but if autistic individuals are not excluded from mixed spaces, and can ‘choose’ whether to access autism-specific spaces, this is segregation by the autistic person’s ‘choice’, and it is a workable alternative to widespread changes to the built environment and how communal areas of the university are organised.

The social life of the college or university, and social anxiety, can lead some autistic individuals to produce coursework without consulting their lecturer or tutor, or attending the preceding lectures or seminars. Some participants feared infantilisation or asking a ‘stupid question’, cautious of giving the impression of ‘low’ functionality. Overall, their fears were unfounded, but some are socialised into this fear from an early age. ‘High-functioning’ autistic individuals learn *differently* to typically developing peers; often explicit information is needed, in common with profoundly autistic individuals living with GLDs. Any ‘gaps’ in the autistic person’s knowledge can be met with incredulity. To avoid any association with individuals with GLDs, some autistic learners ‘choose’ not to approach their lecturers. Some lecturers presume incompetence, others presume competence, relying on student-led grouping strategies, when not all students (for example, Lucinda) feel confident choosing a group for a collaborative project independently. Neither presuming incompetence nor competence is productive.

My findings highlight the need for flexibility in the education sector. Not every method of assessment will suit every candidate; individuals who are neurologically typical will fare better in some assessments (for example, examinations) than others (for example, coursework). But some methods can cause some autistic people to become *ill*. Alex was hospitalised with the stress of ‘a math based uni assignment’. When Lucinda delivers a presentation, ‘I stutter, hyperventilate, shake and tend to talk quite fast in order to get it over with’. Fahim reflected on belonging to an autistic students’ society. The group leader planned activities on behalf of the members, without due consideration for the needs of the intrinsically diverse group. Flexibility, and consultation, facilitate the best possible outcome for the greatest number of people.

Chapter 8: Conclusions

8.1 Introduction

I interviewed 42 autistic students enrolled on further or higher education programmes (from a level one qualification in visual arts to a post-doctoral position in oncology) in the West Midlands, the East Midlands, Yorkshire and Tyne and Wear. I reflected on an eight-day sociology conference, using Goffman's (1963) work on covering as an analytical framework; I had been prepared to disclose information about my diagnosis to others but self-presented as near-NT. My educational trajectory was an insight into transition proper, and, as my brief auto/biographical reflection at the beginning of this thesis illustrates, the transition from my *alma mater* to a second university was turbulent. I drew upon these difficult memories when defining, and refining, my research topic, and analysing my data. Hammersley and Gomm (1997) advise against adopting a political stance and an 'active commitment to some other goal than the production of knowledge' (Hammersley and Gomm, 1997: 51), to prevent bias and error. But Letherby and Bywaters (2007) countered, 'no research, no process of knowledge production, can be free from ideological influences: research is unavoidably political' (Letherby and Bywaters, 2007: 8). I can make no claims to objectivity, given my close proximity to the subject, but any researcher making claims to objectivity does so quixotically or under false pretences.

In this chapter, I will ground the intra-communal hierarchy of impairment (the idea that profoundly autistic individuals are 'less than' 'high-functioning' autistic individuals) and my four degrees of openness (the extent to which the autistic person is willing to disclose information about their diagnosis and the circumstances under which they are prepared to do so) in literature and theory, with a focus on the relevance of each for this thesis and my findings, and the impact this can have on autistic students in FHE. I will then propose further research. My research has addressed *a* gap, introducing autism to the socio-political arena from which it is often excluded and engaging with the hierarchy of impairment in innovative ways, combining Tringo's (1970) theory of the hierarchy of preference for disability groups and Bathje and Pryor (2011) and Sharp et al.'s (2015) ideas around endorsed stigma, but there are gaps yet to fill.

I propose future research with a view to addressing these gaps as an early career researcher, or 'passing the baton' to other established researchers. With a background in public policy, and a very personal relationship with the topic, both as an autistic researcher and as someone with experience of transition, I outline strategies for influencing policies (for example, transition policies). I defend my position that therapies and treatment programmes ought not be exempt from sociological analysis, and end the chapter (and thesis) with a 'call to action', a plea to autistic self-advocates to challenge the intra-communal hierarchy of impairment, it is a plea to *any* party in a position to facilitate autistic students' inclusion in social life and in education. It is a plea for unity and togetherness. Action is needed, and must continue, until no autistic person languishes at the bottom of the arbitrary hierarchy of impairment.

8.2 Grounding the intra-communal hierarchy of impairment

Conditionality shapes the autistic individual's educational trajectory, self-concept, relationships with others (social life) and self-presentation. Conditionality perpetuates the hierarchy of impairment and the intra-communal hierarchy of impairment. Conditionality is the default, the 'common sense' model, to which the autistic person is often subscribed pre-diagnosis. In inauspiciously categorising profound autism as *low-functioning* autism, clinical practitioners perpetuate the intra-communal hierarchy of impairment (Flynn, 2018). In separating profoundly autistic, and moderately autistic, pupils from typically developing and marginally autistic pupils, parents and educators perpetuate the intra-communal hierarchy of impairment (Rogers, 2007). The use of vocabulary inextricably linked to GLDs (for example, 'mong' and 'retard'), standard playground insults, perpetuates the intra-communal hierarchy of impairment (Clark, 2011; Turner, 2017).

Extricating oneself from the hierarchy of impairment is an extraordinary feat. Autism can be tolerated (‘tolerated’ is deliberate here, to reflect its status as ‘lesser’, a burden) in the self and in others on the condition of its minimisation (James, 2015; Scarantino, 2018). Non-autistic individuals, and NT individuals, are willing, on the whole, to sustain an interpersonal relationship with an autistic individual, on the condition of its distance (Gardiner and Iarocci, 2014; Gillespie-Lynch et al., 2015). The autistic learner is welcome to embark on FHE, on the condition that their behaviour is compatible with the code of conduct of the establishment (National Autistic Society, 2019a). The autistic person can celebrate their Autistic Self, on the condition that their Autistic Self is ‘only mildly’ autistic (Scarantino, 2018). Profound autism in others is met with an embarrassed disassociation (distancing), ‘autistic, but not as bad as that’. The participants exhibited no explicit hostility towards profoundly autistic others. But there was an eagerness to position oneself ‘favourably’ in relation to profoundly autistic individuals.

The intra-communal hierarchy of impairment, the hierarchy of impairment perpetuated by, in this instance, ‘high-functioning’ autistic students against relatively profoundly autistic students, is not present in the literature (this is a gap in the literature, which this thesis has begun to address), but it *is grounded* in the literature, notably work by Bathje and Pryor (2011) and Sharp et al. (2015), and in my research findings (my interviews with Hannah and Neil in particular). My socio-political identity as an Autistic person led me to the intra-communal hierarchy of impairment, masking is incompatible with my Self. Distancing is incompatible with my Self.

‘Progress’ is tainted by guilt; in self-presenting as ‘high-functioning’ or ‘asymptomatic’, I fear I have somehow implied that autism is ‘lesser’, that my Self is ‘lesser’, that ‘normalcy’ is the ideal (I explored these themes in chapter 2). My friendships with individuals with moderate GLDs led me to the intra-communal hierarchy of impairment. If ‘high-functioning’ autistic individuals, and students diagnosed with Asperger's Syndrome are 'autistic *but not like that*', I wondered, what of individuals who are '*like that*' (Flynn, 2018)? Why, I questioned, has the idea of autism as 'less than' permeated the thinking of socio-politically Autistic individuals (Morris, 2008)? Those who most closely fit the stereotype of 'the autistic person' are discarded at the bottom of the intra-communal hierarchy of impairment, a hierarchy which cannot be dismantled until it is challenged. What follows is a brief review of the literature of which my ideas were born. I have outlined some of these studies, theories and commentaries previously but not for this purpose.

Rogers' (2007) work on the hierarchy of impairment inspired my thinking on the intra-communal hierarchy of impairment. Rogers (2007) interviewed parents of children diagnosed with SEBDs and GLDs. Some parents reported a reluctance to register their child with a special educational needs school, whilst this might have been in their child's best interests. Visiting the units, parents observed more profoundly disabled children in this specialised learning environment, and were anxious their behaviours, their learning delays, might 'rub off' onto their child. These parents were hopeful their child was 'not as *bad* as' the profoundly disabled children in the unit and could progress by association with typically developing peers.

The intra-communal hierarchy of impairment complements Rogers' (2007) research, bringing the hierarchy closer to its centre, to how disabled individuals, less so their support network (for example, parents and caregivers), perpetuate it. Siblings (Snow, 2015), authors of child and adolescent fiction (Meyer, 2013) and other disabled individuals (Deal, 2003) have also been noted to perpetuate the intra-communal hierarchy of impairment. Some groups of disabled people set themselves against other groups of disabled people, reluctant to be associated with individuals with GLDs, SEBDs, and/or mental ill health. This is an intra-communal hierarchy of impairment, but it differs from the hierarchy I propose. My intra-communal hierarchy of impairment is perpetuated *by* autistic individuals *against* autistic individuals, mine is inextricably linked to the idea of autism as a spectrum, to functionality labels. Hannah, Neil and Philip had all espoused the hierarchy of impairment, each making some reference to 'mild' autism, positioning themselves favourably in comparison to individuals living with profound autism.

Oliver (1990b) confronted the separatism which hindered the formation of the disabled people's movement he envisioned. Different groups of disabled people can have conflicts of interest, where the needs of one group conflict with the needs of another group in 'incompatible' ways, unnecessarily 'pitting' one group of disabled people against another for a time. For Oliver (1990b), and this has been a source of confusion, disabled individuals could shift their focus from impairment to disability, fortifying the disabled people's movement as a unit. The focus on the physiological distracts from the socio-political. Extending the example above, the disabled people's movement is not 'wheelchair users *versus* individuals with visual impairments' but 'disabled people versus restricted access to social life and the built environment'.

Oliver's (1990b) work inspired mine, the separatism of 'high-functioning versus low-functioning' weakens us. We are *all* vegetables (inspiring pity) and supercrips (inspiring awe); the 'and' is deliberate. I am almost simultaneously a supercrip and a vegetable. I function well in university settings; I am a PhD candidate. In this context, I am a supercrip. 'Inspirational'. At the road's edge, in a city centre, Steve clasps my hand. 'Come this side of me', he will warn, as an intimidating youth eyes my laptop. He retrieves a poncho or raincoat from his bookbag and robes me in it, fastening each popper with care. In this context, I am a vegetable. We are *all* infantilised, 'high-functioning' or 'low-functioning'. We are *all* less likely to gain meaningful employment. The vegetable/supercrip dichotomy, infantilisation, and exclusion from the labour market, are most usefully read as *disabilities*. GLDs, sensitivities, and behavioural and emotional dysregulation are best identified as *impairments* (Oliver, 1983). Impairments are not universal. The intra-communal hierarchy of impairment redirects the focus from universal experiences (for example, exclusion from the labour market) to non-universal experiences (i.e. GLDs), hindering our progress as a movement. This is one function of disabled students' societies, such as the society in which Christina took an active role.

Work by LGBTQIA+ thinkers on the 'straight-acting' gay man was a point of reference for me (Al-Kadhi, 2018; Myers, 2013; Stehle, 2018). There is no direct comparison, but the narrative around 'straight-acting' gay men was 'food for thought'. I share this here to allow the reader to trace my train of thought. The 'straight-acting' gay man is a *feminine* gay man, who self-presents as masculine. I stress the 'feminine' here to distinguish between 'straight-acting' and masculine gay men. These men are not passing for heterosexual, these men are not closeted (Myers, 2013). These men are known to be gay men, but the idea of 'acting straight' is to be inconspicuous, to seek to be complimented on their act, to receive the compliment, 'I would never have realised you were gay'. For Joel, 'positive comments […] included people saying how I had nothing to be embarrassed about and many even how they would have never guessed me having the disorder without me telling them'.

These men are covering (Goffman, 1963), happy to share information about their sexual identity with others but reluctant to conduct themselves in a manner they imagine to be consistent with this. The act dictates to the man his taste, habits, behaviour and style. He specifies 'straight-acting only' on his online dating profiles. He alienates and distances himself from feminine-presenting gay men, perpetuates homophobia, and ridicules the feminine gay man. It is at this point that 'acting straight' becomes a cause for concern. Feminine-presenting gay man Myers (2013) challenged the masculine ideal:

> Whether we're carefully arranging ourselves into 'tribes' or behaving in a more traditionally masculine way to avoid 'standing out', we just want to belong, even if it means we have to alienate or deny the existence of everyone else along the way (Myers, 2013: n.p.).

Developing the intra-communal hierarchy of impairment, the parallels with NT-presenting autistic individuals, particularly NT-presenting autistic individuals who were prepared to share information about their diagnosis with others, were stark. There is no clearly defined NT taste, but there are mannerisms and patterns of speech which the NT-presenting autistic individual can mimic effectively (for example, Ryan, 2018):

> I wanted to be more like [neurologically typical film and television characters] than myself. I saw the way that they were revered and admired. So I carefully studied how they spoke, the way they dressed, and carried their bodies. I strove to stand out and—simultaneously—fit in (Ryan, 2018: n.p.).

The alienation might not be explicit, but there is some implicit belief that individuals who ‘fit the mould’ (individuals who more closely conform to the ‘autistic’ stereotype) are ‘less than’, as ‘straight-acting’ gay men are complicit in the misconception that gay men who ‘fit the mould’ are ‘less than’.

Bathje and Pryor (2011) and Sharp et al.’s (2015) work on endorsed stigma also shaped the intra-communal hierarchy of impairment. Endorsed stigma can be defined as the endorsement of stigmatising views of the stigmatised person’s *own community* (or ‘community’). The stigmatised person may or may not espouse this view of *themselves*. Philip, for example, reflected on how ‘when I came to university I thought I would really struggle in group work and presentations, both of which required good communication. But surprisingly I've been pretty strong in both cases’. He had endorsed the view that presentations are generally a weak area for autistic individuals, but discovered he was an exception to this broad rule.

8.3 My four degrees of openness; my original contribution to the field

Goffman (1963) identified how ‘There are important stigmas […] which require the individual to be carefully secret about his [sic] failing to one class of persons […] while systematically exposing himself [sic] to other classes of persons' (Goffman, 1963: 93). Goffman's (1963) work is a product of its time, 'failing' is best read as 'stigmatised identity'. For Goffman (1963), most stigmas (however visible or invisible) are known to some but not to all, and this is reflected in my four degrees of openness. Some of my participants were more willing to disclose information about their diagnosis to peers and teaching staff than other participants, and the circumstances under which my participants were willing to share this information varied along a four-point scale, which I named my degrees of openness.

My four degrees of openness is grounded in the work of Goffman (1956; 1963), and Olney and Brockelman (2010), their work on the presentation of self and the related concept of perception management strategies respectively. Kanuha's (1999) work on stigma (and how non-disclosure did not *necessarily* indicate self-stigma) was also influential here. Not *every* decision a stigmatised person makes is connected to stigma, as not *every* decision a disabled person makes is linked to disability (Oliver, 1983). My four degrees of openness concerns the situations in which the person with a stigmatised identity will see self-disclosure as an appropriate course of action. It ranged from indiscriminately open (Joel, who actively and immediately identified his condition to others) to indiscriminately reticent (Kevin, who deliberately kept his condition, and information about his diagnosis, from staff and other students), and incorporated openness if relevant (Ashley, who chose to defer disclosure until autism was introduced in conversation) and openness if necessary (Katrina, who disclosed information about her diagnosis if necessary, i.e. to diffuse an awkward moment).

My four degrees of openness is an original contribution to sociology, and it is central to my research. The extent to which the autistic learner is prepared to 'come out' can affect their access to support (and consequently their academic outcomes) (Anderson and Stephenson, 2017) and the likelihood of stigma (Chambres et al., 2008; Matthews et al., 2014; Sasson and Morrison, 2017). Without the necessary supports in place, the autistic student risks withdrawal from their programme of study. The transition to college or university is challenging for the autistic student, adjusting to independent living (Glennon, 2001), changes in routine (Gillberg and Gillberg, 1989), and an unfamiliar learning environment (Copley, 2011). Unsupported, some autistic students will not meet the prescribed academic standards. Without support, some autistic students will behave in ways which contravene the college or university's code of conduct, overwhelmed by the enormity of the task of transitioning to FHE. But access to support demands a degree of openness with which not all autistic students in FHE feel comfortable.

The focus now turns to the interplay of the hierarchy of impairment and the intra-communal hierarchy of impairment with the extent to which the autistic student is prepared to share information with others about their diagnosis, and under which circumstances they will 'come out'. The hierarchy of impairment, and intra-communal hierarchy of impairment, effected some participants' perception management strategies, irrespective of their position on my 'four degrees of openness' spectrum. I identified Joel as indiscriminately open, but he had internalised the hierarchy of impairment, using disclosure in the early stages of a working relationship to give lecturers advance notice of his 'weaknesses'. In volunteering information about his diagnosis, he was *warning* staff that he is autistic and positioning autism as a problem. Where participants have been identified as open if relevant, some perpetuated the intra-communal hierarchy of impairment in a similar way to Joel. Sharing information about the diagnosis with others, whether disability services (Philip) or other students (Lucinda) was presumed to be superfluous in 'milder' cases.

Some participants who were identified as open if necessary withheld information about the diagnosis from others, using disclosure as a 'last resort', opting in the first instance to function as neurologically typical. To some, it is objectively 'better' to be mistaken for neurologically typical (Robert), and for one participant, Tom, this was a challenge or a game, the aim of which was to self-present as neurologically typical without an incident which warranted ‘coming out’, losing the game in the event of any such incident. Finally, the hierarchy of impairment, and intra-communal hierarchy of impairment, shaped Kevin’s perception management strategies and his decision not to disclose information about his diagnosis until exceptional circumstances dictated (his tutors received this information from external sources). For Kevin and, he feared, for his tutors, ‘less is more’.

I plan to publish a research paper on my four degrees of openness. I will contend that it is possible for the autistic person to resist stigma and self-stigma, and challenge the misconception that, where an autistic individual is silent about their diagnosis, this is a response to stigma or driven by self-stigma (Kanuha, 1999; Olney and Brockelman, 2010). Non-disclosure is not evidence that autism is ‘less than’, nor is it evidence of the autistic person having internalised this view of their condition. Some autistic individuals *are* indiscriminately reticent, and whether this self-imposed silence is led by self-stigma, anticipated stigma, or relatively poor employment opportunities (National Autistic Society, 2016b), the root cause of this is always *social*, and worthy of sociological attention and analysis, I will propose in the planned paper, with a view to eventual social change.

8.4 Suggestions for further research

Future research projects could be directed towards learning more about the prevailing narrative of autism as ‘less than’, how best to challenge this narrative, and the privileges which the ‘high-functioning’ label confers. The proposed research would empower more autistic individuals to be their authentic, Autistic self, give more autistic individuals ‘permission’ to take pride in their autism, and improve more autistic graduates’ career prospects. The financial commitment and emotion work of FHE would then pay dividends in the labour market; 68% of autistic individuals are unemployed (National Autistic Society, 2016b).

Huseyin (2017) cites joy, kindness, humility, equanimity, non-attachment, trust, tranquillity, courage, discipline, autonomy, wisdom and integrity as key personal qualities. Aside from joy[63], wisdom is the only personal quality which has been medicalised. Using another personal quality as a point of reference, a deficiency of creativity is not grounds for a medical diagnosis. If wisdom (or 'intelligence quotient') is lower than the socially prescribed norm, a person can be diagnosed with GLDs. This is symptomatic of over-medicalisation (Oliver, 1990a), leading to the (intra-communal) hierarchy of impairment with individuals living with GLDs consigned to the lower reaches of society, and this hierarchy goes largely unchallenged. Future work could explore this further and potentially, this work could lead to a solution.

What are the features of the *ideal* college, the *ideal* university, for the autistic learner? How might the ideal be realised? In cases of misconduct, immediate withdrawal from the programme of study is one possible outcome of the ensuing disciplinary hearing. Might future research explore the possibility of transferring offending students to a distance learning programme, as an alternative to withdrawal (the student with SEBDs would not be excluded from FHE, but there would be no risk to university property or other learners)? My research, for the most part, is limited to autistic individuals who *did* disclose their diagnosis (I relied on disability services and non-medical helper Steve to act as gatekeepers). If students are choosing to self-present as NT (or near-NT), if students are passing, or covering, which strategies have these students developed to maintain their self-confidence, and their self-identity, who can support these strategies, and how?

The current study focused on autism and transition *into* FHE, but more research is needed into the transition *out of* FHE (Vincent, 2019). The final year of a person's education is difficult; the student is perfecting their thesis, researching job opportunities, preparing to withdraw from education (having entered the system at four or five years of age) and confronting the realities of

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[63] I refer here to clinical depression.

parting company with good friends. At the time of writing[64], I am 35 years old. At four years old, in January 1990, I was admitted to reception (in the 1989-90 academic year, entry to primary education was graduated, pupils would be admitted *only* if their fifth birthday would fall in that semester). A month-long leave of absence, as I recovered from a head injury, aside, education is *all I have known for 30 years.* Writing a thesis is challenging, but autism compounds these difficulties, for the autistic candidate writing for a neurologically typical audience, an autistic candidate who might shoehorn tangential topics into the thesis, an autistic student with co-morbid dyslexia, and poor time management. I have little opportunity to expand my social circle at the University of Bradford, or my SCONUL host university, but the prospect of parting company with my supervisors is harrowing. I once presumed a PhD would 'compensate' for my diagnosis in the labour market, but my imagined future is unfulfilling, and bleak, and work seems a fanciful dream, a possibility, but a distant possibility.

Thus, whilst for *any* person, graduating from FHE and applying for jobs can be intimidating, for an autistic person, these anxieties can be compounded by a 'fear of the unknown', or the 'insistence' on sameness (National Institute for Health and Care Excellence, 2016) leading to a sense of loss (Vincent, 2019). Some universities have introduced programmes to prepare autistic learners for the workplace (Hurley-Hanson et al., 2019) but there has been no 'roll out' of these programmes. I have worked closely with Steve since September 2003. Steve has been an advocate, a guardian, he has chauffeured me to, and from, my *alma mater*, my second university, the University of Bradford and my SCONUL host university. He will network with others on my behalf, he facilitates my social life, prompts me to eat, crosses me over the road, monitors my social media and warns me not to meltdown. But support from a non-medical helper is conditional on the client's continuation in FHE, or in a postdoctoral position. If I am not offered a postdoctoral position, I will be expected to navigate social life unsupported, and function 'independently'.

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[64] I submitted the thesis for examination in 2019, it is now 2020.

Likewise, Michael was not in the final year of his course at interview, but he too was troubled by his prospects, and chose not to contemplate them, ‘I tend not to think about the future too much, it scares me’. Hudayfa voiced similar concerns, he was in the final year of his degree at interview, he *was* thinking of his prospects post-graduation, and the realities of job interviews and *holding down* a job with autism. Further research is needed to explore how autistic learners navigate these difficult feelings and scenarios, how it might affect autistic final year students’ educational attainment and if there is something to be done to remedy this. Finally, there are some autistic individuals who cannot participate in FHE, as it is currently organised, and other autistic individuals who *could* participate in FHE but do not feel able to do so. What can be done so autistic individuals with complex needs feel able to participate in FHE, and which provisions can be made for autistic individuals whose needs cannot be met in FHE settings?

8.5 Exacting change and influencing policies

I am not satisfied to *acknowledge* the stigma attached to profound autism, to autism overall. It contravenes my Self to trespass into the research field, observe from a distance and withdraw from the field with a PhD to my name, the sole beneficiary of my work. To withdraw from the research field without ‘beating a track’, without challenging the injustices I find within it would be inconsistent with my research identity. Paraphrasing Baden-Powell’s (1941) advice in his final address to the boy scouts, ‘Try and leave this world a little better than you found it’ (Baden-Powell, 1941: n.p.), try and leave the research field a little better than you found it. Destigmatisation is possible, under the following conditions:

> the credibility of new constructions, the status and visibility of actors carrying these constructions, the conclusiveness of expert knowledge about stigmatized groups, the interaction between new constructions and existing cultural ideologies, and the perceived linked fate of the stigmatized and dominant groups (Clair et al., 2016: 223).

PhD research alone cannot create these social conditions. But I can challenge social injustice. My research has uncovered a stigma, hidden in plain sight, the stigma of profound autism, conditional 'inclusion' in social life. On a similar note, PhD research can lead to further research, and in some cases, it can directly influence policy if it is disseminated widely and if the researcher collaborates with targeted policy makers. Researchers who choose to disseminate their findings with a view to exacting change, and researchers who plan to work in partnership with policy makers would do well to take heed of Nutley et al.'s (2002) advice (Letherby and Bywaters, 2007; Nutley et al., 2002). To maximise the probability of policy makers and practitioners identifying their work as a credible source and using their study as a guide to best practice, researchers must endeavour to meet the following conditions.

The research must be timely, relevant in the policy context of the time. The supporting evidence should be clearly presented and germane to the policy maker or practitioner's objectives. When choosing a methodology for their project, researchers ought to consider widely recognised methodologies; studies which use innovative methodologies are less likely to influence policies and practices. Research findings must be convenient for the target policy maker or practitioner, reflect present ideologies and must not be contentious. Practitioners and policy makers will cite evidence as an alternative to expert opinion, where expert opinion is not in their favour. Attracting strong support from high-profile advocates would further the researcher's cause. Practitioners and policy makers must view themselves as co-producers of knowledge, there must be solid, palpable benefits during the implementation phase, and it ought to be possible to reverse the policy, should the need arise.

8.6 A note on therapies and treatment programmes

Treatment programmes, especially ABA, demand engagement with socio-political discussion. The clinical is not outside the remit of sociological analysis; it is in excluding the clinical from sociological debate that autism is excluded from the socio-political sphere. Some propose ABA ought to be reserved for profoundly autistic individuals, but this is symptomatic of the (intra-communal) hierarchy of impairment. If individuals living with profound autism ‘should’ be offered therapy to manage their condition, whereas ‘high-functioning’ autistic persons ‘should’ be exempt from ABA, the implication is autism is ‘less than’. The ‘high-functioning’ Autistic individual (nearer to neurologically typical than a profoundly autistic person) can celebrate autism as the foundation of their positive socio-political identity; this is a privilege not conferred to the profoundly autistic person. Many autistic individuals oppose the use of ABA (Gillespie-Lynch et al., 2017). Gillespie-Lynch et al. (2017) compared autistic individuals and non-autistic individuals, with diverse connections to autism, for example, immediate relatives. The autistic participants were less likely to endorse the individual model of disability. In cases where participants approved normalisation methods, including ABA, stigma (including self-stigma) was greater (i.e. endorsement of the view that autism is ‘less than’ and ought to be managed).

Mills’ (1959) sociological imagination is broad ranging, any action, however mundane, can be subject to sociological analysis. Any individual action or behaviour can be understood in a wider socio-political context. At the individual level, a profoundly autistic person is treated using ABA therapy. At the socio-political level, disabled by ‘social conditions’ (UPIAS, 1976), the profoundly autistic person is registered for ABA therapy to promote conformity to social norms; the socially prescribed ‘norm’ is still upheld as the ‘ideal’ for the disabled person (Davis, 1997). Other marginalised groups have abandoned the ‘ideal of normalcy’. This inconsistency leads to ambiguity, ‘treatment’ programmes for other marginalised groups (for example, conversion therapy for those who self-identify as LGBTQIA+ or skin bleaching for Black individuals) are now dismissed as redundant, damaging interventions. These interventions have been introduced to the socio-political arena. Some have challenged ABA therapy, but overall it retains its status as a legitimate treatment programme, promoting normalcy to those for whom normalcy is the ‘ideal’.

8.7 A call to action

To counteract the intra-communal hierarchy of impairment, a sea change is needed. The transformation must be far-reaching, extending beyond the reaches of the autistic 'community'[65] to non-autistic and neurologically typical others. Insults to intelligence must become a thing of the past. Insults to intelligence are a staple of humour, adding 'comedy value' to sketches, situation comedies and stand-up routines (Clark, 2011). Insults to intelligence are a staple of playground bullies; 'mong' and 'retard' share their roots with 'idiot', 'imbecile' and 'moron'. Insults to intelligence serve a correctional function, when disciplining children (i.e. 'that was a *stupid* thing to have done'). To counteract the intra-communal hierarchy of impairment, there must be no social stigma attached to GLDs, no social disadvantage incurred. To challenge the intra-communal hierarchy of impairment, autism must no longer be categorised as a disorder (which would have devastating consequences, i.e. the loss of supports), it must no longer be 'treated' with therapies, including ABA, a practice which rewards 'good' (NT) behaviours, leading patients to model *their* conduct on NT behaviours. This sea change is unrealistic at this time, but in bringing the intra-communal hierarchy of impairment to light, it is my hope that my work makes a tentative first step towards its downfall.

The system is broken and in desperate need of repair. Five participants chose not to attend their lectures. Five participants missing information, some of it, perhaps, key to their assignments, charged a princely fee for tuition they feel unable to access. Lucinda fared well, her absence seemingly of little to no consequence:

> [I]t didn't really affect me much, the module was all about personal and professional development which I'd had some experience in from college […] so I continued my assignment at home and had it checked over with my study skills tutor to ensure I was on the right track (which I was because I got a first so I couldn't of [sic] missed much).

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[65] For want of a better collective noun for autistic individuals.

But Bethany was ordered to discontinue her course ‘because I have failed two of my modules from my first year. Because of this academic failure, I am not able to appeal this decision as personal circumstances are not taken into account’. Neil might have boasted a 100% attendance record, but Alex, Christina, Vanessa, Lucinda and Bethany were regularly absent. Lucinda might have been awarded a first (70% upwards) for her personal and professional development assignment (the assignment set for the module she ‘chose’ not to attend), but Bethany failed two of her modules (40% downwards) and was withdrawn from her programme without appeal. Hannah and Hank might have ‘grown a thick skin’, some measure of resilience, for Hannah ‘well, it’s only three boys [bullying me], so it ain’t so bad’ and for Hank, ‘I’ve learned to just ignore what people think’, but playground bullies left Neil with emotional scarring. Joel might have been happy to share information about his diagnosis with others, ‘coming out’ at every opportune moment, but Kevin had been fearful, ‘coming out’ *only* when a third party ‘let slip’.

I identified Ilyas and Hannah as socio-politically Autistic, to Ilyas and Hannah, autism was not ‘less than’, and there was no reason to assimilate to NT norms of conduct. Robert was less optimistic, ‘No matter if they figured it out right from the bat or not, I didn't make an effort to disclose it to anybody. As I've said before, weird and quirky is better than Autistic in my mind’. This is quite explicit, autism was ‘less than’ in Robert’s opinion. Vanessa might have taken her own life, had her boyfriend not intervened. These conversations with Alex, Christina, Vanessa, Lucinda, Bethany, Hannah, Hank, Neil, Joel, Kevin, Ilyas, and Robert demonstrate what *could* be achieved, and what *should* be achieved. Whilst there are still autistic learners ‘playing truant’ in fear, still autistic individuals ‘in the closet’, still autistic individuals led to self-harm, still autistic individuals who recognise autism as ‘lesser’, still autistic students in the throes of a battle with *themselves* and while student contracts and learner agreements legitimise these battles, the work of the autistic self-advocate, the work of the social scientist, allies, and *any* interested parties, is not done.

But whilst the system is broken, researchers, self-advocates, disability services, mass and social media outlets, teaching staff, administrative staff, the general public, *everyone* has the power and the obligation to repair it. Hannah had a profound impact on me. I was reminded of my younger self. Hannah was unreservedly Autistic; she introduced tangential topics, wore sunglasses in mid-winter to manage her photophobia, ‘came out’ without reservation, and spoke with great fondness for her Asperger’s Syndrome. She had no ‘filter’. Steve oversaw her education and updated me on her progress. Towards the end of level two, Hannah was asked to withdraw from the programme. Level three programmes demand independence, and self-regulation, and support is not permissible at this level. This saddened me. This was an opportunity lost. For the ‘offence’ of choosing not to disguise her Asperger’s Syndrome, for the ‘offence’ of *being autistic*, she did not progress.

Had my mother not defended me in a college crisis meeting, had Steve not represented my interests in three subsequent disciplinary hearings (one in my *alma mater*, two in my second university), that opportunity might have been stolen from me too. Had it not been for an excellent informal and formal support network, the likelihood is, that opportunity *would* have been stolen from me too. What might Hannah have contributed, what might she have gained, had FHE made space for her Autistic Self? What might Bethany have contributed, or gained from her nursing degree, had her extenuating circumstances carried weight? There are times when I imagine an autistic person, withdrawn from their programme of study, for their ‘difficult differences’. I imagine opportunities missed, potential left unmet, contributions left unmade. With education comes an opportunity to contribute. Education is not the *one* route to these opportunities, but it is a valuable resource, for the individual and for society. Without education, job opportunities are limited.

If doors are closed to individuals who cannot, or choose not to, self-present as NT, or near-NT, doors are closed to the contributions autistic individuals can make. How inclusive is ‘inclusive education’, if by its design, autistic individuals are excluded from it, on a voluntary or involuntary basis, withdrawn or withdrawing from the programme of study? Rogers' (2007) work on children diagnosed with special educational needs in integrated settings highlights the artificiality of the word 'inclusion'. Children living with GLDs are given 'permission' to be in the same classroom as typically developing children, but are effectively excluded from in-class activities, and the social life of the school. Holt et al. (2012) described this as 'a scaling down the spatialities of exclusion from large scale segregation into special schools towards micro-exclusions within school spaces' (Holt et al., 2012: 2201). In many cases, 'inclusion' is at best, partial and at worst, rhetoric. It is unlawful for any college or university to treat a disabled applicant unfavourably (Equality Act, 2010), but once autistic students are following a programme of study, they are more likely to voluntarily withdraw from the course (Sternberg, 2013) or be withdrawn from the course (Anderson and Stephenson, 2017), relative to neurologically typical students.

Overall, in this thesis, I have taken a somewhat pessimistic view of masking. To me, masking represents compliance with the view of autism as 'lesser', a rejection of the Self. Self-presenting as near-NT over an eight-day period was a demeaning experience. It seemed I had betrayed my Autistic self. I am not wont to pretence. But masking (or 'masquerading') serves a social function, and I will explore this here. Referring to research participant 'John', a school pupil who chose not to disclose information about his diagnosis with others, and actively passed for NT, Carrington et al. (2003) identified how 'While masquerading is stressful, it provides an opportunity for students like John to avoid the stigma of labeling and 'fit in' with his peers' (Carrington et al. 2003: 20, sic.). Carrington et al.'s (2003) findings supported a subtler social skills training for autistic pupils, observation and mimicry in a mainstream setting, to better promote the interests of pupils who 'masquerade'.

The benefits of masking are reflected in my findings. My participant Neil (who was, to reiterate, a college student at interview) self-presented as NT, he is currently pursuing a degree in art. Christina reflected on *her* masking behaviour, she had masked from an early age and had been rewarded with social inclusion, ‘I've always passed as neurotypical, even when I was younger. I've been able to socialise and been invited to parties a few times’. With masking comes inclusion in education and in social life. Inclusion in social life can improve autistic individuals’ mental well-being. With poor social relationships self-reported amongst young people with Asperger’s Syndrome (for example, low quality ‘best friendships’, which were characterised by hostility and infidelity), individuals with Asperger’s Syndrome are more vulnerable to depression than others (Whitehouse et al. 2009).

These findings are not incompatible with my socio-political identity, nor are they incompatible with my thesis statement. Masking *can* offer autistic individuals inclusion in education and social life. Without masking, without observation and mimicry, autistic people can be subjected to stigma and abuse. At the point of diagnosis, it is not uncommon for the autistic person to seek solace in the hierarchy of impairment, as a coping mechanism, identified as downward comparison (Wills, 1987), to manage the ‘bad news’. But autism is not objectively ‘lesser’. The hierarchy of impairment is a social construction (Rogers, 2007). Autistic individuals are not excluded from the labour market or social life and do not perpetuate the intra-communal hierarchy of impairment because autism is ‘less than’. Autistic individuals are excluded from the labour market and social life and perpetuate the intra-communal hierarchy of impairment because autism is perceived and widely *misconceived* to be ‘less than’. It is a misconception which has permeated the collective conscious. It is a misconception that can shape the way the ‘high-functioning’ autistic person views autism pre-diagnosis. And it is a misconception that can shape the way the ‘high-functioning’ autistic person views their *Self* and others post-diagnosis.

The consequences of the intra-communal hierarchy of impairment are, therefore, broad ranging, effecting not ‘only’ individuals with GLDs but ‘high-functioning’ autistic individuals. With the facility to self-present as neurologically typical comes the expectation that the person will do so. Exhibiting stereotypically autistic behaviours ‘relegates’ the person to a ‘low-functioning’ status, if only temporarily, with its attendant loss of privilege, the equivalent of ‘messing up’ (Goffman, 1961). To be ‘high-functioning’, the Self must be muted, the Self is ‘bad’. Camouflaging comes at a cost (Russo, 2018), camouflaging can render a person physically and emotionally exhausted from the strain of near-continuous scripting and monitoring their conduct, ‘correcting’ minor quirks, stifling self-stimulatory behaviour, and studying ‘ordinary’ human interaction to perfect their ‘act’.

But to a ‘high-functioning’ autistic individual protecting their position in the hierarchy, the alternative, presenting as profoundly autistic, is worse than this loss of Self. The privileged position in the hierarchy is worth the Self-sacrifice[66]. ‘Normalising’ can lead a person to take their own life (Milton and Moon, 2012). People have *taken their own life* as a consequence of the intra-communal hierarchy of impairment and compliance with the idea of autism as ‘lesser’. *Something must be done*. We must not be tempted to challenge the *stereotype*, we must, instead, challenge the *stigma attached* to the stereotype. In so doing, we do not move forward at the expense of the arbitrary ‘other’, we *move forward together*.

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[66] I differentiate this from self-sacrifice, the act of dying for the good of another.

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[67] This is verbatim.

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