How students on the autism spectrum experience higher education

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How Students on the Autism Spectrum Experience Higher Education

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Candidate Declaration

I hereby declare that:

1. I have not been enrolled for another award of the University, or other academic or professional organisation, whilst undertaking my research degree.

2. None of the material contained in the thesis has been used in any other submission for an academic award.

3. I am aware of and understand the University's policy on plagiarism and certify that this thesis is my own work. The use of all published or other sources of material consulted have been properly and fully acknowledged.

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5. The word count of the thesis is 84888.

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Abstract

As an autistic student, researcher, and lecturer, I am alarmed to see the acknowledgment within literature, that autistic students are the most likely of all students to fail at university. This is despite autistic students being categorised as high achievers within education. This raises an important question, why are autistic students who are considered academically able, still not graduating?

To investigate this, seven autistic students (including myself) engaged in emanciparticipatory research to explore our experiences as students who identify as autistic in Higher Education (HE).

The emanciparticipatory approach taken for this study was developed during and for this research, as a means of addressing the issues with traditional participatory and emanciparticipatory research. Emanciparticipatory is a flexible methodology that aims to develop engagement through accessibility and addressing the researcher-participant relationship, whilst being achievable within the constraints of academia. To do this each student engaged via a means that suited them, they were given as much control as possible and engaged as much or as little as they chose.

The research produced a wealth of data some spanning over four years. Analysis of this data identified five key themes: control of label, sociality, wellbeing, academic supports and additional labour of being a disabled autistic student.

These themes revealed how hostile the ‘whole university experience’ can be, with student goals switching from academic success to surviving in the face of multiple barriers. Yet, the students did not face a complete onslaught of challenges, at times for some, the practice that they encountered from staff and the adaptions to the environment, learning and peer-to-peer relationships promoted a healthy environment where students could engage and indeed succeed beyond their expectations.

From these experiences we then make a number of recommendations to promote good practice and challenge poor practice both within university and research.

Acknowledgements

I’m not the most overly poetic of writers and I do not have a suitable quote perfect for and acknowledgment section. Yet, in an early draft of this thesis I wrote a now removed section on challenging functionality labels, using myself as an example I explained how if it was not for a few key people in my life I would not be here writing this thesis. The alternative might have been that I would not have left the residential school that I grew up in, instead just transferring to the adult services. Not that there is anything bad about such a situation, but it did make me aware about the impact people have had in my life, so:

James ‘Captain’ Carlos, Mr McBride, Mr Randel, Mr Davis (all of them), Miss Miller, Beaver, Mrs Mayer, Mr Mayhew, Dean, Belinda Cooke, Chris Adams, My MSc development psychology peers, the Celtics, the Warriors, the Rams and the Giants.

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I’d of course like to especially thank my family, my supervisory team and my fiancé Francesca who is my world.

Contents of this thesis chapters

Appendices

List of figures.

Chapter 1

Introduction

1.0 Introduction

The study presented in this thesis originally set out to explore how autistic individuals experience the policies, processes and practices of inclusion, as students who identify as autistic in Higher Education (HE). But in doing so an additional issue emerged, which is how disability focused research is conducted. In particular, the relationship between, and positioning of the ‘researcher’ and the ‘participant’ and the division of power. This I feel is an important relationship to explore considering the implications research can have on policy, practice, and ultimately the lives of disabled individuals (Oliver, 1983; Oliver, 1992; Walmsly, 2001; Oliver, 2002; Barnes, Mercer & Shakespeare, 2010; Connolly, Davidson & Collins, 2016; Retief, 2018; Fletcher-Watson et al., 2019; Searle et al., 2019).

Yet it is important to remember that this debate is set against research that could potentially better an individual's life which should be the ultimate goal of research (Hastwell, Harding, Martin & Baron-Cohen, 2013). Discussion around the approach to research must not detract from or overshadow discussion of the experiences of autistic students in HE. Therefore, both foci will have equal representation within the research questions, there will be literature presented and discussed that looks at both methodology and HE and ultimately the original contribution to knowledge of this thesis contributes to both fields.

To understand some of the decisions made around the writing of this thesis it is important to explain how this thesis was constructed. Every word, discussion point and decision that is in this final version of this thesis has been discussed and agreed upon by the other autistic students who not only participated but were involved within the research. Each individual engaged, to varying degrees based upon their own choice, from the moment ethical approval was secured all the way through to the final weeks of writing, including various opportunities to disseminate this research (Connolly, Davidson & Collins, 2016).

This opportunity for input and degree of shared control was not only critical to the principles of my emanciparticipatory research framework as presented in Chapter 3 (Searle et al., 2019). But in ensuring that the participants felt that the resultant thesis was representative of their experiences and that their voice was not diminished in any way through my final write-up (detailed in Chapters 3 to 6). This is a key element of the original contribution to knowledge of this thesis.

1.1 Background to this study

The percentage of HE students with disabilities has increased between 2012 and 2018 from 9% to 12% (HESA, 2019). However, the number of students that identify as autistic attending university has seen a much more significant increase year on year. The Higher Education Statistical Agency (HESA) reports a 77% increase in the number of students that identified as autistic in United Kingdom (UK) universities in the three years prior to 2010/11 (cited Hastwell et al., 2013). The High Achievers Project report, by Chown, Baker-Rogers, Hughes, Cossburn & Byrne (2018) supplies more recent statistics. These researchers contacted approximately 160 universities in the UK of which 99 responded and 84 of these respondents supplied more up-to-date statistics. The report shows that there was an increase in the four years since 2010/11 of around 124% with on average 55 students declaring their autistic identity per university. On an institution by institution basis there was a varied response. One university reported a single autistic student while another reported over 200. When looking at the statistics reported by Hastwell et al. (2013) and Chown et al. (2018) together, the number of students identifying as autistic in UK universities is likely to have increased in excess of 200% since 2010. Chown et al. (2018) also highlight that these numbers are of students declaring their autism and that the actual number of autistic students studying in HE will be greater (Fabri, Andrews & Pukki, 2016). Chown et al. (2018) continue by estimating that there are approximately 9000 autistic HE students currently studying in the UK, who represent 1 in every 250 students.

Understanding the potential impact of this rise in autistic students is important because it alludes to the challenge universities and their autistic students might face in the future. Already there is a recognition that universities are currently struggling to support autistic students (Hastwell et al., 2013; Van Hees, Moyson & Roeyers, 2015; Fabri et al., 2016; Chown et al., 2018; DfE, 2019). This is despite autistic students being identified as exceedingly high achievers suggesting that they are academically capable (NAO, 2009; Van Hees et al., 2015). Yet of all disability subgroups those students who identify as autistic are the most likely to fail at university (Fabri et al., 2016). Compared to the general student population an autistic student is 40% more likely to fail, or perhaps more accurately be failed, than a non-autistic student (Fabri et al., 2016). With a rise in the number of autistic students attending university, it follows that the number of students being let down by universities will also continue to grow if the issues that are resulting in such a high failure rate are left unchecked (Fabri et al., 2016; Chown et al., 2018; DfE, 2019; Searle, Ellis & Kourti, 2019).

To prevent this, it is critical that we reach a more developed understanding of how autistic students are experiencing life at university. We need to identify effective supports that can be built upon and the barriers that continue to threaten student success. Therefore, at its core this study is an investigation into the enablement and disablement of students who identify as autistic.

Relative to other parts of society, legal rights to inclusion through adjustment in HE is a more modern concept. Until the Special Educational Needs and Disability Act (SENDA, 2001) and the amendment to the Disability Discrimination Act part IV (2005) outlawed discrimination within Higher Education, students with a disability had no legal right for reasonable adjustments to be made to the student experience (such as an adjusted assessment for example) in order to be able to participate without the hindrance of exclusionary barriers (Jacklin, 2011). However, with the SENDA (2001) and amendments to the Disability Discrimination Act (2005) this changed and HE institutions were then expected to make reasonable adjustments for the inclusion of students with a disability. These included impairment group specific adaptions and adjustments (Tinklin, Riddell & Wilson, 2004). It must be noted that many universities claim that before this legal requisite, they already had a policy in place that promoted inclusion and equality, building on the original Disability Discrimination Act (1995). It would have been difficult, however, for a student to demand changes as there was no legal requirement prior to 2001 for universities to make such provision (Chown et al., 2018).

As a result of these changes at legislative level, coupled with a more diverse student population, universities now actively promote their inclusive nature, promoting the profile of their Disabled Student Support services through websites and prospectuses. Within these, early contact by disabled students is encouraged in an effort to address any possible barriers to access from developing (DfE, 2019; Sheffield Hallam University, 2017; University of Manchester, 2018). However, this in itself raises some issues. Konur (2006) contends that as a result of the current requirements for help (still current as of the time of writing this chapter) this has created a burden on the institution which needs to adapt to teach disabled students while maintaining academic standards and negotiating reduced financial support. Students are also burdened through the expectation and necessity to declare and accept the enshrined definitions of their disability as constructed through law and policy in order to evidence a need for, and secure adjustments. These obligations also generate within students a general sense of being othered (Couzens et al., 2015).

Research literature that reports on investigations into the effectiveness of inclusion policies and experiences of inclusion for students who identify as autistic in UK Higher Education is relatively small (Gelbar, Smith & Reichow, 2014; Chown et al., 2018; Searle et al., 2019). This is despite the growing number of students enrolling. Additionally the research available tends to focus on specific facets of university life, such as academics (Griffin & Pollak, 2009; Madriaga & Goodley, 2010; Seale, Georgeson, Mamas & Swain, 2015), social life (MacLeod & Green, 2009; Jones, Huws & Beck, 2013; MacLeod, Lewis & Robertson, 2013) or the physical and social environments (Madriaga, 2010).

I propose here, however, that the failure to consider the interconnectivity and interaction of the student with the environment, the university and wider society is a major short fall within this research area (Hastwell et al., 2013; Seale et al., 2015). I sought therefore to address this within my research. My inquiry builds on previous research whilst moving it into new territory as it evidences the need to consider life at university as a whole and complete experience rather than as something that can be known through research as fragmented parts.

1.2 Autism language

Zwaigenbaum (2012) highlights the irony that a developmental condition categorised by a marked resistance to change, has gone through a number of paradigm shifts in the past 15 years. Along with these shifts and reclassifications (as a result of changes between the various diagnostic manuals) has come the inevitable debate around language and terminology (Kenny et al., 2015). I suggest that in the history of autism there has not been a time where the debate has been as lively as it is now. I feel this results from a deep-rooted issue around the power of the voice of autistic people or rather the lack of it (which will be discussed further in the following chapters). Currently debate focuses around the use of functioning labels and levels (APA, 2013; Kenny et al., 2015; WHO, 2018; Alvares et al., 2019), employing Asperger's as a term (Spillers, Sensui & Linton, 2014; Ohan, Ellefson & Corrigan, 2015) and identity first versus person first language (Kenny et al., 2015). How people are positioned within these debates illustrates a divide predominantly between the autistic community (and their allies) and the more dominant non-autistic community (Pellicano, Dinsmore & Charman, 2014; Kenny et al., 2015; Frazier et al., 2018).

I first experienced this divide in person in 2014, presenting at The Autism Show in Manchester. A number of delegates met me after my presentation on autism and inclusion to inform me that they applauded my use of the term ‘Autistic person’. However, a larger proportion of disgruntled delegates met me to suggest if I wanted to advocate for the community (an assumption they had made) then I needed to use terms such as 'person with autism'.

It is argued that placing the person before the condition is important as they are and always will be a person not a diagnostic label (Swain, French & Cameron, 2003). I have always disliked this approach to language as for me, thinking literally, it suggests that the person is 'with' this thing called autism. However, I am autistic, it is not something I bring along with me and can leave behind if I want to. This view is congruent with the autistic community surveyed by Kenny et al. (2015).

The divided opinion I experienced in Manchester is congruent with the findings of Kenny et al. (2015). Their study on terminology, found that there is a divide between autistic people and professionals. The results showed that many autistic people prefer identity first language and many professionals tend to prefer person first language which reflects the disconnect between the autistic community and professionals. This is a disconnect that many autistic people experience beyond just language and how they are termed: it permeates many aspects of everyday life (Frazier et al., 2018). Though many autistic people prefer identity first language and fight for it, there are individuals both autistic and not that question the focus on language with the view that how someone talks about autism is the least of the concerns people should have. Yet Leatherland and Chown (2015) argue the language used signifies an organisation's or a person's ontological position with regards to disability. For example, McGuire (2016) argues citing Titchkosky, (2001), how person first language can lead to the positioning of the disability solely within the individual. McGuire suggests that a person with autism can be seen as a person with a communication impairment and therefore it is only the autistic person's communication that is at fault. This then leads to the push to fix that person's communication rather than the understanding that communication breakdown is a shared issue. Though language might just be words, to use language that positions you within the perspective that sees an autistic person as an issue, can be hurtful and damaging to an autistic person especially when it is a professional who is meant to be promoting the best interests of an autistic person.

Going forward within this thesis I will use identity first terms that I, and the autistic individuals involved in my research, prefer. These terms are ‘autistic person’ or ‘autistic’. This is a position preferred by many in the autism community (Kenny et al., 2015). It is also reflected more recently in the shift in language used by charities such as the National Autistic Society (2018). I will also not use Autistic Spectrum Condition (ASC) or Autistic Spectrum Disorder (ASD) in an effort to move away from these pathologising terms.

Other terms, that are used in this thesis such as 'symptom', 'impairment' and 'deficit' are only used when reporting on information that contains this language or when used by one of the autistic individuals involved in the research as I do not intend my views on language to dictate to others. Though discussion around language occurred with the other autistic students, each individual could use their preferred terminology.

Along with using the term autistic, as a group we have decided to not use functioning labels such as high functioning and low functioning. We came to this decision because we felt, as a group, that functioning labels serve no purpose and can in fact be damaging (see Chapter 5). These labels do not define a person and they do not encapsulate the challenges faced by that person on a minute by minute basis. These labels only serve to promote incorrect stereotypes. Beardon and Chown (2014) highlight how someone may be considered high functioning because they participate socially. However, this participation could be masking high levels of anxiety and significant sensory and social challenges. The emotional labour of keeping these challenges and anxieties under the surface can take its toll on an individual and lead to damaging effects later (Beardon & Chown, 2014). This idea of additional labour is discussed further throughout Chapter 5.

Further to this, labels tend to support the concept of a static diagnosis and yet autism is not static. Within my personal experience the difference between me attracting the label of high functioning autistic academic, or a lower functioning service user in psychiatric care, is the decisions made by a small number of individuals that has allowed me to live in an environment that has enabled me to flourish. I am not essentially different, but my support environments may well have been. To move away from damaging functioning labels, I will not define those involved in the research by them. These terms may however appear within the references to works of other authors.

Though most decisions around language and labels are uniform across the thesis, and decided after discussion with those involved in the research, no definite decision could be made around using the term autism as an umbrella term (inclusive of Asperger's) as represented within the Diagnostic Statistical Manual version five (APA, 2013). Most of the autistic students were accepting of using autism as a term even though they had originally been diagnosed/self-identified as Asperger's. However, one participant preferred to use the term Asperger's. Therefore, it was decided as a group that I would preference the term autism, but when reporting the views of other autistic students, I would use their preferred term.

One of the most contested topics in both the autism community and the wider western world is that of self-identification (Sarrett, 2016). From the title of this thesis it is apparent that I decided to use the phrasing of 'students who identify as autistic' rather than students who are diagnosed as autistic. I did this to maximise access to this research for autistic participants. Research that requires an individual to be diagnosed as autistic limits the research to a number of groups; those whose parents were able to fight for a diagnosis (often parents that are more financially able) (Brett, Warnell, McConachie & Parr, 2016), children and adults with access to professionals with a developed knowledge of autism (Aylott, 2010) and adults who were able to navigate the referral and diagnostic system (Chown & Beardon, 2014). Those who are autistic and do not fall into one of these groups then find themselves excluded from participating in research which is highly significant to their lives. Often these individuals are most at need as they often lack the support around them to enable them to succeed in life (Brugha et al., 2011; Perkins & Berkman, 2012; Cassidy & Rodgers, 2017). Further to this I feel that by choosing to only have officially diagnosed autistic participants for a study, the voice of those unable to gain a diagnosis due to barriers created by a predominant neurotype (PNT) society are having their voice silenced often by PNT researchers through exclusion of participation.

To remove this barrier and to be accessible, formal diagnosis was not required for participation in this study. The only requirement was that the participant themselves identified with the label of autism in some way. Additionally it is also important to highlight, for the discussions that are presented in the findings (see Chapters 4 and 5) that identifying as autistic for some is also not static, some of those involved in the research choose when, where and how they identify and for them that power is an important safety practice (this will be discussed further in the Chapters 4 and 5).

1.3 Personal position

This section is divided into three sub sections. The first identifies my personal position with regards to disability. I discuss how I would like to sit and work within the social model of disability (Oliver, 1983) but the tension this brings being autistic and needing to access supports which require me to submit to medical model definitions of autism (APA, 2013; WHO, 2018; Leatherland, 2018). I discuss this tension and how it has resulted in the need to include discussion around this within the thesis as it is a tension that others also felt within the research.

The second section is around how my personal experiences brought me to research the experiences of students who identify as autistic in HE. This research interest is heavily influenced by my personal background and it is important to acknowledge this for transparency (Dean et al., 2018).

The third section identifies my personal position in relation to the development of what I have called my 'emanciparticipatory' research approach (defined in Chapter 3). My methodological and ethical positions around access, voice and control have developed through a mixture of personal experiences as well as through literature presented in Chapters 2 and 3 and my perspective of autism.

First however, some information about me; I am an autistic male diagnosed as a child which puts me in a privileged position. I attended a mainstream school until the practices of the school caused my parents to withdraw me and I was placed in a special school for autistic children where I stayed until I had completed my General Certificate of Secondary Education (GCSE). I then moved to a college where I was heavily supported with a one-to-one aid from leaving my house in the morning through all my lessons and break periods through to getting home in the evening. I then received similar support through my undergraduate degree which, according to my research, is a great deal more support than college and university students receive now. I have degrees in Physical Education (BA and MA), Autism (MA) and Developmental Psychology (MSc) and so I am a member of the participant population, even sharing the same degree qualification as two of the other autistic students involved. As a final note, though I was able to access support as an undergraduate I have severely struggled in accessing support during my PhD which will be discussed in Chapters 4 and 5. As such I have attempted to write this PhD with no formal support, only able to access the informal support provided by my supervisory team and family. As such I am aware that my spelling, grammar and choice of words are not perfect but this is an issue many autistic and dyslexic students face day-to-day within HE and so this thesis is in a way representative of working within a system not designed for you.

1.4 Positionality and the social model of disability

The social model of disability, developed by Oliver (1983) and disabled people's organisations, incorporates a perspective that rejects the concept of disability as the resultant necessity of an individual's embodied impairment. For the social model, disability instead is the socially constructed barriers within the environment, society, laws, policy and practices that disadvantage and exclude an individual. This understanding of disability, as enabled and maintained through societal attitudes and practices, takes the onus of change off the individual. It becomes the responsibility of society to change and to address these socially constructed barriers to better enable individuals (Oliver, 2013). This position of Oliver (1983) and others (Barnes & Mercer, 2003; Swain, French & Cameron, 2003; Barnes, 2012; Runswick-Cole, 2016) is in direct opposition to the dominant medical model of disability which places disability with an individual whom is constructed as disordered and impaired, requiring a fix in order to become a normal functioning member of society.

I feel I align with the social model more as I can see through my own experience that when I am in supportive environments, I face very little disablement. However, away from these environments I am heavily challenged to the point where I often can not access those spaces and places. This I feel is most important to acknowledge as the experiences I encountered at university were so negative due to socially constructed barriers and so overwhelmingly positive when these barriers were removed.

I used the phrasing ‘I align with the social model’ rather than ‘I place myself within the social model’ purposefully. This is because I understand that in today’s world, we cannot see autism fully through the social model lens. This is because we still need to acknowledge our disability within the medically enshrined definition to be able to access the supports needed to break down some of the socially constructed barriers encountered. As such I cannot advocate for moving fully away from the medical model until the practices of how needs are assessed change, and access to support is no longer dependent upon a medical diagnosis (this is an argument that I develop in Chapter 2). But what I can do is challenge through my research the idea that supports need to be dependent upon the requirements of an externally applied medical diagnosis.

1.5 Positionality as an autistic student

As part of this process of identifying and reflecting on my different positions it is important for transparency at this point to state that my interest in the inclusion of individuals who identify as autistic in Higher Education, stems from my own experience (both positive and negative) of being a student who identifies as autistic.

Currently I am studying in Higher Education and more specifically researching enablement and disablement, concepts that I have personal experience of. As a result of this my close proximity to the subject matter, the concepts of objectivity and subjectivity are themes that run throughout this thesis (see Chapters 1-7).

To better understand my journey and experiences that have led to this interest and ultimately this study presented here, I need to start back at the beginning of my Higher Education life. On day one of entering university I could not have conceived of ending my student life by writing a PhD thesis. I had no role models of autistic people doing this and it seemed far beyond my ability. It did not seem like something that an autistic person could achieve. In fact, after the first lecture my plan was to drop out before the final year as even that felt too demanding. However, the support particularly from the disability services and course leader really enabled me to participate within the course to little disadvantage; so much so that I stayed for postgraduate study (this will be discussed more in Chapter 5).

At that time (after gaining my first master’s) my perception of how inclusive Higher Education could be, was extremely positive. I felt like the adjustments made as a result of the suggestions of the Disabled Student Support (DSS) team enabled me to participate fully in university life and ultimately 'achieve'. As a result of this positive view of HE at the time, I decided to pursue further postgraduate study. To do this I had to change institutions. Moving institutions, I encountered my first experience of policy that was allegedly designed to better the student experience but which actually worked against me as an autistic student (this will be discussed in detail in Chapters 4 and 5). My second university experience differed greatly from my first. I faced disablement in a variety of areas not just academic. I found that my accommodation, the physical environment, and the social aspect of university challenged me from both within and outside of the university.

As a result of this experience I began to explore what it is like for others who identify as autistic studying at university purely for personal curiosity to see how others were experiencing university life. I gave presentations about my experiences and invited other students who identify as autistic to share their experiences too. From this it became apparent that there were differing perspectives. What I found more interesting was that the quality of these experiences even differed within the same institutions. From these discussions and reading literature around disability in HE as a whole, I developed the questions which I have now explored within my research.

1.6 Positionality as an autistic researcher

In this section I will introduce and discuss the reasons why I decided to create and develop my own emanciparticipatory research framework. Like the section above which reported on why I wanted to research around the experiences of autistic students in HE, this section is to present my positionality with regards to me as a researcher. I feel it is necessary in order to give a clear understanding of the personal reasons as to why I considered developing my own framework rather than utilise a more traditional framework. This discussion is based solely on my positionality; a larger more in-depth discussion around emanciparticipatory research will be undertaken within the methodology chapter.

When I set out on this PhD journey, I had a relatively secure personal position on HE. I saw that when done correctly university can be an incredible experience. But when done poorly it can have devastating consequences (which I have both witnessed and experienced). Seeing this dual result pushed me to ask more questions and look closer. A quote by Ellis (1992, p.29) stands out to me when she asks, “Who knows better the right questions to ask than a social scientist who has lived through the experience?” The experience I had was the starting point but the research literature and the experiences of others around me is what has resulted in the thesis presented here.

When I started, I knew what I wanted to investigate but I still needed to determine how. The studies I had undertaken at university partly led my decision making, but so too did the literature that I was engaging with when preparing my proposal as well as the lens through which I see autism.

I perceive each person as experiencing autism slightly differently based on the environment that they are in. Some see autism as a linear continuum (APA, 2013), however I visualise autism more like water, in that it is highly dependent on the environment. Water on the Horn of Africa is incredibly volatile but if you were to scoop that water into a glass suddenly the same water becomes calm. It is the same water, but its reaction is highly dependent on the environment that it is in. As such how each person interacts with their specific environment and the needs that they have are very person specific.

With this perspective I firmly construct my philosophical position in research as one that rejects all positivism as I believe life can not be measured in quantifiable and defined terms where enough experiences grouped together will give a whole truth (Cohen, Manion & Morrison, 2018). I have worked within a positivist position before when I did my Developmental Psychology studies. However, I feel that within this position research can cause damage to both the emancipation effort of the autistic community and the participants involved in positivist research due to the assumptions around knowledge, individuality and truth that positivist researchers take (Giddens, 1976).

For many years interpretivism has been considered the opposite to positivism (Crotty, 1998). Interpretivists (with whom I align myself) argue that there is no singular truth but rather a collection of single experiences interpreted by those experiencing phenomena (Crotty, 1998). It is the job of the interpretivist to explore these different experiences not to come to a single conclusion but to explore possible commonality and differences between these (Creswell, 2009).

Creswell (2009) and Crotty (1998) note that a theoretical paradigm implies a particular ontological and epistemological stance and vice versa. Interpretivist researchers sit within a relativist ontological position as reality is relative to each person, therefore reality can not be generalised but can be explored with regards to commonality and differences (Creswell, 2009). Finally, those that sit within an interpretivist paradigm hold a subjectivist epistemological position as experience is not objective and can not be objectively captured but rather explored through interaction between the researcher and the participant (Creswell, 2009).

Crotty (1998) highlights that the theoretical perspective a researcher takes will underline the whole of their research, feeding into their methodology and methods and I agree to a point. As I see inclusion of all who wish to participate as vital to ensure all experiences are considered equally, then there is a need sometimes to step outside my own theoretical position if that position hinders someone’s participation. For example though I personally reject positivism and the methods and methodologies that more cleanly sit within this paradigm I have to be able to accept a potential participant who would rather work from a positivist perspective and therefore I can not reject the methodologies or methods that sit outside of my paradigm. I however can work within my emanciparticipatory approach to explore methods of research.

As I have said, the literature that I have read has informed my position with regards to the approach that I have taken within this research. Through exploring the literature around disability research within the paradigm of the social model of disability (Oliver, 1983; Oliver, 2010; Barnes et al., 2010 among others), I came across two approaches, Participatory and Emancipatory (Oliver, 1992; Walmsly, 2001; Oliver, 2010; Gibson, 2012). The emancipatory approach especially challenged my understanding of the researcher-participant dynamic. Coming from a more positivist, science focused background (Developmental Psychology) where the researcher-participant power relationship is clearly defined it was different to see studies that challenged this (Gibson, 2012). The aspect that most stood out was the increased accessibility for individuals to participate, control and benefit from the process. Additionally, how the power relationship within these approaches is challenged and how impact is so heavily promoted engaged me and motivated me towards researching in a similar way. A full explanation of my emanciparticipatory approach and why I feel that neither the participatory nor the emancipatory approach were eventually suitable is detailed within Chapter 3.

1.7 Research questions

Autistic students in HE are seen to drop-out or fail more than any other group (Fabri et al., 2016) this is despite being seen as exceedingly high achievers suggesting that they are academically capable (NAO, 2009; Van Hees et al., 2015). Students that are academically able, failing at such significant rates suggests the existence of autism specific issues within HE. When looking at existing literature around the experiences of autistic students in HE there appears to be a focus on the academic supports or a focus on specific elements outside of academics (Gelbar et al., 2014). Yet when looking at literature around being a student in HE there is a long acceptance that studenthood is more than the learning element and that there is a 'whole university student experience' (Holton, 2015; 2016a; 2016b; 2018a). I believe that by not exploring this whole university experience for autistic students then there are possible interconnecting interactions that are going unnoticed. This is truer than ever as universities themselves now acknowledge that being a student is about the whole experience rather than just the learning (Holt, 2008; Sheffield Hallam University, 2017; University of Manchester, 2018). As a result, the first research question focuses on this idea of a whole university student experience and so the research question is:

> Q1. What is the whole university student experience like for students who identify as autistic in Higher Education?

Research that explores autism in HE, much like research exploring autism in other contexts tends to be based around a researcher, often the predominant neurotype (PNT) designing and carrying out research (Gelbar et al., 2014; Anderson, Stephenson, Carter & Carlon, 2019; Fletcher-Watson et al., 2019). As discussed, and as will be discussed further in Chapters 2 and 3 this can result in a number of barriers to participation. I have encountered these barriers when trying to participate in research in the past. It is suggested that the voice of the autistic community is missing from within research, and when there is some involvement of members of the autistic community there is often still a power imbalance resulting in research that in some instances does not reflect the views of autistic participants, and on occasion can still include barriers for member of the autistic community (Pellicano, Dinsmore & Charman, 2014; Chown et al., 2017; Anderson, 2019; Fletcher-Watson et al., 2019).

As a result of the issues outlined and discussed further in Chapters 3 and 4, the second research question focuses on exploring an approach to research that looks to disrupt the traditional power relationship and promote the voice of members of the autistic community whilst trying to remove as many barriers to involvement as possible, and so the research question is:

> Q2. Can research be carried out in a way that challenges the power imbalance of traditional research whilst promoting accessible means of participation?

1.8 Outline of the thesis

This first chapter has introduced the background context to this research, highlighted the two main foci of the research and how I came to develop the rationale for this study, as well as set out my research questions. I also focused significantly on positionality as my experiences as an autistic student heavily influenced the initial direction of this study and my emanciparticipatory approach.

In the next chapter I will develop my rationale for my inquiry further through a presentation of my literature review. This chapter focuses on not just literature that explores the inclusion of autistic students in HE but also the larger discussions around autism and disability that may not overtly impact on the student experience but heavily influence much of the practice and policy that does.

Within Chapter 2 I also discuss each of the separate elements that literature identifies as integral facets of the ‘whole student experience’. In identifying each ‘facet’ separately and analysing the literature I will illustrate why and how there needs to be consideration of the interconnection and interaction between these ‘facets’ of being a student. This discussion will be structured to reflect the order students often first experience each of these facets, starting at pre-enrolment, moving through arrival at university and freshers’ week where the emphasis is on the social facet of being a student, finishing with the academic facet.

Chapter 2 concludes with a discussion reflecting back on this literature and ties together these individual facets, and where relevant, further highlighting the need to explore these different facets together rather than separately in order to have a better understanding of the enablement and disablement of autistic students in HE.

Chapter 3 begins by highlighting the issues around the lack of representation of autistic people within what are identified as the main autism research fields; they are traditional mainstream psychology, biological based research and traditional social science. I then discuss the rise of participatory research in response to the issues of representation within traditional research, before outlining some of the issues I have identified within the participatory literature. Then I move on to the concept of emancipatory, how this differs from participatory research, before putting forward my argument for why this type of research can not truly work within the current constraints of academia.

In response to the issues I highlight with traditional, participatory and emancipatory research I close this third chapter by putting forward my emanciparticipatory approach as a way of moving research design and principles towards emancipatory research that I feel is more achievable within the constraints of academia whilst still providing more control and voice to the autistic population than traditional and participatory research.

Chapter 4 is the methods chapter, in this chapter I discuss how I will use my emanciparticipatory approach outlined in Chapter 3, with regards to the study presented in this thesis. I discuss the recruitment phase, as well as the struggle of what I call ‘structuring the unknown’ as entering the data collection phase I knew very little around how I would collect my data due to the emerging nature of the approach. I follow this by presenting in turn each method of data collection specific to each individual.

I end this fourth chapter by discussing the ethical considerations for this study. However, the ethical discussion goes beyond how I met the ethical guidelines, this chapter finishes with a discussion around how current ethical guidelines may hinder the development and usage of participatory, emanciparticipatory and in the future emancipatory approaches. This links to the discussion that occurs within Chapter 3 around the current constraints of academia. Within this larger ethical discussion I also challenge the use of the term ‘vulnerable’ when discussing minority groups within research, and put forward an argument to either loosen or completely remove the guidelines by which researchers are forced to label participants as vulnerable.

Chapter 5 is the presentation of themes; this chapter is split into two parts as a direct response to concerns from some of the autistic students. There was some worry that what they felt were key experiences for them personally, might get lost in the larger discussion that considers the experiences of everyone. Consistent with the emanciparticipatory approach we discussed different ways of addressing this and decided that we would dedicate part one of the chapter to the presentation of themes specific to each individual. An additional benefit here is that each individual now gets a moment within the thesis to have their voice heard in isolation without being compared to other autistic students in this study or in wider literature.

Chapter 5 part two is more traditional, within this part I present the themes generated from the data as a whole, the themes presented are: control of label, socialness, wellbeing, academic supports and finally additional labour of being a disabled autistic student.

Chapter 6 is the discussion of the themes around the experiences of students who identify as autistic in HE. Here literature is used as part of the discussion on the themes presented in Chapter 5 part two.

Chapter 7 is focused on the presentation and discussion of themes pertinent to the second research question. Here I present themes generated from the data around the experience of being involved in this study. Three themes are presented: firstly ‘Easy, Simple, Accessible’; then ‘Flexible’ and finally ‘Meaningful’. As there is less data on the methods of participation it made sense and to save space to also discuss the themes in this chapter also.

Chapter 8 is the final chapter; here I discuss the limitations, recommendations, plan for dissemination and conclusions before finishing with a focus on what I see as my contribution to original knowledge. I finish on this focus, as this overview of my contribution to knowledge is not the end but the start of translating this original knowledge into practice.

Chapter 2

Literature Review

2.0 Introduction

This chapter focuses on the existing literature around the experiences of students who identify as autistic in HE. This is to gain an understanding of what challenges and good practice is already evidenced within literature to develop a foundation of knowledge which I aim to add to with my own research. Attention will also be given to the methods utilised within this existing research to highlight potential issues and strengths that inform the design of this study.

As has already been discussed in the opening chapter autistic HE students are considered high achievers (Chown et al., 2018), however they are also the group most likely to fail (Fabri et al., 2016). Literature suggests that there are several reasons that an autistic student might find university life challenging. In brief these are, but are not limited to; organisation, processing time, communication with tutors and peers, navigating university systems, sensory, navigating the hidden curriculum and the social nature of university life (Gelbar et al., 2014; Jansen, Petry, Ceulemans, Noens & Baeyens, 2017; Anderson, Carter & Stephenson, 2018).

Each of these issues can be grouped into four categories: academic, environmental, social and university processes. Each of these categories will be explored in turn drawing on literature that highlights not just the issues, but on occasions suggests good practice for eliminating or mitigating the challenges faced.

An issue however with prior literature is that it often explores these categories in isolation, with only a few inquiring into more than one category (Gelbar et al., 2014; Jansen et al., 2017; Anderson et al., 2018). Even then, these studies do not capture and analyse the interactions between these categories but rather investigates them in a vacuum in that they take each in turn without considering the impact of one on the other.

I consider this problematic for understanding and addressing the wide array of challenges that autistic students face. It is stated that autistic students face a unique combination of challenges due to the barriers in the environment, learning and socially (Lucas & James, 2018). Therefore, I also explore within this chapter the problem of focusing solely on specific elements of university life and I present my argument against taking such a perspective.

I argue that universities need to look at the student as more than an individual learning in a vacuum, but rather as a learner who is going through an identity change and being affected by university specific social and environmental interactions that are outside of the academic learning process, but still impact on academic success.

Though looking at the experiences of autistic students outside of learning is not a new phenomenon (Gelbar et al., 2014), I do believe that the interactions of the environment, learning and social life must be explored and I believe that this must occur now as universities are changing. Currently universities are moving from institutions of specific learning to institutions that promote a multi-faceted ‘whole university experience’ approach where the social student has never been more important, which potentially proliferates the issues autistic students face (Holt, 2008; Holton, 2015; 2016a; 2017a; 2017b; 2018a).

At this point I think that it is important to highlight that this discussion is not a reflection of every university. Some universities have moved away from some of the more problematic traditional supports and adjustments that will be discussed, as well as allowing students to engage in university in ways other than what I consider the new social centric approach. However, these universities appear in the minority (Chown et al., 2017; DfE, 2019). Furthermore, these universities often do not have consistent practice across the university, but rather good practice appears within pockets of anomaly (Griffin & Pollak, 2009). Finally, this discussion is based on information available, I understand (and have experienced) tutors, courses and departments that go above and beyond what might be their institution's published practice (Griffin & Pollak, 2009).

2.1 Significance of success and change in direction

When discussing the success of a student in HE this usually references academic success such as passing a course with first class honours. Indeed, the statistics that I presented in the opening chapter of this thesis are based on the number of students who identify as autistic in HE and the number of those students who are unsuccessful in completing their studies (Fabri et al., 2016). Success even feeds into university performance indicators; unsuccessful students cost the university money not just in the loss of that student's payments but there are other financial ramifications associated with the university performance indicator such as the university being considered less desirable (Collings, Swanson & Watkins, 2014).

Academic success is prized, firstly, because success at graduate level can have significant financial benefits potentially leading to a better life for an individual and their family (Hermannsson, Lisenkova, Lecca, Mcgregor & Swales, 2017). This can then impact on the country’s economy and world standing as a more highly skilled work force drives forward innovation. Additionally, this workforce has a higher disposable income allowing for more to be put back into the economy in addition to the taxes from these higher rate earners (Hermannsson et al., 2017). This highlights the significant benefit to the government from placing emphasis on universities producing highly successful, financially productive students.

At a more student level, the impact of academic failure on a person’s self-concept is well documented (Chohan, 2018). Academic failure can lead to negative self-imagery, low self-esteem and self-worth (Chetcuti & Griffiths, 2002; Chohan, 2018). Additionally, external pressure such as from family, a partner or friends can result in a drive to not let others down (Flashman, 2012). This type of stress and anxiety, plus the impact on one's concept of the self, means that academic failure, or the threat of it, can all lead to poorer mental health, physical health and reduced general wellbeing (Hodge, Rice & Reidy, 2019). This can potentially impact on a person’s life long after university (Matthews, 2017). This is the same for any student but for an autistic student who is already more likely to experience a negative sense of self, low self-esteem and self-worth on top of high levels of stress and anxiety and a poorer general level of wellbeing, the impact of failure can be far greater and the individual can 'hit breaking point' far quicker (Beardon, Martin & Woolsey, 2009; Matthews, 2017; Hodge, Rice & Reidy, 2019).

In a study exploring success of autistic students in HE, MacLeod (2016) highlights that for a disabled student there is additional significance to succeeding. She argues that if disabled people are seeking to address their marginalised state through challenging the dominant academic communities, then they need to be able to communicate through standard academic convention and that requires success within HE.

Further, though more implied than explicitly stated, MacLeod (2016) places the emancipation of disabled communities on the shoulders of disabled HE students.

Though this might seem like an exaggeration, when looking at the autistic activist community it is often driven by autistic scholars, which does go some way to supporting MacLeod's thinking. My own PhD for example and move into working within academia, was born out of a want to challenge the barriers I faced within mainstream teaching as a result of being an autistic person, and to do this I needed to achieve academically.

More specific to autistic students there is a drive to succeed fuelled by a need for perfectionism. Lawson (2010) acknowledges that perfectionism is a common psychological autistic trait. Tammet (2006) discusses the impact perfectionism can have on autistic students. He recounts the case of a student who when faced with an assignment would commit far more time than might be expected into a single piece of work. The student would agonise over every letter and use of grammar; starting over from the beginning if there was a mistake.

Autistic students can be so relentless in the pursuit of perfection that there could be additional effects on health and wellbeing as a result of this exhaustive flow-state. This type of flow-state is congruent with Murry's (2018) monotropism and if supported correctly can result in a high standard of work which is important for academic success. But if unsupported could contribute to the high number of unsuccessful autistic students (Tammet, 2006; Beardon et al., 2009; Murry, 2018).

Research findings across the range of studies that focus on different stakeholder findings; establish that academic success is important to the government, the university, tutors, and the students themselves. Therefore, it is understandable that there is a focus on providing academic support for students who may impact on this success. Which in my opinion is a poor justification for support and positions these students as a problem that universities must overcome for financial and reputation reasons.

Yet when recruiting perspective students, universities in an effort to differentiate themselves in a highly competitive recruitment market, and through a better understanding of how to increase academic success amongst their students, have begun to place emphasis beyond the academic learning as key to success (Rutter, Lettice, & Nadeau, 2017). Location (Rutter, 2017), culture and sport (Huesman, Brown, Lee, Kellogg & Radcliffe, 2009; St Quinton & Brunton, 2018), and environment and community (Kampf & Teske, 2013; Müller-Christ et al., 2014) are all now seen as vitally important for the success of a student. In short universities now highlight how factors other than learning can impact on studies, career and ultimately life (Holton, 2016a; 2017a).

This places a new emphasis on what effects the non-academic social aspects of university have on students and the development of the concept of the 'whole university experience' (Holton, 2017b). Yet despite this new shift to a 'whole university experience', the focus of support for students has stayed stagnant, remaining centred only on academic barriers rather than the whole university experience (Shmulsky & Gobbo, 2013; Gelbar et al., 2014; Anderson et al., 2019; DfE, 2019). As a result, universities could become less accessible for autistic students at a time when more and more young autistic adults are seeing university as their next step in life.

2.2 Current Disabled Students Support processes

The process I went through as an 18-year-old student, I thought might have changed in the near 15 years since applying, especially given the changes to DSA funding

(Lewthwaite, 2014). However, through investigation it is clear that there has been very little change in the process, at least at student level (Student Finance England, 2019; DfE, 2019).

For most universities there are two processes at work: the Disabled Student Allowance (DSA) funded by Student Finance England which provides funds for the student's support package and the Disabled Student Support (DSS), (this name varies between institutions) which often works in tandem with DSA to implement the student support package or co-ordinates with a third party to implement the support (Student Finance England, 2019; DfE, 2019). Simply the 'allowance' (DSA) pays for the 'support' (DSS). Though it must be noted DSA is not always required for some support and adjustments (Lewthwaite, 2014). This will be discussed in more depth within this section.

It is important that this process of declaring a disability, obtaining support, and issues with the process are clearly understood, to provide context for later discussion concerning the findings of my study. Therefore, I will now record the pertinent elements of this process.

The process begins prior to the student starting university. A first-choice application is made to a chosen university. If a disability has been disclosed, then often the university's DSS team will contact the perspective student signposting them to the DSA application.

In some instances, as highlighted by a large-scale evaluation of DSA by the Department for Education (DfE, 2019), colleges may prepare students by highlighting what can be disclosed to DSS. Cunnah (2015) argues that early disclosure is vital in ensuring the right support is in place for a student when they start university as this ensures a smooth transition into HE, as well as enabling the right support to be in place for the initial experience of teaching.

Jacklin (2011) and Kendall (2018) claim that although universities do not actively recruit disabled students, they do promote a position of being disability friendly in an effort to encourage engagement with disabled students. In spite of this, both Jacklin (2011) and Kendall (2018) highlight that often the decision to disclose is carefully considered. This is a theme that repeatedly emerged within my research: the requirement on the student to submit to being in need of help. This can impact on the concept of the self at a time when there is more of a conscious exploration of self (Kasworm, 2010). As a result, there may be an unwillingness to disclose. In response, universities and the DfE are currently promoting disclosure and the benefits of doing so (DfE, 2019). Within my research I was keen therefore, to understand how the autistic students involved in this study had experienced disclosure.

Once a perspective student has been contacted, they will be offered some degree of support with the completion of the form. However, the DfE (2019) does highlight that this is very much dependant on the university applied to. DfE research found that 60% of individuals had received information on DSA but only 40% had received support with applying. It is also important to note that within these figures there is no discussion of the type of information or level of support provided for applying.

The DSA application is a form which consists of eight pages. It starts by asking for personal details and other financial support before focusing in on the individual’s disability. The form asks for full details of the disability and gives details of the evidence the applicant must provide. An autistic applicant must:

> provide a written statement or letter from a doctor or appropriate qualified medical professional which confirms a substantial and long-term adverse effect on your ability to carry out normal day-to-day activities. (Student Finance England, 2019, p. 5)

This is done with a separate evidence form and highlights how the onus is on the applicant to gather and pay for this evidence.

Both forms are then submitted and after a number of weeks, barring any issues (discussed later in this chapter), a student will either be granted a level of support or denied funding (Student Finance England, 2019). If a student is denied funding, then often the university will look at the evidence and put some form of support in place though this will not be to the same level received by those students awarded DSA funding.

At this point if an assessment of needs has not already been carried out, the student will be contacted, and an appointment set up. 44% of the time this is carried out at their chosen university and 42% of the time this is carried out at a separate assessment centre (DfE, 2019). For most (68%) the booking of the appointment was reported as easy and overall 81% were satisfied with the experience, with 91% feeling listened to (DfE, 2019). However, it must be noted that at this time the students have not experienced university and so are only able to advise on what support they think they might need based on their experience within secondary and further education, which has little in common with HE. What works in one environment might not work in another. Additionally, this also does not take into account the interwoven aspect of HE which I will go on to highlight as an issue in later discussion.

Following this assessment of needs and regardless of funding, DSS will draw up a ‘learning contract’ (again the name differs between institutions) which will outline the reasonable adjustments that the university will put in place around teaching, assessment, learning, access and other. If funding is granted, there may also be a need for an external third party to supply specialist support. If this is the case the university will co-ordinate this.

If all goes as expected and an enabling learning contract is designed at the start of the course, often there will be little need to make amendments unless the student's circumstances change (Student Finance England, 2019; DfE, 2019). If the circumstances do change learning contracts can be amended with additional support provided if the student has funds left from their allocation. If this is not the case a new application is required to be made.

If there are no issues with the learning contract, then the DSA funding will last the length of the course. Additionally, unlike with student finance loans, a student will not have to repay Student Finance England for this DSA funding whether they finish their course or not.

2.3 Issues with the current process for accessing DSA and DSS

Above I highlighted that students may encounter issues with the DSA application process. As well as more generic issues with the process, there are several autism specific issues that might impact on the process of applying and therefore the support offered. I will now discuss these in more depth.

The first issue associated with the DSA application process which the Department for Education highlights as a priority area to address, is understanding who can apply for DSA; what disabilities come under its umbrella and what type of support can be funded (DfE, 2019). The DfE believes there is a clear misunderstanding by potential users of what DSA can be used for. There is a misconception that DSA is for academic support i.e. spelling and reading (Jacklin, 2011; Kendall, 2018; DfE, 2019). If an individual has a good standard of both, even though they have a diagnosis of autism for example, they may not apply for funding in the belief that DSA can not help them (Jacklin, 2011; Kendall, 2018).

Additionally, for Taylor, Turnbull, Bleasdale, Francis and Forsyth (2016) the wording used by DSA is problematic. The definition of disability is now being taken from the Equality Act (2010) which implies that more ‘mild’ conditions should be considered Special Educational Needs rather than a disability and this has led to further confusion. It is important that students know if they meet the requirements to apply, how to apply and what information will help or hinder an application. If there is misunderstanding at any time this could lead to an applicant not following through with an application. This issue is compounded by the lack of support available with the completing of the DSA forms (Anderson et al., 2018; Kendall, 2018; DfE, 2019) and is contributed to by the second issue below.

The second issue again acknowledged by the DfE (2019), is the amount of communication, and the level of skills, required to gain DSA. First a student must initiate contact to begin the process. Then the student needs to continue communicating with both Student Finance and DSS, usually through email. This is highlighted by the DfE (2019) among others (MacLeod et al., 2013) as a known barrier for autistic individuals and could in some part account for the disparity between the number of autistic students in HE and the number of autistic students receiving DSA (Chown et al., 2018; DfE, 2019).

From my experience this has been something that I have encountered during each application. This resulted in some instances in me not applying for DSA and I have forgone support or self-funded it. Of note, the DfE (2019) report also highlights that since the change in DSA funding in 2014 there has been a worsening of this problem although no reason has been suggested as to why. It is my opinion (informed by both my experience and Lewthwaite, 2014) that with the cutting of funding and resources brought about by the 2014 changes, there is now less support, time and resources to accommodate and follow up students with communication challenges (Lewthwaite, 2014).

Another issue with the DSA process is the reliance on specific evidence and what is accepted as evidence. Evidence is split into two sections, diagnostic assessment outcomes and letters from doctors.

In order for diagnostic assessments to be accepted as evidence of a specific learning disability, the assessment needs to have been carried out after the young person’s 16th birthday (Student Finance England, 2019). This does cause some confusion as this also includes lifelong conditions such as dyslexia and autism. If the assessment was carried out prior to the young person’s 16th birthday another assessment or a doctor’s letter is needed.

Additionally, the letter must explain how the individual’s condition will affect their day-to-day life rather than learning or accessing university, despite funding only being available for learning and accessing university (Student Finance England, 2019).

In relation to this issue of evidence and specific to autistic applicants, the average age for diagnosis is around age eight (Brett et al., 2016). This means that in most cases an autistic person would require a doctor's letter detailing how their autism affects them and this raises some further issues.

Firstly, it is well documented that autistic individuals struggle to access the health service including GPs (Aylott, 2010; Bradshaw, Pellicano, Driel & Urbanowicz, 2019). Looking at the access issues of autistic adults without additional learning difficulties, Bradshaw et al., (2019) identified three categories of barrier that must be overcome for an autistic person to access medical services. These are 1) patient level factors like anxiety, 2) professional level factors like lack of autism specific knowledge and 3) system level factors such as accessibility of environment. These factors create substantial barriers for accessing a key requirement for the DSA funding with no support from student finance or their university, resulting in another potential stage of the process where a student might cease to engage.

The second issue here is the dehumanising process of recounting what is disabled about you. This aspect of the process is heavily shrouded within the medical model of disability with a focus on impairment (Masala & Petretto, 2008). An applicant must accept that in order to gain support they are required to embody the disabled identity or risk being deemed too capable to receive support.

When the issue of evidence was raised by Addington (2019) the response from the government was that the SENCoP (2014) directs schools to prepare the young person for life after school and college, and so it was on schools and colleges to support students in successfully applying for DSA. However, this does not account for individuals who are coming to university after a break in education or students whose college may not have the expertise or resources available to support students in this way (DfE, 2019). It also does not account for the cost associated with re-assessment or for a doctor’s note. Finally, this focus on the colleges and schools does not address the issue that the student must engage with the health service in order to obtain evidence, as reports on an autistic student that are compiled by schools and/or colleges are not accepted as appropriate evidence (Student Finance England, 2019).

Before finishing this section, I must discuss the challenges encountered by minority groups within the autistic community being able to gain a diagnosis in the first instance. Though there is no space here to fully discuss the major issues around autism being stereotyped as a white male condition I feel it is important to spend some time highlighting these issues as access to a diagnosis and thus support is not always equal and there is growing recognition around the additional barriers those from ethnic or cultural minorities encounter as well as a gender bias (Rivet & Matson, 2011; Wijngaarden-Cremers et al., 2014; Brett et al., 2016; Loomes, Hull & Mandy, 2017; Petrou, Parr & Mcconachie, 2018).

Looking at gender, it is often stated that the difference between numbers of autistic males and females is a ratio of 4:1 (Fombonne, 2009; CDC, 2014; Petrou, Parr & Mcconachie, 2018). Though it is not clear why there is greater diagnosis of males there are a number of factors thought to contribute (Petrou et al., 2018). One factor is a believed bias in the diagnostic criteria and perception of autism resulting in professionals and screening instruments not reliably observing female autistic traits (Dworzynski, Ronald, Bolton & Happé, 2012; Loomes et al., 2017; Petrou et al., 2018).

Additionally, Kirkovski, Enticott, and Fitzgerald, (2013) contend that there is a clinically different manifestation of autism in females that is not yet recognised by the majority of diagnosticians or by the APA (2013) or WHO (2016) guidelines and definitions of autism.

The under diagnosis of females is important to highlight in the context of this thesis as this group could be part of the population of undiagnosed autistic students who are not receiving support in HE. But more importantly, the lack of understanding around female presentation of autism may mean that these individuals and the challenges they encounter are not accounted for when developing policy and implementing practice in HE.

With regards race, ethnic and cultural minorities and the additional challenges they encounter epidemiologically, studies show that autism is universal, in that it is just as likely in all people regardless of race or socioeconomic background (Klinger, Dawson & Renner, 2003; Palmer, Blanchard, Jean & Mandell, 2005). Yet there are diagnosis disparities between minority groups and young white males (Begeer, Bouk, Boussaid, Terwogt & Koot, 2009; Williams, Hartmann, Paulson, Raffaele & Urbano, 2019). Harris, Barton and Albert (2014) criticise diagnostic guidelines for not accounting for cultural and linguistic differences stating that misdiagnosis is likely to continue to occur without changes to the diagnostic guidelines. This raises questions around whether the medical definition is a westernised white definition that does not account for differences in race or cultures, and if so, is asking individuals to produce medical evidence in order to access support disadvantaging those we know to be discriminated against by the diagnostic procedure?

2.4 Concluding thoughts on the DSA process

It is estimated that there are around 279,000 disabled students in HE (HESA, 2019) with the DfE (2019) reporting that 87% of disabled students have heard of the DSA.

Of those that receive DSA, the DfE (2019) report that over two thirds agree that the support they receive enables them to participate within their course. This access allows these students to be successful, with the DfE (2019) reporting HESA statistics that students who receive DSA are more successful than students who do not. This highlights that support and adjustments do work in supporting students to be academically successful.

But this also highlights the importance of students being able to access the funding they need. If there are barriers to applying, then it could reasonably be assumed that there are students who are unable to gain the supports they require due to being unable to access this vital funding stream. They are then more likely to have a less successful experience of university.

Moving on and focusing more specifically on autistic students who can access support there is a disparity between their experience and the experience highlighted in the DfE (2019) report. In two recent studies the findings revealed that only 48% of autistic students were happy with their academic support and considered themselves successful and achieving (Gelbar et al., 2015; Jackson et al., 2018). More qualitative literature reveals a number of key challenges that are still an issue despite support (Macleod & Green, 2009; Van Hees et al., 2015; Jansen et al., 2018; Gurbuz, Hanley & Riby, 2019). Accessing support is one issue but there is clearly an issue with the type of support available once accessed. I will now go on to discuss these issues in more depth.

2.5 Academic support and adjustments

One of the earliest studies to explore academic support and adjustments for autistic HE students was a small-scale case study by Taylor (2005). He focused on three students across two years at one university. Reading the nearly fifteen-year-old study it is interesting to see the transformation knowledge has gone through around supporting autistic students. One of the key recommendations to come from Taylor’s (2005) work was that pastoral care should be minimised so as not to embarrass the student. Such a recommendation would be seen as poor practice today, with potential negative effects on not just the student's academic work but also wellbeing (Fabri et al., 2016; Hannam-Swain, 2017).

Yet Taylor (2005) also recommended what would now be considered staple adaptations such as clearly defined instructions, better organisation and timetabling, and better communication between students and tutors.

I draw attention to this older study as I feel, as an autistic student, encouraged through the realisation of how the understanding of the needs of autistic students has progressed in the past decade. The individualistic nature of autism is now better understood.

As a result of this understanding, rather than a model of one size fits all, universities now try to meet with students and develop a more personalised learning contract (Harrison, Bunford, Evans & Owens, 2013; Jansen et al., 2017; Gurbuz et al., 2019). This move to an individualised approach is evidenced in the requirement for an assessment of needs with each student who discloses a disability (Student Finance England, 2019; DfE, 2019). During these meetings a student will discuss what they find challenging when learning and the university DSS officer will put together a learning contract specific to that student to address these challenges (Kendall, 2016). However as discussed there still appears to be a disconnect between the supports offered and what the student experiences (Gelbar et al., 2015; Jackson, Hart & Volkmar, 2018).

One of the most common adjustments and one that does not necessarily require DSA funding, is the provision of course materials in advance (Gelbar et al., 2014; DfE, 2019). The aim is to allow students the extra processing time before sessions so that the students may play a more active role within sessions if they choose. The DfE (2019) highlighted that 35% of participants within their large evaluation reported being able to access materials online prior to sessions. This is congruent with the findings of Gelbar et al. (2014) who found that access to lecture notes was the most common daily adjustment. Fabri et al. (2016) highlight this specifically as good practice for supporting autistic students.

However, there is some evidence that the practice is discouraged by some tutors who feel it promotes laziness (Kendall, 2017). Healey, Bradley, Fuller and Hall (2006) revealed that for some of their participants, tutors discouraged the use of early notes. One of their participants, Lisa, felt so much pressure from her tutors that she forwent using materials supplied through her learning contract entirely. This is somewhat congruent with my own experiences: I had lecturers who would remove key words from the materials that they supplied in advance or would withhold notes until after the sessions to ensure students would attend.

Though my experience and the experience of Lisa occurred before many of the policy changes, in a more recent study by Osborne (2019) 20 participants emphasised a wish that academic staff would understand that they are not lazy or faking to gain benefits and supports that they do not really need. Osborne (2019) adds that if a student has what is considered an invisible disability, they are less likely to be seen as legitimate by academic staff and will struggle to access the adjustments afforded to them within their learning contract.

Furthermore, the DfE’s (2019) own statistics show that only a third of students receive this most basic of adjustments. Additionally, the DfE’s (2019) own student case studies highlighted a want for tutors to wait until after teaching sessions had occurred before making materials available. It could be contended that this practice highlights that some tutors believe basic supports offer some form of advantage that they have to police, highlighting a lack of disability knowledge which is consistent with the participants in Kendall (2017).

Alongside materials being available they also need to be accessible. The DfE (2019) established that making accessible course materials available was the most recorded adjustment in the UK with 55% of all respondents and 60% of DSA receiving students stating they received materials in an accessible form. However, this is still worryingly short of 100% which would be expected given it would be considered making course materials available in an accessible way is a reasonable adjustment under the Equality Act (2010).

The DfE (2019) suggests that both making lecture notes available early and making course materials available in an accessible format was dependent on tutor ‘buy-in’. They highlight that to see this practice become a staple there is a need to increase tutor acceptance.

Tutor acceptance of disabled students appears to be the key for the wellbeing and success of disabled students (Sasson et al., 2017; Gurbuz et al., 2019). The DfE’s (2019) most significant finding was that 74% of their participants were dissatisfied with the support that tutors offered. This was congruent with Gurbuz et al. (2019)

who found that autistic students were dissatisfied with the knowledge and acceptance lecturers had for their disability and how it affected them academically. Their participants associated poor knowledge, awareness, and acceptance with lecturers, highlighting it as a cause of some of the academic challenges they faced.

But the impact of poor acceptance can go beyond academic success. Sasson et al. (2017) note that there is increased depression amongst autistic adults who experience low acceptance. Therefore, it is suggested that increased acceptance and appreciation of the struggles some students might endure need to be developed if a university is trying to create an inclusive learning experience for all students (Gurbuz et al., 2019).

Sasson et al.'s (2017) findings are congruent with the experiences of the participants within Osborne's (2019) study. Osborne's participants voiced the lack of acceptance by tutors as the biggest burden they faced. They highlight how tutors would refuse to change activities or the environment to enable disabled students to participate in classes. Osborne states that this lack of acceptance ensures the erasing of disabled students from the HE classroom.

Another study that explored inclusion in HE by Russell and Topham (2012) also found that tutor acceptance was a barrier to accessing support. Their participants voiced how tutors did not recognise their disability. One participant even wished for a "magic-wand" to make tutors accept and understand the struggles they go through in class (Russell & Topham, 2012, p. 382).

A contributing factor towards poor acceptance is poor knowledge. When working with disabled students Moriña and Carballo (2017) state that it is imperative that staff have the correct level of knowledge to teach, support and work with their students. In their study Moriña and Carballo (2017) found that staff teaching disabled students felt more able and confident in their knowledge after specific training.

In another study by Kendall (2017) 48 lecturers acknowledged the need for more training especially around hidden disabilities. Kendall also found that tutors were open to making reasonable adjustments in class but were unclear as to what these adjustments might be. This suggests that learning contracts are not helping tutors as they do not provide enough information in relation to this and thereby are further complicating the challenge.

Within education there is an expectation that educators keep knowledge around inclusion and disability in line with the needs of their students, but often particularly in relation to autism this is not always the case (Wall, 2007; Chown et al., 2018). In a large review of the inclusion of autistic students in HE, Chown et al. (2018) raise questions around the autism specific knowledge staff have. In their large-scale project, they contacted every university in the UK asking for participation and information. Those institutions that failed to respond or declined were presented with freedom of information requests. This allowed for a relatively large amount of information to be obtained from nearly every university within the UK.

The first of its kind, this study garnered a lot of information on various aspects around the inclusion of students who identify as autistic in HE. Of relevance for this discussion are the results around knowledge. The questionnaire sent to the universities included the question "Do you have an autism expert/specialist on staff to provide your staff with advice on supporting students with autism (academically and pastorally)?" (Chown et al., 2018, p. 5). All except one of the respondents answered: 40 (40%) stated they had no in-house expert, 28 (28%) stated they had one in-house expert and 31 (31%) of respondents stated they had more than one in-house expert.

Delving deeper the questionnaire asked the respondents of the question above to specify the qualification of the specialist 'expert'. Though some withheld a response for various reasons (see Chown et al., 2018) the authors identified that across 63 establishments there were only 18 individuals with a qualification in autism.

Damningly the authors end the section by highlighting that one of the establishment's requirements for an in-house autism specialist did not contain the word autism. This highlights a lack of specialist expertise within institutions to not only support autistic students but also staff, which could be problematic given how much emphasis findings from research place on the need for autism specific knowledge.

Though some basic level of knowledge around autism is expected from tutors, the more specialist knowledge and support is wanted by autistic students to come from mentors or specialist personal support staff (Lucas & James, 2017). Due to the individualistic nature of autism, this desire for a standard base level of knowledge institutional wide with a more personal specialist knowledge, held by someone working one-to-one with a student would be not only best practice (Fabri et al., 2016; Chown et al., 2017) but possibly the most feasible practice.

An example of a university member of staff working one-to-one with a student was documented in a case study by Brazier (2013). The paper though referenced as written by Brazier, is actually written in the words of an Asperger's HE student called Brett (it is not clear why this student is not a named author). Brett takes the reader through the issues he faced while studying, like navigating the online systems with new passwords and logins and accessing lecture notes.

Along the way Brett discusses adaptations and workarounds beyond general good practice for the issues he faced. He particularly highlights the importance of having a go-to personal academic support rather than a list of various names. This is something I have credited to my success in my first two degrees and something which I struggle with since that provision was removed post DSA cutbacks.

Both I and Brett used a single 'go to person' to not just mediate communications vital for HE study but also as a safety net to help reduce anxiety and enable better focus on academic studies (Brazier, 2013). This type of non-medical help has been withdrawn since the changes to DSA. However, universities have responded with the development of mentoring schemes (Lewthwaite, 2014; Lucas & James, 2017).

Similar to the personal one-to-one system myself and Brett experienced, the system of mentoring allows students to meet with their mentor a few times a week for support with academic work and organisation. Griffin and Pollak's (2009) study looked at the experiences of students at one university which used such a mentoring system. They found all but three of their 27 participants highlighted that their mentor was integral to their academic success though they do not go into detail as to the relationship and responsibilities of the mentors.

Additionally, three participants (different to the three noted above) discuss how their mentors go above and beyond supporting them beyond academic study (Griffin & Pollak 2009). This finding is intriguing as the premise of this thesis is to explore not just support with the academic aspect of university but support for students with the greater 'whole university experience'. There has been little evidence within the literature to support this type crossing over to other aspects of student life (Lucas &

James, 2017). Yet Griffin and Pollak (2009) show that it can and does happen, albeit on a small scale here, and they allude to it as unofficial and beyond contracted time.

The type of work that the mentors in Griffin and Pollak (2009) carried out was noted as unofficial. However, there is very little with regards to guidance of the type of work or relationship mentors should have (Lucas & James, 2017). Universities tend to develop their own internal polices with regards to what should and should not happen but as far as Lucas and James (2017) can determine these policies are not developed from academic literature or research.

Indeed, Lucas and James (2017) highlight in their study into mentoring of autistic students that there is very little research in this area. Using a mixed methods approach to understand the experiences of both mentors and mentees they found that mentors feel that autistic students present uniquely different requirements of the mentor-mentee relationship than other disabled students. They found that because autistic students face both academic based and social challenges, mentors need to be highly flexible to adapt to these shifting needs during sessions. They identify that when this is the case both the autistic students and the mentors have a more positive relationship.

In a study exploring the use of mentors in HE in the US by Giust and Valle-Riestra (2017) it was found that again the use of mentors to support students resulted in the increased success of those students. But the study also highlighted that mentors needed to receive ongoing training and support themselves to be flexible to the requirements of their mentees as highlighted by Lucas and James (2017). This suggests a potential gap in knowledge when coupled with the findings of Chown et al. (2018) as there potentially is not any ongoing autism specific development of knowledge for mentors due to the lack of in-house experts to provide it.

Whether it is a mentor, a personal assistant or access to disabled support advisers it is clear that autistic students need increased contact time to either allow for more processing time, clarify communication, reduce anxiety or improve organisation. Having someone to support students appears from qualitative methods-based research literature to be one of the most important aspects autistic students themselves voiced.

Autistic students also specifically highlight time as a support they find key (Madriaga & Goodley, 2010; Gelbar et al., 2014; Anderson et al., 2018; DfE, 2019). Be that extra time for exams, extra time on deadlines or extra contact time with both mentors and lecturers as with Griffin and Pollak (2009).

This contrasts somewhat with Taylor's (2005) recommendation for the reduction of contact time but also highlights how institutions now try to mitigate issues around processing using extra time. The idea being that giving students time to process what is required, time to organise and carry out tasks while meeting with mentors and tutors, and extra time as a safety net if required with assignments and exams, enables students to be less stressed and less anxious resulting in them being more successful (Lovett, 2011).

Students in Madriaga and Goodley’s (2010) study state that although they did not always use the extra time afforded to them, having it allowed them to work with less stress. These findings are congruent with the students in much of the research who used extra time to reduce pressure on them (Griffin & Pollak, 2009; Brazier, 2013; Shmulsky & Gobbo, 2013; McLeod et al., 2017; DfE, 2019).

However, additional time has its issues, students in Madriaga and Goodley (2010) highlighted that there is a forced disclosure with extra time particularly with exams. The students in their study highlighted how they felt uncomfortable discussing the reasons behind extra time as they did not want to disclose their autism to peers.

This is an important issue. Jacklin (2011) and Smith, Woodhead and Chin-Newman (2019) write about how students will disclose to DSS to gain support required for them to achieve but resist disclosure of their disability to peers in an effort to “fit in” which they feel is important for the development of a student identity. Extra time, be it in exams, with tutors or assignments is possibly one of the more overt support mechanisms universities offer, resulting in students choosing to either utilise the support and face discussion around why they get extra or, forgo the adjustment and surrender any positive that may be gained (Madriaga & Goodley, 2010).

Lovett (2011) highlights additional fundamental issues with deadline extensions. They argue that deadline extensions just move the issue for the student to another point in time (Lovett, 2011). Additionally, from my experience as a student and a tutor often the deadline is moved to a point in time where there is less support for students. Deadlines are either moved to the Christmas break or the summer outside of teaching time. The result of this is that students are now experiencing the pressure of a deadline and all the stress and anxiety that comes with this time, with less support available.

Furthermore, it could be contended that extra time, deadline extensions and extra contact time are just superficial 'plasters' for barriers faced by students, almost like giving the student more time makes up for them encountering barriers and challenges created by HE institutions (Hewett, Douglas, McLinden & Keil, 2017).

Extra time does however currently benefit autistic students more than it hinders and though adjustments around time may mask a more deep-rooted issue, providing students with more time where possible does help students and should be encouraged (Fabri et al., 2016).

In an earlier discussion I argued that exploring and understanding how universities need to support autistic students is important now more than ever due to a fundamental shift in the way in which universities teach their curriculum. Gone are the days of solitary sitting listening to lectures followed by 20 hours of personal study. Courses are now taught (and assessed) using a variety of teaching methods including group work, presentations, and time in industry (Sheffield Hallam University, 2017; University of Manchester, 2018). This shift Shmulsky and Gobbo (2013) suggest has resulted in further changes to the way autistic students need to be supported. Though the adaptions discussed above (e.g. extra time, organisation etc.) are still relevant and still highlighted by students as important there are newer challenges impacting on autistic students. The main new challenge is that there is now a greater reliance on social learning across all university courses (Shmulsky & Gobbo, 2013).

There is an increased use of group work not only to facilitate learning but also to assess knowledge (Sutherland-Smith, 2013). Group work is considered to have a number of benefits including better representation of working life, better student support and ultimately improved academic performance (Lavy, 2017). However, group work does rely on a number of aspects to be successful such as communication, working with others, adherence to often ambiguous social rules and understanding of group dynamic, all of which an autistic student can find challenging (Beardon et al., 2009; Lavy, 2017).

A relatively large study was carried out by Beardon et al. (2009), this utilised data collected during the ASPECT consultancy report (Beardon & Edmonds, 2007). Beardon et al. (2009) found that of the 238 participants involved in the original report 135 participants identified as encountering challenges at university particularly around group work due to communication challenges. The authors suggest that in this instance some support for the student in understanding neurotypical behaviour might help, but equally the authors suggest help for the neurotypical students to understand the autistic student's behaviour may also be beneficial. This is an example of how practice needs to take account of the Double Empathy problem (see Milton, 2012).

This type of support for both autistic students and neurotypical students may also help address another issue that arises with group work, and that is acceptance. The impact of low acceptance has already been highlighted with regards to low acceptance from tutors, yet low acceptance from peers has the potential to be even more impactful on health, wellbeing and sense of self due to the ramifications of social positioning (Highlen, 2017). Students who are seen as strange or different by other students face challenges establishing and maintaining a social standing (Holt, 2008; Holton, 2017a). This type of impact can result in increased isolation which in turn can affect the student's academic performance, health and social identity even further (Holt, 2008; Holton, 2017a).

Autistic students who participated within Sarrett’s (2018) US study highlighted that they would like class peers to receive a level of autism awareness training to better inform them of the idiosyncrasies of autistic behaviour, allowing for greater acceptance and understanding of behaviour, thinking, communication challenges and sensory needs. These findings support the recommendations of Beardon et al. (2009).

Sarrett’s (2018) findings could transition well into a UK university and would help some of the concerns that students expressed in Madariaga and Goodley’s (2010) paper. Their participants felt that it was ok to let peers know about dyslexia, but they were concerned about disclosing autism. This suggests a hierarchy of acceptable disability within these students' social groups. Of the eight respondents in their study six stated issues with group work, and in particular the social interactions required to work as a group, suggesting they would rather go it alone than have to navigate the social awkwardness of group members discovering the additional challenges that the participants faced.

The impact of group work cannot be overstated. This is most evident in another large-scale project the Autism&Uni project (Fabri et al., 2016). This inquiry was carried out between 2013 and 2016 and investigated the experiences of autistic HE students across five European countries. In a 2016 published guidance on enabling practice for tutors working with autistic students, which was informed by the findings, there is specific mention of group work and the impact it has on autistic students (Fabri et al., 2016). The text quotes a number of former students who dropped out of university because of, as they explicitly state, the amount of group work they had to do. These participants go further and state that had they not had to engage with such levels of group work they would probably still be at university (Fabri et al., 2016). They suggest that communication is a key factor towards group work being so challenging. The guidance suggests that lecturers facilitate the groups where possible and step in if communication appears to break down (Fabri et al., 2016). The authors go on to recommend that autistic students be given the option of alternative working arrangements, assessment and oral presentation if group work is too challenging for a student (Fabri et al., 2016).

Yet before group work even starts and the recommendations above are implemented, the anticipation of group work can cause anxiety. In a study by Knott and Taylor (2014) they found that students had concerns around the logistics of starting group work, particularly finding a group to work with and then getting going. The autistic students stated they would rather be assigned a group by a tutor instead of them having to find their own group. The participants suggest being assigned a group has the additional benefit of reflecting real working life where they may have to work with people they do not necessarily know. This would also mitigate the anxiety and potential social awkwardness of making initial contact with peers.

Here I would argue that a recommendation would be that through negotiation with the students, the tutor would facilitate the formation of the group using the principles highlighted in Beardon et al. (2009) and Fabri et al. (2016).

However, despite these potential benefits to both professional development and student wellbeing of tutor facilitated group work, the tutors in Knott and Taylor (2014) have a contrasting view to the students. The tutors raised concerns about disadvantaging non-autistic students by placing them in a group with an autistic student and potentially negatively impacting their grade. In this instance the tutors clearly conceptualise the autistic student as a 'burden', a deficit to those who must work with them. This is further evidence in support of my earlier argument around the importance and value of tutor acceptance. This example highlights the potentially damaging view tutors can have of autism and autistic students. Furthermore, this raises a question as to why these tutors are forcing students to be assessed in a manner that they believe autistic students will struggle with as a result.

In this section I have presented some of the research and debate around the academic support and adjustments that universities try to put into place to support autistic students. I have also discussed some of the ramifications both positively and negatively with regards to the supports and adjustments that are generally applied. I will now move onto other aspects that are claimed to impact on a student’s success at university.

2.6 Student identity

Identity is the beliefs, qualities and expressions of a given self or group (Berzonsky, 2011; Berzonskya, Cieciuchb, Duriezc & Soenens, 2011). Identity formation is a major developmental challenge that individuals face often during late teens, early adulthood or during times of change (Erikson, 1968; Marcia, 1980; Daniels & Brooker, 2014; McLean & Syed, 2015; Schwartz, Luyckx & Vignoles, 2011; Topolewska-Siedzik & Cieciuch, 2019). For many, university is the first opportunity they have had to control their own environment and expression of identity, as no longer do parents/carers make decisions or manage their finances (Holdsworth, 2008). This first true experience of independence makes university the perfect opportunity to construct a wholly independent identity (Daniels & Brooker, 2014; Holton, 2017a).

Yet it is not as straight forward as just choosing a random identity: identity is influenced by one’s environment, social group, role and task (Berzonskya et al., 2011; Daniels & Brooker, 2014). Furthermore, a person’s current identity is likely to have an influence on this identity shift. Sometimes their current identity aligns with student identity and there is a need for little movement and sometimes a person’s current identity contradicts the more traditional student identity. This is more evident in non-traditional students such as mature students, first generation students or, in the context of this thesis, autistic students (Daniels & Brooker, 2014; Shepherd, 2020).

In relation to university, preconceived ideas are a further influential factor (Holton, 2017a; 2018a; 2018b). Students can have expectations of what university life is like before entering university and how being a student should be performed. They may imagine it to be about partying, sports, community, activism, sex, drinking, late nights, mess and dirt, sleeping in and a restricted diet (Maunder, Cunliffe, Galvin, Mjali & Rogers, 2013; Loxton, Bunker, Dingle & Wong, 2015; Holton, 2017a; 2018a; 2018b). These ideas create expectations of social norms within the unique environment of university and can influence the development of identity, as safe identities do not stray too far from societal norms (Reay, Crozier & Clayton, 2010; Koefoed & Simonsen, 2012).

In the age of social media preconceived ideas of student life is fostered further. Madge, Meek, Wellens and Hooley (2009) highlight how many students join Facebook groups pre-registration to meet future classmates and flatmates. They specifically note the importance their participants placed on joining their halls' Facebook groups to begin traversing their new identities early.

However, these groups are often targeted by club night promoters, sports organisers and students’ union society groups who further push the rhetoric of 'the student experience' developing a narrative of what being a student is (Holton, 2017b). Currently at the time of writing, the largest halls' Facebook groups are maintained by student club night promotors advertising freshers' week night life activities with a campaign that features the types of students who are at university including 'the drinker', 'the cheapskate' and 'the slacker' (Organised Chaos, n.d.). In doing so they are further reinforcing these idealised student identities (Organised Chaos, n.d.). Holton (2017b) extends this critique by arguing that universities themselves encourage these activities and ideas of university through their marketing.

Yet, putting such issues aside, there may be some benefits to such an online presence and development of a student community pre-registration. A by-product of this type of communication is that the social interaction challenges, that autistic students themselves report facing, are broken down by the communication specific to social media (Ward, Dill-Shackleford & Mazurek, 2018).

Social media communication requires the use of less communication pathways as there are no verbal and non-verbal cues to follow, there is only plain text (Gillespie-Lynch, Kapp, Shane-Simpson, Smith & Hutman, 2014). Further there is more time for the processing of information, ability to edit posts, clearer signs of what are traditionally ambiguous communications such as sarcasm through the use of emojis and ultimately there is more of an understanding that social media posts can be misunderstood (Ward et al., 2018). This therefore removes one of the barriers an individual might face when beginning to interact with peers and get involved with this shared development of student identity pre-arrival at university.

As a result of these pre-registration connections and preconceived ideas of student life, students are arriving at university with a perception of student life already installed and developing. Their first experience of this university life however is when moving into their accommodation, commonly referred to as 'halls' (Maunder et al., 2013). Crafter and Maunder (2012) and Maunder et al. (2013) report that their participants reflected on an abrupt ecstasy upon arrival and a shift in self that continued. They linked this to independence from parents and the joining of a specific society that is student halls.

A student flat contains the key ingredients for the development of this student identity; there is a room that is the individual's own to customise, Chow and Healey (2008) and Holton (2016a) highlight the adornment of posters in student rooms as the expression of this new or shifted identity. Alongside this personal space is the social hub, of the common space, where social interactions happen, and the social identity can begin to develop.

Finally, there are the other flatmates who in most instances are in the same position as other students experiencing independence for the first time whilst also developing a new or adjusted self-identity (Holton, 2016b; 2018a). This collection of perceived ideas of student life and shared first experience of independence, coupled with the university and the students’ union's promotion of 'Freshers’ Week', all contribute to fostering the development of this new identity (Wilcox, Winn & Fyvie-Gauld, 2005).

It may be too sweeping and simplistic to suggest that when a student attends a university there is a change in their identity. But what is clear is that there is normally some shift in identity and the effect this might have on student wellbeing and academic success is of interest to this thesis. There is a growing body of research focused on the formation of an independent student identity in HE, exploring how students can be better supported through this change, in recognition of the potential impact on academic studies (Good & Adams, 2008; Fearon, Nachmias, McLaughlin & Jackson, 2016; Holton, 2016b; Shepherd, 2020).

Yet as with most research in HE most studies position students within a normalised vacuum with no account taken of the individual differences that make up the student population (Moriña, 2017). Yet there are differences and these differences need to be explored to better support all students.

As was suggested in the opening paragraph of this chapter the idea of a student identity forming is that for most students it is the first time they have been away from home. Yet for some students it might be more than just the first time they are away from home: for some, university might be the first time they are away from being ‘disabled’. Whilst in other stages of education there is a heavy emphasis on support, special treatment, parents being heavily involved with schooling, school being heavily involved in home life and free time observed and analysed, university allows an escape from this external involvement at a decision making level and finally they may be independent (Holton, 2016a).

For many disabled children and adolescents their life has been defined by how others construct and respond to their disability and though there is a movement to change this or at least lessen it, it is still there (Prowse, 2009). For many students who attract the label of 'disabled', the biggest opportunity to move away from a label applied to them and reinvent themselves is when going off to university and leaving parents/carers and all the externally imposed disabledness behind (Madariaga & Goodley, 2010; Shepherd, 2020).

University, Shaw (2009) states, is an opportunity for a disabled student to empower themselves. The way that Shaw discusses this taking back of identity inadvertently aligns with the principles of the emancipatory disability rights movement. However here it is less of a movement for national and international change as it is more just students relishing the opportunity to be in control and where possible take control of who they declare themselves to be and how they want to live.

This taking back, though mainly positive, does have some more negative points that need to be highlighted. First there is the idea that the reinvented student may wish to disconnect with disability services in an attempt to gain control which could explain the high number of students not wishing to declare their disability in the first year of HE (Chown et al., 2018; DfE, 2019). This was evidenced in a European study by Mattys, Noens, Evers and Baeyens (2018). The autistic participants in their study highlighted being conflicted between wanting to be normal and accepting difference to gain support. The participants attempted to forgo supports in pursuit of a traditional student identity. Something also observed by Madariaga & Goodley (2010).

Secondly, and more poignant for this identity discussion, is the idea of now needing to ‘fit-in’ to a conceptualised normal society which could include a drive towards partaking in more risky behaviour in an attempt to carry favour, to the detriment of mental and physical health as well as academic success (Holt, 2008; Madariaga & Goodley, 2010; Holton, 2015; 2016b; 2017a; 2017b; 2018b).

Finally, the move to be more independent may take the individual away from family, peers and institutional supports that have so far helped remove socially constructed barriers, which have helped the student to where HE was a possibility. As a result, the student may go through one of the biggest transitions they will ever undertake, without relevant support in place.

Yet there does need to be caution as sometimes a disabled student is portrayed as a helpless feeble individual unable to function or be a relevant member of society without being externally supported and included (Jacklin, 2011). However, this is not the case. Cyrulnik (2002), Hutcheon and Wolbring (2013) and Zakour and Gillespie (2013) among others all highlight that disabled students can often form a resilient identity as a result of the barriers they have had to overcome in the past.

Further, students have had their supports slowly changing and reduced throughout education with the idea of an independent life as the end goal (Moriña, 2017). Therefore, it could be suggested that this self-determined move away from support, whilst still within the confines of an education system, is the logical middle step between highly supported education and unsupported independent life.

However, Moriña (2017) too suggests caution, highlighting that it is too easy to suggest that disengagement in the pursuit of a new identity is always good and 'has to happen at some point'. Students, both those with a disability and those without, should be facilitated and supported in their development of identity. There should not be a need to disengage with support services to develop an independent identity. The two should not be seen as mutually independent of each other as seen by the students in Mattys et al.’s (2018) study, but rather as one supporting the other.

2.7 Concluding thoughts on student identity

Madriaga and Goodley (2010) and Moriña (2017) report that students are taking the opportunity of university to reinvent themselves; they highlight this as possibly the best time to go through such a change, as has been discussed, most students at university are in some form of identity change most notably during the first year. Therefore, generally there is more allowance for, and acceptance of, such a shift by those around them and the behaviours and expressions such an exploration entail.

Further, disabled students are supported, and these supports could facilitate the exploration of identity, ensuring that such an exploration does not risk academic success or the health and wellbeing of the students. This would be much in the same way that hopefully university staff would support all students.

Finally such a shift in identity is seen as a move towards independence which is consistent with the aims of both autistic students and those around them, and so this shift occurring within university might well be the next step in an autistic adult's life journey and this should be supported where possible (Erikson, 1968; Marcia, 1980; Daniels & Brooker, 2014; McLean & Syed, 2015; Schwartz et al., 2011; Topolewska-Siedzik & Cieciuch, 2019).

2.8 The university built environment

This section will discuss the physical built environment of the university where teaching occurs. This includes classrooms, labs, lecture theatres and breakout learning areas. Individuals might choose to go to university for a variety of reasons (Holton, 2018a). However, once they are at university, regardless of their reason, they are believed by the university to be there for one thing and that is to learn. Learning must occur in order for an individual to progress and pass assessments which is a prerequisite for them remaining a student.

Unless the course is a distance learning course, the focus of the learning takes place within teaching environments. Simply then, if you cannot access the environment then you cannot access the learning. For universities to work the environments need to be accessible for all students.

When looking at the literature around inclusive accessible university classrooms concerns begin to arise. The importance of the classroom has been established as essential, yet Camacho, Lopez-Gavira and Díez (2017) state that they could not find any literature dedicated to profiling a fully inclusive university classroom. They highlight that small amounts of literature into inclusion in HE will stumble across a student’s challenges and aids in using a university classroom. However, there is no purposeful investigation into fully inclusive HE classrooms (Camacho et al., 2017).

As a result, discussion here around the classroom environments for autistic students is patched together from papers where the classroom environment has been brought up rather than specifically studied.

Camacho et al. (2017) discuss how university classrooms are traditionally designed to be ergonomically beneficial for traditional students which can create barriers for disabled students. Furniture, noise, lighting, seating plan and the use of the environment all appear within literature as areas of challenge for disabled students (Bogdashina, 2016, Van Hees, Moyson & Roeuers, 2014; Camacho et al., 2017; Vincent et al., 2017).

As was discussed earlier the teaching methodologies often do not account for autistic or disabled students in general. The same is true with the users of the environment. Camacho et al. (2017) suggest that teaching methods of today often involve the manoeuvring of students around the classroom working in groups or manipulation of objects in the environment. This can result in sessions being experienced as chaotic, highly sensory and challenging for any student with sensory, mobility or fine motor challenges (Bogdashina, 2016).

In the study carried out by Osborne (2019) her participants recounted that session plans and teaching methods often did not take account of how they as disabled students would manoeuvre around the classroom and often there was no adjustment during the session once the issues were raised.

Similarly, Hannam-Swain (2018) recounts her experience as a wheelchair user being unable to access the environment due to structural issues within the built environment. She goes further by explaining the additional labour she experiences as a result of constantly having to think ahead as to whether the environment will be suitable for her needs. This additional labour is something that autistic students might also encounter due to their sensory challenges when entering university spaces. This is echoed by Russell and Tophem (2012) whose participants wanted university staff to be aware of the additional burdens they face day-to-day.

Another issue with regards to access for autistic students within these environments is the perspective through which disabled students are regarded. There may be adaptations for socially constructed barriers with regards to work or assessments, however, within the built environment there is still very much a medical model approach (Oliver, 1992; Camacho et al., 2017). The inclusion of disabled students and a shift in the way the curriculum is taught in HE, is a relatively new phenomenon. As a result, classrooms and the built environment in general often predate the university of today. This leads to disabled students (including autistic students) being seen as a puzzle that needs to be made to fit into the pre-existing environment.

An example of this adapting the student rather than the environment appears in Lucas and James (2018) where they highlight how students who have mentors are more able to access the university environment as the mentor supports them in working within the environment. However, the environment should work for the individual and the onus should not be on the individual to work for the environment (Oliver, 1992).

Another example is Madriaga’s (2010) study where a participant was able to enter an environment due to the support of their mentor. However, again, the student should not need to have to access specific supports to enter the built environment of their university.

Ainscow (2015) states that in order for universities to take a meaningful step towards inclusion there needs to be a fundamental change in mindset. Camacho et al. (2017) points towards technology and possibly reframing what the university environment is. Indeed, Pearson and Koppi (2006), Hockings, Brett and Terentjevs (2012) and Seale et al. (2015) all highlight the benefits of e-learning as a means of eliminating the barriers disabled students face. Further, Richardson (2017) highlights the benefits of distance learning for autistic students. However, I disagree as these different paths for higher education do not remove the barriers as researchers claim. Rather the barriers remain, and the students are removed. Such a shift in the inclusion of disabled students would all but erase them from the halls of academia and lead to a lessening of the drive towards the meaningful steps that Ainscow (2015) states are required.

The built environment can be accessible for autistic students; it just requires an understanding of the needs of the individual through better knowledge and acceptance. Further, the sensory, motor and mobility needs of students need to be taken into account when designing all aspects of the learning environment with a thorough understanding of the Social Model of Disability (Oliver, 1992). This requires teaching spaces to be universally designed to meet the needs of the many without requiring the adaptations for the minority, which is currently observed today (Powell, 2013). Also teaching staff need to be aware of the impact that the built environment can have on learning and take this into account when planning sessions.

2.9 Environments beyond the classroom: digs, books and pubs

As has been discussed there is a lot of scaffolding that supports autistic students whilst at university. So much emphasis is placed on obtaining and implementing the right academic and mental health support for students whilst 'in' university (Fossey et al., 2017). But the reality is that for most students, physically being in the university is where they spend the least of their time, only needing to attend between 10-20 hours a week, dependent on course requirements (Sheffield Hallam University, 2017; University of Manchester, 2018).

For the other 150 hours students are often away from most, if not all, of their support as the support does not extend beyond the classroom (Gelbar et al., 2014; Anderson et al., 2018; DfE, 2019). In this next section I will look at a number of the main environments where students spend their time and discuss some of the challenges autistic students face within these environments.

2.10 Digs

One of the places students spend a lot of time is in student accommodation (Holton, 2016a). This is a social hub, a place to eat, sleep and work whilst away from home. Despite this there is relatively little research around the accessibility of the student living accommodation (Mogenet & Rioux, 2014; Holton, 2016a; 2018a; 2018b) and even less with a focus on autistic students' living accommodation (Gelbar et al., 2014; Anderson et al., 2018). Yet we do live in halls, I did for the majority of my university life and so too did the participants of Madriaga (2010).

For many students (including those who identify as autistic) housing biographies are fairly defined; home to halls to house (Rugg, Ford & Burrows, 2004). Of all the environments that need to be accessible for a disabled student outside of the classroom, their living accommodation is arguably the top priority.

Andersson, Sadgrove and Valentine (2012) highlight that halls of residence tend not to have a set policy regarding the placement and support of students with disability beyond legislative rights such as those prescribed under the Equality Act (2010). This reliance on legislation can be problematic, as often front facing services have little understanding of the rights and protections assumed to disabled people and this is even worse for those with a ‘hidden’ disability (Couzens et al., 2015).

With staff lacking in knowledge around both disabilities and the rights afforded to disabled people it could be concluded that it is impossible for them to make anticipatory reasonable adjustments as is the law (Equality Act, 2010). Further it could be argued that when issues are raised, there is less likely to be acceptance of the issues, as is observed in other areas of the university (Russell & Topham, 2012; Camacho et al., 2017; Osbourne, 2019). This could result in either barriers remaining or being addressed slowly, which when you are dealing with an individual’s home is entirely unacceptable.

When building and designing accommodation such as a hall of residence the mandate is often along the lines of cheap, sturdy and easy to clean with most items being uniform and bought in bulk (Poria & Oppewal, 2002; Khozaei, Hassan, Kodmany & Aarab, 2014). When this is the mandate, building sensory accessible halls becomes more difficult or not considered at all (Mostafa, 2014).

Individuals who identify as autistic can often have sensory based differences, Mostafa (2014) and Nagib and Williams (2017) all highlight how often the lived environment needs to be adapted to be accessible and comfortable. These researchers identified that most homes for autistic people have adaptations ranging from blackout curtains, dimmer switches and nightlights to more wholesale architectural adaptations. When the individual moves out of the family home and into independent or supported living often these types of adaptions are made to their new living accommodation (Mostafa, 2014).

However, for those leaving for university the ability to adapt the halls of residence may be limited and vary from halls to halls. From personal experience the owners of the first halls I lived in made structural changes to rooms to accommodate me and the same was done for other students. Other halls I lived in would not even allow me to change the curtains or lightbulbs despite highlighting the need for specific sensory adaptations as a result of a medically diagnosed disability.

When the environment you live in has such a profound impact upon your life, the need to be able to control and adapt it becomes clear (Bogdashina, 2016; Horder, Wilson, Mendez & Murphy, 2014). As more and more student halls are becoming privately owned and not under the control of the university the ability of a student and those who support the student are diminished, and this can have a profound impact on the lives of disabled students and especially autistic students (MacLeod, 2011; Holton, 2016a; 2017).

However not all experiences are negative as can be observed within Madriaga’s (2010) research which included seven participants. These highlighted that, for them, their halls were a point of refuge, a safe zone from the hypersensitive world of HE. They were a place of solitude where a person could relax, work and get away from the world. The paper however does not go into how adaptable and flexible these student halls were and one of the participants highlighted that their halls were just as sensory overloading as the rest of the university. But it does highlight that for some of Madriaga's participants halls of residence were the only place they could truly relax and feel safe, signifying their importance.

2.11 Books

When not in class, university staff would hope students are spending time studying. To support this most universities now provide access to 24hr libraries. These buildings are not just for housing books but rather aimed at providing a space and equipment for students to study.

Of all of the environments discussed in this section the library is possibly the most supported environment for disabled students. Often there will be provisions within their learning contract that also include the library. These can also include library specific provision such as access to specialist equipment, priority access to specialist areas and additional support around library processes (Madriaga, 2010).

With most courses requiring more independent learning than classroom-based learning, there is a likelihood that a student would need to spend more time in the library than in a classroom (Sheffield Hallam University, 2017; University of Manchester, 2018).

Though there is a highlighted lack of research exploring the inclusion of autistic students within HE classrooms, there is even less with regards to the inclusion of autistic students within the library environment. In fact, there is a lack of research on the inclusion of disabled students as a whole. This was best evidenced in three large studies looking at demographic differences with regards to what impacts on students using libraries by White and Stone (2010), Stone and Collins (2013) and Stone, Sharman, Dunn and Woods (2015). These authors explored race, age, gender and culture as possible factors impacting on library use; curiously disability was not examined.

The environment of the library is a small focus within Madriaga's (2010) research. However other literature around autism and HE fails altogether to explore the library despite its importance (Gelbar et al., 2014; Anderson et al., 2018). This discussion therefore will utilise the body of literature around general library use and literature around accessing environments for autistic individuals.

One of the reoccurring themes throughout this chapter is how universities have shifted from traditional institutions of specific independent learning to a more social, co-learning environment. Part of this shift has also included changing university libraries where the traditional book filled building characterised by adherence to rules of silent independent work has morphed into University Resource Centres, filled with technology and areas to meet and discuss (Alvite & Barrionuevo, 2011).

These newer libraries are bright open spaces where social co-learning is the explicit focus. Alvite and Barrionuevo (2011) particularly point out the use of social life to intensify academic learning. Libraries are now a place to hang out and work together rather than independently.

With this however there comes potential issues. In an effort to create more opportunity for social learning, libraries have moved to a more open plan approach which brings a number of sensory issues both through design of the environment and removal of control (Hough & Koenig, 2014). Lighting, surrounding movement, ambient noise and temperature are all sensory challenges autistic individuals are faced with, particularly within these open plan environments (Bogdashina, 2016; Hough & Koenig, 2014). Coupled with the lack of independent control within this type of environment, for sensory reasons alone a library can be incredibly challenging (Madriaga, 2010).

Participants of Madriaga (2010) specifically highlight the inaccessibility of the library. In fact, there is more of a consensus with regards to the inaccessibility of this environment over any other explored within the paper. The participants particularly voiced noise as an issue.

This increase in noise is to be expected with the move towards a more social learning focus. Most of Madriaga's (2010) participants stated that due to the inaccessibility of the library their halls became their place of study. This places even more emphasis on halls of residence to be fully accessible.

There is the further issue related to the new social direction of libraries. They are designed with a focus on promoting sociality which creates anxiety for some students, especially around negotiating the ambiguous social nuance of determining when are you meant to socialise and when are you meant to work (Madriaga, 2010). Feeling that the environment is designed to make you be social and struggling to know and apply a very environmental specific social nuance, can mean the idea of entering this environment is just too much for some (Alvite & Barrionuevo, 2011;

Russell & Topham, 2012; Hough & Koenig, 2014). Simply by designing the building to be more social, a barrier is created for those who find the prospect of social interaction too stressful (Russell & Topham, 2012).

The move towards more social co-learning has resulted in structural changes within libraries. This has then led to sensory issues and anxiety around the more social design. This then results in a corner stone of university learning being inaccessible for autistic students which could impact on academic learning and group work. These issues need to be taken into account both when designing areas of study but also when designing a support package for an autistic student. It might be that other areas are made available and certain supports are not tied to the library such as writing skills tuition.

2.12 Pubs

The final main environment of focus outside of the ‘classroom’ is the students’ union (SU) and related environments. Again, there is very little research that specifically explores the adjustments and barriers associated with the inclusion of autistic students within the SU (see Madriaga, 2010; Gelbar et al., 2014; Anderson et al., 2019).

Participants of Russell and Topham (2012) highlight the importance placed upon SU societies, socials and drinking, and as was discussed in the student identity section of this thesis, there is an emphasis of a ‘whole university experience’. Key to that is the SU both as a body and a building (Brooks, Byford & Sela, 2014; Holton, 2017b 2018b).

The SU is a body of representatives who are key actors in the improvement of university student experience (Raaper, 2018). To do this the SU carries out a number of activities including but not limited to: organising social activities, promoting health and wellbeing, representing the interests of the student body both locally and nationally and advocating for students on academic issues (Brooks et al., 2014). To do this SUs tend to be located within a student union building. These buildings often contain meeting areas both formal and informal such as boardrooms, cafes, bars and games rooms (NUS, 2019).

With the importance placed on social activities and given that the SU representatives are where students who feel discriminated against are partly expected to turn to (NUS, 2019), it is clear that the building that is so integral to the experience of students, has to be accessible.

One study that does explore the SU building was carried out by Madriaga (2010). This yearlong study based upon emancipatory principles worked with eight autistic participants to explore their use of university spaces. One of these spaces being the students’ union. His participants highlight the important position the union occupies as the keystone to social engagement. Most noted that peers, societies and housemates would utilise the union bar as the main social place.

However, the participants highlighted barriers to accessing this space with half of the participants having reservations about entering the space. They noted that it was a loud, chaotic, smelly environment that was not conducive to someone with hypersensitivities (Madriaga, 2010).

The inaccessibility of the students’ union is problematic as the informal nature of the student bar traditionally allows for the breaking down of social barriers in a way that is not possible within class. This allows for peer bonds to form and solidify which can be a valuable resource of course related social capital, which is highly important in this newer socially focused approach to HE that universities are taking (Holt, 2008; Madriaga, 2010). Therefore, the environment being inaccessible due to sensory challenges is stopping some students from creating friendships that can be called upon for group work and co-learning (Madriaga, 2010; Holton, 2016a; 2017b; 2018b).

Madriaga’s (2010) paper also looks at the use of the building by the SU and specifically its use for freshers’ week. Freshers’ week is the 7-14 day period at the start of term often before the timetable starts formally, when students are acclimatising to university and completing relevant admin. During this time the SUs generally put on daily activities to facilitate the development of friendships such as mature students’ mixers, sports and activity sign-up days and ‘get to know you games’. These activities for the most part take place within the SU building.

Some of Madriaga’s (2010) participants highlight how these types of events result in the building being extremely loud, cramped and chaotic. As a result, they discuss being unable to participate in the events finding the building too inaccessible.

Furthermore, a study by Vincent et al. (2017) that was co-authored with the participants, also highlighted that the events that the SU ran during freshers’ week at their university were not accessible for autistic students.

This is concerning in light of Holton’s (2016a) investigation into student social capital. He found that by not taking part in these initial events there was a long-lasting negative impact on students’ ability to ‘fit-in’ whilst at university, which can have dramatic repercussions on both academic success and personal wellbeing (Holt, 2008; Reay et al., 2010; Holton, 2018a; 2018b).

Yet it must be noted that not all participants had issues with this environment. Some of Madriaga's (2010) participants voiced no issue with these events. Some accessed the space with no adjustments or supports, with one participant accessing the space with the support of a mentor. Furthermore, one of the participants gained a job at the bar so spent the majority of their time within this environment.

But that is not to diminish the experiences of some of the participants. One of Madriaga's (2010) participants discussed the loneliness and isolation they encountered from not being able to access this space.

Andersson et al., (2012) found a similar finding with their study. They highlight how a student may not only feel lonely during this initial period, but also face future exclusion, negativity and discrimination from other students at a social level. This can congruously be tied to the development of student identity, as the collective group identity developed and formed while the autistic student was excluded as a result of the inaccessible environment. This results in the student now being too much of an 'outsider' with different likes and dislikes to become a part of the social group at a later stage (Andersson et al., 2012; Curşeu, Janssen & Raab, 2012).

2.13 Concluding thoughts on the built environment

In this section I have highlighted and discussed three different but key environments outside of the teaching space. Of course, these are not the only environments that someone may encounter whilst studying at university (Holton, 2017a). However, each of these environments has been highlighted as integral to university study

(Madriaga, 2010; Holton, 2016a; 2017a; 2018a). Furthermore, these environments are where individuals will spend the majority of their university life (Holton, 2016a; 2017a; 2018a).

When these environments are inaccessible, it not only impacts on the learning for the student, but also can impact on health and wellbeing too. Key barriers that were identified are associated with sensory challenges. Supports can aim to address many of the barriers a student faces such as organisation and processing time, however if an environment is inaccessible due to sensory challenges currently there appears to be very little effort to remove these barriers (Madriaga, 2010; Gelbar et al., 2014; Camacho et al., 2017; DfE, 2019).

These types of environmental barriers could consequently be contributing to the high rate of drop-out amongst autistic students as highlighted by Chown et al. (2018). Therefore, it is my belief that the environment and specifically the sensory profile of environments must be explored further and with more focus than is currently occurring within literature, if there is to be a meaningful attempt to include autistic people within HE.

2.14 The interwoven social aspect

This next section will explore the social aspect of university. As discussed previously there is a heavy social focus to many aspects of university life, interweaving and influencing various parts such as academic success, student identity and wellbeing (Shahini, 2010; Beattie & Thiele, 2016; Darabi, Macaskill & Reidy, 2016; Denovan & Macaskill, 2016a, 2016b).

The social element within university is a difficult concept to plan and build supports for. This is because unlike the above sections, social interactions are not governed by any policy or legislation. Universities cannot create a policy to make one student socialise with another.

However, universities can create opportunities for socialisation to occur. A number of these social opportunities have already been highlighted such as the shift in library focus, the encouragement of group work and co-learning, and the development and promotion of the concept of a ‘social student’ by universities (Holton, 2017a).

How these factors influence the opportunities for social interaction will be explored here. This is to evaluate to what extent a university and its partners such as the SU and halls of residence, can support students, through making adjustments and removing barriers to better facilitate access to these opportunities for social interaction as was evidenced by Madriaga (2010).

To add some structure to this discussion I have identified three often distinct university social categories based on control.

> The first is the social aspect of the halls of residence, or at least in the first year, for most students do not choose their flatmates. This therefore is a ‘constructed opportunity for social interaction’.
>
> In that same vein the second category is the social aspect of a student’s course as students do not choose their peers but rather they are placed with them. Again, this is a ‘constructed opportunity for social interaction’ that is not within the individual’s control.

Finally, the third category is friendship groups and acquaintances. This is self-governed but can be influenced by the other two categories.

University is a highly sociable experience (Fearon, Nachmias, McLaughlin & Jackson 2016). I remember listening to the speech of the students' union president on my first day. He highlighted that as students we are likely to find our partners, our best men, our maid of honours and our lifelong friends whilst at university.

Of course, there was no research to support this claim when it was made, but looking back and seeing so many of the people I went to university with now married to each other, having children, buying houses and staying in contact, it is clear that there was some truth to the statement. Indeed, I myself met my fiancée at university in the SU and our wedding will be made up of family and university friends.

Though the speech made by the SU president cited no literature, there is in fact a growing body of research exploring the social aspects of university that highlights such a lifelong impact (Holton, 2017a). However, like with other areas of HE literature, little focuses specifically on the social aspect for autistic students, and those papers that do often fail to link any of the social discussion to other areas of inclusive investigation (Gelbar et al., 2014; Anderson et al., 2018). In this section I aim to begin to draw together links between social aspects of university, autism and academic success; something that to date has not yet been done within the literature.

The way in which the impact of social interactions, friendships and relationships are understood and analysed is often debated (Holt, 2008; Holton, 2016; 2017a; 2017b). Geographers and sociologists have a number of approaches at their disposal. However, I feel that using Bourdieu’s (1986) theory of Social Capital is the best approach for the micro-society that is HE. This is congruent with Holton (2017a) who explores socialness and its impact on life from Bourdieu's (1986) perspective. He highlights that the specific society of HE is within a societal bubble where you work, eat, sleep and spend spare time. This he argues best exemplifies Bourdieu's (1986) perspective of social capital and therefore is the best lens through which to explore these social interactions and the impact they have whilst studying at university.

Social capital is the network and relationships around an individual in a given society (Holt, 2008). I see this in the context of HE rather simplistically as a student's network that they can lean on when times are hard. The more social capital you have the more people you can turn to and the likelihood they will be in a position to help. This can therefore be seen as the more social capital you have the more likely you are to be academically successful.

I feel that this perspective specifically fits well within this discussion due to Bourdieu's (1986) belief that social capital is not an independent variable but rather influenced by a number of factors that intersect. This therefore creates room for disability and other identities and influences to be considered.

Though when envisioned it was not explicitly aimed at exploring socialness and disability, the flexibility of Bourdieu's (1986) perspective allows it to be used when accounting for multiple influences. Additionally, the ideas of Holt (2008) also adds to our understanding of social capital specifically with regards to disability. Holt (2008) highlights a negative with the notion of social capital. She argues that social capital is embodied within an identity. As a result, this can include some negative aspects of difference being embodied within one's sense of self such as the idea of being a burden. I feel this perspective further adds to the understanding of the experience of autistic students within HE and the longer reaching impact upon health and wellbeing.

Understanding that social capital can have a positive effect if gained, and a negative effect if not, highlights the need to facilitate as much as possible the gaining of such capital. This is in part why universities have shifted to a more social approach, the more social capital you have the better you perform academically. Therefore, universities want students to have large amounts of social capital and so places them in situations to best facilitate this (Holton, 2017a). However, if the policies and practices create barriers for disabled students, then such policies and practices are actively stopping students from generating social capital and impacting on their ability to gain the beneficial effects associated, and exacerbating the negative effects of not having social capital.

2.15 Social aspect of halls

It has long been accepted that the students we live alongside significantly impact upon our Higher Education experience (Pascarella, Terenzini & Blimling, 1994; Taulke-Johnson, 2010; Holton, 2016a). This has been furthered by Kenyon and Heath (2001) who contend that these experiences can influence later life living choices; this is due to student halls being more than just a building.

I see student halls of residence as a living breathing hub of complex social interaction, defined and redefined by its immediate environment, culture and geographical location. It can be both a sanctuary from and cause of stress (Madriaga, 2010; Holton, 2016b). It can be your place of work or a place to escape the weight of academic pressures. It can be the best time of your life or a living nightmare (Madriaga, 2010; Connolly, Davidson & Collins, 2016; Holton, 2016b).

The importance of halls on identity and the challenges faced by the built environment have already been discussed. Here I will discuss how these challenges can interact with the social nature of halls for autistic students.

Most modern halls are designed around a common space with smaller individual rooms for personal space (Holton, 2017a). The result is the largest part of a "home" is often the communal space which promotes socialisation. Through design, flatmates spend a lot of time together and usually this is the greatest source of halls based social capital (Holton, 2017a; 2018b).

Most students in a flat are experiencing university for the first time, so there is a shared experience which further facilitates the development of social capital (Holt, 2008). Additionally, these students are also going through a shared shift in identity towards a society specific, student identity (Erikson, 1968; Marcia, 1980; Daniels & Brooker, 2014; Topolewska-Siedzik & Cieciuch, 2019). This means that there is also a shared identity which again promotes the development of social capital (Holt, 2008). Finally, these students all have similar tasks and skills to learn in the first weeks of university: make friends, learn their new environment and begin to complete registration tasks within the university. This again further facilitates the development of social capital as students begin work to achieve these tasks together. As a result, the first few weeks in halls of residence can be the most important time of a student’s university life (Andersson et al., 2012; Holton, 2017a; 2017b; 2018b).

With such a weight of importance associated with both this time and halls in general any barriers a student might face could be incredibly impactful. Holton (2016a; 2017b) highlights that there is a social culture that is encouraged by both the universities through marketing materials and the students themselves. He states how if you choose to withdraw from this social culture then you dramatically impact your ability to form relationships and generate social capital. He goes on to highlight that this social culture is one of social activities, drinking and coupling/sex.

When exploring the experiences of Madriaga’s (2010) participants there is an expression more of isolation rather than integration. Although participants highlighted that they liked halls and found their halls to be a place for relaxing and escaping, all the experiences could be categorised as self-isolation. Without participating within the socialisation students are positioned by others as different. Holt (2008) argues that social capital needs homogeneity in order to occur, the shared identity, shared experience and shared tasks result in homogenous beings. However, the heterogeneous experiences that Madriaga’s (2010) participants discuss reduce social capital. Though not discussed some conclusions can be considered as to why there is a motivation by some for more isolation.

First there is the idea that halls are used to escape the sensory world of university. If the communal areas are not congruent with the reduced sensory input required, then these areas will be avoided. Further many students in both Madriaga’s (2010) study and Russell and Topham's (2012) highlight an anxiety around entering environments where being social is the overt focus. They discuss the debilitating thoughts around navigating the social nuances of such environment which can lead to individuals disengaging and withdrawing to more personal spaces.

Finally, there are certain activities that are promoted as part of the student experience. As stated earlier, Holton (2016a) highlighted drinking, coupling/sex and participating in student nightlife as the key social activities. If these activities are the types of activities individuals do not like or again have issues with accessing or are made unable to access, then individuals are further seen as outsiders depleting social capital (Holt, 2008; Holton, 2017a; 2018b).

Andersson et al. (2012) evidence the segregation of disabled students during the initial days and weeks of first year halls. They found that disabled students were treated like outsiders by other students. They specifically emphasise how disabled students are left out. This is compounded when these students cannot access the main socialising environments. Without the access to socialisation students can be, and in the studies discussed are, seen as 'outsiders' within their own micro-society of the 'home'. As Holt (2008) highlighted, this positioning can embody an individual's identity leading to negative effects on health, wellbeing and academic success far beyond the first year of halls.

Of course, halls are only meant to be a student's home whilst studying at university in their first year. Most students will move from halls into shared accommodation. Though there are no statistics that track students' movements and there is very little research that explores the reasons why, it is believed that students will often move into shared housing with friends and do so based on social capital (Card & Thomas, 2018). This therefore creates a challenge for students who lack social capital; some may move home, and some may stay in halls. Regardless, both alternatives to shared housing result in a furthering of the individuals 'outsiderness', which again can impact on social capital.

The focus of this discussion has been student accommodation be it halls or shared housing, however there are many students who live at home and travel to university (Pokorny, Holley & Kane, 2016). In this instance Holton (2017a) believes these students are doubly impacted on. First their legitimacy as a member of the student community is questioned and by living at home there may not have been the same shift in identity that other students experience. Additionally, these students are not fully experiencing the ‘student life’ and so by not sharing the same identity and experience these students automatically are seen as outsiders.

Holton (2016a; 2017a; 2018b) also highlights how home students are not seen as engaging in the whole university experience by the university itself. He highlights how marketing promotes the only way to experience the true student life is by living in student halls. It could be argued then that the autistic student living at home will stand little chance of gaining social capital in this way (Holton, 2016a; 2017a; 2018b). However, the home student is also not exposed to the negative effects that Holt (2008) argues will impact upon a person’s sense of self either. As a result, similar to a disabled student living in halls, they will not gain the benefit of this social capital but, unlike a student in halls, nor will they also suffer from any negative effect associated either.

What is clear from this section is that living accommodation can have a profound impact on not just how someone experiences university but also their health, wellbeing and academic success. As such there needs to be more focused research into this element of university for autistic students.

2.16 Social aspect of the course

Much in the same way when students first move into halls there is a shared experience, identity and new life skills (Holton, 2017a), when students first start to meet course peers and begin the first formal timetabled activities there is also a new shared experience, identity and life skills.

Additionally, and importantly there is often a shared interest. It is expected that students are on a course that they are interested in and possibly share the same lifegoals as their peers. As a result, course peers are in a uniquely advantageous position to form networks and relationships and thereby develop social capital (Holt, 2008).

There is a further element to the social aspect of a course and that is the forced interactions through teaching methods and group work (Buriro, Mallah & Chandio, 2013). These are further opportunities for social connections to develop due to a more specific shared experience and task, as well as the extra time these students will have to spend together outside of class to accomplish the task.

With regards to exploring the benefit of these more social teaching methods, Brouwer, Jansen, Flache and Hofman (2016) inquired into academic success and social capital looking at small class sizes. They highlighted how universities have moved towards smaller class sizes for seminars rather than just large lectures in an attempt to increase social learning. They highlight the important impact social relationships can have on academic success (see Hendrickson, Rosen & Aune, 2011; Mamiseishvili, 2012; Rytkönen, Parpala, Lindblom-Ylänne, Virtanen & Postareff, 2012; Rienties, Héliot & Jindal-Snape, 2013; Brooman & Darwent, 2014).

Much has already been discussed in this thesis around the potential barriers that might arise from the move to social teaching and assessment (Buriro et al., 2013). Specific to this section, as with halls, is anxiety around the social interactions and their potentially debilitating effects, resulting in issues with working in groups or co-learning in class (Russell & Topham, 2012). These anxieties can be experienced as so intense that students are willing to leave a course rather than be forced into further interactions (Fabri et al., 2016).

There is additional pressure, as these interactions factor in academic success. Therefore, there is more of a focus on working harmoniously. As a result, it could be argued that under such pressure any difference is magnified with other students taking a vested interest in the input of other students. Ideally this would lead to peers working to better facilitate a disabled student, in order to place everyone in a position to succeed.

However, unfortunately there is more likely to be a widening of any divide as the disabled student is seen as different and a non-member of the group (Holt, 2008). Further to this Holt (2008) argues that an acceptance of difference furthers inequalities and positions the ‘outsiders’ further away from the ‘insiders’. In this instance both the barriers that an individual may face and the label they attract can distance the student away from their peers.

It may be this distancing of those who are seen as different, that results in so many students wanting to lose their disabled identity in order to be accepted as normal (Camacho et al., 2017). This is exemplified by the student in Madriaga and Goodley’s (2010) paper who positioned dyslexia as socially acceptable and autism as not. This student might have had concerns with regards to how the identity of being autistic might position her so far from the social norm that she would be considered an ‘outsider’ (Holt, 2008; Holton, 2018b). It therefore is important that staff within the university communicate to both other staff and students so that they are more aware of disabilities (Beardon et al., 2009). Here Beardon et al. (2009) give recommendations around developing the knowledge and understanding of non-autistic students about autism and wider differences, to counter the negative lens through which difference is seen. However, there would need to be careful consideration as such education would result in the disclosure of a student’s disability.

Whilst increasing peer acceptance of difference could go some way to removing some of the barriers and anxieties, so too could removing the pressure and importance placed on peer socialisation. By removing the assessment and learning aspect from peers socialising there may be less of a focus on difference, allowing those who are positioned as different to exist in the same environments with the focus on the individual rather than on the difference.

2.17 Social aspect of friendships and acquaintances

As highlighted, both flatmates and course peers are the focus of interactions and social opportunities that for the most are outside of an individual's control. Socialising outside of these two groups however is within the control of the individual. This might mean that a student who is seen as different by peers and flatmates might be able to find a social group that they would be considered an ‘insider’ of.

The participants in Russell and Topham's (2012) inquiry highlighted this as a solution to their social conundrum and suggested it should be developed by universities. They wanted a discreet society of the outsiders, with a place to meet that was fully accessible and where the focus was not drinking. Though I think this is a commendable idea it is interesting that they still formed the idea of a social group around the traditional structure of a university society. This could be due to the idea promoted by universities that being part of a society is integral to the ‘whole university experience’ and so the participants did not want to stray too far from the norm (Holt, 2008; Holton, 2017a).

When it comes to friendships there is still a need for shared experience, identity and social life tasks. However, without the constraints of academic work or the idealised view held by most students in halls (Holton, 2016a; 2017a; 2018b) there is more room for non-traditional students to ‘fit-in’.

One of the main sources of social groups away from flatmates and peers is through student societies. Facilitated and funded by the SU, student societies can be based around (within reason) anything from tea drinking to music as long as the pursuit is legal and there are willing students to form a society then the SU will support the group (NUS, 2019).

A key time for these societies is freshers' week when they advertise and hold taster sessions for all students to come and try out. This event is a key event in any student’s calendar. It is so significant that it specifically gets discussed within Madriaga’s (2010) paper on spaces. As was discussed earlier, his participants found the environment that the freshers' fair was held in to be inaccessible for some. The environmental and practice-based decision to hold freshers’ fairs in these types of spaces can directly impact on the access to these social groups for disabled students (Madriaga, 2010; Andersson et al., 2012).

Despite this key event being inaccessible for some it is not inaccessible for all; some students may not have an issue with the sensory environment or be socially anxious about meeting new people. It might be as was the case with one of Madriaga’s (2010) participants that the supports in place as a result of DSA funding allowed him to access the space and also engage with the groups within the space. This is congruent with my experience; I had an aid with me when not in halls. They were able to support me in the joining of a sports team and this group of students, not peers or flatmates became my sole resource for social capital whilst at university and long after.

Some students within Madriaga’s (2010) study were able to join societies. However, they then highlighted a new barrier to socialising with this new group. All of the participants highlighted how the societies would meet and socialise within pubs and the SU which they found inaccessible due to anxiety and/or hypersensitivities. As a result, although a member of societies, these participants highlighted not having any friends and therefore were not optimally gaining social capital.

This focus on socialising within traditional student areas which Holton (2017b) identities as the ‘student bubble’, means that often even when finding a group that was accepting of difference and with a shared interest and experience that transcends perspectives of disabilities, the social gathering can still be inaccessible resulting in isolation (Camacho et al., 2017).

2.18 Concluding thoughts on the interwoven social aspects

Though this is not the experience of every student, those who are able to access and engage in the opportunities for socialisation can flourish and reap the benefits of the social capital gained. However, if a student is not supported and the specific ideals of student life are further marketed by universities, either explicitly or implicitly, then autistic students will go on encountering barriers and not gaining the benefits that other students are engineered to be exposed to.

In stating that however I feel it is important to remember two things when considering the potential positives and negatives of social relationships and their impact on an autistic student. Firstly, some autistic individuals may not be challenged by social interactions and may even thrive like any other student as a result of these interactions as highlighted by Madriaga and Goodley (2010) and Madriaga (2010). By identifying or attracting the label of autistic, a student does not automatically have issues with socialising. Therefore, it is important to treat each individual as an individual.

Secondly and possibly most importantly there are those students who prefer being alone and gain comfort from this through being able to focus their energy on studying and relaxing (Murray, Lesser & Lawson, 2005). It is incredibly important that these students are not seen as wrong or in need of intervention. Though there are benefits of social capital, there might be an increased benefit in wellbeing to a student that chooses to spend time alone. If this is the case, then we need to consider elements of university that force socialising.

The social student is a normative ideal promoted by society and universities and like other PNT normative ideals, should not be positioned as the gold standard (which it currently is) that those around an autistic person should strive to help the autistic person achieve. Doing so only dehumanises an autistic person further and positions their way of life deeper into the abnormal.

There needs to be a melding; the ideal student experience needs to stop being so marketed by universities, and both the environmental and socially constructed barriers a disabled student might face, need to be removed giving the student freedom to engage with the social opportunities highlighted above if they chose.

Furthermore, if students choose not to then that choice needs to be accepted and respected, and not constantly worked against either by teaching methods or those around the student.

As was stated in the opening paragraphs of this section the social aspect is arguably the hardest to support and plan of all the different facets discussed in this chapter. However, as universities move the agenda more and more towards social learning and assessment there has never been a more important time to start addressing some of the issues highlighted.

2.19 Chapter 2 conclusion

At the start of this thesis I highlighted that the research exploring autistic students in HE was relatively small compared to other minority groups within HE (Gelbar et al., 2014; Chown et al., 2018; Searle et al., 2019). This is despite autistic students being 40% more likely to fail and withdraw from university (Fabri et al., 2016). When taking into consideration the findings from Hastwell et al. (2013) and Chown et al. (2018), that show between 2009 and 2018 the number of students identifying as autistic in UK universities increased in excess of 200%, the scale of the problem facing both universities and autistic students becomes visible.

Moving beyond the statistic and percentage points within this chapter I aimed to put together a comprehensive review of the literature exploring autistic students experience in HE. To investigate the positive enabling experiences they had encountered that might promote good practice, as well as the negative experiences and challenges they encountered to both highlight potential pitfalls that might be avoided but also to spotlight shortcomings that readers of this thesis may be able to remove.

What became clear quickly was that research tended to focus only on particular specific facets of university life, such as academics (Griffin & Pollak, 2009; Madriaga & Goodley, 2010; Seale et al., 2015), social life (MacLeod & Green, 2009; Jones et al., 2013; MacLeod et al., 2013) or the physical and social environments (Madriaga, 2010). Yet as an autistic student I felt that there was an interconnection between each of the facets of my university life: sensory issues at home impacted my work and anxiety around socialisation impacted both my living accommodation and group work. Additionally, within disability studies it is strongly claimed that the environment and society, and the policies that govern these, all impact on the life of disabled people (Oliver, 1981; Barnes et al., 2010; Retief, 2018). So, I would suggest that the failure to consider the interconnectivity and interaction of the student with all aspects of the physical, social, political and cultural environments is a major short fall within this research area (Hastwell et al., 2013; Seale et al., 2015).

As a result, I felt it was important to explore these facets of university within my literature review and provide one of the first literature reviews with a comprehensive exploration of the ‘whole student experience’. To do this I looked at the various experiences that the literature highlighted students would go through on their journey through HE. Furthermore, this was guided by my own experiences.

The review of autism and HE literature began with the pre-arrival elements looking at how autistic students access support and some of the barriers to accessing this support such as the need to accept the medical model perspective of being impaired and requiring medical evidence.

I then analysed the experience of students with regards to academic supports and adjustments. What was clear was that when students were offered support and utilised support, they achieved success (DfE, 2019).

However, there were also many students who experienced issues with the support they were offered, such as being discouraged by tutors from using the supports to which they were entitled. These included early access to materials (Healey et al., 2006; Osbourne, 2019) and supports relying on a level of forced disclosure to peers (Madriaga & Goodley, 2010). A major theme from this discussion was the lack of tutor knowledge as a result of insufficient support and training for tutors (Chown et al., 2018; Kendall, 2017). This I believe leads to the poor acceptance of the nature of autism that tutors were seen to display and shows a clear need for better development of knowledge and understanding not just in autism but in acceptance of difference in general (Russell & Topham, 2012; Chown et al., 2018).

I then explored student identity. Though not a universal phenomenon, most students will go through an identity shift when leaving home and becoming independent for the first time (Erikson, 1968; Marcia, 1980; Schwartz et al., 2011; Daniels & Brooker, 2014; McLean & Syed, 2015; Topolewska-Siedzik & Cieciuch, 2019). As a result, the first year of university is a time when many individuals both autistic and non-autistic begin to explore a more independent and mature identity (Holt, 2008; Daniels & Brooker, 2014; Holton, 2017a). But it is not as simple as just choosing a new identity: there are many factors such as past experiences, preconceived ideas of studenthood and social surroundings (particularly flatmates and class peers) which can all influence the development of the student identity.

The most significant point that emerged from this analysis of the literature was around supporting individuals during this period, as the additional labour of trying to navigate the social nuances at this time can result in a negative impact on the mental wellbeing of students, particularly autistic students.

The literature review then turned to the built environment exploring student halls, university buildings, the library and social areas such as the students' union and pubs. Surprisingly, given the focus on making buildings accessible for disabled students, there was very little literature around the built environment and even less around the sensory aspect of these buildings (White & Stone, 2010; Stone & Collins, 2013; Stone et al., 2015; Camacho et al., 2017). From an evaluation of the available literature there appeared to be a theme of the environment changing to suit more modern teaching methods with larger open spaces, moveable furniture, and a focus on social learning. When applying the literature around the changing architecture in HE with literature around sensory processing styles, the hostile environment of the learning spaces became evident. Universities are moving towards a brighter more social environment and this is impacting negatively upon some autistic students (Madriaga, 2010; Alvite & Barrionuevo, 2011). However, some students were able to access these spaces with support (Lucas & James, 2018) though I would argue that access to university spaces should not be dependent upon support, especially when there are known barriers to gaining supports.

Finally, I reflected on the social aspects of university. The social aspect is considered so important that universities are building socialising into their marketing, learning environment and curriculum. As someone who has been a student for 13 years at this point and someone who struggles with the social dimension of collective learning, I have experienced this development first-hand. For example, gone are the silent single person learning booths in libraries as they are replaced with café style social areas with group workstations and a relaxation on noise rules. A design of study spaces that is not conducive to many autistic students.

There is a growing amount of literature exploring the link between the social life, student wellbeing and academic success (Shahini, 2010; Beattie & Thiele, 2016; Darabi et al., 2016; Denovan & Macaskill, 2016a, 2016b). This has been the catalysis for change. Holton, (2017a) argues that this is due to social capital being so important for when students are struggling, as a more social student has more people they can turn to in times of need (Bourdieu, 1986). Here the student identity is important as Holton (2017a) contends that a prerequisite for joining the student social group is a shared student identity. Additionally, there needs to be the ability to access the same spaces as this social group. As a result, if a student struggles to gain a student identity or is unable to access the same social spaces as a student group then they will find it difficult to generate social capital and are therefore denied the benefits of this. This alone is problematic but with a move to a more social student focus by universities this could compound any issues further.

The literature presented contends that the ‘whole student experience’ is only achievable when a student is able to access all student environments, is able to engage unchallenged within social grouping and able to manage the balance between learning and a social life. Although many tutors might declare that not all students are capable of this, many are and those that are not often are not negatively affected enough where it begins to impact on physical and mental wellbeing to the degree highlighted in this chapter. Of course, it is impossible for universities to control a student’s social life but what is possible is for universities to both support students who wish to access this element of university. But also to allow for alternatives for those students, autistic or not, who either do not wish to or are currently unable to access this aspect, alternatives to group work, alternative learning and study spaces, alternative living set-ups and promotion of alternative social events. This would go some way to helping students either access currently closed off spaces and activities or enable students to access these spaces and activities that universities acknowledge are important factors towards a healthy successful student.

Having explored the barriers and enablers that have been identified to date within the research literature I now turn to my own study and the experiences of those involved in this thesis. The next chapter will outline my emanciparticipatory framework for research as well as my argument for its use.

Chapter 3

The Development of Emanciparticipation

3.0 Introduction

Before starting, I wish to make it clear that what I feel is a misuse of terms like participatory and emancipatory, does not detract from some of the work that has used these terms in ways that I hold to be incorrect. Nor do I believe researchers have set out to misuse these terms and of course some researchers have indeed used these terms correctly. I do however feel that often the way in which they are used today is a corruption from research that is produced specifically for the positive impact on the autistic community and now I feel that these terms are utilised to justify the carrying out of research. In essence I feel that some researchers now use these terms without fully following through in practice with the principles of participatory and emancipatory research. This view is congruent with Waltz (2006) and the autistic participants of Fletcher-Watson et al. (2019).

Within this chapter I detail the development of my emanciparticipatory framework. To do this I discuss first the representation, or the lack of, autistic people within traditional research, (Pellicano, Dinsmore & Charman, 2014; Fletcher-Watson et al., 2019). I will then present two alternatives that developed as a response to traditional research approaches.

To start this discussion, I will critique traditional research. Here I use the term traditional as an umbrella term for the more widely used positivist research within medicine and academia (Parker, 2007; Goodley & Lawthom, 2008; Nind, 2011; Pellicano et al., 2014). Both today and historically positivist-based research has been the dominant underpinning philosophy in researching autism (Chappell, 2000; Nind, 2011; Zwicker & Emery, 2014; Yusuf & Elsabbagh, 2015). I will examine the experimental psychological research and then move on to reviewing later biomedical research. These are the biggest forms of autism research to date (Pellicano et al., 2014; Zwicker & Emery, 2014; Yusuf & Elsabbagh, 2015; Autistica, 2017). However, I will argue that these have very little potential to have a positive impact on the lives of autistic people today. I will also discuss social science research that is not participatory or emancipatory and detail why I and others (Milton, 2014; Chown et al., 2017) believe that though better than the traditional psychological and biomedical based research, there are still issues which social science shares with traditional research.

Similarly, I will explain emancipatory research and how this differs from both traditional research and participatory research. Though as I will explain I see emancipatory research as highly powerful, I also discuss how I believe that within academia the emancipatory research approach is unable to be fully engaged with due to the constraints of academia. As such, I put forward an argument that to call research emancipatory whilst under these constraints is inaccurate and will act as a barrier to the emancipation agenda as terms like participatory and emancipatory when used incorrectly will begin to erode the control and influence that autistic individuals are fighting for.

Finally, I will put forward my emanciparticipatory approach which I developed to enable my research. I will position emanciparticipatory research as the mid-point between participatory research, which I feel has lost all value to the activist researchers pushing for a socially just approach to autism research, and emancipatory research which as stated I feel is unable to be realised within academia.

3.1 Research into autism: traditional psychology experiments on the mind

This section is by no means an in-depth discussion on the issues of traditional psychology-based research. This is not required in order to articulate the development of participatory or emancipatory research. However, I do think it is important to acknowledge this, not only because this area along with the later discussion on biological research combined make up nearly 99% of all autism research (Pellicano et al., 2014; Zwicker & Emery, 2014). But also, because both participatory and emancipatory research frameworks are a direct response to the main issues of concern with these traditional types of research (Oliver, 1992; Zarb, 1992; Goodley & Lawthom, 2005; Goodley & Lawthom, 2008; Chown et al., 2017).

Pellicano et al. (2014) highlight that psychology makes up the largest amount of UK based research. This is not surprising as autism is historically tied to this type of research with the first explorations of autism focused on the minds of autistic children. Hans Asperger (1944) and Leo Kanner (1943) observed and tested their young patients noting down their peculiar behaviours. They saw the minds of the children they were observing and testing as abnormal compared to the expected 'normal' behaviour of peers and it is this intrigue that started a 76-year (and counting) obsession that the psychological and medical community has had with exploring and documenting the abnormalities of autistic people (Goodley & Lawthom, 2005; Frith, 2012; Pellicano et al., 2014).

One example of this focus and arguably one of the most influential studies on autism (Chown, 2016) was conducted by Baron-Cohen, Leslie and Frith (1985). This study went on to produce one of the most dominating theories of autism that is still influencing autism research, practice and thinking today (Chown, 2016). Baron-

Cohen et al. (1985) compared autistic children carrying out a false belief task with two control groups; one which they termed 'normal children’ and one was a group of Down's syndrome children. The belief was that the autistic children would show a dysfunctional Theory of Mind. The researchers suggested this was an explanation for the impairments and behaviours that autistic children are observed to have.

This methodological approach of comparing autistic with non-autistic individuals much in the same way as Kanner and Asperger did, is one repeated over and over throughout the history of autism and is still the main approach used in research today (Frith, 2012; Silberman, 2015).

As an autistic person this is concerning as it positions autistic people as dysfunctional, abnormal and below expectations (Runswick-Cole, Mallett & Timimi, 2016). A perspective which Waltz (2006) is concerned is carried through to society and reflected in practice.

The key identifiable features I see of this type of research are:

1) Autistic people are used as participants more akin to a resource than a person, with little to no opportunity to have input into the carrying out of the study.
2) Tests are designed to model behaviour (including the absence of response). Often these tests also place the autistic person in a dehumanising situation in which they are expected to fail.
3) The hopeful outcome is one that provides support for a theory/hypothesis that positions autistic people as less and/or other.
4) Heavily situated within the medical model of disability.

Advocacy and activist organisations claim this type of research adds nothing to the quality of life of autistic individuals (Arnold, 2010), but rather is driven by the obsession of the inquisitive minds of researchers to identify abnormality and difference, in what Arnold (2010) claims is an effort to satisfy their own curiosity. An example of this can be seen in a paper written by Frith (2012) that was also presented at a large conference around the need for cognitive explanations of autism. Frith recounted the history of autism research, before presenting the exciting advancements of today, finally she finishes with her hopes for the future.

I however find it revealing that she did not once discuss the benefit of this research to autistic people’s wellbeing or how such research could improve practice and thereby the quality of life for autistic people and their families. To me it is clear, that the priorities of mainstream psychology are often around learning about autism for nothing more than academic development (Arnold, 2010).

The conclusions I came to of the Firth (2012) paper, can take some support from the research of Pellicano et al. (2014) and Zwicker and Emery (2014) whose studies have asserted that the priorities of the autistic community differ greatly from the direction that research is taking. The main areas autistic people would like research to explore are autism and ageing, autism and females, autism and suicidality, autism and race, and autism and mental wellbeing rather than explanations of autistic behaviour (Pellicano et al., 2014; Zwicker & Emery, 2014; Warner, Cooper & Cusack, 2019). Furthermore, there is a want from autistic people to have more voice and control in research in order to help divert it towards research that can have meaningful impact such as the priorities listed (Milton & Bracher, 2013; Fletcher-Watson et al., 2019).

Building on this, Charlton (2000) (among others such as Goodley & Lawthom, 2005; Parker, 2007; Milton & Bracher, 2013; Fletcher-Watson et al., 2019) argues that by not taking into account the experiential knowledge of disabled people, researchers are not only missing out on the contribution of additional knowledge but by denying their participants input it only reinforces the oppression of the autistic community. Additionally, Parker (2007) claims that this traditional approach only furthers the betrayal of psychologists who are failing to help people.

This view may seem exaggerated, however Waltz (2006) highlights that from the growth of autism research in the 1970s and ‘80s we now have practices such as Applied Behavioural Analysis and other such 'approaches' that are focused on normalisation and getting a child's behaviour to model the same as non-autistic children (Kupferstein, 2018). Additionally, Goodley & Lawthom (2005, p. 136) also acknowledge how mainstream psychology has “inflicted many dangerous and oppressive practices on the minds and bodies of disabled people” and only by moving to more collaborative approaches will there be political and societal change for the better.

In this section I have highlighted how there is a tendency for traditional psychology research to not necessarily place benefits for autistic people at the centre of the research. I have also explored the idea that this mainstream psychology tends to lack the voice of the autistic community and how autistic participants have very little power and can often be placed in dehumanising positions. As a result of this, I and others argue that we need to move away from this traditional type of research if as researchers we are aiming to benefit the communities we are researching (Goodley & Lawthom, 2005; Milton, 2014; Chown et al., 2017; Fletcher-Watson et al., 2019).

3.2. Research into autism: experiments on the body

Parallel to the traditional mainstream psychological research, is biological focused research. While the psychological research explores psychological explanations of behaviour, biological research looks to identify the biological cause of autism (that produces the behaviour psychology is so fascinated with) and then cure or treat it (Yusuf & Elsabbagh, 2015).

Zwicker and Emery (2014) reviewed the allocation of research funding in the US and the UK, they identified a divide in the priority of funding. They position that funding either explores aims to impact now or in the distant future. By this they mean research either impacts on the health and wellbeing of autistic people more immediately or research that is designed to find the genetic cause of autism and enable a cure to be developed to reduce the risk of autism sometime in the future as advancements here would be more over decades. Zwicker and Emery (2014) assess the current funding trend, the US in particular has focus on genetic testing and the seeking out of methods to reduce the risk factors that might lead to autism within an ontology of prevention and cure. Zwicker and Emery (2014), among others, (Pellicano et al., 2014; Yusuf & Elsabbagh, 2015; Autistica, 2017) identify that the current focus is clearly on exploring cure-based research that worryingly appears to disregard the wellbeing of current generations of autistic people.

In Europe, the European Union has greatly increased in its search for a genetic cause and treatment of autism with the extension of funding to the EU-AIMS 2 trials (IMI, 2019). This project alone has received 113 million euros of funding for what they term a pipeline for autism treatments (IMI, 2019). Clearly indicating the priority of the European Union is to develop genetic based diagnostic capabilities and then pursue treatment of autism at a medical level.

Looking specifically at the UK, research carried out by Autistica revealed that nearly half (44%) of autism research funding was spent on animal studies that were designed to explore biological treatments of autism (Autistica, 2017). This highlights the priorities of funding organisations and researchers in the UK are also focused on biological based treatment and cure, with only 27% of funding being spent on the top ten concerns of the autistic community, which are centred upon helping remove societal barriers rather than rehabilitation and cure.

The overview that I am presenting here highlights how the majority of funding around autism goes towards biological funding with the aim of finding means of identification, treatment and ultimately cure. This global recognition that autism is a flaw, firmly positions it as a personal tragedy and further reaffirms the ‘less than’ perspective through which autistic people are seen (Goodley, Lawthom, Liddiard, & Runswick-Cole, 2019). This is furthered by how the priorities of the autistic community that are challenging the traditional research, are again largely ignored by those who claim to have a goal of helping (Pellicano et al., 2014).

Yet, Yusuf and Elsabbagh (2015) argue that evaluations of research priorities by researchers such as Pellicano et al., (2014), are problematic. They argue that the types of stakeholders that are consulted are limited and they call for more professionals and parents to be consulted offering a view of what they term the damaging effects of autism. Yusuf and Elsabbagh (2015) also argue that often scientific research is too complicated for non-professional stakeholders to understand and it is risky to expose non-professional stakeholders to such complexities and then expect them to be able to make informed contributions in the way that the autistic community are asking for (Pellicano et al., 2014; Chown et al., 2017; Fletcher-Watson et al., 2019).

The type of position Yusuf and Elsabbagh (2015) hold is a fundamental problem around greater involvement of stakeholders. Zamora et al. (2016) contend that it should be the responsibility of the scientific community to make their work accessible to all. They suggest that research that is presented in ways that are too complex for non-professional stakeholders should be made accessible or be categorised as unethical.

Additionally, when there is such a clear demand for more funding to be spent on research to help the health and wellbeing of autistic people today over eugenics, then that cannot go ignored (Pellicano et al., 2014). Further, it can be argued that by developing a wider understanding of autism and better supports for ‘today’ you can still positively impact the autistic people of ‘tomorrow’, where genetic focused research sacrifices the health and wellbeing of autistic people today with no guarantee of being able to help the autistic people of tomorrow.

Finally, there is the positioning of autistic people as a genetic mutation that must be identified and eliminated to save the children of tomorrow. It is clear that biomedical research sees autistic individuals as impaired and in need of a fix for the betterment of their parents and society (Yusuf & Elsabbagh, 2015). This is best evidenced in the pushing of the financial ‘cost of autism’ as a means of pursuing more funding for genetic based research (Horlin, Falkmer, Parsons, Albrecht & Falkmer, 2014). Autistic people are being perceived as a drain on resources and with each move forward of this type of agenda autistic people are being seen as less and less human (Goodley, 2014).

3.3 Traditional social science: research *'on'*

Moving on from the more positivist traditional research, there is traditional social science research (Wallace & Wray, 2009). Though less about testing autistic children to see how different they are, this type of research still has issues particularly around impact, accessibility and voice (Macaulay, 2017). The traditional social science research lifecycle often starts with a call for funding submissions with funding being prioritised to submissions that meet the focus of the funders at that time. A researcher(s) will think of ways to meet the requirements of the funding body whilst not straying too far from their own interests.

Once funding is gained a researcher(s) will put together a team and begin to carry out a more in-depth review of literature before designing the study and applying for ethical clearance. Once clearance is gained the researcher(s) will begin to recruit participants either through advertisement or direct contact (Yates, 2003).

Then begins the data collection phase(s). Once this phase(s) is complete the researcher(s) will analyse the data and begin to write up their study. From here the researcher(s) will aim to publish papers, present at conferences and possibly look to inform on practice or policy changes supported by the results of their study (Yates, 2003).

The first glaring issue here is the absence in the design and control of the study of members of the community being investigated (Nind, 2011; Fletcher-Watson et al., 2019). Many of the key decisions are made by researchers who usually do not identify as a member of the community they are investigating and so they are making decisions as an outsider with potentially differing views and priorities than insiders (Zwicker & Emery, 2014, Pellicano et al., 2014, Yusuf & Elsabbagh, 2015; Fletcher-Watson et al., 2017).

Beyond decision making at a larger level such as formulation of the focus of research, more pragmatic decisions around design could also impact on accessibility (Chown et al., 2017; Fletcher-Watson et al., 2019). If research is only accessible to a narrow sample of a community the voice and experiential knowledge of those unable to access research is absent. This again could result in policy and practice development that does not then consider the specific challenges that these members of the community encounter. This was highlighted by the parent participants of Pellicano et al. (2014) who voiced concern that research tends to be made up of those who attract the label of high functioning. This may be due to these individuals being able to both answer the call for participation and actually participate within the research. This group is often the easiest for researchers to work with as the communication style and practice of participants most closely resembles the researcher's own.

Though more emphasis is placed on accessibility to participate as a requirement of ethics (SHU, 2015), fundamental decisions can still lead to members of the community being unable to participate in the research. An example of such a decision would be MacLeod (2016) who recruited her autistic participants through email. This is after publishing a paper (MacLeod & Green, 2009) that highlighted the issue autistic people encounter with responding to emails. A seemingly insignificant decision may create a barrier for participation. In other research highlighted within the literature review participants were interviewed (e.g. Madriaga & Goodley, 2010) or completed a questionnaires (e.g. Clince, Connolly & Nolan, 2016) both requiring specific skills some may find challenging.

Though impact is important within all research there are some issues with the impact aims of traditional research. Much of the research literature that has been reviewed for this thesis aims to impact on the autistic community by adding to a growing body of research and highlighting problematic areas to decision makers (Bastow, Dunleavy & Tinkler, 2016). The issue is that the benefits of research almost always rely on individuals from outside of the research field such as politicians, civil servants and educators (Bastow et al., 2016). The work itself rarely makes a positive difference that is felt by those who participated, or their wider community, a fault of traditional social science acknowledged by Walsh, Elsabbagh, Bolton and Singh (2011a).

I have briefly looked at research carried out within traditional psychology, biology and medicine, and now more traditional social sciences. All have their weaknesses; however, a common flaw was the lack of meaningful representation of the community being explored within the research. As such, other issues such as access and research priorities are left unchallenged from within as well as a vital stream of knowledge missing from the contribution. I now move on to the approaches that developed as a response to these issues and looked to readdress the power imbalance and promote the voice of disabled people.

3.4 The rise of participatory research: research *'with'*

It is important to note that within this chapter it might appear that I am critiquing five different approaches to researching autism as though they have parity in power and effect. But it is important to be clear that almost all (99%) of autism research can be categorised as traditional psychology, biological or traditional social science research (Pellicano et al., 2014). Only a relatively small number of research studies would be classed as participatory or emancipatory (Chown et al., 2017). This clarification is important as after some discussion with the other autistic students involved in this research, they identified a potential misunderstanding (informed by their own misunderstanding), that research has moved from experiments on autistic people to research now being participatory in design with the needs of the autistic participants at the centre of the research design (Walsh et al., 2011a; Yusuf & Elsabbagh, 2015). This sadly is not the case; the research approaches discussed in this part of the chapter and beyond are still in their infancy as a paradigm and collectively make up a small portion of the 1% of autism positive research identified by Pellicano et al. (2014).

Despite the ‘nothing about us, without us’ mantra of organisations in the late 1980s and early ‘90s there was (and indeed still is) a lack of autistic voice within research (Waltz, 2006; Milton, 2014; Fletcher-Watson et al., 2019). Chown et al. (2017) highlights that autism research, appears to be exclusively the domain for the medical and psychology communities to explore, with little room for autistic people. This they, and Milton (2014) argue persists in keeping autism firmly within the medical model of disability.

This linkage of autism research to the medical and psychological research communities highlights a great power disparity within autism research. Psychologists and clinicians dominate the discourse within autism and thus are able to promote their own self-interests (Walsh et al., 2011a). In Walsh et al.'s (2011a) response to Pellicano, Ne’Eman and Stears (2011) they go as far as stating that what Pellicano et al. (2011) considered an oversight around challenging the flow of funding is entirely acceptable considering the potential for their genetic based research compared to the lacklustre social science based research. This view by Walsh et al. (2011a) firmly positions their research importance over other research interests and, what I consider incredibly problematic, over the priorities of the autistic community.

In an effort to address these types of issues, there has been a shift by some towards research approaches that look to relocate the power of the research from the researcher to the participant (Oliver, 1992; Goodley & Lawthom, 2005; Milton, 2014; Chown et al., 2017; Fletcher-Watson et al., 2019). Participatory research seeks to readdress the researcher-participant hierarchy through the researcher engaging in work that meets several key principles. These are; active involvement of the participants in more than a participant role (e.g. co-researchers), decision making shared equally where possible between the researcher and the participants, flexible methods to allow for greater participant agency and, where possible, engagement beyond the data collection phase (Nind, 2011).

Participatory research methods are now more frequently employed within disability research in response to disabled people calling for a more pluralist approach to research (Oliver, 1992; Danieli & Woodhams, 2005). However, as Waltz (2006) points out, this early success with participatory research within disability research did not transition to autism research immediately. This is why participatory research, which is now more of a staple within disability studies, is still considered a new practice within autism research (Fletcher-Watson et al., 2019).

There are many benefits to adopting a participatory framework. Milton and Bracher (2013) highlight the ethical and epistemological issue of not including autistic individuals in social science research that seeks to understand autism. They argue that this could be to the detriment of the research because there are autism specific considerations that may not be considered, as is seen in existing research. But by working with autistic people in a positive participatory way this issue can be mitigated, and research will benefit more autistic individuals due to the wider voice and breadth of experiences that could be accessed (Rivet & Matson, 2011; Wijngaarden-Cremers et al., 2014; Brett et al., 2016; Loomes et al., 2017; Petrou et al., 2018). Wright et al. (2014) contends that participatory research has a greater likelihood of traversing the theory to practice gap and resulting in real impact in a community as there is more priority placed on the wants of the autistic community. Further when looking at minority groups within the autistic community Harris, Barton and Albert (2014) suggest that only by engaging with wider members of the community can you attempt meaningful change, as they are required as agents of change. Wright et al. (2014) also highlight that this will make autism research more sustainable, as funding organisations are more likely to fund research that can evidence meaningful impact which is more likely to occur when engaging with the wider autistic community. This claim is supported by Eder, Tobin, Proser and Shin (2012) who looked at wider impacts of social science and identified that where social science is more impactful is when there is deep engagement with the communities being studied, as they become invested in the outcome of the research within their own communities.

Chown et al. (2017) further highlights a positive for the researcher; they recount how during a study by Martin (2014), sections of a questionnaire were changed as a result of the autistic collaborators making the researcher aware that the wording of some questions was confusing. This, they claim, illustrates how vital input from someone with a similar neurological profile can raise issues that would not otherwise be observed. Milton (2012) would argue that participatory research is vital to help bridge the double empathy gap between understanding of autistic and non-autistic perspective. Earlier I used an example of where an oversight from a study (MacLeod, 2016) resulted in accessibility issues. It could be contended that if the autistic participants had some form of involvement throughout, rather than only around data collection, then this oversight may have been identified as an issue much in the same way as in Martin's (2014) work.

Though the benefits of participatory research to the researcher are important to highlight to encourage more researchers to engage with participatory research, the benefits to the participants and their community ultimately should be the reasons for undertaking it. An often highlighted issue in the sections above is the focus on areas of research that are not a priority for the autistic community. With the greater meaningful involvement of the autistic community that participatory research brings, this is likely to change, with the priorities of the community placed at the forefront of discussion within the research team (Goodley & Lawthom 2005; Pellicano et al., 2014; Zwicker & Emery, 2014; Fletcher-Watson et al., 2019). This additional voice and knowledge may also enable more accessible research, as barriers that may perhaps be challenging within research, that may go unnoticed by PNT researchers who do not encounter them, could be identified as is seen in Chown et al. (2017). This wider accessibility could then address the issues of traditional research, where research is only exploring a narrow scope of autism resulting ultimately in a narrowed practice. With a wider scope the challenges and experiences of the broader autistic community can be accounted for which will hopefully address some of the issues that concern the autistic community such as ageing, gender, race and additional needs.

Yet participatory approaches still have their detractors, Yusuf and Elsabbagh (2015) are concerned around who are considered stakeholders within participatory research, and if these stakeholders have what they see as the true image of the issues. They explain that because a person has a condition it does not mean that they are fully aware of the impact it can cause. They stress that parents should be the key stakeholders as they are more aware of the full impact of autism. Though I wonder if they themselves have any understanding at all, considering the refusal to even consider the priorities they understand the autistic community to have.

Yusuf and Elsabbagh (2015) go on to suggest that this perspective is why parents disagree with autistic people around research priorities and they use this disagreement to justify their focus genetic research. Yet parents like Runswick-Cole (2016) and the parents within Pellicano et al. (2014) would disagree with this notion themselves having similar priorities as autistic people.

The biggest issue however is that as an approach it does not go far enough. Research can be considered participatory with only minor adjustments to what might ordinarily be considered traditional social science research. For example, Madriaga (2010), MacLoed (2016) and Searle et al. (2019) all provided there participants with choices, all be it limited choices, and as such are considered participatory in the modern use of the term (Waltz, 2006). However, these choices are situated within research where true control still sits with the researchers who control what these choices look like and when they are offered.

Additionally, Chappell (2000) who is a proponent of emancipatory research argues that participatory research is still within the control of non-autistic organisations who ultimately dictate the course of research. She states that until control is within the hands of democratic organisations run by disabled people, who are acting as commissioners and funders of the research and to whom the researchers are answerable, then autistic people will still be a resource used in a research agenda that negates their priorities and their voice (Chappell, 2000). A more recent take on this is by Feltcher-Watson et al. (2019) who wrote about the tokenistic inclusion of autistic people within research so that researchers might ‘tick a box’ and have their study considered to be more ethical, more authentic and more progressive. Feltcher-Watson's participants indicated how they had participated in research that claimed it was giving voice and empowering those taking part, but they were left questioning how much impact they really had. This creates a confusing continuum of participatory research where the use of a limited range of options and minimal input from participants, who are then termed as co-researchers, can still fall under the banner of participatory research. Resulting in the term not being a signifier of the progressive, accessible approach that readdresses the power imbalance whilst promoting the voice of autistics that it was initially intended to be (Oliver, 2002; Waltz 2006; Fletcher-Watson et al., 2019).

3.5 Emancipation: research *‘by’*

The distinction between participatory and emancipatory research is not always clear. For example, Chown et al. (2017) highlight that Waltz (2006) suggests participatory research does not require there to be a focus of social change but that this is a key requisite of emancipatory research. Yet Stoeker and Bonacich (1992) assert that social change is a criterion for research to be considered participatory. I feel that in this instance Waltz (2006) is describing the current state of participatory research which as discussed less reflects the principles of what some including myself would see as ‘true’ participatory research (Fletcher-Watson et al., 2019).

When trying to distinguish between participatory and emancipatory research I feel that issues of participatory are a good place to start. The issue that I ended the last section with was around ultimate control of research I argued that ultimately participatory research remains in control of the researchers with participants only involved when the researchers want them to be. This is an issue that led to a special edition of a journal in 1992 in which Oliver (1992), Morris (1992) and Zarb (1992) published their ideas around 'involvement' of disabled people within research. But rather than stopping at involvement they went further putting forward their ideas for an emancipatory research approach to disability research to address the issue of control. In short, they felt that participatory research focused on involvement whereas emancipatory research place focus on control.

This earlier work by Oliver (1992), Morris (1992) and Zarb (1992) led to Oliver's 1997 work which sets out his six elements of emancipatory research. He identified these as being:

1) a description of experience in the face of academics who abstract and distort the experience of disabled people;
2) a redefinition of the problem of disability;
3) a challenge to the ideology and methodology of dominant research paradigms;
4) the development of a methodology and set of techniques commensurate with the emancipatory research paradigm;
5) a description of collective experience in the face of academics who are unaware or ignore the existence of the disability movement; and
6) a monitoring and evaluation of services that are established, controlled and operated by disabled people themselves.

(Oliver, 1997, p. 6)

A year earlier Stone and Priestley (1996) set out their slightly different but still as pioneering set of emancipatory research principles. These are:

> 1) the adoption of a social model of disablement as the epistemological basis for research production;
> 2) the surrender of claims of objectivity through overt political commitment to the struggles of disabled people for self-emancipation;
> 3) the willingness only to undertake research where it will be of practical benefit to the self-empowerment of disabled people and/or the removal of disabling barriers;
> 4) the evaluation of control over research production to ensure full accountability to disabled people and their organisations;
> 5) giving voice to personal as political whilst endeavouring to collectivise the political commonality of individual experiences; and
> 6) the willingness to adopt a plurality of methods for data collection and analysis in response to the changing needs of disabled people.
>
> (Stone & Priestley, 1996, pp. 709-710)

In the development of Chown et al.'s (2017) own key principles of emancipatory research they highlight the similarities between Oliver (1997) and Stone and Priestley (1996). Chown et al. highlight how both papers emphasise the need for adoption of the social model of disability and ideological/methodological perspectives to be accepting of disabled people within the research. Both papers position the voice of the disabled group as centrepieces for emancipatory research and both argue for the control of the research to be with disabled people and their organisations, with Stone and Priestley (1996) extending this to also include an overt political commitment to the emancipation of disabled people. It is this last focus on control being held by disabled people and their organisations I see as the key differentiating factor between participatory and emancipatory research.

After drawing out the commonalities of the principles of both Oliver (1997) and Stone and Priestley (1996), Chown et al. (2017) put forward a more concise autism specific emancipatory framework. Their four criteria are:

> 1) a researcher with autism either identifies and defines the matter(s) requiring investigation or confirms the identification and definition of the problem by others;
> 2) social model of disability at the heart of the project ethos;
> 3) projects are either owned or jointly owned by representatives of the autism community; and
> 4) research outcomes are focused on improving the lives of people with autism.
>
> (Chown et al., 2017, pp. 727-728)

What I feel adds strength to these criteria is that they were put together through research that used a methodology that was built on principles of emancipatory research and as such the autistic community was the main voice in the development of these criteria.

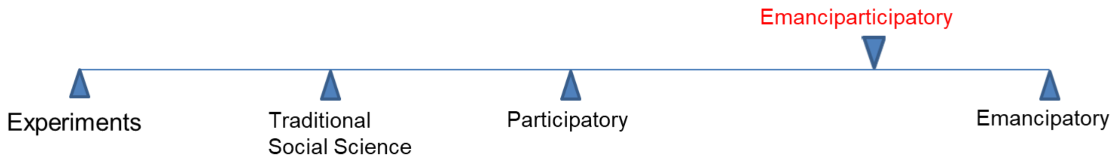
The aim of Oliver (1997), Stone and Priestley (1996) and now Chown et al. (2017) was to establish what they assert are the key principles of emancipatory research. However, in doing so I feel that they have positioned the quality bar, by which disability research is to be measured, out of reach for the current academic landscape. A key principle shared by all three papers and at the heart of emancipatory research is the ownership and control of the research either by disabled people or their organisations or oversight by disabled people or their organisations. Currently within academia there is too much oversight by groups other than the disabled people at the heart of the organisations. Firstly, the university sets out its strategic overview for the university through which it produces guidance for academics. To resist this strategic vision can be difficult especially when the university controls resources. Secondly all research must have ethical clearance (SHU, 2015). In order to obtain this, researchers must put together an argument for the carrying out of their research and not only justify it as safe but also establish its worth. Ultimate control over the study is therefore with the ethics board. The board, as I encountered in this study, can require language to be changed and significant changes to the methods. The ethics board may even define the labels by which those within the research should be addressed e.g. vulnerable (Luna & Vanderpoel, 2013). This again was an issue I encountered and will discuss more in the next chapter.

Finally, academics are writing papers ultimately for publication; this is one reason they are given the time by the university to carry out research. Once a paper is written the manuscript is sent to be peer reviewed. Chown et al. (2017) particularly highlights, that here alterations can be recommended that can have a great impact on the paper. As such the voice of disabled people and control over all aspects of the process, which are key to emancipatory research, is influenced and possibly curtailed from the outside (Nguyen, Stienstra, Gonick, Do & Huynh, 2019).

It is for these reasons I feel that currently emancipatory research is just out of reach and it is exceedingly rare for research undertaken within these restrictions to be able to further the ideals of emancipatory research. As such I felt I needed to develop my own set of principles building on the work of Oliver (1997), Stone and Priestley (1996) and Chown et al. (2017) by developing what I have termed an emanciparticipatory framework. This was with the sole aim of trying to move as close to emancipatory as possible within the confines of academia.

3.6 My emanciparticipatory research approach

As discussed the current definition of emancipatory research I feel is out of reach within academia, and participatory research is only a small step forward from traditional social science research that lacks any real effort to address the issues of power (Fletcher-Watson et al., 2019). As such I am left in a position where I feel neither is suitable for my research, but both have elements that I feel are important for research. Therefore, I decided to develop my emanciparticipatory research approach. This aims to achieve as much of the emancipatory framework as possible, at the same time as addressing some of the issues I have with emancipatory research, whilst working in the confines of academia. It is also a step closer to emancipatory research than participatory research. Below is a visual representation of where I see my emanciparticipatory research paradigm situated along the continuum of research paradigms.



(Figure 1 The position of emanciparticipatory research within the continuum of research paradigms.)

Like Oliver (1997), Stone and Priestley (1996) and Chown et al., (2017) I will now set out and account for my principles of emanciparticipatory research.

The first principle is taken from Chown et al.’s (2017) work: a researcher either identifies as autistic or meaningfully works with autistic co-researchers/stakeholders to decide upon a relevant focus of research. It is crucial that research explores issues of relevance to the community being researched. In instances where these issues are not in alignment with the university’s or funding organisation’s strategic plan, it is on the academic to use their privileged position to challenge these institutions and pursue the matters the community has highlighted.

The second principle is: where possible position the social model of disability at the heart of the research. Unlike Chown et al. (2017) and their criteria for emancipatory research, I say where possible rather than must, as I believe the academic cannot compel others involved in the study to accept the social model. Not all disabled people see disability through the social model lens (e.g. Leatherland, 2018), and it is important not to establish barriers that prevent these individuals from involvement. The researcher must not assert their views over others involved; they can however acknowledge equally the views those involved have (including the academic).

The third principle is that the research should promote the voice of the disabled community through as much sharing of power as possible and where this is not possible such as within academia, there must be complete transparency around decisions made, not only with the community but in publications to reduce misunderstanding, such as those highlighted by Yusuf and Elsabbagh (2015). This includes involvement of members of the community before the instigation of research, through the data collection, through analysis and continuing through the dissemination of the work.

The fourth principle is the utilisation of flexible methods and flexible involvement. The methods of communication, the data collection methods and methods of analysis must take into account individual's strengths and challenges. The researcher must be flexible to meet these requirements to enable involvement. In addition, involvement should not be locked behind a commitment to participate over the course of the research. Researchers need to account for some individuals only wanting part involvement and this should be enabled. Too often participatory and emancipatory research requires a minimum involvement which is generally over a long period of time due to the nature of research (e.g. Madriaga & Goodley, 2010; Searle et al., 2019). This can be overwhelming to some and create inaccessibility for others. Therefore, my emanciparticipatory approach allows for individuals to be offered full involvement but with the ability to opt in and out as they wish.

The fifth principle is that of impact. However, unlike Oliver (1997), Stone and Priestley (1996) and Chown et al.'s (2017) emancipatory approach, I believe that impact should be recognisable throughout the project. Every step of the research should have some positive impact on those involved. Impact after a project can still take a substantial amount of time to occur, sometimes even after those involved within the project are no longer accessing the community which spawned the research. As such I feel it is important that anyone involved in research should gain some form of positive impact. This could be as minor as having someone to converse with on a timetabled schedule or development of a skill. For example, in my research a student had received a presentation on thematic analysis. They then practiced thematic analysis on their findings to build up their confidence for their own final year project where they would be using thematic analysis. Here, through participation the student gained a skill that had an immediate impact on their confidence and possibly in a small way their success.

The sixth and final principle is that the researcher should always aim to include as broad a scope of autistic people within research as possible, to ensure that research does not get dominated by a more vocal and able minority. I feel this point is missing in previous criteria for emancipatory research and as such I have included it here. To do this, researchers should seek out knowledge from the different groups within the autistic community in an effort to use this specialist knowledge to help promote accessibility, impact and dissemination. For example, taking advice from the transgender autistic community on how best to recruit from this community rather than just implementing what is working in other areas of the autistic community.

While emancipatory research remains impossible under the constraints of traditional academia as a result of university policy and oversight, as well as the influence of the peer review process, I feel we should avoid using the term emancipatory research. Instead I put forward using my emanciparticipatory approach whilst we continue to challenge the constraints of traditional academia and make full emancipatory research a realistic option. As such within Chapter 4 I detail how this emanciparticipatory approach is used for this study that explored the experiences of autistic students who identify as autistic in HE.

Chapter 4

Methods, Analysis and Ethics

4.0 Introduction

Within this chapter I will detail the methods utilised within this thesis. My research employs my emanciparticipatory research approach. As such each autistic student had their own specific method of participating including myself. Within this chapter I will detail each of these methods of participation as well as methods of communication.

I begin by discussing the aims of the research and how I intended to not only investigate the experiences of students who identify as autistic in HE, but also to promote the voice of the autistic students involved in this study by challenging traditional researcher-participant power dynamics whilst making the research accessible for all autistic students. How this is achieved is then discussed, as I detail how the emanciparticipatory approach that I set out in Chapter 3 is utilised for this specific research.

I will then discuss the recruitment process and how this was integral for enabling a wider set of voices to be heard, including those who currently do not engage with disabled student services. It is this group that is identified within Chapter 2 and 3 as the voices that are currently missing from the research literature.

I then move on to what I term ‘Structuring the Unknown’. This refers to the process of when I started the data collection phase, within the emanciparticipatory methodology. I did not know what methods I would be using, how many times I would be meeting students or whether anything would change as students could request different methods if they wanted too. Flexibility was important for the research approach but I also needed to complete the research and so I saw it as structuring the unknown. Within this section I will go through each student including myself and explain the methods used as well as the processes I went through with each student.

Following this is the ethics section. Part of the reason for using my emanciparticipatory approach is that I evaluate traditional research as potentially unethical at times. However, within academia I found gaining ethical clearance without compromising my approach incredibly difficult as my approach and the traditional ethical model are at odds; I debate this tension and explain how I conducted my research ethically.

Finally, I then explain the data analysis method used by all the autistic students and detail the seven phases of analysis that I, and on occasion *we*, went through.

4.1 Aims

The primary aim of this study was to explore the experiences of students who identify as autistic in HE. A secondary focus was to analyse and develop how research is carried out with an aim to construct and apply a framework that would address potential power imbalances between researcher and participant whilst providing an accessible means of participation.

As was discussed in Chapter 3, I hold that traditional approaches to research are problematic as often they place the interests of the funders and the researchers above the priorities of the community being investigated (Pellicano et al., 2014). Additionally, participatory research does not go far enough to address the issues of traditional research. This is especially true within the more modern use of the term which is being applied to research that no longer meets the original principles of participatory research (Waltz, 2006).

Whilst I feel participatory research does not go far enough, I also consider emancipatory research as currently being beyond the possibility of practice within the current constructs of academic research, for reasons discussed in Chapter 3. As such it is my opinion that participatory research and currently emancipatory research are not able to fully address the issues that I believe exist with traditional research.

Therefore, I aim to use my emanciparticipatory approach to try and address the issues around the potential power imbalance between researcher and participant. Furthermore, I feel that this framework allows for the utilisation of methods that best work for those who would traditionally attract the label of participants. As such I feel this also addresses issues around accessibility.

The decision to investigate the experiences of students who identify as autistic in Higher Education as discussed in my positionality section (Chapter 1) stems from my own experience. Having experienced both inclusion and barriers throughout my studies I wanted to investigate the experience of other students in an effort to identify common issues and explore to see if there were any successful supports, strategies or practices employed by autistic students within HE.

Specifically focusing on autistic students rather than disabled students in general was due to the unique challenges autistic students face over non-autistic disabled students (NAO, 2009; Hastwell et al., 2013; Fabri et al., 2016; Chown et al., 2018). An autistic student is more likely to fail and withdraw from university than a non-autistic student and is more likely to fail and withdraw than a non-autistic disabled student (Fabric et al., 2016). Yet despite this trend the number of autistic students entering HE is increasing (Hastwell et al., 2013). Therefore, understanding the experiences of these students is paramount for universities to take action to reverse the negative trend of failure. Through this study's aims I wish to contribute knowledge and understanding that may support institutions in making more suitable provisions for autistic students and identifying areas for further support. Additionally, this study also aims to be accessible to any autistic student that wished to be involved.

4.2 Emanciparticipatory research approach within this research

In Chapter 3 I detailed the issues that challenge emancipatory and participatory research and articulated the need for new ways of working. I will now detail how the framework of emanciparticipatory research was applied to this specific study.

One of the key overarching principles of my emanciparticipatory approach is that of control. In this study each autistic student was in control of their own involvement; they chose how to communicate with me, their method of data collection and how much involvement they had in all aspects that pertained to them, including the analysis of their data and the presentation of the final write-up.

Linked to this control is the principle of accessibility. With control each individual was able to decide how they accessed the research which enabled them to be able to choose methods of communication and participation they found accessible. Rather than me putting forward two to three options to choose from as is often seen in participatory research (e.g. Madriaga, 2010; Macleod, 2016; Fabri et al., 2016) each person chose what suited them (I will go into more detail in the following sections).

This made for what felt like messy data collection and analysis phases as there was little consistent structure between each autistic person particularly around how often we met and how much involvement they had and even what stage of the process we were at with some students disseminating their findings while others were engaging for the first time. This messiness will be discussed further, later in this chapter with a deeper discussion taking place in the limitations section in Chapter 8.

In the following sections I will discuss in detail recruitment, contact, issues with structuring data collection, the data collection itself and data analysis.

4.3 Recruitment phase

As with every aspect of this study thought had to be given to accessibility and control. This included first contact and communication throughout the process. It will also continue to be a key element of the dissemination of findings post submission. ‘Researcher – participant’ contact is known to be problematic within autism research (MacLeod et al., 2013; Haas et al., 2016; Fayette & Bond, 2017). Autistic participants can often struggle with keeping regular contact if the communication path chosen by the researcher is a challenge for the participant to access (MacLeod et al., 2013). Additionally, Milton’s (2012) double empathy problem would argue that there could be issues in both directions around understandings within communication, leading to miscommunication between the autistic participant and the PNT researcher.

Lunnay, Borlagdan, McNaughton and Ward (2015) go further to suggest that traditional methods of contact are out of touch with today’s society altogether. Relying on traditional contact methods can act as a barrier from participating to some. This can be compounded more when those potential participants have a communication impairment that impedes access to commonly available communication methods (Lunnay et al., 2015; Hodge, 2018). Therefore, it was paramount that participants were recruited and communicated with, by a method they could access. The best way to achieve this was not to force my communication method onto an autistic student but to let them choose their own method. To do this I sought to spread my recruitment across a number of channels. Following Lunnay et al. (2015) I placed an outline of my study in a number of social media groups. I advertised at a number of autism and disabled student events and there was also information about my study given to students who had heard through word of mouth. Each pathway resulted in interest through a number of different communication channels (social media, phone, email, in person) from potential students from across the country.

Traditionally research with autistic students in HE has utilised Disabled Student Support (DSS) as a means of recruitment (sometimes the sole means of recruitment) (Madriaga, 2010; Madriaga & Goodley, 2010; MacLeod, 2016; Ward & Webster, 2017; MacLeod et al., 2018). However, there are two issues with this means of recruitment: firstly, the sample population is reduced to those receiving support which negates the estimated one third of students not registered with DSS (Fabri et al., 2016). Secondly DSS would use traditional contact methods which as discussed have their issues.

A very specific issue that I also encountered with DSS within the institution in which my research was based, was that during my recruitment phase they were going through a number of personnel and system changes. Though some liaising with DSS occurred including advertisements placed in waiting areas and introductions during autistic student group meetings, I endeavoured to not make DSS my main recruitment tool.

During this call for autistic student involvement the freedom to contact me by their chosen means was explained. Each autistic person who was considering being involved was given or sent the participant information sheet (see Appendix 2) and on occasion I read this information to them.

During this initial communication, they were also asked about further contact and in most cases a pre-contact discussion or meeting occurred: these are detailed in the data collection section below. Though these initial discussions were aimed at understanding how contact would be conducted and how a person would like to participate, it was decided by the autistic individuals that this meeting should make up part of their data collection. This was due to them having discussed what they felt was pertinent to the aims of the research though not always using their specific means of data collection. For further information around the specific details of contact and involvement of each student see the table of involvement (Appendix 6)

4.4 Structuring the unknown

I have entitled this section structuring the unknown. This is because having had an initial communication with the other autistics involved in the study as discussed in the previous section; I was going into the data collection phase with a number of different data collection methods and only a rough time plan.

The only known element was that we would be exploring our experiences of university as autistic students. Furthermore, we knew the focus did not necessarily have to be on curriculum and the lessons and that they could go beyond learning into other areas of “student life” that were important to them. However, this broad scope did leave me with a number of issues.

Firstly, how I would structure data collection phases where potentially anything and everything could change. I discussed these issues with my supervisory team leading up to the data collection phase and worked through the potential issues. For the first issue it was decided that if I attended a session and elements needed to be changed far greater than I could do so in that moment then we would re-schedule the session. This was explained to each person during the initial meeting.

Secondly how would I support individuals that did not know about methods and how I would help them find a method that worked for them? It was decided that I would ask each individual about their likes, dislikes and strengths and then we could narrow it down through a process of elimination. This is how two of my participants, Liam and Doug, ended up with their chosen methods. This process is explained in more detail throughout the rest of this chapter.

Thirdly whether I would achieve some consistency between the individuals if each person spoke about a different aspect of university life, I was concerned that I might only acquire eight or more different light discussions rather than multiple perspectives building on one another. This was more a personal fear that I would end up with no data or limited data. I simply came to terms that this was a possibility and that I would just report on whatever data I had if that was representative of the experiences, then that was the data.

Finally, what action would I take if upon arriving for the data collection phase the person wanted a lot of structure and questions to be the catalyst for their method having previously decided on a very unstructured design. In case of this issue I decided to develop a potential structured opening and follow up questions (see Appendix 1). This structure was based on the path that a generic student takes through university as outlined by Holton's work (2015; 2018b). These questions focused on life before university, schooling, and the decision to come to university, before asking them to discuss their first few weeks at university and then through the different university environments. Ultimately this foresight proved important as in each instance, they all did request to be asked specific questions to begin the discussion.

4.5 Data collection phase

As previously discussed control and choice underpinned the data collection phases. Each autistic student involved was given control of their involvement and choice of data collection methods (Stone & Priestly, 1996; Oliver, 1997; Chown et al., 2017). When discussing data collection phases with each individual, we discussed their likes and dislikes around communication, meetings and so on, in order to seek out preferences for communication and eliminate any methods that would clearly be problematic. But rather than focus on impairments and what they could not do, we focused on the strengths of that person to help narrow the scope and identify a method. This is congruent with the concept of empowerment (Freire, 1972; Stone & Priestly, 1996; Oliver, 1997; Chown et al., 2017). From this I was able to discuss potential data collection methods. For example, one person highlighted that they loved writing. So, we discussed various writing-based methods before finally coming to the idea of a thought diary, which could be written in prior to meetings. This diary would be used by the individual to facilitate discussions of his thoughts. This initial discussion was carried out with each individual. From these discussions the various data collection methods were devised. Through happenstance most methods are in essence interviews though the environments and facilitation of those interviews are far different from those seen within traditional research. Below is an outline of each individual method.

Though each method was different there were a few elements that were consistent across all of the individuals. These mainly revolved around ethical requirements. Before each meeting I presented each person with another copy of the participant information sheet. The key sections based around ethics were also read aloud. Verbal and written consent was then obtained. Debrief information was also provided to each individual and a paraphrased version was read aloud. As I was never truly sure when a student's last meeting was, I needed to go through this debrief procedure after each meeting. These are the elements that stayed consistent; however each individual method was completely different, I will now present each one in turn.

4.6 Liam's thought diary

Liam elected for his name to be used. Liam was a first-year youth and social work student when beginning this project having been a first-year student three times. During his involvement in the research he took time off university before coming back and passing into the second year.

Pre-data collection: For this data collection method Liam asked to meet for his initial communication. During this he asked for clarification around what I meant by 'beyond academics' and so I explained that student life was impacted on by a number of different factors and these in turn can affect each other. With that clear, we moved on to ideas of data collection. Liam discussed his love for writing and a desire to include that in some way. The end result was that he would go away, write about his experience utilising a thought diary that he already used and this would form the basis of data collection.

Data collection phase 1: Liam used the diary, prior and throughout the research, to recount points within his university life and then his thoughts around those points. This diary was very personal to Liam and he used this daily to organise, plan and remember almost all of his life. As such it was not something Liam was willing to hand over as stored data for the study. Instead he used it in the same way that he used it for his day-to-day life. I suggest that this brought a naturalness to the process for him. Following each highlighted incident, we would then discuss his thoughts. Where relevant, to facilitate the conversation further I would refer to my own experiences. Liam had a lot of struggles at university and liked the idea that he was not the only one to go through these struggles. Therefore, when he discussed a similar experience to one that I had Liam welcomed hearing my experience. This was something that Liam found comfort in and was an immediate benefit for him.

Data collection phase 2: This phase took place nearly 12 months after the first phase and focused on what had happened since. Again, the thought diary was used to structure the conversation.

Data collection phase 3: This phase took place around six months after phase two, just as he was in the middle of his second year after a break in study. Again, the thought diary was used to structure the conversation.

Data collection phase 4: took place 12 months after phase 3 as he was finishing his final year.

For each data collection phase, we met at the university. Dictaphones were used to record our discussion. I transcribed these recordings verbatim and the transcriptions made up the raw data that was analysed.

Between phases we did keep in touch planning when to meet discussing how the study was coming along and also to plan and carry out some of the dissemination activities.

4.7 Doug's debate style discussion

Doug is a master's student having already gained an undergraduate degree.

Pre-data collection: During this meeting we discussed various ways people may wish to be involved. After some discussion it was decided that we would follow a traditional interview process for Doug. However, I would take a position of challenging the thought and opinions put forward by him. This was to allow Doug to "defend" his ideas, theories and position on autistic students in HE. This was part of the enjoyment of the conversation for Doug: he stated he found the robotic acceptance of a researcher carrying out an interview challenging; like they would agree with "any old shit".

Data collection phase 1: This phase lasted over two hours. Though this might seem excessive for some this was how Doug wanted to participate. He enjoys long discussions without the pressure of time. Removing the pressure of time allowed for him to relax and participate without feeling stressed.

The discussion utilised the style that we had negotiated together. Like a debate there were topic themes put forward that were generated from the review of the literature. These themes were:

- Pre-enrolment
- Declaring vs not declaring
- Disabled Student Allowance forms

- First year
- Second year
- Third year
- Social life
- Pre-enrolment master's
- Disabled Student Allowance forms
- First few months of master's.

Data collection phase 2: utilised the same style as the first discussion but focused solely on the time since the last data collection phase. As this covered less time this session was only 1.5 hours once we got started.

Both the data collection phases were carried out within a university classroom. Dictaphones were used to record both data collection phases. The recordings were transcribed verbatim and these transcriptions made up the raw data to be analysed. A post analysis discussion took place approximately six months after we completed data collection.

4.8 AR's single interview

AR is a PhD student having gained an undergraduate and a master's degree. She was in the second year of her PhD at the time of her involvement in the research. AR did not want to be named within the study and so will remain anonymous.

Pre-data collection: this communication occurred over around 15 different emails between me and AR. She decided that she wanted to participate but was unsure she could commit the time and that this may mean that she could not be involved. This was possibly due to my explanation of what was involved in the research and presenting ideas of multiple meetings and data analysis. Once it was made clear that time commitment was as much or little as each person wanted, it was decided that we would have a single interview lasting one hour and I would travel to her place of work so as not to disrupt her day.

Data collection phase: a semi-structured interview was used. Questions were asked focusing on:

- Pre-enrolment
- Declaration
- Disabled Student Allowance forms
- Undergraduate
- Social life
- Student housing
- Master’s
- PhD
- Office environment
- Any other questions.

I travelled to her place of work and we conducted the interview in a room she had arranged. The individual wished to remain anonymous and reiterated her choice of only having one, one-hour interview. This also included set up and pack up time. The interview was recorded using Dictaphones and these recordings were transcribed verbatim. The transcriptions made up the raw data to be analysed.

4.9 Shona’s dialog style interview

Shona wished for her name to be used within the research to retain ownership and highlight her involvement. Shona is a master’s student studying MA Autism Spectrum. She had already gained her undergraduate degree some years prior and was returning to study after a career. Shona was in her second year of part-time study when she first started being involved in the research; she was in her third year during her second data collection phase.

Pre-data collection: communication took place over social media and the method of what Shona saw as a more laid-back dialog style interview was decided upon. Though very similar to a traditional interview process this was more laid-back than a typical research interview might be. It took place in a communal public area and both myself and Shona had food and drinks. Further, rather than a format of 'interviewer asks questions, interviewee answers' there was more of a conversational style with questions being asked by both of us and no real structure to the discussion.

Data collection phase 1: we met and found a place to sit within a communal public space often used by students to socialise over some food and drink. In this sense our interview appeared to be no different than any other group using the area. We begin with an unrecorded social chat about life not pertaining to the study then as the conversation flowed towards the topic of HE we took a second to repeat consent and to start recording. During the discussion we kept to very little structure often heading off on a tangent with only a tenuous link to the research focus. This flexibility was the aim of the method here; the discussion was to be as relaxed as possible like a normal everyday conversation, so as not to cause anxiety around getting the answers right. This was achieved by having food and hot drinks and sitting in a comfortable breakout area at university.

Data collection phase 2: took place around six months after the first phase. The same format was used in phase 2 as in phase 1. The same space was used and a number of the same areas where discussed. As a result of the natural flow of the conversation these repeated conversations went uninterrupted, I did not want to stop Shona from discussing what she wanted even if we had already gone over these experiences. New information was gained when discussion got around to what had happened since the last meeting.

As stated, data collection took place in a communal student break out space within the university. Dictaphones where used to record the interview so there was some semblance of being involved in research. The recordings were transcribed verbatim with the transcript then undergoing a heavy redaction process to ensure confidentiality and anonymity of the individuals within Shona's stories. The transcriptions made up the raw data to be analysed.

4.10 Sam's 'The insanity and intrigue of Sam'

Sam wished for his name to be used within the research and wishes to promote that ASD is not about negatives. He was in his final year of a theatre-based degree when he began his involvement with the research and has since graduated.

Pre-data collection: Communication took place both in person and over social media with the details of Sam's chosen method of involvement emerging as we communicated over a number of weeks. Initially we had decided on a traditional interview design. However, as we communicated more, a more creative method began to emerge that utilised both a love and strength of Sam's which was entertaining. An end of course assessment that Sam was doing at the time was based on a similar topic and this would form the basis of our discussions. For the assessment Sam wrote and performed a one man show about living with Asperger's, including university life. Following the show Sam decided to have a number of interviews which also would involve a re-watching of his show with discussion and analysis taking place as we watched.

Interview phase 1: This was a traditional interview taking place in a meeting room. It began with discussion of his history before some clarification of thought. It then moved on to pre-enrolment and we finished the first interview discussing accommodation for his first year.

Interview phase 2: Congruent with the procedure from the first interview we met in the same meeting room, had a catch up and then started the interview. This interview covered academics, student life and relationships. We ended by discussing his performance and organising the next phase of the data collection to re-watch the performance.

The performance phase: This was performed one evening at a local theatre. I watched as a member of the audience. Other than Sam nobody else knew I was watching for research purposes. I did not record or take notes during the show. The show was recorded by Sam and he provided me with a copy.

Performance re-watch phase: Though this may appear to be analysis I feel it important to discuss as both a method of data collection and again as analysis during the analysis section of the thesis. Here we met again in a meeting room that had the appropriate equipment to view the performance footage. We also positioned an audio device with a specialist microphone to be able to record our discussion over the sound of the performance. We discussed the performance both analysing it and asking further probing questions.

Dictaphones were used to record the data collection phases including the performance re-watch but not the live performance. The recordings were transcribed verbatim (though the transcripts underwent a small amount of redacting). These transcripts make up the raw data that will be analysed.

4.11 Nick's ask a question, answer a question

Nick was just becoming more interested with knowing about autism after having an upbringing where his parents hid his diagnosis from him. As such he has never really explored what autism is. Upon seeing the invitation for autistic students to get involved Nick asked a third party to arrange a meeting with me. After discussion with him we decided that we would do a question and answer session where I would ask him about his experiences, and he would ask me about mine.

Pre-data collection: after our initial introductions all contact was made via social media. We decided to meet at various environments around the university including a pub, the SU and a coffee shop for a more relaxed Q&A, this was the choice Nick made. Additionally, we also met in these environments to discuss data analysis and any dissemination of results. Nick had no time limit to his interviews, so we decided to meet until the conversation around topics had be exhausted and he felt he had nothing else to add.

Data collection phase 1: we met at the university then headed for a nearby bar with outdoor seating. The first interview focused on the following:

- Pre-enrolment
- Declaration
- Disabled Student Allowance forms
- Social life
- Student housing
- Group work

- First year.

Data collection phase 2: congruent with phase 1 we met at a mutually agreed meeting point then moved to a café within the university. The procedure was the same as phase 1. The semi-structured interview this time focused on:

- Second year
- Third year
- Contact with tutor
- Group work (again)
- Assessments
- Students' union societies
- Dissertation
- Transition from university to working life.

For data collection phases 3, 4 and 5 we met at the students' union and then went to quiet areas within the building. Having discussed most of the topics around experiences we decided to continue meeting to talk through his experiences since the preceding meeting. Nick was encountering different issues and he wanted these to be included within the study.

Dictaphones were used to record the interviews. These recordings were transcribed verbatim. These transcripts make up the raw data that will be analysed.

4.12 My auto-ethnography

Finally, we come to my means of participation, I had two struggles to work out around my participation. Firstly, if I was going to take part in my own research and secondly if so, how? The first question was easier to answer when I considered it from a power perspective. If I was aiming to develop as much shared power and control as possible through my emanciparticipatory approach, then I really needed to share the responsibility of providing data too. As such it became obvious that I needed to participate within the research.

The next more difficult question was how? The approach to the research dictates that I use a method that I am most comfortable with. I have always felt most comfortable discussing my life whilst occupied with another task. Exploring data collection via interview during a massive shared multiplayer online role-playing game has always intrigued me as this is when I am most relaxed. However, I encountered the issue of having no interviewer so this idea had to be shelved.

Exploring other ways, I came across auto-ethnography and it appeared to be the one method that fit best within my current schedule and for the research. Unlike ethnography where a researcher is placed within a social or cultural group (ethno), the auto-ethnographer writes about themselves (auto) (Wall, 2008).

Auto-ethnography allows for a highly personal account to extend understanding of a particular experience of culture (Holt, 2003). Here my experience and perspective aim to extend the understanding of the experience of being a student who identifies as autistic in HE. Further my experience which is at the heart of this thesis would also be at the heart of the auto-ethnography.

Traditional ethnographic data is collected through interviews, artefacts, observations and photographs (Wall, 2008). Auto-ethnography data can be collected through similar methods. Wall (2008) cites how Sparks (1996) and Ettorre (2005) collected their data through diaries, newspaper cut outs and medical records and Holt (2003) and Duncan (2004) used reflective diaries to support discussions.

Wall (2008) notes that these are not necessarily memory based but highlighted how Ettorre (2005) used memories within her data. As such I used a mixture of my reflective diary from this PhD process, the experiences I gave in discussion with other autistic students as documented through their data collection and I also developed a timeline of my HE experience with help from my records and photos taken of me and my environments over the past 12 years. As these photos are personal, they are not shared within this thesis in the same way that Liam's thought diary is not.

4.13 Analysis

In this section I will describe the method of thematic analysis that was used within this study. Fortunately, all the data generated was done so through spoken dialog, I therefore was able to capture this via a recording device and then transcribe the audio recordings. It is this transcribed data that will be analysed and how this analysis was carried out will be what is explained in this section. I was prepared to need to use a variety of analysis procedures however the students involved in this study all opted for methods that enabled the use of thematic analysis.

Thematic analysis is usually a six-phase process of identifying patterns or 'themes' within qualitative data (Maguire & Delahunt, 2017). For this study I added a seventh phase which involved a combining of data from all the different methods to explore overarching themes.

In thematic analysis a theme can be defined as patterns of information that are relevant to the research topic; often the process focuses on 'key themes' which are an overarching encapsulation of a larger number of specific codes (Maguire & Delahunt, 2017). Codes are single words or phrases that are relevant to the research questions that can be grouped into categories based upon meaning. For example, words and phrases based around positive sensory environments of the living accommodation may be grouped. These categories are then brought together where relevant to create themes, for example if there were two categories say, sensory environments of the living accommodation and sensory environment of common areas these categories might make up a theme of sensory environment.

It is the themes that make up the final findings of the study (Maguire & Delahunt, 2017). Within the following section I will present some background to thematic analysis before detailing each of the seven phases. To aid this section there are examples of the process of analysis, these examples include: excerpts, pictures and tables within Appendix 7, 8 and 9.

Schutz (1964a; 1964b) advocated three essential postulates with regards to analysis of qualitative data, amidst the debate around rigor within social science research. To summarise, he proposed that first a researcher must document the development and thought process of the method and subsequent analysis. Secondly that the words of the participant should be authentically reflected in the researcher's interpretation and that the interpretation is logical and evident. Thirdly that the interpretations should be recognisable to the participants as representative of their experience (Schutz, 1964a; 1964b). More than four decades later qualitative research has developed as a paradigm. However, Schutz's proposals are still regarded as important and remain a valued assess of reliability in qualitative research.

The first of Schutz's (1964a; 1964b) postulates has been met in the sections above of this thesis; the second and third will now be addressed. Though Schutz might not have conceptualised it within these terms he postulated what is considered an essential element of emancipatory and participatory research and is the key facet of emanciparticipatory research: that the voice of the autistic students involved is true to them and not distorted through my own subjective analysis. That is why it is important that if the participant wishes to, they are involved with the data analysis.

Yet a criticism of the participatory and emancipatory based literature discussed in the literature section is that often this is not the case or if it is, it is a watered down version where there is a ‘pre-analysis’ or ‘initial analysis’ carried out by the lead researcher before meeting with participants for their input (Nind, 2011). Sandelowski (2002) argues that participant checking of data that has already been analysed risks the participants' experience of phenomena being replaced with a similar but different experience put forward in the analysed data. Therefore, this participant check becomes a check of an informed distorted account. Though it is a little reductionist to suggest a person's experience can be changed by reading an interpretation of that experience, it is possible that highlighting the inaccuracies of the researcher's interpretation places a burden on the participant which may result in inaccuracies going unchallenged and over the course of long studies such as this one, it can add up to a highly inaccurate account of an experience.

In respecting the principle of choice that underpins this research the autistic students were involved in the data analysis as much as they wanted to be. Two participants opted to be fully involved, three opted to ‘dip in and out’ and one participant opted out. I, as a participant, analysed my experiences both alone and with each student who was involved in their analysis as an example of the process.

One concern of the emanciparticipatory approach was that with no control over the type of data collection methods, I could have ended up with multiple different methods of analysis. If some of these were outside of my own experience I would have not only to learn but also to teach to those who wished to be involved with their analysis (Nind, 2011). This was a concern which I had numerous discussions with my supervisors about and is a potential limitation to this approach. However, in this instance, all of those involved chose methods that could be analysed thematically.

Regardless of whether the autistic person was involved in their analysis or whether I did it myself, I aimed to ensure that even if I was analysing data alone, I was able to represent the individual's experience in ways that captured what it meant to them. To check this, I sent not just my themes but also an account of the steps taken to each student to check that I was making an interpretation of their experience that was recognisable to them. Though this is not perfect and possibly perfection is unobtainable, including the steps it took to arrive at the themes, enabled me to have a conversation with each person to try and ensure the overall themes where true to their own personal experience.

When an autistic person elected to perform the analysis with me, we would practise with a practice transcript I use in the teaching of thematic analysis and then explore transcript excerpts from what would form my data which I would analyse for them to show the process. I would explain what thematic analysis is, how initial reading and coding works, how the codes generate themes and how these themes are collated and presented. We would then practise until they were ready, at which point, we would begin the analysis of their own data. One participant did go further and also attempted some transcribing of their data before they moved on to analysing the transcript to develop their own skills.

As the same method was used with the other autistic individuals when I analysed it myself I shall now address the second of Schutz's (1964a; 1964b) postulates and describe the process of data analysis in a logical and recorded way.

Thematic analysis is a widely used qualitative analytical method (Braun & Clarke 2006). Qualitative analytical methods can be categorised into those that are developed from a theoretical perspective or epistemological position and those that are not informed from a theoretical basis (Braun & Clarke, 2006). Thematic analysis is a method based on the latter. This allows the method to be flexible and can be used with complex data sets or with complex data collection methods (Braun & Clarke, 2006). As has been discussed many times above the data collection method for this research was complex. However, I was incredibly fortunate that all of the methods produced data that could be analysed through thematic analysis. Braun and Clarke (2006) outline six phases to the process of analysis but highlighted that this was in a drive for structure. They acknowledge that adherence to these phases is not a requirement for researchers before they can claim the use of thematic analysis. I found this structure helpful but not needing to adhere to this structure also aids when working with such complex methods and timelines.

Phase one is familiarisation of the data: In order to successfully analyse the data Braun and Clarke (2006) suggest that you must first familiarise yourself with the data. Whether you collected the data yourself or not you must become familiar with it. They suggest the best way to do this is by transcribing it yourself; those that do not will need to read through the transcripts multiple times. As I transcribed each recording myself this enabled my familiarisation with the data however I also listened to the recordings multiple times too. Those autistic adults who wanted to be involved with the analysis were offered the opportunity to transcribe their own recoding.

However due to time commitments nobody decided to do so. However, Shona did trial transcribing to develop the skill for her own studies. Instead of transcribing to familiarise themselves with the transcript the other autistic students read through their transcript.

Phase two is the generation of initial codes: During this phase both semantic and latent features that are considered relevant to the research are highlighted and listed as initial codes. Initial coding of each transcript was carried out using colours and notes to highlight the features within my data (for example see Appendix 7). All codes were data generated in that I did not look for specific codes consciously based on literature.

Phase three is searching for themes: This phase involves sorting all of the different codes into categories if needed, and then themes, collating all the different features highlighted and noted into themes with relevant extracts. These themes are based around meaning or context such as the built environment or perception of labels. Braun and Clarke (2006) state that this is done with all the data sets. For my research this was all the data sets of a given individual. In that each individual’s data was initially analysed in isolation to the other individuals. This was to generate individual specific themes which are presented as such in Chapter 5. As such, I executed all six phases, one at a time with/for each different individual. I utilised various methods of doing this initial search for themes including cutting out codes and extracts from hard copies of transcripts. I used Microsoft Word to highlight the codes and then list the themes and group them together in written lists and I also used a spider diagram process (for example see Appendix 7 and 8). I did this based on the strengths and interest of each individual so they could participate in the analysis if they wished, for example Sam is a physical learner and so handling cuttings of the data best suited him. Whereas Nick and Shona are more comfortable with computers and so Word was utilised for them. This is consistent with the emanciparticipatory approach used throughout.

Phase four is the review of themes: For this phase we reviewed and evaluated the themes we developed; those that are similar may be coupled under a different term or one theme might fold into another. When working with another autistic individual this was done through dialogue: we would discuss in turn each theme and in doing so evaluate its applicability as a theme. When done alone I had this dialogue with myself, working my way through each theme to keep some consistence and logic to the process (Schutz, 1964a; 1964b). I would also return to themes and even the initial codes after a break to check that my coding and theming was consistent. As I worked around when individuals where able to participate, this phase took one academic year which though it was longer than I had anticipated it did allow me to revisit the analysis that I was doing alone many times.

Phase five is defining and naming the themes: In this phase we defined and refined the themes that had developed. Doing this moved us towards our final themes and final labels. For each theme, a detailed analysis of the theme is written highlighting what the theme encapsulates. Again, when working with another autistic student this was done through dialogue, assessing the validity of the theme and theme term.

Phase six is producing the report: once the themes were refined and defined, I wrote the report using concise extracts if needed. This forms the presentation of individual themes in the next chapter (Chapter 5).

For this research however, there was a seventh phase that involved combining individual’s personal themes. As I am writing one research thesis that used multiple data collection methods, I need to collate the analysis for each of these different themes into one final report. To do this I brought the refined and defined themes from each person to each of the other autistic students who still wanted to be involved with the data analysis. Together we went back through phase four and five with all the refined and defined themes from each individual, each time starting from phase four and working through to phase 6. Only two autistic students wished to be involved with this analysis. For more information on the specific involvement of each individual see Appendix 6 the table of involvement.

4.14 Ethical considerations

In this section not only will the ethical considerations undertaken for this study be discussed, but a much larger debate around the boundaries of autism research will also be explored. This study complies with the Sheffield Hallam University ethics, integrity and practice guidelines (SHU, 2015). Ethical approval was applied for and gained from the University ethics committee before any interactions with potential autistic students was sought (see Appendix 5).

The study aimed to not only investigate the experiences of students who identify as autistic in HE but to do so using methods that promote accessibility whist addressing the power relationship between the ‘researcher’ and the ‘participant’. To do this I applied my emanciparticipatory research approach. In doing so a number of areas needed to be given more consideration than is traditionally expected within research. I will now go through these in the order of consideration.

Recruitment needed to go beyond an often used method of emailing autistic students through the DSS (Madriaga, 2010; MacLeod et al., 2018). This was for two reasons firstly we know that autistic students struggle to access emails (MacLoed & Green,

2009) and recruiting through DSS will only recruit those who are able to access the service. Therefore, I needed to apply for ethics to recruit through a number of means that involved both direct and indirect ways including the use of online methods. I needed to ensure that the ways in which I was recruiting were accessible to as many autistic students as possible. Failure to recruit as broadly as possible I feel is an ethical issue.

Part of the recruitment process and an integral part of the research was to establish methods of communication. Often these methods are decided by the researcher (Madriaga, 2010; MacLeod et al., 2018; Searle et al., 2018). My emanciparticipatory approach however requires flexibility to meet the needs and preference of the autistic students. This needed to be taken into consideration during the ethical approval process. To do this ethics was applied for by highlighting this need to be flexible to the participant's needs and why this may have to happen without necessarily submitting and waiting for amendment approval from the ethics committee. Ultimately, I argued that it was less ethical to force someone to communicate in a way that may make them feel anxious or distressed than it was to accommodate a flexibility of practice. Additionally, it was made clear that communication would follow key ethical principles around confidentiality, protection of the autistic individuals, professionalism and abiding with data handling procedures.

Though I had a time scale in mind for how long data collection would take I needed to prepare for the research to take longer. Additionally, those involved in the study could continue to be involved during the analysis and the write up. As such the information that was supplied to each student at the start of the research via participant information sheets (see Appendix 2) was continually reiterated throughout. This information detailed the rights of a participant which included the right to be fully informed, the right to anonymity and confidentiality, the right to withdraw or withhold information and the right to ask questions. Additionally, information about the data handling, storing and destruction was also detailed as well as where to go if they had any concerns around the research or me. Consent was gained before the start of each data collection session (see Appendix 3) and a debrief (see Appendix 4) was carried out at the end of each data collection session as well as each subsequent meeting. Each time we met I also scheduled time for the students to ask any questions and time to clarify or remove anything that we had discussed.

These are the basic and expected ethical considerations for any research. I will now detail some of the deeper ethical considerations that I had to consider before during and after the data collection, analysis and write-up.

4.15 Challenging power

A fundamental principle of emanciparticipatory research as discussed in Chapter 3 is that of shared balance of power. The aim of this shared power is to enable a voice of an often unheard population to be heard and most importantly heard and listened too unhindered. Such an aim can often conflict with ethical guidelines, where the researcher is an overseer and guardian of their participants and only answerable to the higher power of the research committee (Morgan, Cuskelly & Moni, 2014). This means that often in the case of disability, the research is far removed from the population being studied (Morgan et al., 2014). Emanciparticipatory research looks to relocate the research back into the possession of the community being studied.

This is partly achieved through the promotion of voice, however when looking at the ethical guidelines this creates a Voice v Protection dilemma.

The traditional ethics model places the responsibility of protection on the researcher and as such the researcher must have ultimate control. In practice this often means that all decisions are made by the researcher (Chappell, 2000; Nind, 2011). Emanciparticipatory research does not necessarily aim to remove this responsibility from the researcher; if anything it aims to strengthen the researcher's ability by allowing researchers to work with the experiential knowledge of the community to ensure that the research does not cause concern. Martin (2014) almost made a mistake that would have caused confusion and possible distress with their participants had they not been working with autistic individuals who were in a position of power to be able to advise in the creation of research tools. They highlighted the potential issue around how the autistic community might react to a question using their insider knowledge. This allowed Martin to correct the question and avoid potential issues.

Further to this the researcher has a responsibility to not de-humanise their participants and it is argued that whilst research remains in control of organisations, funders and researchers, who are not members or allies of the communities that they are investigating, then research will continue to de-humanise these communities as they are used as a resource to further academic curiosity (Zarb, 1992; Oliver, 1992; Chappell, 2000; Nind, 2014; Milton, 2014; Chown et al., 2017; Fletcher-Watson, 2019).

As discussed, to readdress the power imbalance within this study I as a researcher also took on the responsibility as a participant. I also where possible created opportunity for the other autistic students to make decisions as a group. Throughout this write up there have been examples of where decisions were made as a collective around what we should do, the language we should use and even how the thesis should be written.

This transfer of power was not designed around specific points where I decided others could make decisions, as the giving of power places the person giving the power as some sort of higher authority deciding when others can be involved or not (Freire, 1972). Rather I tried to create the atmosphere where all decisions were open to input and challengeable. As such I believe I was able to go some way towards addressing the issue of power within research. However, I still acknowledge that I was still in a position of power and also I was answerable to and influenced by the ethical oversight of the university. The steps taken are more progressive than participatory research has been in the past however there is still further work required with the ethics committee to move further towards Oliver (1997), Stone and Priestley (1996) and Chown et al., (2017) conceptualisation of emancipatory research.

4.16 It's all in the labels

Decision making is not the only way to attempt to challenge the power imbalance, the language and labels used within the work also provide opportunity to push back against the traditional ‘participant-researcher’ relationship. Participatory research often advocates for the identification of participants as more than participants. This is often seen as essential in challenging the ‘participant-researcher’ power dynamic. This first starts with a move away from the traditional research term of participant in favour of co-researcher, stakeholder and on some occasions co-author (Nind, 2011).

I however have issues with these terms, and I feel they can be misleading to both those involved in the research and those who read the final write-up.

Firstly, co-researcher places the participant on a par with the researcher. If this is the case, then this is entirely acceptable and should be the term used. However, if the participant is only a co-researcher during data collection with some minor involvement in data analysis then I believe that co-researcher is a misleading term (Nind, 2011). It suggests that the individual had an equal say throughout the research process when they do not, and it artificially inflates the amount of power participants are seen to have.

Stakeholder, I believe, is a more acceptable term for someone who has limited input in the research. However, the relationship they have with the study and the community being studied must be detailed (Yusuf & Elsabbagh, 2015). Stakeholders can be anyone with a vested interest in the research population and this can also include professionals working with the community (Yusuf & Elsabbagh, 2015). As such a stakeholder could be just as far removed from the research focus as the researcher, thereby negating any benefit of a participatory or emancipatory approach.

The term co-author is similar to co-researcher and is a term that I hope to be using in the future and may well do when publishing papers from this thesis. Co-author should be the term used when there is full involvement from those who would traditionally be considered participants, which would also include being a named author on any literature produced from the research. An example of when evidently this should have been done but was not is Brazier (2013) who published a paper written in the first person by an autistic student called Brett Schmidt. There is no discussion as to why Brett is not a co-author having penned most of the paper. Without this account, this paper appears to be the poorest example of using the experiences of autistic people without attributing full credit to them. This is exactly the type of research my emanciparticipatory approach aims to challenge and avoid.

The reason why I could not use co-author for this thesis is due to the implications of submitting the thesis as part of my PhD study. I will be submitting this thesis as part of gaining a PhD qualification and so the work was required to be wholly my own which is even declared at the point of submission. Therefore, the actual writing up of the thesis is, and was required to be, my own doing.

I was also resistant to using the term co-researcher even though some of the autistic students were and still are incredibly involved in the research. This is because their involvement was still constrained until after ethical clearance was gained. Ramcharan (2006) argues that with the current research design protocols of gaining ethical approval for a study prior to the study commencing and engagement of the participants of that specific study, results in the disadvantage of emergent designs, such as with emancipatory and emanciparticipatory research where participant involvement would be required before ethics has even been considered. In the future I would like to start a study by applying for ethics to recruit and work with a group to put together the ethics application so co-authors/researchers would be involved in every step of the process as the label would allude too.

For this study however, after consultation with the other autistic students, we decided to go with the simple term of autistic student. This is a term that we all share which will go some way to addressing positions of power within the research and it is also a term that we are all used to as this is part of our current identity. One of the autistic students, Sam, particularly liked the idea that rather than a lone participant we were a collective autistic student body investigating commonalities.

4.17 Vulnerable adults

An issue that I have faced as both a participant in research and as a researcher now, is the idea that autistic individuals are positioned as vulnerable by simply being autistic. Sheffield Hallam University's research ethics committee Code of Practice for Researchers Working with Vulnerable Populations (SHU, 2015, p. 1) states:

> Vulnerable populations in research terms are defined as:
>
> People with learning or communication difficulties or serious mental health problems
>
> Individuals under the care of social services
>
> Persons with a condition or illness which is directly being investigated in the study
>
> Refugees and social minority groups
>
> It is also recognised that vulnerabilities also arise in relation to undertaking research in some social contexts or around particular issues that have affected communities or organisations and the guidelines should also apply in these situations.

Based on this definition, whether you see autism through a pathologising medical lens (APA, 2013; WHO, 2018) or as a distinct culture with its own communication style, ways of thinking and nuanced social rules congruent with a more social model perspective (Straus, 2013). Autistic people would still fall within the category of vulnerable.

There is not the space here to fully explore the debate that any autistic person is vulnerable purely based on their identity, this is something I wish to pursuit properly outside of this thesis. Instead I would rather focus on the argument that autistic HE students should not be automatically labelled vulnerable by explaining why I choose to not position those involved in this research as vulnerable contrary to the guidelines that I am working within. I do just want to state that I do so without breaching any of the conditions upon which ethical approval was agreed for this study.

The starting point for my argument is one based on basic human rights: Article 1 of the Universal Declaration of Human Rights (UDHR, 1948) states that all human beings are ‘equal in dignity and rights’. Autistic students have a right to equality of respect which necessitates being treated without judgement (Chown & Beardon, 2014). I would argue that sweepingly assigning the label of vulnerable, with all the demeaning effects that comes with such a categorisation, is based on a judgment that all autistic people are by definition necessarily ‘vulnerable’. I would consider this world view of autism damaging as it instantly places autism and autistic people as different and lesser to the ‘norm’ and the ‘norm’ in a position of protector or overseer, creating an unethical power imbalance (Marshall, 2013).

The judgements made on who is vulnerable and who is not is argued to be outdated by Luna and Vanderpoel (2013) and Bracken-Roche, Bell and Racine (2016). They assert that the traditional method of labelling anyone who is different as vulnerable is too simplistic and that it can be damaging to the subgroups seen as vulnerable. Luna and Vanderpoel (2013) call instead for a multi-layered approach to vulnerability within research. These layers tend to focus on gaining an understanding of who the people are that you are researching with. Then applying traditional ethical considerations before reflecting on perspective participants understanding of both the research and the potential outcomes.

This multi-layered approach is consistent to the approach that I took with my ethics application. The autistic students are clearly capable and educated enough to reach the highest levels of education and so have already indicated that they are likely to be able to make informed decisions. Bracken-Roche et al. (2016) also highlight that there is very little research to support the notion that someone who is inherently vulnerable automatically lacks decisional capabilities. Only by knowing the participants can that judgment be made.

Additionally, university students contribute to research that does not account for vulnerability such as with the National Student Satisfaction survey and SHU's own module evaluations. In these students are asked qualitative questions around their experiences of life at university. This is not too dissimilar to the research I present in this thesis.

Once a researcher has developed an understanding of the research participants Luna and Vanderpoel (2013) suggest that they then apply standard ethical considerations as a determinant of whether participants are vulnerable or not, this is the approach I took.

Furthermore, Ramcharan (2006) argues that all participants in research are already considered vulnerable within the context of ethics and that 'vulnerable' participants are just considered more vulnerable than those not specifically labelled 'vulnerable'. What is meant here is that from the outset researchers are exploring ways to research with participants without causing harm and researchers are not allowed to interact with participants until they have established that they can do so ethically. As such applying ethical considerations that would be applied to any participant around doing no harm, are the same ethical considerations that should be applied to participants who would attract the label of vulnerable. Some consider this idea of ‘ethical symmetry’ to be the most ethical way to conduct research as researchers are not then discounting people based on ethical assumptions that are misguided (Christensen & Prout, 2002; Sime, 2008; Williams & Rogers, 2016). Similarly, researchers then are also not being ‘less ethical’ with non-vulnerable participants which could be inferred with different ethical guidance for each 'group'.

As explained in this chapter, I utilised methods of communication that best suited those involved in the research. Using these preferred communication methods I was able to answer any questions throughout the study in an accessible way, I was able to repeat the study information and discuss ethical considerations such as confidentiality and anonymity. The potential impact of these on the autistic students were clearly understood as evidenced through the varying levels of anonymity each person selected. Additionally, each person kept me informed of their desired levels of involvement as well as when and how they wanted to be involved.

Finally, Luna and Vanderpoel (2013) suggest the ensuring of participants' understanding about the outcome. Built into the design of this study was time to work with the other autistic students around the setting out of the results and discussion and even the final structure of the write up. This I feel allowed the other autistic students to get a firm grasp of the outcomes of the study; some even presented part of the results at Economic and Social Research Council (ESRC) events in 2016 and 2017.

The ethics committee at SHU do have practice guidelines for researchers, post ethical approval for working with vulnerable participants. These more specific guidelines however proved problematic and this was one of the reasons I wanted to avoid applying for ethics to work with vulnerable participants.

One of the guidelines is to meet in a venue “where you can be clearly observed by others or have another person present throughout” (SHU, 2015, p. 1). As I was not choosing the venue, I could not ensure that it was one where we would be clearly visible to someone else. As a guideline this was totally unnecessary for the research I was carrying out and might even cause more distress to both the other autistic student and also myself.

The second problematic guideline and one that actually would have hindered the participation of one of the autistic students (Nick), was that researchers should avoid developing close personal relationships with “members of vulnerable groups they are researching, and refrain from entering into any obligation (formal or otherwise) to provide practical or emotional support for their respondents” (SHU, 2015, p. 1).

Of course, there was a need to ensure that I did not become an essential wellbeing support to those involved in the study as that would be unethical as research is a time limited process. However, Nick needed to establish a relationship with someone before he felt comfortable enough to participate. Additionally, I was the only other autistic person he knew. Nick felt himself to be struggling at university and he wanted to be part of the research to both ask me questions (and we did a lot around autism, theory and disability rights) but also to hear my stories and trade questions. Had I told Nick that I could not get to know him or sign post him to support I feel Nick would have neither been able to participate nor gain the immediate benefit of participation which is a fundamental element of the emanciparticipatory process. Godefroit-Winkel, Schill, and Hogg, (2019) consider creating relationships with vulnerable participants a necessity that allows you to form better ethical judgements. They held many sessions with their participants and considered it a vital part of their ethical process.

Additionally, I spent three years working with some of the students and it would have been a different experience had I not attempted to develop some form of relationship with those who wanted to participate over the longer period of analysis and write-up.

The idea of vulnerability being an intrinsic property of a population clearly no longer works (Luna & Vanderpoel, 2013; Bracken-Roche et al., 2016). It is the position of Bracken-Roche et al. (2016) and one that I agree with, that we move to an understanding of vulnerability as something that is dynamic and fluid, based on the situational factors of the research rather than automatically applied.

4.18 Ethics conclusion

There is a suggestion that social science research is being forced to comply with rules developed for more intensive psychological and medical research (Ramcharan, 2006; Bracken-Roche et al., 2016; Mapedzahama & Dune, 2017). Mapedzahama and Dune (2017) take this suggestion further when they argue that although social science research may be intrusive it is not invasive: participants are not exposed to additional stress, circumstances or risk than they would not encounter in everyday activity. Though I do feel that ethics has a place and rightfully so, I also feel that emergent methodologies and methods require an emergent model of ethics. Further, the constitution of an ethics committee must reflect where possible the characteristics of the community being investigated. In other areas of this thesis I have discussed where PNT professionals have been at odds with the autistic community around research (Milton, 2012), definitions of autism (Leatherland, 2018), diagnostic assessment tools (Brett et al., 2016), theory (Milton, 2012) and even specific ethical aspects such as communication (MacLeod & Green, 2009). With this being the case, I put forward the notion that an ethical committee without input from the community being investigated runs the risk of approving ethically questionable research and turning down research that in effect could meet the ethical requirements and standards of the autistic community (Backen-Roche et al., 2016).

Within this ethics section I have highlighted how the ethical guidelines were at odds with the approach to research that I was doing. I have explained why I thought it more ethical to argue, in my proposal to the ethics committee, against the total application of those guidelines in order to better meet the ethical requirements of the other autistic students involved in this study. But in doing so I have also detailed how I was still able to remain ethical and produce ethically sound research.

Chapter 5

Part 1

Presentation of Each Individual's Key Themes

5.0 Introduction

I will now present each person in turn based on order of participation. I begin by presenting some information about the individual. This was decided as a means for readers to be introduced to each autistic student as an individual. We all thought this approach would allow the individual to be represented rather than them being positioned as some obscure participant.

After introducing and presenting some information about the individual I identify the key themes from their data that they would like highlighted.

Finally, there are some thoughts presented around the method of participation specific to each individual, before moving on to the next person. This is to achieve an understanding of how each person experienced participating in this study.

As with all elements of this thesis each individuals’ sections and the information within each one, were agreed upon by each individual. Some asked for a lot of information to be included and some asked for less information to be included. Congruent with the emanciparticipatory approach I tailored each section to each person’s request.

5.1 AR

AR is a PhD psychology student who aimed to be completing her PhD in 2019. At the time of our interactions she was in her first year of study. AR had moved to her current university after completing her undergraduate and master’s at another university.

AR identifies in three key ways: as female, autistic and president of the disability society. Her strengths are coping under the pressures of life, academic ability and fighting for disability rights.

AR lives in a private student house, works at the university and is an active member of her university's disability movement. She is comfortable with her label of autistic, accesses disabled student support and is very involved with the development of her learning contract and support package. AR identified a number of areas that impacted on her access to university and is actively working in her role as president of the disabled student society to address these.

Being busy and experienced with traditional interview methods AR wished to have a single one-hour interview though we did communicate via social media and email for periods before. Once the interview had finished, she wished to end our communication and, perhaps in the way of the more traditional participant, cease her involvement.

It was important to AR that I go to her and that the interview took place in her environment where she was in control. During the interview I would learn that the environment is very important to her and so her involvement was contingent on being in her familiar surroundings.

5.2 AR's key themes

These themes were developed from our interview.

Awareness

The first theme that developed from AR's data was lack of awareness from staff and students. She began our interview session continuing on from our email discussion with a focus on what it feels like for her to be an autistic student in university. The language and examples she gave evoke the image of university as a very lonely place when you are not involved and engaging with ‘student life’. AR labelled her memory of being a student as very insular and remarked to me that you can be lonely in a crowd. She recalls her undergraduate and master’s experience as:

> a difficult time I didn’t actually like going to lectures I felt a little isolated from my actual academics that I was there for so I actually stuck with my housemates and became very insular and erm there wasn’t actually a lot of help for the anxieties and stuff when dealing with a massive university with lots of people in it.

She continues:

> it’s just people’s unawareness of it all I guess it’s all in higher education it’s all about erm interacting and networking and stuff and erm that’s kind of a struggle I guess.

The interactions that are required to navigate the student life, and the environments in which these interactions took place, were for many years too much for AR. Instead she would find herself compelled to remove herself from the environment and struggle along either alone or with the close network of friends that she developed.

She goes on to recount an experience that she had as a PhD student accessing a taught session to support her academic development:

> part of the lecture she [the lecturer] wanted us to get talking to the person next to us and I was like really temporarily in this group so I didn’t know anyone so I just didn’t want to do it so I just sat by myself did my own thing and she made a really big deal out of it and erm kinda called me out in front of the whole class and stuff and I had to say to her in front of the whole class I've got autism and then even then she didn’t let it go she was like well does that mean you can't talk to the person next to you erm so that I felt disadvantaged in because I felt like my issues were becoming a problem for her and it didn’t need too.

This lack of awareness of ARs challenges does worry AR a great deal as she has experienced such a lack of awareness and feels continued lack of awareness will impact on her life. She raises concerns she has with her RF2 and her final viva around lack of awareness from examiners which she feels puts her at a disadvantage that would not be experienced by a non-autistic student. This centres particularly around communication and ordering of presentation information. AR feels her communication impairments, specifically with new individuals, will impact on the defence of her thesis and that the time it takes for her to order the information in the correct way in a high-pressure environment will impact on her ability to pass.

The feeling of being disadvantaged is further compounded by a lack of awareness within those whose job it is to support her. AR identifies a lack of autism awareness within her Disabled Student Support service. She asserts that the supports and adjustments proposed are not consistent with her course of study and that the way in which the Disabled Student Support service engaged with her has caused a number of issues. As already highlighted AR finds it challenging to communicate with new people to the point of not accessing services. Her experience of disabled student support was in her words one of being “lumped around quite a lot with different people and it really makes me kinda nervous.”

As a result, she had to fight to be given just one point of contact but feels this should be a norm for autistic students if they wish. The lack of support with moving around the campus and the focus on group work at all levels of the university AR feels stems from a general lack of autism awareness within HE.

Environment

With regards to the environment AR made two overarching points. First the design of the university, she feels, is not conducive for those with cognitive impairments and anxieties. The university is limited to the design of the older buildings and as such rooms tend to be a little all over the place. When AR spoke about this, I remarked that I had problems with finding her room and she stated that I was not the only one who was having difficulty:

> a lot of the things people are reporting is that although a lot of the rooms are complicated there's really no map for this campus that's like got every level of floor on like you ask for it and they are like yeah yeah but you never actually get it and it doesn't really exist anywhere so erm the [incoherent] is difficult cos we are limited on space these buildings are like quite old so the rooms all jig about but erm so yeah that's part of what I'm trying to get them to do is to like actually give us a map and stuff cos I've been here three years and I still can't find my way to certain places like I have to go the long way round or something.

AR felt strongly that this needs to be addressed and has made it one of her first campaigns in her new role of president of the disabled student society. The issue however extends beyond the complexity of traversing the university campus without a map or clear direction. Due to the design there are a number of high footfall areas which AR and a number of her autistic friends find overwhelming especially during busy times in the year such as freshers' week and exam periods. AR highlights that there is no room or space that autistic students can escape to if they are overwhelmed.

She goes on to state how happenstance has allowed her to have her own desk which she believes has been key to her accessing the university. Having her own desk has given AR what most autistic students do not have. This allows her to escape the overwhelming crowds, noise and resultant stress and just get on with her academic work. She is campaigning for autistic students to have access to a space of their own if required as she has experienced the benefit of having one. She discusses how without her own space she would not come into university; she would just sit at home and this is what currently is happening with a lot of autistic students within her university. This need for accessible space is why for her data collection I travel to her so that access to the research was not denied on the bases of space; this AR feels should be the same for access to university.

The Autistic Girl

Awareness was one of the main themes generated however one theme that was specific to her and something she discussed a lot about was, awareness of autistic girls. She suggests that there is a lack of female specific autism awareness. She highlights that you have a generic disabled student model that is applied to autistic students and this often excludes female specific needs. This is compounded more when you are an autistic female as not only is the generic disabled student model lacking female specific adjustments, but the model for autistic students is heavily based on male input and feedback and thus lacks female specific needs. An example she gave was that the cleaning fluids had been replaced with a less sensory impactful cleaning fluid in the male toilets after a campaign but not the female toilets.

5.3 Summary of AR's key themes

- Lack of autism awareness
- The built environment and the sensory aspects within that environment
- Lack of female autistic specific awareness or practice.

5.4 Reflections on method

When AR approached me to participate, she was intrigued by the research but actually did not want to be as involved as emanciparticipatory research is seen to be. This is something Nind (2011) noted might be the case with regards emancipatory research in that it is a big undertaking to commit to the full research process. She wanted to be involved in more of a traditional way. AR preferred to just have the one meeting lasting no longer than an hour and then she did not want any more involvement. This was due to time commitment and stress; she did not want to commit valuable time and she did not want the stress of being involved.

Additionally, AR did not want to travel but did want to do a face-to-face meeting, so I agreed to travel to her. I was able to accommodate all of her preferences and so I feel that her participation was as much a success as others who were involved in the research in a more in-depth and less traditional way.

Voice is important but it is also important not to create barriers for others in a drive to develop voice. Her voice through participation over the course of an hour is just as important and valid as the voices of those involved for three years.

5.5 Shona

Shona is a MA Autism student having come back to university after already graduating aged 21. After a career as an independent financial contractor and having a family she decided to study a Master’s in Autism to better understand her children. Shona states how it was being on the course that made her realise that she was autistic. At the time of data collection Shona did not utilise DSS citing the admin issues as being the main reason. At the time of data analysis, she did have some interaction with disabled student support however this was only minimal. Shona’s strength is her obsessive nature towards things, currently one of those is autism and she frequently refers to autism being her ‘special interest’. Shona finds the social elements difficult but accepts that she needs to engage in order to feed into her special interest. Shona believes the barriers that most impact on her are administration and organisational focus: she emphasises a number of times that she should do something about it but also how in order to do that she must first navigate more administration.

At the beginning of the study Shona voiced that she was interested in research but also did not really know too much about it. Therefore, Shona participated to see what was entailed in a research project and to also see what PhD level work was like as that could be of interest to her in the future. Throughout the study Shona used our time to not only participate but also ask questions about research which she directly used within her own studies. For example, before she attempted transcription and thematic analysis in her own work, she trialed it with her raw data within this research, asking questions and learning about the process.

Shona has presented on the topic of being autistic in HE at both the 2016 and 2017 ESRC Sheffield Festival of Science events that were constructed around my research. Through these Shona reported that she developed her presentation and public speaking skills. These are skills that Shona intends to utilise beyond this study in her own developing career in the field of autism. We also look to continue our work together both on the topic of autism in HE and the emanciparticipatory methodology in general.

Having already gained a degree, worked, and raised a family Shona was doing the degree predominantly for knowledge development. As a result, academic success for her was a little less of a factor in that she wanted to pass each stage but only for the reason of being able to continue with the learning. For Shona, a good grade or social development was not her main goal of studying and she would come to university just to learn about autism if she could regardless of whether she would receive a certificate at the end. As such and due to autism being her special interest there is less stress felt by Shona in terms of achieving high grades or at least there was when we first started meeting. As Shona has progressed through the course, she has developed some internal stress in that she feels she should do well, but out of all of those involved in this study I feel she is the most relaxed about achieving an ultimate successful outcome in academic and social terms.

5.6 Shona's key themes

Shona put forward two main points and a number of smaller points. These were based on both past experience on her undergraduate degree and current experience on her postgraduate degree. Shona acknowledges that the procedural and policy aspects of her past experience are now historical practice. However, her thoughts and feelings with regards to moving away from home and becoming a 'student' and all that it entails are relevant because moving away from home and experiencing halls for the first time is an experience many still go through now.

Shona's themes were developed with her involvement in the analysis of the data from her two interviews.

'The' student identity

With regards to becoming a student, Shona highlighted how when first coming to university her main problem was wanting to fit in. To do this she decided that she needed to embrace the perceived notion of the student identity to fit the mould of the ideal student. She recounts being a student as "Someone that goes out partying and such and is liked by boys and is fun."

Looking back in hindsight she sees how vulnerable she was at the time but remembers that the more she embraced that side the more popular she became and the more at ease with university she was. It did however have an effect on her academic studies as she believed missing out on the social side would lead to her losing what she had gained and so prioritised social life over academics. Shona remarks that this ability to focus, and perhaps over focus, is one that she still has however this is now directed towards study.

When discussing this time in her life, at the Festival of Social Science (2016) Shona recounted the memory of being sat outside upset at her behaviour. She highlights this as the point at which she changed her behaviour and put her focus on to finishing university. Her degree was coming to an end, the feelings of vulnerability got too much and so she needed to focus on academics and remove herself from some of the situations she was in at the time. Switching the focus in this way she was able to finish her degree and graduate.

Additionally, Shona also found a group of friends with whom she could relax more and did not need to do the ‘whole going out partying thing’. This change also really helped her.

This time round though Shona is older and more stable and comfortable with the identity she has formed. She feels less of a need to search out social networks and build social capital as she already has networks outside of university. Shona is also a mature student and so a minority within the larger university. Finally, her goals at university are different from the first time she went because that is what Shona perceived as being what you did at the time. This time she is here to develop her knowledge of autism and it is slowly becoming her special interest.

Additional labour attached to getting support

Shona was on a course she enjoyed, was living at home with her husband and her children and so did not really encounter any issues in her current study except for when it came to gaining support. Shona explains:

> I had this really stressed phase when none of my admin was getting done and I was depressed and anxious and I've been doing it slowly but surely now I'm trying to get down to it and start it but surely you should be helping people in that position not giving them admin to do and if they don't do it they don't get any help.

She goes on to explain that at the time she also had lots of other stress and anxiety in her life and dealing with the additional administration around gaining support was just a low priority for her. Shona explained how the additional labour of being autistic in general means there is a lot going on and gaining support is just more additional labour.

5.7 Summary of Shona's key themes

- As an undergraduate she felt a drive to conform to the idea of the student in order to fit in.
- There is additional labour involved to accessing support and this is at a time of change which comes with its own additional labour on top of just normal life as an autistic person.

5.8 Reflections on method

Shona maybe gained the most practically from participating; she contributed to my research in the years leading up to her dissertation and so used this study as a test for her research; she asked about methodology, method and data analysis. Shona even chose to be involved in the analysis of her data so she could try thematic analysis. She described this as being able to 'mess up with someone watching when it doesn't count' and learn from it here than alone with her research.

5.9 Liam

A note before beginning, the university experience has “battered” Liam, it has been brutal but has not defeated him. Over the past four years of working with him it feels for Liam like he has had to endure knock after knock from his course and university in general. Liam just survived, but he wanted it made clear that for him university was not accessible in any way. This strengthened his desire to be involved in this study and possibly right the wrongs he encountered.

Liam is a Youth and Community Work student now in his final year but was in his third attempt at his first year when he first became involved in this study. His strengths are work ethic, literacy skills and in particular creative writing, and a passion to support and help others. Liam attributes the barriers he faced to accessibility and communication issues.

During his data collection phase, Liam was a home student but at the time of writing he is looking to move into student housing. He is comfortable with his labels and is comfortable with the idea of accessing disabled student support and using the resources and provisions available. However, Liam does not currently use disabled student support due to what he feels is a lack of practical support to access.

Liam placed a lot of emphasis on the institutional barriers to his learning, particularly the way in which his course operates. Outside of academics Liam has had some success and some failure with accessing and enjoying the ‘student life’; he had some issues with joining sports teams particularly around the communication styles the teams use and other access requirements not being met.

Liam did however have great success in being involved in a number of societies and currently has an active life around being a member of those societies. Before university he attended a mainstream school where he received some support and was able to achieve the required grades for university.

Liam’s data collection protocol utilises his love and strength for words as he wrote about his experiences and thoughts in a ‘thought diary’ which he used to facilitate our discussions. In doing so Liam was able to, as he put it, ‘get it straight in his head’ so he ‘gets it all across’. Without doing this Liam believed that he would not be able to give correct or sufficient information. It was important to him that he gets across his points as he was going through a tough time with university and wanted to be involved on the ‘off chance’ it would lead to change and improvement for others.

After the first two meetings Liam was able to help disseminate some of his data as part of my ESRC event for the Sheffield Festival of Social Science. Here Liam was able to present to a number of university professors, lecturers, education authority leaders and Disabled Student Support services. He thrived at the opportunity and has since sought further public speaking opportunities.

5.10 Liam’s key themes

Liam’s themes are developed from a combination of our meetings and communications.

Surviving

Liam used the term surviving to sum up his goal going into the last year. This is what it felt like dealing with the different issues he faced. For him finishing the course alive and healthy would be the success rather than necessarily achieving a 2:1 or a first-class degree. Surviving is Liam's overarching theme with each of the other themes feeding into this idea of surviving. He was concerned that for him and other autistic student’s, university and dealing with all the extra stress and anxiety resulted in both himself and others questioning whether it was worth the potential negative impact on health. He really wanted to finish as he had started and fought so much including retaking his first year three times to get to this point but conceded that university should not be like this. He assesses himself as a good student and when able to participate and not mess up the submission dates of his assignment then he is more than capable. Liam also enjoys learning but he feels he is taking so many “body shots” from other aspects of university; rather than university being about learning it seems that university is about surviving.

Juggling a social life with the stress of uni

Alongside completing the course, Liam also wanted to engage with extracurricular activities to a significant level as the social element of university was what kept him going, but he needed to carefully juggle this with his learning and all the issues and additional work he needed to put in to manage that side of his life.

Liam struggles most with organisation and he puts a lot of effort into coming up with ways that he can help himself organise better. Yet doing so takes a lot of energy so he tries not to juggle too much in order to conserve the mental energy and time to be able to juggle what he needs.

This created a conundrum: he felt that the social side kept him going and all of the stress was due to academic studies. However, he is at university to study so if anything needed to be dropped it would be the social side even though that was the only real positive in his life. It was a 'catch 22' situation which Liam would struggle with throughout his time at university.

Towards the end of his course, Liam needed to also work which added in a third strand of organisation. This further depleted Liam's mental resources. He needed to work and juggle a work life, a social life and his learning. This then became too much. Fortunately though Liam had developed a close group of friends on whom he was able to lean for a social outlet and this he believed somewhat enabled him to continue in the face of the difficulties that he was facing on his course.

When discussing this, Liam could see that the additional labour of dealing with administration and organisation for his course (which is the next theme) left him very little time or energy for accessing the positives in life. This felt like a bleak place to be. This links in with his overarching theme of surviving.

Course at an administration and bureaucracy level

As time went on, Liam highlighted increasingly that the course organisation was the main factor towards his inability to access the course. He termed it the ‘bureaucracy of university’ and highlighted that navigating this was the hardest part, for him, of being a student. Liam asserted that this was hard for all of the students on his course and that it was not just him being autistic that made university bureaucracy difficult.

Talking further on the challenges he faces Liam emphasises that he lacks any form of organisational skills. He states this on several occasions and further presented on this for his Festival of Social Science 2016. As a result of this lack of organisational skills he works hard to develop coping mechanisms and supporting strategies. These include diaries, reminders and leaning on friends.

Yet Liam states how it is the unexpected and enforced change which comes from this ‘bureaucracy of university’ which he cannot plan and prepare for. He gives an example:

> L: … I'm not on about like the lecture is going to be in this place at that time I mean more like the paper work side of things erm and it wasn’t very helpful either that the dates that things were due in kept changing like I've got if you

> look in my diary [shows me one of a number of different diaries] I've got like different colours like based on when things are meant to be due in and what things are meant to be done by when and stuff but the dates would often keep changing all around and we would just get like an email about it and not be told in person
>
> SC: yeah
>
> L: erm and it was driving me up the wall because it was I don't mind things being changed but like as long as I know in enough time and as long as like I don't know I find it more helpful to be told face to face or on the phone at least that kind of thing and I'm there trying to be prepared and organised and suddenly it's all over the place and that's how it feels any way
>
> SC: did you have module handbooks for each module?
>
> L: err we did erm and I'd get the dates out of them and find that those dates were wrong a few weeks later.

Liam wanted to be clear that although he lacks organisational skills he has worked hard to develop strategies and when allowed to plan there are fewer issues. It is when there are last minute changes that Liam finds that he cannot cope; this has led to a great deal of stress and worry. In the past five years there have been a number of missed assignments due to changes of date. This has had an impact on his grade and goes some way to accounting for the two past failed attempts to pass year one.

> But this idea of the 'bureaucracy of university' Liam puts forward goes further than the changing of a few dates. He states it is the structure of sessions, the communication between staff (both academic and administrative) and the administrative work he is required to do. He describes this as a "big rabbit hole of hoops to jump through and boxes to tick and it feels quite separate from the academic work itself."

When these elements layer on top of each other it increases Liam's challenges. For example, Liam wrote down one date, and this was subsequently changed; he was then emailed about it, however email is a communication method Liam really struggles with, noting that he has hundreds of unread emails. His tutors and the disability support team know this. However, the administration team did not and so attempted to communicate through email.

This then led to issues around submission of the assignment which in turn requires Liam to initiate and perform administrative tasks, often unsupported, to get support and extensions for the assignment. All this occurs whilst Liam is writing the assignment and attending university.

For Liam unexpected change, communication breakdown and organisational challenges all interact to compound the problem that from the outside only looks like the disruption of a simple moved hand in date. Additionally, there is then the need to not only deal with the administrative team and his tutors but now Liam is required to deal with the Help process and disabled students support which is a whole other collection of emails, forms and worry.

Identity

Though the pressure Liam felt to succeed and the challenges he faced dominated much of our discussion, Liam also discussed other aspects. Liam never felt the need to hide his autistic identity, in fact he was proud of his label. Liam positions himself firmly on the left of the political spectrum and believes everyone should fight for those oppressed by others. Being autistic and able to fight oppression he sees the need for him to take on the mantel and push for change.

5.11 Summary of Liam's key themes

- It is concerning that education can become reduced to just trying to survive and get out without too much harm.
- Social life was an important support but unnecessary stress and anxiety from outside of his control, removed that support.
- University has a hidden bureaucracy that is impossible to navigate and for disabled students there is more of this to deal with.

5.12 Reflections on method

In spite of discussing Liam's method of participation occurring throughout our time together we did sit and have a discussion specifically about the design of the study. Liam highlighted that he actually does not like participating in research as it can be very open ended and difficult to see what is going to happen during the process of participating. He emphasised that even in questionnaires you can never really know how long the next question is going to take. He highlighted how he also ends up feeling uncomfortable at the thought that his answer could be misinterpreted and the awkwardness of having to highlight this to a stranger; it is worst when that stranger is considered an expert.

Hearing that the open-ended aspect was an issue for Liam I asked if the very open-ended aspect of being involved in this study was an issue for him. He remarked that it was but having control helped. But it was the topic which was the main reason he decided to invest in the study. For him and the troubles he has experienced, a study that may at some point make a difference to someone was the driving factor and not the design; he felt this did help, however.

Specifically looking at his design Liam highlighted that though he felt slight anxiety over participating, being able to use his thought diary helped a lot. It was something that he used all the time to jot down thoughts and organise his life so there was no new method to learn and no need to have to struggle to recall experiences. Liam remarked that there was no real additional work to be involved.

Though we discussed the presentation of his findings and he fed back on what message he wanted to get across Liam had no interest in being involved in the data analysis beyond discussing what themes I had identified.

Further Liam did not want his thought diary itself analysed as this was part of his creative process and too personal to him; it was an aid for recall and not data. Additionally, within this thought diary there was more than just his input to this study and so I also did not want to intrude on this personal possession.

5.13 Doug

Like for the other autistic individuals involved Doug's results section focuses on his voice and what he thought were important findings. But in order to stay congruent with Doug's data collection method some of the 'devil's advocate' counter arguments that I made will be included in this section as they were both a key part of the data collection and also in most instances are the context for what was said.

Doug is a master's student studying part time over three years. When I first started meeting Doug he was in his first year of study and whilst we have worked together, he has progressed through to the final dissertation year. Doug already has an undergraduate degree, but this experience was in his words 'fucking shit'. Doug had a horrendous experience studying for his undergraduate degree. This is captured within these findings as Doug reflects on his undergraduate degree as well as current study. These reflections inform his opinions about autistic students studying in HE.

Doug does have a learning contract and is supported through Disabled Student Support services; he has not taken up all of the support available but has instead selected what works for him. Doug is a live at home student; his mother drops him off at university for his sessions and then collects him once they have finished. Though Doug is a stay at home student now (as home is so close) he was not when he did his undergraduate degree; he reflects on this experience when we discuss living accommodation.

Doug’s data collection protocol consisted of a long debate within our meetings through which we would discuss a point that emerged from an experience. I would provide a counter narrative to Doug’s view and we would debate these, often arriving at no agreed conclusion. It was not an aim to do so. Once we finished one point we moved on to the next experience. The result of this method was extensive and deep discussion about topics that often felt contentious such as whether autistic individuals should be tested before starting university or whether they should be held back to mature before entering university. These views came mainly from Doug's experience of his undergraduate degree when compared to his experiences as a postgraduate student. Doug argues that he is in a far more mature and capable state of mind now that he is older than he was during his undergraduate degree and that with this maturity comes resilience. Though Doug's experience of undergraduate study was horrendous he feels that the maturity that he has now would have reduced the impact of the stress and possibly limited how bad an experience he had. I choose the counter narrative that by going through that experience he built up resilience and if he had to go through that experience now, without having been through it before, he may have the same level of stress and impact. Though of course I do not hold to this opinion fully it is an example of how our sessions played out where I would have to sometimes take a position I did not fully agree with to challenge Doug and encourage him to think. This was what Doug’s data collection protocol, as agreed between us, was designed to do.

At the time of writing Doug is still a student and working towards completion of his MA in Autism with a hope to continue on to study at PhD level. The fact that he is so invested in education after the experience of his undergraduate degree demonstrates that inclusivity and equality are not yet standard across higher education. Doug was clear that the experience he received in his first university and the experience he is receiving now at a different university are completely diverse.

5.14 Doug's key themes

Doug met for what was more of a debate style conversation where I would probe his thinking related to his experiences to drive the conversation on. The themes here are developed from the data across the three different meetings, each of which lasted approximately 1.5-2.5 hours. I was able to check with Doug what sense he made of the themes generated from his data, but he was unable to review the final write up.

Doug's data is based on two different experiences of university, once as an undergraduate student and once whilst studying for his master's. From these two experiences two themes developed; one for each experience.

Lack of tutor awareness

Doug discussed his undergraduate studies and though we debated many different challenges that he faced, the overarching theme was lack of tutor awareness. Doug had supports in place and he had great strategies for reducing stress, such as late night walks and finding quiet areas on campus to read and think but these were not enough on many occasions; lack of care and understanding from tutors took such a toll on Doug that he felt like quitting. On a number of occasions, Doug was told by tutors that he was taking up the place of a good student by being on the course and needing additional input from them. He explains how on the passing of a fellow student the tutor continued to read her name out on the register. When Doug questioned this practice, he was considered a problem student.

Doug had meetings with tutors, his mum and Disabled Student Support but they could not arrive at a conclusive support plan that his tutors where happy with; he was now just seen as a problem student who was taking a coveted place away from a more deserving student and his tutors began to avoid him, missing meetings and spending little time in his learning pod (a lab type workspace).

Doug and DSA

After discussing his past experiences, we moved on to transitioning on to the MA. As a result of his negative undergraduate experience there was a focus on getting this transition and support right. As a result, Doug's mother led the process, disclosing Doug's autism and completing the disability support paperwork and the DSA forms. Doug noted that his mother requested a substantial amount of unnecessary support. In response I asked what support Doug would have asked for if he had completed the forms. Doug responded with "I probably wouldn't have finished the forms or gained any support."

Thankfully though Doug's mother did complete his forms and he is now pleased she did as he uses these to support access to alternative assignments; this takes a great deal of stress off.

5.15 Doug's summary of key themes

- Tutor awareness of autism was poor and tutors were quick to judge Doug's caring about the loss of a peer as challenging behaviour.
- DSA was important but without input from his mum it would not have been possible.

5.16 Reflections on method

Doug wanted to participate in the research as he enjoys talking about autism and this was just another opportunity to have a conversation. Doug also enjoys more debate style thought provoking conversation that allows for greater depth of discussion than simply chatting. Both of us felt that we had pretty much covered the topic of our experiences of being students in HE to saturation without bringing more literature into discussion and moving away from our experiences. We did not really talk about the method of participation after it was decided upon though we have talked about research design and possible barriers to participation as well as research being designed without a good understanding of autism and the ramifications of this on findings.

Though our sessions were incredibly long we both enjoyed the sessions, and both went away after each session intellectually enthused; finishing each session made me excited to start the analysis. Each session also ended with Doug asking when the next session would be and how he would prefer sooner rather than later. I feel this is testament to the accessibility of the session.

5.17 Sam

Sam is a drama and theatre student who graduated during his data collection phase with a 2:1. However he felt he was more than able to strive for a first and feels he was supported by university enough to do so. But instead Sam focused his attention on social development rather than academics and so feels a 2:1 is a fair result.

Sam’s strengths are in acting and his positive mental attitude. Sam did not particularly associate his time at university with disablement or barriers. He believed that his ability to succeed was grounded in those around him, in that he feeds off the energy of the people around him and his positive mental attitude to not let his label impact on his life.

Sam believed that any issue was situated within him and any success was situated in external factors. He believed therefore that all he needed to do was to challenge himself and then nothing could stop him achieving what he wanted. Sam’s data collection method was centred around his strength of acting. As part of his degree course final project Sam wrote and performed a show entitled ‘The insanity and intrigue of Sam’. This show focused on his life as a person with Asperger’s. Relevant to this study was his section on education, university life and the beginning of his adult life.

When discussing reasons for coming to university Sam placed heavy emphasis on social development with a lesser emphasis on academic outcome. However, unlike others who also positioned social development over academics for Sam’s course and future career, connections are more important than academic outcomes so he felt he needed the social side but did not really need the grades; this idea influenced Sam’s university life.

Like others Sam had the opportunity during the study to disseminate his thoughts and ideas not just through his show but also as part of the ESRC event in 2017. Though Sam is a performer at heart, he thrives off the idea of public speaking and performing specifically on the subject of autism and has since developed performances to educate about autism and being autistic

5.18 Summary of Sam’s strengths

Sam specifically wanted his strengths emphasised to any readers before they learn about his challenges.

- Sam’s strengths are in his positive attitude, sociability and performing.
- Sam did not utilise disabled student support because he felt that his label was his issue to deal with and as such he was able to overcome any issues that might have appeared.
- Sam was very clear that university was a means of social development.

5.19 Sam’s key themes

Sam had a very clear view of how he wanted to be represented, such as a separate strengths section. But Sam did acknowledge that I am writing up the study and so I could discuss the full analysis of his findings both strengths and struggles as long as the strengths came first, and he had a final say on anything considered a challenge. I did discuss with him that the negative experiences that he encountered were not because he was weak but rather negative and positive experiences are attributable to many external factors.

Sam’s themes were generated from two long meetings before the show which was mainly around doing some background research around autism for the show, the show itself and two 2-hour long meetings after the show; where we watched the show back together.

Autism as a positive identity

When you meet Sam his positive mental attitude is hard to escape. Our first meeting he was late, it was raining outside and he decided to walk and experience the rain:

the cold of each drop on his skin, the smell that comes with an unexpected shower and the thought of thankfulness for living in a country that receives regular rain. This sums Sam up for me and he agreed with this statement.

This positive mental attitude filters through all of Sam’s life; he sees his autism as a gift that enables him to withstand far more than non-autistic people would due to his ability to be able to focus on things he finds positive in times of stress. His ability to be able to adapt to different situations through taking a step back to analyse the situation and then applying a persona that fits that situation. He sums this up in an anecdote that he used in his one man show:

> When you look at this [holds up a leaf] you see a leaf, I don’t. I'm Asperger’s and I see the amazing construction of individual cells that combine to create this magnificent structure, I smell the scent of life that it gives off, the feel as it brushes gently against my skin, I hold it to the sun to see the light bursting through with tones of green surrounded by the warmth of the white hot sun. When you see a humble leaf in this way you will never need to take a drug for depression because all you will need to do if you're feeling down is simply pick up a leaf and experience its simplistic wonder.

Sam believes that his hypersensitivity to the sensory world that being autistic brings is a strength that will get him through life.

Additionally, in acknowledging that like myself and many others who are autistic he experiences a challenge communicating with others, he sees the challenge as more of an opportunity for a positive (like all challenges he encounters) he explained:

> I just have to give my full attention when I’m communicating which is a beautiful thing that I think people like about me, when I communicate they get all of me I think that’s a strength of my communication in an attempt to overcome a challenge. I also need to put a lot of thought into my communications, so I think I'm able to say more with less.

Sam is very proud of his autism and he openly feels sorry that others will never experience the world in a similar way as him. This positivity filters through the rest of Sam’s themes.

Social over learning

Sam wants to get into the theatre industry and that was the aim before coming to university. His college course was focused around theatre and drama. His work before coming to university was with a Christian drama group and his spare time was filled with developing acting and performing skills.

Sam knew what he wanted and came to university to achieve this. Unlike other courses your grade does not matter to the same extent. Sam stated:

> in the theatre industry who you know is more important than what you can show you know and so I take the time to develop social connections and I try to get involved in as many different groups and societies as possible. That is why I came to university to make connections and those are made in the SU not the library.

We discussed his grades and he admitted that he does not really put the effort in, but he will still leave with a high 2:1. Additionally if Sam wanted a first class degree then he could achieve that but then he would have to compromise on the social side. For him the single most important aspect of university is the networking and he hopes these will see him into the career that he dreams of.

The art of masking

Sam does not find going into social events anxiety provoking as he sees it as an opportunity to perform and so relishes the chance to widen his social circle. Developing on this idea of being in a social situation as a chance to perform we discussed ideas of masking. After I explained the concept of masking (which is the idea of consciously behaving neurotypical in an attempt to hide any perceived difference), he agreed that he probably does mask as he takes on a different character when in social situations:

> That’s how I go about fitting in and getting on with so many people, I look at who is in the room what are the people like and then copy. It’s simple you just behave the same as others and you can become part of the group. I don’t understand why you would go into a social situation and behave in a way that is different to everyone else.

But for Sam this is a strength and not a coping strategy; he sees the ability to change one’s self to fit the social situation as a skill that he has but which some others do not. It is a skill that helps him socially (he’s never been without friends) and with his career: “It’s a skill that I have that will serve me well in life, it will enable me to go places and achieve the things I want to achieve.”

When exploring if this has ever been an issue or gone wrong, he discussed that it only really went wrong when trying to attract girls. He bases his social personas on observations and to a degree characters from TV, theatre and film. This is fine when trying to instigate small talk but when trying to attract a female he believes that he often 'came on too strong' with 'cheesy lines':

> Looking back I'm not embarrassed as much as I was at the time because I can now learn from it. I can see going up to a girl in the bar and being like [quotes himself] ‘hey can I just say your eyes are like diamonds in the night sky’ is just really cheesy. So, I took a step back and looked at how other guys were doing it, I could be a jerk like some guys, but I could tone it down like I see guys doing.

I discussed the side effect of masking which is burnout from needing to keep up the mask. Sam can see that burnout is an effect of this however he enjoys the quiet contemplation and disappearing into his own thoughts for hours, sitting in silence and relaxing after a social event. Sam only sees masking as a positive and where there are issues there is an opportunity to better himself. This is in keeping with his ethos of continued self-development and positive thinking.

When discussing these personas, we discussed other benefits. Sam stated:

> I believe I have a strength for acting because I have been acting all my life. I've been doing [asked for clarification on the terminology] masking all my life

> probably and I have a deep archive of characters that I can go to which is perfect for what I want to do in life. Give me a scene and I can act it. I think that’s why I love improv so much I’m able to just switch in an instant and I'm good at it.

Sam finds becoming a character for a play either as part of his work or as part of his course easy. He can become the role and often gets positive feedback on becoming the character.

However, for the first time there is a problem. For his forthcoming final year Sam needs to play a character that has a lot of sad scenes and intimate scenes with another student. Due to his positive attitude he never gets sad and he is struggling to take up the guise and that is becoming a stress and a worry for him.

I asked if he was going to cover this stress in his show, but Sam did not know whether he wanted to. In the last session when we met he explained that it still was not going well; he had been too 'over the top' again when trying to do the intimate scenes and was still struggling with the sad elements but again Sam saw this as part of building his tradecraft and something that would ultimately make him stronger.

5.20 Summary of Sam’s key themes

- Being autistic is a gift if perceived right
- Masking is a strength not a coping strategy
- It's difficult to juggle both a social life and learning so there needs to be a choice around what is most important.

5.21 Reflecting on method

When discussing how Sam would be involved in the study, he was very intrigued with the idea that he could do whatever he wanted. He instantly wanted to be creative about his participation and wanted to do something that would be ‘bigger than the study’ (his words).

For him participating in the research was secondary to the development of his one man show and as a result in our last meeting he stated that he did not even feel like he participated in the study as he was off doing his own thing with only needing to meet me every so often. Even when we did meet, he was enthused about getting his positive mental attitude out to the world.

For Sam participating in the study was a catalyst of thought and opportunity to disseminate his way of thinking. Since participating in the study he has performed at an ESRC event and he has started a YouTube channel to further spread his ideas around positive thinking and autism to the world.

When I sat down to think about the data collection methods when designing my research and the ethos of the design, the impact of participation on Sam was probably the ideal scenario: someone participating in a way that they did not feel like they are participating and participating in a way that furthers their own aims. I really felt that the research and my PhD was almost a null thought for Sam; instead the focus was on him developing and if there was a contribution to the study it would be more a coincidence. Sam feels he gained more from being involved in the study than I did in that he was about to work through his performance and gain some theoretical foundations for the autism elements.

5.22 Nick

Nick was a Film and Media student whom I first met during his second year. During our time working together he completed his course, graduated and set up his own photography business. Unlike others who are involved in this research Nick has never really disclosed his diagnosis to those around him, including tutors, other students and friends. But he acknowledges that he struggles due to this decision yet believes that these challenges are for him to overcome alone. This drive to overcome challenges that could be considered disablement is what Nick sees as one of his strengths. Nick has always been brought up to understand that a diagnosis of autism is not a crutch, or an excuse and that autism should not hold him back. His understanding of autism as a result is very limited and this resulted in his data collection being based around a ‘Trade of Information’: he talked about his experiences and I talked about autism. As a result of this perspective on his autism Nick did not declare his autism and did not seek disabled student support or DSA. He believes that had he sought the support it would have made no difference as there was “nothing that they could have done”. After our first meetings and through discussion Nick decided that he would reach out to his Faculty Student Support Officer (FSSO) to discuss his autism and issues particularly with group work (which will be discussed in depth below). However, the resulting conversation between the FSSO and his tutors was that group work had to occur in this fashion as in the workplace you cannot choose who you work with. This was not the desired outcome both to myself and Nick who didn’t get the support that he was looking for and more importantly he had been proven (from his perspective) right, that there is nothing that can be done with autism; you just have to get on like everyone else. As a result, Nick never gained any disabled student support whilst at university.

When discussing reasons for coming to university Nick’s passion for creativity was clear: he was here to get the skills and qualification to be able to work in animation and film. In college this creativity plus a computer science focused mind enabled him to succeed at BTEC and he wanted to continue down this route. This led him to university. After his first year it became clear that there was a limited room for Nick to express his passion, so he switched courses. He believes this was for the best and will enable him to do more but also acknowledges that it has created some issues for him (which will be discussed more later).

As reported earlier Nick has graduated from university and has set up his own photography business, he is also developing his portfolio with a look to moving to London for work within the TV and film industry. Nick wanted me to end on this information to inform that as bad as it was he is now in a more healthy environment with a positive outlook on life.

5.23 Nick's key themes

Nick's themes are developed from data collected during our five 'question for a question' interviews we did over two academic years (as detailed in Chapter 4 and Appendix 6). There was time between each session for data to be analysed and I showed Nick this process though I did the analysis and he checked the themes were representative of his experience.

Surviving Uni

The first thing we spoke about in session one was what Nick’s idea of success would be and he was very certain: “Good grade, move to London, get a job and if I find a partner on the way than that’d be me sorted.”

However, as we continue to meet and discuss the challenges that he faced this idea began to change from get a good grade to just surviving long enough to submit the final project and finish.

Nick argues that the work at university is not hard, it's very 'doable', it’s just “All the bull shit that comes along with it, group work, housemates, tutors. It's all just getting to me. I really need to just get my head down work all hours and submit.”

Over the course of the time Nick was involved in the study his health declined and so did the relationships with everyone around him. At the end it became so severe that Nick lived a very insular life, getting to the labs for opening time and then wandering the streets after closing until he was sure his housemates were either out or in bed. Nick was working 14 hours continuously in an attempt to get his studies completed after issues with working in a group and it became apparent that he needed to submit as soon as he could or else his health would take a shaper downward turn.

When checking these themes with Nick he wanted me to add that he did submit on time alone and he graduated with a grade he is happy with and has moved back home where he is recovering well and preparing to head to London in search of a job

Multiple Nicks

Nick sees himself as having three different social identities:

Nick the member of the module groups (Nick's course is heavily based on group work)

Nick the housemate

Nick the friend.

Nick sees himself as different in each of these roles and he associates different stress and anxiety with each too.

For Nick the social identity that troubled him the most was that of his group work. Group work is a major part of his course and so Nick has to regularly be a member of a class group. However, he struggles in two different areas: communication and the working ethos of the groups.

Nick struggles with communicating with the group; he gets incredibly anxious about initiating communication (yet his anxieties leave him needing to communicate in order to clear up any ambiguity and make clear concrete plans) and when he is working within a group he struggles with the communication styles of the other group members. As Nick explains:

> We meet then random topics will be discussed for like half an hour then someone will leave and we get on to discussing what we need to and there will be some stupid ideas put forward agreed on and before I know it everyone is happy and I'm like what just happened we have discussed this list of issues and then I'm the bad one for bringing everyone down.

He gives a more specific example:

> We'd been chatting for about an hour and I was like hey can we sort this out and all I got back was no of course we can't XXX is going away and then they moved back to the discussion. What does that mean XXX is going away then I found out that it had been decided to pause our end of year project because XXX was touring Europe and everyone else decided it was wrong to continue without him. So, I highlighted the issues with that and suddenly I was the bad guy; everyone got the hump with me and walked out.

After a conversation with his tutor, in our second meeting Nick discussed the plan he put together with his tutor. This was to try to not upset the group anymore which made communicating with them so much harder because as he states "I never really know when I'm saying something that would upset them I just want our project done." But this just created more additional stress that he would upset them and that by not talking to them they would 'mess up' and he would fail at university as a result.

This stress of working in groups was compounded with life at his university accommodation. Having lived in halls during his first year with little to no issues beyond a slight feeling of isolation, Nick moved into a student house in his second year. At first he stated that he 'kind of got on with' his housemates but again the more we discussed this the more it seemed that being a flatmate was stressful for Nick. At one point he started being out of the house whenever his housemates would be at home. To do this he would leave the house early in the morning and stay out until between eleven o’clock and midnight in an attempt to avoid contact with his housemates. Nick discussed that rather than big arguments or a massive fallout it was more a build-up of smaller disagreements and issues that just made social interaction between them too stressful and anxiety provoking. So, for him the best course of action was to avoid that stress and anxiety to allow complete concentration on his work.

The third of these social identities was that of a friend and potential partner. This was less of a constant stress, like the other two social identities. However, this was one that Nick felt had the biggest impact on his happiness. Nick found that he was able to get on with stress associated with housing or work but if there was a problem affecting his more personal social life then this would take over his life. He explained with an example of where he had started seeing a girl who was a member of one of his social groups. This relationship consumed his life and looking back in hindsight he can see the huge negative effect that is had upon him. He began to fixate on the relationship to the detriment of other relationships and work. He began only socialising with this person and skipped out on some of his passions to spend time with her. For him during that time having a girlfriend was all encompassing.

The other side of this identity is that of a friend. Nick explains that when he is not working, he enjoys being part of the union society that he is a member of, though due to work he rarely has time for that anymore. But he does enjoy being part of this group when he is able to get along to either practices or on nights out.

In speaking to him about these various different social identities it became apparent that though they are social identities the stress of navigating the social dynamics of the groups has resulted in him actually being very isolated: he works alone, avoids housemates by either working or going out drinking alone and this actually takes time away from being part of a social group that he feels is more accepting, he noted that the group have a number of autistic members or members with close links to autism.

Nick and autistic support

Nick has had a difficult time around his identity as an autistic person. His parents had tried to keep it from him while growing up and he only found out in his late teens. Now he feels his parents' attitude is very much let's just try to forget about this autism thing; as such he had a very negative attitude with it when he first came to university and considered his autism as ‘his cross to bear’. His parents believed in not having him standout, worries that it would have an effect on his life. Therefore, Nick had not looked into having autism support.

However, as his struggle increased, Nick explored getting support and declared to the university FSSO. In doing so he met with the FSSO and his tutors to discuss possible adjustments on the course. The only real adjustment Nick wanted was to not have to work in a group. However, Nick explains that his tutor stated “The course is to prepare students for working in the Film and Media business where teamwork is mandatory and his teamwork ability during the course is important for when we give references.”

With Nick wanting to work in London and needing a reference from a tutor with connections in London it was advised that he continue working within groups (despite the conversation highlighted in the above theme).

5.24 Summary of Nick's key themes

- The challenges of the university were so severe that university became all about survival
- There was a need to compartmentalise the different stresses encountered with different identities
- Sometimes supports and recommendations are not implemented.

5.25 Reflections on method

Nick was involved in the study to learn about autism and I feel that I was able to fulfil his wants; we covered models of disability and how they might impact on practice using some of his experiences as examples. We covered autism theory which he found interesting though he did not really relate to it at the time instead focusing on the medical model perspective that the main cognitive theories take. We discussed sensory challenges which he could relate to the most out of all that we covered, as he does have some hypersensitivities particularly with light and sound which he realised through the reflective process.

We ended our exploration of autism through looking at what is available for the autistic community within the micro-society of the university, locally and nationally. However, Nick was put off participating nationally and had a number of problematic experiences accessing the university and local autistic community and so has decided to tough it alone.

As a whole Nick enjoyed participating and he agreed that he would do something similar again where he learnt something whilst participating.

5.26 Me

When I started this thesis, I wanted to address the power imbalance between the researcher and those that traditionally are labelled participants. I decided that a contribution to doing so would be to position myself as a participant. Additionally, as discussed, the label participant was changed and instead, I became, like the others, an autistic student involved in this study. I made it clear to each of the other students involved that my data would consist of recollections of my experience of university as discussed with them during their sessions; through artefacts from my earlier university experiences and that I would also reflect on the writing of the PhD as a component of my data. This has been discussed at length within the methodology and methods chapter however I thought it was important to repeat it again here.

This is because other changes occurred during the writing of the PhD that are relevant for the findings section. When I started, I was just a student with no other commitments. During my second year as a PhD student I started working as an Associate Lecturer at the same university in which I was studying. During my 'write up year' I took up a full time post as a lecturer in Autism and Education there. This change from a student identity forms a key part of this thesis. I felt that I had lost this student identity when I moved to working full time within the university. As a result of this I was considering limiting my data to before I became a member of staff however after much negotiation (with myself) it became clear that I had not lost the identity of student. Rather I had just gained another identity that students gain and that is one of a student with a job. I am cautious that my new title does have an impact on my student experience to a degree because for many I am no longer seen as a student but as staff or as a colleague and it is important to acknowledge this. However, there are still student issues that I have experienced consistently through my HE life that still impact on me today and so this will form my data.

At the moment of writing I do not access disabled student support. This is for various reasons which will be discussed below. I live with my partner on the outskirts of the city in a non-student area. I do my student related work from home as I find the students' areas within the university inaccessible. This is even more so since I moved home to a quiet area that has drastically reduced the sensory impact of my out of work surroundings. This means that when I do access the university I am usually hypersensitive. I detach my student life from my work life in the same way that I compartmentalise each aspect of my life. I have lived in halls and I have accessed student support in the past with varying degrees of success which will be discussed later in this chapter.

5.27 My key themes

Being a ‘participant’ within this study like the other autistic students involved it was felt that I should also have a similar section dedicated to the main themes of my experience.

This importance of C

I gained my undergraduate degree at Leeds Metropolitan where I also studied my MA Physical Education. Here I experienced an incredibly dark time in my first year due to mental health issues as a result of being unable to adjust to the social side of university. This first year was one of the darkest times in my life and without support I fully believe that I would have been sectioned within the psychiatric system. I stopped eating, developed psychosis as a result of extreme anxiety and spent my days in my room alone; often during slow university periods I spent 5-10 days without human contact. So, I have experienced first-hand the positive impact that having support can have. When I was becoming more withdrawn my personal assistant, ‘C’ was able to step in and discuss ways in which I could become more involved. I was supported to access university sports and was able to live part time at home when I needed to recover.

As my education continued ‘C’, whom I fully trusted, began to explore how to reduce slowly the support package and over the course of the four years I was able to become more independent to the point I only needed support with my dyslexia.

One point of contact

I think vital to the above theme was that ‘C’ was a sole point of contact. He was paid by my social services direct payments scheme to look after my social care needs, bank, bills, doctors, my life really. ‘C’ was paid as my dyslexia tutor and note taker. He was my scribe in my exams and he was also the 'go between' for me and the finance authorities and my tutors. I had one point of contact at the university for all my needs.

The importance of this was never clearer than when I moved university and received one person to help with my organisation, a different person for reading in exams, a different person for writing in exams, a different person for prompting in exams, a different dyslexia person, no point of contact for finance (and this department particularly struggled with communicating with me and still does) and no administrative support. Thankfully after hearing me complain about everything going on my tutor stepped in and took over my organisation and supported me with administration but this was beyond her job description.

Social Issues

I do not really like other people and being sociable. As a PhD student this is not an issue but during my undergraduate and master's study it was a real struggle for me. At undergraduate level I would purposefully choose to work with the laziest students so they would not bother coming to lessons or want to hold meetings and I could get on with doing all the work myself. But living accommodation was a real issue. I felt like a prisoner in my own flat. I would lock myself in my 8x15 foot room with all my food and drinks, no entertainment and sit or sleep until it was time for another lesson. During reading weeks I would sit in my room for 10 days continuously until my 'C' intervened.

I would do anything possible to avoid contact with other students, but this did change to a degree when I started playing American football. The other players knew I did not like to talk but I had the potential to be good which they needed so I would be quiet, and they left me alone in the hope I would continue coming back. After about six months of silence I did start to interact a little more and eventually started going to house parties with them where again they would leave me to relax in peace.

Master's study was a little different however: nobody was a lazy student and they were all very motivated to study so I had to try and get involved and mask the anxiety I had about it.

5.28 Summary of my key themes

- Supports in all aspects of my university life were vital
- Access to one point of contact was critical
- The social element of university can be challenging but also can be a non-issue
- Mandatory group work was the cause of one of the most uncontrollable stresses.

5.29 Reflections on method

I discussed my reflection on method earlier in Chapter 4, but I will cover the salient points again so that my presentation of themes is consistent with everyone else’s. I have always wanted to participate in a study where I gave my data while playing a virtual computer game MMORPG as this is where I am most relaxed and open about myself. However that relies on having an interviewer so I could not do this here. If I participate in my own research again and the design is more open then I might consider paying a graduate student to interview me but for now I have developed an auto-ethnography style that works for me; it has allowed me to collect my data from different sources including when I have discussed my experiences with the other autistic students. This reflects how my data naturally developed rather than me sitting down and trying to draw out data.

5.30 Conclusion to Chapter 5 part 1

Within this first part of the chapter I presented a personal account for each person. This is because each person is an individual and I wanted this study to focus, as far as possible, on the individual. Autistic people are often reduced to numbers: 1 in 68, 9 times more likely, only 15% and so on, but this study aimed to break down this repeated history of faceless participants with little control. I designed this study to enable voice; it therefore only seems fitting for each person to be heard in their own section. Sam particularly liked this as he was able to have a section focused on strengths with the others choosing to have strengths less overtly presented. Additionally, it allowed each student to highlight the themes they really wanted readers to take note of.

Now that each person has put forward what they think is an important aspect of their experience I will explore the themes that developed when looking at all of our experiences as a whole. Within this collective account many of the 'individual' themes are also present but perhaps not to the same degree.

Chapter 5

Part 2

Presentation of Collective Themes

5.31 Introduction

Having presented the key themes that each person identified as capturing the experiences that they felt were the most important, I am now going to move on to the presentation of the collective themes. The collective themes unlike the individual themes are generated when looking at all the data together. As such there will be some similar themes such as around surviving university, issues with academic supports and social challenges but there are also other themes that came through that the students felt were important but not as critical to their own key themes: these included disclosure of autistic identity and the additional labour of being an autistic student.

I will now present these themes before moving on to the discussion in Chapter 6. Though the other autistic students did not identify these themes as their key themes they have reviewed these themes and agreed that they are important representations of the experience of being a student who identifies as autistic in Higher Education.

I will present each theme in turn followed by a summary of that theme. All together there are five themes; some contain sub themes. All the themes are listed below:

Theme 1 Control of label

Theme 2 Sociality

Theme 3 Wellbeing

Theme 4 Academic supports

Theme 5 Additional labour of being a disabled autistic student

5.32 Theme 1 ‘Control of labels’

Firstly, just to reiterate that an official diagnosis was not required to be involved in this study and I did not review any diagnostic paperwork, when discussing labels it is from the perspective of both labels assigned and labels by which individuals identify by. This decision was made to allow those who did not have a formal diagnosis, possibly due to the issues with the diagnosis process as discussed in the literature review, to be involved with the research. Rather than those diagnosed as autistic I opted for those who identify as autistic as a required characteristic for inclusion within the study.

The term 'identifies' suggests some form of control by the individual. They choose to identify or not. All of those involved in this study identify in some way as autistic. Codes around disclosure and control in some form constantly appear throughout the data and these were placed into four categories to make up the theme of disclosure these categories are 1) disclosure to the university, 2) disclosure to close friends, 3) disclosure to peers/housemates and 4) disclosure to the wider student population.

5.33 Disclosure to the university

From the data it was clear that not all students wanted to declare to the university. Nick did not want to cause trouble or be a burden for anyone. Nick stated “I see autism as my cross to bear, like everyone has difficulties and they don’t disrupt those around them, and I need to do the same.” He goes on to state that:

> everyone is struggling but if you can't get through university then you are going to really struggle in industry. Like now is when I need to learn to get by. If I'm the weak link, then I will never be able to work down in London. Plus there are so many real disabled people in the world that are suffering you can't say that having issues remembering to go to the right room or take the right books is a real problem.

As a result of seeing his autism in this way, for a long time Nick kept his autism secret from the university, only disclosing this in his third year. Nick regards his autism (which is how he refers to being autistic it is ‘his’ autism) as 'his cross to bear' and he is incredibly cautious that the challenges he faces should not impact on others around him. Nick feels that by disclosing to the university he is stating that he is officially struggling. Steps will then be taken to minimise this, and Nick will be less able upon leaving. He will have acquired an almost learned helplessness perspective.

Similarly, but from a different perspective Sam also withheld his diagnosis from the university. Sam sees autism in an incredibly positive light. For him autism is a strength that outweighs any negative he might encounter. He enthusiastically stated:

> I feel for everyone else who will never get to see the world as I do. If I'm down I will sit and look at something like a leaf and think about how the cells all interact to create this structure. I'll look at how the light shines through, how it feels on my face, the smell of it. I never need to feel down or sad when something like a leaf can brighten up my day. I feel sorry for all the non-autistic people in the world.

Further Sam also believes that any negative is an opportunity for himself to develop as a person through perseverance. He recounts a time before university as an example of what he means (he later uses this and the leaf example in his show):

> I left school and all my friends behind, I struggled making new friends so I thought to myself no Sam you cannot sit with no friends you must put yourself out there. So I joined a social group I studied how others interacted and sat and thought out how I would interact in that instance. I used being lonely as a driver to learn to make friends and now I can make friends with anyone.

As a result, Sam too thought it would be best not to declare his autism as he also saw facing his challenges alone as a way of developing as a person. It is also interesting that both Sam and Nick who regard autism from opposite perspectives (one as a positive one as a negative) were against acknowledging themselves as disabled. They both view disclosure to the university as accepting the position of being disabled.

All of the remaining autistic students declared their diagnosis to their universities. They considered disclosing as important for gaining support and not being at a disadvantage. However, when discussing disclosure to the university AR and Liam both found that they had to continually disclose, which was something I also experienced throughout my university life and still to this day.

AR explained how it evidenced one of her concerns around the implementation of her learning contract. She stated:

> If I'm having to tell every tutor that I'm autistic and have a learning contract which states I do not need to do this and I get a blank stare back with [quoting a tutor] ‘well will you at least try’, they are clearly not reading my learning contract so what was the point in declaring?

Similarly Liam states:

> we are a small cohort. All our tutors know our names and our placements we see them daily but when I first started, I had to tell each one individually that I was autistic despite having a learning contract. But what really annoys me is that I constantly have to keep telling some that I'm struggling with a task because I'm autistic.

Additionally, Liam adds:

> it's all well and good having a learning contract but I declared to the university not just my tutors so why do I struggle so much with the admin team, finance and the placement people. They are part of the university yet I constantly have to tell them I'm autistic and often nothing changes.

I had a similar experience to both Liam and AR. I constantly had to tell my tutors at undergraduate level that I was autistic and the same with administration and finance. Finance were particularly difficult as they would note down I was autistic, but policy dictated that this note was to be removed after a set period of time. This also applied to the note that they needed to contact me through my advocate. This resulted in me being in debt every year despite having the funds to pay and struggling to communicate with them.

Though Liam and AR disclosed but had issues with this I asked if they thought it was beneficial to do so and they decided it was. AR stated “Though it was a nightmare and I never received anywhere near the support I am entitled too and often tutors made things worse I think without disclosing I'd have failed or worse.” Liam similarly stated:

> at the time you struggle and think what's the point asking for help if you constantly need to remind them but looking back I can see it's been helpful at times mainly because I know I have this thing that offers protection so when I put in a complaint about my tutor it's listened to a little more.

Shona's experience was entirely different. During her undergraduate degree she did not know that she was autistic, and her MA was in autism so it made sense to be very open about her diagnosis to add that perspective to class discussion.

Doug had a similar experience during his MA but this positive experience contrasted greatly with his undergraduate experience. Where Doug encountered a lot of issues with negative associations placed upon his diagnosis from both staff and peers. As a result, he ended up as much as possible avoiding others spending as much time as he could alone.

5.34 Disclosure to peers/housemates

Within the literature there is much emphasis placed on the importance of social capital particularly with class peers and housemates. Much of the literature focuses on positioning and identity within a group. As insiders of a group you are able to lean on other group members for support. Peers have the added advantage of possibly experiencing the same work-related stress or even being able to provide solutions.

Housemates have the advantage of being present during the time when students are away from other support. As such both peers and housemates are suited to be a distinct friendship ring, that’s not always best friends but closer than acquaintances that are able for some to be lent on in times of need congruent with the ideas of social capital.

Though Sam is positive about his autism and will tell anyone who asks, he states:

> I'm not going round telling every person I meet I'm autistic but if people ask I'll tell them and if there is some misunderstanding in a situation which might be down to us both thinking differently I'll let the person know that I'm autistic and it's not their fault.
>
> My housemates know because I'm close with them and of course my course mates know because we spend so much time together. Plus I'm not the only autistic person on my course.

I asked about Sam's first year, knowing that he lived in halls and then has lived in a house with someone he has known for the rest of the time. Sam replied:

> no I didn’t tell my first year housemates but I never saw them I was really into the church in my first year they helped me out so much with transitioning into university so I was with them. They know but my housemates didn't.

He later added:

> when you asked if my housemates from halls knew if I was autistic I said no but I didn’t keep it from them. I just didn’t see them. We weren't friends. It's not like I liked or disliked them. They were just different from me and we didn’t spend time together.

Sam features very little of his first year in his show as he suggests that his first year bears little reflection of his time at university. It was more of a transitional phase and more of a struggle. This echoes my own experience. With his first year not really featuring in his show we spent very little time discussing it and we did not discuss his first year housemates again.

Nick did not disclose to his housemates, highlighting that he really does not get on with them. When we first started meeting, Nick voiced issues with them being loud, dirty and unwilling to engage civilly. As we continued to meet, within a few months interactions with his housemates reduced further.

Again, Nick's perspective on his autism dictated his perception around disclosure to peers:

> they already dislike me and we fall out a lot because they are so unorganised and leave everything to the last minute which makes me anxious but I can’t say anything because they all do this and if I cause a fuss they will just not turn up to meetings or turn up and not have any work.

He added:

> I didn’t choose my group. I got stuck with the ones nobody wants to work with because they are so unreliable and bad, they will probably fail the course if I do not do the work for them […] so no I didn’t tell them I can't rock the boat because if I do then it will all be my fault.

AR was very much like me when it came to disclosing to housemates and peers in that we felt there was no straight forward response. At times in our education we kept our diagnosis secret from those around us and at times we were open about it. We had similar reasoning for this, and it came up in AR's interview. She stated:

> I'm not ashamed of my autism. I'm very autism positive, but I also don’t want it to be the thing that leave the impression of me on someone, know what I mean? Autism is still so misunderstood so if I was to say I'm autistic I can't control the knowledge that person has in every situation.
>
> When I'm with housemates or with friends I know that they will ask questions and uncertainty will be resolved in a positive way but if I was chatting to a guy online or in a club I can't just drop out I'm autistic because it's then difficult to discuss; he'd run a mile.
>
> Similarly if I'm just chatting to someone in the SU about a society, I don’t want to be like, hey before we go on I need to disclose I'm autistic because then we start talking about that not the thing I need to talk about.
>
> Plus my autism is for me to disclose, not others. If I'm chatting to someone and it comes up and we are able to discuss it that’s fine but I can’t drop it on someone if I think they are going to leave without really knowing much about

> autism then sitting with their friends and being like oh she's autistic, isn't that like Sheldon Cooper I'd avoid her because then I am the female Sheldon to those people not me if you get me.

This resonated with me. When I was on my education course it seemed beneficial to me to disclose my diagnosis. When I was with my American football team, I also wanted them to know because I did not want to be seen as weird. I could not mask when I was playing as my focus was on a new skill that if I did not get right would result in me getting hurt. So, I wanted teammates to know about my stimming and aversion to being touched. However, females I hoped to spark a romantic relationship with I would not tell and would be very anxious about them finding out before they knew me.

In my first year of university I did tell my housemates early on. However, I feel this then resulted in me being ostracised and a meeting between my housemates and the university as they thought I would be dangerous to live with. In later years I was more guarded with my disclosure to housemates. In my second year I disclosed after a while and this was received well. In my third year it was received not so well and again I had a troubled time in halls though I was able to escape and spend time with friends. My fourth and fifth year I kept it totally secret due to anxiety of experiencing the same issues I had in my first and third years. Then I moved out of shared accommodation and lived alone until living with my fiancé. Upon reflection many of the issues I faced, were through poor knowledge around autism from those to whom I disclosed so I could recognise the concerns raised by AR and Nick.

5.35 Disclosure to close friends

As might be expected, everyone felt comfortable with disclosing to close friends regardless of their opinion of their own label. Nick who openly struggles with his diagnosis still discloses to close friends including that he struggles with it. He said:

> Though I do not like my diagnosis but when you have such a close friendship with someone you share your worries and concerns and being autistic is a major worry in my life […] friends do not necessarily understand though. [Name removed] does though as she has you but others don't. They think they do and suggest things but they suggest things that will never work.

Asking if Nick had told partners, which was something we discussed with regards to my life, he said "not really, I've never really had one like you. I did have one, but I was more her carer and it got really weird. I'd tell a close friend but not a girlfriend." In a later meeting, Nick brought this back up again stating:

> I'm seeing someone now and she has depression, so I thought I'd tell her I'm autistic and struggle with depression and now that is our shared thing, we support each other rather.

Sam is a member of his students' union society. He highlights the group as important especially in his first year. Although he did not want to talk too much about his first year as he wanted to stay focused on what was going into his show Sam did highlight that along with the church, the performance society enabled him to have something to focus on during the turbulent time of starting university. He says:

> they really were welcoming and I was able to be myself around them. There was no need to put on a front do you get me? You can just go perform and have a drink after. It's a really relaxed vibe which speaks to me a lot as I try to live my life like that. I want my show to be like that. They were part of the reason I was like I'm going to live this life like I am now.

Liam said about his disclosure to close friends:

> Friendships are really important to me. I would do anything for my friends and I feel they would do anything for me so I'm clearly going to tell them I'm autistic and then lean on them when I need. They were all really amazing and they have always been there for me.

Shona said how for her, her friends are mainly within the autism field, so her diagnosis was something to be shared. Doug pointed out he does not really 'do' close friends but is fine with whoever knowing as he does not really care for other opinions as at the end of the day, they are just opinions.

I have never really done close friends and the only people I spend time with are either teammates or ex housemates so I do not really have this distinction between close friends and wider acquaintance that others do.

AR however does have a clear distinction, similar to Nick and to a degree Sam. She states how:

> I do distinguish between friends close friends and people I just go to university with and then there's a level of disclosure. Like I said, I have to be cautious of what knowledge the other person has so if I do disclose I will down play the challenges I face unless the challenge is that person. I can't truly tell anyone that is not a close friend things like if a corridor is too busy I need to go home and cry for an hour […] but thankfully I have my friends. I live with them now and I can always go and shout down or meltdown around them and I know I'll be safe. They are always there for me and I wouldn’t have gotten to PhD level without them.

It is clear that for those with close relationships there is a level of trust and acceptance which has proven incredibly valuable.

5.36 Disclosure to the wider student population

After disclosure to peers, housemates and friends there is a larger circle of less close friends or acquaintances that could be identified as neighbours, other members of societies and clubs, as well as other individuals that students come into contact with on a daily basis. Nick discusses his societies as he “knows there are autistic people in the group though and I see how people are with them, so I'd be ok if people did know but I'm not about to go round telling everyone.” Liam also explains that he is not exactly telling everyone he encounters but he does highlight that:

> If you know me then you are kinda gonna know, do you get what I mean, like I talk about it on Facebook I'll share posts about autism so you're gonna see stuff and be able to work it out.

Both Nick and Liam appear to be unconcerned about whether people in their wider circle of acquaintances know. This is similar to Doug who explained “I don’t really care. I have never really cared. It's hard to not recognise really but I don’t care.”

AR and myself however did care. AR explains it as:

> I really don’t like the idea of someone talking about me. I just want to be in the background and the idea that people are talking about me as autistic bothers me, not because I'm ashamed or anything but like I said they will jump to incorrect conclusions about me. Autism knowledge in society is just so poor that if someone thinks someone is autistic they are just going to assume some of the more negative stuff and once people see you like that they aren’t going to see you differently.

I felt the same as AR as a student before my PhD. Now it is an identity that is very much out there, but I still get anxious like AR does around people misunderstanding or judging me.

5.37 Summary of theme

Each student had differing reasons for both disclosing and withholding. However, the clear similarity between each student was control. The autistic students in this study aimed to control who knew and when and they felt that this was important for them. If this control was removed from them, they felt that there would be ramifications on their life. This highlights the importance of allowing students to be able to control how, when and to whom they disclose.

However AR and Liam used their control to disclose to the university but ran into issues around having to repeatedly disclose and not just to tutors but to other sections of the university which they highlighted as being an extra layer of stress. The idea that by disclosing to the university through the proper channels then all those officials with whom they came into contact would know is a concept that is not delivered in their experience and mine.

Nick and Sam both struggled with the idea that disclosing to the university meant accepting that you were disabled, something that appears throughout literature and was explored within the literature review. Nick who sees autism as an impairment was against disclosing as this felt somehow that it disadvantaged him further. Though Nick conceptualises autism as an impairment he does not regard it as a disability. For him, a disability is something far worse than the challenges which he encounters. Whereas Sam did not want to disclose because he did not see autism as a negative and believed that the university focused on the negatives of autism.

Perception of autism was important for all the autistic students for most of their undergraduate experiences. Nick and Sam didn’t want to be perceived as disabled. However, both appeared accepting for those within an environment to know they were autistic when there were other autistic people also in that environment. AR and I when we were undergraduate students worried around how the poor knowledge of others, about autism, would result in them perceiving us as lesser. Nick, AR and I also worried about how members of the opposite sex would perceive us and so this resulted in us guarding our autistic identity in certain situations.

What is clear is that we all disclosed to close friends and found solace in them knowing; those close to us became the unofficial supports through friendship. But again, it can be seen that this might be because we had some control over the perception that they might have around autism as we are able to explain and influence their perception of us.

5.38 Theme 2 ‘Sociality’

Closely related to the concept of disclosure is sociality. It is related as it became clear that who was in the environment and what the social context was had a major impact on the choice for disclosure. All of the autistic students identified sociality as the foundation for studenthood. Many key decisions whilst at university were made based on the sociality of university, this includes disclosure as discussed, but also decisions around pushing beyond comfort zones, whether to skip academic commitments and how students engaged in lessons.

Shona stated that during her undergraduate degree she conceived being a student as a social person: “someone that goes out partying.” Similarly, Doug stated how everyone around him was “so focused on going out which was great because it meant I would get the labs to myself.”

AR also stated that she was not like other students because she “goes out partying equal share between thinking about doing well and thinking about the next night out.”

AR further discussed feeling detached from the university life as she was not very social. She did not like group work and as such had her learning contract adapted to include being able to opt out of working with others. This in one way meant that AR was more isolated though she did highlight that she lived a very insular life anyway. AR did have a social life but this was focused around a very small number of close friends with whom she lived with and could be herself around. Additionally, Shona highlighted that over the time of her undergraduate course she found a smaller group of people with whom she became close friends. This enabled her to then move away from this idea of a student necessarily being a social student.

This is not to say that the overwhelming experience was that the social element was a negative. Liam’s social life which was very much focused around student based social activities, like going to the SU, being part of SU societies and experiencing the city nightlife with university friends, was the single driving positive force around being a university student. Sam too highlighted that for him being social was the main focus of being at university even if that meant compromising on his learning in an attempt to be more social. Nick, who like Liam was struggling with parts of university life, found he could relax around his society friends. He explains: “They are a really good bunch of people whether it is practice or the quiz or karaoke. I know that I'm going to be welcomed and be able to just be myself and that is really relaxing.” Nick who even struggled with the identity of being autistic was comfortable with those in his society group knowing he was autistic.

I also attribute the turning point of my university life to the development of social relationships with my American Football team and believe that if it was not for my teammates I would not have had the drive to finish university let alone stay for three masters’ degrees that I only did to be able to continue with university sport.

Looking at this theme though the circle of friends that appear to be so important in our university lives are friends not associated with our course. AR’s sole friendship group is her housemates. Mine, Nick’s, Liam’s and Sam’s friendship groups are all linked to the students' union. No one discussed making friends with anyone connected to their course; in fact the opposite was the case. Everyone except for Sam and Shona discussed wanting to do university work alone. Nick even discussed different identities for the different environments, each with their own level of disclosure and social interaction.

This may in part be due to the additional labour involved with navigating the learning environment, whilst trying to focus on learning. As such there may be no energy or focus left available to navigate the social environment during this time.

5.39 Masking to fit in

Within the theme of the social student there is clearly a sub-theme of masking. As a sub-theme it appears to feature in each person's life. Additionally, it is not only one mask but rather multiple masks depending on the environment and who was in that environment

AR discussed masking specifically, explaining how she would often need to withdraw from the world to recover. She stated:

> I try to get through the day, I am aware that I mask a lot and it helps me. I feel that by disappearing into the background I'm not at risk from those around me. The only issue is when I can't keep up the mask, usually due to sensory or just burnout. Then I have to go somewhere quiet and alone. Currently here there is nowhere and that is my first campaign as disability officer: a campaign for a quiet room that we can then as a student body turn into a sensory room. Without it my only choice is to run home when it gets too much … I also struggle to mask when I am unmasked if you get me. Like I've said, I need to control when I disclose however it's difficult to do that when a tutor is stood at the front of a class asking why you are refusing to speak to the person next to you and you have to tell him at that point. The mask isn't about appearing as just another person in the room but rather about showing my challenges aren't affecting me. This is the type of thing that results in a run home to cry for the rest of the day.

She goes on to state: "In order to control the perception of autism I have to gauge how much of myself to expose to any given person and so have to juggle that."

Shona explains that she was probably masking all through her undergraduate study, especially the earlier parts where she was trying to fit in with the other students.

Besides Shona and AR, the other autistic students had either not heard of masking or, in Liam's case, had heard of it but had not sat and thought about it until I asked him to.

After thinking about it and writing up his thoughts Liam discussed wearing a mask when dealing with lecturers and administration. He says how he was able to relax when with his friends and within the SU, however he needed his mask to protect himself from the issues he encounters when trying to access the organisational elements of university. He stated:

> thinking about it before I go and see anyone to do with my course. I have to collect my thoughts [shows his thought diary] and I need to plan how it will go then I build up the courage and head in. I do take on a demeanour to try and hid my anxieties as they can interrupt my thinking and cause no end of issues. I'll speak to my lecturer or the admin and then need to go and sit. I can't plan anything afterwards and its worst if it doesn't go to plan.

Nick loved the concept that masking was a known thing and it was fine to do and normal as he says he must be masking all the time, which is evident from his discussion of disclosure. A large proportion of the time I met with Nick was spent talking about his need to appear normal for others so when we discussed masking specifically there was little to add. I did ask, when he thought he masked, and he stated 'always'.

We did discuss the impact of masking after I explained that there is a negative to masking and how draining it could be for some. Nick thought about it and explained that:

> trying constantly is so draining. It's the biggest drain on my life. I try so hard to appear as normal and not let my issue impact on other people, but other people don't make that easy and I always need to pretend. I pretend in uni, at home, with my parents. I just try and appear normal.

Sam takes a different slant with the ideas of masking and we talked at length around the idea in preparation for his show. As highlighted, he discloses to anyone his label; he does not cover up his diagnosis. But through thinking about interacting in the world we arrived at a discussion around masking and personas. He explained “I'm always in a character in different social situations but that’s just to fit in and be liked. I'm not going to behave in a way that I'm not liked am I.” He adds:

> I analyse the group and see how they are then I'll become more like them. If they are dancing and singing I'll do that but if they are toned down and relaxing thinking about the world I'll do that. Or if I'm in a night club or a bar I'll behave like the other guys in there.

Sam goes on to explain how when he first attended university, he had the wrong approach to girls; his persona was wrong. He had grown up a lover of films and so when he came to university would use a persona that was overly romantic. He remembers saying to one girl:

> Looking back I'm not embarrassed as much as I was at the time because I can now learn from it. I can see going up to a girl in the bar and being like [quotes himself] ‘hey can I just say your eyes are like diamonds in the night sky’ is just really cheesy. So, I took a step back and looked at how other guys were doing it, I could be a jerk like some guys, but I could tone it down like I see guys doing.

This was met with an embarrassing laugh. Looking back at many failed attempts Sam can see his mistake was basing his perception of what others would want on incorrect source material, so he began to look at the people who were successful in that environment and began to inhabit their behaviour:

> you can't be like a cheesy Romeo, girls don’t like that. They like guys that are a bit of a player that they need to tame that’s how you get talking to them. You catch their eye with a smile and a nod then ignore them I've stood and watched guys do that in the bar and in clubs and it works. So now I do my version of that and then when you get chatting to them then you can begin to let them see the real you more.

For Sam masking was not about hiding a diagnosis like Nick; his diagnosis was out there. For Sam masking was about being more successful within his environments and this is why he sees masking as a strength.

In a later meeting when discussing his studies, we touched on this point again. Sam stated that he was struggling with a new role. He'd never struggled with roles before however this new role was causing both him and his group issues. He needed to play the role of a love interest and he was either too sexualised (his club player persona grinding his co-star) or too romantic, both performances resulting in the other actress feeling uncomfortable and others worried about the overall performance. Sam however did not see this as a problem but rather an opportunity to develop as a person.

Until sitting and thinking about masking with both Nick and Liam, both of whom would ask extensively about my experiences, I had not seen how much masking I had done during my middle years at university. In my first couple of years I do not think I masked; I had grown up in a special school where I did not need to mask, I don’t think. It could be what caused so many issues during my first year or it could be that the issues meant I was unable to mask; it would be hard to tell without possibly tainting that memory with the knowledge that I now have. But when I first moved to Sheffield, I came with a bit of a persona already in place. I knew a lot of Sheffield people from American football and this was the reason I was coming to Sheffield. However, when I arrived my new teammates were very different from my friends and teammates in Leeds. Rather than staying in after training and during big game weeks the Sheffield players were very much like the stereotypical student as I discussed in the literature review. They were out constantly socialising as a group morning, noon and night. These were the groups that I had been ostracised from in my first year at Leeds and now I was not only a member but due to my playing ability I was a highly prized member and so masking was easy. I can see I masked at this time whenever I was around others. During this time I had a few unsuccessful relationships: I believe because I had started seeing people when I was masking and felt the need to continue masking when I was with them to the point where I dated people for months, years even, without telling them I was autistic.

Doug was the only one who said he did not mask and he did not really need to: he only came into university for his taught sessions and his MA was in autism so he was surrounded by individuals who were very welcoming of his autism. Doug did however have views on this: he believed that he was only able to be like this due to a maturity that came with age. He states:

> I do think that age is the factor. I don't think they should allow autistic people into university unless they are mentally ready. When I did my undergraduate, I wasn't, and it fucked me up. Yes, saying you can't come until your ready is discrimination, but it stops people getting fucked up and quitting or killing themselves. Masking is a response to the environment you are in when you either can't leave or can't handle other opinions of you which is a very immature thing. Mature people that have accepted their difference don't mask because they don't give a shit about what others think of them.

I do not agree that autistic students should not be allowed to come to university until they have matured, but there is a clear divide of experiences. Those who are older and on postgraduate courses do not feel the need to mask but those on undergraduate courses do, in an attempt to fit in with perceptions of studenthood and perceptions of normal. If masking can be so problematic, then addressing the issues around perceptions of difference might go some way to lessening the need to mask.

5.40 Being alone gets a bad rap

With such a focus on being social in both the literature and with some of the autistic students, being alone might seem like a negative; however, this is not always the case. Doug particularly finds solace in being alone. He recounts:

> There's nothing better on a warm summers day than going to this one garden on campus that I think nobody knows about to just sit and relax in silence. There's something about stepping away from a busy uni in a busy city and finding some peace and quiet alone.

AR also craves opportunity to be alone on campus currently one of her main foci is on the campaign to develop a quiet room where you can be alone and in peace.

Nick enjoys his own company too, living a very solitary life. He explains:

> Outside of when I have to do group work or with the societies then I'm usually alone. I like being alone. I love to game alone. I know you like multiplayer games but I hate them. I want escape and to be alone.

Though there should be no negativity applied to those who wish to be alone it is interesting that many of the autistic individuals discuss being alone as a means of escape either for sensory reasons or because of anxieties. It might be that until there is a major change of university policy, practice and environmental development that finding alone time is the best strategy for some students; this should be remembered when universities are promoting the social student.

5.41 Summary of theme

The social element of university is promoted hard: it is present within the marketing materials, it is a focus within the newer built environments, and it is a key pedagogical principle utilised within the taught curriculum. As a result, if you face challenges around social environments then university can be a very hostile place with little escape from the need to be social. Students explain the need to mask to both fit in to this socialised normality and to also not appear as different through being autistic. Yet even this masking takes its toll as an additional emotional labour. It results in an additional taxation on internal resources and when these run out the result can be damaging to the autistic person. This idea of additional labour is discussed further within the additional labour theme.

What is clear from the data however is how much of an impact the social aspect of university has on everyone involved in this study: we all have negative impacts on wellbeing due to the social side and negative impacts on our learning. As such the social element needs to be better supported and thought about when designing inclusive policy and practice.

5.42 Theme 3 ‘Wellbeing’

Though only one person openly discussed their wellbeing, the analysis revealed wellbeing as a significant theme across all of the autistic students involved. When speaking to students who were involved in the analysis, they even highlighted how wellbeing runs through almost every discussion whether it concerns them doing something for their wellbeing or whether it was an issue that through discussion it became evident that this had a clear impact on their wellbeing.

Of the students Nick was the only one to discuss how what he was going through was impacting on his wellbeing. He discussed finishing his work by doing 15-18 hour days:

> I just want to get done now. I can either take the hit now [to his health when discussing finishing early] and get out of here with a degree and alive or I can continue plodding along living in hell and potentially doing some serious damage to my mental health.

At this time he would leave the house at 6am and not return until 11:30pm or later in an effort to avoid his housemates but also to finish a project that should take a year in around three months so that he could leave university early.

The need to 'power through', to get out before wellbeing 'took a big hit' was similar to Liam who deemed surviving as his goal when going into his last year. Resulting from a mixture of mistakes from the administrative side, his organisation and issues with lecturers, he was struggling and the prospect of failing with severe damage to his mental and physical wellbeing was a real possibility.

Additionally, AR mentioned how on three occasions she ended up running home when things got too much. She interwove the comments as though it was a normal part of being a student; struggling so much that something tips you over the edge and you end up in fight or flight: “It’d be so bad in lectures I'd need to just escape and without a place to go I'd run home.”

I, as reported earlier within the thesis, experienced my darkest period during my first year where a mix of social anxiety and poor living standards had me as close to breaking point as I have ever been. This led to my parents and my support staff discussing what might happen if I needed some emergency supported respite. I was incredibly anxious, had lost almost three stone in weight and was experiencing psychosis. Though it cannot be categorically connected, I also finished the first year being admitted to hospital with unexplained internal bleeding and severe stomach ulcers.

Doug also experienced a major impact on his wellbeing as a result of issues with both tutors and university management that resulted in him needing to take some time to recover after graduating. This occurred too with Nick who also needed to enter into a period of recovery after graduation.

Shona explained how feeling the need to participate in student life to fit in impacted on her wellbeing. So too did Sam who was generally highly positive about his experience but he did admit that sometimes he needed to just escape into the countryside to recover a little as socialising was such a toll he would burn-out.

Whilst wellbeing was not specifically brought up, the toll of existing in environments that were either overly stressful and anxiety provoking or sensory challenging was. So too was how the students dealt with this. Nick explained how he drank, “It's not like a drinking problem but after a day at uni before I face going home I'll go to the bars in town for a bit and have a quiet vodka.” He added, “I’ll also buy an old cheap PC game and go escape in that world for a couple hours.”

AR talked about her home being a bit of a fortress of solitude where she could escape to. But she was concerned that there was nowhere on campus for other autistic students to go when it all gets a little too much.

Liam spent most of his time in each session talking about two things: how bad he was finding the non-learning aspect of his course and general administration and how much of a positive impact being able to go to his different societies was.

5.43 Wellbeing and the environment

A sub-theme of wellbeing is that of the environment. The environment was so intrinsically tied to wellbeing that it was felt that it should be a sub-theme.

AR struggled with the environment the most; with the anxiety of navigating it and the overwhelming sensory impact. She recounts a very powerful image that forms the main captivating opening argument about her campaign for staggered session endings:

> The crossroads where I met you is the main thoroughfare of the uni. When the main classrooms kick out everyone piles into there like at school, but these classes are two hundred and fifty at times and they all converge on one point. One time when I first started there I was walking through and the buzzer went, it stopped me dead in my tracks the high pitch screeching through my ears then bang I'm surrounded by bodies speedily bumping into me all the conversations that were happening in the rooms now out in the corridor all around me then as quickly as it came it went and I sat down and cried.

The environment is such an accepted issue at her university that when AR stood for disabled student president on a platform of campaigning for work on the issues of the environment the lady running against her stood down. Now AR has an office, but she explained that many autistic students still struggle with the environment: “Luckily, I can escape here but I fear for the other students. I think that's why I was able to be elected un-opposed. We all knew that something needs to be done and that I'm very passionate about it.” She goes on: “Imagine having to travel through hell to get to a class. You'd either stop going or arrive and need the lesson to recover.”

The high level of the sensory impact of university also came up with Shona who stated that university was “nice but very noisy, not in like a loud music way but lots of stuff going on in the background.” Shona had hoped to work from home a little more but instead used sensory equipment to access the university which she found worked well.

Nick explained that he struggled with smells, noise, and lights and that was why the library was a ‘no go area’ for him “It's like a student common room: lots of people just talking away even in the silent areas, either talking or eating so you have the noise and the smell to deal with.” As a result, Nick works in some computer labs in another part of the university and he is thankful that he is able to at least study there. Nick also explains that he struggles with his home environment again due to smells. His housemates are not very clean and rarely tidy up after themselves so Nick struggles with the smell of the dirty pots and mouldy rotten food.

Doug however did not discuss sensory issues although he did explain that he often needed to go and find somewhere quiet to either work or think.

It was interesting how often the need to go and find somewhere that was not officially meant to be a quiet space came up. Everyone but Sam and Liam highlighted that they needed to find somewhere to escape to from university life.

5.44 Summary of theme

It was unsettling to learn that when it came to undergraduate experiences everyone discussed the need to escape to recover from being in the university environment. From the data it was clear that all students were experiencing issues that were impacting on their wellbeing more than would be expected for a student, whether that was social anxiety based, environmental based or burnout from the additional labour each student experienced when facing these increased challenges.

It was however encouraging to see that everyone had some way of escaping, whether that was going home or to a quiet area or mental escape through hobbies, interests or positive social activities.

5.45 Theme 4 ‘Academic supports’

What might be surprising is how little we all discussed academic supports. Sam did not have any. Shona and Doug were studying on a course for which supports were baked in and Nick did not try to access them until his last year.

Of slight concern however might be the challenges that those who did access academic support encountered. AR did explicate more than most, even in her short interview, the issues that she had in class around tutors not knowing she was autistic (and she assumed if they did not know then they could not have read her learning contract) and tutors not implementing her adjustments or they did but questioned them.

She explains that on one occasion:

> I was in a seminar and a tutor who I had had issues with before asked us to work in a group. Everyone was in one so I wasn't negatively affecting others' learning. Most were in groups of two but some were a three and a couple of groups of two joined up with others so there wasn't a problem. And he said, 'excuse me why are you not working in a group'. I said 'I have a learning contract that says I can opt out of group work'. His response was 'well at least give it a try'. The girl next to me was obviously a little embarrassed to being forced to work with me.

This is an experience similar to one Nick had. Group work was severely impacting on his health and after advice from friends he disclosed. Completed the paperwork and looked to get some support. His main issue was around group work and he was pleased to hear that it was common to have in a learning contract about not needing to do group work:

> So we had a meeting with my tutor and XXX the disabled lady and my tutor explained the course is to prepare students for working in the Film and Media business where teamwork is mandatory and his teamwork ability during the course is important for when we give references. We would have to say that he can't work in a team if we are asked.

As stated earlier Nick's dream job was working in London and he needed the reference from the tutor with connections, so he decided to persevere. This was the only support Nick looked to have implemented.

The issues that Nick and AR faced not only highlight that supports might not be implemented they also evidence what AR agrees is a worrying lack of awareness from lecturers.

Liam though having issues with his lecturers also encountered issues elsewhere. His course is heavily focused on multiple different placements and so Liam is often in contact with the placement co-ordinator. He found that they, like other areas of administration, did not adjust to his learning contract:

> I ask to be either let know during a teaching session or called about coming in and told face to face so I can put it in my book and my diary. Sometimes they do it and it works great, other times I'll have missed a placement or I'll turn up and I'm not expected or like I said assignment dates will be changed and I won't know and hand in at the wrong time. That’s happened a few times where the data on the slides is wrong so they will email round to tell everyone and then I'll hand in and get a zero mark until I put in the extenuating circumstances form.

I experienced similar issues to Nick and AR as well as Liam. I had more than one occasion where my tutor had asked my Personal Assistant questions during a pop quiz then asked him to still have a go when he said he was staff, or asked him to not be in my group as there was too many and could he move to work with someone without a group. On one occasion ‘C’ was asked to move to work with someone and when he explained who he was the tutor replied, 'well you’ll understand then'. It got to the point where we decided ‘C’ should say, when asked, he was a social worker from the vulnerable adult’s team to just shut down any follow up. I also had issues with student email and many important emails being sent that I would not receive, despite my learning contract clearly stating not to send emails.

An interesting theme between those of us who did seek out learning contracts is that we did not mind others knowing that we had them. I certainly feel there is no stigma attached. However, the term 'learning contract' can be used for a multitude of different reasons and there was a little more hesitation around peers knowing we were autistic. Nick however was very clear that he did not want anyone knowing that he had a learning contract except staff so I do wonder how he would react in similar situations as myself and AR.

Doug and I also had issues more recently with a change in the set-up with regards to how we are supported with spelling. Though not autism related it does cause stress; something both of us are not very good at coping with. The support change now means we have 12 hours and our spelling person is only allowed a set number of students which has resulted in a need for students to meet more regularly; so once a week for six weeks each term rather than like we both prefer which is to meet for all six of our semester hours in one week. I was actually asked to switch to meeting more regularly or lose the supporter I had, whilst Doug found the pressure too much and decided to not use the support system.

There was also a lot of 'grumblings' around applying for supports. We all thought it was worth it when we did apply however the act of completing the form, gathering the evidence and dealing with any of the follow up issues, unless supported like Doug, was additional labour. Also, I have never applied and been successful without issues. Each time there has been something wrong, from an outdated faculty stamp to too much evidence. I have always experienced hold-ups with support. Except for my first year where social services, the university and my parents sat at a table and completed the forms together, in this instance support was in place before my first day.

What is important however is regardless of issues and the additional labour of gaining access to supports then maintaining the supports, all who applied saw a benefit to applying and in some way, some more than others, there was a reduction of stress around each person's specific concerns.

5.46 Summary of theme

It is important to reiterate that when DSA is applied for students are pleased that they did and can see the benefit. However, there is still some confusion about what disabled student support can do for students. Additionally, the perception of those not engaged is that it is for those who deem themselves so disabled that they need help. The image of DSS is one based in the medical model which is inhibiting some students from accessing it.

Further there is additional labour attached to applying for and then maintaining supports which will be discussed further within Theme 5. There are also issues around getting the information about a student's challenges out to lecturers and the wider university, as well as ensuring this information is enacted upon. There are many possible reasons for this that will be discussed in Chapter 6. However, it is clear that if not addressed students will continue to experience challenges and in some cases discrimination and exclusionary practices.

5.47 Theme 5 ‘Additional labour of being a disabled autistic student’

A commonality that has appeared in the discussion of other themes is that of the additional labour the students had to experience from being a disabled student. Like with wellbeing this was not explicitly discussed but it is clear that students had to do more due to being disabled autistic students. Within this theme there are three sub-themes 1) additional labour accessing supports and maintaining supports; 2) additional labour being a social student; 3) additional labour within the environment.

5.48 Additional labour accessing supports and maintaining supports

Like I highlighted additional labour was never explicitly discussed however when reporting on accessing supports and then maintaining those supports it is clear that there is a lot of work that a student needs to do. Within the literature review I highlighted that accessing support requires work and that is evident from the data in this study too. However, what was not discussed in the literature is the additional labour required to maintain supports. By maintain I mean the communication, organisation, planning, social nuances of maintaining a good relationship and continued paperwork required to continue to access and use these supports, all of which tax resources. Moreover, this is before the additional anxiety and stress around worrying about these supports with students asking themselves whether these will be challenged, be there when they arrive or whether they gave incorrect information. Liam explains this:

> I had an organisation lady but you have to be organised to book her and then turn up. She made me sign a contract at the beginning stating that if I was late to a meeting or I missed it I would forfeit that time. I got so paranoid about messing up that I stopped using her. I'm terrible for organisation and it seems bizarre that you have to be organised to access the support for bad organisers.

I had encountered the same issue and we joked that we might have had the same lady. I too became worried, after I missed a meeting and received a rather formal email about it, that I would do it again, so I stopped booking them.

Similarly, with my dyslexia support, after a change in the policy they were only allowed 10 students and so someone like me who saved their hours until the last week was less appealing financially than someone how saw them once a week. After receiving an email asking to meet more regularly for this reason, I became anxious that my support was counting on me and so I stopped seeing him. Further I only accessed disabled support to see him so the next year I did not reapply.

Shona explained how there was a lot going on when she needed to apply, and the idea of administration was too much, so it fell down the priority list. Now it has been sitting there it is too anxiety provoking to go back to without help: “Surely you should be helping people in that position not giving them admin to do and if they don’t do it they don’t get any help that’s just crazy.”

Doug explains when we were discussing personal support:

> It's strange that there is a set arbitrary time that you are allowed to see supports regardless of how fucked up you are. If you're autistic and dyslexic, you get 12 hours. If you're just dyslexic you still get 12 hours. There’s no accounting for processing time. It's just 12 hours which shows no thought goes into it at all.

As a result of this limiting time factor Doug did not want the effort of trying to utilise this support. Though he did use adaptions and extensions around assignments, he did not want to access the other supports his mother applied for. Doug was clear that without his mother applying he would not have applied at all as it's just a lot of paperwork. My mother also applied for me, as did Liam’s and Shona highlighted that she would need support in applying. The idea of beginning the process was obviously a partial barrier for some. AR however applied herself; she likes to take control around her support in an effort to minimise her anxiety:

> If I deal with it all then I know what I'm meant to be getting, when and for how long. I also know where I am up to in the application process and what needs to be gathered to support my case.

AR explains how she is very 'hands on' as a way of reducing anxiety but also acknowledges that this is just more work. “Often you have to set it all up just as you are starting the year, moving and acclimatising. It’s a bit of a hell month to start each year.” AR is often very drained when starting the year with so many new aspects to get used too: new environments, tutors and peers. Applying and organising her supports is just another drain on her.

However, it is not a case of once you have applied and it is set up then supports run smoothly. AR, Liam and myself all had to deal with supports not filtering through or not being put into practice by tutors and administration. As previously explained, AR and myself both had our supports and adjustments challenged by tutors and this gave us an additional worry with each session. AR explains: “It’s a stress getting into class and then when you arrive you have to worry over what is my tutor going to do that results in me looking like a difficult student.”

Doug too was labelled a difficult student when awareness around autism may have resulted in a different course of action by tutors and possibly in different and less damaging experiences for him.

AR expresses concern around the poor autism awareness from her tutors. “They just don’t get it. There is no understanding of autism at all.” Liam explains his tutors also do not understand autism. “They give you a look when you say something is going to be difficult. It’s a ‘but you’re at university’ look.” This perceived lack of awareness results in a building anxiety from the students whilst trying to learn. There is a worry about the reaction of the tutor to the struggles they face. Further, if students are masking to hide their diagnosis, getting into a discussion with tutors, in front of other students in the way that has been highlighted, forcibly removes that mask and control of their identity as AR discussed wanting to have.

Outside of dealing with DSS, support staff and lecturers there is additional labour required when dealing with the wider university, library staff, finance department, accommodation staff, general administration and reception staff, associate lecturers and PhD students and so on. These staff are often not informed about a disclosure of a disability or the adjustments and supports the student is both entitled to and in need of. I remember one time a PhD student who was taking a session asked me why I had not done something and when I replied I struggle with it being autistic he replied with “I don’t know what that is meant to mean but this is a basic thing all university students should be able to do.”

AR avoids the library for two reasons: it's not a very autism friendly environment and she has a poor relationship with the library staff after losing books and complaining about the noise. This is despite the additions of funds to replace lost university items being part of her support plan.

For Liam a large part of his daily stress is around communication with placement support, tutors, administration and his FSSO. He plans to organise his day as much as possible so that he can do what is needed in the day but explains how one of them will just 'throw a spanner in the works':

> You organise before bed, try get a goodnights sleep, wake up feeling good with a plan to deal with 4 jobs. You’ll go into uni and admin, or a tutor or placement co-ordinator will throw a spanner in the works and before you know it you're going home with the original 4 tasks not done and an additional one so the plan for the next day now has an unmanageable amount of stuff to do. This is how I'll end up submitting late. Check deadline will be on my to do list then stuff will get in the way. It’ll take six weeks to deal with that stuff and I'll submit, and it will be two weeks late.

This echoes my experience of dealing with non-academic staff at university.

5.49 The additional labour of being a social student

Alongside the additional labour of accessing and maintaining supports there is the perhaps bigger sub-theme of the additional labour of being a social student. I say bigger because this sub-theme was present in every student’s data but also the impact of this sub-theme appears to be more apparent.

Liam discussed the most about juggling social life and learning. This was not because of late nights and missing lectures through 'burning the candle at both ends' that might traditionally be thought about when someone mentions juggling work life balance, but rather the mental resources that are required for both being sociable and also engaging with learning:

> I have to really plan and organise and that takes a lot of mental energy. I'm thinking about the anxieties, stress, communication issues. I sometimes process conversations a little slower and it's impossible when I'm thinking about other stuff so a lot has to go into being social.

He adds:

> If I have a lot going on with uni then I'm spending my energy there and I can't really spare any of it for going out which is just the worst cos even though going out drains me it ultimately recharges me. It's also the thing driving me to finish. It's important to me.

A lot of time and energy goes into being social. When he is with his friends Liam's focus needs to be on being with them in order to enjoy it and not become lost in conversations. Though not directly discussed Liam finds that when there needs to be focus on learning and the stress that goes with learning, then there is no more resource available to use on being sociable with peers.

I suggested to him when we were analysing his data (he agrees with this conclusion), that it is as if he has enough resource to spend on one thing; either the focus of being sociable, the focus of learning or the focus of all the university organisation, administration, planning and stuff, but not enough for more than one.

AR also explains when discussing wanting to be alone in class:

> I'm there to learn not to make friends. It's hard enough masking to get by in the environment as it is. Throw in the issues with my support, lack of awareness from my tutors and I think I'm dealing with enough. I can't then have the whole being sociable thrown in the mix.

Again, the resources that might go into being sociable are being used elsewhere and so being sociable is not a priority.

For Sam though being sociable is such a priority it takes over from the learning, but he can justify this so does not have the same tension that Liam experiences. Sam is able to focus on being sociable. However, Sam still does invest deeply in being sociable possibly more than most, as he studies everyone who he is in a room in order to identify how to proceed with interacting, and then he is evaluating how it is going. Sam discussed having personas that would allow him to flex to different social environments. However, there is still a similar heavy investment into carrying out these personas.

I on reflection like Sam also wore different masks in different situations and believe that for me the biggest additional labour was juggling all of these different masks. I would be one way in one environment and another way in another environment and I think like Sam this is down to trying to wear the best mask for that given situation.

When we reflected on this idea of the additional labour and the issues that I, Sam and Nick encountered with our living accommodation we thought that it might be due to living accommodation being the one place where we needed to stop masking in order to recharge, however that meant that we could not handle the social element of living with others. When considering AR, her only friends were her housemates, but she still discussed needing to be alone to recover from masking:

> I have to mask at uni and it's really taxing on me. By the end of the day I'm close to the edge which is why if anything goes wrong, I usually just leave uni. I used to need to just go home and be in my room to recover but now my amazing housemates will make an effort to spend time with me to relax and cos I no longer need to mask with them I can just relax and I need less time to be alone when I'm home now.

Being more comfortable around her housemates without masking coincided with an increase of her university work, possibly because she had more resources to utilise elsewhere as she no longer needed to mask or at least as much with her friends and she also had the extra time to relax as just being home was enough rather than having to find time when at home to be alone and relax.

5.50 Additional labour within the environment

Environment was discussed when highlighting specific issues. Yet there is clearly additional labour required with accessing and then being within the different environments of university. Within this section it is more than the university building: it is all the aspects that universities highlight as important to being a successful (based on grade) student, such as accessing the social areas, libraries and living accommodation.

AR highlighted that the university was inaccessible to her for two reasons: its layout was a challenge for her and there were no detailed maps (in visiting her university I struggled with this). AR also highlights the sensory environment as being a significant challenge. The significance of this grows when combined with the other daily additional labours. For example, the anxiety of planning her day, then having to navigate through a fairly inaccessible environment en-route to lessons, and dealing with the issues highlighted around accessing support and adjustments there. This is all while trying to learn, which is the main reason for being there and should be the main focus.

Nick discussed how he was not able to access the library either due to his sensory challenges. “A bit bright for me and it smells horrendous. They have a no hot food policy, but everyone ignores it and people are always eating in there: McDonalds, KFC, curries it really is bad.” Shona highlights how she works:

> It's difficult to find a quiet spot. You’ll discover a place and it'll be good for a couple of weeks then others will discover it and it'll get busy like the place in Norfolk that was great till large groups started to come. So you have to move and find another place.

In a later session she explains “I use ear defenders now and work in there [pointed at the computer lab] nobody really cares so I go work in there.” Shona now uses ear defenders to block out a lot of the sound and works in a room with an above normal amount of natural light meaning fewer of the strip lights are needed on.

I too struggled for a long time to find somewhere to write this PhD. I too could not stand the library due to the smell and noise and I could not work in the PhD centre because I forgot the passcode and I did not complete the paper work for my card access when they suggested. It fills me with anxiety when I think about doing the process now. Luckily, I got my job as an associate lecturer which allowed me to buy a home computer and then when I got my full-time job, I was able to have an office.

Of course, students do not spend all their time in university or the library: living accommodation has a significant impact on students. AR explained how her house was her safe place but also how she would ‘need to find time to be alone to recover’ though this need to find the time lessened over time: as her housemates became more aware and understanding of her needs they were able to support her better.

Liam, Doug and Shona lived at home and did not really discuss home life. Neither did Sam who did not really discuss his living accommodation. I, as stated, struggled with my living accommodation through my first year and really into my master’s when I moved into a flat by myself. Nick did comment about the noise and smell issues in his flat caused by his housemates, however the social aspect was his biggest issue with his house as discussed.

There was very little data around the environment of the classroom. The only other environment that was brought up was by AR who highlighted that her SU was inaccessible because it was so loud with music and a layer of ‘stuff’ at the entrance. “There’s always stuff going on there leafleters, club night promotors, political stuff, artwork, meetings. It's like between the outside world and the inner. SU is a wall of bodies to somehow get through.” She added “but then when you’re in there it is sensory hell so really there is no point.”

Though AR does not need to go in Liam, Nick and Sam need to attend regularly. Sam was fine with the noise, Nick went when it was quiet and turned down other invitations and Liam really enjoys music so has no issue. The other students never brought it up.

5.51 Summary of theme

Of course, university is a stressful time for most students and dealing with staff, learning and assignments is hard regardless of diagnosis. However autistic students are clearly dealing with stress, anxiety and work that is additional to the expected standard of demand placed on students.

Each participant discussed elements of their lives where they have to do more to be able to access the same environments, lessons and social activities as other non-autistic students. This additional labour that these students have to carry out is in addition to an already demanding student life. What is of great concern is that even when students are accessing supports, there is still additional labour involved with accessing and maintaining supports. This includes navigating the tensions between tutors and the supports that students need.

The level of additional labour is so grave that all of the autistic students involved in this study at some point had to opt out of participation within the world and isolate themselves in an attempt to recover. Additional labour clearly is having a negative impact and, as will be discussed in Chapter 6, this additional labour is relatively absent from the literature which is concerning given the impact that it is having on autistic students.

5.52 Conclusion to Chapter 5 part 2

In this chapter I have presented the five key themes and connected sub-themes generated from the research data through the process of thematic analysis. All of the themes presented were also agreed on by the other autistic students involved in this study. These themes were similar to a degree to the individual themes presented in part 1. Yet there were also additional themes that became clear when looking at all of the data as a whole, particularly the theme of additional labour which as will be discussed interweaves throughout all of the themes and has a significant impact on students physical and mental wellbeing. Discussion of this and the other themes will now take place in Chapter 6 below.

Chapter 6

Discussion of Themes Relevant to the First Research Question

6.0 Introduction

The aim of this study was to explore the experiences of students who identify as autistic in HE. But rather than focusing on just the academic aspect, the study looked at the 'whole student experience' and how this experience interweaves with different aspects leading to tension and potential impact elsewhere. This was important as there is so much emphasis from both students and the university on the 'whole student experience', that without focusing on this with autistic students there is a potential for a lack of understanding. This could in turn be contributing to the high levels of failure observed with autistic students (Fabri et al., 2016).

Within this section I will now combine where relevant to this interwoven effect, the themes presented in Chapter 5 and discuss these themes and their interaction with each other with the support of literature.

6.1 The autistic student 'liventity'

A considerable amount of time was spent with each autistic student discussing how they were perceived by others and how they perceive others. Fundamental to this was controlling who knew they were autistic. Both Jacklin (2011) and Kendall (2018) highlight that often the decision to disclose is carefully considered and this does come through in the findings. However, Jacklin (2011) and Kendall (2018) present more of an either-or idea, you either declare or you do not. But what appears and is congruent with my own experience is more of a selective disclosure: Nick did not want to disclose to peers or partners but was comfortable with his society friends as Nick knew already how they perceived autism. AR and I were even more selective deciding on a person by person basis based on our goals within an environment. Rather than identifying as autistic or not, there was more of what I would like to call a ‘liventity’ where identity is a living thing that shifts, and changes based on the environment. If control is so important and students decide who should and should not know about them being autistic, then protecting that person’s control should be at the forefront of any support and adjustments. There are many examples within the data of tutors and other university staff forcing students to disclose through challenging them in class which as will be discussed in other sections is an additional labour that autistic students must deal with.

Though control of labels is the theme it raises an interesting question around who is in control. At first glance it appears that the students are choosing how, when and to whom they disclose. Yet for those disclosing there appears to be some predication around how that disclosure will be perceived. In the example above, (page 221-22) Nick had observed how those in the environment had reacted to having autistic students within the group. However outside of this environment Nick believed students would perceive autism in a negative way. Additionally, AR and I also withheld disclosure based on how others would perceive us being autistic. This indicates that we believe autism has a negative image within society and this is congruent with the participants from Madriaga and Goodley’s (2010) paper who felt comfortable disclosing dyslexia but were cautious about disclosing autism. Additionally, the participants of Sarrett’s (2017) study believed that lack of awareness from other students was the reason why they felt unsure about disclosing.

When students did not disclose to those within their immediate environment then masking was often used in an effort to hide any challenges that a student might be facing in order to fit in. Nick explained how he masked constantly, Sam had many masks for different situations, similar to myself and AR. In all cases masking was used as protection when trying to engage with the expected student lifestyle which everyone identified as going out partying as described by Holton, (2017a; 2018b) and others (Reay et al., 2010; Koefoed & Simonsen, 2012; Maunder et al., 2013; Loxton et al., 2015).

The sub-theme of masking highlights the value undergraduates especially, gave to being a member of this student group (Holt, 2008; Holton, 2017a; Smith et al., 2019). Membership within this student group can be beneficial. Holt (2008) and Holton (2017a; 2018b) highlight that the social capital gained can be integral to a good quality of life, good mental health and academic success. Sam and Liam both engage socially, and both clearly gained support from those social groups.

Yet masking to build this student identity can be taxing: the additional labour of maintaining these masks takes up valuable resources, when combined with other additional labours (discussed later in this chapter), can result in over expenditure leading to burnout (Murray et al., 2005; Murray, 2018). Sam and Liam both knew this and made decisions based on their own specific goals. Sam reduced his investment of resources into the learning in order to be able to socialise more and Liam stripped back other activities, leaving him capable of juggling both socialising and learning unless there was an issue.

Not all students attempted to engage in this ideal student normative social behaviour. Interestingly, those that did not, highlighted that they did not due to other burdens in their life. This suggests that one of the reasons they are unable to participate in this aspect of university life was due to other external factors. If being a social student is considered so important for HE then it might be prudent to, as much as possible when developing their learning contract and inclusion plan, remove some of the other challenges within a student's life enabling them to engage socially.

Awareness is still an issue however even if there is enablement through the removal of other challenges. But better awareness is no easy fix. There could be more involvement from both the students' union and the university in promoting awareness and understanding of difference. This may go some way to changing the perception of autism within the student population as called for by Beardon et al. (2009).

The autistic student identity is a very personal struggle that students appear to be having. There are tensions between wanting to appear as normal, but also embracing the autistic identity, as well as not seeing themselves as disabled, but also needing to access support. This is congruent with the participants of Mattys et al. (2018) paper. Understanding this tension is important when supporting autistic students (Lucas & James, 2017). But there is very little research around disabled student identity that focuses on the nature and experience of studenthood rather than the disability (Holton 2017a; 2018a), and even less that focuses on the tensions that autistic students face, which Lucas and James (2017) claim is specific to autistic students. Though not a main recommendation of this study it would be fruitful I feel to explore further these tensions so that support and adjustments can be better designed. What is clear though from this study is that tutors and the university need to protect the right of a student to control their identity and not force disclosure through challenging students in open forums.

6.2 Learning: the most supported aspect but still not perfect

Though less of a theme than might be expected for a study exploring higher education, learning was still important to the students. When discussing learning there are those who access support and those who do not. Those who do access support, as might be expected, are finding the education side not as stressful as the non-education side and those who do not access support are struggling with the learning aspect just as much as they are the social aspect. This trend is congruent with the DfE's findings (2019).

Accessing disabled student support is clearly a key factor to the student experience for the students involved in this study. This conclusion corresponds with the findings of the DfE (2019) who found that over two thirds of students accessing support feel that the support enables them to participate within their course. As such, a top priority for the DfE (2019) is to increase disclosure rates so that all autistic students access supports that are recognised as making a difference. Chown et al. (2018) identified that on average there are around 55 students declaring their autistic identity per university. However, they argue that this number is low: they believe that the actual number of autistic students in HE is closer to 9000 which would represent around 1 per 250 students. This is similar to the European wide beliefs held by the Autism & Uni project (Fabri et al., 2016) and to a degree the DfE (2019). Research from this department found that 60% of individuals had received information on DSA but only 40% had gone on to receive support, with autistic students being only a small proportion (DfE, 2019).

When looking at reasons for not declaring, the DfE (2019) and research literature (Masala & Petretto, 2008; Jacklin, 2011; Taylor, 2016; Anderson et al., 2018; Kendall, 2018; Hubbard, 2019) suggest that it could be due to: misunderstandings around what disability support is and who it is for, not wanting to position oneself within the impairment focused perspective of disability that the disabled student services perpetuate, wanting to move away from the identity of being broken, and simply students wanting to but encountering barriers to applying.

These reasons come through in the data from the autistic students involved in this study. Nick, Sam and Shona were not receiving DSA support and I too had stopped. Nick did not believe that autism and the challenges he face were significant enough to get help with. Sam did not want to engage with those who say his gift is a disability. Finally, Shona and I were not accessing support due to the additional labour of completing the forms and gathering our evidence.

Each of these reasons is known about and some efforts are being made to address them. The DfE (2019) highlighted efforts to get colleges and schools to better prepare disabled students for HE and within this preparation would be discussion around disabled student support to reduce misunderstanding around the services and also help with the completion of forms. However as highlighted within the literature review, the level of preparation would be conditional on the level of knowledge that those within the schools and colleges have, especially when there is very little guidance or support. This issue is even more significant when considering the findings of NAS (2017) who reveal that teachers themselves feel they lack knowledge around autism.

In order to address the perception of the disabled student services, universities are trying to market further the disabled student services within general university marketing to position it as just another element of university life (Sheffield Hallam University, 2017; University of Manchester, 2018). However, there is still the issue that despite efforts to change the perception of the department, disabled student services continue to operate within a medical model of disability (Konur, 2006;

Couzens et al., 2015). In accessing them, students still must consider themselves as less able, different from other students and in many cases they are required to complete impairment focused paperwork (Couzens et al., 2015). Until universities consider alternative ways (see the recommendations in Chapter 8) of viewing students disabled by the environment, policy and practices, there will still be students willing to forgo supports in order to not be considered as different such as Nick and Sam have.

Yet being supported does not mean that all issues around learning are resolved. Two recent studies revealed that only 48% of autistic students were happy with their academic support and considered themselves successful and achieving (Gelbar et al., 2015; Jackson et al., 2018). The DfE acknowledge that not all students are satisfied with the support that they are receiving (DfE, 2019). AR, Liam, myself a few years ago, and Doug have received support through DSS and though we found it beneficial there are still significant issues that we encountered; it was 'better than nothing' but far from the enabling service that it is positioned to be (Student Finance England, 2018; DfE, 2019).

The biggest issues that the students in this study encountered were learning contracts not being implemented and lack of awareness from tutors. Both of these will be discussed together here as it could be argued that a good learning contract should provide awareness and knowledge to the tutors. But equally good awareness of difference should promote inclusive practices. This would meet many of the adjustments that would typically be required within a learning contract without them needing to be stated (which links to the first recommendation within Chapter 8).

With regards to the type of support offered, AR highlighted that there was a generic model for support regardless of level of study, ability or gender. She argued that almost all of her recommended supports were not relevant to her and some that were she feels were not adapted to level 7 study such as around examination (Chown, Beardon, Martin & Ellis 2015). Doug had issues because his support was for so little time that he was worried about using it up. Yet he had other time 'ring fenced' for support in ways that he would never use but he was unable to trade funds and time from one aspect of support to another. Liam and I both had negative experiences with our 'organisation support' whose role was to help us plan and organise our learning and to help us liaise with tutors and administration. But we had both given up this support due to worry as discussed in Chapter 5. Nick, although he did not apply until his third year, experienced his tutor suggesting that his recommendations would impact on the reference that the tutor would give. This left Nick in a position where his physical and mental health were being negatively impacted.

Possible factors that contribute to these issues focus around lack of autism knowledge and awareness both within disabled student support and with tutors (Fabri et al., 2016). Chown et al. (2017) highlighted that 40% of universities had no in-house “expert”, 28% had one in-house “expert” and 31% had more than one in-house “expert” (expert as a term was not defined). With so few universities having specialist input with regards to the support of the students who are failing the most it is hard to see this trend changing (Fabri et al., 2016).

Knowledge and awareness play a key role in the successful implementation of proper supports (Lucas & James, 2017). I had an experience where my adjustments were challenged by a PhD student leading a session who when I said I was autistic and unable to do a task, asked what autism has to do with it and it is a task students are expected to do. Similar to my experience AR whose learning contract specifically excludes her from group tasks was challenged by her tutor who, when told that she was unable to do the task, responded with 'well that should not stop you talking to the person next to you'. Both were clear examples of poor awareness and understanding. Not dissimilar to our examples, 14 years ago Healey et al. (2006) published an account of a participant whose tutors discouraged the use of some reasonable adjustments. This suggests that this could be a deep-rooted and ongoing practice. Similarly, Osborne’s (2019) participants wish that academic staff would understand that they are not lazy or faking to gain benefits and that they really do need to use supports.

At a larger scale the DfE (2019) highlight that 60% of those respondents that received materials early as a reasonable adjustment (standard for most autistic students) received them in an accessible format. This raises the question as to why tutors are giving the other 40% inaccessible materials meant to promote access and inclusion. Osborne’s (2019) students highlight tutor awareness, understanding and knowledge as an issue so too do Gurbuz et al. (2019) who found that autistic students were dissatisfied with the knowledge and acceptance lecturers had for their disability and how it affected them academically. The DfE (2019) also acknowledge the need for better awareness and knowledge as did the students within this study.

Though the students do encounter issues it is important to reiterate that all those who engage with disabled student support do feel that there is a benefit to doing so and do utilise the supports offered. However, more work is clearly needed to better support those already engaging and to begin to start engaging with those students that currently do not do so.

6.3 Additional labour

From the literature reviewed in Chapter 2 and the data from this study there is a common theme that emerges around all aspects of university life and that is the theme of additional labour. What is meant by this is that whilst it is accepted that university is a stressful place for any student regardless of a diagnosis. For autistic students the additional stress, anxiety, mental resources and time that goes into different elements of university life results in additional work that other students do not necessarily experience. For example, AR described the regular act of going to a lesson. She explained how first she had to deal with the anxiety of being in university, then the sensory environment on the way to her class, anxiety around getting lost, anxiety around whether she would be challenged for her adjustments and whether her tutor was going to force her to disclose her autism in front of everyone.

What AR describes is in addition to the normal pre-lesson stress students may experience. AR’s experience is reflected in the experience of other disabled students that has been captured within research. Hannam-Swain (2017) conceptualises this as the additional labour of being a disabled student. Her additional labour beyond navigating the physical environment was the need to think ahead about her accessibility requirements.

From the data there appears to be additional labour around nearly every aspect of university life. This finding was also experienced by the participants within the research of Russell and Tophem (2012). What their participants wanted most was for university staff to be aware of the additional daily living burdens. Within Chapter 5 additional labour was discussed in three sub-themes that were identified. These were around learning and supports, socialising and the environment. However, it was clear that there is a constant interweaving of these additional labours.

The social element of university is one of the main focuses in the literature review. Research has illustrated how it influences the university environment, the curriculum and the free time of students. Holton (2016a; 2017a; 2017b; 2018b) discussed the importance of fitting in to generate social capital and how by not fitting in and being an outsider, students will not only have a more negative experience of university but they will have a poorer quality of life, mental wellbeing and are likely to be less academically successful. This therefore is one of the main reasons why universities promote the social element of student life. As discussed, the students in this study communicated a desire to fit in with the other students in this social way. However, in doing so they expressed the barriers and 'workaround' that they go through in order to do so. This is where a large portion of a disabled student’s additional daily labour comes from. Students like Liam, AR and Nick talked about how they would plan and organise before engaging socially. They illustrated how they think through their anxieties in an effort to overcome them. They along with Shona, Sam and myself discussed masking as a way of protecting ourselves within these environments and enabling us to fit in better. Alongside planning and running through situations in their head, masking can also be used as a way of accessing environments. Masking is the ability to flex to the social environment and take on the socially acceptable behaviours displayed by those around you (Baldwin & Costley, 2016). AR specifically highlighted that she masked a lot as a means of mitigating her anxieties and accessing the different environments of university, but also highlighted how it would be so taxing on her that often her mask would slip; she would burn out and then fight or flight would manifest and she would have to run home. Sam and Nick also masked: Sam as a means of developing social capital and Nick as a way of engaging with his course through mandatory group work and to hide his diagnosis. Except for Sam each of the examples of masking has been when there was a desire to engage socially. Nick however masked to protect himself against the forced social activity of group work.

All the students identify group work as an area of issue that required a great deal of input in order to participate. However, they also spoke about the additional labour needed before hand and after. Group work used in HE is rising due to the benefits that are argued to be garnered through social learning (Sutherland-Smith, 2013). However, this is compounded with the rise of assessments through group work that then places an additional need on groups to work cohesively (Lavy, 2017). This creates an issue for those who find group work challenging. In a large study by Beardon et al. (2009) 135 participants reported finding group work challenging due to the additional communication requirements. In Madriaga and Goodley’s (2010) paper six participants also highlighted group work as being an issue. To address the issue of group work Shmulsky and Gobbo (2013) suggest increased support for group work as a way to lessen the additional labour for autistic students. Beardon et al. (2009) went further by suggesting not only some support for the student in understanding neurotypical behaviour, but also support to help the neurotypical students to understand the autistic student's behaviour. However, there is an additional step of supporting the tutor in overseeing group work. Knott and Taylor (2013) highlight the stress that finding groups to join can have on students but also noted that tutors did not want to get involved through fear of 'burdening' a group with an autistic student. For issues such as these support for tutors may also help them set up and oversee group work within the class. The supports highlighted here may well have helped both Nick and his tutor.

Of all the areas upon which additional labour occurs, a significant impact though is that around accessing and maintaining supports and utilising supports in the learning environment. As discussed in the above section accessing support can be harder than it is meant to be (DfE, 2019). Additionally, tutors, DSS staff and the wider university community may not either have the knowledge of how to implement recommended adjustments and support strategies, or they may be unaware that they need too. From the data it is clearly a potential cause of stress and anxiety for students. Further, maintaining supports and adjustments that do work can also be an additional labour. Fabri et al. (2016) identified that communication between students and staff may be one of the main causes of stress for students. Liam especially found this to be the case with regards to communication with DSS and administrative staff, sometimes involving taking the day to craft an email. Students have also experienced being placed under pressure from tutors not to use their adjustments and support mechanisms. This not only impacts on the use of the reasonable adjustments but creates a rather socially awkward environment when tutors perceive your disability as laziness, potentially creating more issues (Healey, 2006; Knott & Taylor, 2013; Osbourne, 2019).

Both Liam and I, and to a degree Doug, discussed the additional effort that goes into organising and maintaining supports. Doug never 'bothered' because of perceived issues beforehand and Liam and I stopped using supports when demands were placed on us to use the supports and so we gave them up. Here the policies that they were operating within, and their knowledge of autism, may have contributed towards the issues with the DSS people that were meant to enable us. Lucas and

James (2017) highlight a need for autism specific knowledge for the staff who support autistic students due to the unique social and academic challenges that they face.

The impact of all the additional labour discussed in this section could be part of the contributing factors to such a high drop-out rate of autistic students in HE (Fabri et al., 2016). Supporting this conclusion is the study by Richardson (2017) who studied students who learn through the Open University and so do not encounter many of the issues discussed in this section due to working on their own from a distance. The students in that study not only do not report experiences similar to those presented in this study but they also outperform non-autistic students in the way that might otherwise be expected, given that autistic students are labelled a high achieving group (NAO, 2009; Van Hees, Moyson & Roeyers, 2015).

6.4 The disabling environment of HE

The environment of university is unlike any other: it is part education institution, part activist rallying point, part social club and much more. Within one building you could have a writing retreat as well as a film viewing, music concert, art exhibition, lively sports bar, keynote lecture and students just meeting for brunch, all at the same time.

Within disability studies it is strongly claimed that the environment and the policies that govern these places and spaces all impact on the life of a disabled person (Oliver, 1983; Barnes et al., 2010; Retief, 2018). Yet within autism and HE research there is very little literature on how these are experienced (Madriaga, 2010; Gelbar et al., 2014; Searle et al., 2019). Further, much of the disability research is focused on the access and barriers encountered by those with a physical disability. The sensory environment and the social environment are rarely studied (Madriaga, 2010; Gelbar et al., 2014; Camacho et al., 2017).

This lack of what Camacho et al. (2017) call purposeful investigation into the inclusive higher education classroom environment means that the learning spaces of HE remains inaccessible for many. They highlight that learning spaces are ergonomically designed for the traditional student and not necessarily to be inclusive. Furniture, noise, lighting, seating plan and the use of the environment all combine to create an inaccessible learning space for autistic students (Bogdashina, 2003, Van Hees et al., 2014; Vincent et al., 2017; Camacho et al., 2017). Within the literature none of the students discussed the classrooms though they did discuss their sensory challenges, for students with sensitivities to light, smells, sound and motion can all struggle in classrooms designed to be light, social hubs were the demand for students to manoeuvre around is built into the curriculum.

Two of the few papers that exist which explore the environment of university beyond the classroom are Madriaga's (2010) paper which is titled 'I avoid pubs and the student union like the plague'. This highlights a variety of environments students encounter at university and some of the access issues these environments pose for autistic students and how these impact negatively on the students. The other paper is by Madriaga and Goodley (2010) who describe how the library is inaccessible for one of their students. AR emphasised how she cannot access either the library or the students' union due to sensory issues. Further she feels that sensory issues are misunderstood by those without them. These are so personal that without explanation and linking to possible experiences that they might have had it is hard to encourage people to adjust to the sensory requirements of autistic students. This is best evidenced in the media backlash from the move by Manchester University who asked members of an audience to refrain from clapping to create a more accessible space. This resulted in the media organisations such as the BBC (2018), The Guardian (2018) and The Sun (2018) printing negative headlines that mocked a so-called ban on clapping within universities in favour of ‘jazz hands’. Further these articles then positioned ‘inclusion’ and ‘anxiety’ within inverted commas throughout the articles, giving the impression that these were made up concepts or excuses.

AR was not the only student to struggle with the library environment, Nick also explained that he could not access this space due to sensory issues with the environment. When reviewing the literature around disability access to libraries there is very little, much less than other environments, despite the library being a place a student may spend more time in than a classroom due to the amount of independent learning asked of students. When looking at the literature around libraries, three of the more cited papers on the reasons why access might be an issue are White and Stone, (2010), Stone and Collins (2013) and Stone et al. (2015). What is startling is that all three fail to explore disability access within their research around why students may not be able to access resource centres.

Without autism specific literature to build on to discuss the potential issues I have had to utilise a wider body of literature. Alvite and Barrionuevo (2011) point out the use of social life to support academic learning. They highlight that libraries are now a place to 'hang out' and work together rather than independently. Hough and Koenig (2014) discuss how libraries have changed with less control now by students around lighting, heat and noise. These changes could mean that the sensory issues Nick discussed and highlighted by Madriaga and Goodley’s (2010) student are experienced by other students (Bogdashina, 2003). Though not one of the main recommendations discussed in Chapter 8, the library environment needs to be an area of future research especially if the next environment to be discussed, student halls, continues to be problematic. Students will be left with almost nowhere else to go and work.

6.5 Conclusion

Within this chapter I have discussed the themes generated from the data in relation to the literature that was presented in the literature review. It is clear that the students in this study are encountering some of the issues prevalent within literature. But also, some students are thriving where within literature other students are encountering challenges. This re-emphasises the challenge universities face when developing practice and systems for supporting autistic students. As what is a problem for one student might be a null issue or even a strength for another student.

What was also evident was that when students do encounter issues, the ramifications go beyond academic success and begin to impact on physical and mental wellbeing to the degree some students feel they are in a survive or fall scenario. When looking at possible causes of this, as seen within the literature review, there are specific elements such as disclosure, tutor knowledge and sensory challenges. However, identified within this thesis is the idea of the interactions and ramifications certain challenges can have on other areas of university life. These interwoven aspects such as the identity, additional labour and sociality are not only encountered throughout the ‘whole university experience’ but the lasting effects are felt throughout also. This results in an intricate web of challenges that at first glance from the outside may go unnoticed. Again, this creates additional challenges for university staff when developing ways to reduce the challenges autistic students face. Yet the statistics presented in the opening chapter highlight that there must be some action to address these more complex challenges as autistic students are failing. Though I do not know, and from this study cannot fully know, how to resolve these issues I do put forward some steps that I feel might go some way to helping (see recommendations in Chapter 8).

This sixth chapter has concentrated on the research question that set out to investigate the experiences of students who identify as autistic in HE. However, this was not the only foci of this thesis, in the next chapter I will explore the themes generated from the data around the approach and methods used within this thesis and discuss these themes in relation to literature around participating within research.

Chapter 7

Presentation and Discussion of Method Themes

7.0 Introduction

Within this chapter I will present and discuss the themes generated from data focused on involvement within the study. This will focus on the ethos, participation before and after data collection, methods of participation, data analysis, reflections and dissemination of research.

In our first meetings and towards the end of the study we used some time to discuss taking part in this research. Throughout, and particularly around the analysis, there was also some additional discussion around participation with some of the students. Just like the themes presented in Chapter 5 all themes presented and discussed here are generated through data captured within the process of participation and analysed by either me or through co-analysis with students reflecting on their own data.

From this analysis in relation to method there were three themes identified

Theme 1 Easy, Simple, Accessible

Theme 2 Flexible

Theme 3 Meaningful

Each of these themes will now be presented in turn. As there is less data around methods, simply because they were only specifically discussed once with each person and for a relatively short period of time, these themes are much smaller than the themes presented in Chapter 5. As such it makes sense and saves space to both present the themes and discuss them within the same chapter.

7.1 Theme 1 ‘Easy, Simple, Accessible’

One of the driving forces behind me developing my emanciparticipatory approach was due to finding the expectations of typical research practices inaccessible. As such I wanted to develop research that was accessible and easy to participate in. When analysing the data around the experience of participation I was pleased to note that one of the clear themes was that of simplicity. Shona explained:

> Being involved is only costing me the time to send an email, this hour and what two or three more emails and that's it.

Liam explained:

> I wanted to be involved when I saw the study because I think it is important but like I’ve been saying I have to really think about how much I'm taking on. When you explained that you could see me whenever, over the year and that I didn’t have to do anything but note issues it was kinda easy to take part.

Sam did not select the simplest of methods of participation, but he did find that being able to focus on his strength, in addition to the likelihood that there would be a positive impact of his participation on the wider public, made his participation easier. Similarly, Doug likes more thought-provoking discussion so found being able to meet and discuss really appealing. He also found that without a time constraint he was able to relax.

Shona particularly found speaking to an autistic person easier and Nick explained how he could not really talk about this stuff to a non-autistic person out of fear of judgment.

Communication was also simple for everyone as we just used methods of communication they already used. So, for Liam, we used social media and AR used her work email. The aim of the modes of communication was for them to be the same as those used in that person’s everyday life and I feel that this was achieved.

7.2 Theme 2 ‘Flexible’

Another key aspect of my emanciparticipatory approach is to fit around those involved in the study rather than them having to fit around their involvement. To do this it was key for myself and the methods to be as flexible as possible.

AR would not have been able to participate if I was not able to go to her in the south of the country; everyone else met around my university but it was important that I went to her. Additionally, Nick needed someone who he could cancel at short notice, which he did many times. Doug wanted to participate but he also likes to 'deep dive' on topics more than someone would usually within an interview. For example, we talked about maturity and went from legal discussion, through stages of development, mythology and eastern philosophy. Had we stuck rigidly to a schedule it would have not interested him and he would also have been a little anxious about dragging me off topic.

Again, Sam liked the idea that he could participate in a way that spoke to him. He had participated in a number of student projects out of kindness:

> When I see adverts for participation I volunteer to help out this student that is probably really stressed about getting people and sometimes it's just a questionnaire or at most an interview and it’s ok but I really like this I’m so invested and can't wait for the show.

He added:

> I want to spread peace and knowledge and I get to do that with your help in the show and hopefully with your research focused on getting info out there it can continue.

Liam also liked that I could meet wherever he liked and when, so we often met in the SU, had food and slowly worked our way through his thought diary.

7.3 Theme 3 ‘Meaningful’

I have become slightly obsessed with impact within research, but in a positive way. I really do believe it is vital that researchers not only think about a theory to practice gap but also what I am calling the participation to practice gap. Researchers need to consider what will be the meaningful positive impact on the lives of those involved in their research. Therefore I was very pleased to see that not only had I identified meaningful participation as a theme but so too did the other students, including Sam who called his own participation meaningful and was a positive about the participation for him.

Sam’s show was about his life being autistic and part of that was his education. When I first met Sam, he did not know how he wanted to participate and so we discussed his strengths and identified creativity. This resulted in us putting a significant theoretical element into the education act. This benefited him in two ways: he strengthened this part of his performance, but he was able to pass on positive knowledge which is his goal in life; all while participating in the study. Further Sam was able to become involved with the ESRC events to further spread his positivity and this is now an avenue he is looking at progressing in the future, ‘positive autism improv’.

Liam and AR welcomed the idea that by being involved they would make a difference. For AR spreading the word of female autism awareness was important and, like Sam, Liam was able to participate in an ESRC event.

Shona was not only attracted by the idea of proactively engaging in autism activism she also liked the idea of getting a look behind the 'iron curtain' when helping with analysis: “I was really worried about thematic analysis but practising with you there really helped and it's not practice that has gone to waste.”

Of all the different participation methods and the different meaningful impact that resulted I think the one who gained the most was Nick. He had no idea what autism was and he had no idea where to turn for information. So, we decided that after I ask him one question, he could ask me one and as a result began to understand himself:

> I learnt so much, I learnt that it's not normal to react to smells like this and now I can think about where I go and what I do. I know that there’s no cure and no point in searching and I know why I find it so difficult working with others. I’m not difficult I just don’t understand them because I’m autistic and I’m pleased it's not because I’m a bad person.

I sign-posted Nick to a few organisations to gain some real support and its pleasing that he is finding help to understand himself more.

7.4 Conclusion of themes

I set out to explore the experiences of students who identify as autistic in HE whilst promoting voice through accessible means of participation. As stated in Chapter 5 I feel that I have done this. From these themes I conclude that I was able to utilise an approach that promoted accessibility as students specifically stated that without the ethos of the emanciparticipatory research they would not have been able to participate. More than that I think I was able to engage people in autism research to the point that they took it upon themselves and became active and independent agents within the process. Sam has started an autism positive YouTube channel and performed his show to members of the public numerous times. Nick has started engaging with the autistic community and 50% of the students involved in the study presented their findings at ESRC events with three students first presenting nearly four years before the submission of this thesis.

The impact highlighted above is in addition to the impact that could potentially come in more traditional ways such as influencing policy and practice. Further this thesis may help bring a greater variety of voices into policy and practice discussions.

Finally, the emanciparticipatory approach clearly shows that research can impact positively on those involved and generate a real depth of findings that promote the perspective of those whose voice has historically been obscured or manipulated. The emanciparticipatory approach does this ethically and within the constraints of academia without compromising the principles of the approach.

Going forward I will continue to utilise emanciparticipatory research and hopefully gain positive outcomes similar to those discussed in this chapter.

7.5 Discussion of method findings and conclusion

The hope for this study was that it would result in some form of informed change within HE and that it could show how if done correctly research could be accessible and engaging whilst also being led by those from within the community under investigation. With these in mind, I feel it would be appropriate to conclude as a result of the themes presented in this chapter that the second of those hopes was achieved. In this next section, I will explain and discuss how I have come to this conclusion.

The biggest overarching theme I feel is accessibility. One of the issues of traditional research discussed within Chapter 3 was that often access to research is designed from a non-autistic person’s perspective. Two examples stand out: one where access may have been hindered and one where through the use of autistic experiential knowledge a potential barrier was removed.

In MacLeod (2016) she discusses how her participants were recruited through email advertisement utilising her university's Disabled Student Services. However, I see this as problematic. Firstly, this would limit the sample population to those who are able to access the Disabled Student Services. This, as was discussed in Chapter 2 and the findings of this thesis (Chapter 6), resulted in those who are either undiagnosed or under too much additional labour to access the Disabled Student Services, from being able to participate in her study. Secondly, the author noted how a previous study (MacLeod and Green, 2009) had identified that autistic students struggle with email communication which was the main recruitment tool. This highlights how access can often be overlooked and can result in a very narrow account of autism within research, which as discussed could result in the development of narrow policy or practice (Chown et al., 2017; Fletcher-Watson et al., 2019).

The other example is taken from Chown et al. (2017) who cite one of the author's past experiences (Martin, 2014) where an element of the study design was highlighted by an autistic member of the research team, as a potential cause of confusion. This, had it not been identified, could have resulted in limited access or worse stress for the participant who might become confused. However, the issue was able to be attended to and the potential barrier to participation was removed.

From the ground up this study was designed to be accessible, starting with the advertisement of recruitment, communication, means of participation through to the scheduling of participation, analysis and dissemination of the research. I felt that it was important for me as the academic and the person traditionally in power to be as flexible as I could for each autistic individual. This I believe was a success with the students explaining that they felt that the flexibility enabled them to access the research especially by allowing each student to participate through their preferred means. Additionally this was usually through a means that was either a strength for them or a comfort for them which is a stark contrast to the traditional psychological research that placed autistic participants in the dehumanising situation designed to elicit failure (Baron-Cohen, Leslie & Frith, 1985; Goodley & Lawthom, 2005; Goodley & Lawthom, 2005).

The biggest testament I feel to the access and engagement of this study is how before the study was even completed, students were involved in external events presenting their findings and some have gone on to utilise their chosen means of participation within other aspects of their lives.

The final theme was meaningful contribution. One of the key findings from Fletcher-Watson et al.'s (2019) paper was the tokenistic feeling some autistic participants of participatory research experience. They highlighted how some autistic people feel that when asked to be involved in research it is very much in a tick box way with participants feeling that their voice is simply not really considered, as perhaps typically experienced within a traditional research approach. This highlights two aspects: firstly, that the participants did not feel in control and secondly that the research process and decisions made were not communicated to participants in an effective and transparent way. The inference I receive from Fletcher-Watson et al.'s (2019) participants' past experience is one of uncertainty: they simply were not sure whether they were making a difference or not. I had similar experiences which is why I included transparency within my emanciparticipatory principles. I feel that in doing so I really thought about what and how others can input into the research design and practice and considered whether I really needed ownership of some of these decisions. For example, the structure of this thesis was developed in collaboration with the other autistic students who wanted to be involved in this aspect. As a result of this collaboration I have two sections within the fifth chapter.

Voice and control did not really come through in the data as a theme. This might be because it was embedded so naturally within the study that the students did not notice they were even in a position of power despite this being explained. Above I have highlighted a number of examples when discussing the themes that were generated which could be considered examples of power and control. It could also be that the students did not feel they were in control. However, the demands that they placed upon me would suggest they did not see me as an authority research figure (Milgram, 1963). The aim of this study was to utilise a method that promoted voice and power which I feel this study did. The aim was not to see if students can distinguish their voice and power from the academics and so I am comfortable that this theme did not stand out especially considering the level of engagement the design did garner.

Chapter 8

Limitations, Recommendations, Dissemination of Findings, Conclusion and Contribution to Knowledge

8.0 Introduction

The purpose of this research was two-fold. Firstly, to explore the experiences of students who identify as autistic in HE. Unlike previous literature the intention was to look at what is considered the ‘whole student experience’ across the various aspects that make up ‘being a student’.

Secondly the aim was to conduct this research as a means that promoted the voice of the members involved in the research by challenging the power dynamic between the ‘researcher’ and the ‘participant’. This was to be done through a concept of shared control and voice using my emanciparticipatory approach.

I feel that I achieved these aims and in this section I will outline the recommendations to come from the research, the dissemination plan for continuing the impact of this research and state how in achieving these aims I have contributed to knowledge. However, in achieving these aims there are still areas of limitation within the study and it is important to highlight these so as to inform not only my future research but that of others too. This is where this section will start, with the limitations of this study. I will then move on to the recommendations and then discuss the continued dissemination of this research. Then I will provide the final conclusive thoughts on the thesis before finishing with my contribution to knowledge.

8.1 Limitations

There are several limitations to this study that must be taken into account. I will work through the three that I have identified as important limitations to acknowledge. The limitations that I will discuss here are: the impact on the researcher, the lack of diversity within this study and finally the relatively small sample size.

8.2 Impact on the researcher

As I drew towards the end of my PhD I presented a new talk at a disability research forum entitled ‘Emanciparticipatory research and why everyone should do it but I do not want to do it again’ (Connolly, 2019). Though a tongue-in-cheek title, part of the talk was around the issues I encountered carrying out the research. These issues can be split into two categories: issues as an autistic person and issues as a researcher.

Looking at the issues as an autistic person first, I initially struggled with the idea of needing to communicate with people whom I did not really know. Reaching out to those who had contacted me and asking them for their time was something I found extremely anxiety provoking. I have always found asking for things incredibly daunting and as I started to receive interest this worry became ever more present. For some of the responses I was able to use my preferred method of communication (social media) for others though I had to just grin and bear it, using the telephone and skype to communicate and then ask for time out of their lives. Working with those around me I was able to implement ways to mitigate some of the distress from having to both communicate in a method I was not comfortable with and also ask others for their time. But additionally, there is a certain irony that finally a researcher is having to deal with the challenge of participation rather than those who would traditionally attract the label of participant.

Moving into the data collection phase I also encountered issues when those involved would ask to meet for our sessions in an environment that I found difficult. However, I did have some foresight around this going into the research and how I would deal with demands placed on me that I was uncomfortable with. I decided that I would be open about this with the other autistics and discussed me being as flexible as possible, but if needed, to ask whether we could come to a compromise on occasions. This was acceptable to all those who were involved and so when requests to meet in environments that I was not comfortable in were made, I was able to work with the individual to construct a way that we were both comfortable with. On one occasion this was to meet earlier when the environment was quiet and, on another occasion, this was to move the meeting to a different venue that was still of the same type.

At more of a researcher level the biggest issue that I encountered was the timescale for all the data collection and analysis. Originally I aimed to do the data collection for a year and then analyse and write up in my final year but in reality I had to extend the data collection across three years and analyse as I went, completing analysis in my fourth year. Alongside the extended time schedule, I had to deal with a lot of 'down time'. There were months when I had no students to collect data or analyse with which gave a stop start feel to the study. However an unforeseen benefit for this study is that as a result of the extended time scale I was able to work with students for an incredibly long amount of time and capture experiences from across the length of a course rather than a vertical slice of a few months of a course. Additionally, the time scale extension and the integrated analysis with data collection meant that students were able to start disseminating their findings as the study was still progressing.

8.3 Diversity

An issue with most autism research is that of diversity. Though this study had males and females involved they were all white, British, autistic students. There was no representation from the Black or Asian autistic communities.

Though I attempted to generate as wide an interest in the study that I could by advertising the study in a variety of ways, the only students who responded to adverts were white British. I am pleased that there was a mix of sexes however the research did lack other characteristics of diversity. In future I will aim to take on the recommendations of Zamora et al. (2016) around designing recruitment material specifically for minority groups of the autistic community. Some work has already begun around this with the putting together of an autistic working group made up of what the group have termed ‘missing voices’ within autism research. They have already carried out a number of lectures around autism and race, autism and gender, autism and the traveller community and autism and sexuality, funded by the ESRC (Connolly, Amber, Simmons, Woolard & Wright, 2019). This group will be able to better advise and lead on a more diverse recruitment plan.

8.4 Sample size

My emanciparticipatory approach used for this study by design means that it is highly impractical to move beyond relatively small sample sizes. The time investment needed to work with someone to the depth that the approach allows required me to be flexible with my time.

Conducting this research with a larger sample size would potentially mean that I would not be able to be as flexible, resulting in barriers being created for others. This smaller sample size does limit the generalisability of the findings. However, neither I nor those involved in the study began this process to generalise findings or claim to be representative of all autistic students. We did however begin this process to share our voice and add to the slowly developing literature base.

What is lost with a smaller sample size I believe is mitigated by the depth of involvement each person was able to have, which I feel is a real strength of this research.

8.5 Recommendations

Within this section I will set out l four recommendations; two for practice with regards to supporting students who identify as autistic in HE and two around the use of emanciparticipatory research. Within these four recommendations there will also be additional points around possible foci for future research.

8.6 A meaningful move towards the social model of disability

There are a number of reasons why I believe in a meaningful move towards the social model of disability and I will outline these along with some notes as to why and how this might be achieved. Ainscow (2015) states that in order for universities to take a meaningful step towards inclusion there needs to be a fundamental change in mindset. I believe that this can come from a reframing of disability within the social model. The research literature argues that reasonable adjustments for autistic students would also benefit non-autistic students (Lovett, 2011). This being the case by embedding reasonable adjustments within everyday practice, many of the barriers to access, either philosophical, such as how disability services construct and perceive disability or at a practical level such as completing forms and gathering evidence would be removed.

Currently in universities there are three levels of support as discussed in Chapter 2. The first level requires no evidence, only engagement with disabled student support systems so universities are already set up to provide some adjustments without means testing. The next step would be to remove the need to engage with Disabled Student Services through the provision on every course of adjustments like choice of assignment style, access to verbal over written feedback, lecture materials early, choice of solo work or group work and so on. These are practices already embedded within some departments at my university and enable students like Shona to participate without disadvantage and without the additional labour as explained in Chapter 6.

8.7 Remove the additional labour of having to maintain adjustments

One of the issues that came through in the data was around how students experience additional labour with maintaining the supports and adjustments to which they have access. Accessing supports and adjustments that are designed to enable you, should not impact negatively on your life.

Awareness of difference by all those involved in providing supports and adjustments would go one step towards reducing the additional labour. Another would be to enable a working group of students to continuously evaluate the issues that students face and feeding those back to the disability support team in order to ensure that supports and the wider university are able to respond to developing challenges.

8.8 The next stage of emanciparticipatory research

One of the biggest disappointments with my study is that the level of involvement from the other autistic students within the data collection, the various ESRC events, the analysis, write up and hopefully beyond, was not the same level of input that could be offered during the development of the proposal and ethics application. This recommendation is only a simple one and this is that going forward I suggest that research should be broken down into two phases. Phase one would be a pre-study phase where a proposal and ethical submission to recruit autistic people to create the study proposal and submit ethics as a genuine stakeholder group. This would lead to phase two which would be the actual research project. This ensures that the control of the research and the autistic voice is maintained throughout the project. This will also help progress towards full emancipatory research in the future.

8.9 A reform of the traditional ethics model

Starting small with a reform of the ethics model, I would like to see ethics committees look to include members of all communities that are being researched in the decision-making process. This will help to ensure that the voice of those being prodded, poked and captured in the name of academia can have an impact on the research that investigates them. They will be able to highlight important practices specific to their community and suggest changes to increase accessibility and decrease potential for stress and harm.

A larger more complex suggestion is the moving away from the sweeping labelling of individuals as vulnerable. Ensuring that all research is to the highest ethical standard creating ethical symmetry would mitigate the issues around the labelling of vulnerable participants.

8.10 Dissemination of findings

Congruent with the emanciparticipatory methodology, dissemination of findings is vital. A key principle of the methodology is impact. To have the greatest impact for this inquiry the decision was made to not wait until the final write up to begin the dissemination process, but to start as soon as student experiences begin to be explored as part of the research. Therefore, dissemination has already started and been underway for almost four years now. Additionally, dissemination should include those involved in the research in whatever way possible (for an overview of dissemination see Appendix 10).

The first opportunity to disseminate findings came during the first year of data collection. I, Shona, and Liam presented our experiences that fed into the research at the ESRC Festival of Social Science in Sheffield, after securing funding as part of the festival (Connolly, Davidson & Collins, 2016). The following year I, Shona and Sam presented as part of the ESRC Festival of Social Science in Sheffield again after securing funding from both the ESRC and additional funding from Sheffield Hallam University (Connolly, Connolly, Davidson & Phelam, 2017).

The research has also begun to impact within the university. The findings around the need for more social focused support are beginning to be actioned upon by the Student Services team. The full findings have been presented to the autism specific members of the Student Services team. This team met with some of the other individuals involved in the research and have begun to look at ways of best supporting students' social needs as they transition in, through freshers' week and into the start of university. They are exploring early enrolment, summer camps and peer mentoring systems.

Findings were also presented at several conferences and events targeted at non-academics such as the South Yorkshire Autism Show. The findings have also informed less HE specific presentations to audiences such as South Yorkshire Police, Humberside Police, Derbyshire County Council, all the Northern Seventh Day Adventist churches and several schools in the Sheffield area.

The dissemination will continue post submission, those involved and additional students who were not involved but want to be heard are eager to apply for funding for more events like the ESRC Festival of Social Science in the future.

8.11 Thesis conclusion

Chapter 1 painted a worrying picture as both an autistic student and an autistic lecturer. Fabri et al. (2016) highlighted that when compared to other students (both disabled and non-disabled) autistic students were the most likely to fail and leave university. This is despite autistic students being labelled as high achievers, indicating some students are achieving but others are encountering the worst outcomes (NAO, 2009; Van Hees et al., 2015). What is significant about this is that the number of autistic students continues to grow (Hastwell et al., 2013; Chown et al., 2018) and so it could be assumed that this high rate of negative outcomes will also continue and increase.

Within Chapter 1, I also outlined my personal position indicating that I am an autistic student and how my drive to investigate the experiences of students who identify as autistic in HE, comes from my own experiences and the experiences of those around me. Further, having been denied access to research due to poor design in the past, I wanted to create the most accessible research possible within the constraints of PhD study.

Chapter 2 explored the literature around disability and HE, autism and HE and general HE. Within this chapter I identified that university has changed in the last decade and there is now more of a focus on social learning (Holton 2016a; 2017a; 2018b). This has resulted in changes to the campus environment, the curriculum and to the perception that students have of studenthood. However, supports for autistic students appear not to have gone through a similar transition, thereby creating a disconnect (Lucas & James 2017). Additionally, there appear to be issues with the implementation of academic supports. For example, the DfE (2019) found in their research that 40% of their student respondents indicated that materials provided early, in line with their reasonable adjustments, were inaccessible. Other more qualitative literature indicated tutors were even discouraging students from accessing available adjustments (something that this thesis also found a few examples of).

It was not all bleak however; mentors were indicated within literature to be supportive in enabling students to access the environments and engage socially; something that I had experienced (Madriaga, 2010; Lucas & James, 2017). What was clear from the variety of literature reviewed and discussed was that the interconnected world of the ‘whole student experience’ was discussed in HE literature, but missing from within autism and HE literature which was a gap in the research and one that this study sought to inform.

By the end of Chapter 2 the thesis had outlined the statistics that indicated a problem for autistic students in HE (Chapter 1) and outlined the grounds by which a student can apply for support (Chapter 2). It has also informed on past experiences of autistic students (Chapter 2). Next attention turned to the research approach being used for the study documented in this thesis.

Chapter 3 is where I present the details of my emanciparticipatory research approach and the argument for using this method over more traditional approaches, including participatory and emancipatory research. I begin by highlighting that 99% of research on autism is conducted from the more medical model focused psychology and medical perspective (Pellicano et al., 2014). This type of research involves trying to determine the impairments of autistic people as well as the genetic cause of autism (Zwicker & Emery, 2014; Yusuf & Elsabbagh, 2015). I outline the arguments from autistic people around why we do not want to focus on these priorities; the main one being that the medical and psychological communities acknowledge that not exploring ways to help the autistic people of this generation means that focus can go onto finding potential causes of autism in the future (Zwicker & Emery, 2014; Yusuf & Elsabbagh, 2015).

Then traditional social science is examined highlighting how there is slightly more of a focus on the priorities of autistic people. However, without the meaningful input of autistic people there are still issues, such as access to participation (Chown et al., 2017; Fletcher-Watson et al., 2019). The chapter also details what participatory and emancipatory research approaches are and I highlight some of the issues with both. My main arguments are that participatory approaches currently can involve very little input from autistic people (Nind, 2011; MacLeod, 2016; Fletcher-Watson et al., 2019) and the main control of the research still sits with non-autistic researchers (Chappell, 2000; Fletcher-Watson et al., 2019). Whereas emancipatory research maximises control with those who would normally attract the label of participant (Oliver, 1992; Zarb, 1992). This I argue is currently impossible to do without major compromises.

My emanciparticipatory approach emphasises the provision of as much control as is possible to the members of the community involved. Additionally, if there are elements of control that it is not possible for the researcher to give up or take advice on, then there is complete transparency if these are made apparent. The approach also positions as critical, positive impact for those involved. Furthermore, emanciparticipatory research requires the researcher to explore how to make their research as accessible as possible utilising the expertise of a variety of individuals from within the community being explored.

Using this emanciparticipatory approach and working with other autistic students we developed individual specific means of participation which also include accessible means of communication. This process and the resulting methods are detailed within Chapter 4. Also, within Chapter 4 are the details of the ethical considerations I undertook whilst carrying out this study. By discussing these ethical considerations I also challenge the current ethical model which as I explain I feel does not fit with emergent research or my emanciparticipatory approach which I argue is unethical (Luna & Vanderpoel, 2013; Bracken-Roche et al., 2016).

Chapter 5 it was felt benefited from a separation into two parts. This also allowed me to include the requests from the other autistic students involved. They wanted their key themes to be presented in a way that emphasised what was particularly important to them. As a result, Chapter 5 part 1 is a presentation of each autistic student's key themes.

In part 2 of the fifth chapter the resultant themes from the combined data analysis are presented. Here, using examples from the data, I present the five key themes from across all the students. These five themes are; control of labels, the sociality, wellbeing, academic supports and additional labour of being a disabled autistic student.

Following the presentation of themes Chapter 6 discusses these themes and any interaction between the themes is discussed. From this discussion it is clear there are a number of similarities between the student experiences in this thesis and those in past literature (e.g. Madriaga, 2010; Gurbuz et al., 2019; Osbourne, 2019). But the students of this thesis placed more emphasis on the social element of university rather than the learning aspect. Furthermore, the additional labour of being a student was also a key finding that is lacking within other literature.

Chapter 7 then follows and this chapter presented and discussed the students' experiences of being part of this study. From the data analysed three key themes were generated. These were ease of accessibility, flexibility and meaningful participation. After presenting these themes I make the conclusion that the approach to research appears to have been a success, which is then discussed to conclude the chapter.

Finally, this brings us to this chapter where I outline the limitations and recommendations of the research as well as the dissemination plan. I finish with the original contribution to knowledge and what I hope to do personally with this contribution. I end on this note to signify that after the conclusion the work is still not finished. I have the contribution to knowledge to spread and my own personal aims for the future. The work of this thesis does not stop here: there is still much to do.

8.12 Original contribution to knowledge

In the introductory chapter I highlighted that there were two foci to this thesis and that one could not overshadow the other as I held both to the same value. As such I believe that I contribute to both foci, the first being around investigating the experiences of students who identify as autistic in HE and the second being around the development of a research approach that aims to address the power imbalance within research whilst promoting accessibility. My original contribution to knowledge is:

- A comprehensive literature review that draws together traditional HE literature with; Autism literature, Autism and HE literature and Disability literature, rather than focusing like prior reviews on just literature around autism and HE.
- An exploration of the ‘whole university student experience’ and the interactions between different facets of university life.
- The development of my emanciparticipatory research approach.
- Presenting a challenge to the current ethical model through discussion in Chapter 4 and through the carrying out of my research.
- Providing further evidence that supports the paucity of other disability studies that recognise the possibility and value of participants contributing to dissemination practices throughout the life of the research, the provision of rich, detailed autistic led accounts of experience that have rooted out and exposed disabling practices within university life.

Moving forward I aim to continue to challenge the current ethical model utilised within my institution through my work. I have already presented at an ethics workshop as part of a university wide sharing knowledge conference and I continue to support other researchers to also challenge the current ethical model in a collective effort to establish a disability specific ethical model.

I will also continue to work with and encourage disabled support services to explore ways of supporting autistic students, both diagnosed and undiagnosed, beyond the classroom. As I have shown within the results of this thesis disabling barriers to university existed within the walls of the university and beyond, and without challenging these barriers and supporting students across the whole student experience, then students will continue to fail.

Finally, I will continue to promote my emanciparticipatory approach through both using it for my own future research but also through publication and presentation within the areas of social science research methodology.

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Appendices

How Students on the Autism Spectrum Experience Higher Education

Stephen Connolly

Appendix contents

Appendix 1. Prompt Sheet

Prompt sheet was used to remind me of important steps and provide prompts if planned method was either not working or I was needing to get the conversation rolling. Prompts are based on first meeting subsequent meetings prompts are based off previous meetings and catching up since last meeting.

Time	**Prompt**
Preamble	Remember to say hello!!!!! Check environment is ok offer to move **Consent forms!!!!!**
During	**If opening questions are asked for** What was school/college like? How did you decided what uni/course to do? Did you look at different universities Why university? Application process Pre-registration **If ongoing questions are asked for** Route through uni: arriving, halls, freshers, first few weeks, DSS/DSA, lessons, time was spent where? exams/handins, clubs, nightlife, friends, second year, third year, houses, tutors, mentors, family, organisation, bureaucracy, placement, timetable, group work. Most significant moment.
After	Thank them Reconfirm next communication

Appendix 2 Information sheet

Sheffield
Hallam
University

Exploring the enablement and disablement of students who identify with Autism in Higher Education

Participant Information Sheet

To view a video of the researcher reading this letter please click on the link below

[insert link here]

Hi my name is Stephen Connolly and I am studying for my PhD at Sheffield Hallam University. For this I am conducting a study, looking at the experiences of students who identify as autistic in Higher Education (university). This study is relatively unique as it is a study for autistic individuals and conducted by an autistic researcher (Me).

Aim of the study

There are two main motivations for this study

Firstly to identify the factors that enable or disable students who identify as autistic in higher education and to address a gap in the knowledge by exploring 'all' aspects that may enable or disable a student who identifies as autistic rather than focusing on a specific facet.

Secondly to develop an inclusive research design, that is similar as far as possible with the principles of Emancipatory research. Emancipatory Research is where the participant involved in the research can input into the design process of the study as well as provide data on their experiences.

Why have you been asked to participate?

You have been asked to participate because you have indicated that you are autistic and a student in university and I would like to know about what enables and disables you there.

What you will be asked to do

Unlike many other studies this study is designed to be undertaken however you like (within reason that shall be discussed later) with the maximum amount of input and control over your participation as you'd like. Basically after an initial discussion either via online or by meeting face to face you would be able to choose how you give across your information to me in the later discussions. For example you may wish to create something about your thoughts and feelings to answer the questions or you could meet for a traditional interview or even choose to have an interview over instant message: there are multiple possibilities and you can choose the one that you feel most comfortable with using to participate within the study.

Participation in this study is entirely voluntary and if you decide not to take part in the study this will not outcome on the support you receive from by Sheffield Hallam University.

Your rights as a participant

Participation is voluntary. All results will remain confidential and you will not be asked to provide any identifying information unless you choose too. Your verbal and written consent will be sought prior to each data collection phase. You may withdraw from this study at any time up until the 4 weeks after your last data collection phase. After validation of grade that identifies completion of my PhD all contact information the researcher holds will be destroyed in keeping with Sheffield Hallam's Data Handling procedures and congruent with ethical approval requirements. Anonymised Raw Data will be kept as is the requirement of Sheffield Hallam University and may also be requested by potential publishers and examiners however your participant rights of confidentiality will still be upheld.

What if I disclose information that affects my safety

During the study if you disclose information that may affect your safety of the safety of someone else, I will sign-post you to a service that can provide help and support. If the researcher has a grave concern for your or someone else's safety where sign-posting is not deemed enough they will be obligated to convey this concern to Director of Studies supervising this study which may result in disclosure of personal details.

How to contact the researcher

If you have questions or concerns, regarding the study then please do not hesitate to contact me as follows:

Stephen Connolly b1048121@my.shu.ac.uk

For any problems you feel you cannot raise with me then please contact the supervising faculty member and Director of my Studies: Professor Nick Hodge

n.s.hodge@shu.ac.uk

Faculty of Development and Society,

Sheffield Hallam University- City Campus

Howard Street,

Sheffield, South Yorkshire

S1 1WB

THANK YOU FOR YOUR PARTICIPATION

Appendix 3 Consent form

Sheffield Hallam University

Participant Consent Form

Exploring the enablement and disablement of students who identify with Autism in Higher Education

Please circle as appropriate:

- I have received and read the Information Setter for the above study.
  Yes /No

- I understand that participation in this study is entirely voluntary.
  Yes/No

- I have had the opportunity to ask questions about the study at any time.
  Yes/No

- I understand the purpose of the study, and how I will be involved.
  Yes/No

- I understand my rights as a participant as outlined in the Participant Information Sheet.

Yes/No

- I understand I have the right to withdraw from the study before, during or after up until 4 weeks after my last data collection date, where upon I understand that, my data will be merged with other participants data and will no longer be distinguishable to be withdrawn.

Yes/No

- I understand that my name will remain anonymous and will not be used or displayed unless I later decide to be named.
  Yes/No

In signing below I give consent to participate in the above study.

Signed…………………………… Printed………………………………………..

Please complete and return this form to the researcher.

Appendix 4 Debrief Sheet

Exploring the enablement and disablement of students who identify with Autism in Higher Education

Debrief Sheet

To view a video of the researcher reading this Debrief Sheet please click on the link below.

[Insert Link]

Firstly thank you for your participation in this research project.

What will happen next? The data collection phase has now come to an end; thank you for participating. The next phase of the study is the data analysis phase, for this you are again being invited to have some input into the analysis of your data; you don’t need to attend this next phase to still be a participant within your study and if you so wish I will analyse your data. But if you wish to be involved in this next phase you are invited to attend a data analysis meeting where we can discuss together, with your input, how the data will be analysed. You may also potentially be asked you to clarify specific things to ensure what you said, and thought is fully understood.

With regards to the data collection phase if you have any questions or queries about either your data or the study itself please do not hesitate to contact the researcher using the contact details below. If you have any questions queries or concerns regarding myself or the way in which the research was conducted please contact my Director of Studies again using the details below.

What do I do now? If you wish to participate in the data collection phase then please just indicate to the researcher that you wish to do so.

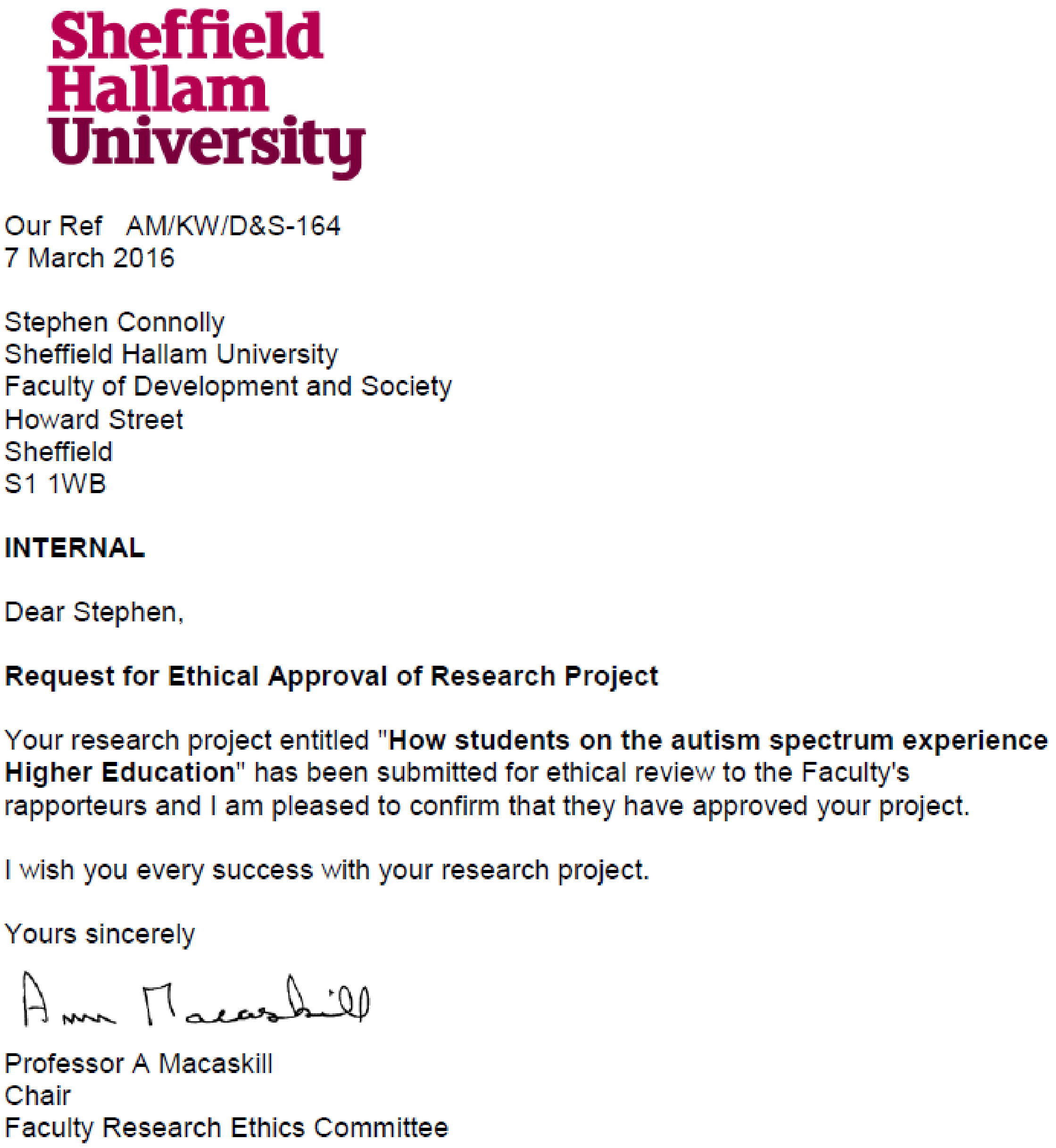
If however you wish to end your participation with just the data collection phase then you will no longer be require to communicate with the researcher. If however you feel that you have gained from discussing your thoughts and feeling to someone or more specifically to someone with autism then please do ask the researcher about local Autism groups or your university Autism Rep if you have one.

Contact information:

Stephen Connolly b1048121@my.shu.ac.uk
Director of Studies: Professor Nick Hodge
n.s.hodge@shu.ac.uk
Faculty of Development and Society,
Sheffield Hallam University- City Campus
Howard Street,
Sheffield, South Yorkshire
S1 1WB

THANK YOU FOR YOUR PARTICIPATION

Appendix 5 Ethical approval letter



Sheffield
Hallam
University

Our Ref AM/KW/D&S-164
7 March 2016

Stephen Connolly
Sheffield Hallam University
Faculty of Development and Society
Howard Street
Sheffield
S1 1WB

INTERNAL

Dear Stephen,

Request for Ethical Approval of Research Project

Your research project entitled "**How students on the autism spectrum experience Higher Education**" has been submitted for ethical review to the Faculty's rapporteurs and I am pleased to confirm that they have approved your project.

I wish you every success with your research project.

Yours sincerely

Ann Macaskill

Professor A Macaskill
Chair
Faculty Research Ethics Committee

Appendix 6 Table of involvement

Name	**Initial Contact**	**Date of First engagement**	**Continued contact**	**Data collection number/time**	**Data analysis**	**Dissemination**
AR	Social Media and email	August 2016	email	1 meeting 1 hour	No further involvement	No further involvement
Liam	Social media	September 2016	Social media and phone	4 meetings 2 hours per meeting	Walked through data analysis did not participate Walked through overall analysis	ESRC event 2016
Shona	Face to Face	September 2016	Social media	2 meetings 1st 2 hours 2nd 2 hours	Participated in coding and discussion of themes	ESRC event 2016 DRF event 2017 part involvement ESRC event 2017
Doug	Face to face	January 2017	Text	Pre data collection meeting 2 hours Data collection meeting 1 2.5hours Data collection meeting 2 1.5hours	one 2hour meeting post analysis approximately 6 months later	No further involvement
Nick	Face to Face via 3rd party organisation initiated by him	January 2018	Social media	5 meetings 1st 2 hours 2nd 3 hours 3rd 1 hour 4th 1 hour 5th 1 hour	Walked through the process pre analysis. Did not analyse. Walked through the process post analysis	No further involvement.

Sam	Social media	January 2018	Social media	2 pre-show meetings 1st 3 hours 2nd 1 hour The show 2 hours 3 post show 1 hour meetings breaking down the show	Participated in the analysis and we did this over 2 2 hour meetings.	ESRC event 2018 Met for 1 dissemination meeting 1 hour pre-event 2 1-hour meetings to discuss YouTube editing of show and dissemination of his data.
Me Stephen	na	na	na	na	na	3 ESRC events 2 DRF events 1 UoS HE inclusion event

Appendix 7 Example coded interview excerpt

Transcript 1 A R

[30 sec of in audible noise]

SC: This has never touch wood this has never failed

AR: laugh

SC: even though this does have a weird recording thing

[break]

SC: Ok so erm obviously my name is stephen im from Sheffield Hallam and my research study is erm ill explain this students that identify with autism for the whole variety erm and the ways in which they erm err are disadvantaged and advantaged due to their identification within higher education. Erm so if you just give me a brief background sort of of your self

AR: yeah so I did my bachelor of science at [university name] in psychology and then I er joined at [university name] to do my PhD in psychology as well erm so yeah

SC: that's nice in [city name]

AR: yeah its lovely

SC: yeah erm its almost like [city name]

AR: but like a tiny bit smaller

SC: yeah erm I used to go there a lot big uni city

AR: yeah

SC: speaking of can you explain to me what you think a student is like when people erm hear you're a know people here people are students what do you think they think of

AR: erm I guess someone that goes out partying really social like will just talk to anyone on campus struggles to get in to uni but somehow does maybe theres an equal share between thinking about doing well and thinking about the next night out it was never really me though like I enjoyed time socialising with friends but im not a live for the weekend and every week night type person like you see erm I'm there to learn not to make friends Its hard enough masking to get by in the environment as it is throw in the issues with my support lack of awareness from my tutors and I think I'm dealing with enough i can't then have the whole being sociable thrown in the mix

SC: ok yeah I can see that defintly more akin to my first year of uni I was the same felt like everyone was living one night to the next while I was just trying to learn I think there was a little impost syndrome there too but also my anxiety of new things already sort of limits what im ok doing so I can see where your coming from I wasn't really a going out person and that kinda left me to being alone cos everyone around me was

AR: Yeah I can see that I go a little lucky though I found some people that also liked to stay in a little too

SC: do you use the SU I know sometimes they can be crazy but sometimes they can be a little more quiet sort of aiming for everyone to a degree at some point

AR: There's always stuff going on there leafleteers, club night promotors, political stuff, artwork, meetings It's like between the outside world and the inner. SU is a wall of bodies to somehow get through. But then when you're in there it is sensory hell so really there is no point.

SC: yeah I can see how some iv been to are like that

AR: yeah

SC: ok so erm so when can erm when you think about disability and how it affects education what are the things that come to mind

AR: erm what my personal issues erm I think when I was doing my bachelors autism was new to me

SC: yeah

AR: so that was a more difficult time I didn't actually like going to lectures I felt a little isolated from my actual academics that I was there for so I actually stuck with my housemates and became very insular and erm there wasn't actually a lot of help for the anxieties and stuff when dealing with a massive university with lots of people in it and then being here doing my PhD similar kinds of things its just peoples unawareness of it all I guess its all in higher education its all about erm interacting and net working and stuff and erm that's kind of a struggle I guess

SC: yeah some pre [stutter] not pre not knowing your diagnosis pre university you were obviously not able able to access the pre going to university stuff your like erm help from disability services and so on

AR: mmm hmm [acknowledgment of yes]

SC: but did you go through your diagnosis process or are you still going through your diagnosis process now that you have started on with within the education system and within work and stuff

AR: so I got my diagnosis when in 2011

SC: yeah

AR: for the last part of my undergrad and for my masters in [city name]

SC: ok so pre coming to [City name] and now that you have your diagnosis to [university name] sorry erm what what erm did they offer during the pre-enrolment phase to you to

AR: nothing really cos I had the DSA [Disabled Student Allowance] id gone through the assessment for that and they'd highlighted that I needed a study facilitator and a non-medical mentor type help

SC: yeah

AR: erm so all I really got pre enrolling was meeting those people really

SC: yeah did you go through DSA your self or was it something you did with the university

AR: erm it was with the university but I initiated it

SC: yeah and did you fill out all the paper work yourself or did you have help from somebody else

AR: err no yeah I did that myself im pretty hands on If I deal with it all then I know what I'm meant to be getting when and for how long I also know where I am up to in the application process and what needs to be gathered to support my case Often you have to set it all up just as you are starting the year, moving and acclimatising It's a bit of a hell month to start each year

SC: ok so you've come to university erm and you had your things diagnosed err identified that you erm would benefit you and make you able to access university better erm hows been using those things that were identified benifited you has there been any issue with using them and so on

AR: erm no so they have been useful but the problem is they don't really apply to the PhD so much so the study facilitator is someone that's meant to come to like lectures and note take and things and I don't really need that so he's just become more of a mentor erm I guess a lot of the university staff aren't autism aware so even though you are given a mentor they are actually especially for females they are not really queued up on the kind of needs its like they are given this model of what disabled students need erm and yeah I think being a PhD student and having a disability like autism means that I don't know the help isn't quite as appropriate

SC: so its not set up for PhD or females

AR: no like I don't think they figure on people that need support getting to PhD level I guess

SC: yeah I can see that erm not that we cant get here but that I can see they don't see it if you get me

AR: yeah

SC: and females you think being a female also

AR: yeah like they don't see females as autistic I don't think and then when they look at autism stuff its very male orientated like they just had a campaign about sensory and there was a petition to get the new air fragrance changed in the toilets and it went really well I was kinda shocked how well it was received maybe it was also effecting other students but they only changed it from the men's all the females toilets kept them like we are meant to like the smelly stuff and we cant be oversensitive to it.

SC: wow what an oversight

AR: yeah they fixed it as soon as it was pointed out but you have to think that the initial decision they did not aim to be sexists but because they thought they were doing right maybe it is because the leader of the campaign was male or something but still they were highlighting that for it was over sensory and impacting the autistic population its like they don't know

SC: yeah have you asked to see whether they have had any autism specific training.

AR: yeah I had a err mental health advisor that I asked specific training and she just kept throwing the question back to me like I said "have you had training in autism" and she said "is it important to you that I have had training in autism" and it just went on like that cos they are more counselor'y so they were like wondering why that was important to me I guess.

SC: ok and do you get to see the same people the same faces throughout the time that you are here or different people erm

AR: erm

SC: each year or each term or each meeting

AR: erm so it should be the same person so my study facilitator is the same person iv had a lot of messing around with my other mentors because people kept leaving so I had one then she left then I had another one come so I put a complaint in and they got me a the err the manager of the service sees me now so I see her regularly so I don't get mucked around with other people .

SC: yeah yeah the changing around is the way they do it at Sheffield Hallam erm so what they did was they restricted the number of hours no they restricted the number of students each facilitator could have therefore each facilitator wanted the most the students that give them the most value so students that get seen the post and obviously im like for me on the PhD course erm I wasn't going to be seeing them very often and therefore I was low value which meant that I was someone that was more passed around so erm I ended up having different faces each time cos I was not as lucrative

AR: yeah

SC: yeah and so It was always someone else so it was nice that you was able to see the

AR: yeah I think it was at the beginning I spelt it out and it was in my DSA assessment cos I had been lumped around quiet a lot with different people and it really makes me kinda nervous so they spelt it out early on that anyone I saw would have to be someone permanent and no erm yeah

SC: yeah when I was at erm leeds met I was there for three years and I got one guy and he was my social facilitator my academic facilitator my spelling and reading guy and then also my exam erm writing and reading person so [incoherent mumbling] that relationship has been able to be with the same person and have that person learn your needs erm something that I can see that iv felt was quite important

AR: yeah I think yeah yeah cos it takes it takes me at least a year to get to know someone erm so I think yeah before that I was just seeing the people that was dropping out id see them for like six months and then they would leave and a new one would come and it take me quite while to get adjusted to someone.

SC: ok erm now is there any instances where you have found that erm you have been disadvantaged as a result of your mmm disability in any aspect of university from accommodation social life erm the university itself

AR: erm the only thing I could think of that is relevant to me are the PhD kind of exams so the upgrade we have a confirmation of candidate halfway from my PhD and its like a mini viva almost and I feel that im erm like at a disadvantage to most people with that because I cant explain myself very well and a lot of it goes on how erm socially you are able to communicate with the examiners and how much networking you have done and how you communicate stuff so that's the only area I feel like and I guess actually I did some I did go to some lectures cos I needed toping up some skills and erm part of the lecture she wanted us to get talking to the person next to us and I was like really temporarily in this group so I didn't know anyone so I just didn't want to do it so I just sat by myself did my own thing and she made a really big deal out of it and erm kinda called me out infront of the whole class and stuff and I had to say to her infront of the whole class iv got autism and then even then she didn't let it go she was like well does that mean you cant talk to the person next to you erm so that I felt disadvantaged in because I felt like my issues were becoming a problem for her and it didn't need too.

SC: erm was that erm

AR: and there was another time similar I was in a seminar and a tutor who I had had issues with before asked us to work in a group everyone was in one so I wasn't negatively effecting others' learning most were in groups of two but some were a three and a couple of groups of two joined up with others so there wasn't a problem and he said 'excuse me why are you not working in a group' I said 'I have a learning contract that says I can opt out of group work' His response was 'well at least give it a try' The girl next to me was obviously a little embarrassed to being forced to work we me

SC: god yeah I can imagine the awkwardness

AR: yeah thinking of it in the space of a year or so this has happened to me twice that's a lot considering I shouldn't encounter it at all

[background noise too high]

AR: do you want me to shut the window would that be better

SC: its up to you

AR: I didn't know if it was ruining your sound or

SC: no im keeping an eye on the levels

AR: o ok that fine

SC: let me just [incoherent mumbeling]

AR: o cool so yeah if I think about actually just going to lecture im coming at this as a PhD student but I do still go I guess and you also want the older stuff too don't you

SC: yeah everything from undergrad onwards I guess

AR: cool well I guess I still just find the lectures really stressful It's a stress getting into class and then when you arrive you have to worry over what is my tutor going to do that results in me looking like a difficult student like if Im having to tell every tutor that I'm autistic and have a learning contract which states I do not need to do this and I get a blank stare back with [quoting a tutor] 'well will you at least try', they are clearly not reading my learning contract so what was the point in declaring

SC: so was that within psychology faculty your faculty which is

AR: yeah that was psychology

SC: psychology

SC: erm [long pause] yeah erm im really lucky I think that my faculty or my department is the autism centre so when I did my RF2 I had to do my presentation some feminist lecturer and some autism lecturers and the odd inclusive education lecturer

AR: yeah

SC: and they didn't really go off of presentation ability just off off of the information and I was allowed to stumble and [incoherent] then they asked their questions which kinda where ok cos I don't know I really like defending my arguments mmm but yeah I really enjoyed my RF2 but umm I don't know how I'll feel about the viva

AR: yeah I think is like getting people that understand in for it

SC: I was told a really good piece of advice pre selection of your external markers if you hold a conference and you present at your own conference or if you hold a poster presentation conference and you bring in six or seven possible external markers and you get to present to them before you have even asked them to be an external marker and then you choose the ones which responded well and obviously didn't argue with any of the points that you made and then erm us the one that is like top like the easiest to speak to and has has tone of voice and accent and things like that find sometimes to speak to people so erm one of the senior lecturers suggested do that before and you also get the experience of hosting a conference

AR: yeah

SC: so I think that is something im going to look into

AR: yeah sounds like an interesting idea I certainly think meeting them before hand

SC: yeah and because you have err asked them yet when it becomes time to ask them they kind of know you a little bit more than some random person from somewhere

AR: yeah

SC: so your more your more likely to get a yes

SC: erm so has there been any the u the university has done something or there has been a policy in place that really aided you so so anything little or big that has [incoherent] its either been introduced or was just part of the university that just aids your ability to to erm access the university like I noticed the room numbering here is like complicated and hard and difficult to over at Sheffield hallam each building has its own number the floor is the next number and the room is the next number and if it is anything special it has a letter at the end and then in the big main building every floor has a different colour as well

AR: I see

SC: so you always know what floor you are on cos the floors colour gets lighter as you go up and dark as you go down

AR: o ok that's cool

SC: so when you get to the bottom of the lift you kind of know what floor floor your on and where in relation to sort of space and time you are and they have tried to do that for people with sensory issues

AR: o right ok

SC: allowing them to get more involved things like that where as these buildings seem really like nook and cranny's and id find navigating round here so hard

AR: its something iv tried to like campaign for cos im running the disabled students society and a lot of the things people where reporting is that although a lot of the rooms are complicated there really is no map for this campus that's like got every level of floor on like you ask for it and they are like yeah yeah but you never actually get it and it doesn't really exist anywhere so erm the [incoherent] is difficult cos we are limited on space these buildings are like quite old so the rooms all jig about but erm so yeah that's part of what im trying to get them to do is to like actually give us a map and stuff cos iv been here three years and I still cant find my way to certain places like I have to go the long way round or something

SC: yeah it really was an experience getting here then waiting for you that place was mad

AR: yeah the crossroads where I met you is the main thoroughfare of the uni when the main classrooms kickout everyone piles into there like at school, but these classes are two hundred and fifty at times and they all converge on one point one time when I first started there I was walking through and the buzzer went it stopped me dead in my tracks the high pitch screeching through my ears then bang I'm surrounded by bodies speedily bumping into me all the conversations that were happening in the rooms now out in the corridor all around me then as quickly as it came it went and I sat down and cried

SC: erm so is there anything that is done naturally that you find enables you to access the university that little bit better

AR: erm I guess that I get my own desk we have an office and that's meant to be hot desking so whoever comes gets a desk but the students with reasonable adjustments erm don't have to hot desk so they get a permanent desk in there so that's really helpful erm that's good I don't think this university does a lot disabled wise I think it is just limited on space and money so what it does erm I don't know its difficult to yeah its difficult to find things

SC: shame it can be difficult without a place to just go

AR: yeah luckily, I can escape here but I fear for the other students. I think that's why I was able to be elected un-opposed We all knew that something needs to be done and that I'm very passionate about it Imagine having to travel through hell to get to a class You'd either stop going or arrive and need the lesson to recover.

[incoherent]

SC: yeah so seeing as you are sort of like erm a special candidate first candidate participant in that you're as I noticed on your email it was president of the disabled students society is there anything that work there has identified as showing the university there inaccessible or more accessible

AR: yeah iv only just started but one of they erm suspect a lot of the student services and one of the issues that im trying to get is like I want a separate room or space for autistic students on campus because they are having a lot of problems erm our campus is like really overwhelming cos it is so small when term starts its like packed with students like you cant get in anywhere in a really small space its like loud and noisy and a lot of the autistic students aren't coming in or are staying away and avoiding lectures because in between times theres no safe place to go so erm I I didn't have my desk as well I wouldn't come in probably ever so im trying to get a room or something that's one of the things we identified the map was another thing and also having some sort of like triaging system or something because we have counselling and wellbeing support services but a lot of the students are too scared to go and actually speak to them or go up to the third floor and actually access them theres no one like there personal tutors are all kind of hit and miss erm I feel like there needs to be something in place like a front of house where if you have an issue you go to erm that kind of thing

SC: do your disabled student services have desks

AR: erm no its all upstairs like we have this thing called icentre or something where I think you have to go if you want an extension or anything but I don't think it is very accessible for the autistic student or anything that don't want to go to a busy place

SC: yeah so the system we have at hallam that is quite useful is that erm if a student has got a err [short pause] like a erm learning contract well your on their work or on anything it notifies you at the top of your screen and those students can email you and say they need an extension they don't have to go in anywhere they can do it from home

AR: ok

SC: and they'll email you and say can I have an extension and like I only just found out iv got the ability to give straight two week extension without having to fill out any paper or anything myself just like yeah sure take the extra two weeks or whatever erm then I can give further to that just notifying those people that they need to get in before the board or well as long as I can mark it before the board erm but erm so theres no from sitting in the reception looking iv noticed that the staff of the disability services reception are also having to deal with all the international students asking for its not disability services its student services but its disability services that are then international students asking for visa and stuff they do a lot of the triaging they can spot when someone needs that little bit of extra help and they will get on the phone to someone and be like I need someone to come and speak to this individual now or in an hour or there on their lunch but if you just take a seat there they will come and grab you thing and I think that that's one of those things that is not in their job description but its one of those services that as they are shutting down front desks is getting lost

AR: umm yeah I think we have cos we have like drop ins and stuff but I don't think a lot of students are aware of them they kinda try cos they are so over subscribed they try and they have got rid of a lot of there people in student services so they try not to shout about it I think its like a need to know basis

SC: Yeah we've moved to a lot more drop in based and a friend of mine went to one and it was a big meeting and it was like desks and they all sat one side and someone sat the other side and someone came in and did a presentation and it was less of a drop in and more of a lecture of how to help yourself

AR: ok [laugh] yeah

SC: it really wasn't what that person was looking for and with the cut changing climate its quite hard particularly with changing to the funding and so on

AR: yeah DSA changes hit I found a lot of things I used to access or they used to offer are no restricted

SC: like the changing of the words so non-medical help isn't no longer given as much funding [incoherent] autisms so massive and most of the help is for social based stuff

AR: yeah

SC: so just looking back sensory is a big one for you then like

AR: yeah its really difficult here and the stress of uni just adds to it itd be so bad in lectures Id need to just escape and without a place to go I run home

SC: god yeah

AR: yeah just looking at the clock im sorry I cant do much longer I have to shot straight off

SC: o yes of course will just ask a little more then we should be done with a few minutes to spare

AR: sure sorry I cant do longer

SC: no no I planned for the time you are giving me and I am very grateful so You are positive about your identity have you always been

AR: its mixed I sometimes I am sometimes I think god it would be easier if I didn't have to deal with all this stuff all I want to do is complete my ethics and x is stopping me but mainly I am fine with it

SC: and what about others knowing

AR: erm nots not as straight forward like I want to be this voice for the down trodden and help out but I also just want to fit in and I don't think you can do both

SC: so who knows and who doesn't and how do you decide

AR: well of course the university knows with me applying and my close friends know also I have definitely changed like when I was doing my undergrad and masters that was it uni and my close friends because I was so worried of people judging me if I was not there to tell them about it now everyone knows I mean im the students union disability officer hard to hide

SC: but undergraduate and masters

AR: yeah I was still getting to grips with it myself so it did take some time and then I didnt want people really Im not ashamed of my autism Im very autism positive but I also dont want it to be the thing that leave the impression of me on someone know what I mean Autism is still so misunderstood so if I was to say Im autistic I cant control the knowledge that person has in every situation When Im with housemates or with friends I know that they will ask questions and uncertainty will be resolved in a positive way but if I was chatting to a guy online or in a club I cant just drop out I'm autistic because its then difficult to discuss hed run a mile Similarly if Im just chatting to someone in the SU about a society I dont want to be like hey before we go on I need to disclose I'm autistic because then we start talking about that not the thing I need to talk about plus my autism is for me to disclose not others If I'm chatting to someone and it comes up and we are able to discuss it thats fine but I cant drop it on someone if I think they are going to leave without really knowing much about autism then sitting with their friends and being like oh shes autistic isnt that like Sheldon Cooper Id avoid her because then I am the female Sheldon to those people not me if you get me

SC: yeah I get you

AR: I really don't like the idea of someone talking about me. I just want to be in the background and the idea that people are talking about me as autistic bothers me, not because I'm ashamed or anything but like I said they will jump to incorrect conclusions about me. Autism knowledge in society is just so poor that if someone thinks someone is autistic they are just going to assume some of the more negative stuff and once people see you like that they aren't going to see you differently.

SC: yeah I can understand that you said you like to be in the background do you think you mask

AR: when I try to get through the day I am aware that I mask a lot and it helps me I feel that by disappearing into the background Im not at risk from those around me The only issue is when I cant keep up the mask usually due to sensory or just burnout Then I have to go somewhere quiet and alone like I said currently here there is nowhere and that is my first campaign as disability officer a campaign for a quiet room that we can then as a student body turn into a sensory room. Without it my only choice is to run home when it gets too much … I also struggle to mask when I am unmasked if you get me. Like I've said I need to control when I disclose however its difficult to do that when a tutor is stood at the front of a class asking why you are refusing to speak to the person next to you and you have to tell him at that point the mask isnt about appearing as just another person in the room but rather about showing my challenges aren't affecting me This is the type of thing that results in a run home to cry for the rest of the day in-order to control the perception of autism I have to gauge how much of myself to expose to any given person and so have to juggle that

SC: yeah [incoherent]

AR: I have to mask at uni and it's really taxing on me By the end of the day Im close to the edge which is why if anything goes wrong, I usually just leave uni I used to need to just go home and be in my room to recover but now my amazing housemates will make an effort to spend time with me to relax and cos I no longer need to mask with them I can just relax and I need less time to be alone when I'm home now.

SC: so is there anything that we have not covered or discussed or that would be pertinent to the question

AR: erm I feel like at this university things are better than at my last university I feel like I know the people slightly easier to get into contact with like at York I didn't know where to go at all like there was the counselling services

SC: awesome thank you for your time

AR: no it was nice thank you for coming all they way down here for me it was nice to meet another autistic PhDer just goes to show we are about haha

SC: haha yeah

5727 words interview time 55 minutes

Appendix 8 Examples of cooperative analysis

Example of the categorising process carried out with Nick and as part of the process when analysing alone

Appendix 9 Coding tables

AR=AR, **L**=Liam, **Sh**=Shona, **D**=Doug, **N**=Nick, **Sa**=Sam, **St**=Stephen (me)

^ = important

Codes identified and group into categories tables show categories grouped to themes and which student's data the codes that match the category under the theme were present in x = present.

Table of themes RQ1

Theme 1 Control of labels	**AR**	**L**	**Sh**	**D**	**N**	**Sa**	**St**
Choice of disclosure ^	x	x	x	x	x	x	x
Forced disclosure tutors	x	x	x	x	x	x	x
Forced disclosure non-academic staff	x	x	x	x	x	x	x
Pre-disclosure to DSS positive perspective	x	x	x	x			x
Disclosure to DSS positive outcome	x	x	x	x			x
Pre-disclosure to DSS negative perspective					x	x	
Disclosure to DSS negative outcome					x		
Pre-disclosure to tutors positive perspective	x		x	x			x
Disclosure to tutors positive outcome			x	x			x
Pre disclosure to tutor negative perspective					x	x	
Disclosure to tutors negative outcome	x			x	x		x
Disclosure to other academic staff outcome	x			x	x		x
Disclosure to administration		x					x
Disclosure to placements		x					x
Pre-disclosure to housemate's positive perspective						x	
Disclosure to housemates positive outcome	x						
Pre-disclosure to housemates negative perspective					x		
Disclosure to housemates negative outcome							x
Pre-disclosure to peers positive perspective			x			x	
Disclosure to peers positive outcome		x	x	x		x	
Pre-disclosure to peers negative perspective	x	x	x	x	x		x
Disclosure to peers negative perspective	x	x	x	x	x		x
Pre-disclosure to close friends positive perspective	x	x	x				

Disclosure to close friends positive outcome	x	x	x			x	x
Pre-disclosure to close friends negative perspective	x	x	x	x	x		x
Disclosure to close friends negative outcome	x	x	x	x	x	x	x
Pre-disclosure to friends not close perspective positive						x	
Disclosure to friends not close outcome positives	x	x	x	x	x	x	x
Pre-disclosure to friends not close negative perspective	x	x	x	x	x		x
Pre-disclosure to other general students positive perspective						x	
Disclosure to other general students positive outcome	x	x	x	x	x	x	x
Pre-disclosure to other general students negative perspective	x	x	x	x	x		x
Disclosure to other general students negative outcome	x	x	x	x	x		x
Pre-disclosure to potential NSA physical partner negative perspective	x				x		x
Disclosure to NSA physical partner negative outcome	x				x		x
Pre-disclosure to potential relationship partner positive perspective		x	x			x	
Disclosure to potential relationship partner positive outcome		x	x			x	x
Disclosure to relationship partner positive outcome							x
Pre-disclosure to potential relationship partner negative perspective	x				x		x
Disclosure to relationship partner negative outcome	x				x		x

Theme 2 Sociality	**AR**	**L**	**So**	**D**	**N**	**Sa**	**St**
Student identity	x	x	x	x	x	x	x
Fitting in ^	x	x	x	x	x	x	x
Fitting in goal		x	x		x	x	x
Being social is very ^ at university		x			x	x	x
Being social is important at university	x		x				
Drinking ^	x	x	x		x	x	x
Clubbing ^	x	x	x		x	x	x
Sex ^	x				x	x	x
Being social with housemates ^	x					x	x
Being social with peers ^		x	x	x	x	x	x
Being social with generic students ^		x	x		x	x	x
Challenges socialising	x	x	x	x	x		x
Skipped commitments for socialising	x	x	x		x	x	x
Masking ^	x	x	x	x	x	x	x
Masking positive effect						x	
Masking negative effect	x	x	x	x	x		x
Masking for safety	x	x	x		x		x
Masking to gain advantage	x	x	x		x	x	x
Group work positive						x	
Group work negative	x	x	x	x	x		x
Group work stress	x	x	x	x	x	x	x
Is sociable		x	x		x	x	
Prefers to be alone	x				x		x
Others are bothered im alone	x			x	x		x
Romantic goals	x				x	x	x
Career goals					x	x	
Additional labour	x	x	x	x	x	x	x
Perspective being social is ^ for others	x	x	x	x	x	x	x

Theme 3 Wellbeing	**AR**	**L**	**So**	**D**	**N**	**Sa**	**St**
Fight or Flight	x	x	x	x	x		x
Anxiety	x	x	x	x	x	x	x
Stress	x	x	x	x	x	x	x
Depression	x	x			x		x
Shut-down	x	x	x		x	x	x
Melt-down	x	x			x		x
Break-down					x		x
Related physical illness	x	x			x		x
Negative self-imagery	x	x	x		x		x
Sensory challenges impact on wellbeing	x	x	x		x	x	x
Others had concern	x	x			x		x
Sleep issues					x		
Break in study	x	x					
Considered dropping out		x		x	x		x
Considered failing not because of work	x	x		x	x		x

Theme 4 Academic supports	**AR**	**L**	**So**	**D**	**N**	**Sa**	**St**
Do not have academic supports by choice					x	x	
Have DSA	x	x		x			
Use DSS	x	x	x	x			x
Have academic supports	x	x	x	x			x
Additional tutor support		x	x	x			x
Additional time assignments		x	x	x			x
Resources	x		x	x			
Organisation support		x		x			
Writing support		x		x			
Pedagogical changes	x	x	x	x			x
Good tutor awareness			x	x			x
Poor tutor awareness	x	x			x		
Positive impact of support	x	x	x	x			x
Negative impact of support	x	x	x	x	x		x
Academic support impacted positive on wellbeing	x	x	x	x			x
Academic support impacted negatively on wellbeing	x	x	x	x			x
Did not receive what I was entitled too		x					

Theme 5 Additional Labour	**AR**	**L**	**So**	**D**	**N**	**Sa**	**St**
Accessing my course was harder than it should be	x	x			x		x
Accessing DSA was difficult	x	x	x				x
Accessing DSS was difficult	x	x	x				x
Accessing halls was difficult	x				x		x
Accessing university difficult	x	x	x	x	x	x	x
Sensory impact work	x	x	x		x		x
Sensory impact social	x	x			x		x
Sensory impact other learning spaces at uni	x	x	x		x		x
Sensory impact classroom	x	x	x	x	x		x
Sensory impact wellbeing	x	x	x	x	x		x
Sensory impact anxiety	x	x	x				x
Organising supports impact	x	x	x	x			x
Organising tutors impact	x	x					x
Organising timetable impact	x	x	x				x
Additional organising	x	x	x				x
Bureaucracy	x	x	x	x	x	x	x
Library impact	x	x	x	x	x	x	x
Finance dept impact		x					x
Placement		x					x
Communication impact	x	x	x	x	x	x	x
Masking	x	x	x		x	x	x
Peers	x	x	x	x	x	x	x
Friends	x	x	x		x	x	x
Being positive	x	x	x		x		x
Female	x						
Students Union	x						x
Medical centre					x		
Sports	x	x					x
Societies	x	x			x	x	x
Parents	x	x			x	x	x

Table of Themes RQ2

Theme 1 Easy, Simple, Accessible	**AR**	**L**	**So**	**D**	**N**	**Sa**	**St**
Comfortable	x	x	x		x	x	
Easy	x	x	x	x	x	x	
Accessible	x	x	x	x	x	x	
Relaxing			x				
Quiet			x				
Normal	x	x		x		x	
Easy to talk	x	x	x	x			

Theme 2 Flexible	**AR**	**L**	**So**	**D**	**N**	**Sa**	**St**
Able to cancel		x			x		
Flexible	x	x	x	x	x	x	
Worked around me	x	x		x	x	x	
Could pause		x			x		

Theme 3 Meaningful	**AR**	**L**	**So**	**D**	**N**	**Sa**	**St**
Meaningful	x	x	x	x	x	x	
Something has come out of it	x	x			x		
I can see it helping	x	x				x	
Did this to help		x					

Appendix 10 Dissemination Activities

Table of dissemination activities

Activity	Involved	Topic	Notes
Autistic Voices Tell All: experiences of higher education. ESRC Sheffield Festival of Social Science.	Stephen Liam Shona	Being autistic in HE	2016 Funded by the ESRC Audience: Mayor, Pro-VC, Tutors, LEA, teachers, social worker department, solicitors, parents, autistic adults.
Doing Emanciparticipatory research presentation	Stephen	Emanciparticipatory research so far	2017 Disability Research Forum. Sheffield Hallam University, Sheffield. Audience: tutors, researchers, Shona, public
The Autistic Soapbox. ESRC Sheffield Festival of Social Science.	Stephen Shona Sam	our lives including HE	2017 Funded by the ESRC Audience: parents, students teachers, children, tutors, public

Inclusion in HE presentation	Stephen	Some results from my PhD and what can they tell us about inclusion in HE	2019 Keynote national conference Audience: Student support officers/staff
Ethics workshop	Stephen	Challenging the traditional ethical model though presentation of PhD	2019 Facutly development day Audience: lectures, researchers PhD students
Emanciparticipatory research and why everyone should do it but I do not want to do it again presentation	Stephen	explaining emanciparticipatory approach to research what I found positive what I found challenging challenging ethics	2019 Disability Research Forum. Sheffield Hallam University, Sheffield. Audience: tutors, researchers, Shona, public
Methodology Methods workshop	Stephen	explaining emanciparticipatory approach challenging ethics discussing accessible methods	2020 Creative methodology and methods workshop Audience: university wide lectures, researchers PhD students

Table of wider related dissemination activities influenced by and including elements of the study

Activity	Involved	Topic	Notes
Additional labour in education presentation	Stephen	The additional labour and how it interacts in education	2018 Sheffield Autism fair Audience: open to public
Police Training sessions	Stephen	The additional labour of autistic life developing stakeholder groups readdressing the power imbalance with the autistic community	2017-2019 South Yorkshire and Humber Police service. Audience: trainee police officers, in service police officers, senior constables
BBC Radio Sheffield interview	Stephen	The additional labour of autistic life	2019 BBC Radio Sheffield Paula Edwards Show
Additional labour of transitions in education presentation	Stephen	The additional labour of transitions in education	2019 South Yorkshire Autism fayre Audience: open to public

Missing Autistic Voices. ESRC Sheffield Festival of Social Science.	Connolly, S., Amber, K., Simmons, M., Woolard, M., Wright, D,	Minority groups within the autistic community	2019 Funded by the ESRC developed with the emanciparticipatory ethos Audience: parents, students teachers, children, tutors, public

Appendix 11 Example literature matrix

The following literature matrix was used to aid construction of the literature review. Being dyslexic, it helped immensely with organisation and memory (Not all papers are used within the thesis. Additionally, sections are completed as was needed for me and are not meant be a summary of a paper)

Ref	**Methods**	**Findings**	**Discussion**	**Notes** (personal thoughts)
Smith C (2007) Support Services for Students with AS in HE	Survey sent out 5 participants	Significant number of students insignificantly sized disability support service	n= 5 (4.9%) response rate. little autism input.	Accommodation and Services
Volkmar et al (2008) Supporting More Able Students on the Autism Spectrum: College and Beyond	Case Vignette	No findings per say	While many universities are quite adept at making accommodations for students with specific learning disabilities and ADHD, they face new challenges when accommodating students on the autism spectrum.	***valuable read***
Bolman Brief Report: 25-Year Follow-up of a High-functioning Autistic Child	Single case study	Despite being academically gifted lad had trouble		Not worth using
Taylor, (2005) Teaching students with autistic spectrum disorders in HE	Long term case study (2 years) 3 students.	Found that autistic students would require adjustments in delivery, assessment and pastoral care.	Little to add due to dated however some of the suggestions around congruent with current practice but also	Ok study for early inclusion in lit chapter

			suggested opposing practice to what would be seen as good practice to	
Getzel (2008) Addressing the Persistence and Retention of Students with Disabilities in Higher Education: Incorporating Key Strategies and Supports on Campus.	Thought piece			As the field of higher education and disability explore the expansion of service options, ongoing research and evaluation efforts are critical to document their effectiveness in addressing the unique learning needs of college students with disabilities.
Richardson, (2009) The attainment and experiences of disabled students in distance education	2351 distance learning students. self-report questionnaire	Reported low quality of course and personal development	***Key Argument*** attainment and experience of disabled students was the same as non-disabled students	The experiences and success fluctuates across the disabled student population the same as it does the non-disabled student population as long as accommodations are made.
Tinklin, Hall (1999) Getting round obstacles: Disabled students' experiences in higher education in Scotland	12 "in depth" case studies	Students face 5 obstacles Physical environment, access of information, entrance to HE, assumptions of normality and levels of		Limitations are relevant still which is scary. **dated**

		awareness.		
Kioko, Makoelle (2014) Inclusion in Higher Education: Learning Experiences of Disabled Students at Winchester University	Semi-structured interviews 4 students 3 lecturers	3 lines of thought become noticeable: learning and teaching experiences; learning and examination support; and good relationships and effective communication.	Inclusion in HE is more complex than that of schooling the mere identification and removal of barriers is not enough as there are a wide array of complex factors involved but research generally looks at the basic removal of barriers.	Paper can be useful when discussing culture of change v removal of barriers.
Madriaga et al (2010)	Systematic survey of disabled (n = 172) and non-disabled (n = 312) students	Both disabled students and non disabled students face barriers.		Congruent with Richardson's 2009 study
Barnard-Brak (2010) Measuring College Students' Attitudes Toward Requesting Accommodations: A National Multi-Institutional Study	n=276 the Attitudes Toward Requesting Accommodations (ATRA) scale. was used to measure	Score high on this you are less likely to ask for accommodations and thus they conclude perform worst		They argue that if you don't ask for help you are more likely to fail. USA disabled students are non-traditional students
Richardson (2010) Course completion and attainment in disabled students taking courses with the Open University UK	Open university statistical data. 66,560 registrations	Students with restricted mobility and students with other disabilities showed lower pass rates than non-disabled students. Students with dyslexia or other specific learning difficulties showed		Where does this sit with regards Richards other papers?

		lower pass rates and poorer grades than non-disabled students. Finally, students with multiple disabilities showed poorer course completion, lower pass rates and poorer grades than nondisabled students.		
Soorenian (2013) Housing and transport: access issues for disabled international students in British universities	n=30 Range of disclosed disabilities 11 British universities 15 email 12 face-to-face 3 telephone interviews		There is an interplay between the students range of identities	Highlights that little research is done on housing and transport for disabled HE students. Students have more than one identity and there is interplay why does research focus on just one?
Collinson et al (2011). Re-Visioning Disability and Dyslexia Down the Camera Lens: Interpretations of Representations on UK University Websites and in a UK Government Guidance Paper.	n=3 Question: what do visual representations of dyslexia and disability look like and what messages do they convey?	Poor representation Limited research Limited disabled voice within the development of website imagery	A need for participation.	What does disability look like when advertising universities? More important what does studenthood look like when advertising university?