Autistic Women's Experiences of Higher Education

Sophie Phillips

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The University of Sheffield
Faculty of Social Sciences
School of Education

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Abstract

This study explores the experiences of autistic women at university. Autism attracts much attention both in popular culture and in research, however this tends to be highly gendered and autistic women are regularly excluded. In addition, little space is given to the autistic experience in research, in favour of medicalised research focusing on autism as pathology. This minimisation of autistic women and their experiences may have many damaging effects on their identities. Within this study I aim to trouble common stereotypes of autism, by drawing out the experiences of this marginalised group in academia. I further challenge stereotypes of autism as I am an autistic researcher. Artefacts and interview data were collected from 11 participants, who all identified as autistic women and were studying at UK universities, to offer insight into their experiences. Within my analysis I focus on the impact of both self-perceptions and the perceptions of others, the postgraduate autistic experience, and the impact of the university environment. These experiences draw out supports and barriers autistic women navigate at university, as well as how the environment could be changed to better assist them. This data indicates that university culture towards autistic people, and more widely minority groups, needs to change to be more accepting and welcoming, to ensure these students are able to experience university in the same way as other students. In addition, this study seeks to highlight how the experience of one minority group may enable wider diversity of academia as a whole, beyond autism.

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1 Introduction

1.1 Introduction

This thesis offers a cultural exploration into autistic women's experiences of Higher Education. I use methods of artefact creation and interviews with eleven participants to elicit their stories. Artefact creation allowed participants the option to express particularly poignant experiences without needing to verbalise them. This enabled a different dimension of access to the research. Autism framing at university may enable appreciation of how autistic women experience university, where they may be academically capable but struggle with the nuances of social interaction and learning environment. Although this study is about autistic women it may act as a catalyst for change for other disabled and non-disabled students.

My study aims to contribute to the accessibility of university to autistic women and highlight both good practice and preventative barriers. In this introduction I offer a brief overview of what autism is, explain the research questions of this study, and outline what the remaining chapters of this thesis contain.

1.2 Autism Overview

Within my thesis I focus on part of the autistic experience. I start my thesis at a point of considering a subsection of the population that are already diagnosed as or identify as autistic. Within the literature review chapter (Chapter 2), I delve into some of the controversies surrounding autism. Here I set out the main considerations about autism that I think it is important for the reader to keep in mind throughout this thesis.

In terms of medical diagnostic manuals, autism is said to be a neurological disorder (American Psychological Association [APA], 2013). If a person is diagnosed with autism they are said to have difficulties in social communication and interaction, and social imagination that limit and impair everyday functioning (APA, 2013). Difficulties in social communication and interaction might include not enjoying social gatherings, using body language atypically, and not maintaining relationships. Social imagination difficulties might consist of processing sensory stimuli differently and finding change of routine difficult. Autism has tended to be presented as a series of deficits compared to the norm, rather than as differences and therefore autism tends to be portrayed in a negative light (Cooper et al., 2021). This medicalised view of autism is criticised by some, particularly as autism currently has no known aetiology. Autism is therefore viewed in many ways. Some researchers argue that it is a different way of thinking (Anderson-Chavarria, 2021) whereas others (for example, Runswick-Cole et al., 2016) question whether autism should exist in its own right. In addition, there are arguments of who should research autism and how participants should be treated (Fletcher-Watson et al., 2019). This lack of agreement of what autism is, who can be autistic and whether it exists as a disability appears to fuel societal stereotypes and a contentious but progressive research field.

1.3 Background to the research

I have set out that autism currently attracts much attention mainly due to the discussions around its existence and make up. Within the field of autism, the majority of research negates the experiences of autistic people and instead favours psychological explanations of characteristics associated with autism (Goldberg, 2017). I consider autistic women at university to be a subset of the population that has not received much attention. Attending university after compulsory schooling is becoming ever more part of traditional lifestyle (Boliver, 2018). Autism in women remains stereotyped as unusual and out of the norm (Harmens et al., 2022). Due to this, it is important that autistic women in Higher Education (HE) are given the opportunity to contribute to current research in order to ensure other autistic women have equal access to university.

Autism as a disability may trouble current thinking. Colloquially some people suggest that adjustments or changes made for autistic people may benefit other people. Autistic women are said to go against the stereotypical view of being a woman in a patriarchal society. Although this can relate to their exclusion from society, this difference may assist in challenging stereotypes of women more generally in society. Thus, whilst I centre my research on the autistic woman, the implications of this research may be extendable beyond autism and challenge stereotypical opinions both with academia and society.

'I have touched on autism troubling current thinking, including its existence and the stereotypes that surround it. Several issues within autism have been extensively debated; especially in relation to the question of whether or not autism is real or constructed. In *Chapter Two: Literature Review* I investigate different theories about autism that touch upon this debate. This is not a philosophical piece of work on the existence - or otherwise - of autism but I want to briefly outline how I understand and conceptualise autism. I rely on the assumption that autism exists, that many people now have shared (but also) different realities in relation to this phenomenon and that many people share an understanding of this complex phenomenon that not only shapes their personhood but also defines themselves as a collective. Hence, like a lot of disability researchers (see Goodley & Lawthom, 2005), I sit in tension with a realist functionalist perspective (where autism has been diagnosed and identified within a person) and a relativist perspective (which recognises understandings of autism are always socially and culturally created).

Some researchers suggest that humans believe what they want to, even if contrary evidence exists (for example Lord et al., 1979). This suggests that the lines between what is real and what is constructed through the influences of others, environment and societal context may be movable and difficult to define. For autism, regardless of whether it is scientifically considered as *real* it is likely to be considered societally *real;* I understand that real and reality are entwined concepts that can be thought about with reference to one another. Therefore, people’s own experiences are valid and their words should be accepted as real to them. Rather than debating the reality or otherwise of autism, my thesis adopts a common practice in disability studies - self-definition - and so my understanding of autism is based on the proposition that people, represented in my thesis, self-identify with the phenomenon of autism. My thesis makes no attempt to assess the validity of this self-definition nor to challenge it. Instead, I respect the self-identification of my participants.

1.4 The Study

My own personal experiences and academic study of autism inspired this study. After being diagnosed as autistic towards the end of my undergraduate degree I was keen to explore what it meant to be autistic further. Requesting adjustments during postgraduate education seemed particularly difficult in some respects due to others not understanding autism and me not being able to articulate what I needed. Therefore, this and my inquisitiveness to explore how other autistic people have found academia has helped shape the research questions I pose in this thesis.

As well as my personal experiences shaping the impetus to research about autistic women at university, I seek to build on the very small research field of autistic women's experiences. So far, I have begun to explore some stark realities of autism that I feel the reader should keep in mind throughout this thesis. I have also highlighted the background to my research, by introducing how autistic university students are afforded minimal space within research. By troubling the stereotypes of autism and drawing out the experiences of a marginalised group in academia, this may provide useful examples to other cultures and minorities. I therefore investigate the cultural experiences of autistic women at university. To attend to this, I pose the following research questions:

1. What barriers and supports to higher education do autistic women students feel they have had at university?
2. In what ways can the university environment be adapted to better accommodate autistic women?
3. What changes would autistic women like to see at university?

These research questions stem from both my own experiences and what the current literature does not attend to. Overall, whilst I seek to focus on how the autistic and woman aspects of a person's identity impact at university and how others respond to the autistic woman, I believe my research questions will enable a much more intersectional discussion, that may start but not end with autism. This will move away from the current autistic versus non-autistic stance that dominates autism literature. In highlighting the barriers and supports autistic women face along with their opinions of how university could be changed to better accommodate them, I seek to present how universities could adapt to ensure autistic women have the best university experience possible.

1.5 Language and Structure of the Thesis

1.5.1 Language about Autism and Disability

Within both academic and societal discourse, debate about the language that should be used to describe autism and autistic people is rife (Botha et al., 2021; Dwyer et al., 2022). Debates tend to centre on whether to use identity-first language (such as ‘autistic person’) or person-first language (such as ‘person with autism’). Bottema-Beutel et al. (2021) posit that there is a lack of consensus on the preferred type of language surrounding autism, particularly between different groups of people. For example, they suggest that autistic people prefer identity-first language whereas autism professionals tend to prefer person-first language (also supported in a previous study by Kenny et al. (2016)). Bottema-Beutel et al. (2021) do not suggest that any one type of language should dominate, but challenge researchers to listen to stakeholders (including autistic people) involved in the research, consider how ableism and language interact, and to justify the language they use.

Within my thesis I consistently use identity first language with regard to autism, as this is my personal preference as an autistic researcher. The majority of participants stated they either preferred identity-first language or had no preference. The only exception to this is when a participant used person-first language in their interview or used within their artefact(s). I honour the language preferences of each participant when writing about them. Although the participants and I held opinions with regard to the use of language around autism, no participant expressed any strong opinions about how disability should be spoken about or how non-disabled people should be described. Therefore, I use a variety of terms to describe disability (when talking more broadly than just about autism) and non-disabled people such as ‘neurotypical’, ‘neurodiverse’, ‘non-autistic’ and ‘non-physical disabilities’.

1.5.2 A Note on the Structure of My Thesis

Throughout the thesis it may be noticeable that some paragraphs are short and only consist of a few sentences. Although this may not be a traditional paragraph format, I prefer to write in this way as I find it simpler and clearer.

1.6 The Presentation of the Thesis

I divide this thesis into nine chapters. Following this introduction, I turn to the literature review. Within this chapter I consider the theories of disability and autism in Higher Education (HE). I provide an overview of some popular models of disability and discuss their relevance and impact on disabled people and practice. I go on to consider how the rise of critical autism studies and feminist disability studies has influenced research and how my own thinking critiques and compliments these. I explore how researching autism within a feminist disability framework may seem challenging. I go on to explain autism more generally and give an overview of some of the ongoing controversies and debates that are linked with it. I then consider autism on more practical terms and explore more empirical research conducted on and with autistic people. I specifically consider autistic women's experiences in HE and highlight the dearth of literature surrounding this. I identify how my research fits into a gap in previous literature. I explore specific aspects autistic women may have to face at university such as masking and others' perceptions of them which may be different due to other intersectionalities.

Within Chapter 3 I document the methods I used in my study. I consider my ontological and epistemological stance that underpin the study. I justify the use of creative methods, particularly with autistic participants and explain my chosen research methods of artefact creation and virtual interviews. In addition, I explore ethical considerations in detail as I argue these are central and paramount to my research. This is particularly due to the potential vulnerability of my participants, both with them being autistic and the data collection taking place within a global pandemic. I end this section by reflecting upon more personal ethical implications of being a disabled researcher myself. Finally, I document my analytical framework and techniques used, and reflect on my journey of analysis.

I split my analysis across four chapters, Chapters 4 to 7. Within the analysis chapters I explore my participants’ daily lives and interactions as autistic women at university. I engage with both the interview data and artefacts, and incorporate my own analysis into what the participants have said. I acknowledge the complexity of autism particularly in how it is viewed both by autistic people and society. I explicitly engage with how participants feel others perceive and treat them, stereotypes that are synonymous with autism, the practical implications of being autistic at university, and the impact this has on them. I now give a more detailed overview of each chapter.

Chapter 4 is dedicated to introducing the 11 participants. First, I discuss the use of creative methods within disability research and then introduce each participant through a pen portrait. Within these pen portraits I document each participant's artefact(s) and summarise what they said when interviewed. No thesis writing is completely free from author bias, however I wanted to provide a chapter of relatively untouched participant stories to give the reader the essence of who the participants were, as this may not be apparent in later analytical chapters.

In Chapter 5, I explore perceptions of autism and the impact these have on autistic women. I divide this chapter into three themes: self-identity, societal perceptions, and perceptions of university. Within the theme of self-identity, I consider how participants view themselves in relation to their autism including their experiences of diagnosis and identity. I draw on work by Perry et al. (2022) to highlight self-acceptance and to explore the potential detrimental impact that hiding autistic mannerisms can have. I then attend to societal perceptions of autistic women. I consider how autism is and is not portrayed in the media and how that could contribute to the knowledge or ignorance about autism in society. I also explore how participants considered themselves to not fit a stereotype of being autistic due to being a woman and the discrimination that could lead to. Within the final section of this chapter, I consider perceptions of university. Specifically, I explore what participants thought other students and staff think of them, and how university systems frame them. I summarise that participants consider society's generally negative and stereotyped perceptions of autistic women to contribute towards poor self-confidence, which extends into the university context.

Within Chapter 6, I analyse experiences of postgraduate autistic students that are not common within undergraduate university study. I focus on the particularly neglected demographic of the postgraduate autistic student. Although research about autistic students' experiences of university is increasing (as I highlight within *Chapter 2: Literature Review*) it overwhelmingly focuses on undergraduate study and seldom considers experiences only likely to occur as a postgraduate student or researcher. This chapter is divided into two themes: Feeling Like an Outsider at a Conference and Navigating Being a Student and Staff Member. First, I attend to conference experiences, which I explore using two subthemes: The Social Burden of Networking and The Benefits of Presenting. I consider the barriers for networking, a task that participants considered an essential part of conference attendance. Participants highlight not understanding social expectations and sensory difficulties to be the biggest barriers to participation. I also explore the impact of presenting at conferences, which was generally a more positive experience for participants. Therefore, I conclude in the conference section that conferences can provide autistic women with both positive and negative aspects to navigate. Second, I turn my attention to how participants negotiate having dual identities, such as being a student and a staff member. I discuss how as a student, participants felt they were afforded different privileges. Depending on what role they were in at the time they felt that they were expected to conform to different norms. Overall, I surmise that most felt supported to an extent as a student, but as an employee less so. I conclude Chapter 6 by suggesting that postgraduate experiences, and particularly those of postgraduate research students, should be considered more widely. This is because the expectations of these courses appear to provide situations that can be difficult for autistic students to navigate.

Chapter 7 compliments Chapter 5 and Chapter 6 as I move from perceptions both within and outside the university context and the experience of autistic postgraduate students, to consider the environment autistic students experience at university, including academic staff impact, the sensory environment and, autistic awareness and acceptance. The premise of this chapter centres around Scott and Sedgewick's (2021, p. 3) declaration that 'autistic voices regarding experiences of university support remain strikingly absent'. I consider how university staff can help or hinder students who are seeking support from them and whether this requires a student to disclose their autism. I also explore how luck contributes to this, particularly in terms of gaining support and thus succeeding at university. I then turn to the impact of the university environment. Here I focus on the sensory impacts of the environment and how it can be changed. I highlight two ideas for future practice that need to be addressed, the physical environment and people's willingness to recognise and minimise sensory difficulties for autistic people. Finally, I highlight autistic voices and look at what participants wanted to change about universities to support them better. Participants expressed that there needs to be more training for both staff and students to increase both awareness and acceptance of autism. This may help to break harmful stereotypes that people may hold about autism and challenge the usually negative thinking about it. Overall, participants expressed that when others were willing to help, listen and support them through any challenges at university, they felt more positive and had a better experience.

Within Chapter 8 I present a discussion, drawing together the analysed data alongside literature and theoretical perspectives. I split this chapter into two sections. In the first section, I explore how my thesis supports and diverges from current theory. I revisit my analytical themes and in combination with reference to theory answer my research questions. I provide nine contributions to Critical Disability Studies (CDS), Critical Autism Studies (CAS) and Feminist Disability Studies (FDS). In the second section I reflect on how I ensured my study adhered to the values of CDS, CAS, FDS and Critical Theory. I explore other theories I could have based my study on. I critically reflect on the methods I used and explore the impact of Critical Theory on my study. Then, I return to my study in the context of CAS and neurodiversity.

Lastly, in Chapter 9 I conclude my thesis. I reiterate the aims of this study and retrace the research process including why autistic women in higher education need to be involved in further research. I highlight again how the findings of this study add to and extend previous literature on similar topics. Finally, I consider the broader implications for this study of how it may be relevant to helping staff at universities understand autistic students better and ensure they are not discriminating against them. I suggest future research within the area of disability that may further the key findings of this study.

2 Literature Review

2.1 Introduction

Within this chapter I provide an overview of some aspects of disability, by focusing both on theories of disability including autism specifically and the practical implications of being autistic at university. I divide this chapter into three sections: theoretical underpinnings of disability, researching autism, and autism at university. In the first section, I include models of disability and an overview of autism, including autism in women. In the second section, I explore how disability is researched including critical disability studies, critical autism studies and feminist disability studies. I suggest how I can use these frameworks within my research. In the third section, I provide a brief overview of autism at university. Within this section I consider the numbers of autistic people attending university and the stigma that autistic people are subject to at university. This third section is relatively short due to the lack of literature that exists about the autistic experience at university. This chapter will not provide an exhaustive account of the literature, but rather aims to introduce some of the debates that surround this research and to give context of where my study sits within the field.

I am interested in disability because of my own lived experience, both positive and negative. I have a desire to ensure other disabled (and particularly autistic) people are not discriminated against in society. I am keen to champion disability as a difference, not as being less human. Goodley (2013) highlights that disability can still be labelled as a problem, rather than an equal difference in society. Disability experience is not just a negative experience; disability identity can bring a sense of belonging to disabled people and reduce their isolation (Smith & Mueller, 2022). A lot of disabled people are passionate about improving the experience they and others have (Smith & Mueller, 2022). In particular, I am interested in women in academia due to my own lived experience as one and the challenges that a male dominated workplace can have on structures and attitudes within academia.

My study aims to investigate how women with autism experience higher education, looking at what additional barriers they face, what positive experiences they have and reflecting on what can be done to make their experience better. Within this, my study will engage with certain aspects of disability: the politics of it, autism, and the lived experience of being autistic.

2.1.1 How the Literature Review was Undertaken

The literature review I provide is inevitably partial due to both the time constraints of the thesis and the ever-changing progressive nature of research. I believe it is therefore important to give an essence of how the literature review was undertaken and the broad search terms used.

I took a narrative approach to the literature review, due to both the practical constraint of time and the diverse number of disciplines autism research spans. Green, Johnson and Adams (2006) describe a narrative approach to summarise or synthesise information. I considered other types of literature reviews like a systematic review or a scoping review, but discounted them due to their nature. For example, Wong et al. (2013) posit that when a topic has been conceptualised in many ways across many disciplinary boundaries a systematic review may not be most efficient.

In order to ensure the timeliness and relevance of my thesis, I predominantly focused my searches on literature written within the last ten years (between July 2012 and July 2022). Broadly the search terms included: ‘autism’ ‘women’ ‘higher education’ and ‘college’ (the latter was used because it is the American term for university). I limited my search to papers written in English. I used a variety of databases including APA PsycArticles, British Education Index, Higher Education Statistics Agency, and Scopus.

2.2 Theoretical Underpinnings of Disability and Autism

2.2.1 The Concept of Disability

Disability is a particularly complicated concept to define. Shakespeare (2017) argues that despite its complicated construction, it is important to define and understand disability. This is because he argues that anybody (who is not born disabled) can become disabled, and most people are likely to become disabled at some point in their life. Considering most people are likely to be disabled for either all or part of their life, conceptualising disability may remove some of the fear and stigmatisation that traditionally surrounds it. Barnes and Mercer (2010) argue this is particularly important as disability is predominantly viewed as a personal tragedy or as an individual failing, especially in Western cultures due to current societal thinking and accepted medical practices.

Disability has been defined in law and through policy making organisations. UK law defines disability under *The Equality Act* as ‘hav[ing] a physical or mental impairment that has a ‘substantial’ and ‘long-term' effect on your ability to do normal daily activities’ (The Government Legal Department, 2022, p. 1). Although there is accompanying guidance to this definition, it highlights how disability affects a single disabled person rather than indicating how it is caused by society. In particular, there is no distinction here between what an individual can do and the satisfaction or ease of that experience. The World Health Organisation (WHO) and The World Bank published the first world report on disability in 2011, which views disability more holistically. They adopted the ICF model (2001) where disability refers to difficulties in one or more areas of functioning: impairments (problems or alterations in body structure or function), activity limitations (difficulties in doing daily activities) and participation restrictions (exclusion from activities). This way of thinking about disability acknowledges that disability can stem from within a person (such as through a physical impairment) or from society (such as through the attitudes of others).

Defining and explaining disability is not limited to law makers and policy influencers. Many researchers also explain the concept. For example, Shakespeare (2017) suggests that disability is relative to the society and place one lives. For example, a person with a vision impairment that can be rectified with glasses may not consider themselves disabled as they can access society well, but, if they lived in a place where glasses are not readily available, they may be considered disabled and not be able to access aspects of society easily. Siebers (2008, p.4) argues that if a person describes their disability as an identity, it can then be viewed not as a biological construct, but rather an ‘elastic social category’ that is controlled by societal factors and is capable of influencing social change.

The ways in which disability is conceptualised is also important to consider. Disability may be seen as a binary category distinct from ability or as a spectrum, due to it commonly having a multifaceted nature. Garland-Thomson (2017) discusses how being disabled and abled are seen as opposing entities, rather than as categories people can transverse. For disability to be seen as a singular binary category however, a reference point has to exist. In the case of disability, this is commonly ability. More recently in literature however, the term dis/ability has been used to highlight that although disability and ability have been traditionally seen as terms that repel against each other, neither can exist without the other (Goodley et al., 2022). Therefore, reinforcing the idea that disability and ability remain distinct from each other as the tensions between ableism and disablism may not exist if disability was understood as a spectrum.

Another way of viewing disability is as a spectrum or continuum, that is ever changing depending on the situation or environment. Gjosaeter et al. (2019) emphasise that disability can change with how an environment interacts with a person's body, therefore meaning the same person could feel differently about how their body works in different situations. This suggests that disability is fluid and influenced by many different factors rather than just impairment.

It is arguable that blurring the lines between disability and ability could lead to the removal of disability as a label and could have both positive and negative implications for those currently classed as disabled. Timpe (2022) argues that disability is defined in different ways depending upon a variety of factors such as research discipline or ontological assumptions and therefore a unified definition and explanation of disability does not exist. This suggests that a person may therefore be disabled under one definition, but not under another, emphasising the transient and fragile nature of disability categorisation. However, it could also position disability as a spectrum, where people are disabled and non-disabled depending on the situation rather than being placed in a singular category they cannot move out of.

Although there may be a common understanding of what disability is, it is a widely debated area which is not always easy to understand. Overall, I understand and conceptualise disability as involving both innate and cultural aspects. Therefore, a person's disability may be more pronounced in certain situations. A way of understanding disability is to use models, which further aid the conceptualisation of disability.

2.2.2 Models of Disability

The modelling of disability can be a useful tool in the explanation and understanding of disability. Gardner (1985) explains that a model is the application of a more well understood system to a less well understood and less developed system. Thus, with the idea of making the less understood system more understandable and easier to conceptualise, in order to aid progression in that field. Llewellyn and Hogan (2000) suggest models, also known as heuristic devices, may assist understanding of situations that are beyond a person's own lived experience and influence. However, Brodwin (2013, p.59-60) argues that sometimes these models 'race ahead of what is actually known, reclassify knowledge through educated guesses and grand syntheses'. Therefore, although models of disability can be useful, they should be treated with some caution.

Ensuring disability models are as true to reality as possible or authentic to the experiences of disabled people is important as they tend to become the basis of legislation and therefore can change how inclusive society is (Berghs et al., 2019). Riddle (2020) argues a model should accurately depict what it is like to live with disability and stipulates that a model of disability should reflect the experience of disabled people, without embellishment or inclusion of desirable concepts. If models of disability do this, they can be incredibly important for societal change and improving the lives of disabled people through new legislation in a world which is not currently fully inclusive.

Through recent decades models have been developed to understand thinking towards disability at particular times. Many models of disability exist, but some are more prominent than others. Disability discourse tends to be dichotomised into two dominant models of disability: the social and medical models. Manago et al. (2017) posit that disability activists and researchers have trouble with why disability is split into these two seemingly mutually exclusive categories. However, Beaudry (2016) argues this dichotomy within understanding can be helpful in providing a simpler explanation of disability.

The medical model suggests that all disability comes from a medical impairment and that human beings can be treated and altered through medical intervention, whereas society is unchangeable (Llewellyn & Hogan, 2000). The emphasis of this model is on humans adapting to the world around them. However, if a person's medical impairment cannot be altered by medical treatment or rehabilitation to adapt to a fixed environment, then it is accepted they will experience reduced participation in society compared to non-medically impaired people (Bunbury, 2019). With this view, society is not to blame for this exclusion, rather that the problems lie within the individual.

Some researchers highlight that the medical model can be associated with the oppression of disabled people as it can highlight how disability is incompatible with society (for example, Chapman & Carel, 2022; Gabel & Peters, 2004). Smart (2004) notes that the medical model is often perceived to indicate experts (such as doctors) to be in control, with the disabled person being the passive entity they are working on. Despite some ongoing criticism of the medical model, it can be useful to use the understanding from this model in certain situations. For example, the medical model focuses on individual 'improvement' and can align with stigma deflections (Manago et al., 2017). This is where the stigmatised person is expected to change something about themselves in order to fit into society, in essence, it is not society's fault that the person is excluded. If stigma associated with a disability can be deflected from society, it can help those around the disabled person to feel more accepting.

This model has come under much criticism by disabled activists and their allies, but is still used today as the predominant model in many fields, including medicine (Reynolds, 2017). The medical model has received critique because it essentially says that exclusion of disabled people does not need to be addressed by society. For example, it can reinforce a disabled person's sick role in society and promote the need for others to pity them (Bunbury, 2019). This is particularly the case through the dichotomy of disabled vs non-disabled people. A person is therefore disabled or non-disabled, as there can be no continuum of ability within the medical model.

In addition, the medical model emphasises diagnostic labels (Manago et al., 2017), made on the basis of scientifically validated techniques rather than focusing on the practical difficulties a disabled person may have in society (regardless of their diagnostic label). Some disabilities do not carry diagnostic labels, for example those who fall into ‘syndromes without a name’ (SWAN) (https://www.undiagnosed.org.uk). With a model that focuses on naming an impairment, those who have difficulties within society can be erased, because their difficulties do not fall into a currently available diagnostic category. This can therefore be dangerous to disabled people as they are only seen to fall into particular disability labels, rather than being supported based on their needs.

Research expanded the medical model to the individual model of disability in the mid-1990s to shift thinking about disability from the medical to the individual. Although similar to the medical model (that disability is solely based within the individual and their impairment (Goodley, 1997)) the individual model also raises questions of honouring and recognising impairment. In contrast to the medical model, an environment can change to accommodate impairment, but it is the responsibility of the disabled person to make it happen (Oliver, 1995). Overall, both the medical model and the individual model of disability focus on an individual, and place no responsibility on society to accommodate disability. Therefore, both models medicalise and individualise disability.

The social model of disability was created by Oliver who was a physically disabled man, who along with other disabled activists did not want disability seen as something that was their fault (Oliver, 1990). The social model views disability and impairment as separate entities (Oliver, 1990). It deems an impairment to be a functional limitation, whereas disablement is socially produced in society (Garbutt & Saltiel, 2020). Distinguishing between impairment and disability is helpful, as it acknowledges that a person has something that is medically limiting but that the actual limitations come from society (Oliver, 1990). Oliver (1990) argued that disability should be viewed as ‘social oppression’ and therefore can be solved through social and political means rather than solely by the impaired individual. His ideas centred on the politicism of British trade unionism. Some researchers highlight criticisms of the social model including that it gives a romanticised view of disability and the way in which society responds to it (Lawson & Beckett, 2021). In relation to autistic people, Dwyer (2022) advocates that embracing the social model (that disability consists of both impairment and environment) may reduce the dominant societal perception of autism, that all autistic traits that deviate from the norm should be reduced in an individual. Within the social and medical model dichotomy debate the social model is preferred by disabled advocates. For example it has been adopted by major disability charities, such as Scope. This adoption will hopefully raise awareness and begin to challenge the medical model which remains most prominent in society.

Some disabled people tend to prefer the majority of concepts put forward in the social model as it can be used to promote change, particularly in situations where disability models seem to solely revolve around the medical and social models (Haegele & Hodge, 2016). It is impossible to homogenise disabled people as a whole however. Although sometimes viewed as a dichotomy of disability models in popular discourse, it is important to appreciate that these two models do not encompass all disability viewpoints. I turn my attention to some of the lesser-known models to show the variety of thought towards modelling disability, rather than to document an exhaustive list. Other models of disability have helped to transform societies and further political discourse, particularly due to the usually nuanced approach they highlight of disability that is sometimes glossed over by the social and medical models. I consider the cultural, minority, limits and relational models of disability.

The cultural model rejects a distinction between disability and impairment as it describes how both biology and culture influence each other (Goodley, 2016; Goodley, 2017). Thus, this model considers how impairment, disability and normality are generated by research, mass media, and everyday discourses (Waldschmidt, 2017). The cultural model therefore intends for disabled bodies to be moved away from being seen as a biologically bad or a broken entity, to considering how disability is part of a socio-culture. It is suggested that disability is the product of culture and is engineered and represented through popular culture. Snyder and Mitchell (2006) term this ‘narrative prosthesis’ as many storylines rely on having a disabled character depicted against a fictional norm. Shakespeare (1994) argues disabled people are ‘objectified’ by cultural representations. Therefore, if a society’s culture is accepting and supportive of people’s differences then disability will not exist in such a binary way. The use of the word dis/ability has come out of the cultural model, to emphasise that it is not just disability that should be problematised, but also how normality and disability interact (Goodley, 2016).

Disability needs to be considered as a cultural artefact, rather than as an unchanging entity as it can be understood differently in different places. Snyder and Mitchell (2006) argue that a culture centred around disability can be created by non-disabled people, for example by placing disabled people in the same physical or metaphorical place meaning that a ‘manufactured location’ exists. This can produce artificial cultures of disability, when disabled people are actually segregated from ‘real’ culture and this should be considered when thinking about how disability interacts with culture more organically.

In contrast to the medical and social models of disability that only focus on one aspect of disability, the cultural model focuses on disability more holistically. It centres on thinking about disability as a mixture of social and medical factors (Retief & Letšosa, 2018). This model does not seek to define disability but looks at how non-disabled and disabled people interact together within a specific culture (Retief & Letšosa, 2018). It is interesting to note that although cultural disability studies is an established research field, it still does not have a unique take on disability that cannot be explained by any other model, although disabled culture has attracted a large research focus (Waldschmidt, 2017). This therefore highlights a disparity between the focus that researchers put on it, and the actual impact it may have.

The minority (also known as the socio-political) model of disability was founded in North America as a political stance to challenge disability policy and society’s unfavourable opinions of disabled people (Hahn, 1996). It is based on how society’s attitudes to disability formed by social construction are the reason that disabled people are disadvantaged in society rather than from the medical impact of any disability (Smart & Smart, 2006). Disabled activists wanted discrimination to be eradicated and to receive the same equality and civil rights as non-disabled people in US law, so disability is viewed as a public rather than personal concern (Smart & Smart, 2006). This model suggests that disability should be viewed as a protective characteristic, much like race or gender and therefore it should not be seen as a cause for discrimination.

It can be beneficial to understand disability through the lens of a minority model because it adds a different political element to disability. The social model stems from British trade unionism, whereas the minority model takes elements from the Black and queer civil rights movement. The minority model gives disabled people status as a minority community, which has been noted to be controversial. This is because it is one of the only minorities that can be transient and not require a person to be born into it (Bogart, Rosa & Slepian, 2019). The minority model connects with the civil rights movement, as disabled activists believed that they should have the disparities they shared with other minorities of people also resolved in law.

In relation to autism, Botha and Frost (2020) highlight that although the medical model asserts autism as a disorder, autism may be a central feature of people's identity. Kapp et al. (2013) state that the neurodiversity movement goes against the view of the medical model that autism is a disorder and requires treatment, and claims a minority status. This enables autistic people to see autism as part of their identity that is as valuable (or mundane) as skin colour, eye colour or sexuality. Dunn and Andrews (2015) advocate that considering autism as part of a person's identity enables autistic people to view their autism how they want to and therefore in a more emancipatory manner than the medical model, or even the social model, imply. Botha and Frost (2020) do suggest that positioning autism as part of a person's identity may induce stress as it requires constant advocacy due to the prevalence of the medical model within society.

The limits model of disability considers disability to be understood with reference to embodiment and limits (Creamer, 2009). Creamer (2009) argues that all human beings experience varying levels of limitations in their everyday lives (for example, no human can fly unaided at present), and therefore limits are an aspect of being human and should not be seen as a negative thing. In addition, Creamer (2009) seeks to dispel the binary between non-disabled and disabled people, but rather focus on how people are linked by their ‘web of experience’ (Creamer, 2009, p. 31). This model therefore potentially sees disability as part of the spectrum of being human, rather than as a separate category of human.

Politically, there may be dangers with the limits model of disability. In questioning the distinction between normality and disability, highlighting that we are all limited and highlighting that our lives progress towards impairment (Creamer, 2012) may minimise the difficulties within society that disabled people have. This could therefore lead to a rhetoric that everybody in society is disabled in some way. However, acknowledgement that anybody could become disabled in their future may be helpful in considering the actual meaning of normality for society. The limits model may indicate with regard to autism that the diagnostic category of autism is removed or transient. This could be impactful for autistic people who consider autism to be part of their identity.

The relational model is Nordic in origin and has three basic assumptions: disability is a person and environment mismatch, disability is contextual, and disability is relative (Tossebro, 2004). The idea of the model is to promote community cohesion between disabled and non-disabled people through the process of ‘normalisation’. Normalisation is assisting disabled people in living as similar a life to their non-disabled peers as possible. This may be through empowering disabled people and disempowering non-disabled people so that there is equal power shared between the groups. It strives to create an integrated generation that will reduce the divide between disabled and non-disabled people. The World Report on Disability (World Bank & WHO, 2011) used this approach. It is helpful to consider disability in this way so that equal power is gained by all in society regardless of disability. The relational model can relate to autism as it highlights the environment and disability mismatch. Goodley and Runswick-Cole (2012) analyse a story of an autistic child called Rosie. They emphasise that at home, where her parents accept her autism she is not disabled as the environment is suited to her autism. Rosie only becomes disabled when the gap between the environment and her impairment becomes too wide and can no longer interact. The relational model suggests change in both the environment and in the autistic person, highlighting a more balanced view than the social model being only concerned with the environment.

All these models have a different stance on disability and all answer what disability is slightly differently (Berkowitz, 1987). I present these models to highlight the different ways that disability can be conceptualised, rather than to identify any distinct preference. Models of disability can also produce reductionist views of disability, as they can reduce it to a set of words rather than actual experiences. Disability models also need to be considered within the cultural contexts they were produced, as one model may not be able to account for different cultures. The majority of disability modelling is western-centric and therefore exclusionary to the Global South (Grech, 2011). The relational model reflects strong welfare systems of support that tend to exist in Nordic countries. Whereas the minority model is based on the overlaps of the Black civil rights movements in the USA. These two cultural examples suggest that disability and the models surrounding it can never be removed from the culture they are created in. Garland Thomson (2002) wrote a matrix of disability which suggests that it is a web of factors that interplay with each other. This perhaps indicates that the definition of disability can change depending on what factors are interrelated and therefore it is difficult to have one overall definition of disability, or indeed one model of disability. Goldiner (2022) argues that current models of disability need to be viewed in clusters rather than as discrete models. For example, in order for a disabled person to receive support they may need to emphasise how society does not meet their needs, whereas if the same person was applying for employment they may need to present a different version of their disability to suggest the company could meet their needs.

2.2.3 Current Debates Within Autism

I turn my focus to a specific disability label, which I base my thesis on. Autism is a particularly controversial diagnosis within the world of disability and in addition to the construct of disability being theorised (as presented above), autism consistently attracts debate.

I am specifically focusing on autism (rather than disability as a whole, or another label) due to my own experiences as an autistic person. I am particularly interested in exploring autistic women without an accompanying learning disability. In order to explore a specific aspect of autism, I present an overview of the condition, to give context into the controversy surrounding autism and why it has attracted so much research interest.

It is important to consider autism as a disability compared to a perceived societal norm, because autism is not the norm. Although some people do not see autism as a disability, rather a difference, the most current dominant discourse is to view autism through its deficits and therefore how it disables people within society. Autism as a condition and an area of research is huge and ever expanding. The exact definition, symptomatology and aetiology of autism are widely debated. This is particularly due to the lack of any conclusive diagnostic medical evidence. I therefore provide only a partial overview by introducing some key themes that are relevant to my research. My aim is to present some debate surrounding autism, but not provide exhaustive accounts. I discuss the dominant models of thinking about autism (by attending to western thinking, economic value, blame culture, media representation and autistic women) and then I consider the neurodiversity perspective as an alternative view of autism.

Despite its relatively short history of less than 100 years, autism has incorporated some very dominant mindsets. These include medicalised thinking of the condition and its impact on diagnosis, autism being a western condition and autism being prevalent in men/boys. This can lead to marginalisation of people who attract an autism diagnosis or portray traits but do not fit into the stereotyped thinking around autism. In addition, it can lead to the marginalisation of researchers who seek to challenge current dominant thinking surrounding autism. However, in order to situate autism in its current research context it is necessary to explore some of these dominant discourses.

2.2.3.1 Diagnosis

The ‘diagnosis’ of autism and its validity is a regularly contested issue (Fletcher-Watson & Happe, 2019). Dominant thinking argues that a person is only autistic once they are clinically diagnosed - a diagnosis that is based on deficits. Autism is commonly diagnosed through observation of behaviours and reports of others that appear to be deficient or different to a perceived norm (American Psychological Association [APA], 2013; World Health Organisation [WHO], 2019). Medically, a person is diagnosed with autism if they are deemed to meet the criteria of either the DSM-V (APA, 2013) or the ICD-11 (WHO, 2019) diagnostic manuals. DSM-V was created in America, whereas the ICD-11 was created in Europe to classify ‘disorders’. These diagnostic criteria are widely accepted to classify the medical explanations of autism. Both these diagnostic manuals describe autism similarly, with minimal differences. To be diagnosed with autism, DSM-V (APA, 2013) requires a person to display deficits in social communication and interaction, and social imagination that have been present since early childhood and ‘limit and impair everyday functioning’ (APA, 2013). Deficits in social communication and interaction could be demonstrated by not communicating ‘appropriately’ through body language. Difficulties understanding others’ feelings and behaviours could suggest impaired social imagination based upon a medical view of autism. The ICD-11 (WHO, 2019) categorises autism as persistent deficits in social interaction and communication alongside inflexible patterns of behaviour (similar to DSM-V, APA 2013) that develop in early childhood and cause impairment in individual functioning [sic]. In contrast to the DSM-V (APA, 2013), the ICD-11 (WHO, 2019) acknowledges that autistic symptoms may not manifest until later in life when ‘social demands exceed limited capacities’. Despite the ICD-11 (WHO, 2019) suggesting that autism may become apparent during development, both the medically based ICD-11 (WHO, 2019) and DSM-V (APA, 2013) stipulate autism to be composed of deficits compared to a perceived developmental norm. This criteria for the diagnosis of autism remains the most common and widely acknowledged. To receive a formal diagnosis of autism in the United Kingdom, a person has to meet the diagnostic criteria from one of these manuals. Although neither is documented as more reliable, the DSM-V manual (APA, 2013) tends to be followed more widely in the UK.

The medical perspective of autism, which is based on a deficit model, can potentially ensure autism is only seen as a negative condition, and in particular presents a person that has been newly diagnosed with reasons of how they differ and are less than the norm of society. It may give information to autistic people about how they are different in order to gain support, however, it also relies on a person fitting into a particular mould to fulfil the diagnostic criteria.

2.2.3.2 A Western Condition

Another such dominant way of thinking is that autism is solely a western condition. Although it is increasing in prevalence worldwide (Chiarotti & Venerosi, 2020), it is frequently seen to be a condition that predominantly affects western society with high technological development, and in particular the UK and USA (Bakare & Munir, 2011). Grinker (2018) argues that disparities in economic development between countries is not the sole reason for diagnostic disparity, and that a multitude of reasons including stereotype and lack of awareness for why a supposedly scientifically validated condition is seldom recognised. Some continents, for example Africa, output less research as to the prevalence of autism (Bakare & Munir, 2011), whereas in Italy autism is seen as a ‘way of being’. Therefore, people with exactly the same symptoms may attract different labels (or no label) depending on the country and cultural context in which they live. Considering disparity in the awareness and understanding of autism, despite other factors across the world, potentially highlights how a condition without confirmed genetic aetiology is not accepted worldwide.

2.2.3.3 Economic value of autism

Autism can either be described as costing society large amounts of money (Rogge & Janssen, 2019), or as creating profit for businesses invested in autism (Broderick, 2022). Grinker (2018, p. 244) explains this mismatch of economics in autism by saying ‘Paradoxically, autism is at once a threat to economic growth and (at least for parts of American society) an engine of economic growth.’ However, Broderick (2022) argues that autism costing the economy a lot of money justifies the autism industry creating profit making initiatives and therefore the paradox of the autism economy is part of neoliberalism.

Autistic people and their families incur significant costs to access services and equipment necessary to help to make the world more accessible, including education and medical equipment (Rogge & Janssen, 2019). Blaxill et al. (2022) speculate whether reducing the amount of people diagnosed with autism would reduce the cost to society.

The rising costs autistic people and their families entail may be fuelled by profit making businesses. McGuire (2016) argues that autism has become a brand, with various merchandise (for example, t-shirts, shoes and balloons) being purchasable covered in autism logos and slogans. She notes that this merchandise fuels a cultural love of autism. If autism was disproven to exist, this profit-making exercise would cease. Broderick (2022) highlights that as autism is frequently seen as the enemy it is also big business, and therefore also economically benefits any business that justifies that they can help autistic people reduce their autistic characteristics. They suggest private schools catering for autistic pupils, providers of autism training and certification, and health insurance are amongst some of the industries to benefit from the existence of autism. Therefore, it is questionable whether companies actually want to eradicate autism, or are promoting this message of autism eradication to sell more products or provide more autism related services.

2.2.3.4 Blame culture on autism

Society is becoming more aware and accepting of autism, but there still appears to be a strong need for some people to seek a cause or cure. Historically, when a child is diagnosed with autism, parents (especially mothers) are blamed for many reasons including ‘poor’ parenting and vaccinations (Zeavin, 2021).

Kanner (1943) proposed that autism stemmed from a mother not giving a child enough attention and love. The aloneness the child experienced made them become autistic. Kanner (1943) described these mothers as ‘refrigerator mothers’ as they acted cold and failed to bond with their child. Although many have since rejected this theory, the ‘refrigerator mother’ theory still appears to be prominent in some research. For example, Smith et al. (2008) explored the impact of a mother’s warmth and praise on ‘reducing’ a child’s autistic symptoms through analysing conversations of the mother about their child. They concluded mothers who spoke more positively about their autistic child had a better relationship with their child and thus the child presented reduced autistic characteristics. This suggests that the mother in particular is still blamed by some for either the diagnosis or prognosis of an autistic child. Zeavin (2021) notes that in a masculine dominated society that all mothers are still subject in some form to criticism of their parenting, regardless of the amount of attention they give to their children. This is sexist and misogynistic to women, who like Zeavin (2021) argue are subjected to blame in parenthood more frequently than men. Parenting may however be scrutinised even more for parents of autistic children.

Another source of parental blame surrounds vaccines. Wakefield et al. (1998, now redacted) published a study suggesting the measles, mumps and rubella (MMR) vaccine usually administered to young children caused autism. The number of parents allowing their children to be vaccinated with MMR dropped considerably after publication. Although many studies were published in following years (for example, Plotkin et al., 2009) highlighting flaws in Wakefield et al.’s (1998) study such as not collecting data in a rigorous way to try and curb this drop in vaccine uptake, the study was not redacted until 2005 due to fraudulent and false links between the vaccine and autism (Davidson, 2017). Despite its redaction, many people still believe the link between vaccines and autism, and therefore do not vaccinate their children or advocate for others not to be vaccinated against harmful diseases under the guise that catching one of these would be better than ‘catching’ autism (Ruiz & Bell, 2014). This resentment from some parents that ‘catching’ autism is worse than being infected with a serious disease demonstrates how autism is situated as an enemy, and how crucial influential research can be. Therefore, parents who vaccinate their child, who then is diagnosed as autistic may be ostracised by others for supposedly inflicting autism on their child.

The examples of 'poor' parenting and controversy surrounding vaccinations I have presented highlight how a blame culture of autism exists, reiterating the negativity surrounding autism. This negativity can lead to parents debating whether to seek a diagnosis for their child, either so that the child can retain their label of 'normal' or to 'normalise' their behaviour to the outside world (Russell and Norwich, 2012). Post diagnosis, this blame culture can lead to autistic people and their families seeking dangerous and traumatic therapies and potential cures. Milton (2014a, p. 6) notes that following an autism diagnosis, supporters commonly ask professionals 'What can we do to help?', which suggests autism is assumed to require intervention or treatment. In order to improve perceptions of autistic people and reduce the blame on their families, especially parents, society looking for something to blame autism on needs to stop and rather be understood as that which can just occur.

2.2.3.5 Media Representation of Autism

Most notably it has been suggested that autism and its metaphors define normalcy. Murray (2008, p.13) argues that 'fascination with the subject [autism] must always be in the terms of the majority audience'. By not having autism, and being able to use metaphors to refer to other people derogatorily, is seen as a normal part of society. Rather than a potential continuation of 'normal', autism is seen as a distinct way of *not* being normal and Murray (2008) argues that autism is seen as different.

Metaphors and representations of autism extend into popular culture. Autistic television and book characters make autistic people either seen as a burden to a neuro-typical caregiver or autism is romanticised. For example, Sheldon in *The Big Bang Theory* (Lorre & Prady, 2007) is depicted to be autistic (despite no actual reference being made). Although he is not the title character in the television programme, he is the character with the greatest popularity and his lived experiences of difference are romanticised for a mainstream audience.

2.2.3.6 Autistic Women

Autism is considered a particularly controversial diagnosis (as discussed above), regardless of how it interacts with other intersections of people's identity. In this section, I specifically discuss how autism is biased towards the cis-gender (a term for those identifying as the gender they were assigned at birth) male and neglects those without this gender, particularly women. In 2017, Loomes et al. suggested the male: female ratio of diagnosis of autism was 3:1, although the gender diagnosis ratio had previously been suggested to be as low as 1.8:1 (Mattila et al., 2011). This latter ratio suggests that autism occurs more frequently in girls and women than previously thought and therefore the impact of autism on girls and women needs to have the same level of research as that which has traditionally focused on men.

Early thinking by Asperger suggested autism was 'a variant of male intelligence' (Asperger, 1944, p. 39); therefore implying that girls and women could not be autistic. Wing and Gould (1979) are attributed to being the first researchers that specifically highlight that autism also occurs in women. Although they published their research over 40 years ago, autistic women can still be subject to both discrimination and oppression as a disabled woman and as a woman with a label of autism. This may be because the experiences of autistic women are repeatedly under-represented within research (for example, Hoyt & Falconi, 2015; Milner et al., 2019; Seers & Hogg, 2021). Hoyt and Falconi (2015) argue that there needs to be an increase in research into the autistic experiences of women, because being biologically female attracts particular health and mortality risks. Autistic adults have been regularly documented in research to have poor outcomes as adults, in comparison to their neurotypical peers (for example, Henninger and Taylor, 2013). Webster and Garvis (2017) argue that successful autistic women benefit from facing challenges and problem solving. In addition, not viewing having an autism diagnosis as something negative assisted the success of their participants. However, this may be difficult considering that autistic women are viewed negatively in society. Milner et al. (2019) argue that in order to reduce common societal gender stereotypes surrounding autism, autistic women's experiences need exposing. Seers and Hogg (2021) highlight that girls and women tend to be encouraged to partake in traditionally feminine roles which may mean that autistic girls and women try harder than autistic boys to fit into this societal discourse, leading to longer time spent undiagnosed.

When relating gender and autism, the potentially most damaging theory to autistic women is the Extreme Male Brain (EMB) theory (Baron-Cohen, 2002), which describes autism to be an extension of the male brain. It assumes that a male brain is better at synthesising than empathising and a female brain displays the opposite: that autism can be deemed to display a cognitive profile of extreme synthesising and very poor empathising – thus being an extreme version of the male profile. Baron-Cohen (2002) further hypothesised that these innate differences are due to different levels of exposure to testosterone in utero. However, these further claims lack concrete biological evidence (Grossi & Fine, 2012; Kung et al., 2016; Ferri et al., 2018). In addition, there is no substantial evidence for brains being biologically constituted for what Baron-Cohen considers 'sex-specific' tasks (Krahn & Fenton 2012). Despite the potential debate over the biological soundness of the EMB theory, the links between autism and innate maleness have been evidenced through autistic female children demonstrating masculinisation by showing a preference for stereotypically masculine toys that do not require imaginative play (Knickmeyer et al., 2008). This theory has been argued to remove womaness from autistic women as it suggests that one cannot have a 'female brain' and have autism (Ridley, 2019).

Despite scientific criticism, the EMB is still a popular theory cementing historic assumptions relating to the binary of gender and differences between cognition and gender. In a society where the dichotomy between maleness and femaleness is dominant and there is less acceptance of a spectrum of genders this can be particularly damaging. Krahn and Fenton (2012) highlight how attributing human characteristics or traits to a specific gender was deemed problematic by feminist theories in the 1980s, but it is still prevalent in society today. Theories such as the EMB reinforce these assumptions of gender dichotomy which may be damaging both for and within the autistic community.

Within societal autism discourse, autistic women are seldom featured and therefore marginalised. Murray (2008) argues that autistic women are not portrayed as often in popular media as society finds it harder to conceptualise autism in women due to the stereotypes that society associates with autism that do not always fit with the autism profile in women. This erasure of autistic women in societal discourse could contribute to gendered negative portrayals against autistic women (Rohmer & Louvet, 2012). This lack of representation of autistic women ensures there are few positive role models in popular media and could fuel further negative stereotypes towards autistic women.

In recent years, some autistic women have sought to challenge this erasure in public discourse by writing about their own stories, both with and without academic slants. Cook and Garnett (2018) begin their edited collection of stories of their and other autistic women's experiences by highlighting how the reader can immerse themselves in their book. They go on to say that the stories presented offer support for other autistic women 24-hours a day. The emphasis that Cook and Garnett (2018) place on their book being supportive, immersive and insightful is notable. This could be understood to highlight the dearth of material available about autistic women's lives and to spotlight that their book is one of the rare collections of stories by autistic women. In addition, the inclusion of autistic protagonists is seldom but slowly evolving in popular children's fiction, such as in Smale's Geek Girl series (first published in 2013). Smale is open about her neurodivergent identity. The inclusion of autistic women in both the sharing of stories and fiction falls on autistic women themselves, which suggests that although there are advocates seeking to reduce the erasure of autistic women in society, the acceptance of this from non-autistic people may be minimal. Townson and Povey (2019) support this suggestion as they recognise that even though there is an increase in the media to include autistic women (including celebrities disclosing their autistic identities) they argue that autistic women are still routinely discriminated against in society. They indicate that this may be due to a time lag between media presence and societal knowledge and so in the future could be beneficial to autistic girls and women, but, currently stigma and erasure are prominent in society.

I have given a partial overview of how autistic women and girls are regularly erased from both autism research discourse and from autism stereotypes in popular culture. I have considered the EMB theory as an example of how theories of autism can negate intersectionality, and are particularly damaging to women. The lack of inclusion of autistic women in autism discourse highlights why this research is so necessary so that more aspects of autistic women’s experiences are brought to the forefront of autism research.

2.2.3.7 Neurodiversity Perspective

In contrast to dominant models of thinking surrounding autism and in particular the view that autism is perceived as a deficit compared to the society norm, other schools of thought describe autism differently, or even suggest that it should not exist at all. Thinking around autism is continually changing, particularly spearheaded by autistic people and their allies who reject the notion that autism should be classified predominantly by deficits. I introduce the neurodiversity paradigm, which considers autism as a difference rather than a deficit.

The most notable challenge towards dominant models and thinking of autism is the neurodiversity paradigm and the subsequent activism of the neurodiversity movement created by its supporters. The model classifies autism and other neurodiverse conditions as a ‘variation in functioning’ as opposed to a negative entity that can only be defined by deficits or needs to be cured (den Houting, 2019). Singer (1999) (who is autistic) is widely credited with first using the term neurodiversity, as she wanted the neurodiverse population to be viewed as a political grouping with comparable rights to other identity groups such as those based on class or race. Since Singer’s (1999) seminal use of the word neurodiversity, its finer points have changed, however, the basic elements and principles remain the same. Kapp et al. (2013) researched people’s viewpoints towards the differences between neurodiversity and the medical model and suggested that there is overlap between the neurodiversity model and the medical model in how people view autism and their own identity if they are an autistic person.

Den Houting (2019) and Ne'eman and Bascom (2020) explicitly highlight that the neurodiversity movement does not seek to remove the idea that autism is a disability. Ne’eman and Pellicano (2022) do however suggest that uncertainty over what the neurodiversity movement stands for and what it encompasses has prompted some negativity and hostility towards it. Neurodiversity can simply describe a person, for example

Walker (2014) terms it a biological fact, or it can be thought of as a paradigm for change and activism. Botha (2021) highlights that the neurodiversity movement wants fundamental humanness of autistic people to be recognised, including their perspectives being listened to. This uncertainty in common discourse surrounding what neurodiversity is, the disability labels it encompasses and the political stance shrouds neurodiversity in mystery, and provides controversy, much in a similar sense to that surrounding autism that I have attended to earlier in this chapter.

Chapman (2020) argues neurodiversity is epistemologically useful, as it can aid understanding and imagining of the world differently to how it is both in positive and negative ways. If autism is considered as a malleable construct through a neurodiversity perspective, then a more malleable society can be imagined and ultimately constructed. Chapman (2020) also argues that identifying as being in a minority group, in this case the neurodiversity movement, improves solidarity and empathy towards others in different minority groups and broadens vocabulary that is used about minority groups. Although the word neurodiversity was predominantly originally claimed primarily by autistic people, it encompasses any neurology condition (for example, dyslexia and dyspraxia) and thus removes some of the arbitrary diagnosis barriers people with similar symptoms and experiences have when they can identify with a group outside a particular specific diagnosis.

There are some challenges to the neurodiversity approach, which do not simply argue that a more dominant model is better, but rather suggest ways in how such a model and associated activism could hinder rather than help autistic people and others affected by autism. For example, splitting neurodiversity and neurotypicality (those who do not identify as having neurodiversity) can produce an ‘us and them’ culture (Runswick-Cole, 2014). Although Singer (1999) sought for the neurodiversity paradigm to encompass intersectionality, more recent research highlights how intersectionality is notably absent from neurodiversity research (Botha & Gillespie-Lynch, 2022; Chapman, 2021; Dekker, 2020). Unless intersectionality is considered more prominently within neurodiversity-based research, the ‘us and them’ culture that Runswick-Cole (2014) suggests will persist.

In addition, the neurodiversity perspective is considered by some researchers to provide a romanticised view of autism. Hughes (2021) argues that viewing autism as an identity which society needs to adapt to, can ignore some aspects of the condition which may be significantly disabling unless society is radically overhauled - which is unlikely to happen fast. Hughes (2021, p. 60) goes on to say that the general wants of the neurodiversity movement such as equal rights, education and employment opportunities, and removal of stigma are useful, but with the neurodiversity paradigm autism should also be acknowledged as having negative and problematic aspects.

2.2.4 Current Debates Within Autism Summary

I have presented an overview of some of the dominant thinking surrounding autism through examples of diagnosis, cultural existence and media portrayal, and some of the lesser dominant thinking around the constitution of autism. In essence although dominant thinking exists, there are regular challenges to this and situations in which it is helpful to view autism in different ways.

What autism exactly is and whether it even exists in its own right continues to be debated by researchers. For example, Douglas et al. (2019) admit that within their latest research project, the authors did not agree on a definition of autism. They acknowledge that the definition of autism changes with society and with the times and that it will be ever changing and moving as the desired societal norm changes. In addition, considering the slight variation in viewpoints of both diagnostic manuals and the differing perspectives surrounding whether autism consists of deficits or is a different way of being, no singular understanding of autism exists.

An entire thesis could be based upon arguing the reality of autism considering the wide variety of debate surrounding it. I have decided to start my thesis from the point that if a person says they are autistic then it is real. I do not want to deconstruct autism in my thesis, but rather work from the basis that a group of people with some similar characteristics exist and need further research attention. My own positionality is that the label of autism could be removed from a person, but how they act is real and unchangeable. I believe what people experience is ‘real’, but that it can be displayed differently depending on the environment.

Overall, all ways of thinking - whether dominant or non-dominant thinking - have positives and negatives to them, have uses in different time periods or situations, and potentially are more similar than different from each other. Thus, although theoretical understanding of models is necessary in research, the priority of this research is to start from women's experiences first, regardless of whether they 'fit' particular models and/or understandings of autism or not.

2.3 Researching Disability

In the previous sections I have considered how disability and then autism are viewed theoretically through models of thinking. I now review literature around how disability and autism have been researched and the potential impact of those research tracts on my own thesis. First, I explore the evolution of Critical Disability Studies, then I turn my attention to Critical Autism Studies and finally to feminist disability studies. The element of criticality is central to both Critical Disability Studies and Critical Autism Studies. Delgado and Stefancic (2013) highlight that being critical, exploring the merits and faults of situations, is easier in hindsight and with different and evolving knowledge. I believe critical to mean reflecting on the past and looking towards how it can help shape the future. Investigating with hindsight using a critical lens fuelled by a desire to learn from previous events is central to my work in order to create change.

2.3.1 Critical Disability Studies

Disability studies have been described as going through waves over time (Woods & Waldock, 2020). Within the first wave of disability studies the social model was developed (Barnes, 2008). Blum (2020) highlights the disability studies field emerged from disability activism contesting that disabled people should not be seen as abnormal or ‘deformed’. This activism inspired the creation of the social model, to highlight that it was hostile cultural norms causing disability oppression rather than a biological impairment. The social model enabled activists to highlight access issues of the built environment, as well as prompting studies of cultural representation and more disability theory (Blum, 2020).

The second wave heavily focused on critiquing the social model of disability as well as shifting some focus of research onto the lived experiences of disabled people (Woods & Waldock, 2020). Fraser (2018) suggests the social model of disability predominantly focuses on physical disability thus negating the experience of people with other forms of impairment or difference.

The third wave, which some disability research now falls into, has been termed 'Critical Disability Studies' (CDS) which brings critical theory into previous disability studies. Goodley (2016, p. 191) explains Critical Disability scholars to be 'people who advocate building upon the foundational perspectives of disability studies whilst integrating new and transformative agendas associated with postcolonial, queer and feminist theories'. Meekosha and Shuttleworth (2009, p. 50) argue that CDS is 'a move away from the preoccupation with binary understandings—social model v. medical model, British v American disability studies, disability v impairment'. Moving away from binary perspectives of disability may help to influence inclusion of disabled people in society. CDS builds on the foundational perspectives of disability studies but is influenced by recent knowledge about diversification (for example, feminist, queer and postcolonial understandings), with the aim of bringing social change (Meekosha & Shuttleworth, 2009). The challenges of a disabled individual are not ignored however but CDS acknowledges how disabled people can be resilient and challenge traditionally negative views of disability (Castrodale, 2017).

My work fits into the aims and objectives of CDS, primarily because I aim to move away from the binary understandings that surround disability. I also think my desire to influence the inclusion and equality of disabled people is championed within CDS. Although I focus on a specific diagnosis, I do not believe that my work will only be relevant to autistic people. It is this broader aim of activism and change that draws me to CDS. In addition, the openness of CDS and the emphasis on incorporating ever changing knowledge on diversification to enable progression has particularly drawn me towards researching within a CDS way of thinking. Goodley (2016, p.19) highlights ‘while critical disability studies might start with disability it never ends with disability’. Goodley’s (2016) view suggests that research findings posited under a CDS framework may have wider implications beyond the field of disability.

2.3.2 Critical Autism Studies

Under the broader remit of critical disability studies (CDS), more specialist subsections and complementary research areas have emerged that reflect the needs and research interests of particular communities. One such is ‘critical autism studies’ (CAS). I provide a partial overview of the history and principles of CAS, in relation to autistic women and higher education. Through this I also link CAS to my own perspectives of autism research as an autistic researcher.

In essence, CAS challenges deficit-based thinking surrounding autism (Roscigno, 2021). O’Dell et al. (2016, p. 168) argue that CAS complements CDS principles but also ‘troubles the common sense understanding of disability’ due to its focus on exploring the manufacture of autism, which in itself is viewed to have a wide range of variation under the single diagnostic term. CAS is said to have been first coined in 2010 in Canada by Davidson and Orsini (2013) and was brought to the interest of the autism studies community in the UK in 2011 (Woods et al., 2018). Although some researchers are likely to have been associated with CAS principles prior to these dates, this emphasises that CAS is still an emerging field that has only been more widely known about by researchers for the last decade.

Davidson and Orsini (2013) suggest that CAS should focus on three elements: how power relations shape autism research, the creation of new narratives of autism to challenge prominent deficit-based constructions of society, and the creation of new analytical frameworks to study the nature and culture of autism. I am particularly interested in exploring power relations with the autism communities and between autistic and non-autistic people in the context of university in order to further both practical implication and research in the field. My focus on autistic women also creates new narratives as their narratives are seldom showcased in research. In 2016, Runswick-Cole et al. explained that to them CAS is underpinned by two interrelated questions of whether the diagnosis of autism is scientifically valid and whether the diagnosis of autism is useful to those labelled with it and their families. To date Runswick-Cole et al.'s (2016) book *Rethinking Autism: Diagnosis, Identity and Equality* remains the most comprehensive collection of writing in the UK about CAS, that has yet to be superseded. Davidson and Orsini (2013) focus their description of CAS on how autism should be researched, whereas Runswick-Cole et al. (2016) consider the practical benefits of being diagnosed as autistic. Both these views are important to think about to ensure the culture of autism is studied, but only in ways that may actually benefit autistic people and wider society.

Ryan and Milton (2023) stipulate that CAS enables research to impact the lives of autistic people by recognising the issues from society that affect them. The exact definition of CAS is difficult to define. CAS has attracted controversy and criticism from some autistic researchers, due to the fundamental questions it poses and the nature of the research sector, including the work of non-autistic researchers. No single definition of CAS appears to be accepted by all researchers who associate with this field of studies. However, Mallipeddi and VanDaalen (2021, p. 2) suggest definitions tend to follow a common trend of the 'investigation of the individual nature of autism and of the ways in which biology and culture intersect to produce disability'. For example, a minority of autistic researchers (for example Milton, 2016) have written scathing reviews of Runswick-Cole et al.'s (2016) book and in particular their definition of CAS. It troubles some autistic researchers that Runswick-Cole et al's. (2016) definition and description of CAS may be seen to seek to erase autism as a 'real' condition. Most troublingly to some autistic researchers (for example, Milton, 2016) is the notion that in asking whether autism is scientifically valid and a useful label, Runswick-Cole et al. (2016) are effectively concluding that it is not. My PhD study explores autistic experiences. Whilst I do not seek to interrogate the validity of the label of autism, I assume autism to be real.

Regardless of whether autism is considered to be 'real' by all researchers and society, there are people who currently identify or are identified by others as being autistic. It is questionable how important having an autistic identity is. For example, if CAS is seeking to forward autism thinking an autistic identity may be considered important, but, it may also be something to attempt to hide to be accepted in society. For example, Botha et al. (2022) explored 20 autistic people's opinions of their autism. Although they note that participants considered their autism as a neutral entity, the impressions they received from others about their autism, and in turn them, was mostly negative. This triggered participants to try and hide what they thought were unacceptable autistic behaviours to fit into a neurotypical society or to challenge negative stereotypes. This suggests autistic identity is a fragile concept that can be impacted by responses to others' opinions and words.

Some autistic researchers are troubled that in CAS research autism is studied as a condition, and autistic people are not necessarily included or at the centre of this research (Woods et al., 2018). In order to ensure autistic people are included in such research, Woods et al. (2018) argue that autistic researchers should be included in all autistic research and go as far as suggesting CAS advocates cultural imperialism (where a dominant community (in this case, non-autistic researchers) place aspects of their culture onto a less dominant one (for example, autistic researchers)). However, this view focuses on emancipating the autistic experience of one subsection of the autistic population (those who are autistic researchers) and does not consider experiences of others affected by autism, or autistic people who are not researchers (including autistic children). Thus, if CAS was based solely around the views of autistic researchers, it would only provide research about, and by, a small subsection of the autistic population.

Woods et al. (2018), however, extend their idea of preserving a research field solely for autistic researchers as they have debated whether to create a new subsection of CAS that is only open to the research of autistic researchers who agree with the neurodiversity movement. Guest (2020) argues that this would seek to reduce the field rather than expand it and produce an echo chamber only open to those who agree with this ideology, by censoring others' viewpoints and ultimately severely restricting the field. Woods et al. (2018) however, have decided to engage with the current field as they did not want to *surrender* the field to non-autistic academics. In addition, Bertilsdotter Rosqvist et al. (2020) promote that a new field entitled 'Neurodiversity Studies' should be formed to reduce research surrounding specific labels and instead consider neurodiversity as a whole. It is thus demonstrated that researchers are continually considering new research fields when they feel they are no longer welcome within existing ones, which may or may not be reserved for chosen researchers. Rather than producing healthy research debate, this may simply create larger rifts between researchers with different life experiences and opinions.

As an autistic researcher in the field, I may be viewed as less compared to non-autistic autism researchers, however my lived experience as an insider is a privileged position in disability research. Ryan and Milton (2023) highlight that there still seems to be a divide between autistic and non-autistic autism researchers, which they suggest is evidenced by autistic researchers tending to cite other autistic researchers, rather than being supported by non-autistic autism researchers. Although I may face potential stigma stemming from my own diagnosis within research, I hope to be part of the movement creating change for autistic people in society. In addition, my positionality and lived experience are fundamental to this research.

I have discussed that Runswick-Cole et al. (2016) argue that CAS exists to trouble current narratives about autism and to cause debate, therefore, the controversy and debate between researchers is necessary to ensure the progression of this field, and ultimately progress in society for autistic people. Grinker (2020) argues that autism can be analysed and researched within itself and in comparison to itself. Overall, although CAS is a contentious field that provokes a lot of controversy, it provides debate that may ultimately further research concerning autism and increase understanding. This is therefore a discipline of study that it is vital to engage with when researching autism.

Mallipeddi and VanDaalen (2021) highlight that although the CAS framework has sought to ensure autism research is conducted through a neurodiverse lens to challenge ableism, overall CAS attributes little importance to other intersectionalities (such as race and gender). It is imperative CAS continues to integrate other intersectionalities to explore how they coincide with autism, as autism is not a unitary experience.

I situate myself and this research within CAS, but aim to ensure I highlight other intersectionalities that may inform debate, rather than focusing on a binary between autistic and non-autistic people. Although other intersections can impact how a researcher is viewed, autistic researchers can attract a particular level of scepticism due to the requirement of a researcher to consider the viewpoints and opinions of others. This is a skill which is commonly classified as a deficit in autism, for example in the Theory of Mind theory proposed by Baron-Cohen et al. (1985). From my perspective CAS will forward autism research. This is because through CAS autism is not analysed within itself, but rather with reference to other intersectionalities and societal issues.

Throughout discussing about both CDS and CAS, I have highlighted similarities between them and at points their differences. I have discussed the nuances of how the aims of this study, alongside my positionality, align with different branches of thinking. Yergeau (2017, in Coda) highlights that central to CDS, CAS and feminist disability studies is the notion of ‘norm-shattering’ against dominant and oppressive thinking and practice. Shattering norms, through both my own positionality as an autistic woman researcher (researching in CAS, which is predominantly dominated by autistic men researchers) and my study aims is therefore much more important to me than neatly fitting into a research discipline.

2.3.3 Feminist Disability Studies

Within my considerations of autism, I highlighted some difficulties autistic women are subject to, due to society’s continued stereotypes of autism as a predominantly male condition. Feminism champions women and pushes back against a society dominated by the patriarchy. However, disability and disabled women occupy an awkward space within feminist studies (Lloyd, 2001). Although there are many contributors to this area of study, I have chosen to focus on the work of three disabled feminist researchers, Morris, Garland-Thomson and Thomas as their work was seminal and caused rifts within established thinking.

‘Double disadvantage’ concerns people who are oppressed by two intersections, for example, being a disabled person and being a woman. It is used by some non-disabled feminist researchers and has become more recently used in research. Morris (1993) argues that although disabled women’s lives are shaped by how disability and gender interact, non-disabled writers' use of ‘double disadvantage’ highlights what disabled women are ‘supposed’ to experience and removes any responsibility from society to seek to reduce this disadvantage in society. It is questionable whether disabled writers should reclaim this term for their own use, as it may be misconstrued when appealing to a mass audience. This is to ensure disabled women are viewed as positively as possible for change to happen. Morris (1996) argued that if people are always oppressed by terms (for example ‘disabled’ and ‘woman’) they will begin to internalise these oppressions and begin to conform to the expectations of what society thinks they should be.

Garland-Thomson (2002) highlights how feminist writing tends to ignore disability, but that she wants to ensure an ability versus disability debate is incorporated to extend the current cultural notions feminism provides. She posits feminist disability studies could unite the category of being a woman, in a space which disabled women do not easily occupy.

Thomas (2006) is another influential writer in the field of feminist disability studies. She argues a disabled person constructs their disability in relation to perceived gender norms. However, Thomas (2006) argues that disabled people should not just be categorised into disabled women and disabled men and seen solely as disadvantaged by both disability and gender. She says other parts of a person’s identity also attract discrimination, for example race and sexuality which creates a much more complex picture of how a person is disadvantaged or excluded. Thomas (2006) does however highlight that the gendered realities of being disabled are important to explore.

These notions of ensuring disability is not ignored, but also not treated as the only other intersection alongside gender highlight interesting considerations for me, researching autism under feminist principles. Goodley (2016, p. 194) highlights that both feminist disability studies and critical disability studies align to ‘destabilise the normative centres of society and culture’. Despite this alignment I question the extension of this alignment to autism, which is still heavily perceived in society as something that sits within a male narrative. Taking Thomas’ (2006) view that intersections beyond gender should be examined to highlight the complexity of disabled people’s lives, feminist disability studies could help autism research to reduce some of the entrenched binaries which mostly relate to gender, in order to reduce current social stereotypes.

Another interesting feature of feminist disability theory which could be highly relevant to autism research is the Misfit Theory (Garland-Thomson, 2011). Garland-Thomson (2011) posits the concept of ‘misfits’, which she explains to be the awkward attempt to put or place two things together that do not fit together. There is no problem with each thing in itself, but, their ‘shapes’ do not join together. She highlights that contextual and temporal shifts can allow a better fit between two things over time. With regard to disability Garland-Thomson (2011) describes fitting to be between a body and the environment, and whilst a perfect fit may never exist, a spectrum tended towards and away from perfection might. She suggests that everybody should encompass their vulnerabilities and acknowledge where they may fit or misfit into the environment (regardless of whether they had a disability label), thus accommodating disability as a variation of being human. Thus, misfit theory can shift individuals between difference and normalcy.

McKinney (2014) and Price (2015) highlight the simplicity of this model as it tends towards physical disability, that the physical environment can be changed for. However, the concepts of fitting into a group or identity beyond the physical environment may still be relevant for autistic people. Autistic women challenge the notion of fitting into a stereotypical perception of the autism narrative and therefore may be considered both misfits to the stereotype of a woman and an autistic person. Garland-Thomson (2011) argues there is power in misfitting in challenging human diversity. An autistic misfit theory could assist in challenging the binaries of normalcy and difference. Thus, holding onto the benefits of the misfit theory and attributing it specifically to autism may enhance considering how autistic women experience university.

2.4 Autism at University

In this section I provide a partial overview of research that has taken place about and with autistic students at university. I highlight how until recently autistic people have remained relatively absent from university research. I particularly emphasise that the experiences of autistic people and research specifically about autistic women are minimal within this area of research. With reference to other intersectionalities, I reflect upon how this lack of research focused on autistic women at university highlights an erasure or lack of interest in this population. I add further detail to some areas of research that feel particularly relevant to autistic women or are generally more well researched due to popularity within the broader research remit of autism in Higher Education.

In the last section, I introduced some of the difficulties autistic women may encounter in society compared to both non-autistic people and autistic men, and the challenges that feminist autism research can have in fitting into pre-established disability and autism-based research fields. Based on the questions posed about autistic women's lives I have chosen to focus my thesis on autistic experiences in Higher Education. I believe this is an area of research that requires focus, based on personal experience and from research. In consideration of my research question, autistic women are under-researched and frequently ignored within autism research. As documented in the previous section, research on autism and a broader societal fascination has tended to focus on autistic children, particularly boys, rather than on autistic women (Happe, 2019). Thus, more research and attention are needed on autistic adults and women in particular.

In addition to the introduction to language use in *Chapter 1: Introduction*, I add further language that will be used in my thesis. In the United Kingdom (UK) the terms 'Higher Education (HE)' and 'University' tend to refer to education available to those aged 18 and over, who have usually completed Further Education (FE) (traditionally A Levels or similar). Within common language both these terms tend to be used interchangeably, and therefore within my research I use both descriptions. In addition, where international researchers are referenced (particularly those in the USA) I will use the term 'college'. It should be noted that in the USA and some other countries, college is more traditionally used to refer to HE, where in the UK it would tend to refer to FE, and thus some American research papers that are referenced will refer to 'college students' for example.

2.4.1 Autistic Statistics in HE

In order to contextualise the number of autistic students in Higher Education (HE), in the academic year 2020/2021, 16,685 UK students (of which, 5,015 were women) declared they had a 'social communication disability/autism spectrum disorder' compared to 6,845 in 2014/2015 (Higher Education Statistics Agency [HESA], 2022). Every academic year since 2014/2015 this figure has increased by approximately 1,500 (HESA, 2022). Therefore, it could be predicted that this trend will continue to grow which highlights the need for autistic students to receive greater attention within HE research, as the autistic student population continues to increase. HESA data on disability only includes students who are registered as a 'home student' (a British national). Therefore, any international autistic students are not included in this data. In addition, if a student declares 'two or more disabilities' HESA categorises them differently. Many people with autism have multiple diagnoses and therefore would fall into this category (for example co-occurring mental health diagnoses, Lai et al., 2019). This means there may be many more students with autism, who identify as having multiple disability labels or who are not British, who are being overlooked within the 'social communication disability/autism spectrum disorder' category numbers.

2.4.2 Stigma

In more recent years, some research has highlighted the stigma autistic students face at university (Gillespie-Lynch et al., 2015; Perry et al., 2022). Stigma refers to a combination of prejudice and discrimination, which may cause the oppressed group to be restricted in what they can do (Link and Phelan, 2001). Others' perceptions of a person can either help or hinder a person to succeed, and therefore it is important to consider how favourably autistic students are considered and whether perceptions need to be addressed.

Medicalised research, which predominantly focuses on how other people view autistic students and describes autism under a medical model, could continue to be hugely damaging within an academic system where students with autism are documented to have particularly low outcomes. This may be particularly the case when stigma is discussed. Schwarz (2008) highlights that autism is still considered to centre around a false dichotomy of high and low functioning labels, that supposedly represent an autistic's person's ability to contribute to society. Reducing an autism diagnosis to either 'high or low functioning' does not acknowledge the widespread abilities a single autistic person may have. If a person is described as 'low functioning' their autonomy may be removed, but if a person is described as 'high functioning' (not having an accompanying learning disability) they may be viewed as not needing support or find it harder to access support (den Houting, 2019). In terms of the university context, the majority of students with autism who attend could be considered 'high functioning' (Beardon et al., 2009) as they have gained the same academic standards as neurotypical students in order to be accepted onto the course. However, this false dichotomy can force other students to perceive things which are untrue and make negative assumptions when a person cannot perform to a perceived norm. The focus of society on classifying autism into a binary model based on supposed functioning abilities likely extends to university.

Much research focuses on the impact of students' relationships with academic staff in helping or hindering their enjoyment and achievement in academia (Guzzardo et al., 2021; Hagenauer & Volet, 2014; Yale, 2019). However, research seldom focuses on the interactions of academic staff and disabled students. I highlight how some studies have given spotlight to the experiences of disabled students and staff. Although these studies focus on the binary of disabled and non-disabled people it is likely that many more factors contribute to why people act a certain way.

Bailey et al. (2020) surveyed 42 autistic university students and interviewed 23 of them regarding their social experiences at university. The majority of their participants identified as male. They conclude that being more socially engaged with peers at university leads to more positive experiences. However, they also highlight that autistic students who are having more positive experiences are more likely to have negative interactions with professors (academic staff), particularly in relation to accessing accommodations. Bailey et al. (2020) attribute this to be due to academic staff perceiving they do not need as much support if they appear to be enjoying university, or students feeling empowered and aware of their rights. Therefore, although an autistic student may be socially connected with peers and thus more involved in university, it does not negate that they may have negative experiences non-autistic peers are unlikely to be subjected to. This may be particularly the case if academic staff hold the perception of binary stereotypes in autism. It is interesting to consider these findings in light of the majority of their participants identifying as male. Societal stereotypes of autism tend to focus on male portrayals (as discussed earlier in this chapter) and thus I would have expected academic staff to be more accommodating in the results of this study. This is because society tends to associate autism with boys/men and so I would have assumed autistic male students struggling to be more acceptable compared with autistic women students struggling. However, knowledge of autism is variable even with reference to established stereotypes. Bailey et al. (2020) state that academic staff need training on neurodiversity and more specifically how to communicate with neurodiverse students.

Scott and Sedgewick (2021) also highlight the importance of good relationships at university on positive mental health of autistic students. They interviewed 12 autistic students about factors surrounding mental health and support at university. Scott and Sedgewick (2021) document that although results showed three themes (relationships, independence and support) they were overarchingly linked by relationships. Relationships were impactful whether they were supportive or stigmatising. Scott and Sedgewick (2021) document mixed responses from participants regarding relationships. Some participants noted that some academic staff were knowledgeable and accepting about autism, enabling them to feel confident in asking for adjustments and accommodations. However, other participants felt staff they had interacted with had a lack of autism awareness and were less accommodating to their needs. These students thus felt stigmatised and unwilling to seek support for any difficulties they had at university. Findings from Bailey et al. (2020) and Scott and Sedgewick (2021) highlight that stigma towards autistic students at university from academic staff still persists, whether it stems from a lack of understanding about autism and its heterogeneity or an unwillingness to provide support.

Potential stigma and isolation of autistic students also extends to peers at university. White et al. (2019) explored university students’ knowledge of autism and attitudes towards autistic people and compared their results to a similar study they conducted five years earlier. They thought that due to a rise in autism being diagnosed and there being greater awareness over the last five years, participants would hold greater knowledge and therefore have more positive attitudes towards autistic students. Although participants did show greater knowledge, negative attitudes towards autistic peers remained except for those who already personally knew an autistic person.

Wang et al. (2022) investigated the opinions of 712 non-autistic university students about their attitudes towards autistic students, using vignettes. Wang et al. (2022) note that previous studies have tended to use vignettes that align with gender stereotyping of autism. Therefore, they used characters in their vignettes with non-binary names and non-gender stereotyped experiences. They documented mixed findings. Participants who were told the character in the vignette was autistic tended to show more favourable attitudes towards autistic people. In addition, similar to the findings of White et al. (2019) participants who had personal or professional experience with autistic people showed more positive attitudes. Their findings suggest that in order for an autistic person to be accepted at university, it is their responsibility to disclose their diagnosis rather than the onus being on other students to simply be inclusive to everybody.

White et al. (2019) and Wang et al. (2022) both highlight how attitudes towards autistic students from their university peers tends to be negative. Although both these studies are primarily looking at how non-autistic students perceive autistic students, they both describe the characteristics of the participants but consider autistic people as a homogenous group. Generally negative attitudes towards any autistic person needs to be changed however more nuanced understandings of stigma in relation to other characteristics may be beneficial to specifically develop stigma tackling initiatives.

Research into how autistic people are generally perceived at university presents an overwhelmingly negative picture. Although there are elements to suggest that some autistic students are well received and supported by academic staff and peers this seems to be the exception rather than the norm (Cage & Howes, 2020). Therefore, autistic students are possibly having to educate other students and staff as well as trying to navigate university themselves. Thus, creating extra labour for themselves in situations where how people react may be not what was hoped for. Some stories that are left untold in the literature surrounding the autistic experience at university feature from the participants in this thesis.

2.4.3 Community

In the previous section I discussed how autistic students may be subject to stigma at university. Of the studies I discussed, some suggested that good relationships may be a protective factor against stigma at university (for example, Bailey et al., 2020; Scott & Sedgewick, 2021). Although good relationships may reduce stigmatisation for autistic women, it may be hard for autistic women to form these good relationships, based on the medical diagnostic criteria that autistic people find social interaction difficult. I therefore turn my attention to literature surrounding communities and belonging. Baumeister and Leary (1995) argue the need to belong is fundamental, which drives people to want to establish and maintain strong relationships with others. It has been theorised that interruptions to feeling a sense of belonging can be of a similar health risk to smoking or obesity (Martino et al., 2015). I briefly explore student communities, and how research about student communities relates to autistic women.

2.4.3.1 Student Communities

Within universities belonging is generally considered to mean how students feel accepted, included and connected to by their institution (Goodenow 1993, p. 80). Fostering a sense of community at university is both beneficial to students and the university because it can increase positive feelings of belonging for students and therefore increases retention rates (Kelly & Mulrooney, 2019; Pedler et al., 2022). Kelly and Mulrooney (2019) surveyed 617 undergraduate students about their opinions and experiences of belonging at university. They concluded that students explained belonging to have positive personal, social and academic benefits. Considering the positive effects being part of a community can have on students, I offer a brief overview of relevant research before turning to consider how autistic students may vary in their experiences of belonging and feeling part of a community.

Ahn and Davis (2020) concluded there to be four domains of belonging in Higher Education: academic, social engagement, surroundings and personal space. They note that surroundings and personal space are domains that are regularly neglected when university belonging is considered. Ahn and Davis (2020) therefore argue that belonging is multidimensional and although social engagement is the most important, academic, surroundings and personal space factors all influence how a student feels they belong. It is therefore important to consider belonging not just in terms of social relationships.

Being part of the university community however may not be easy for all students. Pedler et al. (2022) imply that belonging at university is a privilege for students depending on their background and perception of their own academic ability. They found that students who were the first in their family to attend university and students who regularly considered dropping out felt the least like they belonged to the wider university community. Hussain and Jones (2019) also researched how difference can affect belonging. They explored the sense of belonging of university students of colour attending a primarily white institution. As although experiences of discrimination hinder a student of colour feeling included and can make them feel the university is unsupportive of them, little research has explored how an institutional commitment to diversity affects discrimination and diverse interactions. They conclude that although institutions cannot directly decrease external discrimination, institutions can help to facilitate cohesion outside of academic activities and therefore help to foster a sense of belonging and community that reduces discrimination.

Mulrooney and Kelly (2020) and Vytniorgu et al. (2023) highlight that belonging is not just concerned with people but also how a person feels within a physical space at university. Mulrooney and Kelly (2020) suggest that physical spaces at university can either help or hinder the social interaction of students. Spaces that include elements which a student considers positive (for example an ecologically minded student may prefer an indoor environment containing plants) may make them feel like they belong in the environment and therefore more relaxed in making social connections. Vytniorgu et al. (2023) argue that increased green space ensures a positive environment. Therefore, in considering whether a student feels like they belong or are part of a community, the physical environment and how that impacts them needs to be thought about.

I have provided a brief overview exploring student communities at university and their importance in student cohesion and retention. I have also touched on some reasons why being part of a community and feeling a sense of belonging may be difficult for some students. I now turn to research about autistic people's sense of community at university.

2.4.3.2 Autism Community at University

I have discussed how belonging to a community is considered to both be important in society and within the university context. I now consider whether and how autistic students at university have similar experiences and desires for belonging. Pesonen et al. (2020) highlight that research exploring autistic students' sense of belonging is minimal. Frost et al. (2019) previously noted that having a label of autism, similar to any other shared characteristic between people does not mean that they feel an instant connection together and therefore feel part of a community. Frost et al. (2019) indicate that there is an expectation for autistic people to form their own community distinct from non-autistic people. Considering autistic people stereotypically find social communication difficult, it could be assumed that they do not want to be part of a community outside of other autistic people. Some researchers have explored how a sense of belonging impacts autistic students.

Cage et al. (2020) explored reasons that may affect autistic students in completing their university courses. They surveyed 250 autistic people that had attended university, of which 45 did not complete their studies. They reported that autistic students who dropped out of university were more likely to not feel part of the university community and felt lonely or only had superficial friendships. They highlight that although autistic students may have difficulties with social interaction and participation, the desire to belong and feel part of a community remains. Cage et al. (2020) argue that universities and their student unions need to do more to foster a sense of community that is inclusive to all such as through accessible events and better peer support. This is particularly important considering autistic people are reported to have difficult experiences in young adulthood, at a time they may be entering university (Pesonen et al., 2015).

Pesonen et al. (2020) explored the perceptions of belonging of 11 autistic university students in The Netherlands. Primarily they argue that the 'the construction of autistic students' belonging is not simply an individual phenomenon but a political one' (p. 14) and therefore belonging has a performative element to it based on accepted norms. Pesonen et al. (2020) argue that place is always embodied and the physical environment affects whether and how a person feels they belong. They highlight how an autistic individual experience a place may be different to a non-autistic person and therefore whether they feel they belong in that space may be different. Pesonen et al. (2020) highlight that autistic students actively chose whether to belong or not in different situations at university, indicating agency that may be distinct from non-autistic students. They go on to argue that choosing not to belong may be productive non-belonging, in that choosing not to go to a place they feel they do not belong as their true self, spurred by exclusive internalised discourses is more productive in other ways. Non-belonging emphasises how belonging is politicised as universities should create spaces and environments all students feel they can belong to without having to conceal who they are. I further discuss how the physical environment can impact autistic students further in the next section.

2.4.3.3 Community for Autistic Women

Here I explore how community may be both important but also especially difficult for autistic women, particularly considering the societal disconnect between being autistic and being a woman.

Feeling part of the autistic community is not an automatic experience following an autism diagnosis. Zener (2019) highlights that feeling like being in the autistic community for autistic women may mean different things, depending on whether they sought their own diagnosis or have been encouraged by others to get diagnosed. Zener (2019) suggests that autistic women who seek their own diagnosis to confirm their own suspicions about their identity look out to join autistic women communities online, whereas autistic women who do not think they are autistic before their diagnosis do not. This may mean that people process and internalise how autism affects their own identity differently. It also highlights that autistic people may exercise the choice to join a community following their diagnosis. In addition, Harmens et al. (2022) state that whilst finding communities of autistic people can be important for autistic women post diagnosis, they emphasise that autistic women can face exclusion from both within and outside the autistic community for not fitting stereotypes surrounding autistic women. The same societal stigmas can be reflected in autistic community groups and therefore other autistic people may not accept other autistic people based on their identity.

No research could be found that specifically explores autistic women's community experiences at university. Anecdotally, the stigmas that surround autistic women and those that Harmens et al. (2022) explain also happen within the autistic community may extend to the university environment.

2.4.4 Sensory Aspects of University

Focus on the sensory aspects of autism has increased in popularity in recent years, but it has attracted less attention with regards to university. Dwyer et al. (2021) argue that neurotypical university staff have poor understanding of the sensory issues autistic students experience and therefore are unwilling to accommodate them. Van Hees et al. (2015) highlight that sensory overload can prevent students from participating in both academic and social activities at university. They give examples of flickering lights and people typing on computers as sensory stimuli that are difficult to process. Although a university could prevent flickering lights in its buildings, it is much harder for a university to control students' own personal equipment such as laptops.

Goddard and Cook (2022) explored the barriers autistic students had to joining in social events. As part of their findings, they document that bright lights, overcrowding and noise levels made the university environment inaccessible. They assert that when universities renovate buildings, they should also consider those with non-physical disabilities and until then should implement temporary strategies (such as reducing overcrowding as much as possible) to make environments less sensorily overwhelming. However, meeting the needs of everybody in one place can be particularly difficult and therefore requires careful thought and planning. Goddard and Cook (2022) briefly note how autistic students who were able to attend social activities such as social groups with other autistic students had better social experiences and an increased sense of belonging. Therefore, it may be imperative to ensure the university environment is accessible, not just to reduce sensory overwhelm, but also so that autistic students have the same opportunities to engage in social activities and feel a sense of belonging that other non-autistic students are likely to have.

Dwyer et al. (2021) focus on how sensory sensitivities might impact a student's accommodation experiences at university. They argue that autistic students are vulnerable to sensory overload and so need to have a quiet place to go to, so they can recover. They also highlight that in catered accommodation food sensitivities should be catered for in order to reduce students' anxieties and sensory overload. Dwyer et al. (2021) advocate that new buildings in universities should have sensory refuges built into them to make access for neurodiverse students easier. Although they focus on typical American university accommodation (such as rooms shared by more than one person that are fully catered), which varies slightly from standard UK accommodation, they highlight the need for consideration of sensory difficulties in another aspect of the university experience. These three studies (Dwyer et al., 2021; Goddard & Cook, 2022; Van Hees et al., 2015) emphasise how difficult and overwhelming sensory things can be that non-autistic people may be able to ignore within the university environment.

It should be noted that the sensory aspects of university can extend beyond the buildings at a single university, but also to activities associated with academia. Martin (2020a) argues that conference environments may also provoke sensory overload, in the same way universities can. Postgraduate students may be expected to attend conferences and thus it is important not to negate environments they may frequent as part of their university experience. She states that although some conferences do seek to accommodate sensory sensitivities, there is not always the budget to facilitate this, such as to cater individual food or hire an appropriate space.

2.5 Conclusion

Within this literature review I have provided a partial overview of disability theory and given some context of where autism sits within these theories. I have also explored current debates surrounding autism at university. The aim of this chapter was to introduce some of the debates about the theory of disability and some practical implications around autism. First, I explored the concept of disability and highlighted how difficult it is to define due to its complexities. I discussed how disability is particularly important to continue to research and change policy around, despite its challenges, due to the majority of society either being born disabled or becoming disabled at some point in their life. I also considered how disability can be contextual depending on the way society reacts to and accommodates an impairment. I then attended to models of disability and discussed how they can be used to help understand disability. I focused my discussions on how disability modelling tends to only consider the dichotomy between the social and medical models of disability. I document how disabled activists, academics and allies tend to prefer the social model. I traced other models and considered their contributions to disability discourse. I considered how alternative models can be useful for different situations and that each contributes something unique to the field of disability. I then turned my focus to theoretically exploring autism and attending to some pertinent issues within it. This is because I wanted to bring some current debates within the field to the forefront that autistic women may be subject to. I also dedicated a section to autistic women and highlighted the gender imbalances associated with autism. I ended this section by focusing on the neurodiversity perspective, which considers autism as a difference rather than a deficit. It does accept autism as a disability but seeks to highlight a more positive view compared to traditional societal perspectives.

Second, I considered how disability is researched. I focused on Critical Disability Studies, Critical Autism Studies and Feminist Disability Studies and explored how I will apply principles from these disciplines to my own study. I highlighted how autism research may not easily fit into a disability feminist standpoint, however I seek to challenge these tensions.

Finally, I turned to exploring some literature about autism at university. I focused the partial overview of this section on specific aspects of the autistic university experience. I highlighted that the numbers of autistic students attending university and disclosing their autism continues to rise every year to emphasise why in numerical terms autistic students need to be considered further in research. I specifically explored the stigma that can surround autism at university and suggest that autistic students are generally viewed negatively by both staff and other students. I highlighted that supportive relationships, increased knowledge of autism and a willingness of others to view autism as heterogeneous were factors in reducing stigma. Last in this section I looked at the sensory aspects associated with university. I discussed how aspects of the built environment can be sensorily overwhelming for some autistic students (for example flickering lights), but also that students may have limited access to academic events beyond the physical environment of their university such as conferences.

In reviewing this literature, I have identified some missed opportunities in relation to the literature. My narrative approach to the literature review means that, unlike a systematic review, I am not identifying gaps in the literature. Instead, my review of the literature is more reflective, qualitative and considerate of the place of autistic women in the theoretical empirical literature but also, more pragmatically and politically, the place of these women in universities. My review of the literature led me to three key research questions that I address through my empirical research.

1. What barriers and supports to higher education do autistic women students feel they have had at university?

The numbers of autistic students attending university and disclosing their autism continues to rise every year (as outlined in *section 2.4*), and this clearly demands research and inquiry into this growing number of students. Moreover, my theoretical leanings into feminist disability research and a consideration of key issues such as stigma and community in universities, demands me to seriously engage with the experiences of autistic women as they encounter university.

2. In what ways can the university environment be adapted to better accommodate autistic women?

Whilst reviewing literature I have discussed how autistic students can experience sensory overwhelm at university, but that this research is minimal and seldom extends beyond university lecture theatres and buildings. The environment also impacts a student's sense of belonging and therefore whether they feel part of a community. This second research question permits me to tackle this important issue through my research project.

3. What changes would autistic women like to see at university?

I formulated my final research question from consideration of the elements from CDS and CAS that promote advocacy and empowerment. Through this chapter I highlight how autistic women are routinely excluded from both autism discourse and that of feminist disability studies. In addition, the lack of research identified in Section 2.4 about autistic women at university also highlights the erasure of autistic women students' voices that I argue need to be shared.

Overall, these three research questions are explicitly connected to my literature review which have revealed a paucity of research on the experiences of autistic women in university contexts. My work is not simply engaged with theory, literature and empirical work - I am also interested in creating positive change, inclusive communities and disrupting current practice.

3 Methodology and Methods

3.1 Introduction

In this chapter, I outline my theoretical underpinnings, my methodological approach, research methods and design, sampling and recruitment, research process, ethical considerations and journey through analysis. First, I explore my theoretical underpinnings by examining my ontological and epistemological stances and I argue that it is difficult to attribute any singular stance to my research due to the intertwining concepts within my thesis. I then turn to how my methodology has been influenced by these stances. Second, I explain my reasoning behind choosing to use creative methods and interviewing, and how these will complement each other within the study. I present some debate about these methods and justify their use in my research. Third, I briefly focus on how I chose the sample for my research and recruited participants. Fourth, I reflect on the research process and give an account of what happened in practice and how the research had to adapt to circumstances both in society and to the needs of the participants. Fifth, I highlight some of the ethical considerations that were pertinent to this project, particularly with disability research. Finally, I describe how I analysed the data and reflect upon the process of this.

Throughout the methodological process I kept my research questions in mind. I restate them here:

1. What barriers and supports to higher education do autistic women students feel they have had at university?
2. In what ways can the university environment be adapted to better accommodate autistic women?
3. What changes would autistic women like to see at university?

3.2 Theoretical Underpinnings

In this section I discuss my ontology, epistemology and thoughts on the methodological groundings of my research. Throughout this section, I argue that it is difficult to focus on a single interpretation or adopt a single theoretical position in relation to research. One of the key contributions of qualitative inquiry is that it opens up the researcher to new ways of thinking and demands an openness and flexibility to theoretical ideas and approaches (see for example Banister et al., 2011 for a helpful discussion). I pose this because I believe it is necessary to encompass different elements from a range of theoretical positions in order to create change in research.

3.2.1 Ontology

Ontology is broadly agreed to be the understanding of the nature of reality (Hudson & Ozanne, 1988). Although there are many ontological perspectives, these are mostly divided into two schools of thought: those that believe one single reality exists, independent of human perception and experience (realism), and those who believe reality is created in people's minds and therefore no one true reality can exist (relativism) (Hudson & Ozanne, 1988; Moses & Knutsen, 2012). Although realism and relativism are seemingly dichotomous belief patterns, the distinctions between them (and the shifts a researcher may go through in relation to these different beliefs) could indicate a continuum of thought rather than mutually exclusive perspectives. This is particularly pertinent within my research as I incorporate both realist and relativist principles into my project. Thus, this requires my research to start from a realist perspective, however the collection and documentation of people's personal experiences includes acceptance of a relativist viewpoint. Goodley and Lawthom (2005) argue the vast majority of disability research will involve researchers moving between different ontological positions. The fluidity of my ontological beliefs is therefore key to the success of this research project.

In addition, it is important to consider human nature. Human nature is the way that humans interact with their environment (Lane, 2001). Broadly, different perspectives on human nature are divided into two opposing views: determinism and voluntarism. Determinism focuses on human behaviours stemming from the environment and assumes humans are part of how the universe revolves, whereas voluntarism assumes people create their own environment through behaviour and action (Lane, 2001; Pleasants, 2018). I argue that if humans are deterministic then they would not be able to create change, including to their own beliefs and values. If this were so, society would not be able to adapt and better accommodate autistic people. I believe adaptation and change are possible and therefore consider human nature to follow voluntarism.

Disability could be argued to split the realist and relativist debate. In impairments where the aetiology is known, for example Downs Syndrome which is defined as having an extra chromosome and the presence of particular physical features, the existence of the condition is accepted in society (Vehmas & Makela, 2008). Disabilities without known aetiology, or that mainly present in a non-physical nature, cause difficulties in the dichotomous lines between realism and relativism. Autism is such a disability without a confirmed or universally agreed aetiology, that is predominantly diagnosed on a professional's opinion of how a person fits into standard (but still relatively vague) diagnostic criteria. Happe et al. (2006) note that for autism to be diagnosed a person has to have all features of autism, which occur at an above chance rate indicating that autism exists despite unknown aetiology and therefore must be 'real'. The features of autism referred to here are the 'triad of impairment', that to be diagnosed with autism a person needs to demonstrate deficits in social interaction, social imagination and social communication (Wing & Gould, 1979). Happe et al.'s (2006) position on autism is arguably deficit based. Her work continues to stem from a more scientific viewpoint, a perspective that can position autism solely in terms of deficits. I bring her thinking and work into my thesis as although I do not subscribe to autism being something that should be viewed as purely negative, Happe is a prominent researcher within the world of autism research and this deficit perspective is commonly held across society including in universities. I believe that in order to examine my own belief of whether autism is real or not, I need to consider it from a wide variety of viewpoints. This allows me to both examine whether I think autism to be real or not and by what terms other people define it as. Ultimately, I do consider autism to be real, both as part of my own identity and from examining research such as Happe's and other disability scholars (See *Chapter 2: Literature Review Section 2.2.1 Current Debates with Autism*). At the same time, I am open to critically revisiting my own ontological assumptions in relation to autism through this research project.

Autism is a popular topic of debate (for example, Bovell, 2020; Gernsbacher et al., 2018), mainly due to society's lack of understanding around it and the lack of concrete evidence surrounding aetiology and diagnosis. I believe discussion about autism is especially rife due to it having 'fuzzy borders that overlap normality at one extreme and profound intellectual impairment with other evidence of severe brain malfunction at the other' (Rapin & Tuchman, 2008, p. 129). The use of words generally considered as offensive when describing a person, such as 'malfunction' (indicating a person is not 'normal' or deficient), may spur negative connotations around having an autism diagnosis. Chown (2019) also suggests that the boundaries between meeting a diagnostic threshold for autism and being labelled as having traits of autism are flexible. More recently some researchers (for example, Runswick-Cole, 2016) have questioned the existence of autism, due to the wide range of people of varying abilities that are labelled as autistic. Autism has been viewed as a 'catch all' diagnosis as many people fall under this diagnosis category but present similar symptoms in different ways and therefore its usefulness and meaning to wider society has been questioned. This is particularly the case as autism tends to be seen as either an asset or deficit, rather than a combination of both, by different parts of society. In discussing the ontology of autism, it is evident that societal views towards autism influence the reality of it, such as the language used about it (Rapin & Tuchman, 2008) and diagnostic flexibility (Chown, 2019). However, many autistic people who find their diagnosis helpful argue that they were described in many negative ways prior to having an autism diagnosis. Therefore, if autism is not considered to be real, these people would still exist with the difficulties associated with autism, but be grouped under different societal labels. Chapman (2020) argues that autism remains a useful classification. Autism functions in the world and helps explain the challenges people might face. Removing the label of autism will not remove these people with their difficulties and also strengths from society. My ontological relationship with the reality of autism reflects the wider debates and differing positions on autism.

Qualitative research increasingly tends to be associated with a relativist ontological perspective (Andrews, 2012). Moon & Blackman (2014) detail relativism to assume that reality is different for every individual as it is constructed within the mind and influenced by culture, social norms, time and environment. Therefore, relativism argues that a single shared reality cannot exist as no humans experience the world, and make decisions to act, in the same way. Although my research seeks to gather - and express - individual experiences, and thus could be assumed to follow a relativist perspective, all these experiences are based on the single shared reality of identifying as autistic. Thus, showing further evidence that the boundaries between realism and relativism in my research are fuzzy. Harper (2011) argues that it is a common standpoint to believe elements of both realism and relativism. Moreover, as Goodley and Lawthom (2005) have argued, disability researchers often move in between realism and relativism in their work. One might start with the reality of disability but move quickly into more relativist accounts of disability especially if one is deploying a qualitative inquiry.

Overall, in this ontology section, I have discussed how my research starts from an ontological stance of realism, in taking autism as a single real entity, but ultimately sits in a space along the fuzzy border where realism and relativism meet. I acknowledge I need to include some relativistic principles when analysing data, but also rely on realism when considering autism. In addition, I have presented how disability, and autism in particular, can be divided by the realist and relativist debate predominantly due to the presence, or lack of, concrete aetiology.

3.2.2 Epistemology

Epistemology is how knowledge is created about the nature of reality (Clough & Nutbrown, 2012, p. 30). Many epistemological stances exist, and vary in complexity in the relationship between the object (the truth) and how it is interpreted by a person (Moon & Blackman, 2014). Within disability studies, much research has focused on the epistemology of different positions adopted in relation to the knowledge construction of disability (for example, Goodley et al., 2019). A considerable amount of disability research is based on social constructivism (Barnes et al., 1999), due to the widespread perception that disability is made up of both an impairment and a social construct.

Functionalism is often seen as a basic epistemological view, particularly of disability, as it essentially highlights what a person can or cannot do when compared to a defined norm (Barnes, 1998). More recent Western research tends to disregard functionalism in favour of more complex epistemologies, perhaps due to its simplistic, seemingly outdated nature and the reductionist view of functionalism. Whitehead (2020) is a notable exception as he highlights that much effort has been put into searching for a cause of autism, for example a genetic basis, but that less attention has focused on how autistic people function in a predominantly neurotypical world. This suggests a disjoint between research and society, as many support systems such as financial benefits (Citizens Advice, 2021) require an autistic person to highlight how *they* cannot, or find it significantly difficult to, function in 'normal' society rather than contest how society has imposed barriers on them. Therefore, it is necessary to ensure that different epistemological stances are attended to address particular research questions and to develop a more holistic understanding of phenomena. This is particularly important due to the dominance of functionalism in how we are expected to define disability in society.

Dean (2020) explains radical humanism as an epistemology based around human need, rather than just focusing on what a human can do compared to others. In terms of disability studies, it 'identifies and challenges ableist ideologies' (Goodley, 2016, p. 72) as knowledge is understood with relevance, or resistance, to current disability thinking, hegemonies and wider social norms (Goodley, 2005). I think in order to achieve change, knowledge has to be situated within currently accepted norms. My consideration of how autism is constructed in different ways with regard to social and cultural factors means - especially within higher education - that I will lean on radical humanism to critically understand autism.

Qualitative research that explores lived experiences tends to move towards subjectivism, as this research focuses on people's beliefs, attitudes and own experiences of a situation (Moon & Blackman, 2014). Subjectivism specifically accepts that there can be multiple knowledges from truth claims and reality changes; people impose their own meaning on the world and interpret it how it makes sense to them. This engagement with subjectivity allows understanding of how culture constitutes subjectivity.

Although focusing on one epistemological stance is common in research, Johnson and McRuer (2014, p. 130) argue that within disability research it is important to make and unmake disability epistemologies. This is in order to challenge those who confidently ‘know’ about ‘disability’. People can hold set opinions of disability and what a disabled person needs, which over twenty years ago, Campbell and Oliver (1996, p. 96) attributed to disability studies being focused on ‘the wheelchair brigade’. This focus on providing access for physically disabled people still tends to prevail, due to the usually visual nature of the disability. Although, disability access for any disabled person tends to be poor and as an afterthought, regardless of how visible to others the disability is.

This hierarchical distinction of disability, and of what counts as a disability, has recently become an even more pertinent debate in society due to the Covid-19 pandemic. In the UK (as with many other countries) it became mandatory to wear face coverings in the majority of public indoor situations for all aged over 11, unless exempt due to a medical condition or disability. Official guidance on whether a person should have to disclose the reason for not wearing a mask, or who decides the validity of said reason, is vague (Department of Health and Social Care, 2021). The majority of people who were exempt from wearing face coverings chose to wear some form of lanyard, badge or other item of clothing to highlight that they were exempt (Department of Health and Social Care, 2021), as an explicit way of making ‘invisible’ disabilities visible to wider society. I argue that this is a productive use of a functionalist understanding of disability. One particular example is the sunflower lanyard. Although the sunflower lanyard scheme has been in use since 2016 it has become much more popular due to the law effectively making it necessary to disclose a ‘hidden’ disability (Hidden Disabilities, 2021). Although, much too early to tell, it could therefore be questioned whether autism and other disabilities that are not instantly physically recognisable will now be given as much thought as physical disabilities due to their wider visibility and thus whether epistemological thinking on disability will change in the near future.

Overall, I have described how my research best fits into a radical humanist perspective, but have emphasised the need to be fluid in epistemological thinking and thus incorporate many different schools of thought as appropriate.

3.2.3 Methodology

In consideration of my ontological and epistemological stances, I argue that in my research an idiographic methodology prevails (Goodley & Lawthom, 2005). Idiographic methodologies seek to identify behaviour of individuals within a population, whereas nomothetic methodologies seek to identify behaviours of a population without singling out specific individuals (Conner et al., 2009). Frumkin et al. (2020) investigated the relationship between emotional and physical pain in people with chronic physical pain. They employed both idiographic and nomothetic approaches. They found that at a group level (a nomothetic approach) emotional and physical pain were linked. However, when Frumkin et al. (2020) explored individual experiences further (an idiographic approach) they found some participants did not follow the group trend such as a participant not experiencing a link between emotional and physical pain, and a participant who experienced much stronger links between the types of pain. This study by Frumkin et al. (2020) demonstrates that nomothetic approaches can show trends or generic experiences which may then become a norm, but an idiographic approach allows for more exploration of individual experiences, beyond that of a derived norm. Beail and Williams (2014) highlight that idiographic research exploring individual experience contributes to scientific advancement; adding qualitative depth to knowledge.

The terms ‘lived experiences’ and ‘subjectivities’ have similar but nuanced meanings. It is important to briefly explore their differences. Lived experiences refers to what a person has experienced themselves. This means they have knowledge and understanding that a person who did not have the same lived experience will not have (Mapp, 2008). Subjective experience refers to the emotions, feelings and opinions of a person based on a lived experience. These subjective experiences are also culturally suited and influenced by social interactions (Bhaskar et al, 2018). In this thesis I combine both the lived experience and subjectivities of autistic participants in my research to go further than simply the objective experience, but to also explore how they made participants feel. Milton and Moon (2012) argue that although the autistic lived experience may be studied, not understanding the subjectivities of autistic people contributes to the distrust that the autistic community can hold towards researchers. I do not want to contribute to distrust in the field of autism research. Therefore, I am particularly interested in exploring the subjective experiences (as well as life experiences) of women who are labelled as autistic. I will investigate their lived and subjective experiences at university and how these overlap with other autistic women. I do not seek to gain a representative picture of the experiences autistic women have at university. Stereotypes of autism dominate societal and academic discourse (as discussed in *Chapter 2: Literature Review* and revisited throughout this thesis) and therefore an idiographic approach, whereby participants are considered individually outside of the generic stereotypes, is important. I also accept that this is a small-scale study, including a small number of participants in a given time and place, meaning substantially generalising findings is not appropriate.

Throughout my research I will also engage with ideas from critical theory and feminist disability studies. Critical theory encompasses three divisions: emancipation (empowering participants), participation (considering political agendas) or feminism (assuming culture is inherently masculine) (Moon & Blackman, 2014). I encompass all three divisions of critical theory within my research, although, considering the gap in the literature pertaining to the oppression and invisibility of autistic women within research, ensuring feminist principles are most explicitly expressed was most vital. I seek to empower participants by sharing their stories of university and highlighting what they feel is most important to share both through voice and creative expression. Empowerment is a potentially thorny concept as it involves an exploration of power. In *Chapter 8: Discussion* I critically evaluate whether a researcher can truly empower a participant. I consider how participants' experiences align with current political agendas using critical theory and move into critical disability theory to encompass both disability and feminist agendas. Also, I acknowledge that culture and autism are formed on masculine principles and seek to challenge that through conclusions and recommendations within my thesis.

Feminism emerged from the belief that women should have the same rights as men in terms of social, political, and economic power (Reisenwitz, 2017). Many waves of feminism have occurred (see *Chapter 2: Literature Review* for a fuller explanation). In the context of disability studies, and particularly with regards to autism, feminism can be suggested to sit awkwardly (Morris, 1998; Serra, 2015) due to disabled women being historically given a vulnerable role in society by both feminists and non-feminists. It is inarguable that the majority of women have gained some positives from feminist campaigns, such as the right to vote, but this may still exclude some disabled women where others refuse to accommodate their disability (for example disabled people who are detained or in institutions). In addition, although feminism seeks to promote equality of women and men, it remains relatively fractured around intersectional differences. Some disabled feminists have argued that mainstream feminism fails to promote equality between disabled and non-disabled women (Barnes, 2022; Garland-Thomson, 2002).

However, some researchers argue bringing feminism into disability studies can embrace the awkward in qualitative methodologists (for example, Simplican, 2017) and therefore promote change for disabled women. I want to embrace the tension between disability studies and feminism in order to create change. Many sub-populations of autistic people are routinely neglected from research, including autistic women (Taylor & DaWalt, 2020). In order for autistic women to be given the same status in society as other disabled and neurotypical women, they need to be included in research to ensure their status is promoted and their voices heard. The three aspects of critical theory: emancipation, participation and feminism (Moon & Blackman, 2014) should enable me to embrace the awkward space of including autistic women in research.

In relation to my research, it is primarily based on feminist principles from my positionality as an autistic woman. I bring my own lived and subjective experiences, both positive and negative, of being an autistic woman in a society that has historically marginalised women and in particular autistic women. My data collection and analysis could be understood as being inherently feminist. This could be explained through the notion that the personal is political, which can be central to feminist research (Morris, 1992). Oliveira (2019) emphasises that feminist researchers bring their own culture, understandings and identity to research and need to consider how these impact the meanings being placed on data. I remain explicit throughout this thesis about the different perspectives that I draw on feminism theory - including disabled feminists' theories - throughout my research as although people of all genders can be autistic as discussed in *Chapter 2: Literature Review*, societal stereotypes focus on autistic cis-gender men, thus marginalising autistic women. Throughout my interview questions and analysis - which I will explain below - I was keen to ensure that I considered how the participants' experiences may be different from autistic men. Whilst my research does not include any direct comparison to autistic men, I wanted to emphasise if participants made comparisons concerning gender. Showcasing this marginalised group in my findings and recommendations ensure that autistic women are put at the forefront.

Feminism does not only seek to research women but also examine how oppression relates to gender. When gender and disability interact with one another as Morris (1992) suggests, this intersectionality can influence research to bring a new way of looking at the world. Throughout the interview process and the analysis, I grappled with the notion of intersectionality, as I both wanted to highlight how all my participants' experiences differed, but also present the similarities in order to recommend change. As this study was explorative and based on a topic that has been under-researched, I felt it was necessary to provide some collective conclusions about autistic women students. By requesting participants create artefacts and engage in an interview, I felt able to discuss and visualise experiences at an individual level before exploring collective similarities through thematic analysis. Generating conclusions about a small group of a population may evoke change.

My focus on presenting some general conclusions about my participants as well as showcasing their individual stories led me to consider the relationships between my methodological ideologies and theories of belonging. In particular, about whether the experiences of individual participants would belong within a collective conclusion. In addition, much of the literature discussed throughout this thesis so far has alluded that autistic women are routinely marginalised from belonging as a woman and as an autistic person. I wanted both participant stories to belong together as a group of stories, but also that participants felt they belonged within this research project. I reflected on my own experiences of belonging and these resonate with Kohut et al.'s (1984) identity-proximity theory which they describe as a person not being able to be comfortable as them self without other people who are similar to, or mirror aspects of them. This suggestion that belonging affects identity, particularly influenced my considerations when analysing participants' experiences of interacting with other people. I will unpack this below in my reflections as a disabled researcher.

In summary, I have demonstrated that my theoretical perspectives and opinions behind conducting research are changeable and fluid, such that I can adapt them to the situation and ever-changing nature of research. It can be helpful to define a research project in terms of specific theoretical understandings and therefore primarily my research sits within a realist ontological perspective, a radical humanism epistemology, voluntarism human nature perspective and a predominantly feminist methodology. It is important to recognise that the emphasis of Critical Disability Studies and feminist theories on empowerment and politicisation inform the methodology and analysis of this thesis.

3.3 Research Methods and Design

In order to ensure autistic women felt able to participate in my research and so I could meet the aims of my study, I had to carefully consider the types of research methods to use. Standard qualitative research methods take many forms, including focus groups, interviews, observations and personal accounts (Bryman, 2016). I contemplated using collective methods in order to form discussion of shared experience, but due to logistics and the sensitive nature of my research decided against these. In addition, there is evidence to suggest participants tend not to give such extensive in-depth accounts during collective methods, for example focus groups (Smithson, 2000). I rationalise my choice of artefact creation and interviews in the next two sections. I also discuss how I join these two methods together.

3.3.1 Using Creative Methods

Creative methods broadly refer to participants producing non-verbal data in expressive ways (Gauntlett, 2007). They can be categorised into three approaches: interpretation of ‘found’ materials (for example photo elicitation), researcher-made creations (for example a researcher photographing an environment they are researching) and participant-made creations (for example, documentary making) (Mannay, 2016). Creative methods are gaining popularity within research to challenge methodological problems that exist such as collecting data that does not focus on the spoken word and increasing accessibility (for example, Bagnoli, 2009). This may be due to participants being given more control in how they participate in research and allowing them to process their own understandings in diverse ways (Tarr et al., 2018).

Using art in research has gained immense popularity over the last decade (Leavy, 2020). One example of using art as a research method is Culshaw’s (2019) exploration into the ways in which teachers struggled in secondary schools. She asked participants to make a collage (where items were placed but not stuck onto the paper) to depict how they thought they were struggling as a teacher, which took place during one or two interviews. This creative process allowed her to give participants different ways of expression and use a method that she thought participants would be unfamiliar with. Law and Urry (2004, p. 404) state ‘novelty is always uncomfortable’. However, being uncomfortable may be good and have surprising impacts. Leavy (2020) suggests art can make people reflect on situations differently or express emotions that are previously harder to access. Therefore, using less familiar and potentially uncomfortable research methods may provide richer or more novel data.

Despite potentially uncomfortable aspects when engaging in creativity, creating visual artwork can bring the unsaid or the unseen to the forefront of a research project. Macdonald et al. (2021) highlight how this creates a disability paradox and goes against traditional discourses of disability. They highlight that disability tends to be categorised into the visible and the invisible, but that creative research methods can bring both the visible and invisible into the spotlight. This is particularly pertinent within autism, a disability traditionally seen as invisible. The paradox that Macdonald et al. (2021) suggest surrounding the visible and invisible nature of disability could also be extended to other related paradoxes such as being simultaneously included and excluded. Therefore, I felt it imperative to include creative elements to explore the potentially nuanced and contradictory nature of being autistic at university.

I was keen to incorporate ways of researching that allowed more than just the spoken or written word to be used, both to reduce familiarity and as these ways of communicating can feel alienating to autistic people. Bagnoli (2009), Heath et al. (2009) and Lapum et al. (2015) contend creative methods facilitate participation beyond standard text and talk, and enable exploration of topics less talked about. Therefore, I hoped creative methods would allow participants to express themselves in a way they felt comfortable, favouring autonomy over directivity.

No method is without its limitations, including creative methods, which need to be considered. Brooks et al. (2020) cite that the potential length of time required and participants perceived artistic ability can be barriers to participation in creative methods. I was mindful that some people would refrain from participating because of the creative element, but that it would suit the preferences of others. In addition, I hoped remunerating participants would somewhat compensate for the time required to complete a creative element.

Overall, my decision to use the creative method of artefact production was motivated by my desire to give participants the option to be able to communicate in their preferred way, including non-verbally. This was to give participants choice but also to challenge the traditional methods that dominate qualitative research. Artefact production consisted of participants being given the choice of creating up to three artefacts. I defined an artefact to be any piece of creative expression (such as artwork, film or writing) that depicted a moment at university which they felt their experience as an autistic person to be particularly pertinent.

3.3.2 Interviews

In addition to artefact production, I used online interviews which included elicitation questions about the artefact(s) and other aspects of the study. Participants were able to choose how they wanted their interview conducted from the options of video, voice only or text only. Interviews were chosen to be online due to increased accessibility and cost, prior to the pandemic starting. This was to ensure participants retained as much autonomy as possible over the interview.

Interviews are undoubtedly the most popular research tool in qualitative research (Briggs, 1986; Forsey, 2012), which Atkinson & Silverman (1997) contend is due to the 'interview society' we live in. They suggest that the mass media's use of interviews to elicit personal narratives such as in news reports has made interviews feel incredibly familiar and a standard part of cultural society. It therefore is a familiar tool for most research participants, due to its longstanding existence and accepted formats (Holstein & Gubrium, 2020). Forsey (2012) suggests that the same insight and depth is rarely obtained through other forms of conversation. Interviews being so ingrained in society may be why they are seen as evoking such insight into people's lives. In addition, Elliott (2005) argues people enjoy telling stories.

Traditionally, interviews that are conducted in person (Gray et al., 2020) are seen as a 'gold standard' (Saarijarvi & Bratt, 2021), however, conducting them virtually can enable different accessibility to them (not just within a global pandemic). Practically, online interviewing requires no travel to an interview location and therefore reduces the potential cost of participating in the research (Gray et al., 2020). In turn this may encourage more people to participate or may make researching over a wider geographical area easier for the researcher.

The difference in quality between face-to-face and online interviews has been questioned, but Deakin and Wakefield (2014) report no reduction in quality and contend that participants were actually more open and expressive online. This is particularly important when considering interviews with disabled participants, as online interviews may be more accessible. Benford and Standen (2011) suggest the removal of the problematic aspects of face-to-face communication for autistic people in interviews can make communication easier. However, flexibility needs to exist as Kerschbaum and Price (2017) posit that creating an ideal interview environment is impossible and therefore must be malleable and emerging to change with both the participant and the researcher’s needs. I note that I did choose to only conduct online interviews before the pandemic due to cost, however, as data collection commenced, I had no choice. Further studies, not conducted in a pandemic with greater funding, could consider participants’ preferences much more prominently.

3.3.3 Intermingling of methods

Throughout the consideration of methods for my study I was keen to ensure participants had the opportunity to participate through the deployment of a range of communication styles. Communication difficulties are a commonly documented feature of autism (Happe & Ronald, 2008) and although stereotypical, this does provide the only rationale for being able to go outside the traditionally perceived research norms. By embracing different methods – and intermingling them - I felt this added an element of flexibility to my methodology.

Creating the artefacts allowed communication in a participant’s preferred style, however, ‘artefacts do not exist in a vacuum’ and the experiences and power relations they are based on should be considered (Mannay, 2013, p. 137). In order to gain further insight into participants’ university experiences and the reasons they created an artefact, I combined creativity with a more traditional form of talk offered by an interview.

Clark (2005) describes combining methods as being similar to creating a mosaic, where different methods can be used together to complement each other and create a more detailed picture. I wanted to use this as I felt that it would honour participants' different communication styles whilst gaining insightful data. A mosaic approach such as this potentially gives more depth to the data collected and also provides opportunities for participants not only to tell their stories but also reflect on their own use of creative methods.

3.4 Sampling and Recruitment

My study combined a number of approaches to participant recruitment drawing on distinct inclusion criteria.

3.4.1 Sampling

I used both convenience sampling and snowball sampling. I primarily used Twitter in order to recruit participants. I used Twitter to disseminate my call for participants as I aimed to reach a wide audience of potential participants, but also hoped that potential participants and autistic allies may share my study information with others. I aimed to recruit at least five participants but no more than twenty. I responded to potential participants in the order that they contacted me. I was unsure how many people would apply due to the nature of my study involving creative work and thus was keen to not impose further screening on participants.

3.4.2 Recruitment

Recruiting autistic women who were willing to create artefacts and talk about their experiences had the possibility of being challenging. I believed this due to my research requiring participants to recall experiences which may have been potentially negative and upsetting. Moreover, I was aware of historical violence and disempowering research on autistic people and the ways in which this might have impacted on potential participants (see *Section 3.6: Ethical Considerations* where I explore further this history). These considerations required me to carefully think about how I would advertise my study and recruit in such a way that autistic women felt comfortable to participate.

I decided to disclose that I was an autistic researcher to potential participants. I chose to do this primarily as I thought it might make participants feel more at ease if they knew I was also autistic. I have to acknowledge that I did have feelings of apprehension publicly advertising that I was an autistic researcher due to the generally negative perceptions that exist about autism in society. Grant and Kara (2021) support my concerns as they argue autistic researchers tend to be portrayed by their deficits, rather than their strengths.

However, in some participants' initial communications they said they would not have considered my study if I had not disclosed I was autistic. Grant and Kara (2021) go on to highlight that autistic researchers can have skills that are suited for qualitative research such as increased empathy, loyalty and direct communication. I believe my transparency with participants to be an asset in my research. Pole (2007) stipulates that the relationship between the researcher and participants is key to ensuring reliable research data. I think that by disclosing my own identity I gained participants' trust from the beginning of the study. Perhaps there was a sense, on the part of the participants, that we might share life and subjective experiences.

Whilst I made this disclosure decision to benefit my participants it was also a political act; numbers of autistic autism researchers are still minimal. Dwyer et al. (2021) highlight that autism research has traditionally been shaped by non-autistic researchers and it is only in recent years that autistic researchers have disclosed their autism. Higson-Sweeney et al. (2022) contend that autistic people are only very recently being welcomed to be researchers as opposed to just being researched on. This may give reason to why autistic researchers have been unwilling to disclose their autism previously. This may be due to fear or because autistic researchers did not exist. Jones (2021) argues that autism research conducted by autistic people can help improve the lives of autistic people but is currently a mostly hidden resource. I thus hope my small political act of disclosing my status as an autistic researcher will contribute to the growing number of autistic autism researchers disclosing this part of their identities and highlighting the assets that being autistic may have in research.

I began recruiting participants in January 2020. My primary recruitment tool was through an image I posted on Twitter (see Appendix 1) that summarised the study, stated how I wanted participants to be involved and disclosed I was an autistic researcher. This was shared by around 200 people in the first week of being live. I had a back-up recruitment method of emailing university disability services and asking them to disseminate my study to autistic women students at the beginning of February if I had not recruited enough potential participants on Twitter. I did not need to use this in practice however as I successfully recruited enough participants through Twitter.

The main reason for using Twitter (instead of other social media or online platforms) was because by sharing my recruitment image I could access a large number of people without the need for negotiating with organisational gatekeepers. This would have been the case if I had needed to use my secondary recruitment choice (accessing students via universities). I would have had to rely on other stakeholders, such as university disability services, who would have to sign up to the principles and importance of my study in order to further help recruit for it on my behalf. Bryman (2016) notes that the process of gatekeeping can be politically motivated, as organisations or individuals seek to ensure they are portrayed in a particular light which can therefore require mediation between the researcher and the potentially researched. Whereas, in using Twitter to recruit, I negated the need to negotiate with organisational gatekeepers and only had to negotiate with potential participants, which some term 'auto gatekeepers' as the participant is in charge of their confidentiality (see Kay, 2019). Homan (1991) previously argued that in order for a participant to have full control over what they disclose, they need to have clear information about the researcher and what the research entails. I aimed to be as transparent as possible through both the recruitment and the study to ensure participants were able to act as auto gatekeepers without any coercion.

I decided upon three inclusion criteria for the study, primarily based on my research aims. Inclusion criteria were (1) participants had to identify as a woman, (2) participants identified as autistic and (3) participants were at the time of being recruited studying at university in the United Kingdom (UK). Participants self-screened as identifying as a woman and being autistic, and were required to use their university email address during the research to confirm they were a student. I restricted my study to students at UK universities for practical reasons that participants would be able to speak English and that my research could be streamlined more easily as disability support, on paper, is broadly similar across the UK.

With autism research, there is some debate about whether self-diagnosis of autism is valid. Although some recent autism research (for example, Cooper et al., 2021) does include participants who self-diagnose/identify as autistic without a formal diagnosis, the use of formal diagnostic processes are still a very common practice in research. I decided to not request a formal diagnosis as I am not trained in diagnosing, nor wanted to judge the credibility of people's diagnoses. I also argue that considering an autistic diagnosis involves no medical testing (for example, there is no specific gene related to autism) (see DSM-V, APA, 2013) and there is an argument by some researchers that autism as 'a thing' may not even exist (Runswick-Cole, 2016), self-identification is no less valid than formal diagnosis. I upheld similar values with regard to accepting each participants' self-identification as a woman.

28 autistic women approached me for further information about participating. Of this, two were not included for studying in a different country and three were not current students. Of the remaining 23 participants, four did not respond after being sent further details of the study and eight dropped out after completing the consent form but before completing the research. All eight that dropped out after giving consent cited the pressures of the Covid-19 lockdown as why they were unable to complete the study. These withdrawals all occurred during the beginning of the first UK Covid-19 lockdown, where the impact of Covid-19 was unknown, measures against it were minimal (for example, no vaccines) and fear about the illness was very widespread. This left eleven participants who completed the research.

3.5 Research Process

In this section I outline the process of data collection. I explain what happened in practice and how it went from initial contact to the end of data collection. I feel this process is particularly important to document as I had started collecting data just before the beginning of the UK restrictions relating to the Covid-19 pandemic.

I recruited eleven participants to take part in this study. Many more expressed initial interest in the recruitment advert on Twitter and a further eight people completed the consent form but did not finish the study. These people mostly cited time and stress from the then new restrictions regarding Covid-19 as the reason for them not wishing to take part any longer in the study. All who participated created between one and three artefacts and were interviewed. See Table 1 for an overview of participant demographics and explanation of their artefacts and interview type.

Table 1: Participant Demographics

Participant name (* denotes a pseudonym)	Level of Study	Country of Study	Number of Artefacts	Type of Artefacts	Type of Skype Interview
Billy*	Postgraduate	Wales	3	Photo and Written Description	Text
Cassy*	Postgraduate	Wales	3	Sketches	Voice
Katie*	Postgraduate	England	3	2x Artwork 1x Description	Voice
Kim*	Postgraduate	England	3	1x Artwork 1x Photo	Video
Jess*	Undergraduate	England	2	Poem	Text
Lilly*	Undergraduate	Northern Ireland	3	2 x Paintings 1 x Poem	Text
Megan	Undergraduate	England	2	Written Description	Text
Poppy	Postgraduate	England	1	1x Painting	Voice
Sarah*	Postgraduate	England	2	2x Artwork	Video
Sophia*	Undergraduate	Scotland	3	2x Artwork and Description 1x Description	Video
Sophie	Undergraduate	England	3	2x Sketch and Description	Video

				1x Description	

Table 2 below outlines the process for contacting the participants and how I kept in contact with them during the process of data collection.

Table 2: Communication Schedule

Stages of Communication	Communication
1	Placed recruitment advert on Twitter
2 (On receipt of either a reply to the tweet or an email)	Emailed: -Study Information Sheet (Appendix 2 and 3) -Consent Form (Appendix 4)
3 (On receipt of consent form)	Email to confirm participation, suggest a time frame and contact details of support organisations.
4	Every two weeks in the agreed timeframe (8 weeks) email sent to participants to confirm their continued participation and to address any difficulties / questions
5 (On receipt of agreed number of artefacts)	Email to arrange an interview date and type
6	Interview over Skype
7	Email to thank participants for interview, including debrief information and support contact details
8	Email copy of interview transcript for participant approval

9 (Before conferences/publications)	Email to confirm ongoing consent of participation

For the arts-based element of the research participants were asked to create up to three artefacts in any medium and email them to me before arranging an interview. The brief participants were given was to record experiences at university where they felt their autism had impacted in a positive, negative or neutral way. By having the artefacts emailed to me in advance of the interviews, I was able to take some time to become familiar with them before interviewing the participants. As I discuss in the next chapter (*Chapter 4: Introduction to the Participants*) the original aim was for artefacts to be used as simply a stimulus to aid discussion in the interview. However, as soon as I began to receive the artefacts, I became aware of their sophistication and they moved from being interview prompts to becoming key pieces of data in their own right.

After receiving the artefacts, I arranged an interview with the participant. Participants had the option to have two shorter interviews or one longer interview. All participants opted for a single interview. I conducted the interviews virtually over Skype, initially for reasons discussed in the Ethics Section (see 3.6 Ethical Considerations), but then Covid-19 restrictions forced the majority of research in the UK to go online. I decided that the participants would be able to choose between video calls, voice calls and text conversations in order to be more flexible and understanding to their needs and preferences. This was to try and ensure that participants were able to communicate their answers as comfortably as possible in order to elicit the most insightful data.

The interviews began with me introducing myself, then briefly re-outlining the study, giving a broad overview of the question topics and reminding participants of their right to not answer any question or stop the interview entirely if they wanted to. I followed a semi-structured approach to the interviews (see *Appendix 5* for interview schedule). I focused the interviews on gaining more information about the artefacts the participants had created and the significance of choosing these experiences, and about their university experiences more broadly. I also asked participants to suggest what key terms meant to them such as autism. I thought that participants would use their artefacts as a starting source to stimulate discussion surrounding their wider experiences at university, and that this would help me as an initial source of conversation and connection. However, the majority of participants chose to answer my questions first, before discussing their artefacts. I concluded the interview by asking participants which online retailer they would like their gift voucher for. All of the interviews were recorded and after the interview concluded I downloaded the recordings into a password-protected folder on Google Drive. I then transcribed the interviews ad verbatim, before emailing a copy to the participant. This was so that they could edit the transcript if they were not comfortable with the content of their interview.

3.6 Ethical Considerations

Within a research project, considering the ethical implications of it are paramount to reduce harm to participants. Ethical approval was gained through The University of Sheffield School of Education Ethics Committee. Gaining ethical approval required careful thought and consideration, particularly as the study was deemed by the Ethics Committee to include both vulnerable participants and a vulnerable researcher, due to us all identifying as autistic. I was chosen to have my ethics application and how I had conducted ethics in practice audited by the University Research Ethics Committee (UREC). The UREC randomly chooses a selection of funded PhD students to audit each year. The UREC noted my application demonstrated sensitivity towards the complexities of research with autistic people and a focus on the wellbeing of participants. I consider both some theoretical underpinnings and practical ways I sought to use to ensure my participants were as protected as possible.

Researching within the field of autism is potentially contentious, due to the ethics of autism being of current high interest. Pellicano and Stears (2011) highlight that in recent history autism research and discoveries have rapidly increased media interest, but that little interest has been given to any concerns autistic people may have about it or to the ethics of participation in such research. Fletcher-Watson et al. (2019) note although it is accepted that autism research needs to become more participatory this has been seldom implemented and mistreatment by researchers towards autistic participants still exists. Nicolaidis et al. (2019) created the The Academic Autism Spectrum Partnership in Research and Education (AASPIRE) guidelines as guidance for researchers of how to include autistic adults in research, through encouraging participatory research and ensuring accessibility.

Considering some autistic people's mistreatment in research and concerns regarding previous research I was keen to consider ethics from a person-oriented perspective (focusing on the participant's needs), rather than focusing on the regulatory concerns such as forms and paperwork required to pass an ethics application that Cascio et al. (2021) argue researchers tend to focus on. Cascio et al. (2020) emphasise that many concerns autistic people may have about participating in research will also be pertinent to other minority groups in society, but that the controversies that surround autism, such as historic mistreatment of autistic people in research, means extra consideration should be taken.

Cascio and Racine (2018, p. 177) propose five guiding principles to aid researchers in achieving this: '(1) respect for holistic personhood; (2) acknowledgement of lived world; (3) individualization; (4) focus on researcher-participant relationships and (5) empowerment in decision'. In consideration of these principles and the AASPIRE guidelines (Nicolaidis et al., 2019) I now consider how I attended to the practical considerations of ethics below.

3.6.1 Consent

I gave participants the study information in both written and visual forms to reduce the possibility for misunderstanding (See Appendices 2-4). Loyd (2013) argues that autistic people may prefer information presented visually because it is less cognitively demanding and easier to process the meaning of it.

There is debate about whether to have a one-off consent form or allow participants to consent throughout the research process (Sixtensson, 2022). Some researchers (for example Loyd, 2013) argue that 'process consent' should be employed because people's opinions about their consent can change. This means returning participants to a consent form to check on their understanding and participation. After asking participants to sign the initial consent form, I verbally reasked them for their consent again at the start of the interview. After the interview, I asked participants to review their transcript and remove any information they no longer wanted to share. I also informed them that prior to any dissemination of data, such as at conferences, that I would endeavour to inform them so they were able to help shape what I said about them if they wanted. Gibson et al. (2012, p. 19) argue that 'ethical issues are not confined to the process of data collection' but are also key to consider during analysis and dissemination of research to ensure participants are fairly represented.

Participants were also given the choice of whether to use a pseudonym during the research process or to use their real name and have this associated with their data. Three participants chose to use their real name and the remaining eight wanted to use pseudonyms. I gave participants this choice so that they could have autonomy over issues of anonymity. For example, this allowed participants to consider how anonymity may affect talking freely about their experiences, any potential repercussions from the dissemination of the research project due to identifiability and whether they wanted their name associated with their artefacts.

The three participants who wanted to be known by their real names (Megan, Sophie and Poppy) are able to have their name associated with their voice and opinions. Regardless of a participant's choice, any other personal information, for example university names, were redacted from the data to preserve some anonymity. I made this decision because Ellis (2007) states that within participant accounts, particularly those attributed to a real name, people who do not choose to participate in the research can be talked about without their permission. Ellis (2007) argues that the researcher has the responsibility not to implicate these unknowing participants by ensuring they are not recognisable in the stories that are told.

3.6.2 The Use of Social Media in Research

I recruited participants through a poster image I posted on my personal Twitter account (see *Chapter 9: Appendices*) with the hashtag #AutisticsInAcademia so it could be seen by anyone on Twitter who follows this hashtag. Potential participants were asked to email me for further details. No other part of the study took place on Twitter. I highlight some ethical considerations that surround using social media in research.

I primarily chose to use Twitter for participant recruitment as it was, and continues to be, a platform where there is a large and active community of autistic people, which I am also part of. I briefly touch on the importance of this community and why engaging in it for participant recruitment was so important. Egner (2022) suggests that an autistic community on Twitter is important because in most societal discourse autism is understood in medicalised and simplified terms and that Twitter has become a space where autistic people can discuss what it means to be autistic outside standard cultural norms. This is particularly important as Egner (2019) argues that autistic voices are frequently excluded from scholarship in favour of non-autistic opinions (although this exclusion is decreasing). Guberman (2022) states that Twitter is a place where both autistic people and researchers can discuss and challenge current thinking about autism in order to progress change.

Within my project I was very keen to enable people to participate without the need to include gatekeepers. This was because I felt that often autism access is frequently policed by non-autistic people and I wanted to avoid having other people decide who could participate in the research. Williams (2020) argues that gatekeepers sometimes pre-select potential participants based on what they think the research requires, which does not always match the aims of the researcher. I wanted to give autistic people the opportunity to make the decision for themselves. Andrews (2012) argues that social media networks can facilitate direct communication between the researchers and potential research participants, which can reduce anxiety around participation. This could be because potential participants feel more personally approached and interacted with. By using Twitter, I was able to interact directly with participants in a timely manner without the need for gatekeepers to be involved.

Twitter can enable information to be disseminated quickly. Forgie et al. (2013) document Twitter is intended to allow the quick widespread sharing of conversation. Sibona et al.

(2020) highlight this can be beneficial in advertising a study due to the speed in which information can be spread, via re-tweeting and hashtags, therefore meaning high numbers of people can view a study advertisement. The quick speed at which my recruitment poster was shared and interacted with was helpful in terms of reach and I received a number of enquiries about joining the study. Although the majority of enquiries fitted my selection criteria, some did not (most of these cited that they had finished studying at university). This was difficult to navigate as these people were clearly interested in the research but were not eligible to participate. I thanked them for their interest and for highlighting that my research was important. Arigo et al. (2018) argue that reaching the target audience on Twitter, without alienating other interested parties or attracting negative interest can be very difficult.

Twitter can provide anonymity for its users, which can enable users to feel like they can post freely. This can make verifying identities and ensuring participant criteria is met harder, and O'Connor et al. (2014) highlight that researchers need to acknowledge this in research and use their best judgement when examining participant responses. In order to ensure participants were university students, after engaging with them on Twitter, I requested they email me from a university email account.

Social media platforms appear to be constantly changing, as new platforms become popular and new technological advances are made. Therefore, I argue attending to the ethical implications of social media use within a research project needs regular revisiting through the duration. I recruited participants in early 2020 on Twitter when, in my opinion, the platform appeared popular within the academic community. Towards the end of 2022 after I had completed this study, Twitter became the centre of some controversy after it was purchased by Elon Musk (Fortson, 2022), which prompted some advertisers and users to leave the platform. Although I feel discussing recent ongoing controversies of Twitter is beyond the scope of my research (as I conducted my recruitment prior to these), it has made me consider whether I would use different, or multiple social media platforms in future research.

Aside from the practical ethical considerations of using social media, there is also the consideration of access to the platform. Those without a Twitter account could not access my study. Throughout my research I have strived to ensure accessibility, such as through using research methods that do not solely focus on using spoken word. By using Twitter, those who would otherwise meet my participant criteria were therefore excluded from participation. However, due to the lack of research on autistic women's experiences I felt it most important to advertise to many people, in a sense to pave the way to then explore more nuanced groups of autistic women. I return to this thread in *Chapter 9: Conclusion.*

3.6.3 Participant Payment

As a feminist it was important for me as a researcher to financially renumerate my participants for their involvement in this study. Payment in research is becoming increasingly common across many research fields (Head, 2009), however, it still remains a largely debated ethical concern due to usually vague guidance telling researchers to 'compensate fairly' based on complex institutional policy and practical constraints (Mackinnon et al., 2021; Nicolaidis et al., 2019). Despite the complexities of payment, compensating participants has benefits. For example, Mackinnion et al. (2021) suggest that it balances power relations between a researcher and participants, as researchers tend to be paid to carry out research.

Due to being an ESRC funded PhD student, I have had the privilege of access to a Researcher Training and Support Grant (RTSG). This means I have funds available to support my research and training needs, for example reimbursing participants and attending conferences. It is from this grant that these payments were funded.

Upon completion of the interview and after receiving a participant's artefact(s), each was offered a £20 e-gift voucher to a shop of their choice. One participant chose not to be reimbursed for their time. Hamilton (2009) suggests that giving participants gift vouchers instead of money can be patronising. However, I chose to give payment by gift vouchers, as opposed to money, because they do not count as income and therefore do not need to be declared against any governmental benefits. In addition, gift vouchers were faster to organise through university finance systems. I was aware that some autistic university students may claim means tested benefits and I did not want my participants to be further financially impacted in a negative way by their participation in my research.

E-gift vouchers were used in order to prevent a physical voucher needing to be posted which would have required me to collect more personal data from the participants. Gift vouchers tend to be treated in the same way as cash and therefore physical gift vouchers would have required me to significantly trust the postal system or pay extra for their insurance. In addition, during the Covid-19 pandemic the postal system reduced its service and so participants may not have received their vouchers in a timely manner.

Financial coercion is often cited as a reason to not pay participants for participating in research (Millum & Garnett, 2019), to ensure people do not simply participate in research for money. My study however, focused on life experiences and therefore even if a participant's motive for completing the study was just for financial gain, they would still have rich life experiences to talk about. In addition, Head (2009) suggests that the decision for a person to participate is not solely based on economic gain but rather other factors such as how a researcher advertises their study or connects with the participant community. Thus, I feel that offering payment in itself would not have solely coerced a person to participate.

Despite the minimal risk, I took precautions to avoid potential coercion of research participants. Remuneration was advertised in the 'Call For Participants' (see Appendix 1), but the exact sum was only revealed to participants after they had expressed interest in participating. Participants were only paid after they had completed and emailed me at least one artefact and had participated in the interview. I chose the figure of £20 after estimating it would take my participants up to four hours to complete my study (one hour per artefact creation and a one-hour interview). £5 per hour was less than the minimum wage per hour for the 18-21 age group (my potential youngest participants) which was £6.15 in January 2020. It is assumed that if university students have a part time job then they are working at or close to the minimum wage. I made this decision to ensure that participants were not earning more than they were likely to if they had not participated in my research.

3.6.4 Practical Data Handling Considerations

I conducted virtual interviews on Skype. I set up a Skype account solely for the purpose of this research. After research was collected from each participant, any details saved on Skype (such as name and email in the contacts section) were removed. At the end of the data collection the entire Skype account was deleted.

I chose Skype due to its security features and it being free to use for participants. For example, it has end-to-end encryption which reduces the possibility of the call being hacked by a third party. I was able to record the calls, but the storage time on the system was limited to 30 days (unless the files are downloaded). This is an added security feature that further protects participants' data.

Data was stored on a secure university drive under either a pseudonym or the participant's first name (only) at their request. A spreadsheet with all the participants' full names and contact details was stored separately in a folder with a name that was unconnected to the research.

3.6.5 Ethics of being a Disabled researcher

Within my research I have always been transparent about my own identity as a disabled, and more relevantly to this project, autistic researcher. Some participants said they would not have taken part if I had been a non-autistic researcher. The research distinction between 'insider' versus 'outsider' research has been long debated (Dwyer & Buckle, 2009). I believe that this debate about research positionality is more nuanced than fitting into one of two mutually exclusive categories. Berger (2015) suggests it is important to consider this debate when a researcher is part of the research population. Autism as a singular label is attributed to people with widely different needs, strengths and difficulties. Although I am diagnosed as autistic and share the identity with all of my participants, all of our experiences and other intersectionalities are different. This made me consider intersectional reflexivity

(Sheldon, 2017). Hayfield and Huxley (2015) argue that researchers should not solely focus on how their identity impacts data collection, but rather concentrate on how their own identity may influence data interpretation and analysis. All qualitative research has elements of subjectivity and therefore I believe that as long as I declare my own positionality and beliefs, my own identity is simply part of my research project rather than having a positive or negative impact.

Is it of note that within my research design I had to attend to my own disability and consider my limitations within the research. Kerschbaum and Price (2017) highlight accommodations for participants are often spoken about and emphasised in research to highlight accessibility, however those put in place for the researcher are rarely mentioned. They suggest this is because participants can be portrayed as non-normative but researchers cannot (Kerschbaum & Price, 2017). Chouinard (2020) is a disabled researcher who argues that having an able body and mind in academia is a privilege, particularly when it comes to researching in the ‘field’. This was also highlighted over 20 years earlier by Oliver and Barnes (1997) who identified the barriers and challenges faced by disabled people. Whilst there is no suggestion that all disabled researchers are excluded from research, this suggests that there is still work to do in ensuring equality of research across this intersectionality. Chouinard (2020) also notes that the pressure of conforming to academic practices and norms can lead to scholars becoming disabled; especially in terms of mental health. I therefore feel it is key to emphasise how I made my research work for me as an already disabled researcher, without being further disabled by normative practice or feeling that I must hide this.

Within my research project I decided to conduct all data collection online so that I would not have to travel to see participants. Covid-19 restrictions started a month after my data collection began and made virtual research methods much more popular as they were much less affected by Covid-19 restrictions. Having creative artefact(s) to focus on in the interviews aided me to remain on track and to provide a common focus for discussion between me and the participant. Sheldon (2017) argues that inclusive research can end after data collection as sometimes dissemination methods are exclusive such as inaccessible conferences. Thus, who is able to know the research findings becomes exclusive. I have thus considered how I will disseminate my research - both normatively through the standard written thesis and in more creative ways. I aim to disseminate my research through a publicly accessible exhibition and through the use of social media to reach an audience wider than university level researchers.

3.7 Journey Through Analysis

In this section I outline how I approached the analysis of the data I collected through the artefacts and the interviews. I also consider the links between the different types of data and the challenges that arose as I engaged with the analytical elements of my research. Throughout the analysis I kept my research questions in mind. In allowing participants to create any type of artefact in combination with an interview I knew my data was likely to be messy and multi-layered (O'Dwyer, 2004), but that I needed to produce written analysis that would fit in with the expected norms of a thesis and the broad expectations associated with qualitative data analysis. However, Hunter et al. (2002, p. 388) argue 'there is magic within the method of qualitative data analysis' and therefore I felt I had to immerse myself in the messiness and complexities of the data in order to appreciate the elegance of it. Even though the product of this analysis in later chapters depicts a broadly straightforward thematic analysis, I highlight below how in practice analysis is complex, messy and enlightening.

Participants emailed me copies of all their artefacts before being interviewed. I tended to have the artefacts for at least a week before interviewing the participant. This allowed me time to consider the artefacts without accompanying explanation and wonder at what they might depict. It also gave me time to consider any questions I wanted to ask about them in an interview.

After transcribing each interview, but before coding and taking what I considered to be a more formal type of thematic analysis, I wrote a short summary of each participant and included these with each participants' artefacts in the next chapter (*Chapter 4: Introduction to the Participants*).

Initially, I took to analysing the artefacts and their descriptions from the interview separately to the rest of the interview responses. I put the interview transcripts into NVivo and pulled quotes I thought were about similar topics together. I broadly based my interview analysis on thematic analysis (Braun & Clarke, 2006). I use the term broadly, as Braun et al. (2022, p. 431) highlight that their explanation of thematic analysis is a 'springboard' and 'invitation' rather than a dictatorial set of instructions to follow. I started with an equally rigid approach to the analysis of artefacts (see Appendix 7). Based on Culshaw's (2019) analysis of collages, I devised a table to explore the descriptive, analytical and interpretative nature of each artefact. In addition, I included the descriptions that participants made of their artefact(s) in the interview. Culshaw (2019) considered that previous approaches to analysing images tended to entail a three-step approach allowing the researcher to move from simply describing the image towards attributing meaning beyond what can be seen, and thus is a well-tried out method. Wezyk et al. (2020) conducted a study which involved participants building Lego models. They highlight there are no recommended methods for analysing these models. Therefore, although my data did not just consist of images (but also poems and descriptive writing) which is what Culshaw (2019) bases her analytical descriptions on, I wanted to treat all artefacts in the same way. I felt the lack of rigid guidance in research regarding the analysis of creative pieces that Wezyk et al. (2020) allude to, gave me freedom in the tools of analysis.

I extended the freedom I felt from analysing both creative and interview data into the questions I was asking of the data. I focussed on an exploratory analysis, meaning I did not come to the data with any specific questions, however, from my own experiences and the literature review (*see Chapter 2: Literature Review)* I had some assumptions. One assumption - informed by my literature review - was that participants as a collective would have experienced some form of stigma or negativity from others and that autism would not be presented in a solely negative light. It is important to recognise, then, that my preoccupation with stigma - as one example of theory-led analysis - will have shaped the analysis.

Although I chose to base my analysis (and prior thinking about conducting the data collection) on thematic analysis, it is important to reflect on other frameworks and analytical influences I could have used in my research. For example, Interpretive Phenomenological Analysis (IPA) is a popular framework in similar types of research as it explores personal lived experiences (Eatough & Smith, 2017). Therefore, I could have analysed my data through this framework due to my focus on experiences. Smith and Osborn (2015, p. 41) argue that in IPA 'the researcher is trying to make sense of the participant trying to make sense of what is happening to them'. They go on to suggest that IPA involves the researcher being skilled in interviewing in order to probe further into interesting aspects the participant talks about to ensure the participant gives as fully detailed accounts of their experience as possible. Braun and Clarke (2021) explain that the main difference between IPA and thematic analysis is that in IPA the researcher analyses each transcript before creating themes across all transcripts, whereas in thematic analysis themes are developed across the entire data set. Spiers and Riley (2019) sum up the differences between IPA further by arguing that thematic analysis produces breadth, whereas IPA produces depth. As autistic women's experiences at university have not been extensively studied before, I was keen to demonstrate the breadth of what participants expressed, as opposed to solely focusing on the depth of it. This was to demonstrate the range of experiences autistic women have at university. In addition, Sandelowski & Leeman (2012) argue that using thematic analysis to create themes with shared meaning enables research to have practical outcomes that have more chance of success. This creation of shared meaning to make practical recommendations also influenced my choice of thematic analysis.

There may not be one method or steps of analysis that are best for any one particular type of research. Braun and Clarke (2021) emphasise that there is very rarely only one methodology, method or analytical approach suited to a particular qualitative research project and that researchers devote much effort to justifying why they did or did not use a particular one. They go on to speculate that different qualitative methods, established and non-established analysis frameworks, can produce similar outcomes. Therefore, I argue this research project could have used IPA or another analytical method but potentially would have demonstrated similar findings. It would be interesting to examine this in practice.

Whilst initially analysing the data separately, I did not feel fully immersed in the data by this approach. I realised, like Gleeson (2011) and Grbich (2007) say, that visual and verbal data is embedded in culture and therefore can only be analysed in relation to each other. Rose (2007, p. 57) also highlights that 'visual images do not exist in a vacuum' but are usually accompanied by narrative. I extrapolate this to include all of the artefacts. Also, considering half of my data took the form of creative expression, I felt analysis thus far was uncreative in comparison.

Therefore, I decided to cover a wall of my flat with data, themed by coloured and annotated post-it notes of ideas and links to other themes. I printed out the data multiple times, was able to cut it up, and physically move it (both quotes and artefacts) into different groupings as my thinking changed and progressed. I was privileged to have the space and privacy to do this, but it meant the data was ever present and enabled me to consider it during mundane activities as well as when I allocated specific time to it. Some of the data felt abstract and difficult to understand, therefore in order to understand it further I built small Lego models to enable me to consider data more in depth and to tease out interpretations less abstractly (see Appendix 6). This felt part of the process of playing with and being immersed in the data. When I had placed data in initial groups of themes, I decided to construct a small Lego model to aid my own processing. This was also to challenge myself to condense a theme into an overarching simple explanation. I was then able to put the individual models (that to me explained different parts of my data) together to ensure they created a coherent model as a whole. I imagined this process to be like ensuring separate parts of a Lego set could be played with individually but also function as a whole.

A researcher's own positionality can affect research in many ways (Bradbury-Jones, 2007). In *Section 3.6.5: Ethics of being a Disabled Researcher* I discuss how by being an autistic researcher I am an insider in the research project. I explain how this may have made participants feel more comfortable engaging in my research. Boveda and Annamma (2023) argue that researcher positioning should be revisited throughout the process of knowledge production. My positionality will have also impacted my analytical journey and whilst I argue that this is a strength of my research (see *Section 9.5: Strengths and Limitations)* it is essential to be reflexive through all stages of the research process like Boveda and Annamma (2023) argue. Kacen and Chaitin (2006) posit that a researcher's background influences the lens that they use to filter and make meaning of the data gathered, which may shape the findings of the study. I found some topics very relatable to my own experiences and because I felt more familiar with the topic, I may have been influenced to attribute more weight and focus to those.

During the interview and analytical journey, I found myself reflecting on the similarities between my own experiences and that of the participants. It was a consideration of mine to ensure that I did not unintentionally make my experiences the dominant narrative in the analysis. This is important for me to consider as although I am an autistic woman student myself, I have to keep in mind that even if experiences seem very similar there will be nuanced differences. Dwyer & Buckle (2009) term this 'researcher confusion' and explain that a researcher can inadvertently become a participant if they are not careful - when they are in the throes of analysis - so it is important to ensure that participants' voices are prioritised. I argue that although it is important to keep the idea of bringing participant voices to the forefront of my research, my positionality and the tensions it may create are central to the data analysis.

3.8 An Example of Running Through my Analytical Steps

Before turning to the analysis chapters, I now provide a snapshot of the steps I followed in creating the analytical themes. I do this to allow the reader to understand my analytical steps through a practical example. I also highlight where I resonated most with the data due to my own positionality. Clearly, going through every theme and analytical finding is impractical, so I use this section to offer some specific examples for the reader.

I started the analysis of the interviews through the deployment of NVivo. After reading the transcripts multiple times to familiarise myself with the data, I initially coded the transcripts simply by summarising topics that the participants had discussed (see photo in *Appendix 6: Journey Through Analysis Photographs*). This produced some very general areas of discussion that were predominantly based on my interview questions such as ‘good’ and ‘bad’ university support. However, this initial analysis allowed me to understand the topics that featured most prominently in the participants’ interviews. I pictorially visualised this on NVivo to give me a more visual representation (see photo in *Appendix 6: Journey Through Analysis Photographs*). Although the visual representation helped me to visualise the topics, it did not give me much insight beyond what participants’ spoke about most. This initial analysis helped me to familiarise myself with the data and to reflect upon where my own experiences related to that of the participants. For example, some participants talked about how they found it difficult to network at conferences due to the social interaction and ‘small talk’ required. I had attended conferences where I had experienced similar difficulties and frustrations a short period of time before data collection. The visual representation from NVivo enabled me to reflect on whether I privileged topics I resonated with.

I then turned to the artefacts. I initially explored the artefacts separately using a table based on Culshaw’s (2019) analysis (See *Appendix 7: Artefact Analysis*). The table enabled me to organise my thoughts. For each artefact I considered it alongside the participant’s explanation. I then turned to describing what I could in the artefact, including the structure and form, the analytical meaning of it and finally my interpretation. This was so I could develop both obvious and alternative readings of them. I focused the formation of the themes on what participants said in the interview. Where they spoke about their artefact I included their artefact within the theme. This was because I did not want to separate a participant’s story from their artefacts any further than I needed to.

I finally brought both the artefacts, my interpretation of them and the words of the participants together (which had been in NVivo) by physically displaying them on a wall (see photo in *Appendix 6: Journey Through Analysis Photographs*). Turning to a different medium enabled me to appreciate that the data could be pieced together in different ways. This allowed me to revisit my themes to begin to create more nuanced interpretations. For example, I was able to split ‘bad university support’ into more nuanced areas, such as negative interactions with staff which features as part of the sub-theme ‘Staff Impact’.

Overall, although in the following chapters I present what appears to be traditionally recognised analysis that follows thematic principles, the process to get to that was messy and became significantly different from just summarising quotes.

3.9 Conclusion

In conclusion I have discussed my theoretical underpinnings, research method and given insight into the research process; including my approach to analysis. I have considered the ethical issues behind the research study and focused specifically on those that may affect autistic participants in more detail. I now turn to the analysis of participants’ experiences of being an autistic woman at university in the remaining chapters. In the next chapter (*Chapter 4: Introduction to the Participants*) I provide an overview of how creative methods have been used in disability research.

4 Introduction to the Participants

4.1 Introduction

This chapter introduces the eleven participants by highlighting the artefacts they have produced alongside their interview narratives. I dedicate a chapter to the relatively untouched participant stories because I want the reader to get to know the participants prior to their data being presented analytically. I document both how the interview was conducted and where a participant's artefact(s) fit into what they said.

First, I critically evaluate the use of creative methods within disability research and discuss the values and purpose of introducing participants prior to analysis. Participants were advised they could use any creative expression that could be sent to me via email. All of the artefacts that were sent to me were either pieces of visual art, poetry or descriptive writing. Second, I introduce each participant through a short synopsis of their interview with inclusion of their artefact(s). Participants could opt for a pseudonym (denoted by a name and an asterisk, e.g. Billy*) or to use their real name.

4.2 Using Creative Methods in Disability Research

In the Methods chapter (see *Chapter 3: Methods*) I rationalised my choice for using creative methods within this project. Within that section, I focused on mainly providing a brief overview of what creative methods are and the importance of non-verbal access to research participation. In order to offer more context to the artefact(s) participants created in this study, in this chapter I provide a broader overview of the ways that creative methods have been used in previous research about disability or difference.

Wang et al. (2017) consider that creative research unearths different perspectives and uncertainties. By incorporating creative methods into research, richer data may be produced by participants. In addition, Aldridge (2007) and Walmsley and Johnson (2003) argue that careful consideration of research methods when working with disabled participants is vital to ensure that the researcher can be flexible to the needs of the participants, in order to avoid exclusion. I believed for my participants a mixture of the more commonly found method of interviews, with flexibility in how to participate, and creating artefacts would enable my participants to communicate in a range of ways. This flexibility to participants may not only lead to greater inclusion in research but in turn lead to more in-depth analysis and more complex research outputs.

It is important to consider how disability researchers have used creative methods in their research, in order to examine the impact on participants. A recent study similar to my study in terms of methods is Burch (2022). She investigated disabled adults' experiences and understandings of hate crime using mood boards, semi-structured interviews and collaborative reflections. Mood boards were created in workshops where conversation was recorded, but they were also used to elicit more in-depth discussion and further reflections during semi-structured interviews. One of the reasons Burch (2022) cited that she was keen to use creative methods is because it can encourage different ways of thinking and gives participants different ways of engaging in the research topic. In addition, she argues that using mood boards enabled participants to engage in difficult conversations surrounding hate crime that participants may not have been as willing to disclose if non-creative methods were used. I wanted to try and also improve access for the participants in my study by giving them several ways to communicate their ideas and opinions, which I felt using creative methods allowed.

Bernardi (2020) conducted a cross-cultural study of autistic children in England and Italy focusing on their identities after being given a label of autism. Methodologically, she was interested in how creative practices help children's autonomy and quality of responses in research. In particular she wanted to favour autonomy over directivity, which autistic children in research are rarely afforded. She argues much research tends to engage with children through methods that are similar to the adult-led interactions they experience in school. This therefore continually reproduces research practices that highlight adult-child marginalisation, even if that is not the intended aim, particularly with children who have a label such as autism. Although Bernardi's (2020) participants were children not adults, I liked her consideration of reducing marginalisation in research through creative methods. I also wanted to increase the autonomy my participants had over their participation and therefore reduced my directivity.

Another example of research that has been conducted using creative methods within disability research is Gibson et al. (2013). They used a combination of photography, audio diaries and interviews to explore disabled young men's experiences of transitioning to adulthood. All the participants were diagnosed with Duchenne's Muscular Dystrophy. They were interested in how gender, disability and socio-cultural understandings of social groups intersect. Gibson et al. (2013) used creative methods to document identity, encourage engagement in their research, encourage reflection and provide participants some autonomy in the research. They note however that some participants found it difficult to audio record due to their disability and therefore further flexibility was needed if the study was repeated. I also needed to consider flexibility and any limitations participants had in participating in research. By allowing participants to participate in whatever creative way they wanted to, I provided flexibility for them.

An interesting point to note is that Kerschbaum and Price (2017) argue that a researcher's disability should not be seen as a hindrance but rather as a source of knowledge. Within their research, Kerschbaum and Price (2017) highlight they are disabled and have tapped into their own experiences in order to construct a research project that was as accessible to both them and their participants as possible. I wanted to incorporate methods within my research that I would have felt comfortable with completing as a participant.

Examples given show there is continued scope for creative methods to feature in disability research. Creative methods are able to provide a space for disabled people to 'author their own stories' which allows troubling of normative misconceptions society has about the autonomy of disabled people's lives (Richards et al., 2015). Creativity can thus reduce barriers to participating in research and thus allow stereotypes and misconceptions to be continuously challenged and changed.

4.3 Relation To My Research

At the beginning of my research project, I had intended for the artefact(s) the participants created to be used simply as a stimulus in an interview, as something myself and the participant could use to start the conversation (as mentioned in the *Chapter 3: Methods*). I was keen to have something to start the conversation off, as communication is a common difficulty autistic people have. Although I gave my participants the choice of conducting interviews either through text, voice or video formats I felt that this was not enough to make them fully accessible. I therefore wanted to make the interview more accessible to both my participants and myself, by having an 'ice-breaker' we could discuss if needed.

In reality, participants were keen to discuss the interview questions and most alluded that they welcomed the opportunity to express how they felt about university as an autistic woman, which most had not been able to do before. However, it is impossible to tell what aided this most, the knowledge of the topic of the interview, or having artefacts which participants had produced.

After the first few interviews I realised how central the artefacts were to my research and how I needed to analyse them in their own right, rather than just consider them as a tool to aid conversation in interviews. It became clear that participants were using artefact production as a means of communication, rather than just a starting point in an interview. They described in detail how they had created the artefact and the different meanings of each part of the artefact. The artefacts held a rich amount of data and it was evident participants had deeply considered what they portrayed. This may have been because creativity as a research method can allow participants to reflect and conceptualise ideas in a slower way compared to other research methods to make meaning (Robert & Woods, 2018). Compared to more traditional qualitative research methods creativity can encourage more considered and thoughtful responses. Some participants used their artefacts to describe their experiences and then spoke about how they created it and what different parts of it meant, whereas others repeated the experiences they had created in words. Morris and Paris (2022) argue that although using art in research is growing in popularity, how it is integrated with other qualitative methods is much less established. I wanted to ensure participants had more than one option to express their thoughts and opinions rather than solely through a traditional interview scenario. I was keen to ensure I did not simply skip to analysis without appreciating the artwork and the interviews as whole stories in their own right.

This flexibility in changing how I approached my data collection and attributing more importance to the artefacts the participants produced evidences how my research developed throughout the process. My participants influenced this change, which also inspired me to want to showcase their interviews and artefacts within the written thesis as they became even more important and the forefront of this research.

4.4 Presenting the Pen Portraits

Within this chapter I was keen to provide a summary of participants' transcripts alongside their artefacts to show untouched accounts of their narratives. King and Horrocks (2010, p. 139) argue participants become 'more alive and present in our write up' if their story is documented. However, guidance on how a researcher should construct, present and analyse pen portraits is lacking and left to the researcher to decide (Sheard et al., 2017). I aim to make the participants more personable to the reader by summarising their interview and artefact(s); however, I acknowledge these are not presented entirely without analysis. I hope to enable the reader to feel immersed in the participants of this study, but acknowledge I constructed these participant summaries and so they are tainted with my perspectives.

The synopses all follow a similar pattern, starting with a short biography of the participant, documenting some interview questions and their artefact(s) with descriptions, and finishing with anything else the participants wanted to voice. I denote each pseudonym with an asterix in the title (for example Billy*) but then refrain from using it in the following text and further chapters. I present the summaries in alphabetical order by the participant's first name or pseudonym. Each summary is approximately 400 words, in order to fit into the word count confines of the thesis. Reducing each interview (some of which were approximately 10,000 words in length when transcribed) to such a short summary felt brutal and undoubtedly did include some analysis as I decided what parts of their interviews to include. However, these synopses provide an insight into the lives of participants that would otherwise not feature in the main body of the thesis. In addition, it allows presentation of the participants' artefacts in the context of their opinions and descriptions. Varpio et al. (2017) state that researchers and participants tend to view data from different lenses, as they have different agendas. I acknowledge that in the summaries some participants may have chosen to focus on elements of their interviews that I have not included, as they were unrelated to my research aims. However, within the confines of producing a thesis focusing on particular topics I believe these synopses to be as untouched and unanalysed as possible.

4.5 Participant Summaries

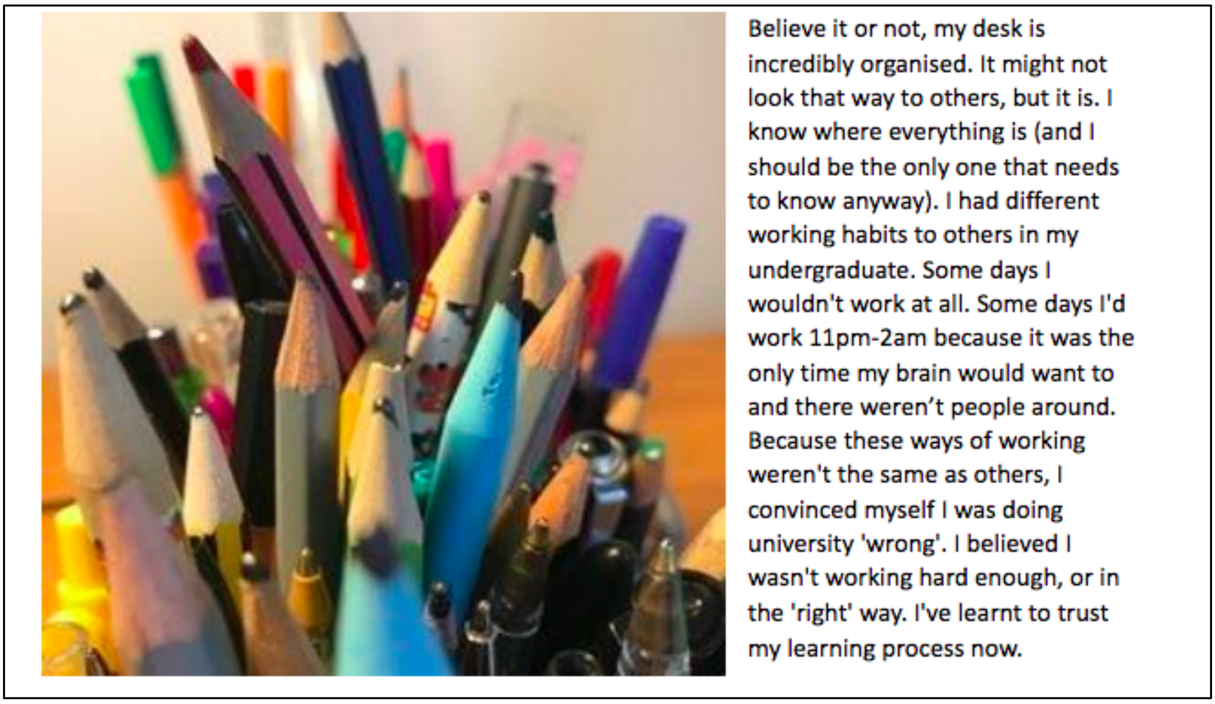
4.5.1 Billy*

Billy was studying for a PhD. She defined autism as another way of being and preferred to use diagnosis first language (autistic instead of person with autism). I conducted Billy's interview via text chat on Skype and so it was a shorter interview than interviews that were conducted verbally.

She described autism to be scientifically defined as a neurodevelopmental disorder, which includes difficulties in social communication and restrictive behaviours. However, Billy said she would rather define it as another way of being, but that that would suggest autistic people do not have bad days. She saw herself as different, but acknowledged that others may view her to have deficits rather than differences and therefore argued it was about perspective.

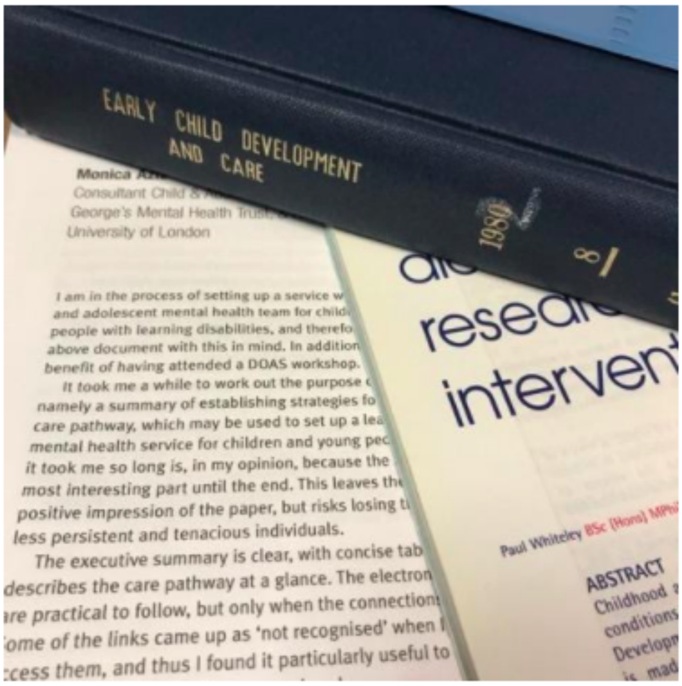
Billy then described her artefacts. Creating the artefacts stirred up both good and bad feelings for her to process. She wanted to combine an image and text as although an image can say '1000 words', she also wanted to write the '1000 words'.

The first artefact (see Figure 1) centred around Billy's learning patterns and how she felt these were 'wrong' because they were different from most other students.



Believe it or not, my desk is incredibly organised. It might not look that way to others, but it is. I know where everything is (and I should be the only one that needs to know anyway). I had different working habits to others in my undergraduate. Some days I wouldn't work at all. Some days I'd work 11pm-2am because it was the only time my brain would want to and there weren't people around. Because these ways of working weren't the same as others, I convinced myself I was doing university 'wrong'. I believed I wasn't working hard enough, or in the 'right' way. I've learnt to trust my learning process now.

Figure 1: Billy's Artefact 1



Today marks the first day in seven years of being in University that I used the library. To mark this momentous occasion I have taken a photo of the journals and book I requested. To say a library is quiet is incorrect. The library is very loud, full of people who clearly do not intend to study, with systems for borrowing/returning/printing that were never explained. There are not any quiet nooks and the system for booking a separate room to study, in peace and solitude has its own inexplicable process of emailing/applying/booking. I'd rather stay at home… So I did.

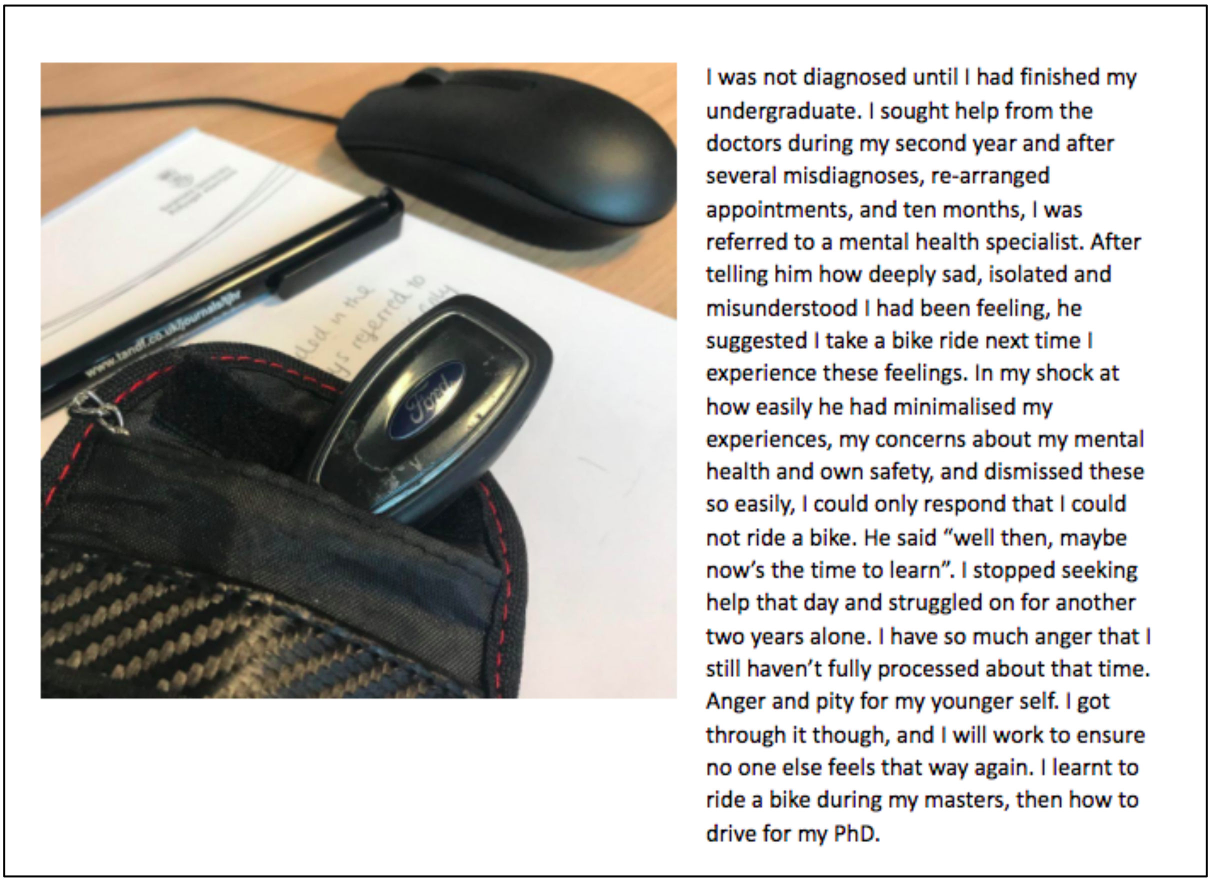
Figure 2: Billy's Artefact 2

Through Figure 2 Billy wanted to emphasise that everybody is taught a particular way to learn, but autistic people's brains may work differently and not be able to conform to these expectations.

Billy's second artefact (see Figure 2) depicted the first three books she took out of the university library on her first visit, seven years after starting university.

She said that the library tends to be viewed as a key element of the learning experience, but somewhere she found inaccessible. Before Billy was diagnosed she felt unable to articulate why these buildings were inaccessible to her.

Billy's final artefact (see Figure 3) depicted how the ability to access support has helped and hindered her achievement.



I was not diagnosed until I had finished my undergraduate. I sought help from the doctors during my second year and after several misdiagnoses, re-arranged appointments, and ten months, I was referred to a mental health specialist. After telling him how deeply sad, isolated and misunderstood I had been feeling, he suggested I take a bike ride next time I experience these feelings. In my shock at how easily he had minimalised my experiences, my concerns about my mental health and own safety, and dismissed these so easily, I could only respond that I could not ride a bike. He said "well then, maybe now's the time to learn". I stopped seeking help that day and struggled on for another two years alone. I have so much anger that I still haven't fully processed about that time. Anger and pity for my younger self. I got through it though, and I will work to ensure no one else feels that way again. I learnt to ride a bike during my masters, then how to drive for my PhD.

Figure 3: Billy's Artefact 3

She felt she was misdiagnosed with just mental health difficulties instead of autism and misunderstood for a long time because she is a woman. She thought the university had supported her mental health poorly.

We then spoke about what barriers and supports were at university. Billy focused on how the university norms and staff lacking disability awareness were barriers. Billy however did say, 'I think there are good individuals trying to make a difference in a sometimes pre-occupied establishment'.

She said the environment could be improved by having better quiet study spaces and more accessible events, which could benefit all students (not just autistic students). She ended the interview by saying that she thought autistic people's voices needed to be heard.

4.5.2 Cassy*

Cassy held a senior role within her university department and was undertaking a PhD as part of her staff development. She had two children who were formally diagnosed with autism. Cassy self-identified as having autism. She preferred identity first language to person first language.

Cassy attributed learning good social skills in formal situations to her dad being a priest. As part of the clergy family, she was required to mix with a range of different people from a young age, such as having dinner one night with aristocracy and the following night with a homeless person. Therefore, she learnt to perform appropriate social skills when required. She was unsure if she had grown up in a different environment whether she would have learnt these skills that are the required norm in society.

Cassy thought the biggest barrier at university was informal socialising, particularly at conferences in situations such as coffee breaks. She felt her presence was tolerated at these events but that nobody wanted to speak to her. This worried Cassy as she thought unstructured time at conferences was most important for networking. In addition, she thought there was a stereotypical opinion of what a student should do in their free time, such as enjoy alcohol, which she felt she did not fit into.

Cassy produced three drawings (see figures 4-6) prior to the interview. All were completed using a computer software package called ‘Remarkable’. Her first artefact (see Figure 4) depicted the different parts of a conference.

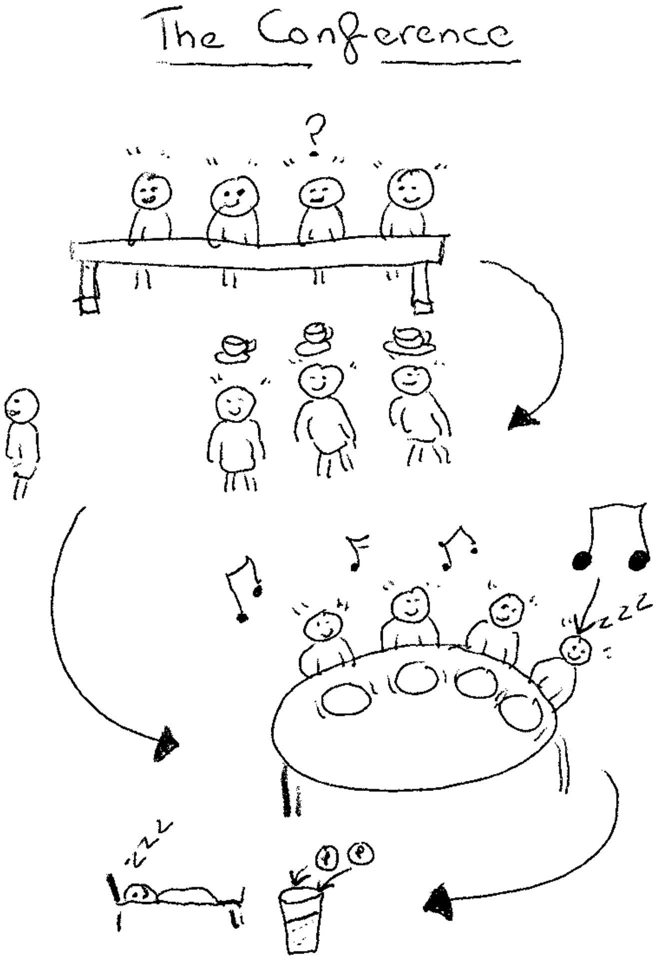


Figure 4: Cassy's Artefact 1 'The Conference'

She worried she would say the wrong thing at conferences and feels exhausted after them. Cassy's second artefact (see Figure 5) was about how she felt when meeting with students in her staff role.

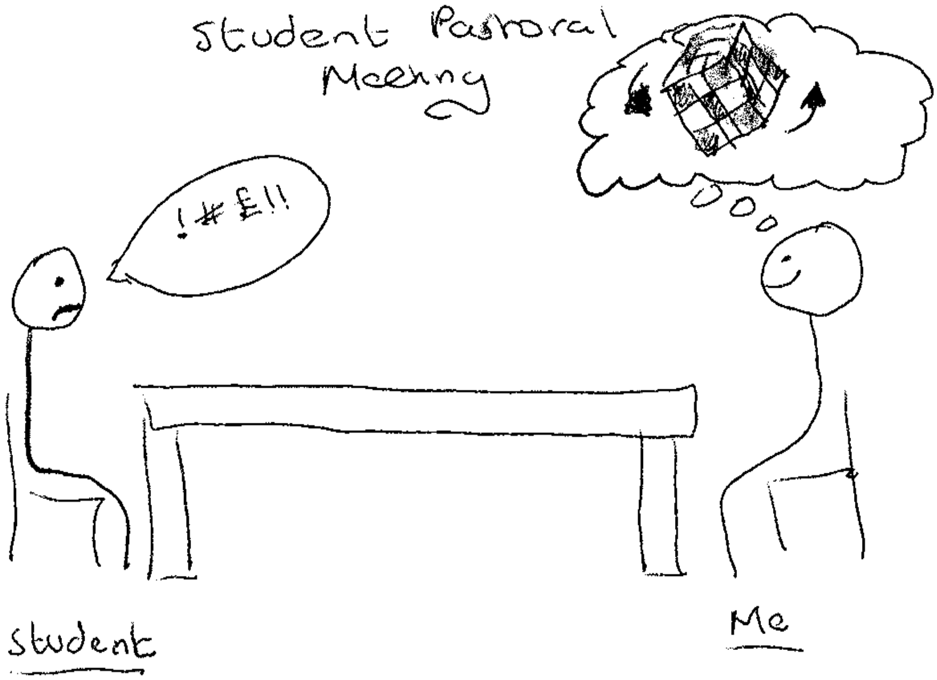


Figure 5: Cassy's Artefact 2 'Student Pastoral Meetings'

She felt like students were puzzles to solve, so that she could work out how to help them best. She termed this 'professional empathy' as intellectually she knew what the student was feeling, but did not feel it herself.

Figure 6 depicted Cassy's third image, where she has drawn butterflies flying out of her head.

Figure 6: Cassy's Artefact 3

She described basing this picture on her husband often saying her ‘brain is full of butterflies’ and tapping her on the head as if her brain is empty. She goes on to say this is how she believes she is perceived by others and is regarded as ‘a bit chaotic and ditzy’ within academia and people were quick to blame situations on her scattiness rather than considering other possibilities.

Cassy discussed how since she made the images she has re-opened them and reflected upon their meanings.

Cassy thought her experiences may have been different if she was an autistic man. She thought she would be judged less for having a ‘scatty’ mind and for not showing emotion. She commented that others do not think she can have autism as she is good with people rather than understanding that autism manifests in many different ways, linked to the environment a person grows up in.

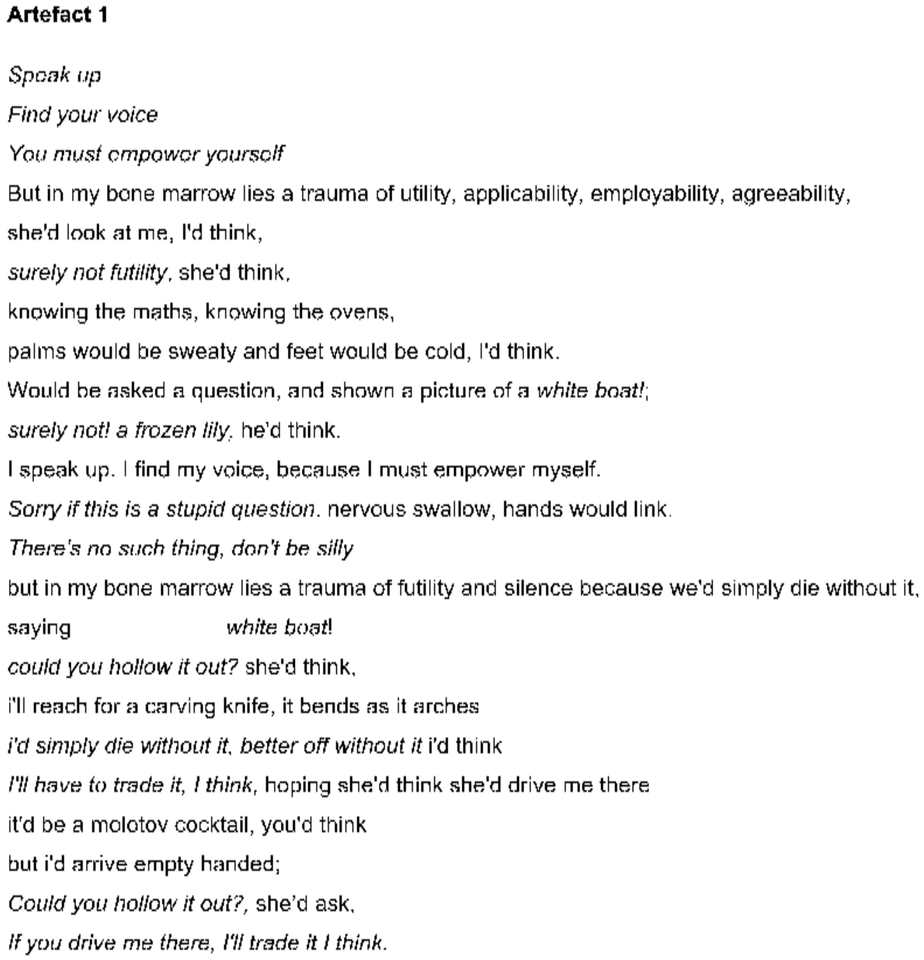
She thought the university environment could be improved to better accommodate autistic women by increasing autism awareness.

4.5.3 Jess*

Jess was in her final year of a Linguistics degree. She preferred to use diagnosis first language about autism. Jess expressed her lesbianism intersected with being an autistic woman.

Jess said she had received good support from her latest university course, even before having a formal diagnosis. Nobody forced her to do anything she cannot do or challenges her autism. However, on a previous course, she felt that lecturers assumed neurotypicality as the norm and were unsympathetic to her difficulties. In addition, Jess noted that being social and finding friends was a barrier at university, which impacted her academic achievement as it affected her confidence and ability to learn with peers.

Jess created two poems as her artefacts. Her first artefact (see Figure 7) was about the things her academic mentor said to her.



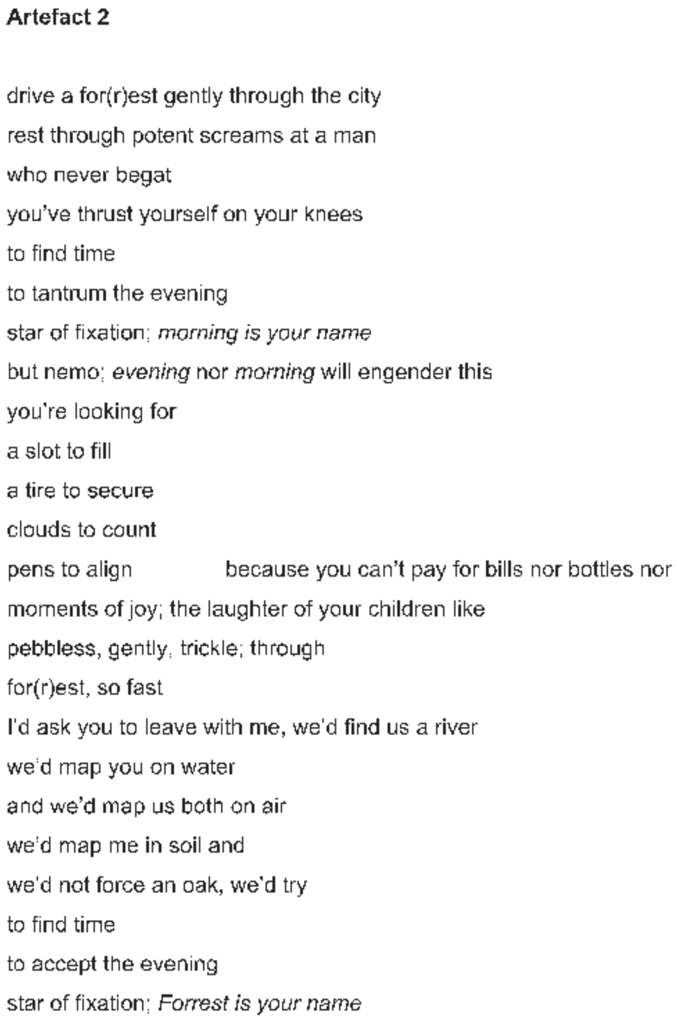
Artefact 1

Speak up
Find your voice
You must empower yourself
But in my bone marrow lies a trauma of utility, applicability, employability, agreeability,
she'd look at me, I'd think,
surely not futility, she'd think,
knowing the maths, knowing the ovens,
palms would be sweaty and feet would be cold, I'd think.
Would be asked a question, and shown a picture of a *white boat!*;
surely not! a frozen lily, he'd think.
I speak up. I find my voice, because I must empower myself.
Sorry if this is a stupid question. nervous swallow, hands would link.
There's no such thing, don't be silly
but in my bone marrow lies a trauma of futility and silence because we'd simply die without it,
saying *white boat*!
could you hollow it out? she'd think,
i'll reach for a carving knife, it bends as it arches
i'd simply die without it, better off without it i'd think
I'll have to trade it, I think, hoping she'd think she'd drive me there
it'd be a molotov cocktail, you'd think
but i'd arrive empty handed;
Could you hollow it out?, she'd ask,
If you drive me there, I'll trade it I think.

Figure 7: Jess' Artefact 1

Jess explored the encouraging things her mentor says to her about self-empowerment, but that she felt unable to instigate them due to fear about eradication, stemming from autistic people historically having been systematically wiped out for existing and speaking out.

Jess's second artefact (see Figure 8) was a response to the film 'Forrest Gump' (Zemeckis, 1994).



Artefact 2

drive a for(r)est gently through the city
rest through potent screams at a man
who never begat
you've thrust yourself on your knees
to find time
to tantrum the evening
star of fixation; *morning is your name*
but nemo; *evening* nor *morning* will engender this
you're looking for
a slot to fill
a tire to secure
clouds to count
pens to align because you can't pay for bills nor bottles nor
moments of joy; the laughter of your children like
pebbless, gently, trickle; through
for(r)est, so fast
I'd ask you to leave with me, we'd find us a river
we'd map you on water
and we'd map us both on air
we'd map me in soil and
we'd not force an oak, we'd try
to find time
to accept the evening
star of fixation; *Forrest is your name*

Figure 8: Jess' Artefact 2

Within her poem Jess expressed how non-autistic people try to name and taxonomise autism (such as in the film) in a way that makes sense to them and that they can benefit from. She also describes how pre-existing notions of autism can be challenged.

Jess found writing poetry cathartic as usually she struggles to put her feelings into words.

Jess thought her experiences would have been different if she was an autistic man, because she thought they were able to get away with behaviour she could not, for example disruptiveness and inappropriate behaviour. She described how autistic women were also punished for not conforming to society's idea of what a woman should be.

Jess noted that at university autistic women are expected to be ‘silent and compliant’, whereas autistic male staff in particular are afforded the privilege of being labelled ‘eccentric’.

She thought university could be made better for autistic women by increasing awareness that autism does not only affect men, a notion that she thinks is false and harmful for autistic women as they are frequently forgotten in society.

4.5.4 Katie*

Katie was a final year PhD student studying Organisational Psychology. She was diagnosed with autism six months before the interview and does not prefer any specific language about autism. The interview was by voice on Skype. Unfortunately, Katie could hear an echo throughout the interview.

She explained autism to be internal, such as how a person thinks about things differently from other people. Katie thought autism was more than just having challenges with social communication as it could include sensory difficulties or co-occur with mental health conditions.

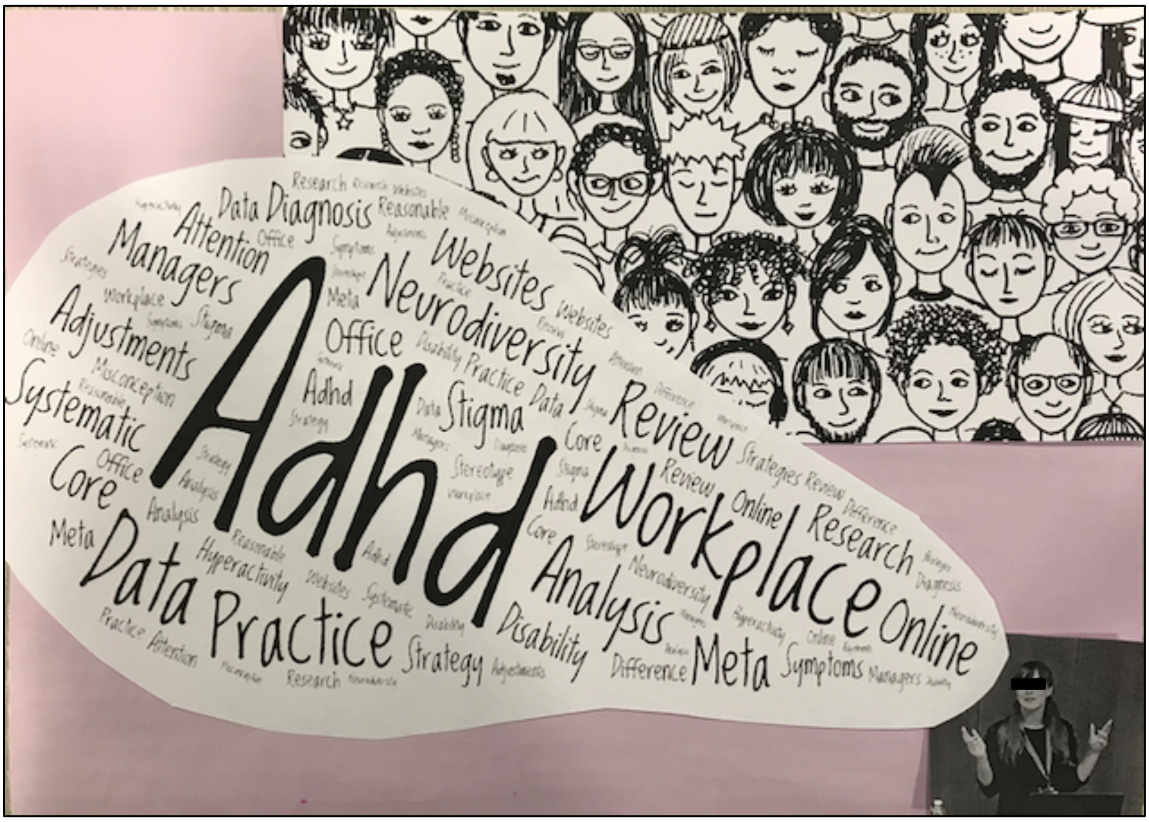
Katie thought the social barrier when starting university was huge. She noted that it was hard to get support without a formal diagnosis, which is also hard to obtain. She thought universities should change their environment to support autistic students and encourage others to accept these changes. Katie did not think changes were costly or very difficult.

We went on to talk about Katie’s artefacts. Her first artefact (see Figure 9) focused on masking (acting in a socially conformist way, when it is unnatural to a person – see Chapters 2 and 6 for more explanation) at a networking event.

Figure 9: Katie’s Artefact 1 'The Broken Mask'

She wanted to show how scary a networking event can be to navigate, but that she does not want others to notice her difficulties.

Katie’s second artefact (see Figure 10) depicted her presenting well at a conference.

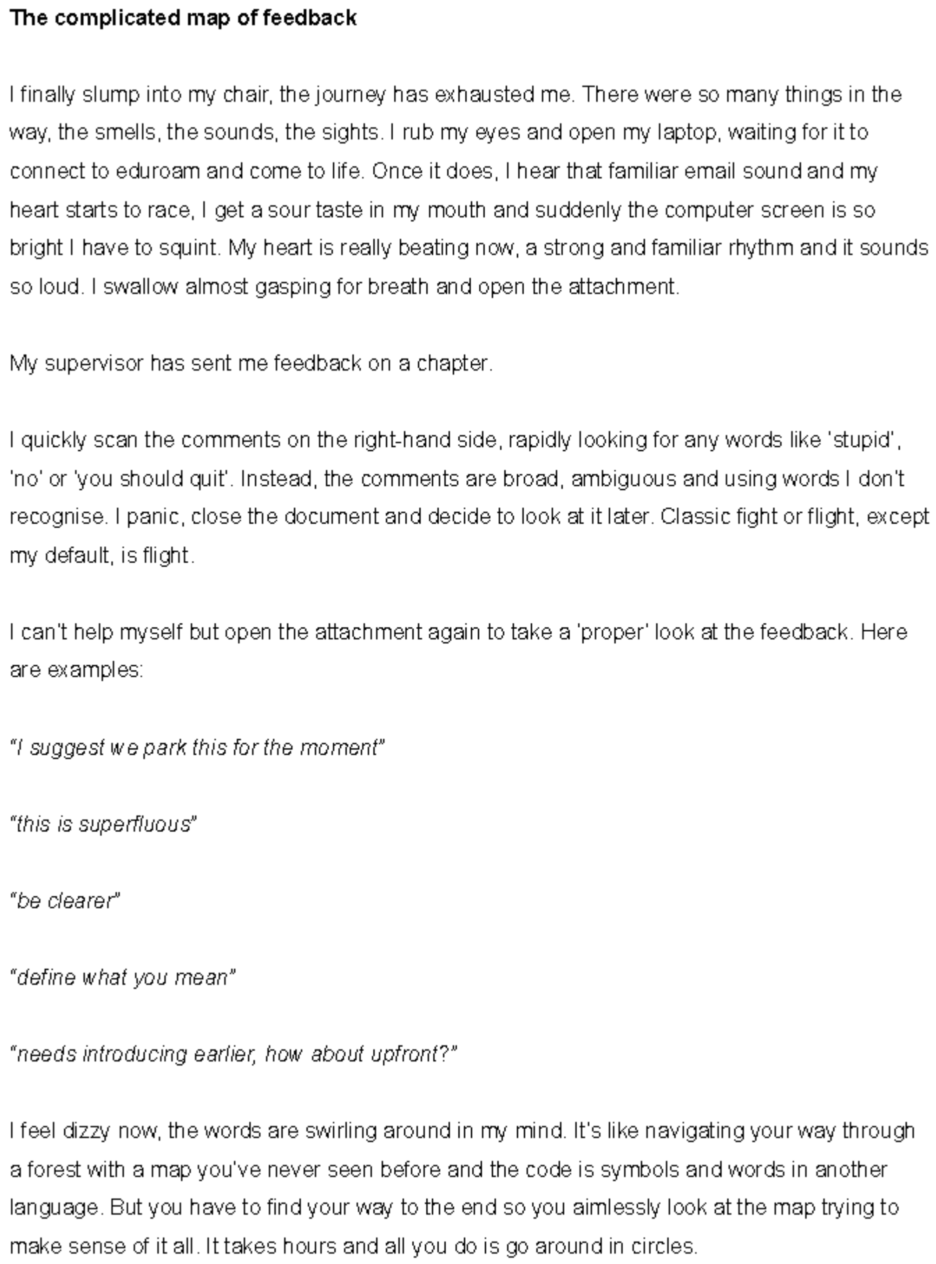


[redacted]

Figure 10: Katie's Artefact 2

Katie wanted to show a situation where her strengths come out, by harnessing her special interest. She enjoyed her presentation and got good feedback from the audience.

Her third artefact (see Figure 11) showed how she found it hard to understand feedback given from her supervisor.



The complicated map of feedback

I finally slump into my chair, the journey has exhausted me. There were so many things in the way, the smells, the sounds, the sights. I rub my eyes and open my laptop, waiting for it to connect to eduroam and come to life. Once it does, I hear that familiar email sound and my heart starts to race, I get a sour taste in my mouth and suddenly the computer screen is so bright I have to squint. My heart is really beating now, a strong and familiar rhythm and it sounds so loud. I swallow almost gasping for breath and open the attachment.

My supervisor has sent me feedback on a chapter.

I quickly scan the comments on the right-hand side, rapidly looking for any words like 'stupid', 'no' or 'you should quit'. Instead, the comments are broad, ambiguous and using words I don't recognise. I panic, close the document and decide to look at it later. Classic fight or flight, except my default, is flight.

I can't help myself but open the attachment again to take a 'proper' look at the feedback. Here are examples:

"I suggest we park this for the moment"

"this is superfluous"

"be clearer"

"define what you mean"

"needs introducing earlier, how about upfront?"

I feel dizzy now, the words are swirling around in my mind. It's like navigating your way through a forest with a map you've never seen before and the code is symbols and words in another language. But you have to find your way to the end so you aimlessly look at the map trying to make sense of it all. It takes hours and all you do is go around in circles.

Figure 11: Katie's Artefact 3 'The Complicated Map of Feedback'

Katie wanted to show what triggered her to go and get an autism diagnosis. She was struggling to understand feedback from her supervisor, but in order to give her more support and time the supervisor needed to justify why.

Katie thought the process of creating the artefacts helped her to reflect on her experiences since she was diagnosed. She thought using art was a powerful way of showing emotion and that it can be both good and bad being autistic.

Katie thought the social expectations of a woman meant society saw her autism as anxiety, rather than as autism manifesting in various ways. She posited that this could then lead to misdiagnosis or mis-judgements and stereotypes from society that autistic men may be less likely to experience.

Finally, Katie thought the university environment could be changed to better suit autistic women by ensuring individualised support and listening to what the autistic student wants.

4.5.5 Kim*

Kim prefers to use diagnosis first language about autism, as she believes if her autism was not there she would be a completely different person. She was an undergraduate student at the time of the interview. The interview took place via video on Skype.

Kim described autism as complex, challenging and difficult, but something special. She identified as disabled and said autism can be difficult. She thought it was easier for neurotypical people in society because she said they tended to deal with difficult events in societally acceptable ways, for example by crying rather than chewing jewellery. Kim was very interested in penguins and liked to talk about them. She said that she noticed other people would ‘share a look’ with each other when she did to highlight she was not adhering to social norms and as if she was odd.

We then spoke about barriers and supports at university. Kim felt lucky as she had generally had good support at her university. She found the process of applying for support difficult, convoluted and required her to emphasise her autism in the assessment. Kim said other students were not always understanding of her autism. However, she thought her university was aware of most of the barriers autistic students faced and attempted to mitigate them as far as possible.

We spoke about Kim’s artefacts. First, she presented an artefact (see Figure 12) about navigating friendships.

Figure 12: Kim's Artefact 1 'Navigating Relationships at Uni'

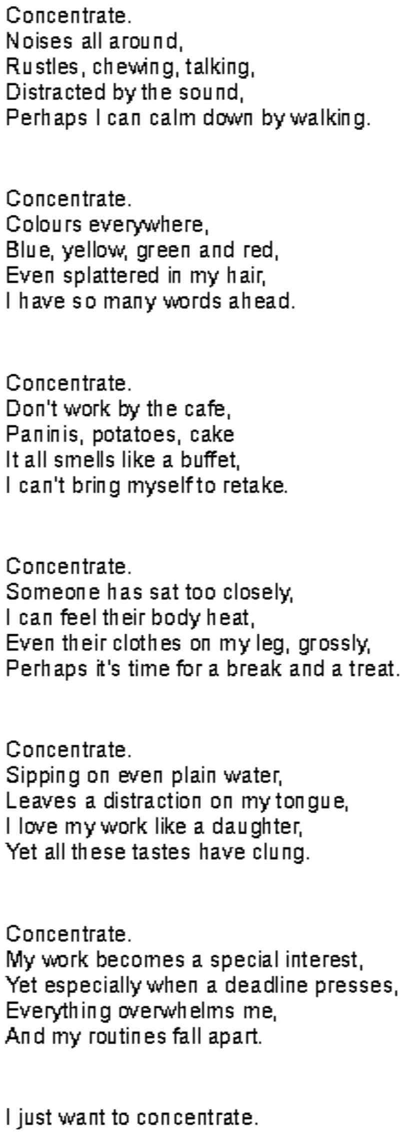
Kim expressed how she finds making and maintaining relationships difficult, but does have some good friends.

Her second artefact (see Figure 13) was about the sensory impact of being in a lecture theatre.

Figure 13: Kim's Artefact 2

Kim used yellow to denote the work she should be doing and the other colours to show distractions, which prevented her from focusing her attention.

Kim’s third artefact (see Figure 14) was a poem about concentrating in the university library.



Concentrate.
Noises all around,
Rustles, chewing, talking,
Distracted by the sound,
Perhaps I can calm down by walking.

Concentrate.
Colours everywhere,
Blue, yellow, green and red,
Even splattered in my hair,
I have so many words ahead.

Concentrate.
Don't work by the cafe,
Paninis, potatoes, cake
It all smells like a buffet,
I can't bring myself to retake.

Concentrate.
Someone has sat too closely,
I can feel their body heat,
Even their clothes on my leg, grossly,
Perhaps it's time for a break and a treat.

Concentrate.
Sipping on even plain water,
Leaves a distraction on my tongue,
I love my work like a daughter,
Yet all these tastes have clung.

Concentrate.
My work becomes a special interest,
Yet especially when a deadline presses,
Everything overwhelms me,
And my routines fall apart.

I just want to concentrate.

Figure 14: Kim's Artefact 3 'Concentrate'

She dedicated a stanza to every sense. Kim found the library very distracting and got frustrated by other students who can work regardless of the sensory input.

Kim said she enjoyed creating her artefacts as it helped her acknowledge how far she had come.

We then went on to talk about whether Kim thought gender affected autistic experiences. She thought the sensory aspects would be similar but that autistic men – particularly white men – are allowed to make more social mistakes than autistic women. However, she thought her special interest of penguins was slightly more socially acceptable than if she was an autistic man.

Kim thought the university could be adapted to accommodate autistic people, by educating staff and other students about autism and the associated stereotypes. She also thought more inclusive social events would help.

4.5.6 Lilly*

Lilly was an undergraduate student studying Biomedical sciences. Her interview was conducted via instant messaging using Skype. Lilly preferred to use diagnosis-first language.

She thought autistic people were more likely to have anxiety and depression compared to the neurotypical population. In addition, Lilly had read that autistic people were more likely to commit suicide that non-autistic people but she thought greater autism awareness could help reduce this.

At university, Lilly cited the main barrier to university as being social, with particular regard to making friends. She wanted people to acknowledge that some autistic people want to make friends but struggle to initiate social interactions. An autism social group and having an autism mentor supported her.

Lilly created three artefacts prior to interview: two images and one poem.

Her first artefact (see Figure 15) was a painting about friendship.

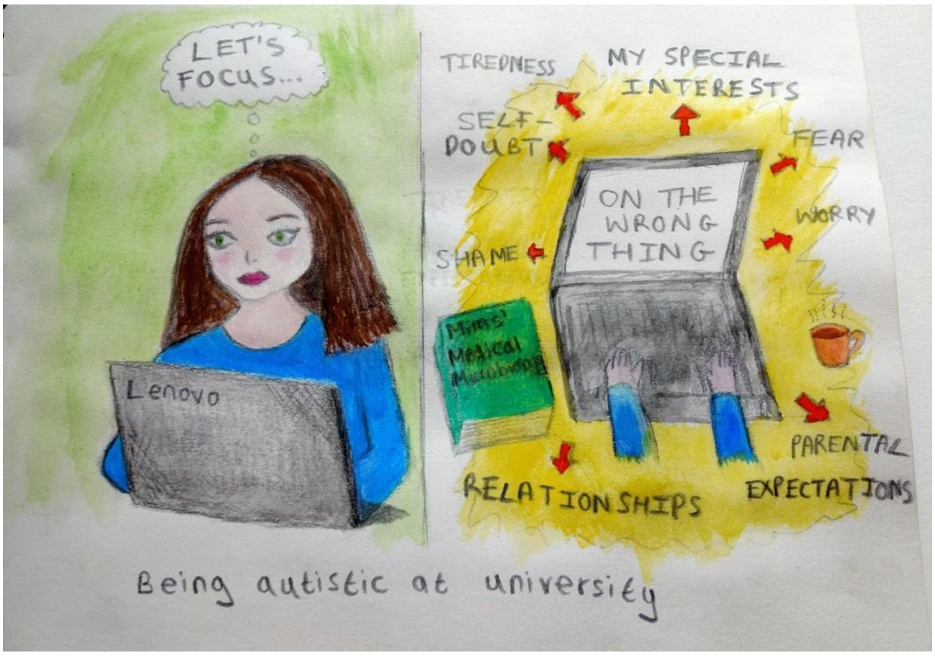


Figure 15: Lilly's Artefact 1 'Being Autistic at University'

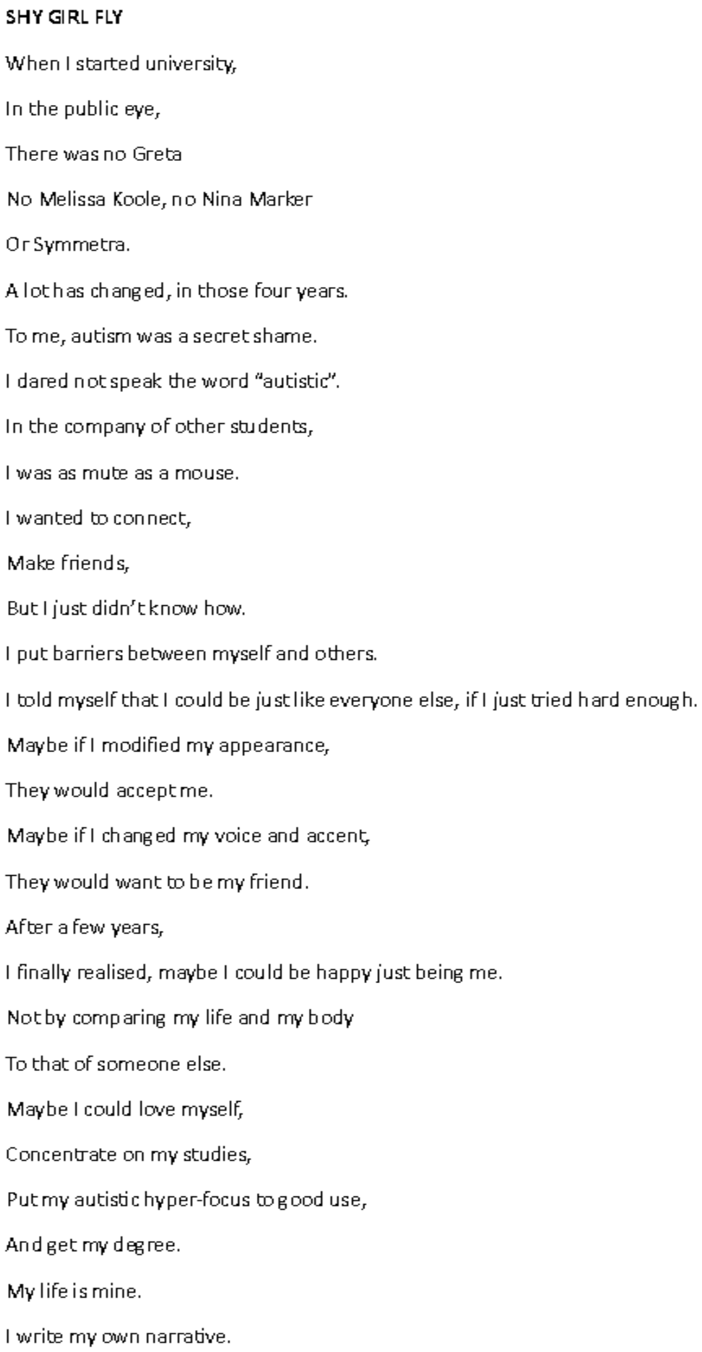
Lilly said this artefact was about making friends with other autistic women at an autism group. She enjoyed meeting others who shared similar interests and difficulties.

Lilly’s second artefact (see Figure 16) was a painting about the difficulties of concentrating at university.

Figure 16: Lilly's Artefact 2 'Friendship with Other Autistic Women'

She found it difficult to focus at university when she had several other pressures to think about.

Her third artefact (see Figure 17) was a poem about how her feelings have changed over the time she has been at university.



SHY GIRL FLY

When I started university,

In the public eye,

There was no Greta

No Melissa Koole, no Nina Marker

Or Symmetra.

A lot has changed, in those four years.

To me, autism was a secret shame.

I dared not speak the word “autistic”.

In the company of other students,

I was as mute as a mouse.

I wanted to connect,

Make friends,

But I just didn’t know how.

I put barriers between myself and others.

I told myself that I could be just like everyone else, if I just tried hard enough.

Maybe if I modified my appearance,

They would accept me.

Maybe if I changed my voice and accent,

They would want to be my friend.

After a few years,

I finally realised, maybe I could be happy just being me.

Not by comparing my life and my body

To that of someone else.

Maybe I could love myself,

Concentrate on my studies,

Put my autistic hyper-focus to good use,

And get my degree.

My life is mine.

I write my own narrative.

Figure 17: Lilly's Artefact 3 'Shy Girl Fly'

Lilly described her feelings of loneliness and not being attractive at the start of university. She gained more confidence throughout university and her thoughts on autism have changed.

Lilly found creating artefacts helped her to reflect on her experiences at university and allowed her to convey messages expressively.

She thought her experiences were influenced by being an autistic woman due to the stereotypes associated with women in society that she felt unable to always meet. Lilly said there was also more pressure on autistic women as these stereotypical behaviours and expectations, driven in part by social media, may not come so naturally.

Lilly thought the university environment could better accommodate autistic women by increasing autism awareness amongst staff and students, for example by running more autism awareness events. She also would have liked an autism group when she first joined university.

4.5.7 Megan

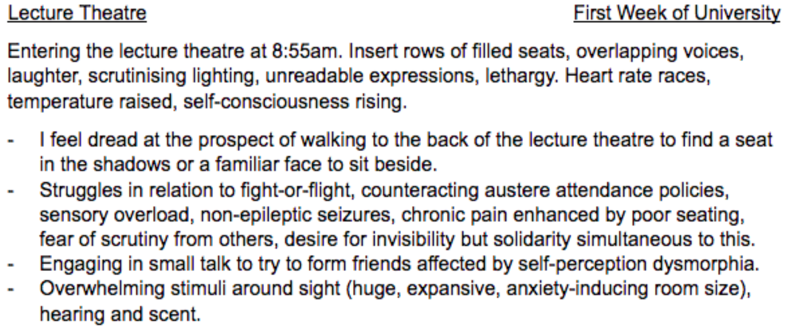
Megan was an undergraduate student. The interview was conducted through instant messaging over Skype. She has a formal diagnosis of autism and preferred to use person first language. Megan also said she has sensory processing disorder (SPD) and auditory processing disorder (APD).

Megan described autism in terms of neurodivergency, that interlinked to her other conditions. She thought autism was both a disability and ability as it helped and hindered her. She said autism affected her perception of how she saw the world.

She thought autistic people were likely to have more negative childhood experiences such as bullying compared to the non-autistic population. Therefore, autistic people may be more likely to experience poorer mental health.

We then spoke about her artefacts. Megan produced two artefacts. She chose to highlight two places at university because she thought they tended to be most populated on campus and thus affected her SPD, APD, autism and mental health conditions the most.

Her first artefact (see Figure 18) looked at her experience of the lecture theatre in her first week at university.



Lecture Theatre — First Week of University

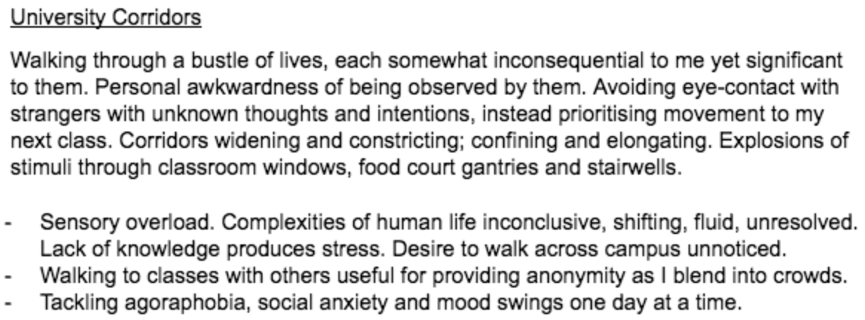
Entering the lecture theatre at 8:55am. Insert rows of filled seats, overlapping voices, laughter, scrutinising lighting, unreadable expressions, lethargy. Heart rate races, temperature raised, self-consciousness rising.

- I feel dread at the prospect of walking to the back of the lecture theatre to find a seat in the shadows or a familiar face to sit beside.
- Struggles in relation to fight-or-flight, counteracting austere attendance policies, sensory overload, non-epileptic seizures, chronic pain enhanced by poor seating, fear of scrutiny from others, desire for invisibility but solidarity simultaneous to this.
- Engaging in small talk to try to form friends affected by self-perception dysmorphia.
- Overwhelming stimuli around sight (huge, expansive, anxiety-inducing room size), hearing and scent.

Figure 18: Megan's Artefact 1 'First Week of University'

Megan said that there could be a greater social pressure on women to engage in conversation with others compared to men in situations such as in a lecture theatre before the lecture started. She thought this may stem from gender stereotyping rather than due to autism however.

Megan's second artefact (see Figure 19) explored her sensory experiences and feelings of walking through university corridors.



University Corridors

Walking through a bustle of lives, each somewhat inconsequential to me yet significant to them. Personal awkwardness of being observed by them. Avoiding eye-contact with strangers with unknown thoughts and intentions, instead prioritising movement to my next class. Corridors widening and constricting; confining and elongating. Explosions of stimuli through classroom windows, food court gantries and stairwells.

- Sensory overload. Complexities of human life inconclusive, shifting, fluid, unresolved. Lack of knowledge produces stress. Desire to walk across campus unnoticed.
- Walking to classes with others useful for providing anonymity as I blend into crowds.
- Tackling agoraphobia, social anxiety and mood swings one day at a time.

Figure 19: Megan's Artefact 2 'University Corridors'

I concluded the interview by asking Megan what barriers and supports she thought existed for women with autism at university. She said the major barrier was not having a support infrastructure in place, potentially due to restricted funding, which may mean that people with autism have nowhere to go for support. She thought 'social support in universities around mental health, 1-1 check-ins and support plans' would help people with autism access support.

Outside university Megan said accessing an autism diagnosis was a significant barrier, but was needed in order to access support. She thought being diagnosed was difficult due to long waiting lists and 'subconscious assumptions and schemas' diagnosis professionals hold relating to autism and gender.

4.5.8 Poppy

Poppy was a postgraduate student who also teaches. She was waiting for a formal autism assessment and has other diagnoses of Dyspraxia and ADHD. She had no language preferences surrounding autism. The interview was conducted by voice only on Skype.

Poppy described autism as a neurodivergent condition, characterised by a spiky profile of strengths and weaknesses. She said it is like a culture with its own language and mannerisms. She thought it was easier to communicate with people from your own culture and therefore autistic and non-autistic people may not understand each other easily.

Poppy went on to describe her artefact (see Figure 20). She said it represented the feeling of when people say unhelpful statements about autism.

Figure 20: Poppy's Artefact 1

She used the background colours to depict a brain and the words spiralling to show sentences going around her mind. The spiralling sentences are statements that other people thought are true about the world, but to her were inaccurate and showed a lack of understanding.

We then talked about the barriers and supports autistic people face at university. The biggest barrier Poppy identified was that the curriculum taught was constructed to cater for ‘neuro-typicality’. She said the curriculum needed to be ‘de-neurotypified’. Poppy also said one university she attended focused on a ‘Sheldon Cooper version’ of autism and only understood that stereotyped view of autism.

Poppy thought her experiences would be different if she was an autistic man because she said society does not understand that autism affects women. For example, she struggled with tone in emails. She was perceived as aggressive, which she thought people would not notice as much if she was a man, due to stereotypes about autistic men.

Penultimately, we discussed how the university environment could be changed to better accommodate autistic women. Poppy discussed changes such as being able to communicate in writing and having quiet spaces to study. She also thought staff needed a better understanding of autism to reduce the need for students to have to repeatedly explain the need for adjustments without potential defensiveness from others.

Poppy concluded by saying that she thought autistic people tend to be negatively judged by others’ pre-ingrained negative stereotypes of autism. Therefore, others were unwilling or felt unable to support autistic students as they assumed they would just present stereotypically.

4.5.9 Sarah*

Sarah was studying for a PGCE and had a PhD. She was diagnosed with autism as an adult after some misdiagnoses of other conditions including schizophrenia.

She defined autism as a different way that the brain works and thus a mindset that included different interests to a non-autistic person. Sarah highlighted that she was only diagnosed as autistic three years ago and so most of her experiences are based on personal hindsight. She said it was very bound up in the personal as she had spent most of her life without the knowledge that she was autistic.

Sarah said the biggest barrier to gaining support for autistic people was communication between the autistic person and the other person/service involved. She said that neither side recognises they are not communicating on the same topic, as in the double-empathy problem (Milton, 2012).

We discussed the barrier and support for autistic women at university. Sarah noted that she started receiving Disabled Students Allowance support prior to 2010 and so was afforded more financial support than current incoming students. She has found a computer and mentoring useful, however had to go through significant bureaucracy and discrimination to get them. She also experienced discriminatory attitudes on school placements and difficulties with university administration staff whilst at university. Although, Sarah said that support on her open day was good.

We then discussed Sarah’s artefacts. Her first artefact (see Figure 21) depicted the sensory impact her undergraduate accommodation had on her.

Figure 21: Sarah's Artefact 1

Sarah’s accommodation was next to a cathedral where the bells were rung at least every fifteen minutes throughout the day. She ‘lived and died by the bells’ which caused her sleep disruption and sensory difficulties. It negatively defined her undergraduate experience.

Sarah’s second artefact (see Figure 22) was a misquoting of Pride and Prejudice by Jane Austen, expressing how she can write her own story. Sarah has requested that only part of her artefact is displayed.

Figure 22: Part of Sarah's Artefact 2

She wanted to show that everybody should write their own story in spite of any barriers, rather than trying to conform to somebody else’s.

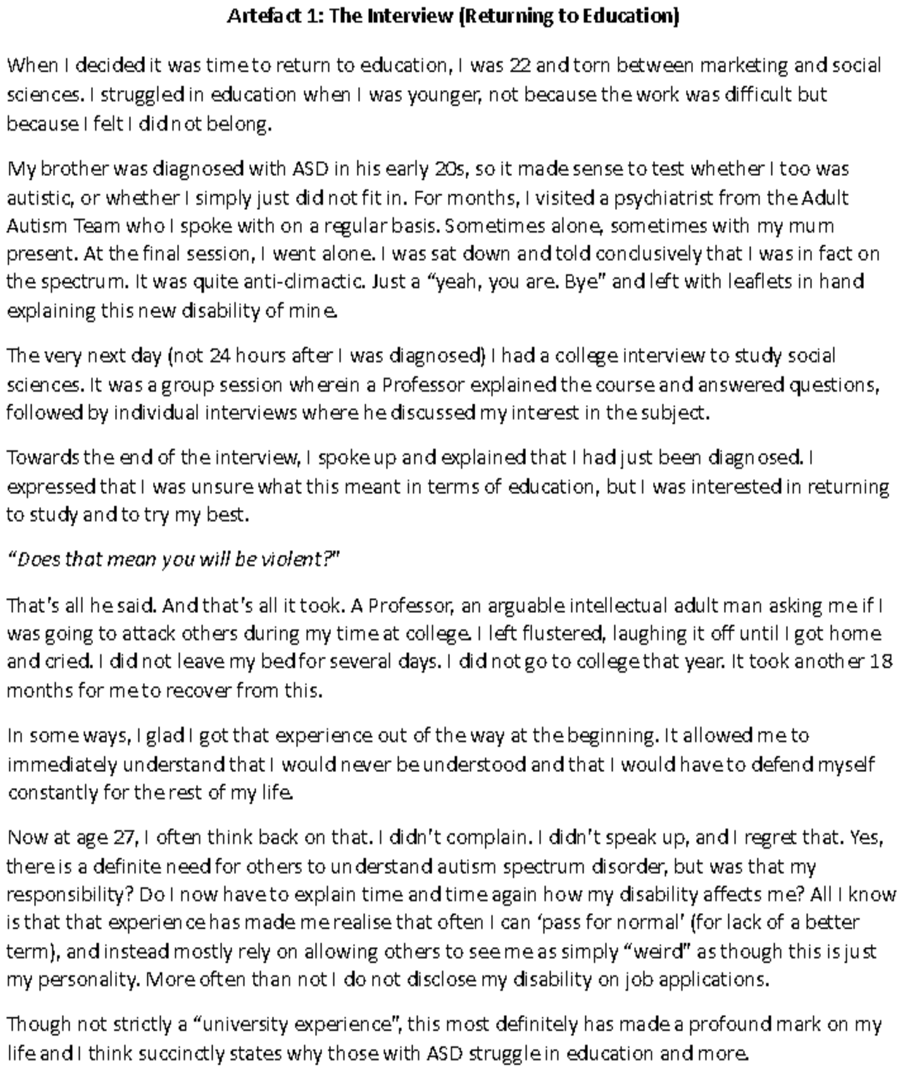
Finally, Sarah ended the interview by highlighting the need to have formal diagnoses in order to gain support. Support then takes a long time to materialise and a person has to know what they need in order to ask for it.

4.5.10 Sophia*

Sophia was a fourth year International Marketing student. She was formally diagnosed with autism as an adult after her brother received a diagnosis. Sophia had no preference regarding language about autism. She explained autism to be ‘a distance from everything’ and having more difficulty in understanding the world.

Sophia said that staff at university were really supportive, especially before she arrived at university, however, university processes such as assessments were not in accessible formats for her.

Sophia made three artefacts, two of which included an image made on Canva. Her first artefact (see Figure 23) was entitled ‘The Interview (Returning to Education)’, describing entering, dropping out and returning to Higher Education.



Artefact 1: The Interview (Returning to Education)

When I decided it was time to return to education, I was 22 and torn between marketing and social sciences. I struggled in education when I was younger, not because the work was difficult but because I felt I did not belong.

My brother was diagnosed with ASD in his early 20s, so it made sense to test whether I too was autistic, or whether I simply just did not fit in. For months, I visited a psychiatrist from the Adult Autism Team who I spoke with on a regular basis. Sometimes alone, sometimes with my mum present. At the final session, I went alone. I was sat down and told conclusively that I was in fact on the spectrum. It was quite anti-climactic. Just a “yeah, you are. Bye” and left with leaflets in hand explaining this new disability of mine.

The very next day (not 24 hours after I was diagnosed) I had a college interview to study social sciences. It was a group session wherein a Professor explained the course and answered questions, followed by individual interviews where he discussed my interest in the subject.

Towards the end of the interview, I spoke up and explained that I had just been diagnosed. I expressed that I was unsure what this meant in terms of education, but I was interested in returning to study and to try my best.

“Does that mean you will be violent?”

That’s all he said. And that’s all it took. A Professor, an arguable intellectual adult man asking me if I was going to attack others during my time at college. I left flustered, laughing it off until I got home and cried. I did not leave my bed for several days. I did not go to college that year. It took another 18 months for me to recover from this.

In some ways, I glad I got that experience out of the way at the beginning. It allowed me to immediately understand that I would never be understood and that I would have to defend myself constantly for the rest of my life.

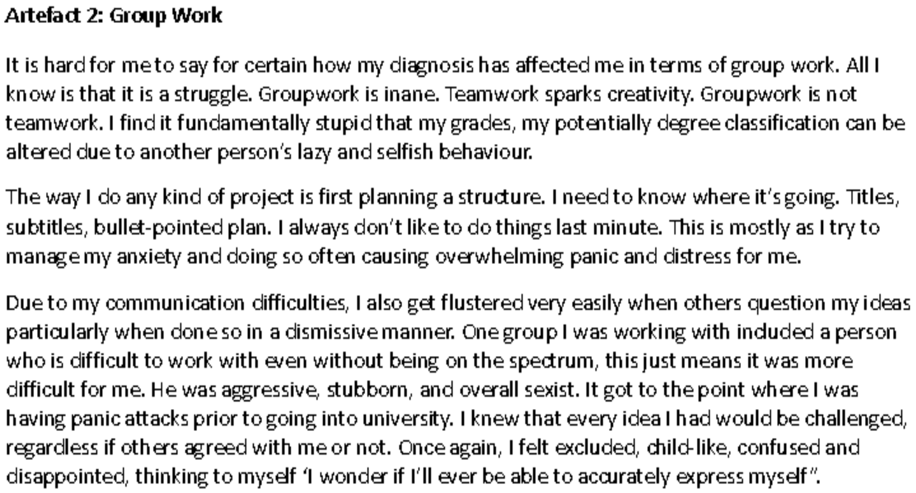
Now at age 27, I often think back on that. I didn’t complain. I didn’t speak up, and I regret that. Yes, there is a definite need for others to understand autism spectrum disorder, but was that my responsibility? Do I now have to explain time and time again how my disability affects me? All I know is that that experience has made me realise that often I can ‘pass for normal’ (for lack of a better term), and instead mostly rely on allowing others to see me as simply “weird” as though this is just my personality. More often than not I do not disclose my disability on job applications.

Though not strictly a “university experience”, this most definitely has made a profound mark on my life and I think succinctly states why those with ASD struggle in education and more.

Figure 23: Sophia’s Artefact 1 ‘The Interview (Returning to Education)’

In this artefact Sophia described feeling that her autism was in hindsight a reason for being bullied at school and struggling in college. She started university and had an incident with a lecturer on her first day and then took a year out, where she reflected upon knowing her boundaries and feeling more comfortable with requiring boundaries because she is autistic.

Sophia’s second artefact (see Figure 24) focused on group work and the difficulties of participating in it.



Artefact 2: Group Work

It is hard for me to say for certain how my diagnosis has affected me in terms of group work. All I know is that it is a struggle. Groupwork is inane. Teamwork sparks creativity. Groupwork is not teamwork. I find it fundamentally stupid that my grades, my potentially degree classification can be altered due to another person’s lazy and selfish behaviour.

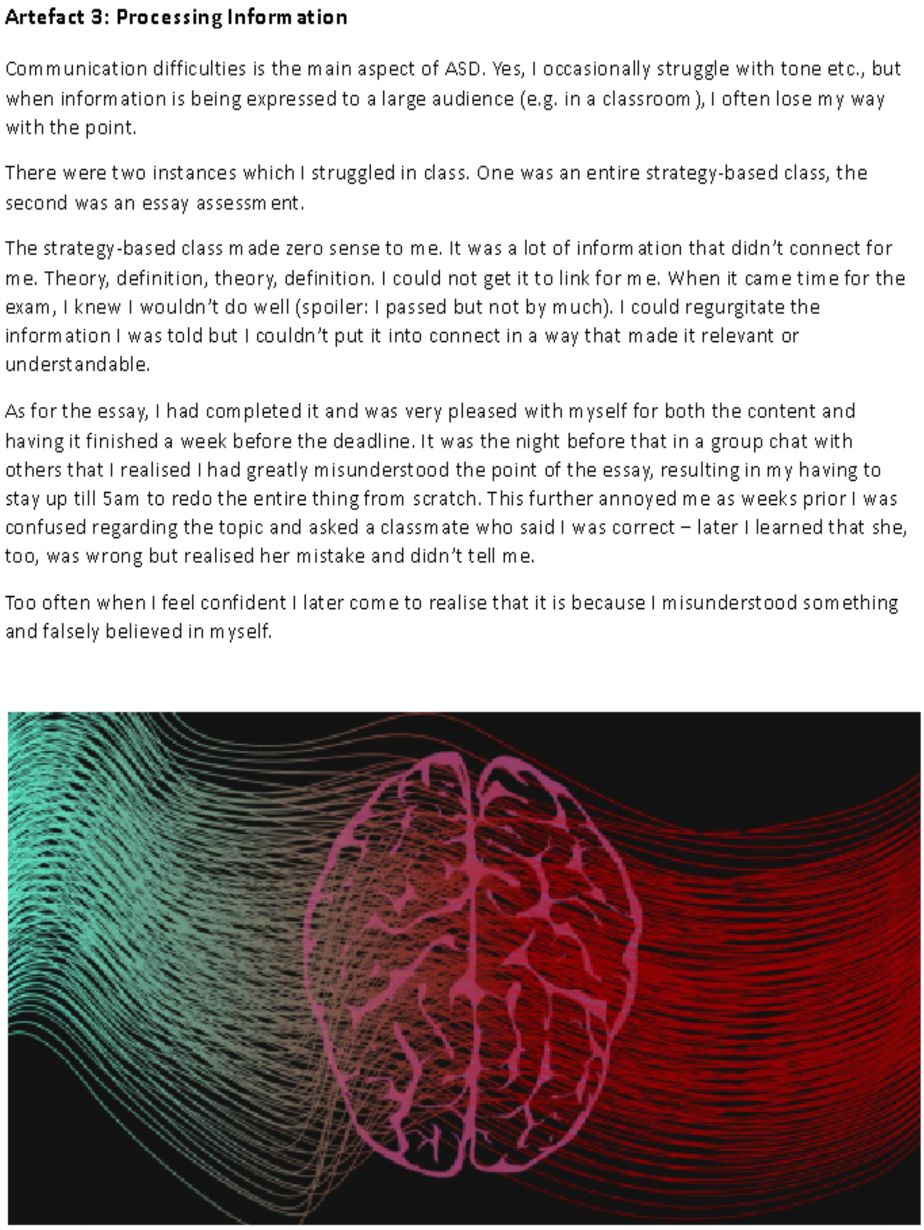
The way I do any kind of project is first planning a structure. I need to know where it’s going. Titles, subtitles, bullet-pointed plan. I always don’t like to do things last minute. This is mostly as I try to manage my anxiety and doing so often causing overwhelming panic and distress for me.

Due to my communication difficulties, I also get flustered very easily when others question my ideas particularly when done so in a dismissive manner. One group I was working with included a person who is difficult to work with even without being on the spectrum, this just means it was more difficult for me. He was aggressive, stubborn, and overall sexist. It got to the point where I was having panic attacks prior to going into university. I knew that every idea I had would be challenged, regardless if others agreed with me or not. Once again, I felt excluded, child-like, confused and disappointed, thinking to myself ‘I wonder if I’ll ever be able to accurately express myself”.

Figure 24: Sophia’s Artefact 2 'Group Work'

She found it difficult to work outside her ‘preferred methods of learning’, which was particularly prominent in groups with others who would rather work in different ways.

Sophia’s third artefact (see Figure 25) looked at information processing.



Artefact 3: Processing Information

Communication difficulties is the main aspect of ASD. Yes, I occasionally struggle with tone etc., but when information is being expressed to a large audience (e.g. in a classroom), I often lose my way with the point.

There were two instances which I struggled in class. One was an entire strategy-based class, the second was an essay assessment.

The strategy-based class made zero sense to me. It was a lot of information that didn't connect for me. Theory, definition, theory, definition. I could not get it to link for me. When it came time for the exam, I knew I wouldn't do well (spoiler: I passed but not by much). I could regurgitate the information I was told but I couldn't put it into connect in a way that made it relevant or understandable.

As for the essay, I had completed it and was very pleased with myself for both the content and having it finished a week before the deadline. It was the night before that in a group chat with others that I realised I had greatly misunderstood the point of the essay, resulting in my having to stay up till 5am to redo the entire thing from scratch. This further annoyed me as weeks prior I was confused regarding the topic and asked a classmate who said I was correct – later I learned that she, too, was wrong but realised her mistake and didn't tell me.

Too often when I feel confident I later come to realise that it is because I misunderstood something and falsely believed in myself.

Figure 25: Sophia's Artefact 3 'Processing Information'

Sophia conveyed that she had misunderstood and misinterpreted some university work and therefore done the wrong thing which has affected her grades.

Sophia enjoyed making time to reflect on her experiences.

Sophia thought that there was a difference in social experiences between autistic women and autistic men as women were generally better at it. Sophia said that as a child her and her brother were referred to as ‘weird’. However, she had friends and he did not, which she attributes to being a girl. She said girls accepted her ‘weird quirkiness’ but that boys isolated her brother’s behaviour. She felt at university she could make friends easily but could not retain them.

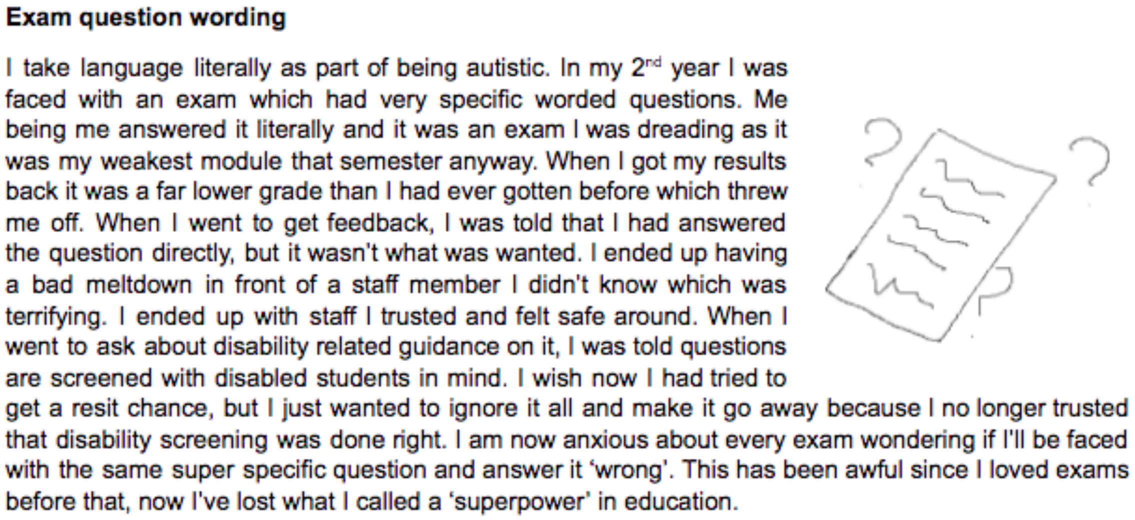
Sophia thought alternative assessment methods and normalising the use of quiet rooms would have enhanced her university experiences.

4.5.11 Sophie

Sophie was a final year undergraduate student studying psychology. She preferred to use identity first language about autism.

She thought her university supported autistic students well such as through mentoring, but tended to base autism friendly events on stereotypes of autistic people. In particular she thought the strikes impacted on her wellbeing, especially because she felt she could not access support regarding their disruption.

We then discussed Sophie's artefacts. Her first artefact (see Figure 26) was about a bad experience of exams.



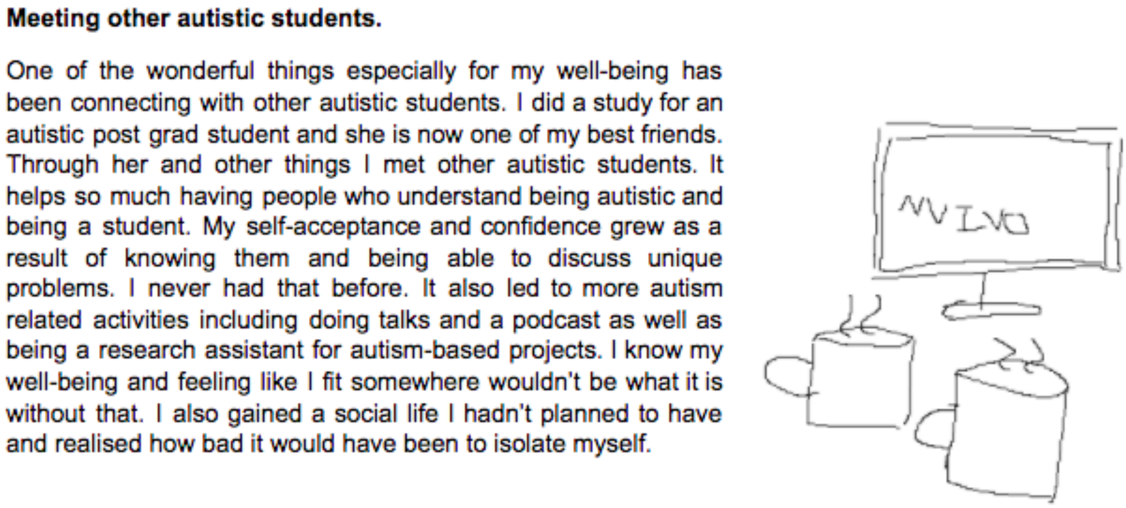
Exam question wording

I take language literally as part of being autistic. In my 2nd year I was faced with an exam which had very specific worded questions. Me being me answered it literally and it was an exam I was dreading as it was my weakest module that semester anyway. When I got my results back it was a far lower grade than I had ever gotten before which threw me off. When I went to get feedback, I was told that I had answered the question directly, but it wasn't what was wanted. I ended up having a bad meltdown in front of a staff member I didn't know which was terrifying. I ended up with staff I trusted and felt safe around. When I went to ask about disability related guidance on it, I was told questions are screened with disabled students in mind. I wish now I had tried to get a resit chance, but I just wanted to ignore it all and make it go away because I no longer trusted that disability screening was done right. I am now anxious about every exam wondering if I'll be faced with the same super specific question and answer it 'wrong'. This has been awful since I loved exams before that, now I've lost what I called a 'superpower' in education.

Figure 26: Sophia's Artefact 1 'Exam Question Wording'

She wanted to show that although she had previously enjoyed exams, a bad experience of not understanding the question has tainted her confidence in her abilities and enjoyment of exams.

Sophie’s second artefact (see Figure 27) was about meeting other autistic students.



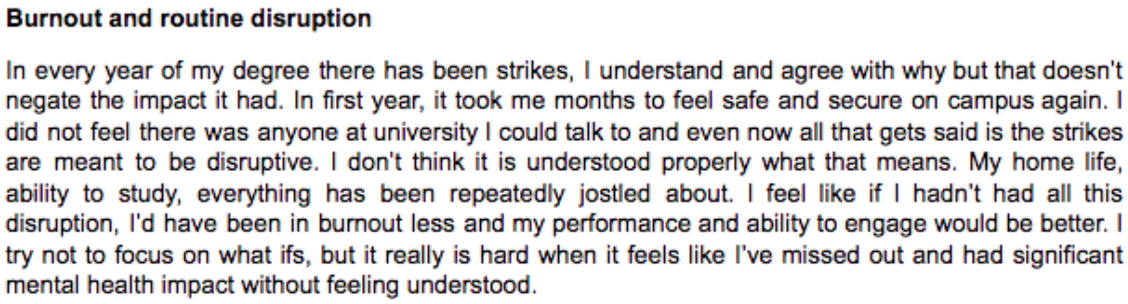
Meeting other autistic students.

One of the wonderful things especially for my well-being has been connecting with other autistic students. I did a study for an autistic post grad student and she is now one of my best friends. Through her and other things I met other autistic students. It helps so much having people who understand being autistic and being a student. My self-acceptance and confidence grew as a result of knowing them and being able to discuss unique problems. I never had that before. It also led to more autism related activities including doing talks and a podcast as well as being a research assistant for autism-based projects. I know my well-being and feeling like I fit somewhere wouldn't be what it is without that. I also gained a social life I hadn't planned to have and realised how bad it would have been to isolate myself.

Figure 27: Sophia's Artefact 2 'Meeting Other Autistic Students'

Sophie wanted to include a positive artefact, as she considered autism to include good aspects. She wanted to emphasise how she had deeper friendships with other autistic people, as there are no connection barriers.

Her third artefact (see figure 28) was about routine disruption and burnout.



Burnout and routine disruption

In every year of my degree there has been strikes, I understand and agree with why but that doesn't negate the impact it had. In first year, it took me months to feel safe and secure on campus again. I did not feel there was anyone at university I could talk to and even now all that gets said is the strikes are meant to be disruptive. I don't think it is understood properly what that means. My home life, ability to study, everything has been repeatedly jostled about. I feel like if I hadn't had all this disruption, I'd have been in burnout less and my performance and ability to engage would be better. I try not to focus on what ifs, but it really is hard when it feels like I've missed out and had significant mental health impact without feeling understood.

Figure 28: Sophia's Artefact 3 'Burnout and Routine Disruption'

Sophie depicted how routine change during the pandemic affected other students, but that she has already been used to significant disruptions from previous university strikes that she felt affected her on the same level. She described non-autistic disruptive and autistic disruptive to be very different.

Sophie said creating her experiences helped her to reflect on both the positive and negative aspects of university.

Sophie thought her experiences would have been similar if she was an autistic man. She said the biggest gender issue is society assuming women cannot have autism, although she had not experienced this. She thought the perception of autistic people either being high or low functioning was damaging. Overall, she thought society's lack of knowledge about autism rather than the link between autism and gender was the biggest factor in discrimination.

She said the university environment could be improved by uncomplicated solutions, such as better training and awareness of autism for staff and students. Sophie thought more detailed information for incoming autistic students about university and also simplifying processes for accessing support would help.

Sophie finished the interview by saying that she hoped universities could connect disabled and autistic students together.

4.6 Conclusion

In this chapter I have discussed using creativity in research, how this relates to my research and have presented summaries of the eleven participant interviews including their artefact(s). I reflected on how the artefacts the participants produced influenced me to change the type of data I analysed in my study.

I provided justification for the use of creative methods in research centred on disability, including the purposes and aims of it. I used the examples to demonstrate some techniques creative methods use and the benefits of them in research.

I have also discussed how creativity has influenced my own research project and considered how my participants' artefact production and interpretation influenced methodological and analytical changes within this project. The unexpected depth of meaning from the artefacts inspired me to analyse them in their own right, rather than just considering them as interview stimulants with no further purpose.

The interviews of the participants have been presented as untouched as possible, to emphasise the participants' words and artefacts. As discussed at the beginning of this chapter this was to ensure that I gave voice to their stories prior to any formal analysis of them. I have discussed that I acknowledge that no account is without any analysis as I, rather than the participants, wrote these synopses with knowledge of my research aims which I could not ignore. Overall, I believe I have introduced my participants in a way that I consider recognises them as individuals. Their identity, the context of when they completed the research, and the artefacts they produced are central to both this chapter and my research project as a whole.

5 Perceptions

5.1 Introduction

Autism is becoming a more prevalent topic within both academia and in wider society, however discussions and portrayals of autistic women and girls are much less prominent (Happe, 2019). How a person perceives themselves and believes they are perceived by other people may be important for their self-esteem and confidence (Cooper et al., 2021). As autism has gained public attention in recent years this may affect how autistic women feel about themselves. Within my thesis I aim to highlight how autism impacts women, which I believe is difficult to separate from how society views autistic women. I consider how self-perception, and how autistic women believe others perceive them, impacts confidence and feelings of belonging.

In this chapter I explore perceptions through three themes: self-identity, societal perceptions and perceptions of university. I focus on two of my three research questions:

1. What barriers and supports to higher education do autistic women students feel they have had at university?
2. What changes would autistic women like to see at university?

Within this chapter I focus on perceptions in relation to being autistic. Within the self-identity theme I analyse how having a formal diagnosis can help identity in some situations but also be a hindrance in other situations. I consider the effects of masking (hiding behaviour and feelings to fit into other situations) and the damaging effects of hiding true identity. Within the societal perceptions theme, I discuss how media stereotypes can influence thinking around autism and consider how this is related to gender. Within the theme of perceived perceptions of university, I look at how the expected mould of a university student impacts autistic students who may not fit into this norm. Overall, I emphasise that perceptions about autism and how autistic people should be accommodated are generally negative but that participants thought that knowing they were autistic was beneficial even if they felt unable to disclose it in all situations.

Within the interviews participants spoke about how they thought others perceived them with reference to their autism. Imagining what others think of a situation or view is commonly referred to as ‘theory of mind’ (Baron-Cohen et al., 1985). It has been extensively suggested that autistic people have significantly reduced ability to consider other people’s thoughts and the reasons behind them (Baron-Cohen et al., 1985). Although I have not conducted a control study, with the aim of contributing to proving or disproving this theory, my analysis suggested that in contrast to the theory of mind hypothesis, my participants were more than capable of considering the perspectives and opinions of others, in agreement with some more recent research (Holt et al., 2021). Participants’ responses within this theme demonstrate that they were able to speculate and critically reflect on what other people may perceive about them. Essentially, this chapter and theme of analysis adds evidence and suggestions counteracting the dominant discourse in autism research about the lack of ability of theory of mind.

5.2 Self-Identity

The theme *self-identity* describes how participants view themselves in relation to their autism. I discuss participants' experiences of diagnosis, positive and negative identity, and masking. Within these themes, I present a picture of the benefits and challenges participants had in gaining a diagnosis and incorporating a label of autism into their identity. I then discuss why they may feel the need to hide their autism (through masking) or equally use it as a platform for change.

Autism diagnoses and self-identifying as autistic have been regularly debated over the last few years, particularly as the diagnosis rate in girls and women has increased in recent years (Green et al., 2019). Some participants noted that there were some benefits of gaining a diagnosis of autism. One of these was that following diagnosis they felt a better understanding of themselves. Sophia explained, ‘When I got diagnosed, it kind of fitted into place … I was like, okay, there’s a reason for this and I can really know my boundaries.’ (Sophia).

Sophia demonstrates her autism diagnosis allowed personal reflection and an understanding as to why these barriers exist for her. In addition, Sophia’s comment shows an example of the functional aspects of an autism diagnosis. It allowed her to exert her boundaries with other people and give a reason for such that is tangible to others. Lewis (2018) argues that apart from allowing eligibility to paid support (which is traditionally associated with gaining a diagnosis), a diagnosis of autism can improve quality of life and mental health outcomes. She argues that this is because people who are unaware that they are autistic can falsely believe something is wrong with them and think that their behaviour or mannerisms are a personal failure. Lewis’ (2018) arguments align with what Sophia says, as she felt she understood herself and had a reason for how she felt and behaved, whereas prior to her diagnosis she was unsure.

In addition to the time it may take to receive a diagnosis of autism as a woman, being misdiagnosed with other conditions first can also be damaging. Gesi et al. (2021) report that women are less likely to be diagnosed and more likely to be misdiagnosed on their first autism evaluation compared to men. Au-Yeung et al. (2019) conducted an online questionnaire with 420 adults, who self-identified as autistic, possibly autistic, or non-autistic about mental health diagnoses they had been given and whether they agreed with them. They highlight that autistic and possibly autistic participants were more likely to be diagnosed as having a mental health condition. Au-Yeung et al. (2019) report that participants attributed this to professionals confusing autism and mental health conditions, and that poor mental health was linked to the challenges of being autistic. Therefore, having the wrong diagnosis, or a diagnosis that only explains some parts of identity, may impact on a sense of self. Sarah spoke about being misdiagnosed with schizophrenia and the impact it had on her.

‘I was misdiagnosed with schizophrenia…It couldn't be autism, basically because I was a girl. And I've lost 15 years of my life to that.’ (Sarah)

This lack of accurate diagnosis for Sarah meant that when she finally got diagnosed with autism she felt she had lost 15 years of her life where she had been given the wrong identity. Katie also highlighted how receiving different diagnoses before autism can also be damaging.

‘I think, you know, it can look very much like anxiety. And then that's what people take it as, but really when you look underneath, how you're really thinking about things that’s when the kind of autism comes out so I think that anxiety and depression can mask what's really happening. And I think that's quite dangerous as a woman because we know that some kind of, you know, some forms of support for anxiety and depression don't work for autistic people as much. So I think that's, that's a risk that you kind of make by, you know, sort of getting those mis-diagnoses, constantly, or people looking at you and judging you as oh she's just shy or she's just anxious.’ (Katie)

Katie considers that mis-diagnoses can lead to others judging you by standards and stereotypes of a different condition. Although autism is not a mental health condition, Stewart et al. (2006) argue the characteristics of autism can overlap with many mental health conditions. Dell’Osso and Carpita (2022) suggest that autistic women often receive a variety of mental health diagnoses as well as autism. They say this may be useful in explaining co-occurring difficulties but may be detrimental if a person’s profile is not considered under a neurodiversity paradigm and thus thought of holistically, rather than as separate or mutually exclusive labels.

Belcher et al. (2022) and Isaac et al. (2022) argue that not being diagnosed with autism in a timely manner is likely to affect a person’s mental health. They suggest this is particularly the case for women as their autism presentation is likely to be different from the typical presentation and therefore recognised later compared to men. Au-Yeung et al. (2019) previously highlighted that although autistic people are more prone to mental health conditions, accurate diagnosis is imperative to ensure the most helpful support can be accessed. Sarah and Katie’s comments highlight the impact of receiving wrong diagnoses and therefore for other women to not have to experience this, clinicians need to be more aware that autism in women may present differently and the consequences of a misdiagnosis on both identity and mental health. Dell'Osso and Carpita's (2022) research suggests that stories similar to Sarah and Katie's are likely to still occur.

Although I have discussed diagnosis with regard to self-identity, it is important for university staff to consider how a misdiagnosis can impact autistic students. Universities may not conduct diagnostic assessments of students in-house, but they are likely to provide sign posting to students who are exploring whether they fulfil diagnostic criteria of a disability. Therefore, it is imperative they do not assist in perpetuating any myths and stigmas which could lead to a student not being able to access the diagnostic assessment they need.

The self-confidence of either autistic women or those who think they may be autistic may be reduced before they reach university. Cassy and Sophia described themselves as being referred to as being 'weird' as children.

'I was the weird kid.' (Cassy)

'Thinking back on my brother and I's childhood. I know it's not like I'm going to use the term weird. We were both classified as weird kids.' (Sophia)

As both Cassy and Sophia can still recount being thought of as, or told they were, weird it is clear this impacted on their sense of identity growing up. Several researchers (Botha et al., 2022; Williams, 2016; Fombonne, 2020) report that autistic people are commonly referred to using derogatory language such as 'weird' or 'quirky'. This ingrained part of their identity others have focused on, may mean they might want to hide other autistic characteristics at university for fear of being labelled as 'weird' in that environment too.

Masking is more recently associated with autistic women as something they do to hide their autistic characteristics in order to appear more neurotypical and conform to social expectations (Hull et al., 2017). Perry et al. (2022) highlight that masking is done to either fit into a non-autistic world or into social relationships, and is typically only discussed in relation to gender. Some participants did not always feel able to, or want to, associate with their autistic identity for fear of not fitting in or being ostracised from a group.

‘When you’re younger the push for conformity, the social push is so huge that it can have a really detrimental effect on you and your wellbeing.’ (Sarah)

Conformity and social pressure to fit into society were highlighted by Cassy.

‘I think especially women can be very good at working with people, because it’s almost, you know, something we’ve had to do from a very young age to get by.’ (Cassy)

Both Sarah and Cassy emphasise how conformity and pressure to present as how society should see you is instilled from a young age, particularly as a woman. They both imply there are social requirements that are required as a woman in society and hence the need to hide their autism to form social relationships, like Perry et al. (2022) suggest. This posits that social skills may not be inherent in autistic women, however they can be learnt or mimicked from a young age. This ability can be described as part of masking or camouflaging (Hull et al., 2017).

Radulski (2022) states that masking can be dangerous as it reduces a person’s self-esteem in their own identity in attempts to fit in with the predominant neurotype. Miller et al.’s (2020) research explores the experiences of eight autistic lesbian, gay, bisexual and transgender (LGBTQ) participants. They found participants masked different identities according to the situation to fit in and that participants sometimes found it difficult to feel part of either the LGBTQ and/or autistic communities. Therefore, perceiving that somebody will not respect your differences (in this case autism) can prevent people from feeling they fit in or are a part of that community. This suggests that although masking might be needed to conform to societal pressures and appears to help somebody engage in a particular group, it can actually have the opposite effect in making autistic people feel even less part of a community or having their own identity. Thus, there may be some personal consequences of masking such as being detrimental to wellbeing and an emotional cost.

Masking can in turn affect mental health. If autistic students fear they do not fit into a perceived norm, they may attempt to mask characteristics to conform. This masking in turn may lead to a decrease in mental health if an autistic person is not comfortable with their own identity. Fem-mentee Collective (2017) argue that masking of emotions or parts of identity is also carried out by non-autistic people. One example they highlight in their research carried out with three participants is that some participants masked emotions to appear more professional when negotiating relationships with colleagues they mentored. This suggests that there may be a trade-off between fitting into a situation in the moment with others and how it impacts the individual masking long term. But, it may be more detrimental for autistic people as masking may need to be conducted for longer periods of time or more frequently compared to others who may only mask for brief periods of time. Considering non-autistic people may mask for less time in fewer situations than an autistic person, it appears that non-autistic masking is rarely talked about. This phenomenon is thus not normalised in societal discourse and so can appear as something that only autistic people, and particularly autistic women do and therefore be documented as behaviour that is substantially different to neurotypical behaviour.

This difficulty in masking for autistic people is highlighted by Megan:

‘I think, with autism affecting face-to-face communication in many individuals (such as myself), it is stressful either conforming or diverging from that social pressure as, for introverts, they may not necessarily want the 'social limelight' in a busy situation like that.’ (Megan)

She explains how it can be ‘stressful’ to conform in social situations. She also explains that diverging from social conformities can be as challenging, perhaps as it requires confidence in one’s own identity to do such. Conversely, one participant was happy to disclose their autism in any situation and had the confidence to do so, due to her own beliefs in championing her own identity and situation.

‘I’m not ashamed to say I’m autistic.’ (Sophie)

This confidence in one’s own identity challenges the common narrative that autistic women want to mask their autistic characteristics. Although as Megan mentioned above it can take energy to diverge from others and therefore this might be why Sophie’s response stands out. Botha et al. (2022) sought the opinions of 20 autistic individuals to understand how they made sense of autism and how they experienced societal stigma that is so frequently associated with autism. They noted overall that participants considered their autism as a neutral entity, but that the impressions they received from others about their autism, and in turn them, was mostly negative. Botha et al. (2022) conclude that participants experienced constant stigma towards them but dealt with it in a variety of ways. These included reclaiming language, masking and challenging negative portrayals of autism. Sophie’s ability to not be ashamed of her autism, in a society that as Botha et al. (2022) suggest is full of constant negativity towards autism, may require excess energy that Megan feels unable to give. Therefore, identity and confidence of one’s own autism and a want to disclose it may be intertwined with a person’s ability or want to constantly have to advocate for themselves against a regularly negative response.

Through this theme of self-identity, I have focused on some positive and negative aspects of the identities of the participants including diagnosis and masking. Analysis has shown that some participants faced barriers in obtaining a diagnosis, but that a diagnosis has provided benefits for them personally. I also touched on the topic of identity, where the positive and negative aspects of identifying as autistic were considered. With regard to masking, I discussed the need to conform from societal pressure and how masking relates to mental health. I concluded that although some autistic women choose not to hide their autistic characteristics and are happy to diverge from the ‘norm’, this also (like masking) can require levels of emotional and physical energy which can be hard to maintain.

5.3 Societal Perceptions

Societal representation of autism can help promote inequity (Janse van Rensburg, 2022), which has been highlighted through the work of critical autism scholars such as Milton (2014b) and Woods et al. (2018). Much autism discourse focuses on how autism symptoms vary depending upon a person's gender (Moore et al., 2022). Participants in this study spoke about their perceptions, including stereotypes, they thought society held about autistic women and how those influenced their experiences in the community. Although these are only their perceptions and may not be an objective representation of society, the messages the autistic women are receiving are important to discuss to ensure that autistic people feel that how they are represented and societal feelings towards them are fair and accurate.

Within this theme I draw on the thoughts of the participants towards the genderedness of autism, and how autism is portrayed in the media. Overall, I consider themes of ignorance, erasure and how different types of portrayal could aid society's knowledge and understanding of autistic women. With relation to gender and autism, participants' views were overwhelmingly negative. Ignorance and dismissal due to not being able to conform to a stereotype was a key feature in how participants' felt they were discriminated against by society for being an autistic woman.

'People's idea of autism is very different depending on if you're male or female…I think that people, like, I don't really know what people's idea of an autistic woman looks like but, and I think that people are very clear of what an autistic man looks like so they sort of try and cater to that person whereas maybe the autistic woman is something they haven't got an idea of sort of reject that outright.' (Poppy)

Poppy suggests that because what an autistic woman looks like is not what people think autism looks like, society simply dismisses it as something that cannot be entertained. Seers and Hogg (2021) explored the experiences of eight autistic women in order to better understand how psychological and societal constructions of autism affected wellbeing. Within their study they suggest that autistic women are expected to conform to the same societal expectations of non-autistic women but may respond to them in unconventional ways. Seers and Hogg (2021) suggest that although autistic women may not be as inherently interested in gender norms compared to non-autistic women, they are interested in others' judgements and stigma. This in turn can influence how autistic women want to act and conform. The intense focus that Seers and Hogg (2021) suggest that society places on all women to conform to the same expectations may be difficult for autistic women. Thus, like Poppy suggests, a stereotypical image of an autistic woman may be helpful for autistic women as something that is easier to conform to - especially when societal perceptions of what a woman should look like appear so ingrained. Seers and Hogg (2021) conclude their study by suggesting that as society's narrow essentialist view of gender norms expands and as gender becomes perceived as a continuous, rather than binary construct, considering autism in light of gender may become redundant. However, views and opinions can take a long time to change and therefore autism being considered without a gender bias may not occur for many years.

This notion of a stereotype of an autistic woman not existing currently, and therefore autistic women not being considered, proved problematic for some of the participants. Sophia, Cassy and Poppy all experienced stigma or ignorance against them for being autistic women because of their gender.

'I think the big gender gap for me with autism is people not thinking you can have autism if you are a woman.' (Sophia)

'I often get told there is no way you can have that kind of score on the autism spectrum or you know the autism quotient or anything like that, because you are so good with people.' (Cassy)

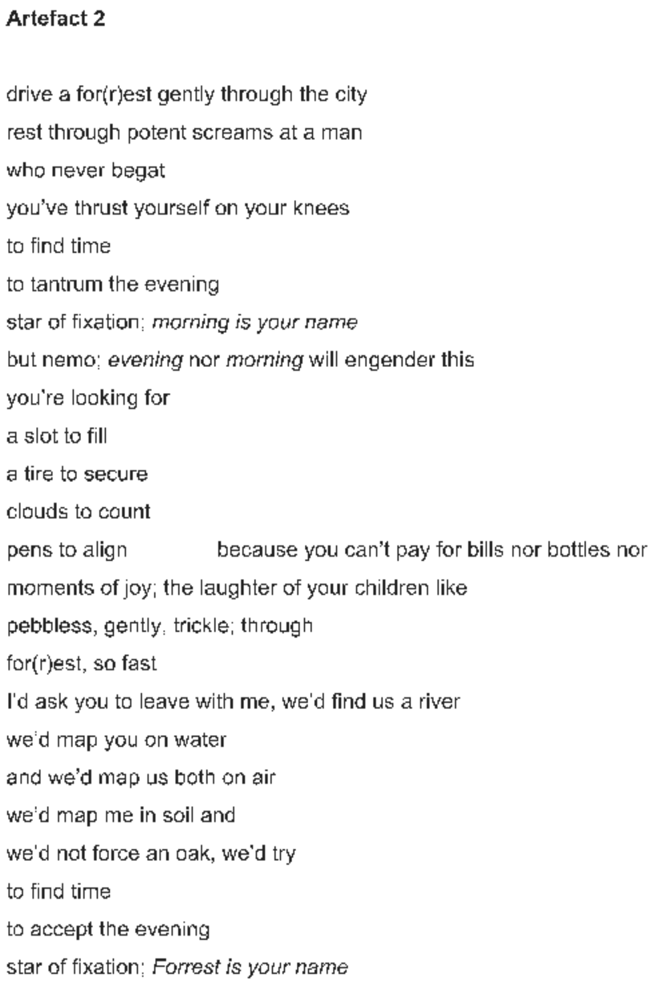
'When someone asked me, when I told like one of my colleagues that someone had asked me if I was autistic she just found it hilarious like the fact that someone might think that about me.' (Poppy)

‘I think because there is this false and harmful notion that "only men are autistic" or that autism is "a male disorder" or that autism is "having a male brain".’ (Jess)

This ignorance about autism occurring in women and a societal perception that only men can be autistic may be damaging to autistic women as they may not feel like they are able to be their true identity in public or feel unaccepted by society.

How autism is portrayed in the media was a topic that participants were keen to talk about and highlight the similarities of ignorance and erasure that occurred in wider society. Some participants felt that they could not relate to autistic characters in fictional media as they were based on stereotypes and included intersectionalities they did not feel they fitted into.

Jess created a poem based on Forrest Gump (Zemeckis, 1994), a film about the life events of a disabled man which has attracted some criticism of its depiction of disabled people (Ketcham, 2020).



Artefact 2

drive a for(r)est gently through the city
rest through potent screams at a man
who never begat
you've thrust yourself on your knees
to find time
to tantrum the evening
star of fixation; *morning is your name*
but nemo; *evening* nor *morning* will engender this
you're looking for
a slot to fill
a tire to secure
clouds to count
pens to align   because you can't pay for bills nor bottles nor
moments of joy; the laughter of your children like
pebbless, gently, trickle; through
for(r)est, so fast
I'd ask you to leave with me, we'd find us a river
we'd map you on water
and we'd map us both on air
we'd map me in soil and
we'd not force an oak, we'd try
to find time
to accept the evening
star of fixation; *Forrest is your name*

Figure 29: Jess' Artefact 2

Jess highlights the stereotypical negatives of autism by using words and phrases like: 'tantrum', 'fixation' and 'pens to align'. She references the character Forrest (from the film) but also talks about a forest, using these homophones (words that sound the same but mean different things) to demonstrate the ease of misunderstanding and confusion about autism. Within the latter half of the poem, Jess looks at the idea of society moving forward together, both with allistic (non-autistic people) and autistic people, past the pre-existing notions of what autism is and coming together as a co-dependent society. This is in contrast to thinking of each other as 'us' and 'them' which can work both ways. She does this through considering nature, only differently (neurotypical people are water, everybody is air, and autistic people are the earth itself) but that everybody needs each other.

Jess explained her poem looks at,

‘Allistics [a word to describe people without a label of autism] trying to name and taxonomise autism and its "reasons" is a big theme, like how allistics try to put it into words (or film) what we are and how we are, but in a way that makes sense to them and how they can benefit from their own portrayal of us.’ (Jess)

Jess’ explanation of her poem suggests that the notion that autistic and non-autistic people may be able to form a co-dependent society is unlikely unless there is any change in how the present media portrays allistic people’s opinions of autistic people. She suggests that media representations can make allistic characters appear as heroes in helping an autistic character, by treating them like a ‘normal’ person, as the autistic character is portrayed as an object of pity (Aspler et al., 2022; Ressa & Goldstein, 2021).

Barnes argued in 1991 that humour that is overtly racist or sexist can be censored but that disability humour and poor representation remains acceptable, which suggests disability is a lesser protected characteristic. Some more recent research highlights there is some movement to changing stereotypes within popular media. Alice and Ellis (2021) posit that the film franchise *Shrek* (Adamson & Jenson, 2001) subverts the traditional narrative of a fairy tale. They argue that the films show both social exclusion and disablement, and interdependence and disability pride through characters that rebel against traditional roles and expectations. Shrek, an ogre is shown as the hero in the films and depicted as a non-normative body. Garland-Thomson (1997) argues that monstrosity (either through a literal or metaphorical monster) tends to be shown in films in comparison to the normative body, therefore representing disability. Alice and Ellis (2021) highlight that although Shrek is viewed as a monster and an outcast, he is also depicted as finding community with others and challenging internalised ableism. This therefore depicts the complex nature of disability. Representations in society of disability as more complex including in popular media and media aimed at children, compared to stereotypically negative depictions like Jess suggests may support society to view disabled people more as part of society, rather than being othered.

Jess also highlights that autism is difficult for people to understand as it has so many different presentations, but that in order for autism to be popular in the media only certain representations are acceptable. Autistic characters are frequently portrayed as having a negative impact on a family or society (Brooks, 2018) or as having a savant ability (Belcher & Maich, 2014). There appears to be very few representations of autism that represent ordinary people. Society seems to require stereotypical representations in order to understand autism (Black et al., 2019). Similarly, Kim suggested:

'When people think of autistic people they either think of a white sixteen year old boy that's very good at maths, or they think of a young child who can't communicate properly' (Kim).

This presentation of autism (as a white middle class boy who is good at maths) that Kim talks about is also documented by Matthews (2019), who highlights how common this stereotype is in the media. He says one popular character that fits all those stereotypes is Sheldon Cooper in *The Big Bang Theory* (Lorre & Prady, 2007), who is frequently used as a reference point within the autism community despite never being explicitly mentioned as autistic in the television programme (Matthews, 2019).

Loftis (2021) and McGuire (2016) argue that a metanarrative of autism in the Western world is that autistic people are either children or child-like. In her comment Kim notes two presentations that she believes society holds of autism, referring to children on both occasions. Loftis (2021) notes this metanarrative is dangerous for adult autistic people because they are either at fault for not curing their autism or that autistic adults only deserve the same autonomy afforded to children. As the fault lies with the autistic adult under society's favoured narrative, access to services for autistic adults may be reduced.

The stereotypes of disability and more specifically autism that Jess and Kim suggest dominate societal discourse. Dean and Nordahl-Hansen (2021) contend that the way in which autism is presented in the media and popular culture influences how society views 'real people' with the condition, meaning it is important that the portrayal is correct. However, Murray (2008) argues that for autism to remain a fascination in popular culture it has to appeal to the majority audience’s beliefs and portrayals. This may mean that autistic fictional characters will never accurately represent the majority of autistic people, as these characters have to be extraordinary. Writing over a decade later, Broderick and Roscigno (2021) maintain that the intended audience for most popular media that includes autistic characters is not autistic people and therefore a portrayal of unstereotypical representation, for example, an autistic woman, may not attract such popularity. This may be why more relatable presentations to autistic people are seen less in popular culture.

Christensen (2020) used the metaphor of Harry Potter (Rowling, 1997) in exploring how three Danish autistic women, all who had autistic children, viewed autism. She was interested in whether her participants viewed autism as part of a spectrum of normality or solely as a difference. The Harry Potter series does not explicitly state that any characters are autistic and has not been widely suggested as doing so by society. However, the series of books could be argued to be about difference. Within Christensen’s (2020) research they discussed how the muggles (non-magical people) could be seen as non-autistic people and the wizards as autistic, as both worlds have different norms and expectations. Nuances became apparent however that wizards can be born to muggle families (referred to as mud-bloods) demonstrating how different worlds can overlap. Although Harry Potter as a metaphor in Christensen’s (2020) research is not used to specifically describe autistic women, it explores how difference can be shown without explicitly labelling it. This therefore begs the question of whether characters should be introduced as explicitly autistic or whether popular media should simply focus on ensuring a variety of people feature to champion intersectionality rather than reinforce stereotypes. Or, whether a variety of differences should occur, such as having multiple characters with a certain disability label with explicitly different personalities and needs.

There is an argument that autistic characters in the media in more recent times are diversifying and becoming more complex (Aspler et al., 2022), although other researchers such as Ressa and Goldstein (2021) argue autism stereotypes in the media remain unchanged. One participant noted that perhaps there is an increase in understanding about the varied nature of autism, regardless of gender which could be due to better media portrayal or societal understanding.

‘It may not be a gender thing so much but it might be that we’re recognising that there’s more than one way to be autistic.’ (Cassy)

This comment suggests that if, and as, autism is more widely known about, gender may not play a large part in society’s construct of it, particularly in relation to stereotypes surrounding autism. However, at the current time portrayals of less stereotypical autistic people, such as autistic women and girls may exist less explicitly and less frequently in media, possibly because autistic women and girls are more able to mask their symptoms or that autism in women is viewed as less common and less acceptable in society. If autism was recognised to present in many different ways like Cassy alludes to, rather than by gender stereotypes (such as autism relating to boys who are very good at maths) then autistic women may not be as marginalised.

Autistic women’s minimal exposure also appears in non-fictional media. Greta Thunberg (an autistic climate change activist) for example, is one of the few autistic women who does appear in non-fictional media. However, as a white teenage activist she is exceptionalised by the media, who regularly highlight her autism as a ‘superpower’ (Ryalls & Mazzarella, 2021). Moriarty (2021) deems that this depiction of autism may be seen as supercrip as Thunberg is seen as challenging her disability in ways seen as inspiring. However, whilst Greta Thunberg is championing her cause and publicly highlighting herself as autistic, possibly to challenge negative stereotypes of autism, not all autistic women or their families will find her relatable, especially if they do not view autism as a ‘superpower’. For other autistic people it may be demoralising. Spies (2021, p. 308) states that ‘It can be frustrating and limiting, especially if people are attempting to live as a supercrip’.

Societal perceptions towards autism can tend to focus on the gendered aspect of the condition and thus erase autistic women who do not fit into society’s standard stereotype of autism. The media is very powerful in cementing or challenging stereotypes (Kehinde et al., 2021). Therefore, the media either needs to change the portrayals of autism it is releasing or until this happens like Ressa and Goldstein (2021) contend society needs to recognise media portrayals may not be wholly accurate and to critically evaluate their relatableness to ‘real life’ autistic people.

5.4 Perceptions of University

Much research that has centred around autism in Higher Education in previous years has focused on non-autistic students’ perceptions of knowledge of autism and perceptions of autistic students (for example, Gardiner & Larocci, 2014; Matthews et al., 2015). More recently, the focus of autism research in HE has shifted more towards autistic students’ experiences (see *Chapter 2: Literature Review*). Despite this shift in more recent research to experiences, I felt exploring what autistic students think other students and staff think of them and how university systems frame them was important. This was in order to understand whether these perceptions were similar or different to what research of neuro-typical students thought and to highlight how autistic feel they are thought of at university and the impact that has on them.

In addition, I think it is important to consider that although data was collected just before and as restrictions of Covid-19 started, I analysed it in earnest after society and specifically academia had started to adapt to working with as little contact with others as possible. As I write this, some academic adjustments implemented in the pandemic are still in place such as some learning remaining online. Therefore, I wonder if some of the participants’ perceptions of what university thinks they should be like would be different if I had collected the data as little as a few months later (when online working practices had started to be better implemented). It is however impossible to tell whether the changes made (and that remain ongoing) during this pandemic will continue to be in place when and if the world is declared to be back to pre-pandemic status.

Several participants alluded that they thought staff within universities had an idea of what a university student should be like and that university events and teaching were focused on this idea of a norm. This norm, participants felt, transcends both academic and social expectations, which they may or may not be able to meet. Both Poppy and Jess highlighted that their experience at university was inflexible and expected conformity. Poppy spoke of how she thought that studying was thought of as more important than any other difficulty or life event.

‘In some ways it's good to have like the inflexibility and the like promotion of studying beyond like over any kind of human issues but in all the way it. The inflexibility could kind of be a bit of a nightmare.’ (Poppy)

‘In education these hurdles [things in education she found difficult] include mandatory presence in classes and assessed in-class participation. In the socio-cultural sense these hurdles concern behaviour or expected behaviour.’ (Jess)

This lack of flexibility that Poppy and Jess argue universities have further suggests that there is an opinion of how a university student should be and the ways in which they should view their studying. Several researchers (for example, Chiu et al., 2021; Jayadeva et al., 2021; Sykes, 2021) explore what the expected attributes of a university student are and what influences these. Sykes (2021) highlights that there is a myth that students are either traditional (which she documents includes living at university, drinking excessive alcohol, being aged 18-21, and white) or non-traditional. She goes on to say the common traits a traditional student has are idealised by both students, staff and external media and thus this myth is repeatedly perpetuated. Jayadeva et al. (2021) highlight that there is little research on how students think others perceive them and the impact these perceptions have on them. They explored this through the use of various activities in focus groups including asking participants to build plasticine models of how they thought they were viewed by other people. The researchers did not appear to define who they meant by other people. The perspectives participants built their models on varied, including how their family or society viewed them. They concluded that there were four common ways participants felt they were constructed by others as university students: ‘hedonistic and lazy; useless and a burden; clever, hardworking, and successful; and a resource to be exploited’ (Jayadeva et al., p.1). The categories Jayadeva et al. (2021) form suggest mixed positive and negative stereotypes of students exist, and a student may span many of these. Chiu et al. (2021) highlight that students in their research mostly considered high grades, influenced by their university's competitive nature and their previous educational experiences, to be the norm at university. External validation from employers and society helps to cement this belief. Overall perceptions of a university student appear to be varied but have some similarities, specifically high academic ability and also prioritising social activities and interactions.

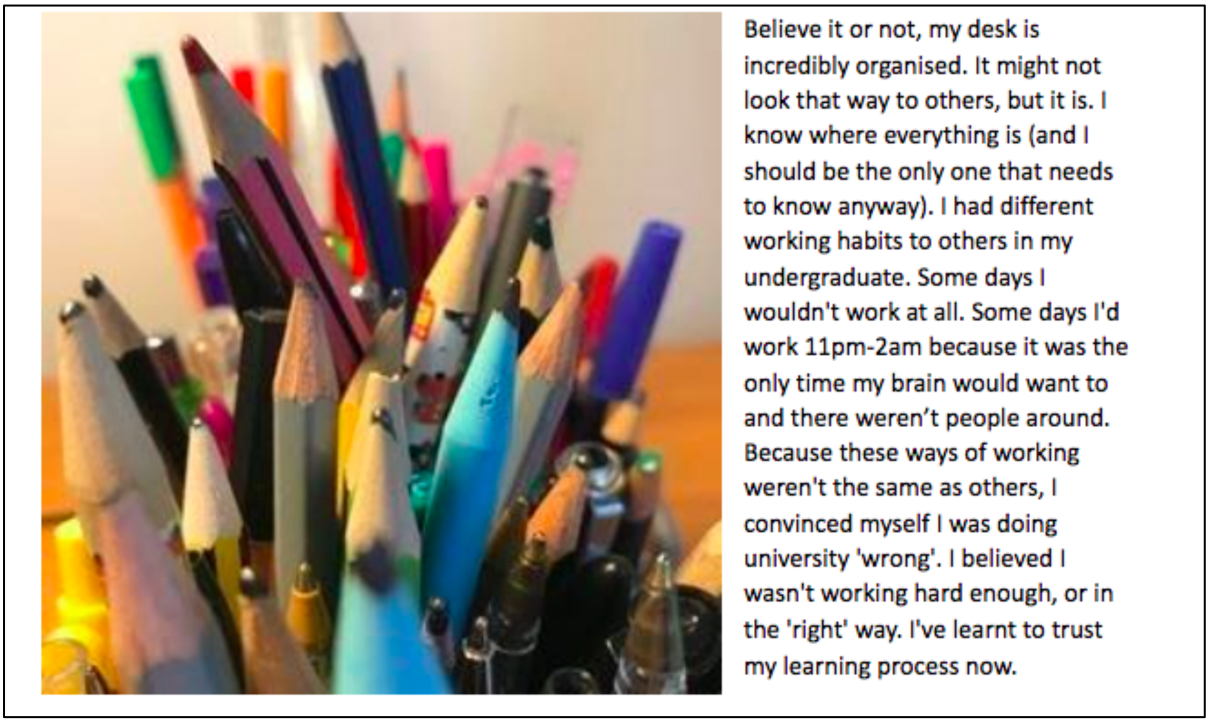
Wong and Chiu (2021) and Koutsouris et al. (2021) state that people related to the university all have expectations of what a university student should be like, regardless of whether these are explicitly stated or not. Sykes (2021) and Wong and Chiu (2021) argue that expectations and ideals held about students can have consequences if students are unable to meet these or have different values. Koutsouris et al. (2021) go on to highlight that this focus can be damaging to students who do not feel they fit a norm and that emphasis should be shifted towards the university and culture change within the institution. Although it is unlikely for people within the university context to be able to hold no expectations of a student, this does not mean that these expectations cannot be challenged and broadened.

In her interview, Billy suggested that stereotypes and assumptions about what a university student should be and how an autistic university student should be, stem from the argument that going to university is not compulsory and thus a student should be able to fit an expected mould. Here Billy is suggesting that if an autistic student cannot fit into student life, they should not come to university.

'...you HAVE to attend a school of some sort until you're 18. So you get EVERYONE. But at uni, I think there's this idea that the people who have gotten into a uni, have chosen to attend, are smart enough or capable enough to not have wellbeing issues beyond the norm.' (Billy, emphasis original)

She highlights that if somebody is able to attend university then they should be able to fit a perceived norm and that they should not display any difficulties beyond the norm. Her comment supports the research of Wong and Chiu (2021) that there are expectations of students, including by the students themselves. These expectations that an autistic student has to fit into an expected mould of a university student could lead to autistic students being fearful that they may be found out as not appearing normal enough or simply feeling not clever enough to be a university student. Sykes (2021) and Wong and Chiu (2021) also suggest that if students feel they cannot meet expectations this could be detrimental to how students feel and achieve at university.

Little attention in previous literature has specifically been given to the disabled university student and how they may feel they deviate from a perceived norm of a university student and the impact that may have on them, both the perceptions of others and their own internal perceptions. Some research has been found to be an exception (for example, Cunnah, 2015). Billy creatively documented how she felt she worked differently to others and thus again did not meet expectations of how a university student should work (see figure 30).



Believe it or not, my desk is incredibly organised. It might not look that way to others, but it is. I know where everything is (and I should be the only one that needs to know anyway). I had different working habits to others in my undergraduate. Some days I wouldn't work at all. Some days I'd work 11pm-2am because it was the only time my brain would want to and there weren't people around. Because these ways of working weren't the same as others, I convinced myself I was doing university 'wrong'. I believed I wasn't working hard enough, or in the 'right' way. I've learnt to trust my learning process now.

Figure 30: Billy's Artefact 1

Billy worried about not being able to do university work in the same way or at the same time as other students, therefore not meeting what she thought a standard university student should be. She states she can now trust her learning process, but that suggests that she was unable to at some point in her university study. This suggests a confidence in knowing that it is okay to deviate from an expected norm or ideal and feeling able to champion this both in her own studying and if challenged by others, which may be difficult to achieve.

Jess, Poppy and Kim extend the idea that there are likely to be expectations of what a university student should be as they have experienced difficulties with university staff who did not seem to understand disability and how a student may not be able to conform to an expected norm due to being autistic. In particular Jess felt neuro-typicality was a standard perception in academia and that it was expected, and Poppy thought that university was constructed on this basis.

‘I particularly remember a situation where I was taunted by a lecturer in a big and full lecture theatre for not keeping up with the information on the slides. He further confronted me after class and questioned my attention during class, to which I responded "I have an LSP (learning support plan)" and he was very taken aback and apologetic. My point with that anecdote is that it seems many lecturers assume neurotypicality as the standard, which is a big issue.’ (Jess)

‘I think that everything is constructed in a way that favours neurotypicality.’ (Poppy)

Jess highlights that from her experience it appears neurotypical students are viewed as the norm which can cause problems for her and other neurodiverse students. If neurotypicality is linked with the norm like Poppy suggests, an assumption of ability (or lack of it) is then made about neurodiversity. She highlights she feels that university is centred around the majority, but more importantly to her it is constructed around the opinion that a university student is neurotypical. Thomas (2007) posits that once a person or group of people are labelled and discredited as abnormal they are open to stigmatisation and oppression. This stigmatisation (of disability in Jess’ example) can lead to situations like Jess’ which result in unwanted confrontation. Jess challenged the lecturer’s comments and self-advocated for her needs. Bruce (2020, p. 433) argues that by disabled students having to self-advocate for academic accommodations they are entitled to, they are effectively asking for ‘permission to learn’ and accept whatever response is given with gratefulness.

Like Jess, Kim also had difficulties with lecturers’ understandings about disability and their willingness to accommodate difference. Austin and Vallejo Pena (2017) highlight that over recent decades the number of disabled students attending university has significantly increased meaning staff need to familiarise themselves with disability in a way they would not have previously needed to. Kim posits that perceptions of disability from academics hindered her ability in lectures, suggesting that the knowledge of academics about disability may still need to be improved.

‘The issues that I have had with lectures etc have just been about ignorance.’ (Kim)

Kim attributed lecturers' attitudes to them being ignorant about autism. Sasson et al. (2017) documents that negative judgements about autistic people are made quickly and can have a negative impact. Autistic students may therefore be othered or stigmatised against. Scott and Sedgewick (2021) note that stigma towards autism exists at university. However, they highlight that after reviewing studies on autism perceptions (for example, Stronach et al., 2019; White et al., 2019) at university, knowledge about autism appears to be increasing both in students and staff and this corresponds to decreasing stigma levels. Jess and Kim's experiences however highlight that ignorance still exists around autistic students at university. Thus, it could be questioned what type of knowledge about autism is increasing and whether it is practical about supporting an autistic student or more focused on a more medical standpoint. This may be why Kim has experienced ignorance from lecturers because they may have known about autism as a condition but not about 'real' autistic people.

Perceptions of not fitting like Billy says or experiences of others' perceptions such as Jess, Poppy and Kim voice may lead to internalised stigma. Where negative stereotypes and perceptions are internalised and believed (Botha et al., 2020). Pearson and Rose (2021) argue that autistic people are regularly shown or told that they are abnormal or impaired. This can be internalised and damaging to an individual's self-esteem and confidence in their abilities.

Thus, if lecturers were more aware of diversity and less focused on what they thought a stereotypical student should be expected to do, ignorance may be reduced. Poppy thought that neuro-typicality being the default stance of the curriculum could be changed to ensure that there was more open-mindedness within academia.

'it's sort of like someone needs to like, it's like decolonising the curriculum, but like de-neurotypifying the curriculum needs to happen because, like so many of the concepts that we learned just don't make any sense. if, if applied to neurodiverse students.' (Poppy)

Poppy suggests that the curriculum needs ‘de-neurotypifying’ as it is not inclusive unless you are of the predominant neuro-type. She does not feel what she is being taught is relatable to her due to not feeling included in what is being taught or others’ views. Thus, the teaching at university may force an autistic person to feel even more distant and like they do not fit in.

Poppy references the movement to decolonise the curriculum. In recent years there has been a growing amount of research on this movement. Abu Moghli and Kadiwal (2021) explain decolonisation in academia to include initiatives to ensure knowledge produced by academics of colour and those from the Global South is included in teaching and university syllabi. The aim of decolonisation is to therefore promote academics of colour, to disrupt knowledge and power matrices and ensure students are not just introduced to knowledge that white western academics have produced (Morreira et al., 2020).

A movement to de-neurotypify the curriculum by amplifying the voices of neurodiverse people may help neurodiverse students feel like they belong in university. Poppy suggests some concepts in the curriculum only apply to neurotypical people. Although there is no recognised movement to de-neurotypify the curriculum yet, there is evidence that some academics are striving for this. Snyder et al. (2019, p. 486) highlight how in their mad studies classes they teach in a ‘mad positive’ which characterises what is on the curriculum, how academics engage with students, and the activism they practise and promote.

The boundaries between ensuring a diverse curriculum and exploiting disabled students themselves can be blurry. Hillary Zisk (2019; 2021) identifies as an autistic student who uses augmented and alternative communication. They took postgraduate classes in communication (where most of the other students were studying to be speech and language therapists) and developmental disorders. Hillary Zisk (2019; 2021) documents how professors in these classes asked them to do presentations on their lived experiences and made comments on how other students were learning a large amount from them being there.

They suggest they were the curriculum and an exhibit to be learnt from. Sinclair (2005) coined the term ‘self-narrating zoo exhibit’ to explain how autistic people are expected to conform in academic settings around neurotypical people. They are expected to narrate their own experience, but only when others are interested in seeing or hearing it, similar to animals in a zoo. Morina et al. (2020) highlight that disabled students are essential in university classes as other students are able to see accommodations and adjustments that can be made. Always being on show or educating others about disability can cause additional labour for disabled students and staff (Gillberg, 2020). Whilst knowledge of lived experience and visibility of disability is important to ensure inclusivity, providing a diverse curriculum should not become an additional responsibility of disabled students or staff.

Abu Moghli and Kadiwal (2021, p. 13) do note that although decolonising the curriculum is needed it should not happen as a trend or as simply a ‘box-ticking exercise’. They and Vandeyar (2022) suggest it should be something that infiltrates the entire university structure and practice of working. Abu Moghli and Kadiwal (2021) suggest that if decolonisation is strived for, curricula and structures are likely to include voices from other minority groups.

De-neurotyping the curriculum could therefore be possible, to ensure neurodiverse voices are heard across a range of disciplines rather than being confined to disability studies but should not be a tokenistic practice or add additional labour to neurodiverse students or staff, and be supported by neurotypical staff.

The idea of a normative university student also extended to how participants talked about the social stereotypes of a student. The social aspects of university also appear to favour a norm which students are expected to comply with if they want to fit in with other students. Sykes (2021) suggests that the societal expectation of students drinking alcohol excessively and going to lots of parties is so intense that students may feel they have to conform to that ideal on social media and when talking publicly when in reality they only engage in this form of socialising infrequently.

‘...you know again there was this expectation of what undergraduates would enjoy and do. And I didn't really feel like I fit in to that, you know, I go to clubs and things like that. And, but I'd have sort of one or two drinks, but I would stop there because I would either fall asleep or it just make me feel weird. And then they'd like it. I get a lot of headaches, I, I've had a lot of headaches since I was a child so I tend not to drink much. So, I mean you know as a student, I think, again, it's sort of the social aspects and the expectations of what an undergraduate is going to enjoy so the university would organise certain events for example the SU, but they weren't really things I sort of bought into. ‘ (Cassy)

Cassy shows how this perception of the focus of alcohol as an undergraduate student may be incredibly damaging to others, especially to those who do not want to drink alcohol or prefer a different type of event. Gambles et al. (2022) emphasises that new students coming to university hold perceptions that alcohol can assist with making friends and reducing anxieties. These ingrained perceptions are unlikely to be helped by the culture at university in the UK that the first week of university is overshadowed by alcohol dominated social events and a promotion of excessive consumption of alcohol (Fuller et al., 2018). A lack of social events not focusing on alcohol may disadvantage students who do not want to consume alcohol or come from a culture of moderation or abstinence of alcohol but want to socialise (Humfrey, 1999). Thurnell-Read et al. (2018) highlight that some international students welcome the experience of the British university drinking culture but that others feel alienated. Conroy et al. (2021) suggest that students and young adults more widely are starting to drink less alcohol. If this trend continues then universities may have to widen their events where the main focus is not alcohol. Universities could increase inclusivity by ensuring that there are events that both focus and do not focus on alcohol to ensure that drinking alcohol is a choice, rather than a pressure.

Although appearing binary, the social and academic expectations of a student may be more connected. Jess highlighted that the lines between social and academic expectations of students can be blurred.

‘I think the assumption that you can "get notes from a classmate" if you're absent, or to have someone to pair up with during presentations, is very present. It's assumed you'll find people to get along with, but I don't.’ (Jess)

Jess’ experiences of feeling she had nobody she could ask for notes from highlights how the social expectations of what a student should be can also impact educational experiences. Not feeling part of a cohort or socially being able to engage with others on a university course may lead to feelings of not belonging. Pesonen et al. (2020) argue there is little research on an autistic person’s sense of belonging at university, which can be very politicised, but is influenced by social interactions and relationships at university. Lawson (2010) suggests that behaviours of autistic students that are not common of neurotypical people should be viewed through an autistic lens and not a neurotypical lens and that autistic students should be taught about neurotypical hidden social rules. Overall, social expectations and perceptions of others can be harmful as they further confirm difficulties that people may have with certain situations.

Some participants noted that they felt or had experienced people projecting different stereotypes on them as an autistic woman, compared to if they were an autistic man within the academy. This perpetuates the societal stereotypes and opinions that autism is more accepted in men rather than women, particularly in those without associated learning disabilities. Jess extensively highlights how she thinks autistic men and women students would be treated differently in academia.

‘...it depends on whether it is a student or a member of staff that is an autistic man. I think autistic male students may be excused for social inappropriateness in class and then still be relatively accepted socially, if he is "just" loud or interruptive. I think if I acted like that, for example, I'd be even more socially excluded. I think autism is marked out much more starkly in women in academia, because people expect us to be silent and compliant there. I think autistic male members of staff could get away with rude comments and inappropriate behaviour and people would blame it on him being "eccentric" or "different" but do nothing about it. An autistic female member of staff behaving inappropriately would probably get her fired very quickly, or under review at least. I have no experience or evidence of this, this is just what I believe would happen.’ (Jess)

Jess highlights that male autistic members of staff may be referred to as eccentric and thus have any quirks or differences in behaviour accepted, whereas autistic women would not be afforded the same privilege. Although Jess states she has no experience or evidence of this, her opinions and perceptions must be shaped by some form of knowledge or experience. Having this perception may hinder her own self-confidence and self-value.

Within academia gender disparity is widespread, including behaviour that it is acceptable. Rosa and Clavero (2022) argue that despite some policy attempts to address gender equality in academia, gender imbalances remain such as pay equity and gender segregation across disciplines. They also highlight that men hold more power than women in academia. Woodhams et al. (2022) posit that women have to demonstrate a male dominated description of merit to progress in their academic career which may lead to presenting a dual personality based on gender norms. Thus, it seems most women will experience at least some gender inequality in their careers.

Although most women in academia are likely to be subjected to gender imbalances and equality, it is interesting to consider where the more ‘disabling’ factor is being autistic or being a woman, or even whether it is the intersection of both of these factors. Sophie suggests that these intersections can be separated with being disabled being more hindering than being a woman.

‘Being disabled is going to give me more barriers in life than being a woman.’ (Sophie)

Although Sophie is not talking about academia specifically, it is likely that academic barriers replicate other barriers in society. Little could be found written about autistic women’s experiences in academia and the impact gender has, however, there is some research regarding disabled women academics more generally. Brown and Leigh (2018) highlight disability disclosure by university staff is minimal. In addition, Lindsay and Fuentes (2022) assert that disabled staff in academia are underrepresented in academia which could explain the lack of research about them. Peterson and Saia (2022) argue that participants (who were all disabled PhD students) in their study viewed their identity of being a woman differently depending on how they were included in academia. The impact of it was less important if they were included. Peterson and Saia (2022) thus advocate that identities should always be viewed through an intersectional lens as the significance of different aspects of identity can change depending on the situation.

The intersectionalities that disabled people have in their identities need to be viewed through an intersectional lens. Universities therefore need to accept that parts of a person's identity can be more or less important depending upon how they are accepted and treated in every situation.

Overall, I have discussed the topics of what participants view a stereotypical university student to look like, how perceptions of autistic students may be influenced by gender and what universities could do to ensure that staff and students do not perpetuate negative stereotypes about autistic students.

Most notably participants felt that they did not fit into what universities framed a stereotypical student as, which meant they either had to be confident in not fitting into a stereotypical image or hide their real selves to fit in. Negative stereotypes surrounding autism were felt to be placed on autistic women students more as an autistic man would be afforded the privilege of being referred to by other adjectives whereas an autistic woman may just be labelled as disruptive or seen to be non-conforming. If universities feel they are unable to make that leap and want neurotypicalness to be the norm, then they need to support autistic people to understand rules and conformities that need to be followed. In order to reduce stereotypes and negative perceptions towards autistic students, participants suggested the curriculum needed to be 'de-neurotypified' and more awareness given to autism to dispel myths and wrong assumptions.

5.5 Conclusion

In conclusion, within this theme of perceptions I have explored the themes of self-identity, societal perceptions and perceptions of university. Within self-identity I have looked into topics such as diagnosis and how that has influenced autistic women's identities and the reasons behind and for masking to fit in. I have also explored the damaging effects masking and hold a negative identity can have on an autistic person.

I discussed society's general ignorance and erasure of autistic women due to a lack of knowledge about the presentation of autism and that it is not solely linked to men. I also explored how the media can help to influence societal stereotypes of autism, by providing a narrow range of portrayals, that are unlikely to be relatable to for autistic women.

Within perceptions of university theme, I discussed the notion that either consciously or subconsciously both staff and students held an opinion of what a good university student should look like and explored how an autistic student may not be able to meet this image and the consequences of that. Participants noted consequences included not feeling like they were studying in the correct way to be a student or that they did not belong at university.

Overall, it can be understood that society's inherently negative perceptions of autism in women and what autistic people can do can be a huge factor in how a person with autism sees themselves. If society was in general more accepting of autism, then autistic women may have more positive identities and beliefs about themselves. These generally negative stereotypes from society extend into the university context, where autistic people do not feel they fit into the assumptions of an ideal university student.

In order to create change the stereotype of autism needs to change to include women, both in academia and in wider society. An example of this discussed is through the media incorporating a wider range of autistic characters in fictional media, and not stereotyping autism as either a superpower or a problem in both fictional and non-fictional media.

However, society could also be educated to not view autistic people in the media as one sole representation but rather appreciate that autism has many different presentations.

If change is created then autistic people may feel the need to mask their autistic identity less and thus be less at risk of mental health difficulties and feel that they do not have to hide their true selves.

6 Exposing The Postgraduate Autistic Student

6.1 Introduction

Within the relatively small research field looking at university experiences from autistic people's points of view, very little appears to focus on the postgraduate autistic experience. Farahar and Foster (2021) pose that until recently the autistic experience was bounded in many stereotypes (including regarding gender and intelligence), which may explain the dearth of research into this area. They go on to say that until recently as autistic academic women they would have been considered 'rare people' (2021, p. 200). Research into the general university experience for autistic people is slowly growing, but the experiences of autistic postgraduate students (especially women) are largely ignored or only touched on in single accounts and autobiographies (for example in Farahar & Foster, 2021; Stewart, 2018). There is a small amount of literature exploring the experiences of disabled postgraduate students, Shinohara et al. (2021) is a notable example. They consider visually impaired doctoral researchers and noted that these graduate students had to work harder than other students to achieve similar prospects. In contrast to this dearth of research on autistic postgraduate students, nearly half of the participants in this current study were postgraduate students. This is interesting because postgraduate students only made up 27% of students in the UK in 2020/2021 (HESA, 2022). There was no stipulation in the research regarding level of study, so I am not sure as to why there was a higher number of these students who offered to take part. It could be because these students have more time to take part in the study and have more reason to want to share their experiences. I especially chose to focus on autistic postgraduate students due to the frequency with which they are ignored in research in favour of the undergraduate autistic student.

In this chapter, I consider how participants navigated conferences including networking and presenting, and negotiated dual identities of being a staff member and a student. I consider two of my research questions in this chapter:

1. What barriers and supports to higher education do autistic women students feel they have had at university?

2. In what ways can the university environment be adapted to better accommodate autistic women?

I attend to some barriers and supports autistic postgraduates experience and examine how the wider university environment could be better adapted. In the first section of this chapter, I attend to how participants navigate conferences. I start by discussing that in-person conferences can be inaccessible to disabled people for a variety of reasons. I then focus my analysis on networking and presenting. I consider that participants found networking difficult due to social complexities they felt they could not adhere to. This in turn led to feeling like an outsider and not belonging in this academic context and not being able to access potential jobs or publication opportunities. I then discuss how presenting at conferences can allow positive feedback from others, which can provide a confidence boost. Overall, I highlight how conforming to perceived behavioural norms at a conference, when networking or presenting, can be emotionally draining and involves additional labour. In the second section of the chapter, I consider how students who as well as being a student also have a professional role, such as teaching, navigate these two roles and the differences between them. I explore how participants felt they were able to access disability accommodations when they were in a student role, but not in a staff role. Overall, through these two areas I draw out two main conclusions. I highlight that the culture of conferences needs to change to be more sensorily inclusive and to ensure that autistic academics feel they belong even if they find meeting traditional norms of a conference participation difficult. Second, I conclude that accommodations afforded to students should also be afforded to staff, especially for postgraduate students that span both roles.

6.2 Feeling Like an Outsider at a Conference

Much research (for example Donlon, 2021; Oester et al., 2017; Rowe, 2018) states conferences are a very important part of being an academic, as they provide opportunities to hear about new and upcoming research, and to meet other researchers with similar interests. Shinohara et al. (2021) highlight that most doctoral research students are expected to attend conferences to share their work. However, in recent years the inaccessibility of traditional face-to-face conferences has been documented due to certain barriers people experience, such as their disability (for example, Shinohara et al., 2021), gender (for example, Nicolazzo & Jourian, 2020), caring responsibilities (Henderson & Moreau, 2020) or wish to avoid alcohol consumption (Burns, 2021). Therefore, although conference attendance is situated as a key part of academia, conferences can exclude a large number of academics.

Some researchers highlight how conferences are not always accommodating to disabled researchers (Brown et al., 2014; Callus, 2017; De Picker, 2020; Gordon & Gledhill, 2018; Irish, 2020; Lindsay & Fuentes, 2022; Martin, 2020a; Martin, 2020b; Mellifont, 2021a; Mellifont, 2021b). They document that disabled academics can be disadvantaged and not able to be fully included in the conference environment due to exclusion. With specific regard to autism, Martin (2020b, p. 12) recognises conferences as ‘profile-raising activities’ that do not tend to be accessible to autistic scholars for many reasons including the social complexities required during networking. Mellifont (2021b) suggests that considering how inclusive neurodiversity conferences are to neurodiverse academics is a new field of interest.

Donlon (2021) predicts that, although Covid-19 has changed the way conferences are delivered, they will remain part of academic life and therefore it is important to understand how autistic researchers experience them, to ensure they are confident attending and feel included when there. Although at the time of writing the majority of academic conferences remain online due to the global pandemic (which they were not during the beginning of data collection), it can be assumed that one day conferences may return to in-person or hybrid events (Donlon, 2021). In light of this, Caravaggi et al. (2021) suggest that social media, particularly Twitter, could be utilised more readily within both in-person and online conferences to promote networking and further discussion.

Participants Cassy and Katie were both studying for a PhD when interviewed and both talked about conference attendance. They both chose to represent their experiences at conferences through artistic depiction as one of their artefacts (see Figures 31-33). Their choice to dedicate one of their artefacts to this topic suggests they feel conferences are a situation where their autism has a big impact.

First, I explore the experiences of Cassy and Katie with regard to networking and presenting talks at conferences. I consider difficulties associated with networking. I highlight how the unwritten rules of social communication and the sensory environment make participating in the social aspects of an academic conference challenging. Then, I discuss the positives of giving conference presentations and the ways in which complimentary feedback contributes to confidence.

6.2.1 The Social Burden of Networking

Oester et al. (2017) suggest that the benefits of conferences are not only being able to listen to presentations on research, but the ability to engage in two-way conversation as it can build research collaborations and enhance an academic’s career. They document that two-way communication tends to happen in hallways and other less formal environments of a conference, such as over coffee and that it is a more natural way of getting to know another person. Oester et al. (2017) conclude that genuine impressions and communication with other people cannot happen over the internet or a phone and thus need to occur in person to develop relationships and aid research collaboration. Considering prior to the pandemic the majority of any events (both academic or otherwise) were held in-person, society's view of communication is likely to mirror Oester et al. (2017).

However, Covid-19 meant that working and conference cultures had to change and many academic events needed to become virtual (Schwarz et al., 2020). Niner and Wasserman (2021) highlight that online conferences can attract a wider audience as cost, environmental impact, travel time and international paperwork are reduced. Sarju (2021) documents her own experiences as a disabled academic during the pandemic. She suggests that virtual conferences can be more accessible to disabled people, but are not exempt from inaccessible features for example inaccurate captioning. Raby and Madden (2021) surveyed conference attendees of a virtual conference and compared it to that of a similar pre-pandemic conference. They found mixed views of online conference networking, as some delegates preferred the more structured social opportunities of online conference spaces but others did not. This suggests that virtual conference networking may not suit everybody, in the same way that in-person conference networking does not. However, a hybrid approach may ensure more people can access networking opportunities.

Both Cassy and Katie described the hardest part of attending conferences to be when they were required to network or socialise in unstructured times such as coffee breaks. If Oester et al. (2017)'s statement that most networking occurs in-person over these unstructured times is true, then Cassy and Katie may find this important part of academic life the hardest. Part of Cassy's 'The Conference' depicts how she feels during coffee breaks. She drew herself as the character on the far left standing without a coffee cup (See Figure 31).

Figure 31: Part of Cassy's Artefact 1 'The Conference'

Cassy also explained how the differences in expectations for different social situations at conferences made it difficult for her to attend, as she was worried about the unstructured social aspects of the conference.

'When it's small gatherings particularly things like meetings or conferences where you are expected to go off and mingle and socialise and forge links. That, for me personally, can be really quite challenging … you know when everybody gets together at a conference and they have cups of coffee and they talk and people sort of say that is really when you do the real networking.' (Cassy)

She describes how the social aspects for her are a barrier to attending conferences as they induce a lot of anxiety, particularly as she is fully aware that conventionally the unstructured time at conferences is where meeting people happens, which may be important for further academic success. Katie experienced similar social difficulties when trying to network at a conference.

‘We are expected to go to lots of networking events, and that's always been a challenge of mine … you're expected to make connections with lots of different people, but I just don't know how it's really really hard for me to do that and it's really exhausting. If I do manage to do it.’ (Katie)

Both Cassy and Katie found the expectations and conference norms of networking to be difficult and off putting about conferences. This could be because social difficulties are a stereotypical part of autism or, like Katie says, something that is just expected that you know how to do but are never explicitly taught. This anxiety of not knowing how to conform or feeling like you should conform might be why socialising at events feels so exhausting. Martin (2020b) says networking in general is not typically suited to autistic social competencies and motivations, nor is small talk not linked to the conference theme. This is further supported by Farahar and Foster (2021, p. 205) who document from their own experiences of being autistic academics that ‘networking is the dreaded academic phenomenon for many an autistic academic, as it pits all our challenges together in one place…’. They describe the challenges to include sensory stimulation, routine changes, unpredictability and the requirement to socialise in conformist ways (such as by making eye contact).

Byrne (2022) highlights there is a hidden social curriculum at university that students are expected to pick up, rather than being taught, which autistic people may find hard to adapt to. This idea could be extrapolated to conference attendance, as there may be norms which autistic people do not pick up on. Therefore, not understanding the social expectations of a conference combined with a lack of natural motivation to want to engage in small talk, due to how difficult it is with others, may make networking very difficult for autistic people. Some researchers have written papers with suggestions of how others could adapt the environment to make it more accessible for some aspects of the autistic student life. For example, Chown et al. (2016) wrote about how PhD vivas could be adapted to ensure they did not disadvantage an autistic candidate. It would be good to have more research about how the hidden concepts of networking could be explicitly detailed to help ensure autistic and other people can be included in conference networking.

Until networking is not considered the gold standard of forming professional research links and access to jobs, rather than just social gain, it might be necessary to engage in. However, conforming to unknown expectations can create emotional stress for autistic students, who then feel like an outsider if they are unable to conform (Cage et al., 2020). Cassy explicitly spoke about feeling like she was unable to join in conversation. Although she was physically present during some periods of time associated with networking, she felt she was not actually included in the conversation. She also depicts these feelings of being an outsider in part of her artefact (see figure 31) as she is the character moving away from the other participants who have coffee cups above their heads. Cassy speaks of not knowing how to conform and be part of the networking rather than just not wanting to be part of it.

‘I find it quite hard to integrate myself. I sort of feel a bit like the nerdy kid on the edge, you know, and I don't really know how to, I feel like everybody's tolerating my presence rather than being able to fit in, and contribute.’ (Cassy)

Like Cassy says this can mean autistic attendees feel isolated and unable to conform to the norm of engaging in networking. She describes feeling ‘tolerated’ by others rather than feeling like she is included within the general conversation. Cassy’s feelings of isolation and exclusion within a networking environment are not exclusive to autistic academics, but feature for other non-dominant groups within academia. Waterfield et al. (2019) explore the experiences of eleven Canadian academics who self-identified as working class or as coming from an impoverished background. They highlight that several of their participants cited conferences to be where they felt most excluded in academia due to not identifying with the cultural capital and expected social norms. Oliver and Morris (2020, p. 765) explore how conferences can be specific places of academic ‘outsider-ness’ particularly for those who do not fit the dominant academic rhetoric of being a white male. They go on to suggest that upholding these norms make it harder for an outsider to be accepted and for a marginalised academic to belong. Oliver and Morris (2020) contend that to be accepted, outsider academics must try and conform as much as possible to accepted norms, without excessively resisting boundaries. Not belonging documented by Cassy, Waterfield et al. (2019) and, Oliver and Morris (2020) is likely to lead to additional emotional labour due to knowledge of not naturally sharing the same culture and the dilemma of whether to accept the normalisation of disbelonging or to challenge it.

Cassy also describes not being able to contribute to conversation during networking. It is questionable what the motivation is of other academics when networking, if they are unwilling to include her in conversation. For example, if somebody feels that they want to participate in order to meet others and learn what they do then Cassy should be included, or whether they just want to promote their own research to others. In addition, a culture of silence exists particularly for academic women, whereby men do not listen to them or allow them to otherwise participate (Aiston & Fo, 2021). Thus, Cassy may be facing multiple intersecting barriers to networking that stem from a range of intersectionalities.

Cassy and Katie described networking to be a very difficult but accepted part of a conference. The ways in which Cassy and Katie approached networking were different, but both included elements of masking (putting on an act/hiding their autistic selves).

Cassy would attempt to network for a while, whilst feeling ‘tolerated’ and then make her excuses to leave, such as by saying she had a phone call she had to make. Whereas Katie would feel much more anxious beforehand but would try and put on a confident image when networking. Both Cassy and Katie appear to mask but in different ways. Cassy gives the impression to others that she is busy and thus unable to engage in further conversation, whereas Katie attempts to appear confident in order to fit in and be able to network with others.

Katie created a painting of her experiences of masking which she specifically attributed to a conference she had been to (see Figure 32).

Figure 32: Katie's Artefact 1 'The Broken Mask'

She described her painting to reflect how she feels she needs to mask at networking events but is always at risk of not being able to keep it up and convince others. Her use of a standardised drama mask in her image might also suggest that she wants to conform to a perceived standard norm that is well recognised and accepted. However, she has given the mask a sad expression, potentially suggesting that conforming to a norm makes her unhappy because it is not her true self. Katie also explains how she feels when masking during networking.

‘First of all you are masking that you are actually nervous about the room and the sound or just being in the wrong place or something like that, because you know that that's not what other people are thinking about. Then it's the mask where you have to pretend that…you are interested in what other people are saying. Then it is…that crack…and it cracks your mask and makes it more difficult to wear. …The background I tried to do different colours to represent different aspects of the room, but that's why I like made it all smudged and blurry because that's how it felt, it just felt like it was just too much.’ (Katie)

Within her artwork and words, Katie highlights two main elements she feels she has to particularly focus on, so that she can portray herself in a way she thinks others will view as acceptable: that the sensory environment does not impact her, and that she is competent in conversation and wants to engage with what others are saying. Katie discusses how sound levels in a room can create a sensory overload, which leads her to worry that other people may notice her distress. Cassy also brings up the sensory aspects of a conference, focusing on the noise levels of a room.

‘It's the noise that it's just the noise…I can't hear. My head hurts, my ears hurt.’ (Cassy)

The main sense that both Cassy and Katie focus on is hearing and the angst it can bring before going into a conference, but also how it makes them feel when they are there. By focusing on the noise, they can hear, it suggests that for Cassy and Katie this is the most overwhelming and important issue within a conference. They both suggest this is something they have to hide in order to fit in and participate in the conference as a whole. Brown et al. (2018) highlight that in-person conferences can be noisy environments and that it is imperative to have a quiet space that attendees can go to. They also advocate for a place where the conference is live-streamed so people can watch it and feel physically part of the conference, but be in a quieter space. Martin (2020a) considers that although some conference organisers are keen to implement an environment that aims to reduce sensory stimulation, budget constraints and available resources such as catering and space can prevent this.

The second element that Katie focuses on is that she wants to appear competent in conversation. Whereas Cassy will try to avoid networking and so she does not have to mask what she is really feeling.

‘When it comes to things like the coffee breaks or conference dinners, I am always trying to find reasons to leave it because I just find that overwhelming I do not find it a good venue for forging links at all. And, you know, for example you know when everybody gets together at a conference and they have cups of coffee and they talk and people sort of saying that is really when you do the real networking. … And so for example I went to a conference recently, and whenever it was coffee time I would always have a conference call to go and meet, some emails to go and do, somebody to go and speak to.’ (Cassy)

Cassy suggests she accepts that she does not feel like she can forge links in that setting and therefore uses the time in a way that she feels is more productive for her. She does however acknowledge that coffee breaks are seen as an accepted way of making links and connecting with other academics, that is harder to do within the formal presentations or via other methods such as online. By opting out of these more difficult social networking occasions, Cassy may have felt she had more energy to go to other parts of the conference and therefore had to prioritise what was most important for her. Yet, it may be detrimental to her long-term prospects if she cannot ever engage in these situations considering the general perception of the importance of face-to-face networking remains.

What is evident through both Cassy and Katie's experiences is the shared experience of masking in order to conform and the feeling that one is expected to be social and make networking connections over coffee breaks and unstructured time. This is also linked to the sensory environment of the conference venue and how in particular noise impacts them and makes them feel. In turn this adds an element of extra labour that they have to endure and navigate which other attendees may not experience at conferences.

Masking (attempting to hide identity to fit into a perceived norm) is particularly prevalent in autistic women and can have both benefits and drawbacks (Sedgewick et al., 2021). Both Cassy and Katie's experiences of networking demonstrate they both mask, but in different ways. Miller et al. (2021) contend that masking is not exclusive to autistic people and may be linked with stigma, but state autistic people report having to mask different less accepted things compared to non-autistic people, such as sensory difficulties. There is also an argument as to whether masking should be required or whether others should be accepting of the range of people that exist in academia. Masking can also be very tiring and may lead to a reduction in self-esteem and self-confidence if an autistic person in academia is trying to always only fit in with the conversation of others and present as a 'normal academic'.

Rutter et al.'s (2021, p. 7) paper by four women researchers (three of whom were disabled, and all researchers acknowledged several intersectionalities within their identities), autoethnographically documenting experiences through some of the pandemic highlights how they felt their networking over the internet and forming their research group reduced isolation. Thus, it could be suggested that not engaging in networking may lead to academic isolation, and therefore a reduction in collaboration and career enhancement opportunities. This may exacerbate existing feelings of exclusion. This could explain why Cassy and Katie attempt to network even though they both find it particularly difficult and overwhelming to do so. Farahar and Foster (2021) also advocate that autistic people can miss out on opportunities by struggling to network. They therefore suggest that either non-autistic colleagues could positively reach out to autistic colleagues to include them in collaborations (thus removing the need to initiate conversation) or that more emphasis be placed on other forms of networking (such as via online platforms or in less sensory overwhelming environments). Although Farahar and Foster (2021) acknowledge networking online can be exhausting, they highlight it can be much easier than face-to-face conversation.

6.2.2 Benefits of Presenting

Katie also had a positive experience at a conference that boosted her self-esteem as she presented her own research and said it was accepted well by others.

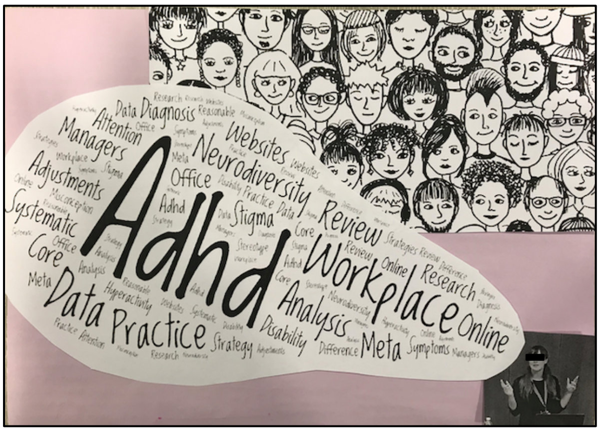


Figure 33: Katie's Artefact 2

She depicted this in Figure 33, where she drew an audience all smiling and looking engaged at what she was saying. Interestingly, she has placed a photo of herself presenting as a very small image in the corner in comparison to the large speech bubble containing her conference presentation. This may suggest she either places more emphasis on what she is saying or that she does not feel confident in herself as a presenter. She goes on to talk about the feedback she received from the presentation.

‘That conference where I felt like I presented the best I ever have…I had great feedback. I had some friends in the audience as well, who had not heard me speak before and they were really, you know, they said that I light up the minute I go on the stage and talk about something that I'm interested in. So I wanted to kind of link that to your you know your special interest and how you can really harness that and in a conference environment, whereas before I've really struggled with that.’ (Katie)

Katie implied she enjoyed presenting which was cemented by feedback from her peers. She talked about the topic of her talk being something she is passionate about. This topic may be a ‘special interest’ (an interest autistic people are said to have that they are particularly focused on (Murray, 2018)). Autistic people are documented to enjoy talking about things they are particularly interested in, sometimes at the detriment of understanding typically accepted social cues and the back and forth of standardly understood conversation (Morgan-Trimmer, 2022). Special interests within autism do not receive much positivity as some see them as obsessive and that they control a person’s ability to do other things. This may however be beneficial in academia if a person’s special interest is what they are researching as they can focus intensely on this without distraction. This is also described as monotropism, when a person focuses on a few interests rather than several at a time (Murray, 2018). This passion may be needed for academia to ensure research is beneficial and progressive. Thus, this may demonstrate that although some characteristics of autism can be seen as negative or unhelpful in certain situations, if the environment and situation for autistic people is right (not just in academia) then monotropism may be extremely positive and an asset (Grove et al., 2018).

The importance of feedback after a conference presentation is highlighted. Katie said she had great feedback and recalls that her friends said she ‘lit up on’ stage. Positive feedback clearly aided her self-esteem and feelings of self-worth on both her ability to present and on the topic, she was researching. This emphasises the benefits of collegiality and support from others, going against an established competitive element that academia is shrouded in (Gaudet et al., 2022). In relation to autistic students specifically, the required social networking to get to a level of collegiality may be difficult due to stereotypical difficulties with communication and socialising.

The combination of how Cassy and Katie experienced both the networking and presenting aspects of the conference is interesting to explore. Although masking may enable an autistic person to fit into a situation and be perceived as conforming to a norm, this can lead to a reduced sense of self and confusion over self-identity (Miller et al., 2021). For example, Katie speaks about feeling confident talking about something she is particularly interested in and so not deliberately hiding her autism, but she tries to hide her autistic self when networking in order to fit a perceived norm. Thus, it is debatable what identity - a true or masked version - of herself she wants to put forward in academic settings and the impact this has on her own confidence and self-esteem.

This is particularly important to consider as within academia creating and promoting a personal brand is becoming more and more important to secure employment (Pretorius & Macaulay, 2021). In Katie's experience she may be conveying different versions of herself during different activities at the same conference, which could be potentially confusing to others and herself. Masking may make this more challenging as by hiding parts of oneself, a researcher may feel invalidated or inauthentic and feel unable to make relationships and form communities based on their true selves (Miller et al., 2021). In addition, it has been mooted that people can have negative experiences whilst masking and not masking, thus making them feel that neither technique is useful and potentially providing low self-esteem (Miller et al., 2021). Masking can therefore be a dangerous technique as it can reduce self-identity and increase the chances of feeling unreal which in turn may lead to internalised stigma.

6.2.3 Summary

Within this section I have highlighted Cassy and Katie's experiences of attending conferences and given specific focus to networking and presenting, including the need to mask and how special interests may be an asset in academia. Both Cassy and Katie highlighted how difficult it was to interact with other conference attendees in order to participate in networking. They cited various barriers such as sensory overload and not knowing the expected social etiquette behind networking. Presenting and obtaining good feedback was however a positive experience Katie had whilst being at a conference. Thus, suggesting that whilst conferences are seen as an important part of academia, they include more challenging aspects alongside beneficial gains for autistic people.

More generally, in recent years, several researchers have highlighted how conferences are not always accommodating to autistic researchers (Martin, 2020a; Martin, 2020b; Mellifont, 2021b) which echoes what both Cassy and Katie have said. De Picker (2020) discusses how being a wheelchair user makes accessibility to conferences difficult. He mentions how lecture theatres often do not have wheelchair spaces and other meeting rooms can also be inaccessible due to poor layout. Irish (2020) recognises similar concerns to De Picker (2020) that conferences are generally poor at accommodating disabled people, but argues that some accommodation for physical disability tends to be considered but any differing accommodation requests are neglected. Irish (2020) suggests a variety of simple ways to ensure conferences are more inclusive to autistic people is to have more structured conversational areas or to move away from the stereotype that breaks should be used for networking. By not accommodating all disabled people, conferences are perpetuating the stereotype that academia is exclusive to only those that can access it. Callus (2017) has previously raised the issue of making conferences about disability most inclusive to those with learning disabilities who are unlikely to access a traditional academic conference. She suggests ensuring that material presented includes easy to read formats and a reduction of complex concepts. Callus' (2017) recommendations would not only mean that people with learning disabilities could access disability conferences, but also lay people who may have other reasons to be interested in the topic.

Since interviewing Cassy and Katie, how conferences are conducted at the moment has changed due to the worldwide pandemic. Many have had to move online, allowing a greater number of people to attend from different places, without the need to travel (Kaku et al., 2021). I have found networking to be reduced as online conferences obviously do not have in-person coffee breaks and discussion can be limited depending upon how the online conference platform is set up. This could be beneficial for autistic people as there is less emphasis on participant engagement and it is easier to take breaks whenever needed. Participants can network in other ways such as on Twitter without the need for talking in person, however this requires confidence to put your ideas in an online space. Presenters are just presenting to a screen rather than a room full of people which may reduce anxiety. This lack of engagement in online conferences may however also be negative for a presenter as encouragement and feedback can be reduced.

As the world transitions out of the pandemic it appears conferences and other academic activities may remain in hybrid forms. Raby and Madden (2021) document that online conferences can provide both positive and negative opportunities to participants and thus there is argument for them to remain. For example, potential cost and travel are reduced but networking and social interaction may also be reduced (which could be seen as a positive as pressure to interact with others may be less). At this moment in time, it is difficult to say what conferences will look like when all worldwide restrictions from Covid-19 are removed. It is however clear that further consideration into ensuring autistic participants feel comfortable in attending and participating in the same way as other delegates is needed.

6.3 Navigating Being Both a Student and a Staff Member

The aim of my research was to focus on the experiences of students within higher education, but for some of the postgraduate students I spoke to, their experience of university also encompassed experiences of the workplace. Part of being a postgraduate student may include teaching, or taking on other roles, which may require work with different people in different professional contexts where students become staff or hold other positions of responsibility. Cassy and Poppy both studied alongside being employed as academic staff at their universities and Sarah was both a student and a trainee school teacher. These participants all spoke about and implied notable differences in how they felt as an employee as opposed to being a student. Conversations brought up topics such as viewing support from a different view including gatekeeping, conforming to expected norms and being afforded different privileges dependent on which role a person was in at the time. Overall, most felt supported to an extent as a student, but less so as an employee. This may have been because of pressure to mask to fit in and not be so open about their autism when employed.

Sarah was undertaking a postgraduate course in teacher training during the research. Prior to this she had completed a PhD. She found there was a negative attitude towards her autism when she was on placement in schools, which she had not experienced to the same degree as a student at university. Although she was a disabled student, the perception she got from the school she completed a placement at was that she had to change her identity and hide her true self as it was not acceptable to be disabled in school.

‘I use microphones, which have been brilliant. They pick out the person I'm trying to speak to from the background noise. … The school clearly were kind of whoa this is a defective disabled person. They aren't colleagues, they are their special needs students, I mean that was clearly the underlying attitude. And so rather than make it so that I could attend things like staff meetings and training, they just told me not to bother.’ (Sarah)

Sarah also struggled with conformity and the expectations of not being ‘allowed’ to be disabled in different settings. Sarah spoke about using microphones in order to mitigate auditory difficulties distinguishing a single voice from background noise. However, Sarah did not feel she received a warm reception when using them. Thus, is it questionable whether she feels she is expected to hide her disability as a teacher, rather than share it and meet an expected standard without any support or adjustments. By saying she felt that she was not a colleague but rather a ‘special needs students’ and as a ‘defective disabled person’ Sarah demonstrates she feels an element of discrimination and very unsupported by the school she was on placement in.

Both Lawrence (2019) and, Wood and Happe (2021) highlight that minimal research has been devoted to autistic teachers, despite much research being focused on autistic children's education. They both document how some autistic trainee teachers have had difficult experiences, for example because of not understanding the expectations other colleagues had. Thus, Sarah's feeling of a lack of support is not documented to be uncommon in the small amount of literature that exists, however, it does not mean it should be the norm. However, Wood and Happe (2021) do say that if autistic educators are supported and feel understood they can be a role model for autistic pupils and provide expertise to colleagues. It may therefore be the willingness of a placement school to include an autistic trainee teacher that encourages them into the profession. Although Sarah undertook placement in a school, many other university courses include placements in different professions where similar experiences may occur. A willingness by placement providers to include autistic students needs to be ensured, which perhaps requires a culture change in acceptance.

In addition, it could be suggested that there is a difference between a consumer (as a student) versus an employee type role (whilst on placement). As a student a person is a paying consumer and so the university may, and should, feel more obliged to make sure support is provided. This consumer identity may also mean a student feels more inclined and empowered to argue for that support. However, as an employee the same person might feel more reluctant as not wanting to challenge in the workplace due to fear of repercussions.

On a more practical level, Sarah cited that communication between the school and the university was poor. She implied the school was not prepared for her and potentially annoyed at the university's lack of communication about her needs. The university did acknowledge full responsibility for the lack of discussion with the school about Sarah's needs after the event but Sarah had lost a placement school by then.

‘So there was an acknowledged problem on their end, and they acknowledged that it was their problem and that they really should have spoken to me over the summer. And no one really quite knows why we didn't other than they were having a reorganisation and they think it may have fallen through the cracks.’ (Sarah)

The lack of communication Sarah talks about between the university and the school may have led to a misunderstanding by the school regarding her needs. In addition, the school may have been annoyed by a lack of information from the university and directed their frustrations towards her, rather than the university. This is particularly important to consider as university placements may be an autistic person’s first experiences of a workplace, especially in a profession they would potentially like to make a career in. This could be significantly helped or hindered by others’ communication or support. Vincent (2019) highlights that autistic students can find it difficult to transition out of university because steps after university are usually less defined and more unknown than previous transitions between different education providers. Thus, more provisions and transition support need to be given to support this change. However, university courses with placements could aid this transition for autistic people, if in contrast to Sarah’s experience, they are well thought out and supported.

Poppy and Cassy were both employed as staff whilst studying their postgraduate courses. They therefore effectively held a dual role all the time, whereas Sarah was either a student (when at university) or a staff member (when at placement). Teaching and studying at the same institution is common, particularly amongst PhD students who may teach or have another responsibility alongside their studies. Their experiences may therefore differ to Sarah’s due to their differing duality. It could be expected that working and studying in institutions where disabled students are supposedly supported well may provide better understanding and acceptance.

In our interview Poppy and I discussed what wellbeing meant and she distinguished between what she would say if she was teaching and what she thought herself.

‘Well if I was teaching students I define it as a state of spiritual, emotional, physical and mental health and the participation in society. Me, I think wellbeing is about having a sense of, having a sense of what your role is and how to play that role.’ (Poppy)

Poppy separated out her own opinions from what she teaches to students. Thus, she is able to conform to the expectations of the university course she teaches on, whilst acknowledging that she actually has a different opinion. This may suggest that being a student versus being an employee enables more diverse opinions and values. Both Poppy and Sarah demonstrate the need to hide their beliefs or identity to fit into different situations and that whilst they can think or act one way as a student, when fulfilling different roles, they have to promote the values of that role, even if they feel they are exclusionary or discriminative. Whether conforming is exhausting or feels natural is questionable.

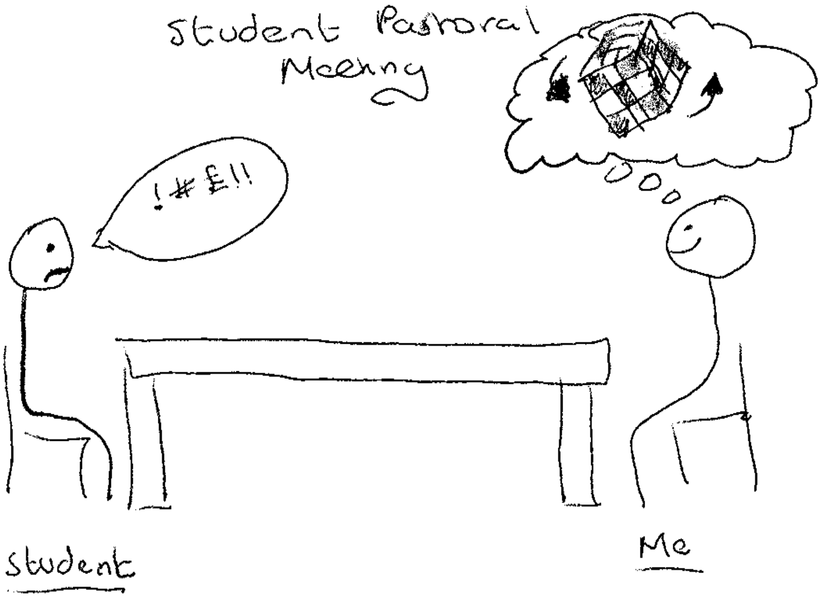


Figure 34: Cassy's Artefact 2 'Student Pastoral Meeting'

In contrast, Cassy had a more mixed experience of how she felt she was accepted in the workplace and had learnt how to manage her autistic difficulties as she negotiated her different roles. She acknowledged some autistic characteristics were strengths in her role as an academic member of staff - or that she has worked on these to make them helpful for her. For example, in Cassy's drawing of a pastoral meeting with a student (see figure 34, above) she uses a metaphor of a Rubik's cube going around in her head to depict that she is problem solving what the student is saying.

Cassy spoke about how she views students as puzzles to solve, which could be interpreted to mean that she does not view students as beings to become emotionally involved with but rather simply as challenges to solve. Sitting either side of a table may denote professionalism, or the size of the table may suggest an element of space or being removed from the situation. Within a professional setting this may however be useful as she can help students without feeling the emotional labour of doing so. Overall, she terms this skill 'professional empathy'. Cassy gives a further example of how this skill is beneficial to her.

'It is not that I don't want to be sad, you know, a student comes to me with terrible situations. You know I've dealt with refugees from Syria, you know, students who had unwanted pregnancies, you know, or have been in abuse situations. And I will sit there and I will understand, in the sense I can sort of intellectually say you know this person is feeling sad. This person is afraid. But I very rarely feel it. … In some ways that helps me with my work, because when I have students come in with terrible problems. I can deal with it sort of in a fairly calm and I guess rational manner.' (Cassy)

Women traditionally engage in nurturing of students more than men, however the intersection of this alongside disability is interesting. In intellectually understanding the emotion but rarely feeling it herself, Cassy is able to help students objectively. This may enable her to give better support. One theory of autism - theory of mind - suggests that autistic people are unable to empathise with others and appreciate others' views and opinions (Baron-Cohen et al., 1985). Although Cassy says she does not feel what her students are feeling, she has developed strategies to help her students without needing to feel their feelings herself. Thus, in contrast to Baron-Cohen et al. (1985) stating that a reduction in theory of mind is a negative, in this situation it may well be a positive and an asset to Cassy's approach.

Although Cassy highlights her approach being useful when working with students, she feels that staff are not always as understanding towards her difficulties, but she does highlight there are some notable exceptions. Cassy spoke about how two professional services staff were very supportive of her and helped her to mitigate some things she finds difficult such as paperwork.

‘...things like executive functioning are a part of the problem area…I'm very lucky that our head of admin and our learning and teaching coordinator is very aware of my sort of shortcomings, as it were, and she's very good at helping me manage that. So, she tends to present sit down and have meetings with me and she will tackle some of the columns, but she will just say I need you to make a decision on this, you know, you've got to choose a or b, so she'll present me with a couple of options and then I will choose from that.’ (Cassy)

For people to help her it suggests she is well respected within the department and colleagues are keen to ensure she succeeds. However, outside of this context it is easier to assume the identity others have placed upon her.

‘I think, you know, I'm constantly being told I'm clumsy…But I just always come up with ditzy and I think I've just assumed that identity to some extent.’ (Cassy)

Cassy also represents these feelings of her identity through a picture of butterflies coming out of her head (see figure 35).

Figure 35: Cassy's Artefact 3

There is a mismatch between Cassy being seen as a good problem solver and as ditzy. Cassy described her husband to often say her head is full of butterflies or knock on it and say it is empty, and she thought other colleagues felt similarly. Although she says she has drawn butterflies as that is what her husband says, she has drawn them escaping from an open head, possibly as a metaphor to suggest her thoughts are getting out into the world to be of value, rather than getting lost or confused. However, her confused expression may also suggest a negative feeling towards butterflies flying out of her head.

In assuming an identity that others have placed upon her, Cassy may be trying to conform to what others think and assume rather than trying to challenge stereotypes or the assumptions people have about disability. It could therefore be assumed that Cassy feels her autistic characteristics are an asset when working with students, but that some colleagues can be less accepting or assume she is just ditzy when she feels she needs some support to assist her identity to always be an asset.

The responses of Poppy, Sarah and Cassy suggest that having more than one role whilst studying can be difficult due to the different personas that may need to be adopted to suit each role. Although non-autistic postgraduate students may also hold more than one role whilst studying (particularly those on postgraduate research courses) they may not need to hide their beliefs or other parts of their identity as much as autistic people do. Negative feelings towards dual roles could be mitigated through a cultural change towards difference, although this may be slow to be adopted.

It is interesting to note the reasons why autistic people feel less supported and more like they need to conform to fit into the workplace compared to university. Disability may be more understood and accepted at university due to neoliberalism and consumerism compared to in a workplace.

6.4 Conclusion

I have discussed the experiences of four participants at conferences and negotiating being a student alongside a staff member or professional. Undergraduate students are less likely to have to navigate these situations in academia and therefore they do not seem to be understood or valued as much within autism research. In addition, I discuss how challenging dominant norms within conferences and having other roles whilst studying as a postgraduate could improve inclusivity and a more accessible academic environment.

Conferences proved challenging in part for Cassy and Katie as they felt they needed to participate in activities such as networking which were sensorily and socially overwhelming. However, although conferences included several distressing aspects, Katie spoke about how she was able to present well and received good feedback from audience members, which aided her self-confidence. Ensuring conferences are more sensory friendly and have less emphasis placed on networking in currently accepted ways, such as over coffee in conference breaks is vital to enable accessibility to autistic academics. In addition, a culture of othering academics who do not meet traditionally expected norms needs to be changed in order for autistic attendees to not feel othered and unwelcome.

The second focus of this chapter was on negotiating being a student and a staff member. Sarah experienced negativity towards her being autistic whilst on school placement which she had not encountered to the same level when solely being a university student. As placements could be an autistic person's first encounter with a workplace ensuring that these are accommodating and a good experience is vital to ensure autistic people do not feel they are discriminated against from transitioning from education to work.

Cassy and Poppy were both students and staff. Postgraduate students may simultaneously be a student and a staff member, therefore their experiences and how they navigate the differences in identities cannot be ignored. This is especially the case for disabled postgraduate students who may be afforded accommodations as a student they are unable to access as staff. However, it should also be considered that autism may hold positive characteristics academic staff need. For example, Cassy especially felt her autism was an asset in her role as a head of department as it enabled her to be both empathetic and practical at the same time when helping students deal with problems that arose. Further research could investigate gathering more information about people's thoughts or experiences of leaving education and transitioning into work. Particularly from autistic postgraduate students as they are mostly ignored by current literature in the field.

In conclusion, experiences of autistic postgraduate students, and particularly women who are stereotypically believed in society to be 'less autistic' than men, cannot be forgotten when the university experience is studied. The postgraduate experience is different from the undergraduate experience. Therefore, this needs acknowledging to expand the currently minimal amount of literature surrounding autistic postgraduate students.

7 Reflections on University Environment

7.1 Introduction

Within this chapter I reflect upon the impact of the university environment on autistic women at university. I attend to all three of my research questions, which I restate here:

1. What barriers and supports to higher education do autistic women students feel they have had at university?
2. In what ways can the university environment be adapted to better accommodate autistic women?
3. What changes would autistic women like to see at university?

The university environment includes how welcoming a place is, with consideration to people's individual experiences and their interactions with others (Cress, 2008). This encompasses how they feel supported more generally and the support they receive due to declaring themselves as an autistic student. This exploration into the experiences of how autistic students interact with their environment may have wider implications in the field of disability. Physical environments tend to be poorly designed for disabled people and that designers need to consider their responsibilities to enabling access (Imrie, 2012; Imrie & Kumar, 1998). Scott and Sedgewick (2021, p. 3) highlight that 'autistic voices regarding experiences of university support remain strikingly absent'. In consideration that spaces may be poorly designed for disabled people and that autistic voices on university support (which may include environment) are minimal, this chapter showcasing usually silenced thoughts about university spaces may create change.

Autistic people can find university difficult to navigate due to the environment or the impact of other people. Autistic students can qualify for Disabled Student Allowance (DSA) (https://www.gov.uk) which can help them to access some formal support, such as a mentor. DSA is a non-repayable fund that disabled students (who can evidence their disability) can apply to, in order to help them cover the cost of support to assist them to finish their university degree (https://www.gov.uk). In addition, autistic students may have approval from a university disability service that for specific situations such as exams accommodations can be made. However, formalised support does not tend to extend beyond specific academic situations, such as to the sensory environment at university.

The environment that autistic students experience beyond formal support is rarely considered in research, although participants tended to focus on this within this study when discussing supports and barriers to university. Considering the effect, the wider support systems and culture of a university as whole had on participants, it needs to be highlighted.

Specifically, I include three topics under the overarching topic of university culture and environment: staff impact, the sensory university environment, and autism awareness and acceptance. First, I explore the impact of relationships that participants had with academic staff. I highlight how several participants felt privileged to have encountered academic staff that had been supportive and helpful towards them. I consider how autistic students attribute good experiences with academic staff to luck and privilege, rather than accessibility. Second, I discuss how participants navigate physical spaces around university, with particular attention to the sensory environment. I examine spaces that are traditionally thought of as synonymous with academia such as lecture theatres and also look at 'non-spaces' such as corridors and consider how they can be sites of exclusion for autistic students. Finally, I discuss participants' experiences of advocating for change and educating others about autism. I illuminate why autistic students need to be listened to and their opinions acted on. Throughout this chapter, I highlight how the culture and environment of university both supports and challenges autistic students by analysing the accounts of participants.

More broadly, in this chapter I provide insight into all three of my research questions. Within the context of university culture, I explore the barriers and supports autistic women experience at university and consider how the university environment impacts them. In addition, I highlight the changes that participants want in order to improve their university experience. This chapter very much relates to *Chapter 5: Perceptions* as how others perceive autistic people may impact how they treat them and therefore the support they are willing to provide. Although I do acknowledge some people’s perceptions in this theme, I focus more on the practical impact this behaviour has on autistic students. Therefore, although these chapters are interconnected, I seek to provide a different focus and present other aspects of the participants’ experiences.

Overall, I suggest that relationships with staff and students’ feeling they have a voice that contributes to influencing change were the biggest factors that influenced participants’ sense of belonging and positivity of university. Participants cited a variety of reasons for this such as luck, privilege and staff knowledge of autism.

7.2 Staff Impact

7.2.1 Academic Staff Impact

Academic staff at university feature considerably in students’ lives through teaching and pastoral ventures. Positive relationships between academic staff and students can help to facilitate learning and success, and go some way to counteracting structural inequalities (Guzzardo et al., 2021; Hagenauer & Volet, 2014; Yale, 2019). Cress (2008) considers positive relationships from academic staff to students to include receiving advice on their course, feeling respected, and emotional support. Cress (2008) found that students who had more positive relationships with academic staff were more likely to rate their university experience more positively.

Although the benefits of *good* relationships with staff are documented, it is also important to consider the impact of *bad* relationships on a student. Yale (2019) highlights within the context of personal tutoring that poor tutoring can be worse than having no tutoring, which in turn can lead to negative emotions for the student surrounding a lack of support and thoughts of leaving university. This is because a student may not feel valued or have different expectations of personal tutoring from the tutor. Relationships between students and staff appear to be a vital component to student success.

In relationships between students and academic staff, the needs of academic staff also need to be considered. Walker and Gleaves (2016) highlight that the pressure on academic staff to be student focused can cause exhaustion and detrimental effects. Bartos and Ives (2019) note the majority of pastoral care by academic staff is carried out by women. Cress (2008) highlights how academic staff act differently with students who are women compared to those who are men. Sexism against women in universities is likely to thus start early in a student's life at university and continue for women who remain in academia. In addition, academics may face other discrimination from the neoliberal academy, such as from being disabled which they have to negotiate with additional labour (Gillberg, 2020). As such, although I explore relationships with academic staff from autistic students' perspectives, it is imperative to remember that academic staff may face similar discriminations from ingrained university culture or students themselves.

Austin and Pena (2017) suggest there is a paucity of research on how university staff impact autistic students' university experiences. This is particularly important as relationships could be difficult to navigate due to autism. As other research highlights the importance of student-staff relationships this area needs much more exploration to ensure autistic students are also considered when thinking about relationships. During the process of this research, it was evident the relationships participants had with university staff were impactful.

I focus this section on highlighting how participants thought university staff were either supportive or unsupportive and present it in a relatively binary way. Although in an ideal world it would be assumed that every student should be supported how they wish, this may not be possible. It is important to consider that the identity of staff members, their own intersections and job roles are likely to inform how they respond to and support students. Lindsay and Fuentes (2022) say that academic workplaces are regularly described as challenging and toxic work environments. Thus, supporting students on top of a challenging workload and toxic environment may be difficult.

With specific focus to the disabled academic (which is seldom focused on in research (Lindsay & Fuentes, 2022)) many receive significant ableism from colleagues or institutional barriers. Lindsay & Fuentes (2022) highlight how disability services are likely to be available to students but not staff in academic institutions, making receiving accommodations and support harder. This implies that disabled students and staff may be subject to the same difficulties when asking others for support and that university staff who are more supportive to students may have had their own difficulties.

Kim highlighted that she felt her supervisors had made extra effort to accommodate her needs and respond to difficulties she had which she attributed to her autism. This made a significant difference to how she felt able to continue and complete her studies.

‘My two supervisors have bent over backwards for me…nothing was too big to ask of them and whenever autism has come into it, the same response has been given and they are very very understanding. … So, I do feel very very privileged to be in a university that is so supportive.’ (Kim)

Kim’s experiences support the conclusions of recent research conducted by Scott and Sedgewick (2021). They are some of the only researchers that include exploration of autistic students and staff relationships at university. They explored the mental health experiences of autistic students and how the university contributed to or mitigated these through a small-scale qualitative study. Although their study did not focus on gender, three quarters of their participants (eight out of twelve participants) identified as female. Participants reported good experiences from staff who held flexible opinions regarding difference and treated them like an individual rather than as a stereotype.

In contrast Scott and Sedgewick (2021) also report that participants said negative experiences with staff put them off seeking support from other staff for fear that these staff may also hold the same stigma or negative attitude towards autism. They concluded that staff should be trained to be confident in supporting autistic students' needs. Similar to this, Sophia in this study felt put off by a lecturer who held a negative attitude towards autism. In her artefact ‘The Interview (Returning to Education)’ (see Figure 23) she documents, ‘The very next day (not 24 hours after I was diagnosed [with autism]) I had a college interview to study social sciences. It was a group session wherein a Professor explained the course and answered questions, followed by individual interviews where he discussed my interest in the subject.

Towards the end of the interview, I spoke up and explained that I had just been diagnosed [with autism]. I expressed that I was unsure what this meant in terms of education, but I was interested in returning to study and to try my best.

“Does that mean you will be violent?”

That’s all he said. And that’s all it took. A Professor, an arguable intellectual adult man asking me if I was going to attack others during my time at college. I left flustered, laughing it off until I got home and cried. I did not leave my bed for several days. I did not go to college that year. It took another 18 months for me to recover from this.’ (Sophia)

Sophia uses the term ‘college’ to mean university. She highlights how one comment from a professor made her feel that she would not be accepted at university and thus she had to withdraw from starting that year. Sophia describes how she thought that a professor should be intellectual and therefore suggests that she should hold his opinions in high regard, even if they are damaging to her and not conducive to a positive relationship. Bailey et al. (2020) argues that professors need training in how to engage with neurodiverse students to ensure inclusivity, but that autistic students also need to be taught self-advocacy and assertive communication skills to be able to self-advocate and challenge discriminatory behaviour. Sophia’s quote suggests she also assumes that other professors will think similarly to him, meaning that all staff may feel a similar hostility towards autistic students, and thus she may not feel able to self-advocate as Bailey et al. (2020) argue autistic students should do.

The professor’s stereotype that Sophia would be violent is backed up by some of the early research on autistic students at university. White et al. (2011) suggest that autistic students are more likely to be aggressive than non-autistic students. The notion that autistic people can be violent is also portrayed in the media. White at al. (2017) posit that within media, autism is sometimes associated with violence such as in a mass murder which may influence public perceptions about autism. Despite the stereotyping of autistic people which is common in the media and some earlier research on autistic students at university suggesting they can be more aggressive than non-autistic students, how Sophia phrases her story suggests that she was hoping the professor may have been more positive and open to difference considering his high intellect.

This demonstrates the importance of individual staff's attitudes towards difference and willingness to adapt to ensure they do not impose stereotypes and stigma upon students, as this could have damaging long term effects on a student's university experience. It seems that positive experiences with staff help students to feel able to have good experiences and feel supported at university.

Although I am specifically interested in how autistic women interact with academic staff at university, it is interesting to consider whether it is the label of autism that affects how academic staff respond. If staff respond to the needs and difficulties of all students in a responsive and kind manner, it minimises the need to disclose labels. Some people may naturally be more open to accepting difference and diversity than others.

Kim and Sophia's opposite experiences of relationships with academic staff suggest the impact of how academic staff treat them and support them to be fundamental in how they feel about university and achievement.

7.2.2 The Variable of Luck

Some participants focused on how luck impacted on how well they were supported. Luck refers to a person's success or failure that occurs by chance. Some recent qualitative research into autistic people's experiences at university has included the concept of luck (for example, Lei & Russell, 2021; Scott & Sedgwick, 2021). These studies do not explore why participants state they are lucky and the impact of whether good support is effectively a lottery. Sophie, Cassy and Kim had received support that they believe helped them, but it is interesting to note that both Sophie, Cassy and Kim describe that they are ‘lucky’ to have a good experience.

‘I am lucky because university is kind to me but I can imagine if it was not that it would be really difficult.’ (Sophie)

‘I am very lucky that our head of admin and our learning and teaching coordinator is very aware of my sort of shortcomings, as it were, and she’s very good at helping me manage that.’ (Cassy)

‘So I do feel very, very lucky to be at [university]...because the support I have received is phenomenal.’ (Kim)

Kim also said she is ‘privileged’. Describing themselves as ‘lucky’ or ‘privileged’ to be so well supported perhaps suggests that they are aware or believe that not all autistic students can access such good support. This suggests participants consider support from others at university to be due to luck rather than their right to access education as autistic people. Katie also implies that there is an element of luck in being well supported as she is unsure that other universities are as inclusive to autistic people.

‘I know I am valued because people know what my strengths are and I think if people are aware of your strengths, then they can see past your challenges and they know that it is, you know, quite simple fixes. I think probably at other universities…I can see it is not being so fair and equal. (Katie)

Katie’s suggestion that other universities may not include autistic students in the way that she has been implies she either believes she should not be receiving such support or she has heard different accounts of other autistic people’s experiences at other universities.

This begs the question of why Sophie, Cassy, Kim and Katie should feel lucky to be supported, rather than it being assumed it will happen. In addition, it is questionable whether an autistic person’s success at university is in part determined by luck, rather than by a right to access and accommodations. This suggests maybe there is some internalised stigma such as was discussed in the previous chapter surrounding how participants perceive the university to view them.

In contrast, some students implied that because they did not have a formal diagnosis of autism, they were not able to be supported in the way they felt they needed to be. Thus, they had no chance of being able to be lucky and receive good support. Hens and Langenberg (2018) suggest that a formal diagnosis of autism can lead to access to support. A formal diagnosis of autism can be seen as a privilege particularly for women due to gender difference in autism (Lai & Baron-Cohen, 2015) or being able to present as non-autistic (Hull et al., 2017). In turn women therefore tend to be diagnosed with autism at a much older age than men (Leedham et al., 2020).

Katie highlighted that she was having difficulty with understanding feedback on her writing from her PhD supervisors. Although the supervisors were keen to accommodate her and change how supervisions were conducted, they were unable to provide more time or support to her as she did not have a formal autism diagnosis and therefore, they could not justify any accommodations within institutional guidelines.

‘Something that kind of triggered my supervisor to tell me that I should probably go for a diagnosis because she was going to have to change the way she gives me feedback.’ (Katie)

Katie’s experience highlights that there may be people in the university who are keen to adapt to students’ needs to ensure they can achieve their potential, but that university structure and processes may prevent this. This is particularly the case as she did not have the privilege of having a formal diagnosis of autism. Katie’s comment suggests that universities can or will only implement support if certain criteria are met, meaning that students who are unable to engage in certain bureaucracy may not be able to access the support they need. This point about universities commonly requiring a formal diagnosis to provide support or accommodate students was also suggested by Poppy.

‘I feel like, in a way, there is a lot more support there for people who are like openly autistic. The thing is you probably still have to fight but at least you have got a starting point.’
(Poppy)

This suggests that luck is based not only on university structures and the staff within, but also on an autistic’s person’s willingness to disclose their diagnosis and be able to advocate for themselves to get support.

Overall, how staff engaged with autistic students had a big impact on how they felt about university. Some participants attributed positive relationships with academic staff to luck, whereas others felt they were unable to access such support due to university policies. This suggests that academic university staff need to promote inclusive atmospheres but also be supported by the policies and expectations of universities.

7.3 The Impact of the Sensory University Environment

The university environment can be conducive or distracting to students’ abilities to achieve. With regard to autism, investigating sensory sensitivities is gaining popularity in research as they can have huge impacts on autistic people’s lives. If the environment is not conducive to learning and students do not feel safe in it, then they may find it harder to learn and cope with. Several participants based at least one artefact on the sensory environment of university, highlighting how important it can be in experiencing university.

The importance of highlighting this is necessary to ensure that this element of the university experience does not hinder an autistic student’s learning. Research into the sensory environment for autistic students in general is minimal, and even less so for specific key parts of the physical university environment.

Within this theme I briefly explore what participants highlight about five areas of university: the library, corridors, lecture theatres, student halls and quiet rooms with particular focus on their sensory experiences. I do not intend to provide a comprehensive analysis of how each space impacts the lives of autistic students, but rather demonstrate that many areas of the university can impact a person's sensory experiences.

7.3.1 Blurred Boundaries in the Library

Libraries are thought of as key places of academic learning and progression for students. Libraries are moving from being archives of information (with physical resources) to being learning centred spaces (Lofty et al., 2022). Historically, the way resources are chosen and organised, and the physical environment can be exclusionary to many people, including disabled people (Dahlkild, 2011). As technology continues to improve, and there is a need for library buildings to be repurposed as spaces for learning, (sometimes referred to as information commons) rather than spaces for information retrieval, it is important that these spaces remain inclusive. Imrie and Kumar (1998) suggest that for spaces to be inclusive, disability has to first be problematised as a socially constructed dynamic and chaotic concept and second there has to be a commitment to including many types of disability labels into a space (rather than focusing on a singular stereotype). In order for libraries to stay key places of learning as they change in purpose and physical state, disability needs to be considered.

The physical library environment featured in many participants' artefacts and interviews, suggesting it was an important place. It was clearly a place that they considered synonymous with completing a university course, but the environment of it tended to be mentioned negatively in regard to the sensory difficulties it provided participants with. Kim documented her sensory experiences of the library in a poem (see Figure 36).

Concentrate.
Noises all around,
Rustles, chewing, talking,
Distracted by the sound,
Perhaps I can calm down by walking.

Concentrate.
Colours everywhere,
Blue, yellow, green and red,
Even splattered in my hair,
I have so many words ahead.

Concentrate.
Don't work by the cafe,
Paninis, potatoes, cake
It all smells like a buffet,
I can't bring myself to retake.

Concentrate.
Someone has sat too closely,
I can feel their body heat,
Even their clothes on my leg, grossly,
Perhaps it's time for a break and a treat.

Concentrate.
Sipping on even plain water,
Leaves a distraction on my tongue,
I love my work like a daughter,
Yet all these tastes have clung.

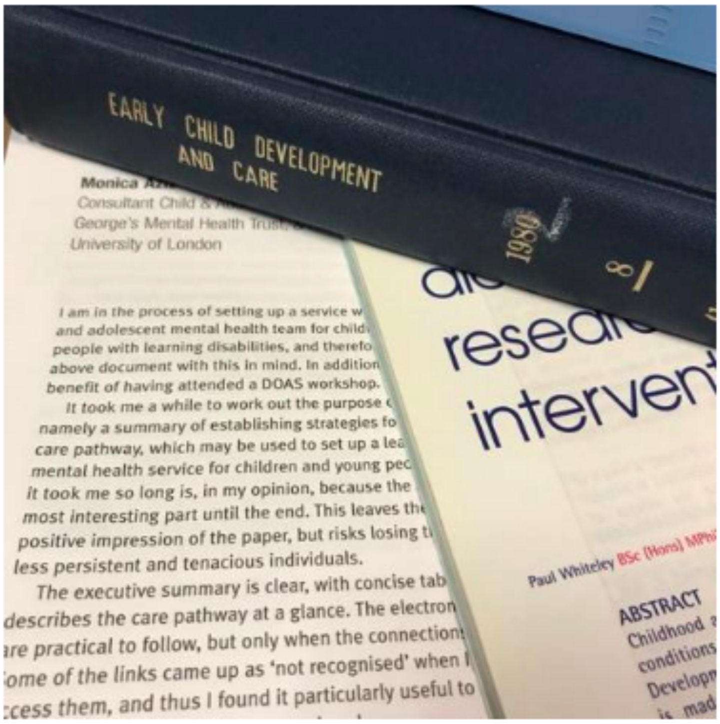
Concentrate.
My work becomes a special interest,
Yet especially when a deadline presses,
Everything overwhelms me,
And my routines fall apart.

Figure 36: Kim's Artefact 3 'Concentrate'

Kim (see Figure 36) describes her poem 'Concentrate' to include a stanza about every sense, and to depict her frustration that other students can seemingly leave writing an assignment until just before a deadline. She feels unable to do this because if the sensory environment in the library is not right for her, she feels unable to work. Her poem suggests that other students are not impacted by the sensory things that annoy her in the library. This may be further emphasised by Kim's use of rhyming couplets to emphasise a rhythm in the first five stanzas which are about senses. This rhythm possibly represents how it appears that every other student can combine daily sensory experiences into their routine or that they do not notice them as they fit into the rhythm of everyday life. However, the last stanza does not follow the same rhyming structure. In this stanza Kim talks about how her routine is disrupted by not being able to concentrate because of all these sensory distractions. The last stanza being a different structure may emphasise this difference and change for Kim.

Boys (2011) asserts that university learning involves much self-directed study, where the boundaries between learning and other activities such as eating and socialising are much less defined. This is in comparison to school where learning and other activities are kept very separate. Boys' (2011) implication that boundaries are blurred at university resonates with Kim's poem especially in her stanza about food and the sensory impact it has on her learning. Having blurred boundaries between learning and other activities may be conducive to learning for some students but not others. Cox (2022) and Lofty et al. (2022) suggest that university libraries should incorporate a wide range of different spaces to accommodate as many types of study style as possible.

Billy also highlights in her artefact (see Figure 37) how the library involves high sensory processing. She attributes this in part to why it took her seven years to feel comfortable going into a university library to check out books.



Today marks the first day in seven years of being in University that I used the library. To mark this momentous occasion I have taken a photo of the journals and book I requested. To say a library is quiet is incorrect. The library is very loud, full of people who clearly do not intend to study, with systems for borrowing/returning/printing that were never explained. There are not any quiet nooks and the system for booking a separate room to study, in peace and solitude has its own inexplicable process of emailing/applying/booking. I'd rather stay at home… So I did.

Figure 37: Billy's Artefact 3

Billy’s composition of her artefact demonstrates how she feels about the library. The books stacked up haphazardly may reflect Billy’s description of how complicated she finds the system within the library to navigate. The description could be interpreted as showing anger rather than pride (of using the library for the first time). Words such as ‘momentous occasion’ seem to be used sarcastically to highlight how a task that is commonly seen as basic has taken so long to achieve due to the barriers she feels put in place by the library systems.

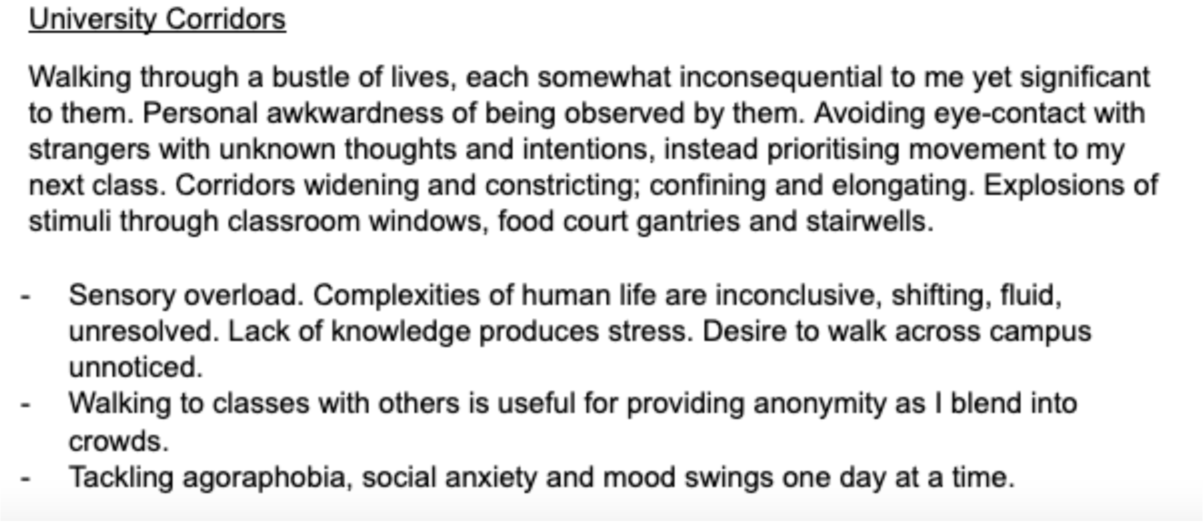
Both Kim and Billy highlight the sensory aspects that a library involves, even though stereotypically libraries can be thought of as quiet places to study. It should be noted that participants only mentioned the library as a physical space to be problematic, rather than online library collections or other resources.

The sensory experiences of Kim and Billy somewhat align with minimal previous literature on autistic students’ experiences of university libraries. Anderson (2018) suggests that although libraries can be used by autistic students to escape other sensory environments, they are problematic spaces that are usually too noisy or too quiet to be comfortable. In addition, Lawrence (2013) and Pionke (2017) suggest that fluorescent lighting used in universities may also impact on the sensory experiences of autistic students. Lawrence (2013) also highlights how universities trending towards an emphasis on group work has made libraries increase their numbers of collaborative and group work spaces, where students are expected to be noisy. She states this could be overwhelming for autistic students.

Both Kim and Billy’s sensory difficulties in the library environment appear to stem from both the physical environment (for example Kim smelling the cafe) and how other people use the physical space. Therefore, changes in both the physical environment and the behaviour of others within it needs to be considered to ensure that library spaces, that are thought to be central to learning by some, are accessible to autistic students. Cox (2022, p. 9) states, ‘to be welcoming the library space has to respond to all these differences and seek to accommodate them’.

7.3.2 Bringing the ‘Non-Space’ of the Corridors to the Forefront

When considering spaces within universities, corridors are not frequently considered, however Chism (2006) argues they can be a site of informal learning at university rather than merely a passageway. Hurdley (2010) contends that corridors are important spaces, both physically and culturally in the everyday life of a university. Although some researchers argue that corridors can be beneficial to informal learning within university, I could only find one study that specifically mentions corridors with regard to autistic students’ experiences (see Goddard & Cook, 2022). Megan highlighted the negative impact university corridors had on her sensory experiences (see figure 38).



University Corridors

Walking through a bustle of lives, each somewhat inconsequential to me yet significant to them. Personal awkwardness of being observed by them. Avoiding eye-contact with strangers with unknown thoughts and intentions, instead prioritising movement to my next class. Corridors widening and constricting; confining and elongating. Explosions of stimuli through classroom windows, food court gantries and stairwells.

- Sensory overload. Complexities of human life are inconclusive, shifting, fluid, unresolved. Lack of knowledge produces stress. Desire to walk across campus unnoticed.
- Walking to classes with others is useful for providing anonymity as I blend into crowds.
- Tackling agoraphobia, social anxiety and mood swings one day at a time.

Figure 38: Megan's Artefact 2 'University Corridors'

Megan explains her experience of walking in corridors both in reality and how she feels they change shape. She uses expressive and descriptive words like ‘explosions’ to convey impact. Notably, she refers to ‘them’ which could reflect that she feels different and isolated from the other people in the corridor. She simultaneously says she does not understand or want to be with people but also wants to walk in groups to allow her to be anonymous. Therefore, it appears corridors and the people within them are a conflicting space for Megan, as their complexities provide both anonymity, but also a feeling of being singled out by sensory overload. Goddard and Cook (2022) explored the social experiences of ten autistic university students. They conclude that some of their participants found the university environment to negatively impact on their social inclusion at university. Goddard and Cook (2022) specifically highlight how overcrowding and noise levels in narrow corridors made the environment less welcoming for autistic students. Megan's experiences of corridors are similar, which suggests more thought needs to be given to the sensory environment corridors elicit.

Corridors are often seen as 'non-spaces' (Pigott et al., 2016). Despite their fairly low status in research, corridors as 'non-spaces' can be sites of exclusion within a neoliberal academy. Holden (2022) explores an infamous 'Corridor B' described by some of her participants as a 'leper colony' (p. 333). This corridor was where academics were allocated offices if they were re-deployed to teaching only contracts, after having been research active. Holden (2022) describes 'Corridor B' as if it is a shameful place to be in, to no longer be thought worthy enough to do research at the university. Therefore, the physical environment of a corridor may not be solely important, but rather the culture and perceptions imposed on it.

In contrast, Samatar et al. (2021) highlight corridors can also be a site of inclusion, particularly when more traditional university spaces become sites of exclusion. Their study explored the lived experiences of five female students of colour at university. One participant chose to work in study booths in corridors rather than in the university library as it was a non-bookable space which she would not be moved out of. Samatar et al. (2021) attribute that studying in the corridor enabled the participant to hold authority, whereas the university library evoked feelings of powerlessness.

Consideration to the autistic experience of university corridors has not afforded much space within research. Mallett and Runswick-Cole (2012) note they discussed their forthcoming disability research (including autism) in 'drafty corridors'. Corridors can thus bring people proximity and casual interaction that they may not experience in offices (Sharif, 2022). Megan highlights that walking through the corridor is like 'walking through a bustle of lives' and therefore although they may be sites of knowledge production and proximity for other people, the sensory overload they provide to autistic students is likely to make corridors an exclusionary place for this type of engagement.

Corridors can be sites of both exclusion and inclusion that may either promote or hinder learning. Careful consideration to how they are perceived may be as important as the physical design of a corridor to ensure they are not unnecessarily labelled exclusive sites.

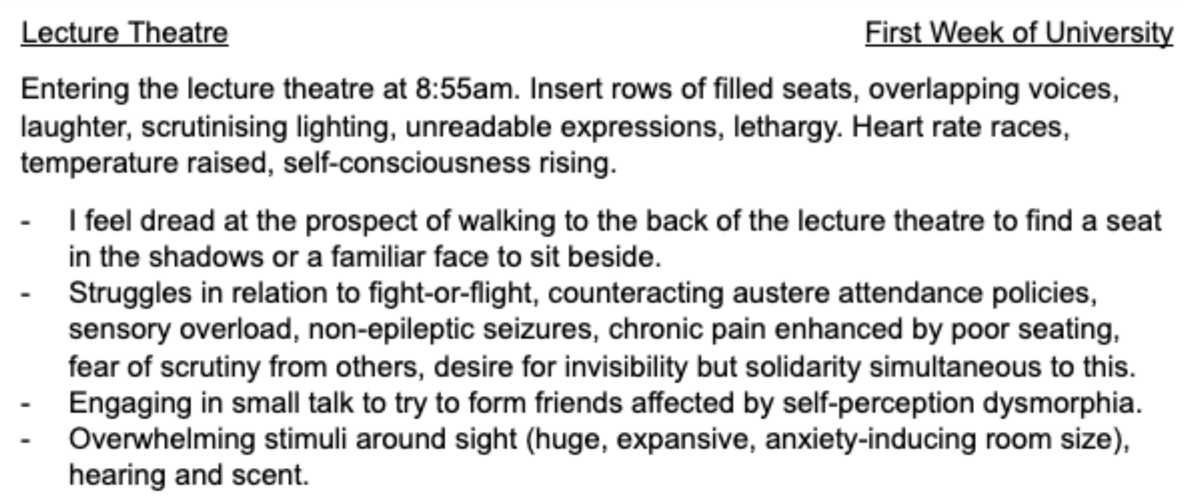
7.3.3 Sensory Barriers to Learning

University life is synonymous with attending lectures as part of learning. The places lectures are held in may impact learning outcomes for autistic students. Both Megan and Kim found lecture theatres to be distracting from lots of sensory input. Kim depicted the sensory distractions when she was in a lecture theatre and particularly focused on noise (see Figure 39).

Figure 39: Kim's Artefact 3

Kim's image shows her sitting at her laptop in a lecture theatre. The yellow is the work that she should be doing and all the other colours show distractions. The spray function is used to show how her attention gets pulled between all the distractions. Kim describes the distractions as both coming from her own laptop (such as emails and social media notifications) and from within the lecture theatre (such as other people walking in late, whispering and sneezing). Overall, she described that she wanted her image to depict her sensory sensitivities, especially to auditory stimuli in a lecture theatre. This was to depict how difficult it is to concentrate when she feels distracted, but also to show how other students seem to be able to focus despite distractions, when she feels she cannot.

Megan also highlighted the sensory impact of being in a lecture theatre, particularly during the first week of university (see Figure 40).



Lecture Theatre First Week of University

Entering the lecture theatre at 8:55am. Insert rows of filled seats, overlapping voices, laughter, scrutinising lighting, unreadable expressions, lethargy. Heart rate races, temperature raised, self-consciousness rising.

- I feel dread at the prospect of walking to the back of the lecture theatre to find a seat in the shadows or a familiar face to sit beside.
- Struggles in relation to fight-or-flight, counteracting austere attendance policies, sensory overload, non-epileptic seizures, chronic pain enhanced by poor seating, fear of scrutiny from others, desire for invisibility but solidarity simultaneous to this.
- Engaging in small talk to try to form friends affected by self-perception dysmorphia.
- Overwhelming stimuli around sight (huge, expansive, anxiety-inducing room size), hearing and scent.

Figure 40: Megan's Artefact 1 'Lecture Theatre'

Megan presents her descriptive text as a list of different sensory aspects of the lecture theatre, followed by short bullet points that may be interpreted as showing momentum to emphasise that these negative sensory experiences keep on happening and happen with speed. Megan said that there is a greater social pressure on women to engage in conversation with others compared to men in situations such as in a lecture theatre before the lecture started. She thought this may stem from gender stereotyping rather than due to autism. However, this stereotype she felt clearly evoked more feelings of anxiousness in an already uncomfortable environment.

Although not able to change the physical design of a lecture theatre, Sheppard's (2021) approach to ensuring the comfort of students is notable. She discusses how she is a disabled lecturer and so seeks to set up an environment of mutual support in her lectures. Sheppard (2021) explains that she does this by disclosing she is disabled and stating how she accommodates herself when teaching. She then states she will help accommodate any student (for example reserving seating). Although primarily this is to accommodate herself, it can benefit her students. This understanding between Sheppard (2021) and her students may foster a culture that adaptations to improve the learning environment are possible within potentially inaccessible institutions.

Overwhelmingly when considering lecture theatres, the key messages of being distracted but also being expected to conform to the environment are highlighted. Kim and Megan found it difficult to concentrate and therefore achieve what they were doing easily when the surroundings were not conducive to their needs. However, if an approach similar to Sheppard (2021) is adopted then potentially the difficulties and anxieties of lecture theatres can be reduced for autistic students.

7.3.4 Sensory Impacts of University Accommodation

The social side of university for autistic students has been somewhat documented in literature (Goddard & Cook, 2022; Jackson et al., 2018; Knott & Taylor, 2014). In this the social experiences of living in student accommodation has been touched upon. However, there is a dearth of literature concerning the impact sensory aspects of student accommodation has on autistic students.

Sarah spoke about how she found her university living accommodation to be sensorily overwhelming particularly in relation to noise.

Figure 41: Sarah's Artefact 1

Sarah described her picture (see Figure 41) to show how her life at university was controlled by the cathedral bells next to her accommodation. The bells went off regularly, starting at 7:25am and going on into the night up to every quarter of an hour each day. She therefore ‘lived and died by the bells’ as they disrupted her sleep. Sarah depicted herself as the clapper in the bell as she felt like she could not prevent this or stop it at any particular time but was constantly battered. The bells provided Sarah with structure, but she said it was unyielding. However, Sarah said that because the bells had rung from the cathedral so often for hundreds of years it was not something that could be changed. She felt it defined her university experience as it was inescapable and made her unwell and exhausted quickly.

Sarah was unable to change accommodation due to a lack of availability and a lack of information when she initially applied. Therefore, although the initial problem was the noise from the bells, other people’s reactions and responses that they were unable to help hindered Sarah’s ability to cope with an environment that could not be changed.

Van Hees et al. (2015) recommend that universities ensure autistic students have sufficient time to rest in order to reduce stress and anxiety from academic and social demands. However, in Sarah’s case she was unable to rest due to the noise in her accommodation. In consideration of Van Hees et al.’s (2015) study she may therefore struggle to cope with other demands of university if she is not well rested. The need for rest may be the same for all students and thus noise might be a problem for all.

Therefore, although not regularly focused on in research, the sensory impact of halls may significantly impact on other areas of an autistic student’s university experience, particularly if they do not allow space to rest and recuperate.

7.3.5 The Controversy of Quiet Rooms

At university quiet rooms tend to be set up with autistic students in mind. Goddard and Cook (2022) note that universities generally have a lack of quiet spaces. Only one participant mentioned that her university had one. Sophia commented on the stigma around using it and the need to normalise it.

‘I think we need to normalise having quiet rooms because we have them on campus now. It kind of feels a bit weird. I have never used them because I feel there is a bit of a stigma seeing someone go in there and you are like why? But even for neurotypical women to have that break and to try and normalise that.’ (Sophia)

Sophia commented on how it was good that her university had a quiet room where people could go if they needed a break, however she felt that there was a stereotype with using quiet spaces which had dissuaded her from using it herself. Thus, it is not just the environment that needs to be adjusted to meet the needs of autistic people but the attitudes of others towards these adjustments.

Anglesey and Cecil-Lemkin (2021) argue that people’s views of a quiet room are very different, for example they describe their experiences at conferences where they have seen quiet rooms be used for typing up dissertations, engaging in networking, breastfeeding and for disabled scholars to rest. They therefore argue that quiet rooms are not always used for their intended purpose of supporting disabled scholars. However, it may be through others’ ignorance that they are unaware of how to use a quiet room or understand a quiet room to be used for different purposes, which in turn may form stereotypes and stigma as Sophia suggests.

Whilst a potential lack of quiet spaces at universities may hinder autistic students’ experiences of university, Sophia’s experiences highlight the need for universities to ensure the purpose of spaces is clearly defined to ensure students can use them effectively.

7.3.6 Sensory Summary

Within this section I presented an overview of some different places around university that can cause sensory overload to autistic students. Specifically, I have explored the library, corridors, student accommodation, lecture theatres and quiet rooms.

Overall, participants highlighted a variety of places at university that cause some sort of sensory overload. Noise was the thing that participants found most difficult to cope with from others. There are likely to be many other places within a university that cause sensory difficulties to both these participants that they did not focus on and to other autistic students that did not participate in this study. Although autistic people are not a homogenous group and thus will not be negatively affected by the same sensory stimuli, some sensory reduction may help them and other people to navigate university easier.

This theme highlights two issues, that to solve or ease sensory overload for autistic students either the physical environment and/or the people's willingness to recognise sensory difficulties needs to change. The university systems people work in need to be more open to enabling the autistic student to not have to, or significantly help them to, access the difficult environment.

In conclusion, consideration needs to be given to ensuring that within each type of space there are places or areas dedicated to reducing sensory overload such as by having reduced noise or lighting. In particular, 'non-space' areas such as corridors need to be given thought to ensure they are not also sensory overloading and thus exclusionary.

7.4 Autism Awareness and Acceptance

Predominantly participants were keen that awareness and acceptance of autistic students at university was increased, both for staff and other students. The focus of this thesis centres around the experiences of autistic women at university. Participants highlighted there were some things that would make their experiences at university better and that they thought would help future autistic students. A key topic for participants was that awareness of autism needs to improve, but staff and students need to not only be aware of autism, but also accept autistic people.

Participants voiced a strong desire to be listened to, both in society and within the university setting, especially when they wanted to advocate for change. Participants also wanted to not only be heard, but for what they said to be taken seriously and acted upon. Thus, being supported by others to make change happen and to improve their university experiences. They however also expressed how difficult this could be. As discussed in the literature review (see *Chapter 2: Literature Review*) there has historically been a prevailing stigma of negativity around autism, including at university (see White et al., 2011), which was supported in this study in *Chapter 5: Perceptions*. Although more recent research seeks to include the views and experiences of autistic people, Scott and Sedgewick (2021) argue that with regards to being asked about university support, autistic people's opinions are less well documented.

Participants expressed that practical changes need to be implemented at university in order to increase both awareness and acceptance of autism, such as training for staff and students. In addition, practical changes may help to break harmful stereotypes that people may hold about autism and challenge the usually negative thinking around it.

The previous sections of this chapter have considered the sensory aspects of the university environment and the impact academic university staff have. I presented that the university environment tends to have a negative sensory impact for participants and that academic staff have both a positive and negative impact on autistic students. Considering the generally negative stance of these sections, I present insight into participants' thoughts on raising awareness of autism and the impact that listening to them at university might have. Within this section I attend to my research question of ‘What changes autistic women would like to see at university?’.

First, I explore the participants' opinions of autism awareness and acceptance. I consider how autism awareness training may help and hinder others' knowledge about autism and how they treat autistic people. Second, I discuss the need to listen to the voices of autistic people within the university. I acknowledge the difficulties autistic students may have advocating for themselves. I conclude by highlighting how some universities may be trying to be inclusive to autistic students through ‘autism-friendly’ events and briefly explore the complexities of this initiative.

Poulsen et al. (2022, p. 3) argue ‘the heart of the message is, in part, about acceptance: embracing and valuing autism as part of the human spectrum’. At the moment, Turnock et al. (2022) suggest that visible autistic traits influence other people’s perceptions and stigma of autism. If autism can be accepted as just another way of being, where autistic people are not stigmatised if they need some support, then awareness of autism as a discrete disability would cease to be needed. However, some participants shared experiences emphasising how universities are not there yet and thus autism awareness and acceptance are clearly still needed to ensure equity.

Kim and Lilly highlighted how they felt lecturers and other students at university simply did not understand what autism was. This made it difficult for them to have positive experiences at university as they did not feel understood. Moriña Díez et al. (2015, p.155) report that disabled students believe lecturers create ‘more barriers than bridges’ with regard to inclusion, which may be due to a lack of awareness and acceptance of autistic people. Kim and Lilly’s comments mirror Moriña Díez et al.’s (2015, p.155) suggestion.

‘I think a lot of it is about education. The issues I have had with lecturers etc have just been about ignorance.’ (Kim)

‘Some lecturers and many of my fellow students are not very autism-aware.’ (Lilly)

Kim suggests that lack of awareness is due to ignorance and may not be due to people actively wanting to perpetuate myths and stereotypes of autistic people. The lack of education and awareness about autism that Kim and Lilly report their lecturers having is particularly important. Educating lecturers about autism might reduce this ignorance which could in turn stop autistic people being subjected to misinformation and stereotypes. Waisman et al. (2022) argue that staff teaching university courses can influence students’ success at university, but that if staff have stigmatising attitudes towards autistic students this can be hindered. I argue that being ignorant about autism may be as damaging as holding a stigmatised attitude as ignorance can lead to misconceptions and inaccuracies being spread. Therefore, an ignorant lecturer may have the same negative effect on an autistic student compared to a lecturer who holds stigmatising beliefs.

In addition, Lilly said that she has had experiences of students not understanding autism. Although other students may not hold as much influence on the academic outcomes of university in the same way lecturers do, they can be crucial for social connectedness and contribute towards positive experiences. Many researchers (Anderson & Butt, 2017; Gardiner & Iarocci, 2014; Gelbar et al., 2015; Gillespie-Lynch et al., 2015; Gobbo & Shmulsky, 2012; Matthews et al., 2015; Obeid et al., 2015) have explored a variety of difficulties autistic students can face at university. These studies consistently conclude that social stigma towards them combined with having to navigate social expectations of university present barriers for autistic students. Therefore, student ignorance and stigma towards autistic students is likely to be as damaging as that from university staff. If stigma from other students is reduced it may make navigating social expectations easier due to an acceptance from others.

One way to reduce ignorance and stigma is to provide training or awareness sessions to both staff and students. With regard to raising awareness and acceptance, participants expressed opinions about what may make effective training on autism at university. Scott and Sedgewick (2021) conclude that staff should be trained to be confident in supporting autistic students' needs. Theoretically wanting people to be trained and what it could look like in practice are two different things. Just increasing a person’s knowledge about autism may not enable them to treat autistic people better as Cassy and Sophie highlight.

‘I think more awareness of how autism looks genuinely would make a difference.’ (Cassy)

‘I think it is just understanding different needs because there is so much stuff that is not talked about with autism.’ (Sophie)

Cassy and Sophie imply that just increasing awareness and therefore knowledge about autism is not enough to make change. The link between increased knowledge about autism and reducing stigma towards autistic people is contested (Kitchin & Karlin, 2021). Payne and Wood (2016) surveyed 1185 American university students about their perceptions towards autistic individuals, in order to suggest ways in which autistic university students could be better included in university life. They conclude that increased experience and exposure to autistic people was associated with better perceptions towards them. Conversely, Stronach et al. (2019) studied knowledge of autism and stigma towards autistic people in both a university and community population. They found that although knowing an autistic person increased knowledge about autism, it had no effect on stigma. The relationship between contact with autistic people and reduced stigma towards them is inconsistent. However, studies of this nature (either of the stigma autistic people face or on non-autistic people's perceptions) tend to group participants into the binary groups of autistic and non-autistic people. The discrepancies in the role of contact with autistic people in reducing stigma (which I illustrate through Payne and Wood (2016) and Stronach et al. (2019)) may be due to other intersecting factors, or that autism is a heterogeneous condition.

Kim highlights that changing ingrained stereotypes and perceptions may be difficult as society appears to already know what autism is, has contact with autistic people, and thus has fixed opinions of it which may be difficult to change.

'I am very lucky that autism is something that you know, everyone's got an autistic cousin or godparent or something these days…people do not look at me as if I have got three heads, but they do not necessarily fully understand what it is and again, they have those stereotypes. So breaking stereotypes via a campaign, I think would be something that I would really like to see universities do.' (Kim)

Kim's suggestion that stereotypes need to be reduced is important to consider. Jones et al. (2021) explored non-autistic people's attitudes towards autism after engaging in a training video including autistic people. They found that compared to people who had watched a video about mental health or no video, those that had watched the autism training video had more positive beliefs about autism and were more willing to engage with autistic people. However, the autism training video did not appear to affect participants' ingrained beliefs about autism as many still connected autism with unpleasant traits. Jones et al. (2021) conclude that training about autism may help to change some beliefs about autism but that ingrained stereotypes and prejudices may be harder to change. However, many researchers (Botha et al., 2022; Gernsbacher et al., 2018; Sarrett, 2018; Waisman et al., 2022) suggest that how knowledge about autism is produced and shared is important as they argue that autistic people can be situated as not meeting an ideal of normalcy. Thus, if autistic people are at the forefront of breaking stereotypes rather than solely being portrayed stereotypically by others, attitudes and ingrained stereotypes may change.

For autistic people to be at the forefront of breaking stereotypes at university and helping to create change, they need to be heard by others and their voices accepted. Billy and Kim both highlight that autistic people want to be listened to but are not always.

‘I think we [autistic people] need to be heard and for what we say to have an impact.’ (Billy)

‘[Autistic] people just want to be listened to and not put in a box.’ (Kim)

Billy focuses not only on the importance of being ‘heard’ but also the value of those contributions having an ‘impact’ on change within the university. Kim suggests that it is important not to minimise what people are saying or assume their opinions and implies the detrimental effect it can have if autistic people are dismissed due to perceived stereotypes.

Billy goes on to suggest that the experts are autistic people and therefore it is key to listen to them.

‘Listening to students with first-hand knowledge. The experts [autistic people] are all out there, all they need to do is ask and a willingness to listen goes a long way.’ (Billy)

Billy’s words mirror the thought that people can be experts by experience and thus influence change. Thus, a culture change may be needed to ensure that the desires of Kim and Billy that autistic people are listened to happens. However, Gillespie-Lynch et al. (2021)

note that autistic people’s knowledge and expertise of autism are frequently overlooked, and they are seldom involved in developing materials to increase autism awareness or educate others about it.

Gillespie-Lynch et al. (2021) produced two trainings on autism, one made in collaboration with autistic students and one made solely by non-autistic professors. When both these trainings were presented to university students, the one made in collaboration with autistic students increased knowledge and acceptance more than the training made with no input from autistic people. This suggests that autistic people may be best placed to teach others about autism. Autistic university students' voices should therefore not be outrightly dismissed because they have important experiences to share which may be able to help university institutions better understand autism.

Jess highlighted how she thought autistic women should be spoken about more, as autism is stereotyped to mainly affect men.

‘I think speaking more openly about autistic women. I think because there is this false and harmful notion that only men are autistic. We need to highlight autistic women’ (Jess).

This example suggests why autistic students should be involved in training. They are best placed to inform others about the knowledge both people in universities and wider society are lacking with regard to autism.

Despite the need for autistic people to be listened to there can be barriers put up by society that mean this is difficult. Jess gave the reason that a lack of listening to autistic people may be due to years of historic violence in research towards disabled people and specifically autistic people.

‘...it’s very present in the back of my mind how us autistic people have been systematically wiped out for existing and part of existing is us voicing our opinions and engendering our existence vocally. It can feel almost problematic to exist and make myself known, because it almost feels like a memory stored in my DNA that I'm in danger if I do.' (Jess)

This suggests that the previous history of those labelled with autism, may prevent current autistic people from wanting to speak out and be heard for fear of repercussions and ableism from others. Despite the potential difficulties in autistic people voicing opinions, it may be vital to ensure change and better experiences. Throughout my analysis of what participants said that related to autistic voice it is evident that it is predominantly society's attitude and perceptions of what autistic people can and cannot decide and advocate for, rather than an unwillingness of autistic people to voice their own opinion.

So far, I have painted a generally negative picture of participants' experiences of other people's lack of autism awareness and their voices and advocacy being silenced or minimised by others. Sophie commented how her university had put on some events that they called 'autism-friendly', but these followed stereotypes of autism. Turnock et al. (2022) suggest 'autism-friendly' spaces should be spaces where how the person fits into the environment is considered, such as making it socially (for example, agreed social rules) and/or physically comfortable (for example, noise reduction). However, there are no set parameters on what an 'autism-friendly' space is and so places and events may be labelled as 'autism-friendly', but do not accommodate effectively. Sophie may have felt she was not accommodated.

'I think when they say things are autism-friendly, they have gone with autism-friendly as if they have listened to some non-autistic person talk about autism in a stereotyped way and it is really not an accurate picture.' (Sophie)

Although Sophie experienced a university putting on a very stereotypical event, what she says implies that her university tried to meet some needs of autistic students and showed willingness for inclusion. I acknowledge that Sophie's experience must have been demoralising and difficult, however, it shows promise that autistic students may be being considered more explicitly by universities.

Overall, participants were hopeful that there is capacity for improvement in inclusivity and believe that this could be done through raising awareness. However, research suggests that training does not always improve perceptions and therefore careful thought into the types of training and awareness, and the intended outcome, is needed. In addition, participants were keen to be listened to, and for their lived expertise in autism to be considered when advocating for their needs. Frost et al. (2019) argue that more autism awareness is not enough, but that society should strive for acceptance, inclusion and empowerment of autistic people. A combination of considering greater awareness and training, listening to and acting on what autistic students have to say and striving to provide inclusive events that do not rely on autistic stereotypes from non-autistic people is key to ensuring autistic students are not disadvantaged at university.

7.5 Conclusion

In this chapter I have considered the environment of the university and the impact of this on participants' experiences. I have attended to the barriers that both academic staff and the sensory environment can provide autistic students. I have also explored the importance of valuing the autistic voice in improving the university environment.

I addressed reflecting on the university environment in three ways: academic staff impact, the sensory university environment, and autism awareness and acceptance. First, I reflected upon the impact of relationships participants had with academic staff. I explored how participants believe luck to be a factor in making and keeping good relationships with staff. Second, I have highlighted how the sensory environment of university can hinder autistic students' participation in traditional student life. I also considered how spaces can impact autistic students' abilities to access and use them effectively. I examined five different areas of the university: libraries, corridors, lecture theatres, student halls and quiet rooms. I highlight how both areas that are traditionally considered alongside learning (such as the library) and 'non-spaces' (for example corridors) can be impactful to an autistic student. Kim's poem 'Concentrate' (see Figure 36) highlights how libraries can become sites of sensory overload, which non-autistic students may not appreciate. I also attended to 'non-spaces' (Pigott et al., 2016) such as corridors, which Hurdley (2010) argues are important sites in everyday university life. This exploration into spaces gives insight into how exclusionary the physical buildings of university can be for autistic students in terms of sensory stimulation. Third, I have explored how participants had experienced a lack of autism awareness from others and the ways in which they would like to see it challenged. I engaged in discussion about listening to the voices of autistic students and the need to include them in training like Gillespie-Lynch et al. (2021) suggest.

Overall, this chapter also achieves an appreciation of how the behaviour of academic staff and spaces within universities can be made inclusive. By incorporating autistic students and accommodating them, through inclusive spaces and meaningful awareness training, autistic students may feel more accommodated in the wider environment of university. Therefore, universities need to consider the environments of university buildings and spaces more conscientiously in order to ensure all university students have some spaces in which they feel comfortable in.

8 Discussion

8.1 Introduction

Within this chapter, I consolidate the findings presented from the thematic *Chapters 4-7* in order to more explicitly explore the research questions and my overarching thesis aim. This study was guided by the broad aim of offering a cultural exploration into autistic women's experiences of Higher Education. In order to attend to this investigation, I set out three research questions:

1. What barriers and supports to higher education do autistic women students feel they have had at university?
2. In what ways can the university environment be adapted to better accommodate autistic women?
3. What changes would autistic women like to see at university?

Before I turn to the main body of the chapter, I briefly remind the reader of the key focus topics of the literature review, to emphasise how the aim and the research questions came about. It is deliberately summative, as I tease out literature from *Chapter 2: Literature Review* in the remainder of this chapter. In my review of the literature, I explored how models help to conceptualise disability and how autism sits within these. I mainly focused on the dichotomy between the social model (Oliver, 1990) and the medical model, which Llewellyn and Hogan (2000) describe as being a pervasive view of disability. I discussed the disconnect between autism and womanhood. I stated that traditionally autism is stereotypically seen as something predominantly associated both with children and with cis-gendered boys and men. I documented how early thinking by Asperger suggested autism was 'a variant of male intelligence' (1944, p. 39), which although has been disproven (as girls and women can also be autistic) societal thinking still tends to resemble this viewpoint.

After delving into models of disability and the foundations of autism discourse, I turned my attention to the theoretical perspectives and empirical research that supported my thesis. I explored how Critical Disability Studies (CDS) focuses on forwarding the study of disability by building on foundational perspectives of disability incorporating transformative agendas (Goodley, 2016). I discussed how Critical Autism Studies seeks to further perspectives from CDS to specifically enable research to impact on the lives of autistic people by recognising the issues from society that affect them (Ryan & Milton, 2023). Lastly, with regard to theory I talked about feminist disability studies. I focused on how disability and disabled women occupy an awkward space within feminist studies (Lloyd, 2001). This was particularly important as autistic women do not fit into stereotypical autism discourse, nor feminism. This therefore meant my research needed to contribute to carving a space for autistic women, addressing a missing voice in feminist research.

I also explored more empirical research surrounding autism, autistic women, and autistic students at university. I highlighted how research on autistic adults is lacking, and turned my attention to university as a traditional step in adult education. I explored how, until recently, autistic people have remained relatively absent from university research, and that the majority of research in this area focused on how non-autistic staff perceive autistic students. In more recent years, some research has highlighted the stigma autistic students face at university (Gillespie-Lynch et al., 2015; Perry et al., 2022), suggesting that autistic students can have negative experiences at university. In addition to research suggesting negative university experiences, there is a lack of research solely exploring autistic women's experiences at university, hence the critical importance of this thesis.

In *Chapters 4-7* I presented the data themes with introductory reference to mainly empirical previous literature. I divide the remainder of this chapter into two sections. In Section One, I first revisit these themes and delve further into how my data connects to theoretical frameworks and reflect on the ways in which it both mirrors and diverges from these. I specifically relate the analysed data to the theoretical frameworks of both Critical Disability Studies (CDS) and Critical Autism Studies (CAS). I reflect both upon the theory I used and speculate on different theories I could have brought into this project. Second, I examine the individual research questions with reference to both my data, literature and theory. Third, I state nine key theoretical contributions my study makes to CDS, CAS and feminist disability studies, again advocating for the vital importance of this thesis towards understanding the educational lives of autistic women.

In Section Two, I look back on how I used theory in practice throughout my research. I was keen to not only relate my findings to theory but ensure that my project philosophy reflected these theories. I revisit CAS and consider how I have used this theory within my project and where my work sits in the field of autism research. Finally, I reflect upon the methods I used and how they were influenced by Critical Theory.

8.2 Section One

8.2.1 Summary of Analysis Chapters

Within my data analysis I organised my data into three chapters: (i) Perceptions; (ii) Exposing the Postgraduate Autistic Student; and (iii) Reflections on University Environment. Here I revisit key messages from these chapters and further reflect on some areas with reference to CDS, CAS, identity theories and feminist disability studies.

8.2.2 Perceptions

Within *Chapter 5: Perceptions,* I explored three themes: Self-identity, Societal Perceptions and Perceptions of University. Through this chapter I drew out key themes from the data. These included participants not always being comfortable with their autistic identity, that autism in women is rarely portrayed in society or public discourse, and that participants felt students and staff at universities held firm opinions of what a university student should be like and that this idealisation was often difficult to live with. Here, I focus on how belonging and identity are linked to feminist disability studies and critical autism studies.

Within *Chapter 2: Literature Review* I pose that Goodley (2016, p. 194) highlights that both feminist disability studies and critical disability studies align to ‘destabilise the normative centres of society and culture’. I go on to question the extension of this alignment to autism, considering that autism does not tend to fit into societal stereotypes of a woman. The data I presented in *Chapter 5: Perceptions* appears to mirror this notion that autism does not fit into how society perceives a woman to be. However, Botha and Frost (2020) highlight that autism may be a central feature of people’s identity and therefore acceptance of this identity by society is needed. Participants highlighted they did not feel they belonged in society, as they had received gendered comments from others regarding being autistic and did not see cultural representations of autism they felt they could relate to in popular media. It appears that some autistic women struggle to balance their own identities when societal images do not affirm these identities.

Within *Chapter 5: Perceptions,* the benefits and barriers of obtaining a diagnosis of autism, were reflected upon by participants. Some participants said that receiving a diagnosis sometimes led to feelings of belonging to a community of other autistic people and a feeling of acceptance, but that diagnosis could also evoke feelings of being an outsider at events and therefore needing to mask their real identity to fit in. This aligns with Zener’s (2019) suggestion that a positive impact of being diagnosed as an autistic woman means that they may seek out communities of other autistic women. However, people process and internalise their autistic identity differently and this may well impact differentially on their decision-making in relation to belonging to a community based on a diagnosis.

Identity and belonging continued to feature throughout the rest of *Chapter 5: Perceptions*. Overall participants felt they did not fit into what university staff and other students framed as the ‘typical student’ and therefore often felt they were viewed negatively. This again either required participants to find confidence in not fitting in or mask their identity in an attempt to conform. In addition, participants felt autistic male students are afforded more leniency for non-conformity. Botha et al. (2022) explored 20 autistic people’s opinions of their autism and argued that participants initially considered their autism as a neutral entity but that the impressions they received from others about their autism were mostly negative. This in turn made their participants consider their autism in a negative light. My own findings suggest similar to Botha et al. (2022) - that other people’s negative words and actions towards autistic people have a significant effect on an autistic person’s identity. Participants suggested that increasing awareness of autism may dispel myths, which could lead to others treating autistic women more positively. This could be further exemplified by de-neurotypifying the curriculum and therefore promoting neurodivergent researchers in university curricula. Smith and Mueller (2022) highlight that a lot of disabled people are passionate about improving the experience they and others have. This was also expressed by my participants in the context of societal beliefs; if society was in general more accepting of autism, then autistic women may have more positive identities and beliefs about themselves.

Overall, within *Chapter 5: Perceptions* it is evident that participants feel the impact of negative stereotypes and feelings towards autistic women is not just a problem in a wider societal context but also at university. Participants do however suggest that greater awareness of autism in women may help to increase their positive perceptions by others.

8.2.3 Exposing the Postgraduate Autistic Student

Within *Chapter 6: Exposing the Postgraduate Autistic Student,* I explored how participants who were postgraduate students felt about experiences that undergraduate students may not encounter. This focuses on participation at conferences and having roles as both a student and a staff member at the same time. I discussed how challenging dominant norms within conferences and having other roles whilst studying as a postgraduate could improve inclusivity and create a more accessible academic environment. But, at the same time, it is important to acknowledge the additional labour this can create for autistic postgraduate students in advocating for themselves and on behalf of future autistic postgraduate students.

The academic environment and expected norms of conferences was a key focus, as this tended to include social interaction in the form of networking. Social interaction is regularly documented to be difficult for autistic people in diagnostic criteria (APA, 2013), and participants found that if they did not engage with this in a way that ‘passed’ as neurotypical that they felt unwelcomed. This finding fits into Kohut et al.’s (1984) identity-proximity theory. They describe that to feel comfortable in a situation, other people need to act in a similar way or be accepting of behaviour. This can lead to feeling a sense of belonging and therefore contribute towards a positive identity. In addition, the environment and atmosphere of the conference was very important to participants and either aided or hindered their enjoyment. In terms of a conference, people may feel a connection to others through the topics of research, but also need to feel like they belong in other aspects, such as through shared experiences of academia.

Being a postgraduate student but also a staff member also featured in the participants' accounts. Participants expressed that when they were a student they were afforded support and accommodations, but as a staff member (even in the same institution) they were not. This negotiation of identity was difficult for participants, particularly as they sometimes felt they had to hide their identity when they were a staff member as being autistic was generally considered negative. Some participants attributed being autistic as a positive in the workplace and cited qualities such as empathy and pragmatism. This suggests acceptance of autism by others is key to success regardless of the role a person is in. Overall, greater research interest needs to be taken with regard to the postgraduate experience, so all of the university experience (not just from an undergraduate perspective) can ensure inclusivity.

8.2.4 Reflections on University Environment

The third chapter of my research findings centred around reflecting on the university environment (see *Chapter 7: Reflections on University Environment*). Primarily I attended to the barriers that both academic staff and the sensory environment can provide autistic students and emphasise how the autistic voice can help to improve them. In addition, participants noted that luck was a factor in whether they encountered supportive staff.

Similar to my discussions in *Chapter 5: Perceptions,* participants were keen for awareness to be raised about the effect the environment has on them. They had experienced a lack of knowledge about autism, which had negatively impacted on their environment. Davidson and Orsini (2013) highlight CAS involves promoting change against ingrained potentially deficit-based ideas that dominate thinking. Raising awareness as a solution to exclusion, appears in two chapters, which is important to note. I chose to focus on autism awareness in light of topics rather than to address awareness as a separate chapter. Universities need to consider the environments of university buildings and spaces more conscientiously in order to ensure all university students have some spaces in which they feel comfortable in. This includes appreciating how the behaviour of people within spaces affects the environment in order to inspire change.

8.2.5 Addressing the Research Questions

Within the overarching topic of the cultural experiences of autistic women at university, I identified three research questions to centre my focus. I interpreted and shared the stories of 11 participants, in the form of creative artefacts and interview summaries. I then analysed these using the broad principles of thematic analysis. I believe I have captured the essence and meanings of the participant stories. Discussing participants' experiences *across* themes enabled conceptualisation of how autistic people's experiences can be both homogeneous and heterogeneous across time and situation.

My thesis consists of four analysis chapters. The first analysis chapter (*Chapter 4: Introduction to the Participants*) gives an overview of each of the participants, including their artefact(s) and a summary of their interview. Within *Chapter 5: Perceptions* I consider self-identity, societal perceptions and perceptions of university. In *Chapter 6: Exposing the Postgraduate Autistic Student* I explore conferences and negotiate the space of being a student and staff member simultaneously. Lastly, in *Chapter 7: Reflections on University Environment* I consider staff impact, the sensory university environment, and autism awareness and acceptance. I now turn my attention to some of the ways in which I have answered each research question with references to the interlinking of themes.

8.2.5.1 Research Question One: What barriers and supports to higher education do autistic women students feel they have had at university?

The heterogeneity of autism would suggest that what may be supportive for one student may be a barrier for another. However, exploring barriers and supports autistic women feel exist at university did raise some commonalities.

Academic staff were cited as either a barrier or support when asking for support, in line with previous research (Scott & Sedgewick, 2021) and featured heavily in participant interviews. This focus on academic staff may be due to the perceptions students hold of academic staff. Participants reported being unwilling to seek support or guidance from other academic staff following a bad experience, suggesting academic staff can be viewed with the same homogeneity as other groups, for example like autistic people can be. The most interesting finding was that participants overwhelmingly attributed supportive experiences with academic staff to luck, rather than by right or expectation. Whilst having supportive experiences is beneficial, this attribution for it is troubling. Sophie, Cassy, Kim and Katie all highlight luck or privilege as the factors behind supportive experiences. Their attribution suggests they assume there is an element of chance in gaining good support and that not all universities and academic staff will provide it. Whilst job descriptions for academic staff with regard to support may vary, this harmful perception that support is provided based on luck needs to change to ensure autistic students are able to access support they need and to avoid placing the onus of support onto particularly supportive staff members.

Social aspects of the wider culture that university seems to require was another common barrier. Networking and making friends at university were highlighted by participants as examples of places of social exclusion and difficulty. Byrne (2022) considers that how to engage socially at university consists of many unwritten rules that autistic students may find hard to learn without explicit teaching. These social barriers could therefore be reduced if autistic people were either taught about unspoken social rules or there were more orchestrated places to meet people, with clear guidance. This may reduce the barriers to making social connections and any subsequent loneliness.

Beyond considering the specific support academic staff offered participants, this lens enables insight that academic staff are viewed as being able to support students but that any support given is out of luck or privilege, rather than by rights or need. This perception alongside the potential of social exclusion presents a picture of uncertainty that may shroud the university experience.

8.2.5.2 Research Question Two: In what ways can the university environment be adapted to better accommodate autistic women?

In considering how the university environment could be improved for autistic students, the sensory aspects of both the physical buildings and how people use them were brought to the forefront of conversation. The main sensory difficulty participants struggled with was noise. This was evident in many settings, such as Sarah mentioning cathedral bells becoming overwhelming in student accommodation and Cassy and Katie talking about noise levels at conferences. Participants highlighted there was some consideration at university to alleviate sensory overwhelm (such as quiet rooms at university) but many ‘non-spaces’ such as corridors had evidently been given less thought.

In relation to changing the ways in which people contributed to the sensory experience, reducing the focus on alcohol or containing it to specific events was mooted. Cassy highlighted the fixation of universities of providing alcohol-based events for undergraduate students as a way to assist with making social connections and I extended this notion of exclusion to others who may not drink alcohol, for example for cultural reasons. Burns (2021) relates this dominance of alcohol to also existing and fuelling academic conferences.

I also argue greater emphasis be placed on the postgraduate autistic student and the different types of environments they may have to traverse, for example, conferences or school placements. Participants’ stories highlight adaptability is firmly centred within the individual. Although some physical environments may be fixed due to architecture, the importance of space and flexibility of others should not be forgotten or negated simply because a student has become a postgraduate.

Overall, ensuring a variety of physical and social environments exist in both university settings and academic events may reduce exclusion of not only autistic women but also anybody else who feels they do not fit into that scenario. In addition, ensuring other students and staff are aware of how their actions may affect others, such as through noise, may assist in ensuring some environments cater to autistic students better.

8.2.5.3 Research Question Three: What changes would autistic women like to see at university?

I dedicate this research question to focusing on what participants wanted to be changed at university in order to improve their experiences or those of future autistic students. I posed this question with an assumption that participants would not have had wholly positive experiences at university. This was based on my own experiences and on relevant literature (for example, Cage & Howes, 2020; Scott & Sedgewick, 2021).

Most notably participants wanted a better understanding and awareness of autism at university. This was particularly with respect to autistic women not fitting the stereotypical profile of autism. As I have highlighted within the first research question, participants documented inconsistency with the knowledge of academic staff and acceptance of autism. Participants hoped that if academic staff and students understood autism better and were more accepting of it, then they would not feel that they needed to mask parts of their identity so much, which would help self-identity and self-acceptance. Common stereotypes such as equating autism with gender and assuming it to only be a deficit featured regularly in narratives. Participants suggested ideas of raising awareness such as training or lectures about autism and de-neurotypifying the curriculum.

Poppy's suggestion that the curriculum needs to be de-neurotypified raises interesting connotations about how progress and advocacy from different minority cultures can be influential (Abu Moghli & Kadiwal, 2021). She was referring to the movement to decolonise the curriculum, which has aimed to ensure knowledge by academics of colour and those from the Global South is brought into mainstream academia. Although there is some scepticism (for example, Abu Moghli & Kadiwal, 2021) that decolonising the curriculum is a trend rather than a true desire for change of university structures and working practices, this movement evidences thinking towards diversity. Apart from amplifying the voice of neurodiverse and by extension disabled academics in general, de-neurotypifying the curriculum could assist a sense of belonging and self-identity in autistic students who may not feel current teachings are relevant to them.

The idea of de-neurotypification should extend to the reduction of stereotypes surrounding autism both societally and those based on a typical university student, both for staff and students. Jess uses the example that a lecturer assumed she should be able to borrow a classmate's notes, but she did not know anybody well enough to ask them. The impact of autism at university, such as the blurred boundaries between academic practices (which an autistic person may excel at) and the social practices (which are stereotypically more troublesome) needs to be brought to the forefront of discussion to ensure both societal stereotypes and stereotypes more readily created in an academic setting of autism are reduced.

As well as wanting a radical overhaul of how autism is presented at university and how training could be achieved, a message of simplicity was also very present in participants' words. Participants wanted to be accepted and treated like any other student. This raises an interesting debate over equality (everybody being treated the same) and equity (recognition that everybody has different support needs). Although participants all wanted to be treated like any other student, this was with a recognition that they needed support that non-autistic students may not need and that a de-neurotypification of university could occur. Overall, participants wanted others at university to be open to difference and accepting of them as individuals, without a reliance on labels and associated stereotypes. Tensions of equality and equity may therefore always remain.

8.2.6 Theoretical Contributions of this Study

In the first section of this chapter, I summarised the findings of this research and discussed them in light of the research questions. I now turn to the key theoretical contributions of my research. I present contributions to the theories of Critical Disability Studies (CDS), Critical Autism Studies (CAS) and Feminist Disability Studies (FDS) and provide justification for these.

Within this study, I make three important contributions in relation to CDS:

1. I have brought an explicit engagement with the autistic experience into the CDS space.

CDS has developed through the writing of third wave theorists and researchers (Goodley, 2016). One of the key aspirations of CDS scholars has been to create a more inclusive space for theorisation and research that works with and beyond the foundational approaches of disability studies such as the social and minority models (Meekosha & Shuttleworth, 2009). My thesis foregrounds the autistic experience; an experience that has hitherto been lacking in the CDS literature (Milton 2014b). By my explicit engagement with the autistic experience, I challenge the CDS space to further engage with disability labels that are harder to define, or do not neatly subscribe to societal discourse about disability.

2. I have highlighted the significance of creative and arts-based methods to CDS inquiry.

I have contributed to the steadily increasing CDS related work that includes creative methods in research to increase accessibility. Such examples include taking the emphasis away from needing to use language to express an opinion. Bernardi (2020) argues that creative methods favour autonomy over directivity, which I was keen to champion in my study. This was important to include in my study as encouraging participants to empower themselves, rather than dictating what they shared and the form of it was a key. In addition, creative methods can encourage different ways of thinking and enable participants to engage in different ways with the research topic (Burch, 2022). Removing stereotypes, such as that storytelling occurs through a predominantly oral medium can ensure research is ethical and accessible for autistic people. CDS acknowledges how disabled people can be resilient and challenge traditionally negative views of disability (Castrodale, 2017). My research enabled creative expression to challenge dominant narratives relating to autism that did not require the use of voice.

3. I have brought the embodied and sensory experiences of participants (which are often overlooked) to the forefront.

By presenting the seldom acknowledged embodied and sensory experiences of participants I am showcasing a part of disability that is often neglected. Embodiment as an autistic person is frequently overlooked, therefore my study supplements this growing focus within CDS theory. I am therefore contributing to widening what can be researched to ensure equality for disabled people.

In relation to CAS, I make three contributions:

1. I provide a feminist perspective that is overlooked by malestream dominance.

Within my thesis I discuss how although CAS seeks to challenge the dominance of non-autistic voices in society, it seldom explores intersectionality in relation to the autistic experience (Mallipeddi & VanDaalen, 2021). This is important because much theory about autism has, and continues to be, focused on male dominated narratives such as the extreme male brain theory (Baron-Cohen, 2002). My research confronts this by focusing on the intersectionality of womanhood in relation to autism. Therefore, I bring a much-needed feminist turn to CAS which will contribute to the continued changing landscape of autism research.

2. I show that creative arts methods also work in the CAS space, which is counter to the dominant discourse that elides autism with a lack of creativity.

Anecdotally, autism tends to be associated with a lack of creativity. This may stem from medicalised diagnostic criteria citing a lack of imagination and repetitive behaviours (APA, 2013). This stereotyping may stifle the type of methods that are used with autistic participants. I help to counter this narrative by using creative methods in my research study. CAS seeks to promote explorations of the power relations between researcher and participant in autism research (Davidson & Orsini, 2013), which creative research methods can help to reduce within an autism sphere.

3. I centre voices of autistic women, to challenge the elision of maleness and autism.

Autism is predominantly theorised and understood by society in relation to boys and men (Happe, 2019; Loomes et al., 2017), which extends to how autism is considered and stereotyped at university. Davidson and Orsini (2013) suggest that CAS should include a focus on challenging prominent deficit-based constructions of society. I argue the disconnect between autism and womanhood is one of these, which CAS does not bring to the forefront. My study centres the voices of autistic women, therefore challenging commonly held stereotypes about the intersection of autism and gender in a university context.

My work provides three offerings with regard to Feminist Disability Studies (FDS):

1. As an autistic researcher I provide a unique autistic feminist voice to what is a mainly neurotypical research community.

Autism does not neatly fit into feminist thinking, as although feminism generally seeks to challenge male oppression, it does not tend to focus on encouraging equality between women, particularly in regard to disability (Garland-Thomson, 2002). Throughout my thesis I emphasised autistic women's exclusion from FDS, for example by embodying my own identity as an autistic woman researcher and bringing my participants' experiences to the forefront. Therefore, my findings regarding the lives of autistic women are really important towards FDS being more inclusive, acknowledging neurodiversity and impairment understandings of disability.

2. I take up Carol Thomas's (for example, 2007) recognition of impairment effects, by taking seriously the realities of being an autistic woman in contemporary Higher Education (HE) in the UK.

My thesis acknowledges the impairment effects that autism can have in HE, without assuming societal stereotypes surrounding the ability to attend university and the impact of autism. An example of an impairment effect that a participant noted was being sensitive to smell (that she attributed to her autism), which was made more difficult to manage by other students' eating strong smelling food in enclosed environments. Thomas (2007) posits that once a person or group of people are labelled and discredited as abnormal, they are open to stigmatisation and oppression. I highlight how university is based on stereotypes associated with neurotypical students and the difficulties this could mean for autistic women. In terms of FDS I contribute that the impairments effect of autism for autistic women need to be brought to the forefront of thinking when considering autism in the university context.

3. My work builds on feminists' work on empowering research methods that take seriously the personal and political lives of autistic women.

Historically, the personal and political lives of autistic women have not been placed at the forefront of research. Morris (1996) argued that if women are regularly oppressed they will internalise this and conform to the expectations of what society thinks they should be. By exploring autistic women's experiences through research methods that enabled a degree of choice, I provided a space where participants could empower themselves to speak out against an oppressive patriarchal society. I have therefore contributed to narratives that seek to disrupt the dominance of autism research being based around the male stereotypes.

8.3 Section Two

8.3.1 Reflections on Using Theory in Practice

In this section I briefly reflect upon my experiences of using Critical Disability Studies (CDS) and Critical Autism Studies (CAS), and leaning on Critical Theory and feminism throughout my study. Although CAS may have been sufficient to base my study on as it deems itself to be a division of CDS, my aim has always been to focus on autistic women, but to produce research conclusions that could be relevant for people with other disability labels and minority groups. I therefore wanted to make it explicit that I was including elements from CDS more broadly as well as CAS.

CAS focuses on how power relations shape autism research and creating new narratives of autism (Davidson & Orsini, 2013). Within my research I have extended this to consider how power relations between autistic and non-autistic people shape the university community, particularly in relation to autistic women. Through my research, using CAS, I have co-created a new narrative with autistic participants of how autistic women experience university, that can be further built on in future research. CAS and CDS promote the element of researching for, and promoting change to challenge oppression by explaining how dominant thinking has enabled disability to be positioned as something to be othered and oppressed. These theories have enabled me to focus on ensuring my research brings inequality, the politics that surround it and ways to tackle it to the forefront, in addition to simply documenting the words of the participants.

I reflect specifically on how I used Critical Theory (especially the divisions of feminism and empowerment) in relation to my research methods in *Section 8.3.4: Critical Reflections on Methods*. The principles of Critical Theory are most evident within my research methods; however, it also influenced the literature I based my project on and the ways in which I analysed my data and linked it to theory. With regards to my feminist principles, I was keen to reference and primarily draw on relevant research by women and autistic authors as far as possible. This was both to emphasise their work but also as a political motivation to demonstrate that autistic researchers may have to advocate for change themselves.

Throughout my thesis I was very aware that autism and feminism do not always align. In *Chapter 2: Literature Review* I discuss that many societal stereotypes that exist around autism are based on autistic men and boys. This notion that autistic women have tended to not belong in societal autism discourse helped to fuel my desire to link autism, women and a sense of belonging together. In addition, feminism itself can separate women, due to its original focus being on the divide in status of men and women, rather than equality between women with different identities (Garland-Thomson, 2002). I therefore felt it important to advocate for both how autistic women felt different, but also the suggestions of my participants of how they could be included by others and therefore belong. I argue these power divides within feminism regarding disability and society's general view of an autistic woman are difficult and take time to change, however, explicitly highlighting these inequalities may prompt further research and practical initiatives towards inclusivity. Overall, I feel the use of CDS, CAS and the divisions of Critical Theory have enabled me to produce research that is politically engaged about autism and also promotes change.

8.3.2 Other Relevant Theories

I set out in this thesis to contribute to the seldom published literature on autistic women in HE. I have therefore concentrated on theories specifically related to disability that challenge existing norms and stereotypes such as CDS and CAS. As I have been studying my PhD (2018-2023), research focus on autism and autism in women has grown. My thesis makes nine key contributions to existing CDS, CAS and FDS theory which I previously discussed. I may have offered different theoretical contributions if I had engaged more prominently with different themes from my data. The topic of belonging featured prominently throughout my analysis. I speculate that I may have presented my data differently if I had used the lens of the theoretical frameworks of community in my thesis. For example, Kelly's (1968) Ecological Theory considers the structure and function of community. It can help with thinking about environmental characteristics that affect the ways in which people interact and relate with each other. This theoretical lens may have enabled me to focus such notions on whether autistic people are a sub-community in themselves or ousted from the university community. Advocacy, empowerment and highlighting oppression may have been included but not been at the forefront of this thesis.

8.3.3 Critical Autism Studies

My thesis centres on autism and the tensions it evokes. Critical Autism Studies (CAS) specifically has provided me with a lens through which I have conducted this study. I reflect here on how CAS has shaped my interpretation of the data and how I executed this study.

Primarily I started this research with an aim to challenge oppression by exposing autistic women's experiences that have seldom been highlighted in research. My initial aim is mirrored by Davidson and Orsini's (2013) description of the principles of CAS. They emphasise the political and change centred focus of CAS. I have held these values central throughout my work, although I do somewhat object to how CAS does not acknowledge the impact of intersectionality with autism; especially the impact of autistic women (Mallipeddi & VanDaalen, 2021). This is particularly important for me considering the experiences of autistic women, who have historically been ignored in both autism research and societal thinking around autism. I appreciated that my participants may also cite the impact of other intersectionalities, but my thesis has illuminated the importance of attending to the significance of being an autistic woman. This provides a key identity for a collective intersectional factor between participants. My study expands the boundaries of CAS by exploring a more intersectional aspect through an attention to the experiences of autistic women.

8.3.4 Critical Reflections on Methods

In *Chapter 3: Methods,* I presented some theoretical rationale behind the choice of my research methods (creative artefact production and interviewing). I began *Chapter 4: Introduction to the Participants* by critically evaluating the use of creative methods with disabled participants. Here I critically reflect upon my research methods through the theoretical lens of critical theory. This is important to include as ensuring I adhered to the principles of critical theory throughout my data collection was key for me in ensuring my research was accessible and empowering.

Critical theory is said to encompass one or more of three divisions: emancipation (empowering participants), participation (considering political agendas) or feminism (assuming culture is inherently masculine) (Moon & Blackman, 2014). The original focus of my research was on emancipation and feminism, due to the overarching topic of sharing autistic women's experiences in a field where this is not commonplace. Within feminism, equality between men and women is sought, however some researchers (for example, Barnes, 2022; Garland-Thomson, 2002) highlight that it does not promote equality between women such as between disabled and non-disabled women.

Throughout my research I employed feminist principles. As stated in my thesis, ensuring a feminist standpoint was incredibly important to me. This initially stemmed from my own experiences as an autistic woman of being marginalised and not always heard. In addition, the masculine stereotypes that surround autism have and continue to impact me. These personal experiences influenced not only the creation of this research project, but also the values that were most important to me when carrying it out. Incorporating and acknowledging my own positionality as an autistic woman researcher is a strength of the project. Oliveira (2019) argues that feminist researchers bring their own culture, understandings and identity to research, which I did, particularly during the analysis. I did not seek to arbitrarily reduce any bias I may bring to the data due to my own identity. However, I provide the reader with a chapter (*See Chapter 4: Introduction to the Participants)* showcasing summaries of the participants' words and artefacts with as little analysis as possible to ensure transparency. I therefore acknowledge and demonstrate to the reader what I bring to the analysis as well as the relatively untouched versions of the participants' accounts.

A prevalent thread throughout my research is how autism is sometimes suggested to sit awkwardly with the context of mainstream feminism (Morris, 1998; Serra, 2015). This is due to feminism predominantly championing women as a whole, but not always including disabled women or indeed promoting equality between women (Garland-Thomson, 2002). Autistic women are also not always seen to fit the stereotypes of an autistic person or of a woman. Simplican (2017) argues that including feminism into studies focusing on disability can help to promote change for disabled women. I was keen to ensure my research methods enabled participants to share their stories through a variety of ways. I felt the freedom of choice in how a participant created an artefact and how they communicated via an interview was important. The flexibility towards participants was key for me in reducing barriers to participation, but it meant that I had artefacts of a variety of different media to analyse. When I initially started the study, I thought the artefacts would be a prompt for discussion and not analysed in their own right. Further study using the same medium of artefact may allow different analyses to take place, including more comparisons or collaborative conclusions. I argue that balancing flexibility and choice for autistic women to aid participation and increasing the ease of analysis is difficult and needs consideration in any further research.

8.3.4.1 Empowerment

One aspect of critical theory - empowerment - felt particularly thorny throughout my research, both in conducting the research and in the analysis of data. I sought to empower participants by sharing their stories of university. At the beginning of my thesis (see *Chapter One: Introduction*) I discuss how this research study presents autistic voices and through that I seek to trouble common stereotypes of autism. I also acknowledge throughout my thesis that no data analysis can be free of researcher bias (in particular, see *Chapter 3: Methods* and *Chapter 4: Introduction to the Participants*). Here I explore the concept of empowerment further and seek to reflect upon whether my study did empower participants.

What empowerment is and how it is defined appears to be a seldom feature in research articles (Ross, 2017). What empowerment encompasses is equally rarely touched upon. Ross (2017) reviews previous scholarship and suggests that empowerment includes either challenging oppression or challenging researcher-participant relationships in research. Manning (2022) notes the importance of ethics and epistemology in the design of research methods and ensuring that differences and 'otherness' are at the forefront of thinking.

Potts and Brown (2015, p.21) discuss that the lines between participants being empowered and exploited in research are very blurry. This is because even if a researcher has their best intentions to carry out empowering research, hierarchical practices such as a researcher/participant divide are very difficult to reduce. Potts and Brown (2015) highlight that even if a researcher considers themselves an insider, as I do in my research study, participants may not feel a sense of parity due to their hierarchical position (participant rather than researcher). I extend this thinking to consider whether the blurry lines between empowerment and exploitation include disempowerment. Vertoont et al. (2022) highlight that the lines between emancipation and disempowerment remain fragile. It is questionable that by highlighting a minority culture in research, are the researchers both highlighting how participants deviate from a societal norm and also disempowering them by emphasising this as different. Considering that concepts such as empowerment, exploitation, disempowerment and emancipation become further complicated by research (Potts & Brown, 2015; Vertoont et al., 2022) regardless of the intentions of a researcher, the debate on what is true empowerment may continue until (and if) the concepts become more discrete entities.

Within my study I told potential participants that I was an autistic student and therefore was open about my position as an insider in the research. Although it is impossible to say how they viewed me in research, some participants commented that they would not have participated in the research if I was not autistic (but did not disclose why). This may be in contrast to Potts and Brown's (2015) thinking as my position as both an insider and as a researcher was clearly important to some participants. It is questionable whether they felt my hierarchical power as the researcher was empowering to them because I was also autistic and so brought my own experiences to the research. I do not believe that if I was not autistic I would not have been able to practically conduct the research in the same way, but some participants clearly felt more able to empower themselves with me as the facilitator.

Using creative methods, where participants were able to create up to three artefacts in a medium they chose as well be virtually interviewed how they wanted to be may also have also enabled participants to be empowered. I believe the element of choice and autonomy within the research process may have facilitated this. Hofmann et al. (2020) reflexively analyse their own experiences as disabled researchers in the fields of accessibility and disability studies. In the context of making accessibility aids, they consider how making something that is useful to somebody else can benefit and empower the receiver, but also highlight how the person or people that do the making may be differently empowered by the experience. This may be through self-acceptance. Part of Critical Disability Studies (CDS) is to challenge oppression, through empowerment. Oliver (1992, p.111) stated 'once people have decided to empower themselves', research must consider how it can best 'facilitate this process'. Cascio et al. (2021) however argue that there are no accepted steps that need to be taken in research to facilitate empowerment. The lack of guidance in how to empower participants in research may mean that it is impossible to say whether, or how, a research project is empowering. Considering a definition of empowerment and how to facilitate it remains blurry in research. I believe I did facilitate empowerment particularly during the research methods. Potentially facilitating the act of creating, reflecting on and processing their own experiences enabled participants to empower themselves even before they shared them with me for the research.

Overall, the use of creative methods and my consideration towards accessing them may therefore have given space for participants to empower themselves in the sense that I was flexible and within broad parameters allowed choice of participation (such as choosing the method of virtual interview and the medium of creative artefact). I believe that it is impossible to say whether a research study is either empowering or disempowering as different stages of the project and within single time points may be either. However, I consider it important to draw on guiding principles of critical theory and CDS to ensure that disempowerment is reduced as much as possible and that research aims to facilitate a participant's own empowerment, rather than aiming to give empowerment. I return to the notion of empowerment in *Section 9.5: Recommendations.*

8.4 Conclusion

In conclusion, in this chapter I have explored my analysed data through a more theoretical lens. I have considered how summaries of the three analysis themes could link to theories of CDS, CAS, FDS and identity. This has allowed me to appreciate my data in light of philosophical thinking. I have also addressed my research questions through the presentation of my data analyses. Most importantly, I demarcated nine key theoretical contributions that my study made (see *Section 8.2.6: Theoretical Contributions of this Study*). I then reflected on my study during this chapter. I have considered the theories I used in this study and speculate theories I could have used. I thought about how I employed CAS throughout my study. I discussed in detail the methods that I used and their relation to the divisions of Critical Theory. This chapter has provided me the space to focus on theory, both how the analysed data links to it and how I used theory in the execution of the project.

9 Conclusion

9.1 Introduction

I set out to explore the experiences of autistic women at university, with the view to delving into the cultural experiences autistic women have as students. The binaries between students and staff were blurred for participants studying postgraduate courses and thus, in places, my thesis transcends a wider view of the cultural experiences of autistic women in academia, not just of students.

The current popularity of autism in societal discourse, ensuring that the majority of society hold some opinion of it, is a theme that runs through the entire thesis. Autistic women do not always fit the narratives of autism held by society and thus I trouble this narrative by solely focusing on autistic women. Through reflecting on both my own and participants' experiences I have sought to contextualise autism within the sphere of university.

I have attended to my research questions throughout this thesis and restate them here:

1. Research Question One: What barriers and supports to higher education do autistic women students feel they have had at university?
2. Research Question Two: In what ways can the university environment be adapted to better accommodate autistic women?
3. Research Question Three: What changes would autistic women like to see at university?

9.2 Summary of Key Findings

I present a brief summary of the key findings. I state key contributions to knowledge and include three key research methodology contributions of my thesis. In the key knowledge contributions, I consider both the overall impact of this thesis and the three research questions (outlined above). I further discuss these findings in relation to my research questions throughout the rest of the conclusion.

9.2.1 Key Knowledge Contributions

1. To my knowledge, this is the first study to focus solely on autistic women at university.
2. Participants attributed good support at university to luck or privilege rather than to expectation, cementing discourse that autistic women do not feel they belong.
3. The sensory environment of university needs more consideration, including places students need to go outside of their own university such as conferences and placements, to ensure inclusivity of autistic people.
4. University curriculum needs to be ‘de-neurotypified’, a term one participant used in reference to initiatives to decolonise university.

9.2.2 Key Research Methodology Contributions

1. I have added to the small, but growing, amount of research conducted by autistic women in the field of autism and therefore have challenged stereotypes and boundaries that academia and society impose.
2. I challenged stereotypes surrounding the perceived ability of a person studying at university by providing as many different communication choices as possible.
3. I used creative methods with autistic women which provided rich data. This therefore added to the growing field of using creative methods in research.

In the remainder of the conclusion, I predominantly consider change. I revisit discussions from the analytical chapters (Chapters 4-7) and consider them with specific reference to the research questions I posed (see above). I highlight how this study informs future practice and suggest some strengths and limitations of this project. I end my thesis by offering some concluding thoughts. I explicitly highlight the contributions to knowledge of this thesis and end by considering the directions in which future research of similar narratives could go.

9.3 Practical Implications

Before I turn to the strengths and limitations of my study, I draw together the findings of all the empirical data to cover broader practical implications of my study, under the overarching aim of exploring autistic women's experiences. I do not seek to highlight every implication my study could provide, but to focus on some I felt particularly drawn to. I discuss practical implications in the context of student and staff perceptions, sensory stimuli and de-neurotypification.

The perception of others and their impact on participants was highlighted throughout my analysis. I argue a culture change is needed within universities, and by extension society, towards inclusivity and acceptance of difference, particularly towards 'invisible' differences. By invisible I include intersections beyond 'invisible disability' such as social class. In an ideal world, this would mean valuing everybody as simply human, rather than by deficits or differences compared to a mythical norm. Using autism as an example, awareness of this could be instigated through lectures or seminars to students and staff surrounding diversity and minimising stereotypes. Gillespie-Lynch et al. (2021) highlight autism training is more effective when autistic people contribute to it. A combination of considering greater awareness and training, with a focus on the important aspects of autism identified by autistic people may ensure autistic women students are perceived less differently. This may also reduce autistic students feeling lucky if they receive support at university.

I also argue the notion of acceptance, that participants have highlighted, needs to be championed for postgraduate students and staff as well. The fuzzy boundaries of being a student and a staff member that some participants documented demonstrates how the neoliberal university privileges students (the consumer) over staff (who may teach the consumer) and the vicious cycle it can create. I argue universities should be willing to give those that transcend to a student and staff role the same disability support in both roles, primarily to support them but also to provide positive role models to disabled students, so that they can exist in academia.

The sensory environment at university was brought to the forefront in many artefacts. Its impact on participants was evidently huge. Universities may be constricted by current architecture, but simple adaptations within buildings can be made, for example ensuring fire alarm tests happen during quieter times of the day or that the times of tests are clearly communicated to students. In addition, more consideration should be given to senses that are less readily thought about such as taste and smell. University food outlets could offer a variety of different types of food to cater for those with taste sensitivities for example.

Lastly, I am drawn to the notion of de-neurotypifying the curriculum. Whilst overhauling a curriculum or university stance is complex (but not unobtainable), fostering a culture of acceptance within academic spaces may be easier. Ensuring that reading lists include material by disabled academics or those who write in a less traditional style and making spaces welcoming to those who are not neurotypical could start a process of change within universities.

9.4 Strengths and Limitations

All research studies have their strengths and limitations. I argue the difference between these is not always clear. I demonstrate the boundaries between a strength and a limitation in my research project can be fuzzy. I focus on some strengths and limitations of my study, in order to promote discussion about these issues when future research projects are designed. I briefly discuss researcher positionality, creative methods, participant demographics, Twitter, Covid-19, and the problem of being limited to only viewpoint of an experience in research.

I believe one of the biggest strengths of my research project was my positionality as an autistic researcher and my willingness to disclose this to potential participants prior to recruitment. As I discussed in the *Chapter 3: Methods* some participants said they would not have participated had I not identified as autistic. This enabled me to access viewpoints of people who may not have participated if I was a non-autistic researcher. However, although I consider it a strength for my research findings, who should and should not conduct autism research is very contentious in the field at the moment (Dwyer et al., 2021) and therefore is also a limitation. I firmly believe that non-autistic researchers should be able to conduct autistic research, but future research on autistic people’s experience should consider the benefits of including an autistic researcher on their team. Also, sensitivity towards the autistic community being wary of non-autistic researchers given negative autism research histories must be acknowledged.

Although creative methods are gaining popularity, it was evident during participant recruitment that advertising a study involving creativity dissuaded some people from participating. In addition, it was clear being asked to be creative was new to some participants. This required me to be flexible and reassuring to participants who were unsure about the standards of their work. However, the creative artefacts produced in addition to interview data provided a rich data set and highlight that research can include non-verbal elements.

I focused my study on autistic women studying at a university in the UK, in order to reduce the sample size. I urge future research to consider autistic women at universities in the Global South, where definitions of autism and disability tend to differ (Kim, 2012).

I believe the use of Twitter as a recruitment tool in my study was both a strength and a limitation. In *Section 3.6.2 The Use of Social Media in Research* I consider the ethics implications of using social media as a tool to recruit participants. Recently, Twitter in particular has been subject to ongoing public ethical criticisms, potentially influencing whether people want to use the platform. It should be noted that I recruited participants via Twitter in early 2020, prior to any concerns about the platform being publicly advertised.

I used Twitter to target a wide audience quickly and cheaply, however my recruitment poster will only have reached the population who use the platform. Herbell and Zauszniewski (2018) highlight that different social media platforms tend to attract different age ranges of users and therefore suggest that in research not looking for a particular age demographic a range of social media platforms should be used. For example, they suggest adults under 30 may prefer Instagram where adults aged 40-50 may prefer Facebook. This is something I would do in future research, as although Herbell and Zauszniewski (2018) use the example of age as a reason for not using different platforms, there may be preventative factors stemming from other things such as disability or cost. In this project I focus on gathering experiences as an exploratory study and therefore sought to include any eligible person who saw my recruitment poster who was happy to share their experiences. In the future I could seek to connect with autistic people who may be marginalised outside of autistic communities on social media.

Although unavoidable and unforeseen, I believe Covid-19 to be a major limitation of this study. Participant recruitment took place prior to and as the pandemic started. Data collection was always planned to be through virtual methods and therefore in that sense the UK lockdown had no impact. However, experiences participants disclosed were therefore based on pre-lockdown experiences. Although they highlight interesting themes surrounding access and exclusion, I wonder how the data might have looked had I collected it as little as six months later (in the midst of a lockdown) or now (as the UK transitions beyond Covid-19). Even as I conclude my thesis Covid-19 still exists and uncertainty around working and studying practices still remain. Therefore, although some of my data may seem obsolete, it may also highlight the ways in which Covid-19 has or has not improved accessibility for autistic women at university.

Finally, when collecting participants' experiences, I have only been able to document situations from the viewpoint of the participant. I could not collect experiences of other people implicated in the participants' stories and so do not know the reasons behind the actions they were said to have carried out. Thus, whilst I present this work through an autistic lens it is part of a bigger picture of society, rather than a singular view.

9.5 Recommendations

Finally, in this chapter, I draw together the findings of all the empirical data to cover broader recommendations of my study, under the overarching aim of exploring autistic women's experiences. I do not seek to highlight every recommendation my study could provide, but to focus on some my analysis drew me to. Pleschova et al. (2021) highlight change can be difficult as it requires trust and a willingness to become vulnerable based on another person's positive expectations of their intentions. However, change can also foster growth and increase inclusivity. I discuss practical implications in the context of empowerment in research, increasing inclusivity, changing the sensory environment and de-neurotypifying the university curriculum.

Recommendation One: Enabling Participants to Empower Themselves

I recommend that researchers consider how they can facilitate participants empowering themselves in, and through, research studies. This will ensure participants feel more comfortable in empowering themselves in oppressed society and also to guarantee high quality data. I have formed this recommendation from both my own self-reflection of how I felt I empowered participants in my study (see *Section 8.3.4 Critical Reflections on Methods*) and the descriptions participants gave about voicing their needs and opinions at university. I justify this recommendation with links to theory from critical theory and critical disability studies.

Throughout the formulation of my research methods, I grappled with my desire to empower participants by giving them a voice and the ethical implications that surround it. Earlier in my discussion I spoke about the lines between exploitation and empowerment in research being blurry (see *Section 8.3.4 Critical Reflections on Methods*). I hoped through being an insider in the research, as an autistic women student I would reduce hierarchical practices in research, however, Potts and Brown (2015) argue that this may not be the case. In *Chapter 4: Methods and Methodology* I reflect that some participants said they would not have participated if I had not been open about my own identity as an autistic woman. Therefore, although I may or may not have impacted hierarchical practices in research as an insider, exposing my identity and personal link to the project influenced some participants to join the study and thus hopefully empower themselves and challenge oppression.

Within the themes I drew out of the data, participants spoke about their experiences of empowering themselves at university. This was particularly expressed in relation to discussions with staff about accessing support or challenging university policies they did not feel accommodated them. In *Section 7.2: Staff Impact* I present how participants tended to describe staff as either supportive or unsupportive, which in turn influenced how they approached challenging oppressive or unhelpful practices at university. This suggests that people have strong influences on whether another person feels comfortable empowering themselves.

Researchers could facilitate a space of empowerment by encouraging choice and flexibility of participation and demonstrating their own links to the research project. This could be through explicitly asking participants what would make participation easier. In addition, researchers could expose whether they were an insider, or explain to participants why they are interested in the research topic. I argue that for participants to feel comfortable in empowering themselves and challenging oppression, a researcher needs to create a supportive and inclusive atmosphere that puts their needs first. This is particularly important if sensitive topics are being explored. Feeling able to empower oneself with a research study, may influence a participant to transfer that confidence and ability to other settings, for example at university.

Recommendation Two: Increase the Inclusion of Autistic People Through Explicit Lectures or Seminars at University

I recommend a culture change is needed within universities, and by extension society, towards inclusivity and acceptance of difference. Although this recommendation could apply to society as a whole, I intend the initial audience to be university management, to filter down to university staff and students. I argue that the focus should particularly focus on ‘invisible’ differences. By invisible I include intersections beyond ‘invisible disability’ such as social class. In an ideal world, this would mean valuing everybody as simply human, rather than by deficits or differences compared to an entrenched norm. Using autism as an example, awareness of this could be instigated through lectures or seminars to students and staff surrounding diversity and minimising stereotypes. Although I use the example of a training session on autism, this could be expanded for disability or difference in general. Gillespie-Lynch et al. (2021) highlight autism training is more effective when autistic people contribute to it. Participants expressed a strong desire to want to be listened to, so that knowledge about autism in general and their own specific needs was accurate and relevant to them (see *Section 7.4: Autism Awareness and Acceptance*). A combination of considering greater awareness and training, with a focus on the important aspects of autism identified by autistic people may ensure autistic women students are perceived less differently. This may also reduce autistic students feeling lucky if they receive support at university, a focus that participants considered in *Section 7.2.2: The Variable of Luck*.

I also argue that it is important to ensure postgraduate autistic students and staff are supported in the same way that undergraduate autistic students might be and a culture of acceptance is developed throughout academia. In *Section 6.3: Navigating Being Both a Student and Staff Member* I discussed how participants found support and acceptance towards them changed depending on the role they were in. Traditionally, universities privilege student support over staff support and therefore I argue that the same disability support in needed, regardless of the role an autistic person has in a university.

In practice, a training session could help to start this change, by including autistic current and former students to increase its effectiveness (Gillespie-Lynch et al., 2021). This could include what they would like other people to know about autism within the university context. I argue that any training session topic should be led by the autistic people involved. Small differences that other students and staff can make based on a training session may be most impactful. One example based on my research might be documenting the range of social lives that autistic people may have. In *Chapter 5: Perceptions* I discuss how university social culture remains dominated by alcohol. Some of the participants talked about how they found it difficult to socialise if they did not want to get drunk, whereas others wanted to engage in that culture. By presenting a range of experiences, it may increase awareness to other students that different types of events may appeal to different people.

It is very important that both feminist theory and intersectionality are considered in any training. Women are not regularly featured in autism discourse (Hoyt & Falconi, 2015) and therefore autism in women students is important to feature in any training, especially as feminism champions equality of women, but does not always feature disabled women (Garland-Thomson, 2002). Training is also important to ensure that autistic people, and especially autistic women do not become ‘self-narrating zoo exhibits’ (Sinclair, 2005). If other people are more knowledgeable, self-advocacy for autistic women may be reduced.

Although CAS does not champion intersectionality (Mallipeddi & VanDaalen, 2021) it is important to include and consider in any training, as the impact and experience of autism may be different depending on other aspects of identity.

Recommendation Three: Involve Autistic Students When Considering the Sensory Environment at University

The sensory environment at university was brought to the forefront in many artefacts. Its impact on participants was evidently huge. In this recommendation I urge university staff and students to consider small changes they can make to improve the sensory environment at university. Within discussions in my research participants talked about how other staff and students can impact the environment for them. Participants highlighted how not only the built environment, but also other people, influence their sensory experiences at university. They suggested activities such as eating strongly smelling food in a library or clicking pens in a lecture theatre impacted them as they felt unable to learn as easily or to interact with their peers (see *Chapter 7: Reflections on University Environment*). My findings support the recent literature (for example Goddard & Cook, 2022; Van Hees et al., 2015) that sensory difficulties can prevent autistic students from participating in academic and social activities at university. It is therefore imperative that universities consider the impact of the environment on both learning and socialising, even if they are constricted by current architecture. For example, providing accessible seating and workspaces as well as considering less thought of sensory impacts like taste and smell.

Recommendation Four: De-Neurotypify the Curriculum

Lastly, I am drawn to the notion of de-neurotypifying the curriculum. The audience for this recommendation is university academics and those responsible for drawing up module outlines. It also applies to university management to expand the concept of de-neurotypification to non-academic elements of the university. This recommendation primarily comes from Poppy who coined the term when speaking about how concepts taught at university tend to be taught from a neurotypical perspective. She references how a movement similar to that of decolonising the curriculum is required. Although other participants did not use the same term, they highlighted that they did not fit into what universities framed as a stereotypical student. This generally affected confidence, as participants felt non-conformity was more accepted for autistic men than autistic women (*see Chapter 5: Perceptions*). Abu Moghli and Kadiwal (2021) explain decolonisation in academia to be about highlighting knowledge produced by academics of colour. This is to disrupt power balances in academia. If participants are able to see work of neurodiverse academics, they may feel that the notion is reduced of what a stereotypical student is, increasing their sense of belonging at university.

In practice, the stories of participants suggested fostering a culture of acceptance within academic spaces. Ensuring that reading lists include material by disabled academics or those who write in a less traditional style (which may include grey literature) and making spaces welcoming to those who are not neurotypical could start a process of change within universities. Whilst overhauling a curriculum or university stance is complex (but not unobtainable), small steps towards this may be easier.

9.6 Concluding Thoughts

In this conclusion I have reflected upon the ways in which I have attended to my research questions and overarching topic of exposing autistic women's experiences at university, which the analysis chapters have focused on. I have attended to my research questions centring on: exploring the barriers and supports of university, how the university environment can be changed, and what participants want to change through three analysis themes. These key themes were: *Perceptions, Exposing the Postgraduate Autistic Student,* and *Reflections on University Environment*. I have included implications of my research and discussed some important strengths and limitations. Through this I have emphasised some ways autistic women, who are regularly excluded from autism discourse, experience university. In doing so I hope to not only have highlighted this sub-population's experiences, but also for this research to be a springboard for those with similarly marginalised identities within an academic context.

Overall, my thesis offers a number of contributions in exploring the lives of autistic women through the context of university. I have used autism as a lens, both to highlight how autistic women experience university, but also to show the challenges a minority group face in a specific societal context. In illuminating how autistic women experience university, I showcase how a marginalised group, both within autism discourse and society respond to alienation and exclusion. This could be extrapolated within the field of disability and for other intersections.

In terms of method, I embraced the medicalised suggestion that autistic people struggle with communication and thus sought to use a variety of ways of expression to try and reduce who (within the research population) could not participate. I rejected stereotypes surrounding the perceived ability of a person studying at university and sought to lessen the need for verbal and/or written communication as far as possible, depending on the choices of the individual participant. Through this I have contributed to current knowledge of autistic experiences using qualitative research.

My positionality as an autistic autism researcher and my own lived experience have shaped this project, including the research topic and the construction of methods. Whilst I argue that both autistic and non-autistic researchers bring unique insights to the field of autism research, autistic autism researchers are still in the minority. Thus, my thesis also contributes to research conducted by the growing number of autistic women researchers challenging stereotypes and boundaries that academia and society impose.

9.6.1 Future Research Directions

I finish with some suggestions of what future research based on similar narratives could consider:

With regard to methods and methodology, I situated my project within feminism and used creating artefacts as a way to allow participants the choice to express their experiences in a non-verbal and ‘non-traditional’ way. Although, as I discuss through my thesis, I only intended for these artefacts to be a starting point for discussion in an interview, the rich data they provided makes me keen to emphasise their benefit in research. In addition, Covid-19 has made video-conferencing tools much more readily available and accessible to the majority of people. In addition, apps that allow people to make videos (such as TikTok) and create digital content have become much more popular since I began this research project. Considering the use of social media (including using photographs and videos) appears to be increasing, I wonder how this in conjunction with the continued change in the digital landscape may have contributed to the types of artefacts produced. I question whether this trend of creating videos and the accessibility of online tools, combined with creative methods may produce different insights and capture a different range of participants in autism research.

Chapter 6: The Postgraduate Autistic highlights the dearth of research documented on autistic postgraduate students and more widely the relatively small field of research regarding disabled researchers. Focusing on how postgraduate students experience university may be beneficial to university structures and policies, especially as universities tend to revolve around the undergraduate university student. In addition, through data collection it became evident that some of my participants' experiences as students were intertwined with their experiences as staff (in various contexts). This negotiation of being a disabled student and staff member at the same time should be considered in more detail, especially within the context of the neoliberal institution.

Throughout my thesis, I make it clear that I explored the experiences of autistic women, which inevitably provides a one-sided account of a story. I briefly touch on this in *9.4 Strengths and Limitations*. However, this was always the aim of the study as the majority of research about autistic people tends to focus on the opinions of others. Future research could seek experiences of academic staff with regards to inclusion (or exclusion) of autistic students, particularly in a 'post' Covid-19 world where neoliberalism at university is prominent. This could provide a more holistic view to ensure autistic women students have supportive and positive university experiences.

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10 Appendices

10.1 Appendix 1: Participant Recruitment Poster

Call For Participants

This research project explores autistic women's experiences of university. It will specifically focus on academic achievement and wellbeing.

You can participate if you self-define as an autistic women and are studying at a UK university.

You will be asked to creatively document between two and four university experiences where you think your autism has affected you. You will then be interviewed about them.

You will receive an e-gift voucher to a shop of your choice for taking part.

For more information contact: Sophie Phillips at slphillips2@sheffield.ac.uk

The University Of Sheffield.

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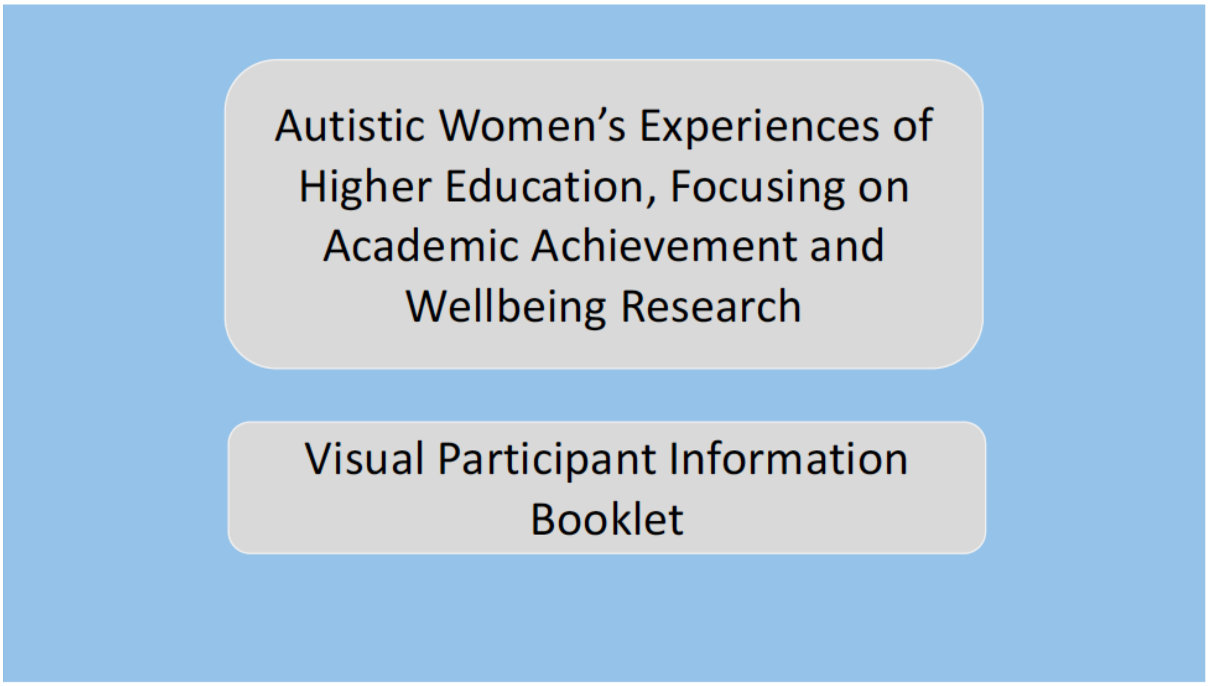
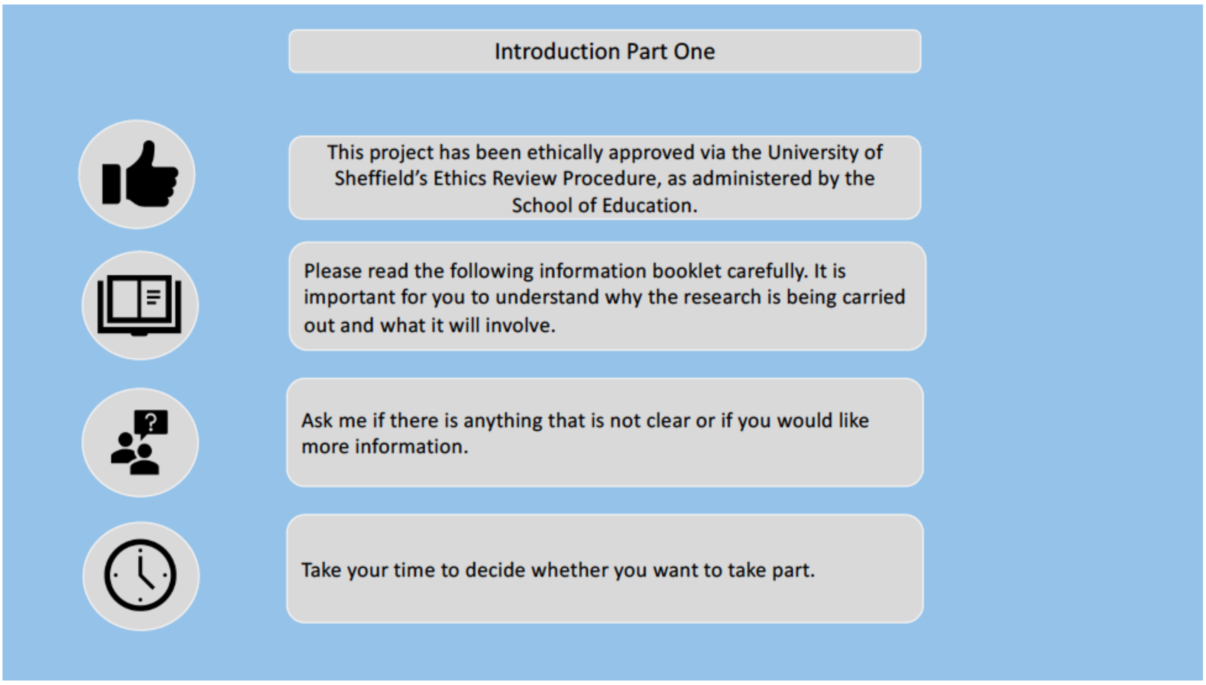
10.2 Appendix 2: Visual Participant Information Booklet



Autistic Women’s Experiences of Higher Education, Focusing on Academic Achievement and Wellbeing Research

Visual Participant Information Booklet



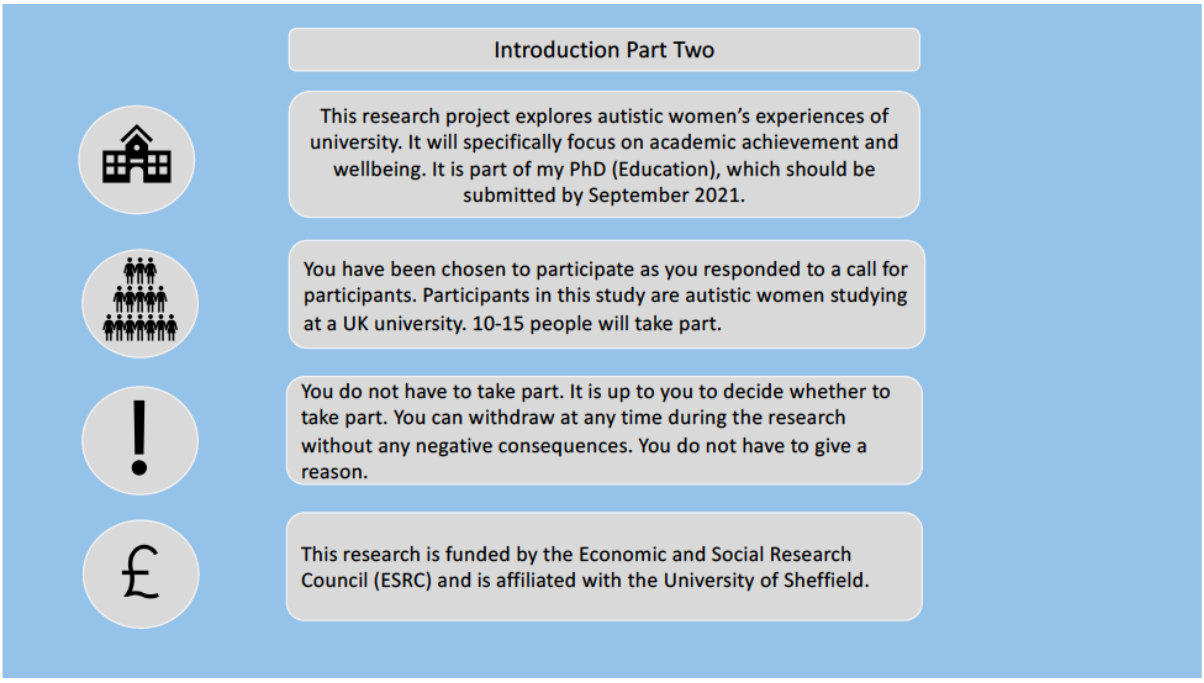
Introduction Part One

This project has been ethically approved via the University of Sheffield’s Ethics Review Procedure, as administered by the School of Education.

Please read the following information booklet carefully. It is important for you to understand why the research is being carried out and what it will involve.

Ask me if there is anything that is not clear or if you would like more information.

Take your time to decide whether you want to take part.



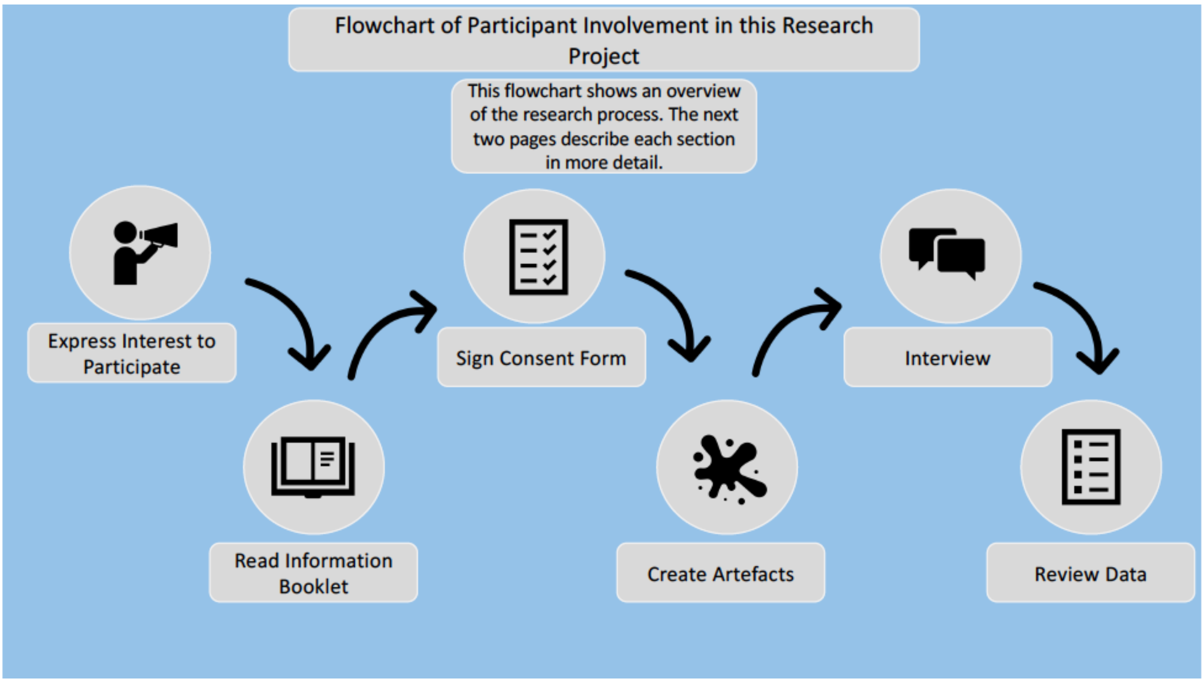
Introduction Part Two

This research project explores autistic women's experiences of university. It will specifically focus on academic achievement and wellbeing. It is part of my PhD (Education), which should be submitted by September 2021.

You have been chosen to participate as you responded to a call for participants. Participants in this study are autistic women studying at a UK university. 10-15 people will take part.

You do not have to take part. It is up to you to decide whether to take part. You can withdraw at any time during the research without any negative consequences. You do not have to give a reason.

This research is funded by the Economic and Social Research Council (ESRC) and is affiliated with the University of Sheffield.



Flowchart of Participant Involvement in this Research Project

This flowchart shows an overview of the research process. The next two pages describe each section in more detail.

Express Interest to Participate

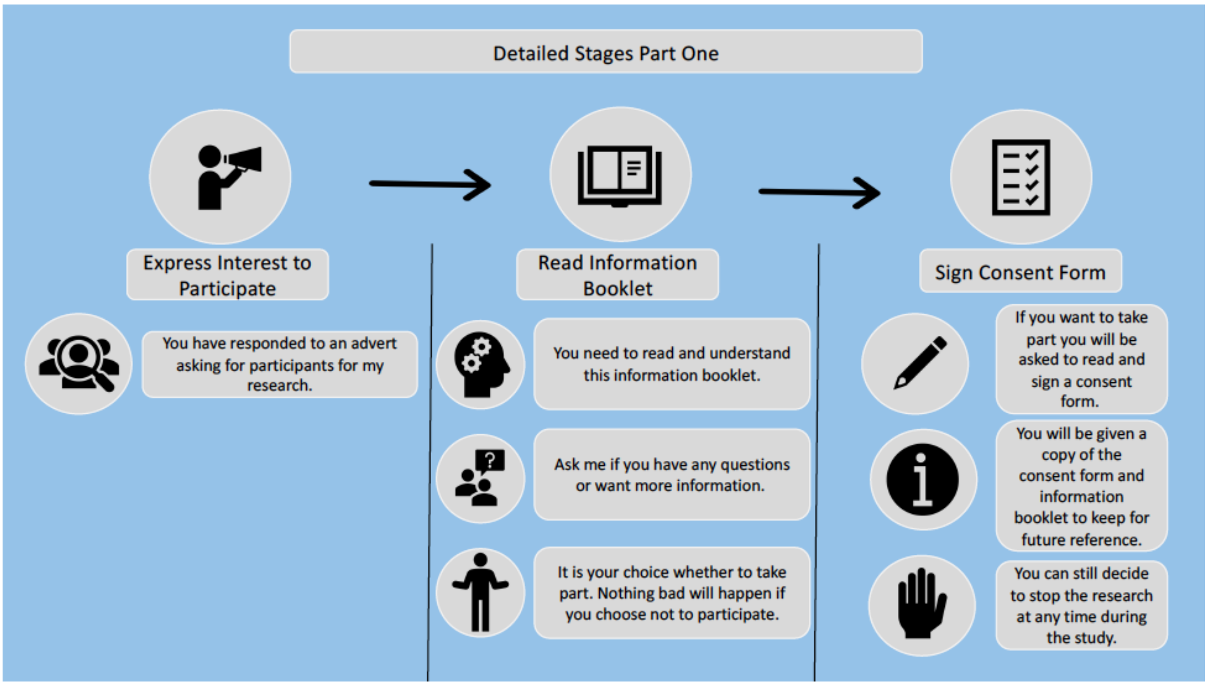
Read Information Booklet

Sign Consent Form

Create Artefacts

Interview

Review Data



Detailed Stages Part One

Express Interest to Participate

You have responded to an advert asking for participants for my research.

Read Information Booklet

You need to read and understand this information booklet.

Ask me if you have any questions or want more information.

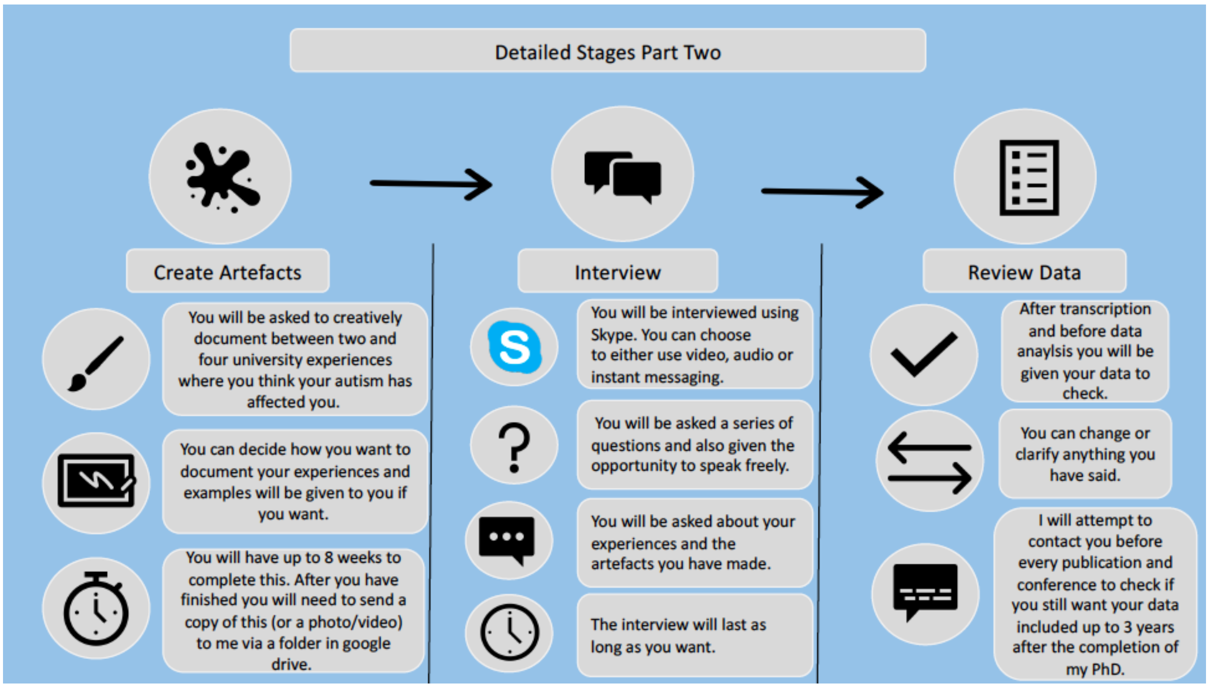
It is your choice whether to take part. Nothing bad will happen if you choose not to participate.

Sign Consent Form

If you want to take part you will be asked to read and sign a consent form.

You will be given a copy of the consent form and information booklet to keep for future reference.

You can still decide to stop the research at any time during the study.



Detailed Stages Part Two

Create Artefacts

You will be asked to creatively document between two and four university experiences where you think your autism has affected you.

You can decide how you want to document your experiences and examples will be given to you if you want.

You will have up to 8 weeks to complete this. After you have finished you will need to send a copy of this (or a photo/video) to me via a folder in google drive.

Interview

You will be interviewed using Skype. You can choose to either use video, audio or instant messaging.

You will be asked a series of questions and also given the opportunity to speak freely.

You will be asked about your experiences and the artefacts you have made.

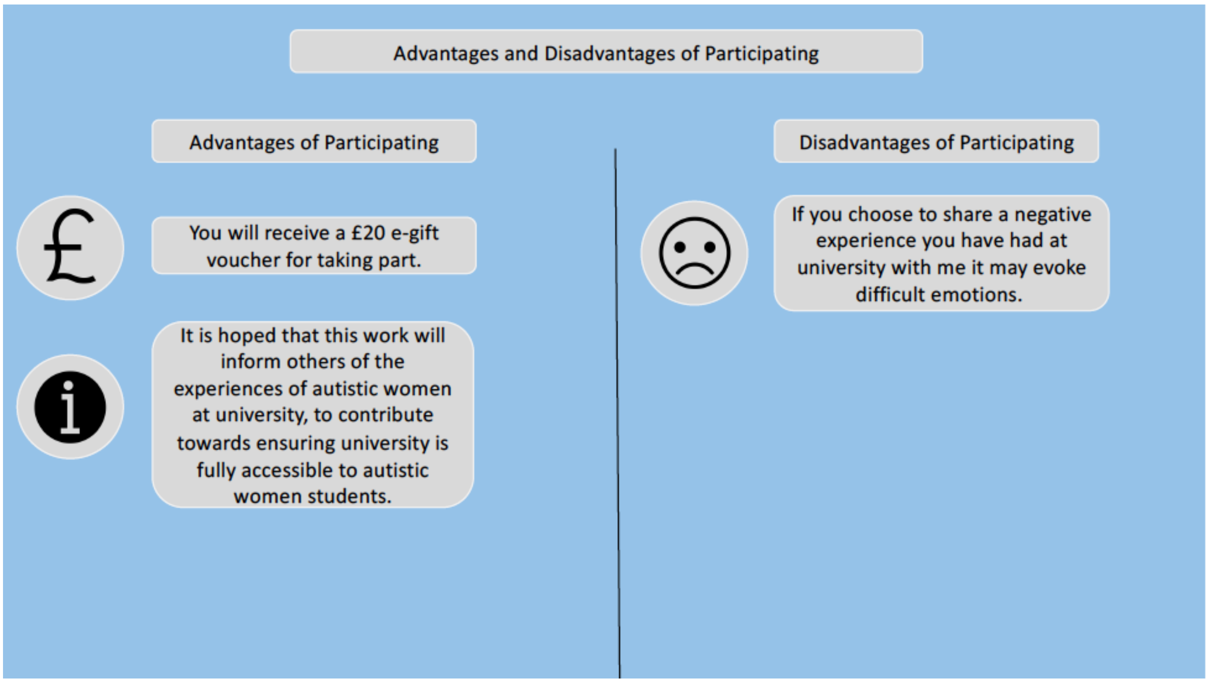
The interview will last as long as you want.

Review Data

After transcription and before data anaylsis you will be given your data to check.

You can change or clarify anything you have said.

I will attempt to contact you before every publication and conference to check if you still want your data included up to 3 years after the completion of my PhD.



Advantages and Disadvantages of Participating

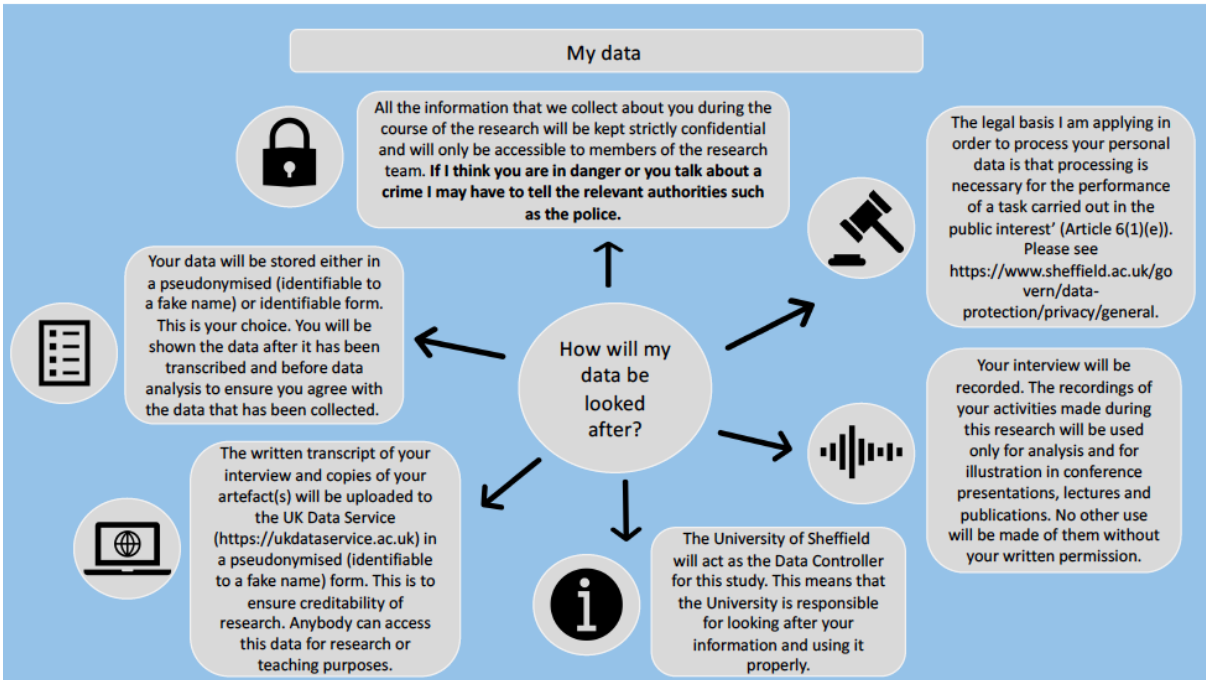
Advantages of Participating

You will receive a £20 e-gift voucher for taking part.

It is hoped that this work will inform others of the experiences of autistic women at university, to contribute towards ensuring university is fully accessible to autistic women students.

Disadvantages of Participating

If you choose to share a negative experience you have had at university with me it may evoke difficult emotions.



My data

How will my data be looked after?

All the information that we collect about you during the course of the research will be kept strictly confidential and will only be accessible to members of the research team. **If I think you are in danger or you talk about a crime I may have to tell the relevant authorities such as the police.**

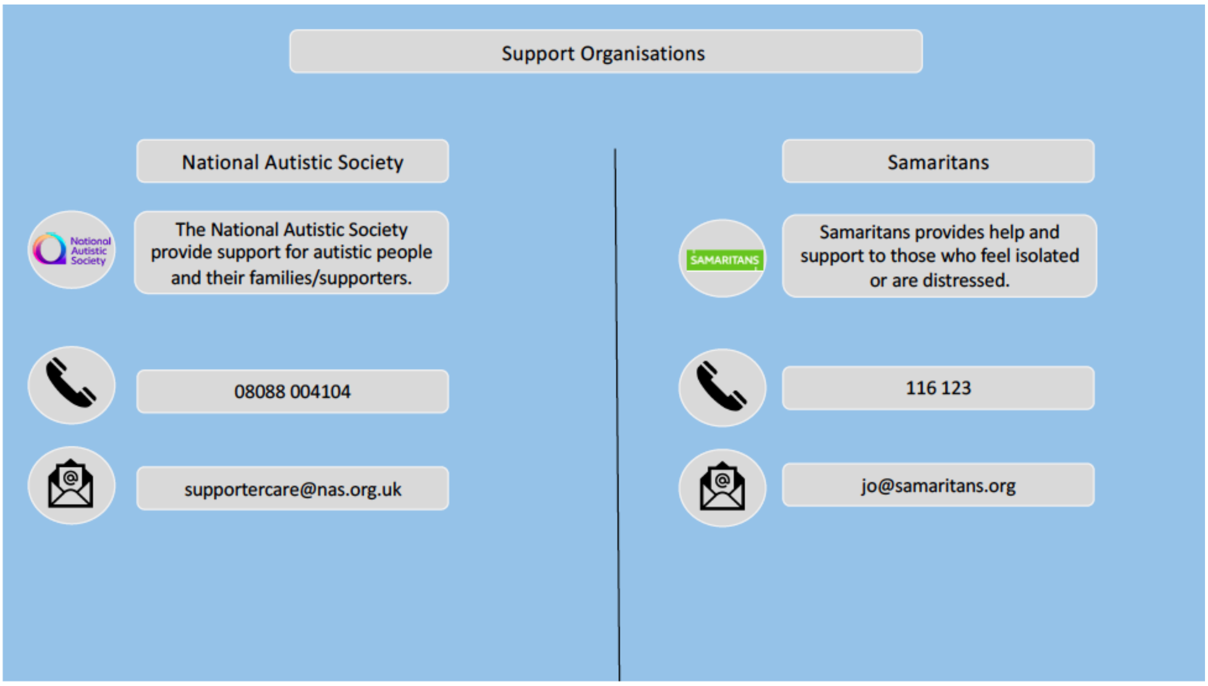
The legal basis I am applying in order to process your personal data is that processing is necessary for the performance of a task carried out in the public interest' (Article 6(1)(e)). Please see https://www.sheffield.ac.uk/govern/data-protection/privacy/general.

Your data will be stored either in a pseudonymised (identifiable to a fake name) or identifiable form. This is your choice. You will be shown the data after it has been transcribed and before data analysis to ensure you agree with the data that has been collected.

Your interview will be recorded. The recordings of your activities made during this research will be used only for analysis and for illustration in conference presentations, lectures and publications. No other use will be made of them without your written permission.

The written transcript of your interview and copies of your artefact(s) will be uploaded to the UK Data Service (https://ukdataservice.ac.uk) in a pseudonymised (identifiable to a fake name) form. This is to ensure creditability of research. Anybody can access this data for research or teaching purposes.

The University of Sheffield will act as the Data Controller for this study. This means that the University is responsible for looking after your information and using it properly.



Support Organisations

National Autistic Society

The National Autistic Society provide support for autistic people and their families/supporters.

☎ 08088 004104

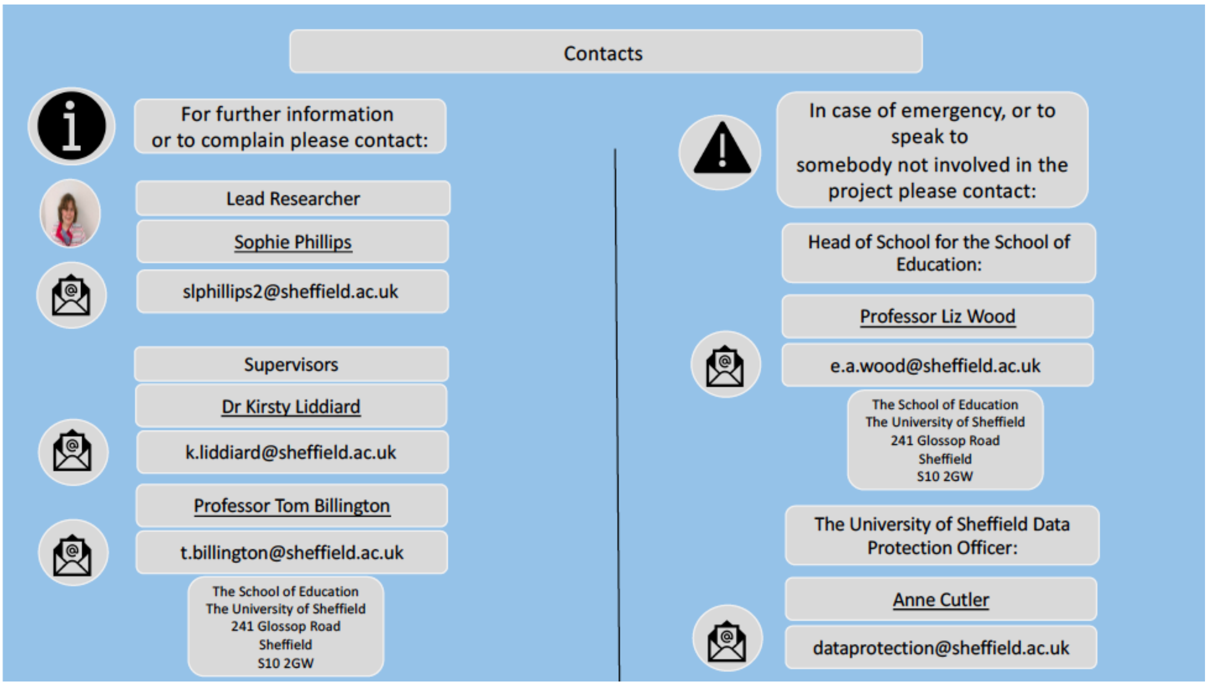
supportercare@nas.org.uk

Samaritans

Samaritans provides help and support to those who feel isolated or are distressed.

☎ 116 123

jo@samaritans.org



Contacts

For further information or to complain please contact:

Lead Researcher

Sophie Phillips

slphillips2@sheffield.ac.uk

Supervisors

Dr Kirsty Liddiard

k.liddiard@sheffield.ac.uk

Professor Tom Billington

t.billington@sheffield.ac.uk

The School of Education
The University of Sheffield
241 Glossop Road
Sheffield
S10 2GW

In case of emergency, or to speak to somebody not involved in the project please contact:

Head of School for the School of Education:

Professor Liz Wood

e.a.wood@sheffield.ac.uk

The School of Education
The University of Sheffield
241 Glossop Road
Sheffield
S10 2GW

The University of Sheffield Data Protection Officer:

Anne Cutler

dataprotection@sheffield.ac.uk

10.3 Appendix 3: Written Information Form

Participant Information Sheet

Autistic Women's Experiences of Higher Education, Focusing on Academic Achievement and Wellbeing

You are being invited to take part in a research project. Before you decide whether or not to participate, it is important for you to understand why the research is being carried out and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask me if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part. Thank you for reading this.

1. What is the project's purpose?

This research project explores autistic women's experiences of university. It will specifically focus on academic achievement and wellbeing. I chose to research autistic women as they are researched much less than autistic men. Overall there is still a bias in autism thinking towards men, and in particular male children. More autistic people are going to university, but little is known about their experiences there. Through this research I want to share the experiences of autistic women at university to highlight the importance of why they should be considered.

I am undertaking this research in part fulfilment of a PhD (Education), which should be submitted by September 2021.

2. Why have I been chosen?

You have been chosen to participate as you responded to a call for participants. Participants in this study are autistic women studying at a UK university. In total between 10 to 15 participants will be recruited.

3. Do I have to take part?

You do not have to take part. It is up to you to decide whether to take part. If you do decide to take part you will be given this information sheet to keep (and be asked to sign a consent form). You can still withdraw at any time without any negative consequences. You do not have to give a reason. If you wish to withdraw from the research, please contact me via email: slphillips2@sheffield.ac.uk.

4. What will happen to me if I take part? What do I have to do?

If you decide to take part in the research, you will create artefacts (like a piece of writing, art work or other item) documenting two to four university experiences and participate in an interview with myself. Overall, it is anticipated the research may take you between three to five hours to complete (approximately one-hour per artefact and a one-hour interview).

Creating University Experiences

You will be asked to creatively document between two and four university experiences where you think your autism has affected you. The university experiences could have made you feel either positive or negative emotions. You can decide how you want to document your experiences and examples will be given to you if you want. You will have up to 8 weeks to complete this. After you have finished you will need to send a copy of this (or a photo/video) to me via email.

Interview

You will then be interviewed through Skype. You can choose to either use video, audio or instant messaging in your interview. You will be asked about the artefacts you have made. You will be asked a series of questions and also given the opportunity to speak freely. The style of interview will be semi-structured. Questions will centre on how your autism affected you during your experiences, what the concepts of wellbeing and academic achievement mean to you, and whether you feel these were affected by these experiences. This will help me to co-construct a definition of these two concepts and produce a shared story of autistic women's experiences in higher education.

5. Will I be recorded, and how will the recorded media be used?

If you choose to have a video or audio interview the audio and/or video will be recorded. If you choose a text-based interview, the text will be saved. The recordings of your activities made during this research will be used only for analysis and for illustration in conference presentations, lectures and publications. No other use will be made of them without your written permission, and no one outside the project will be allowed access to the original recordings.

6. What are the possible disadvantages and risks of taking part?

Although no disadvantages are expected from taking part in the research, if you choose to share a negative experience you have had at university with me it may evoke difficult emotions.

7. What are the possible benefits of taking part?

Participants will receive a £20 e-gift voucher. Although there are no other immediate benefits of taking part in the research, it is hoped that this work will inform others of the experiences of autistic women at university, to contribute towards ensuring university is fully accessible to autistic women students.

8. Will my taking part in this project be kept confidential?

All the information that we collect about you during the course of the research will be kept strictly confidential and will only be accessible to members of the research team. You will not be able to be identified in any reports or publications unless you have given your explicit consent for this. The data you provide will be pseudonymised and uploaded to the UK Data Service (https://www.ukdataservice.ac.uk/). Your personal details will only be included if you explicitly request this.

9. What is the legal basis for processing my personal data?

According to data protection legislation, I am required to inform you that the legal basis I am applying in order to process your personal data is that ‘processing is necessary for the performance of a task carried out in the public interest’ (Article 6(1)(e)). Further information can be found in the University’s Privacy Notice https://www.sheffield.ac.uk/govern/data-protection/privacy/general.

10. What will happen to the data collected, and the results of the research project?

Your data will be stored either in a pseudonymised (identifiable to a fake name) or identifiable form. You can choose the option you prefer. You will be shown the data after it has been transcribed and before data analysis to ensure you agree with the data that has been collected.

Data will be uploaded to the UK Data Service (https://ukdataservice.ac.uk) in a pseudonymised (identifiable to a fake name) form. This is to ensure creditability of research. Due to the nature of this research it is very likely that other researchers may find the data collected to be useful in answering future research questions. I will ask for your explicit consent for your data to be shared in this way.

11. Who is organising and funding the research?

This research is funded by the Economic and Social Research Council (ESRC) and is affiliated with the University of Sheffield.

12. Who is the Data Controller?

The University of Sheffield will act as the Data Controller for this study. This means that the University is responsible for looking after your information and using it properly.

13. Who has ethically reviewed the project?

This project has been ethically approved via the University of Sheffield’s Ethics Review Procedure, as administered by the School of Education.

14. What support organisations can I contact if I need more support?

If you need further support or signposting you can contact:

National Autistic Society:

Phone 0808 800 4104

The Samaritans:

Phone: 116 123

Email: jo@samaritans.org

15. What if something goes wrong and I wish to complain about the research?

During the research, if there is something you are uncomfortable with or want to complain about please contact:

Lead Researcher:
Sophie Phillips
Email: slphillips2@sheffield.ac.uk

In case of emergency or if you want to speak to a person not involved in the project please contact:

Head of School for the School of Education:
Professor Liz Wood
Email: e.a.wood@sheffield.ac.uk

Both based at :
The School of Education
The University of Sheffield
241 Glossop Road
Sheffield
S10 2GW

If your complaint relates to how your personal data has been handled, please contact:

The University of Sheffield Data Protection Officer:
Anne Cutler
Email: dataprotection@sheffield.ac.uk

16. Contact for further information

Lead Researcher:
Sophie Phillips

Email: slphillips2@sheffield.ac.uk

Supervisors:
Dr Kirsty Liddiard
Email: k.liddiard@sheffield.ac.uk

Professor Tom Billington
Email: t.billington@sheffield.ac.uk

All based at:
The School of Education
The University of Sheffield
241 Glossop Road
Sheffield
S10 2GW

This information sheet and a copy of your signed consent form are for you to keep.

10.4 Appendix 4: Consent Form

Autistic Women's Experiences of University Consent Form

Name of Researcher: Sophie Phillips

Please put an X in the appropriate boxes	Yes	No
Taking Part in the Project		
I have read and understood the project information sheet dated ………………….. and/or the project has been fully explained to me.		
Only continue with the consent form if you have answered yes above.		
I have been given the opportunity to ask questions about the project.		
I agree to take part in the project. I understand that taking part in the project will include creating artwork regarding two to four university experiences and at least one interview.		
I understand my involvement in this research is voluntary and I am able to decline from answering any question (for example in interview) I want.		
I understand that I can withdraw from the study at any time before submission of the thesis by emailing Sophie Phillips at slphillips2@sheffield.ac.uk I do not have to give any reasons for why I no longer want to take part and there will be no negative consequences if I choose to withdraw. If I withdraw, I will be paid if I have already created the artefact(s) (artwork) and participated in an interview.		
How my information will be used during and after the project		
I understand my personal details such as name, phone number, address and email address etc. will not be revealed to people outside the project.		
I understand and agree that my words may be quoted and artefacts used in publications, reports, web pages, and other research outputs. I understand that I will not be named in these outputs unless I specifically request this.		

I understand and agree that other authorised researchers will have access to this data only if they agree to preserve the confidentiality of the information as requested in this form.	☐	☐
I understand and agree that other authorised researchers may use my data in publications, reports, web pages, and other research outputs, only if they agree to preserve the confidentiality of the information as requested in this form.	☐	☐
I give permission for my pseudonymised transcripts of my interview and copies of my artefact(s) (without any identifying details) to be uploaded to the UK Data Service (https://www.ukdataservice.ac.uk/) so it can be used for future research and learning.	☐	☐
So that the information you provide can be used legally by the researchers		
I agree to assign the copyright I hold in any materials generated as part of this project to The University of Sheffield.	☐	☐

Name of participant [printed] Signature Date

Name of Researcher [printed] Signature Date

The
University
Of
Sheffield.

Project contact details for further information:

Lead Researcher:

Sophie Phillips

Email: slphillips2@sheffield.ac.uk

Supervisors:

Dr Kirsty Liddiard
Email: k.liddiard@sheffield.ac.uk

Professor Tom Billington
Email: t.billington@sheffield.ac.uk

All based at:
The School of Education
The University of Sheffield
241 Glossop Road
Sheffield
S10 2GW

In case of emergency or if you want to speak to a person not involved in the project please contact:

Head of School for the School of Education:
Professor Liz Wood
Email: e.a.wood@sheffield.ac.uk

Address:
The School of Education
The University of Sheffield
241 Glossop Road
Sheffield
S10 2GW

Copies:
Once all parties have signed this form the participant should receive a copy of the signed and dated participant consent form, the letter/pre-written script/information sheet and any other written information provided to the participants. A copy of the signed and dated

consent form should be placed in the project’s main record (e.g. a site file), which must be kept in a secure location.

10.5 Appendix 5: Interview Schedule

Interview Schedule

The interview will follow a semi-structured protocol and so only key information, key questions and suggested prompts are included.

Introductory Statement
You will be asked some questions about your artefact(s) and the experiences they represent. Specifically, these questions will be about how you created the artefact, the experiences you had and considering the concepts of 'wellbeing' and 'academic achievement'. If you do not want to answer a question you can say 'pass' or tell me you do not want to answer it. Please ask if you would like a question to be said in a different way. You can stop the interview at any time either by telling me you would like a break or to stop completely.

Warm-Up Questions
What language would you like me to use about autism during the interview?
- For example, person first (person with autism) or identity first (autistic).
- How do you like to describe non-autistic people?
- Is there any specific words you would like me to use?
- Is there any specific words you would like me to not use?

Interview questions are written using identity first language; however, language will be changed to
the participant's preference during the interview.

What way do you prefer to describe autism?
- For example as a disability or a difference.
- Do you have a strong preference or theory?

What experiences have you documented?

Did you enjoy creating them?

Defining Concepts

What barriers and supports do you think there are for autistic women accessing university?

- Are they, and in what way are these barriers and supports different for autistic men?
- Are they barriers and support different for non-autistic people?

What does the word ‘wellbeing’ mean to you?

- Have you heard of the word ‘wellbeing’ before? [If not] what do you think it relates to?
- What other words do you think have a similar meaning?
- Where, and in what context, have you heard the word ‘wellbeing’ used?

Do you think the wellbeing of autistic people is considered differently in society to the wellbeing of non-autistic people?

- If so, why? Does this vary dependent on a person’s level of needs?
- Do you think there is a different specifically in Higher Education?

How do you feel the barriers and supports to university impact on your wellbeing?

What does the phrase ‘academic achievement’ mean to you?

- What do you think should be classed as academic achievement?

How do you feel the barriers and supports to university impact on your academic achievement?

What do you believe are the most important concepts at university from your point of view and the university’s point of view?

- Is it solely academic achievement?
- Is wellbeing considered?
- Are there things (other than wellbeing or academic achievement) you think are more important to either you or the university?

The Experiences

Was there anything specific that you feel influenced these experiences?

How do you believe your autism, and in particular being an autistic and a women, influenced these experiences?

- Do you think men have the same experiences?
- Do you think non-autistic people have the same experiences?
- Do you think non-autistic people react in the same way?

Is there anything you feel your university could have done to change or enhance your experiences?

- Is there anything you feel your university should be doing for all autistic students who have or may have similar experiences?
- Could every student at university benefit from something your university could do for autistic students?

In what ways could the university environment be changed to better accommodate autistic women?

- Is the university environment already optimal for autistic women? If not, why not?

How The Artefact(s) Was/Were Created

Has creating your experiences helped you to process them more easily?

Why did you choose to use [method(s) of artwork] to create your artefact(s)?

- For example, is there a reason you have used a particular style?
- Does your method link to the experience you are depicting?

Closing

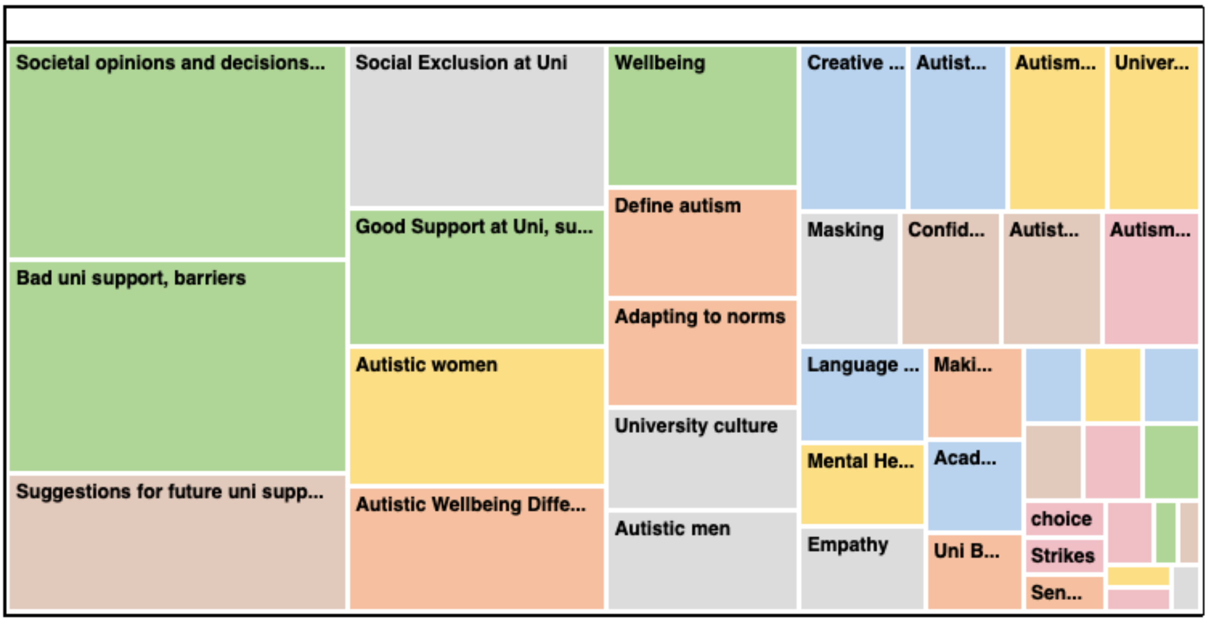
Is there anything else you would like to say?

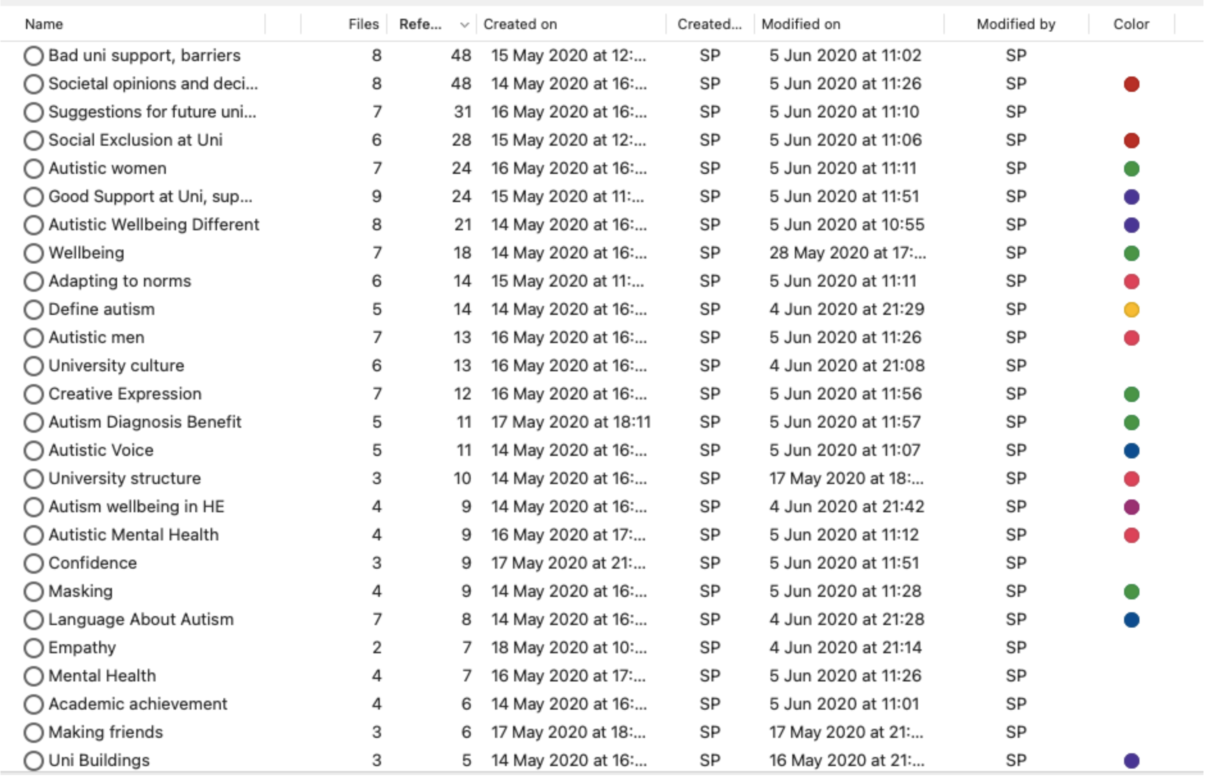
Do you have any questions?

Thank you for taking part in this interview. You will be given a debrief sheet.

10.6 Appendix 6: Journey Through Analysis Photographs

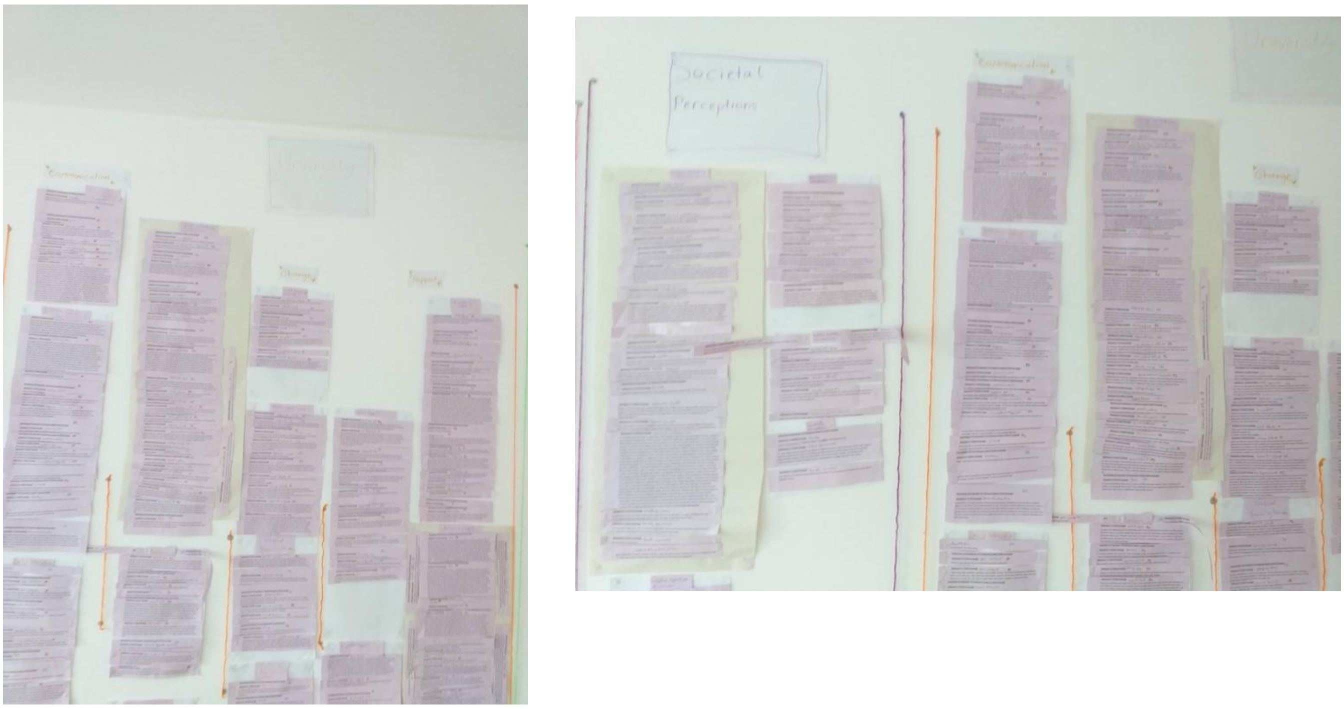
Screenshots from NVivo of data being analysed:



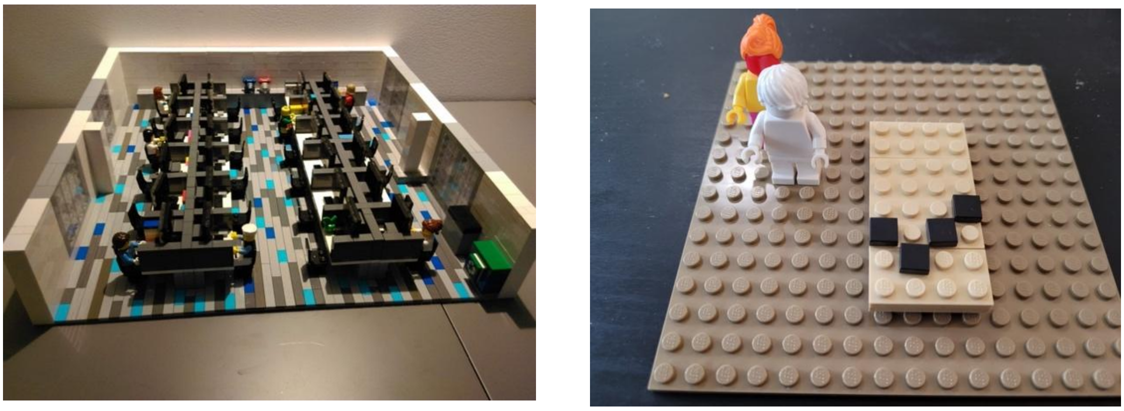


Name	Files	Refe...	Created on	Created...	Modified on	Modified by	Color
○ Bad uni support, barriers	8	48	15 May 2020 at 12:...	SP	5 Jun 2020 at 11:02	SP	
○ Societal opinions and deci...	8	48	14 May 2020 at 16:...	SP	5 Jun 2020 at 11:26	SP	●
○ Suggestions for future uni...	7	31	16 May 2020 at 16:...	SP	5 Jun 2020 at 11:10	SP	
○ Social Exclusion at Uni	6	28	15 May 2020 at 12:...	SP	5 Jun 2020 at 11:06	SP	●
○ Autistic women	7	24	16 May 2020 at 16:...	SP	5 Jun 2020 at 11:11	SP	●
○ Good Support at Uni, sup...	9	24	15 May 2020 at 11:...	SP	5 Jun 2020 at 11:51	SP	●
○ Autistic Wellbeing Different	8	21	14 May 2020 at 16:...	SP	5 Jun 2020 at 10:55	SP	●
○ Wellbeing	7	18	14 May 2020 at 16:...	SP	28 May 2020 at 17:...	SP	●
○ Adapting to norms	6	14	15 May 2020 at 11:...	SP	5 Jun 2020 at 11:11	SP	●
○ Define autism	5	14	14 May 2020 at 16:...	SP	4 Jun 2020 at 21:29	SP	●
○ Autistic men	7	13	16 May 2020 at 16:...	SP	5 Jun 2020 at 11:26	SP	●
○ University culture	6	13	16 May 2020 at 16:...	SP	4 Jun 2020 at 21:08	SP	
○ Creative Expression	7	12	16 May 2020 at 16:...	SP	5 Jun 2020 at 11:56	SP	●
○ Autism Diagnosis Benefit	5	11	17 May 2020 at 18:11	SP	5 Jun 2020 at 11:57	SP	●
○ Autistic Voice	5	11	14 May 2020 at 16:...	SP	5 Jun 2020 at 11:07	SP	●
○ University structure	3	10	14 May 2020 at 16:...	SP	17 May 2020 at 18:...	SP	●
○ Autism wellbeing in HE	4	9	14 May 2020 at 16:...	SP	4 Jun 2020 at 21:42	SP	●
○ Autistic Mental Health	4	9	16 May 2020 at 17:...	SP	5 Jun 2020 at 11:12	SP	●
○ Confidence	3	9	17 May 2020 at 21:...	SP	5 Jun 2020 at 11:51	SP	
○ Masking	4	9	14 May 2020 at 16:...	SP	5 Jun 2020 at 11:28	SP	●
○ Language About Autism	7	8	14 May 2020 at 16:...	SP	4 Jun 2020 at 21:28	SP	●
○ Empathy	2	7	18 May 2020 at 10:...	SP	4 Jun 2020 at 21:14	SP	
○ Mental Health	4	7	16 May 2020 at 17:...	SP	5 Jun 2020 at 11:26	SP	
○ Academic achievement	4	6	14 May 2020 at 16:...	SP	5 Jun 2020 at 11:01	SP	
○ Making friends	3	6	17 May 2020 at 18:...	SP	17 May 2020 at 21:...	SP	
○ Uni Buildings	3	5	14 May 2020 at 16:...	SP	16 May 2020 at 21:...	SP	●

Photos of data being analysed on walls:



Photos of Lego models I created (left, sensory university, right, small model of the start of the perceptions theme):



10.7 Appendix 7: Artefact Analysis (from Culshaw, 2019)

Participant	Title of Artefact	Paraphrased Participant's Explanation of Image	Descriptive – how image is produced, what it contains (colour, content, expressional representations), how it conveys meaning	Analytic – focus on compositional context, space, significance of colour, placement of items, content and visual syntax.	Interpretive – generating obvious and then alternative readings of the image
Lilly*	'Being Autistic at University'	• Lilly* describes the painting as a cartoon showing her trying to focus at her laptop, but being distracted by other things. • She said it was inspired by how hard she found it to concentrate on university work,	• Image is produced using pencil and watercolours. • Image depicts a page split in half, with one side of a person at a laptop with a 'let's focus' speech bubble and the other side with a laptop with lots of descriptive	• The left half uses traditionally calming colours such as green and blue, whereas in contrast the right side uses colours associated with danger and attention-grabbing properties.	• The image could show the calmness hoped for when beginning work but the barriers that she perceives. • Self-perception and worry may impact all attempts at

		when there were lots of other pressures weighing on her mind. This was a particular problem in her first and second year at university, which impacted grades.	words radiating from it. • The person in the image has a non-significant expression. • Image conveys meaning through the use of text and images.	• The page is split in half which may depict a dichotomy between what people see and the worries hidden behind the scenes or what is hoped to occur vs what does occur. • Text is placed as coming out of the computer, as if the turning on of the laptop opens a 'Pandora's box' of emotions and worry.	working, even if the calmness is hoped for.

				- Positioning of the laptop (and text) between a textbook and a coffee cup may demonstrate difficulties within an assumed norm of studying.	
Lilly*	‘Friendship With Other Autistic Women’	- Lilly* said she ‘drew two women in conversation, with the neurodiversity symbol and the Venus symbol to represent women’. - Lilly* says this image was inspired by her making friends with other	- Image is produced using pencil and watercolours. - Image depicts two people looking at each other and smiling. Above them is the sign for woman and the autistic infinity sign.	- The two people are smiling and looking at each other, which suggests interaction. - One person has a coffee cup that could suggest relaxedness.	- This image could suggest conversation can either only occur or is more relaxed between two autistic women.

		autistic women at an autism social club. She enjoyed meeting other students who were also autistic and shared her interests and difficulties.			
Cassy*	‘The Conference’	• Cassy* did not obviously allude to this in conversation.	• Image is produced using a computer software package ‘Remarkable’. • Image is drawn using black lines. • The image appears to be split into four parts, connected with arrows in a linear fashion:	• The images follow a linear pattern, as if the drawings are a flow chart of a day at a conference: listening to talks, coffee breaks, a conference dinner and bed.	• Literally this image depicts a flow chart of events that can happen at a conference. • It could be an interpretation of what people are thinking during a conference.

			people sitting at a table, people with tea or coffee, people around a table and a person in bed.	- All of the people in the images are smiling. Notably including one person who is away from the group during the coffee break image. This suggests emphasis on not wanting to be around a group in that situation. The legs are also drawn differently on this picture and a teacup is absent, possibly to further	

				emphasise the differences between the characters. In the two other groups the people look exactly the same. This may indicate a feeling of sameness and inclusion in those situations.	
Cassy*	‘Student Pastoral Meeting’	• Cassy* said she drew meeting with a student because one of the things she is frequently told is she cannot have the high score she has on the	• Image is produced using a computer software package ‘Remarkable’. • Image is drawn using black lines and shading.	• Sitting either side of a table may denote professionalism, or the size of it may suggest an element of space or being removed	• The picture’s title says it is a meeting. Further interpretation suggests that the image depicts that people are puzzles to be

		autism quotient (or similar test), because she's good with people. - She views students as puzzles – such as Rubik's Cubes to solve and thinks about how she can solve student's problems without becoming too emotionally involved. Which allows her to help students who are in very difficult situations. - She calls this problem solving	- Image shows two people sat at either ends of a table. They are labelled 'me' and 'student'. The student has a speech bubbles above their head, whereas 'me' has a thought bubble above.	from the situation. - The student seems sad from their expression and a speech bubble with angry symbols in it, but this is set against a happy 'me' image. This could suggest the 'me' is happy to hear student problems or is hiding emotion. - A thought bubble containing a Rubik's Cube that appears to be	worked out, rather than emotionally connected denoted also by the space between the two people.

		‘professional empathy’.		spinning (from drawn arrows) suggests the figuring out of a puzzle.	
Cassy*	Untitled [Artefact 3]	• Cassy* bases this image on executive functioning and how people see her, which she believes is an asset. • She says she is regarded as bit chaotic, ditzy and clumsy by lots of people in academia. This repeated assumption of	• Image is produced using a computer software package ‘Remarkable’. • Image is drawn using black lines and shading. • It shows a person with a confused/uncertain expression with an open head and butterflies coming out of it. There are movement lines to	• An open head suggests that thoughts are leaving the head rather than staying inside and getting lost or confused. • The person has a confused and uncertain expression, which could represent a negative feeling towards the	• Traditionally when talking about the body people talk about having butterflies in your stomach and not in your head – to represent nervousness, not flying away. • Possible representation of an empty

		others has led her to assume this identity. - She says that in the last five years she has got a better understanding of who she is and thinks it is not me being ditzy so much that it might just be the way my brain works. - Her husband will often say her brain is full of butterflies all the time and knock her on the head like it's empty.	show that the butterflies are flying up away from the head.	butterflies flying out of the head. - Butterflies can be a metaphor for change or hope which may represent turmoil of thought or ever-changing thoughts. - Lack of colour could depict a factual nature of the image even though other parts of the image contain metaphors.	head, with butterflies as a metaphor for thoughts disappearing. - A possible sadness of butterflies representing change or hope that is lost when they fly away in the image.

		- Having butterflies in her brain and to some extent knowing how she feels herself that she has a very logical approach to solving problems and looking at things quite holistically helps her in academia.			
Poppy	Untitled [Artefact 1]	- Poppy used the colours in the back to depict a brain, but used different colours that all sort of flow into each other.	- Image is painted with writing on top of it. Tones of blue, red, white and black are used. - The image consists of a rough oval shape with short	- The overall shape and colours of the image look like an eye, especially as the text swirls into the middle but leaves a circle shape empty.	- The image could be interpreted as lots of comments made to the author swirling around against a background of

		• She found it hard to describe but said she was not in that mind space, the image represents how it feels when people just say ‘really stupid things like really annoying things’ and you are unsure how to interpret their comment, for example, because they've just given you really unclear information. • Poppy made the words spiral to depict the same	sentences that radiate out from the centre in white pen.	• The text is sentences of things that are stereotypes people may say about autistic people and could have said to the author. • The background is painted in splodges of dark reds and blues. The splodge affect in cooler colours may represent more negative mixed feelings – as cooler colours	seeing the negativity within them.

		sort of thing – that when you are trying to work out what someone wants as opposed to what they have said, the sentences go around your mind as you try and work them out. • She said all the sentences she wrote in the spirals are unhelpful things that people have said to her – that may have made sense to the person saying		can represent sadness.	

		them, but not to her.			
Sarah*	Untitled [Artefact 1]	• Sarah* wanted to show how her life at university was controlled by the cathedral bells next to her accommodation. She felt it defined her university experience as it was inescapable and made her unwell and exhausted quickly. • The bells had gone off for hundreds of years and therefore	• Computer created image of a black bell with a person swinging in it from their feet. • The background is of gradience stripes of red, yellow and green covered in times of the 24-hour clock. • There is a black shadow of a animal like creature in the bell and an image of teeth.	• The bell and person are in black at the front of the image which may suggest it is important in the piece. • The bell is not a solid shape but rather formed black lines hiding a creature and teeth. The non-solidity of it may be significant.	• The person in the bell seems to be grabbing for times but is unable to catch them, possibly signifying the escaping nature of time, but also how important those specific times are. It could also be interpreted as the person falling out of the

		it was accepted as something that happened, rather than something that could be changed. • The bells went off regularly starting at 7:25am and going into the night, up to every quarter of an hour each day. She therefore ‘lived and died by the bells’ as they disrupted her sleep. • The lack of sleep caused her difficulties and so		• The times in the background vary in size but all depict times in 15-minute intervals.	bell into a void of time. • The swirling shapes within the bell suggest time is always chasing the person swinging. • The bright colours in the background may signify the chaos and overwhelming nature of the image.

		did how it affected her (then unknown about) autism. She was able to manage and thus not need to identify her autism when she could sleep. Although the bells provided structure, it was unyielding. ● The picture shows a beast come minotaur in the shadows. The shadow of person on the bell is also the bell chasing the person. The numbers on the 24-			

		hour clock show 15-minute intervals of when the balls went off. She feels like she is the clapper in the bell. The person is hanging in there, but she cannot reach anything and is constantly battered.			
Sarah*	Untitled [Artefact 2]	• Sarah's* artefact is a misquote from Pride and Prejudice's famous beginning focusing on how anybody can write their own story regardless of	• Computer created image, of lots of words in 'wordle' formations on a yellow background. • The main text is a misquote of 'Pride	• The image is contains lots of colours that blend together. • The amount of text suggests significance of the words rather than	• The amount of words could be interpreted as the power of speaking out and writing your own story as opposed to others'

		societal expectations. • Sarah* writes 'it is a truth universally acknowledged that a clever woman in possession of a sharp wit shall write her own story'. The text around the quote is all text from Pride and Prejudice – looking at the idea that the story is about marriage, written by a woman initially under a male pseudonym who	and Prejudice' and the other text is words for the 'real' story.	the colours of the piece.	deciding it and telling it for you.

		never got married or wanted to/did not engage in that world. • The artefact is a type of subvertion – to say 'write your own story' regardless of societal expectations, which is particularly true after gaining an autism diagnosis (seen as not conforming to a norm).			
Kim*	'Navigating Relationships at Uni'	• Kim* chose to create this artefact because she felt	• The photograph montage consists of 12 photographs	• The grey scale to full colour could be interpreted as	• Taking the montage as a whole, rather

		that the social difficulties, particularly with making and keeping friends, that is associated with autism is one of her biggest challenges. • She describes how she has had experiences of relationships breaking down but also has lots of good friends around. • Within her image Kim* has used ‘lightened out’	in a grid formation. • The top line of photographs is in black and white, the bottom line is in full colour and the middle line is a gradient between greyscale and colour. • The photos are all of groups of between 2 and many people, all which include faces hidden (for data protection). Although hard to	meaning going from bad things to good. The piece is entitled ‘navigating relationship at university’ suggesting some journey through it. • In using a grid, all the photographs are of similar size, potentially denoting no significance (except colour) given to any image – that they	than 12 separate photos I think it presents a change of circumstances of the people in it, as some photographs are afforded more colour than others – even though the author is in all of them.

		photographs to show relationships she still has (which make her happy) and greyed out and black and white areas are relationships that have broken down (which make her sad). The half and half images depict an issue within the relationship. • Kim* explained that she should not have to feel responsible for the success or failure of every relationship	pinpoint the author is in all of them.	are all equally important. • The groups of people in the photographs tend to be bigger in the bottom row. This could demonstrate finding more people or wanting to showcase more.	

		as neurotypical people can make ‘social blunders’ too.			
Kim*	Untitled [Artefact 3]	• Kim* wanted to depict her sensory sensitivities – particularly towards auditory things. She wants the image to show how difficult it is to concentrate when she feels distracted, but also to show how neurotypicals seem to be able to focus despite distractions.	• The image is created on a computer on unknown software. • It depicts a laptop, a speech bubble and rectangle outline – possibly a whiteboard – drawn in black. The background is blurred colours of yellow, black and white. • The laptop is positioned opened	• The yellow colour comes from the laptop and speech bubble and the whiteboard. No other areas are highlighted in yellow – a vibrant and sometimes overwhelming colour. This emphasises the importance of these things, however, the blurring of the	• I think this image documents the importance of focusing on a laptop, the board and what a speaker is saying but how that can be difficult through the blur of other things going on in the room.

		• Her image shows her sitting at my laptop in a lecture theatre. The yellow is the work that she should be doing and all the other colours show distractions. The spray function is used to show how her attention gets pulled between all the distractions. • Kim* describes the distractions as both coming from her own laptop (such as emails and social media notifications)	at the front of the picture as if the person viewing the artwork is the laptop user.	background mixed in with red suggests a deliberate distraction from these areas.	

		and from within the lecture theatre (such as people walking in late, whispering and others sneezing).			
Kim*	‘Concentrate’	• Kim*’s poem is about trying to work – and concentrate – in the library. She has written a stanza about every sense. • She says it can be frustrating that some students can leave writing an assignment until just before the deadline, which she	• Poem about concentrating. • Each stanza starts with the word concentrate, has five lines and looks similar. • Lines 2 and 4 rhyme in each stanza.	• The form of the poem is very similar all the way through demonstrating a standard structure.	• The pattern and rhythm of the poem suggests a standardised pattern in which one is meant to concentrate and study. About how each sense should conform to the norm, however the words themselves

		feels unable to do because she can only go into the library if the sensory environment is right – not too quiet, not too loud, not too light and no food smells.			show that with the expected conforming it is hard to concentrate and conform.
Sophie	'Exam Question Wording'	• Sophie wanted to document how a bad experience in an exam had shaken her confidence in exams. She had previously really enjoyed exams and	• Artefact consists of a black and white computer drawn image and a descriptive piece of writing about how an exam went. • The drawing is of a piece of paper with	• The text is to the left of an image suggesting it surrounds the image, or that the image complements the text but is not the central focus.	• The piece conveys frustration and sadness at the experience Sophie had with exams, but also annoyance at the systems supposedly

		felt she scored well in them. - She had struggled to interpret an exam question correctly, which had been screened by disability as having accessible wording. - She felt it impacted her overall average and has worried her that she may misinterpret exam questions in future exams.	three question marks around it.	- The text starts off with a problem and builds up to demonstrate how something 'small' can produce bad consequences.	there to ensure disabled students can understand the exam questions.
Sophie	'Meeting Other Autistic Students'	- Sophie wanted to include a positive artefact (in contrast	- Artefact consists of a black and white computer drawn	- The text talks about how Sophie feels having met	- The artefact explores self-acceptance and

		to her other two more negative ones) as she argues wellbeing can be good as well as bad. - She wanted to be unsociable when she started university, which would be helped by living at home. However, she then thought she would waste opportunities if she was not social at university. - This was helped by attending a pre-	image and a descriptive piece of writing about meeting other autistic students. - The drawing is of two coffee cups in front of a computer that says 'NVivo' on it.	other autistic students at university and how it has helped her wellbeing. - The image of a computer with coffee cups in front could show the two coffee cups – usually linked with being social are more important that what is on the computer.	self confidence in her own identity, especially when meeting others with the same diagnosis as her.

		university outreach scheme for people that were less likely to go to university. • In addition, she met an autistic person who became a good friend through volunteering to be part of her research. This then helped her meet other autistic students. • Sophie argues she will always have deeper connections with her autistic friends compared			

		to non-autistic friends because there are no connection barriers and having some similar experiences.			
Sophie	'Burnout and Routine Disruption'	- Sophie described the artefact to be significant because within the pandemic everybody appears to be struggling with change, however, she feels used to that due to having to cope with the disruption strikes at university have caused her.	- Artefact consists of an opinionative piece of writing about the effects the strikes have had on her.	- The piece documents the effects of the strikes over time, mostly in a chronological fashion.	- The piece may convey anger and frustration at the disruption that has been caused to her studies, but also frustration that the disruption strikes cause appear to be accepted as a norm.

		She wanted to emphasise to her non-autistic friends that how they were feeling is how she feels every time her routine changes, especially when something she really enjoys is changed. • Sophie wanted to convey that she was told the strikes were meant to be disruptive and therefore everybody is disrupted. She said she thought			• Words like ‘jostle’ and ‘disruption’ give the effect of constant change and movement in the piece.

		everyone felt impaired. However, she argues non - autistic disruptive and autistic disruptive are very different things.			
Katie*	‘Broken Mask’	• Katie* wanted capture a networking event that she went to, as there is an expectation to attend them as a PhD student, but they have always been a challenge of hers. • The particular event in her image	• Image is painted, consisting of a multi-coloured background and a drama style face mask on top with cracks in and a missing section on the right-hand side. • The mask is light pink and has a sad	• The multi-coloured background stands out against the mask in front of it due to its lack of colour. • The sad expression on the mask could indicate a sadness at the lack of colour on it or	• The drama mask could be being used to represent autistic masking (where a person hides their true self to mimic how others are acting in a certain context. • The broken sections of the

		was a really good one for her as she could talk about her work with others. • Katie* wanted to portray how she found the environment and expectations at a networking event too overwhelming. This is depicted in the image by the background being smudged and blurry to represent being overwhelmed, and different colours	or resigned expression.	that it does not want to be in front of the colour. • The mask is positioned in the centre of the page.	mask may signify the desire to break through it or that it is very hard to not show one’s real identity – as the mask pushes back against the colours.

		represent different aspects of the room. ● She felt she had to remove herself from the room as the pressure to interact with others was too difficult. When she does network it is exhausting and hard work. ● Katie* said that she feels she wears many different masks at these events to hide different things such as			

		environmental difficulties, social interaction difficulties and low self-confidence. In the image there is a big crack in one side of the mask that represents if something goes wrong it can make the mask more difficult to wear.			
Katie*	‘Conference Presentation’	Chapter 1: Katie* wanted to show where her strengths came out, by depicting a conference where	• Image is a collage of a photograph of Katie* a picture of lots of people and a speech bubble shape filled with a ‘wordle’ of lots of	• The pale pink background – a neutral colour – suggests focus should be on the pieces at the front of the image. All	• Considering all the people in the image seem engaged and the emphasis on the words of the conference

		she felt like she presented the best she ever had on the topic of her special interest. Chapter 2: She describes that usually her mind goes blank she cannot 'get the words out right'. However, for this one she had rote learnt the presentation and practised several times. She said she tended to pick up lots of song lyrics	different sizes of words in it. ● The collage background is pale pink.	other parts of the image are black and white, potentially either to emphasise them or to show how binary it can be of whether people are engaged or not engaged in what is said at conferences. ● All the people in the picture are smiling and look engaged in the speech bubble in front of them. The picture depicts	speech, the picture could be interpreted as showing pride in producing a talk that others are interested in and the self-enjoyment and self-pride of doing it on a topic of interest.

		and things like that and so memory was a strength. Chapter 3: Katie * merged that strength into that picture so she could show a positive experience as she advocates that you can have unique strengths. Chapter 4: She got good feedback and enjoyed it. She had friends who had not heard her speak before who		lots of different kinds of hairstyles and looks, potentially to show that she engaged a wide range of different types of people. ● The speech bubble contains words in different font sizes. The word ‘ADHD’ is significantly bigger which could signify greater importance or the overall theme of	

		said that she lit up the minute she went on the stage and talk about something that she was interested in. Chapter 5: She particularly wanted to link how you can harness your special interest in a conference environment to aid speaking.		what is being talked about. • The photograph of Katie* is small in the bottom righthand corner, suggesting what she is saying (which is much bigger) is more important than herself or to show the speech bubble is coming from her.	
Katie*	‘The Complicated	• Katie*’s artefact documents how difficulties to	• This artefact is a descriptive piece documenting how	• Italicised words indicate words	• The vivid imagery and description

	Map of Feedback’	understand feedback her supervisor was giving her, led to her supervisor suggesting seeking an autism diagnosis so they could put in extra support measures to help her complete her PhD. • Katie* felt worthless because she could not understand the feedback she was given and felt stupid asking questions, or that	Katie* felt when she received feedback from a supervisor.	from her supervisor.	suggest how important her feelings are to her and how the reader should get a feeling of this.

		her writing style was not accessible to the reader – she either went into lots of detail or put in difficult concepts with little explanation. • Her supervisor wanted to support her but needed basis for it. • She now has ‘translation meetings’ where she is given feedback and can then go back with questions at a later date.			

		- Katie* wanted to capture the panic that she feels is a map that you have to work out. That you find out where you are going, and what people mean. She says you get all different instructions and you have to kind of translate it in a way.			
Billy*	Untitled [Artefact 1]	- Billy* said that everybody is taught a certain way to learn and to be. For example, achieving certain number of	- Artefact consists of a colour photograph and a paragraph of text. - The photograph is of a group of	- The photograph and the text do not instantly appear to be linked, however, pencils and pens	- The photograph and text may depict a lack of self confidence in how Billy* learns and

		hours of study, revising a certain way and at particular times in the day. However, autistic brains work differently and not conforming to the "normal" ways of learning comes with guilt and the feeling like you're not "learning right".	pencils and pens (mostly likely in a pencil pot). • The text describes her way of working – with no explicit reference to the photograph.	are commonly associated with learning and writing, and Billy* alludes they are on her desk. • Linking the text to the image further suggests that the pens and pencils are displayed differently or ‘wrongly’ compared to how most people would arrange them. • The image has multiple coloured pencils and pens,	whether is it okay to be different compared to other people or the expected university norms. • This wrongness may extend to how her desk is organised.

				potentially suggesting a creativity or disorganisation. • She describes her desk set up and her working habits, then describes how she feels they are not the same as other students and therefore ‘wrong’.	
Billy*	Untitled [Artefact 2]	• Billy* chose to do a photo about the library because she said it was such a key element of the learning and	• Artefact consists of a colour photograph and a paragraph of text. • The photograph shows three	• The three books are stacked haphazardly in a pile. • The text describes how this is the	• The books stacked up haphazardly may reflect Billy*’s description of how

		university experience. She specified libraries are not autism friendly, in the same way lot of spaces at university are not. • Being un-diagnosed, she said she was unable to articulate necessarily why these buildings were not ‘me-friendly’.	academic text books in a pile. One is open on a nondescript page and the other two are closed. • The text refers to the photograph – that it is describing using a university library for the first time.	first time in seven years Billy* has used a library due to the complicated systems.	complicated she finds the system within the library to navigate. • The description could be interpreted as showing anger rather than pride (of using the library for the first time). Words such as ‘momentous occasion’ seem to be used sarcastically to highlight how a task that is

					commonly seen as basic has taken so long to achieve due to the barriers put in place by the library systems.
Billy*	Untitled [Artefact 3]	• Billy* said that she felt as a woman capable of masking she was misdiagnosed and misunderstood for a long time. • She did not think the university services were up to scratch when it came to supporting her mental health,	• Artefact consists of a colour photograph and a paragraph of text. • The photograph shows car keys, a computer mouse, piece of paper and a pen. • The text describes some of the process leading up to diagnosis and	• The image shows tools that are all used to access wider knowledge and experiences for example car keys could indicate being able to drive. • The text talks about how seeking a diagnosis and	• The photograph shows things that are used to communicate or for accessibility (for example a computer mouse to access a computer), however, the text talks about feeling that a diagnosis was

		especially during her undergraduate degree.	the feelings behind it.	support was minimalised into a professional telling Billy* to ride a bike – which she could not do at the time. The piece ends with her getting support eventually and being able to ride a bike.	inaccessible. The image and the text may be at odds with each other.
Sophia*	'The Interview (Returning to Education)'	- Sophia* documented her experience of returning to education, firstly of excitement and then recovering	- Artefact is a piece of descriptive writing documenting her gaining her autism diagnosis and then attempting to	- Italicised text is used to show a quote from the professor in the piece.	- The piece could be interpreted as conveying confusion and anger. Confusion at what an autism diagnosis

		from a bad experience and feeling content. - She had struggled through school, before having a diagnosis. She felt a diagnosis was a ‘missing puzzle piece’ and helped her understanding. She then felt comfortable to ask for more help. - Sophia* went back to university, had an incident with a lecturer on her 2nd day and then took a year out. From this	return to education following it, where she had a negative experience of ableism.		meant and anger at the university professor for assuming she would be violent if she was autistic.

		experience she discovered it was okay to know her boundaries and felt confident enough to tell others them.			
Sophia*	‘Group Work’	• Sophia* did not allude to this obviously in conversation.	• Artefact is a mix of text and computer-generated imagery. • The text describes how Sophia* thinks her autism effects group work. She includes an example of having difficulties with a particular student during a group work task.	• The feminine figure in the centre of the image is blurry, with lightning bolts, that may show stress or anxiety. • Sophia* highlights ‘group work is not teamwork’, based on how everybody is	• Overall the piece suggests anxiety and stress at having to work in a group – potentially of people who do not want to co-operate.

			• The image has a red to pink background with a symmetrical image in the middle. There are speech bubbles around the outside and a black image of a woman in a circle with lightning bolts in the middle.	focused on their own grades. • The treatment by another student is highlighted showing how other people do not always engage or do not work well in groups.	
Sophia*	‘Processing Information’	• Sophia* wanted to convey how she sometimes misinterprets questions, or does work ‘wrong’ in university projects and has not	• The text explains how she finds communication difficult. Sophia* documents two example of this: misunderstanding	• The brain is in the centre of the image potentially showing importance. • Brain waves are usually shown as lines, which may	• The blue crisper wavy lines going into the brain that turn pink and blurrier may represent how Sophia* feels different

		realised until after she has handed in the work, which is frustrating.	a strategy-based class and an essay. ● Underneath the text is a picture drawn using computer aided design. ● The image shows a pink outline of a brain on a black background with wavy lines going through it.	represent thoughts or information in the image. ● The lines on the left of the image are blue and crisp but turn pink and blurrier on the right of the image.	information goes into her brain, compared to what is expected to come out. The different colours may represent how the information is misunderstood in her brain.
Megan	'Lecture Theatre'	● Megan chose to create these two artefacts as they are the two places within the university campus that she feels are	● The artefact documents the lecture theatre on Megan's first week at university. ● It consists of a short paragraph of	● The piece has a short paragraph of text and then text in bullet points, potentially for emphasis.	● The very long list of different sensory aspects of the lecture theatre, followed by short bullet

		the most populated. These areas are therefore prone to affecting her SPD and autism alongside mental health conditions. - Megan said that there could be a greater social pressure on women to engage in conversation with others compared to men in situations such as in a lecture theatre before the lecture started. She thought this may stem from gender	text written in prose, followed by bullet pointed text. - The text describes what she can see, how her body feels and the emotions she is feeling.	- She uses short sentences, lists and bullet points throughout. - All the text suggests negative experiences. Nothing positive is documented about a lecture theatre.	points may be interpreted as keeping up momentum to emphasise that these negative sensory experiences keep on happening and happen with speed. - Her first paragraph may be setting the environmental scene – which could paint an overwhelming picture –

		stereotyping rather than due to autism however.			followed by all the things she is worried about on top of that. - The whole text portrays fear and a vivid picture of a lecture theatre as a scary place, in contrast to the stereotypical view of one.
Megan	‘University Corridors’	- Megan chose to create these two artefacts as they are the two places within the university campus that she feels are	- The artefact documents Megan’s experiences of walking through university corridors.	- The piece has a short paragraph of text and then text in bullet points, potentially for emphasis.	- The text could be interpreted as explaining her experience of walking in corridors, how she feels they

		the most populated. These areas are therefore prone to affecting her SPD and autism alongside mental health conditions.	● It consists of a short paragraph of text written in prose, followed by bullet pointed text.	● Megan starts by describing the people in the corridor and describing how she feels the corridors look, how the walls move – different from how they are in reality. Bullet points follow, with sentences written in a poetic manner.	change shape and the impact it has on her. ● Expressive and descriptive words like ‘explosions’ convey impact. ● She refers to ‘them’ which could reflect that she feels different and isolated from the other people in the corridor. She simultaneously says she does not understand

					or want to be with people but also wants to walk in groups to allow her to be anonymous.
Jess*	Untitled [Artefact 1]	• Jess* created this poem about how it is difficult to act on the encouraging words her academic mentor says to her with regards to advocating for herself. This is because she feels in danger if she does based on negative historical events	• A poem about speaking up and advocating for yourself. • Some lines are much longer than others. • One long gap of space is used to emphasise the gap of saying ‘white boat’.	• Line lengths vary. • Italics are used to denote the different voices that come through in the poem. • Lots of words ending – ility are used.	• Molotov cocktail suggests trauma and fight within her. Carving knife is also used which may denote the violence she is feeling she has to either fight or defend herself from.

		autistic people have experienced when speaking out. - She says that the poem references the fear and anticipation of misunderstanding and of saying "the wrong thing" and how it seems allistics don't quite understand this. - She feels autistic people have been systematically wiped out for voicing their opinions and speaking out and			

		feels that fear is in her DNA. She especially identifies with how autistic people were treated during the Holocaust. Which she says has left a deep scar on her.			
Jess*	Untitled [Artefact 2]	• Jess* created this poem in a response to the film Forrest Gump, which she argues is seen as very offensive to autistic people. • In addition, she wanted to emphasise 'shame and blame' to show	• A poem about Forrest, from Forrest Gump. • The poem uses short non-rhyming lines. • There is one instance of a large gap in a line. • There are no capital letters or	• The poem starts with general negatives and then starts to talk about a forest.	• The poem highlights the stereotypical negatives of autism, such as by using words and phrases like, tantrum, fixation and 'pens to align'.

		how allistics try to name and taxonomise autism particularly with film in portrayals that make sense to them. • Within the latter half of the poem Jess* looks at the idea of us as a society of allistics and autistics to move past the pre-existing notions of what autism is considered in society and how autistic people feel about society's	full stops, except for the name Forrest and 'I'. Lots of semi colons are however used.		• The poem highlights these things by referencing the character Forrest but also talking about a forest combining how a word can sound the same but mean different things.

		portrayal. She does this through considering nature, only differently (neurotypical people are water, everybody is air, and autists are the earth itself) but that everybody needs each other.			