

**Exploring Educational Transition Experiences and Strengths in Autistic Women**

Rebecca Barker

Submitted in accordance with the requirements for the degree of  
Doctor of Clinical Psychology (D. Clin. Psychol.)

The University of Leeds

School of Medicine

Division of Psychological and Social Medicine

November 2024

The candidate confirms that the work submitted is her own and that appropriate credit has been given where reference has been made to the work of others.

This copy has been supplied on the understanding that it is copyright material and that no quotation from the thesis may be published without proper acknowledgement.

The right of Rebecca Barker to be identified as Author of this work has been asserted by her in accordance with the Copyright, Designs and Patents Act 1988.

© 2024 The University of Leeds and Rebecca Barker

## Acknowledgements

Thank you to the consultant participants who took part in phase A of this research for the insight, advice, and suggestions given in making this research as accessible and relevant as possible.

Thank you to the participants who took part in phase B for giving your time and sharing your experiences so openly.

Thank you to my fantastic supervisors, Dr Paula Clarke, Dr Kerrie Channer, and Dr Ciara Masterson for your constant support, guidance, and expertise. Thank you for believing in me when I didn't believe in myself. I could not have asked for a better supervisory team.

Thank you to Dr Fiona Thorne for your support and kindness over the past three years.

Thank you to my family and friends for your support and patience during this process, and for being my biggest cheerleaders.

And finally, a huge thank you to my husband. Thank you for your endless encouragement and love during the ups and downs of the last three years, and for always believing that I could do this when I didn't think I could.

## Abstract

**Introduction:** Autistic students are increasingly accessing Higher Education (HE). The experiences of autistic women are currently under-researched and poorly understood, especially in HE. Existing literature focuses heavily on the barriers facing autistic students in HE, with strengths being under-researched. Additionally, there is an absence of participatory research in the field of autism. The current study aimed to address these gaps and explore the experiences of autistic women as they transition to HE, with a focus on the strengths that help them to be successful.

**Method:** A consultation phase comprised of three semi-structured interviews with autistic women with experience of attending HE took place to shape the second phase of the research.

This considered the area of interest and methodological approaches. In phase B, six autistic women shared their experience of attending HE via semi-structured interview, email, or survey.

Interpretative Phenomenological Analysis (IPA) was used to analyse the data.

**Results:** Findings from phase A highlighted the importance of research into the area of starting university for autistic women. There was mixed feedback about the female only approach and strengths-based perspective. The importance of individual choice regarding how to take part in research, the information required beforehand, and creating an enabling environment for each individual was highlighted. In phase B, areas of interest included, decision making and preparations for starting university, the experience of transitioning to university, relationships with others, autism as being both a barrier and advantageous in university, the importance of diagnosis, mental health difficulties, and individual relationships to strengths.

**Discussion:** The results are discussed in relation to existing literature around the experiences of autistic students as they transition to HE, the social experiences autistic women may have, and the complex relationship with the concept of strengths. The strengths and limitations of this study are considered, alongside implications and suggestions for future research, before concluding.

## Table of Contents

Chapter One: Introduction .....	14
What is Autism? .....	14
Language Use.....	14
Autism and Education .....	15
Autism and HE .....	16
Problems in access and completion.....	17
Barriers to accessing and succeeding in HE.....	17
Transitioning to HE.....	18
Social challenges as a barrier to success in HE .....	19
Lack of support as a barrier to success in HE.....	20
Mental health difficulties as a barrier to success in HE.....	22
Change as a barrier to success in HE.....	22
Academic challenges as a barrier to success in HE.....	23
Transition support.....	24
An individualised approach to support.....	24
Non-academic support inconsistent .....	27
Strengths based perspective .....	29
Gender differences in autism diagnoses.....	30
Exploring increased autism diagnoses in males .....	30
Rationale and Aims .....	34
1. The personal, social, and academic experiences of autistic women as they .....	34
transition to HE. ....	34
2. The strengths autistic women have that help them to succeed in HE. ....	34
Chapter Two: Method .....	36
Design.....	36
Qualitative Approach.....	36
Ontological Position.....	36
Epistemological Position.....	37
Methodology choice.....	37
Thematic Analysis .....	37
Discourse Analysis .....	38
IPA .....	38
Reflexivity.....	39
Reflexive Statement.....	39

A Participatory Approach .....	41
Methods .....	43
Phase A .....	43
Sample .....	43
Inclusion and Exclusion Criteria .....	43
Recruitment .....	44
Procedure .....	44
Interview Schedule .....	45
Ethical Considerations.....	45
Informed Consent and Withdrawal.....	46
Potential for Distress .....	46
Confidentiality and Privacy .....	46
Data Analysis.....	47
Phase A Results .....	47
Starting university .....	47
Experiences of women .....	48
A strengths-based approach.....	48
Methodology .....	49
Recruitment .....	49
Information given beforehand .....	49
Creating an enabling environment and means of participation .....	50
Phase B Methodology .....	52
Sample.....	52
Inclusion and Exclusion Criteria.....	52
Recruitment.....	53
Interview Schedule.....	53
Survey and Email .....	54
Procedure.....	54
Ethical Considerations.....	54
Chapter Three: Phase B Results.....	56
Carly .....	57
CAR1. Poor treatment by others.....	60
CAR1.1 A vulnerability to abuse. ....	60
CAR1.2 Being treated as inferior by others.....	61
CAR2. Awareness of strengths and weaknesses as an evolving process.....	62
CAR2.1 HE as a place where strengths and weaknesses are exposed.....	62

CAR2.2 Strengths as dynamic. ....	62
CAR2.3 An ability to identify some of my own strengths but these are often interlinked with weaknesses. ....	62
CAR3. A need to be seen as an individual, not a stereotype .....	63
CAR3.1 The importance of understanding individual differences and tailoring support accordingly. ....	63
CAR3.2 Limited understanding of autism from others. ....	63
CAR3.3 A lack of understanding of autistic females. ....	64
CAR3.4 Others assuming my strengths (and weaknesses) as an autistic woman. ....	64
CAR4. Imagining how things could have been different if I had been more effectively supported .....	65
CAR4.1 The difference financial support would have made. ....	65
CAR4.2 Peer support as a necessary but absent resource. ....	65
CAR4.3 The expectation that I should be able to cope as an adult. ....	65
CAR4.4 The need for tailored support outside of the academic. ....	66
CAR4.5 An absence of support prior to and during the transition to university. ....	66
CAR4.6 The importance of early intervention and support. ....	67
CAR5. The academic element of university as inaccessible .....	67
CAR5.1 Masking academic difficulties as unsustainable. ....	67
CAR5.2 Academic expectations that I can't reach. ....	68
CAR6. Trying to make sense of my own experiences. ....	68
CAR6.1 HE as having a negative impact on my sense of self. ....	68
CAR6.2 The wider system has let me down. ....	68
CAR6.3 University as an unmanageable experience. ....	69
CAR6.4 A sense of loss at not being able to follow my dreams. ....	69
CAR7. Considering how support could change in the future .....	69
CAR7.1 Universities need to do more to support autistic students. ....	69
CAR7.2 Universities need to know their students as individuals. ....	70
CAR8. Considering whether the social side of university is important .....	70
CAR8.1 Conforming to neurotypical norms. ....	70
CAR8.2 Questioning whether the social side of university matters. ....	70
CAR8.3 Difficult and limited social connections. ....	71
CAR8.4 Making friends that were similar to me. ....	71
Tiana .....	72
T1. Autism as a deficit in HE .....	74
T2. The importance of positive relationships with peers. ....	75
T2.1 An unusually positive social experience. ....	75

T2.2 Ups and downs of relationships with peers. ....	75
T3. A practical approach to transition.....	76
T4. The need for more nuanced and accessible support.....	76
T4.1 Limited support provided. ....	76
T4.2 A long road to support. ....	76
T4.3 An availability of academic support, but a need for more support outside of the academic. ....	77
T5. The academic element as challenging.....	77
T5.1 Sensory needs as impacted by the academic aspect of university. ....	77
T5.2 A loss of passion for the subject. ....	78
T5.3 Course content as inaccessible. ....	78
T6. Strengths as inaccessible.....	78
T7. Questioning whether I belong.....	79
Sarah.....	79
S1. Difficulties in socialising at university as an autistic woman.....	82
S1.1 Feeling disconnected and isolated despite having strengths in relating to others. ....	82
S1.2 Friendships not being sustained.....	82
S1.3 Having interests that are different to those typically expected of a student. ....	83
S1.4 Communication difficulties as a social barrier. ....	83
S2. Being autistic at university was challenging, but there were advantages too.....	84
S2.1 Being autistic as a barrier and an asset academically. ....	84
S3. University as having a detrimental impact on my mental health.....	85
S3.1 University were flexible with support when I was experiencing mental health difficulties. ....	85
S4. The importance of having a diagnosis in understanding myself.....	85
S5. Questioning whether my experience of HE would be different had I known I was autistic.....	86
S6. I had transition support from family and school, but I still felt unprepared.....	86
S6.1 Practical preparations.....	86
S7. Fluctuating self-belief.....	87
S8. Being aware of my own strengths (and weaknesses).....	87
S8.1 A strength in some situations causes difficulties in another. ....	87
Libby.....	88
L1. I am different to other women I know.....	90
L2. An ongoing process of self-understanding of what being autistic means to me.....	90
L2.1 A process of accepting my diagnosis.....	90
L3. Loss of skills are easier to identify than strengths.....	91



L4. A lack of engagement with the social side of university .....	92
L4.1 A sense of not fitting in.....	92
L4.2 A preference for one-to-one friendships. ....	92
L4.3 My interests are different to a typical student’s interests. ....	92
L4.4 Difficulties in making and sustaining friendships. ....	93
L5. Undergraduate and postgraduate as opposing experiences at transition and beyond .....	93
L5.1 Degree of change as the main factor in the differences in experiences between courses.....	93
L5.2 A shared and unshared experience.....	94
L5.3 The importance of preparation. ....	94
L5.4 A difference in academic support. ....	94
L5.5 Increased demands as making things tough. ....	95
L6. Questioning if things would have been different had I known I was autistic .....	95
L7. University as having a detrimental impact on my mental health.....	96
L8. Knowing my areas of academic strength and difficulty is important .....	96
L9. Aspects of being autistic as being both helpful and unhelpful at university.....	96
Sasha.....	97
SAS1. An overwhelming transitional experience to university.....	99
SAS1.1 Questioning whether I fit in.....	100
SAS1.2 Practical preparations. ....	100
SAS1.3 Difficulty of living in halls. ....	100
SAS1.4 Missed opportunities. ....	101
SAS1.5 Change in different areas of life. ....	101
SAS2. Highs and lows of relationships with others .....	101
SAS2.1 Benefits of a close cohort. ....	101
SAS3. Questioning if things would have been different if I had known I was autistic and sought more support .....	102
SAS3.1 A belief I would have been better supported if I had known I was autistic.....	102
SAS3.2 Being unsure what would have helped me during my time at university.....	102
SAS4. Strengths as being difficult to access, but I do have them .....	103
SAS5. Being autistic as impacting different areas of university life.....	103
SAS6. Making sense of academic difficulties .....	103
SAS6.1 Avoidance of both academic work and help seeking.....	103
SAS6.2 Questioning why I cannot manage like others. ....	104
Catherine .....	104
CAT1. Being autistic was both an advantage and a burden in HE .....	106

CAT1.1 University as a place where I experienced both positive and difficult social relationships. ....	106
CAT1.2 Being autistic meant I was academically advantaged at university.....	108
CAT2. Receiving an autism diagnosis aided my self-understanding, but I'm unsure what impact knowing earlier would have had on my university experience .....	108
CAT3. Transition to HE as an exciting opportunity .....	109
CAT3.1 I had the skills I needed to succeed in HE.....	109
CAT3.2 Transition to HE as an opportunity.....	110
CAT3.3 Support as being in varied in form and availability.....	110
CAT4 The impact of university on my mental and physical health .....	111
CAT5. I have a good awareness of my own strengths.....	111
CAT6. The impact of the supervisory relationship.....	112
Chapter Four: Discussion.....	114
Summary of Results .....	114
What does it mean to be an autistic woman?.....	114
The experience of transitioning to HE as an autistic woman .....	115
Decision-making process and practical preparations .....	116
The experience of autistic women in HE beyond the point of transition .....	118
Both positive and negative social experiences. ....	118
Being autistic as a barrier and an advantage in HE. ....	121
Questioning if things would have been different if I'd known I was autistic. ....	122
Mental health difficulties.....	124
Autistic women's relationship to strengths and how these helped during their time in HE	124
Strengths and limitations.....	126
Research focus.....	127
The participatory approach.....	127
Recruitment approach.....	128
Varying methods of participation .....	129
Quality checks .....	129
Implications.....	130
Future research .....	132
Conclusion.....	133
References.....	136
Appendices.....	154
Appendix A - Phase A Participant Information Sheet.....	154
Appendix B - Phase A Consent Form .....	157

Appendix C - Phase A Topic Guide ..... 158

Appendix D - Ethics Confirmation Email – Phase A ..... 160

Appendix E - List of Support Services ..... 161

Appendix F - Phase B Participant Information Sheet..... 162

Appendix G - Phase B Recruitment Poster..... 165

Appendix H - Phase B Interview Schedule..... 166

Appendix I - Ethics Confirmation Email – Phase B..... 169

**List of Tables**

Table 1. Summary of Participant Demographic Information.....	52
Table 2. Stages of Data Analysis.....	57
Table 3. Carly’s Personal Themes.....	59
Table 4. Tiana’s Personal Themes.....	74
Table 5. Sarah’s personal themes.....	81
Table 6. Libby’s personal themes.....	89
Table 7. Sasha’s personal themes.....	99
Table 8. Catherine’s Personal Themes.....	106

**List of Figures**

**Figure 1.** Arnstein’s Ladder of Participation.....42

## Chapter One: Introduction

This research explored the experiences of autistic women as they transitioned into Higher Education (HE) and the strengths they have that helped them to succeed in such settings. This chapter will consider the broader context in which this research sits and give a rationale for the current research. This will include exploring what autism is, considering language use around autism, and examining autism in relation to the education system. Difficulties encountered by autistic students in HE will be explored, followed by a consideration of existing transition support. Attention will then be paid to commonly seen areas of strength in autistic populations, followed by gender differences in autism diagnoses. Finally, a rationale for this research, alongside aims, will be provided.

### What is Autism?

Autism is an umbrella term for a group of lifelong neurodevelopmental differences that impact how individuals perceive and engage with others and the world around them (NHS England, 2023). Autism is characterised by differences in social communication and interaction, and repeated and restricted interests, and usually becomes apparent at preschool age (APA, 2013). Autism is considered a spectrum due to the variance in presentation, functioning, severity, abilities, and impact on each individual (Adreon & Durocher, 2007; APA, 2013). Autism can occur either with or without intellectual disability, with many autistic people having an IQ in the average range or higher (Baio et al., 2014). Though estimates vary, approximately 1.76% of children in the UK are reported to be on the autistic spectrum (Roman-Urrestarazu et al., 2021) with almost four times as many males being diagnosed as females (Whiteley et al., 2010).

### Language Use

The language used to describe autism and autistic populations is crucial to the way society understands autism, and can inadvertently contribute towards stigmatisation (Buijsman et al., 2023). Therefore, considerable thought was given to the use of language in this thesis. Both discussion with the consultant participants involved in this research, and other research with autistic individuals in the UK has largely demonstrated a preference for identity-first language (i.e. autistic person; Brown, 2011; Kenny et al., 2016; Lei et al., 2021). Therefore, identity-first language will be used throughout this thesis. However, it is acknowledged that there is no one universally accepted way of describing autism and autistic populations, and that individuals will have different semantic preferences (Kenny et al., 2016). Additionally, when considering language used to describe autism, “autism” or “on the autism spectrum” are frequently the most

endorsed terms by autistic populations (Keating et al., 2023; Kenny et al., 2016). As such, the term autism will be used throughout this paper. However, terminology may vary depending on the terms used in the individual research being discussed.

Neurodiversity, a concept generated in the late 1990s, will be used in this thesis to refer to the idea that people experience and interact with the world and others in different ways (Baumer & Frueh, 2021). Neurodiversity as a paradigm can be used when describing all populations but is often used in the context of autism and other developmental differences such as Attention Deficit Hyperactivity Disorder (ADHD), and refers to the diversity of the human mind (Walker, 2021). The concept of neurodiversity aims to increase acceptance and inclusion whilst recognising difference, and encouraging distance from medicalised and deficit focused narratives of such differences (Baumer & Frueh, 2021). Autism is currently largely understood from a medical perspective and is considered a disability. This exacerbates ideas of autism as being deficit laden, whilst ignoring the many and varied strengths that autistic populations possess. The neurodiversity paradigm offers an alternative way of understanding autism, and suggests that diversity is naturally occurring variation in human neurobiology. The medical model and disability language used also perpetuates a focus on individuals and deficits within individuals, rather than considering the impact of the societal context in which individuals exist and placing a responsibility on wider society to be more inclusive (Pellicano & den Houting, 2021), something which the neurodiversity paradigm seeks to challenge.

In contrast, the word neurotypical is often used to describe those without neurodevelopmental differences who are considered to develop and present in ways typically expected by society (Rudy, 2022). Finally, neurodivergence is considered a state of being, with neurodivergent individuals experiencing differences in brain functioning compared to the majority of the population and from that typically expected by society (Walker, 2021).

### **Autism and Education**

More autistic students are attending mainstream schools in the UK than ever before (McConkey, 2020). This is a positive trajectory, as approximately 46% of autistic children and young people have an average or higher than average IQ (Baio et al., 2014; Katusic et al., 2021). This suggests that mainstream schools should be academically suitable settings for many autistic students, if appropriate support is available. The increase in autistic students attending mainstream school could have various explanations, including: the expansion of the diagnostic criteria meaning increased rates of diagnoses, a greater understanding of autism co-occurring and interacting with other developmental disorders, greater public awareness of autism, changes

to how autism is recorded in schools, greater recognition of autism from professionals and therefore improvements in diagnosis, and increased responsibility on education settings to provide appropriate and inclusive support (Adreon & Durocher, 2007; Anderson, 2017; McConkey, 2020).

### **Autism and HE**

As many autistic people have an IQ in the average or higher range, they have the capacity to succeed academically not only in mainstream schools, but also in HE settings (VanBergeijk et al., 2008). Post-secondary education is a goal for many with disabilities (Cameto et al., 2004), and the number of students with a disability accessing HE in the UK is increasing (Higher Education Statistics Agency [HESA], 2022), with the number of students in HE disclosing a disability increasing from 9.5% to 16.7% between 2010 and 2018 (Office for Students, 2020). Despite autistic students still being less likely to attend post-secondary education than their neurotypical peers, and peers in other disability groups (Wei et al., 2013), this appears to be changing. In 2004, 1.8% of students at one HE institution disclosed an autism diagnosis, with this increasing to 2.4% in 2007/08 data (MacLeod & Green, 2009). This increase has continued, with 0.3% of students enrolled at UK universities citing either social communication or an autism spectrum disorder in the 2014/2015 academic year, increasing to 0.66% during the 2022/2023 academic year (HESA, 2023). It is important to note that autism is classed as a disability and to consider the potential that this could perpetuate a deficit focussed narrative around autism and neurodiversity in general. That autism is classed as a disability in HE settings puts responsibility on individuals, with autism being viewed as a problem within the person, and being related to deficits within them. This neglects the responsibility of society in general (including HE institutions) to be more inclusive and for environments to be modified to be neuroaffirmative rather than only meeting the needs of neurotypical students, and requiring additional support for neurodiverse students (Pellicano & den Houting, 2021).

It is likely that the number of autistic students in HE remains an under-estimation, as not all autistic students will disclose their diagnosis to their institution. Many students (especially females) will be undiagnosed, and others may only receive their diagnosis post HE (Cage & Howes, 2020; Wenzel & Brown, 2014; White et al., 2011) with McCrossin (2022) reporting that 80% of autistic females remain undiagnosed at the age of 18. Attending HE is a valued social role, and it is important that autistic students can access HE to experience a sense of belonging, and increase overall quality of life, whilst reducing the likelihood of marginalisation (Hart et al., 2010).



The increase in autistic students accessing HE may be attributed to similar reasons as the increase in autistic students accessing mainstream education more generally, as stated above. Despite this increase, research into the experiences of autistic students in HE remains limited (Barnhill, 2016; Trevisan & Birmingham, 2016). Most autism research continues to focus on children and adolescents (Jang et al., 2014), highlighting a need for increased research with autistic adult populations in HE (Howlin et al., 2015).

### **Problems in access and completion**

Despite the increase in access to HE, autistic populations in the USA continue to both enrol in, and complete postsecondary education, at lower rates than other disability groups (Newman et al., 2011; Shattuck et al., 2012; VanBergeijk et al., 2008). Specific data on withdrawal rates from postsecondary education is minimal (Cage & Howes, 2020), particularly in the UK, and especially in relation to rates of autistic students who may withdraw from HE, with numbers not being officially published (North East Autism Society, n.d.). However, research from the North East Autism Society (n.d.) estimates that 36% of autistic students who enrolled at university in 2019 did not complete their course, compared to 29% of the general student population, with this being the lowest completion rate of all disability groups, suggesting more needs to be done to support students with disabilities, including autism, throughout HE.

The reduced rate of access to, and completion of HE for those with disabilities is concerning. In the general population, a higher level of education is a known predictor of better outcomes in later adulthood (Lambe et al., 2019) and there is no reason to suggest this would be different in autistic populations. “Better outcomes” can be defined in various ways, depending on individual and societal values about what defines success. For example, those with a university education often have higher employment levels, increased salaries, and better health compared to populations who do not have a university education (Department of Education, 2021; Shattuck et al., 2012). These are outcomes that many would define as “better” when compared to the alternative of decreased levels of employment, lower salaries, and poorer health. This further highlights the importance of enabling equitable access to HE for all. With outcomes remaining poorer for autistic students in HE, it is essential that work be undertaken to identify and address barriers for autistic students in HE to enable greater access and the best chance of completion.

### **Barriers to accessing and succeeding in HE**

Much of the existing research into the experiences of autistic students in HE settings has focused on barriers that make transitioning to HE, and succeeding in such an environment, difficult (Davis et al., 2021; Gelbar et al., 2014; Gurbuz et al., 2019; Paskins, 2018; White et al., 2016). This is to be expected when considering the reduced completion rates and increased thoughts of withdrawal from HE by autistic students (Gurbuz et al., 2019), as, for improvements and supports to be implemented, it is essential the barriers are understood before changes can be made.

There are numerous challenges that neurotypical students face when transitioning to university, but these challenges can be exacerbated in autistic populations (Anderson et al., 2017; Peters & Brooks, 2016; Van Hees et al., 2015; White et al., 2016). Some of the challenges include, social and emotional difficulties, increased organisational demands, mental health difficulties, change, difficulty in accessing appropriate support, and academic challenges (Gurbuz et al., 2019; Madaus et al., 2022; Van Hees et al., 2015). Each of these factors can contribute to autistic students completing HE at reduced rates (Cage & Howes, 2020).

### **Transitioning to HE**

Whilst there is existing research into the primary to secondary school transition for autistic students, there is less research into the transition to HE (Hebron, 2017; Peters & Brooks, 2016). With autistic students enrolling at and completing their studies at reduced rates, this suggests that the period of transition to university is crucial, and that thorough transition planning is essential for a successful HE experience. Available research suggests poorer post-school outcomes for autistic populations where transition planning has been of a lower quality (Newman et al., 2011), with a recommendation that transition planning be holistic and commenced as early as possible (Cheak-Zamora, 2015). Current transition plans have poorer outcomes for autistic students than for neurotypical students (Cameto et al., 2004). Additionally, limited numbers of autistic students are involved in their transition planning, and where they are involved, are less likely to be active participants in this process (Hetherington et al., 2010). Some autistic students avoid transition planning for leaving university as a means of coping with the upcoming ending (Vincent, 2019), and it is possible this process of avoidance could be mirrored for starting university, possibly explaining some of the reduced involvement of autistic students in their transition planning.

When engaging in the transition planning process, there are various areas that should be considered, including, the type and size of college, living arrangements, the level of independent living skills the student has, how to disclose their diagnosis, and the identification of various

forms of support (Adreon & Durocher, 2007). Each of these will impact the student's experience, and the level of support they may need, and as such, availability of appropriate support is an essential consideration.

### ***Social challenges as a barrier to success in HE***

Starting HE often includes significant social change, including, meeting new people, increased pressure to attend social events, and potentially living with new people who are not family (often for the first time). Difficulties with the social aspect of HE has been identified as a reason for autistic students withdrawing from HE (Cage & Howes, 2020). Despite an often-stereotypical view that autistic populations do not have a desire to engage in the social aspect of HE (Jaswal & Akhtar, 2019), this is not always accurate. In research with 23 autistic students in HE by Van Hees et al. (2015), one participant expressed a need for social contact to increase their sense of belonging, however, was unsure how to achieve this. This is echoed in other research where autistic students reported feeling like an "outsider" compared to neurotypical students (Cage & Howes, 2020). This demonstrates that autistic students can have insight into their social difficulties, which has the potential to further increase anxiety and lead to a reluctance to engage with others for fear of getting it wrong and exposing their difficulties, which could perpetuate a cycle of further social avoidance and isolation (Van Hees et al., 2015).

Alternatively, at times, social situations can feel easier in post-secondary settings compared to high school settings, due to a shared passion for the chosen subject (Van Hees et al., 2015). The benefits of joining sports clubs and societies have also been highlighted, again, allowing students to be around others with shared interests, this time outside of their area of study (Madaus et al., 2022), with the potential that this could further ease difficulties in social interactions. Despite the possibility that aspects of the social side of university may feel easier than in high school settings for some students, other autistic students have still reported difficulties in navigating this, for example, knowing how to approach staff, knowing when is appropriate to ask questions, and finding it difficult to initiate and maintain conversations with others (Davis et al., 2021; Van Hees et al., 2015). This is unsurprising when the extent of social changes that occur during this time are considered, alongside potential existing differences in social communication for autistic populations compared to neurotypical populations.

For both students who live at university and those who commute, the early weeks can be understandably difficult, with an emphasis on socialisation (Wilcox et al., 2005). For some students, this may be manageable initially, before becoming overwhelming, and leading to autistic students withdrawing and becoming isolated early in their university life (Cage &

Howes, 2020). This isolation may not only lead to difficulties in the social aspect of HE but can also consequently cause disadvantages in other aspects of university life. For example, students who become isolated may not be included in the shared knowledge that other students have with the rest of their social group. Autistic participants with experience of withdrawing from university in the Cage and Howes (2020) study spoke of situations where friends took turns asking their tutors for academic guidance and shared the information with others in their social group. Due to not being a part of such social groups, autistic students reported missing out on this, with difficulties in the social aspect of HE having the potential to subsequently effect the academic element of university.

Finally, there is also concern around the potential for autistic students to be taken advantage of or marginalised in HE settings, due to potential difficulties in understanding social rules and situations, for example, in the areas of communal living, dating, or in the academic setting itself (Fleischer, 2012). This demonstrates just some of the social difficulties that autistic students can experience in HE, and how the various social challenges encountered can act as barriers to both attending and succeeding in such settings.

### ***Lack of support as a barrier to success in HE***

A lack of support from HE settings has been identified as a reason for autistic students withdrawing from HE (Cage & Howes, 2020) and as a barrier to success (Madaus et al., 2022; Paskins, 2018). The North East Autism Society (n.d., para. 5) states “autistic students face a higher education sector that was not designed with them in mind”, with autistic students often not having adjustments put in place that would support them in their studies. As the number of autistic students accessing HE has increased considerably in recent years, this statement is particularly prominent, highlighting that HE environments are designed for neurotypical rather than neurodiverse populations. It also speaks to the importance of person-centered support; a theme reflected in other research (Gurbuz et al., 2019). There also appears to be a disconnect between the support that disability services state can be offered, and the reality of the support provided (North East Autism Society, n.d.), which could lead to further problems should autistic students believe they will be supported, only to ultimately not receive such support.

Autistic students have also reported being unsure what support would be beneficial and how their HE institution could support them more effectively (Cage & Howes, 2020). Such difficulties in introspection may make it difficult for some autistic students to identify what kind of support they need, creating further challenges for universities in offering appropriate support (Cage & Howes, 2020), with the responsibility of identifying support seemingly being placed on

individual students, rather than HE institutions. Despite this, universities can provide support to their autistic students, and, for example, could take an active role in signposting which members of staff can offer support to autistic students, whether this be in the form of allocated tutors, or through disability services, with a centralised contact for support being beneficial (Cage & Howes, 2020). For this to be effective, it is essential that staff offering support are knowledgeable not only about neurodiversity generally, but that they know the student they are supporting individually, along with their own strengths and needs. Consequently, it is hoped that if autistic students are effectively supported by informed and supportive staff, this would reduce thoughts of, or actual withdrawal from HE.

Often, students are reluctant to disclose their autism diagnosis to their HE institution for various reasons, such as: others lacking knowledge about autism, a lack of supportive policies at the institution, and concerns about whether their information will be held confidentially (Van Hees et al., 2015). Autistic students will frequently only disclose their diagnosis when they feel no longer able to cope with the stress they are experiencing, when they have established a feeling of safety, or if their support relates to a specific need (Van Hees et al., 2015). This is concerning as it suggests that students may only seek support when they are reaching crisis point and may already be having thoughts of withdrawing, rather than proactively seeking support which could maintain their wellbeing and help them to remain in university. It also reiterates that autistic students may not always know what support they need (as suggested with support only being sought when they can identify a specific need), and may be reluctant to seek support for difficulties where a clear cause or solution is not apparent.

Effective support and understanding are not consistently available in HE settings, with autistic students sharing experiences of being addressed in a “derogatory” manner and reflecting on a lack of support and recognition of their difficulties from academic staff at their institutions (Cage & Howes, 2020). The benefits of both supportive staff and support more broadly from HE institutions as facilitators to success have been highlighted in research, with a lack of direct support being identified as a major barrier to success, particularly where there is a lack of social support (Madaus et al., 2022; Paskins, 2018; White et al., 2016). Collaboration across institutions has been found to be essential for student success (Barnhill, 2016) with it being essential that staff are appropriately trained to support autistic students. As stated, autistic populations are increasing in UK universities, and it is likely that HE institutions are still learning and adapting to the support needs of this student group, with increased social support often being needed, rather than purely academic support that HE institutions may be more familiar with offering (Barnhill, 2016).

### ***Mental health difficulties as a barrier to success in HE***

The impact of HE on autistic students' mental health is well documented (Anderson et al., 2017; Cage & Howes, 2020; Van Hees et al., 2015) and can be a barrier to success in HE. Existing mental health difficulties can be exacerbated during students' time in postsecondary study due to the impact of increased stress, change, and pressure in different areas of HE life, and is another contributing factor to potential withdrawal (Cage & Howes, 2020; Van Hees et al., 2015). This is especially concerning for autistic students who are already at an increased likelihood of experiencing mental health difficulties when compared to neurotypical populations (Croen et al., 2015; Lai et al., 2019).

Three aspects of university life were suggested by Van Hees et al. (2015), with these being: education, student life, and daily living. Challenges in each of these areas simultaneously (as can happen during the transition period to university), are more likely to lead to deteriorations in students' mental wellbeing, with experiences of anxiety, depression, stress, and isolation being commonplace (Van Hees et al., 2015). For example, difficulties with the time management of academic work and an expectation of increased academic independence could be considered a challenge in the educational aspect of HE. Attempting to make and maintain friendships could be an additional challenge which leads to stress in the social or student life area, and shopping, cooking, and caring more independently for oneself (potentially for the first time) is likely to increase stress in the daily living domain.

The challenge in each of these areas should not be underestimated, with the degree of change students go through when transitioning to HE being substantial. It is therefore unsurprising that this could lead to a deterioration in mental wellbeing, especially for students with existing mental health struggles, or for whom change is particularly difficult. Similar concerns about deterioration in mental health have been expressed by autistic students in HE in the USA, with changes reported including increased anxiety, overeating, and skin picking (Madaus et al., 2022). Additionally, mental health difficulties were found to be one of the most common challenges experienced by autistic students in HE in a systematic review of 24 studies in the UK, USA, Australia, and Belgium between 2015 and 2019 by Davis et al. (2021).

### ***Change as a barrier to success in HE***

As discussed, a major difficulty experienced by autistic students when transitioning to HE is the degree of change experienced (Van Hees et al., 2015). HE requires students to engage academically in different ways than compulsory education. For example, there are frequently

more time management demands, a more active and independent learning style, and an increase in assignments (Fook & Sidhu, 2015) alongside transferring to a new, unfamiliar, and often bigger learning environment. Social changes have already been discussed above, and changes to daily living are particularly prominent for students living away from home who may have to take increased responsibility for a range of daily living tasks and find their way in a new setting (Van Hees et al., 2015).

Understandably, students have expressed anxiety around leaving the familiar setting of their high school (and in some cases their home) and going somewhere new, with their whole life and routine changing (Van Hees et al., 2015). This can be an unsettling and overwhelming time for any student, but when considered alongside the commonly seen desire for structure and routine in autistic students, and difficulties with change, this can lead to increased stress and negatively impact mental wellbeing (Van Hees et al., 2015). Autistic students can also find new situations tiring and overwhelming when starting HE, with excessive energy being used to cope with and process these changes (Van Hees et al., 2015). It is easy to see how this change can lead to a deterioration in mental health and may at times feel too overwhelming and lead to thoughts of withdrawing.

### ***Academic challenges as a barrier to success in HE***

A range of academic challenges have been identified as barriers to succeeding in HE for autistic students. Difficulties with time management, organisational skills, and poor concentration are all traits that can be commonly seen in autistic populations and can lead to increased challenges in adapting to and succeeding in HE, where these skills are often required. As discussed above, effective time management is essential in HE, alongside organisational skills to succeed in an adult and active learning environment, often with multiple competing deadlines. Additionally, challenges in concentration can be amplified in HE settings with differences in teaching style, and larger class sizes (Lowe & Cook, 2003). This could be particularly problematic for autistic students who may be sensitive to sensory input such as noise from others in the classroom, which could impact academic performance (James et al., 2022). Other commonly discussed academic challenges for autistic students include difficulties in written communication and difficulties in participating in group work (Anderson et al., 2017; Davis et al., 2021; Madaus et al., 2022), with the aforementioned social difficulties often seen in autistic populations potentially making group work difficult. Furthermore, a lack of clear instruction from course tutors and inaccessible course material have been cited as further academic difficulties students encounter (Van Hees et al., 2015), with autistic students often

requiring concrete and clear language use (Chahboun et al., 2017). With many of these areas being areas of difficulty more generally for autistic populations, it is clear to see how HE can be an academically challenging setting for autistic students.

## **Transition support**

### ***An individualised approach to support***

Autistic people are a heterogeneous and diverse group, with the challenges of HE varying between individuals (Anderson et al., 2017). The challenges and strengths identified by autistic populations in HE settings are often paradoxical, in that something one person may consider a strength, another could consider challenging (Anderson et al., 2017). Similarly, an attribute that could be considered a strength in one situation, could be a barrier in a different situation. For example, a strength in intense concentration can be beneficial when completing academic assignments to a deadline, however, in the case of competing deadlines, a student may be required to move between tasks, and this intense concentration could make transitioning between tasks difficult. This demonstrates the importance of contextual and individualised support (Thompson et al., 2019), but despite this, support is not always individualised and person-centered (Cheak-Zamora et al., 2015).

### ***Examples of transition support guidelines***

Legislation in the UK, such as the Equality Act (2010) and the Special Educational Needs and Disabilities Act (2001), has placed a responsibility on HE institutions to provide support and make reasonable adjustments to prevent students with a disability being disadvantaged compared to students without a disability. As such, support needs to be considered both during the transition period to HE, and for the duration of the students' time in HE. National guidelines for transition planning in the UK are not clearly available, with certain areas of the country establishing their own guidelines. For example, guidelines for the transition from secondary school to post-secondary education have been developed by Devon County Council, (2022). Despite the guidelines highlighting the importance of individualisation in transition planning, the areas recommended to consider are still rather generalised. For example, the guidelines recommend that visual aids be provided for autistic students to aid the retaining and recalling of information. Whilst this may indeed be useful for some autistic students, it is important that the appropriateness of each suggestion is considered on an individual basis. As such, there is a need for a common, national framework to be used in the UK in relation to transition planning, with the current provision being inconsistent and inadequate (Essex &



Melham, 2019). However, the importance of person-centered planning (Hagner et al., 2014) should not be lost in the development of any national guidelines, with the balance of this likely being a difficult one to navigate.

It is also important to highlight that autistic women are underdiagnosed, receive later diagnoses than their male counterparts, and are frequently misdiagnosed (Lai & Baron-Cohen, 2015). This could result in many autistic women being undiagnosed during their time in HE. As such, it is likely that they will not qualify for support outlined in guidelines as they will not be classified as having a disability, and therefore will not be recognised as requiring additional transition support. This speaks to a wider issue of the different rates of autism diagnoses between men and women, which I will go on to discuss later in this chapter. It also speaks further for the need for students to be supported on the basis of individual need, not on the basis of a diagnosis.

Research into the support students receive both when transitioning to, and during their time in HE is increasing, (Davis et al., 2021; Fabri et al., 2022; Gelbar et al., 2014), but, the programmes and supports that are available have often been adapted from other support programmes and are usually not designed specifically for autistic students (Lambe et al., 2019), who may have additional and different needs compared to students with other disabilities. However, it is important to note that there are some instances of transition programmes having been designed specifically to aid autistic students transitioning to university (Hillier et al., 2018; Hotez et al., 2018; Roberts & Birmingham, 2017). Target areas vary and can include: the improvement of social and communication skills (Hillier et al., 2018; Weiss & Rohland, 2015;), problem solving abilities (Pugliese & White, 2014), and course completion and retention (Kuder & Accardo, 2018) However, these will not be discussed in depth here due to them being limited in relatedness to the experiences of the participants in the current research, with the majority of participants in this research not having a diagnosis during their time in HE, and as such, not qualifying for support from tailored support programmes. Participants in the current research did not reflect on support from specific support programmes offered by their institutions.

### ***How to support autistic students in HE***

Despite high withdrawal rates for students with disabilities generally, HE institutions have particular difficulty in supporting autistic students who may experience additional difficulties in areas such as communication, social skills, and independent living (VanBergeijk et

al., 2008). There is a need for existing support programmes and interventions to be modified to ensure support is appropriate (VanBergeijk et al., 2008). Worryingly, an environmental scan by Ames et al. (2022), found only 6% of HE institutions in Canada provided autism specific support for their students, further suggesting that, whilst HE institutions are providing support for their students with disabilities, this support is rarely tailored to specific disability groups, including autistic students. However, it is important to consider that the Ames et al. (2022) research assessed the support provided by information gathered from internet searches, with the potential that the information may not be up to date. It is possible that additional, tailored supports are in place that are not reflected on institution websites. However, this is also concerning, as, if students are researching institutions, they could be deterred from applying if there appears to be limited support. It is also important to highlight that the levels of support varied across different institutions, again perhaps suggesting the need for consistent guidelines and support for both the transition period and throughout the students' time in HE.

Similarly, research into the types of provision available for autistic students in HE in the UK found several categories of specific provision (Vincent et al., 2022). These included transition to university, specialist tutoring, daily living, social groups, self-advocacy, transition to employment, and peer mentoring. This data was also gathered from information on institution websites. Interestingly, institutions that offered the most provision often belonged to the Russell group, a group of 24 of the leading research focused universities in the UK. The study showed that most provision was directed to supporting students in their transition, and then focused on academic support, with less social and daily living support. It is likely that support is different at each institution. Furthermore, it is also likely that institutions are more experienced in providing academic support to students, potentially explaining the increased focus on such support. However, autistic students may require different types of support compared to neurotypical students, such as social support, and this may be unfamiliar for HE institutions. Additionally, the results of a systematic review (Anderson et al., 2017) demonstrated that many autistic students in HE do not receive adequate support. However, the experience of support received varied between studies in the review, with some students reporting being well supported by their institution, and others not. This review also highlighted the variation in needs of autistic students as a heterogeneous population, demonstrating the importance of individualised support rather than a “one size fits all” approach.

Much of the research into the experiences of autistic students as they transition to university has used parent and educator views on the transition rather than students themselves (Elias et al., 2019; Elias & White, 2018; Gobbo & Shmulsky, 2014), highlighting a need for further research into the perspectives of autistic students into their transition, support needs, and experiences. Overall, from the available research it appears that traditional disability services in HE institutions are not appropriately meeting the needs of autistic students (Ellison, 2013) with insufficient support being reported (Cai & Richdale, 2016).

### ***Non-academic support inconsistent***

As discussed, there are differences in the perspectives of autistic students regarding whether the support they receive in HE is adequate (Anderson et al., 2017). Many autistic students have found the provision of academic support in HE to be adequate, whereas support in non-academic areas has been inadequate (Anderson et al., 2017; Barnhill, 2016; Cai & Richdale, 2016; Lambe et al., 2019). This is concerning as autistic students will likely experience additional barriers such as social and communication difficulties, mental health difficulties, and difficulties with daily living, not solely difficulties in the academic aspect of university (Cai & Richdale, 2016; Madaus et al., 2022). Additionally, it is well documented that many autistic students have the academic capabilities to succeed in HE, with aspects of social and emotional skills making the environment challenging (Zeedyk et al., 2016).

The availability of both academic and social supports for autistic students in HE is inconsistent, with a review by Gelbar et al. (2014) finding more academic support to be available than non-academic support. On the other hand, in their systematic review of 23 articles primarily from the USA, Anderson et al. (2017) found that both academic and non-academic support were largely available. However, it is not only the availability of academic and non-academic support, but the effectiveness and nature of such support that is important, for example, ensuring the support is tailored to the individual's needs. Academic accommodations identified by Anderson et al. (2017) included note takers, assignment extensions, and exam accommodations. Other, more social accommodations included, counselling services, social support groups, and assistance with daily living. This review also demonstrated that it was unusual for requests for support to be declined. However, in line with the review by Gelbar et al. (2014), there were instances identified where students would have preferred social support, but instead received academic support. This could suggest that academic support is more readily available than non-academic support, or that there are miscommunications between the students and the staff approached for support.

An alternative explanation for this difference in availability and provision of academic and social support by HE institutions could be in relation to how universities view their role. For example, it could be that universities traditionally view their role as primarily academic, and as such, have become more accustomed to providing academic support. However, with more research into student mental health, it is hoped that this perspective could be shifting, with universities beginning to take a more active role in supporting students in ways outside of the academic. This idea is supported by education staff in the Essex and Melham (2019) study, who reported the role of a university is not only academic, but also to give students a rounded experience of life skills and enable them to develop as a person, suggesting that success should not always be measured solely by academic progress.

When considering whether the support offered by HE institutions is not only available, but effective, some students reported academic support to be adequate, whereas non-academic support to be inadequate (Cai & Richdale, 2016). Students reported accommodations such as extensions for assignments and flexibility in terms of teaching style to be effective in reducing their academic anxieties. However, difficulties were reported in accessing these, for example, miscommunication with course staff. In interviews with family members of the students in the Cai and Richdale (2016) study, they reported inadequate support in both academic and social aspects of university life. This inconsistency leads to the consideration of whether academic support is sufficient and easily available, and whether autistic students are fully aware of both their needs, and the support they should be receiving to aid them to succeed in HE (Pinder-Amaker, 2014).

Further evidence for the idea that the academic support autistic students receive is more readily available and of higher quality than the non-academic support was demonstrated in the systematic review by Anderson et al. (2017). Whilst students in some studies reported adequate or satisfactory non-academic support, other students did not, and where the support was felt to be inadequate, ongoing difficulties were described by students in terms of the social aspect of university, and difficulties with their mental health. On the other hand, where supports were found to be useful, students reported that their social skills had improved because of these.

One of the social supports rated most highly in the Anderson et al. (2017) review was both academic and non-academic mentoring (which likely looked different at each institution), with students identifying improvements in a range of areas following this kind of support. However, some students reporting finding it difficult to communicate their needs to a stranger and finding the process “humiliating”. This further highlights the importance of working with

students individually to assess their needs and identify appropriate supports that can be put in place (Van Hees et al., 2015). The mixed findings regarding the support autistic students receive at university is suggestive of inconsistent support across different HE institutions.

### **Strengths based perspective**

Much of the existing research into the experiences of autistic students in HE is focused on barriers to access and success (Davis et al., 2021; Gelbar et al., 2014; Paskins, 2018; White et al., 2016). Whilst it is important that the challenges and barriers autistic students face are recognised, explored, and understood, in order that changes can be made and appropriate support implemented, it is not unreasonable to suggest that such a deficit saturated narrative could negatively impact autistic students' wellbeing (Milton & Sims, 2016; Seers & Hogg, 2021).

Autistic students often have a range of academic strengths that are conducive to study in HE, including: reading and writing skills, attention to detail, an ability to hyperfocus, memory, persistence, and passion for their area of study (Anderson et al., 2017; Essex & Melham, 2019; Gurbuz et al., 2019; Madaus et al., 2022; Russell et al., 2019). Autistic students also frequently possess strengths that enable them to be successful outside of the academic arena, including determination, fairness, a willingness to listen, and time management (Madaus et al., 2022). Again, it is important to note that strengths vary within autistic populations, further highlighting the need for individualised assessments of needs and support. For example, research has suggested that time management can be an area of difficulty for many autistic students (Madaus et al., 2022; Van Hees et al., 2015). However, individual variation within the Madaus et al. (2022) research itself shows that some autistic students perceive this a strength. Additionally, despite autistic populations often being perceived as having difficulties with social communication, some students have identified aspects of their social skills as a strength, such as empathy and compassion (Russell et al., 2019), further purporting the individualised nature of perceptions of strengths and challenges, and the importance of challenging stereotypes.

As discussed, it is important to remember that both strengths and barriers are individualised and can be paradoxical, with a trait that one autistic person may view as a strength, another may see as an area of weakness. Similarly, it is difficult to categorise a trait as a strength or weakness, as the way in which they interact with the context is dynamic. An example of this is an individual's attention to detail. A strength in attention to detail can result in high quality work but can also lead to difficulties with time management (Russell et al., 2019), or an ability to hyperfocus may be helpful when working to a deadline, but could be problematic in the case of multiple deadlines, or a need to move between tasks. Overall, it is essential that

institutions focus on strengths to enable not only greater access to HE for autistic students, but to change the experience of autistic students in such settings (Thompson et al., 2018) and as a means of moving away from a deficit saturated narrative of autism.

### **Gender differences in autism diagnoses**

When considering gender, it is necessary to differentiate between the terms ‘gender’ and ‘sex’. Gender refers to socially constructed roles, norms, and behaviours expected of men, women, girls, boys, and gender diverse populations, and can change across time and culture (World Health Organisation, n.d.; Unger 2020). Sex, on the other hand, refers to the biological attributes of a person, including chromosomes and reproductive organs (World Health Organisation, n.d.). The term gender identity reflects how an individual makes sense of their gender, which may or may not align with their sex assigned at birth (Warrier et al., 2020), with narratives of gender as a binary concept being problematic (Hyde et al., 2019). With a move away from gender being viewed as binary, this leads to increased complexity in defining the terms male and female (Lindqvist et al., 2021).

As previously stated, it is important to note that four times as many males are diagnosed as autistic than females (Whiteley et al., 2010). Despite limited research, there are also increased rates of autism diagnoses in gender diverse populations compared to non-gender diverse populations, with 4% of autistic children being reported to identify as gender diverse, compared to 0.7% children without an autism diagnosis (May at al., 2016; Stagg & Vincent, 2019; Warrier et al., 2020).

### ***Exploring increased autism diagnoses in males***

I will now go on to discuss the potential reasons for increased autism diagnoses in males, and the importance of research into autistic girls and women. For the purposes of this thesis, the focus is on women, due to the under assessment, reduced diagnoses, misdiagnoses, later diagnoses, and reduced research into the experiences of autistic women (Lai & Baron-Cohen, 2015; Lai et al., 2015; Rynkiewicz et al., 2019; Zener, 2019). Various reasons have been suggested for the difference in the rate of diagnosis between genders, which I will go on to discuss.

Girls and women with higher IQs are less likely to receive an autism diagnosis or to receive it later in life compared to those with a lower IQ (Loomes et al., 2017; Rynkiewicz et al., 2016). This difference could be due to an increase in the abilities of high ability girls and women to camouflage, with autism often being missed in these populations by current assessment

methods, with additional difficulties often needing to be apparent to meet the threshold for diagnosis (Dworzynski et al., 2012). This will be particularly relevant for women attending HE who are likely to have higher IQs. Additionally, whilst women comprise 56.5% of the undergraduate population in the UK (Office for Students, 2022), the majority of research into the experiences of autistic students in HE is completed with male participants (Cai & Richdale, 2016; Madaus et al., 2022; Tarallo, 2012; Van Hees et al., 2015), highlighting a need for research into autistic females in HE specifically.

Another potential reason for the difference in rates of autism diagnoses between men and women is the extreme male brain theory (Baron-Cohen, 2002). This theory proposes that the profile of autism is more characteristic of males than females and can be supported by research into play preferences between young boys and girls (Davis & Hines, 2020) which suggests that boys are more likely to show interest in patterns and systems, whereas girls are more likely to be interested in social situations and relationships. Therefore, it could be understood that the higher prevalence of autistic males is to be expected, as males are less likely to have an interest or skills in social interaction, which forms part of the diagnostic criteria for autism. However, such differences in play could also be due to differences in how children are socialised rather than an innate preference for certain types of play, with the potential that gender stereotyping could have an impact on toy choice, rather than this being innate in children. The extreme male brain theory proposes that certain characteristics contribute to “maleness” and that individuals should fit societal ideas about what it is to be male, ignoring the increasingly complex concept of gender, and as such, taking a reductionist approach to explaining autism (Ridley, 2019).

Hormonal differences may also contribute to differences in autistic traits between genders, with higher levels of prenatal testosterone being found to be increased during certain periods of pregnancy with males, and being positively correlated with autistic traits in children (Auyeung et al., 2009; Hines et al., 2015). Again, this is suggestive that autism may be more common in males than females due to biological differences. However, other research has found no association between prenatal testosterone and autistic traits in adolescents and young adults (Dooley et al., 2022), suggesting the increased testosterone may not be a factor in autism, as autism is a lifelong condition, and therefore this correlation would be expected to be seen across the lifespan. However, the sample in the Auyeung et al. (2009) and Dooley et al. (2022) studies overlapped, which is interesting when considering the differing findings of the studies. Dooley et al. (2022) suggested that these differences could be explained in terms of increased peer comparison and social motivation impacting the reporting of autistic traits by the young people taking part.

Despite the above evidence which suggests biological differences as a reason for the differences in rates of autism diagnosis in males and females, there is also an argument that autistic girls and women present differently to autistic boys and men, leading to an underdiagnosed population of autistic women. It has been suggested that the female autism phenotype, the way autism is expressed in women, whilst representative of the diagnostic criteria for autism, may be expressed differently to how expressions are typically expected in line with diagnostic criteria (Hull et al., 2020). This underdiagnosis is more likely when it is considered that diagnostic criteria are based on male populations and presentations (Mandy et al., 2012).

There are several reasons why autism may be underdiagnosed in girls and women. One suggestion is that girls may show fewer obvious social difficulties than boys (Head et al., 2014; Hiller et al., 2014). However, autistic women often experience increased difficulties in maintaining friendships long-term compared to autistic males (Hiller et al., 2014) and may experience increased difficulty in managing conflict within relationships compared to males (Sedgewick et al., 2019). Therefore, on the surface it may appear that autistic women have fewer social impairments and have increased social motivation compared to autistic males (Head et al., 2014; Hiller et al., 2014), however, in reality, there may be more nuanced difficulties that are less obvious to others, further providing another potential reason for autistic traits being missed in women.

Additionally, research proposes that girls are more likely to internalise mood symptoms or emotional difficulties, with higher levels of depression being noted in autistic girls compared to both neurotypical girls and autistic boys (Solomon et al., 2012). In contrast, autistic boys are more likely to display cooccurring externalising difficulties such as hyperactivity and inattention than girls (May et al., 2016). As boys are more likely to exhibit externalised symptoms of distress, it is not unreasonable to suggest that they may come to the attention of professionals sooner than girls, resulting in them potentially receiving support for potential emotional wellbeing needs, and consequently having potential autism recognised sooner than girls, who may go under the radar, or be interpreted as shy. Similarly, autistic women are more likely to be misdiagnosed with anxiety rather than autism (Bargiela et al., 2016), further contributing to the reduction and misdiagnosing of autism in females.

Furthermore, research suggests that girls are less likely to exhibit restricted and repetitive behaviour than boys (Mandy et al., 2012), with such traits often being more visible to others compared to other aspects of the diagnostic criteria. If girls and women are exhibiting these behaviours less, this provides another reason for autism being missed in female populations,



with some of the visible autistic traits not being observed by others and therefore it being less likely that autism will be recognised by others. If females are exhibiting such behaviours less, this could also further support the notion that it is not that autism occurs less frequently in girls, but that they present differently and are under-diagnosed as traits can be more difficult to identify in females (Hull et al., 2020). Girls are therefore likely to be under-referred for assessment in the first place if their traits are less visibly obvious compared to those of boys.

Alternatively, other research has suggested that girls and women still experience restricted and repetitive interests, but that these are different in nature to those exhibited by boys, and to those typically expected in autistic populations, for example, they may be interpreted as more typical interests for their age (Antezana et al., 2019), resulting in an increased likelihood of potential autism being missed. For example, research by Nowell et al. (2019) found that parents of autistic boys reported their child was more likely to have interests in areas relating to physics, such as vehicles, machines, Lego, and spinning objects, whereas parents of autistic girls reported their child's interests more often fell into areas of television and psychology, with this suggesting that autistic boys' interests are more recognisable as interests typically expected to be seen in autistic populations, further perpetuating the idea that a more female typical presentation of autism may go under recognised.

It is also possible that the gender differences in rates of diagnosis could be attributed somewhat to differences in the socialisation of boys and girls, which could subsequently lead to girls and women being more effectively able to mask their traits of autism (Krahn & Fenton, 2012). Girls and women have been found to more frequently camouflage their autistic traits, by means of masking or compensating for them, when compared to autistic boys and men (Lai et al., 2015), providing a further reason for the reduced diagnosis of autism in girls and women.

Despite the reason, autistic women often receive their diagnosis later than autistic men (Begeer et al., 2013; Giarelli et al., 2010). This is concerning and could also contribute to difficulties experienced in HE by autistic women who may still be adjusting to their diagnosis, if recent, or may not be eligible to receive adequate support if undiagnosed. Similarly, women and those around them may be unaware they are autistic, and as such this could lead to confusion and negatively impact sense of self if struggles feel unexplained.

Whilst the focus on research into the experiences of autistic males may be understandable when considering the differences in rates of diagnoses (regardless of the reasons for this), it remains a concern that the experiences of autistic women are not being captured and understood (Matthews et al., 2019). The dominance of research into autistic males could have

perpetuated a bias in how we understand autism generally, and especially with female populations. Therefore, it is essential that more females are recruited and included in autism research.

Finally, whilst some challenges in HE will be apparent for both male and female autistic populations, there are also barriers that are unique to autistic women. For example, navigating female friendships with neurotypical friends, (such as greater use of emotion focused language in peer groups), barriers to accessing support services due to delayed diagnosis, and female specific health issues (Mademtzi et al., 2018; Milner et al., 2019). This further highlights the importance of female specific research as their experiences differ to those of their male counterparts, and are currently underrepresented in existing literature. Regardless of the reason for females having reduced rates of diagnosis, autistic women are present in HE institutions, and their unique support needs, and strengths need to be understood for them to fully utilise their time in HE successfully.

### **Rationale and Aims**

This thesis sought to answer the question, what are the experiences of autistic women as they transition to HE, and what strengths do they have that help them succeed? As such, the aims of this thesis were to explore the following:

1. The personal, social, and academic experiences of autistic women as they transition to HE.
2. The strengths autistic women have that help them to succeed in HE.

Research into the experiences of autistic students in HE remains limited, particularly research with autistic women, as described above. Current research also focuses heavily on barriers that can make succeeding in education more difficult. Whilst an increased understanding of barriers is essential to improve experiences, autistic students also have strengths that can be conducive to success in HE, and these strengths are presently under researched. Furthermore, autistic voices are under-represented in research, which could perpetuate stigma, and a notion that autistic populations do not understand their own experiences, and means their priorities can be misrepresented in the academic research. As such, the direct involvement of autistic women in this research is essential.

In order to achieve these aims, a search of existing literature was conducted to ascertain what research was already available. To do this, the research was broken down into the two main

parts, the experiences of autistic women as they transitioned to university, and the strengths they have which help them to succeed. Key terms were extracted from each question. The first question included terms relating to, education, transition, autism, and women, alongside generated synonyms to ensure as much relevant literature as possible was captured. The second included, autism, succeed, education, strength, and help, alongside synonyms. The databases PsycInfo and ERIC were chosen as appropriate databases to conduct the literature search, with the hope that they would capture both psychology and education related research. No time or country limits were used in the search. Each part of the research question was searched in each database. In total, 567 results were found across both searches on both databases. From reading the paper titles and abstracts, papers were then put into virtual piles of “likely relevant”, “maybe relevant”, and “likely not relevant” for this thesis. Initially, 59 papers were placed in the “likely relevant” pile, with this being too many to be feasibly used in the research. As such, deeper reading of the papers took place, with a table designed and used to capture the key points of each paper, and help to consider whether it was directly related to the current research. Additional emphasis was placed on more recent research, and research conducted in the UK at this point.

It is hoped that this research will promote more inclusive practice in HE settings, emphasising the role that HE institutions have in ensuring they are accessible for all, rather than putting the responsibility on individual students to adapt to them. It is further hoped that this will subsequently improve the experiences of autistic women in such settings. It is also hoped that by better understanding the transition period, this will allow for recommendations to be made to make the transition period more successful, and hopefully, in turn, improve access and completion rates. Additionally, through highlighting the strengths of autistic students, this research aims to shape how these strengths are considered in HE, enabling support to be specifically tailored to utilise these strengths. It is also hoped that a strengths-based approach will positively impact autistic students’ perceptions of themselves.

Furthermore, research conducted with autistic students themselves is still limited, with much of the available research being carried out with parents and staff teams around the autistic person. This leads to autistic voices being underrepresented in the literature. It is essential that autistic students are given a voice in research, and a space to discuss their own experiences and perceptions of what is helpful when striving to succeed in HE. However, it is not only important that the experiences of autistic students themselves are researched, but that autistic populations are as fully included in the research process as possible by means of coproduction. As such, autistic women with experiences of attending HE will not only be participants in this research, but also consulted regarding the area of interest and design of the research.

## Chapter Two: Method

### Design

This section will outline the rationale for the chosen methodology, Interpretative Phenomenological Analysis (IPA), and consider where it sits in relation to its ontological and epistemological positions. It will provide further information about IPA and alternative methods that were considered. The participatory approach used and how this shaped the research will also be outlined, followed by discussion about the procedure, inclusion and exclusion criteria, ethical considerations, and analytic method used.

### Qualitative Approach

Qualitative research is concerned with individual meaning and perspective, and can aid understanding of how people experience and make sense of the world (Hammarberg et al., 2016; Willig, 2013). Qualitative research can generate rich data, especially from groups whose voices are often under-represented (Howitt & Cramer, 2010; Sofaer, 1999). There are various qualitative methods, and such approaches are increasing in popularity in psychology (Demuth, 2015). This research will also take a participatory approach, meaning that those impacted by the research will be involved in the design process (den Houting et al., 2021).

### Ontological Position

Ontology refers to the fundamental theories or beliefs about what reality is and is concerned with understanding what there is to know (Vanson, 2014; Willig, 2013). Ontological schools of thought sit on a continuum with realism and relativism being the main schools of thought positioned at each end of this. Realists believe there is an external, objective reality independent of our own ideas and perceptions (Willig, 2013). Realists believe that data collected is reflective of this objective reality and is uncompromised by researcher beliefs (Giacomini, 2010).

At the other end of the continuum is relativism. Relativists propose that reality is subjective and dependent on individual perspectives. Therefore, relativists believe that individuals only have access to their own version of reality, depending on their own beliefs, ideas, perspectives, and values (Giacomini, 2010, Willig, 2013). They believe therefore that any data collected in research is a representation of one reality, not the only reality.

Critical realism is a perspective that sits somewhere between realism and relativism. Critical realists believe there is an objective reality, however, that this is interpreted in

accordance with individual experiences, beliefs, and perceptions (Vincent & O'Mahoney, 2018). Therefore, this position proposes that there can be different perceptions of reality (Fletcher, 2017). This project aligns with the critical realism perspective as it is exploring the lived experiences of autistic women as they transition to HE and their own strengths. It is assumed that experiences cannot be accessed without some degree of subjectivity, meaning there will likely be multiple realities perceived by different participants, rather than there being one objective and single reality (Danermark, 2002).

### **Epistemological Position**

Epistemology refers to how reality is accessed and how knowledge is obtained (Giacomini, 2010; Vanson, 2014). Epistemological positions are also located on a continuum. At one end is positivist epistemology, and at the other, critical and ideological (Giacomini, 2010).

Positivist epistemology assumes that data collected corresponds directly to reality. Positivism proposes that knowledge can be obtained by objective and measurable observations (Giacomini, 2010), and usually takes a realist ontological position. Interpretive, critical, and ideological epistemologies flow from a relativist ontology and assume that dominant discourses construct the main and common ideas about reality (Giacomini, 2010). Such approaches propose that subjective experience (and the interpretation of experience), values, and social constructs shape reality, which is different for each individual. Therefore, those who position themselves in an interpretive, critical, or ideological way believe that data collected reflects individual experience and meaning made from such experiences (Vanson, 2014).

Ontology and epistemology are linked, as our ontological position will naturally shape our beliefs on what knowledge we can acquire, and how (our epistemological position). Therefore, when considering the critical realist perspective of this research, the epistemological position takes a phenomenological approach, with the aim being to produce information about the subjective experiences of participants.

### **Methodology choice**

#### ***Thematic Analysis***

An initial methodology that was considered for this project was thematic analysis (TA). TA is widely used in qualitative research, with codes being generated from data, which are then used to identify patterns or themes to explain an experience (Braun & Clarke, 2006). TA is not grounded in a particular epistemological position, and whilst this can offer flexibility (Braun & Clarke, 2013), it can also lead to differences in the way it is conducted (Nowell et al., 2017). TA

is also frequently used for larger samples, with the sample used in this research being small. Additionally, with TA being focused on finding patterns in data, whereas this study was focused on individual experience rather than identifying themes across participant data, it was decided that TA was not an appropriate methodology choice.

### ***Discourse Analysis***

Discourse analysis (DA) was another methodology considered for this project and originates in discursive psychology (Willig, 2013). DA considers both the language used by participants, and the wider context of this, for example, social and cultural positions, to aid understanding of how reality is constructed (Gee, 2014). The use of DA is preferred in natural settings where conversation is free flowing (Willig, 2013), which is not the case for the data collection in this study. Additionally, DA focuses on a connection between language and the social world (Taylor, 2013). Despite language use being important in this research, it was not the focus on the project, with it instead focusing on individual lived experience. As such, DA was not considered an appropriate methodology choice.

### ***IPA***

IPA was chosen as an appropriate methodology for this research due to its focus on lived experience, whilst also acknowledging interpretations both from the participant and researcher (Eatough & Smith, 2017; Smith & Osborn, 2015). The three core aspects of IPA are phenomenology, hermeneutics, and idiography. Rather than seeking an objective understanding of an event, phenomenology is concerned with how events are experienced by individuals, and the perceptions they make (Smith & Osborn, 2015). IPA also uses hermeneutic phenomenology, (where hermeneutics relate to interpretation) and tries to understand how individuals experience and make sense of an event (Pietkiewicz & Smith, 2014). IPA assumes that researchers cannot ever fully understand or access participants' direct experiences, as the researcher will also be influenced by their own perceptions and lived experience. Thus, the researcher is interpreting an event or experience that has already been interpreted by the participant, known as the double hermeneutic (Willig, 2013). As such, reflexivity is essential in IPA. Another feature of IPA is idiography, which involves considering individual cases in depth, and understanding their unique experiences and perceptions (Pietkiewicz & Smith, 2014). Each case is analysed independently before general themes or shared experiences are identified (Pietkiewicz & Smith, 2014; Smith & Osborn, 2015). As individual accounts and experiences were important in this research, rather than seeking themes or making generalisations, it was felt that IPA was a suitable methodological choice for the research, to ensure each individual's lived experience and the

sense they made of this were accurately reflected, with the sample being small enough that each participant could be held in mind throughout (Smith et al., 1999).

## **Reflexivity**

The role of reflexivity is essential in qualitative research, and especially IPA. Gouldner (1971, p.16), as cited in Dowling (2006), suggests that reflexivity relates to the “analytic attention to the researcher’s role in qualitative research”, suggesting that the researcher is not separate from the data they are conducting or analysing. Colbourne and Sque (2004) further define reflexivity as “an activity of self-inspection”.

Qualitative research and IPA involve the researcher’s own interpretations of the data. As such, engaging in self-inspection is important in identifying subjectivity in the analytic process (Patnaik, 2013). Therefore, reflexivity is essential to conduct high quality qualitative research (Haynes, 2012). Reflexivity within this project included keeping a reflective log, utilising an IPA peer support group, and the use of thesis supervision with experienced supervisors.

## ***Reflexive Statement***

The following statement considers how I came to choose my field of study for this thesis, and how my background and experiences have influenced my choices throughout the research process. In writing my reflexive statement, I used notes from my reflective journal to aid the construction of the statement.

I am a thirty-year-old, White British female, currently living with my husband in the West Yorkshire town where I was brought up. I am in my final year of training to be a clinical psychologist, and prior to this, had several years’ experience working in the NHS in adult acute inpatient services and a neurodevelopmental CAMHS service, as both a support worker and an assistant psychologist. As such, I approach this research with my own ideas, beliefs, and values that are shaped by my past experiences.

Whilst studying for my psychology A-Level, I became passionate about the area and was drawn to progress and work within psychology. I recognise my desire to work in this area is at least partly related to a desire to understand experiences of distress encountered in my personal life. During both training and clinical positions prior to training, I have grown as the type of practitioner I would like to be and explored the clinical areas I am most passionate about. The clinical experiences and opportunities I had, have undoubtedly shaped the clinical and research interests I have today.

Though not strongly aligned to a particular research idea when I commenced training, from my time working in a CAMHS neurodevelopmental service, I was curious about the experiences of the girls and young women who were referred for assessment by the service. Despite not exploring the referral rates and data formally, it was clear through my observations that the number of girls referred for autism assessment by the service were lower than that of the numbers of boys, and that when girls were seen, they seemed to be generally older than boys who were referred. When considering my identity as a woman, it is hardly surprising that I was drawn to explore the experiences of girls and women, particularly when there appeared to be differences in experiences for females compared to males. Additionally, as a woman who has had to pursue medical investigations and challenge medical professionals' opinions regarding my personal health care needs, I am approaching this research with personal experience of being a woman who has had perhaps inequitable interactions with the health service based on my gender.

At the outset of the project, I experienced nerves both in relation to the task of completing a large-scale research project, and doing so in the area of autism, where I felt pressure to do the research justice. I questioned whether it was my place to take on such a project from my position as a neurotypical woman. As such, the participatory approach of the research was even more important. The early stages of the project development were shaped by reading around the experiences of autistic women more broadly. Whilst discussing research ideas with those around me, I was also struck by personal stories of the experiences of autistic students in university, an area I had not considered before, with my prior work being in services with children and young people. As I read more into this area, I noted the reduced research into the experiences of autistic women in HE, but also the deficit focused nature of much of the research, which was mirrored in some of the discussions I was having with those around me. This led me to wonder what was being missed in terms of the strengths autistic women have, with them clearly having the ability to succeed in HE, having been accepted in the first place. Clinically, I had also observed the feedback given as part of autism assessments within the service I worked in, with these seeming heavily focused on difficulties the young person may experience. When I considered these things together, I began to wonder what impact this had on autistic women's perceptions of themselves. From my reading, it became apparent that other researchers were also highlighting the need for research to be more strengths-based, and as such, the strengths-based perspective of this research grew, with it being important to me to challenge a long-standing view of autism being defined by deficits.

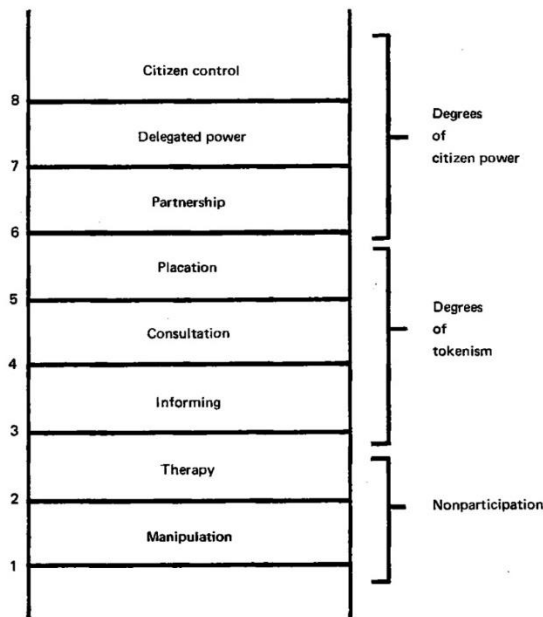


I have tried to remain mindful throughout the research of how my experiences, values, and beliefs will have influenced how I have approached the research. To aid this process, I kept a journal throughout, enabling me to note key thoughts, feelings, and reflections at various points of the process. I hope that this has enabled me to maintain an awareness of biases in how I have approached all aspects of the research. Both supervision and a peer support group have also been beneficial in enhancing self-reflexivity. This project has been challenging at times; however, I believe in its value, and have found it incredibly worthwhile and the participant accounts engaging and moving.

### **A Participatory Approach**

Participatory research is “working together (engaging) with the community that is affected by research to make decisions about that research” (den Houting et al., 2021). Participatory approaches have been increasing in health research and with minority communities over recent years, however, such approaches are still rare in autism research (den Houting et al., 2021). Participatory research takes various forms, though ideally involves academic researchers working collaboratively with communities impacted by the research at all stages of the research process (den Houting et al., 2021).

One diagrammatic way of understanding participatory research, is through the Ladder of Citizen Participation (Arnstein, 1969) as seen in Figure 1. This was developed to demonstrate individuals’ power in designing social programmes, and can also be used when thinking about levels of participation in research. Arnstein (1969) refers to a difference between the “empty ritual” of participation, and individuals having genuine power to impact the design process. Participants have historically been excluded from research, with research often being done “on” rather than “with”. For more inclusive participatory research, a redistribution of power is essential, with Arnstein’s (1969) ladder describing nonparticipation at the bottom of the ladder, to tokenistic involvement, to citizens (participants) having power and control over the design of research at the top of the ladder. Den Houting et al., (2021) designed a hierarchy of participatory research based on Arnstein’s (1969) original Ladder of Citizen Participation. Den Houting et al., (2021)’s hierarchy includes academics holding the power at the bottom of the hierarchy, with research being “done to” communities in the form of coercing and educating, before moving towards “doing for” communities which includes informing, consulting, and engaging. The top of the hierarchy demonstrates communities that are being researched holding the power and research being “done with”, in the form of co-production, being community led, and the community that will be impacted by the research having control.

**Figure 1.** Arnstein's Ladder of Participation

Research conducted with autistic populations remains limited, with much research continuing to be carried out with networks around the autistic person. Therefore, autistic voices are often under-represented in literature. It is essential that autistic students are given a voice in research, and a space to discuss their own experiences and perceptions of what is helpful when striving to succeed in HE. Literature also demonstrates a disconnect between researchers and autistic communities (Chown et al., 2017; Keating, 2021; Woods & Waltz, 2019). Whilst researchers often believe themselves to be engaged and connected with the autistic community, autistic communities do not share this view (Pellicano et al., 2014). One reason suggested for this disconnect is a lack of active involvement of autistic populations in research (Gowen et al., 2019). In focus groups with autistic people and their parents by Gowen et al. (2019), the importance of explaining the rationale and benefits of the research to the population of study were clearly communicated. Similarly, historically, research findings have rarely been shared with autistic populations (Keating, 2021), with the participants in the Gowen et al. (2019) research further emphasising the importance of outcomes being shared with the population being studied.

One way of working towards bridging the gap between researchers and the autistic community is through participatory research, meaning that autistic populations are involved in all stages of the research. This ensures a more even balance of power between researchers and

populations being researched (Cornwall & Jewkes, 1995). Gowen et al. (2019) developed a set of guidelines for conducting research with autistic populations, which includes, how to set up research studies, how to recruit, considerations to hold in mind during the research, and things to hold in mind once the research is completed, all with the aim of being more participatory. Despite this, there is still limited participatory research in the autism literature that goes beyond the tokenistic (Michael, 2021), with reasons such as the structure of academic environments not being conducive to participatory research (for example, time and financial constraints), and a lack of support and guidance from senior academic supervisors to undertake participatory research (Pickard et al., 2022).

However, whilst there is still limited participatory research in autism research, this does seem to be changing, with some examples of successful participatory research (Pavlopoulou & Dimitriou, 2020) and guidelines by Gowen et al. (2019) to encourage and guide such research. Therefore, it is important that this research includes the voices of autistic students, and that the design was guided by consultation from consultant participants.

## **Methods**

As the importance of participatory research was essential in this study, the research was comprised of two phases which I will go onto discuss separately. Phase A was a consultation phase, to help shape the aims and methodology of phase B.

### **Phase A**

The main aim of phase A was to ensure that the research question aligned with priorities of those directly affected by the research, and that the research was as accessible as possible for autistic women in terms of the methodology used.

### ***Sample***

Three participants acted as consultants during phase A. The aim was for a sample size of between two and four. The rationale for this decision was partly due to the time constraints of the project, with recruiting over four consultant participants being potentially difficult. However, sufficient consultant participants were desired so that a range of perspectives were heard to help guide the research. After initially recruiting two participants, with some differing ideas about the project's progression, it was deemed that a third participant would be useful, and efforts were made to successfully recruit a final consultant participant.

### ***Inclusion and Exclusion Criteria***

The inclusion criteria for phase A were as follows:

- Identified as female.
- Aged 18 or over.
- Identified as autistic.
- Had experience of attending HE.
- Sufficient degree of understanding of written and spoken English.

It was essential that participants in phase A had some degree of homogeneity in order that there was an element of shared experience, to ensure their experiences were relevant in meeting the research aims.

Consultant participants were not required to have completed their time in HE, with it only being essential that they had experience of attending in some capacity. Following discussion within the research team, it was decided that participants would not specifically be asked whether they had a formal autism diagnosis or not in this phase. Additionally, it was decided that participants who identified as female would be eligible to take part in the research, with the research team being keen to be inclusive, but also for the research to have a focus on women as an under-researched population.

### ***Recruitment***

Potential participants were identified through existing channels, including both professional and personal contacts of the research team. For example, existing connections to coproduction groups or with individuals or organisations who worked in neurodiversity. Information about the research was provided verbally or via email at this stage. Organisational contacts shared the study details with potential participants who they thought might be interested in taking part and met the inclusion criteria. Potential participants were provided with the lead researcher's email address and made email contact if they decided they wanted more information or to take part.

### ***Procedure***

Recruitment began in September 2022, when emails with basic details of the project were sent to contacts of the research team to establish initial interest. The emailed contacts circulated the study information amongst the networks they worked for, or with individuals whom they thought might be interested. Interested potential participants contacted the lead researcher via

email. An email acknowledgement was sent to such potential participants advising that further contact would be made following ethical approval.

Once ethical approval was granted (MREC 22-088), email contact was re-established with three potential participants who had previously expressed an interest in taking part, though two emails failed to deliver, with it being assumed that the contacts had used their work email addresses and since left their respective services. One potential participant got back in touch to confirm they were still interested in taking part. Two further participants were recruited. One was a personal contact of the lead researcher who was aware of the research, and, after hearing differing opinions from the first two participants, efforts were made to recruit a third participant, a contact of a fellow trainee clinical psychologist. All potential participants were reminded of the voluntary nature of participation at the point of initial contact, and at the point of interview. Once contact was established, potential participants were emailed a copy of the participant information sheet (Appendix A) and consent form (Appendix B) and asked to return to the lead researcher should they still wish to take part, with the opportunity to ask any questions given.

A suitable time for a one-to-one, semi-structured interview was arranged with each of the participants, with the option given to hold this face-to-face, over the phone, or via video technology. Interviews lasted approximately between 60 and 90 minutes. One interview was conducted over Zoom and the other two over the phone. Handwritten notes were taken during interviews. Interviews were not recorded.

### ***Interview Schedule***

Semi-structured interviews were chosen as they allow for rich, first-hand data, with the expectation that topics of importance for the participant could be explored, whilst also maintaining some degree of focus for the researcher (Petrescu et al., 2017). Additionally, one of the main strengths of using semi-structured interviews is the reciprocity that can be generated between both parties (Galletta, 2013), which felt especially important considering the participatory approach of the project. See Appendix C for the topic guide.

The topic guide was designed in collaboration with supervisors to seek the consultant participants' thoughts on both the research area of interest, and the proposed methodology for phase B.

### **Ethical Considerations**

Ethical approval for phase A was sought and gained from the University of Leeds School of Medicine Research Ethics Committee on 21<sup>st</sup> August 2023 (reference number: MREC 22-088). See Appendix D for confirmation email.

### ***Informed Consent and Withdrawal***

Participants were provided with an electronic version of the participant information sheet and given the opportunity to ask questions both prior to the interview (via email), prior to commencing the interview, and post-interview. Participants were reminded at the start of the interview that participation was voluntary and that they could withdraw without giving a reason, either prior to taking part in the interview, or for up to seven days afterwards. However, participants were advised that despite being able to withdraw their data for up to seven days post-interview, the researcher's thinking would likely have already been shaped by their contributions. No participants withdrew after completing the consent form or taking part in the interview.

### ***Potential for Distress***

It was acknowledged that discussing experiences of transitioning to university and considering individual strengths could be sensitive or distressing for some participants. Participants were made aware, via the participant information sheet, that as a trainee clinical psychologist, the interviewer had the necessary skills to help manage and support with any distress or discomfort experienced. The participant information sheet also advised participants that they could terminate the interview at any point. Participants were reminded of this verbally at the start of their interview. Participants were also provided with a sheet with sources of support following the interview (Appendix E). All interviews were conducted in typical working hours to ensure the availability of support from supervisors should sensitive, distressing, or risk information be disclosed.

### ***Confidentiality and Privacy***

Participants were made aware that any information disclosed would remain confidential unless there was deemed to be a risk to themselves or others, in which case the lead researcher would have a duty of care to disclose this. No participants disclosed any information that was deemed a risk issue.

All data collected was handled in accordance with the University of Leeds data protection policy and general data protection regulations. Consent forms were stored electronically in a password protected file, in a folder on the lead researcher's encrypted

University One Drive space. Handwritten notes were typed up and stored in a separate password protected folder on the same One Drive space, with each participant being given a participant number to ensure anonymity. Handwritten notes were kept in a locked drawer in the lead researcher's home until they had been typed up, at which point they were shredded.

### **Data Analysis**

Handwritten notes taken during the interview were typed up individually, then compiled onto one document under a heading for each question. Each participant's responses were transferred onto the document, using colour coded text to enable the differentiation of each participant and their response. This allowed for ease of comparison between responses. No formal analytic method was used for this phase of the research.

### **Phase A Results**

The results of phase A will now be presented. Feedback on the proposed area of research will be presented first, followed by feedback on the design and accessibility of the research. Each participant was given a pseudonym to ensure anonymity.

#### **Starting university**

Each participant in phase A reflected on the area of starting university as being an important one to research, with Sarah stating it was "*really really important*" and a "*worthwhile area to look into*". Sarah further shared how she, "*found it a real shock to the system starting uni*", providing context to her belief that this area was valuable to research. Tiana also spoke of the change that accompanied a transitioning to HE, and reflected that some autistic students will "*need help more than others*". Carly emphasised how this was a "*vulnerable transition point in someone's life*".

When considering the time frame that could be classed as the transition period, the consultant participants had different thoughts. Tiana stated she felt "*settled after two weeks*" and suggested a two-week transition period, with this starting when she moved to her university accommodation. Tiana also spoke briefly about periods of time spent visiting home and returning to university, with "*each one being different*", and seemingly being experienced as subsequent transition points. Sarah and Carly, however, held different views on the transition period. Sarah spoke of transition as beginning from attendance at open days, and Carly felt that it needed to be considered "*before finishing AS levels*" and "*as early as possible*".

As each of the participants agreed that the transition to university was an important area to research, this aspect of the research question was deemed suitable. The different ideas regarding what time period could be classed as the transition was helpful in anticipating the varied lengths of time participants might refer to in phase B when considering their own transition.

### **Experiences of women**

The consultant participants were asked about their thoughts on the research being into the experiences of women only, with mixed feedback. Tiana explained how she felt this was “*a good thing*” due to, “*a lot of research on autistics is done on boys*” with “*barely anything towards girls*”, suggesting that she saw a gap in research with autistic women and welcomed the female only approach. Sarah also shared how she felt this approach was “*beneficial*”, with there being, “*So much research into male experiences*”, suggesting there is less research into female experiences. Sarah further discussed the possibility of including non-binary populations, querying whether the research could include “*non-male populations rather than female*”. Carly expressed similar thoughts, sharing that it would be, “*good to explore issues to do with a female presentation of autism*”, though questioned whether the research could take a more presentation focused approach to participation rather than being based on gender, for example, including males who mask and compensate, rather than focusing solely on females.

Following this feedback, the research team discussed the female only approach and how this would be defined. Ultimately, a decision was made to include only participants who identified as female, to ensure that women as an under-researched group were the focus. Whilst the benefits of recruiting those with a more female typical presentation of autism rather than females themselves were acknowledged, it was deemed too complicated to recruit participants based on presentation.

### **A strengths-based approach**

Again, there were mixed thoughts about the proposed strengths-based approach of the research. Tiana shared how she felt this was “*a good thing*”, going on to talk of how she “*mostly see my autism as a bad thing rather than good, so it’s reassuring*”. Sarah also felt that it would be “*beneficial*” to take a strengths based approach, stating how “*A lot of the time someone sees an autistic person and sees what they can’t do or aren’t as good at doing*”, stating, “*If I was more confident in the things I can do...I might have an easier time at uni*”. This suggests Tiana



and Sarah experience autism as being viewed as a deficit, and that a focus on strengths would have the potential to challenge such a narrative both for themselves and wider society.

However, Carly held an alternative view of the strengths-based approach, with her expressing how this “*dismisses the very real issues that autistic people face*”. Carly stated, “*A more nuanced approach would be preferable which takes into account both strengths and limitations*”. This led to reflections on both the complexity of asking participants to access their own strengths, and the potential that this could be experienced as dismissive of the challenges autistic women face. As such, a decision was made to continue with a strengths-based approach, but with this being held less rigidly, with more openness to discussing barriers in addition to strengths, in part to ensure challenges faced were not minimised or interpreted as being dismissed.

## **Methodology**

### ***Recruitment***

Participants were asked for their thoughts on recruitment channels for phase B. Tiana shared, “*social media is probably the way to go about it*”, and provided suggestions regarding the wording of advertising material, “*be, fairly specific in the words you use, and...let them know what it’s all about*” explaining that “*it would put me off if it’s vague*”. Sarah also suggested social media as an avenue for recruitment. Carly suggested support groups, disability services, and online forums that could be helpful to approach for support with recruitment. Following this feedback, various recruitment avenues were pursued for phase B, as will be discussed on page 56.

### ***Information given beforehand***

Tiana shared how the information given to her prior to taking part in phase A felt “*a little bit too wordy*” with her advising that future information should “*Be straight to the point*”. Tiana also shared how she was “*ok not knowing the questions in advance*” but that “*some people might want it in advance*”. Interestingly, Sarah felt the amount of information shared for phase A was, “*enough*”, stating it was, “*Detailed but not too much*”, and that more information could be “*daunting*”. Carly however, felt that “*as much information as possible*” should be shared with potential participants ahead of them taking part in the research. Carly expressed how a blurb about the researcher would be helpful, and, for participants taking part in person, photos of buildings and directions to reach the meeting point. Carly also shared that a “*list of discussion*

*points in advance*” would be a helpful resource to *“give us additional processing time and to minimise the unexpected.”*

There were clear differences in individual preferences for information shared before taking part in the research. This was held in mind when proceeding to phase B. Easy read material was produced for individuals who may have required this, though no participants in phase B requested it. The opportunity to ask questions and for further information was also emphasised, with check-in emails being sent to participants who took part via email or the via the survey link to allow a space for additional questions.

### ***Creating an enabling environment and means of participation***

When considering how to make the environment most enabling for those taking part, Tiana spoke of how *“somewhere that’s not too noisy”* was important as *“some sounds can really easily block other sounds”*. Carly also spoke of the importance of *“a quiet room with ...dimmed lighting”* and suggested the participant themselves be able to adjust lighting and blinds where possible in the event of an in-person meeting. Ultimately however, no participants in phase B chose an in-person interview.

When considering the form that meetings should take, Tiana felt it was important to *“ask each person”*, as *“Some people might want a group, some might want 1:1, some might want a call, some might want Zoom...”*, with her highlighting the importance of individual choice in how to take part: *“If it’s all just one way, some won’t be open to do it”*. Sarah and Carly echoed these thoughts, with Sarah stating, *“keep the mode of doing it flexible”*, sharing how she, *“appreciated the offer for this phase”*. Carly also suggested, *“ask for individual’s preference”*, explaining how she would prefer a one-to-one interview and would not want to attend a group. She also considered how some autistic individuals may prefer phone contact. Carly summarised, *“Give people the option of completing it however they find easiest”*. Sarah explained how she personally finds *“questionnaires can be good”*, but could also be *“too boxed in”*, with there often being a need for more space. She went on to share that *“interviews are a good way to go”*, and advised against focus groups, explaining how, *“people might speak over each other”*.

With this information in mind, the research team agreed that participation could take the form of either an interview (in person, over the phone, or via video call), a survey, or by emailing questions to participants. Each method of participation was used during phase B, emphasising the differences in individual preference and the importance of offering different means of participation.

Similarly, when asked about communication needs, Tiana stated this would, “*depend on the person*”. Tiana felt it would be helpful for participants to have the option of getting back in touch with the researcher after the meeting to provide additional information should they wish. Sarah emphasised the importance of “*processing time*”, and for participants to be aware that they could go back at a later point should they think of additional points they would like to add. She was also in agreement with the offer for participants to be able to follow up with an email should they have further points to add later, explaining how if she had “*something sensitive*” to say, this may be difficult to verbalise, and would likely be easier to email. Carly similarly advocated for a person-centered approach, ensuring an enabling environment, stating, “*Ask if they require any reasonable adjustments*”, and to be able to bring someone for support should the participant so wish.

When considering the provision of a voucher after taking part, Tiana shared that this may increase the motivation of some to take part, though it may not matter to others, with her explaining that she was unsure whether anything should be offered. Sarah also shared how she was unsure whether vouchers should be offered, stating that it could, “*push anxious people to take part*”, with her holding a belief that, “*Most autistic females passionate about voices being heard anyway*”. Carly felt this should not be necessary but would be a nice gesture. As such, it was decided that a £10 Amazon voucher would be offered for participation, to ensure participants were recognised for their participation, with this hopefully not being too much to “*push anxious people to take part*”.

## Phase B Methodology

### Sample

For phase B, the aim was for a sample of between six and twelve participants. See Table 1 for participant demographic data.

**Table 1. Summary of Participant Demographic Information**

	Carly*	Tiana*	Sarah*	Libby	Sasha	Catherine
Age	50s	20s	20s	30s	30s	40s
Ethnicity	Australian and British	Mixed white and South American	White British	White British	White British	White Northern - European
Formal diagnosis or self-identify	Formal diagnosis	Formal diagnosis	Formal diagnosis	Formal diagnosis	Self-identifies	Formal diagnosis
Diagnosed before or after HE	Formally diagnosed after HE study	Before	After	After	N/A	During fourth degree
Method of participation	Phone interview	Email	Online survey	Online survey	Email	Email

\* Indicates participants who also took part in phase A.

### Inclusion and Exclusion Criteria

The inclusion criteria for phase B were the same as for phase A. One of the consultant participants in phase A had fed back that whilst they felt it was important to explore the female presentation of autism, it could be useful for the research to include males who present in a way more typical of autistic females and focus on the presentation of the individual rather than gender. This was discussed with supervisors, and whilst being keen to be inclusive, and acknowledging that presentations of autism vary considerably and are more complex than male or female presentations, it was not deemed feasible to differentiate participants with a more

female typical presentation. In addition, part of the rationale for the research was that autistic women are under-represented in research compared with autistic men. Therefore, it was decided that the inclusion criteria would remain as participants who identified as female.

Additionally, further discussions were held regarding whether a formal autism diagnosis was required to take part in the research, but it was agreed that participants self-identifying as autistic would be sufficient, in part due to the reduced diagnoses in females and often later received diagnoses in this population.

## **Recruitment**

Following ethical approval being given, recruitment began in a variety of forms. The three participants from phase A were contacted via email to ask if they would still like to take part in phase B, having consented to be contacted again at the end of their first interview. Each expressed a continued interest, and as such, a phase B participant information sheet was emailed to them (see Appendix F).

A recruitment poster (Appendix G) was also shared on my personal social media pages, including Facebook, Instagram, and LinkedIn, which was subsequently shared by friends, family, and colleagues who also signposted to other organisations and individuals who they thought may be able to help with recruitment, or be willing to further share the recruitment poster. Several individuals reached out after seeing this advertisement, seeking further information about the study.

Prior to gaining ethical approval, several organisations and groups were approached to ask if they would be willing to share the details of the study with their networks. Organisations contacted included Leeds Autism AIM, Touchstone Support, Huddersfield Support Group for Autism, Leeds Asperger Adults, University of Leeds Disability services, and the University of York Disability Support service. Once ethical approval was granted, contact was re-established with the organisations who had agreed to share the study details, with several agreeing to share with their own networks.

## **Interview Schedule**

For similar reasons to those outlined for phase A, a semi-structured interview approach was used for participants who chose to participate in interview format. The interview schedule was developed to focus on the main areas of interest, including being a woman in HE, being an autistic woman in HE, transitioning to HE, and individual strengths. See Appendix H for phase B interview schedule.

## **Survey and Email**

The online survey option of participation was produced using Jisc Online Surveys (<https://www.onlinesurveys.ac.uk/>) and included the same main questions as the interview, with a text box being given for responses. Prompts and areas participants might like to consider when answering each question were also provided, which were asked as follow-up questions in the interview format. Similarly, participants could choose to have questions emailed out to them, with them either responding directly via return email, or writing their responses into a word document and emailing this back to the lead researcher.

## **Procedure**

Recruitment for phase B began in March 2024 following ethical approval being granted. The means of participation were kept open following feedback from participants in phase A, to make it as accessible as possible. As such, the option to take part in a semi-structured interview (face to face, over the phone, or via video technology), an online survey, or a back-and-forth email conversation was given to participants.

When a participant's preference was to take part in an interview or email, a participant information sheet was provided via email (Appendix F), along with a link to complete an online consent form. After completion of the consent form, a participant ID was generated and provided to the participant, who then provided this to the lead researcher, at which point an interview was arranged or the questions emailed out to the participant. For participants who chose to take part via an online survey, they were provided with an information sheet (Appendix F), and a link to the survey, with the consent form embedded in the survey, with them being unable to progress with the survey until consent was given. Three participants chose to take part via email, two via survey, and one via phone interview.

## **Ethical Considerations**

Ethical approval for phase B was sought and gained from the University of Leeds School of Medicine Research Ethics Committee on 19<sup>th</sup> March 2024 (reference number: (MREC 23-028)). See Appendix I for confirmation email.

Similar ethical considerations were taken into consideration for phase B as were for phase A, including the potential for distress, confidentiality, and the informed consent and withdrawal process. Participants were given seven days within which they could request to withdraw their data, though no participants requested to do so in either phase.

Participants were made aware that any information disclosed would remain confidential unless there was deemed to be a risk to themselves or others, in which case the lead researcher would have a duty of care to disclose this. No participants in either phase disclosed any information that was deemed a risk issue.

All data collected was handled in accordance with the University of Leeds data protection policy and General Data Protection Regulations (GDPR). Where the interview method was chosen, a recording was taken with the participant's consent and stored securely on the lead researcher's encrypted University One Drive until transcription had taken place, at which point the recording was deleted. Interviews were scheduled within working hours in case there was a need to liaise with supervisors around any risk issues. No risk issues were apparent in either phase.

### Chapter Three: Phase B Results

The results from phase B will be outlined as a series of pen portraits, to situate each participant in context, enabling them to “come alive” for the reader (Hollway & Jefferson, 2000). Pen portraits provide descriptive information about each participant to give context to their experiences and subsequent interpretations made from their data (Elliot et al., 1999; Hollway & Jefferson, 2000). Each pen portrait will include demographic information and the context within which the participant took part, as well as reflections on the process from the researcher. Following this, personal themes identified during analysis will be outlined and discussed. A pseudonym has been allocated to each participant using a random name generator. On reflection, participants could have been asked for any preferences about what their pseudonym should be. The absence of group level analysis in this chapter was a deliberate design choice, with it being deemed more important to tell each participant’s individual and unique story of their experiences in HE. It was felt that to try and group the accounts together and identify themes contrasted with the individualistic nature of the research. When the limited inclusion of autistic populations in research is considered, it felt all the more important that the voices of the women themselves were heard, rather than another layer of interpretation being added on by the researcher, with it being essential that analysis stayed close to the words of the participants themselves. Furthermore, when we consider the range of diversity in human neurobiology as being naturally occurring, it is important that research is conducted in a way that acknowledges this, rather than attempting to group experiences and potentially neglect this diversity.



**Table 2. Stages of Data Analysis**

Stage	Action
1	Listening to and transcribing of the first participant's interview.
2	Re-listening to the first participant's interview a further twice.
3	Reading and re-reading of the first participant's transcript to fully immerse self in the data.
4	Making annotations and exploratory comments on language use, context, or early interpretations in the right-hand margin of the transcript during further reading of the transcript.
5	Conceptualising emerging themes in the left-hand margin of the transcript based on exploratory comments on the right hand margin.
6	Searching for connections across emergent the themes and grouping them together to form themes from the clusters identified.
7	Downloading copies of survey and or email data from subsequent participants and following from step three as above.

It is important to reconsider the double hermeneutic of IPA at this point, with the researcher attempting to seek an understanding of the participants' own sense-making of their experiences. As such, the analysis outlined reflects only one possible interpretation of the experiences shared, despite attempts to ensure credibility. Subthemes will be used throughout the accounts to illustrate the creation of each overall theme.

### **Carly**

Carly was the first person to take part in phase B and chose to participate via phone call.. During the call, we navigated a minor interruption of someone entering the room, and the call disconnecting at a similar point. Despite these interruptions to the flow of the interview, it felt relatively easy to restart the conversation, and Carly was confident she had a private space where she could talk openly.

Carly was living in the UK after growing up overseas. She was given a working diagnosis of autism as a child, however, this was withheld from her, and she was unaware she was autistic until she was in her 40s, after requesting to see her records. Carly ultimately received a private autism diagnosis in the UK.

Carly spoke of how she “*unravelling*” during her time at university, and of the struggles she experienced. Carly enrolled on several HE courses, having experiences of withdrawing and of courses taking longer to complete than would typically be expected.

When considering what it meant to Carly to be a woman, Carly considered the complexity of gender as a social construct. Carly referred to this being a topic that you could “*write jolly essays on*”, and this led me to reflect on the complexity of the question being asked. Carly also explained “*I’m struggling a bit*” when asked what being an autistic woman meant to her. She described how autistic females can be unrecognised as autistic, especially if stereotyped understandings of autism were not met. Carly reflected on how expressed behaviour is often not seen as autistic in females, and how this could lead to negative interpretations of the person by others, with an inference that this is likely different for males.

As Carly was the first person to take part in phase B and the only person who took part via interview, I was a little nervous. In some ways, Carly made my role easier due to her passion and needing little prompting to provide examples for topics she discussed. Conversely, aspects of the interview felt difficult to contain, with the scope of the interview being wider than anticipated. At the end of the interview, I had an abundance of useful information and experience to draw upon, but also a sense that there were certain avenues I would have liked to have explored further, however, did not feel able due to difficulties in interjecting. I reflected afterwards on my reluctance to interject and considered whether this was due to ensuring Carly felt her voice and experiences were heard and not dismissed, due to nerves, or due to social and communicational cues being reduced over the phone, making it difficult for both myself to find a time to interject, and for Carly to recognise I wanted to comment.

**Table 3. Carly's Personal Themes**

Theme	Subtheme
CAR1. Poor treatment by others	CAR1.1 A vulnerability to abuse CAR1.2 Being treated as inferior by others
CAR2. Awareness of strengths and weaknesses as an evolving process	CAR2.1 HE as a place where strengths and weaknesses are exposed CAR2.2 Strengths as dynamic CAR2.3 An ability to identify some of my own strengths but these are often interlinked with weaknesses
CAR3. A need to be seen as an individual not a stereotype	CAR3.1 The importance of understanding individual differences and tailoring support accordingly CAR3.2 Limited understanding of autism from others CAR3.3 A lack of understanding of autistic females CAR3.4 Others assuming my strengths (and weaknesses) as an autistic woman
CAR4. Imagining how things could have been different if I had been more effectively supported	CAR4.1 The difference financial support would have made CAR4.2 Peer support as a necessary but absent resource CAR4.3 The expectation that I should be able to cope as an adult CAR4.4 The need for tailored support outside of the academic CAR4.5 An absence of support prior to and during the transition to university

Theme	Subtheme
	CAR4.6 The importance of early intervention and support
CAR5. The academic element of university as inaccessible	CAR5.1 Masking academic difficulties as unsustainable CAR5.2 Academic expectations that I can't reach
CAR6. Trying to make sense of my own experiences	CAR6.1 HE as having a negative impact on my sense of self CAR6.2 The wider system has let me down CAR6.3 University as an unmanageable experience CAR6.4 A sense of loss at not being able to follow my dreams
CAR7. Considering how support could change in the future	CAR7.1 Universities need to do more to support autistic students CAR7.2 Universities need to know their students as individuals
CAR8. Considering whether the social side of university is important	CAR8.1 Conforming to neurotypical norms CAR8.2 Questioning whether the social side of university matters CAR8.3 Difficult and limited social connections CAR8.4 Making friends that were similar to me

***CAR1. Poor treatment by others***

***CAR1.1 A vulnerability to abuse.***

This subtheme considers not only Carly's reflections of herself (and other autistic women) as being vulnerable to abuse generally, but also her specific experiences of abuse in HE. Carly shared, *"it's not unusual for autistic people to get into abusive situations...autistic women are very vulnerable to domestic abuse"*. At times, it was difficult to disentangle whether Carly spoke solely of her own experiences, or whether she shared experiences of other autistic women, with this being one such occasion where this was unclear. However, I sensed that Carly was trying to convey the severity of the experiences she faced whilst in HE where she explained, *"I was vulnerable to people...he was literally stalking me"*. Carly's use of the word *"literally"* added emphasis to her statement, further highlighting the importance of what Carly wanted to communicate, and perhaps emphasising the severity of the situation she faced. This statement provides a clear example of a time when Carly herself experienced threatening behaviour from others and conveys a sense of her feeling unsafe.

### ***CAR1.2 Being treated as inferior by others.***

This subtheme reflects Carly's experience of being seen as lesser than her neurotypical peers during her time in HE because of her autistic identity. Carly reflected on *"not being treated with the respect or understanding I should have"*, with her implying that stigmatised views and a lack of knowledge about autism in others was a cause of such treatment. The lack of respect Carly refers to is also suggestive of discrimination she experienced during her time in HE due to being autistic. Carly referred to assumptions others made about her and her abilities in HE, with these seemingly being based in the deficits that Carly may have as an autistic woman. For instance, Carly shared *"if people suspect you're autistic, they...look down on you and that can affect how they perceive what you are doing"*. For example, during one course, Carly recalled, *"There is obviously discrimination and people think you're inferior...in terms of your thinking or communication skills and that impacts your marks or how people treat you or perceive you"*. It is apparent that others made assumptions about Carly and her abilities once they were aware she was autistic, with Carly suggesting that such assumptions influenced the marking of academic work. This demonstrates that not only were others holding stereotyped views about Carly and her abilities, but that she also experienced active discrimination in terms of others' behaviour towards her, with her being treated as *"inferior"*. Carly directly referred to the discrimination she faced, stating, *"if people sense that you're autistic, there is obviously discrimination"*. During Carly's interview, I felt a strong sense of injustice from Carly at the way she was treated by others both during her time in HE, and in other settings, alongside a desire for improved autism awareness in the general population. This appeared to feed Carly's passion for contributing to research, and for things to be different for autistic women in the future.

## ***CAR2. Awareness of strengths and weaknesses as an evolving process***

### ***CAR2.1 HE as a place where strengths and weaknesses are exposed.***

Carly had experience of attending several HE courses both in the UK and overseas, and explained how a lack of self-understanding led to her having a “*lack of insight*” into her abilities. Carly inferred this had impacted her choice of appropriate courses to suit her skillset. As above, it was difficult to establish whether Carly was referring directly to her own experiences, or also considering the experiences of other autistic women. This was apparent with the use of the word “*they*” when Carly shared, “*they go into it blind*”, where she referred to the lack of nuanced understanding autistic women have about their abilities when accessing HE, and additionally, what skills might be required of them to successfully navigate their chosen course. Given Carly’s experience of withdrawing from HE courses due to difficulties being exposed, it would not be unfair to assume that Carly does refer to her own experience in this statement. The idea that Carly was unaware of her areas of strength and difficulty was further emphasised as she stated, “*every course I do, some different aspect of my neurodivergence was unmasked*”, highlighting that her time in HE was an ongoing process of learning about herself, with the inference that had she had more insight into her areas of strength and weakness, she could have been better informed when choosing a course of study. This suggests that Carly’s time in HE was difficult due to her lack of knowledge of her own strengths and weaknesses, with her choosing courses that were not compatible with her abilities. This speaks to a wider issue of the importance that Carly placed on in-depth profiling for autistic women, rather than them merely being given the label of autism, in order that individual needs and abilities are understood by both the autistic individual and those around them.

### ***CAR2.2 Strengths as dynamic.***

Carly reflected on the way strengths relate to individual contexts as being variable, with her explaining, “*that can be an advantage or a disadvantage depending on what is required... what the situation needs*”. This suggests it is difficult to categorise traits or characteristics as strengths or weaknesses, as a perceived strength in one situation may be a barrier to succeeding in another. This led me to reflect on the difficulty that participants may experience when being asked to think about their strengths, with this likely being context and intensity dependent.

***CAR2.3 An ability to identify some of my own strengths but these are often interlinked with weaknesses.***

During her interview, Carly recognised strengths she possessed as an autistic woman: “*thinking in a lot more detail and a lot more in-depth.*”, and “*Once I do understand...I...become really, really good at stuff*”, with her notably referring to her ability to be detailed and thorough when seeking knowledge. Similarly, when considering autistic women more broadly, she was further able to identify advantages and strengths to being an autistic woman: “*autistic people have a lot more empathy for other people...a lot more...accepting of different people*”. Carly goes on to reflect that, “*they [autistic women] wouldn't be at uni if they weren't intelligent*”. Carly shared various strengths that she, (or other autistic women) possess, from academic intelligence to emotional intelligence. However, she also considered areas of difficulty simultaneously, suggesting that strengths can be difficult to consider in isolation, and often bring up thoughts of areas of difficulty as well, for example, “*I can be much more in-depth...even though it takes me a lot longer to assimilate information*”, and “*it takes me longer to learn, I'm a slow learner...but once I do understand it...I understand it really in-depth*”.

### ***CAR3. A need to be seen as an individual, not a stereotype***

#### ***CAR3.1 The importance of understanding individual differences and tailoring support accordingly.***

Throughout her interview, Carly spoke of the limited usefulness of “*bog standard*” interventions to support autistic women, with her being passionate around the need for “*more than a label*” with “*personal adjustments*” being essential. Carly reflected on the complexity and variance in autistic presentations, with it being important that “*there's more tailored recommendations for the woman*”. It was not only the support that Carly felt needed to be individualised, but also for others to understand her as an individual rather than a stereotype, with her describing the differences in difficulties that autistic women may experience, and a thorough understanding of these being crucial: “*it's teasing out the executive functioning difficulties*”. I understood that the difficulties experienced are nuanced and can often be difficult to identify through Carly's use of the word “*teasing*”, implying that this is not an easy process, perhaps both for others and the autistic individual themselves. Carly discussed executive functioning several times, with importance being placed on knowing an individual's areas of relative strength and weakness, and what this means for them as a person, rather than others making assumptions about the person on the basis of them being autistic.

#### ***CAR3.2 Limited understanding of autism from others.***

Carly's childhood working diagnosis of autism was kept from her as "*people used to think you could grow out of it*" and there was a sense that she had "*overcome*" autism as she was seen to be "*doing well*". Carly reflected on feeling it was wrong for her working diagnosis not to be shared with her school, as this has gone on to impact the support she received throughout her educational life. However, Carly acknowledged "*it wasn't understood as much as it is nowadays*", which is suggestive of hope that things may be different for autistic women in the education system now, with an increased understanding of autism being lifelong, and of what it means to be autistic. Carly also reflected that much of the understanding around autism was heavily stereotyped, for example, "*I didn't meet the stereotype of what an autistic person is...I can speak well. I've done well at school. I've had a couple of relationships. I've got a couple of friends.*", with her explaining that professionals had written that she could not be autistic as, "*I'd been married before, had children and had a paying job*", further emphasizing a stereotyped understanding of autism, and that improved understanding around the individualised nature of autism is needed. As part of her desire for things to change for other autistic women attending HE, Carly reflected on the importance of training in HE: "*autism specific training needs to be mandatory for staff*".

### ***CAR3.3 A lack of understanding of autistic females.***

Carly spoke of a lack of understanding of autism generally, however she particularly noted the lack of awareness around autistic females: "*As an autistic woman, you're not recognised as autistic...if you're a stereotypical autistic male into computers...or maths...it's understood and recognised by other people*". This suggests that Carly feels autism is still overlooked as a possibility for females. I felt a sense of injustice around this from Carly, with her reflecting on "*gendered expectations*" that continue to exist around autism, with a sense that as a female, "*you're expected to fit in with people much more than a man...there's different expectations in terms of how you behave*". Here, Carly highlighted a disparity in the societal expectations placed on men and women and how this also impacts how autism is viewed by others, with autism seemingly still being held in mind as a predominantly male experience.

### ***CAR3.4 Others assuming my strengths (and weaknesses) as an autistic woman.***

This subtheme relates to Carly's reflections on how others assume her areas of strength and weakness based on her being autistic, rather than getting to know her individual attributes. This highlights the continued presence of stereotyped views held by others of autistic people being a homogenous population. Carly recalled a lecturer suggesting she was not suitable for the course she was studying due to her being autistic: "*they said, 'well you shouldn't be doing the*



*course because...by it's very essence is about communication and as an autistic person...that...is about issues with communicating'”, demonstrating an assumption made that because she is autistic, communication would be problematic for Carly, rather than exploring her individual abilities. Carly further spoke of her parents having a desire for her to study accountancy, with her believing this was due to an assumption about where her strengths would lay as an autistic woman: “I think they just had it in their brain, oh autistic people are good with numbers”.*

***CAR4. Imagining how things could have been different if I had been more effectively supported***

***CAR4.1 The difference financial support would have made.***

One of the main difficulties Carly reflected on was the need to work part-time whilst completing her degree, with this contributing to her, “*handing in scrappy work*”. Carly reflected on not being eligible for student funding, and as such, it was a necessity that she had paid work. However, the demands of this alongside academic work were difficult for Carly to manage, with not having, “*the financials in place*”, putting her at a disadvantage compared to others and leaving her managing various demands at once. Carly frequently referred to the lack of financial support she received whilst in HE, with a sense that if this were increased, it would have reduced the demands placed on her and allowed her to focus her attention fully on her academic work. Carly inferred that this may have led to improvements in her academic work and reduced her stress.

***CAR4.2 Peer support as a necessary but absent resource.***

Carly spoke of the importance of peer support, believing that the availability of this would have, “*made the transition easier*”. Carly felt that pairing existing autistic students with new autistic students would be helpful. I understood that the benefits of this would include having a connection with someone who may have a shared (or similar) experience and sharing what they had already learnt with newer students. For example, Carly suggested, “*what have they found useful for navigating relationships and not getting exploited*”. This suggests the purpose of peer support for Carly would be to focus on support outside of the academic, and on navigating relationships with others and managing vulnerability.

***CAR4.3 The expectation that I should be able to cope as an adult.***

Carly reflected on a wider issue of support for autistic individuals reducing once they reach adulthood. This speaks to an issue of autism often being viewed as a childhood experience rather than lifelong, with Carly reflecting, “*it's almost like, in the NHS's brain...your autism*

*goes away when you're an adult*". This sudden reduction in support, likened by Carly as, "*a sudden cliff edge*", coincides with "*when the person is making the transition from home to uni*", with the timing of this reduction in support likely being difficult when considering the degree of change the person is often experiencing at such a time. I understood Carly's reflections to suggest that once an autistic individual reaches adulthood, there is an expectation that they should be able to cope with challenges they previously may have had support with, and to navigate new challenges independently. The use of the term, "*cliff edge*" gave me a sense of the sudden and dramatic withdrawal of support services. I understood from Carly that this felt an unfair expectation placed on autistic students and further reiterates a lack of understanding of autism as being lifelong.

#### ***CAR4.4 The need for tailored support outside of the academic.***

Carly discussed an assumption being made of "*you're intelligent, therefore you can cope*". This suggested that, as Carly presented as academically able, difficulties in other areas were overlooked, with minimal support offered in such areas. Carly went on to identify specific areas where support could be improved whilst bearing autistic women and their individual needs in mind specifically: "*Counselling and mental health services need to be able to better cater to the differing needs of autistic students - especially autistic female students*", suggesting the needs of autistic females may differ from those of autistic males, and that more recognition needs to be given by HE institutions for this. I understood Carly to mean that HE institutions have a responsibility to provide support outside of the academic to their students, and to not overlook the needs of students who may present on the surface as able. This is especially important when considering autistic students, who may have additional support needs, and to ensure that the unique needs of autistic women are held in mind. When considering the importance of individualised support, Carly appeared to wonder whether her experience in HE may have been different had she "*had these small adjustments in place*", with a sense of her both wondering whether things could have been different and emphasising the importance of support being tailored to each student's needs, rather than institutions assuming what their autistic students may need.

#### ***CAR4.5 An absence of support prior to and during the transition to university.***

Carly shared that she only had, "*two or three weeks...for me to try and get accommodation sorted*", suggesting the transition felt rushed, and that Carly would have preferred more time to prepare. Carly gave a sense of being alone and isolated during her transition to university, with her stating, "*I had nobody there looking out for me*". I understood

that since this transition, Carly had given considerable thought to how things may have been different for her, with her reflecting on the importance of early transition planning and suggesting where things could be different: *“uni link in with these prospective students whilst they are still in college”*, and *“if they don’t get the support they need at school, then they’re not gonna get the support they need at uni”*. This suggests that early and supportive transition planning for university is important, rather than a rushed transition with minimal support, as was experienced by Carly. Carly expressed the *“prelude of going to uni”* as being as important as the transition period itself when supporting students, serving as a reminder that the transition to HE begins before the physical move.

#### ***CAR4.6 The importance of early intervention and support.***

Finally, when considering how things may have been different for Carly had she received more appropriate support, Carly discussed how staff at her institution could have intervened earlier, stating, *“I should have been gotten out of that course before my marks went down”*. Carly reflected on the impact that low marks had on her future academic career and the steps she had taken to bring her grades back up, with this being both time and energy intensive. Carly placed a responsibility on HE staff to engage in *“close monitoring and tough discussions”* with their students, where it is apparent that they are experiencing difficulties. It seems that Carly felt she was allowed to continue with the course for too long, and the difficulties she experienced were either not recognised by staff, or effective support was not implemented. Carly appeared to be left with an uncertainty about whether her journey through HE could have been different had these things happened earlier in her course.

#### ***CAR5. The academic element of university as inaccessible***

##### ***CAR5.1 Masking academic difficulties as unsustainable.***

Carly shared a narrative of being able to compensate for the difficulties experienced academically at the start of university, as she recognised that: *“I sound a lot more intelligent than I am when it comes to...writing essays under pressure”*, and that she could hide her difficulties through excessive work: *“if you’re up all night, no one cares”*. Carly described how she could succeed academically but would spend excessive amounts of time on her work, working late into the night, and due to the increased independence at university, others were largely unaware of the extensive time and effort put into achieving academic success. However, Carly went onto explain, *“eventually it will fall apart”*, suggesting that such compensation is not sustainable long-term.

### ***CAR5.2 Academic expectations that I can't reach.***

Carly expressed some self-belief in her abilities to succeed in her chosen course: “*I can do it*”, but that to succeed, she required accommodations to be made, with her recognising the challenges she faced: “*I can't meet the time frames that non neurodivergent people can*”. Carly reflected on, “*a mismatch in expectations versus what the person is capable of doing*”, suggesting that the expectations from the programme were often misaligned with her perception of her abilities. Carly went on to question, “*how I ever got past it by the skin of my teeth*”, implying that she scraped through, and perhaps was pushed to her limits. I considered the importance of HE institutions having an awareness of the strengths and difficulties their individual students might experience, and the need for expectations to be adapted accordingly.

### ***CAR6. Trying to make sense of my own experiences***

#### ***CAR6.1 HE as having a negative impact on my sense of self.***

Whilst Carly spent a considerable amount of time reflecting on how the wider system let her down, she also referred to times where she had doubted herself and questioned whether she was to blame for the difficulties she encountered, sharing thoughts she experienced at the time, such as, “*if I just try harder*” and expressing how she was “*embarrassed at how much I've struggled*”. This suggests that Carly, at times, attributed blame to herself for her struggles at university. Carly also shared the impact that these struggles had on her: “*it's extremely damaging because you feel like a total failure*” and “*I felt quite...disappointed in myself*”. Hearing Carly reflect on her experience of failure was difficult, especially as this seemed in contrast to the successful and knowledgeable woman I was speaking to on the phone.

#### ***CAR6.2 The wider system has let me down.***

However, it was not just herself Carly blamed for her struggles during HE. She also recognised areas where the wider system had let her down and made it difficult for her to succeed as an autistic woman. Primarily, Carly reflected on the disadvantages that came with being unaware of her autism diagnosis during her time in HE, and questioned whether things may have been different had she known she was autistic at the time. Carly reflected on the need for “*systemic change*”, in relation to autism assessment and diagnosis, though expressed hopelessness that this would happen: “*I can't see that happening in the foreseeable future*”. Carly used language around the need to “*fight*” and “*battle*” for a diagnosis, giving a sense that it is autistic individuals against some ‘other’. In this case, potentially the NHS: “*you can't get it [assessment] on the NHS without fighting for five years*”, the education system: “*you need*

*systemic change...whereby...autistic people are getting the support much earlier on in their education*", and the student loans system: *"opportunities for autistic students to access loans, grants, or scholarships"*. This gives the impression of a mismatch between what the system offers, and what is needed for autistic students to be successful in HE. The war related language is suggestive of this requiring energy, strength, and determination, traits that Carly demonstrated, but that not every autistic woman may have when pursuing a diagnosis. When considering the different parts of much wider systems that need to come together to form change for autistic students, it is not difficult to understand Carly's sense of hopelessness for change.

### ***CAR6.3 University as an unmanageable experience.***

Carly gave a sense of university not only being difficult, but becoming completely unmanageable and that everything *"unraveled"* during her time there, with a sense of inevitability that if a person experiences difficulties in aspects of their executive functioning, *"it will all fall apart"*. This experience was so distressing for Carly that she described how she *"certainly wouldn't want to live it again"* and continues to *"find it quite upsetting to think about"*. When considering what it was about the experience that made it so unmanageable, Carly suggested a *"massive change in expectations and demands"* contributed to her experience, which Carly felt contributed to her *"getting bipolar"*. The impact of the experience on Carly is considerable with it still being difficult for her to think about several years later.

### ***CAR6.4 A sense of loss at not being able to follow my dreams.***

Carly spoke of her experiences of withdrawing from HE courses as *"your dreams are dashed"*, and referred to not being able to follow her passion as a *"grief"*. Carly expressed passion for her first chosen HE course, stating, *"I would have loved to have done it"*, with a sadness and sense of loss that she was unable to pursue this, and perhaps it still being something that Carly is coming to terms with.

## ***CAR7. Considering how support could change in the future***

### ***CAR7.1 Universities need to do more to support autistic students.***

In addition to reflecting on her own experiences in HE, Carly provided thoughts on what institutions could do to better support autistic students at university in the future. Carly felt the role of universities in providing support is not solely academic, with a belief that universities should support their students in seeking assessments for autism where needed: *"the uni needs to do something...some sort of fund for people to get autism diagnosis"*. However, Carly also felt that universities should have an increased role with the screening of potential students prior to

them commencing on the course, with her suggesting, “*doing specialised pre-course testing...specific to the different courses to pick up potential issues early on*”. Carly suggested that universities should have an increased responsibility to ensure the students accepted onto their courses have not just the broader academic abilities to succeed, but have the more nuanced skills needed for success on different courses. Carly further reflected that universities should have a responsibility to ensure “*close monitoring*” with staff “*jumping in as necessary*” when it becomes apparent that students are experiencing difficulties, with it seeming that Carly felt she was allowed to struggle for too long before staff intervened.

***CAR7.2 Universities need to know their students as individuals.***

Carly expressed how universities need to hold their students in mind as individuals, including ensuring they are a good match for the course, with her believing that currently, “*they’re really selling a course, they’re not thinking, is this student the best match for the course*”. From this, Carly seems to suggest that HE institutions are not keeping their students’ interests in mind, and suggests their priority is to fill the spaces on their courses. Carly further emphasised the importance of universities being “*clipped on*” and having an awareness of their students’ individual circumstances where it could impact their success on the course, for example, personal difficulties students are experiencing. However, this is dependent on students sharing this information with the university.

***CAR8. Considering whether the social side of university is important***

***CAR8.1 Conforming to neurotypical norms.***

Carly reflected on an experience of attempting to conform to neurotypical norms in HE, with this being experienced as time consuming and tiring. Carly gave examples of repeated email drafts, “*my first draft, it sounds quite blunt and very direct...then I’ll re-write it so it sounds more friendly*”. I got a sense that whilst Carly felt this was necessary in terms of meeting the expectations of neurotypical peers, there was also irritation that she should have to change her style of communication. The idea that this does not necessarily make sense to Carly is demonstrated when she says, “*I’ll add on all this flowery small talk*”, which gives a sense of unnecessary elaboration being used when it may not be needed, highlighting a difference in the communication expectations between Carly and her neurotypical peers. This is time and energy consuming for Carly, who states, “*there might be three drafts before you get the email*”, suggesting that the need to revisit and edit her emails prior to sending can be draining for her.

***CAR8.2 Questioning whether the social side of university matters.***

At times, Carly presented a view that the social element of university was of little importance to her, with her stating she *“wasn't there to socialise or make friends”*, which gave a sense of Carly having other priorities outside of the social during her time in HE. Carly instead spoke of the academic element of university as being her priority: *“it's one thing to be socially unpopular or awkward, it's another to not be able to cope with the work”*, which suggests that difficulties in the social side of university were of less importance to Carly, whereas succeeding academically was more important. However, at another point during the interview, Carly suggested that upon commencing HE, *“you're more concerned with the social aspect – are you being accepted?”*, proposing that there is some desire to fit in and for acceptance. I sensed conflict from Carly when discussing this, with the academic element often being of most importance to her, however, it seemed that during the transition period, there was some apprehension about whether she would fit in. It also seemed this could be tiring for Carly, with her experiencing a sense of having to *“be good at the social stuff all the time”*, which sounded draining, and suggests that this was not something that came naturally for her.

#### ***CAR8.3 Difficult and limited social connections.***

Carly reflected on difficulties in her social relationships in HE, speaking of how *“they [other students] just weren't interested in me, we didn't click”*, suggesting an element of disconnection from her peers. This also suggests that it was not Carly who was uninterested in establishing relationships with others, but rather the disinterest came from her peers. Not only did Carly describe difficulties with social interactions with others, but she also reflected on a sense of her being the one to *“try much harder than the other person in a friendship”*, suggesting that the responsibility of maintaining friendships, or repairing ruptures to these fell to her, in a similar way to *“if there's any communication breakdown or dispute...the autistic person's always at blame”*. This suggests that whilst there may be barriers in communication between neurotypical and neurodiverse populations, the blame for difficulties encountered, and the responsibility to “fix” it, usually lays with the autistic individual, which leads to a sense of injustice, and of assumptions being made about Carly's ability to communicate as an autistic woman.

#### ***CAR8.4 Making friends that were similar to me.***

Carly shared how, *“autistic people gravitate towards each other and click naturally”*, suggesting an ease around other autistic people that was not always apparent with neurotypical populations. Carly spoke of making one friend during her time in HE, and although she was not

formally diagnosed as autistic, Carly reflected that she “*strongly suspects*” she was, further evidencing it being easier to establish relationships with other autistic women.

### **Tiana**

Tiana was the second participant to take part in phase B. Tiana was the first participant to take part in this phase via email, with questions being emailed to her and her emailing her responses back on a Word document.

Tiana received a formal autism diagnosis at approximately aged three. She transitioned to HE straight after sitting her A-Levels. Tiana reflected on having not wanted to attend university initially, however changed her mind after attending a convention where a specific institution stood out to her.

When considering what it meant to Tiana to be a woman, she advised that it was not something she thought about. Tiana answered similarly when asked to consider what it meant to her to be an autistic woman in HE. She went on to discuss how she only shared her diagnosis with certain people at university, though began to speak more about it in her final year, perhaps suggesting a need to feel secure in established and safe relationships prior to disclosing. This led me to consider the different ways in which people make sense of and interact with being autistic, and I got a sense that Tiana preferred not to think about it too much. It further made me think about the complexity of asking individuals to consider what their gender means to them, especially if this is not something they have previously given much thought to, with it perhaps seeming quite an abstract concept.

Tiana had difficulties recalling her experience of transitioning to HE. At times, it seemed that Tiana made attempts to distance herself from her diagnosis, with a sense that the topic of autism could be a difficult one for her to discuss.

There were notable advantages and disadvantages to Tiana’s chosen method of participation. Tiana’s responses were concise and directly related to the questions. However, there were times where an interview may have been helpful in terms of asking follow-up questions or seeking examples to expand on the detail given and consolidate my understanding of Tiana’s responses.

Tiana’s understanding of the difficulties she faced as an autistic woman at university were often internalised as problems within Tiana herself. Tiana’s response was uncomfortable to read at times, as knowing the participant personally, it was difficult to read some of her sense making of her experiences, for example that she does not think she has any strengths.





**Table 4. Tiana's Personal Themes**

Theme	Subtheme
T1. Autism as a deficit in HE	
T2. The importance of positive relationships with peers	T2.1 An unusually positive social experience T2.2 Ups and downs of relationships with peers
T3. A practical approach to transition	
T4. The need for more nuanced and accessible support	T4.1 Limited support provided T4.2 A long road to support T4.3 An availability of academic support, but a need for more support outside of the academic
T5. The academic element as challenging	T5.1 Sensory needs as impacted by the academic aspect of university T5.2 A loss of passion for the subject T5.3 Course content as inaccessible
T6. Strengths as inaccessible	
T7. Questioning whether I belong	

### ***T1. Autism as a deficit in HE***

Tiana held a deficit focused narrative when considering what it meant to her to be autistic, including the negative impact it had on her time in HE, stating, “*my autism made every aspect of uni difficult*”. I got a sense of the sizeable impact being autistic had on Tiana, with her finding it difficult to identify any positives: “*I can't think of any advantages [of being autistic]*”.

I considered the energy it must have taken Tiana to navigate the HE setting where every aspect of it was harder than for neurotypical populations. Tiana also expressed a helplessness that things could have been different, as demonstrated when asked if there was anything that could have made her time in HE easier, with her responding “*sadly, I don’t think so*”. This further speaks to Tiana making sense of her struggles as a deficit within her, with her being unable to consider how support or environmental changes could have made things easier for her, which is suggestive of a sense that external support could not change the internalised deficits within herself.

## ***T2. The importance of positive relationships with peers***

### ***T2.1 An unusually positive social experience.***

Tiana seemed to suggest that she had expected relationships with others at university would be difficult, and that there was an element of surprise when there were positives to such relationships, describing the social aspect of university as: “*surprisingly quite good*”. Tiana went on to describe how she made friendships in each area of her university life: “*flat, course and my [sport] team*”, and that these relationships were sustained outside of the HE setting: “*I’m still in contact with some of them to this day*”. As such, I wondered whether Tiana had previously experienced difficulties in relationships with others, and had low expectations about how these would be in university. It would have been helpful to explore further with Tiana more specifically what was “*good*” about her relationships with her peers, and how sustained relationships look now.

### ***T2.2 Ups and downs of relationships with peers.***

Tiana wrote about times of “*fun and laughter with my flatmates*” during both her “*first and final year*”. However, she also reflected on a different experience in her second year when, “*I didn’t get along with my flatmates*”, with her citing, “*a personality clash*” as the reason for difficulties experienced. It would have been interesting to explore further with Tiana the specifics of what made her second year at university difficult, and the difference in relationships between then and her first and final years. Tiana also reflected on the friends made in her sports club: “*I suffered a loss and my [sporting] team mates were incredibly supportive*”. This suggests that Tiana’s teammates went beyond what she had expected in terms of supporting her through a difficult time, and made me think of the first subtheme, with the use of “*incredibly*” perhaps further implying a sense of surprise at how supportive they were. This also made me consider

how unsettling it could have been for Tiana, having had a positive experience in her first year, before things changed in her second year.

### ***T3. A practical approach to transition***

Tiana painted a picture of a largely practical transition to HE and thought of how she prepared as any other student starting university would: *“The transitions I did were the same as people who aren’t autistic”*. I wondered whether Tiana knew what to expect of university, and if she had considered whether being autistic would have an impact on her transition to, and experience of, HE. I considered whether Tiana may have been unsure what to expect, and as such, focussed more on practical preparations, with it being difficult to prepare for something that is largely unknown. I also wondered whether she experienced anxiety about such unknowns when starting HE, and preparing practically was a way of having some control over at least one element of the transition. Despite the preparations being largely practical: *“Buying the necessary items”*, there is also evidence of Tiana trying to prepare herself for the social side of university by connecting with her flatmates in advance of starting the course: *“I found two of my flatmates on social media before living there”*. It would have been interesting to explore this further with Tiana, in terms of who initiated the contact, and what purpose or effect this had.

### ***T4. The need for more nuanced and accessible support***

#### ***T4.1 Limited support provided.***

Tiana recalled being supported during her time in HE but seemed to imply that more support would have been helpful: *“I had support but not a lot of it”*. This suggests that whilst Tiana acknowledged the support she had, it did not fully meet her needs. This further implies that had more support been available, it could have made a difference to Tiana’s university experience. Alternatively, it could be that further support was available, and Tiana was not aware of this, or that she was avoidant of seeking excessive support.

#### ***T4.2 A long road to support.***

Despite Tiana being provided with some support, it seems this was not immediately accessible upon starting university, with her recalling, *“There was quite a long process to put the support in place”*. I wondered whether university staff were aware that Tiana was autistic before she commenced HE. Whilst unclear, it led me to consider that, assuming university staff were aware, it seemed an oversight for the support to not be available upon her joining. I considered the impact that lacking support in the early weeks could have had on Tiana. Arguably the earlier weeks are when support is most crucial (though this is not to dismiss the importance of sustained

support), and I could not help but consider how much more difficult it could have been for Tiana without support at this time compared to if she had access to appropriate support. However, I also considered that university staff may not have known that Tiana was autistic, as she did not clarify whether she told the university before starting. I also thought about how difficult it could be for the institution to put support in place prior to Tiana starting, should they be unaware of her individual needs, and the importance of institutions getting to know their students' during the period before the actual transition to university. However, this could also be difficult should students be unaware of their own support needs. It also made me reflect on the way that support is currently an "add on" in HE, with the HE environment being designed for neurotypical populations, rather than taking the diversity of the student population into consideration.

***T4.3 An availability of academic support, but a need for more support outside of the academic.***

When sharing the type of support she received at university, Tiana reflected that, "*The support I received was mostly for the academic side*". Tiana gave an example of being given, "*extra time to finish my logbook*" as one of the academic accommodations made. Despite some support with the academic element, Tiana expressed, "*I should've received more academic support*", which suggests that whilst there was support available, it was not sufficient to meet her needs. This led me to wonder whether Tiana's individual academic needs were considered, or whether the support she was offered were generic accommodations. However, it is difficult to know without further conversation with Tiana. Not only did Tiana reflect on the academic support being insufficient, but she expressed that she should have received "*some emotional support*". This perhaps infers that Tiana struggled with her emotional wellbeing whilst at university, and that support in this area would have been beneficial. It made me wonder whether many of Tiana's experiences were unobserved by university staff. Alternatively, if her difficulties were observed, it could be that universities do not see it as their role to provide support in such areas.

***T5. The academic element as challenging***

***T5.1 Sensory needs as impacted by the academic aspect of university.***

Tiana recalled how the academic aspect of HE "*affect[ed] my sensory issues*", and gave an example of: "*when I had to do presentations...that was when the anxiety and sensory issues kicked in*". It was difficult to tell what sensory difficulties Tiana experienced, with her finding it difficult to recall. I wondered whether this difficulty in recall was related to an increase in her

anxiety at such times. However, it is important to note that regardless of the form these took, Tiana experienced specific sensory issues, which I wondered whether is something that is often overlooked by HE institutions.

### ***T5.2 A loss of passion for the subject.***

Tiana shared that being autistic “*impacted my ability to do assignments*”, with this having the subsequent effect of “*losing my passion for my course*”. This suggests that the stress and pressure of managing assignments led to Tiana experiencing a decrease in enthusiasm for her subject. It seems that Tiana’s perception of her subject had changed from something she had a passion for, to something that she had to prove herself in and which was difficult academically. However, it was not only her passion for the course that Tiana began to question, with her also questioning her abilities, as seen from the quote: “*questioned why I got accepted*”. This made me think of potential imposter syndrome, which I understand to be the experience of self-doubt of skills and abilities, or a belief of being incompetent, despite objective evidence being suggestive of success. It also made me consider whether Tiana saw other students struggling similarly in HE, or whether she felt alone in this.

### ***T5.3 Course content as inaccessible.***

Tiana explained that she “*found it hard to understand the work*”, with her not only finding it difficult, but there also being an element of comparison to her peers, who she believed were accessing the course material easier than herself: “*I found it harder to understand my tasks/projects than my coursemates*”. It would be interesting to explore this further with Tiana to consider whether this was an internal sense she had, or whether she actively discussed how her peers were finding the academic element of university. “*It took me a while for me to get going with it*” further suggests initiation difficulties with the work, or perhaps that Tiana needed longer to process what was expected of her, which could be difficult when working to a deadline. This subtheme led me to reflect on the importance of HE institutions considering the diversity of learning profiles and preferences of their students, so they can be supported to access the material in a way that works for them.

### ***T6. Strengths as inaccessible***

When considering strengths that Tiana may have, she shared, “*I don’t think I have any strengths*”. This led me to again consider the deficit saturated discourse that often surrounds autism, and to wonder of the impact this may have had on Tiana. I was sad to read her belief that she had no strengths, and felt a pull to want to share observations I had made about her strengths

to reframe her narrative. It also made me think again of how HE institutions and society in general understand autism, especially when considering some of the language used, and the focus on areas of difficulty, with strengths often being overlooked. Had Tiana chosen an interview method, I would have hoped to have explored this further with her.

### ***T7. Questioning whether I belong***

Tiana shared a compelling quote: *“being autistic is living in a world that wasn’t made for you... it’s like being in a play where everyone except you has a script”*. This felt powerful and suggested that Tiana experienced a sense that she not only did not fit in HE, but also in the world in general. This statement painted a picture of Tiana having a sense of being exposed as not fitting in, and it being obvious to others that she is somehow different. I got the impression that Tiana interpreted others around her navigating the world with relative ease, with her being on the outskirts of interactions with others, being unsure what her role is. I wondered whether this reflected a sense of anxiety at the potential for such exposure regarding not knowing how to act or present oneself.

### **Sarah**

The third participant to take part in phase B was Sarah. She chose to take part via the online survey option, being the first participant to do so. Sarah received her formal autism diagnosis at the age of 26. She reflected on her experiences of both undergraduate and master’s study. Sarah explained how she had gone straight to university after completing A-Levels, with the main reason for going to university being her desire to study her subject of interest. Sarah also reflected on pressure from her school to attend university, and a drive in herself to be the first person in her family to attend. She wrote about choosing to live at university despite it being in her hometown, to have *“the full university experience”*.

Similarly to other participants, Sarah expressed uncertainty around what being a woman meant to her, stating, *“being a woman is so complex and versatile that its hard to define”*. However, Sarah also explained how she experienced being *“more vulnerable and at threat”*, presumably in comparison to how she imagined the male experience. Sarah reflected on how being a woman interacted with being autistic, explaining, *“being an autistic woman can be a real struggle sometimes (due to stigma and the way other women communicate)”*, which is suggestive of stigma still being a common issue faced by autistic women. Sarah reflected on finding it difficult to consider what being an autistic woman in HE meant to her as she had not received her diagnosis until after she had completed HE.

I got the sense that in taking part via the survey, Sarah was allowed more time and space to give considered answers to the questions asked. I reflected that the written response options may have been advantageous, with space for thought before answering, whereas there is a potential that verbal responses could have led to a pressure to answer straight away, with less space for thought. There were times where, had Sarah chosen to take part in the form of an interview, I would have used the opportunity to explore certain areas more with her, or to seek clarification, however, this was not possible with the survey method.



**Table 5. Sarah's personal themes**

Theme	Subtheme
S1. Difficulties in socialising at university as an autistic woman	<p>S1.1 Feeling disconnected and isolated despite having strengths in relating to others</p> <p>S1.2 Friendships not being sustained</p> <p>S1.3 Having interests that are different to those typically expected of a student</p> <p>S1.4 Communication difficulties as a social barrier</p>
S2. Being autistic at university was challenging, but there were advantages too	S2.1 Being autistic as a barrier and an asset academically
S3. University as having a detrimental impact on my mental health	S3.1 University were flexible with support when I was experiencing mental health difficulties
S4. The importance of having a diagnosis in understanding myself	
S5. Questioning whether my experience of HE would be different had I known I was autistic	
S6. I had transition support from family and school, but I still felt unprepared	S6.1 Practical preparations
S7. Fluctuating self-belief	
S8. Being aware of my own strengths (and weaknesses)	S8.1 A strength in some situations causes difficulties in another

## ***S1. Difficulties in socialising at university as an autistic woman***

### ***S1.1 Feeling disconnected and isolated despite having strengths in relating to others.***

Sarah identified traits in herself that could be expected to make relationships with others easier, for example, *“I am compassionate, kind, and friendly”*. However, Sarah reflected that despite this, there were barriers that made forming relationships with others difficult, with her describing how she is *“so anxious and shy that I don't put myself out there enough to make friends”*, and of how it was *“incredibly hard to socialise and make friends”* at university. She also reflected on being different to her peers: *“I've always known I was different and didn't fit in”*, with her suggesting her relational difficulties have been longstanding and attributing much of her social struggles to being autistic: *“I do believe a lot of my struggles with socialising is related to my autism”*. I understood that Sarah perceived her difficulties in relationships with others as a problem internal to her, from the quote: *“I really struggle to socialise and communicate in a ‘normal’ way”*, suggesting that she was the one who was not interacting as others would expect, and that the way others were communicating was more typical, and neglecting the variation of human experience. Sarah also reflected on how she was, *“more isolated than most people at uni”*, and referred to moving to live at home midway through her course, which could have led to her experiencing an increased sense of isolation. Sarah wrote about her experiences of, *“anxiety and my rejection sensitivity”* making it *“harder to speak up in lectures/classes and [I] struggled to participate in groups which also influenced my ability to socialise and make friends”*. I had not previously considered the impact that being quiet in the classroom setting could have on establishing relationships with others, having previously held the academic and social elements of university separately in my mind. However, Sarah's reflections made me consider how quietness in the academic side of university could also impact relationships formed with course mates both inside and outside the classroom, with peer learning activities in the classroom also offering social opportunities. This seemingly further contributed to a feeling of disconnection and isolation, with the possibility that Sarah was somewhat invisible in lectures, and this was mirrored outside of the classroom.

### ***S1.2 Friendships not being sustained.***

Despite more general difficulties in connecting with others at university, Sarah did write of friendships she made, however, these were not without their problems. Sarah wrote about becoming, *“best friends with my flat mate in first year”*, speaking of how they *“were very*

close”, but then “*began to drift apart because we didn’t see each other as often*”. I understood that Sarah was speaking of a friendship that was reliant on regular in-person contact to maintain it. This is further referred to when Sarah stated, “*Once she graduated, we almost completely lost touch and are no longer friends*”. This made me wonder what difficulties Sarah experienced in sustaining friendships where in-person contact was lessened, and whether she had experienced this in other relationships.

### ***S1.3 Having interests that are different to those typically expected of a student.***

Sarah reflected on how “*A large aspect of socialising at university... is drinking/party culture, and because I’ve never enjoyed that...it automatically meant that I was at a disadvantage when it came to being social*”. Sarah seemed to suggest that it is both expected that students enjoy partying and drinking, and that was the reality of the situation she found herself in: “*my interests are different to those typically expected of a student*”. Sarah suggested that she was different to her peers, as this was not something she enjoyed, and that by not having an interest in this aspect of HE life, she was disadvantaged when it came to socialising. However, it was not only the drinking aspect that Sarah found disadvantaged her, but the limited range of societies that were on offer: “*any societies that existed were all athletic which wasn’t something I was interested in, so I has no good opportunity to try and make friends with the same interests*”. This suggests the increased focus on sporting societies disadvantaged non-sporty students, and limited their opportunities to exposure to peers with similar interests to themselves, with Sarah explaining that she “*didn’t join any societies*”. I wondered whether there being a lack of societies that interested Sarah further enhanced her sense of being different to her peers.

### ***S1.4 Communication difficulties as a social barrier.***

Sarah shared, “*My difficulty with communication...made it harder to connect with people at university*”, which suggested that she made sense of her social struggles as being a difficulty or problem within her, as she stated, “*my difficulty*”, with her taking ownership of this. This suggests that Sarah’s communication style is different to what may be typically expected. However, she went on to state: “*being an autistic woman can be a real struggle sometimes (due to...the way other women communicate)*”, which suggests that she sometimes understands the difficulty as being in the way other women communicate, rather than the responsibility for the difficulty falling solely on her. This suggests some degree of fluctuation of how Sarah makes sense of the communication difficulties she has experienced, and perhaps leads to a suggestion that it is not one or the other who is responsible for the difficulties, but instead a misalignment of

different approaches to communication. Regardless of the reason for this difference in communication, Sarah clearly experienced this as having an impact on the way she was able to connect with others, with the suggestion that she was often misunderstood by others, or she was misunderstanding of them.

## ***S2. Being autistic at university was challenging, but there were advantages too***

### ***S2.1 Being autistic as a barrier and an asset academically.***

Sarah reflected on how being autistic impacted her academically in several ways, including more general difficulties: *“I really struggled in general with university work and deadlines”*, and more specific difficulties: *“I had trouble adapting to the academic writing style and what was expected of me at university”*. This suggests that the style of work was different in HE, compared to what Sarah had been used to previously. However, Sarah also wrote about strengths that helped her during the academic element of HE. Sarah shared how she was *“grateful for my ability to see fine details, notice patterns, and hyperfocus because I do think that this helped me with aspects of the academic work”*. I enjoyed reading Sarah’s account of being able to identify strengths that aided her in HE, and that not only could she identify them in herself, but that she was *“grateful”* for them. Sarah wrote about her subject of study as being *“a special interest of mine, and my passion for it is what drove me to finish my degrees”*. Sarah also shared how her ability to *“see a lot more detail than others”* aided her with the research side of her degree. Additionally, Sarah reflected, *“I’m able to see and hear opposing views and find compromises”*, something which she found was a strength in *“approaching group work”*. This was interesting, as it could be expected that group work could be difficult for autistic students with the need to communicate and work closely with other students, however, it was something that Sarah identified as having a strength in. She also shared how she often found herself *“hyperfocusing on one assignment at a time”*, and whilst this could be interpreted as a strength in some situations, for example when working to a deadline, Sarah also reflected on the difficulties that this could bring: *“I particularly struggled during times when I had multiple assignment deadlines in the same week...I’m not good at managing multiple big pieces of work at once, because I’m not good at stepping away and going to work on a different topic”*. As managing multiple deadlines can often happen in HE, it is easy to see how Sarah struggled with this. Despite Sarah highlighting strengths she had available to her, she did spend more time considering the ways in which being autistic had led to university feeling difficult, with her explaining *“sometimes it feels so debilitating having my brain and normal everyday things can feel impossible”*, with the use of the word *“debilitating”* describing just how difficult it could be

for Sarah. Sarah reflected on what appeared to be a situation of being informed about deadlines earlier in the academic year that were for later in the year: *“I struggled having such long periods of time to do work...because I'm not great at planning”* and that she *“would rather hyperfocus for a few days and get a piece of work done in a short space of time”*. This again shows times where the ability to hyperfocus can be both helpful and unhelpful, especially when considering the need to plan and manage time more independently. When considering the increased independence that can come with attending HE, Sarah shared how *“I am quite independent which means I can be left to my own devices...(but unfortunately this also means I'm unlikely to ask for help even)”*, again demonstrating an area of strength in being independent, that could likely often serve Sarah well at university, however, there being an alternative angle to this, with it making it difficult for Sarah to ask for help when needed. A further difficulty that Sarah reflected on was her ability to respond to feedback given to her by staff: *“I couldn't change the way I approached my work”*, and she wrote about how she often *“repeated myself in assignments...rather than being concise”*. Sarah explained she did this to ensure that she was not misunderstood, however, recognised that this could be problematic.

### ***S3. University as having a detrimental impact on my mental health***

#### ***S3.1 University were flexible with support when I was experiencing mental health difficulties.***

Sarah shared how she had *“struggles with mental health”* in university, with *“heightened”* anxiety, becoming *“burnt out”*, and experiences of *“imposter syndrome”*. Sarah shared how the university staff were *“flexible with giving me extensions, more than for the average student”*. Sarah did not write of any other ways in which she was supported with her mental health difficulties and bereavement she experienced, which could suggest the accommodations provided were largely academic. This perhaps speaks to a wider issue of the types of support available in HE settings. It is also difficult to tell from the written response whether Sarah felt this support was sufficient for the situation she was in, or whether she would have expected further support. I interpreted Sarah's statement as her being grateful for the support she had with the use of the phrase, *“more than for the average student”*, which suggests the support Sarah received did not go unnoticed by her.

### ***S4. The importance of having a diagnosis in understanding myself***

This theme was generated through Sarah's reflections on the helpfulness of having an autism diagnosis in aiding increased understanding of herself. Sarah stated, *“My diagnosis has*

*really helped my whole life click into place*". It seems that once Sarah was formally diagnosed, different parts of herself made sense, where they had not before. Sarah also shared how: *"I feel more comfortable in my own skin since discovering my diagnosis"*, which resonates with her stating how she had always felt *"different"* to others. I wondered whether it was a relief to have an explanation for why she felt had felt different for so long, and that she realised she was not alone in her experiences. I also wondered whether Sarah's diagnosis led to a more compassionate self-understanding. The importance of having a diagnosis was further referred to where Sarah reflected, *"I was more able to ask for support [when pursuing a diagnosis]"*, which suggests that without a diagnosis, Sarah may have felt undeserving of support, or perhaps that she should have been able to manage without additional support. However, when seeking a diagnosis and there potentially being an explanation for her struggles, it could be that Sarah felt more able to ask for help. This perhaps relates to the largely medicalised understanding of autism and neurodiversity that is held by society. Upon reading Sarah's response, I was drawn to consider whether Sarah had a sense of needing a "legitimate" reason for seeking support, which the pursual of an autism diagnosis gave her. This further speaks to the importance of early diagnosis.

#### ***S5. Questioning whether my experience of HE would be different had I known I was autistic***

This theme was generated through a wondering from Sarah of whether her HE experience would have been different had she known she was autistic. Sarah wrote about a belief that she would have had a more *"positive"* university experience had she known, elaborating to say, *"I think my time at university would have been significantly easier and more enjoyable"*. Sarah went on to further explain, *"I struggled so much at university... because I didn't KNOW about my autism"*, implying that things could have been different for her, had she known that she was autistic. It was clear from her capitalisation that Sarah wanted to emphasise this. I wondered whether it was not the struggles themselves that had impacted Sarah at university, but whether there was an internalised self-blame for her struggles, with her having no other explanation for them at the time. On the other hand, once she had a diagnosis, this could have eased some of that experience and increased Sarah's capacity for self-compassion. Sarah further stated, *"I just seemed to fall at every hurdle and struggle my way through things with no understanding of why I was that way"*, further emphasising her difficulties, which implies that the lack of understanding around the reason for these was as difficult as the struggles themselves.

#### ***S6. I had transition support from family and school, but I still felt unprepared***

##### ***S6.1 Practical preparations.***

Sarah reflected on how she “*was as prepared as I possible could be*” when transitioning to university, with her seemingly referring to the practical side of transition. Sarah shared how she “*made huge lists...and bought/organised these all summer long*”. However, Sarah also wrote about how she “*didn't really prepare emotionally*”, instead focusing on the practicalities of the transition. This made me consider both what form emotional preparations might take, and what the reason was for limited preparations in this way. I wondered whether this was related to a reluctance to engage in that side of transition to avoid potentially uncomfortable emotions, or whether there was an uncertainty of how to prepare emotionally. I considered how a practical transition is likely quite logical and structured, though emotional preparations might be less clear.

### ***S7. Fluctuating self-belief***

This theme arose from an uncertain narrative from Sarah regarding her belief in her abilities to succeed in HE. Sarah wrote about “*constantly feeling as though I wasn't as smart/good as my peers*”, which made me think of both the heightened sense of comparison to peers in HE, and of Sarah’s own belief in herself. I felt a sense of sadness at the comparison and doubt Sarah wrote of and wondered whether Sarah experienced heightened anxiety at the constant comparison. However, later in her response, Sarah stated how “*I wanted to prove that I could do it, because I knew that I could*”, suggesting that the self-doubt fluctuated, with her at times, believing that she could complete the course. It would have been interesting to explore further with Sarah whether there were specific times when self-doubt was more prominent and times when she had increased self-belief, and to think about what else was happening for Sarah at these times.

### ***S8. Being aware of my own strengths (and weaknesses)***

#### ***S8.1 A strength in some situations causes difficulties in another.***

Sarah’s categorising of strengths was interesting, with her giving an example of, “*I am quite independent...(but unfortunately this also means I'm unlikely to ask for help)*”. This suggests that whilst Sarah identified independence as a strength, she also recognised the detrimental impact that being too independent can have. This again made me consider the difficulty in asking participants to conceptualise a strength, with them being both context dependent, and likely impacted by the degree of the which the strength is held. For example, in Sarah’s case, independence can be seen as positive, but when this comes to the extent of not seeking support when needed, it is also clear how this can be problematic too.

## Libby

Libby was the fourth participant to take part in phase B, and chose to take part via survey. Libby attended HE for both undergraduate and postgraduate study. Prior to attending HE, she attended sixth form college. When considering her rationale for attending HE, Libby shared that she “*picked my career path quite early on*”, and presumably knew that she would need to attend university to achieve this. Libby explained a contributing factor to her decision making regarding where to attend university was her being “*unsure about living in halls*”, and that she received input from her parents who “*wanted me to live at home*”. However, Libby identified that her parents “*did not pressure me to attend a particular university*”, suggesting that the ultimate decision was hers. Libby “*lived at home and commuted*” during her undergraduate course, but “*moved away*” for her postgraduate study. Libby reflected on being limited in the universities she could attend for both undergraduate and postgraduate study, due to her desire to study courses only offered by select institutions.

Knowing Libby personally, I had to ensure that any interpretation was based on the written information provided, and that I was not holding in mind a prior understanding of Libby from conversations had outside of the research space. This was challenging at times, and meant returning frequently to the data to ensure I was accurately relaying the information Libby had provided, and ensuring interpretations were based solely on this.



**Table 6. Libby's personal themes**

Theme	Subtheme
L1. I am different to other women I know	
L2. An ongoing process of self-understanding of what being autistic means to me	L2.1 A process of accepting my diagnosis
L3. Loss of skills are easier to identify than strengths	
L4. A lack of engagement with the social side of university	L4.1 A sense of not fitting in L4.2 A preference for one-to-one friendships L4.3 My interests are different to a typical student's interests L4.4 Difficulties in making and sustaining friendships
L5. Undergraduate and Postgraduate as opposing experiences at transition and beyond	L5.1 Degree of change as the main factor in the differences in experiences between courses L5.2 A shared and unshared experience L5.3 The importance of preparation L5.4 A difference in academic support L5.5 Increased demands as making things tough
L6. Questioning if things would have been different had I known I was autistic	
L7. University as having a detrimental impact on my mental health	

Theme	Subtheme
L8. Knowing my areas of academic strength and difficulty is important	
L9. Aspects of being autistic as being both helpful and unhelpful at university	

### ***L1. I am different to other women I know***

Libby reflected comprehensively about what being a woman meant to her. She seemed to have a complex relationship with her identity as a woman, with her describing it as a “*part of my identity I have struggled with*”. I felt a sense of tension at her experience, and of her still trying to make sense of this. Libby defined women as, “*kind, strong, caring, consistent and constant*”, and thought of how she “*used to identify as so*”, but seemed more uncertain as to whether she held those qualities currently, speaking to a “*loss of identity generally*”. I felt that Libby previously had a stronger sense of her identity, and that she more closely aligned with other women she knew, but this has changed, with her explaining, “*I don’t see myself like the women in my life*”. Libby further explained, “*I don’t fit in. I feel like an outsider and imposter*”. I felt a pull to want to explore this further with Libby, and understand why she sees herself as such, as I felt a sadness for her when reading this. I understood that Libby continues to be on a journey of exploring what being a woman means to her.

### ***L2. An ongoing process of self-understanding of what being autistic means to me***

#### ***L2.1 A process of accepting my diagnosis.***

Libby wrote about how she had only, “*recently received my formal diagnosis*”, and as such, was, “*still learning to accept my diagnosis and experiences*”. Libby explained that she felt it would be “*a long learning process*” to understand what autism means to her, and she wrote about how she could “*often get frustrated at myself for finding aspects of life difficult that I believe others do not.*”. Libby also reflected on past experiences of “*trusted health care professionals and family dismissing my thoughts*”. Due to her experiences of being dismissed by others, it is possible that Libby’s difficulties in accepting her autism diagnosis will be amplified, with her having perhaps made sense of her experiences through a different lens previously. I also wondered about the impact that multiple instances of being disregarded by others when sharing

her thoughts had on Libby's confidence in trusting her own understanding of herself. Libby went on to reflect: *"my earlier experience with professionals...disregard for potential neurodiversity and potential misdiagnoses and mis-prescribed medication impacted my ability to self-identity as autistic."* Libby spoke of this being a reason for her being supported to seek a formal diagnosis, with her having difficulty in *"allowing myself to accept and explore my potential neurodiversity"* without a formal diagnosis in place. I understood this to mean that Libby required a formal diagnosis to provide a sense of legitimacy to her exploring whether she may be neurodivergent. Libby shared that she is still *"learning about what autism means for me"* and *"I believe this will be a long learning process"*.

Libby shared a *"sadness for the younger version of myself who didn't know they were autistic and were disregarded and potentially mismedicated"*. I felt a sense of injustice at reading about Libby's misdiagnoses and experiences of being dismissed. I considered the difference in rates of diagnoses between men and women, with it seeming that potential autism was not considered by the professionals working with Libby, despite her querying this with them herself. It also made me wonder, having been previously dismissed by others, whether Libby had tried to distance herself from an autism diagnosis and accept other diagnoses, and now was tasked with shifting her understanding again, with this potentially being a confusing process.

### ***L3. Loss of skills are easier to identify than strengths***

Libby seemed to find it easier to identify areas where she had lost skills, compared to identifying strengths and resources she still had. She explained, *"I have lost a number of skills and I'm unsure on my individual strengths, perhaps as I have been so focussed on my difficulties and deficits"*. This is suggestive of a largely deficit focused view of herself as an individual, and I wondered whether this was related to a deficit focused understanding of autism being held by wider society. Libby further reflected on how, since *"experiencing burnout"*, she had *"lost a number of skills and struggle to identify any strengths"*. This led me to consider the impact of the burnout Libby had experienced, and I understood that things had completely changed for Libby since this point, or at least her perception of herself had changed. I wondered whether, had I liaised with Libby prior to her experience of burnout, she may have provided a different account of her strengths. However, it was encouraging to hear a hopefulness from Libby, or at least an idea of the kind of strengths she would like to have: *"I hope however, that I hold kindness, compassion, and curiosity."* Knowing Libby personally, it also felt difficult to hear her wonder whether she holds such qualities rather than having confidence in herself, and I felt a pull to reassure her that she does have such qualities.

#### ***L4. A lack of engagement with the social side of university***

##### ***L4.1 A sense of not fitting in.***

Libby shared how she *"felt out of place and like I was different"* to her peers in HE, with her explaining how, *"it did bother me at times"*. It felt important to separate the lack of desire to attend social events, which Libby seemed content with, and the sense of not fitting in, which was something less comfortable for Libby. Libby reflected on how not fitting in meant that she *"attended one event but left early due to feeling uncomfortable"*. This made me consider whether Libby had attempted to force herself to attend events at university as a means of mixing with others despite it perhaps not being her usual type of activity, or whether there was something about the specific event that led her to feel uncomfortable and put her off attending further events.

##### ***L4.2 A preference for one-to-one friendships.***

Libby reflected on a preference for one-to-one friendships, explaining, *"I wasn't interested in socialising in large groups"*, and of how she, *"found large social situations overwhelming so would remove myself and avoid them."* It seemed that Libby had a clear understanding of the types of friendships she preferred, speaking of how she, *"made one good friend"* and how they *"did a lot just the two of us"*, demonstrating a strong preference for more intimate friendships. Libby reflected on how this friendship, *"stemmed from them engaging with me continuously"*, which implies a need for frequent contact for a friendship to be formed. I was interested to consider what it was about such contact that was important for Libby when establishing a relationship. I wondered whether it took time for Libby to feel safe in relationships, which could explain the benefits of continuous engagement from the other person in developing a secure friendship. Libby also explained how she made *"some friends by proxy through them [her friend]"*, which implies that her friend potentially found it easier to make friends than Libby, and as such, Libby made some friends through her, though could have found establishing such friendships difficult on her own.

##### ***L4.3 My interests are different to a typical student's interests.***

Libby shared how she *"struggled somewhat to make friends"*, and felt that this was partly due to her not being *"interested in socialising in large groups or drinking/clubbing like most other students seemed to be"*. Libby wrote about how *"a lot of the social life"* in HE was centered around *"drinking or going to clubs/bars"*, which put Libby at a disadvantage in making connections with others, with her not having interests that aligned with this. I thought of the

varied interests that students will likely have at university, however, that there still seems to be an increased focus on drinking and club culture, which could either push students out of their comfort zone as a means of trying to socialise in an environment they may not be comfortable in, or leave students without an interest in this area increasingly isolated.

#### ***L4.4 Difficulties in making and sustaining friendships.***

Libby spoke of the difficulties she experienced in making friends during HE: *"I found it difficult to develop friendships or social groups"*. She reflected on how this difficulty was apparent across both aspects of her postgraduate course, stating that she *"struggled to develop social relationships at both university and placement"*, resulting in her feeling *"alone"* in the process. This led me to consider my own experiences of a postgraduate course encompassing both university and placement, and of how difficult it must be to feel alone during such a process. I experienced a sense of sadness for Libby and considered the potential impact of having so few peer relationships, in terms of a lack of others going through a shared experience who understood the complexities of the course, and could offer support.

#### ***L5. Undergraduate and postgraduate as opposing experiences at transition and beyond***

##### ***L5.1 Degree of change as the main factor in the differences in experiences between courses.***

Libby summarised her understanding of why she had different experiences between her undergraduate and postgraduate courses when she stated, *"the difference between the two transition periods seemed to be the amount of changes"*, with Libby holding a belief that, *"the mass amount of changes...led to a quick decrease in my wellbeing."* This suggests that Libby experienced less change when transitioning to her undergraduate course, whereas this was heightened at postgraduate, something which she found difficult. Libby referred directly to this when she explained, *"for undergrad I changed to a new education provider and new people, but had the constant of home life, whereas for postgrad there was no consistency in any aspect (new education, new people, new workplace and role, new location, new travel...)"*, which refers to the degree of change experienced as being challenging. It seems that with her home life as a constant during her undergraduate study, Libby was able to cope with the transition to university, however, when there were changes in all areas of her life in her postgraduate transition, this became unmanageable. Libby referred to her undergraduate experience as being *"quite routine for 3 years"*, whereas her *"transition...into PG education was...difficult. I think...this had to do with various changes and stressors at the same time"*. This also made me wonder if the

increased difficulty experienced by Libby at postgraduate had been a shock after adapting well to undergraduate.

### ***L5.2 A shared and unshared experience.***

Libby reflected on how her difference in experience between undergraduate and postgraduate could be partly explained by whether her peers were going through a similar transition. For example, Libby shared how, when she was transitioning to undergraduate, “*my peers were also transition to university*”, which she reflected made it feel more like a “*natural transition, and not something I was doing alone*”. However, during her transition to postgraduate, Libby shared that her “*peers were not progressing to something similar*”, which led to her feeling “*very much alone in this process, where other's weren't sharing the experience*”. I had not previously considered that perhaps a transition to undergraduate is common and likely often seen as a natural transition for many leaving post-secondary study. However, a transition to postgraduate study is less common, and I imagine especially to a course such as Libby’s which required her to move and manage both university and placement demands. I considered the impact having others going through a similar experience could have, with this seemingly being important for Libby. Libby’s sense of being “*alone*” in the process really struck me, with a sense that she had nobody else to turn to during the transition period.

### ***L5.3 The importance of preparation.***

A further difference that emerged in Libby’s transition experiences to undergraduate and postgraduate study was the amount of preparation time. Libby shared, “*for UG I prepared practically for a long...time*”, discussing how she familiarised herself with the course, campus, and staff prior to commencing, with this making the transition, “*less overwhelming*”. She also wrote about how she prepared for “*18 months prior*” to attending, which I assume gave her time to not only prepare practically, but to emotionally prepare. However, when preparing for her postgraduate course, Libby had less chance to prepare, with her highlighting the importance of having “*time and space*” to prepare to aid the transition experience.

### ***L5.4 A difference in academic support.***

Libby reflected on the difference in academic support she received during her time on both HE courses: “*There was a lot of academic support from both my school and university during that transition period [to UG]*”, compared to: “*There was also a lot less academic support*”, in postgraduate study. I considered whether the difference in support provided was related to an expectation from staff on postgraduate courses that there would be an existing

ability to manage academically in HE from experiences had during undergraduate study, but also thought of how the demands increased substantially for Libby around this time, and how this likely influenced her perceptions of her ability to cope academically. Libby shared how she *“found it helpful to have the academic support for guidance and reassurance”*, which suggests that perhaps she had some confidence in her ability to complete the academic work, but found the reassurance that could be offered important. Regardless of the reason, whether for guidance or reassurance, the reduction of support in postgraduate study impacted Libby’s transitional experience.

### ***L5.5 Increased demands as making things tough.***

Libby reflected on the demands and expectations placed on her during undergraduate and postgraduate as being different. She listed the demands placed on her in postgraduate: *“the academic demands, plus placement demands, plus constant appraisal, along with financial demands..., having to travel a vast distance weekly, and staying in temporary accommodation were all stressors”*. This list felt exhausting to read, and it made me consider how draining the experience must have been for Libby. Libby wrote about a different experience at undergraduate, sharing, *“I was able to dedicate all my time to completing the assignments [at UG], which allowed for me to generally do well”*. This highlighted the impact that increased demands had on Libby during her experience in postgraduate, and how different this felt to her undergraduate experience, where she could fully focus on academic demands.

### ***L6. Questioning if things would have been different had I known I was autistic***

This theme was generated from Libby querying: *“I do wonder if had I known I was Autistic my time as a post grad would have been very different”*. She expressed how she *“would have been able to ask for support and learn about my triggers, difficulties, and strengths”*, speaking to an idea that a formal diagnosis is important in increasing self-understanding. This also implies that Libby saw having a diagnosis as enabling her to seek support, which I understood as having a diagnosis giving her a legitimate reason to seek additional support, and without this, there is expectation that Libby should have been able to cope independently. It would be interesting to explore if this was the understanding Libby had or whether the need for a diagnosis to seek support was a message held more widely within the university system. Libby also wrote about how, by not knowing that she was autistic, this *“impacted my experience”*. I understood this to be partly due to her having less space to explore her strengths and difficulties and partly due to feeling less able to seek support. This highlights the importance of early

diagnosis for women, with a strongly held belief from Libby that her HE experiences could have been different had she known she was autistic at the time.

### ***L7. University as having a detrimental impact on my mental health***

Libby reflected on how she was *"relatively well"* when commencing her postgraduate course, however, *"the mass amount of changes...led to a quick decrease in my wellbeing."* Libby did not give specific examples of how her wellbeing was impacted. She wrote about her experience of *"autistic burnout"*, though reflected that it was assumed to be *"mental health disorders"*, due to her not being diagnosed as autistic at the time. This made me wonder, had Libby known that she was autistic, whether she would have had more chance to explore the impact of change for her and whether she would have been able to prepare differently for her postgraduate transition, and subsequently whether the impact on her mental state would have been lessened. However, it is impossible to know for certain the difference this could have made. It is concerning the impact that the transition to postgraduate study had on Libby, when taking into consideration the already heightened risk for mental health difficulties in autistic populations.

### ***L8. Knowing my areas of academic strength and difficulty is important***

This theme was generated from Libby's awareness of the difficulties and advantages she had in relation to her academic experiences. Libby shared how she experienced deadlines during undergraduate study as *"stressful and anxiety provoking"*, and how she *"found it hard to start work or progress far with it until near the deadline."* Libby understood this difficulty with initiation regarding her academic work as being related to *"needing the stress of an external deadline to motivate me"*. This made me consider the importance of deadlines for autistic students completing work, and I wondered whether having smaller deadlines along the way to a bigger deadline would have been helpful for Libby.

### ***L9. Aspects of being autistic as being both helpful and unhelpful at university***

Libby shared how being autistic *"did impact my PG experience"*, though also shared, *"it is hard to say for certain"* with her not having a diagnosis at the time. I got the sense that Libby was still trying to understand the specific impact that being autistic had on her HE experiences, and to differentiate what was related to being autistic, and what could be related to other parts of herself. Libby reported aspects of being autistic that were likely advantageous to her, and other aspects that made HE difficult. For example, she shared how, during her postgraduate course, *"There was a lot of social stimulation, which is something I know now I struggle with"*, with this leading to difficulties in certain aspects of HE. Libby explained this is something she *"now"*



knows is difficult for her, suggesting that at the time, she was unaware this was difficult for her, which again refers to the importance of early diagnosis, with the opportunity for increased self-exploration. I was also interested to read Libby's reflection of, "*I did not contemplate any other options rather than to continue forward with my PG course*", something which she attributed to her "*own rigidity*" that she believes was "*somewhat unhelpful*". This made me want to explore further with Libby whether, at the time, or in hindsight, she considered pursuing a different course or career option. This is another area where Libby reported a different experience at undergraduate compared to postgraduate, with her explaining how, "*my experience of Autism...helped me to achieve a good degree*", which she attributed to the "*rigidity of UG courses*". However, as discussed above, there were times where Libby interpreted her rigidity as unhelpful, which further reiterates the importance of the context of a situation as determining whether something is a strength or barrier.

### **Sasha**

Sasha took part in the research via email. Sasha does not have a formal autism diagnosis but reflected on how she is "*more recently recognising that I might be autistic*", with her explaining she had been querying this for approximately two years. Sasha wrote about being in "*denial*", and with only recently accepting that she may be autistic, does not have a "*strong connection*" to what being autistic means to her. Sasha shared her uncertainty about seeking a formal assessment, explaining "*waiting lists are long*", and "*it wouldn't change much for myself*". I assumed that this meant that she was already exploring who she was with potential neurodiversity in mind, and that a formal diagnosis would add little to Sasha's self-understanding.

Sasha reflected on her struggles to consider what it meant to her to be a woman, with her describing it as "*hard to define exactly what a woman is*". Sasha shared how she had "*never been super feminine, but I'm not very masculine either*", and shared a sense of feeling "*empowered*" when "*challenging the stereotypes*". It would have been helpful to clarify what type of stereotypes Sasha referred to, and whether this was in relation to being autistic, or wider female stereotypes.

Sasha explained how she changed her mind several times when considering her post school options, with her exploring different avenues and sharing how she "*never wanted to go to university*" as it "*didn't suit me at the time*". Sasha shared that she could not have imagined, "*living in student halls*", which she described as "*daunting*", and this seems to have contributed to her not wanting to attend HE. I wondered whether, when imagining university life, Sasha saw

this as including living away from home, with this seemingly being the more intimidating aspect, rather than the academic element. However, on choosing her career path, Sasha realised that she “*needed to go to university*” to achieve her desired career.

Sasha struggled to recall her decision making regarding where to attend HE but felt that she was “*pretty influenced by where others were applying*”, including her college peers, and by the experience a previous partner had at a certain university. Despite Sasha applying to several universities across the country, she also applied to one closer to home in an area that she was “*familiar with*”, with some of her friends applying there, and on the basis that it was, “*supposed to be good*” for her chosen subject.

**Table 7. Sasha's personal themes**

Theme	Subtheme
SAS1. An overwhelming transitional experience to university	SAS1.1 Questioning whether I fit in
	SAS1.2 Practical preparations
	SAS1.3 Difficulty of living in halls
	SAS1.4 Missed opportunities
	SAS1.5 Change in different areas of life
SAS2. Highs and lows of relationships with others	SAS2.1 Benefits of a close cohort
SAS3. Questioning if things would have been different if I had known I was autistic and sought more support	SAS3.1 A belief I would have been better supported if I had known I was autistic
	SAS3.2 Being unsure what would have helped me during my time at university
SAS4. Strengths as being difficult to access, but I do have them	
SAS5. Being autistic as impacting different areas of university life	
SAS6. Making sense of academic difficulties	SAS6.1 Avoidance of both academic work and help seeking
	SAS6.2 Questioning why I cannot manage like others

---

*SAS1. An overwhelming transitional experience to university*

### ***SAS1.1 Questioning whether I fit in.***

Sasha reflected on how, early in her university life, she would “*go to the communal areas...when others weren't there*”, with this seemingly being related to her feeling as though she did not fit in, rather than a desire not to interact with others, with her explaining that she “*felt so out of place*”. I understood this to be related to a fear of how others perceived her, or a lack of confidence in Sasha to establish herself in communal areas of her accommodation, rather than a lack of desire to engage socially. Sasha shared how she “*liked socialising to try and get over it*”, which is further suggestive of a nervousness at interacting with others, alongside a desire to push herself in such situations.

### ***SAS1.2 Practical preparations.***

Sasha could not recall how she “*emotionally prepared for it [university]*”, and instead reflected on the practical preparations for her transition to HE. She wrote about “*planning my accommodation and getting the things together that I needed*” and how she was “*doing more of the practical and buying things I needed*”. Sasha reflected on how this felt as though she were, “*just going with the motions, ticking the boxes*”, which made me think of Sasha doing these types of things because she had to, or because it is what was expected and needed, rather than out of eagerness. I considered how practical preparations are likely clearer, whereas it might be less clear how to emotionally or mentally prepare for such a transition. Sasha referred to this when she shared how she prepared “*not so much*” emotionally, but that the practical preparations “*in turn made me feel emotionally prepared*”, suggesting there were benefits to a practical preparation other than being practically prepared. I wondered whether preparing practically simultaneously gave a space to process the transition emotionally. Sasha also reflected that, as neither of her parents had been to university, they were limited in how they could prepare her, with them being supportive, but this taking the form of “*financially and practically with the move*”. This led me to consider what Sasha’s expectations may have been about attending university, and the difference that students with parents who had previously attended university may have in terms of expectations, and how this may influence preparedness.

### ***SAS1.3 Difficulty of living in halls.***

As stated, Sasha shared how part of her reason for not wanting to attend university was due to how she “*could never imagine living in student halls*”. Sasha described feeling “*really nervous*” about moving into student accommodation, explaining how, it was “*daunting*” to have to “*submerge myself into student culture*”. I understood living in halls as making the university

experience intimidating and “daunting” for Sasha. Sasha wrote about struggles she experienced when living in halls as, “*the space is not fully your own*”, suggesting that sharing a space with others was difficult. Sasha shared more specifically, how the “*noise of others*” could be challenging, especially when she had to be up early for placement, with the housemates having “*differing schedules*”, which seemed to increase the difficult dynamics of shared housing, and led “*to falling out*” in the house. Sasha described how it “*wasn't really the best experience at times*”, however, ultimately summarised that she, “*did enjoy parts of it and I'm glad I got to experience it*”. I wondered whether Sasha felt this way at the time, or whether this was more recent, having had some space from the experience.

#### ***SAS1.4 Missed opportunities.***

Sasha shared how she was in a March intake of students and reflected on how this meant that she “*missed out on the usual freshers experience*”. I wondered whether this led Sasha to feel less integrated into university life as she had missed opportunities that often seem an essential part of starting university and perhaps this led to her feeling less part of the university community. Sasha further shared how she “*missed out on a lot of opportunities that comes with starting in September*”. Sasha queried whether delaying her start until the following September would have made her transition easier, with the timing seemingly being an important and difficult aspect of the transition for her.

#### ***SAS1.5 Change in different areas of life.***

Sasha reflected on how she was, “*balancing a lot of new experiences*” when she transitioned to university, including: “*lectures, friendships, placements, environments, and also living in a new city*”. It would have been interesting to explore whether some demands were more impactful than others. I wondered whether change in so many areas of life was overwhelming and stressful for Sasha, with this being implied through the listing approach taken, and I thought about placement as an additional demand alongside a change in academic demands.

### ***SAS2. Highs and lows of relationships with others***

#### ***SAS2.1 Benefits of a close cohort.***

Despite Sasha acknowledging some difficulties in sustaining relationships with others, she was able to identify how being a “*close cohort*” had benefits, explaining that they were able to “*utilise each other's experiences on placement*”. I understood this to mean that Sasha felt close to peers on her course, with there being an element of a shared experience that made it

easier to connect and empathise. This is especially important when considering that not all university courses have the added element of a placement experience, with students on other courses not being able to relate to the experience and demands in the same way.

Sasha reflected on how she “*really struggled with maintaining friendships in my first year*”, however, explained how these difficulties were somewhat mitigated during the early weeks of university, writing, “*I made friends quickly actually in the beginning because everyone was in the same boat trying to link up and form connections!*”. Sasha went on to speak of making “*really close friends with a girl in my halls on the same course*” however that during her first year they “*fell out...and we just kept clashing*”, which suggests that despite an eagerness to form friendships, incompatibilities could later become apparent. Sasha also reflected on how she “*struggled to maintain friendships from back home too*”, though it was unclear why this was difficult.

***SAS3. Questioning if things would have been different if I had known I was autistic and sought more support***

***SAS3.1 A belief I would have been better supported if I had known I was autistic.***

When talking about being autistic, Sasha shared how she “*didn't recognise this about myself at the time*” and had she known, she was confident that “*it [support] would be provided*”. Sasha reflected on how this meant that she “*didn't get my needs fulfilled like I probably could have*”. I wondered whether Sasha would have felt more able to ask for support had she known she was autistic. Sasha wrote, “*if you...know the support you will need*”, which made me think of more than a diagnosis being needed, but that there is an importance of having an awareness of specific support needs, which not all students may have. I also thought further about the focus on having a diagnosis for support to be given in HE currently, rather than a flexible system that is accommodating to the varying needs of students.

***SAS3.2 Being unsure what would have helped me during my time at university.***

Despite Sasha holding a belief that she would have been better supported had she known she was autistic, she also wrote about being “*not sure what could have made it any easier*”. This speaks to the need for awareness of what kind of support would be helpful as this will be different for each student. I was unsure whether Sasha meant that she doubted any support would have made it easier, or that she was unsure exactly what support would have helped her. I considered how this makes providing support difficult for universities. I also thought of the importance of early diagnosis, with this giving more time for individuals to explore their

strengths and areas of need in relation to being autistic, whereas there may be less opportunity for this if diagnosis is delayed.

***SAS4. Strengths as being difficult to access, but I do have them***

When asked to consider her strengths, Sasha stated, *“That is actually harder than you think”*, and I wondered whether the difficulty of the question had taken Sasha by surprise. However, Sasha was able to identify a range of strengths, stating, *“I am caring and loyal towards others, always wanting to help others. I would say I’m actually very adaptable. I find ways to make things work for me even if it takes some time to make those changes. I’m open minded”*. Despite this feeling difficult for Sasha, it was encouraging to hear her express some of her own strengths.

***SAS5. Being autistic as impacting different areas of university life***

When considering whether being autistic had impacted her university experience, Sasha shared *“I really do think it has now reflecting back on it”*. I got the sense from Sasha’s account that much of her understanding of the way in which her university experience was impacted has been through reflecting back on her experiences. Sasha gave some examples of aspects of her experience that were impacted, stating, *“My anxiety was constant in university, just from overwhelm”* and *“I maybe misinterpreted a lot.”* Whilst having a couple of examples about areas that Sasha felt were impacted by her being autistic, it would have been helpful to explore more in-depth whether there were other areas that she thinks were impacted.

***SAS6. Making sense of academic difficulties***

***SAS6.1 Avoidance of both academic work and help seeking.***

Sasha shared how she was *“was quite avoidant of doing the work”* and would put *“work off until the last minute”*. She gave an example of how she had *“left the dissertation to pretty last minute”* and went on to explain how this resulted in her spending, *“29 hours in the library in one go”*. Sasha explained how this *“made me feel so physically ill”*, and that she often became *“overwhelmed”* when having left work to the last minute. I was curious to understand more of Sasha’s interpretations of the purpose of the avoidance of academic work and whether this was related to her struggles with the work, or whether there was an element of needing an external deadline to increase motivation. Sasha also reflected on there being *“opportunities to meet with our tutors for support and guidance...but I didn’t want to go to it so that I wouldn’t be seen as stupid”*. I felt a sense of sadness for Sasha at reading this, with it seeming that her capability to access support was hindered due to fears of how she would be perceived by her

tutors, despite opportunities for support being offered, which would suggest that the need for support is common amongst students. Sasha was able to share how she overcame some of these obstacles: *“I...relied a lot on picking up ideas from friends on the course...seeing how they were tackling it and head in a similar direction”*.

Sasha also spoke of difficulties in planning, explaining, *“I just couldn't plan my time”*, with her attributing some of this to being *“avoidant”*, due to *“a lack of confidence”*. I wondered whether this difficulty in planning was also related to Sasha's limited confidence in her abilities and potential anxiety arising from this.

### ***SAS6.2 Questioning why I cannot manage like others.***

Sasha shared how she *“felt like I should just “know” how to do things, as everyone else did, or so it seemed anyway”*. This suggests an element of comparison, with Sasha seemingly comparing herself to her peers and making assumptions about how others were coping, whilst interpreting this as her not finding it as accessible as others. Through Sasha stating, *“or so it seemed”*, I wondered whether she has reflected on this since, and now maybe holds a different stance on the difficulties as something that were more shared amongst her peers, whereas at the time, she saw it as a difficulty that just she was experiencing.

### **Catherine**

Catherine was the final participant to take part in Phase B and opted to take part via email. Catherine received a formal autism diagnosis in her late 30s, during her final course of BA study. She shared her experiences of completing multiple HE courses. Catherine shared how she progressed straight from school to study for her first degree internationally. She shared how *“Going to university was always something I expected to do and was expected of me”*. Catherine wrote about the decision-making process regarding what she would study, sharing how she considered study in the *“creative arts”* but knew that her *“parents would not support”* this. This suggests that university decisions were not made by Catherine alone, but with her parents' input. Catherine wrote about being *“desperate to move to the UK”*. She discussed how she researched the top ten UK universities (excluding Oxford and Cambridge) and applied to the next four on the list. Catherine wrote about her decision to return to HE on subsequent occasions as being related to job prospects, and to study in an area she had always wanted to.

When considering what being a woman meant to Catherine, she shared how others had told her *“that ‘I don't act like other women’”*, with her referring to societal expectations of women by going on to discuss how she feels she is *“more assertive, direct and willing to show*



*my intellect than most women*". However, Catherine was uncertain whether this was related to being autistic, or partly cultural: *"I am from a country of direct speakers where women are more equal with men"*. Catherine also shared *"I often have to push harder to be heard and taken seriously, in particular around older men"*, suggesting an ongoing experience of gender inequality, that is perhaps intersected with age. Regarding her autistic identity, Catherine wrote about how she *"had gone my whole life knowing that I was different...but without an explanation"*. Catherine seemed to have a positive understanding of being autistic, sharing, *"being autistic means my brain works differently from most people"*, with her giving several examples of where this could be advantageous: *"I process information more efficiently than most...and am less prone to biases"*. She also considered how she finds *"sensory input to be more intense"*, with her feeling that this could be both *"a benefit...and a burden"*.

**Table 8. Catherine's Personal Themes**

Theme	Subtheme
CAT1. Being autistic was both an advantage and a burden in HE	CAT1.1 University as a place where I experienced both positive and difficult social relationships CAT1.2 Being autistic meant I was academically advantaged at university
CAT2. Receiving an autism diagnosis aided my self-understanding, but I'm unsure what impact knowing earlier would have had on my university experience	
CAT3. Transition to HE as an exciting opportunity	CAT3.1 I had the skills I needed to succeed in HE CAT3.2 Transition to HE as an opportunity CAT3.3 Support as being in varied in form and availability
CAT4. The impact of university on my mental and physical health	
CAT5. I have a good awareness of my own strengths	
CAT6. The impact of the supervisory relationship	

***CAT1. Being autistic was both an advantage and a burden in HE***

***CAT1.1 University as a place where I experienced both positive and difficult social relationships.***

Catherine reflected on the social connections she made during each of her degrees, with some positive and some difficult experiences discussed. Catherine reflected: *"I made most of my friends in my first year through the international student's group...we were a mixed bunch"*, describing them as *"kind and fun"*, and speaking of how *"they kept me safe, like a group of older brothers"* suggesting they were a group of males. It would have been interesting to explore the need that was met in Catherine making friends with other international students, and I assumed that this could be related to feeling understood and connected to others who had shared experiences. I also considered what it may be that Catherine values in friendships, with her discussing kindness, fun, and safety. Being kept safe by friends felt powerful and led me to consider whether this was physical safety, emotional safety, or an element of both, and I thought about the different functions each of these might serve. I assumed that Catherine referred to an emotional safety, and this made me consider that she may have felt free to be herself in such a friendship group and I wondered whether she had previous friendships where she had not felt this way.

Catherine wrote about meeting her *"now-husband"* just before her third year and shared how finding him and his friends *"was like finding my people"*, which led me to consider whether Catherine had not felt like she fully fit in prior to this point in her university life, and again, made me think of this group as people that she could be fully herself around. This could have been more prominent as Catherine wrote about how during her second year, she *"lived with the same girls I lived with in halls...it did not go well"*, which could have made finding people she connected with more important and meaningful after a difficult experience the previous academic year. When considering times that did not go well with others, Catherine wrote about how she *"fell out with these girls"*, citing a *"mismatch in communication"* as a reason for difficulties experienced, going on to say, *"These interactions just did not make sense to me and still do not"*. Catherine spoke further of this when she explained *"My main issue was dealing with people who did not communicate directly or rationally"*, with her seeming clear in her understanding of the issues she experienced being based in communication differences. When considering advantages and disadvantages to being autistic in HE, Catherine shared how the *"disadvantages were largely social"*.

However, Catherine also considered times she had made friends with others on her course, whom she had more in common with: *"they were the more studious kind of student, like me"*. This made me think more broadly about how friendships are formed, and I assumed that having similarities or shared values was important for Catherine in establishing relationships with others. Overall, it seemed that despite some difficulties in relationships with others, things

worked out socially for Catherine: *“when I did find my people they were really good people”*. This quote is powerful in demonstrating the impact valued friendships had on Catherine, especially when she considered the *“joy and richness”* they gave to her life. Catherine wrote about making *“good friends with a group of lads who lived in a shared house near me”*. This led me to wonder whether there were elements of living with others that made sustaining friendships difficult for Catherine, and whether she found establishing friendships with males easier than females. During her last BA, Catherine shared how she *“had no trouble socially”*, and explained she thinks this was because: *“I was...a lot older and had a lot more life experience, confidence and social skills”*, which gives further insight into Catherine’s understanding of her social difficulties. Despite her suggesting previously that her peers had not communicated *“rationally”*, and perhaps putting an element of responsibility on others, here, Catherine writes of herself as having more *“social skills”*, which suggests areas where she could have seen herself as being partially responsible for previous struggles too.

***CAT1.2 Being autistic meant I was academically advantaged at university.***

Catherine reflected on how being autistic was an advantage to her academically during her time in HE, sharing how she had *“always been gifted academically”* and that she *“thrived academically”*, suggesting that adapting to learning at the university level came naturally to her. I was struck by Catherine’s use of the word *“thrived”*, suggesting that she not only succeeded academically, but that it was a place where she flourished. Catherine shared what she believed made the academic element of university accessible for her: *“I...make connections between information more easily than most. This means that I tend to pick things up quickly and my learning is deeper.”* Catherine directly attributed her academic success to being autistic: *“I did not struggle with any academic aspect of my first BA or second BA. Autism certainly played a role in this.”* Catherine wrote about how she had a *“thirst for knowledge”* and found learning *“enjoyable”*. She also shared, *“I was there to study”* and that she was *“less influenced by social pressures to go out and party”*, which infers that some of her peers were more easily influenced by the *“party culture”* at university, which could have had a subsequent impact on their academic experience. However, it seems from Catherine’s account that the academic aspect of HE was the most important to her, and she was not easily influenced by others to attend social events.

***CAT2. Receiving an autism diagnosis aided my self-understanding, but I’m unsure what impact knowing earlier would have had on my university experience***

Catherine wrote about how “*Diagnosis gave me a profoundly better understanding of myself*”, highlighting the important role diagnosis had for her. She shared how she “*had gone my whole life knowing I was different from others...but without an explanation*”. I got a sense of confusion and conflict within Catherine when reading this. I wondered whether receiving a diagnosis made her feel less alone in knowing there was a reason she may feel differently to others, and reassured that there may be others with similar experiences to her. Catherine shared: “*I think it would have helped to know I was autistic*”, though also questioned “*I do sometimes wonder if having a diagnosis would have meant that I would have been less adventurous*”. I was curious about the sense Catherine made of being autistic. Whilst she noticed various strengths she has that she attributed to being autistic, the wondering of whether she would have been “*less adventurous*”, had she been aware she was autistic made me question this further. I wondered whether it was due to stigmatised views about what autistic people can and cannot do, and whether such views may have potentially held Catherine back had she known.

Catherine shared how, since her diagnosis, “*my anxiety has been much better*”, and I wondered whether the two things were related. I wondered whether this improvement in anxiety was related to the sense of feeling different that Catherine had reflected on, and whether this was reduced due to having a diagnosis and knowing there were other people with similar experiences to her. Despite this importance of having a diagnosis, Catherine explained, “*I don’t know how it would have changed my earlier experiences of uni*”.

### ***CAT3. Transition to HE as an exciting opportunity***

#### ***CAT3.1 I had the skills I needed to succeed in HE.***

Catherine wrote about both academic and daily living skills she possessed when transitioning to university. For example, “*I did benefit from the fact that I could do the basic adult tasks such as shopping for food, cooking, and cleaning*”, going on to suggest that some of her peers found this “*challenging*”. This suggests that the ability to complete daily living tasks was not new to Catherine, and as such, was less of a change to adapt to. Catherine explained, “*My parents raised me to be able to look after myself*”. It seems that Catherine also felt prepared academically for university, discussing how she had a “*more advanced education in the international baccalaureate than those who had taken A-levels*”, with her already being able to “*write academic essays*”. I wondered whether the higher level of academic work in HE, and often increase in responsibility for undertaking daily living tasks could be difficult for many students. However, Catherine shared how she was already competent in such areas, hence perhaps contributing to a manageable transition experience.

### ***CAT3.2 Transition to HE as an opportunity.***

Catherine reflected on her preparation for attending HE, sharing how it was “*mainly packing and getting ready to live in another country*”, which seemed largely practical. Catherine also emphasised how she prepared academically for HE by “*reading the material sent to me by my university*”, with her seeming eager to be academically prepared. I understood from Catherine’s account that she was confident in her academic ability, and I presumed the reading preparations she undertook were likely out of a passion to learn about her subject. Catherine reflected on a process of “*choosing clothes, books and objects that made me feel like the version of myself I wanted to be at uni. Someone cultured and intellectual.*”, which I understood to represent university as being a chance to reinvent and progress into a different version of oneself.

### ***CAT3.3 Support as being in varied in form and availability.***

Despite not spending extensive space reflecting on the support she received at university, Catherine did write about this. I wondered whether the reduced focus on this was due to Catherine feeling academically able and as though she did not require support in this area, with it being possible that academic support may be the first type of support that participants thought of when considering support in HE. However, Catherine wrote about how a “*fellow autistic...was a real help in my understanding what accommodations I needed and how to achieve them*”. I assumed this was during Catherine’s final degree, post-diagnosis. I wondered whether this spoke to a wider issue of Catherine not being sure what support was available, or what accommodations would be helpful. This made me consider the importance of having a diagnosis in a timely manner, in that it would give students more time to explore both their strengths and support needs and be more informed of this in HE. It seems that the support from another autistic student was valuable for Catherine. When considering the direct transition to HE, Catherine shared how she “*did not really have any support*” other than largely practical support from her parents in “*booking travel etc.*”. However, Catherine did state how, “*emotional support would have been welcome*” to aid her in having “*better understanding of myself and my strengths and vulnerabilities*”, perhaps speaking to an imbalance of academic and emotional support provided by universities.

Catherine wrote of how she was “*excited and looking forward to moving to a new place*”, sharing how she “*always knew I was going to uni*”. As such, it is possible that she may have been preparing for this for many years. Catherine “*moved a lot as a young child, so I was*

*used to it*", which could suggest this was less intimidating for her than might otherwise be expected.

#### ***CAT4 The impact of university on my mental and physical health***

Catherine shared her experiences of having "*depression (and bad anxiety...)*" during her time in HE and attributed this to "*being undiagnosed*", suggesting that not having a diagnosis contributed to her mental health struggles. Catherine wrote of the impact anxiety had on her time in HE: "*It made things very difficult internally, but less so externally. I hid it well...*". This led me to consider the struggle Catherine experienced internally, and I wondered whether this was made more difficult due to her not feeling able to share this with others. I also considered how difficult it would have been for the university to support Catherine with her presenting differently externally compared to her internal experience. However, it was not only her experience of mental health difficulties that Catherine discussed, with her also reflecting on how her physical health was affected during her time in HE. Catherine shared how she had "*always struggled with my health*" and that she was "*diagnosed with chronic illness towards the end of my studies*". Catherine reflected on how this meant she was "*running on empty much of the time*", with her finding the "*workload too much*". Catherine wrote about it taking "*huge effort to get through every day*", and I thought how exhausting this must have been for Catherine with both substantial physical and mental health difficulties, in addition to managing academic demands.

#### ***CAT5. I have a good awareness of my own strengths***

Throughout Catherine's account, it was refreshing to hear her speak about the strengths she possesses. Whilst it is difficult to tell from writing, I got a sense that identifying her strengths came relatively easily to Catherine. She touched on various strengths, including "*I am value-driven, rather than socially driven. I can do the right thing even if it does not make me popular. (autism)*". Where Catherine included "*(autism)*" in her writing, I assumed this to mean that she attributed this directly to being autistic. I got a sense of doing the right thing being a strongly held value for Catherine, and of her standing by her values, even if this led to ruptures with others. I wondered whether this contributed to difficulties in relationships with peers as discussed in theme one and considered the strength it can take to act in such a way, especially when already feeling different to others.

Catherine shared how she is "*a good planner, I research things thoroughly and I am good at organising time and resources. (autism)*". Such attributes could clearly be strengths in

an HE setting, with the need to manage time and plan to ensure the completion of academic work. Catherine also shared how she is “*kind, understanding, and accepting of differences*” and considered why she may be so: “*probably due to feeling like an outsider for much of my life, which is probably due to autism*”. I was saddened to hear Catherine’s experiences of feeling like an outsider, and that she felt this was likely due to being autistic. However, it was interesting to see her write of how this experience had contributed to a strength in being accepting and understanding of others. I wondered whether Catherine had experienced others as not being accepting of her in relation to being autistic, and as such, wanted to ensure others had a different experience to her.

Catherine also wrote about having a strength in “*Creativity...(autism)*”, which could be unexpected, as creativity is often something that can be seen as difficult for autistic individuals and highlights the individualised nature of autism. Catherine wrote about areas of strength she had which undoubtedly would be of benefit in a HE setting, including, “*The ability to absorb and comprehend new information and make connections between different areas of understanding. (autism but also a good education)*”. This is not surprising when considering how Catherine stated she “*enjoy[s] learning immensely*”. Catherine’s eagerness to learn can also be seen when she states that she has “*A very logical thinking process, with less tendency towards cognitive biases, or at least the willingness to be wrong*”, going on to explain how “*I want to be correct rather than 'right' and can change my mind. (autism)*”. This suggests that Catherine is open to changing her opinions and would rather have a correct understanding of something than stick firmly with her previously held views, with her not fearing being wrong, and having a desire to acquire knowledge. Catherine also reflected on where her attributes could be both an asset and a “*burden*”, for example, sharing how she experiences her sensory sensitivities as “*both a benefit, as it makes me creative and intellectual, and a burden, as it tires me out and snaps my executive function*”, alluding to the idea that strengths are not static, and that an attribute may not always be all positive, or all negative, but context and intensity dependent. I assumed the use of the word “*snaps*” to mean that it depletes Catherine’s executive functioning.

#### ***CAT6. The impact of the supervisory relationship***

When discussing her postgraduate experience, Catherine shared how she, “*had a terrible time*”, seemingly attributing this to the experience she had with her supervisor, describing her as, “*very unkind*”. Catherine explained “*my supervisor made being in the office so uncomfortable*”, giving a sense of the significance of the impact the relationship had. However, from Catherine’s account, it seems that it was not only the direct supervisory relationship that this impacted, but



that it had a subsequent effect on the work she produced, with her describing how being in “*a constant state of stress*” influenced her “*processing and ability to learn*”. Catherine had previously written positively about her academic ability and her enjoyment of learning, but I sensed the difficulty this relationship caused, not only with her supervisor, but also academically.

This chapter has outlined the varied HE experiences of the participants who took part, with areas of commonality and difference considered. I will now go on to discuss and interpret the results alongside existing, relevant literature, and further discuss areas of particular significance.

## Chapter Four: Discussion

This thesis set out to explore the following:

1. The personal, social, and academic experiences of autistic women as they transition to HE.
2. The strengths autistic women have that help them to succeed in HE.

The participants discussed various aspects of their HE experiences, and these will be explored alongside existing literature in this chapter. This chapter will be less of a summary of themes identified, as it was deemed more important to tell each participant's story, with each having a unique HE experience. Therefore, it was felt that to try and group the accounts together and identify themes contrasted with the individualistic nature of the research. Instead, areas of interest from participant accounts will be explored in more detail, and where there are similarities or contrasts in experiences, these will also be discussed. Due to the exploratory nature of this thesis, there will likely be more new literature introduced in this chapter than would typically be expected. Strengths and limitations of the research will be considered, followed by implications and suggestions for future research, before concluding.

### Summary of Results

#### *What does it mean to be an autistic woman?*

Two inclusion criteria for this research were identifying as a woman and as autistic. Multiple participants described difficulty in defining what being a woman meant to them. This is unsurprising when considering the complexities in defining the social construct of gender (Lindqvist et al., 2021; Unger, 2020). Libby and Catherine reflected on seeing themselves differently to other women, suggesting they do not align with dominant narratives of what it is to be a woman. Libby reported feeling like an “outsider” and of being uncertain of her identity as a woman. Catherine reflected on being more assertive and unafraid to demonstrate her intellect compared to other women. She described difficulties in disentangling whether this was related to being autistic or cultural, with her explaining that women are “*more equal with men*” in her country. Ideas about what it is to be a woman vary across countries and cultures (Bonvillain, 2020), which could explain the difficulty Catherine experienced in understanding why she feels different, with there potentially being an interaction of culture and autism. Regardless of the reason, some participants in this research did not align with gendered expectations around what it is to be a woman, with this sense of difference seemingly being a common experience for autistic women (Kanfischer et al., 2017).

The participants also had different ways of relating to their autistic identity, with some finding the question difficult to answer. Tiana advised that she did not think about being autistic, with an assumption by myself that this was related to the deficit saturated narrative Tiana held about this, and it causing her discomfort to think about. Carly reflected on the different experience she perceived herself to have as an autistic woman compared to autistic men, suggesting that females are "*not recognised as autistic*". This echoes existing research, with autism often not being considered as a possibility for women, and misdiagnoses and late diagnoses being commonplace, whereas autism is held more in mind by clinicians when interacting with men (Dworzynski et al., 2012; Milner et al., 2019). Other participants such as Libby and Sasha, were recently diagnosed or only recently accepting they may be autistic, with Libby still exploring what being autistic meant to her, and Sasha similarly finding the question difficult to answer. However, Libby reflected on the difficulties she encountered with being autistic, writing of how she felt "*frustrated*" at herself for finding things difficult, which she perceived others not to find difficult. This demonstrates a range of differences in how the participants related to their autistic identity.

When considering why it might have felt difficult for the participants to identify what being autistic meant to them, I reflected on Catherine's uncertainty of why she is more assertive than other women, and whether this is due to her culture or being autistic. I wondered whether this was also difficult for other participants, in terms of identifying specifically what traits or aspects of themselves were attributed to being autistic, or what could be attributed to other aspects of their identity, for example, culture, religion, class, or upbringing, with this likely being difficult to establish. It could be that the participants wanted to be certain what parts of themselves were related to being autistic when answering questions about this, and that this can be difficult to determine.

### ***The experience of transitioning to HE as an autistic woman***

A significant focus of this research was the transition period to university, with this meaning different things to different participants. When reflecting on this transition, participants spoke of the decision-making process about whether to attend university, which university to attend, and shared their experiences of the transition itself. Whilst there is a body of research into transition planning for HE, including the importance of students' involvement in this process (Adreon & Durocher, 2017; Cheak-Zamora, 2015; Newman et al., 2011), the majority of participants in the current research reflected on less formal means of transition planning, and how they prepared for HE without formal support. This was to be expected, as most participants

only received formal autism diagnoses after they had completed their time in HE or in Sasha's case, did not have a formal diagnosis at all. As such, they would not be expected to have received dedicated transition support, with support currently being largely accessed through a medicalised model and diagnoses often being crucial to open the door to support. This speaks to a wider systemic issue of the need for students to be supported as individuals with unique needs without there being a need for a formal diagnosis to access support, with broader changes to HE institutions being essential to be inclusive of a diverse student population (Pesonen et al., 2021).

The participants shared differing transitional experiences, with Tiana and Sasha not initially wanting to attend university, whereas Sarah, Libby, and Catherine had planned to attend university for longer periods of time. Libby shared opposing experiences of multiple transitions, comparing her transition to undergraduate study and postgraduate study. This led me to reflect on the various factors that can influence a transition experience, for example, the student's living arrangements and their individual support needs (Adreon & Durocher, 2017). It also reminded me that no two transitional experiences are the same, even for the same person.

Libby reflected on the degree of change she experienced as having a significant impact on her transitional experience. When transitioning to her undergraduate course, there remained many constants in her life despite her educational change, whereas when transitioning to postgraduate study, there were multiple changes and limited stability, with this seemingly contributing towards a difficult experience. It is not surprising that the degree of change caused difficulties in Libby's transitional experience, with change being a commonly seen difficulty for autistic students in HE, and with the degree of change experienced at the transition to HE often being an overwhelming one (Cage & Howes, 2020; Van Hees et al., 2015). Catherine also experienced a significant degree of change in moving to the UK but experienced this differently to Libby. Catherine wrote of being "*desperate*" and "*excited*" to move and reflected on transitioning with apparent ease. This contrast could be perhaps explained by Catherine being more familiar with moving, with her writing of how she moved frequently as a child, and also having wanted to study in the UK since childhood, which perhaps gave her increased opportunity to prepare for this and her seemingly being excited for it, compared to Libby, who spoke of having less opportunity to prepare for her postgraduate study, and seemingly did not have a desire to move, but this being necessary for her future career ambitions.

### ***Decision-making process and practical preparations***

Sasha and Tiana had not initially wanted to attend university, with a specific institution standing out to Tiana which changed her mind, and Sasha needing to go to achieve her desired

career. However, others had different journeys to HE. For example, Sarah gave multiple reasons for her decision to attend, including how she had wanted to attend university to study a particular subject, and of “*pressure from...school*” to attend. Both Libby and Sasha reported career ambitions as driving factors for them attending. Catherine's experience differed, with her seemingly having known from a young age that she would attend HE. She also reflected on her decision to return to HE for various reasons, including career prospects, and to study in an area of interest to her. The differing rationales for attending university in this research align with existing literature on the topic, with enhanced career prospects being the most common reason for students opting to attend university (Balloo et al., 2017). However, there are various reasons, such as to prove oneself to others, for fulfilment, enjoyment of learning, persuasion from teachers, and expectations from others (Kennett et al., 2011). Each of these reasons were also seen in the participants' accounts in this research, with each having a unique journey and decision-making process around attending university.

The decision regarding which institution to attend differed between participants, with different aspects of HE seemingly being important to different individuals. Libby chose to attend a local university for her undergraduate study where she could live at home. Alternatively, despite attending a local university, Sarah chose to live in student halls, as she wanted to have “*the full university experience*”, highlighting a difference in expectations and priorities about what it would mean to attend HE. Catherine was intent on studying abroad, but open to studying at several top universities in the UK. Conversely, Tiana was attracted to one specific institution. Carly and Sasha based their choices on which institution offered the courses they wanted to study, with Sasha also considering the reputations and the locality of institutions. Most participants chose to live at university, in contrast to other research discussed, where the majority of autistic students continued to live at home whilst attending university (Cai & Richdale, 2016). Again, from the accounts in this research, the decision to move to university is for various reasons, including limited institutions offering desired courses, a desire to have the “*full university experience*”, and a desire to study abroad.

There was variation and similarities in how each participant prepared for university. Practical preparations were commonly discussed, for example, Tiana, Sarah, and Catherine reflected on making lists of what they needed, buying items, and packing, with a notable absence of considering how they prepared psychologically or emotionally. As there are many unknowns with starting university, this could have made it difficult to prepare emotionally, whereas it could be easier to consider the physical items needed and to prepare practically. Despite not always being referred to directly, I wondered whether the participants experienced anxiety when

preparing to transition to university with it being difficult to anticipate what the transition might be like. There are many unknowns when starting HE, for example what peers and staff will be like, and the academic expectations, as has been discussed previously by working class students in HE in research by Scanlon et al. (2020). Therefore, preparing practically could give a sense of control in an otherwise unpredictable situation. Libby reflected on becoming familiar with the campus, the course, and the staff team. Despite her identifying this as a practical preparation, I wondered whether there was an element of Libby psychologically and emotionally preparing herself by engaging in these activities too, to ease any anxieties and uncertainties about what the staff and course may be like, as well as giving her practical knowledge. Sasha directly referred to the lack of emotional preparation she engaged in, though also shared how *“Doing more of the practical preparation... made me feel emotionally prepared”*, and I wondered whether this was similar for Libby. This highlights an increased focus on practical preparations the participants engaged in when transitioning to HE, though this could also give the participants a space to process and prepare emotionally.

Catherine also reflected on transitioning to university as an opportunity to change as a person, sharing how she chose items to take with her that allowed her to *“feel like the version of myself I wanted to be”*. This led me to think of attending HE as being viewed primarily as an academic transition, but how it also provides an opportunity for identity change and personal growth, as seen in existing research with students transitioning to university, where identity change was noted during the transition process (Cassidy & Trew, 2004; Manzi et al., 2010).

### ***The experience of autistic women in HE beyond the point of transition***

When considering the participants' overall experiences in HE, various topics were considered, including: social experiences, autism as being both a barrier and an advantage in HE, the importance of having a diagnosis, the internalising or externalising of problems, and a need to be understood and supported as an individual rather than stereotyped assumptions being made by others.

#### **Both positive and negative social experiences.**

The participants shared mixed experiences, both between and within accounts, about their social relationships in HE. Participants reflected on feeling different to others, for example, Carly stated, *“we didn't click”*, with Sarah referencing a similar experience and writing of being *“more isolated than most people at uni”*. This experience is consistent with existing literature (Cages & Howes, 2020), where autistic students who withdrew from university described

*“feeling like an outsider”* in HE. Similarly, in the current research, Libby spoke of how she had dropped out of her sports team due to feeling *“intimidated and uncomfortable by the social aspect”*, which echoes experiences in the Van Hees et al., (2015) study, where a fear of making social errors impacted students’ confidence to engage socially with others, which then perpetuated social isolation. Similarly to research by Madaus et al. (2022), it seemed that Libby valued having a social network but was also aware of difficulties she was experiencing. Libby went on to directly state that she, *“felt out of place and like I was different”*. It is clear from Libby’s account how worries about being different or being uncomfortable in social situations could lead to a cycle of increased isolation.

Several participants also spoke of their interests being different to what might be typically expected of a university student, with Sarah reflecting on how it *“meant that I was at a disadvantage when it came to being social”*, and Libby explaining that she was not *“interested in socialising in large groups or drinking/clubbing like most other students”*. This is consistent with prior research, which speaks of the range of social activities being limited at university, with a focus on partying and alcohol as means of socialising (Gurbuz et al., 2019). This could potentially both increase a sense of difference in autistic students if their interests do not align with the interests of their university peers and could also perpetuate isolation and limit opportunities for developing relationships with others.

Both Tiana and Sasha spoke of highs and lows of their relationships with others, with Tiana speaking of *“a personality clash”* with her housemates. On the other hand, she also reflected on positive aspects of her relationships with others, speaking of the support she received from her peers, and of the longevity of relationships made. Tiana reflected on *“surprisingly quite good”* relationships she had during her time in HE. I was struck by Tiana’s use of the term *“surprisingly good”*, and I wondered whether this had been an area where she had encountered difficulties previously, and whether she had expected to encounter similar difficulties in her relationships in HE. Sasha similarly shared an experience of when she *“made really close friends”* but reflected on how they *“kept clashing”*, using similar language to Tiana to describe the difficulties she experienced in her friendships. Like Sasha, other participants also reflected on the difficulties in maintaining friendships they had established both during university, and friendships from home. For example, Sarah spoke of friendships not being sustained when physical proximity decreased, reflecting on a friendship where they had been *“very close”* but that they *“began to drift apart because we didn’t see each other as often”*. Sasha also reflected on difficulties in maintaining friendships from home whilst at university, again possibly speaking of the importance of geographic proximity in friendships. The

importance of proximity in sustaining friendships has been discussed in existing literature which considered the impact of living in the same town or attending the same school on the maintenance and sustaining of friendships (Preciado et al., 2012), with closer proximity positively impacting friendships. Despite the participants in the Preciado et al., (2012) research being adolescents, it could be expected that a similar pattern would be seen in a HE student sample and has certainly been discussed by the participants in the current research as seen in Sarah's reflections.

Libby also reflected on social difficulties she encountered in HE, reflecting on a friendship with a peer who was "*constantly engaging*" with her. When further considering ideas around the formation and maintenance of friendships, level of communication has been identified as an important factor in the maintenance of friendships during the high school to college transition (Oswald & Clark, 2003), which seemed similar to Libby's experience. As there are often communication differences between neurotypical and neurodiverse populations (APA, 2013), this could also potentially explain some of the difficulties in sustaining friendships in HE. However, there are other elements to the formation and maintenance of friendships, for example, similarity, with people who are similar and have more in common often finding it easier to sustain friendships (Laursen, 2017). This is important when considering examples such as Libby withdrawing from her sports team. In such a team, she would have met individuals with at least one shared interest, and it is interesting to consider if her social network would have been different had she carried on as part of the team. On the other hand, Tiana spoke of making friends in different areas of her university life, including her accommodation (which could speak to the importance of proximity in friendships), and her course, and her sports team (which could relate to the importance of similarity and shared interests). Carly also spoke directly to this, talking of making a friend whom she suspected was also autistic, again suggesting an area of similarity, or at least an element of shared experience that enabled connection. This demonstrates the varied functions that friendships can have, and the factors that can aid the establishing and sustaining of friendships.

Sasha spoke in detail about her early social experiences at university, speaking of how she "*really struggled with maintaining friendships in my first year*". However, it seemed that this was not always the case, with her describing how establishing friendships was initially manageable: "*I made friends quickly actually in the beginning because everyone was in the same boat trying to link up and form connections*" before the relationships broke down, with Sasha sharing how they "*just kept clashing*". Similarly, in interviews with autistic people who



had withdrawn from university by Cage and Howes (2020), one participant reflected on how they managed to attend some freshers events early on, before masking became too difficult.

Finally, Catherine reflected on a sense of safety in friendships. It would have been interesting to explore further with Catherine what type of safety she referred to when she spoke of her friends keeping her safe, and the function of this. For example, whether she felt a physical sense of safety with friends, or whether there something about her feeling able to be herself around such friends, with the importance of this being highlighted in a scoping review of autistic individuals' perceptions of friendship, which demonstrated that relationships were successful when autistic individuals were accepted for who they were by others (Black et al., 2024).

From the level of detail and examples given, it seems that the social element of university was an important part of the university experience for participants. When considering existing research, this is not surprising, with Cage and Howes (2020) suggesting that a lack of social identification could act as a barrier to the completion of HE, further supporting the idea that the social element of HE is an important one.

### **Being autistic as a barrier and an advantage in HE.**

The relationship to being autistic and how this impacted HE experiences differed for different participants. Despite existing literature highlighting academic difficulties that autistic students may experience (Anderson et al., 2017; Davis et al., 2021; Madaus et al., 2022) and whilst Tiana similarly delivered a heavily deficit focused narrative of being autistic in HE, others had a more balanced perspective. Despite some similarity to Tiana where Sarah shared how “*almost all aspects of my autism made life challenging*”, she also acknowledged areas she excelled in, for example, sharing how she “*thrived*” regarding independence. Sarah and Libby considered being autistic to be both a barrier and an asset academically, for example, describing difficulties in adapting to the writing style, but also of advantages of being able to hyperfocus and in pattern recognition. Carly shared how the academic element of HE was inaccessible for her, however, compared to Tiana who located the responsibility for the difficulties she experienced in herself, Carly externalised the responsibility for making the content accessible as being with the university, demonstrating similarities where the participants encountered academic barriers, but differences in how they made sense of this. Tiana also shared that she found it “*harder to understand my tasks/projects than my coursemates*”, again locating the difficulty within herself. Catherine however, had a contrasting experience of the academic element of university, sharing how being autistic was advantageous to her academically, and seemed to have little issue in accessing this part of HE. When considering the academic element

of HE specifically, both Libby and Sasha spoke of an avoidance of academic work. Whilst Libby required the pressure of a deadline to motivate her, it would have been interesting to explore this further with Sasha, to identify if she felt her avoidance was for similar reasons to Libby, or whether there were other factors influencing this. It is clear from the participant experiences that whilst there can be academic difficulties encountered in HE as an autistic student, there are also aspects of being autistic that can be helpful academically, and that this will be different for each student.

The area of support received at university was also spoken of by participants in this research. Sasha spoke of being unsure what support would be helpful to her, which was similar to Tiana, who did not believe anything could have made her time in HE easier. This could be interpreted as deficits being internalised by the participants, or could alternatively be explained by the wider HE environment being set up to favour neurotypical students over neurodiverse students. This experience contrasted with Carly's account, where she identified various areas of support that could have positively impacted her HE experiences, including financial support, peer support, early intervention, and support outside of the academic. This aligns with existing research which has demonstrated that non-academic support in HE is often inadequate (Anderson et al., 2017; Barnhill, 2016; Cai & Richdale, 2015; Lambe et al., 2019), and could relate to the role that HE institutions see themselves as having, in terms of providing academic rather than non-academic support. Some participants reflected on how they may have felt more able to ask for support had they had a formal diagnosis at the time, suggesting that the responsibility of identifying support falls to the individual rather than the institution, and that formal diagnosis is seen as a requirement to access support

### **Questioning if things would have been different if I'd known I was autistic.**

The importance of having an autism diagnosis in HE was highlighted by several participants, with most formally diagnosed participants receiving their diagnosis after, or during their time in HE. This is unsurprising as women are more likely to go un-diagnosed, be misdiagnosed, or receive a diagnosis later than males (Cage & Howes, 2020; Lai & Baron-Cohen, 2015). Both Libby and Sasha queried whether their HE experiences would have been different had they been diagnosed prior to HE. Sasha wondered whether she would have been better supported during HE had she known. This reflects a theme generated in the Cage and Howes, (2020) research, "*Accessing diagnosis – if only I had known*", which resonated with many of the participants' experiences in this research. For example, Sarah felt that her HE experience would have been "*significantly easier and more enjoyable*" had she known she was

autistic at the time, with there being an assumption that increased support would have been available had she been diagnosed. Libby echoed Sarah's thoughts, stating, "*I do wonder if had I known I was Autistic my time as a post grad would have been very different*". Sasha also questioned whether having an autism diagnosis "*would have changed my experience of higher education*", again with a belief that she would have been better supported had she known. Libby shared similar thoughts that she may have felt more able to ask for support had she known she was autistic at the time, with there being an inference that there needs to be a "reason" to seek support, and having an autism diagnosis would have given this reason. I wondered whether feeling more able to seek support with a formal diagnosis in place was related to diagnosis giving individuals increased understanding of themselves and their difficulties, or of them having a legitimate reason to seek support. It is possible that the wondering of participants in this research of whether they would have had different HE experiences could be rooted in this, and whether they would have felt more able to live authentically as themselves were they aware they were autistic (Seers & Hogg, 2021). This perhaps speaks to a wider issue of students needing a "reason" to seek support, rather than HE institutions being flexible to students varying needs without the need for a diagnosis. This further evidences that HE institutions are designed in such a way as to favour neurotypical students, with environment not being designed with a diverse student body in mind, and instead, support being viewed as an addition for students who have a formal diagnosis, rather than flexibility and inclusivity being part of the HE culture.

Whilst Catherine discussed how having a diagnosis allowed for increased self-understanding, she also queried had she known she was autistic, whether this would have made her less adventurous. As stated on page 144 of the results chapter, I wondered whether this was in relation to stigma and a deficit saturated narrative around what autistic people can and cannot do, and if, had Catherine known she were autistic at the time, such narratives would have potentially held her back, or led to her making different choices.

Sarah reflected on how having an autism diagnosis helped her life "*click into place*" and suggested that she may have had increased self-understanding. This was echoed in Libby's account, where she spoke of recognising different areas that she struggles with since receiving her diagnosis, such as certain sensory experiences. This further reiterates the importance of early diagnosis in allowing for the exploration of the self, in order that an individual knows areas where they may need additional support and could ask for this, as well as getting to know their own strengths and using them to their advantage.

Catherine reflected on how the anxiety she experienced had improved since receiving an autism diagnosis. Though it is impossible to determine if there is a cause-and-effect relationship, it is interesting to consider this as a possibility. I considered whether this could be related to the findings from Seers and Hogg (2021) with diagnosis leading to an increasingly compassionate self-understanding and an ease in being authentic, with this perhaps leading to a reduction in anxiety.

### **Mental health difficulties.**

It is well documented that autistic students are at increased risk of experiencing mental health difficulties compared to neurotypical students (Croen et al., 2015; Lai et al., 2019). Therefore, it is unsurprising that the majority of participants in this research reflected on a decrease in mental wellbeing whilst at university, with increases in anxiety being particularly prominent. Sarah for example, seemed to suggest she struggled with anxiety prior to university, but shared how this was “*definitely heightened during university*”, emphasising that existing mental health difficulties could be exacerbated during university, as is consistent with existing research (Cage & Howes, 2020; Van Hees et al., 2015). Libby specifically identified “*the mass amount of changes*” she experienced when transitioning to postgraduate study as leading to a “*decrease in my wellbeing*”, suggesting that change was a reason for mental health struggles, again, which is consistent with existing research in the area (Cage & Howes, 2020; Van Hees et al., 2015). Therefore, it is essential that the degree of change and the impact this can have on autistic students be recognised by HE institutions, with appropriate support tailored to the needs of autistic women being highly important.

### ***Autistic women’s relationship to strengths and how these helped during their time in HE***

Exploring participants’ relationships to their strengths and how these helped them succeed in HE was an important part of this research. The participants conceptualised their strengths differently and had different relationships to the idea of strengths. Some participants such as Catherine identified their own strengths with seeming ease, whereas others, such as Tiana found this difficult. Others were more nuanced, with Sasha explaining how it was difficult to identify strengths but was still able to do so. Libby reflected more on a loss of skills she had experienced, and on strengths that she hoped she had, rather than confidently believing she possessed such strengths. I wondered whether this was related to the burnout Libby spoke of. Despite literature into autistic burnout being minimal, it has been described as an “*exhaustion of internal resources*”, and a loss of various skills (Raymaker et al., 2020), with Libby alluding to

such a loss of skills. I wondered whether this had led her to doubt her abilities in various areas and question various parts of herself.

This is an appropriate point to consider the link between strengths and weaknesses, with some of the participants reflecting on weaknesses they identified in themselves at the same time as strengths, despite this not being asked about directly. Carly, for example, spoke of weaknesses or areas of difficulty she noticed in herself at the same time as identifying strengths, talking of how she can be “*much more in depth*” whilst also referring to being “*a slow learner*”. Similarly in Sarah’s account, she wrote about a strength in being independent, but also of areas where this caused her difficulty, for example her reluctance to ask for help. This demonstrates an association between strengths and weaknesses, with it being difficult to separate the two. When designing the research, I was keen to focus on strengths and wanted to avoid discussion of weakness. However, in phase A, a participant shared that this could be perceived as dismissing of the challenges faced by autistic women, which led to increased openness to the inclusion of weaknesses. On reflection, it also felt somewhat naive to expect that strengths would be accessed at the exclusion of weaknesses, with the two often being considered together, and the separation of them not always being possible or necessary (Russell et al., 2019).

Additionally, participants spoke of strengths as evolving and being dynamic in various ways. Sasha notably explained that a question around strengths was difficult to answer, and I wondered whether it felt uncomfortable to identify her own strengths. However, I also considered how, with strengths not being static, this could make identifying them difficult. A strength in one situation can be problematic in another (Russell et al., 2019). Additionally, the intensity of a particular trait or quality could impact whether this is interpreted as a strength or not. For example, Sarah’s reflection on her independence being a strength, but that the intensity of it could also cause her problems.

Similarly, Sarah provided another example of a strength in her ability to “*hyperfocus*”, but also reflected on how this could be problematic when managing multiple deadlines, with her speaking of her being “*not good at stepping away and going to work on a different topic*”. Having multiple and competing deadlines can happen frequently in HE, and whilst the ability to hyperfocus may be a strength when working to one deadline, when there are competing demands, this could be problematic. This conceptualisation of strengths highlighted not only the complexity of the question being asked when asking participants to identify their strengths, but also the importance of the intensity of which the strength is held.

Whilst some of the strengths self-identified by participants were aligned with strengths identified in existing literature, for example, an ability to hyperfocus, a desire to acquire accurate knowledge, and attention to detail (Anderson et al., 2017; Barnhill, 2016; Gurbuz et al., 2019), both Sarah and Catherine identified areas of strength that may not always be associated with strengths in autistic populations. Sarah spoke of group work as a strength, with this often referred to as an area of difficulty in autistic populations (Anderson et al., 2017; Davis et al., 2021; Madaus et al., 2022). Similarly, Catherine reflected on a strength in creativity, which contrasts with a strongly held discourse of creativity being a weakness in autistic populations (Essex & Melham, 2019; Quirici, 2015). Carly also spoke of autistic populations as having a strength in empathy, a sentiment that was echoed by several of the participants who used words such as “*compassionate*”, “*caring*”, and “*open minded*” to describe themselves. I wondered whether potential experiences of being treated badly by others, or experiences of stigma had led to increased compassion, empathy, and open mindedness from the participants in this research, with it being possible that they have a desire to ensure others are not treated badly on the basis of being different, and a belief that people should be accepted for who they are. It is impossible to know if this is related to difficult experiences participants have had with others, however, both Libby and Catherine reflected on feeling like outsiders, and I wondered whether this led to an increased desire to ensure others did not feel this way. Despite a commonly held assumption that empathy can be difficult for autistic populations, this aligns with research from Russell et al., (2019) with autistic participants in this research describing themselves as empathetic and compassionate to “*others on the spectrum*”. Additionally, this could be related to a sense of fairness, which has been identified as a strength in autistic populations (Madaus et al., 2022).

This demonstrates that each autistic person will have different strengths, and grouping such a population can be problematic, despite there being some areas of commonly seen strength and difficulty. This aligns with the concept of neurodiversity as relating to the diversity of the human mind (Walker, 2021). This further highlights the importance of autistic students being treated as individuals, with HE institutions getting to know them as such, and being aware of their strengths and weaknesses, rather than assuming what autistic students may have strength or difficulty in, as seen in existing literature with there being a need for person-centered approaches rather than diagnostic-focused approaches (Astle et al., 2022). For example, Carly reflected on how her parents assumed she would be “*good with numbers*” and as such wanted her to study in a certain area, and spoke of staff suggesting she was not suitable for a certain HE course because she was autistic.

### **Strengths and limitations**

### ***Research focus***

As discussed in the introduction chapter, despite women making up over half of undergraduate populations, the majority of research into the experiences of autistic students in such settings is completed with male populations (Cai & Richdale, 2016; Madaus et al., 2022; Van Hees et al., 2015), demonstrating a gap and need for research into the experiences of autistic women. The novelty of this research is especially prominent when taking into account the strengths-based perspective utilised. This was important, as the majority of consultant participants in phase A valued a strengths-based approach and spoke of how they often viewed being autistic through a lens of things they could not do, suggesting that it would be beneficial to consider strengths autistic women have. That this was seen as beneficial is unsurprising when considering the impact a deficit focused understanding of autism could have on an individual's wellbeing (Milton & Sims, 2016), with it being important that potentially stereotyped and deficit laden narratives around autism are challenged. The personal stories shared by the participants in this research add rich and detailed understanding to the experiences of autistic women in various aspects of university life. As such, it is hoped that this research has value and meaning for the female autistic community.

### ***The participatory approach***

The participatory design of this research was valuable, especially in the field of autism research, where such approaches remain rare (den Houting et al., 2021). Not engaging with the community at the heart of research means the voices of those who will be impacted by the research are absent, with this posing a risk that researchers could wrongly assume the priorities and preferences of the research population, rather than working in collaboration with them to establish these. The participatory approach therefore, is a strength in the design, ensuring that the priorities and voices of autistic women are central to the research, and that the research is as accessible as possible for autistic populations, thus hopefully leading to research that is inclusive and findings that are valuable to the population of interest.

However, the participatory approach taken in this research could have gone further to ensure the full inclusion of autistic women at each stage of the research. When considering both Arnstein's (1969) Ladder of Participation and Den Houting et al.'s (2021) hierarchy for community participation in research, it is evident that there are further steps that could be taken to ensure the research could be more of an equal partnership between researcher and the research population. This was difficult for several reasons. Firstly, as the research was conducted to fulfil a thesis project, it would not have been possible to hand over full control and power to the

population of interest, due to the requirement for the lead researcher to demonstrate skills in designing, conducting, and analysing a large-scale research project. Similarly, the time frame of the project made full collaboration difficult. On reflection for example, it would have been more inclusive to design the interview schedule collaboratively with autistic women, or at least share this with the consultant participants and ask for their feedback before use in phase B. As such, whilst this research took steps towards participation with the autistic community, future research could and should go further to work towards full collaboration and community control, to ensure that power ultimately lays with the community of interest rather than researchers, and to work towards building relationships between the autistic community and academic researchers.

### ***Recruitment approach***

It was perhaps unclear in recruitment advertising that both formally diagnosed and self-identifying autistic women could take part in the research. Only one participant in phase B self-identified as autistic, which could have limited both the reach of the research, and the experiences shared. This could have been clearer on the recruitment poster, with it being possible that women who self-identify as autistic may not have felt they were eligible to take part. However, it is also possible that those who self-identify as autistic may feel unable to take part without a formal diagnosis. For example, Libby spoke of the importance of her having a formal autism diagnosis to accept that she could be autistic, with it being possible that women who self-identified as autistic may not have felt legitimately able to take part. Therefore, experiences of women who self-identify as autistic could have been under-represented.

The recruitment methods used allowed for a specific group of participants to be identified, but the varying recruitment methods allowed recruitment to reach participants in different geographical areas. It was more likely that participants would be recruited from the Leeds area, with advertising taking place in the disability services reception at the University of Leeds, and especially more likely within the West Yorkshire area, with coproduction and autism groups being approached in this area. Similarly, as the research team were Leeds-based, it makes sense that information about the study would have spread by word of mouth, with connections being more likely to be reached in the Leeds and wider West Yorkshire area. However, the use of social media advertising hopefully allowed for the research to reach wider populations.

Yet, there continues to be a risk of selection bias, in that individuals who chose to take part in the research could have had especially negative or positive experiences of HE and felt compelled to share their experiences. Other autistic women may have chosen not to take part had they not had a particularly positive or negative experience and as such potentially felt less



compelled to talk about it. Similarly, if an autistic student had a particularly difficult time in HE, it would not be unreasonable to assume they may not want to talk about their experiences, with there being the potential that the experiences reflected in the research were limited.

Despite there being some degree of demographic diversity between the participants, especially when considering age, other areas were not as diverse, for example the majority of the participants reported being White, and British. As such, there may be differences between individuals that were not captured by this research.

### ***Varying methods of participation***

As discussed, participants taking part in phase B were given the option to take part via interview, survey, or email. This was a positive design choice in ensuring the research was as accessible as possible for those taking part and enabled participant choice, and was something that was advocated for by the consultant participants in phase A. Additionally, as each offered means of participation was utilised by at least one participant in phase B, this emphasises the individualised nature of preferred means of communication, and further highlights the importance of choice in research. However, this was not without its difficulties. Where written means of communication were chosen, there were areas it would have been useful to explore further if communicating verbally with the participant, for example prompting for examples or more detail where needed. This was not possible where responses had been sent in writing. It was also difficult at times to get a thorough sense of the person and make informed inferences with written response, due to not being able to pick up on cues such as tone of voice. However, there were also advantages to written responses, which were often more concise, potentially due to participants having the time to think and consider their response rather than verbal communication where there may be an increased pressure for an immediate response.

### ***Quality checks***

Several quality checks were used throughout this research. I attempted to maintain a sufficient degree of reflexivity, and kept a reflective journal throughout the process, which gave me a space to consider aspects of the decision-making process, as well as reflecting on thoughts and feelings at different stages of the research. This also allowed me to check in with when personal experience felt to be closely related to the topic of interest and to re-ground myself in what was the participants' experience, and what was mine, ensuring their story and experience was accurately reflected. However, as is the nature of IPA and the double hermeneutic, my own thoughts, feelings, and experiences will have undoubtedly impacted the analytic process (Smith

et al., 2009). Another researcher may have made different interpretations from the information given by the participants, or indeed, I may have made different interpretations had I engaged in the analytic process at a different time or analysed the participants' data in a different order. It is natural that interpretations from the first participants data to be analysed will have impacted the interpretation of later analysis. To mitigate this, themes were discussed with a research supervisor, which allowed for different perspectives of the themes generated and the themes were edited and amended as necessary. This encouraged further returning to the original data to ensure themes were accurately reflective of the participants' experiences. I was also involved in an IPA peer support group, which acted as a space for sharing experiences of IPA and supporting each other with queries and challenges during the process. On reflection, the credibility of interpretations and themes made could have been enhanced by sharing themes with the participants themselves and seeking feedback, however, time constraints did not allow for this.

### ***Positionality***

As discussed in my reflexive statement on page 40, my identity as a neurotypical woman will have undoubtedly impacted the way in which the data was analysed and presented during the write up. Doubts about my legitimacy to conduct this research has undoubtedly impacted the analytic approach taken, with a focus on individual stories over group level themes. Whilst this is in part fitting with the conceptualisation of neurodiversity and a focus on difference, this will also have been heightened by my anxiety around putting my interpretations as a neurotypical woman, on information given by neurodiverse participants, and a desire to ensure their voices are heard. This is positive in some ways, as it means that the voices of the participants are accurately captured in an area of research where the voices of those impacted by the research are often neglected. However, the anxiety experienced about misrepresenting the data has also led to a lack of broader, group level themes, which could also have been helpful in identifying patterns in experiences.

### **Implications**

The participants shared their individual experiences of attending HE as autistic women. There were differences in the experiences, but also similarities that emerged from their accounts. Much of the existing research in this area has, understandably, focused on the barriers and challenges that autistic women face in HE, yet this research took a strengths-focused approach. In taking this approach, this has hopefully opened a strengths-focused narrative and served to lessen autism being viewed in terms of deficits. It is hoped that this could contribute to a changing discourse around how autism is understood. This has allowed for insights into both

how autistic women relate to their own strengths, and hopefully highlights to HE institutions that being aware of autistic students' strengths is as important as being aware of their weaknesses.

Another implication relates to the participants' experiences of transition to HE and beyond, which could serve as valuable information for HE institutions when considering how to support autistic students. However, the experiences also speak to a wider issue of late female diagnosis. The majority of women who took part were not diagnosed either formally or self-recognised they could be autistic until after their time in HE. This is consistent with existing knowledge that females are frequently late diagnosed, misdiagnosed, and under-diagnosed in relation to autism (Lai & Baron-Cohen, 2015; Lai et al., 2015; Rynkiewicz et al., 2019; Zener, 2019), and are often diagnosed after their time in HE (Cage & Howes, 2020). This therefore makes it difficult for institutions to offer support when students themselves are unaware they could be autistic and also gives individuals less opportunity to explore their own areas of strength and weakness in relation to autism. As such, this speaks to the importance of early recognition and diagnosis of autistic women, which Carly referred to frequently in her interview. This suggests that professionals need to be more aware of autism when working with females. Whilst the importance of health care professionals holding autism in mind when meeting with girls and women may seem clear, it is also important that other professionals who may encounter autistic girls and women, such as teachers and social workers are trained in recognising autistic females, to ensure that they are being referred as early as possible to work towards closing the gap in rates of diagnosis between males and females, subsequently allowing HE institutions to more effectively support their students, and for students to better understand themselves. To provide one example, existing research demonstrates that special educational needs coordinators are less confident in recognising autism in girls than boys (Gray et al., 2021), which would imply that girls will be referred less frequently for assessment than boys by these professionals.

An additional implication of this research refers to the need for wider, systemic change in HE institutions and beyond. Multiple participants in this research wondered how their HE experiences could have been different had they known they were autistic during their time in HE. Whilst the need for earlier diagnosis for females is indeed important, that the participants felt unable to access support in HE without a diagnosis, speaks of HE institutions and wider society being designed without neurodiverse populations in mind. HE institutions could work to overhaul the HE system, with increased flexibility and inclusivity in all areas of HE, rather than support being needed as an addition when students do not fit neurotypical norms. This is not to negate the importance of having a diagnostic label, which was of upmost importance for some participants in this research, but instead to ensure that students in HE are encouraged to flourish

as individuals with diverse needs and strengths, with this diversity celebrated in an inclusive setting, rather than the need for additional support for which a diagnosis is required. A societal shift in how we understand difference, which the neurodiversity paradigm is starting to move towards, and a focus on how contexts can be more inclusive and flexible rather than putting the responsibility on individuals to fit environments designed for neurotypical populations is essential.

Despite some similarities in participant accounts, there were also differences. For example, whilst some participants reported that the academic aspect of HE was completely inaccessible to them, Catherine reflected on the ease of which she found the academic element, with the social side being more difficult for her. This further demonstrates the need for autistic individuals to be treated as individuals. Several participants reflected on this in their responses, explaining that stereotyped understandings of autism, and generic supports were limited in usefulness, and instead, that a comprehensive understanding of each students' strengths and support needs is essential. This could change the way universities approach and support their autistic students, with a need for a thorough understanding of each student in order that they can be supported effectively.

Finally, a key implication from this research, is the importance of individual choice in how to engage in research. Similarly to the need for autistic students to be understood as individuals by their HE institutions, it is also important that autistic research participants are given as much choice as possible about how they take part in research. The varied preferences were apparent in this research, with each offered method of participation being utilised at least once, and in phase A, the consultant participants highlighted the importance of individual choice. It is hoped that this will encourage future researchers working with autistic populations to offer as much choice and flexibility as possible. It is also important for researchers to understand the individual needs of their participants, for example, consultant participants in phase A expressed differences in various aspects of the research, not just preferred means of participation, but for example, the amount of information they would like beforehand, and accommodations that could be helpful to them. As such, it is not only HE institutions that need to work to understand their autistic students, but researchers also need to make research as accessible as possible for autistic students, to ensure they feel comfortable taking part, and consequently have their voices heard in research.

### **Future research**

There were various aspects of HE the participants discussed, and each other these could be addressed more specifically in future research. For example, most participants spoke extensively about their social experiences, and further research into the social experiences of autistic women in HE would likely lead to deeper insights and understanding. The social experiences of autistic women in HE specifically should be addressed, as there are likely elements to female friendships and interactions which will be unique in comparison to friendships in autistic male populations.

As discussed, this research aimed to be participatory, however, there were additional steps that could have been taken to ensure it was a fully participatory piece of research. Future research, therefore, could aim to increase the levels of participation seen in this research, to continue to work towards full control of research being given to autistic populations, and ensure there is inclusion by the population that will be affected by the research, in each part of the research process.

It would be interesting to explore the transition to HE as it happens with autistic women. For example, Tiana reported difficulties in recalling elements of her transition, and several other participants spoke more of the practical preparations they made before going to university. Reasons for this have been discussed, for example, it potentially being easier to know how to prepare practically, with emotional and mental preparations being difficult especially when it is unclear exactly what HE will look like until the students are there. Therefore, research conducted with autistic women as they undertake the transition could be insightful in aiding participants to reflect on any emotional preparations they did engage in, whilst living the experience.

## **Conclusion**

The number of autistic students in HE is increasing (HESA, 2023), though this remains lower than students from other disability groups (Wei et al., 2013). Despite this, there is limited research into the transitional experiences of autistic women in HE. Where there is research, much of this is with male participants, with female experiences being underrepresented (Cai & Richdale, 2016; Madaus et al., 2022; Van Hees et al., 2015). Additionally, there is increased research into the barriers and challenges autistic students face in HE, which, whilst important, could contribute to a narrative of autism as being grounded in deficits, with strengths being excluded. Therefore, this study aimed to explore the social, personal, and academic experiences of autistic women as they transitioned to HE and to explore the strengths they have that helped them to be successful in these settings.

There is also often a disconnect between the autistic community and autism researchers. As such, this research included a consultation phase to ensure the voices and priorities of autistic women were accurately captured. A qualitative IPA method allowed for appropriate exploration of this group who are currently under-represented in the literature. IPA also allowed for detailed exploration and analysis of each account, with the individual stories deemed more important than group level analysis.

Both phases demonstrated the differing preferences of participants in how to engage in research. The importance of being as open as possible regarding preferred means of participation was demonstrated, with differences between participants including, the amount of information preferred prior to participation, and accommodations that may be needed, with the importance of asking each individual seeming of most importance, and not making assumptions about what a person may need on the basis of them being autistic.

There were no group level themes identified, but rather areas of interest for various reasons, sometimes related to commonalities in the findings, or at other times, related to differences. The findings further highlight the individualised nature of autism, with different experiences highlighted between participants. The participants spoke of differences in how they related to their identities as a woman and to being autistic, with some having more comprehensive ideas about this compared to others, and some finding it easier to think about than others. There were also differences in the participants' decision making around going to university, and whilst they varied in how they experienced the transition, there were also similarities in terms of how they prepared for it, with preparations seeming largely practical in nature.

The social aspect of HE was reflected on substantially by the participants in phase B, with a mixture of difficult experiences, with some participants explaining how it was difficult to both make and sustain friendships, but also examples of positive relationships which were sustained after leaving HE. Considering the amount of space that participants dedicated to reflecting on their social experiences, it seems that this was an important aspect of their HE experiences. Similarly, the participants reflected on the academic experience they had, again, with differences in experiences. Some provided examples of where being autistic was advantageous academically, and others reflected on the academic aspect being inaccessible to them and of being autistic as a barrier to academic success.

The participants had different conceptualisations of being autistic, with some holding a perception of being autistic as problematic and as making their life as a student harder, whereas

others were able to provide examples of where they felt that being autistic was beneficial to them in HE. This further demonstrates the individualised nature of autism. Similarly, there were differences in how the participants made sense of difficulties experienced, with some internalising such difficulties and seeing it as a deficit within themselves, and others externalising the experience, and considering ways in which the institution and wider systems had let them down. Another point of interest was how most participants had not received formal diagnoses during their time in HE, with several participants wondering whether they would have had a different HE experience had they known they were autistic at the time.

Some key implications of this research include the importance of participatory research. It is important that research participants are given as much flexibility and choice as possible in how to take part in research. It is hoped that the focus on strengths will go some way in contributing to changing understanding of, and discourse around autism, hopefully contributing to a move away from a deficit focused narrative and towards a more balanced and nuanced understanding. It is also hoped that the results of this research demonstrate the importance of autism as being recognised as highly individualised, with both HE institutions and research settings needing to hold this in mind when working with autistic populations. Finally, the importance of early diagnosis was demonstrated, with difficulties of late diagnosis being demonstrated throughout the study.

Overall, this study highlighted the variety of experiences that autistic women have in HE, whilst at the same time identifying areas of commonality. These findings come at a time where numbers of autistic students are increasingly accessing HE and should provide valuable insights into the experiences of such students, and as such, hopefully bring the attention of HE institutions to the individualised needs of their students, both those diagnosed as autistic and those who are not.

## References

- Adreon, D., & Durocher, J. S. (2007). Evaluating the college transition needs of individuals with high-functioning autism spectrum disorders. *Intervention in School and Clinic, 42*(5), 271-279. <https://doi.org/10.1177/10534512070420050201>
- American Psychiatric Association, DSM-5 Task Force. (2013). *Diagnostic and statistical manual of mental disorders: DSM-5™* (5th ed.). American Psychiatric Publishing, Inc.. <https://doi.org/10.1176/appi.books.9780890425596>
- Ames, M. E., Coombs, C. E., Duerksen, K. N., Vincent, J., & McMorris, C. A. (2022). Canadian mapping of autism-specific supports for postsecondary students. *Research in Autism Spectrum Disorders, 90*, 101899. <https://doi.org/10.1016/j.rasd.2021.101899>
- Anderson, A. H., Stephenson, J., & Carter, M. (2017). A systematic literature review of the experiences and supports of students with autism spectrum disorder in post-secondary education. *Research in Autism Spectrum Disorders, 39*, 33-53. <https://doi.org/10.1016/j.rasd.2017.04.002>
- Antezana, L., Factor, R. S., Condy, E. E., Strege, M. V., Scarpa, A., & Richey, J. A. (2019). Gender differences in restricted and repetitive behaviors and interests in youth with autism. *Autism Research, 12*(2), 274-283. <https://doi.org/10.1002/aur.2049>
- Arnstein, S. R. (1969). A ladder of citizen participation. *Journal of the American Institute of Planners, 35*(4), 216-224.
- Astle, D. E., Holmes, J., Kievit, R., & Gathercole, S. E. (2022). Annual Research Review: The transdiagnostic revolution in neurodevelopmental disorders. *Journal of Child Psychology and Psychiatry, 63*(4), 397-417.
- Autistic students most likely to drop out of university: investigation. (n.d.). *North East Autism Society*. <https://www.ne-as.org.uk/news/autistic-students-most-likely-to-drop-out-of-university-investigation>
- Auyeung, B., Baron-Cohen, S., Ashwin, E., Knickmeyer, R., Taylor, K., & Hackett, G. (2009). Fetal testosterone and autistic traits. *British Journal of Psychology, 100*(1), 1-22. <https://doi.org/10.1348/000712608X311731>
- Baio, J., Wiggins, L., Christensen, D. L., Maenner, M. J., Daniels, J., Warren, Z., Kurzius-Spencer, M., Zahorodny, W., Rosenberg, C. R., White, T., Durkin, M. S., Imm, P., Nikolaou, L., Yeargin-Allsopp, M., Lee, L., Harrington, R., Lopez, M., Fitzgerald, R. T.,



- Hewitt, A., ...Dowling, N. F. (2014). Prevalence of autism spectrum disorder among children aged 8 years—autism and developmental disabilities monitoring network, 11 sites, United States, 2010. *Morbidity and Mortality Weekly Report*, 63(2), 1. doi: 10.15585/mmwr.ss6706a1
- Baloo, K., Pauli, R., & Worrell, M. (2017). Undergraduates' personal circumstances, expectations and reasons for attending university. *Studies in Higher Education*, 42(8), 1373-1384. <https://doi.org/10.1080/03075079.2017.1373138>
- Bargiela, S., Steward, R., & Mandy, W. (2016). The experiences of late-diagnosed women with autism spectrum conditions: An investigation of the female autism phenotype. *Journal of Autism and Developmental Disorders*, 46(10), 3281-3294. [https://DOI 10.1007/s10803-016-2872-8](https://doi.org/10.1007/s10803-016-2872-8)
- Barnhill, G. P. (2016). Supporting students with Asperger syndrome on college campuses: Current practices. *Focus on Autism and Other Developmental Disabilities*, 31(1), 3-15. <https://doi.org/10.1177/1088357614523121>
- Baron-Cohen, S. (2002). The extreme male brain theory of autism. *Trends in Cognitive Sciences*, 6(6), 248-254. [https://DOI: 10.1016/s1364-6613\(02\)01904-6](https://doi.org/10.1016/s1364-6613(02)01904-6)
- Baumer, N., & Frueh, J. (2021). *What is neurodiversity?* Harvard Health. <https://www.health.harvard.edu/blog/what-is-neurodiversity-202111232645>
- Begeer, S., Mandell, D., Wijnker-Holmes, B., Venderbosch, S., Rem, D., Stekelenburg, F., & Koot, H. M. (2013). Sex differences in the timing of identification among children and adults with autism spectrum disorders. *Journal of Autism and Developmental Disorders*, 43(5), 1151-1156. [https:// DOI: 10.1007/s10803-012-1656-z](https://doi.org/10.1007/s10803-012-1656-z)
- Black, M. H., Kuzminski, R., Wang, J., Ang, J., Lee, C., Hafidzuddin, S., & McGarry, S. (2024). Experiences of friendships for individuals on the autism spectrum: A scoping review. *Review Journal of Autism and Developmental Disorders*, 11(1), 184-209. <https://doi.org/10.1007/s40489-022-00332-8>
- Bonvillain, N. (2020). *Women and men: Cultural constructs of gender*. Rowman & Littlefield Publishers.
- Brown, L. (2011, August, 4). *The significance of semantics: Person-first language: Why it matters*. Autistic Hoya. <https://www.autistichoya.com/2011/08/significance-of-semantics-person-first.html>

- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative research in psychology*, 3(2), 77-101. [https://DOI:10.1191/1478088706qp063oa](https://doi.org/10.1191/1478088706qp063oa)
- Braun, V., & Clarke, V. (2013). *Successful qualitative research: A practical guide for beginners*. Sage
- Buijsman, R., Begeer, S., & Scheeren, A. M. (2023). 'Autistic person' or 'person with autism'? Person-first language preference in Dutch adults with autism and parents. *Autism*, 27(3), 788-795. <https://doi.org/10.1177/1362361322111791>
- Cage, E., & Howes, J. (2020). Dropping out and moving on: A qualitative study of autistic people's experiences of university. *Autism*, 24(7), 1664-1675. <https://doi.org/10.1177/1362361320918750>
- Cai, R. Y., & Richdale, A. L. (2016). Educational experiences and needs of higher education students with autism spectrum disorder. *Journal of Autism and Developmental Disorders*, 46, 31-41. [https://DOI 10.1007/s10803-015-2535-1](https://doi.org/10.1007/s10803-015-2535-1)
- Cameto, R., Levine, P., & Wagner, M. (2004). Transition planning for students with disabilities: A special topic report of findings from the national longitudinal transition study-2 (NLTS2). *National Center for Special Education Research*.
- Cassidy, C., & Trew, K. (2004). Identity change in Northern Ireland: A longitudinal study of students' transition to university. *Journal of Social Issues*, 60(3), 523-540. <https://doi.org/10.1111/j.0022-4537.2004.00370.x>
- Chahboun, S., Vulchanov, V., Saldana, D., Eshuis, H., & Vulchanova, M. (2017). Can you tell it by the prime? A study of metaphorical priming in high-functioning autism in comparison with matched controls. *International Journal of Language & Communication Disorders*, 52(6), 766-785. <https://doi.org/10.1111/1460-6984.12314>
- Cheak-Zamora, N. C., Teti, M., & First, J. (2015). 'Transitions are scary for our kids, and they're scary for us': Family member and youth perspectives on the challenges of transitioning to adulthood with autism. *Journal of Applied Research in Intellectual Disabilities*, 28(6), 548-560. <https://doi.org/10.1111/jar.12150>
- Chown, N., Robinson, J., Beardon, L., Downing, J., Hughes, L., Leatherland, J., Fox, K., Hickman, L., & MacGregor, D. (2017). Improving research about us, with us: A draft framework for inclusive autism research. *Disability & Society*, 32(5), 720-734. <https://doi.org/10.1080/09687599.2017.1320273>

- Colbourne, L., & Sque, M. (2004). Split personalities: Role conflict between the nurse and the nurse researcher. *NT Research*, 9(4), 297-304.  
<https://doi.org/10.1177/136140960400900410>
- Cornwall, A., & Jewkes, R. (1995). What is participatory research? *Social Science & Medicine*, 41(12), 1667-1676. [https://doi.org/10.1016/0277-9536\(95\)00127-S](https://doi.org/10.1016/0277-9536(95)00127-S)
- Croen, L. A., Zerbo, O., Qian, Y., Massolo, M. L., Rich, S., Sidney, S., & Kripke, C. (2015). The health status of adults on the autism spectrum. *Autism*, 19(7), 814-823.  
<https://DOI:10.1177/1362361315577517>
- Danermark, B. (2002). Interdisciplinary research and critical realism the example of disability research. *Alethia*, 5(1), 56-64. <https://DOI:10.1558/aleth.v5i1.56>
- Davis, J. T., & Hines, M. (2020). How large are gender differences in toy preferences? A systematic review and meta-analysis of toy preference research. *Archives of Sexual Behavior*, 49(2), 373-394. <https://doi.org/10.1007/s10508-019-01624-7>
- Davis, M. T., Watts, G. W., & López, E. J. (2021). A systematic review of firsthand experiences and supports for students with autism spectrum disorder in higher education. *Research in Autism Spectrum Disorders*, 84, 101769. <https://DOI:10.1016/j.rasd.2021.101769>
- Demuth, C. (2015). New directions in qualitative research in psychology. *Integrative Psychological and Behavioral Science*, 49, 125-133. <https://doi.org/10.1007/s12124-015-9303-9>
- den Houting, J., Higgins, J., Isaacs, K., Mahony, J., & Pellicano, E. (2021). 'I'm not just a guinea pig': Academic and community perceptions of participatory autism research. *Autism*, 25(1), 148-163. <https://doi.org/10.1177/1362361320951696>
- Department of Education. (2021, June 10). *Graduate Labour Market Statistics*. <https://explore-education-statistics.service.gov.uk/find-statistics/graduate-labour-markets/2020>
- Devon County Council. (2022, October 4). *Transition: autism additional guidance – primary to secondary and secondary to post-16 (appendix 2020)*.  
<https://www.devon.gov.uk/support-schools-settings/inclusion/transition/transition-autism-additional-guidance-primary-to-secondary-and-secondary-to-post-16/>
- Dooley, N., Ruigrok, A., Holt, R., Allison, C., Tsompanidis, A., Waldman, J., Auyeung, B., Lombardo, M. V., & Baron-Cohen, S. (2022). Is there an association between prenatal

- testosterone and autistic traits in adolescents?. *Psychoneuroendocrinology*, *136*, 105623. <https://doi.org/10.1016/j.psyneuen.2021.105623>
- Dowling, M. (2006). Approaches to reflexivity in qualitative research. *Nurse Researcher*, *13*(3). <https://DOI: 10.7748/nr2006.04.13.3.7.c5975>
- Dworzynski, K., Ronald, A., Bolton, P., & Happé, F. (2012). How different are girls and boys above and below the diagnostic threshold for autism spectrum disorders?. *Journal of the American Academy of Child & Adolescent Psychiatry*, *51*(8), 788-797. <https://doi.org/10.1016/j.jaac.2012.05.018>
- Eatough, V., & Smith, J. A. (2017). Interpretative phenomenological analysis. *The Sage Handbook of Qualitative Research in Psychology*, 193-209.
- Elias, R., Muskett, A. E., & White, S. W. (2019). Educator perspectives on the postsecondary transition difficulties of students with autism. *Autism*, *23*(1), 260-264. <https://doi.org/10.1177/1362361317726246>
- Elias, R., & White, S. W. (2018). Autism goes to college: Understanding the needs of a student population on the rise. *Journal of Autism and Developmental Disorders*, *48*(3), 732-746. <https://doi:10.1007/s10803-017-3075-7>
- Ellison, L. M. (2013). Assessing the readiness of higher education to instruct and support students with Asperger's Disorder. *Theses, Dissertations and Capstones*. Paper 428. *Equality Act 2010*.
- Essex, J., & Melham, P. (2019). Experiences of educational transition: young women with ASD, and the staff supporting them, speak. *Support for Learning*, *34*(1), 86-111. [https:// DOI: 10.1111/1467-9604.12235](https://DOI: 10.1111/1467-9604.12235)
- Fabri, M., Fenton, G., Andrews, P., & Beaton, M. (2022). Experiences of higher education students on the autism spectrum: Stories of low mood and high resilience. *International Journal of Disability, Development and Education*, *69*(4), 1411-1429. <https://doi.org/10.1080/1034912X.2020.1767764>
- Fleischer, A. S. (2012). Support to students with Asperger syndrome in higher education—the perspectives of three relatives and three coordinators. *International Journal of Rehabilitation Research*, *35*(1), 54-61. <https://DOI: 10.1097/MRR.0b013e32834f4d3b>

- Fletcher, A. J. (2017). Applying critical realism in qualitative research: methodology meets method. *International Journal of Social Research Methodology*, 20(2), 181-194. <https://doi.org/10.1080/13645579.2016.1144401>
- Fook, C. Y., & Sidhu, G. K. (2015). Investigating learning challenges faced by students in higher education. *Procedia-Social and Behavioral Sciences*, 186, 604-612. [https://doi: 10.1016/j.sbspro.2015.04.001](https://doi.org/10.1016/j.sbspro.2015.04.001)
- Gee, J. P. (2014). *An introduction to discourse analysis: Theory and method*. Routledge. <https://doi.org/10.4324/9781315819679>
- Gelbar, N. W., Smith, I., & Reichow, B. (2014). Systematic review of articles describing experience and supports of individuals with autism enrolled in college and university programs. *Journal of Autism and Developmental Disorders*, 44(10), 2593-2601. [https://DOI 10.1007/s10803-014-2135-5](https://doi.org/10.1007/s10803-014-2135-5)
- Giacomini, M. (2010). Theory matters in qualitative health research. *The SAGE Handbook of Qualitative Methods in Health Research*, 125-156. <https://doi.org/10.4135/9781446268247.n8>
- Giarelli, E., Wiggins, L. D., Rice, C. E., Levy, S. E., Kirby, R. S., Pinto-Martin, J., & Mandell, D. (2010). Sex differences in the evaluation and diagnosis of autism spectrum disorders among children. *Disability and Health Journal*, 3(2), 107-116. [https://doi: 10.1016/j.dhjo.2009.07.001](https://doi.org/10.1016/j.dhjo.2009.07.001)
- Gobbo, K., & Shmulsky, S. (2014). Faculty experience with college students with autism spectrum disorders: A qualitative study of challenges and solutions. *Focus on Autism and Other Developmental Disabilities*, 29(1), 13-22. [https://DOI: 10.1177/1088357613504989](https://doi.org/10.1177/1088357613504989)
- Gowen, E., Taylor, R., Bleazard, T., Greenstein, A., Baimbridge, P., & Poole, D. (2019). Guidelines for conducting research studies with the autism community. *Autism Policy & Practice*, 2(1 A new beginning), 29.
- Gray, L., Bownas, E., Hicks, L., Hutcheson-Galbraith, E., & Harrison, S. (2021). Towards a better understanding of girls on the autism spectrum: Educational support and parental perspectives. *Educational Psychology in Practice*, 37(1), 74-93. <https://doi.org/10.1080/02667363.2020.1863188>

- Gurbuz, E., Hanley, M., & Riby, D. M. (2019). University students with autism: The social and academic experiences of university in the UK. *Journal of Autism and Developmental Disorders*, 49(2), 617-631. [https://DOI: 10.1007/s10803-018-3741-4](https://doi.org/10.1007/s10803-018-3741-4)
- Hagner, D., Kurtz, A., May, J., & Cloutier, H. (2014). Person-centered planning for transition-aged youth with autism spectrum disorders. *Journal of Rehabilitation*, 80(1), 4-10.
- Hammarberg, K., Kirkman, M., & De Lacey, S. (2016). Qualitative research methods: when to use them and how to judge them. *Human Reproduction*, 31(3), 498-501. <https://doi.org/10.1093/humrep/dev334>
- Hart, D., Grigal, M., & Weir, C. (2010). Expanding the paradigm: Postsecondary education options for individuals with autism spectrum disorder and intellectual disabilities. *Focus on Autism and Other Developmental Disabilities*, 25(3), 134-150. [https://DOI: 10.1177/1088357610373759](https://doi.org/10.1177/1088357610373759)
- Haynes, K. (2012). Reflexivity in qualitative research. *Qualitative Organizational Research: Core Methods and Current Challenges*, 26, 72-89. <https://doi.org/10.4135/9781526435620.n5>
- Head, A. M., McGillivray, J. A., & Stokes, M. A. (2014). Gender differences in emotionality and sociability in children with autism spectrum disorders. *Molecular Autism*, 5, 1-9. [https://DOI: 10.1186/2040-2392-5-19](https://doi.org/10.1186/2040-2392-5-19)
- Hebron, J. (2017). The transition from primary to secondary school for students with autism spectrum conditions. In *Supporting Social Inclusion for Students with Autism Spectrum Disorders* (pp. 84-99). Routledge. [https://DOI:10.4324/9781315641348-8](https://doi.org/10.4324/9781315641348-8)
- HESA. (2022, February 10). *What are HE students' progression rates and qualifications?: Personal characteristics*. <https://www.hesa.ac.uk/data-and-analysis/students/outcomes/characteristics>
- HESA. (2023, January, 31). *Who's studying in HE?: Personal characteristics*. <https://www.hesa.ac.uk/data-and-analysis/students/whos-in-he/characteristics>
- Hetherington, S. A., Durant-Jones, L., Johnson, K., Nolan, K., Smith, E., Taylor-Brown, S., & Tuttle, J. (2010). The lived experiences of adolescents with disabilities and their parents in transition planning. *Focus on Autism and Other Developmental Disabilities*, 25(3), 163-172. [https://DOI:10.1177/1088357610373760](https://doi.org/10.1177/1088357610373760)

- Hillier, A., Goldstein, J., Murphy, D., Trietsch, R., Keeves, J., Mendes, E., & Queenan, A. (2018). Supporting university students with autism spectrum disorder. *Autism, 22*(1), 20-28. [https://DOI: 10.1177/1362361317699584](https://doi.org/10.1177/1362361317699584)
- Hines, M., Constantinescu, M., & Spencer, D. (2015). Early androgen exposure and human gender development. *Biology of Sex Differences, 6*, 1-10. [https://DOI 10.1186/s13293-015-0022-1](https://doi.org/10.1186/s13293-015-0022-1)
- Hotez, E., Shane-Simpson, C., Obeid, R., DeNigris, D., Siller, M., Costikas, C., Pickens, J., Massa, A., Giannola, M., D'Onofrio, J., & Gillespie-Lynch, K. (2018). Designing a summer transition program for incoming and current college students on the autism spectrum: A participatory approach. *Frontiers in Psychology, 9*, 46. <https://doi.org/10.3389/fpsyg.2018.00046>
- Howitt, D., & Cramer, D. (2010). Introduction to qualitative methods in psychology.
- Howlin, P., Arciuli, J., Begeer, S., Brock, J., Clarke, K., Costley, D., Di Rita, P., Falkmer, T., Glozia, N., Gray, K., Guastella, A., Horstead, S., Rice, L., Stancliffe, R. J., West, S., Yam, C., & Einfeld, S. (2015). Research on adults with autism spectrum disorder: Roundtable report. *Journal of Intellectual and Developmental Disability, 40*(4), 388-393. <https://doi.org/10.3109/13668250.2015.1064343>
- Hull, L., Petrides, K. V., & Mandy, W. (2020). The female autism phenotype and camouflaging: A narrative review. *Review Journal of Autism and Developmental Disorders, 7*, 306-317. [https://DOI:10.1007/s40489-020-00197-9](https://doi.org/10.1007/s40489-020-00197-9)
- Hyde, J. S., Bigler, R. S., Joel, D., Tate, C. C., & van Anders, S. M. (2019). The future of sex and gender in psychology: Five challenges to the gender binary. *American Psychologist, 74*(2), 171. <https://doi.org/10.1037/amp0000307>
- James, P., Schafer, E., Wolfe, J., Matthews, L., Browning, S., Oleson, J., Sorensen, E., Rance, G., Sheils., & Dunn, A. (2022). Increased rate of listening difficulties in autistic children. *Journal of Communication Disorders, 99*(106252). <https://doi.org/10.1016/j.jcomdis.2022.106252>
- Jang, J., Matson, J. L., Adams, H. L., Konst, M. J., Cervantes, P. E., & Goldin, R. L. (2014). What are the ages of persons studied in autism research: A 20-year review. *Research in Autism Spectrum Disorders, 8*(12), 1756-1760. <https://doi.org/10.1016/j.rasd.2014.08.008>



- Jaswal, V. K., & Akhtar, N. (2019). Being versus appearing socially uninterested: Challenging assumptions about social motivation in autism. *Behavioral and Brain Sciences*, 42, e82. <https://doi:10.1017/S0140525X18001826>
- Kanfiszer, L., Davies, F., & Collins, S. (2017). 'I was just so different': The experiences of women diagnosed with an autism spectrum disorder in adulthood in relation to gender and social relationships. *Autism*, 21(6), 661-669. <https://doi.org/10.1177/1362361316687987>
- Katusic, M. Z., Myers, S. M., Weaver, A. L., & Voigt, R. G. (2021). IQ in autism spectrum disorder: A population-based birth cohort study. *Pediatrics*, 148(6). <https://doi.org/10.1542/peds.2020-049899>
- Keating, C. T. (2021). Participatory autism research: how consultation benefits everyone. *Frontiers in Psychology*, 3729. <https://doi.org/10.3389/fpsyg.2021.713982>
- Keating, C. T., Hickman, L., Leung, J., Monk, R., Montgomery, A., Heath, H., & Sowden, S. (2023). Autism-related language preferences of English-speaking individuals across the globe: A mixed methods investigation. *Autism Research*, 16(2), 406-428. [https://DOI: 10.1002/aur.2864](https://DOI:10.1002/aur.2864)
- Kennett, D. J., Reed, M. J., & Lam, D. (2011). The importance of directly asking students their reasons for attending higher education. *Issues in Educational Research*, 21(1), 65-74. <http://www.iier.org.au/iier21/kennett.html>
- Kenny, L., Hattersley, C., Molins, B., Buckley, C., Povey, C., & Pellicano, E. (2016). Which terms should be used to describe autism? Perspectives from the UK autism community. *Autism*, 20(4), 442-462 [https:// DOI: 10.1177/1362361315588200](https://DOI:10.1177/1362361315588200)
- Krahn, T. M., & Fenton, A. (2012). The extreme male brain theory of autism and the potential adverse effects for boys and girls with autism. *Journal of Bioethical Inquiry*, 9(1), 93-103. [https://DOI 10.1007/s11673-011-9350-y](https://DOI10.1007/s11673-011-9350-y)
- Kuder, S. J., & Accardo, A. (2018). What works for college students with autism spectrum disorder. *Journal of Autism and Developmental Disorders*, 48, 722-731. <https://doi.org/10.1007/s10803-017-3434-4>
- Lai, M. C., & Baron-Cohen, S. (2015). Identifying the lost generation of adults with autism spectrum conditions. *The Lancet Psychiatry*, 2(11), 1013-1027. [https://doi.org/10.1016/s2215-0366\(15\)00277-1](https://doi.org/10.1016/s2215-0366(15)00277-1)



- Lai, M. C., Kasee, C., Besney, R., Bonato, S., Hull, L., Mandy, W., Szatmari, P., & Ameis, S. H. (2019). Prevalence of co-occurring mental health diagnoses in the autism population: A systematic review and meta-analysis. *The Lancet Psychiatry*, 6(10), 819-829. [https://doi: 10.1016/S2215-0366\(19\)30289-5](https://doi.org/10.1016/S2215-0366(19)30289-5)
- Lai, M. C., Lombardo, M. V., Auyeung, B., Chakrabarti, B., & Baron-Cohen, S. (2015). Sex/gender differences and autism: Setting the scene for future research. *Journal of the American Academy of Child & Adolescent Psychiatry*, 54(1), 11-24. <https://doi.org/10.1016/j.jaac.2014.10.003>
- Lambe, S., Russell, A., Butler, C., Fletcher, S., Ashwin, C., & Brosnan, M. (2019). Autism and the transition to university from the student perspective. *Autism*, 23(6), 1531-1541. <https://DOI: 10.1177/1362361318803935>
- Laursen, B. (2017). Making and keeping friends: The importance of being similar. *Child Development Perspectives*, 11(4), 282-289. <https://doi.org/10.1111/cdep.12246>
- Lei, J., Jones, L., & Brosnan, M. (2021). Exploring an e-learning community's response to the language and terminology use in autism from two massive open online courses on autism education and technology use. *Autism*, 25(5), 1349-1367. <https://doi.org/10.1177/1362361320987963>
- Lindqvist, A., Sendén, M. G., & Renström, E. A. (2021). What is gender, anyway: a review of the options for operationalising gender. *Psychology & Sexuality*, 12(4), 332-344. <https://doi.org/10.1080/19419899.2020.1729844>
- Loomes, R., Hull, L., & Mandy, W. P. L. (2017). What is the male-to-female ratio in autism spectrum disorder? A systematic review and meta-analysis. *Journal of the American Academy of Child & Adolescent Psychiatry*, 56(6), 466-474. <https://DOI: 10.1016/j.jaac.2017.03.013>
- Lowe, H., & Cook, A. (2003). Mind the gap: Are students prepared for higher education?. *Journal of Further and Higher Education*, 27(1), 53-76. <https://doi.org/10.1080/03098770305629>
- MacLeod, A., & Green, S. (2009). Beyond the books: Case study of a collaborative and holistic support model for university students with Asperger syndrome. *Studies in Higher Education*, 34(6), 631-646. <https://doi.org/10.1080/03075070802590643>

- Madaus, J., Reis, S., Gelbar, N., Delgado, J., & Cascio, A. (2022). Perceptions of Factors that Facilitate and Impede Learning Among Twice-Exceptional College Students with Autism Spectrum Disorder. *Neurobiology of Learning and Memory*, 107627. <https://doi.org/10.1016/j.nlm.2022.107627>
- Mademtzi, M., Singh, P., Shic, F., & Koenig, K. (2018). Challenges of females with autism: A parental perspective. *Journal of Autism and Developmental Disorders*, 48(4), 1301-1310. [https://DOI: 10.1007/s10803-017-3341-8](https://doi.org/10.1007/s10803-017-3341-8)
- Mandy, W., Chilvers, R., Chowdhury, U., Salter, G., Seigal, A., & Skuse, D. (2012). Sex differences in autism spectrum disorder: evidence from a large sample of children and adolescents. *Journal of Autism and Developmental Disorders*, 42(7), 1304-1313. [https://DOI 10.1007/s10803-011-1356-0](https://doi.org/10.1007/s10803-011-1356-0)
- Manzi, C., Vignoles, V. L., & Regalia, C. (2010). Accommodating a new identity: Possible selves, identity change and well-being across two life-transitions. *European Journal of Social Psychology*, 40(6), 970-984. <https://doi.org/10.1002/ejsp.669>
- Matthews, L. K., Wall, K. H., Hoffman, Y., Pantale, A., & De Martinis, J. (2019). The unheard voices of transition: The experiences of four female young adults with ASD as they prepare to graduate. *The High School Journal*, 102(4), 283-296. <https://doi.org/10.1353/hsj.2019.0010>
- May, T., Cornish, K., & Rinehart, N. J. (2016). Gender profiles of behavioral attention in children with autism spectrum disorder. *Journal of Attention Disorders*, 20(7), 627-635. <https://doi.org/10.1177/1087054712455502>
- McConkey, R. (2020). The rise in the numbers of pupils identified by schools with autism spectrum disorder (ASD): A comparison of the four countries in the United Kingdom. *Support for Learning*, 35(2), 132-143. <https://doi.org/10.1111/1467-9604.12296>
- McCrossin, R. (2022). Finding the true number of females with autistic spectrum disorder by estimating the biases in initial recognition and clinical diagnosis. *Children*, 9(2), 272. <https://doi.org/10.3390/children9020272>
- Michael, C. (2021). Is being othered a co-occurring condition of autism? *Autism in Adulthood*, 3(2), 118-119. [https://doi: 10.1089/aut.2021.0019](https://doi.org/10.1089/aut.2021.0019)

- Milton, D., & Sims, T. (2016). How is a sense of well-being and belonging constructed in the accounts of autistic adults? *Disability & Society*, *31*(4), 520-534.  
<https://doi.org/10.1080/09687599.2016.1186529>
- Milner, V., McIntosh, H., Colvert, E., & Happé, F. (2019). A qualitative exploration of the female experience of autism spectrum disorder (ASD). *Journal of Autism and Developmental Disorders*, *49*, 2389-2402. [https:// DOI: 10.1007/s10803-019-03906-4](https://doi.org/10.1007/s10803-019-03906-4)
- Newman, L., Wagner, M., Knokey, A. M., Marder, C., Nagle, K., Shaver, D., & Wei, X. (2011). The post-high school outcomes of young adults with disabilities up to 8 years after high school: A report from the national longitudinal transition study-2 (NLTS2). NCSER 2011-3005. *National Center for Special Education Research*.  
[https://DOI:10.13140/RG.2.2.20600.57600](https://doi.org/10.13140/RG.2.2.20600.57600)
- NHS England. (2023, December 12). Meeting the needs of autistic adults in mental health services. <https://www.england.nhs.uk/long-read/meeting-the-needs-of-autistic-adults-in-mental-health-services/>
- Nowell, S. W., Jones, D. R., & Harrop, C. (2019). Circumscribed interests in autism: Are there sex differences?. *Advances in Autism*, *5*(3), 187-198. <https://doi.org/10.1108/AIA-09-2018-0032>
- Nowell, S., Norris, J. M., White, D. E., & Moules, N. J. (2017). Thematic analysis: Striving to meet the trustworthiness criteria. *International Journal of Qualitative Methods*, *16*, 1-13.  
<https://doi.org/10.1177/1609406917733847>
- Office for Students. (2020, July 27). *Disabled Students*.  
<https://www.officeforstudents.org.uk/advice-and-guidance/promoting-equal-opportunities/effective-practice/disabled-students/>
- Office for Students. (2022, November 11). *Equality, diversity and student characteristics data*.  
<https://www.officeforstudents.org.uk/data-and-analysis/student-characteristics-data/population-data-dashboard/>
- Oswald, D. L., & Clark, E. M. (2003). Best friends forever?: High school best friendships and the transition to college. *Personal Relationships*, *10*(2), 187-196.  
<https://doi.org/10.1111/1475-6811.00045>

- Paskins, R. T. (2018). Supporting students with autism spectrum disorder in post-secondary education settings: Common barriers and needed accommodations and supports. *All Graduate Theses and Dissertations*. 7284.
- Patnaik, E. (2013). Reflexivity: Situating the researcher in qualitative research. *Humanities and Social Science Studies*, 2(2), 98-106.
- Pavlopoulou, G., & Dimitriou, D. (2020). In their own words, in their own photos: Adolescent females' siblinghood experiences, needs and perspectives growing up with a preverbal autistic brother or sister. *Research in Developmental Disabilities*, 97, 103556.  
[https://DOI: 10.1016/j.ridd.2019.103556](https://doi.org/10.1016/j.ridd.2019.103556)
- Pellicano, E., & den Houting, J. (2022). Annual research review: Shifting from 'normal science' to neurodiversity in autism science. *Journal of Child Psychology and Psychiatry*, 63(4), 381-396. <https://doi.org/10.1111/jcpp.13534>
- Pellicano, E., Dinsmore, A., & Charman, T. (2014). Views on researcher-community engagement in autism research in the United Kingdom: A mixed-methods study. *PLoS One*, 9(10), e109946. <https://doi.org/10.1371/journal.pone.0109946>
- Pesonen, H. V., Waltz, M., Fabri, M., Lahdelma, M., & Syurina, E. V. (2021). Students and graduates with autism: Perceptions of support when preparing for transition from university to work. *European Journal of Special Needs Education*, 36(4), 531-546.  
<https://doi.org/10.1080/08856257.2020.1769982>
- Peters, R., & Brooks, R. (2016). Parental perspectives on the transition to secondary school for students with Asperger syndrome and high-functioning autism: A pilot survey study. *British Journal of Special Education*, 43(1), 75-91. <https://doi.org/10.1111/1467-8578.12125>
- Petrescu, S. H., Lazar, A., Cioban, C., & Doroftei, I. (2017). Semi-structured interview. *Qualitative Research in Regional Geography: A Methodological Approach*, 37-50.
- Pickard, H., Pellicano, E., den Houting, J., & Crane, L. (2022). Participatory autism research: Early career and established researchers' views and experiences. *Autism*, 26(1), 75-87.  
<https://doi.org/10.1177/13623613211019594>
- Pietkiewicz, I., & Smith, J. A. (2014). A practical guide to using interpretative phenomenological analysis in qualitative research psychology. *Psychological Journal*, 20(1), 7-14.  
[https://DOI: 10.14691/CPJ.20.1.7](https://doi.org/10.14691/CPJ.20.1.7)

- Pinder-Amaker, S. (2014). Identifying the unmet needs of college students on the autism spectrum. *Harvard Review of Psychiatry*, 22(2), 125-137. [https://DOI: 10.1097/HRP.0000000000000032](https://doi.org/10.1097/HRP.0000000000000032)
- Preciado, P., Snijders, T. A., Burk, W. J., Stattin, H., & Kerr, M. (2012). Does proximity matter? Distance dependence of adolescent friendships. *Social Networks*, 34(1), 18-31. [https://doi: 10.1016/j.socnet.2011.01.002](https://doi.org/10.1016/j.socnet.2011.01.002)
- Pugliese, C. E., & White, S. W. (2014). Brief report: Problem solving therapy in college students with autism spectrum disorders: Feasibility and preliminary efficacy. *Journal of Autism and Developmental Disorders*, 44(3), 719-729. [https://DOI 10.1007/s10803-013-1914-8](https://doi.org/10.1007/s10803-013-1914-8)
- Quirici, M. (2015). Geniuses without imagination: Discourses of autism, ability, and achievement. *Journal of Literary & Cultural Disability Studies*, 9(1), 71-88. <https://doi.org/10.3828/jlcds.2015.5>
- Raymaker, D. M., Teo, A. R., Steckler, N. A., Lentz, B., Scharer, M., Delos Santos, A., Kapp, S. K., Hunter, M., Joyce, A., & Nicolaidis, C. (2020). "Having all of your internal resources exhausted beyond measure and being left with no clean-up crew": Defining autistic burnout. *Autism in Adulthood*, 2(2), 132-143. <https://doi.org/10.1089/aut.2019.0079>
- Ridley, R. (2019). Some difficulties behind the concept of the 'Extreme male brain' in autism research. A theoretical review. *Research in Autism Spectrum Disorders*, 57, 19-27. <https://doi.org/10.1016/j.rasd.2018.09.007>
- Roberts, N., & Birmingham, E. (2017). Mentoring university students with ASD: A mentee-centered approach. *Journal of Autism and Developmental Disorders*, 47, 1038-1050. [https://DOI: 10.1007/s10803-016-2997-9](https://doi.org/10.1007/s10803-016-2997-9)
- Roman-Urrestarazu, A., van Kessel, R., Allison, C., Matthews, F. E., Brayne, C., & Baron-Cohen, S. (2021). Association of race/ethnicity and social disadvantage with autism prevalence in 7 million school children in England. *JAMA Pediatrics*, 175(6), e210054-e210054. [https:// doi:10.1001/jamapediatrics.2021.0054](https://doi.org/10.1001/jamapediatrics.2021.0054)
- Rudy, L. J. (2022, August, 27). *What does Neurotypical mean?* Verywell Health. <https://www.verywellhealth.com/what-does-it-mean-to-be-neurotypical-260047>
- Russell, G., Kapp, S. K., Elliott, D., Elphick, C., Gwernan-Jones, R., & Owens, C. (2019). Mapping the autistic advantage from the accounts of adults diagnosed with autism: A

- qualitative study. *Autism in Adulthood*, 1(2), 124-133.  
<https://doi.org/10.1089/aut.2018.0035>
- Rynkiewicz, A., Janas-Kozik, M., & Słopeń, A. (2019). Girls and women with autism. *Psychiatr Pol*, 53(4), 737-752. <https://doi.org/10.12740/PP/OnlineFirst/95098>
- Rynkiewicz, A., Schuller, B., Marchi, E., Piana, S., Camurri, A., Lassalle, A., & Baron-Cohen, S. (2016). An investigation of the ‘female camouflage effect’ in autism using a computerized ADOS-2 and a test of sex/gender differences. *Molecular Autism*, 7, 1-8.  
[https://DOI 10.1186/s13229-016-0073-0](https://DOI.10.1186/s13229-016-0073-0)
- Scanlon, M., Leahy, P., Jenkinson, H., & Powell, F. (2020). ‘My biggest fear was whether or not I would make friends’: Working-class students’ reflections on their transition to university in Ireland. *Journal of Further and Higher Education*, 44(6), 753-765.  
<https://doi.org/10.1080/0309877X.2019.1597030>
- Sedgewick, F., Hill, V., & Pellicano, E. (2019). ‘It’s different for girls’: Gender differences in the friendships and conflict of autistic and neurotypical adolescents. *Autism*, 23(5), 1119-1132. [https://DOI: 10.1177/1362361318794930](https://DOI:10.1177/1362361318794930)
- Seers, K., & Hogg, R. C. (2021). You don’t look autistic’: A qualitative exploration of women’s experiences of being the ‘autistic other’. *Autism*, 25(6), 1553-1564. [https://DOI: 10.1177/1362361321993722](https://DOI:10.1177/1362361321993722)
- Shattuck, P. T., Narendorf, S. C., Cooper, B., Sterzing, P. R., Wagner, M., & Taylor, J. L. (2012). Postsecondary education and employment among youth with an autism spectrum disorder. *Pediatrics*, 129(6), 1042-1049. [https://doi: 10.1542/peds.2011-2864](https://doi:10.1542/peds.2011-2864)
- Smith, J. A., Jarman, M., & Osborn, M. (1999). Doing interpretative phenomenological analysis. *Qualitative Health Psychology: Theories and Methods*, 1(1), 218-240.  
<https://doi.org/10.4135/9781446217870.n14>
- Smith, J. A., & Osborn, M. (2015). Interpretative phenomenological analysis as a useful methodology for research on the lived experience of pain. *British Journal of Pain*, 9(1), 41-42. [https://doi: 10.1177/2049463714541642](https://doi:10.1177/2049463714541642)
- Sofaer, S. (1999). Qualitative methods: what are they and why use them?. *Health Services Research*, 34(5 Pt 2), 1101.
- Solomon, M., Miller, M., Taylor, S. L., Hinshaw, S. P., & Carter, C. S. (2012). Autism symptoms and internalizing psychopathology in girls and boys with autism spectrum disorders.

*Journal of Autism and Developmental Disorders*, 42(1), 48-59. [https://DOI: 10.1007/s10803-011-1215-z](https://doi.org/10.1007/s10803-011-1215-z)

*Special Educational Needs and Disabilities Act 2001*.

Stagg, S. D., & Vincent, J. (2019). Autistic traits in individuals self-defining as transgender or nonbinary. *European Psychiatry*, 61, 17-22. [https://DOI: 10.1016/j.eurpsy.2019.06.003](https://doi.org/10.1016/j.eurpsy.2019.06.003)

Tarallo, A. E. (2012). *Understanding students with autism spectrum disorders in higher education* (Doctoral dissertation, Northeastern University).

Taylor, S. (2013). *What is discourse analysis?* (p. 128). Bloomsbury Academic.

Thompson, C., Bölte, S., Falkmer, T., & Girdler, S. (2019). Viewpoints on how students with autism can best navigate university. *Scandinavian Journal of Occupational Therapy*, 26(4), 294-305. <https://doi.org/10.1080/11038128.2018.1495761>

Thompson, C., Falkmer, T., Evans, K., Bölte, S., & Girdler, S. (2018). A realist evaluation of peer mentoring support for university students with autism. *British Journal of Special Education*, 45(4), 412-434. <https://doi.org/10.1111/1467-8578.12241>

Trevisan, D., & Birmingham, E. (2016). Examining the relationship between autistic traits and college adjustment. *Autism*, 20(6), 719-729. [https://DOI: 10.1177/1362361315604530](https://doi.org/10.1177/1362361315604530)

Unger, R. (2020). *Representations: Social Constructions of Gender*. Routledge.

VanBergeijk, E., Klin, A., & Volkmar, F. (2008). Supporting more able students on the autism spectrum: College and beyond. *Journal of Autism and Developmental Disorders*, 38(7), 1359-1370. [https://DOI: 10.1007/s10803-007-0524-8](https://doi.org/10.1007/s10803-007-0524-8)

Van Hees, V., Moyson, T., & Roeyers, H. (2015). Higher education experiences of students with autism spectrum disorder: Challenges, benefits and support needs. *Journal of Autism and Developmental Disorders*, 45(6), 1673-1688. [https:// DOI: 10.1007/s10803-014-2324-2](https://doi.org/10.1007/s10803-014-2324-2)

Vanson, S. (2014). *What on earth are ontology and epistemology?* The Performance Solutions. <https://theperformancesolution.com/earth-ontology-epistemology/>

Vincent, S., & O'Mahoney, J. (2018). Critical realism and qualitative research: An introductory overview. *The Sage Handbook of Qualitative Business and Management Research Methods*. <https://doi.org/10.4135/9781526430212.n13>



- Vincent, J. (2019). It's the fear of the unknown: Transition from higher education for young autistic adults. *Autism*, 23(6), 1575-1585. [https:// DOI: 10.1177/1362361318822498](https://doi.org/10.1177/1362361318822498)
- Vincent, J., Rowe, H., & Johnson, J. (2022). Parity of participation for autistic students: Mapping provision across UK higher education institutions. *Research in Education*, 112(1), 20-38. <https://doi.org/10.1177/0034523720981123>
- Walker, N. (2021). What is neurodiversity.
- Warrier, V., Greenberg, D. M., Weir, E., Buckingham, C., Smith, P., Lai, M. C., Allison, C., & Baron-Cohen, S. (2020). Elevated rates of autism, other neurodevelopmental and psychiatric diagnoses, and autistic traits in transgender and gender-diverse individuals. *Nature Communications*, 11(1), 3959. [https://doi: 10.1038/s41467-020-17794-1](https://doi.org/10.1038/s41467-020-17794-1)
- Weiss, A. L., & Rohland, P. (2015). Implementing a communication coaching program for students with autism spectrum disorders in postsecondary education. *Topics in Language Disorders*, 35(4), 345-361. [https://DOI: 10.1097/TLD.0000000000000071](https://doi.org/10.1097/TLD.0000000000000071)
- Wei, X., Yu, J. W., Shattuck, P., McCracken, M., & Blackorby, J. (2013). Science, technology, engineering, and mathematics (STEM) participation among college students with an autism spectrum disorder. *Journal of Autism and Developmental Disorders*, 43(7), 1539-1546. [https://doi: 10.1007/s10803-012-1700-z](https://doi.org/10.1007/s10803-012-1700-z)
- Wenzel, C., & Brown, J. T. (2014). Beyond academic intelligence: Increasing college success for students on the autism spectrum. *Handbook of Autism and Pervasive Developmental Disorders, Fourth Edition*. <https://doi.org/10.1002/9781118911389.hautc39>
- White, S. W., Elias, R., Salinas, C. E., Capriola, N., Conner, C. M., Asselin, S. B., Miyazaki, Y., Mazefsky, C. A., Howlin, P., & Getzel, E. E. (2016). Students with autism spectrum disorder in college: Results from a preliminary mixed methods needs analysis. *Research in Developmental Disabilities*, 56, 29-40. [https://doi: 10.1016/j.ridd.2016.05.010](https://doi.org/10.1016/j.ridd.2016.05.010)
- White, S. W., Ollendick, T. H., & Bray, B. C. (2011). College students on the autism spectrum: Prevalence and associated problems. *Autism*, 15(6), 683-701. [https://DOI: 10.1177/1362361310393363](https://doi.org/10.1177/1362361310393363)
- Whiteley, P., Todd, L., Carr, K., & Shattock, P. (2010). Gender ratios in autism, Asperger syndrome and autism spectrum disorder. *Autism Insights*, 2, 17.
- Wilcox, P., Winn, S., & Fyvie-Gauld, M. (2005). 'It was nothing to do with the university, it was just the people': The role of social support in the first-year experience of higher



education. *Studies in Higher Education*, 30(6), 707-722.

<https://doi.org/10.1080/03075070500340036>

Willig, C. (2013). *Introducing Qualitative Research in Psychology*. Open University Press.

Woods, R., & Waltz, M. (2019). The strength of autistic expertise and its implications for autism knowledge production: A response to Damian Milton. *Autonomy, the Critical Journal of Interdisciplinary Autism Studies*, 1(6).

World Health Organisation. (n.d.). Gender and health. [https://www.who.int/health-topics/gender#tab=tab\\_1](https://www.who.int/health-topics/gender#tab=tab_1)

Zeedyk, S. M., Tipton, L. A., & Blacher, J. (2016). Educational supports for high functioning youth with ASD: The postsecondary pathway to college. *Focus on Autism and Other Developmental Disabilities*, 31(1), 37-48. <https://doi.org/10.1177/1088357614525435>

Zener, D. (2019). Journey to diagnosis for women with autism. *Advances in Autism*, 5(1), 2-13. <https://doi.org/10.1108/AIA-10-2018-0041>

## Appendices

### Appendix A - Phase A Participant Information Sheet

Faculty of Medicine and Health



UNIVERSITY OF LEEDS

#### Participant Information Sheet

##### Consultation Phase - Exploring Educational Transition Experiences and Strengths in Autistic Women

You are being invited to take part in shaping a research project into the experiences of autistic women in higher education. We are particularly interested in autistic women's experiences of transitioning to higher education (i.e., starting university) and their perceptions of strengths that have aided this transition. This information sheet will provide you with information about why the research is being conducted and what it will involve. It is important that you take the time to read the following information carefully and understand what is being asked of you. If you have any questions, or if anything is not clear, please ask the research team using the details below.

##### What is the purpose of the project?

An increasing number of autistic students are accessing higher education, with these numbers expected to continue to grow. Yet, compared to other disability groups, autistic populations have lower graduation rates. Existing research is largely focused on the barriers facing autistic students as they transition into higher education, and is also comprised heavily of data from male participants. This highlights a need for increased research into the experiences of autistic women as they transition into higher education, and additionally, into the strengths they possess that enables them to succeed in such a setting.

Furthermore, autistic voices are currently underrepresented in research. This project aims to involve autistic women with an experience of attending higher education in the design and planning stages, to ensure that the research is in line with their priorities, and is conducted in the most accessible way for autistic populations.

This project will be conducted to fulfil a thesis requirement, by Rebecca Gibson, a Trainee Clinical Psychologist at the University of Leeds.

The aim of the project is to explore the experiences of autistic women as they transition into higher education, and to explore strengths they have which enable them to be successful in such a setting.

##### Why have I been chosen?

You have been chosen to take part in this research as you have identified that as an autistic woman who is currently at, or has previously attended a higher education institution, you might be interested in sharing your experiences and shaping the research area of interest and methodology of the research.

##### Do I have to take part?

You do not have to take part in this research. It is up to you whether you wish to take part or not. Participation is entirely voluntary and should you decline to take part, there will be no negative consequences of this. If you do decide to take part, you will be given a copy of this information sheet and be asked to sign a consent form, and you can still withdraw at any point, until seven days after completing the interview.



However, it is important to note that whilst direct contributions and quotations can be withdrawn up until this point, information you have provided will likely have already influenced the thinking and direction of the research team, meaning it may not be possible to remove your contributions more broadly. You do not have to give a reason for declining to take part or withdrawing from the project.

#### **What do I have to do?**

If you decide to take part in the research, you will be asked to take part in an interview that is anticipated to last up to 60-90 minutes. The interview will be with Rebecca Gibson (Trainee Clinical Psychologist) from the University of Leeds. The interview can either be completed in person at the University of Leeds, remotely via Microsoft Teams/Zoom, or over the phone depending on your personal preference. The interview will consider what areas you think are important to research regarding autistic women and higher education, and have a focus on how the research can be most accessible for an autistic population.

The research itself is expected to last until May 2024 date, with it being possible that you may be asked if you would like to take part in further interviews or provide further feedback at various points of the process.

#### **What are the possible disadvantages and risks of taking part?**

We understand that there is potential for distress when reflecting on your own experiences and sharing what is important to you. As a Trainee Clinical Psychologist, Rebecca has the skills to help you manage any distress or discomfort you might experience, and will give time to reflect on this together. You can terminate the interview at any point.

#### **What are the possible benefits of taking part?**

It is hoped that this work may be a useful opportunity for autistic women to be more involved in academic research and be given a space to have their voices heard. Taking part in this research will ultimately hopefully contribute to more inclusive practices in higher education and improve the experiences of autistic women in such settings. Taking part in this phase of the research will also enable the research to be carried out in a way which feels most accessible for autistic populations. As a thank you for taking part in this phase of the research, you will be offered a £20 Amazon voucher.

#### **Will I be recorded, and how will the recorded media be used?**

The interview will not be audio/video recorded. Only handwritten notes will be taken during the interview. Nobody outside of the research project will have access to these notes.

#### **Ethical Approval**

Ethical approval has been given by the School of Medicine Ethics Committee at the University of Leeds (DClinREC ref number: MREC 22-088).

#### **Use, dissemination and storage of research data**

As described, data collected will be used to fulfil a thesis project for the Clinical Psychology Programme at the University of Leeds. However, it is also hoped that the research will have real world implications in understanding and improving the experiences of autistic women in higher education, as well as enabling autistic voices to be heard more in academic research. For the purpose of the researcher's studies, a thesis document will be produced. No individuals will be identifiable in the report, with identifiable information being anonymised.



Any data collected will be handled in accordance with the University of Leeds data protection policy and the general data protection regulations. Any paper data will be scanned or typed up, and the paper notes shredded at the earliest opportunity. The resulting files will be transferred to a secure University of Leeds One Drive account. Should there be a period of time between these notes being taken and scanning taken place, these notes will be fully anonymised with identifying features removed and locked in a drawer when they are not in use.

At the end of the lead researcher's time at the University of Leeds, any e-data will be transferred to another member of the research team, who will store them in an access controlled folder in a secure storage area. Anonymised data collected may be used in future research by other genuine researchers.

The University of Leeds Research Participant Privacy Notice can be found via a link on the following webpage: <https://dataprotection.leeds.ac.uk/information-for-researchers/>.

#### **What will happen to my personal information?**

Confidentiality will be maintained throughout the research. The only times confidentiality would be broken would be if the researcher deemed there to be a risk to the safety of the yourself or others, in which case they would have a duty of care to involve others as appropriate.

Due to the nature of interviews, participants will not be anonymous to the researcher. However, any participant data will be anonymised, and a participant number or pseudonym will be allocated following notes being taken, ensuring any data used in the write up will be anonymous, and participants will not be able to be identified in resulting publications.

#### **Who is organising/ funding the research?**

The research will be conducted by Rebecca Gibson (Trainee Clinical Psychologist) at the University of Leeds and supervised by Dr Paula Clarke (Associate Professor in Psychological Approaches to Childhood and Inclusive Education), Dr Ciara Masterson (Academic Director of the Clinical Psychology Programme), and Dr Kerrie Channer (Clinical Tutor on the Clinical Psychology Programme).

#### **Contact for further information**

For any further information please contact:  
Rebecca Gibson: [umrq@leeds.ac.uk](mailto:umrq@leeds.ac.uk)

#### **Finally...**

You will be given a copy of this information sheet to keep and a signed copy of your completed consent form, should you agree to take part in this research.

Thank you for taking the time to read the information on this sheet.

## Appendix B - Phase A Consent Form

Faculty of Health and Medicine



UNIVERSITY OF LEEDS

<b>Consent to take part in: Consultation Phase - Exploring Educational Transition Experiences and Strengths in Autistic Women.</b>	<b>Add your initials next to the statement if you agree</b>
I confirm that I have read and understand the information sheet explaining the above research project and I have had the opportunity to ask questions about the project.	
I understand that my participation is voluntary and that I am free to withdraw up to seven days post-interview (using the researcher's contact details on the information sheet), without giving any reason and without there being any negative consequences. In addition, should I not wish to answer any particular question or questions, I am free to decline.	
I give permission for members of the research team to have access to my anonymised responses. I understand that my name will not be linked with the research materials, and I will not be identified or identifiable in the report or reports that result from the research. I understand that my responses will be kept strictly confidential unless the researcher perceives there to be a risk to myself or others.	
I agree for the data collected from me in an anonymised form to be stored and used in relevant future research by other genuine researchers.	
I understand that the researcher and subsequent researchers may use my anonymised words in publications, reports, web pages, and other research outputs.	
I understand that relevant sections of the data collected during the study, may be looked at by auditors from the University of Leeds where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.	
I agree to take part in the above research project and will inform the lead researcher should my contact details change during the project and, if necessary, afterwards.	

Name of participant	
Participant's signature	
Date	
Name of lead researcher	
Signature	
Date*	

## Appendix C - Phase A Topic Guide

### Topic Guide

Questions deliberately open in order to be responsive to each participant.

Introductory element with opportunity to introduce the research team, what the DClin is, what the research is about, how long the research will last, and to find out a bit about the consultants etc.

Questions about the aims of the research	Questions about the methodology
<p>"To what extent do you think research into this area of starting university is important?"</p> <p>"Why did you want to take part in this study? What was it that drew you to take part?"</p> <p>"As part of this research, we're only interested in the experiences of women, what are your thoughts on that?"</p> <p>"We're focusing primarily on strengths that have helped with that period of time when starting university, what do you think about that?"</p>	<p>Explain why participatory research is important – different types of this etc.</p> <p>"We are planning to recruit participants through adverting within the <a href="#">UoJ</a> and use of social media. Do you have any other thoughts on what might be an effective means of recruiting participants? Where would be good to advertise?"</p>
<p>"A big part of my project is going to be based around starting university, and I'm not asking too much about that today, but I wonder if you could tell me briefly about your experiences of starting university?"</p> <p>If positive experience – "What made it good?" or if negative, "Can you tell me what could have been done differently to improve your experience?"</p>	<p>"For the second part of this research, what information would be useful to have in advance of the meeting? Would it have been useful for me to share certain things with you before today's appointment?"</p>
<p>"We're still grappling a little with how to access the concept of individual strengths – do you have any thoughts on how we could get people to think about their strengths?"</p>	<p>"How can we create an enabling environment for those taking part?"</p> <p>"What are your thoughts on remote or face to face meetings? Is there anything we should be holding in mind in relation to this?"</p> <p>"Is there anything we should be holding in mind in terms of both expressive and receptive communication needs?" E.g., How much scaffolding might need to be given, anything to be aware of in terms of sequencing and timing of information given and received?</p>
<p>"In your opinion, what would you consider that transition period to university to be?" – Prompts if needed – from applying, attending open days, etc.</p>	<p>"Would it be useful to be able to make contact after the meeting for anything the participants may have missed or forgotten to share?"</p>
	<p>"Currently, I'm imagining that this research will be a qualitative piece of research, and assuming that data collection might take the form of</p>

	interviews, however, this is still subject to your feedback. Do you have any thoughts on what might be useful ways of gathering information from participants, e.g., preferred ways of communicating – writing down, use of photos, interviews, questionnaires etc.”.
	“Would it be beneficial for participants to be offered an incentive for taking part in this research?”.

Consider asking consultants to meet again to think about reviewing the interview schedule for phase B, to consider analytic method, and dissemination plans.



## Appendix D - Ethics Confirmation Email – Phase A

### MREC 22-088 - Study Approval Confirmation



Medicine and Health Univ Ethics Review <FMHUniEthics@leeds.ac.uk>  
21/08/2023 09:41

To: Rebecca Gibson Cc: Paula Clarke; Ciara Masterson

Dear Rebecca

#### MREC 22-088 – Exploring Educational Transition Experiences and Strengths in Autistic Women

**NB: All approvals/comments are subject to compliance with current University of Leeds and UK Government advice regarding the Covid-19 pandemic.**

We are pleased to inform you that your research ethics application has been reviewed by the School of Medicine Research Ethics Committee (SoMREC) and we can confirm that ethics approval is granted based on the documentation received at date of this email.

Please retain this email as evidence of approval in your study file.

Please notify the committee if you intend to make any amendments to the research as submitted and approved to date. This includes recruitment methodology; all changes must receive ethical approval prior to implementation. Please see <https://ris.leeds.ac.uk/research-ethics-and-integrity/applying-for-an-amendment/> or contact the Research Ethics & Governance Administrator for further information [fmhuniethics@leeds.ac.uk](mailto:fmhuniethics@leeds.ac.uk) if required.

Ethics approval does not infer you have the right of access to any member of staff or student or documents and the premises of the University of Leeds. Nor does it imply any right of access to the premises of any other organisation, including clinical areas. The committee takes no responsibility for you gaining access to staff, students and/or premises prior to, during or following your research activities.

Please note: You are expected to keep a record of all your approved documentation, as well as documents such as sample consent forms, risk assessments and other documents relating to the study. This should be kept in your study file, which should be readily available for audit purposes. You will be given a two week notice period if your project is to be audited.

It is our policy to remind everyone that it is your responsibility to comply with Health and Safety, Data Protection and any other legal and/or professional guidelines there may be.

I hope the study goes well.

Best wishes

Sou Chung

*On behalf of Dr Naomi Quinton, CHAIR, SoMREC*

---

Sou Sit Chung, Research Ethics Administrator, The Secretariat, University of Leeds, LS2 9NL, [s.chung@leeds.ac.uk](mailto:s.chung@leeds.ac.uk)  
Please note my working hours are Monday to Friday 9am – 12.30pm



## Appendix E - List of Support Services

### Support Services

Please find below a range of services should you require any further support following taking part in the research.

**In an emergency or life threatening situation or if you feel unable to keep yourself safe:**

**Telephone:** 999

#### GP surgery

For illnesses that are not life-threatening, or if you think you need support but not immediately, contact your GP surgery. Outside of normal surgery hours you can still phone your GP, but you will usually be directed to an out-of-hours service. During out-of-hours periods you can also call NHS 111.

#### Leeds Nightline

**Phoneline:** 0113 380 1285

**Email:** [listening@leeds.nightline.ac.uk](mailto:listening@leeds.nightline.ac.uk)

**Website:** [leeds.nightline.ac.uk](http://leeds.nightline.ac.uk)

Leeds Nightline is a confidential listening and information service for students over the age of 16 in Leeds, based at Leeds University Union. The service is open between 8pm and 8am.

#### Shout

**Text:** 85258

**Website:** [giveusashout.org](http://giveusashout.org)

Shout is a 24/7, confidential, and free text service for anyone in the UK who is struggling to cope. By texting "SHOUT" to 85258, trained volunteers will respond and listen without judgement, and may provide extra resources and tools.

#### Single Point of Access (SPA) Leeds

**Phone:** 0800 183 1485

A 24/7, freephone service for people needing urgent support for their mental health. A Leeds and York Partnership NHS Foundation Trust service.

#### Samaritans

**Helpline:** 116 123 (24 hours a day)

**Website:** [www.samaritans.org](http://www.samaritans.org)

**Email:** [jo@samaritans.org](mailto:jo@samaritans.org)

Samaritans provides confidential non-judgmental emotional support, 24 hours a day for people who are experiencing feelings of distress or despair, including those which could lead to suicide.

## Appendix F - Phase B Participant Information Sheet

Faculty of Medicine and Health



UNIVERSITY OF LEEDS

### Participant Information Sheet

#### Exploring Educational Transition Experiences and Strengths in Autistic Women

You are being invited to take part in a research project into your experiences of the transition process to higher education and strengths that have helped you during this period. This information sheet will provide you with information about why the research is being conducted and what it will involve. It is important that you take the time to read the following information carefully and understand what is being asked of you. If you have any questions, or if anything is not clear, please ask the research team using the details below. Please take the time to consider if you would like to take part in the research or not.

#### What is the purpose of the project?

An increasing number of autistic students are accessing higher education, with these numbers expected to continue to grow. Yet, compared to other disability groups, autistic populations have lower graduation rates. Additionally, research into the transition experiences of autistic students into higher education is limited. Where there is research, this is largely focused on the barriers facing autistic students as they transition into higher education, and is also comprised heavily of data from male participants. This highlights a need for increased research into the experiences of autistic women as they transition into higher education, and additionally, into the strengths they possess that enables them to succeed in such a setting.

As part of the Clinical Psychology programme at the University of Leeds, trainees are required to complete a thesis project, and as such, this research will be conducted to fulfil this requirement, by Rebecca Barker, a Trainee Clinical Psychologist at the University of Leeds.

The aim of the project is to explore the experiences of autistic women as they transition into higher education, and to explore strengths they have which enable them to be successful in such a setting.

#### Why have I been chosen?

You have been chosen to take part in this research as you have identified that as an autistic woman who is currently at, or has previously attended university, you might be interested in sharing your experiences.

#### Do I have to take part?

You do not have to take part in this research. It is up to you whether you wish to take part or not. Participation is entirely voluntary and should you decline to take part, there will be no negative consequences of this. If you do decide to take part, you will be given a copy of this information sheet and be asked to sign a consent form, and you can still withdraw at any point, until seven days after completing the interview/survey/email questions, when data will be anonymised. You do not have to give a reason for declining to take part or withdrawing from the project.



### **What do I have to do?**

If you decide to take part in the research, you will be asked to take part in an interview, complete an online survey, or respond to a series of questions via email, whichever option is your preferred method. Any contact either via email or in the form of an interview will be with a researcher from the University of Leeds. Should an interview be your preference, this can be completed either in person at the University of Leeds, or remotely via Microsoft Teams/Zoom, or over the phone depending on your personal preference. Questions will be based on your experience of transitioning to higher education and perceived strengths that have enabled you to be successful. Topics of interest may include both perceived social and academic strengths, and your experiences of transitioning to and attending university.

The research itself is expected to last until May 2024, but you will only be required to attend one interview or respond to questions in writing once.

### **What are the possible disadvantages and risks of taking part?**

The researcher understands that there is potential for distress when reflecting on your own experiences. The researcher is a Trainee Clinical Psychologist and has the skills to help you manage any distress or discomfort you might experience, and will give time to reflect on this together. The participant may terminate the interview or decide not to respond to further questions in writing at any time.

### **What are the possible benefits of taking part?**

Whilst there are no immediate benefits for those participating in the project, it is hoped that this work may be a useful space for participants to reflect on their own experiences and to contribute to more inclusive practices in higher education and hopefully improve the experience of autistic women in higher education.

As a thank you for taking part in this research, you will be offered a £10 Amazon voucher.

### **Will I be recorded, and how will the recorded media be used?**

Interviews will be audio recorded only for the purpose of later transcription. These recordings will be deleted once transcribed and will not be used for any other purpose. Video recordings taken on Zoom will be deleted immediately, with only audio recordings retained for transcription. Nobody outside of the research project will have access to these recordings.

### **Ethical Approval**

Ethical approval has been sought from the School of Medicine Research ethics committee at the University of Leeds (application ref number: MREC 23-028).

### **Use, dissemination and storage of research data**

As described, data collected will be used to fulfil a thesis project for the Clinical Psychology Programme at the University of Leeds. However, it is also hoped that the research will have real world implications in understanding and improving the experiences of autistic women in higher education. For the purpose of the researcher's studies, a thesis document will be produced. No individuals will be identifiable in the report, with identifiable information being anonymised when interviews are transcribed.

Any data collected will be handled in accordance with the University of Leeds data protection policy and the general data protection regulations. Interviews will be audio recorded using MS Teams/Zoom, and transferred to a secure University of Leeds One Drive account on the day of recording and deleted from the device/software. Where Zoom is used, only audio files



from the Zoom meetings will be retained, all other files (containing visual records) will be deleted straight after the meeting.

Any paper data will be scanned or typed up, and the paper notes shredded at the earliest opportunity. The resulting files will be transferred to a secure University of Leeds One Drive account. Any handwritten notes will be fully anonymised, with no identifying features documented. Only your participation number will be written at the top of the page to enable the data to be withdrawn should this be requested in the seven days post participation. Should there be a period of time between these notes being taken and scanning taken place, they will be kept locked in a drawer when they are not in use.

At the end of the lead researcher's time at the University of Leeds, any e-data will be transferred to another member of the research team, who will store them in an access controlled folder in a secure storage area.

The University of Leeds Research Participant Privacy Notice can be found via a link on the following webpage: <https://dataprotection.leeds.ac.uk/information-for-researchers/>.

### **What will happen to my personal information?**

Confidentiality will be maintained throughout the research. The only times confidentiality would be broken would be if the researcher deemed there to be a risk to the safety of the yourself or others, in which case they would have a duty of care to involve others as appropriate.

Due to the nature of interviews, participants taking part in this way will not be anonymous to the researcher. However, during the transcription of the files, participant data will be anonymised, and a participant number or pseudonym allocated, ensuring any data used in the write up will be anonymous, and participants will not be able to be identified in resulting publications.

### **Who is organising/ funding the research?**

The research will be conducted by Rebecca Barker (Trainee Clinical Psychologist) at the University of Leeds and supervised by Dr Paula Clarke (Associate Professor in Psychological Approaches to Childhood and Inclusive Education), Dr Ciara Masterson (Academic Director of the Clinical Psychology Programme), and Dr Kerrie Channer (Clinical Tutor on the Clinical Psychology Programme).

### **Contact for further information**

For any further information please contact:  
Rebecca Barker: [umrg@leeds.ac.uk](mailto:umrg@leeds.ac.uk)

### **Finally...**

You will be given a copy of this information sheet to keep and a signed copy of your completed consent form, should you agree to take part in this research.

Thank you for taking the time to read the information on this sheet.

## Appendix G - Phase B Recruitment Poster

  
UNIVERSITY OF LEEDS

**Participants Needed!**  
**Exploring Educational Transition Experiences and Strengths in Autistic Women**

We are seeking autistic women with experiences of attending higher education to share their experiences

**About the research**

An increasing number of autistic students are accessing higher education, vet, compared to other disability groups, autistic populations have lower graduation rates. Existing research is largely focused on the barriers facing autistic students as they transition into higher education. and is also comprised heavily of data from male participants.

As such, we are looking for autistic women with experience of attending university or other higher education settings to share their experiences of transitioning to university. We are particularly interested in the strengths that autistic women possess which help them succeed in these settings. Taking part could be in the form of an interview, completing a questionnaire or an email conversation.

**About the researcher**

My name is Rebecca Barker, I am a Trainee Clinical Psychologist at the University of Leeds. Prior to training, I have worked in Neurodevelopmental CAMHS prior to training and am particularly interested in the experiences of autistic women.



**If you have any questions or would like to express an interest, please contact the lead researcher Rebecca Barker at: [umrg@leeds.ac.uk](mailto:umrg@leeds.ac.uk) or scan the QR code.**





## Appendix H - Phase B Interview Schedule

### Exploring Educational Transition Experiences and Strengths in Autistic Women

<p><b>Introduction Questions:</b></p> <p>Age, ethnicity, gender, when did you attend <u>uqj</u>?</p> <p><b>1. Core Question: Can you tell me a little about what you were doing before you went to <u>uqj</u>?</b></p> <p>Prompts/Follow-up Questions:</p> <p>A) Were you in education immediately before going to <u>uqj</u> or did you have a gap? B) If had a gap - what did you do during this time?</p> <p><b>2. Core Question: What made you decide to go to <u>uqj</u>?</b></p> <p>Prompts/Follow-up Questions:</p> <p>A) What are you studying/did you study? B) Where did you/are you studying and how did you make this decision? C) How did you decide on this subject and institution? D) Did anyone else help you with your decision?</p> <p><b>3. Core Question: Can you tell me a little about your <u>uqj</u> experience?</b></p> <p>Prompts/Follow-up Questions:</p> <p>A) Did/do you live at home or at <u>uqj</u>? B) If general positive <u>uqj</u> experience – “What was good about your experience?” or if negative, “Can you tell me what could have been done differently to improve your experience?”.</p>
<p><b>Being Autistic</b></p> <p>I am interested in the experiences of autistic women – what word would you use for autism?</p> <p><b>4. Core Question: What does being [insert preferred word] autistic mean to you?</b></p> <p>Prompts/Follow-up Questions:</p> <p>A) Are you diagnosed as autistic? B) When did you receive your diagnosis?</p> <p><b>Being an Autistic Woman in Higher Education</b></p> <p><b>5. Core Question: What does being a woman mean to you?</b></p> <p><b>6. Core Question: What does being an autistic woman in higher education mean to you?</b></p> <p>Prompts/Follow-up Questions:</p> <p>A) If you have a formal diagnosis, did/have you shared this with the university? For example, at applying, with disability services, with certain staff members?</p>
<p><b>Transition Questions:</b></p> <p><b>7. Core Question: I am interested in the transition period to university - what is your understanding of the word 'transition'?</b></p> <p>Prompts/Follow-up Questions:</p> <p>A) When I say the word transition, what do you think about? B) What other words do you think of in relation to transition?</p> <p><b>8. Core Question: Can you briefly tell me about your experience of transitioning to <u>uqj</u>?</b></p> <p>Prompts/Follow-up Questions:</p>

- A) When did you start thinking about whether you might like to go to university and what you might like to study?
- B) What period of time do you think about in relation to transitioning to higher education?
- C) When did you start to think about and prepare for the transition to higher education?
- D) Was there anything that helped with that transition?
- E) Was there anything that made it difficult?
- F) Was there anything that could have made it easier?

**9. Core Question: Was there anything you did personally to prepare for the transition to higher education?**

Prompts/Follow-up Questions:

- A) Anything that helped you to prepare practically, emotionally, or in any other way?

**10. Core Question: Did you have any support when planning the transition to university?**

Prompts/Follow-up Questions:

- A) You might want to think about areas such as academically (including support in lectures/seminars, or with assignments), support with independent daily living skills, support in joining sports clubs or societies, and wellbeing support etc. Including, thinking about support before, during, and after the transition.
- B) Who supported you at these times? E.g., family, friends, school, college, university etc.
- C) Was there any formal transition planning? What did this look like? Were you fully involved in this? Was there anything it didn't cover that you would have liked it to? Was there anything that was particularly helpful/unhelpful about it?
- D) If you were supported – did the support meet your needs?
- E) Is there any other form of support that would have been helpful?

**Strengths and Difficulties:**

**I'm interested in the strengths that autistic students have that help them to succeed at university...**

**11. Core Question: Has your experience of being [autistic] impacted your university experience? If so, please give detail.**

Prompts/Follow-up Questions:

- A) Are there advantages to being [autistic] in higher education?
- B) Are there disadvantages?

**12. Core Question: Academic demands are high at university. Can you remember a time you were struggling with the academic aspect of university and provide an example of this here.**

Prompts/Follow-up Questions:

- A) How did you get through that?
- B) Do you think being [autistic] had an impact on how you engaged with the academic side of university?
- C) Were there any times when being [autistic] made it harder/easier academically at university?

**13. Core Question: What was/is your experience of the social aspect of university?**

Prompts/Follow-up Questions:

- A) Did you form friendships with others at university – e.g., flatmates, course mates, through social clubs?
- B) Can you think of times this went well or times it was more difficult? Prompt for detail.

**14. Core Question: Were there any aspects of being autistic that made university challenging?**

Prompts/Follow-up Questions:

- A) E.g., communication, emotional, sensory, anxiety, need for sameness etc.

15. Were there any aspects of being autistic that made university better/easier?

16. Core Question: If I asked you to tell me some of your strengths, what would your strengths be?

Prompts/Follow-up Questions:

A) Do you think you have any strengths that have developed because of being [autistic]?

B) If unsure – what might your family and friends say are your strengths?



## Appendix I - Ethics Confirmation Email – Phase B

↩ Reply   ↩ Reply all   → Forward   📁 Archive   🗑

MREC 23-028 - Study Approval Confirmation with Comments



Medicine and Health Univ Ethics Review <FMHUniEthics@leeds.ac.uk>  
19/03/2024 12:37

To: Rebecca Barker Cc: Paula Clarke; Kerrie Channer; Ciara Masterson

Dear Becca

MREC 23-028 – Exploring Educational Transition Experiences and Strengths in Autistic Women (Phase B)

I am pleased to inform you that the above research ethics application has been reviewed by School of Medicine Ethics Committee and I can confirm a favourable ethical opinion based on the documentation received at date of this email.

The reviewers had some comments for your consideration which are below, these do not impact your approval. If you decide to update any documents in response to these comments please submit these to this email address for storage.

1. The applicant may want to ensure that all original audio recordings are kept for a minimum of 7 days to aid withdrawal.
2. Equally, if all participants are allocated a participant number to keep a note of, and the transcription is noted with this, the recording could be deleted earlier (i.e. once transcribed).

*Please retain this email as evidence of approval in your study file.*

Please notify the committee if you intend to make any amendments to the original research as submitted and approved to date. This includes recruitment methodology; all changes must receive ethical approval prior to implementation. Please see [http://ris.leeds.ac.uk/downloads/download/179/amendment\\_form](http://ris.leeds.ac.uk/downloads/download/179/amendment_form) or contact the Research Ethics & Governance Administrator for further information ([fmhuniethics@leeds.ac.uk](mailto:fmhuniethics@leeds.ac.uk)) if required.

Ethics approval does not infer you have the right of access to any member of staff or student or documents and the premises of the University of Leeds. Nor does it imply any right of access to the premises of any other organisation, including clinical areas. The committee takes no responsibility for you gaining access to staff, students and/or premises prior to, during or following your research activities.

*Please note:* You are expected to keep a record of all your approved documentation, as well as documents such as sample consent forms, risk assessments and other documents relating to the study. This should be kept in your study file, which should be readily available for audit purposes. You will be given a two week notice period if your project is to be audited.

If you require this confirmation in letter form, for example to show to external funders, then please do email me. I am happy to provide this if required.

It is our policy to remind everyone that it is your responsibility to comply with Health and Safety, Data Protection and any other legal and/or professional guidelines there may be.

I hope the study goes well.

Very best wishes,

Sou

On behalf of Dr Klaus Witte, CHAIR, SoMREC

---