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**AN EXAMINATION OF THE  
SUPPORT OF AUTISTIC  
STUDENTS IN TRANSITION**

**ANDREW ROBERT LEWIS SMITH**

A thesis submitted to the University of Huddersfield in partial fulfilment of the requirements for the degree of Master of Arts by Research

The University of Huddersfield

Submission date October 2018

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## **Abstract**

This research seeks to examine the experiences of disability support workers who assist autistic students in the transition process from further education to higher education. As an autistic person who has gone through the transition process I reflect on my own experiences in view of my research findings and through my experiences as an autistic person.

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## **Dedications and Acknowledgements**

I would like to thank Ms D Philip for her support and guidance as my main course supervisor.

## **List of abbreviations**

ASC – Autistic Spectrum Condition

ASD – Autistic Spectrum Disorder

DSM – Diagnostic and Statistical Manual

ICD – International Classification of Diseases

NAS – National Autistic Society





## **Chapter 1 - Introduction**

The basis for this study came from my personal experiences as an autistic student who had gone from further education to higher education and from volunteering in the autistic community and the narratives I heard about the transition experience from further education to higher education.

I heard differing narratives of how the transition had gone in terms of support for autistic students and this piqued my interest as to why there seemed to be so many wide-ranging views and experiences of transition. I began to wonder if there were any significant problems or issues in relation to transition that affected autistic students.

I set out with the aim of exploring if there were any issues in relation to transition but this changed to an examination of the experiences of disability support workers who have experience of supporting autistic students during the transition process and how they experienced this.

At this point I wanted to discover how my experiences as an autistic student compared to the experiences of the disability support workers and reflect on how this made me feel about my own experience and if it changed my own views on transition.

I decided to focus on experience and meaning because I wanted to discover in-depth and in detail what it meant to be a disability support worker how they supported autistic students.

Issues that arose are how to assist someone with a complex and at times misunderstood condition and achieve a balance between doing too much and doing too little.

## **Chapter 2 – Qualifying Statement**

### **2.1 Introduction**

This qualifying statement is intended to give background understanding to my position in my research as an autistic person who has gone through the process of transition. In parts of my thesis I reflect on my own experiences of transition from further education to higher education to give a first hand and personal account of what it is to experience the transition process as an autistic student. To understand how and why I have formed my perspectives on transition and what those perspectives are, I feel it is important to reflect on my personal experience of autism and education.

### **2.2 Background**

I was diagnosed with Asperger syndrome as an adult in October 2008 after many years of feeling out of sync with society. For many years before this I was confused and bewildered at the world I inhabited and struggled to understand people and behaviour. People would stare at me as if they understood my thoughts and I would look at them blankly not knowing what to say or do.

Other people would ask me questions and I tried as quickly as I could to process their words into something meaningful, but my response seemed only to confuse them further. I would read instructions, write down instructions and believe that I had understood and interpreted them yet when it came to be carrying out the task everything went wrong, and I could not understand why. I would spend more time trying to work out where I had gone wrong and worrying why than resolving the task.

This made society a difficult place for me to feel a part of and to contribute to. To mitigate the feelings of living on the fringes of society I adopted the persona of a class clown to fit in with society and lower the expectations I had of myself and others had of me. The aim of this was to reduce the pressure I felt to understand myself and society.

### **2.3 Return to Education**

After my diagnosis I decided to return to full time education to better myself academically and be more acceptable to society as a person. Achieving academically was a strong motivational factor as I have always believed I could achieve more academically than I have, and I saw this as an opportunity to learn and understand more about myself and people.

I enrolled on an Access to Higher Education course at Bradford College and was soon enjoying learning again and achieving more than I believed I was capable of. Some of the course I struggled with, time management and planning, but I understand why now. Autistic people tend to live in the moment and experience people and the surroundings they are in there and then rather than taking the time to stand back and reflect on what is happen around them and adjust their behaviour accordingly to the situation.

### **2.4 Understanding Behaviours**

This ability to adjust behaviour quickly and seemingly without thought appears to come naturally to neurotypical people but not to autistic people who like time to understand and comprehend the meaning and implications behind what is said and what is happening to a deep and detailed level. And this is one of the problems I experience and other people on the autistic spectrum experience in deciding what is and what is important, and needs understand and comprehending and what is not.

Again, it is as if neurotypical people possess magical powers in being able to sort through all the words and symbols that come at them from all directions and produce the perfect plan whereas the autistic person is left confused, bewildered, and lost in this world of incomprehensible sounds and images.

## **2.5 Staying Strong**

But I persevered and passed my Access to Higher Education course and enrolled at the University of Huddersfield on a sociology degree course. I wanted to learn about the world around me, the world I find so difficult to understand and make sense of and try and work out where I fitted into this world.

And studying for a degree was hard, very hard. This was because sociology and society are an abstract concept created by members of society so that people can be controlled and directed for the benefit of a few to the detriment of the many. That is my understanding of it at this moment in time.

## **2.6 Reflections**

On reflection I was studying an abstract subject with a logical mind whilst conforming to the standards set by neurotypicals. None of this is right or wrong, quite often we find ourselves in situations that from a distance seemed to be acceptable yet when we get into the situation we find ourselves confused and bewildered yet excited and intrigued. And a lot of these situations are of our own making because people whether autistic or neurotypical have an innate desire to find out and understand what is going on around them and why.

## **2.7 Success**

And I passed my degree. I passed it with a second class with honours and decided to pursue a masters by research with the focus on autism. I went

into my master's degree with the same mindset I had for my degree, I had to fit into the neurotypical world and understand the world and society as neurotypicals do not as I do as an autistic person.

## **2.8 Continuing Struggles**

And I have struggled with my masters. I have struggled with deciding what would be the focus of my research and how to approach it. Structuring my dissertation has been my biggest obstacle. Constantly worrying about what is expected of me what the people who will assess my work are looking for and if I am good enough to achieve this.

## **2.9 Understanding My Autistic Mind**

And I am doing all of this while trying to apply my autistic mind in a neurotypical way. Reading book after book after book about how to do this and how to do that, all written from a neurological perspective. And getting nowhere.

So, for this dissertation I have decided to take a different approach to writing it. Rather than write it from the perspective of an autistic person trying to fit into the neurotypical world I am writing it from the perspective of an autistic person living in the neurotypical world.

## **2.10 The Transition Process**

In addition, I have been through this process which means I have experienced it and given it a meaning prior to writing my dissertation. In many ways this could be a disadvantage and that is understandable. Having experienced a process or a situation it is inevitable that you will form your own opinions about it based on what you experienced.

But for me this is true of any process or situation we experience in life whether it is the first time or the hundredth we still gain knowledge and understanding about that process or experience and give it meaning.

Whether that meaning changes depends on any number of indeterminable factors that could influence our perspective of a process or situation.

I believe that the fact that I have been through the transition process should be an advantage especially as it is from the perspective of an autistic person. I have learnt through my volunteer work with the autistic community that every autistic person is different and experiences situations differently and this gives them a different perspective possibly even more so than a neurotypical person because of the depth and breadth of the autistic spectrum.

### **2.11 Experiences of Other Autistic People**

Whilst I am interested in my own experiences of transition I am also interested in the experiences of other autistic students who have gone through transition and how it has affected them. This is so I can compare and relate my experience to their experience and in doing so move the transition process on so that it benefits more autistic students and is more inclusive and acceptable for autistic students across the spectrum.

This approach brings with it advantages and disadvantages. When I do a literature review I recognise what is being said and why without having to give it a second thought. To me it all makes sense. But then I remember that for someone else reading it, it may not and how I interpret what has been written may be of interest to others not familiar with the autistic world.

### **2.12 Writing from My Perspective**

Similarly, when writing the findings and discussion and methodology sections they are from my perspective as an autistic person experiencing life through a different lens and not from the perspective of an autistic person trying to be neurotypical to fit in with society. This means that whilst

qualitative research is seen by many as being abstract I have applied my inherent logic and structure to it for it to fit how my autistic mind works. Doing my dissertation this way may not prove to be the right way, but it is my way, my own piece of work done in the only way I understand and feel comfortable doing. I have learnt that what I consider to be common sense others find interesting and new, much the same way as I do when neurotypicals talk about the world they inhabit.

## **Chapter 3 – Literature Review**

### **3.1 Introduction**

The purpose of this literature review is to explore and discuss contemporary articles and essays that focus on autism and transition between further and higher educational establishments. The literature was reviewed to examine perspectives about autism, support, and transition for autistic students from a variety of academic and professional backgrounds to form a deeper understanding of the issues and challenges support workers face when supporting autistic students in transition from further education to higher education. The review begins with an exploration of autism, what it is, how it affects people and any issues and challenges autistic people can face particularly the impact it can have on change and transition. The support of autistic students in transition will be examined from differing perspectives to determine areas of importance when considering support needs and accommodations.

### **3.2 Understanding Autism**

Autism as defined by Baron-Cohen (2008), NAS (2018), is a neurological developmental condition that affects how a person interprets and understands the world around them. People are born with autism, it does not develop due to old age like dementia (NHS Choices 2017) or occur because of a brain injury like a stroke (NHS Choices 2017). Autism is a spectrum condition and manifests itself differently in people. This can make autism difficult to diagnose especially in children (NAS 2018) and people who are considered high functioning or have Asperger's syndrome (NAS 2018).

People who are diagnosed with autism have problems with social interaction, social communication and their brains develop differently compared to the social and medical marker of neurotypically developed brains as Baron-Cohen (2008) and the NAS (2018) explain. This can result in a limited imagination, repetitive behaviour, overthinking and be at risk of developing anxiety and depression, (Baron-Cohen 2008), (NAS 2018).

Baron-Cohen (2008) writes about how autism affects people in several ways and the NAS (2018) go on to discuss how people will experience autism differently in terms of autistic attributes and severity. People with autism experience difficulties in social situations and with social communication, with sensory issues, noise, lights, and smells and enjoy structure and routine (Boucher, 2017).

Baron-Cohen (1997) discusses in detail the way in which the autistic mind operates and from this it can be deduced that there are differences in comparison with the neurotypical mind. This is a highly complex area which is beyond the scope of this thesis, but it needs to be mentioned briefly for context and contrast to be seen and any assumptions to be explored however briefly. It is assumed that that neurotypical people experience difficulties with social and sensory issues and enjoy structure and routine, but the differences arise in how these experiences are processed and dealt with mentally (Boucher, 2017). A neurotypical person may experience problems in a social situation and deal with it by either understanding what is happening and why and resolve the situation or if there is a lack of understanding dismiss the situation as irrelevant and move on (Boucher, 2017).

Neurotypical people appear to have a natural ability to understand and resolve a situation and decide what is and what is not irrelevant that autistic people do not (Boucher, 2017). An autistic person will not be able to

understand and resolve the situation and will either do nothing or do something inappropriate to the situation. They will dwell on what the situation is, sometimes for weeks, how to approach it, what the other person requires and how to resolve it to the satisfaction of everyone. In extreme cases the situation will take over the autistic persons reality and they will consider multiple permutations on how to resolve it and the possible outcomes if they use one of the permutations. Considering the situation can come at the expense of personal hygiene, eating healthy and other events in their lives (Boucher, 2017).

People with autism face numerous challenges in society and these challenges can have an impact on transition. Interpreting verbal and non-verbal communication (NAS 2018) where an autistic person may misunderstand the meaning of what is being said or taking things too literally. Baron-Cohen (2008) says that social interactions can cause autistic people significant problems when trying to read and understand other peoples' feelings or intentions and they can have difficulties expressing their own feelings which can lead to misunderstandings.

The NAS (2018) explain how behaviours and routines can be restricted and repetitive due to the autistic person finding society complicated and overwhelming and needing familiarity with the world around them for them to make sense of their surroundings and fit in as Baron-Cohen (2008) states in the only way they can. Rules can be difficult for autistic people to understand (NAS 2018) and once interpreted in one way it can be a problem for the autistic person to reinterpret the same rules in a different way as Baron-Cohen (2008) states. Autistic people can have highly focused interests (NAS 2018) and can pursue this interest to the exclusion of people and situations going on around them. These interests can change over time but for many autistic people there is a deep built in need for them to have

interests they can actively pursue. The NAS (2018) explain how sensory issues with lights, noise, smells, touch, pain, and movement can impact on an autistic person as over or under stimulation of the senses and have the potential to cause an autistic person pain and suffering.

### **3.3 The Impact of Change and Transition**

Change as Baron-Cohen (2008) states is a particularly difficult challenge for autistic people and one form of change is transition (NAS 2018). The difficulties for autistic people lie in need for sameness, structure, familiarity a desire for things to be done the same way repeatedly that allows an autistic person to feel safe and secure in an environment and perform to the best of their abilities. When this change occurs as in the transition from further education to higher education it can cause immense difficulties and challenges for the autistic person involved (NAS 2018), (Baron-Cohen 2008). Their routine and structure are disrupted along with the familiarity of their surroundings. It is not only the uncertainty of the future but how to plan and anticipate what may or may not happen which causes overwhelming feelings of stress and anxiety that can lead to an inability to function effectively in society and a lack of ability to manage the transition process effectively with or without the help of others (NAS 2018), (Baron-Cohen 2008).

This can then lead to an autistic person communicating to others that they understand the transition process and what is expected of them and what they can expect during the process, when in fact they do not understand the process and the expectations and are unable to communicate this to anyone because of fear of feeling stupid in asking questions and / or inability to visualise the possible permutations of what may and may not happen during the transition process and consequently not know what are the relevant questions to ask.

The literature reviewed agrees with the definition of autism by Baron-Cohen (2008) and the NAS (2018) on what autism is, what causes autism and the difficulties and challenges autistic people face. Adreon and Durocher (2007), Mitchell and Beresford (2014) and Van Hees, Moyson and Roeyers (2015) agree with Baron-Cohen (2008) and the NAS (2018) on the definition of autism, what causes autism and how it manifests itself in people. The definitions and descriptions of autism are important as consensus is needed as to what autism is and its effects are needed from professionals and academics so that society has an understanding and awareness of autism and stereotypes and socially constructed ideas about autism can be challenged and corrected where necessary.

### **3.4 Context in My Research**

Barnhill (2016) and Griffin et al (2014) discuss issues around autism and transition and these would suggest that having an understanding of autism as Adreon and Durocher (2007) state, its causes and how it affects those with the condition and those around them is essential if support in transition between further education and higher education establishments is to be developed and implemented effectively and with the minimum of disruption to the autistic student and their family and friends.

Adreon and Durocher (2007), Westbrook et al (2015) and Zeedyk, Tipton and Blacher (2016), discuss various issues that may occur during transition from further education to higher education and this highlights the importance of how the transition is supported and how this is made known to the autistic student can make the difference between a student who understands the full context of what is expected of them and what they are expected to be able to do academically, socially and living independently and a student who feels overwhelmed by the transition and is overly worried and anxious about what is happening and what is expected of them.

### **3.5 Increasing Numbers of Autistic Students**

Another factor that needs to be taken into consideration is the increasing numbers of autistic students who are enrolling in higher education having finished studying at a further education establishment. This creates a need to ensure that the complex academic, social, and independent support needs of autistic students are met and that the perspectives and experiences of autistic students, support professionals and family are considered when considering effective support plans.

Barnhill (2016), finds that there is an increase in applications from autistic students to colleges and universities, and it can be assumed that this number will rise. It can be assumed that a continuation in the number of autistic students enrolling in college and university will result in an increased demand for support each year. The issue with this research is that it is based on American data and it cannot be assumed that the same information will be applicable to UK colleges and universities.

Statistics from the Higher Education Statistics Agency show that for the year 2016/17 (Appendix 2) there was a total of 9,440 students enrolled in a higher education establishment who had declared themselves as having a social communication or autistic spectrum disorder. Figures for previous years at this level are difficult to compare because there was not the breakdown of enrolments by disability that there was in 2016/17. In 2012/13 (Appendix 1) there was 221,145 students enrolled who declared a disability and this rose to 279,115 in 2016/17 an increase of 26.21%. This is a substantial increase and it would be reasonable to assume that contained within this increase from 2012/13 to 2016/17 there was an increase in the number of students with a social communication or autistic spectrum disorder.

When the increase in females who are being diagnosed with an autistic spectrum disorder and the complex support needs of autistic students is factored in, it can be seen how important research is in these areas because numbers of autistic students are on the increase and the complex support needs indicate that this will have a growing impact on the financial and time resources of further and higher education establishments.

This is an area that does have its controversies as Baron-Cohen (2008) explores in detail. These controversies on why there is an increase in autistic people are still evident in contemporary society (Zhai et al 2017) and it can be assumed will be for some time. This is relevant as changes in what constitutes autism as in DSM 5 (American Psychiatric Association 2018) will affect diagnostic rates and could increase or decrease the number of autistic students entering further and higher education.

As Boucher (2017) asserts the way autism has been classified by DSM and ICD has changed over time and the classifications are now much more broader in terms of what is included. This can be seen in the changing descriptions, DSM-III is Infantile Autism and DSM-5 is Autism Spectrum Disorder (Boucher, 2017). These changes in descriptions reflect how knowledge and understanding of what autism is has advanced and changed, how it affects people and who it affects. It can be assumed that this will have an impact on the number of people who are diagnosed as more people will come under the classification of autism today than would have done in 1980 when DSM-III was published. The original classifications diagnosed people with intellectual disabilities, the classic 'Kanner' autism presentation (Boucher, 2017). Classifications have since broadened to include behavioural and developmental characteristics such as language delay and repetitive

behaviour which are not necessarily indicative of an intellectual disability (Boucher, 2017).

The changes in classification have an impact on how autism is diagnosed by professionals and who is eligible for an assessment and gains a diagnosis as Matson and Kozlowski (2011) discuss. Conditions such as ADHD and depression that may have been diagnosed separately from autism in the past are now being diagnosed as autism for various reasons (Coo et al, 2008). These changes in classification and diagnosis have an impact on the number of children and adults who are diagnosed with an ASD (Hansen et al, 2015) and people who would not previously have met the criteria for ASD now do and this accounts for a large part of the increase in people with a diagnosis of an ASD. It is reasonable to assume that this will impact on the number of people entering HE because the classification is now much broader and includes more categories that were not previously included and people who would previously not have received a diagnosis of autism now meet the criteria for a diagnosis.

With these increases in the number of people obtaining a diagnosis of an ASD comes a corresponding increase in the numbers of autistic students attending a HE establishment and an increase in the demand for disability services.

The changes in classification and diagnosis result in more children and adults being diagnosed with an ASD and more people entering or in HE obtain a diagnosis who may not have received one previously. The broadening of and improvements in classification and diagnosis accounts for the apparent increase in numbers of autistic people and the increase in numbers of autistic students rather than an absolute increase in numbers of autistic people by birth rate alone.

I acknowledge that these studies were carried out in countries other than the UK and studies conducted in the UK may produce different results. However, because the changes in criteria and classification are worldwide and not limited to one country I am making the assumption that any changes in criteria and classification will impact to a lesser or greater degree on the diagnostic rates of autism within that country and consequently impact on the number of people who are diagnosed with an ASD. Further studies in different countries would be required to clarify the exact impact changes in diagnostic criteria and classification impact on the number of people diagnosed with an ASD and it is beyond the scope of this thesis to conduct such research.

### **3.6 Autism and Transition**

Autistic people can find change difficult to understand and to manage effectively. This is due to change being an abstract and unpredictable experience for an autistic person and one where it can feel that they have little or no control over. This feeling of abstract unpredictability can cause the autistic person to shut down neurological functions to preserve themselves from what they see as impending doom. This shutdown of internal neurological functions can manifest itself to society as an autistic crisis which can vary from non-verbal behaviour where the autistic student will find it impossible to speak to anyone to violent outbursts where the autistic student will be liable to act aggressively towards other students or cause physical harm to another student.

As can be seen it can be distressing and disruptive to both the autistic student and to other students around them. How transition is explained and managed by student support services is essentially important for a smooth transition that is satisfactory for all involved.

Adreon and Durocher 2007 – problem behaviours associated with autism such as social interaction, social communication, and repetitive and restricted behaviours, may be observed in college age students who will be contemplating transition to a higher education establishment. Zeedyk et al (2016) state how success in adulthood for those with ASD rarely comes easily because of the problems ASD students encounter with the social and academic environments at higher education. Planning for the future of these individuals is crucial as Wagner, Newman, Cameto, Garza and Levine (2005) say of the ASD student is to be in the best position to achieve their full potential.

Adreon and Durocher (2007) discuss the impact of what type and size of higher education establishment to go to can have on the transition process. Other factors Adreon and Durocher (2007) discuss are assessing and teaching independent living skills, discussing when and how to disclose a disability. They go on to identify the importance of identifying appropriate academic supports and accommodations, social supports, and strategies to assist in adjusting to the higher education environment which are vital in formulating a transition plan. An Educational Health Care plan (GOV.UK No Date) can have an impact here. If the student has a plan in place then the place of higher education will have an idea of what support and accommodations the student needs because the plan will have their details. The student will lose any support provided through the plan when they move to higher education.

Zeedyk et al (2016) say that transition planning should focus on important pre-college decisions and careful thought needs to be applied as to how this transition planning is managed in terms what the stages are, when the stages are implemented and who is involved in the transition planning. If these

stages are not managed thoughtfully there is a risk of the transition process becoming confusing for everyone involved and missing important timelines.

Adreon and Durocher (2007), identify several interventions that need to be considered if a planning strategy is to be effective. These interventions include medical, prescription medicines and the eligibility for education services. It was found that the unique needs of ASD students were not always considered when these interventions were discussed, and this will have an impact on a transition in terms of success. This is not an exhaustive list and it is possible that some autistic students will need a more tailored transition planning strategy to the way that autism affects them as no two students will have the same support requirements. But having an effective planning strategy is essential if the student is going to have a chance of making a successful transition and if they are going to have the prospect of making a successful start academically and socially to their university life.

Blacher (2001) highlights the issues adolescents have when transitioning to adulthood, but these issues can be magnified if the adolescent is in a transition from further education to higher education during the transition to adulthood. The challenges for autistic people transitioning to adulthood are quite unique but for those adolescents on the autism spectrum the challenges are unique in comparison to a neurotypical person and this needs to be considered when planning for a transition.

Adreon and Durocher (2007), identify possible issues that support staff, tutors and students may encounter in autistic students in transition including difficulty with academic content, organising workloads, time management and study skills. These issues can be exacerbated if the students in need of services are not identified due to the hidden nature of their disability and if they are reluctant to disclose their disability. Larger class sizes in higher

education and the limited contact between lecturers and students are further considerations that need to be considered as new issues the autistic student will encounter in the transition to higher education. An autistic student may encounter or display one or more of these issues. These issues need to be considered when devising a template or a transition plan so that as many possible scenarios can be accounted for as early as possible in the transition process. This will assist support services in preparing a tailored transition plan for the autistic student that can mitigate any complications that may arise.

Mesibov, Shea and Adams (2001), stress the need for professionals and educators to move beyond the mere consideration of vocational capabilities to ensure the success of autistic students in transition. What this means is considering the challenges many autistic people have with social skills and understanding and interpreting non-verbal communication. Independent living skills need to be taken into consideration as well. For an autistic student these challenges can have as much as if not more of an impact on their chances of academic success as vocational abilities do.

If these considerations of moving beyond can be considered at the transition stage the effect of them on the autistic students' academic success can be reduced. This point emphasises the importance of having as many people as possible aware of the challenges that autistic people face and of how situations beyond the classroom can have an immense impact in the classroom.

Geller and Greenberg (2010) suggest that having a continuous development programme based around social and life skills, sex education, expectations of higher education and appropriate behaviour may help to mitigate some of the challenges autistic students face in their academic and social lives. This type of programme would need to be variable to cater for the different needs

of individual autistic students and would ideally be something that could be incorporated at school and throughout college and university. This would be advantageous to the autistic person and to wider society as it would enable the autistic person to have a wider and deeper understanding of the world around them and in a situation, such as transition they would have a better understanding of the processes involved and the need for these processes. The cost of such a programme could be expensive but if such a programme was introduced as early as possible the cost could be spread over several years thereby easing the financial burden of any programme providers.

Hart, Grigal and Weir (2010) draw attention to the need for self-advocacy for autistic students as they become adults as well as the increased participation with social groups through support mentors. Self-advocacy does sound like a good idea but in practice this could prove difficult. This is because many autistic people do not recognise the problems they have because the way an autistic person thinks and sees the world can stop them understanding why others consider their behaviour in social settings to be a problem. An autistic person will focus on what they perceive to be a problem, and this may not correspond to what others around them see as a problem. This then creates issues with self-advocacy as the autistic person may advocate for the wrong issue. In transition this may result in issues such as living independently, and safe guarding not being raised as issues by the autistic person because to them they are not a problem and they do not understand the impact they have on their own and others' lives.

It can be surmised from the findings of Howlin (2003) that to make the most of their skills in adulthood individuals on the spectrum will need to be provided with assistance with living accommodations, decision making about appropriate environments and help with social needs. The question is who will provide the assistance and what level of support will individuals need?

This is particularly pertinent to transition from further education to higher education as support needs may depend on how the individual perceives their support levels which as previously discussed may not be communicated effectively and can vary dramatically daily which further complicates the transition process. As Taylor (2005) states, teaching individuals with Asperger syndrome and high functioning autism at the post-secondary level presents challenges because often these disabilities are not as obvious as other more commonly understood disabilities such as blindness and deafness. College faculty staff and other students may not be able to recognise Asperger syndrome and high functioning autism and hence do not make accommodations or adjustments that are typically made for individuals with more obvious disabilities.

The challenges that Taylor (2005) relates to can be considerable both for the autistic person and those around them. For the individual concerned they may appear to be neurotypical, but their appearance could hide a multitude of issues for that person which are not visible to tutors and other students. Many autistic people who are in further and higher education will have developed their own way of masking their autism and this can further complicate the ability of those around them to accommodate adjustments. It is this ability to mask any issues and create an appearance of normalcy that can be the biggest obstacle when needing adjustments that accommodate their needs.

Similarly, when tutors and students are looking to make accommodations it is easier for them if they can see what the disability is and adjust their behaviour accordingly. If they are faced with an individual who appears normal it can be difficult for them to understand and comprehend what adjustments, they need to make to accommodate that individual especially if the autistic person finds it difficult to verbalise what adjustments they need.

Barnhill (2016) found that college personal may not have received training to understand the complexities of these disorders and this is a problem for any autistic students, for support services and for the wider education environment. For any autistic students if the college personal has not received the necessary training needed to understand autism and how it affects an individual it is impossible for the college personal to provide effective adjustments and accommodate the individual needs of each autistic student because the knowledge is not present. But for the further or higher education establishment this can prove to be an immense exercise to undertake in terms of manpower and financial resources. The cost of training all college personal to be aware of the range of complexities of a condition such as autism may prove prohibitive and not cost effective and it may be decided that some autistic students will inevitably not succeed at their studies and leave before they complete them.

In transition from further education to higher education it is essential that it is explained to the autistic student involved that not all college personal will be aware of autism and how it can affect people and if that they have any problems to contact support services. Another aspect of this is that the autistic student may have come from an environment in further education where they have had one-to-one support with an individual who has a high level of knowledge of autism but when they move to higher education this one-to-one will not be available. As is discussed further in the findings section this can be distressing for the autistic student and this needs to be accommodated during the transition period.

Barnhill (2016) additionally found that the diagnosis of Asperger syndrome is often delayed until adulthood and college students may arrive on campus without the diagnosis or they may be misdiagnosed and not realise they

need accommodations. In further education this may not have been an issue due to the smaller environment and more intimate nature of further education. In the larger and less intimate surroundings of higher education any issues the student has will be exacerbated by these new surroundings and this is when problems will become apparent. Before and during transition it can be made known to student's what autism is and how it can manifest itself and that there is support available.

Barnhill (2016) found that on occasion students who have received the diagnosis of Asperger syndrome and high functioning autism choose not to disclose their diagnosis and gain access to support services (Simmerborn Flesicher 2012) until a significant problem has arisen (Gobbo and Shmulsjy 2012).

The literature reviewed indicates that there exists a need for effective support during transition that accommodates the needs of individual autistic students and recognises the complexities of autism and the challenging behaviours that can be observed at times.

### **3.7 Limitations of the Literature Review**

The literature review for my study is limited in several ways. Literature that specifically relates to supporting autistic students in transition from further education to higher education is limited in its availability and scope. Much of the available literature concentrates on the transition from secondary school to college. There are different challenges between transitioning from secondary school to college and transitioning from further education to higher education and these have been taken into consideration when conducting the research.

Another limitation of the available literature that needs to be taken into consideration is the country of origin of the literature. Much of the literature concentrates on the American education system which has differences in age ranges of students and of teaching styles. Again, this has been taken into consideration.

A final limitation is that of the research participants who are the focus of the literature reviewed. The participants involved in the research were parents or students and this limits the direction of the research and the findings and analysis because while parents and students have views on transition and support they are not involved in providing student support from the perspective of the further or higher education establishment.

### **3.8 Gaps in the Research**

Whilst there are limitations in the research this does create gaps in the current research available. My research concentrates on filling one of these gaps by examining the perspectives of support professionals involved in supporting autistic students transitioning from further education to higher education. In getting these perspectives I am aiming to add another layer of important information to an area that is growing in interest to education establishments, parents, and autistic students due to the increasing numbers of autistic students enrolling in higher education and the support needs of these students.

### **3.9 Conclusion**

From the literature reviewed it can be surmised that autism is a complex and diverse condition that affects different people in different ways and this brings with it, its own issues. Understanding the extent of these variations and the effect they have in an individual and their environment can be

problematic and time consuming when evaluating the support needs of autistic students. Forming transition plans and arranging suitable accommodations that recognise their social and academic limitations and look to mitigate these as much as possible are essential so that the student can have a stress-free transition and make a successful start to higher education.

# Chapter 4 – Research Methodology

## 4.1 Introduction

The purpose of this section is to evaluate my approach to methodology, my research strategy and my approaches to research and how it underpins my research and influences my experiences as an autistic person. I will examine how these approaches are formed and the importance they have in the context of my research. I will then examine and discuss issues around selecting a suitable approach to gathering information for my study and elements that need to be considered for the process of gathering information.

## 4.2 Research Strategy

My first task for my research study was to devise a strategy. As Denscombe (2017) explains a research strategy entails a board approach that includes:

- A distinct research logic and rationale
- A plan of action to address
- A clearly identified research problem

My first consideration was the feasibility of my study and whether I could obtain access to the participants I would need to be able to get the information I was looking for. Denscombe (2017) states that it is vital that the researcher can get access to people and documents because these will be crucial to the success of the study.

I am involved with the local autistic community with autistic people and autistic professionals and this provided me with means to ask people for advice as to suitable people who would be able to take part in my study. As previously mentioned I have gone through the process of transition and this has brought me into contact with autistic professionals in further and higher

education environments and this was another source of advice I could explore.

I drew up a list of autistic people I know and categorised them by experience of working with autistic people and the field in which they gained this experience. From this I was able to reduce the first list down possible participants who met the requirement of working with autistic people in a further and higher education environment and approach them as to the possibility of taking part in my study.

I approached two people I knew in a higher education environment and a place of further education to enquire if they knew of someone who would be interested in taking part in my study. After I had discussed my research aims, objectives and my reasons for wanting to conduct the research I was able to move onto the next stage of my strategy.

Having established that I had a suitable number of participants who were interested in my research and willing to take part in it I then explored research strategies and how to approach the study. As Denscombe (2017) says research strategies are neither good or bad or right or wrong on their own but only change to good or bad or right or wrong when they are viewed in relation to how they will be used by the researcher in their study. The important point to remember is, is the strategy likely to be successful in achieving the aims of the research and can the researcher justify their choice of strategy (Denscombe 2017).

I examined several strategies (Denscombe 2017) including surveys, case studies and grounded theory. I decided against using a survey as I wanted deep and detailed information and I was not seeking to test theory. Using a case study would not be feasible because of the time constraints I had, and

grounded theory was rejected because as with a survey I was not seeking to clarify or produce a new theory (Denscombe 2017).

I chose to use the strategy of phenomenology as it closely resembled the aims of my study and what I was trying to achieve. A phenomenological approach to research seeks to understand the experiences of a phenomenon in society through the views and opinions of another person (Denscombe 2017). This was the closest strategy that fitted with my aim of understanding how disability support workers in further and higher education experience supporting autistic students in transition from further education to higher education. I chose this strategy because I believed it had the most chance of success for my study aims (Denscombe 2017).

Phenomenology does have its disadvantages in that it is viewed as lacking scientific rigour, is associated with description and not analysis and generalisation from the findings is difficult because of the small numbers of participants involved in the research (Denscombe 2017) but for my research aims I deemed the advantages to outweigh the disadvantages.

Because of my choice of research strategy, I chose to do a qualitative study. This was due to phenomenology being associated with words as units of analyses due to the search for meaning gained from experience and not with numbers as in a quantitative study (Denscombe 2017) and the advantages of interviewing, depth of information and insights into experiences that I was looking for.

### **4.3 Philosophical Approach**

My philosophical stance reflects a phenomenological approach (Appelrouth and Edles 2011), (Denscombe 2014) in that each one of us experiences a process or situation differently to another person even when we go through the same process or situation at the same time. In the case of my research the support workers go through the process and experience of supporting

autistic students in transition and this process could be viewed as being the same for all autistic students and even for all disabled students and the resulting experience gained from the process is the same.

My theory is that even though we go through the same process of transition from further education to higher education each individual autistic person will experience the process differently and even though these differences may be insignificant to a non-autistic person but be immense to the autistic person. The same applies to a support worker involved in supporting autistic students. The same theory applies to a support worker who may appear to support each autistic student in the same way but will have different adaptations for each autistic student to create the best education experience for each individual student.

#### **4.4 Epistemological Approach**

My epistemological assumption is positioned on a constructivist approach (Bryman 2012). Adopting Gray (2014) I assert that knowledge is constructed from experience and this accounts for differences in knowledge between people. People can go through the same experience but gain differing levels of knowledge depending on other circumstances surrounding their experience. If a person has a personal interest in a process or situation such as having a family member in the same situation, gives them something they can relate to and gives their experience of the process or situation meaning. Through having a personal interest and this personal interest giving the process or situation more meaning for the person they construct knowledge of the process or situation.

For a person with no personal interest in the process or situation their experience will be different, and it will have less meaning for them and they will gain less knowledge of the process and situation. These differences may be small and may not be observable to some people, but for the person who

is receiving support in this example the differences will be noticeable and can make the difference between a good transition experience and a bad one.

Using this view, it can be argued that autism is a social construct using language as discourse which clearly defines autism apart from other neurological conditions as Smith (2009) postulates. This fits with my philosophical stance of phenomenology as construction of knowledge through meaning gained from experience (Appelrouth and Edles 2011), (Denscombe 2014) and it can be argued is used to define and label a group of people identified as having different behavioural characteristics as conjectured by Edwards (2009) to other people in society. This process of differentiation through discourse (Roberts 2006) results in autistic people having specific support needs in certain social and behavioural situations to reduce the impact the different personal characteristics have on them when compared to non-autistic people (Baron-Cohen 1997). Scully (2009) discusses this in the context of disabled bodies but in my view, it can be equally applied to what society views as disabled minds as well.

My epistemological stance fit closely with a constructivist approach as defined by Bryman (2012) and Gray (2014) as I comprehend the world to be socially constructed and this is reflected in the different views, opinions and levels of knowledge people have because every individual constructs their own version of reality according to the influences in their social environment they inhabit and their reality can change depending on their personal circumstances and depending on the social environment they find themselves in.

#### **4.5 Theoretical Stance**

My theory for my study is phenomenology and this is closely associated with a constructivist epistemology in that both are concerned with how individuals construct their social reality as Appelrouth and Edles (2011) and Denscombe (2014) suggest. Alfred Schutz was a leading figure in the development of phenomenological sociology and was influenced by the work of Edmund Husserl and Max Weber (Appelrouth and Edles 2011). This resulted in his influential work *The Phenomenology of the Social World* (Appelrouth and Edles 2011) which considered objectivity vs subjectivity in the social sciences and the nature of human action (Walsh and Lehnert 1967). Schutz was interested in how humans experience the world in terms of meaningful objects and relations and believed that humans existed in the lifeworld and all situations are measured and given meaning against the backdrop of the lifeworld (Appelrouth and Edles 2011).

In the context of supporting autistic students in transition from further education to higher education the situation is the transition and the measurement is the support given to the autistic student in terms of understanding the needs of the student and being able to accommodate the support needs so that the autistic student has a successful transition.

Schutz believed that the lifeworld is intersubjective and this intersubjectivity allows human beings from a variety of different backgrounds to function and interact together (Appelrouth and Edles 2011). In the context of my study the lived experience of the autistic student in the form of having a diagnosis of autism and the lived experience of the disability support worker in the form of experience of autism from a combination of personal, academic, and professional allow the two to interact together and devise a transition support plan that accommodates the autistic students' needs and is accommodatable by the disability support worker in terms of resources.

This results in a lifeworld which according to Schutz is continuously constructed and deconstructed according to the lived social and cultural experiences of the individual and the effect these experiences have on their world and the meaning they then give their experiences (Appelrouth and Edles 2011). In the case of an autistic student transitioning from further education to higher education the meaning they give to the experience of transition would depend on whether they felt they had, had a positive or negative experience of transition and how they had constructed and deconstructed this experience to give it a subjective meaning they can relate to personally (Appelrouth and Edles 2011).

Through these processes stocks of knowledge are developed (Appelrouth and Edles 2011). Schutz refer to these stocks of knowledge as the recipes for accomplishing everyday tasks and these recipes that form the knowledge base for the individual are constructed from the experiences we have every day and the meanings we give those experiences. In transition a disability support worker will gain knowledge of autism through personal, professional, and academic experience and use this to build a knowledge base to use in supporting an autistic student in transition. For the autistic student they will experience autism uniquely as to how it affects them and give this meaning. This meaning enables the autistic student to understand what works for them and what does not in relation to the transition process.

Problems could arise when a disability support worker believes that their experience and knowledge outweigh the transition experience of the autistic student and needs are either not accommodated at all or are accommodated in a way that causes the autistic student distress and anxiety. The question is how do disability support workers ensure that the needs of autistic students in transition are accommodated sufficiently to cause the autistic student the minimum distress and anxiety?

The advantages of a constructivist / phenomenological approach to research as Denscombe (2014) notes is that it is suited to small scale research projects, the individual experiences can be interesting and authentic, and this can reflect a humanistic style of research.

This approach does come with disadvantages (Denscombe 2014) in that it is viewed as lacking scientific rigour and is associated with the description of events rather than the analysis of them. Because the studies are small it is not possible to generalise the findings to the general population and the attention to the mundane features of life may be off putting to some as may the feasibility of suspending common sense.

For my research into individual experiences of supporting autistic students in transition I feel that the advantages outweigh the disadvantages. This is because I am interested in the minute details and intricacies that make up the autistic experience for people and how these are accommodated for and supported by disability support services. I believe it is the small intricacies and details that can make the difference between a successful transition and an unsuccessful one and to fully understand and appreciate autistic behaviour and interactions with neurotypical students and disability support workers a phenomenological / constructivist approach is the best one.

#### **4.6 Personal Experiences in the Context of My Methodological Approach**

I have approached my personal experience of living as an autistic person and having gone through and experienced the process of transition from further education to higher education in an autoethnographic way. This is because it is an experience cannot be ignored because of the inherent bias

in my research whether consciously or sub-consciously and to negate any such accusations of bias.

In reflecting on my personal experience of transition I have considered my age, gender, ethnicity, social background, and cultural background. All these factors have an influential part in determining how I approach and experience transition and differences in one can result in a different experience of transition.

This can be illustrated through my age and cultural background. In further education I was able to socialise more easily because my fellow students were of a similar age and cultural background in terms of music and television programmes and these shared interests gave us a starting point from which to build relationships. Additionally, the fact that we were in the same classes as each other for much of the course and this played a factor in the transition from my first year to my second year because there was a sense of familiarity and continuity which for myself as an autistic person was comforting and enabled me to transition with the minimum of disruption.

In higher education I was in a very different position. I was the oldest most of the time and this was reflected in different cultural backgrounds through age which made finding common interests to build social relationships difficult as interests in factors such as music and television were very different. In higher education you are far more fragmented in terms of having the same people with you in the same lectures and the feelings of familiarity and continuity are not experienced as they are in further education and can result in a disrupted transition. This impacts on how you approach transition and the experience of transition as an autistic person because you are looking for familiarity and continuity so that you feel comforted and feelings of stress and anxiety are alleviated. When you do not

have these feelings, they can result in a heightened state of stress and anxiety and this can mean a disrupted transition.

The autoethnographic methodology has the advantage of focusing on processes and relationships that lie below the surface of events and putting these into context rather than having aspects of the experience in isolation. It gives a fresh perspective on events and experiences and can create a new self-awareness in the researcher of their role and position in the study. It does have its disadvantages in that it can be viewed as unreliable because the results are hard to replicate and rely on how the researcher has interpreted the event or process. It can be viewed as a standalone story with no structure and care must be taken to ensure that this is avoided.

In considering my position as an autistic person who has gone through the process of transition I feel that it is beneficial to have my experiences documented in my research as this brings a first-person account of what the process of transition can be like and provides a reference point for comparisons with the experiences and opinions of the respondents.

#### **4.7 Research Interviews**

As phenomenology is associated with detailed descriptions, opinions and experiences the clearest direction for a method of data collection was interviews (Denscombe 2017). As Denscombe (2017) explains interviews can be structured, semi-structured or unstructured. Each method has their advantages and disadvantages in what information can be gathered and the role of the interviewer within the interview. As an inexperienced interviewer who had not conducted a research interview before I chose to conduct a semi-structured one-to-one interview as I felt this would give me flexibility in choosing the research topics and the participants flexibility in their responses. In this scenario both interviewer and participant could change the

direction of the interview if they wanted to elaborate further on a particular point and it gave the interview a structure to work within and bring the interview back on track if I felt it was going too far away from my research aims (Denscombe 2017).

Denscombe (2017) explains how the interviewer can influence the participants through how they perceive the person asking the questions. To mitigate perceptions of myself as the interviewer I prepared a 'Research Statement' (Appendix 3) that explained my background as an autistic person who has gone through the process of transition and my aims and reasons for conducting the research. This was well received by all the participants and one remarked that they felt able to be more open knowing that I was an autistic person.

As an inexperienced interviewer I found it overwhelming planning my interviews. I researched conducting interviews on YouTube (Graham. R. Gibbs 2011) for insight into the interview procedures. This was a useful resource because it allowed me to visualise what I needed to do to prepare for the interviews and put myself in the place of interviewer and participant. After viewing (Graham. R. Gibbs 2011) I decided to conduct a pilot interview with one of my fellow researchers. This proved to be useful because colleague considered my questions (Appendix 4) to be well researched, interesting, and relevant to my study and when I asked further questions these were relevant in the context of what was being researched and I kept any extraneous verbalising to a minimum. The pilot study proved to be a useful exercise in that it highlighted my strengths and weaknesses and allowed me to focus on areas I could improve on with my interview technique whilst refining my questions further.

I allowed the interviewees to choose a location and time that was suitable for them as this allowed them to be in a place that they felt familiar and comfortable with and I anticipated that this would enable them to feel more relaxed and this in turn would elicit the in-depth and meaningful responses I was seeking from my participants.

I recorded the interviews using a digital recorder and all participants were notified of this prior to agreeing to the interview. As Denscombe (2017) states audio recordings are a permanent recording of the interview and allow the interviewer to rely on the recording rather than memory when transcribing the interview later. Denscombe (2017) goes on to say that they do not pick up on non-verbal communication, but this was not something I was looking for in my interviews so was not considered to be a disadvantage in this instance.

As Denscombe (2017) advises duplicates were made of the recordings to protect the originals against corruptions or loss. The recordings were given unique codes, so they could be identified for transcribing purposes. The interviews were transcribed by myself using software on the internet. This proved to be cumbersome and time consuming as well as exhausting mentally, but I did get deep into my interviews straight away using this method and listening to them intently. One of the issues with this method is that you pick up on themes within the interviews and consider ways in which your research can go therefore it is important to remain focused on your initial research aims and keep notes of further directions your research can go in for the future.

#### **4.8 Categorisation and coding of Transcripts**

In 5.1 I discuss how I used categories from a previous study, autism@uni (autism@uni 2014), to structure my research. I employed this strategy

because of my inexperience as a researcher and time constraints. Consequently, this led to my questions and the subsequent answers being coded and categorised prior to them being analysed. This process enabled me to concentrate on analysing the similarities and differences in the responses from the interviewees and not overly concern myself with the categorisation and coding of the transcripts.

After analysing the responses, I was able to build a detailed account of the experiences of the interviewees from their responses and compare and contrast them to my own experiences. Having autism and having gone through the transition process from FE to HE gave me an advantage in knowing and understanding what was important to look for when researching and analysing my topic. This enabled me to pay attention to the nuances in the respondents interviews and this gave me the detailed descriptions of their experiences that I was looking for.

I did attempt to use Microsoft Excel and Nvivo 11 to code the interview responses in order to gain an insight into the similarities and differences of the responses between different categories. This process proved to be too time consuming in the limited amount of time I had available and I concluded not to pursue this process because I needed more time to learn and understand Nvivo 11 in order to use it successfully.

#### **4.9 Ensuring the Quality of the Data**

Denscombe (2017) explains the difficulties in validating qualitative research. Denscombe (2017) goes on to say how it is difficult to replicate a qualitative study. This is due to the social setting the research takes place in and being able to replicate the same social setting for a study that was looking for the same themes. The role of the researcher in the study (Denscombe 2017) plays a part in being able to replicate a study too. To find a researcher with

the same experience of autism who has gone through the transition process I the same way I have is impossible as it would be to find participants who at the time of interview had gone through the same experiences as my participants had. Even if I was to interview the same participants on a different date it is entirely plausible that I would get at least some if not all questions answered differently.

Denscombe (2017) identifies the issue of being the extent to which qualitative researchers can demonstrate accuracy and appropriateness with their data. Whilst no steps can be taken to guarantee validity of qualitative research data there are steps that can be taken to reassure readers of the study that it is reasonably likely to be accurate and appropriate (Denscombe 2017). These include validation of the data by the respondents, the use of grounding of the data within the field and triangulation. To validate my research, I draw on my experience as an autistic person who has gone through the transition process to ensure as far as can be reasonably certain that the data I have collected is a valid representation of the experiences of the participants.

As Denscombe (2017) discusses, some of the disadvantages of phenomenological research are that it is viewed as by some as lacking scientific rigour, is associated with description and analysis and it is questionable as to how far the findings from phenomenological research can be generalised to larger population samples. Some view phenomenological research as unreliable because of this. The issue of reliability of the data in terms of replicability and generalisation is a valid one in my view, but I would argue that the rich, detailed and insightful descriptions gathered through phenomenological research would not be revealed through a larger scale study due to the necessary constraints such as time and cost, that are required to facilitate such a study (Denscombe 2017). These constraints lead

to an inability to gather detailed information as seen in phenomenological research, but the results are viewed as more reliable and generalisable to larger population samples.

Generalisability of qualitative research as Denscombe (2017) discusses is difficult and because of the complex nature of autism in different people and the individual way in which people experience autism it would be very difficult to make generalisations about autistic students and disability support workers. What can be ascertained from my research is that due to the singularity of social and behavioural identifiers within autistic people a generalisation of them cannot be made.

I have discussed my experience of transition as an autistic person in my 'Qualifying Statement' and how I declared this to the participants prior to them consenting to take part in my study. Denscombe (2017) brings up the issue of objectivity of the researcher but I hope I have answered any questions surrounding my objectivity within the thesis. I mention objectivity here as I do recognise it as an issue in qualitative research and one that needs to be addressed.

#### **4.10 Ethical Considerations**

Ethical considerations are of particular importance to research as Denscombe (2017) discusses. There is an increasing need to obtain approval from an ethics committee before the research begins to ensure that the design of the study protects the interests of all people involved in it. I filled in the appropriate ethical considerations document prior to my approaching potential participants for my study. Because the participants I was approaching were viewed as professionals in their field there was an assumption that they would understand the nature of my study and my reasons for approaching them to participate and would not need support

within the interview. I obtained ethical approval without any problems arising.

I did inform the participants of their ethical rights in that their interests would be protected, and participation was voluntary and based on informed consent. At all times I consider that I operated in an open and honest manner with respect to my study and my participants as Denscombe (2017) writes about. All my participants signed a written consent form that complied with the University of Huddersfield's legal requirements for ethics in research. The consent form had information about the identity of the researcher, information about the research, the expectations of the participants, right to withdraw consent, details around confidentiality and security data, ownership and use of the data and was signed by the participants and the researcher.

All participants were informed that the recorded interviews would be protected under data protection laws of the United Kingdom and in accordance with the data protection policies of the University of Huddersfield.

# Chapter 5 – Findings and Discussion

## 5.1 Introduction

I had already selected the categories for my questions from the autism@uni study which was done by Dr Marc Fabri from Leeds Beckett University. I did this to provide me with a structure and order for my interviews. Because of this some of the answers may not be as wide ranging as is possible with an unstructured interview but the answers should be more relevant and focused than in an unstructured interview.

The results from the interview provided me with a range of information that was interesting for its depth and breadth. Consequently, I had a vast amount of information to code and manage. In order to get something meaningful from my interviews I have kept my original structure and have drawn on my personal experience as an autistic person who has gone through transition from further education to higher education and from my experience gained through my involvement with autistic people and autism professionals.

For ease of reading participants quotes are in *italics* and single quotation marks. (new paragraph)

Below is a summary of the participant Information:

A) Gender – female

Age range – 35 – 44

Ethnic group – White British

Profession – Learning Support Worker

B) Gender – Female

Age range – 35 – 44

Ethnic group – White British

Profession – Disability Advisor

C) Gender – Male

Age range – 45 – 54

Ethnic group – White British

Profession – Head of Student Services

## **5.2 Experience of Autism**

The first topic is experience of autism and the aim is not just to discover not just what the participants experience of autism is, but to evaluate how they turn this experience into knowledge and what autism means to them. How a person gains experience of a condition such as autism is important because their experience condition can influence their perception of not only that condition but how they view people diagnosed with autism and how they support people who are diagnosed with that autism.

The participants were asked what their personal, professional and academic experience of autism was. This was to ascertain how exposed they have been to the diversity and complexity of autism. Having more exposure to a condition such as autism can enable and equip the person with the skills necessary to understand what different autistic students need in terms of accommodating their individual requirements to enable a successful transition.

The personal experiences of the participants have similar themes running through them as can be ascertained from their responses. The respondents first talked about a common topic of family members with a diagnosis of autism. Participant One cites having family members: *'I've also got people in*

*my family who've got Aspergers and a diagnosis of autism as well'.*

Participant Two responded: *'I have a son who was diagnosed with ASC when he was 5',* and Participant Three: *'my eldest brother is not diagnosed but my niece is, his daughter is'.*

These responses reveal how the first connection the respondents had with autism is with family members and this is important because this first connection is important in developing an interest in autism and how it affects people.

These family interactions have the potential to become personal and allow the respondents to observe behaviours and the cause and effect of these behaviours more closely and learn how to mitigate the effect of these behaviours on the autistic person and on those around them who may be affected by their behaviour.

This is useful experience for those working in support as they learn coping strategies and interventions based on real life experience as can be seen from their responses: Participant One: *'I had to do quite a lot of interventions and this can be transferred to situations such as transition from further education to higher education'.* They went on to say: *'There is a need to be aware that this is one autistic person you are dealing with and that what is effective with this autistic person may not be effective with another and coping strategies and interventions may need modifying in some way in order to work effectively with another autistic person'.* From this answer it can be seen that the respondent has learnt from their personal experiences and been able to move beyond viewing autism as a condition that affects people similarly and view it as one that affects every autistic people differently.

This personal experience of autism can give a deeper insight as to how autism affects people on a daily basis and how people learn effective strategies in order to cope with daily life and the impact it can have on the autistic person, their family and friends and on those they come into contact with.

The participants further discuss their personal experiences of autism in the interviews. Participant Two begins by discussing how they fought for their son to have the right support in education and to ensure that they had in place the adjustments they required so that had an equal opportunity with their NT counterparts to be successful in education: *'making sure he's got the right education'*.

They go on to discuss how this led to them being involved with social and support groups for parents of autistic children and in volunteering at a nursery for children with severe disabilities including autism. It is clear from these experiences that Participant Two was personally motivated to add to their personal experience of living with a person with autism by studying for a degree in psychology to add academic knowledge to the personal knowledge they already had. This combination of personal experience and academic knowledge gave them a strong foundation to build on when they moved into disability support.

Participant One identifies a similar theme in that they worked in residential care and as a special needs teacher and studied for a degree in a disability related subject in order to build on the personal experience they had of autism before moving into disability support. Participant Three also had personal experience of a family member with a diagnosis of autism and goes on to describe how they took a different approach to the other respondents by working in mental health prior to working in disability support. This

approach equipped the respondent with exposure to a wide range of mental health conditions which enabled them to learn and understand how different mental health conditions affect people and how they cope with living with them. This experience whilst not autism specific can still provide valuable insights into how people experience mental health and how they devise coping strategies to manage them which the respondent has used to enable them to support autistic people in education.

What these responses show is the wide variety of experience that the participants have gained from personal, professional and in the case of two of the participants academic experience. Because autism is such a complex condition this wide range of experience is invaluable in gaining an all-round understanding of autism and how it affects people in their daily life and how it is viewed in wider society and as will be discussed further on this experience and understanding is essential in supporting autistic students in transition from further education to higher education.

This experience and knowledge of autism and its effects enables the participants to develop a deeper understanding of what autism is and what it means to live with autism. We see some variation here in what that understanding is for the participants.

Participant One describes how autism for them is *'a developmental disability that impacts on individuals in so many individual ways that it's hard to define and describe as one particular issue'*. They go on to say: *'it impacts on everybody differently and how it emerges in people is incredibly different'*.

These two statements are insightful because it highlights some of the ways autistic people are perceived by those not familiar with autism and how

these can manifest themselves as stereotypes in society and create misconceptions and misunderstandings amongst neurotypical people.

Autism, because it is a spectrum condition can consequently be difficult for people unfamiliar with the range of issues and challenges that autistic people face to understand. This range can cover the mildest of symptoms to the most severe. When people are faced with the most severe of problems it is easier for them to understand the issues and challenges that person faces in their daily life. They can see how autism is manifesting itself physically in that person and this makes it easier for them to understand what autism is and how difficult it can be to live with the condition.

On an autistic person with mild symptoms it is harder to observe autistic characteristics because the person comes across as neurotypical in appearance, speech and behaviour but their autism can affect them as much as the person whose autism is more visible. This is where the range of ways that autism can affect someone comes manifests itself in different ways.

Depending on how severe the symptoms are they can be visible or invisible but the affect they have on the person is common across the autistic spectrum. What is different is the reaction from society to that person and this can have an effect on an individual who is in transition from further education to higher education.

Typically, a person who has severe autism will not attend a higher education establishment because their support needs will be too great and there is an assumption that an individual attending a higher education establishment will have a certain amount of independence irrespective of their autism or other disability. In reality this means that those individuals who are identifiably autistic will not be seen within a higher education environment

but those who are not identifiable as autistic will be and this is where problems can be encountered for the autistic person, support staff, academic staff and other students.

Because the autistic symptoms are not visible other students and academic staff may assume that the student in front of them is not autistic or does not have any issues or challenges. This assumption is in part due to the stereotypes of autism in society such as Rainman as to the invisibility of autism in the person. But the autistic person who exhibits no visible symptoms of autism still shares the same issues and challenges the person who is stereotypically autistic and has visible autistic symptoms.

It is the assumptions of others that can make the issues and challenges that the autistic person already faces even harder to overcome in their mind. In the mind of the autistic person they are misunderstood and believe that no-one cares about them, how they feel or the issues and problems they encounter on a daily basis.

This can compound the issues and challenges that the autistic person is facing before, during and after transition to higher education and make the prospect of moving to higher education even more daunting. These issues and challenges can be especially difficult when the invisible autistic student displays autistic behaviour in situations as these instances of what is typical autistic behaviour can be upsetting and disruptive to anyone around who witnesses it and can create further problems and misunderstandings for all involved.

In my own experience people look at you and see a person who is not autistic and has no issues that people associate with autism. This can make how you connect with other people difficult and confusing and lead to feeling

that you do not fit into the academic and social culture of further and higher education. You feel that you are constantly having to explain yourself to tutors and students and this detracts from the further and higher education experience. Participant Two explains this feeling succinctly when they describe it as: *'you are trying to fit into the world but it is as if the world does not want you to fit in despite all your best efforts to try and fit in and be accepted by society'*. This in turn can lead to feelings of social isolation, anxiety and depression which may have an effect on transition.

What is the issue here is the perception of not fitting in and of being in a new and confusing place and this can impact on devising a new routine at the new educational establishment which would give the autistic person a base to build on and enable them to make attempts to fit into the new academic and social environment they find themselves in. This new routine may not be established for some time and by the time it is it may be too late for it to have a positive effect on the academic and social life of the student.

Participant Two goes on to describe further what autism means to them by discussing routine and the importance of routine to an autistic person: *'as I understand it the need to stick to routine'*. Routine can be essential for an autistic person to function and the transition to higher education will break the routine they have established at their place of further education and need to establish a new routine as quickly as possible at their new place of higher education.

All of the participants had personal experience of autism in some capacity. Participant Two has a son who has a diagnosis of autism and this can be viewed as direct experience because they experience the effects of autism every day. Participants One and Three have family members with a diagnosis of autism and this can be viewed as indirect experience because

they will not have contact with the autistic person every day but will instead experience autism on an ad-hoc basis so to speak.

Personal experience is important with regards to understanding autism. Daily or weekly exposure can help to build a picture of how diverse autism is and can reveal minute details that may be missed with more infrequent exposure. These minute details can be used to devise support that is tailored to the individual because the small details that can make the difference in support being successful or not. This personal experience must be tempered with the knowledge that experience of one autistic person, however frequent and in-depth that experience is, is only one person and another autistic person may exhibit very different behavioural and sensory characteristics and require different methods of support to accommodate their needs.

Academic knowledge as Participants One and Two have can give a person exposure to the diverse and complex range of attributes that autism covers. This can assist someone in learning and understanding about the behavioural and sensory issues that can affect an autistic person and the various ways in which their individual needs can be accommodated and supported. This academic knowledge needs to be converted into real life experience and this is where problems can arise. Converting academic knowledge into dealing with real life situations can prove problematic as in real life situations can get out of control quickly and unexpectedly and result in an autistic person who goes into meltdown and avoids certain situations because of their memories of them.

All three participants have professional experience through paid and voluntary work. Professional experience will give the person exposure to the complex and diverse range of behavioural and sensory challenges an autistic person can experience. As this professional experience builds up and the

support worker is exposed to the spectrum of autistic people and they can build up their experience to become knowledge that can be used to support autistic students in transition and accommodate their differing needs. There is the possibility still that this professional experience will not encompass the full range of the autistic spectrum and this could be due to supporting the autistic students in similar situations, so techniques are learnt on how to support an autistic student in transition, but the question remains if those techniques can be used in different situations.

It can be seen that in order to have a full understanding of the needs and challenges of autistic students a combination of personal, academic and professional experience is preferable as this equips the support worker with the practical and theoretical knowledge and skills to support an autistic student in transition in a variety of settings. Supporting autistic students can be complex and challenging and support workers need a wide range of knowledge and experience to draw upon to achieve this.

My own experience of support and the experience that support workers claim to possess has been mixed. Quite often a support worker will say they have experience of autism yet when it comes to effectively accommodating my specific needs it was clear that their experience of autism was limited as I felt there was some issues around communicating my needs as succinctly as I intended them to be. This could have been my inability to accurately describe my needs exactly as I intended as much as the lack of diverse experience on the part of the support worker. An issue I feel I have had is because I am high functioning and verbally articulate this is mistaken for an ability on my part to function closer to a non-autistic person than an autistic person. What is happening is my ability to communicate and mask my behavioural and sensory issues effectively mean my autistic needs are not

met and assumptions are made on this basis that I can cope when in fact I cannot.

All three participants have personal experience of autism in some way and also have worked in some capacity either with autistic people or with individuals with a recognised mental health condition. Additionally two of the participants have studied at degree level in a relevant subject. This wide range of experience and contact with differing sources builds a wide range of knowledge of autism and how it is different in every person with autism. This puts the participants in a better position in which to support autistic students and anticipate differences and changes in behaviour between autistic students that may have otherwise have caused confusion and been potentially upsetting for everyone concerned.

### **5.3 Meaning of Autism**

Meaning goes deeper than experience and knowledge and as such can be difficult to quantify and make sense of in a research study. When people apply meaning to a subject it can be assumed that they have an emotional attachment to a subject that goes beyond possessing experience and knowledge. What autism means to a person is important because this can be a signifier that the person is willing to go further to learn about autism in ways that are not taught in books and which can only be learnt by assisting and supporting autistic people over a period of time. This meaning can be understood in the way they perceive autism and autistic people, their attitude towards autism and autistic people and their feelings and emotions around autism and autistic people. Having negative feelings of these definitions can result in an autistic student receiving poor quality support during transition whereas having positive qualities can result in an autistic student receiving high quality support that is tailored towards their individual needs.

The participants were asked what autism meant to them. This question was asked to ascertain if autism went beyond knowledge and experience for them. Whilst this can be difficult to quantify as previously stated, I was looking for answers that went beyond statistics.

Participant One says that for them autism: *'is a developmental disability and it impacts on individuals in individual ways and that it is hard to define as one particular issue'*. They go on to say that it: *'impacts and emerges differently in different people'*.

Participant Two when discussing what autism means to them said: *'the different ways it comes out in different people, the commonality of problems people have and that people with autism are trying to fit into the world'*.

They go on to say that: *'there is a need for autistic people to stick to routine and that information is processed by autistic people in a different way in contrast to neurotypical people'*.

For Participant Three they state that autism means: *'many different frameworks and how it fits within their background of mental health support and the work they do in supporting students'*.

What is interesting here is the way that autism has a common meaning of difference for the three participants and this is something that is repeated in the literature as well. Recognising that autistic people are different is important if they are to be understood and effective strategies put in place to support them through transition from further education to higher education.

This recognition of difference can be attributed to the experience the participants have of autism through personal, academic and personal interactions. This example illustrates the importance of having knowledge and understanding of a condition such as autism from a wide range of perspectives as it allows for a fuller meaning of the condition to develop which can be an advantage when supporting students with autism.

What this example illustrates is the range of language that can be used to describe a condition such as autism and this is where care is needed. The language that is used in society to describe a complex condition such as autism can be confusing and off putting to a neurotypical person particularly when professionals involved with supporting autistic students differ in how they depict the condition to others.

Care needs to be taken when describing conditions and it raises the question of whether uniformity amongst professionals would help neurotypical people understand autism easier and whether such a uniformity of terminology can be achieved and if it would be of benefit to autistic students.

In my experience autism appears to have three distinct meanings. Some people treat you an equal and do not see you as a person who has deficits when compared to the socially acceptable norms of society. For other people autism means you are somehow deficient in some form of social, behavioural or intellectual capacity and are not the equal of other people in society. For a third person you are a burden on society who is using autism as an excuse to avoid making a contribution to society.

The three participants talk about how autism is different with everyone who they have met and how this makes it hard to define in one term but there is also a commonality of problems that autistic people face. This indicates that the knowledge they have gained from their experiences with family

members, studies and work has connected with them on an emotional level and autism for them is more than terminology in a book but is a condition that affects the individual and those around them on many levels.

#### **5.4 Social and Physical Environment**

The social and physical environment can be challenging for all autistic people irrelevant of where they are on the spectrum and can affect their ability to function effectively. The social and physical environment can make the difference between an autistic person being able to function effectively in society and making a contribution and that person melting down and withdrawing from society. In transition the social and physical environment can make the difference between a successful transition and an unsuccessful one. Of interest here are how the participants view educational environments, how the participants view the relationship autistic students have with the educational environments and the effect they believe that these environments have on the autistic students.

Beginning with the social environment Participant One feels that:

*'there is a lot of considerations to take into account around group work and discussions and this centres around picking up on and understanding the pragmatic inferences and nuances within speech and facial expressions that all students will experience in that environment but will be problematic for autistic students who have difficulties picking up on non-verbal communication'*. In this environment the pace can be fast between academic discussions and this pace can engulfing and confusing for an autistic student.

As Participant One says: *'there is a lot of socialisation involved in higher education and the social side of higher education has the potential to be really upsetting or problematic for an autistic student who struggles with social experiences'*.

For Participant One the physical environment centres on the social processing involved with noise, lights and smells and how an autistic person in a new environment can have problems with this and that it will impact on their overall experience of higher education.

Participant Two view is: *'further education is a lot smaller than higher education and that students will have more one-to-one time with tutors and that further education is more regimented in terms of classroom time'*. They go on to add: *'the timetable is less changeable in further education and because many of the students are under eighteen there is a lot more parental involvement and that they are more looked after in further education than higher education because of this'*.

They draw on their personal experiences as a mother with a child in further education to highlight the fact that there are more chances to socialise in further education because the students are given areas to go where they can mix and socialise. The difference between further education and higher education for Participant Two is: *'the vastness of the campus'*. and they emphasise how: *'this can cause problems finding your way around'*, and how: *'changeable the timetable will be'*, adding: *'The opportunities to socialise are less in higher education and there is a lot more self-directed study and it is up to the student to plan their own study time'*.

Participant Two describes the impact on an autistic student going from further education to higher education: *'as huge'*. This they feel: *'is due to the perimeters being less defined in higher education compared to further education and because of this you are able to do what you want to do'*.

It is this lack of structure in comparison to further education that can make higher education a confusing world for an autistic student Participant Two believes.

For Participant Three the social environment: *'consists of where people live and sleep, where our friends and family are, how we experience life and the connections and disconnections we make in life'*, and the physical environment: *'is made up of what we are able to do in that environment, how we get around and our safety within those environments'*. Participant Three emphasises how: *'being in a different environment can be very difficult as can being in an enclosed space and in isolation'*.

For the social environment Participant Three highlights expectations that: *'students will want to do this and students will want to do that'*, as a factor in the social expectations of students'. They go on to add how students develop interests in different aspects of university life such as the social and academic can influence and affect their direction at university with regards to successfully completing their studies or not and having activities beyond their academic studies.

All the participants highlight issues that are of concern both for the autistic student and for support services. Going from a further education environment that has more structure to a higher education environment with less structure and more flexibility can be distressing for an autistic student. This is due to the lack of boundaries in higher education and this can make it difficult for the autistic student to visualise and comprehend boundaries if they are not clear and well defined.

This can result in a feeling of confusion and being lost in the higher education environment as the autistic student tries to establish what the

boundaries are and why they are set in that way. In my experience at further education everything is set out, what you have to do and how you have to do it. This is comforting for the autistic student as they can operate within those parameters to the best of their ability.

In higher education you are expected to make decisions for yourself and be able to justify those decisions and this can be where problems arise for the autistic student. The range of books you can read is vast and the information within the books can differ which only adds to the confusion. Book A says do this but Book B says do that and with so many books available finding a book that suits you and your mindset can be virtually impossible. I struggled choosing books and this is time wasted as you are spending time in the library looking for books and then wondering if the book you have chosen is one that is suitable for what you are trying to say.

It is only on reflection that you realise that any of the books in the library are suitable. The university staff have chosen them and they would not choose them if they were unsuitable and the other factor for me was realising that I was in charge of what I read, how I interpret the information and how I write it up. But quite often this realisation that you are in control takes weeks and months before you act on it and it can be too late then as you are so far behind with your studies you have the added pressure of playing catch up too. This will not be the case for every subject. For subjects such as mathematics and computer programming there is more logic and structure to begin with than for subjects such as sociology or psychology where you have more 'what if' scenarios and the outcomes are subject to human behaviour which is not linear and predictable and the results of which are often speculative.

Another aspect that all three participants discuss is that of socialising and communicating. In further education you tend to be with the same people for the same lessons which gives you the opportunity to build relationships and this structure is comforting for the autistic student as they can familiarise themselves with their fellow students and get to know them at a pace that is suitable for them. In contrast at higher education your lectures are spread out over the campus and you can be sat with different students in all your lectures. In this situation you can feel lost and isolated especially when it appears that all your fellow students know each other. This can be upsetting and distressing and can result in you losing focus and concentration in lectures. Because I was a mature student I was in some way able to take myself out of this situation using the age gap between myself and the other students and how this impacts on views on music and socialising as a way of justifying to myself why I did not feel the need to socialise with other students.

Whilst this worked for myself this would not be the same for other students especially those who are with students of a similar age and this can create issues with social isolation if the autistic student has problems socialising with other students.

Communication can be an area where autistic students have issues and challenges. This is because most communication is non-verbal and for neurotypicals is instinctive. Non-verbal communication is done without thought or hesitation and these invisible signals are given, received and understood throughout the day. For an individual who is on the autistic spectrum non-verbal communication is a mystery and I can compare it to looking at a wall and waiting for a response. This can cause immense problems and misunderstandings as the literature and the participants discuss. For someone with autism the world can appear to be confusing and

isolating as people around you communicate telepathically and understand what is happening without having to work at it.

For neurotypicals the autistic person can seem aloof, disinterested and ignorant because they do not respond at all or in an appropriate manner. This can create misunderstandings between people and can result in disagreements and social isolation for the autistic person who struggles to understand what they have done wrong and why they are being ignored.

The social and physical environment for myself was mixed. I chose my further education establishment because it was local for me and therefore I had familiarity with it. All my classrooms were located on the same corridor, so it was easy to navigate and find the rooms. Socially because I was on an Adult Education course I was with students who were of a similar age to myself and had shared interests. This made it easier to make friends and be able to talk to someone.

Choosing my higher education establishment was very different. I went to one and it was far too large for me to cope with and everybody seemed to be rushing about which I found off-putting. The university whilst having a very good reputation and being seen as one of the top universities in the country was very overwhelming for me and I chose not to go there because mentally I would not be able to cope with the environment. I could not picture the campus in my mind and this put me off going there. The university I did choose was smaller but easier to navigate and I could picture the campus in my mind and this was a big factor in choosing this university. That is not to say I did not have any problems navigating around the campus, I did, but they were easier for me to resolve and to locate the room I needed to find.

Socially university was very different. I am a mature student but the universities idea of mature and my own are different. A mature student at university is a person over the age of twenty-one whereas my own view of a mature student is a person over the age of thirty. This required me to revise my idea of what a mature student is.

The student population at university is younger and more diverse than at college and I felt that I struggled to make friends and fit in. My defence mechanism I devised to enable me to cope with my social environment was to remove myself from the social environment of the younger students by reminding myself that being older than them resulted in different cultural tastes and different use of language culturally. This enable me to distance myself from the younger students and not to worry about not fitting in.

The differences between the social and physical environments of FE and HE are clearly recognised here and this allows the participants to discuss how this may impact on an autistic student in terms of campus size and timetables for example and how this can affect the autistic student emotionally causing them anxiety and confusion. This awareness can be used to explain to the autistic student the differences they will encounter and tailor an individual support plan for that student to enable them to understand the changes they are facing and mitigate them as much as possible for the autistic student.

## **5.5 Social Isolation**

The next topic is social isolation This can be an area where the autistic student in transition from further education to higher education can have multiple issues that contribute to their experience of social isolation and these issues can be brought on and compounded by other factors that are brought on by their own behaviours or are beyond their control.

Social isolation whether actual or perceived can be immensely damaging mentally and physical. Understanding why you feel socially isolated and why someone finds themselves in this situation is vital in the transition process because of the need to ensure the mental and physical wellbeing of the autistic student.

The participants were asked how they viewed social isolation and how they would support an autistic student who was experiencing the effects of social isolation.

Participant One begins by discussing how people: *'may be experiencing a negative impact of being in and around people and they may isolate themselves purposely to negate the anxiety they experience being in and around people'*. They go on to explain how: *'this may be a good thing in the short term but long term this may have an impact on the persons mental health'*.

Supporting someone who is experiencing social isolation can be difficult, but Participant One offers solutions in the form of: *'accessing the counselling team at a higher education institute'*, and by: *'encouraging the autistic person experiencing social isolation to speak to their doctor or a family member or friend they trust and feel they can open up to'*.

For Participant Two their experience has shown them that: *'many of the autistic students they come into contact with find themselves socially isolated'*, and this is especially so for those autistic students who: *'have moved away from home and are living in a new environment without the structure and support they have had at home'*.

Another factor for Participant Two that impacts on an autistic student is the type of support they have in higher education compared to the support they have had at home and in further education. Support in higher education is: *'limited to when the autistic student is physically in education'*. Support does not extend to living outside of higher education and for an autistic student coming from a supported environment to an environment where support is limited this can be difficult to adapt to and add to the feelings of being overwhelmed by the transition to higher education.

An issue that Participant Two believes has an impact on social isolation is the preparation they have had for living on their own or with other people they are unfamiliar with. Some of the challenges that autistic students may encounter are: *'knowing how to share accommodation, not wanting to socialise by going to the pub and not knowing what to expect or what is expected of them'*.

Participant Three focuses on how: *'society perceives social isolation'*, and how: *'this can be a problem in itself'*, as they explain: *'the perception of social isolation can be of someone who is sat in a room not having any contact with the outside world. This perception can give a false representation of social isolation and how an individual experiences it'*.

Participant Three quantifies this misperception by discussing how an individual can: *'experience social isolation even when they are surrounded by people'*, and how this can be a problem for autistic students in transition from further education to higher education when they move from a familiar and supportive environment to one that is unfamiliar and the perceived support available to them becomes more fragmented'.

Supporting an autistic student who is experiencing social isolation is very individual for Participant Three but some of the strategies that can be employed are: *'finding out the interests of the student and exploring if these interests can be matched with societies that the student's union run or support groups that student services run'*. What they feel is most important is in assessing what social isolation is for the individual and what interests the student has and filling the social isolation with those interests.

Social isolation can be devastating for an autistic student who has come from a familiar and supportive environment where they can talk to people who they know about any issues and challenges they may encounter to one where they are on their own in a new and unfamiliar environment surrounded by people who they don't know and do not understand how to socialise with them. If this is a new emotion for them they may not be able to verbalise it to support services which will further compound the existing problem and can potentially lead to the feelings of social isolation increasing due to them not expressing themselves in a way that gets across the problems they are experiencing.

The effects of social isolation can be invisible to people around the individual and as one of the participants has stated the perception that someone is socially isolated only when they are alone is one that is flawed. Social isolation for myself means feeling detached from society even if you are surrounded by people. If you do not know these people and are wanting to get to know them this can increase the feelings of social isolation for the individual, but they can appear to be coping well to others who they come into contact with.

Social isolation in my experience is an emotion that can strike at any time and the effects can be devastating. It is for myself a debilitating condition

that affects your mental wellbeing and influences how you perceive your social environment. The experience of social isolation can be draining on you not only on your mental wellbeing but on your physical wellbeing too.

Mentally I experienced feelings of confusion as to why people are not sociable towards me in the way that I perceive they are towards others. Is this something I am doing wrong, some social skill I am lacking in? Am I mixing with the wrong people or am I trying too hard to integrate myself with others? These questions have no immediate answers when you are in the moment of experiencing social isolation and this leads to feelings of anxiety and worthlessness as you try to unravel the confusion in your mind. You feel unable to leave your immediate environment and begin, unknowingly to isolate yourself further from society and consequently make your situation worse.

The effects of social isolation on your mental wellbeing have, in my experience a direct influence on your physical wellbeing because the anxiety that comes with social isolation leaves you feeling low and tired and unable to do even the most simple of tasks and perform at your best.

When going through a transition from further education to higher education the perception that you need to make friends and feel accepted can be overwhelming and when the reality does not meet your expectations this can lead to social isolation and have a direct and crippling effect on your start to higher education.

The recognition from the three participants that social isolation can be something that is instigated by the autistic student or by those around them shows an insight into how social isolation can originate quickly in the process of transitioning from FE to HE. Awareness was shown of how societies

perceptions of social isolation and the false representation can be problematic for those affected by social isolation and those supporting them and the challenges that can arise from these representations.

## **5.6 The Meaning of Support**

Support can mean something different to those who give support and those who receive it. If there are any differences in the understanding of what support is and what support is available, they need to be resolved as soon as possible. How knowledge of support is gained and understood by individuals will vary across society and within support services. Different support service workers will have their own views on what support means and this will influence decisions made by them when supporting autistic students in transition in both what they chose to support and how this support is given.

The participants were asked what support meant to them in terms of providing support for autistic students in transition from further education to higher education. This is important because differing views on support will create the possibility of inconsistencies in how support is provided, and the level of support provided. To gain a better overall picture of support and what it means a similar study would need to be conducted on autistic students to get their views on what support means and how they perceive it should be provided.

When asked what support meant to them Participant One said: *'supports a very broad term'*. They went on to state that: *'people would need support in knowing exactly what they want to do...because they can have a course of study but is it right for them?'*

Specific areas where support may be needed were financial, travel, finding their way around a new environment, accommodation and living independently. In the classroom the autistic student may need support in how they learn with options available including having a note taker, additional time for assignments and someone to sit down with them and breakdown tasks and instructions into manageable chunks for the student.

For Participant Two support meant: *'allowing an individual to access the same things that any other person would with the extra help needed'*. They then discussed policies and legal requirements to ensure that a student with a disability is not at a disadvantage compared to their non-disabled students and allows the disabled student to access the same things that any other student would be able to. They talked about the need for reasonable adjustments to be put in place and emphasised the need to work with individuals to ensure that the right support is in place for them.

When Participant Three was asked the same question they answered that support is: *'essential for life'*, and that as people: *'we need to be loved and cared for'*, and stated that: *'care is across the spectrum from the most basic to end of life care'*. They then went on to say that: *'support was enabling people to achieve what they came to university to achieve and supporting them in making good decisions'*. They expanded on the final point by asking the question: *'how do we enable people to make good decisions first?'*, and finished off by saying that: *'support services are there to enable but not to do'*.

Participants One and Two view support as education based whereas it could be argued that Participant Three views it as more wide-ranging and affecting people in all areas of their life not just when they are in education although they finished off the interview by discussing support in education.

Participant One discussed how support encompasses areas of life outside of the classroom as well as inside it. This comment reflects how Participant One is aware that autistic students may need support with issues such as travel, and accommodation and that support includes areas that may not normally be associated with a traditional view of support in an educational establishment.

One other point that is worth mentioning is the different views that support services have within further and higher education. Participant One who comes from a further education background discusses support inside and outside the classroom whereas Participant Two who comes from a higher education background previously stated that support was only available in the education establishment itself and was not available outside because a student in higher education whether they are disabled or able-bodied are assumed to have a level of independence and have the necessary life skills to manage finances, cook a meal and keep their accommodation in an acceptable condition. It could be assumed that from Participant Ones answer that this perceived level of independence is not assumed in further education and this is an area that will be discussed further in the dissertation as it has repercussions with another factor that impacts on an autistic student in transition.

In my own experience of support in both further and higher education establishments there was a difference for me it what support meant to tutors and to the establishment. In further education the support was integrated into academic life and if you had any problems your tutor would direct you to student support and take an active interest in how they dealt with the situation.

In comparison the support in higher education was more detached from academic life and this took on a more abstract meaning for me where I have to make the decision whether or not to go to support and if so which support service I would access. That is not to say that tutors did not give advice when they could. But the advice was indirect and informal rather than direct and formal as it was in further education.

From an autistic perspective this indirect and abstract advice could be confusing as an autistic person functions better with direct answers and instructions which are not open to interpretation. When the answer or instruction is abstract or indirect the autistic person can be left feeling anxious and confused and they may not access the support they need because of this as I did not on occasion. This can result in problems not being resolved at an early stage and the problem getting bigger which may result in taking up more resources in order for it to be resolved. A different approach where support means a service that is integrated within the structure of the educational establishment and advice at a base level is direct and formal would suit an autistic person better and would result in less confusion over ambiguous responses and less drain on resources. It can be seen that support is a broad term and is applicable to many situations. The participants recognised the need for support inside and outside of the educational establishment but there are crucial differences in how support is provided. In FE there is more support available both inside and outside of the classroom and much of this is one-to-one. In contrast support in HE is more about enabling the individual to become more independent in their studies, home life and social life and is limited to the classroom. There is the potential here for autistic students to feel that they are on their own and have no-one to turn to and this is recognised by the participants when they describe the differences in support between FE and HE. All three participants demonstrate knowledge of support and understand

how it can impact on an autistic student in different educational establishments.

### **5.7 Deficits of Autism**

Deficits are a result of societal constructions on what is considered to be socially acceptable and deemed normal and what is considered to be in flawed when compared to the acceptable social constructions in society. Some deficits are visible, having a limb missing for example but some deficits are invisible, and autism is considered by some to be an invisible deficit.

Recognising that there are deficits in autism is vital if support is to be directed in the right areas for the benefit of autistic students, fellow students and tutors in order to minimise any psychological effects the self-perception of being deficient according to a social construction may have.

Understanding the deficits of autism and how they can affect an autistic person is important as the autistic person can then be supported in how their perceived deficits affect them and so that awareness of autism can be promoted and managed in a way that is inclusive and not exclusive and the socially constructed deficits of autism can be challenged.

The participants were asked what they considered to be the deficits of autism. This question was asked to ascertain how the participants perceived autistic people and whether this view followed the socially constructed view of autism or if they based their perception on their experience and understanding of autism.

Participant One stated that they: *'did not like the word deficit and preferred the term difference'*, and said that: *'it is very personal as to what an individual will consider a deficit and what they will not'*, adding that some

behaviours that society may view as a deficit include: *'visual processing issues and how it might be very tiring for them cause they're putting a hundred and fifty percent into the day'*. Anxiety was not considered to be a deficit for Participant One but was mentioned due to the impact it has on everything an autistic person does.

Participant Two stated that: *'deficits are mainly the unaccepting of the world rather than the individual'* and went on to say: *'deficits are often caused by a lack of inflexibility in the environment of people with autism'*. Another main deficit for Participant Two was the lack of success for autistic people: *'there's no reason why those individuals who often have got high intelligence shouldn't be just as successful in the world as everybody else'*, *'we know that doesn't happen unfortunately'*.

For Participant Three they agreed with Participant One in saying that deficits in autism are: *'very individual'*, and feels that: *'the isolation can be huge for some'*, adding: *'the disconnection of understanding of somebody else for some can be really big'*.

As Participants One and Two stated having a behavioural characteristic that is viewed as a deficit by society is personal to the individual and does not necessarily mean that, that individual will consider themselves to have a deficit. Participant One also said that they: *'did not like the term deficit and preferred the term difference'*.

This example shows the effect language can have on how a person or a subsection of society is perceived by society. The term deficit implies that someone is lacking an attribute that other people in society possess and that this deficit makes that person less of a person and less capable of contributing to society than others who are perceived to have this attribute.

This social construction of what is and what is not a deficit and the language used in expressing the deficit have the ability to have a profound and long-lasting effect on a person and can dramatically alter their perception of their self-worth and their life chances.

In comparison the term difference does not imply that a person is somehow deficit in a facet that is needed to living a successful life in society and make a contribution to society. Difference implies that a person needs help and support in some areas, but in other areas they are capable of living and of making a contribution to society.

This distinction is important in support because the terms have the ability to have a substantial influence on how a person views themselves and their approach to transition from further education to higher education. If they believe themselves to have a deficit this can be made worse by the prospect of going to higher education and the extra pressure this brings in terms of learning and personal expectations. The term difference is less pressured and the view from the person would be that they can achieve what they set out to do but they will need help and support to do it.

It is important to remember that it is highly unlikely that the term deficit would be mentioned by support staff but this term may be used by family and friends inadvertently and by people who are less understanding of autism than others.

Some autistic people need a high level of personal support to function and this is recognised. However, in the context of this dissertation it is assumed that because the autistic person has got through further education and has

got a place in higher education that their level of personal support is minimal and that this will not have an impact on their ability to study.

The language people use to describe autism and autistic people does have an impact on your mindset and your identity as a person. Comments that are made whether intentional or unintentional have the power to bring you down or build you up. One of the major issues for myself is the time spent thinking about these comments and analysing them as to why this person said this, do they realise what they are saying, do they know me and other questions you ask yourself. Autistic people are known for dwelling too long on what people say and overanalysing the words used. This is because they are trying to find the meaning behind the words used and understand the logic for using the words from the other persons viewpoint and from their own.

The three participants demonstrated that there is deficits around autism and some of those such as visual processing are personal others such as the unaccepting world have roots in society. This displays knowledge that deficits can be both personal and constructed by society and equally beyond the control of the affected individual.

## **5.8 Strengths of Autism**

Strengths as with deficits is a social construction and are used to define what society considers to be important behavioural traits in people. These behavioural traits are used to enable people to identify with how to fit in with society and to conform to what society considers to be socially acceptable such as being polite or a behavioural trait that gives a person a perceived advantage over others and is often portrayed as an aspirational behavioural trait such as determination in overcoming odds in sport.

Portraying and recognising the strengths that autistic people have is important if society is to be made aware of the contribution to society autistic people can make. Balancing the deficits with strengths is essential if society is to understand the wide range of skills and attributes autistic people possess and not view them as limited and a burden on society.

The participants were asked what they considered to be the strengths of autism. As with the deficits question this was asked to ascertain how the support workers viewed autistic people.

Participant One felt that timekeeping was a strength of autism: *'people with autism that will always turn up 100% of the time'*, and went on to add: *'they may have a particular focus and have excellent attention to detail'*.

Participant Two felt an: *'overall feeling of awe for autistic people because there seems to be a complete lack of malice involved with people with ASC'*, and the: *'the ability to focus on one thing in such detail together with the ability to separate emotion from what needs to be done'*, was perceived as a massive skill by Participant Two as was: *'the honesty of autistic people'*.

Participant Three considered the ability to: *'learn to live and deal with a disability'*, combined with: *'having to jump higher or deal with things differently'*, as strengths of autistic people and ended by saying: *'small considerations can make a big difference'*.

All three participants felt that autistic people have strengths and have much to offer society. What came across is that the deficits can mask the strengths, and this can make it difficult for some people in society to see autistic people as an asset and not as a liability. As one participant said autistic people sometimes have to jump higher or deal with everyday

situations and events differently and whilst this can be seen as a strength it can also be draining on the autistic person mentally and physically and leave them unable to carry on.

My experience of strengths is very mixed. This is because I am constantly trying to balance the strengths others perceive I have with the deficits I perceive I have and how these contribute to who I am and my personal identity. It can be difficult to accept that you have strengths when you have been told you are deficient in so many socially acceptable behavioural traits and this can mean that the strengths you have are not exploited to the full and you do not realise your full potential.

Equally important is recognising the strengths of autism and here all three participants make valid points for the strengths of autism. These points include the ability to focus in detail, timekeeping and learning to live with a disability. Having knowledge of the strengths of autism can allow others to focus on them and build on these strengths rather than trying to overcome any deficits.

## **5.9 Expectations of Autistic Students**

Expectations of students during transition can have an immense impact on the process for them and their family and friends. Expectations will vary enormously from student to student and can alter during the transition process. Expectations of what the transition process will be like and how their needs will be accommodated can cause an autistic student extreme anxiety and stress and result in low mood and a fear of the changes that are associated with transition.

It is important that these expectations are managed in a way that the student understands what is happening and why but is not unduly worried

about the transition process to the point where it is of detriment to their wellbeing.

The participants were asked what they would perceive as the expectations of autistic students who are going through the transition process and how they would manage these expectations. If the support workers perception of the expectations of autistic students during transition was appropriate, then the chances of managing a successful transition for an autistic student would increase.

Participant One said that the expectations are: *'a very personal thing'* and went on to say: *'some autistic students will have a fixed idea and they'll stick to that whereas others will ignore and avoid and just decide this is it'*. They added that: *'transition well it's so limited in what they're given in terms of information about the process and what will happen'*.

Participant One believed that: *'we have to go in and experience what an environment is like and gain and understanding of what is expected of us rather than building up our own picture'*. As part of their role Participant One tried: *'to offer students coming in and looking around and meeting people in order to give autistic students an idea of what they will experience when they move to further education'*.

Participant Two said: *'it is about 'the visits and finding out and talking'* and: *'making sure that we're honest and upfront about the challenges'*. They felt that: *'there's an expectation of it being more like college'* and added: *'that it's not like that and for an autistic student that can be a bit confusing because you won't get told how to take notes, it's up to you'*. They expanded on this point by adding: *'it's up to you to find how that works'*.

Participant Two offered: *'applicant days and advance information for autistic students'* but stressed that it is about: *'being there at the beginning and getting the general feeling of the place'*. In supporting a student Participant Two felt: *'providing a mentor'* to *'put some structure in place'* was important as was *'managing those expectations'* which they added *'are quite difficult'*.

Participant Three agreed with Participant One saying: *'it depends on the individual'* adding: *'some people have great aspirations that they are going to just fit in easily. Some autistic students may expect to be working with people who are only wanting to achieve the greatest'*, but as Participant Three says *'that is not always the case'*.

In Participant Three's experience some students: *'come and expect to party all the time'* and have to be reminded that: *'you do actually have to attend and you do actually have to study'*. For Participant Three managing those expectations is: *'about us being good communicators'* and *'sitting down and talking to people'* and *'looking at what we can do'*.

They mentioned that autistic students should not make any: *'presumptions about support'*, *'you know that they're going to have support 24 hours a day'* adding that it is: *'looking at somebody's needs, wants and what the expectations are of what we can achieve'*. An important point that Participant Three made was: *'we would see a student as soon as, you know as soon as they're kind of accepted here'*. This was in order to: *'look at what kind of support we can put in place and most tellingly it's about being honest'*.

All three participants expressed a very good knowledge of what the expectations of autistic students may be when transitioning to higher education. Evidence of this is the knowledge that expectations are a very individual experience and each autistic student will have different expectations of higher education.

Going in and experiencing the environment before they start at their higher education establishment was another theme and this is an important consideration as this can make expectations more realistic and allow the autistic student to create a picture in their mind of what the environment will be like and build on that mentally so that when they arrive at university it is not as daunting as going there and not knowing what to expect. Managing these expectations are all important and trying to achieve a fine balance between overwhelming and underwhelming can prove difficult especially when each autistic student needs will be different and managing them effectively could prove difficult and frustrating.

My own experience of expectations in transition is different because of my previous experience of transition in a wide variety of settings. I had attended college previously and knew what to expect from a college environment. For my university I had some visits prior to me starting which enable me to acclimatise to the size and layout of the campus. I knew it would be a bigger environment, but I was still not prepared for the lectures and the noise and sounds as I was expecting a quiet environment with everyone listening attentively to the lecturer. This was far from the case and on some occasions, I had to leave the lecture because of the noise levels. I was not prepared for the library either due to the size of the library, the range of books available and the noise levels from students talking and whispering. This was quite overwhelming for me for quite a while and I had

to readjustment my reconceived perceptions of what it was like to study in an university environment.

Having knowledge of what autistic students may expect from HE and understanding where these expectations are constructed from can assist people in support in explaining to autistic students the myths and realities of student life in HE and put in place events such as open days and providing mentors to guide autistic students through HE.

### **5.10 Becoming an Adult**

The transition between further education and higher education will not be the only major change that autistic students will face during this period in their lives. For many there will be the added transition to adulthood and the expectations that come with this transition. Becoming an adult is a transition that many people go through and it is important for a number of reasons. The perceptions of who you are and what you can achieve change overnight and people's expectations of what you are capable of change overnight.

This is an added pressure for an autistic student and one that cannot be avoided. Becoming an adult is a socially constructed phenomenon and happens overnight and the expectations that go with becoming an adult occur overnight in unison. This transition means that the autistic student is expected to conform to the social expectations of what being an adult is and how an adult is expected to behave in addition to being in a new and different social and academic environment.

The participants were asked what they considered to be becoming an adult meant to them. This question was asked to ascertain if the participants went beyond the socially constructed conventions of what becoming an adult

meant and considered other factors that may impact on an autistic person's experience during this transition.

Participant One said: *'there's the newly developed sense of independence and freedom'* and went on to mention more serious issues, *'make sure people are aware of safeguarding issue'* and *'keeping themselves safe both financially, physically, sexually'*. From their perspective as a support worker there was a need: *'to give people informed choice and consent options'* and *'they might need support in some areas'*. The caveat to all this was: *'they might refuse it all and just do what they want to do'*.

Participant Two said: *'we have to accept that being an adult happens, whatever that actually does mean'*. They commented on the societal expectations: *'society will expect you to take responsibility'* and how these are socially constructed, *'a student might not actually be ready to take responsibility until they're 21, legally at 18 they're classed as an adult and therefore will be expected to be able to'*. They go on to add: *'the students here will be classed as adults from 18 onwards'* and *'whether students have got the capacity to do what's expected of adults at 18 is another matter and there doesn't seem to be flexibility in that'*. They finish by asking: *'I'd be interested to see what the definition is, but as a society we've decided that's 18+ haven't we and that an individual has the capacity to make decisions in terms of their own life and financially on their own'*.

Participant Three starts by mentioning that: *'there's a biological thing about an adult at 25 when our brains stop developing'* before asking the question: *'what makes an adult?'* answering their own question with *'is that independence?'* An important point they raise is: *'one of the difficulties here is the expectation that somebodies an adult'* and *'it's all arguable and*

*questionable', adding 'if somebody is having difficulties...what can we do to facilitate that support'?*

It can be seen from the responses of the participants that reaching and becoming an adult is a difficult period of transition even for those who have gone through the experience themselves. The expectation that when you reach eighteen you are capable of looking after yourself independently and taking responsibility for your decisions and actions puts immense pressure on any person going through this period. For an autistic student who is also trying to understand and comprehend the changes going from further education to higher education this additional pressure has the potential to send any anxiety and stress they may be experiencing to levels where they cannot manage them, and this will then impact upon their transition period.

For myself become an adult was very different to how it appears to be in today's society. The expectations were centred around getting a job and being able to drink in public houses and nightclubs. This could have been because of the way society and culture was shaped and defined when I turned eighteen or it could have been because as an autistic person I was unaware of what was expected of me as an adult and I did not know or understand the consequences that come with becoming an adult.

As I have got older I have slowly begun to understand what it is to be an adult and what society expects of me and why. For many of my friends this appeared to come naturally but for me it has been a long, difficult process of attempting to understand the societal demands of adulthood and adjusting my behaviour accordingly. This has not always worked out for the best and in many ways I am still trying to understand and comprehend what it is to be an adult. This is a common theme among autistic people.

The transition from adolescent to adult is a difficult time for most people and especially so for an autistic student making the transition from FE to HE. This change brings with it socially constructed and legal classifications of what is and is not expected of an adult and this can have implications in how an autistic student deals effectively with this transition. All three participants demonstrate knowledge and understanding in what the expectations of becoming an adult are and this will enable them to support autistic students through this process.

### **5.11 Conclusion**

The participants answered a wide variety of questions and they demonstrated an extensive range of experience and knowledge. This experience and knowledge has been gained through a combination of personal experience, professional experience and in the case of two participants academic achievement. This has equipped the participants with a wide variety of skills and abilities which they use to support autistic students who are transitioning from further education to higher education and to give them the best experience they can in their transition.

The support the participants can give to autistic students in transition is tempered by the constraints that are imposed on them in terms of time available with students, policy and regulation limitations and funding available. These constraints can mean that the participants are unable to provide the support service they would like to and they provide the best service that they can under rules and regulations imposed on them.

## Chapter 6 Conclusion

It can be seen from the study that supporting autistic students in transition is a complex and precarious process for several reasons. First and foremost is the complex nature of autism and how it manifests itself differently in different students and can change in a person day-to-day. This can make devising support plans difficult because there is not a one size fits all plan that can be implemented for all students. Whilst the overall support strategy can be one size within that there is a clear need for flexibility and diversity within that to ensure all autistic students are supported equally and fairly and have the best chance possible at the start of their higher education.

I feel that my research has made a contribution to the body of research that has been conducted previously in this field by giving a voice to disability support workers who have been in my view neglected in previous studies. By adding their voice to the research already out there a more complete picture of the transition process and what it involves can be created and added to through more research.

Further research could be conducted over a wider demographic and a longer time period to gain a fuller understanding of the issues disability support workers face in preparing autistic students for higher education. This would enable common themes to be identified on a deeper and more detailed level than I have been able to do and to discover support strategies and best practice from disability support workers.

# Appendices

## Appendix 1

HE student enrolments by personal characteristics 2012/13 to 2016/17

- Data source: HESA
- **Data source link:** <https://www.hesa.ac.uk/data-and-analysis/sfr247/figure-4>
- Last updated: Jan-18

Category	2012/13	2013/14	2014/15	2015/16	2016/17
<b>Sex</b>					
Female	1,314,750	1,289,090	1,273,335	1,288,680	1,314,035
Male	1,025,295	1,010,035	992,370	991,670	1,002,820
Other	425	230	375	480	1,025
<b>Age group</b>					
20 and under	873,450	880,580	903,470	928,610	950,090
21-24 years	624,925	622,200	604,720	615,830	637,320
25-29 years	274,040	265,985	260,400	258,360	258,340
30 years and over	567,440	530,385	497,165	477,805	471,905
Age unknown	615	215	330	225	225
<b>Disability status</b>					
Known disability	221,145	229,215	239,425	256,995	279,115
No known disability	2,119,325	2,070,140	2,026,655	2,023,835	2,038,760
<b>Ethnicity</b>					
White	1,507,815	1,459,735	1,418,685	1,417,300	1,425,665

Category	2012/13	2013/14	2014/15	2015/16	2016/17
Black	117,380	116,635	117,465	122,150	130,020
Asian	171,370	172,195	175,235	183,510	192,780
Other (including mixed)	79,575	81,535	84,525	90,030	96,305
Not known	38,660	33,590	33,290	29,320	30,360
Total UK domiciled students	1,914,795	1,863,690	1,829,195	1,842,315	1,875,125
Total all students	2,340,470	2,299,355	2,266,075	2,280,830	2,317,880

## Appendix 2

### UK domiciled student enrolments by disability and sex 2016/17

- Data source: HESA
- **Data source link:** <https://www.hesa.ac.uk/data-and-analysis/students/table-15>
- Last updated: Feb-18

Disability	Female	Male	Other	Total
A specific learning difficulty	62,565	47,270	80	109,915
Blind or a serious visual impairment	1,515	1,490	0	3,010
Deaf or a serious hearing impairment	3,200	1,960	0	5,160
A physical impairment or mobility issues	5,020	3,080	10	8,110
Mental health condition	37,725	15,200	120	53,045
Social communication/Autistic spectrum disorder	2,170	7,245	30	9,440
A long-standing illness or health condition	16,000	9,405	15	25,420
Two or more conditions	17,765	8,870	70	26,705
Another disability, impairment or medical condition	13,400	7,830	5	21,235
No known disability	917,570	695,025	500	1,613,095
<b>Total</b>	<b>1,076,920</b>	<b>797,380</b>	<b>830</b>	<b>1,875,125</b>

### **Appendix 3**

#### Research Statement

**Research Project:** 'How do professionals experience autism and use this to support autistic students in transition from further education to higher education?'

#### Invitation to participate

I am inviting you to take part in my research project which is exploring how professionals experience autism and use this to support autistic students in transition from further education to higher education.

Before you decide to take part it is essential that you understand fully why the research is being done and what it will involve.

Please read the following information carefully and discuss it with others if you wish.

Please ask if there is anything that you don't understand or if you would like further information.

Thank you.

What is the purpose of the project?

I was diagnosed with Asperger's Syndrome, a form of autism in October 2008 and soon after found myself unemployed.

This was a time of intense reflection for me as I re-evaluated the life I had lived up to that point. Family, education, work and social life took on a different meaning for me and I spent a lot of time reflection on how my undiagnosed Asperger's Syndrome how affected my lived experience up to that point and how it would now give my life a different meaning now I was seeing the world through different eyes.

I took the decision to return to education in September 2009 and enrolled at Bradford College on an 'Access to Higher Education' course. In July 2011 I successfully passed the course and enrolled at the University of Huddersfield on a degree course in Sociology in September 2011.

During this time I transitioned from further education to higher education and I developed an interest in how autistic students experience this transition and how professionals support autistic students during this transition.

I want to explore how professionals in different support settings experience autism and what autism means to them. Then I want to explore how professionals use this experience to support autistic students during transition.

Why have you been chosen?

You have been chosen to participate in my research because you fit the profile of a education professional who is currently working with autistic students in a support capacity.

Everybody will gain experience of autism differently and I am interested to explore how this difference in gained experience influences their approach to support for autistic students.

Do I have to take part?

Participation in the research is entirely voluntary and you may withdraw at any time should you decide that you no longer wish to take part.

What do I have to do?

All participants will be invited to take part in a taped interview that will last approximately one hour.

They will be asked about their personal experience of autism and how this influences how they approach and contributes to their role in supporting autistic students in transition from further education to higher education.

At the end of the interview participants will be asked to provide some demographic information about themselves, for example, age range, marital status, housing location and work role.

What are the advantages of taking part?

The research will allow participants to reflect on their experience of autism and how this influences and contributes to their role as a professional involved in supporting autistic students.

Will all my details be kept confidential?

Yes. All the participants in the research will be kept anonymous. In the interview transcriptions, participants will be given pseudonyms e.g. Participant A, B etc to protect their identity. The research will be conducted in accordance with British Educational Research Association (BERA) guidelines and with ethical approval from the University of Huddersfield.

What will happen to the information collected by the researcher?

The information collected from the interviews will provide the data for the study. The data will be used to build up a picture of how a professional's experience of autism contributes to their role in supporting autistic students during transition from further education to higher education.

It will also provide an insight into how we can experience a condition such as autism differently and use this experience to achieve the same goal.

The information you provide will be compared with the data collected from other participants to establish similarities and differences.

The raw data e.g. tape recording transcriptions will be kept in a secure location as part of the research project but the tape recordings of the interviews will be destroyed.

Who can I contact for further information?

The research has been approved by the University of Huddersfield and carried out under the supervision of staff from the School of Education and Professional Development. If you would like to discuss any aspects of my research you can contact my research supervisor Debs Philip. Her email is: [d.philip@hud.ac.uk](mailto:d.philip@hud.ac.uk) and her number is: 01484 478294.

Thank you

I would like to thank you for reading these guidelines. I hope you now have sufficient information to decide whether or not you wish to participate. However, if you have any further questions I will be happy to answer them.

Andrew Smith  
Post Graduate Researcher  
MRes Education  
University of Huddersfield

Contact: [andrew.smith@hud.ac.uk](mailto:andrew.smith@hud.ac.uk)

## **Appendix 4**

### INTERVIEW STRUCTURE

ANDREW SMITH

Thursday, 06 July 2017

### HOW WILL THE INTERVIEW BE CONDUCTED?

#### PERPARATION

- Ensure that both parties are sitting at a table a short distance apart with the sound recorder positioned in between.
- Have the clock positioned in a place that is clearly visible to the researcher.
- Make sure that all relevant papers are ready and in order of use.

#### WELCOME AND INTRODUCTION

- Welcome the participant and thank them for agreeing to take part.
- I will ask some questions about your opinion and attitude towards issues surrounding students with autism in transition from further education to higher education. This is an informal interview and whilst I have some topics I would like to cover it is fine if we go slightly off topic and explore different avenues of transition and autism in students.
- Introduce the topic by summarising the Participant Information Sheet and check that the participant is well informed.
- I expect the interview to last around one hour but it may go slightly over if we are in the middle of discussing a topic.
- Obtain written consent using the Consent Form.
- Do I have your permission to record the interview?
- This interview will be recorded by myself the interviewer and the interview will be recorded digitally and transcribed by myself.
- All answers will be anonymised when written up in my thesis and the respondent will have the opportunity to review the transcript in the dissertation before it is submitted if they want to.
- All interviews will be stored in accordance with the University of Huddersfield's guidelines and a copy of these guidelines can be provided if required.
- Make it clear that when talking about autistic students in transition they can be any age but must have a formal diagnosis of an autistic spectrum disorder by a NHS psychologist and they are transitioning from a further education establishment to a higher education establishment.
- Do you have any questions?

## Remember...

- Can you expand on that?
- Can you explain a bit more about that?
- Can you give me an example?
- How did you do that?
- Can you explain in more detail what you mean?
- How do you feel about that?
- Explain what you mean by?

## Begin the interview by starting recording

## Questions

### AUTISM

#### What does autism mean to you?

- What do you know about autism?
- What is your understanding of autism?
- What is your experience of autism?
- How have you gained your knowledge, understanding and experience of autism?

### THE SOCIAL AND PHYSICAL ENVIRONMENT

#### What do you feel makes up the social and physical environment of further or higher education?

- What is your knowledge and understanding of social interaction and social communication?
- How would you assist and support someone who was struggling with their social interaction and social communication?
- What is your knowledge and understanding of sensory overload?
- How would you assist and support someone who was struggling with sensory overload?
- What is your knowledge and understanding of social isolation?
- How would you assist and support someone who was struggling with social isolation?
- What would you consider to be a suitable social and physical environment for autistic students?

### LACK OF APPROPRIATE SUPPORT

#### What does support mean to you?

- How do you ensure appropriate support is available in transition from FE to HE?
- What do you consider to be the deficits of autism?
- What do you consider to be the strengths of autism?
- How do you ensure autistic students are supported?
- Are there any barriers to providing appropriate support?
- When do you feel support for autistic students should begin?

## UNREALISTIC EXPECTATIONS BY THE STUDENT

Are there any expectations of students during transition?

- What do you consider to be unrealistic expectations of academic and social life at university?
- How would you manage any unrealistic expectations from autistic students?

## CHALLENGES CONCERNING ASSESSMENT

Can anything arise concerning assessment during transition?

- What could you do for an autistic student if they approached you around assessment?

## TRANSITIONING TO ADULT LIFE

What does becoming an adult mean to you?

- What could be involved in the transition to adult life for an autistic student?
- How would you assist and support an autistic student in the transition to adult life?

## POLICIES

What are your thoughts and feelings about the policies involving autism?

- Do they provide you with a framework to work in?
- Do they constrict your work?

Policies are:

- Autism Care Act 2014
- Equality Act 2010
- Children and Families Act 2014

Do you have anything more you would like to add?

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