“Sick, but not sick enough”

Exploring Experiences of Individuals with Rare Neurodiverse Conditions

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Abstract

This dissertation explores and details the experiences of individuals with neurological differences within the education system, portraying the thoughts and feelings shared by those who have found their learning experiences more challenging than the neurotypical majority who dominate society. The study arose from the authors own personal history and experiences as a neurodiverse student, compelling her to conduct research into the experiences of others who are and have been in a similar position to her. The purpose of this dissertation is to highlight the challenges and barriers faced by neurodiverse individuals, as well as to uncover some of the 'invisible' symptoms and how these affect experiences within the education system. Use of a focus group and a questionnaire featuring a mixed methods approach have allowed for a broad and thorough inquiry. The accounts detailed throughout the two interviews have enabled the study to remain personal, which the author believes to be essential in mirroring the unique experiences of her neurologically diverse participants. Thematic analysis identifies and highlights the tangible and more abstract barriers within the education system, as well as the detrimental effects of stigma and stereotypes. The concept of an 'invisible illness' is also discussed, something which both participants and author deem highly significant in shaping their academic and social experiences. The implications of the study suggest that the education system must do more to encourage students who are eligible to take their place in higher education by supporting their application and continuing to provide necessary guidance throughout their studies. Equally, the findings suggest the need to better equip staff with specific training about neurological differences, 'invisible' symptoms and their implications. This dissertation has the potential for further development, identifying a gap in research and lack of disability awareness.

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Prologue:

Blog Extract: How to: A University Guide*

“The unknown can be a lot scarier when life itself is a challenge. When you can just about get through the day at home with support from your family and friends. When you're constantly worried about how accessible this new city and your new home will be!”

“My anxiety went through the roof those few months leading up to university. I hardly got a wink of sleep worrying about how I'd settle into this new place far away from home. My mind going round and round in circles to whether or not I'd make supportive friends who'd understand and accept my condition. Whether I'd make it into lectures that were a long walk away and if I'd be able to manage my mental health issues along with all this”.

*Extract from my blog ataxicfantastic.blogspot

Blog Extract: The privilege of prioritizing your education*

“Prioritizing your education is a privilege that not everyone can afford, to tell you the truth this is something that I am struggling to come to terms with. Chronic illness is all consuming and recently it has got the better of me. No matter how much I try to avoid it, no matter how many times I try to outsmart or control it- it's always there. Of course there are good days, or better said, easier days but it's still there lingering in the background, a gentle reminder of all the challenges I have yet to face”

“It wasn't till a few weeks ago that everything caught up with me. My mental health just deteriorated rapidly, the stress of trying to prioritize my education over my own wellbeing had taken its toll and I finally admitted (to myself) that this was not a sustainable way to live. I don't have an acute illness that will go away eventually. This is something I am going to live with for the rest of my life, something I am going to have to learn how to manage and learn how to live with. Something that I must make a priority”

***Extract from my blog ataxicfantastic.blogspot**

Chapter One- Introduction

> *"Limiting neurodiversity only to those with autism and related differences, however, resembles limiting ethnic diversity to discourse about individuals of African American descent" (Baker, 2011 as cited in Runswick-Cole, 2014, p.1120)*

Neurodiversity has been acknowledged as a natural and essential human variation, composed of infinite forms of neurocognitive functioning (Walker, 2014). The neurodiversity movement, paradigm and studies surrounding neurodiversity offer an essential and alternative way of exploring conditions that were traditionally pathologies by the healthy neurotypical majority, who do not display any neurologically atypical behaviours or patterns of thought, who dominate society. Due to the invisibility of many symptoms, the challenges that many neurodiverse individuals face may go unrecognised and un-detected and are often belittled or seen as trivial because others fail to spot the difficulties they are having (Holland, 2017). My overall experiences of navigating through life and through my years in school prompted me to question whether the emotions, barriers and challenges I faced were common amongst other neurodiverse individuals.

At 17 years old, after almost a decade of investigations and interventions, I was diagnosed with Ataxia two months before I started university in 2017. Originating from the Greek language, Ataxia refers to the loss of coordination due to muscle weakness (Burke & Hammans, 2012), symptoms include slurred speech, abnormal eye movement and poor proprioception. Although research has progressed rapidly over the last few years, there is unfortunately no cure yet (Burke & Hammans, 2012). My type of ataxia is called AOA2 (Ataxia with oculomotor apraxia type 2), it is known as an Autosomal Recessive Ataxia, meaning that "Two defective copies of the gene (one from each parent) are required to manifest symptoms; thus, parents as carriers are usually asymptomatic" (Akbar & Ashizawa, 2015, p. 227). Despite ataxia being a rare neurodegenerative condition, it has been estimated that roughly 2 in a million have AOA2 (Koenig & Moreira, 2004). Although there may be no cure, treatment including physiotherapy, mobility aids and educational support are available to help control manifestations (Koenig & Moreira, 2004). Having this diagnosis motivated me to focus on disability throughout my studies at university and developed an interest in labelling, stereotypes and the detrimental effect these can have on individuals who are not regarded as part of conventional society. Consequently, reinforcing stigmas, marginalising and ostracising those who do not comply with the norm. My concern is whether these stereotypes and conventions also define me, whether because I deviated from the orthodox, aesthetically normal woman, I was less valuable (LaChapelle, Lavoie, Higgins & Hadjistavropoulos, 2014).

It was not until last summer that I began relying on a walking stick to help me manage my Ataxia, up until then my neurological illness often went undetected. These years presented a plethora of challenges, especially during my educational experience, as no one could easily recognize the obstacles I faced. Moving from an illness that was invisible to an illness that was more visible and the challenges I had experienced during that time motivated me to explore this specific issue which revolves around those who also have a condition that is not visible. The first blog extract is from two months into my life as a student at the University of Sheffield. The second I wrote during my second year. Both extracts provide a glimpse into my university experience as a neurodiverse student. The anxiety I felt leading up to and during my time at university had to do with the thought that no one would understand my condition, no one could immediately tell what was wrong with me and even if I told them they would immediately ask “oh, so like autism?”. Research conducted by Mayada (2012), exploring the global prevalence of Autism, reported one in one hundred and sixty children suffer from a form of Autism, making it one of the most accepted and known neurological disorders. Consequently, for many the term neurodiverse is synonymous with Autism. I recognised people’s lack of insight into the lives of individuals with rare forms of neurological illnesses identified the need for me to raise awareness surrounding how these individuals manage in an education system governed by conventions and norms. Thus, it is my intention to explore the lives of those with lesser known neurological conditions, including Ataxia and Multiple Sclerosis.

Research aim

The aim of this study is to explore the lived experiences of individuals with rare Neurodiverse conditions within the UK education system to raise awareness about the challenges they face by having a condition that is not always visible.

Key Research Questions

1. Does today’s education system accommodate and provide for a neurodiverse community?
2. Is there a neurological hierarchy within the neurodiverse community?

The first research question will help shape my dissertation and will provide ground for further exploration and development; the objective of this question is to uncover whether more needs to be done to include those with neurological conditions. The second research was developed after having carried out my research and identifying a key theme.

Structure of disseration

The introduction sought to provide the background and context for this research. In the literature review, I identify and discuss the issues and debates relevant to this study. This includes an exploration of the history of neurodiversity , providing a thorough critical analysis and a discussion of the social and academic implications. In chapter three, I discuss the methodology and methods providing a justification for the methodological approach used for this study. This chapter details how my positionality and experiences have shaped my research and methodological choices and the ethical considerations that were mediated throughout my research. Chapter four discusses and interprets the findings from my data, exploring the key themes identified throughout my analysis. Throughout the final chapter I will reflect on my research, discussing any resulting implications and suggestions for further study.

Chapter two- Literature Review

2. 1 Introduction

The purpose of this literature review is to explore the relevant issues and debates about neurodiversity and its implications. This will shape my perspectives and develop my understanding about the ways in which Neurodiversity and its challenges have previously been understood. Additionally, I shall introduce the topic of neurodiversity, providing an in-depth exploration and critical account. I will then discuss the stigma and stereotypes that impact those who diverge from the norm. Finally, I shall consider the relationship between neurodiversity and the classroom, questioning whether the classroom suitably accommodates those with neurological challenges.

2.2 Exploring neurodiversity

Autistic sociologist Judy Singer coined the term neurodiversity in 1998, according to Comberousse (2019). Singer recognized that the diversity "…we observe and value around us, can also be applied to people whose brains are different…" (Comberousse, 2019, n.p.), thus identifying a necessity for terminology which encapsulated a cerebral divergence from the neurotypical norm. Unlike disability, a neurological disorder may not always be easily recognized and may be misinterpreted; this is due to the fact that some symptoms are not always visible (Burke & Hammans, 2012). However it has been suggested that neurodiversity "…has its roots in the social model of disability" (Comberousse, 2019, n.p.), therefore due to this and the scarcity of literature focusing solely on neurodiversity; I shall use the strikingly similar terms 'disability' and 'neurodiversity' as interchangeable throughout this literature review.

Following Judy Singer's developments in the field of 'neurodiversity', much observational research and critical discussion has materialized within the natural and social sciences. (Comberousse, 2019). Exploration, interpretation and critique of the models of disability – an arguably similar concept to neurodiversity (Comberousse, 2019) has ensued as well as a scrutiny of neurodiversity itself. Walker (2014) argues that neurodiversity is a concept which embodies "…the infinite variation in neurocognitive functioning…" (p.1) concurring that neurodiversity is just a natural human variation and by no means a deficit. For decades now the neurodiversity movement has fought to bridge the gap between neurodivergent individuals who deviate from the norm, and neurotypical members of society (den Houting, 2018). Suggesting that neurodiversity is not something that should be thought of as a problem that needs to be eradicated but rather as a slight deviation from the norm that makes up our wonderfully diverse and charismatic society (Comberousse, 2019). It may be argued that supporting the neurodiversity movement is the social model of disability, a term coined by Mike Oliver in 1983.

The social model of disability proposes that it is society that disables an individual rather than their medical condition, shifting the blame and responsibility from the individual onto society. This model argues that the barriers, labels and challenges in society set out to confine and restrict those with disabilities are more impeding and isolating than the disability itself (Oliver, 2013). Arguing that it is fundamental to change our focus from those with limitations to the "…social environments [which] impose limitations on certain groups or categories of people" (Oliver, 1983, cited in Hughes, 2010, p.509). Much like the advocates for the neurodiversity movement, Oliver believes that it is not the neurodivergent individual that needs to change in order to access our society but rather society which needs to learn to adapt to and cooperate with those who have limitations in order to provide a more approachable and cohesive environment (den Houting, 2018).

Rather than focusing on the limitations as a result of the impairments possessed by an individual, the social model of disability chooses to focus on the outcomes that result from challenging and tackling any barriers and the extra support which can be made available to those who require it (Hughes, 2010). Thus, it can be argued that similarly to the neurodiversity movement, Oliver's (1983) social model of disability strives for equality in the disabled and neurodiverse community (Oliver, 2013). Whilst reflecting on his earlier work Oliver (2013) concurs that, although there has been remarkable changes from the way in which disabled individuals are represented in the media to the accessibility of public transport and buildings, there are still some barriers that are proving to be more intractable and still remain unaccommodating to those with limitations. Oliver (2013) argues that the hegemonic structure of the education system has scarcely been challenged – although he acknowledges some effort to alter and accommodate disabled individuals in secondary schools- ; Oliver (2013) also criticizes employment conglomerates for failing to challenge and change the physical barriers which employees have to face on a daily basis. Equally, the neurodiversity movement recognizes that we need different types of accessibility in mainstream society that accommodate different, non-mainstream ways of thinking (Comberousse, 2019).

Other external factors that can shape inequality have been identified by social theorist and feminist Kimberlé Crenshaw. According to Boston (2017), Crenshaw first coined the intersectionality theory in 1989. This theory argues that discrimination and social injustice are results of the interdependent and overlapping social systems such as patriarchy, class systems and race (Boston, 2017). Crenshaw explores how different forms of discrimination can be interlinked, and argues, *"[t]he tension broke, however, when we learned that we would not be excluded because of our race, but that I would have to go around to the back door because I was a female." (Crenshaw, 1989, p.169).* Although society has vastly changed since 1989, it is undeniable that Crenshaw's concept of intersectionality remains as relevant as ever. It has been argued that there is an apparent relationship between the intersectionality theory and the neurodiversity paradigm -A similar concept to the neurodiversity movement , a paradigm which argues that neurodivergence is just a natural human variation (Walker, 2014)-, a strong and consistant bond which enable these concepts to draw from eachother creating an interesting dialogue between the two (Strand, 2017). The reciprical and interchanging relationship between the neurodiversity paradigm and the intersectionality has been discussed and explored by Strand (2017), arguing that the core principles of each concept sychronously strengthen one another. The common ground between both concept lies within the aim which is to highlight the disadvantages which have been historically under represented and have led to the marginalization of individuals (Strand, 2017). Strand argues that the intersectionality theory is critical for the neurodiversity paradigm and activists as both seek to highlight the under-represented and often seek to expose intersectional invisibility and uncover "…the complex ways power circulates at all levels of interaction throughout culture and society" (Strand, 2017, n.p.).

2.2.1 Exploring Neurodiversity- Critiques

Before I set out to further explore neurodiversity and it's implications, I must first acknowledge the criticisms and limitations attached to each concept. The neurodiversity movement has received much criticism since it was first established. Runswick- Cole (2015) has taken a more pessimistic stance, arguing that instead of making individuals feel more accepted, the two binary opposite terms 'neurodivergent' and 'neurotypical' can infact do more harm than good. Denouncing that these two opposing concepts may create an 'us' and 'them mentality, thus categorizing society (Russell, 2019). Seidel corroborates this divisive perspective by concurring that the pointless propagation and demagoguery can "…could only exacerbate tensions and undermine advocacy efforts" (as cited in Russell, 2019, p.290). Further critiquing the neurotypical/neurodiverse divide is Armstrong (2015) who, whilst supporting Runswick-Cole's argument also offers a more positive view, questioning the term neurotypical. Armstrong (2015) argues that it is not as concrete and explicit as suggested by neurodiversity advocates. Claiming that there should be no 'norm' when exploring the human mind, there should be no standard way of thinking and behaving as everyone is different. Raising the question “…how do we decide whether any individual human brain or mind is abnormal or normal?” (Armstrong, 2015, as cited in Russell, 2019, p.290). Following on from this divisive perspective is the argument that the Neurodiversity movement demands and elicits conformity. Hiari (2018) concurs that “The neurodiversity movement epitomizes groupthink” (as cited in Russell, 2019, p.300). Arguing that instead of bridging the gap between neurotypical and neurodiverse groups (den Houting, 2018), the movement actually creates a divide in society, requiring individuals to conform to either one of the two groups.

Whilst exploring the social model of disability (Hughes, 2010) and it’s critiques, I have concluded that the strongest counter argument is that of its binary opposite model, the medical model of disability, which can provide a clear and concise alternative approach (Comberousse, 2019). The social model of disability, as proposed by Oliver in 1983, shifts the responsibility from the individual onto society, seeing disability as a social construct which is completely separate from illness (Hughes, 2010). However, the medical model of disability does not distinguish between the two, seeing neurodiversity as something that needs to be treated and cured and not something that should be accepted and accommodated (Comberousse, 2019). Oliver (1983) describes this as the medicalization of disability, arguing that the model focuses on curing the individual rather than alleviating social conditions (Hughes, 2010). The medical model by its very nature criticizes Oliver’s work as it views disability as an “individual problem tied to the functional limitations of the bodies of people with impairments” (Swain, French, & Cameron, 2003, as cited in Krcek, 2013, p.6), thus ignoring all other external factors that may affect an individual. Arguing that the social model does not reflect or assume autonomy or individuality but generalizes disability as a result of an individuals environment. However, Rudnick (2017) describes both models as “…neither mutually exclusive…nor are they jointly exhaustive (p.2). Arguing that each model, although independent of each other, can also be applied simultaneously to explain health and social impairments. Therefore suggesting that there is a dichotomous relationship between both models is misleading and false (Rudnick, 2017).

The intersectionality theory argues that a compilation of social systems overlap so that an individual experiences multiple forms of opression at once, supporting the notion that someone is rarely just one being but a multiplicity of beings. (Strand, 2017). Social analysts have often found difficulties when interpreting and applying Crenshaw’s theory as they argue that people’s views and experiences are often misrepresented (Malinsky, Bright, & Thompson, 2016). Social analysts have criticised the intersectionality theory as there is little oppportunity to “…study intersectional hypotheses by quantitative means…” (Malinsky, Bright, & Thompson, 2016, p.61). Foley contends that “although intersectionality can usefully describe the effects of multiple oppressions… it does not offer an adequate explanatory framework for addressing the root causes…” (2019, p.11). She also provides a Marxist critique, distinguishing between opression and exploitation, a distinction that was not touched on by Crenshaw (1989). Foley (2019) provides the examples of race not causing racism and gender not causing sexism. Thus, it may be argued that the intersectionality theory alone cannot explain the cause and root of opression but only the social structures which msy lead to discrimination.

2.3 Stigma and Stereotypes

The book Outsider (1963) composed by sociologist Howard Becker clearly encapsulates and articulates the labelling theory. The term ‘outsiders’ was frequently used to refer to individuals who were labelled as a result of as a result of deviation from the norm and resistance to conform to society’s rules. Becker (1963) argued that labels were a consequence of society’s reaction to a behavior, contending that it was society who decided which behaviors were deviant and which were acceptable.

> *Deviance is not a quality of the act the person commits, but rather a consequence of the application by others of rules and sanctions to an “offender”. The deviant is one to whom that label has successfully been applied; deviant behavior is behavior that people so label (Becker, 1963, p.9).*

Becker contends that labelling does not occur as a result of a behavior itself, but the way in which society responds to and perceives that behavior. Moreover, Becker (1963) highlights the fact that there are individuals who have not broken any rules but are still labelled as deviant from society. He stresses the complementary nature between those who deviate from the norm and society, further discussing deviant behavior as predetermined by society as it does not comply with their set of norms. Therefore, concluding that “deviance is not a quality that lies in behavior itself, but in the interaction between the person who commits an act and those who respond to it” (Becker, 1963, p.14). Corroborating Becker is Professor of Sociology Mårten Söder, who in 1989 revisited the labelling theory as a social construct of disability. Similarly, to Becker, Söder (1989) rejected simplistic reliance on clinical attitudes that had dominated research into disability and began to take into account external factors such as societal influences. Söder concurs that through labelling the term ‘disabled’ is given meaning which affects a disabled individuals self-image. However, Söder expanded on Becker’s work by contending that there are three approaches to the phenomenon that disability is socially constructed.

The first approach is the ‘Epidemiological Approach’. It is a casual approach regarding the relationship between disability and the environment, questioning which social factors, like one’s work environment, contributed towards the “…deficiency of an individual…” (Söder, 1989, p.118). This is approach supports Oliver’s (1983) Social Model of Disability. The second approach, known as the ‘Adaptability Approach’ offers a contrasting view that, although disability is still the outcome of the realtionship between an individual and their environment, disability is ultimatley due to the individual’s failure to adjust to society. Perhaps this approach offers a more medicalised persepective on the relationship between disability and social factors. The third approach is the ‘Social Constructivist Approach’ and suggests that we get to know the world through meanings and labels, “our relation to the world is conditioned by our interaction with others.” (Söder, 1989, p.119). Söder refers back to Becker by contending that the meaning attached to physical and mental deviations is what defines disability. *“Labelling is the term used for stereotyping and categorizing someone as being in a particular group and then attaching a label to denote that group and its characteristics” (Brain & Mukherji, 2005, p.160).*

Society is often unsure how to perceive and label those with disabilities as they are neither ill nor healthy. Therefore others are unsure on how to behave towards them and what behavior they should expect from them, thus marginalizing them as ‘abnormal’ and consequently developing misinformed stigmas and stereotypes (Green, 2005). In order for stigma and stereotypes to continue maintaining meaning, something other than labelling must occur (Merton, 1948). Merton contended that those who were labelled eventually ended up adopting that label as part of their set of characteristics. He coined this the self-fulfilling prophecy, a concept depicting how “…in the beginning, a *false* definition of the situation, evoking a new behaviour which makes the originally false conception come *true*” (Merton, 1948, p.506). Merton argues that it is the self-fulfilling prophecy which defines and explains social dynamics today, concurring that stereotypes and stigma are products of societal forces which are adopted by individuals thus allowing for prejudice to persevere (Merton, 1948). The intersectionality theory coined by Crenshaw (1989) argues that discrimination as a result of the overlapping and interdependent labels set out by social systems (Malinsky, Bright, & Thompson, 2016). Crenshaw (1989) corroborates Söder (1989), concurring that it is the combination of these socially constructed labels that allows for social injustice and creates a divide between ‘us and ‘them’ based on perceived social deviation and not adhering to the culturally constructed norm (Malinsky, Bright, & Thompson, 2016; Becker, 1963).

Strengthening Crenshaw’s intersectionality theory, contending that discrimination is a result of the overlapping of multiple oppressive systems, is Lloyd, who in 1992 developed his ‘double discrimination theory’ (Coleman, 2014). Similarly to Crenshaw, Llyod argued there is an inherent systemic unjustice within society whereby an individual may be subject to prejudice and opression as a result of multiple misconceptions and stereotypes. Lloyd’s (1992) theory suggests that disabled females fall victim of multiple oppressive stereotypes than disabled men due to their gender. Lloyd contends that because their ability to nurture and care for others is more limited due to their disability, their feminine gender role is thus questioned and tarnished. Additionally, as argued by Frederickson and Roberts (1997), the objectification theory implies that women are scrutinized and valued based on the perception of others. However, as pointed out by Diekman and Eagly (2000), it is not just women who face this ‘double discrimination’ but also men. They suggested that characteristics conventionally assigned to men are unrealistic and insurmountable for disabled men. Perhaps inspiring both Crenshaw and Lloyd was Deborah King (1988). According to Strand (2017), King made a remarkable intervention by outlining how oppressive stereotypes are not additive- as implied by the ‘double discrimination theory’- but are instead intersecting. However, King proposes “multiple jeopardy” as a more fitting description, explaining that “"[t]he modifier 'multiple' refers not only to several, simultaneous oppressions but to the multiplicative relationships among them as well" (Strand, 2017, n.p.).

2.4 Neurodiversity in the classroom

Due to humankind’s voyeuristic nature children begin to absorb and interpret their surroundings from a young age, in 1952 Piaget coined this critical stage in child development the pre-operational stage. It’s during these years that young children begin their educational journey, Piaget has alluded to the pre-operational stage as being a hallmark stage as they really start to develop a mind of their own (Cherry, 2019). Much of this psychological development is influenced by teacher’s and the attitudes that they observe.

An approach to amending and preventing physical abnormalities amongst children has been expressed through this painting (figure 1) which can be found in Michel Foucault’s work from 1977. The book *Discipline and Punish* features this image titled: *Orthapedics or the art of preventing and correcting deformities of the body in children* (1749). Suggesting that the perception and understandings of disability from that time may derive from the medical model (Arehart, 2008). Although back then this image may have had more literal meaning, it may now hold more metaphorical connotations. The neurodiversity movement contends that many neurodiverse conditions are labelled as ‘invisible illnesses’ (Comberousse, 2019). Thus the vast majority of neurotypical peers and staff may not recognise someone who is neurodiverse and may be unknowingly trying to correct a biological abnormality. However, this image may also be alluding to Oliver’s (1983) social model of disability by suggesting that materials found in one’s environment can be used to accommodate disabled individuals. Due to their vicarious nature, it is in the classroom that children observe and learn what is perceived as the norm and what is deemed as socially acceptable, as a consequence of these observations children then begin to recognize that society is split into ‘us’ and ‘them’(Goodley, Runswick-Cole & Liddiard, 2016). Whilst interpreting child development psychologist Piaget (1952) devised a series of conventional steps in child development, however it has been argued that this has consequently tarnished any child who deviates from his list as ‘problematic’ (Davies, 1995). Disabled childhood critics have highlighted the importance and significance of the experiences of disabled children when helping develop a deeper understanding of the identity and embodiment of disabled individuals (Curran and Runswick-Cole, 2014). There has been a significant shift in the field of childhood studies from objectively studying *about* children with disabilities towards subjective studies involving children with disabilities (Alderson, 2008). Moore (2004) contends that there is an intrinsic difference between difference and inequality, arguing that disabled individuals are able to achieve the same results in a classroom setting but the difference is in their approach. Despite this, whilst deliberating over the “dimensions of difference”, Moore discusses class, gender and race but fails to pertain to the subject of disability. This may be because disability itself ironically does not discriminate, anyone can be affected by disability regardless of their gender, race, ethnicity or socio-economic background. Perhaps in order to fight the stigma and taboo of the “DisHuman” child (Goodley, Runswick-Cole & Liddiard, 2016), it may be essential to weave disability history into the educational curriculum, encouraging children to understand disability, thus normalizing it (Ismail, 201).

“Learning is a relatively permanent change in behavior brought about by practice or experience” (Sheldon, 1997, p.477). After thoroughly researching and enquiring into the often unnoted topic that is neurodiversity, I would argue that that there is still a gap in the education system.Whilst discussing what is meant by the term ‘learning’, Sheldon (1997) contended that learning itself is a process subject to differences in ability and the “…observable change is a product…” (Sheldon, 1997, p.478). Thus suggesting that those in educational roles should distinguish between then two, accepting that those with neurological differences may take a different approach and process whilst learning, therefore expecting the same outcome as their neurotypical peers is entirely inequitable and unjust. Sheldon (1997) proposed a new definition of learning; viewing learning as a process allowing for indivividual differences, rather than a "…consequence of mere biological growth" (Sheldon, 1997, p.479).

2.5 Conclusion and Reflection

"Characterizing disability is a steady matter of social debate and social construction…" (Krcek, 2013, n.p.)

The aim of this literature review was to explore neurodiversity and its implications, helping me identify a gap in research on the social implications of neurodiversity amongst people in the education system. In this literature review I identified what it means to be neurodiverse, explored the concept of neurodiversity as a natural neurological variation (Walker, 2014), and distinguished it from the more broader term 'disability'. However, I also recognized its inclusion within the disability movement, in particular Oliver's (1983) Social Model. Throughout my review it has come to my attention that in the majority of articles and narratives investigating all aspects of social inequality there is a complete negligence when discussing and recognizing disability as an inequality (Gillborn & Mirza, 2000), much less the topic of neurodiversity which is scarcely even touched upon. Many members of the neurodiversity paradigm have failed to discuss more uncommon neuro problems, thus implying that there is a neurological hierarchy with more common neurological problems having greater significance (Comberousse, 2019; Russell, 2019; Walker, 2014). Thus, it could be contended that although neurodiversity itself may result in inequality and discrimination, more unusual types and 'invisible' neurological abnormalities may also be subject to a form of 'double discrimination' (Coleman , 2014) within the neurodiversity paradigm. This literature review has helped me identify a gap in neurological research and strengthened my motivation to carry out my research on individuals with more unheard of neurological differences.

Additionally, the potential presence of a neurological hierarchy has propelled me to reflect upon this implication. Having a rare, often unheard of (Koenig & Moreira, 2004), neurological condition myself has incited an unnerving frustration within me. This is due to more uncommon neurological conditions going unrecognized, overthrown by more accepted conditions such as Autism which has been perceived as the most significant neurological disorder amongst researchers such as Krcek (2013). Due to this disregard and underrepresentation I have often come across individuals who have shown a complete lack of compassion and understanding. Furthermore, if these rarer neurological conditions are to go unnoticed in the education system many students and staff may not achieve their full potential because their teachers and colleagues may fail to recognize and appreciate the different way in which their mind works (Sheldon, 1997)

Chapter Three – Methodology and Methods

3.1 Introduction

This study sought to explore the lived experiences of individuals with rare Neurodiverse conditions within the UK education system to raise awareness about the challenges they face by having a condition that is not always visible. This chapter details the methodological approach I and choices I have employed in order to gather subjective and detailed data

In this chapter, I discuss my positionality, justifying why and how this has shaped my research and influenced my methodological choices. As a qualitative study, I employed a quantitative questionnaire in the hope that my predominantly personal and subjective data could be further understood and corroborated (Clough & Nutbrown, 2012). This approach allowed me to gain insights into the educational experiences of individuals with neurological differences, analysing and exploring the perspectives from the neurodiverse community and the predominant neurotypical population (Bell & Waters, 2014). My sample demographic included both staff and students and enabled me to "…see the same thing from different perspectives and thus be able to confirm or challenge the findings…" (Laws, 2013 as cited in Bell & Waters, 2014, p.120). This approach allowed me to subjectively explore the thoughts, feelings and experiences of my participants; analyse and interpret the meaning conveyed within their responses (Thomas, 2017). I shall discuss my positionality as a member of the neurodiverse community, which I believe will be an advantage, allowing me to immerse myself "…in the research contexts in which we are interested…" (Thomas, 2017, p.110).

3.2 Positionality

"all social research sets out with specific purposes from a particular position and aims to persuade readers of its significance" (Clough & Nutbrown, 2012, p.1).

In the complex world of social sciences, a paradigm situates researchers, defining us as either positivists or interpretivists. The paradigm under which we are situated is determined by our approach to knowledge, centred around "…how we seek knowledge and how we use it" (Thomas, 2017, p.107). A paradigm consists of the epistemological and ontological thoughts and beliefs that govern the researcher's mentality and ethos, thus influencing the research process (Bell & Waters, 2014). As I was interested in exploring the thoughts and experiences of individuals with a rare

Neurodiverse condition, I adopted an interpretivist stance, embracing different views and ideas whilst acknowledging my own position throughout the process (Opie, 2004). When I reflected on my social and educational experiences, I realised that it was not solely my disability that restricted me, but it was often the often-intangible barriers within the education system. Having a chronic neurological disorder, I had many similar experiences and comparable thoughts as my participants, and this enabled me to interpret and understand a world which could only be understood "…through [my participants'] own eyes" (Rubin & Babbie, 2007, p.51). I adopted an open minded and eclectic school of thought, intrinsically influenced and guided by a concept which shaped and contextualized my research (Clough and Nutbrown, 2012).

As noted in the introductory chapter, a few months before I began my university experience, I was diagnosed with Ataxia, a rare neurological condition. Due to the distinctive symptoms of Ataxia, I often appeared intoxicated and my behaviour would mimic that of people who are drunk (National Ataxia Foundation, 2010). Over the last year, I have been questioned by bouncers and shop floor assistants about having one drink too many. This situation is not uncommon. Wallace (2006) recalls, during an interview with Helen Turner, how she was once almost escorted off the plane by security as they believed her to be intoxicated. This often leads to the dehumanisation and intolerance of those who are neurodiverse because they do not adhere to social norms (Perkins, 2002). Taking an interpretivist approach offered me unique insight into understanding and interpreting the experiences recalled by participants (Clough & Nutbrown, 2012) and knowledge acquired was "…on the basis of [me] being [me], interviewing someone else being them" (Thomas, 2017, p.145). Sharing a significant characteristic with the majority of my participants meant that as an insider, my social and educational experiences were similar to each of theirs and thus I was able to vicariously explore and understand their perspective (Rubin & Babbie, 2007). This insiderness helped me to be more confident during interviews and focus group discussions as I asked open ended questions. Knowing that my neurodiversity was unique, the power was balanced between me and my participants and this gave them confidence at times to lead the conversation as they shared their experience. Considering that I value people's subjective experiences, I adopted an approach which accepted that people are people and are not predictable (Thomas, 2017) and where our social worlds are constructed based on our knowledge of others. Researchers believe that "it is meaningless to adopt the stance of the disinterested observer" (Thomas, 2017, p.167), thus it was imperative that I made the most of the empathetic and perceptive traits that I possessed as an insider (Rubin & Babbie, 2007).

3.3. Methodology

This was a qualitative research study. Qualitative research emphasises that "…the main instrument of social investigation is the researcher" (Burgess, 1982 as cited in Thomas, 2017, p.164), relying on and accentuating the interpretations of the researcher. Qualitative research allows for a critical realist perspective providing "…an underpinning structure and language to guide good research by asking what the entities, causal powers, dependencies and relations are…" (O'Mahoney & Vincent, 2019, p.207). Thus, a qualitative methodology enabled me to contextually analyse my data, distinguishing from what is tangible and what is merely a social construct. However, although the majority of my research is qualitative, I did employ some quantitative methods, the data from which was explained in more depth using qualitative methods (Clough & Nutbrown, 2012) enabling me to"…explore the subjective meanings behind questionnaire responses and to develop quantitative measures…" (Coyle & Williams, 2000, p.1235). A qualitative methodology shaped my philosophy as an interpretivist researcher and allowed for a wholly holistic exploration into the unique experiences (Clough & Nutbrown, 2012) of those with neurological differences. An interpretive approach is typically aligned with qualitative methodology, and interpretivists often employ qualitative approaches to search for subjectivity (Peshkin,1988), distinguishing between ontology and epistemology whilst simultaneously bridging the gap between the two (O'Mahoney & Vincent, 2019). Throughout my research I accomplished this by using face to face interviews and focus groups which allowed me to gain a deeper understanding than positivist, scientific approaches would.

I deemed it only natural to also adopt features of interpretive phenomenological research, studying a situation from within (Thomas, 2017). Phenomenological researchers have the exclusive opportunity to carry out their subjective research where they explore and interpret the unique experiences of their participants, learning and developing their understanding through subjectively analysing their participants (Collins, 2018). Knibbe and Versteeg (2008) contend that "In phenomenological anthropology…there is…greater emphasis on experience…" (P.49); considering my interpretivist position, adopting a methodological approach often used by anthropologists, who subjectively study people, seemed the most organic and logical step to take (Whittle, 2018). Phenomenology and interpretivism go hand in hand; accepting that people are people and are not predictable, rejecting an objective view and allowing for a shift in behaviour. (Collins, 2018). Phenomenology relays a transcendent truth that serves as a "…foundation for evaluating worldviews or examining the complex and enigmatic character of the human condition" (Jackson, 1996 as cited in Knibbe & Versteeg, 2008, p.49) without reducing them unrelated principles. Thus, it was imperative that I made the most of the empathetic and perceptive traits that I possessed as an insider (Rubin & Babbie, 2007).

3.3.2 Sampling

Participant (Pseudonym)	Neurological Condition	Age	Educational Position
Andrea	MS	5	Ex Lecturer
Laura	Friederichs Ataxia	22	Student
Olivia **Alex** **Ellie** **James**	Neurotypical	22-27	Students
Questionnaire	Ataxia, MS, Dyspraxia	18-25	Students

Table 1: Table showing demographics of sample

Due to my research being situated within an interpretivist paradigm (Thomas, 2017), sample size was not as important as the quality and insightfulness of the answers given by my participants. It was important to ensure validity throughout my research to then establish "…credible conclusions…[where] research offers can bear the weight of the interpretation that is put on it" (Sapsford & Jupp, 1996 as cited in Bell, 2010, p.120). In order to gain a range of different perspectives to then compare and "…confirm or challenge findings…" (Laws, 2013 as cited in Bell & Waters, 2014, p.120). I chose to employ different forms of sampling. The first method of sampling I used was a convenience sample (Opie, 2004) to identify four participants for the focus group discussion. This form of sampling was chosen as a result of practicality, consisting of neurotypical university students who themselves had strict work schedules. In this sample all participants belonged to neurotypical majority of the population (Comberousse, 2019), thus finding and selecting participants was by no means a challenge. The second method was an interview, in order to gain an insightful perspective into the educational experiences of those with neurological differences I carried out two interviews. I used purposive sampling (Opie, 2004) when selecting these participants as they were chosen based on their neurological difference. For my final sample I identified a small number of neurodiverse individuals who were able to participate in my study. This involved a method of sampling known as snowball sampling (Opie, 2004) which I chose as I believed that it would be the best option in order to explore and investigate a niche sample of individuals.

3.3.1 Methods and Procedures

This section focuses on my research methods and the steps taken to support the collection of data; I employed a questionnaire, interviews, and a focus group discussion to do this.

Firstly, I conducted an online questionnaire using a combination of qualitative and quantitative questions as I anticipated that many of my participants would struggle to provide longer, qualitative responses due to having symptoms such as fatigue, tremors affecting fine motor control, and brain fog (Recovery Brands LLC, 2018). Thus, I also thought the quantitative method utilised throughout my questionnaire would "…complement…predominantly qualitative data..." (Clough & Nutbrown, 2012, p.124) that I had gathered via other methods. Unlike participants in my focus group and interviews, I had no face-to-face contact with the respondents of my questionnaire, thus I thought that these participants would feel more at ease to answer freely (Clough & Nutbrown, 2012). My questionnaire consisted mostly of closed questions including multiple choice, Likert scales and dichotomous questions (Thomas, 2017). I was aware that closed questions would not allow my participants to further explain their unique experience, therefore I included open, qualitative questions to allow for further elaboration (Bell & Waters, 2014). To distribute my questionnaire, I attended an Ataxia UK conference in October 2019 and compiled a list of emails from individuals willing to take part. Although I had sent out my questionnaire to 30 individuals, I had anticipated that not all would reply, due to complex health reasons and symptoms such as fatigue and memory impediments. Both of my interviewees provided copious amount of information surrounding their experience within the education system.

I then carried out two separate semi structured interviews involving neurodiverse participants belonging to different age groups, with the intention that this would convey my research as a holistic and universal exploration into the experiences of neurodiverse individuals. I chose this method because of its adaptability, and my awareness that the interviews were “a conversation between the interviewer and respondent …” (Moser & Kalton, 1971 as cited in Bell & Waters, 2014, p.178). I avoided leading questions and the used emotive language wherever possible so as not to influence the respondents’ answer (Bell & Waters,2014). These were factors I deemed to be incredibly important when discussing such a personal and sensitive topic as neurodiversity. Throughout both interviews I followed a semi-structured framework and shaped the interview and regulating the conversation to “…prevent aimless rambling” (Opie, 2004, p.118), yet simultaneously still allowing my participant’s personal experiences to guide the interview.

The final method I used to collect data was a focus group discussion which I facilitated with four students belonging to the predominant neurotypical community. The discussion allowed participants to interact with one another, exchanging thoughts and ideas, providing an insight into the *perceived* experiences of neurodiverse individuals (Clough & Nutbrown, 2012). As the conversation evolved, I periodically checked with participants and asked questions such as ‘is this what everybody thinks’? so that I could obtain a complete set of results encompassing the views of all participants. The participants in my focus group were a little more hesitant at the beginning as they did not really understand what was meant by the term neurodiversity. So that I could begin interpreting and analysing the data extracted from my results.

3.3.3 Analysis

I used a thematic analysis framework to analyse data gathered from my interviews and focus group discussion. (appendix 5). This helped identify the challenges experienced by my participants, although I already had a rough idea of what these would be due to belonging to the neurodiverse community myself. Thematic analysis meant searching for “…themes that emerge[d] as being important to the description of the phenomenon” (Fereday & Muir-Cochrane, 2006, p.82). Recurring topics emerged from my data and these patterns became the categories for analysis (Fereday & Muir-Cochrane, 2006). I undertook a constant comparative method, this involved collating my data several times comparing the lexis, phrases and searching for any other common denominators (Thomas, 2017). I colour coded my data by identify patterns and recurring themes (Thomas, 2017).

3.4 Ethical Practice

"Ethics has to do with the application of moral principles…to be respectful and to be fair" (Sieber, 1993 as cited in Opie, 2004, p.25)

Before commencing my journey as a researcher, I completed the online ethics process with The School of Education Ethics Committee (appendix 4). This process included developing a detailed participant information sheet and consent form which was given to participants, to obtain informed consent, prior to my data collection process. Participants were informed of their rights, assuring confidentiality. I also composed an online information sheet and ethical consent form for my participants (appendix 1 and 2) and an audio version (appendix 3) of each document to suit the needs of my neurodiverse participants and their particular neurological condition (Recovery Brands LLC, 2018).

Because I suffer with fatigue and other symptoms similar to my participants I allowed participants plenty of time to complete their questionnaire and answer questions during the interviews and the focus group discussion. I reassured my interviewees that I was happy to conduct their interview over multiple sittings and I that I would be able to conduct telephone interviews if they did not have the energy to meet with me in person. Therefore, it is evident that, although the methods chosen were based on an interpretivist philosophy, the central motive for employing this flexible and inclusive approach was to consider the ethical considerations required when interacting with each participant.

3.5 Conclusion

Reflecting on my positionality and literature review has shaped my philosophy of research and consequently my methodological choices. Many of the themes explored resonated strongly with my own phenomenological experience. Through phenomenologically exploring the experiences of neurodiverse individuals, one can begin to interpret and distinguish between the tangible and what is merely socially constructed. "…we create our social worlds depending on what we know of others" (Thomas, 2017, p.167); if, as contended by Oliver (1983), the majority of barriers experienced by those with neurological differences are shaped by societal 'norms', then the way to address these is by tackling the stigma and the stereotypes conveyed throughout society (Green, 2005). Furthermore, I felt that my Insider perspective (Thomas, 2017) enabled me to make sensible and considerate ethical choices, as I understood the challenges and needs of my participants.

Chapter Four- Findings and discussion

4.1 Introduction

This chapter seeks to identify and discuss the significant findings of this research. I used thematic analysis to explore, interpret and question participants' experiences and thoughts (Fereday & Muir-Cochrane, 2006). The four key themes explored include avoiding the truth due to misconceptions, stigma and stereotypes, barriers preventing individuals from achieving their full potential and participating in the education system and, finally, the challenges faced when suffering from an illness that is not easily visible. The overarching findings highlighted the insecurities and vulnerability, endured by my neurodiverse participants, induced by stigma and stereotypes. These themes enabled me to interpret the implications of my research, suggesting how the social and educational experiences of individuals with neurological differences might be improved.

4.2 'An Outsider'

An undeniable theme identified in my interviews with neurodiverse individuals was the 'little white lies' and excuses they made with the intention of making their illness and its symptoms more acceptable and palatable to others, but also an attempt to fit into what society has deemed as the 'norm' (Foucault, 1975). During her interview, ex-lecturer Andrea discussed how she had once lied to other members of staff about her neurological condition when she transitioned from walking without an aid to relying on crutches. She recollected:

I was in a meeting once and other members of staff who I only vaguely knew asked me what was wrong. I told them that I had a really bad snowboarding accident and their reaction was so different to when I tell people I have MS. As if somehow that was a more acceptable reason.

This wilful misrepresentation of reality is explained by Söder (1989), who contends that "Our relation to the world is conditioned by our interaction with others." (p.119). When asked why she was inclined to cover up her MS, Andrea explained that it was not just for her benefit but rather to avoid making others feel uncomfortable. Söder (1989) argues that society is unsure how to perceive and label those with disabilities, hence why Andrea felt the urge to cover up her neurological difference. A snowboarding accident holds connotations of something cool, adventurous and fun, unlike a disability which evokes pity, sympathy and suffering. More significantly, disability holds connotations of being an ‘outsider’ (Becker, 1963), thus using something more understandable and relatable such as snowboarding normalised Andrea’s dependency on her crutches. Another reason Andrea may have masked her chronic illness as a more relatable injury, alludes to the desire to fit in with the ‘norm’ (Foucault, 1975). Bao (2013) contends that what one desires is based on the social, historical and political discourses that govern society. Andrea may not just have wanted to fit in but may also have had a subconscious desire to belong to the neurotypical community that dominates society. This desire stems from, as discussed by McRobbie (2011), joyful affirmation, encapsulating the pleasure we experience when we feel that we belong.

Stigma and stereotypes were a recurring theme throughout my interview. Andrea acknowledged her fear that people may assume that, because she has a neurological difference, her cognitive functioning was also impaired. Andrea admitted to being quite affected by the labels that had been given to her and hoped that these would not influence the way other staff members perceived her suitability for the teaching profession. During Laura’s interview, she recalled how she had been diagnosed just a few months before attending university. Admitting that she saw university as an *‘escape’,* allowing her to ignore her diagnosis and the potential implications as she was wholly focused on settling in at university. Laura recalled how this had worked for the first year but, as her condition progressed during her second and final year at university, she became increasingly aware of the stigma and stereotypes that were attributed to her neurological disability. Laura discussed how many members of staff and students did not understand the extent of her difficulties and would often patronise her, making her hyper aware of her ‘otherness’ (Becker, 1963). She recalled how she often felt that peers were less interested in talking to her, suggesting that ‘*…others probably saw me as some sort of alien*’. This implied that others were wary of her differences, perceiving her as unrelatable, labelling her as ‘abnormal’ (Green, 2005) and thus marginalising her (Becker, 1963). Laura disclosed how she had also experienced inequality as her neurological disability and her gender overlapped and interconnected, creating nuances of disadvantage and discrimination. She discussed how in school she often felt excluded in certain activities, such as in P.E (physical education), not just because of her disability but also due to her gender. Laura also recalled how she was often teased by her male peers for her lack of hand-eye coordination and her distinct run; many comments alluded to her gender, unaware of the neurological difficulties she faced. Laura’s experiences of the education system fit perfectly with Crenshaw’s (1989) intersectionality theory, providing a relevant example corroborating Crenshaw’s theory.

When asked “If you didn't go onto, HE [Higher Education] please state why” a handful of participants in my questionnaire admitted a fear of isolation, rejection and a fear of not belonging. Many of my neurodiverse participants indicated that the social factors involved in attending HE evoked anxiety and tainted their decision. The fear of being perceived as an “outsider” (Becker, 1963) was so overwhelming that it prevented them from going onto HE. It was apparent that the apprehension of not belonging or fitting in surpassed any excitement typically associated with leaving school and going onto HE. A couple of participants described how they dropped out after their first year due to this sense of not belonging to the ‘norm’ (Foucault, 1975). One participant detailed how *‘There is a lot of stigma regarding these* [invisible] *disabilities and a some of the help makes you feel special but not in a good way’*; highlighting how many amendments put into place to include those with disabilities actually reinforce the notion of ‘us’ and ‘them’ (Becker, 1963).

4.3 Building Bridges not Barriers

Another recurring theme highlighted the barriers within the education system that prevented the social integration of my participants. However, it was interesting to find that most of my participants detailed the socially constructed obstacles such as disability awareness rather than the more tangible barriers restricting accessibility. Thus, stressing the significance of Oliver’s (1983) Social Model of Disability. He contends “…social environments impose limitations on certain groups or categories of people.’. (Oliver, 1983, cited in Hughes, 2010, p.509), suggesting it is imperative that society switches their focus from the concrete and tangible barriers in our environment, to the often more abstract and socially constructed obstacles that hinder those with additional needs. When asked how confident she felt when asking for help Andrea reported how, during the beginning of her illness she often felt as if she was asking for too much help. Because staff did not understand her neurological condition and its implications, they may have perceived Andrea as ‘problematic’ (Davies, 1995), overlooking her legitimate needs. Andrea recalled how *'…after 4 or 5 times asking for additional help I began feeling like a burden’*. This highlighted not just the physical but the emotional strain that these socially constructed barriers can have on those with impairments. Surprisingly, Andrea also drew attention to the inevitable stereotype that tainted the legitimacy of her need for help, admitting that she *‘…didn’t want to fall into the stereotype of a girl’* just because she required additional help. Thus, supporting Lloyd’s (1992) double discrimination theory, highlighting the apprehension and fear of being subject to discrimination not only due to a neurological difference but also gender.

Replying to the same questions, Laura supported what Andrea had said. Affirming that she too felt like a *‘burden’* resulting in her struggling on her own rather than asking for help. Therefore, validating Oliver’s (1983) Social Model of Disability, suggesting that instead of the focus being on her limitations, the attention should be on lecturers accommodating her, shifting the responsibility and relieving her of the label *'burden'*. Laura also recalled a time when she attended a lecture but had to sit at the back due to the *'amphitheatre styled seating'.* She detailed how the lack of handrails featured in the lecture theatre made it impossible for her to sit anywhere else. Laura went on to explain that *'…there was a wheelchair entrance at the front, I feel like people just associate disability with wheelchairs and forget other types of accessibility'*. Laura's account highlighted the crucial need to familiarize members of staff with different neurological conditions and their implications. Further to this, it could be argued that to truly tackle these barriers we must focus on working as a community; for example, in Laura's case architects working with the university to restrict any potential barriers.

Findings from the questionnaire data showed that, when asked "Did you find that there were barriers which prevented you from participating and achieving your full potential whilst in the education system?" half of the respondents to my questionnaire admitted to having experienced limitations whilst in the education system, 16.7% said that they sometimes find this to be true. When asked to develop these answers one participant recalled how *'I found that using a laptop seemed like hassle for my teachers'*, suggesting that if teachers and those in authority within the education system do not understand and allow for different types of learning then this impedes the learning of those with neurological conditions; potentially reinforcing Andrea's claim of feeling like a *'burden'*. Supporting the need to allow for different learning styles were my neurotypical participants in my focus group. Whilst discussing the barriers within the education system Olivia questioned why the same form of examination is used to assess those with neurological differences. Further explaining how, to succeed in her course *'…must use shorthand, which means that anyone who has trouble writing can't take part'*. Sheldon (1997) argued that the process of learning changes depending on factors such as ability and information processing. He proposed that staff members should adjust their teachings and forms of assessment, allowing for neurological differences in the classroom. Thus, suggesting that to make the education system as accessible as possible we must consider different forms of assessment tailored to different neurological needs.

An understanding of neurological symptoms and their implications is vital to ensure that there are no barriers and limitations preventing participation within the education system. Findings from one interview, with Laura, detailed how her course *'…involved a work placement with 0-3 year olds so it was very fatiguing'* limiting what she could do, restricting her participation and thus hindering her potential to achieve top grades. This highlights the need to equip teachers and staff with knowledge about these neurological conditions so that all students are given equal opportunities to succeed. Further to this, respondents of the questionnaire referred to the *'pace of lectures'* and the *'distance between lectures'* preventing them from participating, concluding that these barriers exist due to the

'…lack of understanding and knowledge'. Thus, once more highlighting the need to equip teachers and other members of staff with knowledge about neurodiversity to ensure that these students are in a supportive learning environment. In response to the question in the questionnaire "What would you change about the education system in terms of disability to ensure that it was more accessible?" all 15 respondents alluded to physical barriers, calling for such things as automatic doors and handrails. However, more than half of the respondents emphasized the need for understanding and awareness. One respondent concluded by explaining the lack of awareness about symptoms and the implications on learning, *'I don't think they realize how much fatigue can affect someone and the work they need to do'*, suggesting that if staff were more aware of the challenges faced by neurodiverse students then they would be better equipped to help them manage their learning. An interesting point raised by a handful of participants in my questionnaire detailed the barriers which affected not just their academic experience but also their social experience of the education system. One respondent recalled *'…not being able to access the flats which I think prevented me from socializing equally…'*, highlighting the implications that physical barriers have on the social experiences of the education system. Pittman (1986) explored school dropout rates, concluding that "…social alienation/isolation is a plausible explanation for dropping out" (p.12), criticizing the "…lack of social integration…" (p.12) as a primary reason for dropouts.

4.4 A Neurological hierarchy

Discussing the notion of a hierarchical order within the neurodiversity paradigm, Andrea disclosed how a lack of awareness around less familiar neurological conditions was having a detrimental impact on the way staff and students perceived her. *'They thought I was lazy, unmotivated and disorganized. They knew I was sick but not sick enough to warrant my behaviour'* she detailed society is unclear on how to label, perceive and interact with neurodiverse individuals because they are neither ill nor healthy. Thus, highlighting how and why the neurodiverse community are misrepresented and misunderstood due to this uncertainty (Green, 2005). During the interview, Andrea continued to discuss the lack of awareness about lesser known neurological illness' and their symptoms, adding that she believed there is a *'…massive hierarchy between more common and more known things like Autism and lesser known illnesses such as MS because more common ones are understood'*. While further addressing the concept of a neurological hierarchy with Laura during her interview, she further developed Andrea's thoughts by reflecting on her own experiences*. '…I felt ashamed and abnormal…we should all be in this together, but I feel like there's some intrinsic hierarchy and me and my disease are at the bottom…'*, underlining her distress and dismay at this lack of awareness Laura continued to detail how she was often not supported according to her specific needs because everyone just assumed the symptoms of her Ataxia were the same as any other neurological condition. She detailed how she often felt that her neurological condition was belittled because it was not as recognised as more common conditions such as Autism. She concluded *'…stop putting us in the same box and treating us as if we have the same condition…'* This can be supported by Runswick- Cole (2014), who argues that "The term 'neurodiverse' has been claimed by people labelled with autism…" (p.1120). She argues that the neurodiversity community has been limited to those with Autism due to a lack of awareness surrounding other neurological disorders, contending that the neurodiversity community is often synonymously thought to include 'autistics and their cousins' (Ortega 2009 as cited in Runswick-Cole, 2014, p.1120)

Laura highlighted how the label neurodiverse is just an umbrella term for many different neurological conditions; implying that the neurodiversity paradigm itself is introspectively antithetical. Instead of celebrating "…the infinite variation in neurocognitive functioning…" (Walker, 2014, n.p.), the lack of awareness around lesser known neurological differences has shaped and built this hierarchy between diseases. Thus, this supports Hiari (2018) who concurs that "The neurodiversity movement epitomizes groupthink" (as cited in Russell, 2019, p.300). Contending that, instead of bridging the gap between both the neurodiverse and neurotypical communities the paradigm is essentially categorizing society into 'us' and 'them', not allowing for any differences within these two groups (den Houting, 2018).Andrea discussed a potential reason why the spotlight has been on diseases such as Autism, suggesting that *'…diseases such as Autism do not diverge from what's perceived as normal, as much as rarer disease such as MS'*. Andrea implied that there is a correlation between conditions that are more astray from the 'norm' and awareness, contending that the less one diverges from what society deems as the 'norm' then the more acceptance they will get. Andrea raised the question of whether the more known and talked about conditions were acknowledged because they were more relatable to the 'norm'. This can be supported by Runswick-Cole who discusses how the neurodiversity movement troubles the dominance of the ideal healthy, able bodied neoliberal. "Neoliberalism tolerates those who can mimic the neoliberal ideal type" (Runswick-Cole, 2014, p.1126) This lack of awareness and acceptance surrounding rarer neurological conditions was highlighted by Alex in my focus group. When asking what I meant by neurodiverse she immediately used Autism as an example, accentuating the need to raise awareness about other neurological conditions.

4.5 My invisible illness

The final theme I had identified throughout my research concerned the concept of an invisible illness. A theme discussed by most of my participants detailing and disclosing the emotional and physical challenges of having an illness that is not easily visible and recognizable.

Detailing how having an invisible illness had affected her professional life, ex-lecturer Andrea discussed how having an illness that is not easily recognizable left her feeling very *'… isolated and alone because no one could easily identify what was wrong…',* referring back to how the lack of understanding and awareness has contributed to this feeling of isolation and separation. This awful feeling is shared by many other disabled individuals including Disabled Student's Officer Heather Armstrong (2015) who, like Andrea is a disabled member of staff. Discussing invisible illness', she discloses "It breaks my heart that these people feel like they have to explain themselves to complete strangers who judged them just by the way they looked" (Armstrong, 2015). Further detailing how she has been made to feel ashamed for appearing "… *'not disabled enough' or 'not disabled at all'…",* supporting Andrea's earlier revelation confessing '*They knew I was sick but not sick enough…'.* Both neurodiverse members of staff highlight the challenges faced when you have an illness that is often misunderstood and not acknowledged. Andrea also discussed the physical *challenges*, recollecting how she would often receive *'…filthy looks'* when using the disabled parking as she was still able to walk. Similarly, Armstrong (2015) revealed how she would receive "…side-eyes for using an accessible toilet…" because she did not appear disabled (n.p.).

Laura expressed her dismay at the lack of communication within society, contending that the biggest challenge when it comes to having an unrecognizable illness is having to explain herself repeatedly *'…I'm tired of explaining myself, I just think…, the healthcare system should communicate these things to my uni… or the uni should have my medical records…'.* Highlighting the necessity for an interconnected society is Ainsworth, who, in 2018 carried out a study hoping to raise awareness of 'invisible illness' in the education system. From her research Ainsworth (2018) found that common challenges faced by young individuals with invisible illnesses highlighted "…problems with communication and trust, as well as difficulty in understanding the erratic nature of many chronic illnesses" (p1.0) concluding that the collaboration between healthcare professionals and the education system is essential to tackle the challenges that come with having an invisible illness. Laura also detailed the additional prejudice she felt because she did not fit the stereotype of a disabled person. Although Laura is now using a wheelchair for support she admitted that in secondary school she used to feel envious of those in wheelchairs *'…It's so difficult because of course I was lucky that I could still walk but I was so tired of feeling judged for not looking disabled…'*

Laura further developed her answer, alluding to the double discrimination theory (Lloyd, 1992) suggesting that she was not only criticized because of her disability but was ironically judged for not conforming to the stereotypical image of disability.

When responding to the question 'What would you change about the education system in terms of disability to ensure that it was more accessible', many of the participants in my questionnaire highlighted the challenges they had to face that were not as easily recognizable. Many participants underlined the prejudice they received due to their invisible symptoms such as fatigue, arguing that there should be more awareness raised to tackle the misconceptions surrounding these *'…masked manifestations…'*. One participant discussed how the education system should make *'…more of an effort to raise awareness of those of us who don't have the disability to a severe level and normalize them'*, contending that more needs to be done to help those with invisible illnesses that do not present themselves in a stereotypical fashion. Interpreting and discussing the concept of an invisible illness have driven me to reflect on my own phenomenological experiences, confirming that I am not the only neurodiverse individual who is challenged by the concept of an invisible illness. I often face scrutiny and feel a sense of self-condemnation because a large part of my neurological illness is not visible. The comments from my participants surrounding invisible illnesses and their symptoms has allowed me to explore and develop my own opinion about having an invisible illness, reassuring me that I am the only one facing a "…silent challenge…" (Holland, 2017)

4.6 Conclusion

This chapter discussed my findings from my interviews, focus group discussion and questionnaire. Using thematic analysis, I explored the common themes which highlighted the implications of having a neurological disorder within the education system. Theories and concepts, such as an 'Outsider' (Becker, 1963) and the double discrimination theory (Lloyd, 1992), explored in my literature review, were discussed and applied to real life scenarios, bringing together my empirical and theoretical research. Many of the themes discussed resonated with me and could be applied to my own experiences. Overall, this chapter highlighted the powerful impact that stigma and stereotypes have on not only the challenges that neurodiverse individuals face, but also on the perception that the neurotypical community has. In addition to this I found that the majority of my neurotypical participants discussed the tangible and physical barriers that may impede a neurodiverse individuals experiences of the education system; however they interestingly failed to acknowledge the more abstract and emotional obstacles described by my neurodiverse participants. This suggests that more needs to be done to highlight the often-invisible barriers that hinder the experiences of neurodiverse individuals within the education system, thus bridging the gap between “Us” and “Them”.

Chapter Five – Conclusion

5.1 Introduction

This dissertation intended to explore the experiences of neurodiverse individuals within the education system. I adopted an interpretivist approach, employing a qualitative methodology consisting of interviews, a focus group and a quantitative questionnaire. Thematic analysis revealed a consensus that society is caught up in a narrative consisting of stereotypes, shackled by stigma and the norm. My participants described neurodiversity as an invisible illness, with many of my neurotypical participants not acknowledging it as the challenges paired with neurodiversity are not always immediately obvious. In this final section I revisit the aims and objectives of this study, reviewing and further developing the research question. Moreover, I will reflect on my research experience, considering how it has shaped my understanding and views. Thereafter, I will outline the implications of my research and suggestions for future development.

5.2 Research aim

The aim of this study was to explore the lived experiences of individuals with rare Neurodiverse conditions within the UK education system. This study achieved its aim by highlighting the challenges and obstacles that come with having an illness that is not always visible. The findings highlighted the barriers and often uncomfortable realities faced by neurodiverse individuals, ranging from the perplexing stigma, stereotypes and social taboo of having an illness that is often misunderstood, to the physical and tangible restrictions that hinder the educational experiences of those with a neurological disorder.

5.3 Research Questions

1. Does today’s education system accommodate and provide for a neurodiverse community?

The data collated from all sources highlights a range of opinions suggesting that, although on paper the education system is prepared to receive and welcome neurodiverse staff and students, much more needs to be done to encourage and integrate this community. Physical adaptations such as ramps and automatic doors were not as relevant as the intangible and often invisible obstacles that interfered with and prevented participation.

2. Is there a neurological hierarchy within the neurodiverse community?

Belonging to the neurodiverse community myself, the lack of knowledge and understanding about rarer and often much more severe neurological disorders prompted me to question whether some form of hierarchy was present within the neurodiverse community. Both participants and respondents were interested by this question, as individuals with rarer neurological disorders were keen and prepared to respond to this question wholeheartedly. Both interviewees acknowledged that there was a neurological hierarchy between more common neurological differences such as Autism and lesser known conditions such as Multiple Sclerosis. This hierarchy left participants feeling isolated and marginalized due to misunderstanding and misconceptions, supporting Runswick-Cole's (2014) argument that the Autistic community has adopted the label neurodiverse as their own.

5.4 Implications for future educational policy making

Throughout my research, both participants and respondents indicated that more needs to be done to normalize and humanize the differences between the neurodiverse community and the neurotypical majority, focusing on rarer and less accepted ailments. Introducing disability history into the curriculum from an early age will help tackle stigma surrounding neurodiversity. Additionally, through better equipping staff with the skills and training required to identify and support complex neurological conditions, we may be able to tackle the barriers that prevent neurodiverse individuals from achieving their full potential.

5.5 Reflection and Tribute

As the author of this dissertation, I embraced this study with tenacity and vigour, always prioritizing my participants, making suitable adjustments to accommodate their needs. Having been diagnosed not long ago, I often found the empirical and theoretical research a challenge as it deeply resonated with me and brought up many emotions that I had not yet dealt with. Throughout my research I attempted to understand the root of all the stigma, stereotypes that result in the marginalization of the neurodiverse community. The lack of previous social research, and the enthusiasm expressed by my participants confirmed that neurodiversity was a topic worthy of further exploration and attention.

Sadly, in December of 2019 a potential participant, and more importantly a friend, passed away at the tender age of 19 due to complications linked with her neurological condition. I had met this young woman for the first time in 2018, a year after being diagnosed myself. She, along with many others let me know that I was not alone in facing this battle, offering kind words and her support. She showed great dignity and mental strength, empowering me to embrace my differences. Her determination and perseverance have made a significant impact on my own attitude and prompted me to discuss neurodiversity throughout my academic journey. I deemed it important to highlight the tragic and often fatal consequences many rare, yet severe neurological conditions can have.

5.6 Conclusion

In this chapter, I have revisited the key points of the dissertation highlighted in my introduction and answered my research questions. The research showed that acceptance, tolerance and understanding marginally surpass physical barriers that hinder participants' educational experiences. I reflected on my experience during this process, relaying the significant and emotionally straining impact of the loss of my friend, which undoubtedly has triggered many unwanted feelings about my own neurological condition and the progression of my Ataxia.

Reference List

Ainsworth, S. (2018). SP0038 Raising awareness of invisible illnesses in schools and education. Annals of the Rheumatic Diseases, 77(10).

Andrews, K. (2017, June 15). The votes of ethnic minorities made a big difference to the general election – Labour should take note. Retrieved from Independent: http://www.independent.co.uk/voices/ethnic-minority-vote-general-election-labour-jeremy-corbyn-racial-faultlines-anti-immigration-a7791101.html

Areheart, B. A. (2008). When Disability Isn't "Just Right": The Entrenchment of the Medical Model of Disability and the Goldilocks Dilemma. Indiana Law Journal, 52.

Armstrong, H. (2015, December 3). "But you don't look disabled..." -Invisible barriers to education. Retrieved from nus connect: https://www.nusconnect.org.uk/articles/but-you-don-t-look-disabled-invisible-barriers-to-education

Bao, H. (2013) A Queer: Comrade in Sydney. Interventions, 15 (1) , 127-140.

Bartlett, S., & Burton, D. (2016). Social factors, gender, ethnicity and achievement. In S.

Bartlett, & D. Burton, Introduction to education studies 4th ed. (pp. 288-291). SAGE.
Becker, H. S. (1963). Outsiders: Studies in the sociology of deviance. New York: The Free Press.

Bedei, C. (2019). How I Deal with Loneliness When My Disability Stops Me Leaving The House. Retrieved from Refinery29: https://www.refinery29.com/en-gb/loneliness-chronic-illness

Bell, J. (2010). Doing Your Research Project: A guide for first-time researchers in education, health and social science. Berkshire: Open University Press.

Bell, J., & Waters, S. (2014). Doing Your Research Project: A Guide for First Time Researchers. Berkshire: Open University Press.

Brisenden, S. (1986). Independent Living and the Medical Model of Disability. Disability, Handicap & Society, 1(2), 173-178.

Burke, G., & Hammans, S. (2012). Symptoms and signs. In Medicine (Vol. 40, pp. 435-439). London: Elsevier Ltd.

Carey, T. (2015, July 19). Inside the mind of a teenager: A parent's guide. Retrieved from The Telegraph: http://www.telegraph.co.uk/news/health/children/11739219/Revealed-Inside-the-mind-of-a-teenager.html

Cherry, K. (2019, June 26). The Preoperational Stage of Cognitive Development. Retrieved from very well mind: https://www.verywellmind.com/preoperational-stage-of-cognitive-development-2795461

Clough, P., & Nutbrown, C. (2012). A Student's Guide to Methodology. London: SAGE

Publications.

Coleman, J. M. (2014). How gender and disability stereotypes influence judgements of disabled women and men. Multiple forms of prejudice, 177-189.

Coleman, J. M., Brunell, A. B., & Haugen, I. M. (2014). How gender and disability stereotypes influence judgements of disabled women and men. Multiple forms of prejudice, 177-189.

Collins, Hillary (2010). Creative Research: The Theory and Practice of Research for the Creative Industries (Required Reading Range). Design management (1). Switzerland

Comberousse, S. (2019, September 25). A Beginner's Guide to Neurodiversity. Retrieved from Learning disability today: https://www.learningdisabilitytoday.co.uk/a-beginners-guide-to-neurodiversity

Coyle, J., & Williams, B. (2000). An exploration of the epistemological intricacies of using qualitative data to develop a quantitative measure of user views of health care. Journal of Advanced Nursing, 31(5), 1235-1243.

Crenshaw, K. (1989). Demarginalizing the Intersection of Race and Sex: A Black Feminist Critique of Antidiscrimination Doctrine, Feminist Theory and Antiracist Politics. University of Chicago Legal Forum, 1(8), 139-167.

Curran, T., & Runswick- Cole, K. (2014). Disabled children's childhood studies: a distinct approach? Disability & Society, 1617-1630.

Den Houting, J. (2018). Neurodiversity: an insider's perspective. Autism, 23(2), 271-273.

Everaert, E. (2014). Bandura's bobo doll experiment and violence in the media. Social Cosmos, 74-80.

Farrelly, P. (Director). (1994). Dumb and dumber [Motion Picture].

Fereday, J., & Muir-Cochrane, E. (2006). Demonstrating Rigor Using Thematic Analysis: A Hybrid Approach of Inductive and Deductive Coding and Theme Development. International Journal of Qualitative Methods, 5(1), 80-91.

Foley, B. (2019, September 26). Intersectionality: A Marxist Critique. New Labor Forum, 28(3), 10-13. Retrieved from MR online: https://mronline.org/2018/10/22/intersectionality-a-marxist-critique/

Foucault, M. (1975). Discipline and Punish: The Birth of the prison. Penguin Books, Ltd.

foundation, M. h. (2015). Children and young people. Retrieved from Mental health foundation: https://www.mentalhealth.org.uk/a-to-z/c/children-and-young-people

Gillborn, D., & Mirza, H. S. (2000). Mapping race, class and gender: A synthesis of research evidence. Educational inequality, 6-27.

Goodley, D., Runswick-Cole, K., & Liddiard, K. (2016). The DisHuman child. Discourse: studies in the cultural politics of education, 770-784.

Green, S. (2005). Living Stigma: The Impact of Labeling, Stereotyping, Separation, Status Loss, and Discrimination in the Lives of Individuals with Disabilities and Their Families. Sociological Inquiry, 197–215.

Hawkins, K., & Kumutat, L. (2015, September 10). Ouch Blog: Is it wrong to imply disabled people are not "normal"? Retrieved from BBC News: http://www.bbc.co.uk/news/blogs-ouch-34197074

Hayes, M. T., & Black, R. S. (2003). Troubling Signs: Disability, Hollywood Movies. Disability Studies Quarterly, 23, 1-18.

Holland, J. (2017, June 6). The hidden challenges of invisible disabilities. Retrieved from BBC Work life: https://www.bbc.com/worklife/article/20170605-the-hidden-challenges-of-invisible-disabilities

Hornby, G. (2011). Inclusive education for children with special educational needs. International journal of disability, development and education, 321-329.

Hughes, R. (2010). The social model of disability. British Journal of Healthcare Assistant, 4(10), 508-511.

Ismail, S. (2012, September 26). Why disability history should be on the school curriculum. Retrieved from The Guardian Online: https://www.theguardian.com/social-care-network/2012/sep/26/disability-history-school-curriculum

Kamenetsky, S. B., Dimakos, C., Aslemand, A., Saleh, A., & Ali-Mohammed, S. (2016). Eliciting Help Without Pity: The Effect of Changing Media Images. Journal of Social Work in Disability & Rehabilitation, 1-21.

Keith, L., & Dalley, G. (1992). Pride against prejudice: transforming attitudes to disability. Disability Handicap an society, 375-381.

Koenig, M., & Moreira, M.-C. (2004, November 15). Ataxia with Oculomotor Apraxia Type 2. Gene Reviews.

Knibbe, K., & Versteeg, P. (2008). Assessing Phenomenology in Anthropology: Lessons from the Study of Religion and Experience. Critique of Anthropology, 28(1), 47–62.

Krcek, T. E. (2013). Deconstructing Disability and Neurodiversity: Controversial Issues for Autism and Implication for Social Work. Journal of Progressive Human Services, 24(1), 4-22.

LaChapelle, D. L., Lavoie, S., Higgins, N. C., & Hadjistavropoulos, T. (2014). Attractiveness, diagnostic ambiguity, and disability cues impact perceptions of women with pain. Rehabilitation Psychology, 59(2), 162–170.

Maia, R. C., & Vimiero, A. C. (2015). Political Studies. Recognition and Moral Progress: A Case Study, 63, 161-180.

Malinsky, D., Bright, L. K., & Thompson, M. (2016). Causally Interpreting Intersectionality Theory. Philosophy of Science, 60-81.

Mayada et al. Global prevalence of autism and other pervasive developmental disorders. Autism Res. 2012 Jun; 5(3): 160–179.

McLeod, S. (2008). Social Roles. Retrieved from Simply Psychology: https://www.simplypsychology.org/social-roles.html

McRobbie, A. (2011) Introduction, Cultural Studies, 25 (2), 139-146.

Merton, R. (1948). The Self-Fulfilling. The Antioch Review, 504-521.

Momene, R. (2015, December 18). negative attitudes and stereotypes to disability. Retrieved from atlascorps.org: http://www.atlascorps.org/blog/negative-stereotypes-and-attitudes-linked-to-disability/

Moore, R. (2004). Differentiation inequality and the educational process. In Education and Society: Issues and Explanations in the Sociology of Education (pp. 7-19). Cambridge: Polity.

Mukherji, P., & Brain, C. (2005). Understanding child psychology. Cheltenham: Nelson Thornes Ltd.

National Ataxia Foundation. (2010). What is Ataxia? Retrieved from National Ataxia Foundation: https://ataxia.org/what-is-ataxia/

Nugent, P. M. (2013, April 7). Mundane Realism. Retrieved from Psychology dictionary: https://psychologydictionary.org/mundane-realism/

Oliver, M. (2013). The social model of disability: thirty years on. Disability and society, 28(7), 1024-1026.

O'Mahoney, J., & Vincent, S. (2019). Critical Realism and Qualitative Research: An Introductory Overview. The SAGE Handbook of Qualitative Business and Management Research Methods: History and Traditions, 201-216.

Opie, C. (2004). Doing educational research. London: SAGE Publications.

Perkins, H. W. (2002). Social norms and the prevention of alcohol misuse in collegiate contexts. Journal of studies on alcohol and drugs, 164-172.

Peshkin, A. (1988). In Search of Subjectivity. One's Own. Educational Researcher, 17(7), 17-21. Retrieved April 29, 2020, from www.jstor.org/stable/1174381

Piaget, J. (1952). The origins of intelligence in children. New York: International Universities Press, Inc.

Pittman, R. (1986). Importance of Personal, Social Factors as Potential Means for Reducing High School Dropout Rate. The High School Journal, 70(1), 7-13.

Robert, P., & Gephart. (2019). Qualitative Research as Interpretive Social Science. The SAGE Handbook of Qualitative Business and Management Research Methods: History and Traditions, 33-53.

Rubin, A., & Babbie, E. (2007). Research methods for social work. Belmont, Calif.: Thomson Brooks/Cole.

Rudnick, A. (2017). The medical versus the social model of disability: A false dichotomy. Physical Medicine and Rehabilitation Research, 2(6).

Russell, G. (2019). Critiques of the Neurodiversity Movement. In S. K. Kapp, Autistic Community and the Neurodiversity Movement (pp. 287-303). Singapore: Palgrave Macmillan.

Sheldon, J. L. (1997). Learning is a Process: Toward an Improved Definition of Learning. The Journal of Psychology, 131(5), 477-480.

Shifrer, D. (2013). Stigma of a Label: Educational Expectations for High School Students Labeled with. Journal of Health and Social Behavior, 462-480.

Söder, M. (1989). Disability as a social construct: the labelling. European Journal of Special Needs Education,, 4(2), 117-129.

Sprayberry, T. L. (2014, April 17). Disability Doesn't Need Your Pity. Retrieved from huffingtonpost.com: https://www.huffingtonpost.com/trisha-lynn-sprayberry/disability-doesnt-need-your-pity_b_5154273.html

Stack, M., & Janz, H. L. (2017, August 28). Think disability is a tragedy? We pity you. Retrieved from theconversation.com: https://theconversation.com/think-disability-is-a-tragedy-we-pity-you-82047

Strand, L. R. (2017, June 1). Charting Relations between Intersectionality Theory and the Neurodiversity Paradigm. Disability Studies Quarterly, 37(2).

The University of Sheffield. (2016, January 25). Role of 'professional love' in early years settings studied by University of Sheffield researchers. Retrieved from The University Of Sheffield: https://www.sheffield.ac.uk/news/nr/professional-love-early-years-1.543307

Thomas, G. (2017). How To Do Your Research Project: A Guide For Students. London: SAGE Publications.

Thomas, G. (2017). How To Do Your Research Project: A Guide For Students. London: SAGE Publications.

Trueman, C. N. (2015, May 22). Functionalism and Education. Retrieved from History learning site: http://www.historylearningsite.co.uk/sociology/education-and-sociology/functionalism-and-education/

Walker, N. (2014, September 27). Neurodiversity: Some Basic Terms & Definitions. Retrieved from neurocosmopolitanism: https://neurocosmopolitanism.com/neurodiversity-some-basic-terms-definitions/

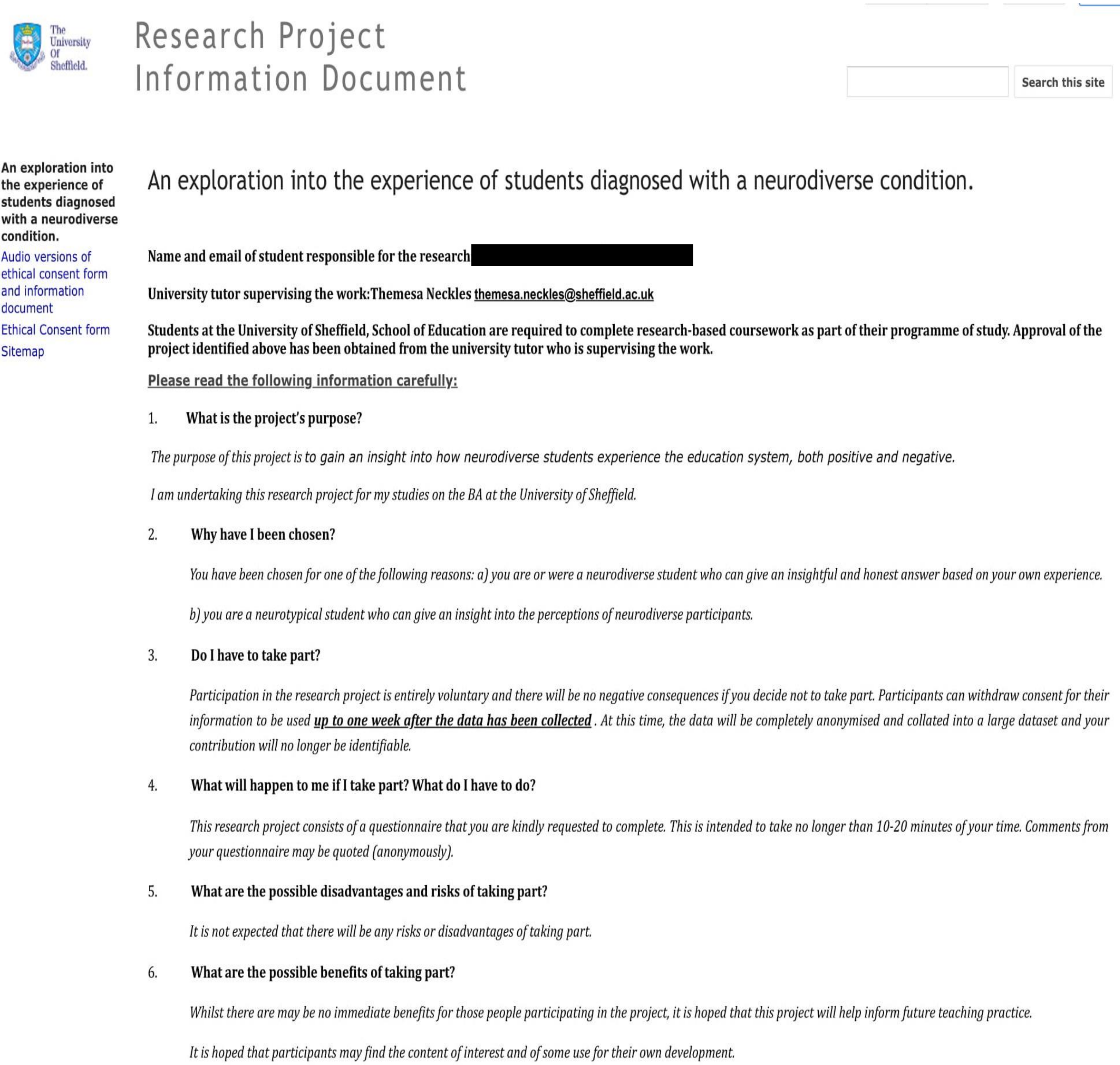
Wallace, J. (2006, August 27). First person: My condition means people always assume I'm drunk. Retrieved from The Guardian: https://www.theguardian.com/lifeandstyle/2009/aug/27/first-person-coping-with-ataxia

Whittle, A. (2018). Ethnomethodology. In C. C. Cassell, The SAGE Handbook of Qualitative

Business and Management Research Methods: History and Traditions (pp. 217-232). London: SAGE publications.

YW Boston. (2017, March 29). What is intersectionality, and what does it have to do with me? Retrieved from YW Boston: https://www.ywboston.org/2017/03/what-is-intersectionality-and-what-does-it-have-to-do-with-me/

Appendix 1: Written participant information sheet



Research Project Information Document

An exploration into the experience of students diagnosed with a neurodiverse condition.

Audio versions of ethical consent form and information document

Ethical Consent form

Sitemap

An exploration into the experience of students diagnosed with a neurodiverse condition.

Name and email of student responsible for the research[redacted]

University tutor supervising the work:Themesa Neckles themesa.neckles@sheffield.ac.uk

Students at the University of Sheffield, School of Education are required to complete research-based coursework as part of their programme of study. Approval of the project identified above has been obtained from the university tutor who is supervising the work.

Please read the following information carefully:

1. **What is the project's purpose?**

The purpose of this project is *to gain an insight into how neurodiverse students experience the education system, both positive and negative.*

I am undertaking this research project for my studies on the BA at the University of Sheffield.

2. **Why have I been chosen?**

You have been chosen for one of the following reasons: a) you are or were a neurodiverse student who can give an insightful and honest answer based on your own experience.

b) you are a neurotypical student who can give an insight into the perceptions of neurodiverse participants.

3. **Do I have to take part?**

Participation in the research project is entirely voluntary and there will be no negative consequences if you decide not to take part. Participants can withdraw consent for their information to be used ***up to one week after the data has been collected*** *. At this time, the data will be completely anonymised and collated into a large dataset and your contribution will no longer be identifiable.*

4. **What will happen to me if I take part? What do I have to do?**

This research project consists of a questionnaire that you are kindly requested to complete. This is intended to take no longer than 10-20 minutes of your time. Comments from your questionnaire may be quoted (anonymously).

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

It is not expected that there will be any risks or disadvantages of taking part.

6. **What are the possible benefits of taking part?**

Whilst there are may be no immediate benefits for those people participating in the project, it is hoped that this project will help inform future teaching practice.

It is hoped that participants may find the content of interest and of some use for their own development.

7. **What happens if the research study stops earlier than expected?**

If the research study stops earlier than expected you will be informed of when and why this has occurred. You will still have the option to withdraw consent for your data to be used.

8. **What if something goes wrong?**

If you wish to make a complaint, or withdraw your consent for participation in the study you can contact the researcher (Miss Clark, tclark4@sheffield.ac.uk) in the first instance.

If you have any further concerns arising, such as your treatment by the principal researcher or something serious occurring during or following your participation in the project, please see the contact details at the end of this document.

7. **Will my taking part in this project be kept confidential?**

All the information that we collect about you during the course of the research will be kept strictly confidential except in cases where a disclosure is made about criminal activity or risks to public safety, in which case the researcher is legally obliged to report such information to the relevant authorities. Participants will not be able to be identified in any reports or publications.

8. **What is the legal basis for processing my personal data?**

This data will be stored and processed in the United Kingdom. *Therefore, according to data protection legislation, we are required to inform you that the legal basis we are applying in order to process your personal data is that 'processing is necessary for the performance of a task carried out in the public interest' (Article 6(1)(e)). Further information can be found in the University's Privacy Notice https://www.sheffield.ac.uk/govern/data-protection/privacy/general.*

No data will be transferred outside of the EU.

8. **What will happen to the results of the research project?**

These results will form part of my research project and some of my findings may be published in academic journals.

9. **Who has ethically reviewed the project?**

This project has been ethically approved by a panel of reviewers at the University of Sheffield School of Education. The University's Research Ethics Committee monitors the application and delivery of the University's Ethics Review Procedure across the University.

11. **Will I be audio or video-recorded, and how will the recorded media be used?**

Any recordings of your activities made during this research will be used only for analysis and for illustration in my project. All contributions will be anonymous. No other use will be made of them without your written permission, and no one outside the project will be allowed access to the original recordings.

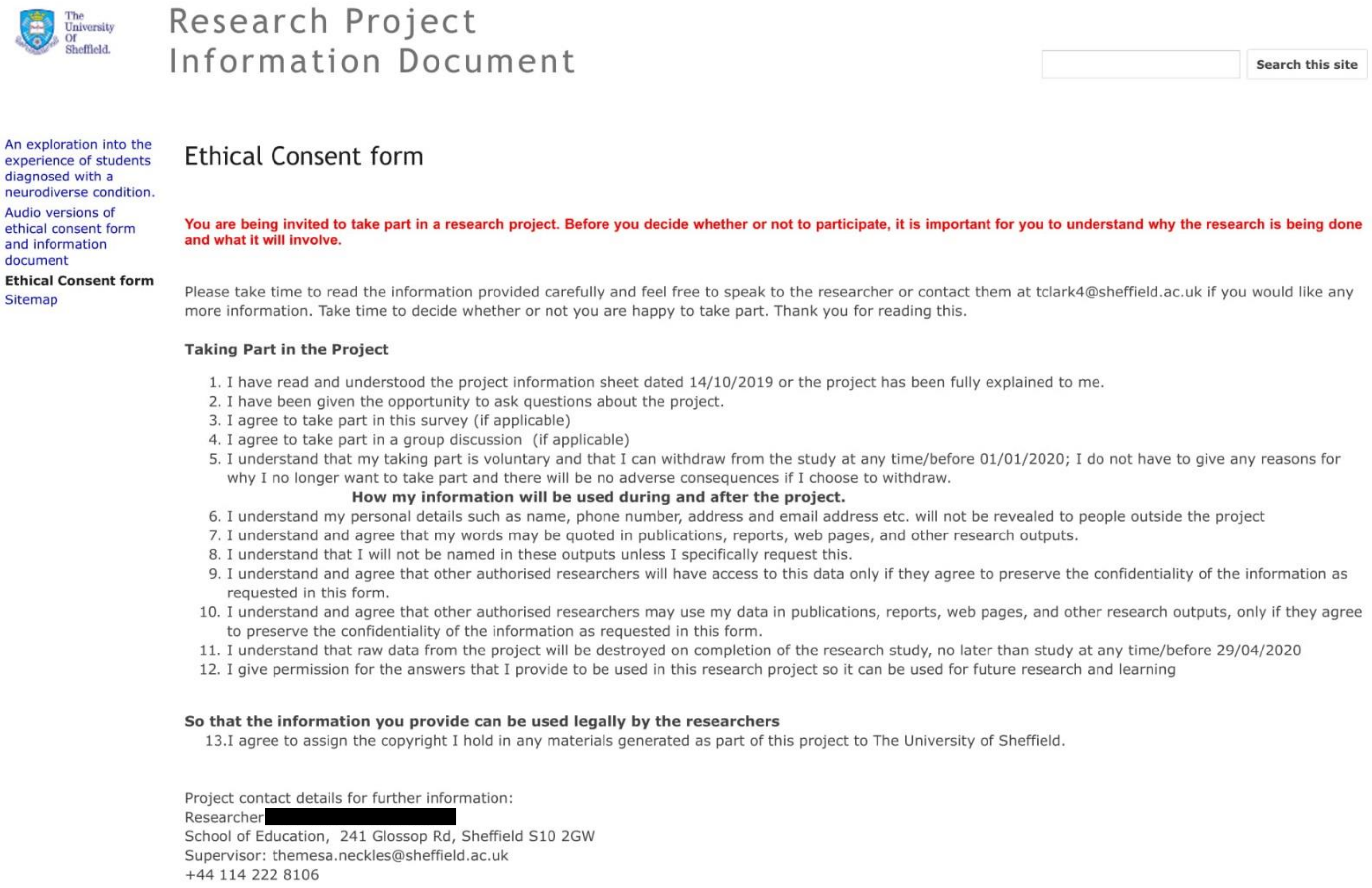
12. **Who is the Data Controller?**

The University of Sheffield *will act as the data controller for this study. This means that The University is responsible for looking after your information and using it properly.*

If there is concern about any aspect of this research project it should be addressed in the first instance to the BA course director: Mark Payne School of Education: mark.payne@sheffield.ac.uk

In addition to these avenues the University also has a complaints procedure, details of which may be found at: www.shef.ac.uk/ssid/procedures/grid.html#complaints

Appendix 2: Written ethical consent form



Ethical Consent form

You are being invited to take part in a research project. Before you decide whether or not to participate, it is important for you to understand why the research is being done and what it will involve.

Please take time to read the information provided carefully and feel free to speak to the researcher or contact them at tclark4@sheffield.ac.uk if you would like any more information. Take time to decide whether or not you are happy to take part. Thank you for reading this.

Taking Part in the Project

1. I have read and understood the project information sheet dated 14/10/2019 or the project has been fully explained to me.
2. I have been given the opportunity to ask questions about the project.
3. I agree to take part in this survey (if applicable)
4. I agree to take part in a group discussion (if applicable)
5. I understand that my taking part is voluntary and that I can withdraw from the study at any time/before 01/01/2020; I do not have to give any reasons for why I no longer want to take part and there will be no adverse consequences if I choose to withdraw.

How my information will be used during and after the project.

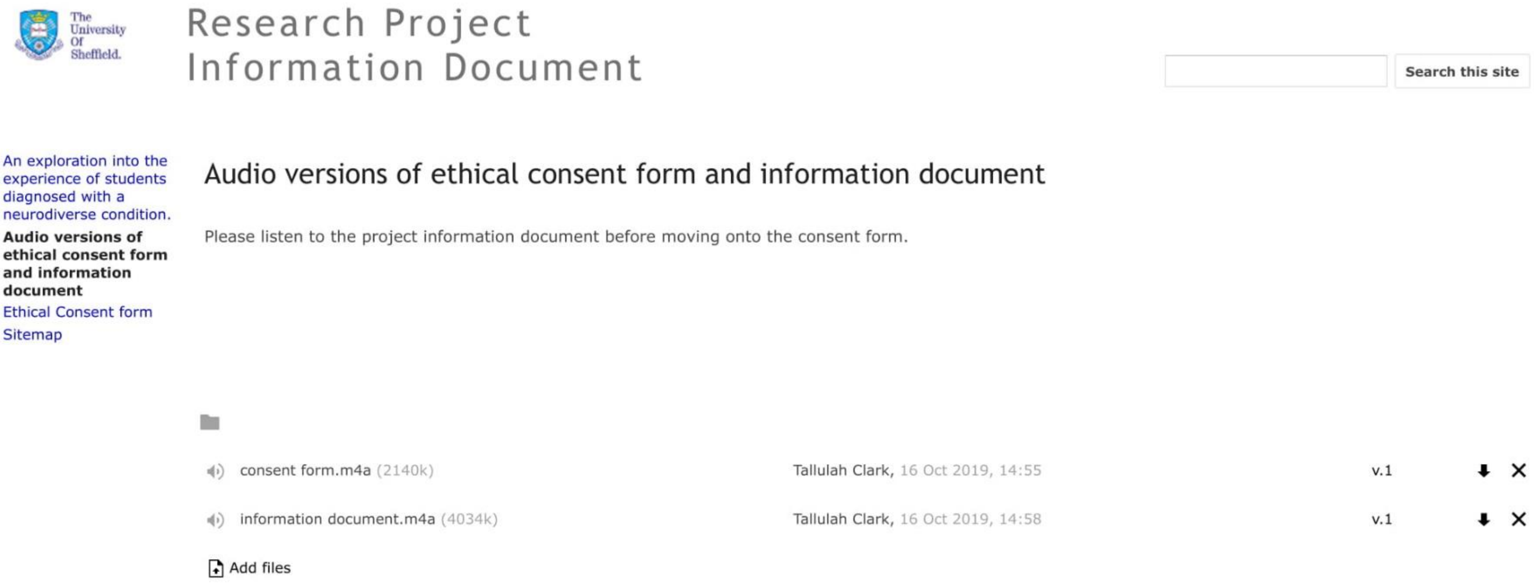
6. I understand my personal details such as name, phone number, address and email address etc. will not be revealed to people outside the project
7. I understand and agree that my words may be quoted in publications, reports, web pages, and other research outputs.
8. I understand that I will not be named in these outputs unless I specifically request this.
9. I understand and agree that other authorised researchers will have access to this data only if they agree to preserve the confidentiality of the information as requested in this form.
10. I understand and agree that other authorised researchers may use my data in publications, reports, web pages, and other research outputs, only if they agree to preserve the confidentiality of the information as requested in this form.
11. I understand that raw data from the project will be destroyed on completion of the research study, no later than study at any time/before 29/04/2020
12. I give permission for the answers that I provide to be used in this research project so it can be used for future research and learning

So that the information you provide can be used legally by the researchers

13.I agree to assign the copyright I hold in any materials generated as part of this project to The University of Sheffield.

Project contact details for further information:
Researcher [redacted]
School of Education, 241 Glossop Rd, Sheffield S10 2GW
Supervisor: themesa.neckles@sheffield.ac.uk
+44 114 222 8106

Appendix 3: Participant information sheet and consent form- audio version



Research Project
Information Document

Audio versions of ethical consent form and information document

Please listen to the project information document before moving onto the consent form.

consent form.m4a (2140k) Tallulah Clark, 16 Oct 2019, 14:55 v.1

information document.m4a (4034k) Tallulah Clark, 16 Oct 2019, 14:58 v.1

Appendix 4: Ethical approval letter

The University Of Sheffield.

Downloaded: 04/04/2020
Approved: 22/10/2019

Registration number:

School of Education

Dear

PROJECT TITLE: An exploration into the experiences of neurodiverse students in the UK education system
APPLICATION: Reference Number 031214
ORIGINAL APPLICATION: Reference Number 022769

On behalf of the University ethics reviewers who reviewed your project, I am pleased to inform you that on 22/10/2019 the above-named project was **approved** on ethics grounds, on the basis that you will adhere to the following documentation that you submitted for ethics review:

- University research ethics application form 031214 (form submission date: 14/10/2019); (expected project end date: 28/04/2020). This is an en bloc application based on University research ethics application form 022769
- Participant information sheet 1071388 version 1 (14/10/2019).
- Participant consent form 1071389 version 1 (14/10/2019).

If during the course of the project you need to deviate significantly from the above-approved documentation please inform me since written approval will be required.

Yours sincerely

David Hyatt
Ethics Administrator School of Education

Appendix 5: Colour coding for transcripts

Colour coding of transcripts
Red
An invisible illness
Green
Stigma and Stereotypes
Orange
Implications
Blue
Barriers within the education system

Appendix 6: Interview One – Participant 1- Ex Lecturer with Multiple Sclerosis

What is your experience of neurodiversity in the education system?

Interestingly enough, I was working at Loughborough University as my MS started getting worse, so it's quite shocking how some of the modern buildings were really accessible but some of the older buildings I couldn't get into and they had to change the venue for me to teach.

I often feel embarrassed or ashamed when asking for additional help, how confident did you feel as an employee when asking for help?

Yes, in the beginning sometimes I felt as if I was asking for too much help, after 4 or 5 times asking for additional help I began feeling like a burden. I also didn't want to fall into the stereotype of a girl. Accessing buildings and meeting rooms became more and more challenging which is why I eventually left.

Would you have felt more comfortable if staff and students were more aware and informed in regards to your, or anyone's neurological condition?

Yes I think so, I also tried to cover it up as I was afraid they'd perceive my neurological disorder as affecting my cognitive abilities.

Could you give me an example?

So, in 2011 I had an operation on my knee and had to use crutches but due to my MS the operation affected me quite badly so I carried on relying on the crutches and when people would ask I would just tell them that the operation went wrong. So apart from a couple other lecturers and students that I knew well, up until 2016 which was when I left, everybody thought I'd had an operation that went wrong.
Yeah, I've even covered it up. If I tell someone that I have a disability they get really uncomfortable.
Another quite funny example is when I was in a meeting once and other members of staff who I only vaguely knew asked me what was wrong I told them that I had a really bad snowboarding accident and their reaction was so different to when I tell people I have MS. As if somehow that was a more acceptable reason.

Why do you think that was?

Probably because it's cool, snowboarding it's sporty, adventurous and just has more acceptable connotations. So I'd definitely say that is a prime example of the negative stigma attached to neurological disabilities. They pitied me but not in a patronising way.
People were interested in talking to me when I told them that I'd had a snowboarding accident but when I told them that it was a neurological disorder they'd often try to subtly start talking to someone else or they'd assume I'm about to do something strange.

Would you say that there is some sort of neurological hierarchy between those who have rarer diseases and those with neurological conditions that are more recognised?

Definitely, before I was in my wheelchair or used any aid people didn't understand my invisible illness. They thought I was lazy, unmotivated and disorganized. They knew I was sick but not sick (p.5 of lit review) enough to warrant my behaviour. They just didn't understand when it took me longer mentally and physically. I think there is a massive hierarchy between more common and more known things like autism and lesser known illnesses such as MS because more common ones are understood. Perhaps this is because diseases such as autism do not diverge from what's perceived as normal, as much as rarer disease such as MS.

So going back to the accessibility of your experience of the education system, would you say there were *any barriers?*

Yes, not just whilst teaching- which was actually the most accessible part. But the whole experience. Not all doors were automatic, so I had to always ask someone to open the door for me. Just small things like that, small things that go unnoticed by neurotypical members of society.

Yes I agree, and finally what would you change about the education system to ensure that it was more accessible?

Well, for starters the automatic doors, small things that in the grand scheme of things the university could afford but don't prioritize. I would also ensure that all staff were fully trained and aware of neurological conditions and the support that other staff members and students may need without having to repeatedly ask for help. Because most neurological conditions are not visible, it is crucial to remind both staff and students to be aware. Having an invisible illness made me, a member of staff, feel isolated and alone because no one could easily identify what was wrong, so I can't imagine what it must be like for students. This goes back to a lack of awareness and understanding.
The mental and emotional side of this is challenging but the physical side is too, I remember in the beginning people didn't understand because I was walking but I also used the disabled car parking space. I got a lot of filthy looks!

Thank you for your time

Appendix 7: Focus group with neurotypical students

Focus Group

Me: So the purpose of this focus group is to explore how neurotypical students perceive neurodiverse students, ie. The challenges they may face, what could be done to improve this etc

Me: So the first question is….

A: [interrupts] Hang on, can you explain what neurodiversity is

C: Yeah, I was gonna ask that……

A: Like Autism?… what would a neurodiverse student be to us

Me: Of course, so anyone who behaves differently or finds thinks more of a challenge due to their neurological difference.

Me: So, how do you think neurodiverse students feel when going on to higher education in comparison to their neurotypical peers, do you think they worry about not being given equal opportunities?

A: Well they're not are they? There's a statistic I think, about the number of disabled students who go to uni, it's the same as working class people- it's really low.

B: I'd say you'd assume they were out of their comfort zone, because I'd imagine if you live quite far away and you have xyz as a disability you have a certain set of… I don't know like a certain doctor you're familiar with or like a support network basically. And I can imagine coming to uni…

A: [interrupts] daunting

B: Yeah, yeah, it just might give them more anxiety

Me: So do you think that may stop them from applying?

C: Deffo, but I'd have thought that they'd look into it with the uni's themselves, like here they have the DDSS which I know is there to support students but I'm not sure on how helpful it actually is

A: Disabled Support services? Yeah but not every illness is visible, we probably can't see all the symptoms so it isn't immediately obvious how to help

Me: how accessible do you think the education system is

B: Well, when I was going through middle school not very, I suppose there wasn't as much press about accessibility, disability and especially neurodiversity which is even worse cos you can't always tell.

Me: So do you think it's changed now?

B: I don't know but it should, when I was at school there was a kid in my class with some sort of neurological issue and no one knew how to help. Some teachers even saw him as a nuisance or just 'slow' because no one understood, they couldn't see anything wrong.

C: Accessible as in getting into uni?

A: Like assessments and stuff?

Me: Yeah, so how accessible do you think it is getting into higher education and once you're there?

C: Well I assume it must be harder because they have to take so much more into account, so no wonder it puts people off.

A: also, I guess people with neurological differences have different ways of learning so they probably need adjustments, but in terms of exams don't they do that?

C: Yeah, my friend has that…

B: From what I'm aware they accommodate you quite well

A: But again, we don't know cos we don't have to go through it, I think there's extra time but it's the same sort of assessments though. You would think they'd tailor it…

C: [interrupts] Yeah, the girl on my course had extra time but that's all

A: You'd think they'd change the assessment type depending on the condition

B: When you say accessible do you mean physically as well?

Me: Yeah every aspect

B: I feel like I know of ramps

C: Yeah and there's lots of lifts everywhere

A: A girl on my course though had a lecture right after another one but had to walk 15 minutes uphill to get there. So even though some things are put in place maybe more needs to be done to amend situations like this.

B: Yeah, if it takes me 10 minutes to walk to my next lecture it must take years if you have some sort of physical disability

Me: Do you think that there are barriers in the education system for neurodiverse students?

A: Well assessments are the main things surely? If people learn in different styles yet are being assessed the same way, it's not accommodating at all is it?

C: In my module they haven't given us any other way, it's all exams.

B: It's all set in stone.

C: and if you're the one who needs anything different, you're the one that needs to approach someone to try an change it which I can imagine then just wastes time.

A: Yeah in my course [journalism] we have to use shorthand, which means that anyone who has trouble writing can't take part

Me: so do you think that neurodiverse students would feel more at ease within the education system if staff were more at informed about the difficulties that they face?

B: It's a difficult one because it's like a split, staff deffinatley need to be informed, we are a more diverse society and the education system likes to preach about widening participation but with that said are staff being taught about it in the first place? Maybe that's the problem here, staff aren't being taught how to cater for a demographic of people.

C: So maybe our [tuition] fees should go towards that before refurbishing the students union.

A: I know lots of people who have LSP [learning support plans] in place but because there are so many students staff don’t read them.

B: Maybe there should some sort of priority system for those with more complex needs.

Me: How confident do you think neurodiverse students feel when asking for help in an academic environment?

B: Well I hate asking for help and that’s just the few times I don’t understand something, but if you’re asking for help a handful of times it might get quite tiring.

A: I feel like when I ask for help, I’m taking up valuable time so when someone is having difficulty grasping a concept it must be really hard.

B: And it goes back to not reading the LSP thoroughly and not being aware about neurodiversity. Some lecturers or even peers make jokes at your expense, say, if you ask the same question more than once and if you’ve got a neurological problem it must be horrible.

Me: What would you change about the education system in terms of accessibility?

A: Well I feel like entry is a massive thing

B: I feel like at the moment it’s a top down approach, I think it works like a pyramid doesn’t it? If they encourage more disabled students to go onto higher education, then staff will have to get more clued up because there will be a higher percentage. They won’t be able to ignore it.