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To what extent does an invisible
disability impact an individual's
identity

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Abstract

This study explores the ways that an invisible disability can impact a person's sense of identity. The term invisible disability refers to conditions which are hidden due to a lack (for the most part) of external signs of disability or aids that represent states of impairment. It includes conditions which can sometimes be associated with signifiers (like blindness or deafness) as well as conditions which are rarely associated with external signs of impairment (here referring to dyslexia and mental health problems). The research has found a strong relationship between the lack of an external signifier of disability and issues of identity formation in persons participating in higher education. The study involved a series of semi-structured interviews which explored key factors of everyday life; in order to establish whether or not these conditions can affect the way individuals associate with their disability in relation to their identity. Participants totalled 20 and consisted of 5 individuals from each of the four different impairment groups. There were two major themes uncovered in this research which appear to have a significant impact on the identity formation processes of those with specifically invisible disabilities. The first theme was the impact of having to constantly disclose and explain a disability in order to have others understand and adapt behaviour and meet specific requirements. This led to a series of significant social situations for all those in this research including handling the frustration of having to acknowledge their condition regularly as a part of what they are and confronting misrepresentation; being perceived in a way other than the way that individual desires to be seen. The other theme was the role of community and the unique relationship that invisible disability creates for these disabled individuals with other members of society and in relation to their career and disability-based engagements. This study also acknowledges a deviation from expected findings which sees the true impact of invisible conditions on relationships specifically close personal relationships and the way that ability to conceal; the impairment affects identity formation for the disabled people themselves.

Chapter 1: Introduction

“93% of disabled people don’t use a wheelchair”

(visibility93.com 2018)

This research explores a gap in existing literature which has become apparent as a result of both research into existing papers and prior primary study. The main goal of the study is to understand if/how the specific nature of a certain type of disability (invisible) affects individuals’ sense of identity. The study explores invisible disabilities and questions the ways that four specific invisible conditions could impact the identity formation process of adults in higher education. This was through a series of semi structured interviews using interview questions which explore how students thought about their education, future career goals, relationships (both public and private) and community and leisure activities. These factors combine to create an extensive review of how an individual lives and how their condition may or may not be impacting on certain elements of their social and academic existence. These reviews included a concomitating impact of disability on decision making processes (specifically regarding work and leisure activities) as it is apparent from existing literature that there are several papers which state that disability can impact individuals’ choices. Whether this is educationally (Henderson, Houtenville and Wang 2017), socially (Jenkins 2008) or in help seeking behaviour and relationships (Heaslip 2016, Pryce et al 2016).

The motivations for this research have come, not only from the apparent gap in existing research, but also from personal experience and prior primary research. The research which already exists shows that disclosure as a process can impact people’s approaches to their lives. There is numerous study which view the significant difference to identity formation which can be caused by a disabling condition (Riddell and Watson 2003, Craib 1998). This includes a personal study conducted as part of my undergraduate degree exploring the difference in identity formation processes for individuals with and without external aids for their conditions (Aspland 2018, which can be accessed if desired by contacting me personally as well as a copy being held at the University of Kent SSPSSR office). The fact is however, that there is no research yet in existence which explores the specific

impact of the invisible disability on the dimensions of identity which are critical for understanding identity and the self and this is the gap which this study intends to begin to fill (with more research hopefully coming in the future). Another of the motivations for this research is the role of personal experience and interest. As a visually impaired individual who has no clear external aid, I have often wondered if my process of identity formation and how it has been affected by my disability is personal or part of a wider social phenomenon.

Before going into the findings of the interviews it is first necessary to consider and define the main elements of the question itself; these being the invisible nature of the condition and the term disability itself. The term “invisible” refers to the covert nature of a disability which makes it unique from other forms of disabling condition. Examples in society include a wide variety of conditions which can impact the lives of individuals without being externally visible. These can be related to disability and/or situations where a certain trait of the desired identity is not reflected in the external appearance of the individual themselves. This research will focus specifically on the ways that disabilities can be invisible and the ways that this can impact thoughts, behaviours and life choices. Coined by a number of different academics from the late 1990’s I will focus on the definition provided by Wilkinson as he discussed the self-experience of having an invisible condition (in his case a hearing impairment) (Wilkinson 2008, Hadley 2014).

“if I were in a wheelchair people would immediately mark me as a disabled person [...] But as someone who doesn’t have a marker of impairment [...] there is no visual indication of my being disabled” (Wilkinson 2008).

This definition reflects the real-life experience of an invisible disability and provides a comparison between having an invisible impairment as appose to a visible impairment and the way that this can impact thought processes whilst existing in a wider social context.

The fundamental social theory which encapsulates the power of social interaction and awareness in shaping the realities of life for individuals with many forms of disability is the social model of disability. There is a growing belief that the problem

with disability research is that society is not taking responsibility for its role in turning impairment to “disability”. This study therefore utilises the definitions of impairment and disability as established by the UPIAS (Union of the Physically Impaired Against Segregation) organisation in the UK in their text *Fundamental Principles of Disability* published in 1976, which read as follows:

“Impairment: lacking part or all of a limb, or having a defective limb, organ or mechanism of the body.

Disability: the disadvantage or restriction of activity caused by a contemporary social organisation which takes no or little account of people who have physical impairments and thus excludes them from participation in the mainstream of social activities.” (UPIAS 1976 3-4).

Whilst competing definitions present in previous academic works may cause confusion throughout the literature review it is my belief that this is still the best course of analysis for the findings of this study. These editions tie disability directly to the social world and will convey the participants’ responses regarding identity to the role of the social world. This will strengthen the relationship between the dimensions of identity (to be discussed in detail in the literature review) and the role of invisible disability and related stigma.

Alongside invisibility another major theory used and discussed throughout this research to underpin many of the responses and ideas will be the concept of spoiled identity as conceptualised by Erving Goffman in his 1963 work *Stigma: Notes on the Management of Spoiled Identity*. His theory utilised the ideas of social stigma and the power of public judgement in impacting the identity processes for people with disabilities. It is related to the historical prejudice related to disparity and the fact that if an individual has a clear disability then this is what defines them, no other element of their being can become their primary disability because of the strength of this social judgement. This study explores whether this concept is still as relevant as when it was first coined and more importantly whether stigma has the same impact on people in the 21st century as it once did. Much of the contemporary research into disability and identity has seen a social change leading to more acceptance of disability as part of one’s self rather than it being an unavoidable part of who a person is. This research explores whether this same social change has come about

for those whose disability is not necessarily externally clear to the general public. This research explores these conditions and the impact they may have on processes of identity formation and decision making in order to form conclusions which may fill the gap in existing research regarding the social significance of invisible disabilities. The research will utilise the theories of Wilkinson (invisible disability) and the concept of spoiled identity as constructed by Goffman to generate ideas as a base for this study.

Using these definitions as a base for analysis, the research will explore four different conditions which could all be classified as invisible disabilities; these being visual impairment, hearing impairment, dyslexia and mental health conditions (focusing on anxiety and depression).

The first of these two conditions could be defined in the wider category of sensory impairments. These disabilities are often visible as they will be represented through external aid apparatus such as glasses, a white cane or a hearing aid. However, for many across the UK these are conditions which are either uncured by current methods or are not considered disabling enough to be in requirement of aid (applying mostly to more advanced conditions which may be on the verge of qualifying for a guide dog or white cane). I have conducted previous research into the impact of the visibility of a visual impairment. Those who must choose to disclose their disability to others whilst out in public are often less inclined to associate their sight loss as part of who they are, thus reflecting the potential identity crisis which can be caused by the requirement for disclosure associated with an invisible disability. I intend to use this research to expand on these findings and to discover whether or not this phenomenon applies more generally to a variety of invisible disabilities. I have thus expanded sensory impairments to include hearing loss and have also added neurological conditions as an alternative form of hidden disability.

The other two conditions dyslexia and mental illness (anxiety and depression) are also impairments which can be classified as invisible. They are rarely externally recognisable as is the case for sensory conditions and yet they are often just as significant in the lives of those that they impact. This research will consider each of these conditions in order to decide whether or not there are similarities in social reactions to these disabilities and specifically their invisible state. Overall, these four disabilities (visual, auditory, dyslexia and mental health) will be analysed in order to

discover the impact on identity formation and social interactions which is caused by the presence of an invisible disability.

Chapter 2: Literature Review

This review summarises the literature used within this study and will act as a justification for the current study's necessity.

The review contains two sections, section one covers general ideas and theories linking disability and identity including a breakdown of the social model approach to disability studies. It also acknowledges some key theories of identity research from primarily philosophical and sociological perspectives. Section two focuses on specific knowledge linking the four disability types (visual, auditory, mental health and dyslexia) to different social concepts. The section also links identity formation processes and the inherent link between social interaction and identity.

Overall, this literature has shaped the study and underpinned the various conclusions and considerations.

The primary theories relevant to this research are that of invisible disability (as defined in the introduction) and stigma, including spoiled identity (Goffman 1963, Wilkinson 2008).

Wilkinson focuses on the impact of becoming the disabled individual and acknowledges the importance that "fitting in" has on shaping the way a person perceives their disability. The opportunity to pass as able-bodied can lead those with invisible conditions to feel pressured to maintain this façade; an idea which can be tough to manage in situations where their impairment becomes clear. His literature highlights (through stories of personal experience) the social experience of a group of disabled people otherwise neglected. Although other papers have dealt with the nature of passing behaviours and the role that disclosure can have on a person's sense of self, few other authors have specifically researched the unique field of invisible conditions.

Goffman's 1963 work *Stigma: Notes on the Management of Spoiled Identity*, explores the theoretical role of social perceptions in shaping an individual's sense of being and the way they present themselves both through chosen and inherent traits. He outlines three types of stigma in his text, character trait, physical and stigma of group identity. Although each of these has a unique relevance to this research, for the purposes of this research I will be focusing on the significance of character trait and physical stigma. Physical stigma in particular is the type most commonly

associated with disability: “an individual who might have been received easily in ordinary social intercourse to possess a trait which can obtrude itself upon attention and turn those of us whom he meets away from him” (Goffman 1963, quote taken from Goffman 1968 P15).

Stigma engages with social prejudice and develops ideas regarding the role of the wider public in shaping self, due to stereotyping associated with certain characteristics including race, gender and most importantly disability (Goffman 1963). Other theories by Goffman deal with the struggle of identity formation and the battle that can go on between a person’s true identity (backstage identity) and the person they present to the world (front stage identity). He believed that identity was a fluid concept which engaged with the different roles an individual takes on in their life, and the importance that these can have in different social situations (Goffman 1956). In relation to disability the external characteristics of impairment are often noted to create spoiled identity, wherein the social world first perceives the impairment and makes judgements on the individual’s behalf before they have had the chance to portray themselves in the desired way. This can lead to disability overtaking other more valued identify traits due to its external prominence in social life. In terms of the later theory by Goffman, this review includes a discussion of the contemporary relevance of the theory and a consideration of the more modern interpretations of stigma in relation to disability and identity both separately and as a single concept.

Part 1: Theories and Concepts of Disability and Identity

The Social Model of Disability

The research's key definitions are taken from UPIAS *Fundamental Principles of Disability*, following the social model of disability related to individualist theory; concluding that disability is created by the inadequacy of modern infrastructure and society to provide an accessible environment for all forms of impairment (Barnes and Mercer 2003), as opposed to a challenge to be dealt with by the impaired person themselves (which would be the case of utilising the medical model).

The social model was generated in the late 1970's, to present an alternative to the prevailing medical definition of disability. It presented the first series of ideas that showed how the social world needed to adapt to the needs of disabled individuals and that being disabled was more than just a diagnosis of impairment provided by a doctor.

Written by disability activist Mike Oliver, *The Politics of Disablement* documented his realisation that a large percentage of the UK population were simply used to struggling in their day to day lives with impairments. The text proposes that with a few simple alterations, the social world and its infrastructure could adapt and encourage interaction, allowing individuals to thrive regardless of their level of disablement (Oliver 1990).

The power of the social model lies in its transformation of the prevailing public image of disabled people; that they were fundamentally lesser than able-bodied people and that they were not as capable (Oliver and Barnes 2012).

The social model of disability states that it is not the inability of the disabled, but the inadequacy of their social environment which restricts their abilities.

Oliver's work also challenged disability literature, aiming to empower the disabled person through wider society. Acceptance and accommodation of disabled people's needs, should, he argued, ultimately be defined by the disabled person; allowing them to flourish in society (Oliver 1990).

In a recent documentary *Kicking Down the Doors: From Borstal boy to University professor (2018)* (created by his alma mater, The University of Kent) he outlined how the campus has changed over the years and gave his thoughts regarding the significance of modern equality trends in changing the way that disabled people coped nowadays. He was however, keen to add that there were still holes in accessibility development (University of Kent 2018). This reflects the true ways that the social model has been implemented throughout western society, whilst acknowledging further improvements are needed to meet accessibility requirements.

This model is the most significant with regard to this research, due to the truly social nature of the ideas and the ways they acknowledge the involvement of wider public actions in the lives of disabled individuals.

When asked about the theory's relevance to the social experience of invisible disabilities specifically, Oliver was seen to fall back on the statement that his ideas were merely a theory and their ability to resonate with different formulations of disability was not proven. The model can be victim to many different interpretations. It can be argued that this theory has created a deeper understanding, which means that there is now a way to see disability in the social world, however it may not be equally relevant for all variations of condition.

These latter comments reflect some of the contemporary issues with the ways that Oliver (and other social model theorists) differentiated the terms impairment and disability. Although his fundamental premise that the two should be considered as separate concerns, based on social development, seems to hold true, in literature which has followed the social model the term disability has often been used in place of impairment and vice versa.

This has created an inconsistency which can cause issues for disability studies scholars. Within this research one such inconsistency has occurred in that the pervading term used to describe (as Oliver would call them) 'impairments' with no

external signs is “hidden” or “invisible Disability.” Used to refer to the condition itself this reflects some variation from the terminology of the social model whilst conforming to its ideas.

Examples of this inconsistency can be seen throughout literature referred to in this text as well as wider literature. Firstly, throughout Hadley’s work authors of different chapters have used impairment and disability interchangeably thus reflecting the significant issue of the contemporary use of the social model. This work is a compilation of different authors ideas about disability and this has created a change in the ways that disability and hidden disability as terms are used (Hadley 2014). Other examples of this can be seen throughout the referred to literature including within Kattari, Olzman and Hanna’s 2018 work exploring the power of micro aggressions and ableism on identity. From the offset they reference invisible disability and continue to use this term throughout to mean both disability and impairment. They have in addition made reference to “hidden” disability further reflecting the ways that different terminology can be used to refer to the same or similar circumstances when it comes to invisible conditions (Kattari et al 2018). Other works including Moloney, Brown, Ciciukatie and Foley (2019) and Mills (2017) explore hidden disability and physical impairment in relation to social scenarios without taking note of the ways that the terms can be adapted. Their studies exploring: the social perception of service dogs and disclosure processes for disabled women in the workforce (Mills then Moloney respectively) engage with the real-world experiences of hidden impairment whilst utilising a variety of terms to illustrate their points. This does not however impact the ability for the reader to engage with their findings but are simply further examples of times that the social model’s definitions have not been strictly adhered to (Mills 2017, Moloney, Brown, Ciciukatie and Foley 2019).

This same inconsistency is present in wider society as the terminology of the social model has not become common public discourse. This has led to impaired individuals being unaware of the academic differentiation between impairment and disability. Examples of this are present across media outlets including the news, social media and other social platforms and reflects the variation in use of disability related terminology. News headlines which read “Disabled Derbyshire woman set to

take on Parkrun” and “The New way to Travel if you are Disabled and use Access” are common, in circumstances where the social model would argue that Impairment or Impaired person fit the description more accurately (Waring 2021. Rose 2020). This is not to say that this causes any issue but simply provides evidence of the normalisation of “disability” as a term to encapsulate all forms of impairment in social parlance.

Furthermore, television and online media programmes use the term disability and disabled just as commonly as news outlets. Groups such as “The Social” have provided the opportunity for “young disabled people across Scotland to tell their story” (BBC Scotland 2020). This series is only one of the few recently released shows exploring the lives of individuals with impairments. They are often referred to as disabilities particularly in the title of the shows in order to draw an audience. This can be seen in shows like “Alex Brooker: Disability and Me” (aired BBC TWO in November 2020) and “Silenced: The Hidden Story of Disabled Britain” (aired BBC TWO in February 2021). These many examples prove that socially disability is synonymous with impairment and reflects the need to alter the view of terminology presented by the social model.

In relation to this research, it is therefore important to state that although the underlying concepts associated with the social model are fundamental, the terminological structure is less distinct. This is due, in equal parts, to the lack of awareness of the public (specifically participants) and the use of “hidden disability” as a recognised term where “hidden impairment” would better suit social model distinctions.

With this theory in mind it is possible to analyse the most recent social policy and societal attempts to accommodate and raise awareness for different forms of disability. Specifically, there has recently been a drive to raise awareness of different forms of invisible disability, through creation of new symbols of impairment. The wheelchair symbol which has come to represent the international depiction of disability was created in 1968 and over the following years has come to be one of the only symbols to represent impairment in the social world, thus gaining the title “the international symbol of access” (Guffey 2015). The programme titled Visability93

saw several artists and designers from McCann London create a series of different symbols for impairments, which are more specific to different conditions in an attempt to raise awareness of invisible disabilities in western society.

The symbols are variations of the standard male and female bathroom signs altered to reflect certain disabling conditions including gaps at the sides of the head for deafness and a coloured triangle inside the head to represent dyslexia (Visibility93.com 2018). Reactions to the new iconography have been varied, a popular view is that the symbols are an attempt for the social world to appear more considerate of disabilities without asking the advice or opinion of the impaired. There remains a question of whether these symbols will improve any of the fundamental issues which impede the lives of the people themselves (Giacon 2018). This reflects the prevalence of the issues raised by Oliver that society, despite its appearance to be progressive, still has a long way to go before the requirements of the disabled individuals are sought and met.

Dimensions of identity

Identity will be used throughout this study with the majority of analysis focusing on the role of social identity and its effect on the self. Although there are a number of different interpretations of identity, I intend to define identity predominantly socially as “the individual's knowledge that he/she belongs to certain social groups together with some emotional and value significance to him/her of the group membership” (Tajfel 1972 p31 cited in Abrams and Hogg 1990 p2).

However, I also feel it is important to acknowledge that elements of identity are personal. This has particular relevance to disability studies as it is often associated with the individual body as much as being a part of the social group. “Personal identify refers to “me” versus “not me” categorisations- all the attributes that come to the fore when the perceiver makes interpersonal comparisons with in group members” (Onorato and Turner 2004 p259). Both play an important role in identity formation but for the purposes of this study the social elements will be the prime focus.

Social identity as outlined by Tajfel and Turner in the 1979 work engages with the three stages of identity formation and conceptualises the ways that the social world

can facilitate association with a certain characteristic or group as part of a person's identity. The stage of "social categorisation" is important in relation to identity formation as this is when an individual begins to tie one's self to a certain element of their being and can be the primary source of self-concept (Tajfel and Turner 1979. Tajfel 2010).

Research by Dirth and Branscombe explored the power of applying the social identity approach to disability studies (Dirth and Branscombe 2018). In particular the role of social categorisation is important in terms of identity as individuals relate to others based on characteristics that they share. The issue with invisible disability is that it is tougher to discern shared characteristics. Nevertheless, social identity is the clearest way to outline identity in this research as it connects disability as an element of personal identity and disability as a way of grouping people in the social world.

Overall, for the purposes of this research the term identity refers to social identity as outlined by these aforementioned theorists. This, alongside Goffman's conceptualisation of identity (to be discussed later in relation to social stigma), forms the basis of the following analysis of dimensions of identity.

Before exploring the social factors that could impact an individual's process of identity formation, it is first important to outline the ways that disability has been seen to intersect with identity research (other than Goffman's theory aforementioned). These can range from the ways that a person can see their disability affecting their future and their life course, to the ways that this condition can change relationships and the social elements of existence.

One of the most significant approaches to identity research for disability scholars is the narrative view of identity. This posits that identity is based around the story that a person chooses to tell about themselves, including the extent to which each person associates with certain elements of their being. This is important for disability studies as it shows the potential that external influences can have in the construction of the self.

The philosophical routes of this theory lie in the conceptualisation of the self and the ways that the self is simply a social construct which can be altered based on choice

and identity associations (Niles 1999). Academics have often shown that disabled people have different narratives and the ways that this shapes their identity. Research by Frank, whose analysis of disabled narratives was based around the testimony of persons who suffered from terminal illnesses was a key example of this. He saw that there were three main discourses which these individuals can present based on the extent to which they associate with their identity and how they spoke about disability as part of their being (Frank 1995).

The first of these narrative reactions is the restitution narrative which focuses on the time when the illness is no longer an issue (in the case of the conditions in this study this is likely to be a focus on potential treatment and cure of the disability).

Individuals see the chronic illness as a short-term state which can be overcome leading to a return to life as it was before the illness. The second reaction is that of the chaos narrative. These individuals see their illness as an interruption which they have no control over, it cannot be changed by action or will to succeed. This can be damaging particularly for those with conditions such as mental health problems as it presents healing as potentially impossible and can cause submission to the illness leading to a lack of self-belief.

Finally, there is the concept of the quest narrative which sees illness and disability as something to be overcome through productive means. This narrative sees illness as an embodied state which can be adapted to, and eventually can lead to a positive transformation through being given the opportunity to better one's self through challenge.

Another of the important theories which brings disability into the formation of identity is the concept of biographical disruption and the ways that the onset of a disability (at any stage in life) can impact the way one thinks about their future and their life trajectory. For some it takes a long time to accept the true impact of a disabling condition on their future, such that their identity can be considered to be in crisis as they are unable to engage with their new state of impairment (Yuill, Crinson and Duncan 2012). It has been shown in previous research that the level of external disability can be a strong factor which prevents individuals from coming to terms with their disability and materially change their life course (discovered in undergraduate dissertation research unpublished to date). It is believed that the lack of opportunity

to disclose their disability in public, forces an individual to face their condition and the social stigma attached; this is likely to speed up their adaptation into their new disabled body (Morden, Jinks and Nio Ong 2017). Thus, invisible disabilities present an interesting variation, their ability to pass and fit in could lead to a delayed adaption to their disability.

Furthermore, research by Wedgewood et al has explored the specific impact of biographical disruption during the transition to adulthood. This is of strong significance to this research as I intend to explore the ways that identity formation can be affected by disability present during identity formation (Wedgewood et al 2020). Having life interrupted at such a critical point in their self-formation can lead to trauma surrounding creating a clear and cohesive sense of self. This research stated that it was particularly tough for young people to discern their sense of self, due to the disruption of disability and the way this interfered with their vision for the future. This reflects the idea that disability diagnosed during childhood or adolescence can have a profound and lasting effect on future prospects including how the individual thinks about themselves and their life, biographical disruption therefore plays a key role in the identity formation processes of young people with illnesses and disabilities (Wedgewood 2020).

In association with this idea of biographical disruption, there is also the concept of educational decision making. This refers to the ways that certain conditions or experiences whilst growing up can shape the thought processes of young people, particularly when deciding on their educational futures. Regarding disability, the concept of educational decision making can often lead to some feelings of constraints because of the limits a disability can impose. This can be both physical and psychological, such as children feeling they are incapable of performing particular roles in their later life because of the impact their condition could, whether real or perceived, have on their future careers.

Although the concept of trade identity is becoming less and less prominent in contemporary society, there is still a consideration (particularly enforced throughout

an individual's time in education) that your choice of career is directly related to your identity and who you will become in the future.

This can be seen throughout the education system as children are encouraged to think of themselves as following a certain career path from an early age. Whether this is real or imagined this still can create a sense of purpose or desire for a certain job, which can be taken away or altered by a disabling condition.

Recent research by Henderson, Houtenville and Wang (2017) explored the relationship between disability and the likelihood that an adult will return to education at a later age. They linked this to the lack of understanding of how best to educate disabled individuals at a younger age. This reflects the fact that disabled adults are more likely to choose to re-enter the education system (as such having this as part of their life) when they feel more able to manage their disability and use education to better their life. Overall, education and the choices that an individual make regarding their education and career trajectory are important dimensions of the identity formation for disabled people.

With these different dimensions of identity studies in mind, the next stage for this review is to analyse the specific concepts which are relevant to this research from the wider field of disability studies. These will consider identity studies research and incorporate wider theories acknowledged as significant to this study including invisible disabilities and spoiled identity.

Identity, Relationships and Disability

Disabilities can also have a significant impact on the formation of relationships and the associations a person maintains, whether they be close personal or in the wider public. These relationships with family, friends and the wider social world are critical in defining ourselves as individuals and contribute to some of the most important elements of identity formation. For the purposes of this research, we will consider relationships with the education system, family and friends, support networks including the disabled community and wider public support.

The medical support system is often seen to be responsible for reinforcing the stigma of what is visible and what is expected of a person with a disability (Mason 2001). There are numerous ways the healthcare system can support individuals to feel secure about their disability being an element of their sense of self. Medical professionals are becoming better acquainted with the impact that an invisible disability can have on disabled individuals' confidence and sense of self. Whether this is through counselling for mental health problems, providing technological support for those with sensory impairments, access to disabled communities and finally through support tools.

Recent literature explores the ways that the social world is prepared to aid those with mental health and sensory impairments. The relationship between support networks and the disabled individual has changed across history. The contemporary approach to disabled-able relations is of critical significance to this research. Studies exploring help seeking behaviours within medical facilities, found that the extent an individual seeks help is directly related to how disabled society has made them feel.

Sensory impairments can cause individuals to be in denial, as they attempt to pass in society (as to be later discussed). Mental health sufferers question acceptance & understanding, concluding that medical professionals will chose to medicate rather than investigate the underlying issues (Lynch and Trenoweth 2008. Lamm and Leat 2013). Other approaches to help seeking behaviours are often more specifically related to the more private support networks that an individual has; in order to feel a strong and capable independent person. Research has explored the ways that certain disabilities and social situations can be difficult for both the impaired person and their family as they develop techniques to adapt in these new scenarios. Research has explored the significance of a strong support network in aiding them to feel strong and gain help from the wider social world (Heaslip 2016). He concluded that a strong support network aided disabled individuals in feeling secure, both in public and private engagement. This security/confidence enabled them to request & gain assistance when required, linking public ability with the power of their private support groups (often family or otherwise close friends).

Another element which dictates the ways that these individuals interact with their social and physical environment is the extent to which they feel able to seek help with their condition whilst out in public. Feeling confident to seek assistance in public spaces is often determined by the ability to negotiate the infrastructure of the space itself. This can be anything from the infrastructure of public space, to the retail sector, wherein being able to easily mobilise leads individuals to feel secure in seeking help with their needs. Research has shown that for some the access that they have to public spaces is shaped by the lack of adaptation to their disability. The extent to which public areas are making note of the social model concept and adapting their environment to the needs of the disabled has been explored by Jenkins, Yuen and Vogtle who formed the conclusion that there are still some ways that infrastructure (specifically in reference to visual impairment) has impacted disabled individuals' ability in their lives (Jenkins, Yuen and Vogtle 2015). Thus, reflecting the need for further public space changes in order to meet accessibility and aid special requirement needs. Disabled people are often forced to point out these flaws and seek help overcoming them, both in the moment of struggle and in the future.

The medical sphere is insufficiently prepared to manage all disabilities, partly due to the stereotyping of what it means to be disabled. Help seeking behaviours are critical in understanding the impact an individual's disability has on their identity and the extent to which they associate themselves with their condition as part of who they are. Seeking assistance, through medical intervention, for their condition causes disclosure with its associated frustrations for people who hope to ignore the impact their condition has on their life (as stated in Frank's considerations of narrative and illness). Access to medical help and stigma in healthcare are two critical issues in the lives of disabled individuals especially for those whose condition is rare or does not conform to the traditional expectations of disability (Scambler 2008).

Initiatives, started by the Department for Education and other UK governmental bodies, seek to find the best way to nurture and support disabled students throughout their time in education. Whilst the system gets less rigid as the stages of education progress (secondary through to further and higher) there are still

measures in place throughout higher education which aim to provide students with the best opportunities during their time in education. In terms of higher education, these systems differ within every university, however all comply with existing programmes and initiatives laid out by governments and medical professions (Grimes et al 2019). For many with disabilities the choice of university is impacted by how well equipped that are and the reputation of the wellbeing department.

Ensuring that an individual can pursue their education, having all necessary tools and resources in place, is critical in allowing disabled people a full range of subjects and therefore limiting their impairment's impact. They can undertake any activities they desire without concern for accessibility, this is critical in separating one's self from their disability, allowing the freedom to explore other elements of identity. Overall, this has a profound impact on identity formation; being able to discover a sense of self without struggling with an impairment.

Social Stigma, Ableism and “Passing” Behaviours

It is important to bring to light the dominant terms and theories associated with this particular subsect of disability studies. Excluding the already defined spoiled identity and invisible disability, these three terms (social stigma, ableism and passing) represent some of the most significant for this study as they contain the current social and academic writings which surround this research. Invisible disabilities provide a unique perspective on these terms as they remove the idea of visibility immediate perception-based stigma from the findings; an idea which is particularly interesting when exploring passing behaviours and the way individuals attempt to veil their conditions in certain social circumstances.

Firstly, social stigma refers to the preconceptions and ideals present in society, which can influence individuals' thoughts and behaviour regarding a particular social issue. Historically stigma has been shown to different degrees to have caused a social divide between those who were considered to be within the social norms and those who were not. Classic academic works including Durkheim's *The Rules of Sociological Method* (1895) and Goffman's *Stigma* (1963) defined social stigma as a predominantly negative symptom of being an outlier in a certain society often associated with race, gender, illness and sexuality. Social stigma was a way of

classifying the social isolation and alienation which came as a result of the social segregation. In relation to disability, social stigma has, over recent years, been considered to be reduced due to the continuation of the “progressive” social movements born in the 1970’s which fight for the rights and equality of disabled persons (Hunt 1966). However, recent research has shown that although outright discrimination and intolerance towards disabled persons has decreased (due to both legal and social change) the nature of prejudice has changed rather than disappeared. It is now more frequent that research finds the oppression of disabled individuals through micro-aggressions and other forms of covert social exclusion (Kattari, Olzman and Hanna 2018). A micro-aggression is an action which is taken in a social situation which in some, often unconscious, way negatively impacts an individual from a marginalised group. Examples of this can be seen against race, gender, sexuality or disability. Actions can include verbal cues such as the more colloquial use of terms such as “gay” or “retard” or other more physical actions such as men standing for women on a train which, in contemporary culture can be congruent to singling out someone based on their characteristics (Ward and Premack 2020). Although the majority of these actions are undertaken without the intent to cause harm or offense, they are none the less jarring to the minority individual and can cause a hostile social environment.

Micro-aggressions in the context of disability are often associated with ableism. Although the two concepts are distinct from one another, ableism is the social trend which sees individuals judged based on what it is assumed they should be able to do. This is often associated with concealable or invisible conditions where members of wider society are unaware that an impairment is present. Wider society make judgements about ability based on outward appearance. It is through these judgements that micro-aggressions become more common, individuals make comments or take actions without a full awareness of disability (Byrne-Haber 2018). In the case of ableism this often presents through statements or exclusions based on perceived ability or inability. These actions (although not violent or intentional in nature) can cause severe psychological harm to impaired individuals as it often reinforces the idea that they are lesser than others. This adds to the interpretation of the social model put forth in this thesis, as stated in the earlier section as it reflects the modern ways that society is creating a disabling environment for impaired persons.

As well as Goffman's work, which provides many of the important theoretical baselines for this and other identity related research, there have been several more modern important papers and books which explore the power of social stigma in relation to the lives of disabled individuals. Modern works have explored the relationship between social stigma and disability with certain works focusing specifically on the perception of adolescents and the power of the labelling associated with social stigma in relation to disability. Research by Mueller (2019) explores the ways that adolescent individuals discuss disability and how their social environment has meant that they are creators of disability. Whether this is that they themselves are disabled and are deciding what that means to them or they are able and are viewing the disabled other, young people create disability through their understanding of the social world and the social norm. Mueller concludes that social stigma begins at an early age and is created through processes of socialisation. Other studies have engaged with the role of stigma in contemporary society for adults navigating public spaces. A study (Moloney, Brown, Ciciurkatie and Foley 2019) exploring the role of disclosure and stigma management for women in work has concluded that the ability to choose whether to disclose a disability is important for women attempting to negotiate the world of work. Participants were keen to overcome their disability and expressed views which showed that they wished to be seen primarily as employees rather than disabled people due to the social stigma which comes automatically as a result of being disabled in modern society. Overall these more modern studies have shown that social stigma in relation to disability is still a present issue and have drawn conclusions about what it means to be disabled in modern society. The research reflects the changes in stigma studies including the fact that modern studies of stigma have acknowledged the role of certain societies in shaping stigma through socialisation processes.

Much of the literature which deals with these terms and ideas is also interested in the growing concerns regarding ableism and the fact that for many disabled individuals there are a lot of assumptions and expectations about their ability and the ways that society expects them to behave. This is particularly important for those with invisible disabilities as there is often an assumption that, because they do not "look disabled"

they are therefore either being overdramatic or are less deserving of assistance than those who look conventionally disabled (Dunn 2019). One of the most significant issues associated with the social dominance of ableist rhetoric is the prevalence of micro-aggressions and their ability to isolate disabled individuals from their wider social world. Terms and phrases which have become common place, including “listen up” (to gain a groups attention) or “acting crazy” (to define certain types of behaviour) can have unforeseen and often unintended impacts on people who suffer from certain conditions; turning these phrases into triggers which constantly remind them that they are different from the able population (Kattari, Olzman and Hanna 2018). The new goal, for social activists is to remove these phrases from common speech. Following previous approaches, they have sought to remove certain language from common parlance due to its offensive connotations for other marginalised groups. This includes phrases such as removal of “gay” as an insult or the now taboo use of racial slurs across the western world (Foucault 1976). It is language and social behaviour like this which present a challenge to disabled individuals who are simply attempting to successfully navigate the social world without feeling oppressed or unequal to the rest of society.

As well as this idea of ableism, other studies have acknowledged a number of phrases which could be deemed as detrimental in the lives of individual’s with mental health problems. This term saneism (also known as mentalism) reflects the ways that common phrases and behaviours can have unforeseen effects on the thought processes of people with mental health problems (Wolframe 2013). Common use of phrases such as ‘feeling depressed’ or ‘feeling anxious’ have meant that the medical undertones have been watered down, losing the severity of their connotations (Esper 1968). This can lead those who suffer from mental health conditions to feel that they are not being taken seriously when they speak about their problems as others around them can sometimes feel they are being dramatic or simply referring to a mood rather than a long-term medical condition. This has a similar effect to that of ableism in that it makes those who suffer with these impairments feel that they are being undermined by the common use of these terms, which should be reserved as medical definitions.

Another field of research which deals with the role of external appearance of an individual and the impact that this can have on processes of identity formation is the study of embodiment. The role of the body in a temporal space in the physical social

world has been of interest to a range of minority scholars due to the power of perception in contemporary western society. A lot of research has gone into exploring the role of the body in fields including gender and race studies and the process of becoming the person the world expects to see. Regarding disability much of this literature deals with similar ideas to spoiled identity theory as it sees the individual as being trapped in the dysfunctional body of the disabled person (Barnes 2016). Barnes' work, exploring the disabled body as a social symbol of minority, investigates in detail the true impact of the disabled body on social interaction and existence. She engages with the idea that the minority body is not necessarily a hindrance and explores the ways that the minority body can be used as a tool to shape a successful social life (Barnes 2016). Being stuck inside a body which will not function the way others do can be an infuriating process and have a strong impact on how a person sees themselves and the world around them. This has been explored through the relationship between power and the body which extends to include the disabled body and the ways that embodying disability can lead to a power imbalance. Some studies have seen the role of the disabled body as having a strong emotional attachment and causing distress. It is tough to escape the body when one must constantly face the challenges that it presents as part of the wider inadequate infrastructure (Hargreaves 2006. Jenkins, Yuen and Vogtle 2015). This will prove to be the most interesting element of disability which could be different for those with invisible condition due to the inherent lack of the disabled exterior. Social reactions and interactions will be different as the disabled body is not present without acknowledgment or interaction and as such the relationship with disability in social circumstance is unique.

One of the associated concepts of the utmost importance to this research is the idea of passing and the ways that certain disabilities can mask themselves in certain social contexts (Kafer 2016). This term refers to the fact that there is an extent to which certain disabilities can become covert given the right social circumstances. This is particularly significant in relation to invisible disabilities as they are, by definition, unseen ailments (Bone 2017). This can be both an advantage and a disadvantage to individuals out in the social world as it brings forth the consideration of the practice of disclosure and the requirement of further decision making in relation to their disability. Studies have shown that passing behaviour and the

decision not to disclose a condition can present both positive and negative outcomes. One study by Von Shrader, Mazer and Bruyer (2014) has shown that individuals are more likely to be hired by a company if they choose to disclose their condition later in the hiring process. This is because employers are more likely to see the disability as making an individual incapable of keeping up with a job if it is disclosed before they have met this person. This conflicts with the 2010 Equality Act, which prevents discriminatory behaviour on such minority-based grounds. This is tough to prove as the practice of excluding candidates on the basis of disability would not be publicised. This represents the real and ever-present inequality in employment opportunities for disabled people across the UK.

These discriminatory actions undermine disabled individuals desire to create a secure and comfortable identity for themselves that engages with their disability, regardless of the level of visibility to the wider social world.

Part 2: Invisible disabilities

Once establishing that invisible disabilities were often missing from disability literature, I endeavoured to select a manageable number of conditions which would conform to the invisible label whilst also being present in the lives of students and younger people in general. The first condition came to me easily for, as noted in my introduction I have both personal and previous academic experience with invisible visual impairments. The key trait which drew me to this condition is the extent to which members of the public related “blindness” with external aids such as guide dogs or white canes (Aspland 2018. Available on request from University of Kent). Further research was needed to explore the impact of this correlation in more detail.

Secondly, I desired to find a second condition which was similarly associated with external aids in public opinion. It soon became clear that hearing impairment was often associated with hearing aids due to their wide availability as a “solution” for hearing loss. The literature exploring this phenomenon is quick to point out that (similar to sight loss) there are a large number of impairments which cannot be fixed with hearing aids (Dawes, Maslin and Munro 2014). As well as this there is a social stigma surrounding sign language and the ways that people with hearing impairments are able to communicate with others. It has been seen that if an individual is using special forms of communication such as having a communication partner they are more likely to be stigmatised in public as their partner becomes their external signifier of disability, thus rendering the condition visible in public (Baker, Leighton and Ferguson 2017). This reflects the fact that deafness, and hearing loss overall, is a condition which is walking the line between invisible and visible as has been established by Wilkinson in his discussion of invisible disability (Wilkinson 2008). It was therefore clear to me that this needed to be added to my study as there seemed to be a lot of juxtaposing ideas about hearing loss in British society.

When creating this study, I also felt that it would be necessary to explore a number of conditions which were not associated with particular assistive technology. I wanted to focus on conditions which may have roots or serious implications for individuals throughout their teen years into early adulthood as this was established

as a critical stage in the identity formation process. I therefore decided upon Dyslexia due to its links to education and childhood. It has no clear external symptoms but research has linked it to feelings of inadequacy in relation to education (Geake 2009). I was curious to explore the social impact in more detail, both in relation to education, life prospects and identity formation.

One of the unique qualities aforementioned is the fact that Dyslexia is not always considered to be a disability (often being grouped with learning difficulties instead). I feel that this is perhaps an oversight and that in grouping the condition differently it could create a new view of the ways that it impacts individuals, especially at a time where education and identity formation are so critically connected. In a society where reading, writing and visual interpretation are so critical it seems neglectful for research to ignore the impact of such a subtle but significant condition and the ways it can affect an individual's role in society.

Finally, in choosing my last condition I wanted to focus on an impairment which affected a large number of people for a significant percentage of their lives but had roots in younger ages once again. There has, over recent years been increased levels of media attention which explores the rising number of young people diagnosed with mental health conditions. With over 70% of depression cases being diagnosed before the age of 24 and rising concerns around CYPMHS (Child and Young Person's Mental Health Services), it seemed critical that some form of mental illness featured in this study (Mental Health Foundation 2018. NHS 2019d). Having satisfied both of the criteria I desired to explore (affecting young people in education and an invisible condition), I decided to move forward with this study using anxiety and depression as the final conditions (grouped under the label of "mental health conditions").

Sensory Disability

The specific field of sensory impairment has been of interest to disability studies scholars (particularly in recent years) due to its proliferation across the globe and the lack of corresponding literature (McRuer 2018). One of the first things to be proclaimed is the fact that for many individuals with sight and hearing problems there is a clear solution or treatment which can be easily accessed via the NHS and other

health related organisations. Much of the following research however assumes that the condition itself is one which would be classified as invisible and for whatever reason cannot be labelled by an external form of discourse such as a hearing aid or a white cane. The power of these symbols will be explored throughout this section of the literature review, as well as the social implications of having or not having an aid on identity formation processes. The section will also explore the significance of age and communities on identity formation for people with sensory impairments.

Looking specifically at visual impairment there are over 90 different types of sight loss currently recognised in the UK, many of which cannot be addressed through the use of glasses. The UK population includes over 2 million people with some form of sight loss, 360,000 of which are registered as blind or partially sighted (NHS 2018). This figure is expected to rise to over 4 million by the year 2050 according to the Royal National Institute for the Blind (RNIB). A small number of people who are registered blind actually experience the “complete darkness” which has become socially tied to the term blind (RNIB 2018). Despite this there are still strong misconceptions that visual impairment is distinct from blindness, while for many it is not, as the level which can classify an individual as blind will still allow them a percentage of sight. Thus, research like this study are important in giving a voice to individuals who suffer with sight loss in order to provide society with a more accurate impression of what it means to be blind or visually impaired.

The second sensory condition is hearing impairment, this condition was chosen particularly due to its prevalence across the UK and the strength of the community that surrounds those with hearing loss. It was calculated in 2014 that around 1 in 6 people in the UK suffer from hearing loss, making it a more common condition than all other disabilities in this study (NHS Inform 2014). Hearing loss is often associated strongly with the use of hearing aids, the process of ageing which has long been synonymous with these aids (Dawes, Maslin and Munro 2014). The role of hearing loss in the lives of younger people will be of particular interest as it seems there is public association between hearing loss and age, this could play an important role in the identity formation of the individuals affected. The severity of hearing loss is clearly a factor, however there is a large discrepancy in the impact the disability has

on individual's lives as any level of hearing loss effects day to day life and therefore impacts their sense of identity.

Firstly, one of the biggest identity markers which has been seen to be forced upon individuals with sensory impairments is the concept of ageing and the relationship between sight and hearing loss and the concepts of weakness and ageing. This has been seen to impact, in profoundly negative ways, the identity formation processes of both younger and older persons with a sensory impairment. Visual impairment research has shown that the association between sight loss and old age has put a shadow over the life of the individual as they fight the stigma which makes them feel older and less capable due simply to their visual impairment (Priestley 2003).

Individuals with hearing impairments show similar feelings of ageing and show that the stigma of old age is also a consideration in their decision-making process when choosing whether to use hearing aids or not (Daves, Maslin and Munro 2014).

Western media and social stigma have painted hearing loss as a symptom of ageing and as such has increased the oppression of those with hearing loss as they fight against the stigma of ageing (Schacht 2008). It has been noted that many of popular programmes have utilised deafness as a comedic tool to create an older character which has led to stigma which makes individuals associate age with hearing loss and impairment.

Alternative ideas about age have explored the relationship between age of onset and identity formation. Stafford (2017) has concluded that children are more likely to associate their impairment with their sense of identity than older persons whose disability is onset later in life. This reflects that in terms of formation a younger onset is more likely to allow a secure identity connection than older onset despite the social stigma relating sensory disability with old age and frailty. This idea is also supported by research into the concept of biographical disruption and chronic illness as children who are diagnosed with illness are more likely to be able to factor this into their life long term as they have known little else than this condition (Yuill, Crinson and Duncan 2012). The later in life a hearing impairment is onset the better the language and communication skills are for the individual involved. This is primarily due to the

critical power of hearing as a sense through the early years of life as part of the socialisation and education process (Kermit 2019).

This was a consideration in the age range of the participants for this research, ensuring those involved were old enough to be aware of how their impairments affected them and to potentially feel impacted by the social stigmas associated with age.

The social phenomena associated (the most strongly) with deafness is the sense of community and the unique nature of their relationships. A number of studies have noted that individuals who are deaf or hearing impaired and are part of a community or support group exhibit feelings of unity and a common belief that they are tied together due to their unique view of the world (Atherton 2012. Gregory 1991). Atherton's book explores the true power of the deaf community of individuals across Britain and explores how the community is critical in creating an environment in which deaf people can enjoy leisure activities. This connection has been seen to be alienating to others who would be considered to be outsiders because of their ability to hear fully, this presents an interesting inversion to the normative assumptions of ableism which state that disabled individuals are the most likely to be isolated due to their inability to perform certain tasks. This insider and outsider mentality is one of the critical factors in identifying with an element of one's self. The identity theory by Tajfel and Turner identifies the concept of social categorisation and comparison in the process of social identity formation (Tajfel and Turner 1979). Similar ideas about in and out group relationships were present in visual impairment communities although these were often more welcoming to outsiders and were often based more specifically around particular conditions or a common aid, such as a guide dog or use of a new technological aid (Mills 2017). Visually impaired communities were often tied to more charities and research goals as many of these foundations formed the links between these individuals rather than the fact of their sight loss being enough to bring these people together.

One of the critical elements which represents the social expectations surrounding sensory impairment is the strength of the tie between external symbols and the conditions themselves. This has been explored in articles which see the power of service dogs and white canes as a symbol of blindness and hearing aids as a

symbol of deafness (Mills 2017, Goodman 2008). The power of these associations has meant that individuals who identify as blind or severely visually impaired who do not have a service dog are often faced with comments about getting a dog and the dog being in ways “a perk” of the impairment. This draws issues surrounding what it means to be disabled and engages with the issues surrounding the disabled body as earlier discussed leading to problems of identity and negotiating a world where disability often only looks one way. Service dog handlers are faced with the lack of awareness regarding the lack of etiquette known by the general public about how to behave in front of these dogs whilst in training as the public often treat the dogs as if they were ordinary domestic pets (Mills 2017).

This relationship between the social need for some form of external symbol of sensory impairment and the associated feelings of social alienation for those without any form of symbol can also be tied to disclosure practices. The ability to choose whether or not to disclose a disability when out in public is one which is unique to individuals who suffer from conditions which could be labelled as invisible. Although not exclusive to sensory over neurological impairments the difference with sensory impairments is the social expectation of a symbol and the ways this can impact decision making processes. One of the most significant scenarios in which the choice of whether or not to disclose a condition has been explored is in the employment process. Research by Von Shrader, Mazer and Bruyer explored the discrimination which can be apparent against those with hearing impairments as they explored the likelihood of individuals being employed for a position based on which stage of the interview process they disclosed their disability (Von Shrader, Mazer and Bruyer 2014). As mentioned earlier there is a disadvantage to gaining employment for those who have a disability and this ability to choose not to disclose the conditions could be seen to be giving individuals an edge in the employment process. This is sometimes considered to be required to gain employment due to the sheer number of unemployed disabled people in western society.

Disclosure of disability and the relationship to safety in the social world has also been explored in a series of more psychological studies, these studies relate strongly to the way that mental health conditions can impact on a person’s day to day life.

One of the leading studies on the need for awareness of invisible disabilities and more specifically invisible trauma is Kafer's study on the impact of trauma on the need for disclosure practices. Much like many common mental health conditions there are certain triggers which exist in the social world which can be seen to upset the delicate mental wellbeing of a person with a cognitive issue (Kafer 2016). This also links to the earlier discussed practice of the social model of disability and reflects the ongoing need for a more conscious social landscape which takes a greater responsibility for the wellbeing of these members of society (Oliver 1990B). The ability to disclose a disability is one of the critical differences between visible and invisible disabilities due to the impact this can have on how a person thinks of themselves. This could be through the psychosocial or even psychological impact of constantly acknowledging their disability and discussing it with others (Southwell 2012), creating a unique relationship of disability and identity for those with invisible conditions.

As well as this there has been documented to be a clear link between the presence of a sensory impairment and the likelihood of developing a mental health condition such as depression or anxiety (specifically social anxiety or isolation). The dominant reason for this link is the power of social isolation and the fact that much of the social environment is based around the ability to relate to others using both visual and auditory communication. Historically deafness and blindness have been considered such limiting conditions that for the most part it was assumed that people who were deaf or blind were incapable of thriving in the social world. This, for obvious reasons, can lead to these people becoming purposeless and depressed as they are unable to form relationships with the wider world or make a useful contribution to their society. The other dimension in this concept is the more contemporary notion that the social world can be at best overwhelming and ill-equipped to suit the needs of people with sensory impairments (Denmark 1994. Rydzewska 2019). Social anxiety can arise as a result of being unable to control or interpret the world around them, which can be a challenge for people with sensory impairments. Research into the impacts of multisensory environments (specifically for people with sight problems) has found that issues can range from uneven ground to low lighting and can cause a variety of issues as blind people attempt to go about their day to day activities. This constant struggle with everyday social life can cause people to become isolated and

even lead to individuals choosing to stay in the private sphere of the home where they feel secure.

Whilst this results from their sensory impairment, their desire to remain inside due to the stress and concerns related to the wider public world is one of the common symptoms of anxiety, thus creating a mental health disability from a sensory impairment, as individuals experience negative emotions in association with the social world (Buss 1980).

Mental Health Conditions

The field of mental health studies has received increasing attention over recent years, primarily due to awareness that mental health conditions have been disregarded and its impact in contemporary society is now recognised. Mental health conditions are one of the most varied conditions considered in this study and the research has narrowed the field from all mental health conditions to focus on depression and anxiety as these are conditions which manifest in public spaces without clear physical ticks. More than 8 million people in the UK suffer from anxiety, the second highest mental health problem in the UK. Depression is the most common with nearly 20% of the UK population showing symptoms of the condition at some point in their lives. The highest percentage (75%) of depression sufferers are diagnosed by the age of 24; this onset, during the key age for formation of self, often leads to this becoming part of a person's life and impacting their identity formation (Mental Health Foundation 2019). Mental health conditions have been a hot topic for social studies research over recent years due to ever increasing interest from both the UK media and government into the significance of mental health conditions. Studies have confirmed that mental health conditions are equally as significant as physical disabilities in creating social isolation.

A new term has been coined to reflect the ways the social world is responsible for the alienation of persons with mental health conditions known as "saneism", to be explored later in the wider iterative review (Mental Health Foundation 2019).

Historically, mental health problems have been considered to be signs of stupidity, physical disease and at sometimes incest. One of the more sociological texts which explores the social changes for mental health care is *Madness and Civilisation*

(1961) by Michel Foucault whose work moved through recent history tracking the ways that isolation has progressed to medicalisation and finally to adaptation and cure. His work applies discursive analysis to the study of mental health conditions in order to present the power of language; social circumstance can change the view of these conditions and rethinking these factors can enact social change and progress (Foucault 1961). Mental health research has only become part of the medical sphere since the start of the 20th century, the evolution of medical science led to treatment for mental health conditions moving from penitentiaries to hospitals. Over the past 20 years it has become one of the major concerns for policy makers in government and other institutions who deal with these issues such as educational establishments and prisons (Scull 1993. Sorel 2013). Mental health care in the 21st century is, in theory, the best state that has ever existed. That said, these conditions remain challenging due to complexity and diversity of mental health impairments and society's lack of awareness and support for every condition. This is evident in research exploring the variety of existing treatments for adolescent mental illness as written by Corcoran in her 2010 work. There are dedicated chapters exploring the treatments for anxiety and depression in young people, the conditions on which this thesis focuses (Corcoran 2010 Chapters 5 and 7).

Considering that over 70% of individuals who suffer from mental illness globally receive no treatment throughout their lives (Henderson, Evans-Lacko and Thornicroft 2013), the recent focus on improving mental health services in the UK reflects an accurate point for concern in healthcare. Across the UK there have been a growing number of schemes and institutions providing treatment and prevention for those suffering with mental health impairments. Schemes including *Beyond Places of Safety* have acknowledged the need for increased funding to programmes aimed to support those with, or at risk of developing, mental health conditions. This reflects the ways that society has adapted to engage with the need for increased healthcare (Department of Health 2014) and demonstrates that society is more aware of mental health issues and reflects the social progress occurring in relation to these conditions (NHS Direct 2018).

Before embarking upon an analysis of the two specific mental health conditions this thesis has chosen to focus on (for the reasons stated at the start of part 2), it is first important to explore the literature which discusses the impact of the stigmatisation of mental health conditions in general. Although I have explored stigma as a social phenomenon earlier in this chapter there are some elements of the stigmatisation of mental health conditions (referred to as psychiatric stigma) which require specific attention due to their implications for a person's identity formation. Peter Byrne in his 1997 work *Psychiatric Stigma* outlined the stereotypes present in media representations of patients under psychiatric care, outlining four main stereotypes in media coverage. He observed that the "label of mental illness changes the perceptions of observers even in the absence of abnormal behaviour." (Byrne 1997 p618). It is the association with mental health services and, disclosure in other forms which ties an individual to the public stigma. Overall psychiatric stigma is distinct from physical stigma as it is more associated with the choices of the individual and the extent to which they chose to associate with services tied to their condition rather than external characteristics which reinforces the stigma.

A multitude of sources suggest that one of the strongest barriers to mental health care is the stigma and discrimination faced by individuals once diagnosed with mental illnesses. One study has concluded that there are four different reasons why mental health conditions are so strongly stigmatised as negative. These were:

"1) lack of knowledge to identify features of mental illness, 2) ignorance about how to access treatment, 3) prejudice against people who have mental illnesses and 4) expectation of discrimination against people diagnosed with mental illness." (Henderson, Evans-Lacko and Thornicroft 2013 p.1).

These conclusions reflect the concerns of those with mental illness and the lack of public knowledge which can lead to stigma from wider society. Further studies have shown that adults with severe mental illness are unlikely to seek help or treatment due to the same perceived prejudice from others (Quinn and Knifton 2014. Hack et al 2020). This latter research by Hack et al has quantified the extent to which adults with severe mental illness are truly resistant to seeking treatment (for any of a number of reasons, including those stated in other studies). Stigma has also been tied to the health care providers themselves. Stigmatisation by providers of care services can negatively affect an individual's perceptions as to their own illness and

their own chances of recovery. This shows that not only is pursuing help itself a stigmatised practice but also that healthcare professionals can enforce negative labels through stigma (Deli, Vidovic, Vaughn and Sasaki 2020). Overall, these studies have shown how the stigmatisation of mental illness has come not only from an ignorant public but also through a toxic relationship with care and support services; created both internally and externally to the organisations themselves.

Unlike other conditions explored in this research there is a significant area of literature which deals with the “concealable” nature of mental illness and the issues that this creates. A number of studies by Diane Quinn and others (2014) have explored the ways that the ability to conceal a stigmatised condition can lead to additional identity formation concerns. This research, although predominantly quantitative, shines a light on a wealth of different concealable stigmatised conditions, one of which being mental illness.

Conclusions surround the ways that individuals who live with a concealable stigmatised condition deal with the anticipation regarding disclosure or being “found out” as a stigmatised person. Mental illness was found to be the condition with the highest levels of centrality (fixation on the condition as part of a person’s identity). This reflects the concerns around mental health and the extent to which it becomes congruent with a person’s sense of self, whether or not it is being concealed (Quinn et al 2014 p9).

Anticipated stigma is the term which refers to the feelings of anxiety relating to potential instances of judgement or prejudice which individuals with certain impairments feel. As aforementioned concealable conditions create a unique type of stigma in which individuals could in fact become anxious when no stigmatising events occur. Research has shown that certain concealable conditions and the anticipation that they create can in fact lead to detrimental psychological and physical health symptoms. Thus, it can be argued that not only does anticipated stigma impact those with existing mental illness but it can also increase the chances that other groups may develop mental health problems (O’Donnell, Corrigan and Gallagher 2015). The ‘what if’ nature of a concealable condition often leads those disabled individuals to suffer from increased levels of social anxiety as they

constantly negotiate the line between “fitting in” and becoming a stigmatised individual.

This anticipated stigma can introduce an overall decision for those with a mental illness, whether to “come out” and live your condition. Research by Weisz, Quinn and Williams (2016) explored the social and personal benefits of encompassing a concealable stigmatised condition as an element of an individual’s identity. They concluded that “being out” about their concealable stigmatised condition can have profound positive effects on their identity and stigma management processes.

Overall, this research reflects how the invisible nature of mental health conditions has created a new stigma which has a profound impact on identity formation. Having a mental illness automatically makes an individual “stigmatised” and can create a conflict around coming to terms with mental illness as an element of self and concealing the condition in order to prevent anticipated stigma in the social world.

There is also research that reflects the extent to which a course of study (specifically degree) can increase wellbeing or decrease mental health. Being a student, in general, can create stress which can lead to higher risk of mental illness (Parasole 2017). Research by Henderson et al in 2016 highlighted the increased issues for students on professional degree programmes. They found that law students and medical students suffered with poor mental health and increased rates of suicide ideation (Henderson et al 2016). These conclusions regarding the link between mental illness and degree level study is important to acknowledge as this research is focused on the experiences of students in higher education. These findings imply that this thesis is likely to uncover stronger links between certain subjects of study and risk of developing a mental health condition. This pressure to succeed in education is also one of the contributing factors highlighted by Parasole which has increased levels of depression and anxiety in young people over recent generations (Parasole 2017).

Modern mental health studies have seen an evolution from the earlier discussed archaic view of neurological issues to consider the true adaptability to the social world for those who suffer with depression and or anxiety. Texts exploring the power

of social anxiety, and the self-consciousness this can ensue, have recognised that many of the thoughts and concerns of anxiety sufferers mimic the problems that young people experience growing up, including the process of generating a sense of self and forming identity (Buss 1980).

Social anxiety (as defined earlier in this review) refers to the specific form of anxiety which impacts people's thoughts and decision-making processes in the social world. It can include small issues, such as becoming panicked or stressed by day to day social interactions such as speaking with shop workers or travelling via public transport. It can also however relate to more debilitating issues such as the fear of coming into contact with other people whilst out or having concerns about being unsafe or being involved in a dangerous situation. This can lead to a person wishing to stay inside, demonstrating traits typically associated with agoraphobics (Sarason and Spielberger 1975).

Anxiety itself has been associated with a more general feeling of angst and has become synonymous with stress and concern rather than being its own medical diagnosis.

Anxious behaviour impacts social interactions, demonstrating traits including nervousness and shyness as well as being prone to bouts of blunt behaviour or sudden mood swings. This can lead to periods of social isolation. These behaviours create a stereotype of anxiety and have led to assumptions about individuals' ability, which this research will consider and challenge, especially engaging with the effect the lack of signifiers of inability has when combined with these traits.

True identity can be contradicted by the symptoms and behaviours of anxiety and can lead to crises of identity for those who are handling the illness (Spielberger 1966). Stein's text *Identity and anxiety: Survival of the person in mass society* engages with the true impact of the condition on the lives of those it affects, including the fact that anxiety has been known to overtake other elements of an individual's identity which they consider to be more important. Suffering with anxiety can lead individuals to feel isolated and prevent their participation in social environments, creating a barrier between true identity and the self created whilst suffering from anxiety. This text strongly ties anxiety and identity and draws on the power of the invisible nature of the condition as individuals feel they should be able to do

whatever they want to but are being held back by an invisible force which stops them from finding their true self (Stein 1960).

Depression and the academic papers associated with this specific mental health condition are different to anxiety, those who suffer from depression are likely to face more internal crises as the source of depression is often unclear and therefore complex to treat. Both conditions can cause individuals to isolate and avoid social interactions (Trickett 1996). Depression is often related to identity formation and the life of the individual; although it also has medical and genetic roots.

The social elements of depression can be triggered by issues such as having a lot of stress regarding work or having trouble in relationships. Depression has been tied to certain medications and certain social environments. It can be triggered by life events, for example, post-natal depression or post-traumatic stress disorder, which see depression as a symptom rather than a condition in its own right (Pilkington, Reavley and Jorm 2013).

It is put forth by multiple scholars including Donnellan (2003) and Gilbert (2000) that counselling is one of the best routes to coping with the condition and yet it is still for the most part an illness which can dominate the lives of some who are unable to find accurate treatment. Whether this is due to a lack of social preparation or simply the healthcare industry being ill-equipped to deal with the symptoms of depression.

The growth of mental health problems as an element of a young person's identity has caused a lot of controversy over recent years due to its proliferation on social media websites, where individuals share their mental health and self-harm stories and can often be considered to be glorifying the condition as something to be desirable or part of a sense of self. It has been discovered that there is a strong link between the act of social comparison on social media platform Instagram and increasing levels of depression (Hwang 2019). Social networking has created a platform through which young people can compare their lives and experiences. They often attribute value to themselves as a result of this comparison, stemming from their desire to appear successful. Further studies conducted in the US have also

linked social media and mental illness relating the pressures of online life as an addition to the stresses of everyday reality (Yazdavar et al 2020). This shows how rising interaction with social media in the lives of young people can make them more vulnerable to mental illnesses including depression and anxiety.

Further research has also linked trivialisation of mental illness to attitudes on social media. It has been found that although social media is reflective of society's increasing openness to discussing mental health care, there are some issues regarding trivialisation about support. This reflects that young people should be wary of relying on social media as a way of seeking mental health support but also acknowledges that there are some benefits of using social media as an outlet for sufferers (Robinson, Turk, Jilka and Cella 2019).

Overall, there is a significant amount of research exploring the impact of mental illness on individuals as a whole and on young people in particular. General research exploring the role of stigmatisation and mental health programmes has reflected the social development of mental health awareness. More specific literature exploring anxiety and depression has reflected the immense social impact of these conditions on their sufferers. Contemporary literature exploring the role of social media for young people has also highlighted a severe issue which has been created rather than dealt with by contemporary society. Mental health is a vast and complex field of study but the preceding literature has created a ground on which to explore its impact on identity and the role of its invisible nature.

Dyslexia

Dyslexia is defined as a neurological condition which has many different variations including dyspraxia (associated with a lack of external coordination), dyscalculia (impacting the ability to compute numerical data and perform arithmetic equations) and dysgraphia (a more recently diagnosed form of dyslexia impacting hand eye coordination in the form of handwriting and artwork). The oldest form of this condition however is Dyslexia itself, which impacts reading and writing and is the most common form of the problem and often diagnosed in school aged children. This association with the education system and childhood has meant that much of the focus for dyslexia studies lies in policy reform and the role of the Department of

Education in raising awareness for coping methods and adapted inclusive teaching strategies (Department of Education 2015).

With around 1 in 10 individuals suffering from dyslexia in the UK, it is an ever-present issue and cause for concern particularly within the education system. This condition, affecting the brain's ability to process visual cues accurately, can come in several different forms (including dyscalculia which impacts with processing of numbers and dyspraxia which impacts motor function and reflexes). It is often diagnosed during the formative years and is therefore associated with the education system and young children. Despite this, not all schools are equipped to diagnose the condition, resulting in parents being forced to turn to private diagnosis practices which, even according to the NHS website, can be costly and time consuming (NHS 2019C). This condition also has no clear external markers, outside of those noted during learning, and as such qualifies as an invisible disability. It's impact on participants' identify formation will provide a different perspective to those of the other disabilities due to the strength of the ties to the education system (as was earlier noted in the breakdown of the division making behind the condition choice).

Medically, dyslexia, in all its forms, is considered to be a hereditary condition. This has been noted to have a profound effect on the extent to which the condition becomes part of a person's identity. It has been noted that when a disability like this is present in other members of a family there is a higher level of understanding and a greater belief that the condition can be handled well and that an individual can still succeed as they see others thriving with the same condition (Todd 1998).

One of the great overarching debates which exists in dyslexia studies in the present day is the realities of how dyslexia, as a term or a diagnosis, has lessened in efficacy in the western world. Once an individual is diagnosed as being dyslexic it is assumed that they are on the road to being able to cope with their condition and overcome the social deficit it causes. Elliot states that, in reality, the term and diagnosis acts as a label and does not necessarily benefit the sufferer (Elliot 2014). This difference between the expectation of aid related to a medical diagnosis and the reality of the social reaction to the condition is likely to come across as one of the major issues plaguing the dyslexic as they attempt to negotiate the social world.

Much of the literature exploring the social impact of dyslexia focuses on the educational deprivation and the resultant issues in later life. Whether this is the sense of inadequacy, when an individual is unable to complete their education in the same way as others, or in the feelings of isolation from social activities and groups which can be caused when a dyslexic person is unable to keep up with others whether socially or academically.

There are a lot of issues surrounding the diagnosis of dyslexia which can also cause children to feel that they are simply not as intelligent as others due to their struggles to keep up in their classes (Geake 2009).

These academic challenges can significantly influence choices regarding further education and career.

The school system is supposed to be prepared to deal with all forms of dyslexia with special resources and allowances, which aim to make dyslexic children feel they are able to keep up in classes. A number of government documents and policy changes have highlighted the ways that the education system is supposedly taking responsibility for caring for and supporting dyslexic learners, and yet individuals continue to struggle. Policies including the Department for Education's *Developing A Dyslexia Friendly Learning Environment* (2015) the Department for Skills and Education's *Special Education Needs: Code of practice* (2001) and the numbers of school and county council specific policies outline the ways that dyslexia "should" be dealt with by the education system. The reality however as has been experienced by individuals going through education with dyslexia shows that often these needs are poorly met (Kent County Council 2015. Essex County Council 2011).

Hartas' (2006) *Dyslexia in the early years* explores the true impact of the condition on early years education and the ways that teaching practices should be altered in order to make the condition more manageable. The struggles associated with the education system can have a significant impact on the identity formation of these individuals due to the early social exclusion, which can become implanted in the thoughts of the person affected. Introduction into the education system is the first-time individuals are given the opportunity to articulately interact with others in their peer group, this can lead to comparison of themselves with others and the initial shaping of who they are and what their place is, in the social world (Geake 2009). Overall, the education system is one of the most significant stages in the life course

of those with dyslexia as it is both the most likely stage for the condition to be diagnosed and also the first instance where individuals are able to compare their abilities to others.

A major theme of dyslexic identity research is the association between dyslexia and artistic endeavours. Many individuals who have dyslexia, or one of its associated conditions, gravitate towards professions and activities which incorporate creative expression, whether artistic or physical. Some of the symptoms of dyslexia can support sufferers and lead to both occupational and leisure activity success. Many individuals with dyslexia display characteristics of spiritic behaviour and impulsion which lend themselves to certain tasks including expression through artistic formats and invention whether this is physically through new technology or creatively through art, drama and animation (Pfeffer and Tabibi 2015). West's text *In the Mind's Eye: Visual thinkers, gifted people with dyslexia and other learning difficulties, computer images and the ironies of creativity* (1997) explores the relationship between dyslexia and creative learning considering the role of visual images over written texts and the power that this unique way of thinking and learning has on the minds of those with cognitive learning difficulties. Research into the relationship between creative thinking and developmental dyslexia has been undertaken by academics in order to discover the significance of the unique way these individuals learn. Many famous creative individuals have dyslexia and have benefitted from this perspective on information, enabling their creation of new and innovative works of art and other creative mediums (creative review 2005).

Dyslexia is associated with mental health problems and social isolation caused by the inferiority felt when an individual is faced with a social situation where they may end up appearing uneducated or illiterate due to their inability to comprehend written information.

Research has stated that there is a link between reading difficulties and conditions including depression and anxiety, due to the increased self-consciousness and self-doubt which stems from the struggles that can come on a day to day basis.

Research as far back as the 1970's acknowledged this fact and has seen the lifelong impact that developing mental health conditions can have alongside the initial disability of dyslexia (Benton 1979). Other research by Leitao et al has spoken with children with dyslexia and their parents in order to establish the ways the condition affects these children on a personal level. They conclude that there is a relationship between feelings of depression and anxiety in children and the ways that their parents felt they have dealt with the condition in both their schooling and their wider lives (Leitao et al 2017). Research considered the reasons behind this link between mental health issues and reading difficulties has recommended several programmes be initiated to explore this link through the healthcare profession (Boyes et al 2016). Overall, it is interesting that a condition which on the surface is so far detached from mental health problems, may shed some light on the reasons that these individuals feel isolated and could point towards ways that this connection can be broken.

Conclusions

Overall existing research has proved to have a lot to say about the power of disability in identify formation. The review has acknowledged the ways that the social model of disability has developed and is apparent in relation to the wider social world and social infrastructure in contemporary society. There are also a number of different dimensions of identify research which have particular significance to the study of disability including the role of biographical disruption and the role of wider relationships in creating and shaping an individual's identity. The one significant sociological theory underpinning the use of all the ideas in this research is the work of Goffman and his study of stigma and the ways this has shaped identity over the years. Spoiled identify can have profound impact on disabled identity such as the external state of seeming disabled. However, for the purposes of this research the disabilities are invisible and as such the spoiled identify has taken a different, unique, shape.

This study has explored existing research on the four disabilities, noting the different approaches and opinions, to form the foundations for the study. Various social studies have shaped how each disability is presented in society and the social issues created in relation to the disabilities themselves. In summary, this will allow readers of this research to have an overall understanding of not only the specific disabilities and their existing research but the ways that wider identify research has been applied to disability and social perceptions.

Using this research as a foundation, I was able to create a research question which engages with the gaps in the literature and the ways that social research would benefit from the new study. The question and the elements of research which it is going to explore is outlined in the following section in order to provide a basis on which the question was shaped before the research itself is undertaken.

Chapter 3: Methodology

In order to conduct the research in the most efficient and productive way I had to make a series of important decisions regarding the research itself and the methods I intended to utilise to generate the most valid results possible. This ranged from the decisions regarding the best sampling technique (which turned out to be a stratified sample for the four disability categories) to the actual data collection process (semi structured, one on one interviews). This also includes acknowledging the limitations of this research and the ways that this can impact the study and how they could be improved in future studies. Research exploring the most effective and ethical ways to research individuals with impairments and disabilities is extensive and provides a firm basis on which to make decisions regarding the methodological structure of this study. Research dealing with the best ways to interview individuals with impairments varies from physical inclusion to ensuring informed consent, but all are valued when considering how best to involve your participants.

One of my first thoughts and potential conflicts of interest lay in my motivation and the potential for an overly subjective analysis of findings. Liamputtong (2011) explored the role of the researcher in the process of qualitative research with disabled individuals. They stated that in order to gain the most valid insight, a researcher must relay on a certain amount of self-disclosure. This openness creates a rapport between the researcher and participant and generates a level of trust on the part of the researcher which encourages disclosure of more sensitive or intimate thoughts, feelings or experiences. With regard to my own research this seemed both logical and useful based on my personal experiences (as a disabled person). Openness created an understanding between myself and the participants which allowed for a better relationship and more detailed responses. Liamputtong also states the value of acknowledging emotional engagement in interviewing wherein the researcher may feel personally connected and affected by the experiences of their participants. Overall, this acknowledgement that interviewing disabled people can often be a more subjective process, is critical in starting the study and evaluating the validity of the findings.

Furthermore, it is critical to consider the nature of empowerment and the shifting dynamics of power in contemporary disability research. This includes a discussion of

the importance of emancipatory disability research and consideration of my position as a disabled researcher.

Historically, the “medical gaze” has famously been derogatory to those with disabilities and has labelled impairment as a problem which should be studied in search of a cure (Foucault 1963). Doctors and medical studies focused on the ability to cure an impairment studied the disabled body as something which is broken and in need of fixing. This puts the impaired individual in a position of inferiority and creates a power imbalance within medical research.

However contemporary configurations of disability research focus on the power of research as an emancipatory act. Emancipatory research was first noted by renowned disability studies advocate Mike Oliver (1990) and refers to the process by which disabled individuals claim back their identity by participating in research engaging with their conditions. Oliver valued the importance of disabled people taking their rights into their own hands and using their voices to demand equality. Emancipatory research builds on this notion by reflecting how disabled people can use research as a way of freeing themselves.

Researchers including Colin Barnes (2003) and Geof Mercer (2002) have engaged with the difference that recent years have had for disability research. They also document the changes which should be working to increase the stability and freedom for disabled individuals to engage in all forms of research be it medical, social or otherwise. Traits including accountability, use of the social model and a careful consideration of the choice of methods and the environment are key in shaping good emancipatory research. These researchers focus on the ways that disability research can aim to create a free and open environment for studying impairment and the ways that this can positively impact the participants.

This new perspective on disability dramatically changed the role of the disabled person in research, from the passive studied specimen to an active contributor in a study. I endeavoured to create a research process which, wherever possible, gave power to the participants despite the more traditional research method. I hoped that the adjustments I have made to the research structure gave participants the space to

voice their concerns and thoughts about the role of their impairment in their lives and in wider society. I have done this predominantly through the interview style (which was led by the participant allowing them to explore themes that were important to them rather than following a rigid interview structure) and through ensuring comfort, consent and understanding. Overall, I hoped that these changes would ensure that participants felt part of the research.

Another element of this shifting power dynamic is my personal role as a disabled individual. Although the research is not specifically participatory in design, there are elements of engagement which create a sense of participation in this study. I was able to disclose personal experiences to create a stronger rapport and a more comfortable setting for participants (Sandland 2017). As discussed throughout this section the role of the researcher and the participant relationship are changing and it is now more the case that researchers are taking steps to acknowledge their vulnerabilities. I have taken the time to consider my role as a disabled person and how this could lead to a subjective analysis of the research and continue to consider my own preconceived ideas about disability.

As earlier stated, other considerations when shaping the research method were the role of impairment in ensuring informed consent and creating a safe and accommodating environment and interview process. The process of gaining informed consent is a fundamental procedure in ensuring good ethical practice for any researcher. However, this can often be more challenging when dealing with impaired individuals. Research exploring the best way to ensure informed consent has established that the key is to differentiate the format of the consent documents in order to best accommodate all needs. Studies highlight the value of considering consent in both social research and in other formats such as medical procedures, documenting the need for mutual understanding and a safe and comfortable environment (Raspa et al 2020. Kalunga and Nkhata 2018).

Ensuring that consent forms were differentiated was a key concern when creating my methodology and as such I created two different forms of consent in order to ensure full understanding. The first was a more traditional consent form which participants were asked to read and sign then return to me as can be seen in

appendix B. This worked well for those with mental health problems and hearing impairments but was a source of concern for those with visual impairments and dyslexia as these were conditions which were often associated with difficulty reading and interpreting information. For this reason, I created a second series of consent statements which could be read to the participants with their verbal consent in order to ensure full understanding of their role and rights as a research participant. These statements can be seen in appendix B in the alternative form. Between these two forms I was able to feel confident that I had attained full informed consent and that my participants understood their rights including the rights to withdraw and right to confidentiality, which should have ensured their comfort throughout the study.

The other significant consideration when beginning the research process was the consideration about whether there needed to be changes in the interview environment. Due to a lack of support resources such as sign language interpreters and access friendly meeting places, many of the interviews took place either over phone or messenger services. Research has shown that technology related solutions like this are increasingly able to solve accessibility concerns and allow for more inclusive research (Silver and Lewins 2014. Paulus and Lester in Ward and Delamont 2020). This will be explored further when discussing the coding and analysis process as this required further technological support. Ensuring a safe and comfortable interview process including the environment required me to consider each participant's needs and to create a comfortable setting (Liamputtong 2011).

These considerations amongst others were some of the main concerns relating to researching disabled participants. Ensuring an inclusive and comfortable research process alongside ensuring clear ethical lines and informed consent are key. Other factors including the use of technology for the benefit of the research and creating a safe space and good participant-researcher relationship were important as earlier addressed.

Research Question

From studying all of this research, I was able to construct a research question which engages with the literature surrounding stigma, disability and identity. This enabled me as a researcher to consider a wide range of the important existing literature and to identify the gaps in written works surrounding the significance of certain invisible disabilities and their link to disability. The question itself engages with the primary subjects of the study, those being invisible disability and identity formation.

“To what extent does an invisible disability impact an individual’s identity?”

From this I was able to consider the significant smaller questions including the following:

- Do different invisible conditions experience disability differently?
- Are the social interactions of those with invisible conditions different from externally visible disabilities?
- Does age and educational attainment play a role in shaping identity for those with invisible conditions?
- How do these individuals’ lives play out regarding their disability and how does this shape their identity?

These questions were answered during the interviews and considered throughout the analysis in order to generate findings regarding the discovered relationships between these concepts.

Research Method

When generating the hypothesis, I utilised a mix of inductive and deductive methods for my qualitative studies. This study was not based in grounded theory and yet extensive reading on grounded theory was important in engaging with contemporary conceptualisations of research. This being said there are elements of this study which have benefited from this engagement with grounded theory including the coding, analysis and sampling processes.

Grounded theory represents a differently structured approach to data collection and analysis, which is often favoured in qualitative research. Generated by Glaser and Strauss this form of analysis allows researchers to develop ideas as part of their ongoing study including thematic inference based on ongoing findings (Chamaz 2006 Chapter 2).

As earlier stated, I mixed deductive steps with steps outlined through grounded theory. The main ways that grounded theory was acknowledged were in the following decisions:

“- Data collection and analysis occur simultaneously

- Categories and analytic codes developed from data.
- Theoretical sampling used to refine categories
- Categories interpreted into a theoretical framework.”

(Taken from a list of attributes of Grounded theory by Noble and Mitchell 2016). In terms of the research this meant using the data to create the themes in the research (as opposed to the interview categories).

These elements were important to the study and contributed to the strength of the conclusions particularly with regard to the interview process.

Another aspect of grounded theory which was utilised was the sampling, based on relevance to the study rather than creating population representativity which was a new approach, valued for its benefits to social studies. As well as this coding was an ongoing process which highlighted ideas as they became apparent and engaged with them as part of the data collection process (Chamaz 2006 Chapter 3).

Where this study takes a more deductive route (as earlier mentioned) is through the use of the literature review. I felt that this was an important step before conducting analysis independently and thus conducted both a concept framework (to support the interview guide) and a literature review (to support data analysis) rather than exploring these after the data collection as stated in grounded theory.

Overall, elements of grounded theory have been of great use to this research, but I felt that deductive reasoning should also be integrated. As a researcher new to the field the more systematic elements of deductive research provided a stronger basis than the unsystematic root of grounded theory. Once these decisions were made, I was able to begin shaping other areas of the study including creating interview guides and gathering a sample.

Due to the sensitive nature of the topic (discussing the impact of an individual's disability) there was a clear need to keep the data collection private. The need for consideration when dealing with sensitive topics in qualitative research has been explored by researchers in the past who have concluded that focus groups are not effective due to the fact that individuals may not be open to disclosing personal information with a large group of strangers present (Aston 2014). I have therefore decided that the research would benefit from a semi structured interview method. This is due to the fact that it requires in-depth discussion and elements of oral history narratives; participants are encouraged to speak about their lives and their past.

I decided upon semi structured interviews due to the fact that they would allow the freedom, throughout the interview process, to incorporate new themes and ideas as they become apparent (Bloor 2016 in Silverman 2016). This would allow for all themes which seem significant to be used and explored as is congruent with a grounded theory data analysis as earlier noted. Interviews were planned to last around an hour (perhaps slightly longer depending on the rapport generated during the interview) in order to keep participants interested without them feeling that taking part would take up too much of their personal time.

I also decided to use a recording device (as will be elaborated on in the discussion of the analysis method) and was therefore able to allow the participants themselves to choose where they wished of the interviews to take place (allowing for the most comfortable situation possible which is critical when discussing sensitive topics). Given that all of the participants had some form of impairment there was likely to be a lot of variation in the needs of the interview environment; I have therefore aimed to

be as accommodating as possible to the needs of each individual which would create a more comfortable interview process (Barnes and Mercer 2010). This is alongside the number of interviews which took place over the phone and messenger services where they were required to create full access for participants.

Once the research method had been decided upon, I was able to create a concept framework which provided a topic-by-topic guide to the interview process exploring certain existing research into key fields and acknowledging the significance of this topic for this specific research study (see in appendix E). It was based predominantly on themes in identity literature and engaged with elements of identity as established in research discussed in the literature review chapter. I explored elements of social identity including leisure time and personal identity including personal ambition and future plans and goals.

The interview guide itself came as a result of prevailing themes in the concept framework exploring major themes in identify research forming the basis for the interview questions. When shaping the guide, I was careful to ensure that topics took a logical and gentle route dealing with tougher topics such as relationships and personal feelings about disability later in the questions. Furthermore, the final question of the study was one which has interested me on a personal note as well as academically and required participants to think back over the discussion which had just taken place in order to confront their overall relationship with their disability. I asked the participants "if you could remove your disability from your life all together. Would you do it? Would you be the same person?" Ending on such a provoking question linked responses directly back to the research questions and created a strong note on which to begin drawing conclusions from the findings.

Topics were created to target different elements of the questions designed to underpin the overall study as were stated in the "research question" section of this chapter. The topic "work and leisure" aimed to deal with the question of age and educational attainment and the topic "community" dealt with more social elements of the lives of the participants.

More generally, these questions were often open ended and encouraged participants to discuss their thoughts and feelings in more detail. Overall, the interview guide was carefully structured in order to ensure the comfort of the participants whilst still hopefully generating in depth and valid responses that answer the research questions.

Once the interviews had begun the semi structured element began to play a key role. Participants began to include extra details regarding the role of the public and the ways that their daily activities were impacted by their invisible conditions. I therefore began to focus more of the questions in the research towards how the public have affected the participants if at all. This will be discussed in more detail as I discuss the coding and analysis elements of the study later in this chapter, acknowledging this approach as a significant strength of the chosen coding practices and the coding structure.

Ethics

There were a lot of ethical consideration to this research including the sensitive nature of the topic as established in the research method discussion and the delicate age of the sample which had been considered when selecting the participants themselves. Ethical approval was obtained from the research ethics board at the University of Kent and enabled the interviews to proceed with the aforementioned sample on the university campus. A gatekeeper was also requested to help gain access to the sample from the wellbeing department at the University (a description of the role of which can be found in the “Participants” section of this chapter). A copy of the ethics application including copies of the information sheet, consent forms and interview topic guide (Appendix A). The ethics outlined, among other things, the sampling technique and the measures taken in order to avoid discomfort whilst discussing sensitive topics with the chosen participants. There are also details about the confidentiality measures taken including the security of interview files and the anonymising tactics for relaying quotes throughout this paper (using pseudonyms for the participants safety). Copies of the consent forms and information sheets for recruiting participants and a topic guide for the interviews are included, as well as the

ethics form and are also attached separately (appendices B, C and D). Copies of the University of Kent privacy policy were also attached to the information sheets so that any person considering taking part in the research could be fully informed about how the university would aid in protecting their rights regarding safety and privacy.

Overall, this should ensure that participants feel comfortable throughout the research process which will protect them both as interviewees and myself as the researcher.

Participants

Once the specific parameters of the study and the desired research questions had been established, the next factor to decide upon in terms of the methodology was who exactly would be sought after to participate. There are a number of studies that acknowledge the significance of the formative years in creating an individual's adult identity, including research which explores the true impact of the adolescent period on identity formation by Hatano and Sugimura (2017); this study acknowledges the significance of this formative period in shaping identity. These years were stated as being between 18 and 25, the age when an individual is best able to define their identity based on who they have decided to be. Additional research by Katstaficas, Futch, Fine and Sirin (2011) discusses the importance of research exploring identity formation in the formative years and states that the key to deep analytic research in qualitative methods is to ensure a pluralistic approach. The term pluralism refers to the way that a task is approached, employing a group-oriented method which ensures the voices of all involved are considered in forming both the method itself and the end results. With regard to this research this was ensuring the participants' opinions were included in the research process. This will be utilised to an extent in the study predominantly through use of a semi structured method and a consideration of the thoughts of the interviewees in shaping the study. This approach will be of critical importance as it will ensure the participants feel included in the research process as well as providing the study itself with an inclusive consideration, which could expand on the ideas first formed in the research. The research sampled students from two different campuses in the UK. These universities were chosen predominantly due to the fact that I as a researcher have access to gatekeepers who would allow me to send my information sheet out to all students who may qualify for the study. The goal for the sample itself was to have around 4-6 individuals who

suffer from each of the four conditions (visual impairment, hearing impairment, mental health problems and dyslexia). This will make for a total of around 20 participants generating a sample big enough to potentially gain insightful and interesting data.

With regard to the gatekeepers used in this research I was able to use an individual from each of the wellbeing services in order to gain access to the sample. As part of the induction and settling in process at each university they have a meeting with students who are registered as individuals in need of support each year. I gave each of the gatekeepers an overview of the types of participants I would like to speak with and asked them to keep an eye out for suitable candidates. I gave each a copy of the information sheet and asked them to offer one to any students who fit the profile for the study. Through this means the participants were able to gain my contact information and learn a bit about the study thus giving them the option to contact me to take part. Between the two different well-being departments I was able to obtain 15 of the 20 participants I interviewed. The remaining 5 were individuals whom I had come across throughout my course of study and through disability-based events on both campuses including the disability history month events at the University of Kent in November 2018.

This method of recruitment was efficient and meant that the participants were located in a timely manner; leaving ample time to conduct the interviews and data analysis. This is not however to say that this was the best method. A discussion of some of the key limitations of this recruitment strategy will follow in the “Limitations” section.

I was able to conduct 20 interviews with five people from each of the established impairment categories. Participants were able to fill out consent forms in different formats best suited their needs and were given the opportunity to ask any questions before and during the study. Individuals came from a variety of different academic disciplines and varied between the two universities. Of the 20 participants there were 13 women and 7 men ensuring that every category had a mix of men and women despite the discrepancy in gender stratification. Demographically I took note of gender and age (university students between the ages of 18 and 25) as well as

ensuring that every participant spoke fluent English in order to ensure good communication.

After participants had emailed to say that they were interested in taking part I sent them an information sheet (if one had not already been obtained through gatekeepers) and awaited confirmation of interest. We then had to decide upon a time and place for the interviews. For a number of reasons based predominantly on access and availability the interviews were scheduled to take place in a variety of locations including a few which were conducted over text due to issues with face to face communication. Three interviews with hearing impaired people were conducted over text and two of the interviews with visually impaired people were conducted over the phone. The rest were conducted either in meeting rooms at their chosen university or in a location of their choosing such as a coffee shop or at their place of residence. It was essentially the choice of the participant as to where they wanted the interview to take place so long as it did not require too much travel. Interviews as anticipated lasted an average of 1 hour 30 minutes and explored all of the themes as put forth in the conceptual framework (appendix E).

Coding and Analysis

Once the interviews had begun being conducted the next important step was to decide on the best way to undertake the coding and thematic analysis process. Of the available methods there were two options which stood out as potentially the best. These were thematic analysis and interpretive phenomenological analysis (IPA). Both had their strengths and as such a decision had to be made.

IPA is a method known for its in-depth coding process through which each participant's responses are considered both by theme and based on discursive choices. Many of the traits of IPA coincide with the goals set for this study including focus on lived experiences and one to one interview processes (Larkin, Watts and Clinton 2006). However, there were certain constraints which turned the research away from this method including the time required to explore each participant's responses and the in-depth nature of discussion using this form of analysis (Larkin and Thompson 2011). Using IPA often means that the sample of the study has to be quite small (Guihen 2020). With the different sample groups which I desired to interview this meant that any conclusions would be very subjective and it would be tough to conclude whether the findings pointed to any useful social phenomena. Overall, despite the benefits I decided to explore other methodological options.

Alternatively, thematic analysis has other benefits including the freedom to explore themes as they appear based on analysis of transcripts and the more wide-reaching coding process which allows interviewers to study a larger sample of participants responses (Terry and Hayfield 2020). Thematic analysis allowed me to begin the coding process as soon as interviews were completed and also gave me the opportunity to review the interviews and to acknowledge any reoccurring ideas from preceding interviews. This strengthened the interview process and allowed me to engage with themes which became clear throughout the process rather than sticking to the pre-decided questions and themes in order to gain the best insight into the topics which participants found the most important. This top-down approach focused primarily on larger themes and dealt with the smaller subcategories in more detail once initial coding had concluded. This gave me the structure provided by grounded coding methods alongside the freedom and looseness of dealing in wider categories (Terry and Hayfield 2020). Once all interview were concluded the larger themes were analysed in depth in order to obtain more focused concepts which pointed to more specific social phenomenon.

Alongside this, thematic analysis provided a time-oriented way of dissecting the interviews and ensured that there was sufficient time to analyse findings. Given time constraints of this research I was forced to consider this as a factor when timetabling the study. In future it may be beneficial to employ a more detail-oriented form of analysis

Thematic analysis was chosen due to the existing research which shows its benefits when dealing with in depth qualitative research.

Th next step was to create a coding framework which would allow for the more efficient thematic analytic process. As discussed above, elements of the coding process built upon ideas put forth by grounded theory advocates, particularly those regarding category definition based on ongoing interview outcomes. This provided a clear way of coding findings based on common ideas and terms. Coding of the interview recordings was based primarily on the inductive process of finding, noting and grouping common ideas. In line with the thematic analysis this meant utilising thematic coding (Yi 2018). Words and phrases were manually coded based on their meaning into groups which shared common ideas. I created a hierarchical coding framework which engaged with ideas of varying levels of significance and began the process of grouping code into themes (Medelyan 2020). From here thematic analysis could begin to create a theoretical framework using smaller ideas as subcategories for larger dominant themes.

It is also important to acknowledge the role of technology in the coding process as many of these procedures were undertaken using recording and notetaking software. Work by Boyatzis explains the ways that thematic analysis works and the ways that it

can enhance the richness of analytic findings (Boyatzis 1998). I had decided that the coding would come directly from the recordings of the interviews, predominantly due to my sight loss which makes reading transcriptions tougher and more straining. I also felt that this gave me the freedom to revisit the interviews and the emotions conveyed by the participants as I consider their responses and the feelings behind them. This decision was also backed up by research which engaged with the value of utilising software to support interviewing and coding processes (Paulus and Lester 2020. Chapter 37). As earlier stated, I utilised recording devices and notetaking software in order to record the interviews. I was then able to colour code the themes in the recording programme and jump between points of the interview based on which theme I desired to explore. Although the research piece itself predominantly engages with QDAS, they acknowledge the role of other software which allows for better management and organisation of qualitative data.

Using audio notetaker software I was able to analyse the interviews and code themes based on different colours. Once the important terms and ideas had been coded, I went through and grouped these codes into the major themes of the research. Once the first few interviews had been conducted and coded in this way, I had a first round of themes from which I could conduct a thematic analysis. As the interviews progressed, each new interview will be analysed based on the existing themes and I will be vigilant to include any new themes which emerged as a result of the extra interviews. With these themes decided and the important quotes chosen from the findings I will then be able to come to any significant conclusions about the validity of the original hypothesis and research question regarding disability and identity formation.

It is then my hope that the research, once completed, will be of use to the wider disability studies community and that it will provide insight into the power of an invisible disability as a factor in the identity formation processes of individuals entering early adulthood. Whether this is through the publication of the study itself or simply the inspiration for other research in the future this study aims to have a significant effect on the wider social world.

Limitations

There are a number of limitations which have come as a result of the time and resource constraints of the study. Firstly, I have had to contain the number of different invisible conditions which I studied due to the lack of time to interview people preventing a more varied sample. This has meant that further research would

benefit from a second round of interviews exploring other invisible conditions including more internal disabilities such as Chromes disease and conditions which are often prone to flare ups such as fibromyalgia. As well as this there is the limitation of the lack of geographic variation of the sample breakdown and the lack of demographic diversity. Although I have attempted to get as equal a separation in gender and the two different locations as possible this was still an issue based on both time and ethics access.

For example, the recruitment process meant that I was only able to speak with individuals who had engaged in some way with student support services. It is often the case that people who are able to seek help and support with their conditions have some level of affinity with their impairment and as such will have engaged with it as an element of their self. This brings into question whether the findings of the study truly reflects the thoughts of those with these invisible conditions or if the results have been biased through the recruitment system.

Further research would benefit from a wider sample in order to discern whether or not the phenomenon noted in this research is repetitive of a wider social issue.

The method I have chosen here should be the most effective in answering the research question for all the reasons that were mentioned throughout this methodology but it is still important to consider the things which this choice of method excludes, which could limit the overall research. Firstly, choosing interviews over a more anonymous method such as surveys means that participants will be dealing with a certain level of interview effect as they may attempt to give responses which I (as the researcher) would want to hear rather than exactly how they would naturally respond to the questions. This could impact the research and may have skewed the findings as respondents tell me what I want to hear rather than their real experience. Another consideration is the recording method for the research and the fact that it can often be tough to go back through the interviews when they are solely recorded audibly. It takes much longer to go through the entire discussion when analysing and as such could slow the research process. However, measures have been put in place regarding coding methods to ensure the most efficient time management. Interviewer effect could also impact the results as individuals desire to respond to questions in ways which I (as the researcher) would find interesting or useful rather than in the genuine way they would respond if the conversation was not

part of a research paper. All of these limitations have been considered when shaping the study and it has been concluded that the chosen methods outweighed the weaknesses and I have formed the method form this.

Results

This research has generated some significant and interesting results which point to specific and otherwise undocumented trends in identity formation for these specific categories of disability. Three main themes came as a result of this research and each has unique properties which impact individual's identity in profound ways.

Chapter 4: Invisible disability and identity formation, explores the relationship between invisible disability, misunderstanding and identity. Existing research posits that the main issue with accepting disability as an element of one's self is the constant exposure to the disabled body and the impact this has on social perception and ability to define one's self. However, in these instances the lack of external signifiers of disability are to blame for an inability to accept the role of the disability in life, whether this is through frustration, misrepresentation or assumptions about what disability should look like. Chapter 5: Community and Hidden disability; explores the role of community and leisure activities in the lives of those with invisible conditions. Community is a critical element of identity especially in the explored age range and as such is of crucial significance to this analysis of disability and identity. Overall, the following analysis considers several dimensions of contemporary identity and their relationship to invisible disability, presenting ideas which have up until this point been unexplored by disability research, in this specific sense.

Chapter 4: Invisible Disability and Identity Formation

One of the cornerstones of social stigma and disability research is the work of Erving Goffman and his conceptualisation of spoiled identity. Goffman's principle engages with the ways that an externally recognisable condition such as a disability signified by a wheelchair, a stutter or a cane can lead to public judgement and prejudice about their abilities and who they are, more widely, as individuals. He also engages to a lesser extent with invisible conditions acknowledging that 'backstage' concerns and thought processes can generate stigma and impact ability to connect the internal self with the external self through actions due to impairment. These principles were fundamental in the construction of social stigma and the ways that identity formation processes can be impacted by the social expectations of disability and the ableism associated with a lack of external signifier. This research formed the base for this study. The points discussed throughout the literature review were also considered in relation to the following findings which see a new relationship between stigma, identity and hidden disability.

The inverse appears to be true regarding the identity formation processes of people with invisible disabilities. They attempt to negotiate the social world with no clear external signifiers of their impairment. The public assumption about a person with an invisible condition is that they are, in fact, fully able and cannot possibly be disabled without a clear sign which lets the world know what their impairment is. It therefore becomes the responsibility of the disabled person to disclose and explain their invisible condition whenever they may need assistance in public or even private spaces. The act of disclosure forces the individual to constantly be aware of their disability; constantly having to battle between their identity as a disabled person and their other primary identity traits. Every time an individual is forced to explain what is "wrong with them" and what help they require they are having to acknowledge their impairment and become the disabled person again. This ongoing process of embodying the disabled identity can be frustrating and even distressing as an individual attempts to create an identity for themselves. There were three dominant

thought processes which became apparent in relation to this idea of spoiled identity and disclosure,* which are impacting the lives of these disabled individuals. These are: misrepresentation, frustration and relationships (specifically the lack of expected findings in relation to personal connections and relationships). These concepts have had a marked impact on the social lives and identity formation processes for all four of these invisible disability groups.

Misrepresentation

The theme which reoccurred the most throughout these interviews was a feeling of being misunderstood and not being able to present themselves as they intend to be seen in social situations. Individuals with invisible disabilities are often victims of judgement since the impairment is unseen and as such unknown to the majority of the public. Their behaviours are considered to be socially abnormal rather than traits associated with a particular disability, this leads individuals to feel the wider social world is against them and they cannot simply be themselves without prejudice from the wider public.

The person may be assumed to be drunk (due to balance issues created by a hearing impairment), staring (visual impairment), rude/blunt (when struggling with feelings of anxiety or depression) or illiterate (which was seen as a problem by one participant who was struggling to read whilst out in public). It is evident that wider public assumptions are present when people fail to recognise that impairments are often the causes of issues in the social world. The problem is when sometimes the individual is not even given the opportunity to disclose their disability (therefore explaining their behaviour) they are left feeling that strangers are judging them based on this incorrect perception. This can cause the disabled person to feel they are misrepresented in public based on assumptions about who they are which do not take their condition into account.

Carol was a psychology student and was very aware of the impact that her disability was having on the way she was perceived by others in public. She kept her hearing aids under her hair and was very clear that she enjoyed “the freedom of people not always knowing” (Carol). However, when asked specifically about the impact the

invisibility of her condition has had on her life, she expressed a lot of negative thoughts about how she believed the public viewed her. Members of the public had approached her about seeming drunk in the middle of the day and had said some upsetting things in reference to this misperception.

“it’s a real struggle, I drink very rarely so it is a bit insulting when people think I am drunk at 10 in the morning” (Carol).

The reality for Carol (and for others with hearing loss) was that her balance was constantly affected by her impairment and meant that she often appeared unstable. A lack of public understanding meant that for many with hearing loss this trait, which in reality is a symptom of their condition, is perceived as a deliberate state caused by intoxicants including alcohol. This misrepresentation has a strong impact on the identity formation processes of these deaf participants as they feel they are victims of a prejudice which stems from a misunderstanding of the realities of having a disability. Without any external signifiers (as was the case for these participants) the symptoms are not related to the condition and as such can cause self-consciousness and concern about public stigma.

“I am a pretty helpful person but sometimes when I am out people ask me for directions or advice or something, but I don’t hear them. It makes me feel bad because that is not who I am! But I guess people don’t know my truth” (Danielle)

Being constantly faced with the ignorance of the general public can lead to feelings of inadequacy through misunderstanding. The person that an individual wants to be no longer aligns with the identity being projected due to the symptoms of their disability.

This issue of misrepresentation was also apparent in the accounts of those with visual impairments, as expressed by Ian who found that he was often in uncomfortable situations because of the social problems that could be caused by his sight loss. He found that when he was out in public people would think he was being rude and either staring at them or ignoring them due to his trouble looking in the correct direction due to his sight problem (which meant that he looked out of his peripheral vision rather than central). He was very rarely given the opportunity to

discuss the cause of his behaviour with the strangers as they are often passing interactions, but they can still leave a mark on the identity of the individual themselves.

“it gets so frustrating and makes me feel like everyone is judging me just cause sometimes someone will ask me why I am staring at them or a shop assistant will ignore me because I am not very good at making eye contact.... People think I am ignoring them. Even my friends forget I can’t see them and get a bit annoyed with me” (Ian)

“I can’t be arsed to explain every time someone thinks I am ignoring them, or I bump into them by accident that I am blind. It would be nice if people could just be a little less aggressive and let me be” (Grace)

For those who suffer with visual (and to an extent hearing) impairments there is an added dimension to why their condition is not considered as seriously which stems from the commonality of the external aids for those in this disability subset. This can increase the misrepresentation of the public as they expect to see certain aids and behaviours (as will be discussed in the stereotyping section of this chapter).

“people always tell me that, even if they know me, they forget, ‘it’s not like you have glasses or anything’ they say. But I just wish they would stop caring so much if I accidentally ignore them or if I seem like I am staring. The general public are even worse, they judge me without knowing me at all” (Fred)

This increases judgement of behaviours like staring or accidentally ignoring people as strangers and acquaintances are more likely to judge before considering explanations.

The illiteracy aforementioned regarding how dyslexic individuals can be misjudged in public is evident mainly in the accounts of the personal experiences they have faced when living their everyday life. Their condition has therefore become in need of disclosure in order to reconcile a social situation. Members of the public (particularly in professional situations as was clear from the accounts of these participants) judge those with dyslexia as being uneducated. They often see the condition as something

which mainly affects children and can be overcome in adulthood. This can have a devastating effect on the confidence and self-worth of those with dyslexia as they face having to either conceal or explain why they struggle to comprehend written text. Katie a 20-year-old hairdressing student stated that in her part time job as a hairdresser's assistant she often struggles to spell clients names and they...

“sometimes get offended and angry and treat me as if I was stupid. It makes me feel bad because sometimes the names are so simple, but my brain just won't put the right letters down on paper. Then I either have to explain the dyslexia or just leave it, strangers think I am stupid. Kinda sucks but I get over it” (Katie).

This misconception can have a profound impact on the identity formation processes of people with dyslexia as they find it difficult to explain that they are often highly intelligent individuals who sometimes struggle to convey this to others. Some of the dyslexic participants in this study have chosen their career path based on avoiding activities which are difficult for them. For example, Olivia was very proud of her choice of degree in physics and explained that she had chosen this because it “made sense to her.” She loved that it meant that she did not have to constantly address her condition as she was able to keep up with equations and formulas with minimal struggle (something which seemed surprising to me based on the existing literature on the impact of dyslexia on education),

“I feel free to do my course and it is rare that I get behind. I love physics and I love that I am able to overcome my dyslexia and just be who I want... It doesn't define me at uni like it did at school” (Olivia)

Also, Maria, an animation student who wished to pursue a career in animating “or any other job with art and technology” (Maria). Each of these students evidently sought careers to avoid issues with their disability in order to protect themselves from being judged as stupid, uneducated or illiterate (all of which are words which the participants themselves used to define their interactions with members of the public).

“working in animation is my dream because I reckon people won't care that I am dyslexic. Whenever people hear that I have that disability I always felt that they think less of me. In animation there is nothing to misread or miswrite I am just another animator doing my work” (Maria)

Overall it appears that there are a few occasions where those with invisible disabilities feel they are being singled out or treated differently because of their impairment. They cannot simply make members of the public understand that they are disabled, which can lead to people judging them before they understand the true extent of their circumstances.

Finally, for those with mental health problems the misrepresentation comes from the normalisation of language surrounding mental health and the ramifications for those who suffer from these conditions in their day to day life. This concept known as saneism (discussed in the earlier literature review) was a strong influence on how participants in this research felt they were being judged and contributed to their sense of isolation or prejudice. They were well aware of the ways that terms including crazy and depressed have been drawn into everyday speech. This can have a profoundly negative effect on those with mental health problems creating an environment where expressing their issues feels tough, or even impossible as they are faced with their worries not being taken seriously.

“everyone says stuff like ‘I am so depressed’ and ‘god this is making me crazy’ but for me it is so real. People don’t seem to take my problems seriously because I don’t look any different to all these normal people who say the same stuff, but for me it is so real. That is why I sometimes feel I can’t talk to people about my feelings” (Victoria)

Dealing with the constant onslaught of messages which use terms and conditions such as these in a jovial and often casual way has degraded the meaning of many of these terms and has brought them into the mainstream. There are instances in which certain symptoms of anxiety have led participants to feel that others think they are being rude. Participants including Robert and Steven felt that, at times, they were unable to be their true selves due to the impact that their anxiety can have on their personality.

“some days people see me, and I am a bit quiet and closed off. It is not in my character normally and sometimes my friends assume they have upset me or done something wrong when they haven’t” (Steven)

“if I am having a bad day or I have to meet strangers for the first time that makes my anxiety way worse and it stresses me that I come across super rude when actually I am just uncomfortable. I never get the chance to explain that I have a mental health problem or even if I have the chance it doesn't feel like the right thing to do... it doesn't seem relevant to the reason I am meeting the new people which is usually a work event” (Patrick)

(Patrick's work in journalism meant he went to a lot of networking events in which he had to attempt to control his anxiety and the perception that new people had of him).

The condition being hidden means that it is tough for individuals to explain why they are behaving the way they do and as such leads others to gain the wrong impression about who they are and how they desire to portray themselves. This can not only impact the social abilities of these people but can even limit their career progression as much of the time the first impression of these people does not reflect their true personality as this is masked by their condition. The difference in the lives of those with hidden disabilities exists not only in their perception and social experience but also in potential social roles. They can be overlooked as a result of their condition. Patrick felt that he was overlooked for career progression as a result of his disability, however he was unable to prove this as it was felt that he was not as suited for promotion due to the impact his condition can sometimes have on his demeanour and his ability to interact with strangers. On certain days and in certain scenarios his mental health condition could flare up. This could represent a further study opportunity which engages with the impact of invisible disabilities on engaging with social roles and creating a space for oneself in society.

Overall, each of these misconceptions and misinterpretations have had significant impacts on each of the participants in this study. In terms of identity formation there is a lot of ways that this constant misrepresentation has caused issues when it comes to being whoever they desire to be. Whether it is attempting to see past judgments from members of the public who do not understand that some disabilities do not have signifiers or through ensuring that they are surrounded by individuals who are aware and accept these traits as symptoms. When an individual is constantly forced to confront the invisibility of their condition through the reactions and lack of understanding of the public, this leads to frustration. They have to handle

the reality of being perceived as something other than what they wish to be. In order to overcome these emotions individuals, need to be part of a society which does not assume people's situations before getting to know them. This is not to say that disabled individuals whose conditions are externally visible do not suffer socially with issues of misrepresentation but simply exploring the unique way that those with hidden conditions live and the circumstance they experience.

Frustration and Exhaustion

Misrepresentation can often be difficult for disabled individuals to process, leading to issues including social isolation and low self-esteem. For those with invisible conditions there are also feelings of frustration and exhaustion stemming from the constant need to disclose and discuss their condition with strangers. This relates disability to personal identity through social interaction, the feelings of frustration and exhaustion which present themselves whenever participants are forced to explain their disability can severely impact their sense of self. Every impairment group had participants who reflected this same idea about how the invisibility of their condition can cause feelings of frustration as they face having to constantly explain their situation to strangers due to the simple lack of external signifier; this was often draining and tiresome. It is simply due to the lack of an external signifier that participants are forced to disclose this personal information. The problem seems to be that they appear able and as such, characteristics which could be considered symptoms of their condition are judged as being rude or out of place to the wider public as they cannot see the underlying disability. Beth, a deaf woman who was born with no hearing in her left ear, was studying to become a care assistant. She found that she was often very aggravated by the way that her hearing loss was misunderstood. She suffered from other conditions which were all related to an overarching disability which made her condition externally visible to an extent as she has one arm which is shorter than the other. She felt that it was necessary for members of the public to be more understanding of a wider range of conditions and stated, in reference to having to explain her experiences that:

“Annoying that some people can’t understand disability” (Beth)

And later adding:

“I wish people would always be kind and help me without needing a full bloody medical history (laughs)” (Beth)

Despite accommodating for her impairment (conversing in messages rather than in person due to a lack of sign language interpreter as mentioned in the methodology) Beth still spoke in very short statements when asked if there was a reason for this, she replied

“I have gotten really used to not saying much because I can’t usually hear the answer, I suppose... it is just easier” (Beth)

This felt like a significant comment on the overarching lack of understanding and preparedness in society and the deep-seated impact it can have on behaviour for those with disabilities in general.

For Beth as well as others in this research, this constant requirement to explain that they had problems negotiating certain elements of their life (and the frustration which it causes) is consistent and relates to the lack of understanding regarding the different ways that disability can present itself. As established within the literature review it is not only those in wheelchairs (or other assistive apparatus) who are disabled and the fight to make this clearer to society is often agonising for those who suffer from these hidden conditions. The invisible element of Beth’s condition was as much a source of irritation as it is for the majority of the other participants. They felt that the public were uneducated and failed to understand hidden disability as a part of individual’s everyday lives. This was also the case for Holly who was a Sociology student whose visual impairment had been with her since she was 10. She expressed feelings of frustration at the fact that people would constantly stare at her or make comments whenever she struggled to read worksheets or slides in lectures; she seemed to feel that people thought she was somehow doing something wrong because they couldn’t see her condition.

“people look at me like I’m doing something weird and I just get so angry with them! Why should I have to explain to everyone that I can’t see just because they expect me to behave in a certain way... I bet if I had a cane, they would leave me alone” (Holly).

As a sociology student she seemed far more aware of the social phenomenon that was present and thought that people on her course should be far more understanding due to their similarly educated position.

“we learn all the time about stigma and labelling but people still seem to expect everyone to conform to the same social norms” (Holly)

Her frustration was representative of wider feelings of exhaustion at the lack of understanding which was present within a society which claims to be more tolerant and understanding. The impact that this can have on a person’s sense of self is critical, especially at this stage of their lives, as they attempt to negotiate having a disability with new and often challenging roles. The constant need to confront their condition in order to gain acceptance of their needs causes these individuals to feel tied to their disability and can strain their sense of self.

“my hearing aids are usually hidden by my hair. I do it on purpose, but it is annoying to have to keep telling everyone. I just want to be the same as everyone sometimes, it is so annoying at times”

“I am happy to talk about my deafness just not alllll the time” (extended all is indicative often emphasis given by Carol herself) (Carol)

The struggle for those with hidden disabilities is that they are never able to simply be disabled, but instead are forever forced to explain how their impairment affects them and what help they need. This can be distressing as the participants become exhausted by this disclosure which can impact their confidence and their relationship to others and the social world at large. If their conditions were visible, they would be accepted as disabled without having to explain themselves, this would give them the freedom to explore other elements of their identity without constantly being forced back to be the disabled student.

For those with dyslexia the frustration process comes from a slightly different place. It is not the actual disclosure, but is the fact that society has a tendency to dismiss the condition as not that serious and something that the disabled person is expected to overcome. Natalie expressed this feeling the most succinctly in reference to her experiences with lecturers who felt that she did not require special attention simply because of her disability. She was very disappointed about how her condition had

been dismissed and felt that she could have improved her essays if she had the extra time and support, she needed.

“whenever I tell my lecturers about my dyslexia, they usually have one of two reactions, they either are totally fine with it or they seem to question why I even think I need help in the first place. They would never be like that if I had some other learning problem. Like if I only had one hand, they wouldn’t think twice about me needing special help” (Natalie)

Being constantly told that your condition is not serious enough to require help can not only be frustrating in terms of having to disclose it every time you require assistance but also as it can make the participant feel inferior as they have to deal with their disability without the support of others. Lewis also felt agitated by the constant demand to explain his condition and the reactions that he had from others when he explained that he was disabled. He felt that he had not been taken seriously when he has asked for assistance and that his disability was more of a joke.

“I get so sick of being laughed at, it’s like my condition is just me being dumb and that I don’t really need help... they seem to look at me like ‘figure it our idiot’ and it is so annoying” (Lewis)

These feelings of exhaustion and frustration stem from the fact at they are not being taken seriously and the ways that even when a condition is disclosed there is little to no respect for their needs. Trying to accept their disability can be increasingly difficult as they are constantly told that their condition is not really a disability and that they are simply being stupid (similar responses to those in relation to the misrepresentation associated with dyslexia in the form of assumed illiteracy or lack of education).

There is also a lot of frustration for those who suffer with anxiety and depression. These conditions are already considered to be very isolating due to the social stigma attached which has often led to people feeling uncomfortable discussing their feelings when anxiety strikes. The hidden nature of the condition is particularly frustrating for some participants as they attempt to negotiate a life where they do not want to be “the person with the depression” (Victoria), but they also need support and understanding from others).

“it really is sorta frustrating to me ...in a way, it is worse that it’s completely hidden because people don’t know and you know you don’t really want to broadcast it... most times people assume that you are fine” (Robert)

The invisibility of mental health conditions can lead to individuals feeling socially isolated and can also make them more inclined to keep their problems to themselves. It can be exhausting to have to handle mental health struggles alone and yet the current social framework means that many individuals feel they must deal with their disability alone.

“I get depressed then I just lock myself away from everyone else. I don’t want people to see me and think I am just morbid and boring when it is just the condition playing up” (Tracey)

This can have a significant impact on identity formation due to the effect that feeling alone can have on an individual’s ability to socialise, build relationships and participate in education and other extracurricular hobbies. For Steven whose anxiety took full hold when he moved to university, the frustration of feeling that nobody took his condition seriously came as a result of the sanist language used in western society as well as the thoughts that mental health conditions can simply be medicated away.

“I was struggling with the fact that nobody could see my struggle and that the doctors just wanted to give me pills... then when I tried to explain it to people, they would sometimes just brush off anxiety like ‘everybody gets anxious, you’ll be fine” (Steven)

When an individual is suffering from a bout of anxiety or depression there is little that many can do to ease the condition but an awareness of the reality of an individual’s feelings can help others to understand and accommodate certain feelings and behaviours. Simply acknowledging the struggles of mental health problems can have a profound impact and allow individuals to engage with their condition whilst not isolating themselves and will also give people the chance to deconstruct western interpretations of mental illness through questioning sanist language and social perceptions. This creates the freedom for individuals to relax about having a bad day and allowing them to be who they wish to be without segregating themselves when symptoms increase. This helps to break down the frustration regarding the presentation of mental health problems in public spaces.

Overall, there are a lot of negative feelings regarding how these individuals' disabilities have impacted their social lives. The frustration and exhaustion that come as a result of having to negotiate the social world whilst having to potentially disclose their personal challenges to strangers is of critical significance to this study. The impact that this can have on individual's identity formation is significant as it points to the way that an invisible condition can have more of a negative impact on lives. Disclosure creates a new relationship with their disability as part of their sense of self. Participants shared a concern about how the social world perceived them, becoming exhausted by the battle to discover themselves whilst handling the looming presence of their disability. They all felt that it was unnecessary to have to constantly explain their disability and wished that members of the general public should be more accommodating without having to ask for an explanation. Frustration lies in the need to discuss their condition with strangers simply because of the lack of signifiers.

Relationships

Each of these accounts and issues has explored the ways that individuals who are unaware of the underlying disability have acted and reacted in relation to the disclosure or associated behaviour for hidden disability. Existing literature implies that closer personal relationships will present a more supportive and understanding environment as they are aware of the disability and have formed a strong relationship with the individual regardless of this. Whether this is friends or family, these relationships represent a different view of invisible disability which not only supports elements of the inversion theory but also contradicts this research's expectations regarding support networks and acceptance (based on literature from the earlier review exploring the role of family in supporting disabled people, such as Heaslip (2016)).

The reality however is that for the majority of people there were feelings of support and relief that they have a strong network of friends and family. Many also expressed that they felt their relationships were not the reason they were able to shape their identity but were simply something which is expected in contemporary western

society. Participants felt that their relationships were important to them but were no more special to them than relationships would be if they were not disabled. Having close friends to help them decide who they are is critical in identity formation but was not critical in shaping individuals and the role that their condition played in their identity. It was often other institutions such as work or education which dictated the role of their disability in their sense of self due to the power they had at this significant stage in their life. This is likely because of the power of the social world in shaping individuals' identities, particularly in relation to disability (as was dictated by the social model). Being a part of the public sphere and engaging with the ways that members of the general public see and approach you is widely considered one of the most important factors for identity formation and as such close relations are often simply there but do not shape identity as much as support the choices the disabled individual makes. The interesting element of this section is that for every individual who conforms to the expected response regarding their family; this being, using their family as comfort and as a support network there is another participant who hides their impairment or feels that their family do not understand or forget that they are disabled due to the lack of external signifiers of impairment.

One of the fields in which support and relationships were assumed to be the most significant was within mental health studies. Individuals with anxiety and depression are often prone to feelings of social isolation and social prejudice due to the lack of public understanding and the internalisation of feelings and emotions associated with these illnesses. Participants with depression highlighted that they often felt they were a burden on their family and friends and that this was the reason they isolated themselves to an extent whilst their condition was most prevalent.

Tracey felt that her family were always there for her but often chose to hide her slumps from them as she did not want them to worry about her and how she was coping. She felt this was easier because of the invisible nature of her condition.

“it is easy to hide when I am feeling down from my family. They are supportive and all but I don't like to share my feelings with them all the time... it would be tough to hide if I had a physical disability yeah, like if I had a condition that meant I had a limp or a twitch I couldn't really hide that” (Tracey)

This was not what was expected of the results of this study as it was assumed, due to the results of existing research, that participants would feel their family and friends were there and helping them to cope with their disability.

“I love my family and they are always there for me... I guess that is sometimes the problem. Every time I look sad, they think I need help and get all weird with me. They don't know the difference between a bad day and a bad turn, it is difficult. I find I try to keep things to myself because they get so weird and worry with me so much”
(Steven)

“I have a friend with anxiety and I usually talk to her because she gets it more than anyone else. Reading a book about depression just isn't the same as experiencing it. My family try and I love them for that” (Steven)

Feeling confident and able to engage with their condition and discuss it with closer friends and relations is often considered to be a critical step in engaging with disability as an element of one's identity. This habit of hiding and isolating oneself because of the invisible nature of a condition presents a potentially worrying link between invisibility and identity. Comments made by Tracey (see above) and others imply that this lack of connection between their impairment and their close relationships could be damaging to their ability to come to terms with their disability and could lead to further disassociation of their condition from themselves, potentially leading to negative associations with disability or even an identity crisis.

Another way that thoughts and behaviour surrounding close relationships varied from what was expected was the ways that dyslexic individuals felt that they were not even being taken seriously by their family at points. This led to similar thoughts around hiding their condition and hoping that close relations would leave them to get on with things as opposed to *“interfering with my process to get by”* (Olivia). The ability to mask the symptoms and struggles associated with these impairments gives participants the option to cut out their close relations and to attempt to live their lives without support. Whether this aids them in the long term is tough to say, but it appears from the responses of participants that this creates an occasional sense of freedom from the conditions; the people closest to them are not constantly engaging with their disability as part of their identity.

“I think my family sometimes forget I have dyslexia. Sometimes they are as bad as strangers when they judge me but then when they remember they always feel bad, but it is still super annoying” (Natalie)

This concept of forgetting is unresearched for the most part by disability scholars as it is often taken for granted disabled individuals' conditions would be acknowledged by their friends and family. Considering the potential that these responses present the norm in the experiences of those with invisible conditions means the possibility that there is a whole other relationship between disability when it is invisible and how this plays out in their close encounters with friends and relatives.

With regard to those with sensory impairments it was expected that there were elements of help seeking behaviour which extended to the ability to know how to ask for help negotiating public spaces as well as being able to discuss both social and emotional problems with family and friends. Existing literature implied that the special requirements which come with having a sensory impairment mean that these participants are in need of support within the home and in the wider social world. The strongest correlation between feeling comfortable with their disability and having a strong support network was present for those with hearing impairment. Deaf adults often benefit from their family learning sign language and many of the close relations learnt in order to communicate better with their loved one. Carol expressed great love and admiration for her family who attempt to accommodate her impairment. She was keen to express that her family were always there for her and thus reflected the thoughts that were more expected from the majority of these individuals.

“my family are amazing. They all learnt BSL and are always there for me when I need them. I honestly do not know what I would do without them” (Carol).*

*BSL here referring to British Sign Language.

This positive response is more expected of the role of relationships in families with disabilities, but this is not the whole story. Where there was one positive response there was equally others who felt that they were not benefitting much from their relationships. One of the strongest responses came from Anna who felt that her family abandoned her when she lost her hearing. She had moved in with her

boyfriend and was pleased with the support she received from him but was very affected by the reactions of the family and the way they responded to her diagnosis.

“my family don’t care about me. Once I went dead, they thought I was too much hard work. I moved in with my boyfriend and he is great, but my family just couldn’t be bothered to learn how to help me” (Anna)

She felt that her condition meant that her family had decided to abandon her, reflecting a real divide between what is expected from the family members of disabled people. Overall, individuals with hearing loss presented little to no consistency in their responses regarding the role of close personal relationships and their disability.

For those with visual impairment there were mostly positive responses which reflected the feelings expected based on the findings of the literature review. Every individual with sight loss felt that their family were there for them and felt well supported. They all discussed the fact that they were not friends with others with visual problems other than in the support groups mentioned in the following chapter, and that they sought comfort mostly from their family.

“I love my friends, they kept me sane through the school system. If it weren’t for them, I would probably have gone a bit mad before now. They are always there when I need them and for the most part they remember when I need help. Sometimes they forget but it is never really a problem, like I still love them, and they get there in the end. It is sorta nice that they forget because it makes me feel like one of the groups and not just the disabled one. I feel accepted I guess because the sight loss can’t always be seen so it lets them see me for me” (Fred)

“my family are always there for me, they don’t take my condition too seriously and we are always able to joke about it. I think that is super important in my family to have a laugh. Problem is, when people don’t know I am disabled they think we are mental! We are always making weird jokes about me being blind and it takes a lot of explaining to make strangers see the truth” (Holly)

People with sight loss were all overwhelmingly positive about their relationships with their friends and family and overall, were the only group who expressed these

feelings almost exclusively. This is not to say that others from every group did not express positive feelings but simply that they were the most aligned in their responses.

Overall, responses to questions regarding relationships with friends and family were varied but for the most part did not reflect the anticipated thoughts based on existing literature. Some of those examples, including the responses from Natalie and Tracey, showed that the invisible nature of the conditions plays a serious role in explaining why these responses are different than expected. Even family members who live with participants day to day can be prone to forget that their family member or friend is disabled, and this can lead to a greater struggle to identify with their condition for those with the impairment. A larger sample would be required in order to discern whether there is a trend in relation to the impact of invisible disability on relationships and identity. The sample provided interesting results, but responses were varied which reflect the need for further research to establish whether there is a trend here or not.

Conclusions

Overall, there were multiple ways these conditions impacted on the day to day lives of the participants. This has had a profound impact on many of the identity formation processes and social interactions for those involved. This is through general feelings of frustration which stem from the lack of understanding of invisible disabilities and the constant requirement to explain the disability and its impact in a person's life. Processes of identity formation often rely on the impression and interaction with other members of society and as such the reactions and behaviours of friends and acquaintances.

The most striking result of this study which stands in direct relation to answering the question was the impact of misrepresentation on the identify formation of these participants. Invisible disabilities mean that on first meeting or seeing a person, strangers are entirely unaware that they have some form of impairment. This can

often mean that there is an assumption about what their behaviour says about them. This has led to a lot of misunderstanding from the public as they attempt to rationalise and explain behaviour which can sometimes be a symptom of their disability. Whether this means people feel they are drunk when they are not or even that they cannot read or write well, these assumptions can have a profound impact on their thought processes altering how the participant sees themselves and even their place in society. This can also impact the role that their condition has in their identity as they may choose to associate either more or less with their condition due to the extent to which they must explain their behaviour and the further intricacies of having a hidden disability. Misrepresentation also impacted the lives of those with mental health conditions as they have experienced a lot of social prejudice which stems from the external symptoms of the disability and the way that this changes how individuals perceive them regardless of their true personality. When going through the process of trying to decide who you are and what your role is in society these constant scenarios can discourage individuals from shaping their identity as they struggle to segregate these misrepresentations from their true identity.

Feelings of frustration were apparent in the accounts of individuals from every impairment group. They were mainly fed up with the constant need to disclose and discuss their conditions in order to explain their needs and behaviours. Whether this was in order to gain the support they required from their lecturers at university or to excuse certain behaviours and actions such as explaining whenever you mishear or accidentally ignore a person whilst out in public. The combination of these constant needs to discuss their disability and how it affects them is felt to come from the lack of external signifier as participants felt that if they had a more visible impairment, they would not be required to explain their actions as regularly. Participants believed that if they had visible conditions people would take on board their disability more willingly and they would therefore be required to explain their needs less frequently. When attempting to craft an identity for oneself it can often be difficult for these participants to constantly have to negotiate talking to acquaintances about their disability before they can discuss the other elements of their identity which they find either more or equally important in the construction of their sense of self. For those with visible disabilities it is often accepted without much discussion because others can see the external characteristics associated with the disability. Modern society

has created a state where it is considered to be intrusive to ask individuals about their disability, particularly if it is external but for those with hidden condition it is not until the stranger asks a question relating to an action, need or behaviour that it is clear that there is an impairment present.

The surprising exception to the social expectations was the unique instances where the close personal relations added to the problem of misunderstanding and misrepresentation for those with invisible disabilities. It is assumed that individuals with disabilities are primarily supported by their close friends and family members as they are the closest to this person and as such, they are able to open up to them about their struggles. This has been true to an extent for those with invisible conditions, but another phenomenon seems to have also become apparent which is uniquely based on the ability to hide or mask symptoms or struggles of their condition. Individuals felt that they do not want to burden their family with their condition and as such hide the bad days or struggles by acting as though everything is okay. The other way that identity formation surrounding hidden disabilities has been impacted by family and friend reactions and responses is the fact that they can forget that their friend or relation is dealing with a disability and can sometimes act inappropriately. The act of forgetting that an individual is disabled can lead to the need for the disabled person to have to remind their family that they struggle with certain things which can be jarring or tough to handle. It is assumed that family and close friends are an unyielding support group whose presence in the lives of disabled people is fundamental to their construction of their social and personal identity. This study has acknowledged that an invisible condition can lead to struggles in this area as the individual is either forced to remind others about their condition or chooses to hide the symptoms in order to lessen, the burdens for their close relations.

These three factors combine in the lives of those with invisible disabilities causing them to question what their condition means to them and how it impacts their identity and their everyday life. Whether it is through having to constantly face the disability through explanations creating frustration, through handling and overcoming misrepresentations about what it means to have these conditions. To defy the social

stereotypes about ability and how they should live as disabled people or through the assumptions that people make about what it should look like to have a disability. Having to educate strangers about how the condition affects them in real life is critical, having a hidden disability can often be difficult. Trying to establish who you are and what your disability means amongst these constant interruptions can be challenging and can sometimes lead to attempts to use the invisibility of the condition to disassociate from it as part of who you are. This concept is explored in parts throughout these chapters as individuals struggle to know when to disclose and when to adopt passing behaviours in order to avoid answering questions.

Chapter 5: Community and Hidden Disability

The relationship between community and disability is of key significance to this research, due to the strength of its connection to identity formation. This study found two main themes relating to community and the contemporary presence of leisure communities in the lives of these with invisible disabilities. The first way that disability and community intersect is through the participant's choice of leisure activities; the ways that certain conditions can impact how individuals choose to participate in hobbies. For some, leisure communities can provide a safe space, where there is no need to discuss or even disclose their disability. Whether this is an art group for those with dyslexia or audiobook for someone with sight loss, there are a lot of examples where individuals are able to "pass" for fully able in certain leisure groups. This can generate feelings of normality and ease which provide those with invisible conditions some solace from the constant requirement to explain their disability. The invisibility of these conditions can cause issues in terms of the ways that participants are forced to disclose their problems. This can sometimes cause isolation as individuals choose not to join certain groups simply to avoid the fuss of explaining their condition and needs. This has a strong impact on identity formation as it can not only prevent engagement with elements of the self but can also lead to low self-esteem due to feelings of incompetence or self-doubt.

Community has undergone a shift in recent years which has seen relationships move from the public forums to the digital world which has had a profound impact on the following chapter (particularly the latter sections on support groups). It is important to acknowledge the writings of Anthony Giddens and the role that the changing nature of relationships can play in online interactions. For Giddens modern relationships have been through a shift which has seen them morph from physical to digital encounters. They are based more on the facts an individual chooses to portray about themselves than the stigmas which can be attached to them by social stereotypes and embodied characteristics (Giddens 1991). This is clearly of interest to this study of the role of online community in the lives of those with invisible disabilities. It reflects the aforementioned desire (in the opening chapter) to be able to exist in the social world without the need to concern oneself with the potential requirement of disability disclosure. In the online world an individual can put forth whichever

elements of their identity they feel are the most important to them without having to explain away or discuss other conflicting identity traits. With regard to this research specifically Giddens' work is integral in explaining the true comfort that an online persona can have as it provides a space for individuals with disabilities to acknowledge their frustrations, questions and achievements in a space full of people who understand what they are going through. Giddens' work focuses on the new way that interactions exist and can foster relationships without having to hide undesirable traits of the self (Giddens and Sutton 2010).

The second unique finding is the role of online support groups and the power that these have; allowing participants to become more comfortable with their conditions. There is extensive literature exploring the ways that the online world and, the anonymity that the digital sphere can provide, can affect people's lives and senses of self. Online support groups provided the participants of this study with various benefits which gave them the freedom to explore their identity and its potential relation to their conditions. However, there is a clear disconnect between what is stated by researchers in reference to the escapism experienced by those with disabilities through online avatars and the reality for those with invisible disabilities. The other main benefit provided by the online support groups is the ability to avoid social interactions in accessing the support itself. This allows them to avoid the often-frustrating exchanges (which was earlier acknowledged), in which they must explain their disability and why they do not 'look disabled'. Whether it is through assuming the role of an advice giver for others, or by providing participants with a safe space to share concerns and to turn to when things become tough; online support groups are the foundation of contemporary disability community and are of critical significance in understanding identity formation.

Disability and Leisure Communities

Community can mean different things based on different situations and for many, this includes leisure groups and the relationships that can come as a result of these connections. Many disabilities can isolate individuals from these leisure groups and can therefore cause social alienation. For those with invisible disabilities this can be

particularly difficult as they face the added issue of having to disclose their disability to this new community before being able to display their enthusiasm for the activity itself. Invisible disability has for the most part led to one of two approaches to joining leisure communities. For some this alienation and frustration regarding disclosure leads individuals to exclude themselves from activities. However, for others, leisure groups provide a safe space in which they can express their love for a certain hobby without having to constantly confront their condition. Each of these approaches has a profound impact on identity whether it is positive or negative.

Ian was a visually impaired participant who shared his experience with leisure societies:

“I wanted to join the running society, but I was nervous about tripping or getting lost. I tried to explain but because I didn’t need a running aid, they were just sort of assuming I could run fine., a little consideration would have been nice. I decided to just run at the gym. Stupid really” (Ian)

Ian felt that he was unable to do exactly what he wanted because people didn’t seem to take his disability seriously enough. This was due to the hidden nature of his condition and the impact that this has on other’s impressions of his true ability. He thought that if he had a condition which would require a white cane or guide then he may have been better included in the group but chose to segregate himself rather than constantly explain exactly how his disability affected him. This was predominantly due to the fear that people would underestimate his skills if they were constantly reminded that he was disabled through use of an external aid.

“if I had a symbol cane, they would never have questioned my needs but then they would probably think I couldn’t see at all. It is so frustrating” (Ian)

This view was symptomatic of that of many of the other participants feelings, as they struggled to find the balance between managing their disability and being part of other groups which they identify with.

Another example of the social isolation which can be caused by invisible disabilities is the ways that mental health conditions have affected participation in leisure

activities. There is a strong correlation between anxiety and the concern of engaging with certain extracurricular activities. For some with anxiety or depression there is a struggle to relate to other groups in the wider community due to the often-isolating effects of the condition. Examples of how this has impacted participants can be seen in the accounts of Robert, who felt that he was sometimes unable to join certain groups; because of the impact his condition had on his ability to interact in social situations. During his time at university he wanted to join the football team but was concerned that his anxiety would sometimes prevent him from taking part in matches. He also showed concern that he would be overwhelmed by the pressure of keeping up with the social occasions. He felt that people would not understand his need for time off when his anxiety became overwhelming and was concerned that whenever his symptoms became apparent people would assume the wrong things about him (feelings which were discussed in chapter 1 in reference to misrepresentation).

“I loved playing football and it totally stopped me doing anything like that. I had no self-confidence even though as I was younger, when I was at school, I was quite good ... I think the fact that you live with anxiety makes you doubt your overall competence.”

“sometimes my symptoms mean I can’t join in and other people seem to think that I am not dedicated. It is hard to try to tell them that I am not doing it on purpose, I want to take part, but my illness won’t let me. People can’t see that” (Robert).

And for Steven who worried that he would be expected to fulfil requirements which he might be unable to, due to the often-sudden impact of his bouts of depression. He dreamed of joining the student union but decided that in order to excel on his academic course he was better off focusing on his studies rather than other extracurricular commitments.

“I do want to join the student union, but it seemed like it could be quite stressful.

(interviewer: was that what stopped you?)

I guess so, my depression sort of gets in the way. I decided that I should just focus on my work. It was a shame, but I had to be realistic and I know myself,

ya know. Politics was hard work, so I just stick to rugby and drinking as my hobbies (laughs)” (Steven)

Steven was so concerned about how he would be treated when trying to explain how his depression and anxiety would affect his ability to participate in this society that he chose not to be a member at all. He expressed concerns that his disability would be forgotten about because it was not external and that whenever he needed time to himself it would be perceived as a lack of enthusiasm.

“if people saw me when I was feeling down, they might judge me. I can’t help it, but it isn’t worth the hassle of constantly trying to seem okay to avoid questions” (Steven)

For these participants it is a challenge to be who they want to be and engage with their true identity because of the impact their mental health conditions can have on their ability to interact in certain social situations. Overall, this reflects the underlying issue that those with mental health problems struggle with. They experience spoiled identify symptoms due more to the lack of signifier than the impact of a social stigma based on external characteristics. Although a community can often be there for those with invisible disabilities, the fact that their conditions are unseen can mean they face ridicule due to the lack of understanding from the general public.

Conversely to these negative ramifications of hidden disabilities on leisure group participation there is also a lot of examples of times when having this hidden disability is not a barrier to taking part in things. For many there are ways around their condition and certain type of leisure activity provide them with the opportunity to escape their condition and to embrace other elements of their identity. The invisible element of these conditions has at times allowed them to be whomever they chose, to be able to ignore their disability for a while. For those with dyslexia specifically there was a strong relationship between joining groups centred around activity and creative media-based expression such as art, animation or movies as well as taking part in other activities which do not require reading or comprehension such as fitness and other physical activities which help to distract from their disability.

“I love drawing and I am always doodling on stuff. It is just easy, and I don’t have to stress or worry about getting stuck.” (Maria)

Maria has spent much of her life finding comfort in artistic expression and is building her future career goals around this passion. Her course in animation allows her freedom to explore her love without having to constantly face some of the challenges that her dyslexia can cause. She felt such a strong connection with the other members of her course and the local anime society; which she attributed to her ability to fit in without having to discuss her dyslexia. She was very open about her condition in general and much like others from her impairment group she enjoyed having the freedom to take part in her hobbies and, to an extent, her academic life free from the struggles that dyslexia can cause. Maria's experience strongly reflected the feelings of the other dyslexic participants. They each chose hobbies which allowed them some respite from the stress of disability including Lewis' love for exercise, Natalie's love of hiking and Maria and Olivia's interest in art.

“working out gives me the space to forget about my dyslexia and I am just like everyone else in the gym. We are all just regular sweaty gym people” (Lewis)

These communities were all very significant in the lives of these participants and were critical to them as they discussed what made them who they were. The ability to share hobbies and to take part in activities creates a sense of normality which these participants seem to appreciate. Being involved in these communities often allows for participants including Beth, Holly and Maria to become more involved in leisure communities and to make friends who either understand or do not need to confront the participants' personal struggles on a regular basis.

Another way that these disabilities have created a unique community group is through the movement to online spaces including new apps and other accessibility software. Although this may not be unique to those with invisible conditions, certain elements are born of the relationship with disability that invisible conditions uniquely foster. The use of common apps and technology which aids those with predominantly sensory issues such as audiobooks for reading with visual impairments or special transcription societies for those with hearing loss. Individuals with disabilities have adapted their leisure activities in order to gain the most benefits for themselves. This in turn leads to unique community connections which can often bring together people with the same disabilities due to common interests.

“I guess I am a bit weird, but I like to buy a book even if I can’t see it. Then I get the audiobook and I listen along with the book. it is a sort of reading (laughs). Me and some of my sight loss friends share an audible account so we don’t have to spend as much money on books every time“ (Holly)

“the hearing aid apps I use allow me to discreetly check my levels and change the volume without being singled out as the deaf one. Loads of people I know use the same thing. We can even be friends on the app!” (Eddie)

Being able to engage with hobbies and interests through more accessible means is a triumph of contemporary society, as technology has evolved to allow for more equal access. This being said, there are certain elements of having an invisible disability which can cause more deep-rooted issues in relation to engaging with one’s sense of self (as discussed in chapter 1). The ability to appear the same as others can often be a feature of the lives of those with invisible conditions due to the ease of enacting passing behaviours. Overall, communities including online sites and accessibility software users can often allow for those with certain disabilities to feel more included in day to day lives and activities.

Online Support Groups

The other way that community has shifted in recent years is the movement from face to face to digital support communities. This relates in part to the previous point which explored how invisible disabilities benefit from online leisure groups. The online world also has a series of other benefits, some of which seem to aid those with invisible conditions, not exclusively but, substantially. This comes through use of support groups on social media platforms (predominantly Facebook) which allows individuals with certain impairments to seek and provide advice, without having to go into the public sphere and deal with the issue of disclosure which can be apparent when dealing face to face.

The dominant community group which people said that they were members of were online support groups, based on the social media network Facebook. Primarily due to ease of access. With over 2 billion people per month across the globe using Facebook (as of December 2018) this social media network provides people with access to the largest number of potentially likeminded individuals to share their

problems and concerns with (Smith 2018 from Brandwatch.com). For example, Jess, a visually impaired (postgraduate) philanthropy student expressed her logic behind joining support groups on Facebook:

“I already had Facebook, so I just searched for sight loss groups and it popped up. I guess it is nice having people there straight away on my newsfeed...the thought of meeting strangers in public to talk about my problems does not appeal” (Jess)

There is a lot of existing literature which explores the ways that disabled bodies interact in online spaces and the impact that the movement away from face to face interaction has had on the relationship between society, identity and reality. This research explores the ways that the online world can often provide a form of escapism for those who have disabilities, as they are able to transcend their temporal body and become whomever they desire to be through construction of a digital avatar (Kleeman 2007). The role of the online community has been well researched by digital culture academics, as the power of the online world has grown exponentially over recent years. One of the most significant researchers to note in the prelude to this analysis is the pioneer Jean Baudrillard (1981) and his work exploring hyper reality and simulation. His theories focus on the ways that reality has shifted in order to accommodate the new power of the digital world. Simulation is connected with the ways that the line between real and digital is becoming more and more blurred. The impact of this on the lives of all members of society is substantial and therefore it seems obvious that there will be an impact on the lives of those with disabilities. Hyper reality allows for technology to integrate with the real world and to generate a world which could be considered to be more accessible. In terms of this chapter, this theory represents the transformation that technological advances have had on social life. Online life has had a huge impact on contemporary social life and an impact on modern realities and identities.

Having to face their disability can sometimes create a jarring effect for those who are not used to having everyone know they are disabled straight away as people in an online support group would, this can lead to concerns regarding their disabled identify overtaking other more personally favoured traits. This was the case for

individuals who suffered with dyslexia. They are used to living with their condition without people understanding or taking their condition seriously (as has been established) and as such are sometimes hesitant to become members of online support groups because members would immediately be aware that they are disabled.

Alternatively, others viewed online communities as an opportunity to be amongst people who understand what they are going through:

“it was awesome being able to log on and immediately be surrounded by people who got what I was going through. People had super helpful tips and tricks and nobody ever questioned how serious my dyslexia was which felt super comforting” (Olivia)

Being able to be a part of a group who understood and accepted their condition is important for those with conditions like dyslexia due to the amount of people who dismiss the disability as being insignificant or of minimal impact to the individual's lives. The reality is that being accepted and taken seriously was important to these people and that the burden of their impairment was lessened by the tips given by online forums.

“I joined a couple years ago and I was super surprised how many people from my uni had dyslexia, it was great to be able to find these people because looking at someone you can't tell if they are dyslexic and it is a pretty weird thing to go around asking people.” (Natalie)

Despite the fact that having everyone in a group know they are disabled being quite daunting, many of the participants felt relieved by the ability to join these groups and to have their condition accepted and supported. In a world where they are often considered to not be “disabled enough” because of the invisibility of their condition it is freeing to find a safe space in which they can discuss their problems and find help and support.

It was established by some of these participants that there was a lack of acceptance in the disabled communities of individuals with hidden conditions. This can have a significant impact on the relationship that a person has with their disability and the wider community associated with it. Some of the participants from this research

shared feelings of isolation from their own disability group because they do not have any signifiers of their condition.

“I feel like I don’t fit in with other blind people because they all have their aids and stuff and I am just there like ‘I am blind like you!’ I just look too normal to fit in and I feel judged” (Ian)

Online forums present a space for all individuals regardless of the external visibility of their disability to share and compare their situations and to seek help from each other without feeling singled out due to the hidden nature of their condition. This was particularly strong for those with sensory impairments as many people in this group had some form of signifier such as a hearing aid, white cane or glasses.

“when I use the online group, it feels like everyone just accepts that I am deaf, and they don’t question why I don’t use my hearing aids. I can just be a deaf person like everyone else and not feel like I have to explain myself” (Danielle)

Having a hidden impairment can lead to a lot of prejudice not only from outside of the disabled community but also to an extent from others with variations of the disability. The words “blind” and “deaf” encompass a lot of different diagnosis and as such communities are often unaware of all the forms that the disability can take. The online support forum provides individuals with a safe space to seek help with their disability without requiring disclosure of the exact symptoms of their situation. Overall, online support communities provide a very unique comfort for those with invisible conditions due to the lack of embodied appearance which can lead to judgment in face to face support communities. This can impact identity formation due to the fact that participants can explore what their disability means to them through the freedom of the online forum without being reminded of their lack of external signifier.

The simplicity of having support at their fingertips was noted by people across all four of the disability categories but was felt the most strongly by those with anxiety and/or depression. The severity of the condition at certain times meant that having constant access to others who would understand and show compassion was sometimes integral to the participants’ wellbeing.

“being able to talk to someone whenever I need to has been so important for me. Even in the middle of the night there are still people who know what is wrong and can help to sort it” (Patrick)

For Patrick who suffers from anxiety and depression the onset of certain negative feelings can be sudden and unexpected. Patrick was only 18 and had just begun studying towards his dream career in journalism. He was very positive about what he could achieve despite his condition and felt that the role of online support groups was to allow him to continue improving whilst he handles his bad days.

“I love being able to go online and share my worries without having to look people in the face and see their judgement and stuff. I like not knowing them and them not knowing me” (Tracey)

Although this accessibility is not unique to specifically invisible conditions, participants in this research all enjoyed the freedom and anonymity which came from the online forums. Whether these feelings are unique to those with invisible conditions cannot be established from this research alone.

Participants including Patrick and Robert have stated that having the ability to talk to someone whenever and wherever their feelings overwhelmed them was fundamental in helping them handle their condition. Robert expressed his reasons for using online forums as being predominantly to reassure himself that he is not alone, making him able to cope better with his own situation. Elements of the symptoms of mental health problems can often make individuals feel isolated and alone particularly because it is tough to find others with the same condition outside of the online world. This is due to the lack of external aid or symbol for all those with these conditions unlike other impairments which have external signifiers.

“logging on like, Oh! Well at least I’m not the only one” (Robert)

He then went on to say that:

“That two o’clock in the morning ceiling stare is the worst place to be” (Robert)

Constant access to help and advice is critical for overcoming a condition which can be so unpredictable and helps them to become who they desire to be without their disability getting in the way. Mental health conditions can sometimes (as stated by

the participants) stand in the way of other activities and interests and as such, proper management is important to allow full development of their true identity. It seems that the invisibility of these conditions is what prevents participants from speaking with others in real world situations about their problems as they don't feel they will be understood. This is important not only with regard to their identity and the extent to which the community group becomes part of their social circle, but also on a more critical level, the access to this support group can be fundamental in terms of wellbeing and can sometimes even save lives.

The internet (predominantly Facebook) has provided a forum for expression and understanding through a community of global proportions connecting individuals with the same disabilities to encourage unity. Generating the ability to communicate with individuals whenever and wherever they feel the need. This is fundamental in aiding the management of these disabilities and despite their lack of external signifiers, these participants all feel accepted by these forums making them free to discuss their problems. People can be themselves and use the online world to express who they desire to be without judgement or prejudice.

Work and disability

One of the most defining elements of an individual's life, once they have reached adulthood, is often their job and the way that work plays a role in their lives.

Regarding identity it is clear that there is a connection between having a disability and choosing to work in a field related to disability research. In order to highlight the extent to which this group of individuals were able to embrace their disability as part of their identity and part of their employment goals, this section focuses on four of the participants who have centred their future work around their disability and the difference they could make in disabled communities with their experience and education. Choosing to include disability as an element of their career shows a choice to relate with disability as part of their sense of self. Being constantly surrounded by disability related tasks and goals means that it is almost impossible to dismiss the condition as part of their own life.

Multiple individuals in this research have chosen careers which are based in disability resources or support, with a further three working in their free time, volunteering for disability charities and organisations. The reasons that these participants have given were critical in understanding the extent to which they are engaging with their own disability as a part of who they are, as well as understanding how for some their disability has changed their life goals and what they deem important in their lives. This idea, although not necessarily unique to those with invisible disabilities, is intensely related to identity formation. Some of the thoughts behind their decisions were fostered by the hidden nature of their condition (making these elements unique to these individuals). This reflected the effect biographical disruption can have as individuals employ a quest style narrative (as Frank has outlined) which engages with the idea that their disability will impact their future but they find the most productive way to proceed with their life is by adapting their future goals. Fred, a computer science student (who suffered from a sight impairment) was profoundly affected by his condition with regard to his thoughts about the future and his career goals. As a kid he claimed that he had always been “in love with computers” and he had spent much of his childhood breaking apart his consoles and “learning what was inside”. He began to lose his sight when he was 13, and he found that he might have to adapt his career goals.

“I guess I was just glad I could help others who have similar problems to me and still do what I love. People don’t see my disability, but it has given me a new perspective on my life.” (Fred).

Fred decided to create technology to help individuals with disabilities in order to feel that his condition could be used for good. He expressed no regret or sadness that he had lost his sight and felt proud to have the ability to help others using the insight that his condition had afforded him about how disability can impact people’s lives.

“I want to give people a way to get on with their lives without having to fuff about with constantly needing help with stuff. They can use apps to get past their disability and nobody will know they even have a problem.” (Fred)

The striking thing about Fred’s and other’s responses is the fact that they saw their change in mindset as a purely positive thing which reflects their new awareness of the lives of others. Fred found that the invisible nature of his condition and the ways that this impacted his life provided a unique view of disability and made him feel that

he was able to provide a service for others in a similar position. Drawing on this meant that he thought of himself as an entrepreneur who was able to use his disability to make a difference, thus solidifying the relationship between his disability and the formation of identity.

Others felt even more strongly that although their condition had prevented them from pursuing a certain career path, their disability had provided new opportunities for them. Although Jess felt that she was forced to change her future plans because of her visual impairment she felt she was able to make a difference in her new role. She stated that growing up she always wanted to be involved in writing and dreamt of working for a publishing firm because of her love of reading.

“I never really did anything else when I was a kid, I just read books and wrote stories. When I lost my sight, I didn’t know what to do anymore... and people didn’t get it like one person asked why I stopped reading at school and when I said I couldn’t they asked why I didn’t just get glasses” (Jess)

Once the full severity of her sight loss became apparent, she decided that she had to rethink her career as she began to suffer from a lot of anxiety about the difficulty of working in publishing with a sight problem. She formed connections with individuals working within sight loss charities and began to think about changing her job aspirations. From the connections which she had gained she decided that a career in a charity would be for the best as she felt strong connections with both the cause itself and the people who worked for these organisations.

“if I worked in publishing people wouldn’t understand why I was so slow at reading and it would mean that I just look like I am really bad at my job. I would have to keep telling everyone that I suffer with a sight condition and it would just mean I was constantly thinking about being blind. It would just suck and remind me that I can’t do some things as well as normal people” (Jess).

Jess was extremely positive about the ways that her life had turned out and was pleased that she was able to find the job that she had as a result of her visual impairment. She felt that this was the perfect job for her and that she would never have known how rewarding she would have found this career if it weren’t for her sight loss. This reflects the fact that for some the disability opens doors which they

never expected but still shows that sometimes the lack of understanding in the workplace can ruin the dreams of people with certain disabilities.

“I can just be a part of the team and nobody will constantly ask what is wrong with me. They would just leave me alone to do my job instead of trying to figure out why I don’t wear glasses or why I don’t have a cane” (Jess).

For Jess the invisibility of her disability made her feel that she constantly had to talk about it with others, but she believed that once she was within a disability conscious environment people would be more understanding and wouldn’t ask a lot of questions about her lack of disability signifiers.

Another example of the ways that individuals used their disability to shape a career was Anna’s response when asked about what she hoped to do once she had completed her photography degree. She stated that growing up she had always wanted to become a photographer yet as her condition worsened, she felt drawn to medical photography. She stated that:

“my mum was nurse in care homes when I was little and when I grew up, I always visit hospital ... my passion hobbies are photography since I was like 14” (Anna).

She associated her childhood with being in and around hospitals and joining her parents in volunteering for medically based organisations and as such felt a strong pull towards combining her love for photography with her life experience in hospitals and hearing about care homes with her mum. It was clear that her hearing loss only enhanced her feelings towards her career and made her more focused on achieving highly in her course in order to gain employment later in life.

“people don’t know I am deaf they just appreciate my good work... I like that at work I am just another staff member and if I become a photographer it will be so important; people won’t even think about my deafness...I hope” (Anna).

Unlike Fred, Anna enjoyed the ability to have a career which does not tie directly to her condition, but she still felt that because of her condition she chose a career which is related to the medical profession. The invisibility of her disability meant that she was able to be a photographer without also negotiating her disabled identity and

thus Anna is able to have a career separate from her disability. This may not be the case for those with visible disabilities as their conditions are tougher to hide. People therefore are more likely to enact social stigma on them as it is a social phenomenon which is often inescapable of the disability is externally apparent.

Finally, even in instances where individuals have pursued careers which are in no way related to their disability, there are still connections between having a disability and engaging with the disabled community and working part time or voluntarily with others with disabilities. This applied particularly to those with mental health problems. Some of the people felt that they were in a privileged position as they felt they were able to engage with their condition better than others who may not have come to terms with their disability and its true significance.

Steven felt that once he had come to terms with his condition, he would benefit from helping others as a way of dealing with his disability himself.

“I man the phone lines for the mental health helpline at our uni usually a couple of nights a week. I do it to make myself feel like I am making a difference and I think it is better for me to say that I understand when people are talking about their problems because I really do get rather more than someone who has never dealt with the condition.” (Steven)

He felt that being able to help others to manage their mental health was a way of living with his own struggles. He stated gratitude that a similar helpline was available for him when he was having a hard time and wanted to give back. When asked if the invisible nature of the condition had anything to do with his decision to work over the phone rather than in person, he was unsure but saw some ways the two could have been related.

“I don’t know to be honest I like the anonymity of being over the phone. If I helped people face to face then they would recognise me and think of me as the guy with anxiety, I guess I don’t want that to be the only reasons that some people recognise me. I spend so much of my life with nobody knowing, that I am just used to it only being a problem when I chose to tell people what is wrong with me”. (Steven).

Although he was uncertain whether or not his choice to work on the phone helpline was related to the fact he lived with an invisible rather than visible condition, the fact that he considered the potential of being recognised as *“the guy with anxiety”* (Steven) showed that this element of his disability had a deep impact on how he perceived himself and how he attempted to display himself to the wider society.

Overall, each of these individuals presented a different reason as to why they chose to connect their career with their disability, but each felt that they had benefitted from this connection and saw their disabilities as a positive part of their future life and career. Engaging with their disability as an element of their future career reflects acceptance of the disability as a part of one’s life and overall, as part of one’s self confirming the connection with disability as an element of identity.

Conclusions

The role of online support groups in community networking and identity formation is critical to this research. Every person I spoke with was aware of, and to some extent involved with, online forums based around their specific disability. Online support groups have come to stand in for real world face to face interactions and have been shown to have a number of substantial benefits over the older form of community support, some of which are unique to those with invisible conditions. This is particularly apparent for those with mental health conditions, as the ability to have access to support and guidance whenever they need it is critical in the lives of those with anxiety and depression. For the other groups (sensory and dyslexic) the lure of the online support groups is much more about convenience. As well as this every participant enjoyed having the freedom to use these forums without having to explain their condition, including the critical fact that they did not have to explain why they did not have any external signifiers of their disability. They can access their community whilst continuing with their day to day lives, whether this is through finding others with similar interests and hobbies who have the same disability or, simply to find or even give aid to those within the support group. Overall every individual spoken with in this research has benefitted in some way or another through the use of online support groups. They have played a significant role in the

identity formation processes of every participant of this study. Being a part of a disabled community means something different for every individual person but all feelings are rooted in a desire to have their condition acknowledged without concern about the stigma which influences the opinions of individuals in the physical world, based predominantly on the lack of external signifier.

As well as this, the physical communities which are formed through common interests and hobbies are often impacted in some way or another by invisible disabilities. For some their condition can lead to feelings of exclusion leading people to choosing not to take part, due to the potential stigma which could be put on them as they attempt to explain and manage their condition to more able-bodied individuals. However, for others, specifically those with dyslexia, (and for some with sensory impairments) there is a freedom which comes as a result of joining certain leisure communities in which the individual can transcend their disability and be part of something without having to acknowledge their impairment. Both of these circumstances can have a profound effect on identity due to the power that hobbies have in young adults' perceptions of themselves.

The relationship between disability and work has long been established as many of the institutions based around disabilities including charities are prepared to accommodate other disabled individuals. However, the reasons that those with invisible disabilities chose to integrate themselves into disability related occupations have varied in parts from those stated by previous research. Engaging with their condition and the unique ways that its invisible nature has impacted their lives and may be impacting the lives of others provides these participants with a sense of duty and a previously unstudied link between career, invisible disability and identity. This perspective on work and the power of the invisible disability in shaping career goals and assisting others with similar conditions is the lynchpin for some when considering what their disability means to them and how they accept their condition as part of their ongoing life. Being a part of their disability community and pursuing a career whether paid or voluntary has aided each of these participants in discovering who they are and the role of disability in their lives.

Overall, the invisibility of their conditions can have a significant effect on the ways that individuals approach joining certain community groups. They feel that the unseen nature of their impairment can sometimes make others quicker to judge, making their disability tougher to explain to others. Online support groups prevent the participants from having to explain why they do not 'look disabled' in relation to the conventional perceptions of disability. They allow individuals to embrace their disability and to find whatever benefits suit them from this community whether it is finding help or helping others. Face to face community groups can be perceived to be difficult to negotiate due to the participant's concern regarding their acceptance, (which came as a result of the challenge of disclosure). Regarding leisure communities, some felt too able bodied to join disability specific groups but also felt too impaired to join able bodied groups. The relationship between invisible disability, community and identity is complicated but each point reflects a clear trend for those with invisible disabilities and creates a strength for this new approach to disability research.

Chapter 6: Conclusion

This research set out to explore whether there was a relationship between the presence of an invisible disability and the process of identity formation. The study came about as a result of a gap in literature surrounding this variation of disability and the way it impacts sufferers. The results show new ideas about the power of social stigma in identity development and imply that there is a strong relationship between these two concepts (invisible disability and identity). The inversion of Goffman's principle of spoiled identity has been found. Misunderstanding of disabled individual's behaviour leads members of the public to make assumptions about their ability without knowing their personal situation. The constant need to explain their disability through disclosure of their situation had a profound impact on identity formation; those with invisible disabilities are forced to confront their condition regularly.

Research Design

Once deciding upon a main research question I had to begin shaping the research design itself. This included a number of important decisions including the breakdown of the sample (both demographically and in terms of which disabilities should be explored). This meant deciding which population should be studied and in this case that was young people (between the ages of 18 and 25) who were studying in higher education. This was for a number of reasons predominantly those backed by existing identity and education research. Following is a discussion of the literature and how it has been applied to the study in terms of selecting a sample.

It was first important to establish how the role of adolescence was key in the process of identity formation in order to decide upon a suitable age range for the participants of the research. Studies which have been mentioned earlier in this thesis back up the link between adolescence and identity formation processes. Work by Hatano and Sugarman (2017) has explored the power of adolescence in identity formation. They raised important questions about the contemporary role of "youth" and how it, as a time period, was critical for shaping an individual's sense of self. Their findings

engaged with ideas regarding the role of both social and cultural factors and identified two forms of adolescent identity: the stable and the transitional. It is easy to see how these ideas can be related to the current study as participants often struggled to create a stable identity out of an impairment which presented itself sporadically.

Further research by Katstaficas, Fuitch Fine and Sirin (2011) also engaged with the social factors impacting identity formation in youth; utilising methodological pluralism to build strong roots in the lives of the young participants. The study explored the identity formation experiences of young people and how their age influenced how they saw themselves. The study was qualitative and asked the participants to describe themselves through artwork and videos and explain their creations. Their conclusions surrounded the fact that many of the participants struggled to define their identity and suggested that their age was a major contributor to their identity crisis. Overall, this supported the idea that youth is a key stage of identity formation.

Their study was significant in its design and showed great steps forward in exploring the true multidimensional self that exists in contemporary societies across the globe. With these examples in mind, it seemed clear that a study exploring identity formation should be based in a young adult demographic. This teamed with the growing expectation on British young people to pursue higher education shaped the sampling decisions for this research.

Once youth had been established as the key age for the research, I also read more in order to narrow the sample further. I next used existing literature to establish the link between disability, identity formation and education. Education particularly higher education is an important step in the lives of any individual as it often marks the first steps into fully independent living and begins the path to working life. Researchers have linked this step with identity formation and grounding an individual's sense of self. Research has linked academic 'ableism' to disabled identity issues. Research by Nicole Brown (2020) has noted the negative impact of this move to independence through which disabled individuals can often feel inferior or judged when struggling with academic work. This reflects how a move to higher education can create increased expectations of disabled individuals which can sometimes create

pressure, leading to identity issues. The findings of this study can support ideas about the link between disability and higher education as it further highlights the concerns for students regarding their education and access to support. The ableism discovered in this paper however, stemmed from the invisible nature of the conditions. The struggle to ensure support through disclosure creates concerns regarding confidence and ability in their courses at university.

Overall, one of the most sensitive times in identity development (as mentioned in the literature review) is adolescence into young adulthood. Individuals are deciding who they are and what their place in society should be. Therefore, the study was based in this time frame, specifically higher education. It was important to acknowledge the role of education in the lives of the participants and the ways that this, in particular, can impact both identity formation and career trajectory. This decision was strengthened when exploring in greater depth the literature on dyslexia and the sheer volume of research tying identity to education (as was discussed in the literature review).

Findings

Once the study had concluded, the findings could be grouped into two clear categories (as noted in the opening paragraph) based on their overarching ideas and themes.

Firstly, invisible disability and identity explored the power of the lack of signifier in creating and enforcing social stigma, as participants do not look disabled, in the traditional sense, dictated by the international symbol of access and other presentations of disability. This disclosure caused significant frustration and annoyance to participants as they are constantly forced to confront and explain their disability to others.

It has become the case that the lack of the disabled symbol creates a need to become the disabled person more frequently through disclosure. This represents an

inversion of the way social stigma is generally considered to impact people; it is the lack of a signifier which forces the person to engage with their condition.

Whenever they were confronted with ignorance on the part of members of the public, they became an educator, being forced to explain their condition, including their reasoning for not using an aid. This issue also impacted participants' thoughts about their future, as they felt they were less capable of things due to the constant reminder of impairment. This chapter also acknowledged an unexpected lack of consistency in participants' responses regarding the role of close relationships in identity formation.

Respondents felt that they had good support networks of mainly close friends and family but often expressed the opinion that this was only what was expected of families in society. There were no particular comments which separate the relationships of those with invisible disabilities from those of any other form of disability or even from able-bodied individuals. Contemporary western society stands on the value of strong relationships and the power of support networks in the lives of young adults as it has been defined as critical to personal development to have strong close relationships.

This variation of response regarding close relationships was an unexpected and interesting finding and was the main way that the research defied expectations.

As well as this there have been interesting results with regard to leisure and community and their links to invisible disabilities. Participants chose to associate with certain groups and to take part in certain leisure activities simply because of how it suited their disability. Having invisible conditions meant that many felt it was tough to join leisure groups as they were forced to disclose their disability. Some felt that joining groups that were created with their condition in mind was best, but for others the ability to blend with people who do not have a disability brought an element of norm to their life that they enjoyed. It is well established in disability literature that there is a strong relationship between the disability types included in this study and community support groups created to aid them. The difference in this study is the extent to which these individuals used social media and other online support groups to gain access to others with their conditions. This was for a number of reasons including the fact that it was easy, but also because they were able to be part of the

group without explaining their lack of external signifier as is the case for face to face support groups.

These support groups are often critical in the identity formation processes of these individuals; due to the power of community in understanding the role that disability plays in an individual's life. The community chapter also explored the attachment between disability and the likelihood that individuals work with or in a role which in some way aids others with disabilities. Participants felt that their condition puts them in a place of responsibility, especially when considered alongside their academic background as they seek new ways to assist others with disabilities. The unique nature of invisible disabilities often leads to unique employment opportunities and a special view of disability, which also fosters a new area for academic research.

The main point to discern overall is to what extent these conclusions affected participants. It is fortunately clear to see that for every different disability studied here, these conclusions were accurate to either a greater or lesser extent. In terms of sensory impairment these conclusions are strong and individuals with these conditions all felt the pressure predominantly due to the fact that sight and hearing loss are socially tied to aids more than mental health and dyslexia. For those with sensory impairments there is an expectation that they will have some form of aid, whereas dyslexia and mental health conditions are less associated with the external symbol of disability. Individuals with these issues fall victim to assumptions regarding their demeanour and body language, the expectations are more about mood and ability to engage in social interactions, leading to social stigma until the reality of the condition is disclosed. Overall, regardless of the reason for the stigma, individuals with invisible disabilities are victims of ableist assumptions, their appearance leading society to expect standard able-bodied function without support.

There are a number of substantial strengths and weaknesses of this research which reflect the role of the methodology, the researcher effect and the constraints of the research based on the available time and resources. Firstly, one of the major strengths of the research was in the rapport which was gained from the personal connection with the participants. My visual impairment and experience of invisible disability provided valuable insight and understanding with participants, allowing me

to connect through sharing personal stories. This also enabled participants to feel at ease and share their personal experience, challenges & issues.

Another strength of research lies in the interview recordings and the ability this gave me to reflect on the tone in which individuals spoke about certain topics. This allowed me to more clearly discern significant positive and negative statements against certain phrases which were intended casually or sarcastically. This could also be further utilised for a more discursive analysis of the study, focusing on the way's individuals spoke about their disability, rather than the thoughts that they chose to express.

Much of the existing literature that engages with the concept of invisible disability has themes in common with the findings of the study, including the rhetoric surrounding passing behaviours, disclosure and ableist/sanist phrases and its impact on behaviour. This commonality strengthens the research and provides grounds to gain confidence about the conclusions about the relationship between invisible disability and identity.

Future Research

This research provides a stepping stone for future studies into the impact of invisible disability on identity formation. Further studies should be undertaken in order to explore a wider variety of conditions and a wider range of individuals in order to gain a better picture of invisible conditions. One of the major limitations of this research was the time and resource constraints. In order to confirm whether or not this research truly reflects a wider social trend, studies should continue to explore the impact of invisible disability by expanding the variety of invisible conditions and the demographic variation in the samples themselves.

Further research also needs to engage with the themes and thoughts which were not conclusively discussed throughout this research including a more in-depth analysis of the nature of relationships as was briefly discussed in relation to misrepresentation and identity in the opening chapter of this research. Responses in

relation to the nature of relationships and the role of invisible conditions were varied from participants with two clear but juxtaposing rhetorics being present.

This will discover whether the ability to hide their condition makes individuals less able to discuss their condition with close relations and thus less able to engage with their disability as an element of their identity.

Another example of a theme which would require further research in order to confirm its relevance to this analysis of invisible identity is the relationship between work, invisible disability and identity. This research established that for those who choose to take on a career or leisure activity which includes an element of disability work there is a strong likelihood that they are able to engage with their condition as a part of who they are and to feel more comfortable on a day to day basis navigating society. However, further research would allow academics to pursue this idea in relation to those who do not work in disability and how this plays out in relation to their identity.

Overall, this research has brought to light potentially significant considerations and ideas which could redefine what it means to be disabled, introducing a new social phenomenon related to invisible disability and the impact that a lack of embodiment can have on social stigma and identity formation. This could help social theorists and policy makers to understand how minority groups interact in the social world and to expand education regarding the true impact of invisible disability and the associated stigma which has come as a result of the lack of general knowledge.

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Appendix

A: Ethics forms

If any of the questions in Section IV(B) and/or IV(C) and/or IV(D) is answered 'yes', a full ethics application must be made to the REAG. This also applies for studies not defined as 'research' in the narrow sense, i.e. evaluations/audits, etc. Complete this form and send it to the Faculties Support Office along with supporting documentation: a copy of the full research proposal; any participant information sheets and consent forms; any surveys, interview schedules; any advertising material or proposed website wording. **It is important to note that you must not commence any research with human participants until full approval has been given by the Research Ethics Advisory Group - you will be notified via email when this has been granted.**

During term time we aim to process a research ethics application within two weeks, however during vacation periods and busy times (e.g. exams and marking period) it can take up to four weeks.

It is the applicant's responsibility to ensure that their application is submitted in good time.

Overview

Name of Applicant(s)

Charlotte Aspland

Contact Details (Please include your Kuok address, email and telephone number)

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Title of Project

To What Extent Does an Invisible Disability Impact an Individual's Identity?

This research investigates the potential effects of having a certain type of disability on a person's identity formation. I will conduct a series of semi structured interviews on a number of students between the ages of 18 and 25, as this age is significant in the identity formation process This research will use a thematic analysis to explore how different elements of day to day life are potentially impacted by a person's condition. It explores both personal and social identity and investigates a vast number of aspects of modern life including careers and relationships. The type of disability explored is that of invisible disabilities. These are conditions which are not externally clear without the use of an aid due to a lack of physical symptoms such as mental health problems and sensory impairments (visual and auditory).

Name of Supervisor(s) (If applicable)

Michael Calnan

Ben Baumberg Geiger

Risks and ethical issues

Please list the principle inclusion and exclusion criteria

The participants will be men and women students between the ages of 18 and 25. The main criteria will be the presence of a type of disability (as each will be diagnosed with either a visual impairment, a hearing impairment or a neurological condition such as dyslexia or mental health problems specifically anxiety or depression).

The socio-economic situation of these students will only be indirectly considered as it is difficult to pinpoint the familial income of each student as they are often congregated at universities from all over the UK.

All students will also be UK residents.

How long will each research participant be in the study in total, from when they give informed consent until their last contact with the research team?

The participants will begin their participation around January to early February as they initially agree to be part of the research itself. They will then remain in contact indirectly with the team until the time of the submission of the final research piece. Although the direct interview process will only last around an hour and every participant will have the option to withdraw or ask any questions about the study at any point.

What are the potential risks and burdens for research participants and how will you minimise them? (Describe any risks and burdens that could occur as a result of participation in the research, such as pain, discomfort, distress, intrusion, inconvenience or changes to lifestyle. Describe what steps would be taken to minimise risks and burdens as far as possible)

There are several potential risks to the participants with regard to how the topics of discussion may impact them psychologically and emotionally. There may be a certain level of discomfort since the participants will be disclosing information about their life and their struggles.

The touch guide has been provided to establish what kinds of questions will be asked which may be sensitive or potentially cause discomfort. (see appendix C)

Please describe what measures you have in place in the event of any unexpected outcomes or adverse effects to participants arising from involvement in the project

Every participant will be informed of the local counselling and wellbeing services available at their university and will be told that if they should feel uncomfortable following or even during this process, they can get inContact with the wellbeing department, failing this there will also Beth option to withdraw from the study and to speak to any more direct medical aids such as doctors and mental health care professionals.

Will interviews/questionnaires or group discussions include topics that might be sensitive, embarrassing or upsetting, or is it possible that criminal or other disclosures requiring action could occur during the study?

The topics discussed may potentially cause embarrassment and distress but there will be no obvious or necessary criminal or other disclosure which could require action.
If yes, please describe the procedures in place to deal with these issues
Topics will be approached delicately and the participants will be reminded that they are under no obligation to reveal any information they do not wish to. As well as this there will be post interview debriefing which allows for participant to access counselling contacts and having the right to withdraw their participation.
What is the potential benefit to research participants?
Being able to discuss their lives and speak about the ways that their condition may have sub consciously altered their decision making and identity formation processes could lead to sense of internal peace. Disclosure of their day to day lives may also allow them to gain a new perspective on their life. As well as this I may be able (with their permission) be able to put in contact different participants who may have things in common including giving them a platform to discuss their disability which may help with acceptance and creating a new way to deal with their condition.
What are the potential risks to the researchers themselves?
Risks to the researchers themselves are minimal and are mainly a result of disclosing personal information to the participants in order to generate a stronger rap
Will there be any risks to the University? (Consider issues such as reputational risk; research that may give rise to contentious or controversial findings; could the funder be considered controversial or have the potential to cause reputational risk to the University?)
N/A
Will any intervention or procedure, which would normally be considered a part of routine care, be withheld from the research participants? (If yes, give details and justification). For example, the disturbance of a school child's day or access to their normal educational entitlement and curriculum).
N/A

Recruitment and informed consent

How and by whom will potential participants, records or samples be identified?

Using contacts at wellbeing departments at universities will provide access to the relevant groups of individuals who may be interested in taking part in the research. Information sheets will be passed on by a member of the accessibility team (Ben Watson) via email to all those who may be interested. They will then be able to contact me via the information provided to gain more information and to organise a face to face interview.

Will this involve reviewing or screening identifiable personal information of potential participants or any other person? (If 'yes', give details)
N/A
Has prior consent been obtained or will it be obtained for access to identifiable personal information?
Any people interested in taking part will contact me directly thus consent will only be needed once initial contact has been made.
Will you obtain informed consent from or on behalf of research participants? (If 'yes' please give details. If you are not planning to gain consent, please explain why not).
Informed consent will be obtained from participants at the start of the process and consent forms will be issued to all at the beginning of the individual interviews. For any participants who would rather be dictated the consent statements a list of verbal questions will be read aloud and consent will be recorded audibly.
Will you record informed consent in writing? (If 'no', how will it be recorded?)
Consent will be recorded both in writing and through audio recording based on the needs of the participants. Those with visual impairment and those with dyslexia may prefer their consent to be read aloud in order to feel secure that they are well informed before the start of the process. Consent forms and questions can be seen in Appendices A and B,
How long will you allow potential participants to decide whether or not to take part?
I hope to begin the interviews within a week or two of the initial contact but will ensure that the participants are aware that their responses to the interview questions can be withdrawn at any point before the publication of the final research if they change their mind.,
What arrangements have been made for persons who might not adequately understand verbal explanations or written information given in English, or have special communication needs? (egg, translation, use of interpreters?)
An alternative format will be provided for any participants who are not capable of reading and signing a written consent form. This will be a read series of questions and statements which the informant will be asked to agree to verbally and their response will be recorded.
If no arrangements will be made, explain the reasons (e.g., resource constraints)
N/A

Confidentiality

In this section personal data means any data relating to a participant who could potentially be identified. It includes pseudonymised data capable of being linked to a participant through a unique code number.

If you will be undertaking any of the following activities at any stage (including in the identification of potential participants) please give details and explain the safeguarding measures you will employ

- Electronic transfer by magnetic or optical media, email or computer networks
- Sharing of personal data outside the European Economic Area
- Use of personal addresses, postcodes, faxes, emails or telephone numbers
- Publication of direct quotations from respondents
- Publication of data that might allow identification of individuals, either directly or indirectly
- Use of audio/visual recording devices
- Storage of personal data on any of the following:
 - Manual files
 - University computers
 - Home or other personal computers
 - Private company computers
 - Laptop computers

During the identification process potential participants will be given my university email address and will be asked to contact me through this. This will open a line of communication through which data could be hacked or accessed. In order to best prevent this there will be an attempt to only speak on the basics of our meeting then discuss more personal data during the face to face interviews themselves.

As well as this there will likely be direct quotations from the participants themselves, but they will be anonymised, informant names will be replaced by pseudonyms to allow the informant to remain confidential.

Information will be stored on a personal laptop which will only be used on a private home WIFI network. this means that the personal data will be kept secure and in order to increase this safety all information will also be kept in a locked folder.

How will you ensure the confidentiality of personal data? (e.g., anonymisation or pseudonymisation of data)

The names of the participants will be anonymised, pseudonyms will be used when direct quotes are taken for the published data.

Who will have access to participants' personal data during the study?

Only I, as the lead researcher, will have access to the personal data of the participants in order to ensure their privacy. Personal data will also be deleted once anonymous information has been generated.

How long will personal data be stored or accessed after the study has ended? (If longer than 12 months, please justify)

The interviews will take place over the course of around 6 weeks culminating in March 2019. Following this the findings and personal data will be stored in secure files on a personal laptop while the thematic analysis takes place. This should be complete by June 2019 at which point all original personal data will be deleted leaving only the anonymised information about the participants for the publication itself.

Please note: as best practice, and as a requirement of many funders, where practical, researchers must develop a data management and sharing plan to enable the data to be made available for re-use, e.g., for secondary research, and so sufficient metadata must be conserved to enable this while maintaining confidentiality commitments and the security of data.

Incentives and payments

Will research participants receive any payments, reimbursement of expenses or any other benefits or incentives for taking part in this research? (If 'yes', please give details)

No incentives will be offered although a hot drink will be offered in order to make the participants comfortable.

Will individual researchers receive any personal payment over and above normal salary, or any other benefits or incentives, for taking part in this research? (If 'yes', please give details)

N/A

Does the Chief Investigator or any other investigator/collaborator have any direct personal involvement (e.g. financial, shareholding, personal relationship, etc) in the organisations sponsoring or funding the research that may give rise to a possible conflict of interest? (If 'yes', please give details)

N/A

Publication and dissemination

How do you intend to report and disseminate the results of the study? If you do not plan to report or disseminate the results, please give your justification

The final research piece will be submitted to the University by the thesis deadline in September 2019 and any decisions on further publication will be made by the department after assessment of the thesis. Copies of the final report will be made available to any of the interested participants regardless of full publication of findings.

Will you inform participants of the results? (Please give details of how you will inform participants or justify if not doing so)

The participants will be given the option to receive a copy of the completed study if they wish to discover what the results of the research were. They will only be informed of results prior to publication if they contact the researcher with concerns about being involved. This is because copies of the published research will be available to all participants once the research is finished,

Management of the research

Other key investigators/collaborators. (Please include all grant co-applicants, protocol authors and other key members of the Chief Investigator's team, including non-doctoral student researchers)

Accessibility advisor (a role in the wellbeing department at the University of Kent in which he helps disabled student swath both support and assisting by providing access to new technologies) Ben Watson will be aiding in sample collection by passing on information sheets to potential participants as well as the two above mentioned supervisors to the study.

Has this or a similar application been previously rejected by a research Ethics Committee in the UK or another country? (If yes, please give details of rejected application and explain in the summary of main issues how the reasons for the unfavourable opinion have been addressed in this application)

N/A

How long do you expect the study to last?

- | | | |
|------------------------------------|---------------------------------|-------------------------------|
| • Planned start date:
14.1.2019 | • Planned end date:
1.9.2019 | • Total duration: 8
months |
|------------------------------------|---------------------------------|-------------------------------|

Where will the research take place?

Canterbury -with interviews taking place either in Canterbury town in a quiet location such as the library or a small coffee shop or on campus based on the convenience for the participants.

Insurance/indemnity

Does UoK's insurer need to be notified about your project before insurance cover can be provided?

The majority of research carried out at UoK is covered automatically by existing policies, however, if your project entails more than usual risk or involves an overseas country in the developing world or where there is or has recently been conflict, please check with the Insurance Office that cover can be provided. Please give details below.

N/A

Children

Do you plan to include any participants who are children under 16? (If no, go to next section)

N/A

Please specify the potential age range of children under 16 who will be included and give reasons for carrying out the research with this age group

N/A

Please describe the arrangements for seeking informed consent from a person with parental responsibility and/or from children able to give consent for themselves
N/A
If you intend to provide children under 16 with information about the research and seek their consent or agreement, please outline how this process will vary according to their age and level of understanding
N/A

Participants unable to consent for themselves	
Do you plan to include any participants who are adults unable to consent for themselves through physical or mental incapacity? (If yes, the research must be reviewed by an NHS REC or SCREC)	
N/A	
Is the research related to the 'impairing condition' that causes the lack of capacity, or to the treatment of those with that condition?	
<input type="checkbox"/> Yes	If 'yes' proceed to next question
<input checked="" type="checkbox"/> No	If 'no' the study should proceed without involving those who do not have the capacity to consent to participation
Could the research be undertaken as effectively with people who do have the capacity to consent to participate?	
<input type="checkbox"/> Yes	If 'yes' then the study should exclude those without the capacity to consent to participation
<input checked="" type="checkbox"/> No	If 'no' then the inclusion of people without capacity in the study can be justified
Is it possible that the capacity of participants could fluctuate during the research? (If yes, the research must be reviewed by an NHS REC or SCREC)	
N/A	
Who inside or outside the research team will decide whether or not the participants have the capacity to give consent? What training/experience will they have to enable them to reach this decision?	
The lead researcher will make all decisions regarding the capacity of the participants. If uncertain then the wellbeing team at the university may be contacted to aid in ensuring participant safety and wellbeing.	
What will be the criteria for withdrawal of participants?	
All participants will be told and reminded that they have the right to withdraw at any stage of the process and if any participants do choose to do so then all information related to them and their responses will be removed from the research with no questions asked about reason for withdrawal.	

Declaration

To be signed by the Chief Investigator

- I agree to comply, and will ensure that all researchers involved with the study comply with all relevant legislation, accepted ethical practice, University of Kent policies and appropriate professional ethical guidelines during the conduct of this research project
- If any significant changes are made to the design of the research, I will notify the Faculty of Social Sciences Research Ethics and Advisory Group (REAG) and understand that further review may be required before I can proceed to implement the change(s)
- I agree that I will notify the Faculty of Social Sciences Research Ethics Advisory Group of any unexpected adverse events that may occur during my research
- I agree to notify the Faculty of Social Sciences Research Ethics Advisory Group of any complaints I receive in connection with this research project

What to do next

Send your completed form, along with all supporting documentation, to the Faculties Support Office, at fsoethics@kent.ac.uk.

Checklist

Please ensure you have included the following with your application (where relevant):

- Full research proposal (current project)
- Participant information sheet
- Consent form
- Covering letter (if relevant)
- Any questionnaires/interview schedules/topic guides to be used
- Any approved instruments/measures to be used
- Any advertising material to be used to recruit participants
- Confirmation that project is covered by UoK insurance policies (if necessary)

Appendix
Consent form
Consent statement

Consent form

Title of project:	<i>To What Extent Does an Invisible Disability Impact an Individual's Identity?</i>
Name of investigator:	Charlotte Aspland
Participant Identification Pseudonym for this project:	
<p>1. I confirm I have read and understand the information sheet dated for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.</p>	<p style="text-align: right;">Please initial box</p> <p style="text-align: center;">•</p>
<p>2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason. (contact Charlotte Aspland at ca481@kent.ac.uk if you wish to withdraw or ask questions after the completion of the study).</p>	<p style="text-align: center;">•</p>
<p>3. I understand that my responses will be anonymised before analysis. I give permission for members of the research team to have access to my anonymised responses.</p> <p>4. I agree to having my responses recorded for analytic purposes once made private. I also agree to allow all anonymised responses to be published once results are generated.</p>	<p style="text-align: center;">• •</p>
<p>5. I agree to take part in the above research project.</p>	<p style="text-align: center;">•</p>

Name of participant	Date	Signature
Name of person taking consent <i>(if different from lead researcher)</i>	Date	Signature

To be signed and dated in presence of the participant

	Date	Signature
--	------	-----------

Consent statement

Verbal consent statements to be recorded from those who are unable to read the consent form

Do you understand the information provided to you regarding this research and do you agree to take part in this research process? Have you asked any questions you have considered and have they been sufficiently answered?

Do you understand that your participation in this research is voluntary and that you can withdraw at any time without giving any reason? Please contact Charlotte Aspland at ca481@kent.ac.uk if you wish to do so.

Do you understand that our information will be anonymised before analysis in order to ensure your privacy? Do you give permission for researchers (myself and my supervisor only) to have access to these anonymised responses? (on the chance that this research is published do you give further permission for these responses to be published?)

Do you agree to take part in the above research project?

Do you agree to have this interview recorded for analytic purposes?

Topic Guide

To what extent does an invisible disability shape an individual's identity?

1) Introduction

To begin the interview process, I will ask the respondents to speak a bit about their conditions and what they feel are the main constraints it has put on them (if any) this will include

- Confirm consent and questions
- What are the outstanding moments about your life, what elements of your day to day existence are the most important to you? What are the most important elements of your life e.g.: jobs, experiences, relationships?
- Details of the specific disability
- Age of onset (this will provide a good boundary for the thematic analysis of the impact of age)
- Offered treatments and options for help

2) Work and Leisure

This section will look at how respondents feel their condition has affected their decision regarding their career and their choice of activities in their free time. This will also explore current educational goals and the future prospects they may foster.

- What does your current educational track have to do with your future hopes and goals?
- What job do you aspire to have after completion of your university course?
- Has your disability affected employment in your life thus far?
- What do you enjoy doing in your free time?
- Overall, is there anything either work or leisure wise that you feel is unattainable because of your condition? How has this impacted your decision making?

3) Community

In relation to how a disability can affect an individual's social life there have been many studies which show the power of a disabled community. As such this question will follow on from relationships to explore how respondents feel about the disabled community and whether or not they are connected with their own.

- Are you aware of any local community groups associated with your disability? are you a member of said organisations?
- Why/why not?

- Do you feel that this community has helped you deal with your condition in your daily life?

4) Relationships

Firstly, the interview will approach the discussion of disability based on the impact it has had on the participants ability to both maintain current relationships and generate new ones.

The questions will be along the lines of:

- How do your family feel about your condition? Do you feel supported by them?
- Do you consider yourself to be a sociable person? Do you find it easy to communicate with new people?
- Do you feel you have a strong support network?

5) Disability and Identity

Finally, I will ask questions which relate to the research question a bit more directly.

- Do you think the fact that your condition did not immediately clear to the public impacts you?
- Do you think people ever think about you in association with your disability?
- Is there any additional help or aids you believe could help you in your future endeavours? Such as equipment that could be provided by the education system support or external state assistance.

6) Conclusions

At the conclusion of the interviews there will be an opportunity for any final comments or final questions

- Final thoughts
- Debrief
- Final consent

Information Sheet

Participant Information Sheet

Disability and identity study

Research Question: To What Extent Does an Invisible Disability Impact an Individual's Identity?

I am a postgraduate researcher at the University of Kent and am looking for participants to take part in a research project exploring the link between certain types of disability and processes of identity formation.

This research study is to investigate the day to day lives and goals of individuals who have been diagnosed with an invisible disability. By invisible I am referring to conditions which are not immediately visible to members of the general public such as mental health issues and some forms of sensory impairment in which a person has no physical deformity to show a disability. This will mean that participants are either dyslexic, suffer from a mental health condition (anxiety or depression), or have a **severe** sensory condition (visual or auditory impairment). all participants are between the ages of 18 and 25 as this is a significant age for making decisions about one's identity. They are all also university students. The study will ask each informant a series of questions about their life and their work, hopes and relationships exploring the choices they make and potential critical elements of their identity which have been formed as a result of these connections with certain individuals and groups within a day to day life?

Duration: It is expected that the interviews themselves will last around one hour and the analysis process should be completed by July 2019.

Participation in this research is entirely the choice of the participant and they have the right to withdraw at any point if they chose to do so. This research has been approved by the University of Kent ethics board who are aware of the study's intent and ensuring the wellbeing of the participants. The questions will be about work, leisure, relationships and community and as such may bring up some personal thoughts and feelings this creates a risk of discomfort as these could be considered sensitive topics for some.

It is however also my hope that being given the opportunity to discuss your life and your goals will provide all who take part with a chance to express thoughts that they may not otherwise feel they have the freedom to speak about. It may also provide participants with links to others in their local area who are members of the same disabled conditions as they have by giving them the names of communities and organisations which work in the local area to aid in social connection which could help to widen community ties and provide support for all involved. All information provided will be kept private and the use of pseudonyms will prevent any participants true identity from being discovered.

The research data will be stored on a personal laptop in the form of transcriptions from the original audio files once it is all anonymised in order to be available for further research, but all personal data will be removed from the data set. All findings will be available to the participants in the study just prior to the publication of the research in order to allow all those involved to discover the results of the study in advance of its completion.

If you wish to be involved in his research or have any other questions before making a decision please contact the lead researcher Charlotte Aspland by email at ca481@kent.ac.uk or by telephone at 07825567200

Please feel free to ask any questions you may have and please note that asking questions or showing interest does not obligate any involvement. You can hold the right to withdraw at any point without explanation or reason and remove yourself from the study if you choose to do so.

Thank you for taking the time to read about this research and I hope you are interested in being a part of the study.

Charlotte Aspland

Lead Researcher

Ca481@kent.ac.uk

B: Consent forms

Consent form

Title of project:	<i>To What Extent Does an Invisible Disability Impact an Individual's Identity?</i>	
Name of investigator:	Charlotte Aspland	
Participant Identification Pseudonym for this project:		
<p>1. I confirm I have read and understand the information sheet dated for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.</p>	<p>Please initial box</p> <p>.</p>	
<p>2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason. (contact Charlotte Aspland at ca481@kent.ac.uk if you wish to withdraw or ask questions after the completion of the study).</p>		
<p>3. I understand that my responses will be anonymised before analysis. I give permission for members of the research team to have access to my anonymised responses.</p> <p>4. I agree to having my responses recorded for analytic purposes once made private. I also agree to allow all anonymised responses to be published once results are generated.</p>		
<p>5. I agree to take part in the above research project.</p>		

Name of participant	Date	Signature
Name of person taking consent <i>(if different from lead researcher)</i>	Date	Signature

To be signed and dated in presence of the participant

Lead researcher	Date	Signature

Consent statement

Verbal consent statements to be recorded from those who are unable to read the consent form

Do you understand the information provided to you regarding this research and do you agree to take part in this research process? Have you asked any questions you have considered and have they been sufficiently answered?

Do you understand that your participation in this research is voluntary and that you can withdraw at any time without giving any reason? Please contact Charlotte Aspland at ca481@kent.ac.uk if you wish to do so.

Do you understand that our information will be anonymised before analysis in order to ensure your privacy? Do you give permission for researchers (myself and my supervisor only) to have access to these anonymised responses? (on the chance that this research is published do you give further permission for these responses to be published?)

Do you agree to take part in the above research project?

Do you agree to have this interview recorded for analytic purposes?

C: Information Sheet

Participant Information Sheet

Disability and identity study

Research Question: To What Extent Does an Invisible Disability Impact an Individual's Identity?

I am a postgraduate researcher at the University of Kent and am looking for participants to take part in a research project exploring the link between certain types of disability and processes of identity formation.

This research study is to investigate the day to day lives and goals of individuals who have been diagnosed with an invisible disability. By invisible I am referring to conditions which are not immediately visible to members of the general public such as mental health issues and some forms of sensory impairment in which a person has no physical deformity to show a disability. This will mean that participants are either dyslexic, suffer from a mental health condition (anxiety or depression), or have a **severe** sensory condition (visual or auditory impairment). all participants are between the ages of 18 and 25 as this is a significant age for making decisions about one's identity. They are all also university students. The study will ask each informant a series of questions about their life and their work, hopes and relationships exploring the choices they make and potential critical elements of their identity which have been formed as a result of these connections with certain individuals and groups within a day to day life?

Duration: It is expected that the interviews themselves will last around one hour and the analysis process should be completed by July 2019.

Participation in this research is entirely the choice of the participant and they have the right to withdraw at any point if they chose to do so. This research has been approved by the University of Kent ethics board who are aware of the study's intent and ensuring the wellbeing of the participants. The questions will be about work, leisure, relationships and community and as such may bring up some personal thoughts and feelings this creates a risk of discomfort as these could be considered sensitive topics for some.

It is however also my hope that being given the opportunity to discuss your life and your goals will provide all who take part with a chance to express thoughts that they may not otherwise feel they have the freedom to speak about. It may also provide participants with links to others in their local area who are members of the same disabled conditions as they have by giving them the names of communities and organisations which work in the local area to aid in social connection which could help to widen community ties and provide support for all involved. All information provided will be kept private and the use of pseudonyms will prevent any participants true identity from being discovered.

The research data will be stored on a personal laptop in the form of transcriptions from the original audio files once it is all anonymised in order to be available for further research, but all personal data will be removed from the data set. All findings will be available to the participants in the study just prior to the publication of the research in order to allow all those involved to discover the results of the study in advance of its completion.

If you wish to be involved in this research or have any other questions before making a decision please contact the lead researcher Charlotte Aspland by email at ca481@kent.ac.uk or by telephone at 07825567200

Please feel free to ask any questions you may have and please note that asking questions or showing interest does not obligate any involvement. You can hold the right to withdraw at any point without explanation or reason and remove yourself from the study if you choose to do so.

Thank you for taking the time to read about this research and I hope you are interested in being a part of the study.

Charlotte Aspland

Lead Researcher

Ca481@kent.ac.uk

D: Topic Guide

To what extent does an invisible disability shape an individual's identity?

7) Introduction

To begin the interview process, I will ask the respondents to speak a bit about their conditions and what they feel are the main constraints it has put on them (if any) this will include

- Confirm consent and questions
- What are the outstanding moments about your life, what elements of your day to day existence are the most important to you? What are the most important elements of your life e.g.: jobs, experiences, relationships?
- Details of the specific disability
- Age of onset (this will provide a good boundary for the thematic analysis of the impact of age)
- Offered treatments and options for help

8) Work and Leisure

This section will look at how respondents feel their condition has affected their decision regarding their career and their choice of activities in their free time. This will also explore current educational goals and the future prospects they may foster.

- What does your current educational track have to do with your future hopes and goals?
- What job do you aspire to have after completion of your university course?
- Has your disability affected employment in your life thus far?
- What do you enjoy doing in your free time?
- Overall, is there anything either work or leisure wise that you feel is unattainable because of your condition? How has this impacted your decision making?

9) Community

In relation to how a disability can affect an individual's social life there have been many studies which show the power of a disabled community. As such this question will follow on from relationships to explore how respondents feel about the disabled community and whether or not they are connected with their own.

- Are you aware of any local community groups associated with your disability? are you a member of said organisations?
- Why/why not?

- Do you feel that this community has helped you deal with your condition in your daily life?

10) Relationships

Firstly, the interview will approach the discussion of disability based on the impact it has had on the participants ability to both maintain current relationships and generate new ones.

The questions will be along the lines of:

- How do your family feel about your condition? Do you feel supported by them?
- Do you consider yourself to be a sociable person? Do you find it easy to communicate with new people?
- Do you feel you have a strong support network?

11) Disability and Identity

Finally, I will ask questions which relate to the research question a bit more directly.

- Do you think the fact that your condition did not immediately clear to the public impacts you?
- Do you think people ever think about you in association with your disability?
- Is there any additional help or aids you believe could help you in your future endeavours? Such as equipment that could be provided by the education system support or external state assistance.

12) Conclusions

At the conclusion of the interviews there will be an opportunity for any final comments or final questions

- Final thoughts
- Debrief
- Final consent

E: Concept Framework

To what extent does an invisible disability shape an individual's identity?

Main themes

Identity

This research is dealing with concerns surrounding identity formation and its relationship to disability. Specifically, I will utilise the concept of spoiled identity as discussed by Erving Goffman back in the 1950's. This concept outlines the impact that having a disability can have on a person's 'front stage' identity. The spoiled identity refers to the negative stereotypes placed on a person who can be identified as disabled. Whether or not this individual wishes for their condition to be a part of their identity is not their decision as the social world assumes their capabilities based on their external appearance.

In studying this phenomenon, it is important to consider the historical context of the original study given the social progress that has occurred since this theory was originally created, it may be the case that this idea is outdated and that there is no longer a disconnect between a disabled person's external identity and their true self. In order to explore this concept thoroughly within this research I intend to discuss (predominantly through the initial biographical discussion) the power that a disability has on a person's core identity.

Bone, M. (2017). Trapped behind the glass: crip theory and disability identity. *disability and society*. 32 (9), 1297-1314.

Goffman, E (1956). *The Presentation of Self in Everyday Life*. New York: Vintage: Random House.

Disability

The specific disability as classified by my sample themselves is that of the invisible disability, this focus is fuelled by a lack of research into this particular disability sub culture and its impact on an individual process of identity formation particularly on this age group as a young and influential group. This different type of disability classification focuses on the point that these individuals do not have any dominant external signs of their condition. With the disabilities I have chosen for this research there is also the possibility that wider society expect a certain stereotyped symptom of the disability itself. Whether this is a hearing aid or glasses for the sensory condition

or a response based more in body language such as stress for those with neurological conditions. This study and its interview template focus on the underlying fact that these conditions are not externally obvious and explores the potential identity conflicts which may arise from this lack of visibility of the disability itself.

Hadley, B (2014). *Disability, Public Space, Performance and Spectatorship*. UK: Palgrave Macmillan.,.

Wilkinson, A (2008). *Aaron Wilkinson - performance video collaboration*. London: Live art development agency.

Wider themes

With these two overarching themes in mind the interview template will be taken on board with regard to a number of wider themes, the responses to which should help to generate an idea about the identity impact of these conditions on respondent's identity formation. This will be discussed mainly through their day to day choices and experiences and the way they chose to shape and speak about their lives with regard to their disability.

Community

There are a lot of studies which point to the power of disability such as mental health conditions and deafness in particular to generate a strong close-knit community for people with these conditions. The strength of these communities to shape an individual's association with their sense of both social and personal identity. Whether or not individuals with invisible disabilities contribute to their condition's community relates directly to their identity and association with their condition. It has been shown in both my and others previous research that certain conditions which require an aid leads to an almost unavoidable connection with their disability and fosters relationships with others who have the same disability.

Gregory, S and Hartley, G. (1992). Defining the Deaf Community. In *Constructing Deafness*. Milton Keynes: The Open University. 21-46.

Work and Leisure

For people at a university level the future a particularly work and careers are soon to be strong considerations for these participants. The extent to which a person's disability factors into their decision about what career they hope to pursue, represents another element of mainly personal identity. An individual's decision

about what they want/expect their future to look like is based on what they feel as a person will be their key strengths and purpose in life.

Research into the effect of disclosing a disability on an individual's job prospects has been undertaken and has shown that the later in the employment process someone discloses their condition the more likely they are to gain employment from this company. This was undertaken with regard to deafness but the general ideas expressed about having the ability to withhold their disability can have on a person's future employability.

With regard to leisure I intend to explore the impact of disability in decision making regarding what to do in free time. Leisure time and the activities that a person chooses to partake in is often a very strong defining feature of identity in the modern world.

Schrader S. Mazer, V. Bruyere, S. (2014). Perspectives on disability disclosure: the importance of employer practices and workplace climate. *Employ Response Rights*. 26 (1), 237-255.

Relationships

Another area which has been looked into by both disability and identity theorists is the impact of conditions on relationships. Whether this is public such as work relations or private like close family relations. There is a significant impact logged of having a disability on a person's relationships. Research looking at how disabilities can impact particularly private relationships has been undertaken by a number of researchers and often concludes that there is a shift in the way a person is treated based on how their family perceived them as a result of their condition.

Researchers such as Heaslip, NAME and NAME look at the help seeking behaviours and altered relationships with family and close friends for people with disabilities. They all state that, although in different ways there is always some form of change to the relations between an individual and their social circle because of a disabling condition. This study will take on board these ideas in order to explore whether or not individuals with invisible disabilities in particular struggle with how to confront their day to day relationships whilst also negotiating their disability.

Heaslip, S (2016). *an investigation into the psychological help seeking attitudes of persons with visual impairments*. Vancouver: The university of British Columbia.

Lam, K. Leat, S. (2013). Barriers to accessing low vision care: the patient's perspective. *Can J Ophthalmology*. 43 (1), 458-463.

Age

As part of the methodology of this research the sample has been confined to the university student, whose average age is between 18 and 25. With this in mind there is a necessary consideration of the impact of being disabled at a certain age which needs to be studied. There has been a clear link established between these formative years and the likelihood of being diagnosed with a mental health condition especially anxiety and depression for people who are also going through the stress of a higher education system. There are also a lot of research links between Dyslexia and youth. This is mainly due to the link between this condition and education in the earlier years. As well as this there are a number of studies which link disability to feelings of aging and older age. Society associate's disability and certain handicaps (particularly sensory impairments) with older people as it is well documents that older people are more likely to suffer from these as simply age related. These strong links with age represents the fact that there are social expectations of certain disabilities and this research will take this on board and explore how this specific stratum of disabled individuals are affected by this stereotype.

Benton, A and Pearl, D (1978). *Dyslexia: An analysis of current knowledge*. New York: Oxford University Press. 3-61.

Hauser-Cram, P (2018). *children with disabilities: A longitudinal study of children development and parent wellbeing*. London: Blackwell.

Priestley, M. (2003). 'it's like your hair going grey' or is it? impairment disability and the habitus of old age. In: Riddell and Watson *Disability, Culture and Identity*. Edinburgh: Pearson Education Limited. 51-65.