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**Is honesty the best policy?
An assessment of the importance of disclosure to
the social experience of students with mental
health difficulties in Higher Education**

Submitted for the Degree of Master of Arts in
Disability Studies

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Abstract

Entering Higher Education can present many challenges for students, including moving away from home and living independently for the first time, adapting to higher-level study, and integrating into a new social environment. While this experience offers many opportunities, those with mental health difficulties are faced with additional challenges, including navigating a social environment that may be inaccessible, and making decisions about whether to disclose their mental health difficulty, and the implications of this.

This research explores the social experiences of students with mental health difficulties and their experiences of disclosure to peers, to develop a greater understanding of the issues these students face in the social environment of Higher Education. Data were collected through qualitative, face-to-face interviews with students from two institutions in the North of England. Students' perceptions of university social culture and the accessibility of university social events were explored, with particular emphasis on disclosure decisions in social contexts, the influences on these, and the experiences of disclosing.

The findings indicate the culture of excessive drinking in universities and pressure to participate in this can create additional pressure for students with mental health difficulties, and this culture is widely disliked. Disclosure decisions are often made due to difficulties integrating into this culture, but such decisions are fraught with difficulties and perceived risk.

Students' perspectives of the social side of university and mental health disclosure in social contexts are largely unheard, and this research aims to provide a greater understanding of the cultural barriers facing students with mental health difficulties in university social contexts, the importance of disclosure and the impact of this on their relationships with other students.

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Chapter One: Introduction

Mental health difficulties (MHD) affect a large proportion of people, with around one in ten experiencing a common MHD such as depression or anxiety at any one time (McManus et al. 2009), and one in four affected by mental illness in a year (Time to Change 2015). It is well established that people who live with MHD experience stigma and discrimination (Time to Change 2015) and this can have a substantial negative impact on people's lives. Studies show people who disclose MHD in a job application are less likely to be offered work (Wahl 1999), and particularly those with more stigmatised conditions such as schizophrenia (Scheidt 1999). Those in work also face additional challenges, and fear being overlooked for promotions, or being dismissed if they choose to disclose (Irvine 2011), in addition to social and cultural barriers.

Mental health is a particularly pertinent issue within the context of Higher Education (HE), as the age at which the onset of MHD is most common is when many make the transition to university (Quinn et al. 2009), with 75% of people experiencing their first episode before the age of 24 (Reavley and Jorm 2010). University presents an opportunity for students to develop knowledge and skills to support future employment or ambitions, and also to become more independent, make new friends and forge a new social life (Riddell et al. 2005). The university experience can present substantial challenges for students with MHD, both academically (Riddell et al. 2005) and socially (Demery et al. 2012). It is therefore important to understand the experiences of these students, and to identify areas where they may not have the same social opportunities as others. Existing research on the experiences of students with MHD has largely focused on academic issues, such as the provisions available through Disabled Students' Allowances (DSA) (Jones 2011), adjustments in learning and teaching contexts (Riddell et al. 2005) and the benefits of inclusive practice (Tinklin et al. 2006). The social side of university life has been somewhat overlooked (Wilcox et al. 2005), although it is evident that students attach significant importance to this element of the HE experience (Willcoxson et al. 2011), and

campus culture directly impacts on academic development and social engagement (Rankin 2005, cited in Tetreault et al. 2013). Excessive drinking plays a central role in campus culture (Colby et al. 2009), and such activities risk being inaccessible to some groups of students, including those with MHD, who may feel unable to participate due to social anxiety or the impact of alcohol consumption on their mental health (Demery et al. 2012). An inaccessible social culture means that establishing a friendship network can be more difficult for students with MHD, leading to feelings of isolation and distress (Buote et al. 2007; Demery et al. 2012). For this reason, the social experiences of students with MHD, their perceptions of the social culture of HE and their experiences of disclosure require further understanding. The social culture of university can be hard to navigate, and students are faced with difficult decisions around whether to disclose their MHD. Disclosure has an impact on relationships with peers and social involvement at university, and is therefore an important area of study. This research aims to explore these issues and increase understanding of this neglected and integral area of the student experience.

1.1 Researcher's role

Interest in this area stems from my work as a disability adviser in a UK university. This role centres on supporting disabled students with issues relating to their studies, including the provision of reasonable adjustments to learning, teaching and assessment. Non-academic issues are largely outside of the scope of the role, and the support offered here is limited. It is clear that social issues can have a substantial impact on academic performance, and that social experiences at university can have a significant influence on students' wellbeing, both within and outside HE.

1.2 Research aims and structure

The purpose of this research is to explore the social experiences of students with MHD in HE, with an aim to address the following questions through semi-structured interviews with students across two institutions:

What are students' experiences of the social side of university life and how does having a MHD affect this?

What can be done to improve the quality of the student social experience for students with MHD?

What are students' experiences of disclosing a MHD to their peers?

What factors influence students' decisions to disclose or not?

Chapter Two will examine existing literature on the HE landscape, including the social barriers facing disabled students, and those with MHD specifically, including disclosure issues. Chapter Three will outline the research methodology, including discussion of the adopted ontological perspective, ethical considerations, data generation strategy and recruitment of participants. Chapters Four, Five and Six will present the research findings, focussing on students' experiences of campus culture, factors influencing disclosure decisions, and experiences of disclosure respectively. Drawing on data generated from student interviews and with reference to the existing literature, consideration will be given to whether the findings are reflective of previous research. Chapter Seven will summarise the findings and reflect on the implications of the conclusions, with thought given to how the research could be expanded to provide greater insight.

Following completion of this research, the findings will be disseminated to the participating universities and students' unions. It is hoped that the insights provided may have some practical uses for services that support students with MHD, through developing a better understanding of barriers facing these students, and providing suggestions for potential improvements to service provision.

1.3 Terminology

In the context of this research, the term 'mental health difficulties' (MHD) will be used to cover a variety of conditions, including neurotic (experiencing extreme forms of common emotions, as seen in depression and anxiety) and psychotic symptoms (experiencing a distorted sense of reality) (Mental Health Foundation 2015) and a wide range of different and complex diagnoses. This term has been chosen as being intentionally broad and politically neutral, as words such as *disability*, *impairment* and *disorder* can provoke negative reactions within the context of mental health, and can create confusion among those who experience MHD but do not consider themselves 'disabled' (Irvine 2011, Watson 2002, Riddell et al. 2005). With this in mind, an approach based on the social model of disability will be adopted.

1.4 Definitions of disability

Traditionally, disability has been regarded as an individual issue, with the disabled person perceived as abnormal or deficient (Barnes and Mercer 2010). Referred to as the medical or individual model, disability is regarded as a personal tragedy, with the burden borne by society (Barnes and Mercer 2003). This perspective has been rejected by disability activists (Oliver 1983), who propose an alternative based on a distinction between impairment and disability, where:

"...it is society which disables [...] people. Disability is something imposed on top of our impairments..." (Oliver 1996:22 cited in Shakespeare and Watson 2002).

While the social model undoubtedly offers a useful political framework for examining issues of disability and highlighting inequality and oppression (Oliver 2013), it has been criticised for ignoring the experience of impairment (Shakespeare 2006; Thomas 1999). Indeed, the emotional impact of living with an impairment is often ignored in literature on the social model. In the field of mental health in particular, people may see the effects of their impairment as a barrier, and while

society and the environment contribute to the experience of exclusion, it can be difficult to separate the experiences of impairment and disability (Shakespeare 2006; Crow 1996). Nevertheless, the social model offers a helpful perspective for addressing the research questions, and attempts will be made to identify social barriers that exclude students with MHD from full participation in the university experience.

Chapter Two: Setting the scene: disability, disclosure and the university experience

2.1 Introduction

In this chapter, current issues facing disabled students will be examined through literature, including participation, legislation and support provisions. The social culture of university will then be considered in more depth, with reference to literature from the field of disability studies, youth studies and beyond. Discussion will reflect on the prevalence of 'lad culture' and excessive drinking, and barriers this presents for students with MHD, before considering issues of disclosure and its social impact.

2.2 Disabled students in Higher Education

Figures show disabled students as a group are underrepresented in HE (Riddell et al. 2005), where 9.8% of the student population are thought to be disabled (HESA 2014), compared to 19% of the working age population (Office for Disability Issues 2014). While HESA (2014) data show the percentage of disabled students in HE appears to have increased in recent years, it is not possible to know if this reflects a genuine increase in participation, or if other factors are responsible, such as increased rates of disclosure.

Changes to legislation governing the work of HE institutions have also been significant in recent years. Under the Equality Act (2010), universities and students' unions have an 'anticipatory duty' to people with protected characteristics. Riddell et al. (2005) describe this as a move away from previous 'reactive' models of support, requiring institutions to anticipate the needs of the population and make appropriate adjustments proactively, before any access issues arise. If widely implemented, this duty could also negate the need for some students to disclose an impairment in order to gain full access to their studies. However, this reality is

clearly a long way off. Currently, students are required to disclose and provide written evidence of an impairment in order to access funding through Disabled Students' Allowances (DSAs). Forthcoming cuts to the provision of DSAs in 2016 (Willetts 2014) are likely to impact on the support provisions available, and these changes could also affect disclosure rates (Lewthwaite 2014), as students may feel that the reduced support available is not beneficial enough to justify disclosure of an impairment, creating an invisible community of disabled students. Lewthwaite (2014) identifies that changes could also discourage disabled applicants from applying for university at all, leading to a decline in participation. While the proposed cuts have been widely criticised (Lewthwaite, 2014), Tinklin et al. (2006) and Riddell et al. (2005) consider that the concept of requiring universities to make their courses and facilities accessible and adopt inclusive practices more widely is a positive move, and suggests a shift towards more social model thinking. However, the drastic nature of the cuts will require a substantial change of culture for HE institutions, creating uncertainty for disabled students as universities decide how to respond to the changes.

Issues around academic support are of utmost importance for disabled students, but Wilcox et al. (2005) suggests the university experience is not solely based on learning and teaching activities, and for many, the social aspects of HE play a central role in decisions to go to and remain at university. While the desire to expand social horizons and forge new friendships can be a key motivator, literature demonstrates that starting university presents significant emotional challenges for new students (Demery et al. 2012), and this is particularly the case for those with MHD, who identify specific concerns around making friends and 'fitting in' (Riddell et al. 2005).

2.3 The university social experience

Aside from the academic challenges of starting a degree and studying at HE level, starting university often involves moving away from home, living independently for the first time, and forging a new social world (Riddell et al. 2005). While the impact of being disabled in an academic context has been researched extensively, little

attention has been given to the challenges and barriers to university social life (Wilcox et al. 2005). However, this is clearly an important area, as difficulty in integrating into the social environment at university is a principal reason for attrition in first-year undergraduates (Willcoxson et al. 2011, Wilcox et al. 2005). Much of the literature examining social experiences in university settings is from the US (Tetreault et al. 2013; Rankin 2005) and Canada (Buote et al. 2007) and the issue appeared under-researched in the UK. Where social issues in UK universities have been explored, literature focuses primarily on the culture of drinking (Dempster 2011; Crozier et al. 2008) and the importance of forming friendships (McCune et al. 2010; Wilcox et al. 2005). While these issues are significant and affect the whole student population, the voices of disabled students are largely unheard within these contexts, indicating a gap in our understanding of how the university social environment impacts on disabled students and those with MHD.

Buote et al. (2007) identify that, for many students, starting university comes with high expectations, but the reality of the experience may not live up to these, and students may encounter transitional difficulties they had not anticipated. It is here that establishing new friendships appears to be of particular importance, and the emotional support and sense of belonging offered is key to enabling students to adjust to new surroundings (Buote et al. 2007). Friendships formed through university accommodation are frequently cited as the most important at university, with social networks formed through shared accommodation fulfilling a number of roles, including that of a 'family' (Wilcox et al. 2005).

For students who choose to live at home while attending university, establishing a new social network can be more difficult. Many of these students may make a strategic choice to opt out of university social circles, and curtail their involvement in clubs, societies and social events, to avoid interactions that can create feelings of exclusion, discomfort and social anxiety (Crozier et al. 2008). Conversely, those who do not live on campus and have an established social network may have less of a need to form new relationships at university, but Buote et al. (2007) argue that a lack of openness to forming new friendships can lead to poorer social experiences.

Crozier et al. (2008) identify that the importance of the social experience for students in HE is often linked to their socio-economic background. Those from middle class backgrounds saw university as an opportunity to expand their social horizons in addition to getting a degree, while those from working class backgrounds were more concerned with getting a degree and the potential economic benefits of doing so, and saw their time at university as 'a means to an end' (Crozier et al 2008:175). This also appears to be the case for mature students, who are typically less interested in the social elements of university than their younger peers (McCune et al. 2010). Therefore, the background and motivations of students for coming to university are likely to impact on their social involvement.

The campus climate of university is also particularly relevant in influencing levels of social engagement (Rankin 2005, cited in Tetreault et al. 2013). Some of the social activities typically promoted by universities are potentially difficult to access for students who in some way deviate from the 'typical' student stereotype. NUS (2014) research suggests the social culture of UK universities centres around large-scale events that encourage drinking alcohol, often to excess. Indeed, research exploring drinking habits in students found that excessive drinking was not only considered a 'normal' part of student life, but is actively encouraged (Dempster 2011). The 'night-time economy' found in universities is particularly associated with sports teams and societies and is often considered to be a typically male trait (Dempster 2011). However, Dempster (2011) found that female students also engaged in such behaviour, although this was perceived negatively by male students, suggesting that traditional gendered attitudes towards drinking are still common among the university community. NUS (2012) research describes this phenomenon as 'lad culture', and identifies that such behaviours are exclusionary to female students, with many perceiving the behaviours of (male) students under the influence to be misogynistic and threatening. Additionally, research conducted on the experiences of LGBTQ (Formby 2015) and international (Soorenian 2013) students also identifies this culture as an issue, and recommends that students' unions and societies offer a more diverse range of activities that do not centre on drinking (NUS 2014). This would suggest that the stereotypical university social culture does not cater for the

needs of a diverse student population, and parallels exist between the experiences of students with MHD and other oppressed groups. Students managing their mental health symptoms with medication may be excluded from participating in traditional university social activities, and those who choose to drink while on medication may risk exacerbating their symptoms (Demery et al. 2012). This culture of risk-taking behaviour could be particularly problematic for students with conditions such as bipolar or borderline personality disorder, where there is already a higher risk of developing a substance use disorder (Richardson 2011). In addition, many of these activities can be inaccessible to those with social anxiety or panic disorders due to the size of the venues and the number of people present.

It is against this backdrop that students with MHD must make disclosure decisions. Such decisions are important and complex, with far-reaching implications.

2.4 Perspectives on disability disclosure

Students frequently report a reluctance to disclose a disability, and particularly a MHD, to their university (Martin 2010). The support framework within universities requires students to disclose in order to access support, but worryingly, an Australian study found that, of those students who had disclosed a MHD to their university, 65% regretted doing so and would discourage other students from disclosing (McLean and Andrews 1999, cited in Martin 2010). Reasons provided included concerns about not being believed or being resented for getting 'special treatment' (Martin 2010). While disabled students often choose not to disclose, it is clear that this presents its own difficulties, and Burris (2006) identifies that the burden of keeping an unseen impairment secret can cause significant long-term distress. In addition, it would seem that non-disclosure in an academic context leads to feelings of disempowerment, such as when academic deadlines are not met due to disability-related reasons and penalties are applied (Martin 2010).

Disclosure is often promoted as a positive and helpful step in academic contexts, but there are many factors to consider that may impact on decisions to disclose, and

ultimately whether people expect the overall outcome to be positive or negative. Perceived benefits to disclosure in academic contexts include access to adjustments and specialist support, the opportunity to educate others and challenge stigma, and psychological relief from the stress of trying to conceal a MHD (Corrigan and Matthews 2003). Other potential impacts include being viewed as less competent than others, the effects of stigma (Corry 2008; Quinn 2009) and being observed more closely and critically (Irvine 2011).

While disclosure in academic contexts has been widely researched (Riddell et al 2005; Tinklin et al. 2006), literature on social disclosure in HE is sparse. This area appears to be under-researched, and literature on the experiences of LGBTQ students (Formby 2015) may offer more insight into the issues than the limited research from the field of disability studies. Corrigan and Matthews (2003) consider mental health disclosure in parallel with 'coming out' as LGBTQ, and identify that the associated costs and benefits of coming out are broadly similar, particularly in terms of stigma. However, mental health disclosure in social contexts generally is viewed positively by mental health organisations (Time to Change 2015) and is also considered a useful and empowering step to recovery (Corrigan and Matthews 2011). Within university settings where forming friendships is of particular importance (Buote et al. 2007), mental health disclosure may facilitate this process for those who have MHD, who may otherwise appear moody and withdrawn. Green et al. (2006) suggest that such behaviour is often attributed to an anti-social personality, when an explanation of external factors such as having a MHD may lead to more positive outcomes, such as greater understanding and support from others. After considering the potential outcomes of disclosure, the extent of disclosure is a complex issue, and people must decide when to disclose, who to disclose to, and how much information to share (Irvine 2011). Concern about stigma appears to play a major part in the decision-making process.

2.5 Stigma

Stigma is widely discussed in relation to disability and mental health. It is commonly acknowledged that disabled people can experience stigmatisation (Olney and Brockelman 2003; Matthews 2003; Jones 2011; Quinn 2009) and this is particularly the case with MHD, where there is a general lack of understanding about the associated challenges (Mind 2014).

Goffman defines stigma as a discrediting attribute “which is incongruous with our stereotype of what a given type of individual should be” (Goffman 1963:13) and that stigma is created by the relationship between attribute and stereotype. Within this context, conforming to a stereotype can be considered as a desirable state of being, and an expression of what is considered ‘normal’ and socially acceptable. It is deviation from perceived normality that is often considered undesirable (Morris 1991).

Regardless of the controversy around the subject (Finkelstein 1980), the concept of stigma is regularly discussed in relation to disability and mental health, and its existence rarely questioned. It would seem that stigma is regularly experienced by those with MHD, and plays a significant role in decisions to disclose. The *Stigma Shout* survey conducted in 2008 was a national research project involving mental health service users and those who care for people with a mental health diagnosis, and used questionnaires and workshops across the country to explore issues of stigma and discrimination. This research found that 89% of mental health service users reported stigma and discrimination had a negative impact on their lives, with two-thirds reporting that stigma had stopped them engaging in social activities (Corry 2008). It would seem that the fear of stigma, rather than stigma itself, prevents people from disclosing their MHD, particularly when applying for jobs, but that disclosure experiences in social settings are less negative, despite substantial worry about doing so (Corry 2008).

Corrigan and Matthews (2003) assert the most effective way to combat stigma is for people to have more contact with those with stigmatised characteristics, and that mental health disclosure on an individual level has wider benefits for helping to reduce stigma in society. Therefore 'broadcasting', an approach of full and open disclosure, (Corrigan and Matthews 2003) may be desirable.

2.6 Conclusion

This chapter has examined literature on the challenges facing students with MHD at university, including issues around disclosure and the social environment. It would appear that there is limited literature on this topic, indicating a potential gap in our understanding of these students' experiences. This research may help address this gap.

The literature examined suggests the social culture of university and the prominence of large-scale events and excessive drinking can present significant challenges to students with MHD in terms of participation (Colby et al. 2008), and that friendships offering emotional support are particularly important (Buote et al. 2007). Decisions around whether or not to disclose a MHD are also fraught with difficulty, and while choosing to disclose may help to change perceptions of MHD in wider society (Corrigan and Matthews 2003), there are substantial risks on an individual level, most prominently experiencing the effects of stigma (Corry 2008).

The next chapter will outline the research perspective and methodology to be adopted to explore these issues further.

Chapter Three: Putting plans into practice: research methodology

3.1. Introduction

In this chapter, the practical considerations of conducting the research will be examined. Ontological and epistemological perspectives shall be established, and a suitable methodology will be outlined, giving thought to ethical considerations, sampling and recruitment, data analysis and dissemination of the findings.

3.2 Research perspective

The ontological perspective adopted in this research is influenced by the social model of disability, and by personal experience of working as a disability adviser in a university. The view is held that students' own perspectives on their experience have empirical value, and that interpreting these experiences will provide valuable insight into the issues being explored. This interpretive ontology rejects the idea that it is possible to objectively or independently observe social reality, and asserts that any observations made are subject to our own interpretation, influenced by our individual view of the world and our own, subjective experiences (Shakespeare 2007; Blaikie 2007; Punch 2005; Creswell 2009). Interpretive approaches to disability research have been criticised by some, who have stated that such research rarely leads to improvements in service provision (Oliver 1992). However, potential exists to influence policy and to provide a voice for disabled people (Oliver 1992).

In line with this approach and a belief that the social model provides a helpful framework for looking at issues of accessibility and inclusion (Oliver 2013), some principles of emancipatory research will be considered and adopted where possible. Key principles of emancipatory research include redressing the balance of power between the researcher and the researched (Oliver 1992) and prioritising disabled people's voices (Shakespeare 2006) while remaining accountable to the disabled community (Barnes 2003). While emancipatory research has been criticised by some

for lacking objectivity (Barnes 1992), it is appropriate within the field of disability studies to strive to highlight issues of oppression and inequality and to document the experiences of disabled people in a useful and accessible way. It is hoped that this research will meet some of these objectives and identify how the HE environment and culture oppresses disabled students, specifically those with mental health difficulties (Barton 2005).

Some proponents of the emancipatory paradigm would argue that disability research cannot be undertaken by non-disabled researchers:

“Non-disabled people, no matter how much they love us, do not know the inside experience of being disabled. Moreover, they are in a position to escape the stigma.” (Gill 1994, cited in Shakespeare 2006:185)

This view is rejected by many leading disabled researchers (Shakespeare 2006; Barnes 1992), who assert that being disabled does not automatically ensure an affinity with all disabled people. Indeed, experience of oppression may be more directly attributed to other characteristics such as race or sexuality (Shakespeare 2006) and a social model perspective is not accepted universally (Barnes 1992). This is likely to be the case with MHD, where many who experience these issues do not have a disabled identity (Irvine 2011). Stone and Priestley (1996) also discuss the challenges of being a non-disabled researcher in the field of disability studies, and suggest that conflict exists between maintaining academic credibility and achieving political or emancipatory objectives. In the case of this research, it is hoped that the role of an ‘ally’ can be adopted:

“An ally has to find ways of using all their skills, knowledge and abilities without taking over and without taking any power away from disabled people.” (Holdsworth 1993:5, cited in Shakespeare 2006: 197)

With these perspectives established, and with a wish to fully include the voices of disabled people in the research, attention must now be given to the ethical implications.

3.3 Ethical considerations

Research of this nature requires robust consideration of ethical issues, and this research has been subject to a full ethical review from the University of Leeds Research Ethics Committee (Appendix A). Full approval was received on 10 March 2015 (Appendix G). The main ethical considerations in this research fall into three broad categories: consent and confidentiality, potential for distress, and conflict of interest.

Consent and confidentiality

For research to be valid and ethical, participants must be fully aware of what participating will involve, how their data will be used and stored, and the benefits and risks of participating (Hall and Hall 2004). This information was outlined to participants by email, through the participant information sheet (Appendix D) and consent form (Appendix F) in particular. These communications are discussed in more detail in 'Sampling and recruitment'. Students were encouraged to ask questions at any stage of the recruitment process, including before the interviews commenced. Participants were asked to re-read the information and the right to withdraw was reiterated before the consent forms were signed.

Confidentiality was also an important consideration. To maintain the anonymity of those participating, student names have been excluded, in addition to referring to the institutions as University A and University B. This reflects common practice in similar research (Riddell, Tinklin et al. 2005; Crozier et al. 2008). The act of participation will also be kept confidential from the students' university and from any support services.

Potential for distress

The sensitive nature of the subjects being discussed had potential to cause distress, and steps were taken to support students appropriately should it become necessary. Students were aware that they could terminate the interview at any time should they wish to, and should they disclose anything that suggested they may be at risk of harm, this information would be passed to the appropriate support services. An information pack was prepared and given to each participant at the end of the interview, containing details of support services available within their university, in their local area, and online. Should students require support with a specific issue, they would be signposted to the appropriate resource, and services were researched in advance to facilitate this. Information packs were distributed as planned, and no incidents occurred.

Conflict of interest

It is acknowledged that my role as a disability adviser and as a researcher creates potential conflict. Students from University B could be known to me in my professional capacity, and there is potential for students to think the research is affiliated with their university, or that participation could affect their support provision. To reduce this risk, interviews focussed on non-academic elements of the university experience, and participants were reassured that their involvement in the research has no bearing on their support now or in the future, as outlined in the consent form.

Through the submission of the Ethical Review Form and accompanying documents, these ethical issues have been addressed and potential risks have been identified and appropriate strategies implemented.

3.4 Data generation methods

Having examined the ethical issues, a suitable methodology was identified. Students from two universities in the same city were involved in the research:

University A

This institution is part of the Russell Group and is ranked in to Top 100 universities in the world.

University B

This institution gained university status in 1992 and has a strong emphasis on employability and work placements.

These institutions were selected due to the links I already have through my employment at University B. The disability support services at both universities have strong links with each other, and my professional role in University B has allowed me to work with University A to allow a broader spectrum of students to participate.

Sampling and recruitment

The sampling frame was identified with the assistance of the disability support services at each university. A purposive, targeted sample (Punch 2005; Kumar 2011) of students with a 'disability code' indicating that they have disclosed a mental health difficulty was identified, and these students were contacted with basic information about the research (Appendix B). The 82 students who responded to this initial communication were sent a participant information sheet and interview schedule (Appendix E), and asked to complete a short online form to confirm their interest in participating and that they were not excluded from participating due to being under the care of a legal representative. 29 students responded. The first four students to reply from each university were invited to interview (Appendix C), and additional demographical information was collected through an online form.

Limitations

It is acknowledged that the sampling method chosen here is reliant on participants self-selecting, and that there are benefits and risks associated this approach. Self-selection means that those who volunteer are likely to be interested in the topics being researched and be open about their experiences. However, they may have had very positive or negative experiences that have motivated them to participate (Kumar 2011). This method also means that students with multiple impairments were excluded, in addition to those who have chosen not to disclose to the institution. While these excluded groups could offer a unique perspective on the research topic, contacting the whole student body at both institutions (around 60,000 students) seems impractical and excessive given the scale of the research and the number of intended interviews.

3.5 Interviews

The research questions were explored through the use of qualitative, semi-structured interviews. A benefit of this approach is participants can lead the conversation and decide which topics are most important to them, with the interviewer prompting them when necessary, as well as clarifying any ambiguity (Longhurst 2010; Kumar 2011). The interview schedule was used to ensure the relevant topics were covered while allowing for flexibility in structure and facilitating a more natural conversation (Kvale 1996).

Participant profiles

Eight students were invited for interviews initially, although one asked to withdraw before an interview could be scheduled, and another arranged an interview but did not attend. Two more students were then contacted so that the planned number of interviews could take place. Eight face-to-face interviews were conducted across the two universities. Participant profiles can be found in Appendix H. Participants' ages ranged between 19 and 43, with five students over the age of 21 and two aged 40 or

above, and therefore classed as 'mature' (UCAS 2015). More females (five) than males (two) were interviewed, with one student not identifying as male or female. The majority of students were studying full-time at undergraduate level, although two were postgraduates, including one studying part-time.

Depression and anxiety were the most commonly disclosed mental health diagnoses, which is unsurprising due to their prevalence in the UK, where nearly one-tenth of the population experience these conditions (McManus et al. 2009). However, some participants also had less common diagnoses, such as borderline personality disorder (BPD), obsessive-compulsive disorder (OCD), seasonal affective disorder (SAD) and anorexia nervosa. One student also had a diagnosis of Asperger's syndrome, although this is often categorised as a specific learning difficulty or communication difference, rather than a MHD. As the students volunteered to participate with full knowledge of the purpose of the research, attention will focus on the experiences of these students on disclosing their own conditions, and it is not intended to consider the classifications of any of the disclosed diagnoses.

The sample used here cannot be considered to be representative of the general population of students with MHD for a number of reasons, including the sample size, the high percentage of mature students and the low number of male students (Punch 2005). Therefore, in accordance with an interpretative ontology, analysis will focus on recording and understanding the experiences of those who participated, rather than attempting to make generalisations.

3.6 Data analysis and dissemination

The audio recordings of the interviews were transcribed in full (including non-verbal cues where appropriate) and sent to the participants for comment, in accordance with emancipatory principles (Barnes 1992). Two students sent additional contributions via email.

Transcripts were analysed using *NVivo* software and employing qualitative data analysis techniques. Transcripts were reviewed and key themes identified, with quotes extracted to illustrate the findings. These findings will be considered in the chapters that follow, with reference to relevant existing literature (Creswell 2009; Punch 2005).

In accordance with emancipatory principles and following completion of the dissertation, it is intended to disseminate the findings to the participating universities. This is so that the findings may have some practical application and so students' experiences can be used to influence future policy on supporting disabled students by identifying social and environmental barriers to social inclusion. This shorter document will be written and sent to participating students for their feedback. Any comments received will be incorporated before the document is sent to each institution.

3.7 Conclusion

In this chapter, the methodology to be used has been outlined. An interpretive ontology was adopted, with elements of an emancipatory paradigm incorporated where possible. Participants were identified and recruited using purposive sampling of students from two universities, and semi-structured interviews form the basis of data generation. Ethical issues have been identified and addressed, with full ethical approval received. Data analysis will be based on interview transcripts, from which key themes will be identified and discussed, using student quotes to support the arguments and referring back to existing literature. Data generated will now be examined and implications of the findings considered, beginning with an exploration of students' experiences of the social culture at university.

Chapter Four: Disclosure in context: the university social experience

4.1 Introduction

In order to understand the challenges of mental health disclosure, it is necessary to understand the social context in which disclosure is made. The social environment at university presents challenges for students with MHD. As discussed in Chapter Two, a culture focussed on large-scale events and excessive drinking creates significant barriers to participation, and the transition to university in particular can be stressful. Establishing good friendships in the early stages of university is extremely important (Buote et al. 2007), and reliable social networks such as friends made through student accommodation can be a valuable source of support for students experiencing difficulties (Wilcox et al. 2005). In this chapter, students' experiences of the social side of university life are explored, and potential improvements discussed.

4.2 Transition and freshers' week

The first few weeks of university were regarded as an anxiety-inducing time. For many, this involves moving away from home and living with strangers, getting used to a new town, navigating a unfamiliar social world (Riddell et al. 2005) and forming new friendships (Wilcox et al. 2005), in addition to making disclosure decisions. One student described the added anxiety of moving away from established support networks at home.

"It was hard because my routine had been constructed around support services and seeing doctors and my CPN [Community Psychiatric Nurse] and things like that... [Once I got to university] it was like, 'who do I turn to and who is going to do what, and what happens if it all falls apart?'" (B2)

Feeling pressured to go out and embrace the freshers' week experience, despite feelings of anxiety about doing so, was a common experience.

“I didn’t really engage as much because it’s a confidence thing [...] I’ve spent a lot of time in hospital and a bit out of the loop of socialising and things, that was quite a difficult time. I felt too nervous and anxious to try and take part in a lot of things. I didn’t really have that much of a freshers’ week experience.”

(A4)

As established by Willcoxson et al. (2011), difficulty integrating socially at university is a key reason cited by students for dropping out. These early experiences are clearly an important influence on students’ sense of belonging, and have a significant effect on disclosure decisions. The social pressure continued beyond freshers’ week, and held particular prominence in the context of social drinking.

4.3 Drinking and clubbing

The university culture of drinking alcohol and clubbing was acknowledged by all participants (Colby et al. 2009; NUS 2012) and largely disliked. The reasons given for this were numerous and reflected the findings of existing research, including social anxiety in large crowds, the relationship between alcohol consumption and effects on mental health (Demery et al. 2012), alcohol being used as basis for building friendships, and the normalisation of excessive drinking with the expectation that this is an enjoyable activity (NUS 2012).

One student described her decision not to drink as being a key factor in her disclosure decision, and acknowledged that this choice differentiated her from her peers.

“I spoke to [my housemates] all about it, because I don’t drink because of my anti-depressants [...], so I let them know to be like, ‘don’t think I’m weird if I say I don’t want to drink’ because I don’t. And that was one of the leading things in disclosing it to other students...” (B1)

Alcohol appears to be used as a mechanism for making friends, creating talking points through shared experiences. The students in Colby et al.'s (2009) study also described this, and suggested that students sometimes drink to avoid being left out of social circles. This culture creates additional barriers to forming friendships for those students who do not drink (NUS 2012). Student A2 also described developing an alcohol dependency when they started their course, a common experience for people with BPD (Richardson 2011).

"I do [drink], but I'm trying not to so much now because I got into a bit of an abusive cycle of drinking. [...] the way people make friends is by going out getting smashed and then they have something to talk about. It's quite difficult to get involved when all anyone wants to talk about is 'you were so funny last night, you were really drunk'. So I think there's definitely a lot of pressure to join in with that." (A2)

Others felt that excessive drinking was pointless, and that going to a club and staying sober would be an unpleasant experience.

"I don't understand the culture, if you're going to go out and have a nice time, what's the point in getting so drunk you don't remember it? It doesn't make any sense to me." (B4)

"I don't enjoy clubbing really at all, and I can enjoy it for an hour or two if I'm drunk, but I think sober I would just be like, horrified." (A2)

Aside from drinking, clubbing presents significant environmental barriers for students with MHD, although this experience is not exclusive to this group of students, as discussed in Chapter Two (NUS 2014; Formby 2015). Several students reported high levels of anxiety in large crowds, and that clubbing was not a viable option, particularly if they had not disclosed and others were not aware of the social difficulties they may experience.

“It’s too many people, it’s really loud, flashing lights, it’s late at night, and drunk [...] I think it’s just sensory overload for me, it’s just way too much.”
(A2)

“I can't go to clubs because that's one of the situations that causes me anxiety, [...] so therefore a night out where I can get drunk and go to a club is not really... I can't do it.” (A3)

Despite these issues, students felt pressure to participate and that they would be judged negatively if they chose not to drink, as reflected in research by the NUS (2012). It would appear that, within a university setting, choosing not to drink or not to go clubbing can be stigmatising, as individuals making this choice may not fit the stereotype of a ‘typical student’ (Goffman 1963).

“I know there are events on for people who don't want to drink but there is definitely a culture of ‘you’re boring if you don’t drink’ [...] I think it's definitely difficult to integrate into a friend group if you don’t drink.” (A2)

“I feel like I can’t say ‘I’m having a bad night, I don’t feel very good, I’m just going to stay in’, I feel like I have to think of excuses. So for me that was quite stressful because I was like, ‘how many times can I get away with not going out before they force me to?’” (B1)

The culture of clubbing and drinking as a means of forming friendships can be especially challenging for mature students. This group may face additional barriers to social involvement due to other life commitments, and may be less able to participate fully in the social aspects of HE life (McCune et al. 2010). Living off campus in particular can make socialising more difficult.

“I think I would like to socialise more with people, and if I lived locally it would make it easier to do it on my terms. [...] if I want to go on a night out, I have to stay over somewhere and that for me is quite an anxiety-inducing prospect.”

[...] For me it's kind of all or nothing [...] I know it's going to be hard work, so it's about whether it's worth it." (A3)

"We've got home, we got other lives and responsibilities and houses to run and friendships and relationships [...]. For mature students this is just part of life for three years." (B2)

This highlights a difference in attitudes to socialising at university between mature and younger students, and reflects the findings of McCune et al (2010), who suggest that mature students may be less motivated by the social elements of the HE experience, and are likely to be more focussed on their studies.

4.4 Friendships

As established in existing research (Wilcox et al. 2005), the students interviewed described their housemates as a central part of their social circle, and as those they were most likely to confide in, disclose to and socialise with. Several students also considered relationships with others who have MHD to be particularly important, and that these friendships offered support and understanding that was unavailable elsewhere.

"One of my flatmates, she suffers with anxiety [...], so I've felt like I can talk to her a lot more about it, especially when there's been times that I've been really bad [...] it's sometimes quite nice to have somebody who actually understands from their own experience..." (B1)

While such relationships are helpful, two students discussed the potential drawbacks of close friendships with others who are going through similar experiences.

"[...] it's such a kind of bubble it almost becomes a normality, it's normal to have an eating disorder because everyone has [...]. Most of my friends have mental health problems and I don't want that to become normal." (A4)

“I can sometimes find it difficult having friends that also have mental health difficulties because of having to look out for them a lot [...] if you and your friend are both unwell at the same time [...] you can make each other worse.”

(B1)

For some, having a disabled identity created feelings of solidarity towards other disabled students, although their specific experiences were different. Student A1 experienced a sense of commonality with another disabled student on his course, which formed the basis of a friendship.

“One of my fellow students has got macular degeneration [...] we had much more in common, and we could talk about the kind of issues of disability and talk about what disclosure means, what it means at particular times, and how macular degeneration might impact on him as a student...” (A1)

This student saw the experience of disablement as an opportunity to bond with other students. Those who did not appear to have a disabled identity saw their MHD as a barrier to building relationships.

“I worry a lot more about what other people think than I probably should. And I think that does make it harder for me to make friends. And I tend to avoid certain situations because I know that I'd struggle with it because of my mental health, and that probably does limit my social interactions and the connections that I can make with people.” (A3)

While the issue of disabled identity has not been explored in this research, one student did discuss having a disabled identity, but adopted an individual or medical model perspective (Irvine 2011), describing her perceived personal deficits, rather than identifying barriers in the environment or society (Barnes and Mercer 2010).

“I think I’ve had to accept that I am pretty disabled at this point because I can’t function very well a lot of the time. I do have to claim benefits, I have had to take years out of studying, I struggle to going to uni for 10 hours a week so I don't think I'd be able to hold down a job so... I don't like to think of myself as disabled, but the reality of it is I probably am.”(A2)

The implications of this perspective are wide-ranging, and require consideration at length. However, within this context, a personal identity based on an individual model of disability may create feelings of failure when students are not able to fully engage with every aspect of the university social experience. Such a belief may influence disclosure decisions (Irvine 2011), and this area would benefit from further exploration. The pressure to successfully balance study with social demands while remaining mentally well is also apparent, and can contribute to feelings of inadequacy.

“I've got doctors telling me ‘you need to sleep regularly, you need to eat well, [...] you need to make sure that you have a relaxing time before you go to bed so you can sleep, [...] and none of that meshes with university life which is staying up pretty late, drink a lot and still manage to do all your work somehow. Like, have a massive social life, but also don't fail your degree. I find it really difficult to do both at once.” (A2)

It is evident that the university experience is multi-faceted, and that while academic issues are clearly important (Riddell et al. 2005), the social aspects of HE have a profound effect on students’ experiences (Buote et al. 2007; Wilcox et al 2005). The students’ accounts of their social experiences suggest that there are substantial improvements to be made to this aspect of university life, and consideration will now be given as to how to enhance the university experience for students with MHD.

4.5 Areas for improvement

Students were asked how their social experiences at university could be improved, and a wide range of suggestions were made. Various barriers were identified, and in line with the social model of disability (Barnes and Mercer 2010; Oliver 2013), ideas on how to remove some of these barriers were shared. These suggestions could be broadly categorised as awareness raising, peer support and a more diverse range of social activities.

Awareness raising

It was felt that the majority of the student community were not well educated in matters around MHD (Quinn et al. 2009; Mind 2014), and that greater understanding would facilitate openness and disclosure, as well as 'normalising' the experience of having MHD.

"[...] anything that makes it seem more normal and more everyday is quite helpful. [...] if there was more education of students in general, then you might feel a little bit more confident that they wouldn't jump to conclusions."

(A3)

Mental health awareness days were mentioned as being potentially helpful in terms of opening up conversations, and more encouragement to disclose was also seen as beneficial in reducing stigma and increasing acceptance, as established by Corrigan and Matthews (2003).

"[if] emails were sent round encouraging people to disclose to the university, then it would be something that other students would be more aware of, so even though it's not saying, 'these people have mental health problems' [...] it makes everybody aware that there are going to be people on your course who have problems, so not to be surprised or as taken aback if someone if someone tells you that they have." (B1)

Some students also expressed a desire to share their own experiences to educate others and adopt Corrigan and Matthews' (2003) approach of 'broadcasting'.

"I think what would be really cool is to talk to people who don't have mental health difficulties, and then someone who's interested in learning about it and be able to teach them. Being able to share experience with them. And I would like to know what they think about it as well." (B3)

Acceptance from other students appears to be important, and some suggested that support networks outside of accommodation or course groups could be beneficial.

Peer support

The idea of a 'mental health society' was suggested by several students. Suggestions including regular, face-to-face meetings or an online community, offering opportunities to share experiences, support each other, disclose and socialise in a safe environment.

"When I was at home, there was a support group that I went to a couple of times, [...] you'd go there and be with people who had similar problems and they'd just talk about anything, like you'd just meet and have a chat, and you'd know that if you wanted to you could talk to them and they could offer you advice, [...] you could talk about normal things." (B1)

"[...] if it was something for people with mental health disorders [...] just meet up even if it's just something like just going out on a night out like all the other students and societies, at least it would be something for them to do with other people who understand more than maybe the general populace do." (B4)

It is pertinent to note that both universities in this research already have a student-

led society for those with MHD. However, the students in this research seemed largely unaware of this, suggesting that these societies need to increase their visibility in order to attract members. One student was aware of her university's mental health group, but was sceptical about its benefits.

"They do have a [mental health society] here and they do World Mental Health Day and stuff but I don't really think much happens away from it. It doesn't have much impact." (A2)

While students appear to support the concept of a mental health group existing, some were less sure of whether they would participate.

"If there was an actual mental health group, I don't know if it's something I'd join..." (B4)

Another student from University B was unsupportive of the idea.

"I don't think you should have a mental health disability social group because that would be way too stigmatising." (B2)

Despite her reservations about a mental health society, student B2 considered peer support to be important, and suggested an alternative approach.

"[...] some sort of mentoring scheme where third years with mental health problems who have gone through university mentor first years who have mental health problems. [...] Like a buddy system where you meet once a week and say 'how's it going' so they can pass on their experience, and what they've learnt and experienced as well." (B2)

Students appear to value opportunities to share experiences with others who have MHD, and clearly identified areas for improvement in the area of peer support. This area requires development, although further consideration would be needed to

implement these ideas. In line with emancipatory principles, it is desirable for peer support networks to be student-led (Oliver 1992; Barnes 1992), but a collaborative approach between support services and student-led societies may be beneficial to help establish new services or develop existing ones. As found by Formby (2015) in her research on LGBTQ students, students also expressed a desire to participate in wider social activities open to all students and not be restricted to activities for specific groups, but felt that some of the available events could be made more accessible.

Social activities

The students in this research expressed interest in a variety of activities, including tea-drinking, wine-tasting, board games, juggling, bowling, pub quizzes, craft, cinema trips, music and going for walks. Going for meals or coffee in small groups was popular, and students enjoyed the opportunity to socialise without the added pressure of navigating large crowds or busy surroundings, such as pubs and clubs. Socialising in student accommodation was common.

“I go out very occasionally, it’s more go round to a friend’s house, have some drinks, watch a film or go out for dinner a lot with people who know my situation, which can be really nice.” (A4)

While students with MHD worry about appearing anti-social by not participating in certain activities such as clubbing (NUS 2012), it is evident that they do wish to have a social life and develop friendships through shared interests and participate in the social culture of university (Buote et al. 2007). Both universities offered activities that were of interest to the students in this research, but these were often inaccessible. A key barrier preventing students with MHD from attending social events appears to be the time of day they occur, as identified by the NUS (2014). Students felt there are too many evening events, and more daytime activities would be preferable. Reasons for this include lower energy levels and higher levels of mental distress by the evening (University B Students’ Union 2015), decreased

motivation to leave the house once they have arrived home after lectures, and travel difficulties for those living off-campus.

“For me, actually having things earlier in the evening, [...] one of the things to do with my mental health is that I need a lot of sleep. So anything that is late, even if I lived in [city] I probably wouldn’t go to. So things that started at, I don’t know, 5-7pm instead of starting at 8 or 9pm, that might be helpful.”

(A3)

Small-scale structured activities that did not involve excessive drinking were regarded as most accessible (NUS 2014), although it was noted that many special interest groups met in pubs and had ‘socials’ focussed around alcohol.

“I think you can get away with not drinking, but a lot of events are hosted in bars [...] I know that I went to a poetry slam, and that was in a bar, and I think they have weekly group sessions which probably are alcohol-related, but I think a lot of the big social events are alcohol-themed.” (A2)

While an active social life at university was desired by the majority, it was accepted that MHD could sometimes prevent students from participating, however ‘accessible’ the event.

“[...] there were a lot of events on at the halls [...] non-drinking events and all the rest of it, but I just didn't get involved with it so I think its a tricky one, because you can have all the events in the world but I’m probably not going to get to them regardless.” (A2)

This creates a challenge for those organising student social activities, as a well-designed, well-promoted and accessible event could still be poorly attended. However, attempts to consider the needs of students with MHD in event planning would certainly support those students who are well enough to engage, and such events could also appeal to other students who are not attracted to the traditional,

alcohol-based events and do not fit the 'typical student' stereotype (Goffman 1963).

4.6 Conclusion

This chapter has explored students' thoughts and experiences on the social culture of university and established the context in which disclosure decisions are made. Students perceive that social activities are largely focussed on pubs, clubs and excessive drinking (Colby et al. 2009; NUS 2012, NUS 2014), and these activities create substantial barriers to social participation for those with MHD. It is against this backdrop that students are making complex decisions about mental health disclosure. Socialising in smaller groups where drinking alcohol was not the main focus was preferable, and students enjoyed close relationships with their housemates, while also valuing relationships with others who have MHD. Students identified several areas for improvement to the social environment at university, including awareness-raising, peer support and greater flexibility and variety in social events.

University creates opportunities for students to forge new friendships and have new social experiences (Riddell et al. 2005; Buote et al. 2007). However, there are significant barriers to disclosure and social participation for students with MHD and further efforts are required by universities and students' unions to support those who may not fit the 'typical student' stereotype to integrate socially.

Having explored the social environment in which students are making disclosure decisions, Chapter Five will examine the factors influencing these decisions.

Chapter Five: To disclose or not to disclose? Influences on disclosure decisions

5.1 Introduction

Students with MHD are faced with an important and difficult decision about whether or not to disclose at university. While disclosure to the HE institution allows greater access to support services (Riddell et al.2005), the benefits of disclosing to peers are less obvious, and the potential disadvantages are substantial. Students articulated a variety of issues that had influenced their decisions around mental health disclosure, and it is clear that such decisions are not made lightly (Olney and Brockelman 2003; Irvine 2011). Emerging themes include fear of negative reactions including stigmatisation and being treated differently, feeling that disclosure cannot be avoided, and a desire to have open and honest relationships.

5.2 Before university

The issue of disclosure was considered by the majority of students before they commenced their studies, and it would appear that disclosure or non-disclosure is generally planned, rather than spontaneous. Disclosure can also be considered to be an on-going process throughout a student's time at university, as they continue to make and review decisions about who to disclose to and how much to share (Irvine 2011). Several students described the thought of disclosing as a source of anxiety.

“The process of telling people and stuff like that is something that is really really stressful, and I really had to deliberate about that before doing it.” (B4)

Some explained the need to build up a sense of trust before sharing anything personal with other students.

"I sort of wanted to wait-and-see a bit, because I didn't feel comfortable just coming out of it straight away..." (A2)

"I'm living with new people next year and [...] I will end up probably telling them. I'm not going to do it immediately [...] I'll probably do it the way I did it here [current accommodation]- a couple of weeks, once everyone's settled in and everyone's acquainted and I can decide if I like them or not and how much I trust them." (B4)

While these students identified they intended to disclose their MHD when they felt that the situation was right, two students decided not to disclose anything.

"I was telling nobody. [...] all the staff know [...] but all my cohort, nobody knows. No-one at all." (B2)

"I consciously thought, I don't want to tell anyone. I thought, let this be my past. [...] Everyone from home knew about it, and it kind of felt like this... 'thing' and I didn't like it, I wanted to get away from it." (A4)

Decisions not to disclose can be difficult to manage and can cause considerable strain on relationships (Burriss 2006, Olney and Brockelman 2003). In the case of students B2 and A4 who had initially chosen not to disclose, only B2 maintained this throughout her studies, and appeared to regret this decision as she approached the end of her course.

"I feel like I've hidden a part of me [...]. And it's hard keeping a part of your life from friends for three years." (B2)

B2 is a mature student, and studying with younger people also creates additional difficulties. As discussed in Chapter Two, McCune et al (2010) established that mature students can experience feelings of isolation due to differences in social

circumstances and a perceived lack of maturity in younger students. This appears to deter mature students from disclosing.

“ [...] sometimes I feel a bit sad that I’ve not felt that I can trust [classmates] with things. But that was my decision at the beginning, because I was in my late 30s then and they’re going to be 18 [...] It’s bad enough that I am a mature student and how are they going to take that, but obviously I’m a student with a psychiatric diagnosis as well.” (B2)

It would appear that student B2 felt, as a mature student, she already faced additional difficulties in integrating socially (McCune et al. 2010), and that disclosing a MHD would further stigmatise her.

5.3 Stigma and stereotypes

It appears that the main factor discouraging students from making a disclosure is fear of stigma (Corry 2008). As identified by Olney and Brockelman (2003), those with hidden impairments often feel the behaviour of others towards them changes once they become aware of their impairment, and this relates to the stigma surrounding MHD and the associated stereotypes. Such changes include increased cautiousness and being watched more closely (Irvine 2011). This creates challenges for students, who wish to be seen as individuals with personalities, rather than being perceived as being unpredictable, ‘different’ and difficult to talk to (Green et al. 2003). While the existence of mental health stigma was acknowledged by all participants, the issue appears to be particularly pertinent to those with less common and more misunderstood diagnoses, such as BPD (Aviram et al. 2006) and anorexia, and behaviours such as self-harming. Those who had been hospitalised for reasons relating to their MHD also attached particular stigma to this experience.

As established in Chapter Four, students perceived a lack of understanding from the general population about MHD (Mind 2014), and cited stereotypes as an example.

“[...] if I tell someone I have depression, they are immediately looking at my wrists [...] and are avoidant of saying anything because they think I'm going to get set off by the slightest thing and run away crying and jump in front of a car or something.” (B4)

“[...] my personality is usually quite bubbly, [...] I think people think that you're supposed to be sad all the time if you've got depression.” (B3)

Students were generally keen to dispel myths around MHD, but acknowledged that being open about their experiences made them vulnerable to the effects of stigma (Corry 2008).

“I think that the stigma is a big thing, and that it has affected me in terms of wanting to disclose it. I think if there wasn't the stigma I wouldn't be as bothered about it. [...] It wouldn't be a big deal and no-one would really care as much.” (B1)

Some behaviours associated with MHD were also perceived to carry particular stigma, especially self-harm.

“I think a lot of people probably see self-harm as selfish, dangerous, attention-seeking, manipulative... this ties in to the stigma surrounding BPD as well. Some people say things like 'just kill yourself if you want to' [...] People assume it's attention seeking, and are embarrassed.” (A2, via email)

Self-harming behaviour also influences students' disclosure decisions, and the sometimes-visible signs of self-harming often removed the element of choice.

5.4 The 'choice' to disclose

MHD are often considered to be an 'unseen' disability, and as such, there is an assumption that those with MHD can make a free choice about whether or not to

disclose. Several students did not feel that this was the case, and described how their circumstances made it impossible to conceal their MHD. The likelihood of being 'found out' was a factor in disclosure decisions (Olney and Brockelman 2003). Such circumstances included hospital admissions, and physical signs of illness, such as those associated with anorexia.

'My housemate [...] knows about everything. [...] I met her on the course and she found out because I had to go to the hospital and had to explain it, and again it was very much... I didn't choose it, I chose not to tell her. It's just... you can't really lie. [...] And you know, it becomes obvious, as much as I'd like to have hidden it, it was quite obvious.' (A4)

Three students used self-harm as a way of dealing with their feelings, and described the difficulty of concealing the scars as a reason for disclosure.

"If I'm feeling unwell it means I'm thinking about self-harming and I don't want to tell people about that. I think with my flatmates because they saw the cuts on my arms, I thought that I should explain it, but otherwise I don't like talking about it..." (B3)

"One of the positives to telling my housemates everything is that I can wear short sleeves indoors!" (A2, via email)

Having time out due to hospital admissions also raised questions that students felt obliged to answer.

"[...] I've got a big gap that I can't explain [...] and the only way that I can explain the past [...] is by saying, you know 'I've not been very well because of this'. I can't... otherwise there is no explaining it. So I've kind of been forced, I think." (A4)

Other factors also make it difficult to conceal the presence of an ‘unseen’ disability from their peers, particularly in academic settings. Several students who had academic support in place cited their ‘reasonable adjustments’ as a factor in their decisions to disclose. This included adjustments to assessments, and the presence of support workers.

“[...] when I had to do a presentation, I had the option to do it where my group did it just to my tutors... For me that was potentially more scary than if I didn’t do it in front of everybody that they’d wonder, ‘why didn’t you do it in front of everybody?’” (B1)

“... [notetaker’s] role is kind of very clear and I’m getting used to that, because in some ways that is my kind of... white cane or wheelchair or kind of visible sign of... here is a person with an invisible disability becoming visible by the presence of a notetaker. [...]” (A1)

Martin (2010) identifies that students with reasonable adjustments may be seen by others as having special treatment, and that this can be interpreted as giving them an unfair advantage.

“[...] other students can say, ‘did you manage to hand in your work?’ and I’ll mention that I’ve got a [support agreement] and an extension [...] They’ll be like, ‘oh yeah, lucky you’.” (B3)

For some students, partial disclosure through having reasonable adjustments removes the pressure of making full disclosures, which others may find distressing.

5.5 Causing worry and being treated differently

While it was widely acknowledged that disclosing a MHD is challenging for the discloser, some also considered the implications for those who the information is

shared with. Several students felt they were putting a burden onto others by disclosing.

"...sometimes I think that people don't want to know, that they would find it an awkward thing to talk about. (A3)

This was particularly an issue for students living in shared accommodation.

"When I got the diagnosis I felt obliged to tell my flatmates [...], they're going to be living with me for the next year, it would be a bit unfair just to expect them to put up with it... So if anyone wants to go and arrange other accommodation that would probably be easier and less stressful for them to live, I should give them the opportunity." (B4)

While acknowledging that disclosing a MHD may cause their housemates worry, students did not want to be treated differently (University B Students' Union 2015), and the fear of this happening has a substantial influence on disclosure decisions (Olney and Brockelman 2003). This was something that students were keen to avoid, and they felt that such treatment was unhelpful.

"I wanted to move away from the psychiatric patient person to a student and be treated just as a student like everybody else." (B2)

"With anything after [disclosure] you see about a person, you see everything through the lens of the diagnosis." (A1)

Students were particularly concerned that peers would be unduly cautious in interactions for fear of causing offence.

"I'd rather people just treat me as they would normally, they don't have to be on tenterhooks when they're around me..." (B1)

“When someone is making special treatment for you it makes you feel different. It’s like highlighting it, putting a neon sign above your head saying ‘depressed, watch out’.” (B4)

Honest and upfront relationships were valued highly.

5.6 Openness and honesty

Despite the difficulties faced when making disclosure decisions, students considered that being open about their mental health difficulties was important in forging friendships.

“If you are going to be [...] friends with someone, it is something that will inevitably have to come out. [...] it’s letting them know who you are, and it makes it easier to talk and to break down a few barriers... if you’re holding something back from someone, it’s going to get in the way of making any sort of relationship...” (B4)

In addition, some saw disclosure as providing reassurance for themselves should their mental health deteriorate, and friendships provided a safety net through difficult periods.

“I feel that it is quite important for [friends] to know in case there was ever like an emergency or if anything ever happened, and then I was like stuck with no-one to talk to [...] it’s better for them to know first.” (B1)

Irvine (2011) discusses the potential to educate others as a benefit to disclosing. This was also identified by the students in this research, and presents an opportunity to challenge stereotypes. Corrigan and Matthews (2003) also identify this type of disclosure as ‘broadcasting’.

“[...] having the opportunity to explain to people what it’s meant to have had an eating disorder and things is actually quite... not rewarding, but it’s nice to be able to kind of clarify things and reduce misconceptions...” (A4)

Students appear to value opportunities to speak openly about their experiences, and felt that this was the best way of reducing the stigma around MHD, reflecting the findings of Corrigan and Matthews (2003), as discussed in Chapter Four.

5.7 Conclusion

It would seem that decisions to disclose a MHD are extremely complex and hold much importance. The biggest issue deterring students from disclosing is worry over negative reactions, and fear of stigma is particularly prominent (Corry 2008). For many, disclosure does not feel like a choice, and students may feel obliged to disclose if they feel that their MHD are likely to be discovered (Olney and Brockelman 2003), either through physical signs, hospital admissions or through accessing support. Disclosure decisions are also influenced by a desire not to be treated differently, and not wanting to burden others.

Bearing these factors in mind, students’ experiences of disclosing can now be examined.

Chapter Six: Is honesty the best policy? Experiences of disclosure

6.1 Introduction

Having established some of the issues students considered before making disclosure decisions, this chapter will examine experiences of disclosing a MHD in university social contexts. Experiences of disclosure were largely positive, and students were generally happy with the responses from peers. However, some undesirable reactions were received, centred largely around support provisions and the perception of students with MHD being given advantages (Martin 2010), and other sceptical reactions. Students chose their audiences carefully, and disclosure was principally on a perceived 'need-to-know' basis, and where trust was already established. There was general agreement that disclosure was beneficial, and the majority would encourage other students to disclose.

6.2 Methods of disclosure

All but one of the students interviewed had disclosed some information about their MHD, either to their housemates or classmates. This reflects the findings of University B Students' Union (2015), which found friends were the most common group students disclosed to. However, the students in this research all disclosed to their university, so cannot be considered to be representative of the wider student population, where the proportion that discloses to the university is very small (University B Students' Union 2015). Disclosure to housemates was most common among those living in student accommodation, as these relationships tend to be the strongest, as established in Chapter Four (Wilcox et al. 2005). Most students had considered the issue of disclosure before coming to university, and had been highly anxious about the prospect of disclosing. One student had taken the unusual step of disclosing to students before starting her course, taking a proactive approach to contact her housemates before moving into halls.

"I found the Facebook page for my accommodation, [...] and just wondered if anyone else was looking at the same time, and they were so that was really good... I found them all and stuff, so that was nice, so I spoke to them all about it..." (B1)

This approach appeared to have worked well for student B1, who considered that disclosing in advance had benefits for her housemates as well as herself.

"[...] I said it over the internet, so I didn't have to face up to them [...] I didn't want it to be something that I suddenly dropped into conversation, and then they'd have to panic about how they were going to cope with it [...]. I just felt that it was important for me to let them know ahead of time [...] but they all took it really well, and were all really lovely about it, so that's good." (B1)

One mature student also found an innovative way to disclose in an academic context on a previous course, using a class presentation on a relevant topic as a tool to make a partial disclosure.

"[...] we had to do a presentation [...], and I decided to do the presentation on inclusion for people with disabilities [...]. So, '[...] I am a person with a disability, I have a daughter with a disability, these are our experiences'. It made a very safe way to do a whole kind of class disclosure in a way they didn't draw attention to me [...]. So that felt very manageable and managed." (A1)

Others took a more traditional approach, with most choosing to disclose on a one-to-one, face-to-face basis.

"[name] was the first person I told and I told him, 'I have a thing that I need to decide what to do about', so sort of asking him for advice almost. And once I told him, he then asked me questions and it was a conversation we had." (A3)

“I spoke to [my housemates] individually. [...] I kind of just... when they came back in I had a chat with them and said [...] ‘look, you know I’ve been having some problems, I’ve been to the doctor’s and they told me I’ve got this, I’ve got this medication, it’s going to do this, and what do you think?’” (B4)

For some students, the option of a controlled, one-to-one disclosure was taken away. Student B4 made a disclosure to a friend, who then passed on the information without consent.

“[...] it’s something that I hope other people who know won’t tell people. And someone I do know did tell people [...]. I had a mental breakdown on her and told her, and then half the accommodation knew afterwards, which is why I don’t want to tell everyone, because some people just can’t keep it to themselves.” (B4)

For student A2, a concerned friend played a part in their disclosure to housemates.

“[...] one of my friends from home [...] ended up texting my housemates because they were worried about me, so they said to me ‘I’m going to get in touch with your housemates, just so you know, because I’m concerned’. So they found out some stuff through her.” (A2)

A further disclosure was also made following a period of increased symptoms, which resulted in hospitalisation and made it impossible to conceal their MHD.

“Well, [my housemates] sort of know everything now I think. Because I got quite unwell at the start of this year, [...] and they ended up having to deal with quite a lot of it, taking me to A&E and all that rigmarole, so I think they’re quite in the loop about it now.” (A2)

In this instance, disclosure appears to have taken place with minimal involvement from the student, and it is unclear how much the student would have disclosed in

different circumstances. It would appear, having made the decision to disclose, students also need to consider how much information they are willing to share (Irvine 2011; Corrigan and Matthews 2003), and this varied substantially.

6.3 Extent of disclosure

Student A1 chose to disclose a disability on his current course by having support workers present in lectures. However, the reasons for the support worker were not shared.

“I make the choice [...] to disclose in a non-verbal way, to disclose by having a support worker. And it might be that I've got dyslexia, it might be that I've got... any kind of range of reasons why anyone might have a notetaker. I've not had to disclose what that is.” (A1)

The approach of disclosing some information but without much detail was common, particularly in academic settings.

“[...] there's three guys that I work with and I tell. Like I'll tell them that I've got new medication so I'll be... in a funny mood. And I try to keep it light and don't take it too seriously [...]. And they don't ask what the medication is for...” (B3)

While student B2 decided not to disclose her MHD to peers at university, disclosures made outside of HE were also partial or selective (Corrigan and Matthews 2003), largely for reasons of stigma relating to her diagnosis of BPD (Corry 2008).

“If anybody says ‘what do you have’ I just say depression, I won't say borderline. [...] Depression is seen as a less, I don't know what the word is, stigmatising illness, and people are becoming more aware that more people have it and it's not... you're not mad.” (B2)

Others felt comfortable taking a more open, direct approach, broadcasting their individual experiences in detail (Corrigan and Matthews 2003).

“I go through when I was diagnosed with it and that I’m on my anti-depressants and stuff, and how long I’ve been on them for and how it affects me and the issues that it can cause. [...] I think it’s helpful for them to know and understand how it affects me personally as well, then they can be aware.” (B1)

It should be noted that students appear to vary the extent of their disclosure between different people, as found by Corrigan and Matthews (2003). Fuller disclosure to housemates and partial or selective disclosure to classmates was common, and this reflects whether students feel that these people ‘need to know’.

“I only see [friend] on my course, we don’t really meet up outside unless it’s for a bit of work or something. We’re not going on nights out or anything or meeting up at the pub. So he doesn’t really need to know.” (B4)

Students also tended to be more open with those that had some personal experience of MHD, either directly or indirectly, or those that they felt would be more understanding.

“My flatmate that I told first, her sister was going through similar things and that’s why I found it was easier to talk to her. I don’t see a particular need to tell other students.” (B3)

Students clearly choose carefully when making disclosure decisions, and the anticipated reactions are a key part of this. Students were unanimously concerned about negative reactions (Morris 1991), but most found their experiences were more positive than expected.

6.4 Reactions to disclosure

One common reaction that students encountered following a mental health disclosure was to be asked questions about their experiences. Having shared something very personal, students appeared to welcome the chance to explain things further, and saw this as an opportunity to challenge commonly held misconceptions about MHD, which also has benefits for reducing stigma in wider society (Corrigan and Matthews 2003), as established in Chapter Two.

“People have asked more questions which I think is a very positive thing, because I always want to kind of talk about it truthfully. And not the kind of skew you might get from other accounts. So I think in some ways it’s been quite positive.” (A4)

While the majority of students experienced an encouraging reaction to their disclosure, and were asked questions they were happy to answer, some were less comfortable with peers’ reactions.

Some students experienced negative reactions after disclosing, particularly around reasonable adjustments in study contexts and DSA funding. There were some perceptions that students with DSA and other support were getting unfair advantages. This was cited by Martin (2010) as a principle reason that students are reluctant to disclose.

“I get the DSA allowance, and a couple of them were saying ‘that’s really unfair, I can’t believe you get that, I should get that’, like that kind of thing. So I think it’s been a bit of a learning curve for them. And then they sort of saw how bad it can get and were like, ‘okay’....” (A2)

Others encountered some scepticism after disclosing, largely due to fixed beliefs about mental health, based on stereotypes (Morris 1991; Goffman 1963).

“I have always had quite funny reactions, not in a bad way, but whenever I’ve told anybody, they’re like ‘what, you? [...] But you’re always happy’, and I’m like ‘yeah, I’m not just going to go round like, ‘oh I’m so sad’ all the time’... So it sort of surprises everybody...” (B3)

As discussed in Chapter Five, students are often reluctant to disclose for fear of being treated differently (Irvine 2011; Green et al. 2003; University B Students’ Union 2015). On the whole, this did not appear to happen, with most reporting that reactions were generally good and that people were supportive. However, student B4 felt that some of his interactions with friends changed once they were aware of his MHD.

“[...] there is a lot less of the... banter [...] It’s not everyone I know, but people are much more careful about... how they joke with me. They probably think they’re doing a really good job of hiding it, but they’re not. [...] So they are bit nervous about the way they talk to me because they think that I’m going to run away into my room and cry and do God knows what.” (B4)

Others found that, while their friends were supportive, their relationships changed due to well-intentioned, but ill-informed attempts to ‘help’.

“When I was really bad they were actually very good, because they’d bring me food and try make me eat and things like that. But I think when I was doing a bit better, they’d just be going on at me, like [...], ‘you need to go to the library, you need to read something, you need to get out of the house’. [...] ‘you need to do exercise, [...] ‘you need to eat better’. And it was sort of like, I know all of this, but if it was that simple I would’ve done it by now, believe me!” (A2)

Despite these issues, students appeared to find it reassuring to know others were aware of their MHD, and took comfort from knowing people were looking out for them and could provide support when needed.

6.5 Reflections on disclosure experiences

Peers form an important part of students' support networks (Buote et al. 2007), and the benefits of disclosure to peers appear to outweigh the risks in the majority of cases. When asked whether they would encourage other students with MHD to disclose to their peers, there was unanimous agreement that disclosing to trusted friends was helpful, and could help build stronger relationships. Disclosure also allows students to be seen as individuals with personalities, and not simply as moody and anti-social (Green et al. 2006).

"I can be [...] really withdrawn, and sometimes I don't want to talk to anybody and not want to go out and all the rest of it. [...] they just assumed I didn't like them or something... so now they have a reason for it, I think it makes more sense for them so it's easier and I think that's probably improved our relationship. Because I definitely feel a lot closer to people than I did last year, which does help with my symptoms as well..." (A3)

Students considered their experiences of disclosing were better than expected, and that disclosing provided relief from the burden of trying to hide their MHD (Burriss 2006; Corrigan and Matthews 2003).

"I think it is good to disclose. I think it can be helpful because it takes away some of the pressure [...] you don't have to try quite so hard to pretend that you're fine." (A3)

It would appear, despite the significant difficulties involved in disclosing a MHD, the students in this study felt that disclosing has benefits, including emotional support and reassurance, increased understanding, leading to stronger relationships with peers. This is contrary to the findings of McLean and Andrews (1999, cited in Martin 2010) that 65% of students who disclosed a MHD at university would discourage others from doing so, and is an encouraging sign that perhaps negative disclosure experiences are becoming less common.

6.6 Conclusion

This chapter has examined students' experiences of disclosing a MHD to their peers. With the exception of two students, disclosure was most common in face-to-face, one-to-one situations, where trust was already established. Students varied the amount of information they shared in different situations, with some simply telling peers they have reasonable adjustments, and others making full disclosures of the diagnosis and its impact. Negative reactions were focussed on support provisions and perceived financial advantages (Martin 2010), and reactions of disbelief were reported when students did not conform to stereotypes of people with MHD. Despite the lack of understanding, students generally felt that disclosing was beneficial and important, and would encourage others to disclose if they felt comfortable to do so.

Chapter Seven: Conclusion

The aim of this research was to record and understand the experiences of students with MHD in HE, the barriers faced around disclosure and social participation, and the importance of disclosure on social experiences at university. Relevant literature was reviewed, and a suitable methodology was outlined. Eight students from two universities were asked about their experiences through semi-structured interviews, which were transcribed and analysed. Through this analysis, general themes have emerged.

A dominant theme emerging from examination of the university social culture was the prominence of drinking and clubbing (Colby et al. 2008). Such activities were often considered inaccessible, and various barriers to participation were discussed, including social anxiety, a pressure to drink excessively and associated risks (Demery et al. 2012), and feeling forced to participate for fear of being perceived as boring or anti-social by not doing so (Colby et al 2008). Students preferred to socialise on a smaller scale, and socialising in student accommodation or with structured activities was common. Students expressed a wide variety of interests, but were prevented from attending some events, due to the time of day they occurred. A desire for more events during the day was noted, and it was felt that too many events took place in the evenings. Students also felt that raising mental health awareness across the university would be helpful in reducing stigma and making disclosure easier (Corrigan and Matthews 2003). Potential benefits of a student-led mental health society were discussed, although it was unclear whether students would attend such a society regularly. However, the concept of peer support was welcomed and highly valued.

Students consider disclosure to be important, and disclosure decisions are extremely complex, influenced primarily by the anticipated reactions of others. Fear of stigma is prominent (Corry 2008), along with concerns about being treated differently (University B Students' Union 2015). Those with more complex diagnoses appear to

be particularly concerned about the effects of stigma, and may only disclose if they feel it is unavoidable, such as when their difficulties become visible through self-harm or a deterioration of physical health (Olney and Brockelman 2003).

Experiences of disclosure were largely positive, and were better than students expected. A common reaction to disclosure was to be asked questions, and students welcomed the opportunity to speak honestly about their experiences and increase understanding about MHD (Corrigan and Matthews 2003). Some unwanted responses were recorded, and these were largely reactions of scepticism, often founded on stereotypes (Goffman 1963; Quinn et al. 2009), or an ill-informed opinion that the academic and financial support provided to students with MHD was unfair and gave them advantages (Martin 2010). Overall, students agreed that disclosure was important and helpful, and would advise others in their position to disclose to someone they trust.

These conclusions provide insight into the experience of being a student with a MHD, and the additional social challenges they face. In accordance with a social model perspective, various barriers to full participation have been identified, and it is clear that there is considerable work to be done before students with MHD have full access to the social opportunities that university presents. For these reasons, the findings of this research will be disseminated to the students' unions and mental health services at the participating universities, outlining the barriers that have been identified and students' suggestions for improvements. It is hoped that this information may be used to facilitate the planning of future events and enable the needs of students with MHD to be given greater consideration.

While the conclusions of this research do generally reflect the limited existing literature, the small sample size means the findings cannot be generalised to the rest of the student population. In particular, the sampling method adopted here necessarily excludes students with multiple impairments, and also those who chose not to disclose to their university. This is particularly significant, as students who do not disclose to their university may also be less likely to disclose to their peers. This

invisible group may provide a different and important perspective on the issues discussed, and may also be the group where most work is required to support disclosure. This is a potential area for further research, and a revised methodology and sampling procedure may be appropriate.

Another issue that has not been explored is the area of MHD and disabled identity. This holds particular significance around the subject of disclosure, as those without a disabled identity may not perceive that they have anything to disclose (Irvine 2011) and may not seek support that would be beneficial. An exploration of how university students perceive their MHD and whether they have a disabled identity could enhance understanding of this wider issue, and the implications of this are significant in terms of how students seek support, and which services they approach.

It is clear that students with MHD have substantial challenges at university, both academically and socially. They must decide whether or not to disclose and the implications of doing so, while also navigating a new social environment, forming relationships, and succeeding academically. The social elements of the university experience are important to students, and the challenges in this area are significant. Universities need to be more aware of the institutional and social barriers that exist for students with MHD, and place greater emphasis on attempting to remove these barriers.

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Appendices

- A. Ethical review form**
- B. Initial information email to potential participants**
- C. Invitation to participate email**
- D. Participant information sheet**
- E. Interview schedule**
- F. Consent form**
- G. Ethics committee favourable opinion letter**
- H. Participant profiles**

A. Ethical review formUNIVERSITY OF LEEDS RESEARCH ETHICS COMMITTEE APPLICATION FORM ¹

UNIVERSITY OF LEEDS

Please read each question carefully, taking note of instructions and completing all parts. If a question is not applicable please indicate so. The superscripted numbers (eg⁸) refer to sections of the guidance notes, available at <http://ris.leeds.ac.uk/uoethicsapplication>. Where a question asks for information which you have previously provided in answer to another question, please just refer to your earlier answer rather than repeating information.

Research ethics training courses: <http://www.sddu.leeds.ac.uk/sddu-research-ethics-courses.html>

To help us process your application enter the following reference numbers, if known and if applicable:

Ethics reference number:	AREA 14-083
Student number and/ or grant reference:	200825987

PART A: Summary

A.1 Which [Faculty Research Ethics Committee](#) would you like to consider this application?²

ESSL/ Environment/ LUBS (AREA)

A.2 Title of the research³

Is honesty the best policy? How disclosure of mental health difficulties affects social experience in Higher Education

A.3 Principal investigator's contact details⁴

Name (<i>Title, first name, surname</i>)	Mrs Laura Mella
--	-----------------

Position	Student
Department/ School/ Institute	Centre for Disability Studies
Faculty	School of Sociology and Social Policy
Work address (<i>including postcode</i>)	N/A – distance learner, studying from home
Telephone number	
University of Leeds email address	ss13lmm@leeds.ac.uk

A.4 Purpose of the research:⁵ (Tick as appropriate)

- Research
- X Educational qualification: ***Please specify: __MA Disability Studies__***_____
- Educational Research & Evaluation⁶
- Medical Audit or Health Service Evaluation⁷
- Other

A.5 Select from the list below to describe your research: (You may select more than one)

- X Research on or with human participants
- Research with has potential significant environmental impact.⁸ ***If yes, please give details:***

- X Research working with data of human participants
- X New data collected by qualitative methods
New data collected by quantitative methods
- New data collected from observing individuals or populations
- Research working with aggregated or population data
- Research using already published data or data in the public domain
- Research working with human tissue samples⁹

A.6 Will the research involve any of the following:¹⁰ (You may select more than one)

If your research involves any of the following an application must be made to the National Research Ethics Service (NRES) via IRAS www.myresearchproject.org.uk as NHS ethical approval will be required. There is no need to complete any more of this form. Contact governance-ethics@leeds.ac.uk for advice.

- Patients and users of the NHS (including NHS patients treated in the private sector)¹¹
- Individuals identified as potential participants because of their status as relatives or carers of patients and users of the NHS
- Research involving adults in Scotland, Wales or England who lack the capacity to consent for themselves¹²
- A prison or a young offender institution in England and Wales (and is health related)¹⁴
- Clinical trial of a medicinal product or medical device¹⁵
- Access to data, organs or other bodily material of past and present NHS patients⁹
- Use of human tissue (including non-NHS sources) where the collection is not covered by a Human Tissue Authority licence⁹
- Foetal material and IVF involving NHS patients
- The recently deceased under NHS care
- X None of the above

You must inform the Research Ethics Administrator of your NRES number and approval date once approval has been obtained.

If the University of Leeds is not the Lead Institution, or approval has been granted elsewhere (e.g. NHS) then you should contact the local Research Ethics Committee for guidance. The UoL Ethics Committee need to be assured that any relevant local ethical issues have been addressed.

A.7 Will the research involve NHS staff recruited as potential research participants (by virtue of their professional role) or NHS premises/ facilities?

- Yes X No

If yes, ethical approval must be sought from the University of Leeds. Please note that NHS R&D approval is needed in addition: www.myresearchproject.org.uk. Contact governance-ethics@leeds.ac.uk for advice.

A.8 Will the participants be from any of the following groups? (Tick as appropriate)

- Children under 16¹⁶ *Specify age group:*

- Adults with learning disabilities¹²
- X Adults with other forms of mental incapacity or mental illness
- Adults in emergency situations
- Prisoners or young offenders¹⁴
- Those who could be considered to have a particularly dependent relationship with the investigator, eg members of staff, students¹⁷
- Other vulnerable groups
- No participants from any of the above groups

Please justify the inclusion of the above groups, explaining why the research cannot be conducted on non-vulnerable groups.

The purpose of the research is to learn about the experiences of HE students with mental health difficulties, and in particular, issues around disclosing mental health difficulties to their peers. It is therefore important that student perspectives form a key part of the research.

It is the researcher's responsibility to check whether a DBS check (or equivalent) is required and to obtain one if it is needed. See also <http://www.homeoffice.gov.uk/agencies-public-bodies/dbs> and http://store.leeds.ac.uk/browse/extra_info.asp?modid=1&prodid=2162&deptid=34&compid=1&prodvarid=0&catid=243.

A.9 Give a short summary of the research¹⁸

This section must be completed in language comprehensible to the lay person. Do not simply reproduce or refer to the protocol, although the protocol can also be submitted to provide any technical information that you think the ethics committee may require. This section should cover the main parts of the proposal.

The research project proposed will focus on the experiences of disabled students in Higher Education, and those with mental health difficulties specifically. The aim is to discover why students choose to disclose or not disclose their mental health difficulties to other students, and the effect this has on their relationships with peers and their social experiences.

The researcher aims to conduct 8 interviews with students with mental health difficulties, across 2 different universities. These interviews will be semi-structured and will discuss students' experiences of disclosure, what influenced their decisions to disclose/not disclose, whether they feel that stigma is an issue, their social experiences while at university, and what could be changed to make the university

social environment more accessible. The interviews will be audio recorded and transcribed, and the recordings will be analysed by identifying key themes and discussing these, using student data to support the arguments. Upon completion of the research for the MA, a shorter report will be written and sent to the participating institutions, the students' union at both universities, and the students that participated (see C21 for more information).

A.10 What are the main ethical issues with the research and how will these be addressed?¹⁹

Indicate any issues on which you would welcome advice from the ethics committee.

Informed consent

For the consent obtained to be valid, participants must be fully informed about the purpose of the research, what participating will involve, and be aware of any potential risks that could arise from their involvement. This study involves semi-structured interviews, so it will be important to inform participants about the topics that will be discussed during the interviews, so that they can decide whether or not they would like to take part. Participants will be given full information about the research through the email invite, which will contain an information sheet with a summary of the study and what participating will involve, and how their information will be used, in a question and answer format. This information sheet will be based on an example available from the University of Leeds Research and Innovation Service (see attached – participant information sheet 2).

Aside from the information sheet that will explain all of the above to potential participants, students who volunteer to be interviewed will also have this information explained before the interview commences, and will be given the opportunity to ask any questions. In particular, the purpose of the study will need to be explained clearly, as the researcher's job as a Disability Adviser could cause confusion about why the research is being carried out (see section below on Researcher's role). Participants will also be reassured that the information they provide during the interview will not impact on any academic support they are currently accessing or may access in the future.

Students will be asked to sign a consent form before the interviews are scheduled to indicate that they have read the information sheet and are aware of how their information will be used, and their right to withdraw. The consent form will also be discussed again before the interview commences, to give participants the

opportunity to ask any questions.

Potential for distress

As the interviews will cover issues such as friendships with other students, social inclusion and potentially sensitive matters around mental health, participants will need to be fully aware of the kinds of topics to be covered during the interview. The email invite will include a list of subjects to be discussed, so that potential participants can make an informed choice about their possible involvement. Due to the nature of the subjects being discussed, it is possible that some participants could become distressed during the interview. Should a student become distressed during their conversation with the researcher, the interview will be terminated and any data generated will be discarded, and participants will be given the opportunity to access support for these issues should they require it. Both institutions in the study offer counselling services to students and have good links to external sources of support. All students being interviewed will be asked if they would like any support following the interview. Students wishing to access support will be signposted to the counselling service, and given an information pack containing contact details for sources of support within their university, in the wider community and also online resources (See attached sheets – Support Services – University A/B, Participant information pack).

Confidentiality and anonymity

Confidentiality and anonymity are of particular importance, as participants may disclose sensitive information, which must be treated appropriately. To ensure that the identity of participants is protected, their names will not be included in any of the documentation. If a direct quote is used at any stage, a pseudonym will be given. In addition, the names of the two participating institutions will not be used, and will be described as 'University A' and 'University B'. On addition, the identities of any students who choose to participate will not be shared with anyone except the researcher.

Right to withdraw

Participants will be told in the invite email that if they choose to participate, they can withdraw at any time. Before the interview commences, they will be reminded that they can stop the interview at any time should they wish, and that should they change their mind about participating after the interview, they can contact the researcher and ask for their data to be removed from the study and deleted.

Researcher's role

The researcher works as a Disability Adviser at one of the participating institutions and it is possible that some of the students who volunteer to participate will be known to the researcher in their professional capacity. This could create confusion for participants at one of the institutions, who may think that the research is in some way linked to their academic support. It will be explained in the information sheet that the researcher is completing the research outside of their professional role and in their capacity as a student at the University of Leeds (not a participating institution). It will also be explained that the purpose of the research is primarily for

an MA, but that the findings will be disseminated to the participating institutions.

The researcher will make it clear that involvement in the research will have no bearing on the students' academic support, that the disability team will not be aware of who has participated, and that any comments made about the disability service will be not be passed on and will be treated confidentially. As the focus of the research is on experiences of disclosure in social settings, it is not intended to discuss issues around academic support. The decision to focus on social aspects has been made to ensure that the risk of conflict between the researcher's role as student and Disability Adviser is minimised.

PART B: About the research team

B.1 To be completed by students only²⁰

Qualification working towards (eg Masters, PhD)	MA Disability Studies
Supervisor's name (Title, first name, surname)	Dr Tom Campbell
Department/ School/ Institute	Centre for Disability Studies
Faculty	School of Sociology and Social Policy
Work address (including postcode)	Room 11.16, Social Sciences Building, University of Leeds, LS2 9JT
Supervisor's telephone number	0113 343 0135
Supervisor's email address	t.w.campbell@leeds.ac.uk
Module name and number (if applicable)	MM4969 Dissertation

B.2 Other members of the research team (eg co-investigators, co-supervisors) ²¹

Name (<i>Title, first name, surname</i>)	
Position	
Department/ School/ Institute	
Faculty	
Work address (<i>including postcode</i>)	

Telephone number	
Email address	

Name (Title, first name, surname)	
Position	
Department/ School/ Institute	
Faculty	
Work address (including postcode)	
Telephone number	
Email address	

Part C: The research

C.1 What are the aims of the study?²² (Must be in language comprehensible to a lay person.)

To provide answers to the following questions:

What are students' experiences of disclosing a mental health difficulty to their peers?

What factors have influenced the decision to disclose or not disclose?

Does disclosure of or having a mental health difficulty affect the social aspect of the Higher Education experience?

What can be done to improve the quality of the student social experience for students with mental health difficulties?

These questions arise from an examination of existing literature on the subject of mental health disclosure and student mental health specifically. Issues of disclosure to institutions are well-researched, but the social impact of disclosure and issues affecting disclosure to peers are less-frequently reported on. The subject is a timely one for investigation, as there have been several high profile campaigns recently, aimed at trying to reduce the stigma of mental health difficulties, such as the *Time to Change* campaign. These have meant that issues of mental health are currently in the public eye, and this increased exposure may impact on the experiences of students in HE.

C.2 Describe the design of the research. Qualitative methods as well as quantitative methods should be included. (Must be in language comprehensible to a lay person.)

It is important that the study can provide information about the aims that it intends to address. If a study cannot answer the questions/ add to the knowledge base that it intends to, due to the way that it is designed, then wasting participants' time could be an ethical issue.

This research is rooted in the social model of disability (UPIAS 1976), and will aim to establish what social and environmental barriers exist for students with mental health difficulties, and the impact of these on students' social experiences. As the student perspective is central to answering the research questions, a qualitative approach to data generation will be adopted, with semi-structured interviews being the primary method employed. Students with a disclosed mental health difficulty at the two participating institutions will be contacted by the disability teams and asked if are interested in participating or would like more information. Those who respond will be sent a further email, including an information sheet outlining the nature of the research and what their participation will involve (see attached documents – initial email and invite email). Potential participants will also be able to contact the researcher to ask questions before they decide if they would like to participate. The first four students to reply from each university will be selected, and other respondents will be thanked for their interest and advised that enough participants have already been found. The interviews will be conducted at the participants' university, in a private room. A list of pre-determined topics will be discussed (see attached document - interview schedule) and the researcher will adopt an informal, relaxed style to try and put the participants at ease. The topics have been designed to ensure that sufficient information is captured to address the research questions, and also to allow students to speak flexibly without being constrained to short answers. The interviews will be audio recorded and transcribed later. Each interview will be supplemented with a short questionnaire to capture some basic details about the participants, such as age, gender, course and diagnosis (if applicable), which potential participants will be asked to complete if they are interested in participating. This will be used to consider the demographic of the participants, and will help indicate whether the sample is reflective of the student population. Following transcription of the recordings and analysis of the questionnaires, the transcriptions will be reviewed and key themes will be identified and coded. This data will form the basis of the analysis, and student quotes will be used to support the findings.

All names will be changed to preserve confidentiality of the participants. Following formal submission and feedback, a shorter report will be written and sent to the students that participated so that they can see the findings. In addition, the report will be sent to the disability department and students' union at each of the participating universities, so that the findings will be available to services that support students with mental health difficulties. It is hoped that the report may be useful for future event planning.

C.3 What will participants be asked to do in the study?²³ (e.g. number of visits, time, travel required, interviews)

Participants will be asked to participate in a semi-structured interview, lasting no more than one hour. The interview will take place on their university campus (either in the Students' Union or a teaching building), and a room will be booked for this purpose. Participants will be asked to complete a consent form before the interview commences, and also a short questionnaire to capture personal details such as age, gender, subject studied and any mental health diagnoses.

The interviews will be audio recorded, and participants will be sent a copy of the transcription to review and amend afterwards should they wish to.

C.4 Does the research involve an international collaborator or research conducted overseas?²⁴

(Tick as appropriate)

Yes No

If yes, describe any ethical review procedures that you will need to comply with in that country:

Describe the measures you have taken to comply with these:

Include copies of any ethical approval letters/ certificates with your application.

C.5 Proposed study dates and duration

Research start date (DD/MM/YY): 19 January 2015
(DD/MM/YY): 1 September 2015

Research end date

Fieldwork start date (DD/MM/YY): 1 March 2015
(DD/MM/YY): 31 July 2015

Fieldwork end date

C.6. Where will the research be undertaken? (i.e. in the street, on UoL premises, in schools)²⁵

The research will be on the university campus where the participants are based. Interview rooms will be booked in the Students' Union or in a teaching building that will provide a private and quiet place for the interviews to be conducted.

RECRUITMENT & CONSENT PROCESSES

How participants are recruited is important to ensure that they are not induced or coerced into participation. The way participants are identified may have a bearing on whether the results can be generalised. Explain each point and give details for subgroups separately if appropriate.

C.7 How will potential participants in the study be:

(i) identified?

Potential participants will be identified from a report within each of the participating institutions, of students who have disclosed a mental health difficulty, either as part of their university application or after commencing study. They will have a UCAS disability code that indicates they have disclosed this information. The researcher will not have access to this information, and the disability team in each university will generate the report and send out the invites without the researcher accessing the data directly, for data protection reasons. The heads of the Disability Services in both institutions have given their consent for students to be contacted regarding this research.

(ii) approached?

Potential participants will be approached by an email from the disability team in each university, on behalf of the researcher. The initial email will include basic information about the study, and students will be asked to supply their email address if they are interested in participating, or would like more information (see attached document – initial email). Students who respond to this initial email will be sent an invite to participate, with the participant information sheet and interview schedule attached.

(iii) recruited?²⁶

Potential participants will decide for themselves whether they would like to be interviewed. They will respond to the email if they wish to be involved. After responding, students will be asked to read and return the consent form within 7 days, along with their availability, so that the interview can be scheduled.

C.8 Will you be excluding any groups of people, and if so what is the rationale for that?²⁷

Excluding certain groups of people, intentionally or unintentionally may be unethical in some circumstances. It may be wholly appropriate to exclude groups of people in other cases

The potential participants will be students with a disability code indicating that they have disclosed a mental health difficulty to their HEI. Students that have disclosed other impairments will be excluded for the purposes of the research, to ensure that all data generated is relevant to the research question. Students with no disclosed disability will also be excluded. This decision has been made to enable consideration of the differences in disclosing to the institution and disclosing to peers, and whether making an institutional disclosure means that students are also open with other students. In addition, including students with no disclosed disability would

mean contacting several thousand students in each institution, which would be impractical and also disproportionate to the number of students needed for the research.

C.9 How many participants will be recruited and how was the number decided upon?²⁸

It is important to ensure that enough participants are recruited to be able to answer the aims of the research.

It is the researcher's aim to interview 8 students in total, 4 from each participating institution. This has been discussed with the research supervisor, and it is felt that 8 qualitative interviews should provide sufficient data to address the research questions. This is also in line with other published studies that have adopted a similar methodology (Quinn et al. 2009, Demery et al.2012).

If you have a formal power calculation please replicate it here.

Remember to include all advertising material (posters, emails etc) as part of your application

C10 Will the research involve any element of deception?²⁹

If yes, please describe why this is necessary and whether participants will be informed at the end of the study.

No.

C.11 Will [informed consent](#) be obtained from the research participants?³⁰

X Yes No

If yes, give details of how it will be done. Give details of any particular steps to provide information (in addition to a written information sheet) e.g. videos, interactive material. If you are not going to be obtaining informed consent you will need to justify this.

Potential participants will be informed about the purpose of the research in the invite email. They will receive an information sheet explaining what the research is for, how their data will be used and how to withdraw should they wish to. This information will also be outlined by the researcher verbally before the interview commences. It will also be reiterated to students that they can choose to withdraw from the study at any stage, without having to give a reason, and that participation will have no impact on the support available from their university. Participants will also be able to contact the researcher by email with any questions at any time, and can ask questions during the interview process. They will also be asked to sign a consent form by email before the interviews take place, and at the start of the interview the researcher will check that the participants have read the information

provided, and understand the purpose and scope of the research, what their participation will involve, how their data will be used, how to opt out and how they can get support for any issues raised. They will be asked to sign a hard copy of the consent form before the interview commences, and be given a copy to take away.

If participants are to be recruited from any of potentially vulnerable groups, give details of extra steps taken to assure their protection. Describe any arrangements to be made for obtaining consent from a legal representative.

The potential participants in this study will have mental health difficulties. However, any student who is under the care of a legal representative will automatically be excluded from the study. This will be established through the reply questionnaire. As discussed elsewhere, steps will be taken to ensure that participants requiring support after the interview will be signposted to the appropriate services within their university, and also given information about external sources of support (see attached sheets – support services and participant information pack). In addition, should a participant disclose anything that suggests they may be a risk to themselves or others, the participant will be informed that this information will be passed onto relevant services within their institution, to ensure that they receive the correct support.

Copies of any written consent form, written information and all other explanatory material should accompany this application. The information sheet should make explicit that participants can withdraw from the research at any time, if the research design permits.

Sample information sheets and consent forms are available from the University ethical review webpage at <http://ris.leeds.ac.uk/InvolvingResearchParticipants>.

C.12 Describe whether participants will be able to withdraw from the study, and up to what point (eg if data is to be anonymised). If withdrawal is not possible, explain why not.

Participants will be able to withdraw from the study at any time, by contacting the researcher by email. While the data in the report will be anonymised, the researcher will have a separate list of names of participants, and these will be linked to the recordings/transcripts. Should a participant wish to withdraw, the transcript, recording and any other data will be deleted.

C.13 How long will the participant have to decide whether to take part in the research?³¹

It may be appropriate to recruit participants on the spot for low risk research; however consideration is usually necessary for riskier projects.

The invite email will give students a deadline by which to register their interest in

being interviewed. This deadline will be 2 weeks from the date the email was sent, which should provide sufficient time to read the information about the study and make a decision about participating.

C.14 What arrangements have been made for participants who might not adequately understand verbal explanations or written information, or who have special communication needs?³² (e.g. translation, use of interpreters etc. It is important that groups of people are not excluded due to language barriers or disabilities, where assistance can be given.)

The students that will be approached to participate have disclosed a mental health difficulty, but the researcher will not be aware of any other impairments that might require access arrangements that have not been disclosed. Potential participants will be asked to contact the researcher should they require information in an alternative format or need additional support to participate, and this will be provided as necessary.

C.15 Will individual or group interviews/ questionnaires discuss any topics or issues that might be sensitive, embarrassing or upsetting, or is it possible that criminal or other disclosures requiring action could take place during the study (e.g. during interviews or group discussions)?³³ The [information sheet](#) should explain under what circumstances action may be taken.

X Yes No *If yes, give details of procedures in place to deal with these issues.*

As discussed in section A10, there is a possibility that some participants could become distressed due to the sensitive nature of the topics being discussed during the interview. The researcher is a Disability Adviser, and is experienced in conducting interviews with students with mental health difficulties. Issues around disclosure of sensitive information are an integral part of this role, and this experience will be beneficial in the context of the proposed research.

Students needing support with any of the issues raised during the interview will be signposted to the university counselling service and given a pack of information containing details of support services within the university, in the wider community and online (see attached documents).

Participants will also be told that, should they disclose anything that suggests they may be at risk to themselves or others, that this information will need to be passed on to their university so that they can receive the required support.

C.16 Will individual research participants receive any payments, fees, reimbursement of expenses or any other incentives or benefits for taking part in this research?³⁴

X Yes No

If Yes, please describe the amount, number and size of incentives and on what basis this was decided.

Participants will also be given a £5 gift voucher as a thank you for their time. This is at the request of one of the participating institutions. It is not intended that the voucher will act as an incentive, but as an expression of thanks to those that participated and an acknowledgment of their contribution.

RISKS OF THE STUDY

C.17 What are the potential benefits and/ or risks for research participants?³⁵

Benefits

There are no immediate benefits for participants being interviewed, although they will receive a gift voucher as a thank you. However, the outcome of the research could benefit future students, as the findings will be disseminated to the participating institutions and could support potential improvements to the social provision for students with mental health difficulties in the future.

Risks

As discussed above, it is possible that participating in the interview could upset some students, as they will be asked to think about their mental health difficulties and the impact it has on their social involvement at university. To try and reduce the impact of this, students who have been interviewed will be signposted to support services. Students will also be given a list of useful contacts should they wish to seek additional support outside of the university (see attached documents).

C.18 Does the research involve any risks to the researchers themselves, or people not directly involved in the research? *Eg lone working*³⁶

Yes X No

If yes, please describe: _____

Is a **risk assessment** necessary for this research?

X Yes No If yes, please include a copy of your risk assessment form with your application.

NB: Risk assessments are a University requirement for all fieldwork taking place off campus. For guidance contact your Faculty Health and Safety Manager or visit <http://www.leeds.ac.uk/safety/fieldwork/index.htm>.

RESEARCH DATA

C.19 Will the research involve any of the following activities at any stage (including identification of potential research participants)? (Tick as appropriate)

- Examination of personal records by those who would not normally have access
 - Access to research data on individuals by people from outside the research team
 - Electronic transfer of data
 - Sharing data with other organisations
 - Exporting data outside the European Union
 - X Use of personal addresses, postcodes, faxes, e-mails or telephone numbers
 - X Publication of direct quotations from respondents
 - Publication of data that might allow identification of individuals to be identified
 - X Use of audio/visual recording devices
 - FLASH memory or other portable storage devices
- Storage of personal data on or including any of the following:
- Manual files
 - Home or other personal computers
 - Private company computers
 - Laptop computers

C.20 How will the research team ensure confidentiality and security of personal data? E.g. anonymisation procedures, secure storage and coding of data.³⁷ Refer to <http://ris.leeds.ac.uk/ResearchDataManagement>

All personal data relating to the study will be stored on the University of Leeds M drive and accessible by the researcher and supervisor.

A list will be kept of all the students who are interviewed, and they will be allocated a pseudonym for the purposes of the report. The list of participants will be kept until the work has been submitted, so that participants can be identified should they wish to withdraw. All reference to the participants and their institutions will be anonymised in the final report and appendix.

C.21 How will you make your research data available to others in line with: the University's, funding bodies' and publishers' policies on making the results of publically funded research publically available (while not compromising requirements around data protection legislation)? (max 200 words) Refer to <http://ris.leeds.ac.uk/ResearchDataManagement>

This research is not bound by any funding requirements. However, it is intended that, once the study has been completed and formal feedback has been received, that a shorter report will be written and sent to the participating institutions and participating students. This includes the disability teams and the students' unions. This shorter report will be written in adherence to the same data protection issues as the original report, and all student and institution names will be omitted and pseudonyms used when appropriate.

This report will be drafted and sent to the participants for comment before it is sent to the university departments. This is to ensure that any sensitive issues are reported appropriately and that the participants are happy for the information to be shared. They will be offered the chance to amend or omit any of the information they provided should they wish, and will be given a date by which to respond with any changes they wish to make. Following this, the report will be finalised and disseminated, with recipients offered the chance to meet with the researcher to discuss the findings further.

C.22 How do you intend to share the research data? (Indicate with an 'X')

- Depositing in a specialist data centre or archive
- Submitting to a journal to support a publication
- Depositing in a self-archiving system or an institutional repository
- Dissemination via a project or institutional website
- Informal peer-to-peer exchange
- No plans to report or disseminate the data

X Other, please state: Report sent to Students' Union and disability teams at the participating institutions (see C21).

C.23 How do you intend to report and disseminate the results of the study? (Indicate with an 'X')

- Peer reviewed journals
- Internal report
- Conference presentation
- Publication on website

C.27 Does the research involve external funding? (Tick as appropriate)

Yes No *If yes, what is the source of this funding?*

PART D: Declarations

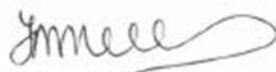
Declaration by Chief Investigators

1. The information in this form is accurate to the best of my knowledge and belief and I take full responsibility for it.
2. I undertake to abide by the University's ethical and health & safety guidelines, and the ethical principles underlying good practice guidelines appropriate to my discipline.
3. If the research is approved I undertake to adhere to the study protocol, the terms of this application and any conditions set out by the Research Ethics Committee.
4. I undertake to seek an ethical opinion from the REC before implementing substantial amendments to the protocol.
5. I undertake to submit progress reports if required.
6. I am aware of my responsibility to be up to date and comply with the requirements of the law and relevant guidelines relating to security and confidentiality of patient or other personal data, including the need to register when necessary with the appropriate Data Protection Officer.
7. I understand that research records/ data may be subject to inspection for audit purposes if required in future.
8. I understand that personal data about me as a researcher in this application will be held by the relevant RECs and that this will be managed according to the principles established in the Data Protection Act.
9. I understand that the Ethics Committee may choose to audit this project at any point after approval.

Sharing information for training purposes: Optional – please tick as appropriate:

- I would be content for members of other Research Ethics Committees to have access to the information in the application in confidence for training purposes. All personal identifiers and references to researchers, funders and research units would be removed.

Principal Investigator



Signature of Principal Investigator: _____

(This needs to be an actual signature rather than just typed. Electronic signatures are acceptable)

Print name: Laura Mella Date: 25/2/2015

Supervisor of student research: I have read, edited and agree with the form above.

Supervisor's signature: (This needs to be an actual signature rather than just typed.
Electronic signatures are acceptable)

Print name: Dr Tom Campbell Date: (dd/mm/yyyy):

.....

Please submit your form **by email** to researchethics@leeds.ac.uk or if you are in the Faculty of Medicine and Health FMHUniEthics@leeds.ac.uk. **Remember to include any supporting material** such as your participant information sheet, consent form, interview questions and recruitment material with your application.

B. Initial information email to potential participants

Dear Student

We are emailing to let you know about a research project on students' experiences of disclosing mental health difficulties, and were wondering if you might be interested in participating. We are contacting you because you have disclosed a mental health difficulty to the university, either as part of your application or since starting your course. Your details have not been passed to the researcher.

The research is being conducted as part of an MA in Disability Studies at the University of Leeds, and will involve attending an informal interview of no more than one hour, to be held at [name of university]. The interview will cover some of the following topics:

- Your experiences of disclosing a mental health difficulty to other students
- The factors that influenced your decisions to disclose or not disclose
- The effect of your mental health on your social experiences at university
- Your views on social activities at university

The research is being conducted independently of the university, and will have no impact on your current or future support. Your university will not know whether you have participated, and any data collected will be anonymised.

If you are interested in learning more about the research, please **click on the link below** and provide your contact details. This does not commit you to participating.

[link to online form]

The researcher will then contact you with more information about the project, and you will have an opportunity to ask any questions, and decide if you would like to be involved. If you are not interested in the research, you can ignore this email. There is no need to reply or complete the form.

Thank you for your time, and we hope your studies are going well.

Kind regards
[Disability Service]

C. Invitation to participate email

Dear Student

You recently responded to an email to say that you were interested in hearing more about a research project on students' experiences of disclosing a mental health difficulty. Thank you for your interest. This email is to explain a bit more about the project so you can decide if you would like to be involved.

My name is Laura Mella, and I am currently working towards my MA in Disability Studies at the University of Leeds through distance learning. I am also a disability adviser at [name of university]. The research project is part of my dissertation, and the final report will be submitted to the University of Leeds in September 2015.

As explained in the previous email you received, the research will involve attending an informal interview of no more than one hour, to be held at [name of university]. The interview will cover some of the following topics:

- Your experiences of disclosing a mental health difficulty to other students
- The factors that influenced your decisions to disclose or not disclose
- Whether your mental health has affected your social experiences at university
- Your views on social activities at university

Attached is an **Interview Schedule**, which provides more detail about the subjects to be covered during the interview.

The attached **Participant Information Sheet** also tells you a bit more about the research and how your data will be used if you choose to participate. If you think you might be interested in participating, please read this information carefully. You can also contact me with my questions you have about the project before you decide.

Participating is entirely voluntary. If you do not wish to participate, you do not need to do anything further. If you are interested in participating, please click on the link below and complete the reply form by **[date]**.

[link to online form]

Students will be selected for interview in order of response. If you are selected and are still happy to be interviewed, I will contact you again to arrange a suitable time to meet, and send you a consent form to complete. Interviews can also be conducted over the telephone or Skype/FaceTime if this is easier for you. You will receive a £5 gift voucher as a thank you for your participation.

I would be happy to answer any questions you may have about the research at any time, and my contact details are below. You can also contact my supervisor, Dr Tom Campbell, if you would like any further information. If you need any of this information in an alternative format, this can be provided, so please get in touch with your requirements.

I hope you may be interested in being involved in or learning more about this project, and I look forward to hearing from you.

Student number: 200825987

Kind regards
Laura

Laura Mella
Student: MA Disability Studies, University of Leeds
Email: ss13lmm@leeds.ac.uk

Research Supervisor

Dr Tom Campbell
School of Sociology and Social Policy
University of Leeds
t.w.campbell@leeds.ac.uk

Ethical approval number: AREA 14-083

D. Participant information sheet

You are being invited to take part in a research project. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Please ask if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

Title of the research

Is honesty the best policy? How disclosure of mental health difficulties affects social experience in Higher Education.

What is the purpose of the project?

This research is being conducted as part of an MA in Disability Studies at the University of Leeds. The final report will be submitted as a dissertation. The project aims to find out about students' experiences of disclosing a mental health difficulty to other students, the impact of mental health difficulties on students' social lives, and to consider what improvements can be made.

Who is the researcher?

The researcher is Laura Mella, a student working towards an MA in Disability Studies at the University of Leeds. Laura is also a disability adviser at [name of university]. The research is being conducted by Laura as an individual, and not by your university. Your disability department is aware of the research, but will not be involved at any stage.

Why have I been chosen?

You have been invited to participate in this research because you have disclosed a mental health difficulty to your university, either as part of your application or since you have started your course. Other students who have disclosed the same information will also be invited to take part, and students from [University A] and [University B] will be contacted.

What do I have to do?

If you decide to take part, you will have an informal interview with the researcher. This should take no more than one hour, and will take place at your university. The interviews will be audio recorded, and you will be able to review the transcription and make any amendments afterwards.

Do I have to take part?

It is up to you to decide whether or not to take part. If you do decide to participate, you will be asked to sign a consent form, confirming that you understand the purpose of the study and how the information you provide will be used. You can still withdraw at any time without it affecting any support that you are entitled to in any way. You do not have to give a reason. You can also withdraw after completing the interview if you want to, and your data will be deleted and removed from the study.

What type of information will be sought from me? Why do you need this information?

The purpose of this project is to find out about students' experiences of disclosing a mental health difficulty to other students, and the reasons why students chose to disclose or not to disclose. The interview will also cover some social issues, such as your experience of the social side of university and whether you think this is affected by having a mental health

difficulty. As students' experience is key to understanding these issues fully, it is crucial to include the views of students, and the data generated through the interviews will form the basis of the research project.

Are there any risks to taking part?

There are no immediate risks to taking part in the research. However, some students may find it upsetting to think about their mental health difficulties in this context. If you become distressed during the interview, the interview will be stopped. The researcher can also signpost you to the counselling service at your university, and give you information about further sources of support.

What are the benefits of taking part?

As a thank you for participating, you will be given a £5 gift voucher. While there will be no immediate benefits for those participating in the project, it is hoped that this work will provide information about how to better support students with mental health difficulties in the future.

Will my participation in this project be kept confidential?

No-one will know about your participation apart from the researcher and the research supervisor. The university will not be aware of your involvement, and participation will have no impact on your support now or in the future. All the information that collected about you during the course of the research will be kept strictly confidential, and will be stored securely for no more than two years before being deleted. You will not be able to be identified in any reports or publications, and names will be changed in the final report.

If you disclose anything during the interview that suggests that you might be at risk of harm to yourself or to others, the researcher has a duty to pass this information on, and will contact the relevant services with this information. This is to ensure that you receive the appropriate support. The researcher will tell you if they need to do this.

What will happen to the results of the research project?

The final project will be submitted to the University of Leeds as part of an MA in Disability Studies. A shorter report will also be written and sent to the disability department at your university, and also to the Students' Union, summarising the findings. You can also have a copy of this report if you would like to see it.

Contacts for further information

If you have any questions about the research, please contact Laura Mella or Dr Tom Campbell using the details below.

Researcher

Laura Mella
Student: MA Disability Studies (distance learning)
University of Leeds
ss13lmm@leeds.ac.uk

Research Supervisor

Dr Tom Campbell
School of Sociology and Social Policy
University of Leeds
t.w.campbell@leeds.ac.uk

Student number: 200825987

Thank you for taking the time to read this information. You should keep a copy of this sheet for future reference.

E. Interview schedule

School of Sociology and Social Policy
Interview Schedule 29/1/2015

Interview schedule

This document gives a brief overview of the areas that will be discussed during the interview. It is not an exhaustive list.

The interview will be informal, and will be more like a conversation, without a formal question and answer structure. This document is designed to give you an idea of the kind of topics that will be covered, so that you can make an informed decision about whether or not you would like to take part in the research. Please contact the researcher if you have any questions about this information.

Background information

History of your mental health difficulty
The decision to come to university
Thoughts about disclosure before starting university

Experiences of disclosure to other students

Factors affecting the decision to disclose/not disclose
Extent of disclosure
The benefits/disadvantages of disclosing a mental health difficulty
Thoughts about disclosing in the future
Barriers to disclosure

Social experiences and relationships

Freshers' week and the start of university
Your social life
Friendships with students
University social culture

F. Consent form

Consent to take part in research: Is honesty the best policy? How disclosure of mental health difficulties affects social experience in Higher Education	Add your initials next to the statement if you agree
I confirm that I have read and understand the information sheet dated 29 January 2015 about the above research project and I have had the opportunity to ask questions about the project.	
I understand that my participation is voluntary and that I am free to withdraw at any time without giving a reason and without there being any negative consequences. I understand that if I choose to withdraw, the data I provided will be deleted and not be used in the research. In addition, should I not wish to answer any particular question or questions, I am free to decline. Lead researcher: Laura Mella ss13lmm@leeds.ac.uk Research supervisor: Dr Tom Campbell t.w.campbell@leeds.ac.uk	
I understand that this research is being conducted by the researcher in their capacity as a student, and is being conducted for the primary purpose of completing an MA.	
I understand that participation in this research will have no bearing on any support I receive at university, and that any comments I make about support services will not be attributable to me.	
I understand that should I disclose anything that suggests I am at risk of harm to myself or others, the researcher may need to pass on this information to the appropriate persons.	
I understand that my name will not be linked with the research materials, and I will not be identified or identifiable in the report or reports that result from the research. I understand that my responses will be kept strictly confidential.	
I agree to take part in the above research project and will inform the lead researcher should my contact details change.	

Name of participant	
Participant's signature	
Date	
Name of lead researcher	Laura Mella
Signature	

Student number: 200825987

Date*	

*To be signed and dated in the presence of the participant.

G. Ethics committee favourable opinion letter

Performance, Governance and Operations
Research & Innovation Service
Charles Thackrah Building
101 Clarendon Road
Leeds LS2 9LJ Tel: 0113 343 4873
Email: ResearchEthics@leeds.ac.uk



UNIVERSITY OF LEEDS

Laura Mella
Centre for Disability Studies
School of Sociology and Social Policy
University of Leeds
Leeds, LS2 9JT

ESSL, Environment and LUBS (AREA) Faculty Research Ethics Committee University of Leeds

10 March 2015

Dear Laura

Title of study: Is honesty the best policy? How disclosure of mental health difficulties affects social experience in Higher Education
Ethics reference: AREA 14-083

I am pleased to inform you that the above research application has been reviewed by the ESSL, Environment and LUBS (AREA) Faculty Research Ethics Committee and following receipt of your response to the Committee's initial comments, I can confirm a favourable ethical opinion as of the date of this letter. The following documentation was considered:

Document	Version	Date
AREA 14-083 Ethical Review Form - final amended 24.2.15.doc	2	25/02/15
AREA 14-083 Fieldwork assessment form - medium risk2.doc	2	25/02/15
AREA 14-083 Initial email 24.2.15.docx	2	25/02/15
AREA 14-083 Invite email2 - amended 24.2.15.docx	2	25/02/15
AREA 14-083 Interview schedule2.docx	2	25/02/15
AREA 14-083 Participant information pack.docx	2	25/02/15
AREA 14-083 Participant information sheet2 - amended 24.2.15.docx	2	25/02/15
AREA 14-083 Participant consent form2 amended 24.2.15.doc	2	25/02/15
AREA 14-083 researcher's response.msg	1	25/02/15
AREA 14-083 Support Services - University A.docx	1	25/02/15
AREA 14-083 Support Services - University B.docx	1	25/02/15
AREA 14-083 Ethical Review Form - final.doc	1	30/01/15
AREA 14-083 Fieldwork assessment form - medium risk2.doc	1	30/01/15

AREA 14-083 Invite email2.docx	1	30/01/15
AREA 14-083 Participant information sheet2.docx	1	30/01/15
AREA 14-083 Participant consent form2.doc	1	30/01/15
AREA 14-083 Interview schedule2.docx	1	30/01/15

Please notify the committee if you intend to make any amendments to the original research as submitted at date of this approval, including changes to recruitment methodology. All changes must receive ethical approval prior to implementation. The amendment form is available at <http://ris.leeds.ac.uk/EthicsAmendment>.

Please note: You are expected to keep a record of all your approved documentation, as well as documents such as sample consent forms, and other documents relating to the study. This should be kept in your study file, which should be readily available for audit purposes. You will be given a two week notice period if your project is to be audited. There is a checklist listing examples of documents to be kept which is available at <http://ris.leeds.ac.uk/EthicsAudits>.

We welcome feedback on your experience of the ethical review process and suggestions for improvement. Please email any comments to ResearchEthics@leeds.ac.uk.

Yours sincerely

Jennifer Blaikie
Senior Research Ethics Administrator, Research & Innovation Service
On behalf of Dr Andrew Evans, Chair, [AREA Faculty Research Ethics Committee](#)

CC: Student's supervisor(s)

H. Participant profiles

Student code	Gender	Age	Diagnoses (as described by student)	University	Level of study	Subject area	Living with
A1	Male	43	Seasonal Affective Disorder (SAD) Autism Spectrum Disorder – Asperger’s Syndrome	A	Postgraduate Part-time	Humanities	Family
A2	Other	21	Depression with emotionally unstable personality traits (borderline personality disorder)	A	Undergraduate Taking time out of full-time study	Humanities	Students
A3	Female	26	Depression Anxiety	A	Postgraduate Full-time	Health	Family
A4	Female	23	Anorexia Nervosa Obsessive Compulsive Disorder (OCD) Depression	A	Undergraduate Full-time	Health	Students
B1	Female	19	Depression Anxiety	B	Undergraduate Full-time	Arts	Students
B2	Female	40	Depression Borderline personality disorder (BPD)	B	Undergraduate Full-time	Social Sciences	Family
B3	Female	24	Major depressive disorder Generalised anxiety disorder	B	Undergraduate Full-time	Computing	Students
B4	Male	20	Moderate depression with anxiety	B	Undergraduate Full-time	Social Sciences	Students