Exploring the Identity and Relationship Experiences of Lesbian and Bisexual Women with Intellectual Disabilities

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ABSTRACT

Women with intellectual disabilities who are attracted to other women have been largely neglected from research and remain a hidden and marginalised group in society. To date, a small body of literature has explored the experiences of people with intellectual disabilities who are lesbian, gay or bisexual (LGB); however, women with intellectual disabilities have featured either in very small numbers, or not at all.

This research sought to address this gap and explore the specific experiences of women with intellectual disabilities who identify as LGB. The research aimed to gain insight into how women with intellectual disabilities described and understood their LGB identity, where they felt included and excluded in their day-to-day lives and if they felt supported in their expression of same-sex attraction.

Six women with intellectual disabilities took part in semi-structured interviews, with four of the women participating in an additional photovoice interview. Data was analysed using thematic analysis, during which, three main themes were identified: 'non-heterosexual identity as difficult', 'the impact of invisibility and difference' and 'visibility and a positive sense of self'. Participants described feeling isolated, invisible and excluded due to the stigma of having a disability and a minority sexuality. Indeed, the women described feeling judged and discriminated against because of their sexuality, but isolated and unaccepted by the non-disabled lesbian, gay, bisexual and transgender (LGBT) community. The participatory research method of photovoice, however, enabled participants to also present the areas of their lives where they felt loved, accepted and supported.

Implications for future research are considered, as well as a consideration of what support is needed to help this marginalised, oppressed and hidden group in society.

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1. INTRODUCTION

1.1 Overview

This research sets out to explore the relationship experiences and sexual identities of lesbian and bisexual women labelled with intellectual disabilities. In this chapter I provide a context for the study, including an outline of the terminology used and a review of the literature on the sexuality of people with intellectual disabilities. In particular, I focus on research that has explored the experiences of lesbian, gay and bisexual (LGB) people with intellectual disabilities and highlight gaps in the field, with a particular spotlight on the experiences of women. I conclude with the rationale and aims for the study.

1.2 Terminology

1.2.1. Intellectual Disabilities

The use of the term 'intellectual disabilities' is relatively recent. In the UK, nomenclature used to describe a similar construct were previously 'mental handicap' and 'learning disability', while in the United States of America, individuals had been described as 'mentally retarded' (British Psychological Society, 2015). The term intellectual disability has evolved in part to replace such labels, which were seen to be dehumanising and demeaning (Parmenter, 2011). Indeed, the evolving nature of the language associated with intellectual disabilities has often marked an attempt to escape the stigma attached to previous terminology (Webb, 2013). Although a full exploration of this is outside of the scope of this research, the socially constructed nature of intellectual disabilities is important to recognise. 'Intellectual disability', and related constructs, have been created and sustained through social processes (Rapley, 2004).

Throughout this thesis the term intellectual disability is favoured due to its common academic and international usage. However, in the recruitment

information and interviews the term learning disability was preferred, as it is still the most commonly used, and often best understood, term within services that support adults with intellectual disabilities in the UK (Abbott & Burns, 2007).

In their guidance on the assessment and diagnosis of intellectual disabilities, the British Psychological Society (2015) provides a definition of intellectual disability which has the following three key elements:

- a significant impairment of intellectual functioning;
- a significant impairment of adaptive behaviour (social functioning); with
- both impairments arising before adulthood.

A significant impairment of intellectual functioning is usually further defined to an Intelligence Quotient (IQ) score of less than 70. Despite agreement in all three major international classification systems on this criterion, there has been considerable debate and disagreement on the usefulness of IQ scoring in this context and on the accuracy of IQ testing for people with an intellectual disability (British Psychological Society, 2015). However, it remains as the standard way that people are assessed as to whether they 'fit' the criteria of intellectual disabilities.

1.2.2. Sexuality

According to Weeks (2010), current understandings of the word 'sexuality', meaning being 'sexual', developed in the nineteenth century when it came to be understood as the: "personalized sexual feelings that distinguished one person from another (*my* sexuality), while hinting at that mysterious essence that attracts us to each other" (p. 5).

According to the World Health Organization (2010), sexuality is a central aspect of human life which:

"encompasses sex, gender identity and role, sexual orientation, eroticism, pleasure, intimacy and reproduction. Sexuality is experienced and expressed in thoughts, fantasies, desires, beliefs, attitudes, values, behaviour, practices, roles and relationships. While sexuality can include

all these dimensions, not all of them are always experienced or expressed. Sexuality is influenced by the interaction of biological, psychological, social, economic, political, cultural, ethical, legal, historical, religious and spiritual factors" (p.10).

Here the WHO definition clearly places sex and sexuality beyond simply the realms of biology and the body, instead a complex interaction of environmental, social, cognitive and biological factors impact on how sexuality is understood and expressed. Within the domain of sexuality, 'sexual orientation' can be understood as describing a pattern of emotional, romantic or sexual attractions to people of the opposite sex or gender (heterosexuality), the same sex or gender (homosexuality, such as gay or lesbian), or to both sexes or more than one gender (bisexuality) (American Psychological Association, 2012).

There are, however, no universally agreed definitions of the terms 'gay', 'lesbian' and 'bisexual' and many cultural variations in how alternative sexual identities are understood and labelled (Clarke, Ellis, Peel, & Riggs, 2010). Indeed, non-western cultures use different concepts to describe non-heterosexuality or gender variation. Furthermore, although individuals in western cultures are labeled as 'homosexual', 'heterosexual' and 'bisexual', these constructions do not provide a comprehensive definition of sexuality, as they do not account for variation between the constructs and across an individual's lifetime (World Health Organisation, 2010).

Although these categories continue to be widely used, research suggests that sexual orientation occurs on a continuum rather than discrete categories (Kinsey, Pomeroy, Martin, & Gebhard, 1953; Kinsey, Pomeroy, & Martin, 2003; Klein, 2014). Little is known about reasons for individual preferences for one identity over another, given that evidence has shown same-sex behaviours, attractions and fantasies to be widespread even amongst a large proportion of people who identify as heterosexual (Laumann, Gagnon, Michael, & Micheals, 1994; YouGov, 2015). Furthermore, people of all orientations have been shown to experience sexual fluidity across time and context (Savin-Williams, 2014). Such findings have questioned the essentialist approach to sexuality which has

centered on the idea that sexuality is a 'natural', innate and a fixed aspect of identity (Kitzinger & Wilkinson, 1995).

Although social constructionists have acknowledged the constructed nature of identity categories, they have largely retained them; queers theorists, however, challenge this further, arguing that identity categories, such as 'lesbian' or 'gay', act as "regulatory fictions" that reproduce heteronormative concepts of sex and gender (Butler, 1990, p. 13). Queer theory can be hard to define due to "many queer theories" within it (Warner, 2004, p. 332). However, queer theorists have traditionally questioned the usefulness of identity categories, arguing that power operates through their very production, and therefore they see the deconstruction of identity categories as the priority to resist heteronormativity (Clarke & Peel, 2007).

However, queer theory has been criticised for creating a new binary between everything queer versus everything not (summarised as heteronormativity) and for casting the boundaries of inclusivity so wide as to become meaningless, unable to account for any internal differences (Gamson & Moon, 2004). Critics have also argued that queer theory is elitist and inaccessible to most people, and therefore remains the reserve of mostly white, middle-class academics (Jeffries, 2003). Perhaps most significantly, queer theory is seen to wholly undermine the LGBT rights movement, as the deconstruction of identity categories makes political action difficult (Gamson, 1995; Jeffries, 2003). Of particular relevance to this research, it can ignore the material realities of oppression and deny a voice to non-heterosexual individuals who have just begun to acquire rights through the use of identity categories (Gamson, 1995; Jeffries, 2003).

A full exploration of the debate between the social constructionist, or essentialist and biological, understandings of sexual orientation is outside of the scope of this thesis. However, it is important to acknowledge the role of social and historical contexts in influencing the experience and expression of individual sexuality (Weeks, 2010). Indeed, queer theorists themselves have argued that to have a greater impact on oppression and a greater understanding of

sexuality it is important to explore the social construction of sexuality, rather than pursue irresolvable debates about aetiology (Macbride-Stewart, 2008).

For consistency, in this study, identity categories of 'lesbian', 'gay' and 'bisexual' (LGB) are maintained, under the umbrella of non-heterosexuality, with the addition of 'transsexual' (LGBT) when the reference is inclusive of gender non-conformance. However, there is an acknowledgement that these are not fixed and permanent 'identities' but may fluctuate over time or be more or less useful in different contexts. Within the context of this research, sexuality is understood to be constructed through interactions between the individual and wider society, and its development is dependent on the ability to express basic human needs, including intimacy, emotional expression and love (World Association for Sexual Health, 1999).

1.3 Sexual Identity Development

The process of forming a minority sexual identity has been much written about in research (Cass, 1979, 1984; Coleman, 1982; Markowe, 1996; Troiden, 1989). These models of sexual identity formation typically outline stages which an individual progresses through from initial identity confusion to an eventual acceptance and embracement of LGB identity (Cass, 1979, 1984; Coleman, 1982). In Cass' (1979) six stage model, individuals move from 'identity awareness', a first acknowledgement of feeling 'different', to identity tolerance, acceptance, pride and eventually 'identity synthesis' in which the identity has been accepted and integrated alongside other identities. While a number of these theories have been based on research with gay men, which has then been assumed to apply to LGB women (Milton & MacDonald, 1984; Troiden, 1989), some theorists have particularly focused on lesbian and gay women's experiences which focus particularly on constructions of lesbianism and identity formation in the context of gender inequality (Markowe, 1996).

However, identity formation or 'coming out' models have been criticised for being too linear, essentialist and for failing to account for individual and cultural differences (Liddle, 2007). As can be seen in the section above on sexuality (in

1.2.2), the basic assumption of a final and static sexual identity does not fit the experiences of many people who demonstrate fluidity and fluctuations in both sexual attraction and identity over time (Savin-Williams, 2014, 2016). Crucially for this research, the models also fail to account for other personal and social identities, instead seeing sexual minority identity as most dominant (Meyer, 2013). The experiences of individuals who have to manage diverse minority identities, including disabled or ethnic minority identities, have not been adequately accounted for.

Despite their problems, however, identity formation theories can offer a perspective on some of the potential barriers and experiences for people who identify as non-heterosexual. Indeed, Cass (1979) herself acknowledged that the model she proposed was context specific, not true for "all people" (p. 235) and may need to be updated to accommodate societal and attitudinal changes. Thus, although such models should not be considered an overarching or all encompassing explanatory theory of non-heterosexual experience, they can provide a means to understand some of the ways in which 'coming out' or identifying as LGB can be experienced for some individuals; indeed, feelings of difference, identity confusion and psychological conflict has been shown to be common experiences for a number of LGB people from a wide variety of backgrounds (Land & Kitzinger, 2008; Macbride-Stewart, 2008; Markowe, 1996; Schubotz & McNamee, 2009). Perhaps for this reason the models continue to be regularly referred to and cited in research; used to offer a perspective on understanding the psychosocial adjustment involved in LGB identity formation.

1.3.1. Stigma and Minority Stress

The process of forming an LGB identity has been shown to often have negative effects on self-esteem and psychological well-being (Grossman & Kerner, 1998). In Goffman's (1968) work on stigma, he suggested that when an individual possessed an attribute which marked them as different, especially an attribute perceived to be undesirable, they become "reduced in our minds from a whole and usual person to a tainted, discounted one" (Goffman, 1963, p. 12). Meyer (1995) argued that stigmatised individuals experience "minority stress", a chronic stress experienced by LGB individuals who are stigmatised in a

heterosexist society. Minority stressors were thought of as acting in three main ways: internalized homophobia, the process of turning societal negative attitudes about non-heterosexuality inwards on the self; stigma, involving the expectation of rejection and discrimination from others; and actual direct experiences of discrimination and violence (Meyer, 1995, 2013).

Meyer (2013) argued that minority stress helps to explain the higher prevalence rates of mental distress found in sexual minority populations, as the "stigma, prejudice, and discrimination create a hostile and stressful social environment" (p.3). Individuals who identify as LGB have been consistently found to have higher rates of mental distress and lower wellbeing when compared to individuals who identity as heterosexual (King et al., 2008; Semlyen, King, Varney, & Hagger-Johnson, 2016). They are also more likely to self-harm, abuse substances and to think about or attempt suicide (King et al., 2008). Meyer's (2013) minority stress model attributes this to the effects of marginalisation, bullying, homophobia, rejection and internalisation of discrimination. Of course people with intellectual disabilities too, have been stigmatised by society and occupy a devalued social position due to non-conformance to societal norms and expectations. Thus a minority stress model can also be applied to individuals who have similarly been marginalised, rejected and discriminated against due to disability (Bennett & Coyle, 2007; McCarthy, 2010). The potential impact of occupying both of these stigmatised identities will be considered in this research.

1.4 History of Sexuality for People with Intellectual Disabilities

Understanding current attitudes towards the rights and sexuality of women with intellectual disabilities has its origins in how people with intellectual disabilities have been viewed and treated historically. People with intellectual disabilities have often been seen as either a sexual threat to society, requiring segregation and, in some cases, sterilisation, or as innocent, asexual and in need of protection from sex (McCarthy, 1999).

At the time of the industrial revolution in the West, with changes to the social order created by industrialised work and the ideologies of 'rationality', people with intellectual disabilities were increasingly placed into institutions, commonly known as asylums (McCarthy, 1999). Here both 'imbeciles' and 'lunatics' were kept alongside other social 'deviants' such as the physically disabled, the elderly and the unemployed (Scull, 1993). With the arrival of the eugenics movement in the early 20th century, fears about 'undesirable' people reproducing excessively and threatening national intelligence led to the increasing segregation of people with intellectual disabilities and, in some countries, the compulsory sterilisation of women with intellectual disabilities (Murphy & Callaghan, 2004; Tilley, Walmsley, Earle, & Atkinson, 2012). Institutionalisation was used as a way to separate people with intellectual disabilities from society, from the opposite sex (in segregated wards), and prevent them from procreating. This was especially true for women with intellectual disabilities who along with other women, such as unmarried mothers, were labelled 'feeble-minded' and were thought to be immoral, promiscuous and likely to produce many children similar to themselves (Kempton & Kahn, 1991).

While the early institutions had been created in the spirit of education and rehabilitation, they had become repressive and de-humanising environments that were now influenced by a medical model with a focus on diagnosis and treatment. The tendency to institutionalise people with intellectual disabilities continued throughout the twentieth century, reaching a peak in the 1960s when there were 64,000 people with intellectual disabilities in large institutions and long-stay hospitals in the UK (Bone, Spain, & Martin, 1972). However, in the 1960s and 70s, a series of public scandals publicised the appalling conditions within institutional hospitals and strong activist campaigns began to advocate for changes to the way people with intellectual disabilities were supported (Whittuck, 2014).

Alongside the gradual closure of long-stay hospitals came a shift in values and beliefs about how people with intellectual disabilities should be supported to live their lives (Bennett & Coyle, 2007). The principles of 'normalisation' expounded that people with intellectual disabilities should have the right to an 'ordinary life'

in the community (Wolfensberger, 1970). Smaller residential homes became more accepted and the rights of people to live in the community.

With the backdrop of normalisation, coupled with the sexual liberation of the 1960s and the wider availability of effective contraception, the sexual rights of people with intellectual disabilities gradually came to be recognised. In the 1970s and 80s there was a large growth in sex education materials for people with intellectual disabilities, although they were largely heterosexist, featuring only heterosexual relationships (McCarthy, 1999). The advancement of HIV and AIDS played a part in the urgency and need to provide good safer sex education. It may also explain the initial research attention on minority sexualities in people with intellectual disabilities being dominated by a focus on men who have sex with men and their sexual behaviours (Cambridge, 1996; Thompson, 1994).

Gradually attitudes towards the sexuality of people with intellectual disabilities became more liberal and the rights of people to have romantic and sexual relationships became increasingly enshrined in policies and practice. Building on the ideas of normalisation and personalisation, the UK Government issued two white papers, Valuing People and Valuing People Now (Department of Health, 2001, 2009), which promoted the rights of people with intellectual disabilities to lead full and independent lives; the strategies promoted inclusion in the community and more choice and control for people with intellectual disabilities including better health, access to housing, jobs and education and the right to romantic and sexual relationships.

However, despite much progress in advancing the rights of people with intellectual disabilities to have sex and relationships, a number of attitudinal barriers continue to exist. Indeed, the social constructions of sexuality of people with intellectual disabilities have often persevered, with people regularly being seen as asexual and infantilised as forever children or adolescents, or as a threat or risk to themselves or others. As will be explored in the next section, when sexuality is recognised for people with intellectual disabilities, it is too often assumed to be heterosexual.

1.5 Sexuality in People with Intellectual Disabilities: The Current Picture

While much progress has been made, the expression of sexuality in people with intellectual disabilities still regularly evokes anxiety and discomfort in those around them.

1.5.1. Attitudes of Family and Staff to Sexuality in People with Intellectual Disabilities

1.4.1.1 Attitudes of family: There is evidence to suggest that parents of people with intellectual disabilities find it harder to accept their son or daughters sexuality than paid support staff do (Evans, McGuire, Healy, & Carley, 2009). Parents report feeling anxious about the vulnerability of their sons and daughters and fearful that they might be sexually abused or exploited (Foley, 2013). Indeed, research has shown that some parents were reluctant for people with intellectual disabilities to have sex or relationships at all (Garbutt, Boycott-Garnett, Tattersall, & Dunn, 2010).

Other research has shown parents to be in favour of friendships and relationships for their children, but non-sexual ones only. For instance, in Fitzgerald and Wither's (2013) study, women with intellectual disabilities talked about being restricted and regulated by others, including staff and parents, who viewed being in a relationship as permissible as long as they were not sexual: "she said it's alright to have a cuddle and then leave it at that and a kiss but that's all, not more than that" (p.9). Similarly, Evans et al. (2009) surveyed 153 parents of people with intellectual disabilities in Ireland and found that 80% of the parents thought that there should only be friendships and non-intimate relationships between people with intellectual disabilities.

Research has shown that this conservatism from parents is felt and understood by young people with intellectual disabilities. Garbutt, Boycott-Garnett, Tattersall and Dunn (2010) explored who young people would talk to about relationships and only one young person out of 17 said they would tell their parents; a young man in the group commented that if he had asked his parents for condoms they would think he was 'insane' (Garbutt et al., 2010).

1.4.1.2 Attitudes of staff: In relation to support with sex and relationships staff support has commonly focused exclusively on the avoidance of risk, dominated by concerns of sexually transmitted disease, abuse and pregnancy; rather than attention given to empowering people with intellectual disabilities to have loving and sexually satisfying relationships (Abbott & Burns, 2007; Thompson, 2001). There has also been differences in attitudes towards men and women with intellectual disabilities, with women being viewed as sexually innocent and naïve (Young, Gore, & McCarthy, 2012).

1.5.2. Attitudes of Staff Towards LGBT People with Intellectual Disabilities

Cambridge (1997a) argued that staff who support adults with intellectual disabilities are likely to hold the same heterosexist assumptions as the rest of society, and research into staff views has shown this regularly to be true (Abbott & Howarth, 2007; Clarke & Finnegan, 2005; Grieve, McLaren, Lindsay, & Culling, 2009; Yool, Langdon, & Garner, 2003; Young et al., 2012).

Research which surveyed 702 support staff in the UK found that while 76% said that they would support a person with intellectual disabilities to develop a heterosexual relationship, only 41% said they would do the same for a same-sex relationship (Clarke & Finnegan, 2005). Young, Gore and McCarthy (2012) found that 5 out of 10 staff they interviewed felt that same-sex relationships in those they supported were either anxiety provoking or inappropriate. While some research has indicated that certain factors, such as age of staff or level of training, affected the likelihood of homophobic or heterosexist attitudes (Evans et al., 2009). For instance, a study by Grieve and colleagues (2009) identified that negative attitudes towards LGBT relationships for people with intellectual disabilities was more likely from nursing home staff than community care staff and from those with less training.

Abbott and Howarth (2005) interviewed 71 members of staff across 20 services in the UK and found that most staff were unwilling to proactively raise issues of sexuality with the individuals they supported. Furthermore, the staff interviewed reported added anxiety about supporting adults with intellectual disabilities with

same-sex relationships; they reported that they lacked confidence, felt that policy and training was absent and were fearful of negative reactions from others, such as parents and other colleagues (Abbott & Burns, 2007; Abbott & Howarth, 2005). They were also seen to be influenced by their own sometimes prejudicial attitudes about homosexuality (Abbott & Burns, 2007; Abbott & Howarth, 2005). Whereas, on the other hand, staff who identified as LGBT themselves were not usually out to the individuals they supported, which the authors hypothesized helped to perpetuate the lack of LGBT role models for people with intellectual disabilities (Abbott & Howarth 2005).

Whilst this research by no means suggests that all staff hold such negative attitudes towards homosexuality, and there are examples of positive practice, it has certainly been viewed as problematic by a proportion of staff across a wide variety of studies. Non-heterosexual sex and relationships for people with intellectual disabilities regularly raises levels of anxiety and discomfort in staff. Accounts from staff have shown that supporting people with intellectual disabilities with sex and relationships already felt difficult and potentially problematic, so that supporting them within the context of an LGBT sexuality was nearly " inconceivable" (Abbott & Burns, 2007, p. 35) .

1.5.3. Sex Education

Despite the growth in sex education materials for people with intellectual disabilities there are still a number of people with intellectual disabilities who do not receive any formalised sex education (Garbutt, Boycott-Garnett, et al., 2010). Indeed, research has also shown that young people with intellectual disabilities, parents and teachers all thought that sex education for people with intellectual disabilities needed improvement (Garbutt, Boycott-Garnett, et al., 2010).

Sex education has been seen to deal predominantly with the mechanics of sex rather than information about sexual pleasure (Garbutt, Boycott-Garnett, et al., 2010). While accessible sex education materials have regularly neglected same-sex relationships and had a strong heterosexual bias (Burns & Davies, 2011; McCarthy, 1999).

Thus, it comes as no surprise that the sexual knowledge of a number of people with intellectual disabilities has been found to be inaccurate or partial and inconsistent (Murphy & Callaghan, 2004; Servais, 2006). Research has indicated that women with intellectual disabilities might be especially disadvantaged in knowledge related to sex and sexuality. Garbutt et al. (2010) found that young women with intellectual disabilities knew less than young men about all matters related to sex, except for the topic of periods. Furthermore, Fitzgerald and Withers (2013) found many women with intellectual disabilities believed that sex was 'dirty' and should not be talked about at all.

1.5.4. People with Intellectual Disabilities and Relationships

Research has shown that a romantic partner is highly valued by people with intellectual disabilities who value the support, companionship and social status associated with having a partner (Bates, Terry, & Popple, 2017; Rushbrooke, Murray, & Townsend, 2014). Many people with intellectual disabilities place a high value on the positive aspects of romantic relationships such as feeling loved, cared for and supported, as well as sharing intimacy and affection (Bates et al., 2017). Furthermore, when representing themselves to others using pictures, a number of people with intellectual disabilities were seen to represent themselves with a firm sexual identity, which contrasted with others' representations of people with intellectual disabilities as more passive and non-sexual (Gleeson, 2011).

However, people with intellectual disabilities face a number of barriers to establishing and maintaining a romantic relationship. Attitudinal and service restrictions, such as restrictive policies of support organisations have been shown to limit sexual expression; indeed people with intellectual disabilities have had their sexuality denied, prohibited or heavily supervised (Bernert, 2011). Furthermore, people with intellectual disabilities can be reliant on others in their life, such as family or support staff, to enable closer relationships to develop, and to facilitate social and leisure activities (Russell & Flynn, 2010). Support is vital for people with higher support needs who have struggled to develop and maintain relationships without it (Bates et al., 2017).

Some people with intellectual disabilities may not be able to consent to having a sexual relationship. Furthermore, a high number of people with intellectual disabilities have experienced some form of sexual abuse (McCarthy, 2014; Thompson, 2001). Generally, however, if people with intellectual disabilities are given sufficient social support and accessible sex and relationships education, many individuals can engage in safe, healthy and happy romantic and/or sexual relationships (Bates et al., 2017; Rushbrooke et al., 2014; Sinclair, Unruh, Lindstrom, & Scanlon, 2015). Indeed, research suggests that people with intellectual disabilities are better protected from abuse when their sexuality is recognised and supported (Sinclair et al., 2015). Furthermore, a number of people with intellectual disabilities have spoken about the importance of intimacy and affection in a relationship, which for some was not sexual in nature (Bates et al., 2017).

1.5.5. Attitudes Towards Homosexuality from People with Intellectual Disabilities
Attitudes and knowledge about minority sexualities obviously varies widely amongst people with intellectual disabilities; however, research has indicated that people with intellectual disabilities may have even poorer understandings of same-sex relationships than heterosexual ones and may have adopted wider societal attitudes that stigmatise homosexuality (Garbutt, Boycott-Garnett, et al., 2010; Healy, McGuire, Evans, & Carley, 2009; Murphy & Callaghan, 2004). Garbutt, Boycott-Garnett, Tatterall and Dunn (2010) conducted participatory research in England with over 20 young people with intellectual disabilities using drama and found that while most of the young people knew what gay and lesbian meant, some of them were unsure if LGBT people could have sex, with three of the young people believing that it was against the law. They also found that some of the young people were reluctant to act as a gay character, indicating that they may have adopted prejudicial attitudes towards people with a minority sexuality (Garbutt, Boycott-Garnett, et al., 2010).

Research particularly with women with intellectual disabilities has similarly found knowledge of homosexuality to be low. Burns and Davies (2011) investigated the attitudes of 27 women with intellectual disabilities in the UK

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towards homosexuality and found that participants had limited knowledge of homosexuality, in particular regarding lesbian relationships, and often expressed prejudiced and homophobic views. Hollomotz (2011) found that non-heterosexual identities had rarely been discussed with the 17 women in her research. Similarly, Fitzgerald and Withers (2013) found that many of the women they interviewed did not know the meaning of words used to describe sexual orientation, such as homosexual, lesbian and gay, and tended to hold negative views of homosexuality, describing it as 'horrible' and 'wrong'. Attitudes from some of the women interviewed appeared to relate to the idea that sex and sexuality were biologically and physically determined: "I know you have sex with a man 'cos you're a woman and you have different parts to your body" (Fitzgerald et al., 2013, p.7).

1.5.6. LGB Identity Formation for People with Intellectual Disabilities

Talking about and exploring sexual identity is a deeply personal form of self-expression (Azzopardi-Lane & Callus, 2015). People with intellectual disabilities often have few places to make their voices heard and so are particularly disadvantaged from the opportunity to express, or often even discuss, their sexuality (Azzopardi-Lane & Callus, 2015).

Currently knowledge is lacking around issues related to sexuality and disability (Fitzgerald et al., 2013). Relatively little is known about LGB identity formation for people with intellectual disabilities and there is currently little research on LGB disabled people's experiences in relation to their sexual identity and what meaning they make of their experiences. However, identifying outside of the heterosexual norm has been shown to be complex and clouded by a number of personal and systemic barriers for people with intellectual disabilities (Wilson et al., 2016). Butler (2012) suggested that a lack of support in developing and expressing an LGB identity for people with intellectual disabilities can result in "internalised homophobia, confusion, or resistance: relabelled 'challenging behaviour'" (p. 216).

Despite progressive guidance in the UK outlining the rights of people with intellectual disabilities to sex and relationships, such as Valuing People Now (Department of Health, 2009), attitudes towards sexual relationships for people with intellectual disabilities remains largely conservative and often in contravention of those rights. Furthermore, despite progressive legislation in the realm of LGBT rights (such as the Equality Act 2010 and Marriage (Same-sex Couples) Act 2013), good support for people with intellectual disabilities with minority sexualities has been harder to find. Research has shown that sex education is still extremely variable and more education on same-sex relationships is needed. Considering the possibility of a homosexual identity for people with intellectual disabilities has regularly been viewed as outside of the realms of possibility or a 'step too far' for family members or staff and there remain a number of obstacles to people with intellectual disabilities developing a sexual identity.

1.6 Role of Clinical Psychologists

Within current research in this area, there is little mention of the role of clinical psychologists and thus it seems that this is an area where clinical psychologists have been largely absent. Some consideration of the current role and the relevance to clinical psychology is needed.

1.6.1. Institutionalised Homophobia

Historically homosexuality was pathologised by the psychology and psychiatry professions, only being removed as a 'mental illness' in the DSM (Diagnostics and Statistics Manual) in 1973 (Clarke et al., 2010). Indeed, in the UK treatments for 'homosexuality' were provided by the NHS up until the 1970s (Smith, King, & Bartlett, 2004).

After the removal of homosexuality as an 'illness', a segment of the discipline developed an approach to psychology which was affirmative, accepting and inclusive of LGB identities. Early affirmative psychological research sought to

prove the psychological health of LGB individuals and promote their 'sameness' to heterosexuals (Macbride-Stewart, 2008).

Thus, current approaches to working with LGBT clients have become less pathologising and more accepting and affirmative (British Psychological Society, 2012). However, it has been argued that psychology practice has not gone far enough to address embedded homophobia and heteronormativity in the discipline (Hodges & McManus, 2006). For example, clinical psychology training has been noted to be inadequate and inconsistent in dealing with LGB issues (Anderson, 2012; Shaw, Butler, & Marriott, 2008). Thus, clinical psychologists may still feel particularly unskilled at supporting LGB clients, or feel unconfident in responding to LGB related issues.

1.6.2. Therapeutic Disdain

Psychologists are similarly still repairing the legacy of 'therapeutic disdain' shown to people with intellectual disabilities who were seen as not suited to psychological therapies (Bender, 1993). Any difficulties were assumed to be organically mediated or environmentally contingent and thus there was no need for individual or group therapies as people with intellectual disabilities were not 'psychologically minded' or developed enough (The British Psychological Society, 2016);. As a consequence, the emotional and psychological needs of people with intellectual disabilities were largely ignored until the late 1990s (Arthur, 2003).

Although this situation has changed, and a range of therapies are now offered to people with intellectual disabilities (The British Psychological Society, 2016); psychologists can still be accused of focusing their practice largely on cognitive and capacity assessments, and individualised interventions such as behavioural approaches to challenging behaviour. This continues to ignore the broader psychological needs and quality of life for people with intellectual disabilities, which would need to address social inequalities and marginalisation.

1.6.3. Problematising Sexuality for People with Intellectual Disabilities

One of the core roles of clinical psychologists within community teams for adults with intellectual disabilities has been to complete specialised assessments of capacity in relation to decisions, such as the decision to consent to sexual relationships (British Psychological Society, 2011). Capacity assessments related to sex usually arise when a sexual relationship is seen to be problematic, abusive or should be prohibited (Series, 2015). Psychologists have therefore been involved in supporting, or rather assessing, adults with intellectual disabilities when sex and relationships have been seen to become a problem, or an anticipated problem.

Psychologists therefore hold a position of power over the sexualities of people with intellectual disabilities. Indeed, far from being a straight-forward or objective task, the assessment of capacity to consent to sexual relationships is known to be complex, with no clear guidance on when a person 'knows enough' (Acton, 2015; Murphy & Callaghan, 2004; Series, 2015).

Despite this role in assessing sexual expression in people with intellectual disabilities, it appears that psychologists have done little to proactively support the development of positive, healthy, sexual identities for people with intellectual disabilities. Even less so, do psychologists appear to have been involved in supporting LGBT people with intellectual disabilities who are even further marginalised within services. Instead, due to service structures and prioritising of resources, a reactive response to sexuality has been maintained.

1.7 Literature Search

To explore the specific experiences voiced by people with intellectual disabilities who express a non-heterosexual sexual identity, a full review of the literature was conducted. A literature search was performed using PsycINFO, Academic Search Complete and CINAHL with a range of search terms for intellectual disability, combined with a range of terms for sexual minorities across all years. Furthermore, Google Scholar and grey literature were also explored and the reference lists of key papers were reviewed for further relevant studies.   The

search was restricted to research published in English and in peer-reviewed journals. For full details of the search terms used see Appendix 1. The literature search process is outlined in Figure 1.

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┌──────────────────────────────────────────┐
│  Searches conducted across: psychINFO,     │
│  Academic Search Complete, and CINAHL using│
│  the search terms outlined.                │
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│  A total of 449 papers were identified                     │
│                                                            │
│  (PsychINFO = 276, CINAHL = 48 papers, Academic Search     │
│  Complete = 125)                                           │
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│  Analysis of titles and abstracts to check for     │
│  relevance and compare study to the inclusion      │
│  criteria.  Duplicated studies                     │
│  were also removed.                                │
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│  21 studies identified as relevant to  │
│  the research area                     │
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│  Full text papers reviewed.    │
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│  A total of 5 studies were identified in which the │
│  research explored specifically the experience of  │
│  people with intellectual disabilites about their  │
│  LGB sexual identity                               │
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│  1 additional study identified         │
│  through reference lists               │
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│  6 core research studies identified    │
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Figure 1. Literature search process

During the literature search a number of studies were identified which broadly related to the research area, including for example, research into staff views on the sexuality of people with intellectual disabilities (Abbott & Howarth, 2007;

Grieve et al., 2009) and a review paper of research into the experiences of people with intellectual disabilities who identify as LGBT (McCann, Lee, & Brown, 2016). Additionally, other research was identified as directly hearing from LGBT people with intellectual disabilities but solely focused on sexual practices, sexual health or HIV (Cambridge, 1996, 1997a; McClelland et al., 2012; Thompson, 2001). Although these studies were incorporated into the general narrative review of this topic area, they were not included as a core study due to the absence of the voice of people with intellectual disabilities about their sexual identity.

1.8 Hearing from LGBT People with Intellectual Disabilities: The Research

As shown in Figure 1, only a limited number of research projects have been conducted directly with LGB people with intellectual disabilities that explore their sexual identity and aspects of their relationships experiences; a total of six keys studies were identified. A brief summary of the studies, including the country of origin, type of analysis, sample and key findings can be found in the table in Appendix 2. The next section provides a review of these studies, followed by a look across the research at some of the main findings and an analysis of any limitations and gaps in the research.

In one of the earliest explorations of identity in non-heterosexual people with intellectual disabilities in the UK, Withers and colleagues (2001) evaluated a pilot support group for five men with intellectual disabilities who had sex with men. At the beginning of the group the men were described to be engaging in high-risk sexual practices in the community. They were also seen to show discomfort with their sexuality, choosing to talk solely about their behaviours rather than labelling themselves as gay, and they were observed to talk about homosexuality in purely negative ways. Using content analysis to analyse the eighth group meeting, the researchers identified that over the course of the group the men had started to have more contact with gay culture, had begun to self-identify as gay and, in two instances, had talked positively about homosexuality (Withers et al., 2001). However, a weakness of the study was the omission of any pre-group interviews or baseline measures so that the

comparisons were anecdotal rather than empirical. Nevertheless, it demonstrated that the group was valued by the men and gave some initial insights into the experiences of having an intellectual disability and minority sexuality.

Bennett and Coyle (2007) extended this research by interviewing 10 men with intellectual disabilities, particularly looking to explore their constructions of a gay identity and both societal and institutional responses to their sexuality. They discovered that participants were aware of negative societal attitudes directed at both gay men and people with intellectual disabilities and felt isolated and cut off from gay social contexts. Bennett and Coyle (2007) argue that the men were put in position of being a 'minority within a minority' which exposed them to multiple oppressions and multiple threats to their identity. The men also described the added difficulties of having sexual or romantic relationships in the context of living in residential care with associated rules and restrictions placed on their lives. The study provided the first in-depth look at some of the challenges of developing a minority sexual identity within the context of additional stigma and discrimination experienced due to disability.

The largest study to date was a three year research project conducted by the Norah Fry Research Centre, which interviewed 20 LGBT people with intellectual disabilites (11 men and 9 women), and 71 members of staff (Abbott & Burns, 2007; Abbott & Howarth, 2005). They found that participants spoke of the importance of love and relationships in their lives and used LGBT labels to self-identify. Participants had been fearful of coming out, the process of revealing their sexual orientation to others, but had done so to at least one person. However, participants also described experiencing bullying and discrimination and felt isolated from the LGBT community (Abbott & Burns, 2007). The researchers reported a number of accounts of the distress and isolation felt by participants, which included accounts of self-injury and suicide attempts. Furthermore, while participants were keen to meet other LGBT people, their support staff often did not see this as their role. The researchers concluded that the mental, emotional and sexual health of people with intellectual disabilities who are LGBT was being failed by services who were not meeting their needs (Abbott, 2015; Abbott & Burns, 2007; Abbott & Howarth, 2005).

A study in the Netherlands explored the lived experiences of 21 people with intellectual disabilites, 19 men and two women (Stoffelen, Kok, Hospers, & Curfs, 2013). The study is somewhat let down by the lack of any information on the methods of anyalsis and rather descriptive themes such as, 'support', 'family' and 'partner'. However, within these themes there are clear messages from people with intellectual disabilites about their sexual identity and the responses of others. Within the group, 10 of the men reported having been sexually abused, mostly in their youth, and a number described experiencing negative reactions from others due to their sexuality, from work colleagues, family members and members of the public. Participants who were in a couple (n=9) spoke mostly in a postive way about their relationships. Other participants desired more support with relationships, especially with seeking a partner. Some of the participants were older than in some of the other studies (20-62 years old; mean=40.5) and described being more comfortable in their sexuality than when they were younger, although many still hid their sexuality in many contexts.

In one of the most recent papers identified, Dinwoodie, Greenhill and Cookson (2016) explored how five LGBT people with intellectual disabilities experienced their sexual identities. Participants consisted of three men, one woman and one trans woman who had all received support from an LGBT specific NHS service. The researchers hoped to investigate if increasingly liberal attitudes towards homosexuality in the UK, demonstrated by legislative changes such as the Equality Act 2010 and the Marriage (Same Sex Couples) Act 2013, had had any effect on LGBT people with intellectual disabilities. Using IPA the researchers identified four main themes that included: common experiences of bullying and abuse, how participants understood their sexuality, how other responded to their sexuality and how they navigated acceptance from others. They identified that while participants generally accepted their sexuality, it was still regularly problematised by others.

The most recent study identified, used narrative analysis to investigate the experiences of LGBT people with intellectual disabilities who had attended an LGBT support group within a secure inpatient setting (Tallentire et al., 2016).

They used a participatory approach where all participants were co-researchers and were invited to take part in the analysis and dissemination of the research. They had a total of 18 co-researchers (17 men and one woman), of which nine were individually interviewed, eight contributed written information and one participant took part in the analysis only. The research showed that the LGBT group supported members with their sexual identity development, helped to improve self-esteem and gave participants a sense of purpose in their lives which helped with their recovery. The research was conducted in a very particular context, almost solely with men and in a secure setting; however, it showed the positive outcomes of an LGBT support group and the importance of those who attended being able to identify with other LGBT people with intellectual disabilities.

1.8.1. Experience of Discrimination

A striking commonality between the studies was the inclusion of themes or accounts of participants' experiences of discrimination and abuse. In a number of studies all of the participants had experienced bullying or discrimination related to their sexuality and/or disability (Bennett & Coyle, 2007; Dinwoodie et al., 2016). While in a number of the other studies the vast majority of participants had experienced discrimination, abuse and name-calling (Abbott & Burns, 2007; Stoffelen et al., 2013; Tallentire et al., 2016). For example, a total of 19 out of 20 participants in Abbot and Howarth's (2005) study had experienced discrimination or harassment due to their sexuality, including from their family, members of staff or from strangers in the street. Incidents across the studies included participants being told they could not bring a partner back to where they lived (Abbott & Howarth, 2005), experiencing verbal abuse in the community, "…I walk down the street and they say 'You're a fucking queer' " (Bennett & Coyle, 2007, p. 134), to physical threats and violence, "people throw coffee in my face" (Dinwoodie et al., 2016, p. 4).

1.8.2. Sexual Identity Formation and Sexuality Labels

Participants in Dinwoodie et al. (2016) had quite clear ideas about their sexuality and used sexual identity labels such as 'lesbian' or 'gay'; they described non-heterosexuality as personally conventional for them and

described knowing that they were attracted to the same-sex from a young age (Dinwoodie et al., 2016). Participants familiarity and relative comfort with their sexual identity was also found in a number of the other studies (Abbott & Burns, 2007; Bennett & Coyle, 2007; Stoffelen et al., 2013). However, despite the sense of having a clear sexual identity, some of the participants described a sense of powerlessness and vulnerability in their gay identity which caused them to try to hide it or 'act straight' (Dinwoodie et al., 2016; Stoffelen et al., 2013). Other research into LGBT support groups for people with intellectual disabilities identified initial difficulty with using identity labels or talking openly about their sexuality, which was helped by attending the group (Tallentire et al., 2016; Withers et al., 2001)

1.8.3. Reluctance to Come Out

Abbott and Burns (2007) identified a theme across participants responses which indicated that people with intellectual disabilites were reluctant to come out due to fear of the consequences. They highlight that this fear is regularly shared by many non-disabled LGB people who fear rejection or discrimination when revealing their sexuality. However, the fears for people with intellectual disabilities seemed to hold additional negative consequences, with people believing they could be denied access to services they receive or be forced to move; "You might even get dropped from the centre altogether"(Mark; Abbott & Burns, 2007, p.33). Other studies also found similar difficulties with coming out, caused by fear, internalised heterosexism and participants feeling the need to continue to conceal their sexuality (Dinwoodie et al., 2016; Withers et al., 2001). Futhermore, when they did come out, some of the participants experienced people not believing them or trying to persuade them that were actually heterosexual:

> "My mum says, "You're gay? You don't know what it is to be gay. You don't understand. You're not gay, you don't know what you are talking about…"." (Ann; Abbott & Burns, 2007, p.32).

1.8.4. Restrictions

A number of studies highlighted that restrictions, lack of privacy and denial of their rights for people with intellectual disabilities made romantic or sexual

relationships very difficult (Bennett & Coyle, 2007; Stoffelen et al., 2013). Some participants described a lack of privacy created by their living environment, which meant they felt unable to have any romantic or sexual relationships in their home (Bennett & Coyle, 2007). While others spoke of being actively denied the opportunity to bring a partner back or rules forbidding sex put in place by staff or institutions (Abbott & Burns, 2007; Stoffelen et al., 2013). Similarly, in a study exploring the sexual health of 10 LGBT young people with intellectual disabilities in Canada, the researchers found many young people faced restrictive practices, which meant that they were engaging in high risk sexual activities; as one participant articulated: "if the group home isn't going to let you have sex in the group home, you are probably going to have sex outside" (McClelland et al., 2012, p. 815). People with intellectual disabilities have been regularly shown to live in a state of perpetual or suspended adolescence where their sexuality has not been recognised and they have been forced to hide any romantic or sexual relations (Fitzgerald et al., 2013).

1.8.5. Relationships and Love

Stofflen et al. (2013) found that out of 21 participants, nine people (all men) were in a long-term relationship and nine participants (including seven men and two women) were single but indicated that finding a partner was important to them. Abbot and Burns (2007) also reported that love was a central theme of participants who had spoken frequently of their desire to love and be in a relationship, although only a small number of them were. While Bennett and Coyle (2007) identified that all the men in their research wanted a wider network of gay friends. Interestingly, while Stofflen et al. (2013) and Abbot and Burns (2007) identified love as highly imporant to participants, the other four studies made little mention of it.

1.8.6. Support and Support Groups

A number of studies identfied gaps in support for LGBT people with intellectual disabilities, while a few demonstrated support which had been appreciated. Some LGBT people with intellectual disabilities expressed the wish that staff were more supportive of their sexuality and wanted more support to find friends and partners (Abbott & Burns, 2007; McCann et al., 2016; Stoffelen et al.,

2013).   Support from LGBT staff who were open about their sexuality was valued by participants in the Netherlands, who said it made it easier for them to discuss issues related to their own sexuality (Stoffelen et al., 2013). Research from LGBT support groups for people with intellectual disabilities demonstrated that these groups were highly valued and enabled participants to be more confident in their sexual identities "…because I'm gay, I like going, I'm going to the group to bring it up, it's coming out who you really are" (Tallentire et al., 2016, p. 9). Although this research has been predominently with gay men with intellectual disabilities, including just one female participant (Tallentire et al., 2016), a non-empirical review of another LGBT group has identified that a female only event had been very well received (Elderton & Jones, 2011). Five female members of the LGBT support group had requested an event or group solely for women and for two young women this was the first time they had met another gay woman (Elderton & Jones, 2011).

1.8.7. Summary

As can be seen, although the research base is slowly widening, there is still a limited body of research conducted directly with people with an intellectual disability who express a non-heterosexual identity. Accounts from LGBT people with intellectual disabilities have shown that they have regularly been victims of homophobia and discrimination, felt isolated and wanted staff to be more supportive of their sexuality and with finding relationships. They also reported being fearful of the consequences of coming out and recounted the many restrictions on their lives that can make relationships more difficult. Nevertheless, participants also spoke of the importance of love and relationships and the positives of being able to identify with other LGBT people. The near complete absence of women from this research, however, is evident and needs further exploration.

1.9 The Absence of Women

1.9.1. Paucity of Research with LGBT Women with Intellectual Disabilities

A striking find from the literature is that LGB women with intellectual disabilities are almost entirely absent from research; either featuring in very small numbers (Dinwoodie et al., 2016; Elderton, Clarke, Jones, & Stacey, 2014; Stoffelen et al., 2013; Tallentire et al., 2016), or not at all (Bennett & Coyle, 2007; Cambridge, 1996; Withers et al., 2001). Nearly two decades ago, McCarthy (1999) found that lesbian sexuality was one of the least researched and least understood forms of sexual expression for women with intellectual disabilities and to-date that situation has not changed.

Finding lesbian and bisexual women with intellectual disabilities in research and clinical work has been reported to be difficult. Abbot and Howarth (2005) stated that, whereas they found gay men with intellectual disabilities quite easily, they "struggled to find nine lesbian or bisexual women with learning difficulties across the whole of the UK" (p.x). Similarly, McCarthy (1999) reported that out of approximately 70 women with intellectual disabilities she supported with sex education, only one woman talked about having feelings for other women.

There is no obvious reason to assume that women with intellectual disabilities would be attracted to women in different proportions to the general population (McCarthy, 1999). Thus, there is a large gap in our current knowledge as to why so few LGB women with intellectual disabilities have presented both in research and clinically and remain such a hidden and invisible population. Within the little research that has included women, it is hard to identify their particular voices and concerns due to their marginal position in the research; nevertheless an attempt will be made to do so below.

1.9.2. Research Findings with LGBT Women with Intellectual Disabilities

The largest sample of women within the identified studies was the Norah Fry research project which involved nine LGBT women with intellectual disabilites (Abbott & Burns, 2007; Abbott & Howarth, 2005). However, because the themes were combined with the 11 male participants, who were still the

majority, it is difficult to isolate the findings which were particularly pertinent for the LGBT women in the study. Indeed, although the authors themselves highlighted the relative invisibility of lesbian women with intellectual disabilities and how difficult recruiting women had been, they missed the opportunity to explore this gender difference further and to think about what might have differed in the womens accounts.

Furthermore, some of the research has been so dominated by men that the voices and themes of women were almost entirely absent in the findings. For example, in Stoffelen, Kok, Hospers and Curf's (2013) study in the Netherlands there were 19 men and two women. Within the results there was a large theme identified about current and past sexual experiences, including relationships and HIV prevention; however, the authors note at the end that the two female participants were reported to have had no sexual experiences. Furthermore, in the research conducted by Tallentire et al. (2016) it is not even made clear what role the one female participant played in the research, whether she was one of the nine co-researchers who were interviewed or whether she acted just in the analysis stage.

One of the most recent studies of the experiences of LGBT people with intellectual disabilities had just one female participant, Alice, who identified as lesbian, and one trans female, Jennifer, who identified as bisexual (Dinwoodie et al., 2016). Within this research it was also hard to identify particular themes that were more pertinent or particularly relevant to the female participants due to their very low numbers. The lesbian participant was identified to have spoken about experiencing abuse less than the other participants, perhaps highlighting that the more extreme incidences of discrimination, including physical violence and threats, were more regularly geared towards gay men or trans people with intellectual disabilities. The authors reported also that clothing was seen to be important in how Alice and Jennifer expressed their sexuality (Dinwoodie et al., 2016).

One potential point to note from exploring the studies more closely, it appears that some of the women in the research might have been some of the most isolated individuals interviewed (Abbott & Burns, 2007; Dinwoodie et al., 2016).

In Abbott and Burns (2007) study, some of the female participants talked about not knowing any other lesbian women: "Nobody to talk to and that's what hurts the most." (p.33). Similarly, in Dinwoodie et al. (2016), Alice spoke about her isolation and being the only gay person at the intellectual disability service she attended where she felt "a bit out of it" when others talked about relationships and at the service's speed dating event (Dinwoodie et al., 2016, p. 8). However, it is not possible to corroborate this idea as the numbers of women were either so low, or the researchers themselves did not note what particular gender differences there may have been between LGBT men and women with intellectual disabilities in the research.

1.10 Research Methodologies

A majority of studies in this area, with people with intellectual disabilities who identity as LGBT, have involved traditional research methods in which researcher-participant power dynamics restrict participants to answering the questions posed by the researcher. Indeed, only one of the studies identified used a participatory and inclusive approach in the research and this included just one female co-researcher (Tallentire et al., 2016). This is disappointing for such a marginalised group, where greater participation could help to re-balance the power differential in research. Participatory approaches to research typically involve more meaningful participation and influence by people with intellectual disabilities than traditional research methods (Turnbull, Friesen, & Ramirez, 1998); people with intellectual disabilities are involved as more than research subjects but as partners who are actively engaged in some or all of the research process (Povee, Bishop, & Roberts, 2014). Indeed, proponents of participatory and inclusive research argue that it is collaborative, empowering and especially needed in research with minority groups (Turnbull et al., 1998; Walmsley & Johnson, 2003). Thus, a number of authors have argued that more research with people with intellectual disabilities should take a participatory and inclusive approach (Knox, Mok, & Parmenter, 2000; Marshall et al., 2012; Povee et al., 2014).

Furthermore, perhaps due to the methodologies adopted in research with LGBT people with intellectual disabilities to date, there has often remained a central focus on the negative aspects of people's experiences and the difficulties with expressing a lesbian, gay or bisexual identity, rather than the strengths or resilience of this marginalised group. Although research explored some aspects of love, relationships and good support, there has been less focus on where LGB people with intellectual disabilities have felt included and supported in their sexual identity. Therefore, knowledge about what helps and supports people with intellectual disabilities to develop positive sexual identities is still very limited.

1.11 Summary and Rationale for the Research

People with intellectual disabilities have been marginalised and dehumanised throughout history, and continue to face a wide range of compounding social inequalities today. Indeed, research shows that people with intellectual disabilities are some of the most socially excluded people in society; they are more likely to live in poverty than their non-disabled peers, are at greater risk of social exclusion, more likely to have poorer health and more likely to experience mental health problems or distress (Department of Health, 2009; Emerson & Hatton, 2008).

Individuals who identify as LGBT are also more likely to experience mental health problems, including depression, anxiety and psychosis and are more likely to self-harm, abuse substances and to think about or attempt suicide (King et al., 2008); which a number of theorists have attributed to the effects of 'layered stigma' or 'minority stress' on LGBT people, caused by bullying, homophobia, rejection and internalisation of discrimination (Meyer, 2013).

People with intellectual disabilities who hold both of these stigmatised positions have been shown to suffer the consequences of oppression and marginalisation (Dinwoodie et al., 2016). Research with LGBT people with intellectual disabilities has shown that they are often isolated and marginalised from the LGBT community, suffer discrimination due to both their disability and sexuality,

and regularly lack support and acceptance of their sexuality. While western societies have shown increased acceptance of same-sex relationships, demonstrated by legislative changes such as marriage equality for LGBT couples; thus far, these changes seem to have done little to support the acceptance of people with intellectual disabilities who express a non-heterosexual identity (Tallentire et al., 2016).

As has been demonstrated, there is a limited evidence base exploring the experiences of LGBT people with intellectual disabilities and there is a near absence of women within the research. The voices of LGB women with intellectual disabilities have been dwarfed by male voices and recognition of their potential different needs, wants and experiences have been ignored. This leaves LGB women with intellectual disabilities as a silent and hidden group in society.

This is problematic for a number of reasons, not least because research indicates that lesbian, gay and bisexual women with intellectual disabilities experiences are likely to be different to that of gay men with intellectual disabilities. Indeed, Clarke et al. (2010) warn of the potential pitfalls of assuming that LGBT people can be treated as one homogenous group, also known as the 'gender empty' model of same-sex relationships. Feminist scholars have for years argued that gender norms impact on all people; to ignore gender between lesbians and gay men is to ignore that within LGBT spaces men's voices regularly supersede those of women (Clarke et al., 2010; Humphrey, 2000).

Women might be additionally disadvantaged in expressing their sexuality compared to gay men with intellectual disabilities, or at the very least, differently disadvantaged. Indeed, the intersection of gender, disability and sexuality needs to be considered. Within society women with intellectual disabilities have regularly been positioned as asexual 'perpetual children' who are without gender. Research is needed to explore the experiences of women who challenge this idea, women whose overlapping marginalisation also includes non-heterosexuality and being labelled as intellectually disabled.

With so few women with intellectual disabilities understood to be lesbian or bisexual, it must be assumed that a large majority never accept or express their sexuality. Hiding a core aspect of personal identity or never developing a positive sense of self, might create a number of personal or inter-relational difficulties. Indeed, research in the general population has shown that not being able to express your sexuality in a positive way can lead to emotional, physical and mental health problems (Herek & Garnets, 2007). Such individuals can be seen to live a kind of 'half life', never having accepted a complete or 'full' sense of themselves (Abbott & Burns, 2007; Pachankis, 2007). For people with intellectual disabilities, who might have additional communication and support needs, such experiences and negative perceptions of the self may be internalised, and contribute to the high rates of mental health problems noted amongst people with intellectual disabilities; or alternatively might be expressed outwardly as challenging behaviour, which similarly is well documented in this population (Butler, 2012).

Currently support services, psychologists and other health professionals are not doing enough to support the needs of women with intellectual disabilities who identify as LGB. To further the rights of people with intellectual disabilities who identify as non-heterosexual, or those who are questioning their sexual orientation, more awareness is needed of the experiences of individuals and the approaches that might be able to support people personally and systemically. Indeed, it is hoped that this research will reveal what clinical psychologists and other clinicians need to do to better to support LGB women with intellectual disabilities; both on an individual and group basis, and also when thinking about changes needed within service models and the wider community. Unless we understand the needs and experiences of women with intellectual disabilities who are lesbian, gay and bisexual, little can be offered in the way of effective support.

1.11.1. Research Questions
This research sought to explore the specific needs and experiences of women with intellectual disabilities who are LGB. Particularly thinking about how lesbian, gay or bisexual women with intellectual disabilities experience,

understand and express their sexual identity. In doing so, through the use of semi-structured interviews and photovoice, it was hoped that new insight would be gained about the lives of this marginalised and hidden group in society. The research questions were:

- How do LBG women with intellectual disabilities describe and experience their sexual identity and how does this influence their sense of self?
- Where do women with intellectual disabilities who are lesbian or bisexual feel included and excluded in society and what impact does this have on their identity?
- What psycho-social support have women with intellectual disabilities found helpful in their expression of same-sex attraction?

2. METHODOLOGY

2.1 Chapter Overview

In this section, I will outline the epistemological stance and design of the research. The recruitment, interview and analysis procedures will be explained, including the theoretical approach taken to these stages. I will also provide details of the participant demographics and consider my own role within the research.

2.2 Epistemological Position

Epistemology is a branch of philosophy occupied with the theory of knowledge, it considers "the nature of knowledge and the methods of obtaining it" (Burr, 2003, p. 202). Willig (2013) purports that there are three main epistemological frameworks within qualitative research: realism, phenomenology and social constructionism. Realist research assumes that there is a real world to investigate and report, social constructionism is generally more relativist and would question this assumption of knowledge, focusing instead on how knowledge is derived and 'constructed' through social processes, and phenomenology is concerned with the subjective experience of participants, rather than the structures which give rise to their experiences (Willig, 2013).

This research was undertaken from a critical-realist position, which can be seen to lie somewhere in the middle of the realism-relativism continuum (Harper, 2012). Similar to relativism, it purports that the way things are perceived depends upon subjective beliefs and explanations (Madill, Jordan, & Shirley, 2000). Indeed, critical realism has much in common with constructionist positions because of this acceptance of subjectivity in the production of knowledge (Madill et al., 2000; Willig, 2013). However, critical realism also retains elements of a realist position in the acknowledgement of embodied reality and subjective experience. In this sense, taking a critical realist position

can be understood as being ontologically realist but epistemologically relativist (Harper, 2012).

Willig (2013) argues that a realist approach can be most valuable when the research aims to try to 'give voice' to a marginalised group in society by assuming that what participants tell the researcher about their experiences "reflects a social reality which needs to be exposed, acknowledged and understood" (p.16).   However, a naive realist view would ignore the role of the researcher in 'giving voice'; overlooking the selection and editing of the particular narratives chosen (Braun & Clarke, 2006). Thus, while the material realities of participants are acknowledged, a critical realist position also acknowledges that the beliefs and perspectives of the researcher and participants have an impact on the data gathered and are situated in a specific context and time.

Radical social constructionism, which is more resolutely relativist, has been criticised for leading to moral relativism, due to the inability to distinguish between any number of multiple perspectives. It's also been criticised for being too pre-occupied with discourse with inadequate focus on the material and physical aspects of individual experience such as embodiment. Taking disability as an example, the social model of disability (Oliver, 1996) takes a social constructionist approach to disability, which was hugely influential in critiquing the biological reductionism of the medical model of disability; instead arguing that disability is a consequence of societal barriers and oppression. However, the social model of disability has been criticised for ignoring the embodied experience of living with impairment for people with disabilities, which cannot be accounted for by societal barriers alone. Thus, critics, such as Shakespeare (2013), argue for a critical realist understanding of disability which is able to account for the complex experience of disability which takes into account disabling factors produced by social structures and the lived experience of impairment.

Consequently, a critical realist position is taken in this research which, similar to weak constructionism, assumes that how people engage with a particular issue is socially constructed, but that the issue does have a material basis and pertain

to the real world (Joffe, 2012). For instance, while the constructions of sexuality and intellectual disability are acknowledged, there is an understanding that occupying such a position within a particular sociocultural context, and being exposed to, for instance, oppression and sexual minority stigma, pertains to a real experience which can be investigated and explored (Willig, 2013).

2.3 Recruitment

2.3.1 Recruitment Method

Participants were recruited by publicising the research as widely as possible through support organisations. The researcher contacted third sector and charity organisations; both organisations designed to support people with intellectual disabilities, such as advocacy groups, charities and support providers, and also organisations focused on supporting and advocating for LGBT people, such as LGBT charities and local support services. The organisations contacted ranged from large national charities to small local LGBT groups and intellectual disability support providers. Contact was made primarily via email which contained the study information, research flier and information sheet (Appendices 3-5). But the researcher also contacted a large number of organisations by telephone, to either follow up the email contact or to find out who best to send the information to. A number of organisations agreed to send the information onto other contacts or email distribution lists and some of them also shared the research information on their social media platforms.

The researcher also attended some venues to explain and publicise the research directly, this included a networking group for staff supporting people with relationships, an LGBT disability support group and a community group for women with intellectual disabilities. Furthermore, the researcher also video-called an LGBT support group for people with intellectual disabilities who had been interested to find out more about the research.

One of the participants was recruited via contact with the researcher at a group; whereas in other instances, a contact person, such as a member of staff or family member, identified a potential participant and informed them of the

research using the information sheet (Appendix 5). The contact person then let the researcher know if the person was potentially interested in taking part. For some participants correspondence continued through this contact person, whereas, in other instances participants gave permission for the researcher to contact them directly.

2.3.2 Inclusion and Exclusion Criteria

The inclusion criteria for this study included that participants were over 18 and identified as female. They had a diagnosed intellectual disability, demonstrated either through an assessment report or through the receipt of support from a health and social care team for people with intellectual disabilities (teams which requires individuals to have an intellectual disability before offering support). Participants either identified as gay, lesbian or bisexual, or have had, or would like, a same-sex relationship. The participants also needed to be English speaking and have sufficient verbal communication to enable them to talk about their experiences, which effectively meant that they presented with mild to moderate intellectual disabilities.

This research focused specifically on the experiences related to a non-heterosexual identity for women with intellectual disabilities; therefore, it was inclusive of trans women with intellectual disabilities who also identified as lesbian or bisexual but did not set out to explore the specific experiences of gender identity on its own. Indeed, very often researchers have included trans by using the label LGBT, but have then failed to address the specific experiences of trans people and how they might differ to the experiences of LGB people (Clarke et al., 2010). By being clear from the outset it was hoped that any trans LGB women would feel able to take part in this research but that the study would remain focused on the aim to explore sexuality and non-heterosexual identities specifically. In practice, no LGB trans women with intellectual disabilities were identified to take part in the research.

2.3.3 Recruitment Difficulties

As recruitment of non-heterosexual women with intellectual disabilities had been identified to be difficult in previous research studies (Abbott & Howarth,

2005), it was hypothesised that it may be difficult in this research also. However, there was also some optimism at finding LGBT women with intellectual disabilities because the researcher had a number of contacts within intellectual disability organisations and was based in the busy capital of London. It was also thought that there might potentially be more women with intellectual disabilities who might be openly gay than had been identified in past research. For instance, Abbott and Howarth's (2005) research project took place more than a decade ago and much had changed in the socio-political landscape of the UK since that time, including equal marriage legislation and increasing representation of non-heterosexual individuals in advertising and the media (Nölke, 2018).

However, recruitment did prove to be extremely difficult and took over eight months. Over that time the researcher had contacted over 200 provider organisations and charities. Many organisations were very positive about the research but explained that they knew no women with intellectual disabilities who were openly LGBT, some organisations also expressed that this was an area that they felt more support was needed, while other organisations did not respond to the researcher's enquiries.

There was a point in the research when the project was in jeopardy of being abandoned or completely redirected because recruitment was proving to be so difficult. Indeed, the researcher and research supervisor discussed the possibility of broadening the focus to include gay men with intellectual disabilities as a number of the contacts during recruitment said they knew men who might be interested in taking part. However, as this was a large change to research aim, to explore specifically the experiences of women, any changes to the research aims and questions were delayed as long as possible. Eventually, when the first participants were identified, they were spread over a large geographical region and so the researcher submitted an amendment to the UEL Ethics Board to get approval to also conduct interviews via video-call (using Skype) if needed. After approval was granted, slowly participants were identified and the study was able to go ahead. However, this method of recruiting and communication through partner organisations and individuals required substantial investment of time from the researcher.

<u>2.3.4 Participant Demographics</u>

Six women participated in the study and their ages ranged from 26 to 40 years old (with a mean age of 33). Participants were all white British and lived in various locations across the UK (see Table 1).

Table 1: Participant demographics information

Participant*	Age	Geographical region	Living situation
Heather	40	Norfolk	Independent
Sofie	28	West Sussex	Living with family
Alex	26	Derbyshire	Living with family
Louise	36	Lancashire	Supported accommodation
Sharon	39	Lancashire	Supported accommodation
Cora	27	London	Supported accommodation

* All names are pseudonyms

All six women self-identified as lesbian or bisexual, or were in a same-sex relationship and were 'out' to key people in their lives. Four out of six of the women were in a relationship. Two of the women were in a relationship with each other and chose to be interviewed together. All participants were offered to have someone accompany them in their interview if they wished to. Four of the participants chose for someone else to be present and the supporter was informed not to participate in the interview.

2.4 Interview Process

Data was collected via two separate interviews, a semi-structured individual interview which all participants took part in (2 chose to be interviewed together) and an additional individual photovoice interview which four women participated in (see Appendices 6.1 and 6.2 for interview schedules). There were nine interviews in total, which lasted between 50 - 65 minutes for the first interview and 31- 51 minutes for the photovoice interview (totalling 7.5 hours). The interviews were conducted either in person or via Skype (video-call) and were

audio recorded. Face-to-face interviews were conducted in meeting rooms in locations familiar to the participant; in both cases this was in an office of the support organisation through which the participant had heard about the research. Skype interviews were conducted via computer in a space that was private and free from interruptions; two of these were in the participant's home and one was in the office of the support organisation.

2.5 Photovoice

2.5.1. Photovoice: An Example of Participatory, Inclusive Research

Photovoice, as first outlined by Wang and Burris (1997), is a method of participatory research which seeks to move away from participants in research being limited to 'subjects' but, instead, enables them to share expertise and knowledge.   Photovoice uses photography to engage participants in the research process by asking them to take photographs that illustrate the research topic. The photographs can then be incorporated into the research in a variety of ways, including group discussions or as a basis for individual interviews. It enables the perspective of participants to be heard more authentically and effectively through the photographs they choose and it has since been used with a variety of marginalised and underrepresented groups (Schleien, Brake, Miller, & Walton, 2013).

2.5.2. Photovoice with People with Intellectual Disabilities

Within intellectual disability research the number of studies which have adopted photovoice methodologies is very limited; however, the few studies which have adopted this approach have shown a number of benefits (Booth & Booth, 2003; Jurkowski, 2008; Povee et al., 2014; Schleien et al., 2013). For example, Booth and Booth (2003) used photovoice with mothers who had intellectual disabilities in which they took photographs of what they considered to be most important. The use of photovoice enabled their lives to be talked about and documented in an entirely different way to a traditional research interview and challenged prejudiced views of the women as 'different' mums (Booth & Booth, 2003).

Jurkowski (2008) described some of the benefits of photovoice as including the ability to obtain data from the homes and lived experiences of people with intellectual disabilities. Similarly Povee, Bishop and Roberts (2014) argued that:

> "By placing a camera directly in the hands of people with intellectual disabilities, the researcher is able to gain a unique insight into their viewpoints and social realities, resulting in research that more accurately represents their experiences" (p. 905)

Photovoice enables active participation in the research process and the photographic method itself has been seen to foster pride and confidence in participants (Jurkowski, 2008).

There is no known research to-date that uses photovoice to explore the sexual identities of people with intellectual disabilities. Although it has been used effectively to explore sexuality and intimacy with people with physical disabilities in South Africa (Hunt, Braathen, Swartz, Carew, & Rohleder, 2018). In using photovoice as part of this research it was hoped that it would provide a flexible and creative basis for investigating participants experiences, which would enable the exploration not just of difficulties but also of the strengths of LGB women with intellectual disabilities.

2.5.3. Photovoice Procedure

At the end of the initial interview, the photovoice interview procedure was again explained to participants and they were offered the choice to take part. All of the women were keen to participate, however, lack of staff support meant that unfortunately two of the participants were unable to take part, as they needed support from staff to arrange the second Skype interview. Therefore, four women participated and were invited to take pictures which:

- Showed where they felt included
- Showed where they felt excluded
- Connected to them being lesbian, gay or bisexual

The first participant who wished to take part in the photovoice interview asked whether she could use pictures that she already had. The intention was for the photographs to be the choice and control of participants, so it was agreed that they could be either new pictures or ones already taken. This was also explained to all subsequent participants and all of the women chose to use photographs which they already had. Thus a photo-elicitation method was utilised, focusing on existing images, rather than one of photo-production (Reavey, 2011). Then, after a short period, participants were interviewed again using their photos as the basis of the discussion (see Appendix 6.2 for the photovoice interview schedule). Furthermore, the photographs were also used in the analysis stage, as described below in section 2.7.3.

2.6 Ethical Considerations

Willig (2013) outlines five main ethical considerations which need to be thought about within qualitative research: informed consent, no deception, right to withdraw, debriefing and confidentiality. This study had no deception, with the aims and methods being thoroughly transparent. Each of the other areas will be addressed below.

2.6.1. Capacity and Consent

According to the principles outlined in Section 1 of the Mental Capacity Act 2005 (MCA) an individual must be assumed to have capacity unless it is established otherwise. Section 3 of the MCA (2005) states that a person is unable to make a decision if they are unable to do the following:

- understand the information relevant to the decision
- retain the information
- use or weigh the information as part of the process of making the decision
- communicate the decision (whether by talking, using sign language or any other means).

As described above, the majority of participants were put in touch with the research through a supporter, someone who felt that they had the capacity to consent to take part. This person explained the study to the individual prior to contact from the researcher. At the start of the interviews, the accessible easy-read information sheet about the study was presented to participants and verbally explained (Appendix 5). In the process of gaining consent and in order to ascertain what the participant had understood the researcher had a short conversation with each participant, asking them to repeat back what the research was about and gave them the opportunity to ask any questions. By having a conversation with each participant in this way, the researcher was able to check the four areas identified in the MCA (outlined above); if the researcher had any doubt about a person's capacity to consent then they would have not been invited to participate further.

Of the six participants, however, there were no concerns raised about their capacity to consent. Once a person consented to taking part in the research verbally, they were asked also to sign a consent form (Appendix 7). However, it was also understood that consent is a continual process which involves on-going communication between the researcher and participants (Hughes & Castro Romero, 2015). During interviews and interactions with participants the researcher continued to monitor participant responses and behaviour and gave participants a number of opportunities to state their continued wish to participate in the research or to withdraw.

In addition, consent was also gained from participants after the photovoice interviews about the possible use of the photographs in the write-up of the research. Using an accessible photo consent form (Appendix 8) it was explained that participants did not need to agree to photograph use and that declining would not affect them in any way. It was also explained that, if they were happy to include their pictures, then they could choose which ones and anyone else depicted in the photographs would also need to consent to being included.

2.6.2. Confidentiality

It was explained to participants that their interview was confidential unless they disclosed that they, or someone they knew, were at risk of harm. In such an occurrence, confidentiality would be broken in order to follow safeguarding procedures. This was also explained in the information sheet. However, there were no issues raised during the interviews which gave the interviewer concerns that there were any immediate risks to participants and a need to break confidentiality.

2.6.3. Right to Withdraw

The information sheet was given to participants in advance of the interview and discussed again at the start of the interview. This explained to participants that they could stop at any time in the interview and choose to withdraw (Appendix 5). Indeed, participants were free to withdraw from the research up until three weeks after the interview had taken place and were informed that any decision to decline participation would not affect them in anyway. It was also reiterated that they did not have to answer questions if they did not want to and they could take a break at any time. There were opportunities for any questions or clarification throughout the research process. During the interviews, two participants chose to have a short break, but no participants became distressed or chose to withdraw.

2.6.4. Debriefing

After the interview, all participants were asked about the process of the interview and had the opportunity to reflect on the how they felt taking part, included a focus on their well-being. The researcher also had a written list of local services to offer participants if needed following the interview. Participants were also asked if they would like to be contacted with results from the research once the study was completed and all were keen to be contacted.

2.6.5. Ethical Approval

Ethical approval was sought for and granted by the University of East London, School of Psychology Research Ethics Sub-committee. Initially the approval

was granted with minor amendments that were responded to by the researcher and subsequently approved (Appendices 9.1-9.3). There was also an amendment to the research process requested, as described above, which added interviews via video calling and the option for organisations to publicise the research on social media; the request was approved (see Appendix 9.4).

2.7 Data Analysis

2.7.1. Transcription

The author transcribed all the audio recordings verbatim, using a transcription framework similar to that advocated by Parker (2005; see Appendix 10 for a table of transcription conventions). Transcriptions were then checked for accuracy by reading them together with the audio recordings and making any corrections. At this point the researcher also started to make brief notes in the margin of the transcript of initial areas of interest; beginning the first stage of analysis, which involved a familiarisation with the data (Bruan, Clarke, & Terry, 2015).

2.7.2. Thematic Analysis

Thematic analysis is a flexible and adaptable method used to analyse qualitative data which recognises and organises data into patterns of meaning (Braun & Clarke, 2006). Inductive thematic analysis offered a good fit with both the research aims, the epistemological position and the methodology of this research and was therefore utilised in analysing the interview data.

The approach taken to the data was inductive, so that the identification of codes and themes was done in a 'bottom up' way, rather than being driven by pre-existing theoretical frameworks and interests (Braun & Clarke, 2006). Although, of course, the research cannot be completely free from the influence of the previous knowledge and approach of the researcher, so some elements of a deductive approach were possible (Joffe, 2012).

Another distinction usually made when using thematic analysis is whether themes were semantic (and explicit), located at the surface meaning of the data; or whether they were latent (and implicit), where the researcher has gone beyond the initial meaning to interpret what a participant has said (Braun & Clarke, 2006). Often a realist epistemology lends itself to more descriptive, semantic themes and constructionist research can be associated with more interpretative themes. However, often researchers draw on both types of theme and a critical realist position particularly lends itself to identifying themes which are both explicit and implicit (Joffe, 2012); consequently, within this research a combination of both semantic and latent themes were identified.

The following stages outline the process used to analyse the interview data, as suggested by Braun and Clarke (2006):

Phase one: Familiarisation with the data
As described above, the interviews were transcribed and checked for accuracy. They were then read and re-read to help familiarisation and initial ideas were typed in the margin.

Phase two: Generation of initial codes
According to Braun, Clarke and Terry (2015) a code is "a succinct label (a word or a short phrase) that captures a key analytical idea in the data and conveys this to the researcher" (p.100). A good code is said to be one that conveys the main idea in the data without having to look at the data itself. The coding phase was conducted on a qualitative software package, NVivo (version 11). Transcripts were uploaded into NVivo and the researcher went through each transcript individually to generate initial codes. An example transcript with codes and the initial list of codes can be found in Appendices 11-12. As coding progresses across the data new ideas develop, therefore, to ensure consistency between earlier data items and later ones, coding was repeated across the all the data again an additional time.

Phase three: Search for themes
Once the entire interview data had been coded, each code had a table of related data extracts (see Appendix 13 for example of grouped extracts).

Codes were then clustered into groups to begin to start identifying relationships between them and possible themes. Here, a theme is understood to hold a broader level of meaning than a code and should have a "central organising concept" or idea which underpins the theme (Bruan et al., 2015, p. 102). Thus, once a potential theme was identified all of the related codes were grouped together on NVivo and checked for internal consistency within the theme.

Phase four: Review of themes

This phase focused on reviewing and refining themes. Each theme was studied to check that it had enough data to support it and related to the research questions. In this process some themes altered slightly or merged together. Here, a thematic map and thematic table was helpful to see the relationship between potential themes and sub themes visually (Appendices 14-15). The thematic map changed as the themes changed in a recursive and developing process. Furthermore, themes were discussed and reviewed with the research supervisor for a further check of validity.

Phase five: Define and name the themes

This stage provides a final check of the themes created by checking the clarity and essence of each theme. Then deciding on a name for each of the themes and subthemes which best represents the focus.

Phase six: Produce the report

Finally data extracts were chosen to present and analyse in the report. At which point the analysis needed to represent the data and its significance.

2.7.3. Thematic Analysis of Visual Data

As described above, thematic analysis provides a way to compare interview data and search for common themes. Moreover, thematic analysis has also been used to analyse visual data (Gleeson, 2011). Gleeson (2011) argued that thematic analysis is well suited to analysis of visual data as it can allow for firstly more descriptive analysis (semantic), before moving to further interpretation and latent meanings to explore patterns across visual images. This approach,

which she termed 'polytextual thematic analysis', looks to capture recurring patterns of form and content across images.

The process for analysing visual data followed the stages outlined below, as purported by Gleeson (2011):

- The images were looked at repeatedly, noting any features that evoked potential themes.
- Written descriptions of the effect of each image were collated.
- When a theme across images was identified, the relevant materials were collected together to see if the theme appeared distinct.
- Brief descriptions were created for each theme.
- All images were analysed again to see if themes were relevant in earlier images, revising the descriptions of themes as necessary, until no new themes emerged.
- Theme descriptions were checked to see that they were distinct and clear.
- Observations were made where themes began to cluster together into higher order themes.
- Higher order themes were defined and checked against each other. Judgements were made about which themes best address the research question(s) for write up.

The visual data was analysed mostly independently of the conversational data from the photovoice interviews (which was analysed together with the other interview data, as described in 2.7.2); however, where a participant spoke directly and particularly about a detail in a photograph or a specific feeling evoked by the image, then this data was also used to aide the analysis.

2.8 Researcher Reflexivity

Within qualitative research there is an acknowledgement that the researcher will influence and shape the research. Reflexivity is, therefore, important in encouraging researchers to "foreground, and reflect upon, the ways in which the

person of the researcher is implicated in the research and its findings" (Willig, 2013, p. 25).

A number of personal experiences were of relevance to this research. Prior to clinical doctorate training, I worked with adults with intellectual disabilities for over seven years and became very passionate about the rights of people with intellectual disabilities. I started this work in 2008 when Valuing People (Department of Health, 2001) was being responded to within services and then further influenced by Valuing People Now (2009). This was an exciting time of change in intellectual disability services, when the ideas of personalisation, choice and control and individualised care budgets were changing the way services were designed and the way the voices of people with intellectual disabilities was being responded to. I was aware from this clinical experience, however, that sex and relationships often eluded people with intellectual disabilities. I felt that people were regularly not supported in a proactive way to increase their social network and opportunities. I found it difficult to accept that a number of people with intellectual disabilities were within the community but remained isolated and reliant sometimes solely on paid members of staff.

Coming into this research I was, therefore, aware of my own value base and prior experience and how this might make me particularly receptive to certain issues, such as the rights of people with intellectual disabilities, and potentially the failings of services. By being aware of this potential bias within me, I had to be mindful to remain open to the experiences of the women I interviewed and not to make assumptions about their lives and experiences. I was aware of my own propensity to pick out the areas of peoples lives in which services were seen to be failing them or they were not receiving helpful responses from other people and wider society. For this reason, I had to ensure a focus also on what might have been helpful for individuals and where they felt most included and best supported.

Furthermore, I was aware of my own position as a self-identified gay woman. Here, I occupied an 'insider' perspective which could have aided the research in some ways, by being able to disclose this to participants and perhaps share some degree of common language or experience (Clarke et al., 2010). Pitman

(2002) described her own experience of being an 'insider' in LGB research, and felt that she "shared an understanding of oppression" with her participants (p.285). However, I was very aware that this position could also lead to potential bias, if I were to see things from my own perspective of understanding and assume too much in common with participants. Indeed, the experiences of LGB women with intellectual disabilities might have been more different than similar to my own experiences, in which case I was aware that I may not be viewed as an 'insider' at all.

In order to aid my personal reflexivity, throughout the research process, I kept a reflective diary (Appendix 16). This allowed me to continually reflect on these aspects of my identity alongside the research. I used the diary to remain curious about my own role within the research and the impact of my personal experiences on the way I interviewed women, how they responded to me and how I subsequently analysed the data.

3. RESULTS

3.1 Chapter Overview

This chapter will outline the main research findings using a thematic map and an exploration of the themes identified in both sets of data. Extracts from the interviews will be used to demonstrate and support the author's interpretations.

Brief interjections from the researcher have been omitted from these extracts to improve readability. Any information added for clarification is signified by square brackets and any words removed to reduce length is shown by the use of three ellipses in parentheses (…); where there was a short pause in speech three ellipses are used on their own "…". All names used are pseudonyms.

3.2 Thematic Map

During the analysis three main themes were identified in the data with subthemes under each, as demonstrated in Figure 2.
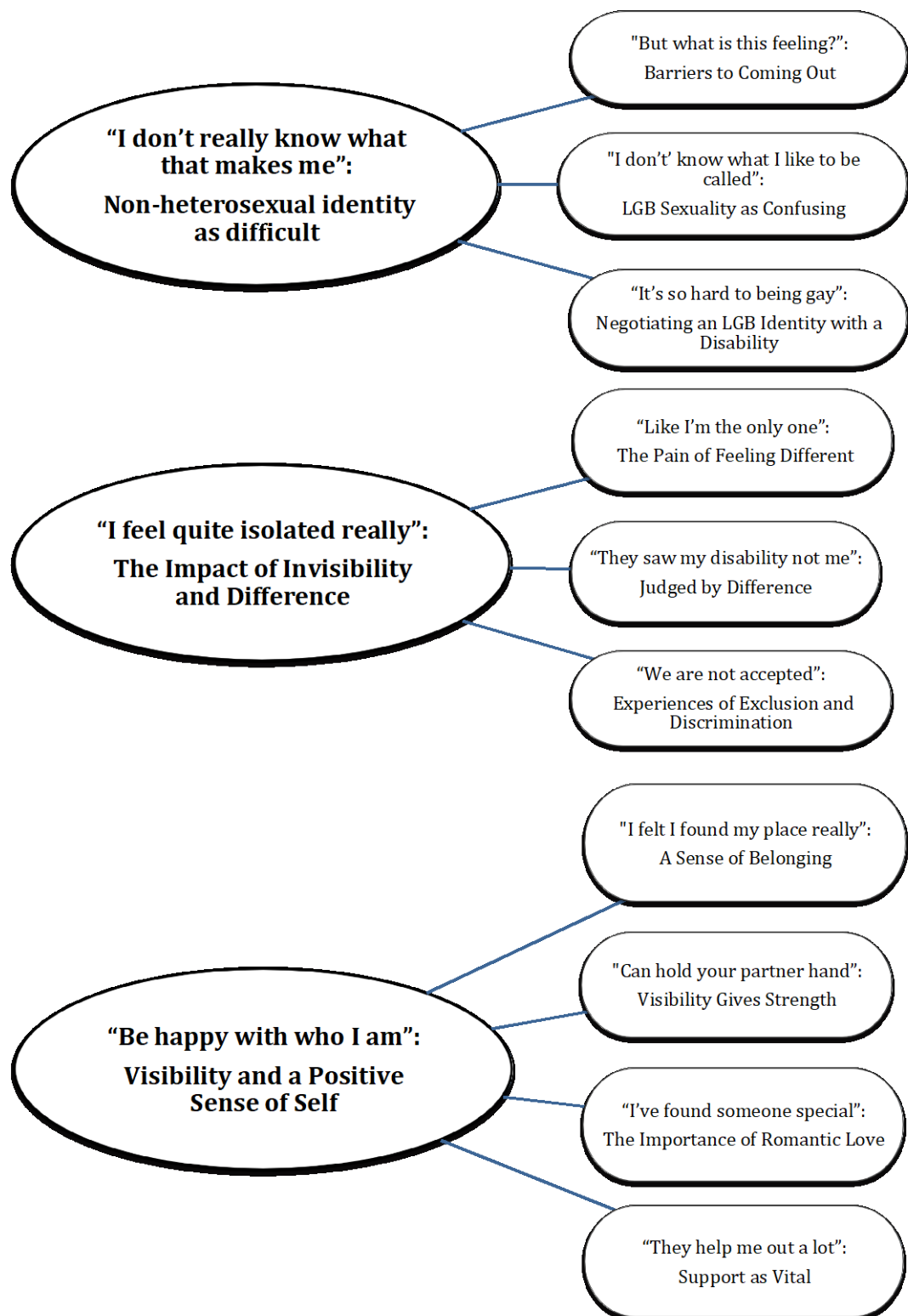
Figure 2. Thematic map

3.3 Theme One: "I don't really know what that makes me": Non-heterosexual identity as difficult

The first overarching theme identified in the interviews related to participants' descriptions of the challenges they faced due to their sexuality. As well as a general sense of things being difficult because they were non-heterosexual, "it's so hard to being gay" (Louise); participants spoke specifically about the difficulty of coming out to friends and family and alluded to a continued confusion over using LGBT identity terms and language to apply to themselves and confusion about their sexual identity.

3.3.1. "But what is this feeling?": Barriers to Coming Out

'Coming out' has been described as the process of disclosing one's sexual minority identity to self and others (Jhang, 2018). A number of the participants described the experience of coming out to those close to them as very difficult. This included a difficulty with voicing it to people in their lives, particularly their families.

> Louise: Well it is hard for me to tell my dad and my brother

> Sharon: It is hard with my mum and dad as well.

> Cora: I said I want to tell mum but I'm too scared to tell mum…

Of course LGB women with intellectual disabilities are not alone in the fear expressed in relation to 'outing' themselves to others. The coming out process can be emotionally difficult and a potential major life stressor. As is common, a fear articulated by some of the women, was a worry about the reactions that they would receive.

> Heather: I spent ages before I came out. I was terrified. Because I was thinking people wouldn't accept me and people would think I'm different. So yeah that took a very long time.

Cora: I think I was in my early twenties. I was a bit confused.

Interviewer: Mm. What was confusing?

Cora: Who I was. If I was ready to come out. I was a bit scared.

Heather, who 'came out' later in life, talked about the difficulty she experienced with talking to someone and needing to build up courage to do so. The first person she talked to was a female member of staff whom she knew identified as a lesbian, perhaps indicating the importance of having a shared sense of identity.

However, part of the difficulty of identifying as LGB also seemed to relate to being in an already de-valued social position. When Cora discussed first being attracted to a woman she linked the confusion she felt with also having an intellectual disability:

Cora: Mm it's hard if you have learning difficulties. That is quite hard.

Interviewer: Why is it hard?

Cora: Because you don't want to be judged people outside in the world …

Heather also spoke of worries about being judged and other negative reactions from paid care staff that can be in the powerful position of withdrawing or denying their support. She also describes a fear of not being believed by others, as she hypothesised about why other people with intellectual disabilities might also find coming out difficult.

Heather: It's hard for them to come out and sometimes there's loads of barriers in place for them. Like support, sometimes the support don't agree with it or they deny it. Or it could be they're not believed. It's just really difficult for some people to actually come out. They probably feel it inside but coming out is completely different.

Heather's concerns show that people with intellectual disabilities rarely feel in control of their own lives, so much so that even if they were to tell people about their sexuality, the legitimacy of their claim might be questioned, or might be completely negated as untrue. Which relates to her own experience from family members who questioned her sexual identity:

> Heather: They just said that it's like a phase.... Yeah it's just a phase, something I'm going through, but I don't think it was.

In describing her sexuality as "just a phase", the response of Heather's family can be seen to potentially silence her and dismiss her experience as trivial. This may be experienced as infantilising, because a phase is something (often unpleasant or childish) that is transient and seen to pass as a person grows or matures. Therefore, Heather is not perceived to have enough maturity or knowledge deemed needed to know her sexuality. The response she receives from others can also be seen to leave her with a continued sense of doubt, as she states that she does not "think" her sexuality was a phase, which most likely may come as a consequence of other statements of hers being challenged or discounted over the years.

3.3.2. "I don't' know what I like to be called": LGB Sexuality as Confusing

Five of the participants described being confused and unsure of the term to use to describe their sexuality or relationships. To some extent this could be explained perhaps by not feeling represented by any one sexual identity label, finding the concepts confusing, or a disinterest in being labelled:

> Cora: I don't know what I like to be called.

> Alex: I don't know, you have to put a label on it and that's really hard.

Alternatively, the quotes above could also indicate that participants do not experience themselves as having agency and/or control in defining their sexuality. Their uncertainty affected how they spoke about this aspect of their

lives, which seemed indistinct and inexplicit, and may be consistent with earlier stages of coming out models. It was unclear whom these women identified most strongly with and whether they had a firm understanding of whom they were attracted to or what they wanted from a relationship. Indeed, for some of the participants talking about this aspect of their identity seemed much less familiar.

Interviewer: …what would you call yourself? Would you say that you're lesbian, gay or bisexual or something else?

Alex: Something in the middle I think, I don't really know.

Heather: Well I'm sort of torn between lesbian and bi. I think I might be bi more than anything.

Interviewer: Okay

Heather: But I'm more interested in women than I am men.

Interviewer: Okay

Heather: I don't really know what that makes me. I'm just me.

Other participants seemed to struggle to attach language to their sexuality at all. For example, for Louise and Sharon, their sexuality was not understood in terms of LGBT language, but by being together as a couple. Indeed, at the beginning of the interview they were unclear what these terms were referring to.

Sharon: I know what you think that I want to say… our relationship, will you think about that. I want to say about Louise and me together, but I wonder what that means?

Louise: I think Sharon's saying… is that don't understand what is it mean, to be altogether, what is gay?

Interviewer: You don't understand what being gay means?

Sharon: Yeah.
(…)

Sharon: If it is a gay. Is that what gay is? Kissing and touching, touching and kissing.

In contrast, however, one of the participants expressed a firm and sure response in relation to her sexual identity. In response to a question about what terminology she would use to describe her sexuality, she replied confidently:

Sofie: Gay because I like women more than men.

It seems important to note, that she was also the only woman in the research to describe feeling accepted in all parts of her life; she felt that her family and staff were all very supportive of her sexual identity, she had support to attend LGBT support groups and felt that she had never experienced any anti-gay stigma or prejudice from others. For Sofie, a non-heterosexual identity seemed a simple and logical conclusion from her sexual attraction to other women:

Sofie: Because men don't even attract me… but I've got male friends but they don't even attract me. Yeah. I don't know why because I'm used to like being… fancying women because they're more hotter.

When talking about their experience of identifying as LGB, four of the participants described having had some help or support from others in being able to talk about their sexuality. This support came from family members and support staff.

Sofie: At school I used to have like boyfriends but then I didn't like it and then my mum knew I was gay because one day she bought like a girl magazine and she knew straight away that I was gay so I just came out.
                (…)
Interviewer: So do you think your mum realised before you did?
Sofie: I think so. Because she could tell that I… she was buying these bloke magazines for me, so she was like to me "you're not gay are you?", I think along those lines and I just said yeah.

It is interesting to observe that even Sofie, who was more confident in her sexuality, perhaps found it easier to indicate her sexuality through her actions or disinterest in the opposite sex (through the magazine), rather than to initiate a verbal discussion or actively identify herself as gay. Here she was instead labelled through the intervention of her mum.

Whereas for Louise and Sharon, attendance at a sex and relationships training, which talked about different sexualities, enabled them to fully realise that they could be together. Here an interruption by a support worker in the interview is included in the extract for greater context.

> Louise: Me and Sharon was good friends for a long time, but we all decide that we want to be gay.
>
> Interviewer: Yeah. So how did you discover that you liked each other like that?
>
> Louise: Um [supporter's name]?
>
> Supporter: From my point of view it's not a new thing. I think your feelings were growing. But when we went on the relationship training…
>
> Louise: Oh yeah training.
>
> Supporter: When we went on training that gave you the confidence to say that's how you both felt really. That's from my point. Because when we did the training about two years ago you were very good friends, but once you know that that was okay and that was good to be… good to be gay, to be girlfriends, that made you comfortable to say, is that right?
>
> Louise
> & Sharon: Yeah, yeah.

Here the intervention of staff support, to help Louise and Sharon to move their relationship from a friendship into something more, was instrumental to them becoming a couple. However, it is clear that the intimacy of their relationship was already evident but that they were held back from acting on this, potentially out of fear and a lack of information and knowledge of same-sex relationships. It further appears that staff chose to support Louise and Sharon in their same-sex

relationship through directing them to a formal training space, which may indicate a discomfort with talking to them or supporting them in their sexuality in less formal ways at least initially.

3.3.3. "It's so hard to being gay": Negotiating an LGB Identity with a Disability

All the participants described life as more difficult due to their sexuality and disability. Three of the participants talked in general terms about this, about a sense of life being more difficult being in a sexual minority.

> Interviewer: Do you think there are particular things about being a woman with a learning disability who's LGBT which is hard?
>
> Alex: Um well it's hard full stop innit I guess.
>
> Interviewer: Can you tell me more?
>
> Alex: Well (inaudible), when people don't understand and like … I think that like now I realise I left college behind it's better to be in the workplace.

Alex expressed a hope that entering the workplace may prove easier than her experiences at school and college, where she had felt unaccepted and misunderstood due to her sexuality.

Three participants identified specific things that they felt were especially difficult, such as finding a partner.

> Heather: Well I want a relationship, I really do. But it's how I get it I don't know.

> Interviewer: Before you met [partner] was it easy or hard to meet people?
>
> Cora: Quite hard, because there's not a lot of people out there. But it's not easy. Because I'm a bit shy person. If I like someone I find it hard to tell them. Because I might be

(inaudible) or I might be let down or something. I find it really hard.

This difficulty links to the intersectionality of being a sexual minority with an intellectual disability. Some of the women seemed to feel very alone and isolated because it was so hard to meet people and form relationships. They spoke of not seeing other people 'like them', not having spaces to meet people (as well as not knowing where to go) and, crucially, the support to go to places.

Participants also spoke of other things that felt difficult due to their disability. For instance, Alex, who had some social communication difficulties, spoke about finding flirting and reading people's interest in her as extremely confusing. Talking about the one other LGBT women she knew at her college she described their interactions as difficult to read.

Alex: I think she might be flirting with me but she bangs on about her female partner and how much she hates her and that.

Interviewer: Right so you find that confusing?

Alex: Yeah I'm like is she trying to play me…does she want to be my friend or not friend or I don't know.

The participants who were in a relationship spoke about having difficulties in their relationships at times, which in part related to needing emotional and practical support. For instance, Sofie described talking to staff and her family when she felt worried that her relationship might break down.

Sofie: … if I've got a problem with like my relationship or I need help trying to say something to my girlfriend if I'm worried about stuff they'll [support staff] help me say it in a way so that I don't upset her.

Although a combination of the impact of having a disability and being in a sexual minority meant that developing a sexual identity was difficult, participants did not feel like this in all contexts. Despite the barriers, the participants were

also able to form trusting relationships and have experiences where they did feel accepted and included, as explored in theme three.

3.4 Theme Two: "I feel quite isolated really": The Impact of Invisibility and Difference

Another prominent theme identified in the data centred on a sense of isolation and aloneness for some of the women. Here a number of the women described painful experiences caused by perceptions of difference from others in their lives, invisibility of non-heterosexual people with intellectual disabilities amongst both disability and LGBT contexts, and of direct experiences of prejudice and anti-gay stigma.

3.4.1. "Like I'm the only one": The Pain of Feeling Different

All the participants knew very few, if any, other women with an intellectual disability who also identified as lesbian, gay or bisexual.   For some participants this marked them out as different:

Cora:	Yeah and it not easy being disabled and not a lot of people are out there like us. Because I haven't seen a lot of disabled people, learning difficulties people at the Pride. There should be more people like us.
Interviewer:	So you feel you don't really see people like you?
Cora:	Not really, I don't think so.

| Heather: | Well there's other people, and there's me. |

Here, participants demonstrated that they felt different to others in both the LGBT community, due to their disability, and also to other people with intellectual disabilities, due to their sexuality, as a doubly stigmatised "minority in a minority" (Bennett & Coyle, 2007). Moreover, this difference was accompanied by a sense of loneliness and isolation, of not seeing other people 'like me':

> Heather: It feels quite weird, like I'm the only one. It's like… it feels, I feel quite isolated really.

Heather showed the impact of being doubly stigmatised in her conclusion that she would never meet a female partner who was able to accept her for who she was:

> Heather: …because knowing you haven't got a learning disability who's going to want people with learning disabilities and mental health problems?

And again later she concludes:

> Heather: "I don't think no one will have me"

Some of the women also spoke about feeling like they do not fit in within wider society. This was experienced as feeling uncomfortable in settings where they were expected to conform to societal expectations or norms.

3.4.2. "They saw my disability not me": Judged by Difference

Some of the participants felt that having an intellectual disability obscured all other aspects of their identity. Having a disability affected how they were viewed and treated by others:

> Heather: Well I think that having a learning disability affects what other people may see of you. That's just my feeling. That's just my feeling. If you've got a learning disability / mental health problems as well, I think it's like people see that more than they do anything else.

> Cora: I wish… I wish that everyone be… people are equals. People with learning not always… people [should] treat people the same.

Heather identified that having a difference in terms of an intellectual disability was hugely stigmatising; moreover, she felt that identifying as LGB as well was almost 'too much', as if having so much perceived difference could not be comprehended or tolerated by others. Her experience of being 'othered' and not understood was, thus, further enhanced by her sexuality:

> Heather: Because people don't accept people with learning disabilities anyway, really. It's really difficult for people to get their heads around and so having, being bi as well or lesbian that would be really difficult for them…

Reported responses from members of staff indicated disbelief that someone with an intellectual disability could have a sexual identity, even less so a non-heterosexual one. Heather described the reaction of a member of staff in a provider organisation to an invite to an LGBT event for people with intellectual disabilities:

> Heather: Some people we rang up said, "Oh, none of our people are like that".

Judgements were also made to other participants by what they wore or how they looked. Sofie and Cora, who both had short hair and dressed in androgynous clothes, both spoke about other people making stereotypical judgements about them:

> Sofie: And also people have called me loads of times a boy, because I dress in boys clothes because I'm gay so people have called me a boy a few times...

> Cora: They think all women who have short hair be lesbians. People think they have short hair that you might be gay. But not a lot of women who have short hair is gay. What people say they have short hair or you wear boys clothes you might be gay.
> Interviewer: So you think that's a good thing or bad thing?

<blockquote>
Cora: I think that stereotypes.
</blockquote>

The women thus described negative responses to their perceived difference in a number of different contexts.

3.4.3. "We are not accepted": Experiences of Exclusion and Discrimination

Experiences of exclusion were discernible across different areas of the participants' lives, namely within the LGBT community, within families and within wider society.

3.4.3.1 Within the LGBT community: A number of participants spoke about the LGBT community not feeling welcoming and accepting of them due to their disability:

<blockquote>
Interviewer: What would you think would be helpful for women with learning disabilities who are LGBT?

Cora: Let them go out there, like in the gay world. For people having learning difficulties.

Interviewer: What would help that?

Cora: To accept them. It's really annoying that because we might have learning difficulties we feel like we are not accepted. Nowhere for us to go to make friends or anything.
</blockquote>

Here the exclusion was felt, in terms of the attitudes from non-disabled others in the LGBT community, in being "not accepted", which meant that there was seen to be no space in the "gay world" for disabled individuals. By alluding to an 'other' world to which LGB people with intellectual disabilities were excluded from, Cora identified no inclusive 'world' for her, as she would presumably also be excluded from the alternative heterosexual, 'straight world'.

As well as attitudinal barriers, a number of participants described very practical barriers to accessing LGBT specific venues or spaces, which made it either unwelcoming or inaccessible for people with disabilities:

Cora: I feel like there's not a lot of places that are for us to go, like a gay club or whatever. People in wheelchairs. Like gay pubs or things like that. There should be places like wheelchair people like they would hang out with their mates and things. They need to think about people with wheelchairs as well, to get in. If they want to have a good time.

Cora is able-bodied but was aware of the lack of accessibility of venues to people she knows who have physical disabilities; however, she also included herself in the feeling of exclusion.

Similarly, Alex, who has an intellectual disability and autism, described the difficulty of being in spaces where she struggled to manage crowds and noise. She described an incident where adjustments to make it easier for her were promised but then ignored.

Alex: …like when they said they keep the… if you're in a gay bar and they said oh we'll just keep the music on low and then sort of deliberately turn it up…

This feeling of exclusion also extended to LGBT Pride events. For a number of participants Pride was experienced in a positive way (as detailed later), but for Cora the event was hugely disappointing due to her experience of inaccessibility. Cora's partner has a physical disability and they found they had nowhere to go and no one to help them at the event.

Cora: I've been to gay Pride. But I think like if your disabled or learning difficulties it's really hard to be honest. (…) [Name] my partner has leg problem and she felt left out because there no where her to sit. We didn't know where it was. No one don't know where it is and that. I thought that not really nice. People like her feel bit left out. (…)

Interviewer: What was that like having problems there?

> Cora: Bit upsetting, a little bit. That we wanted to join and have a good time. And a lot of people there don't have learning difficulties. Feel people who got learning difficulties want to go.

Here it can be seen that at an LGBT Pride event Cora and her partner had expected to visibly celebrate their sexual identity, but instead the barriers of that context meant their disabled identity became more prominent and excluded them from the celebration.

Unsurprisingly perhaps, given the experience of exclusion from the LGBT community and the experience of difference among others with intellectual disabilities, three of the women spoke about needing spaces specifically for people with intellectual disabilities who are LGBT. Each of them commented on the lack of groups or events and there needing to be more available. Moreover, Alex and Heather had both been involved in projects which tried to create something for people with intellectual disabilities and sexual minorities because there were so little available.

> Alex: There's nothing out there so that's why we did our own group.

> Heather: Because there's no… there's not many places that do people with learning disabilities and LGBT. There's hardly anywhere really and no organisations that I know of do it. We want to be the first.

The need for a space that feels welcoming for people with intellectual disabilities who are LGBT might alleviate some of the experience of exclusion from the wider LGBT community and provide support for those who need it. In the words of Alex, it could provide a place where people feel like they "belong in the world":

> Interviewer: What would be good about that?

> Alex: Well just having more out there and meeting people and making people feel like sometimes they can belong in the world. Like because you get all sorts of crazy chicks who have really bad experiences and like we want them all to be okay.

3.4.3.2 Within families: A further aspect of exclusion within the interviews was identified by three of the participants who described difficult responses to their sexuality from their families. For Sharon and Louise their relationship seemed a huge shock to their families, who were unable to speak about their relationship and were not able to offer them any support or acceptance.

> Sharon: My mum and dad don't say a word, anything like that.
> Louise: I think Sharon's saying, um Sharon don't understand what Sharon's parents understand at all about me and Sharon are… are together, being gay.
> Interviewer: They didn't understand?
> Louise: No.

For Heather, her family denied and dismissed her sexuality outright.

> Heather: My family don't want to know, they… my nanny and my aunty say it's just a phase and I said no it's always been there, I've never just, I've never been able to talk about it because I've been afraid of what my family would say. So I found the courage to say it. And she said "Oh don't be so silly. It's just a phase you're going through". And "okay", and left it as that… they didn't understand.

The emotional toil of this lack of acceptance and feeling silenced within their families was evident in these conversations.

> Sharon: Yeah it is [upsetting] for me yeah. I can't stop crying, I can't stop crying, it hurt me.

Heather's experience was the most extreme, as it caused her to lose touch with her family entirely.

> Heather: I'll always seek from my nanny some reassurance and I don't get it. I don't get nothing like that. I haven't got a mum and dad. And so I seek guidance off my nanny but it's really difficult. It's really, really hard, she don't understand, she won't accept me.

3.4.3.2 Within wider society: A number of participants spoke of incidents of homophobia, anti-gay stigma and heterosexism. Cora described being uncomfortable in the community because she had experienced directly anti-gay prejudice and discrimination on more than one occasion:

> Cora: When I kiss [partner] on the streets, sometimes people look at you or call you names and that.

This included being called names such as "dyke" and being shouted at. She felt particularly unsafe in her home city which was causing her to want to move away.

Cora and Alex had also experienced anti-gay prejudice from people they knew or within settings they attended. They both spoke about experiencing negative reactions to their sexuality from religious people and organisations; Cora described this as the 'homophobic church' she was part of, which she then left, but recalled this as a difficult time of her life.

> Cora: When I tell someone, I thought she was a friend, like saying horrible stuff like you would go to hell and all that.

Within school and college, Alex alluded to upsetting experiences of anti-gay prejudice when she experienced being silenced about her sexuality.

> Interviewer: Are there times that you don't tell people [that you're LGBT]?

Alex: Um sometimes at church they don't like you to talk about it. Or sometimes at the college if you're in a big class or something. Or I don't know.

Interviewer: So there's some places that you don't think it's that okay to talk about it?

Alex: Yeah they [the teachers] always go on about safe spaces.

Interviewer: Okay, what does that mean?

Alex: I don't know, I never really understood what it meant.

Alex had been told by teachers to only talk about her sexuality in a 'safe space' but was unclear what this had meant, which had the effect of making her feel as if it was unsafe to talk about her sexuality anywhere; thus she felt silenced from expressing, or discussing, her sexuality in the school and in other environments. It is also of note that, despite not being a religious school, the teachers had reportedly drawn on religious reasons for not talking about non-heterosexuality. Recalling these experiences appeared upsetting for Alex and something which she found difficult to discuss:

Interviewer: How did they (school) respond to you being LGBT?

Alex: Oh just nonsense about the bible. … They got like… um… I don't know. There was this crazy lady, I don't know, I don't want to talk about it.

3.5 Theme Three: "Be happy with who I am": Visibility and a Positive Sense of Self

The last main theme identified throughout the interviews related to participants experiences of being loved, accepted and supported. The experiences captured within this theme gave participants a sense of belonging, connection and inclusion. Participants described the importance of love and relationships in their lives and recounted experiences of connection with other LGBT people. Furthermore, the importance of visibility of LGBT communities was expressed by a number of the participants as very important and linked to positive feelings about their sexual identity.

3.5.1. "I felt I found my place really": A Sense of Belonging

Despite the difficulties of coming out to friends and family identified above, the importance of having come out to others about their sexuality was evident in how a number of participants spoke about these experiences. Several of the participants talked about a fear they experienced before telling someone about their feelings, needing to build up courage to do so and the personal benefits of having done so.

For Sharon being able to tell her family gave her an enormous sense of achievement. She described being at an annual review meeting, which would have had a number of people present, and building up the courage to tell her parents in the meeting.

> Sharon: … I try to do mesen [myself], so anyway I just told them … "mum and dad…" I said, "look I do love my girlfriend a lot. That make me feel inside me and [Louise] as well". But I can't believe what my mum and dad think you know. That make me shocked and it make me happy (…) I can't believe it, I can't believe I told them me self.

Sharon expressed a sense a shock and pleasure at having been able to tell her parents herself, perhaps without staff talking on her behalf. A sense of her relief was also evident, demonstrating the emotional burden of feeling that she had been keeping these feelings hidden. Participants' experiences indicated that coming out was seen as a challenge to be overcome, which could lead to personal growth and other positive benefits. The importance of feeling internally and externally consistent, with oneself and others, was seen to be vital.

> Heather: But I found people that I trust and talked to them about it and it weren't too bad to be honest with you, apart from my nanny. But yeah it was… I'm glad I did because it's out in the open now.

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Sofie: I think it was quite nice to tell them so they knew because otherwise… otherwise if I didn't tell them they would know that I'm keeping stuff from them and I hate doing that…

For one of the participants, the process of talking to her family about her sexuality also had the outcome of feeling closer in their relationship.

Cora: I think it make me and my mum more closer I think. Me and mum always be close but I think when I tell her I think it make me and more close, more closer I think. I feel I can tell her anything.

For the three oldest participants who all came out at a later age, in their late 30s, coming out as LGB seemed to hold particular significance in developing a positive sense of self. For Sharon and Louise it helped to further cement and recognise their relationship with one another, whereas Heather described feeling like she had finally located a place of belonging and acceptance.

Heather: …and then I started getting involved in Pride. And I felt I found my place really. I found that's where I belonged. I felt comfortable being there.

Thus coming out to other people helped lead to feeling accepted by others, and ultimately, was important in enabling a feeling of acceptance towards the self.

3.5.2. "Can hold your partner hand": Visibility Gives Strength

A recurrent theme within a number of the interviews was the importance and meaning of LGBT Pride events for the women. While participants spoke of not being accepted in the LGBT community because of their disability, the community of LGBT Pride events nevertheless gave them an important sense of visibility and freedom. Four of the participants talked about these events positively and, in the photovoice interview, three of them chose to share images of them at Pride events.

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Pride was described as a place of celebration and fun:

>Alex: Yeah friendships and stupid costume… just making a laugh and a joke about it and feeling safe on the lorry, not being pushed in the crowd (…) and there's loud music and just we can make a lot of friends and be a bit crazy.

>Heather: Yeah, it's a celebration. Pride is a celebration of LGBTQ and it's open for all and it's where everyone's equal and everyone's the same as each other and accepting everybody for who they are really.

In contrast to other contexts where participants described feeling different, isolated and alone, here the open acceptance and celebration of sexual diversity was significant for them. Indeed, Pride was experienced as a place of equality and inclusion. Furthermore, for two of the participants it was also a place where they felt a sense of safety which they did not experience at other times.

>Heather: I find that picture really good. That everyone's included, everyone's happy. You feel safe, you feel safe at Pride. (…) even though there's loads and loads and loads of people. And I don't usually do loads and loads and loads of people but when I was there I actually felt quite safe. I felt like everybody was like a family sort of thing. It's really, really powerful.

>Cora: Because not have seeing other people out on the street... You can hold your partner hand or whatever.
>Interviewer: So you can hold their hand at Pride?
>Cora: And don't get judged… like homophobic or something.

LGBT Pride events were important to a number of participants because it allowed them to be visible and seen in the community. This might be

particularly important, given the experience of isolation, invisibility and experience of 'othering' described by many of the women. Indeed, a number of the participants described the importance of seeing other LGBT people alongside them, individuals whom they may have felt a shared sense of identity. For women who otherwise felt they did not fit into the 'gay world' of bars and clubs and the 'straight' disabled world, this sense of belonging and inclusion might feel particularly novel and significant.

Sofie: …Just make a stand and show people what you are, [people] that are straight.

Interviewer: So more of that, more of the being visible and making a stand and…?

Sofie: Yeah because otherwise people will just think that gay people are straight.

Interviewer: So gay Pride was fun and it also meant something to you?

Cora: Be happy with who I am.

Interviewer: (…) and did you say not feel alone?

Cora: Yeah to see all LGBT people out there.

For one of the participants, the importance of visibility also related to heterosexual people attending LGBT Pride events showing their support and acceptance of people who are non-heterosexual.

Interviewer: And what about going to Pride, is that important to you?

Sofie: Yeah it is because a lot of people that are gay or so on, they still come, like if you're… even my mum's been to watch me or help. Because when I was in it, like before my mum was in it with me, because obviously she's straight and married she was in it with me to support me. Because a lot of people who come to Pride that aren't like obviously gay but they still come and have fun watching all of us march.

However, it is important to note that LGBT Pride events were not universally experienced as inclusive and accessible to the women; as noted earlier (section 3.4.3.1), Cora described feeling that her and her partner were on the outside of the event, both in terms of experiencing practical barriers, and in their invisibility and difference to others. Thus, the visibility of pride events was crucial in the celebration and embracement of sexual diversity, but invisibility of disability within it meant that it could also be experienced as a place of exclusion.

3.5.3. "I've found someone special": The Importance of Romantic Love

All of the participants who were in a relationship spoke of the importance of their partners and their relationship to them. They spoke about being in love and a sense of happiness and belonging.

Interviewer:	And is there anything else that's important in that picture?
Sofie:	I think it's because we love each other in that picture, because we're both like happy.

Interviewer:	I'm hearing how important your relationship is.
Sharon:	It is great really. I'm happy with that.
Louise:	Yeah I'm happy about it as well. Me and you together.
Sharon:	That's all I want to do really.

Interviewer:	How does it relate to your life?
Cora:	That I've found someone special (…)
Interviewer:	What did you say… the special person in your life?
Cora:	Mm
Interviewer:	And is that… why is that important to you?
Cora:	I love her. …[laughs] I'm being a bit shy now.

How participants spoke about their relationships showed the high value they placed on being in a romantic relationship and the positive benefits they felt of not being "on my own any more" (Cora), of being in love and having someone who cared for and supported them. Relationships clearly provided love and companionship to participants and they talked highly of the role of their partners

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in their lives. The one participant who wanted to be in a relationship but was not, spoke most negatively about herself and felt most isolated from others. Indeed, being in a valued relationship might have provided a buffer to some of participants from some of the impact of the experiences of being multiply stigmatised by others, by reducing the sense of invisibility and difference from all others.

3.5.4. "They help me out a lot": Support as Vital

Another subtheme identified in the women's accounts was the importance of having good support; feeling able to rely on those around them for emotional and practical support related to their sexuality. The consequence of this support had wide reaching effects on the person's identity and level of comfort with their sexuality.

Louise:	Well I need support staff to support me
Sharon:	And me
Louise:	And Sharon as well. If I feel comfortable in our relationship together.
Interviewer:	You needed them [staff] to help you feel comfortable?
Louise:	Yeah
Interviewer:	And they were able to do that?
Louise:	Yeah
Sharon:	Yes
Interviewer:	Yeah so they [support staff] are good people to talk to as well about your relationship?
Sofie:	Yeah they help me out a lot, as well as my family.
Cora:	I think my club, when I tell them they help me and like make me feel better about myself and all that.

In contrast to the three participants who discussed difficulties with telling their families, three participants spoke about how important their families were in accepting and supporting their sexuality.

Interviewer:	Have you had any support with being LGBT?
Alex:	Yeah we've had loads of it. You've got to know where to look (…)
Interviewer:	And have you had help to find things?
Alex:	Yeah (…) my mum's helping me.

Interviewer:	Tell me why you chose that picture?
Sofia:	Cos it's my family and they're very supportive towards me.

Two participants also discussed the importance of LGBT support groups for people with intellectual disabilities which they attending and helped connect with others and "not feel like I'm on my own" (Cora).

For some of the participants the visibility and support from support staff, especially women, who openly identified as LGB was significant. Participants seemed to find it easier to speak to another LGB woman about their sexuality or relationship.

Alex:	I feel safe with her and yeah and she's gay as well and she's had female partners before.

Heather:	But I've only just recently sort of come out because of (name) really. She was a lady, she's a lesbian and I felt I could talk to her.

Heather's account suggested that it might be easier for LGB women with intellectual disabilities to discuss their sexuality with other openly LGB women. For her this seemed particularly important in enabling her to discuss her sexuality for the first time and provided a gateway by which she was then able to come out to other heterosexual people in her life.

3.6 Photovoice Summary

Of the four women who participated in the second photovoice interview, all of them chose photos which demonstrated where they felt included, happy and connected. This included pictures of them with their families, with their partners or friends and photos of them at LGBT Pride events or LGBT related venues (see Appendix 17 for example photographs grouped by participant).

Analysis of the photographs led to the identification of four higher order themes, as demonstrated in Table 2.

Table 2: Themes from visual analysis

	Theme
Theme 1	Vibrancy and Celebration
Theme 2	Reaching Out to LGBT Others
Theme 3	Connection and Love
Theme 4	Valued Social Roles

3.6.1. Theme 1: Vibrancy and Celebration

A striking observation noted in many of the photographs was the colour and vibrancy displayed. In large part this was due to the prevalence of rainbow flags and rainbow colours in a number of the photos.

First created in 1978, the rainbow flag, often referred to as the 'gay flag' or 'LGBT pride flag', usually consists of six bright layered colours, and has become a worldwide symbol of solidarity and pride for the LGBT community (Mindock, 2017; Simmonds, 2017).

Figure 3. Theme 'Vibrancy and Celebration' Through Rainbow Colours

With a predominance of rainbow colours, the images stand as bright displays with symbolic meaning in their celebration of sexual diversity.

When asked about why she chose a photo of a rainbow flag outside a museum, Cora demonstrated the importance of this symbol of LGBT Pride for her. Remarking on the fact that she had never seen a museum with a 'gay flag' outside it:

> Interviewer: And so you haven't seen a museum do that before?
> Cora: No
> Interviewer: What did you think when you saw it?
> Cora: Happy
> (…)
> Interviewer: Did it mean something for you to see that?
> Cora: Being happy with who I am.

Cora attributes importance personal happiness to the representation of the rainbow flag. Thus, the flag can be seen to induce positive emotions from the meaning and symbolism it represents.

Within this theme the celebratory and joyful aspect of many of the photos were captured. LGBT Pride events and symbols are presented where people are outside in the street, waving banners or flags and smiling. Participants are seen among the crowds or centred, some wearing rainbow coloured items of clothing. They show LGBT pride events as jubilant celebrations of sexual diversity.

Figure 4. Theme 'Vibrancy and Celebration' at LGBT Pride Events

Moreover, the photos held meaning to the participants who seemed to enjoy re-telling the situations or events depicted in the photos or were able to recall emotions at the time and what it meant for them to look at the picture again.

> Alex: I like this picture because I've got my rainbow jacket and I
> just feel like I'm dancing inside…

3.6.2. Theme 2: Reaching Out to LGBT Others

Three photographs from two of the participants were of posters or planning information from groups that they were involved in setting up. The images were more formalised, with no personal information or clues as to the individuals' behind the information. Rather, the images seemed designed to be more inclusive and reach a wider audience. In the design of each, there is the use of the symbolic rainbow flags and/or rainbow colours throughout, and thus they demonstrate clearly the intention to invite people who identity as LGBT.

Furthermore, they were particularly designed for LGBT others who also identify as having a learning disability or autism. Indeed, one of the images (shown below) includes a number of images of people with disabilities.

Here the women can be seen to want to actively seek other LGBT individuals with intellectual disabilities or autism. The importance of meeting others 'like me' can be seen in the attempts to proactively reach out to others, and also in the selection of these images for the photovoice interview. Here the women demonstrate not only their sense of isolation and what they feel is missing from their lives (being able to meet LGBT others, make friends, socialise etc.), but also exhibit their own agency at seeking to do something about it. Moreover, it also enabled discussion about important others, a member of staff and a family member, who were instrumental at supporting them to set up the events.

Figure 5. Theme 'Reaching Out to LGBT Others'

3.6.3. Theme 3: Connection and Love

A number of photographs participants chose were of them with important others in their lives, such as family, friends or partners. These photos were noticeable in the closeness demonstrated. Sofia chose an image of her on holiday in an idyllic location with her large family grouped together with her in the middle. Whereas Alex chose a photograph of her and a friend at a gay bar where they were holding hands and hugging tightly, clearly partying together.

Figure 6. Theme 'Connection and Love'

Cora and Sofie were both in a relationship and chose a photograph with their partners. In both they are seen smiling and embracing in the photos.

It was noticed, also, that using the photos as a basis for the discussion enabled them to talk about their relationship in more depth than they had done in the first interview. Details such as where they had met their partner, what they liked to do together and what their partner meant to them.

Sofia:	Yeah that's my girlfriend and me, in [place name] along the seafront, that was when we first got together I think it was. (…)
Interviewer:	Is there anything else that's important in that picture?
Sofia:	I think it's because we love each other in that picture, because we're both like happy.

In contrast to pictures of places or things, the women talked about these important people in their life and demonstrated themselves as part of relationships, families and friendships.

3.6.4. Theme 4: Valued Social Roles
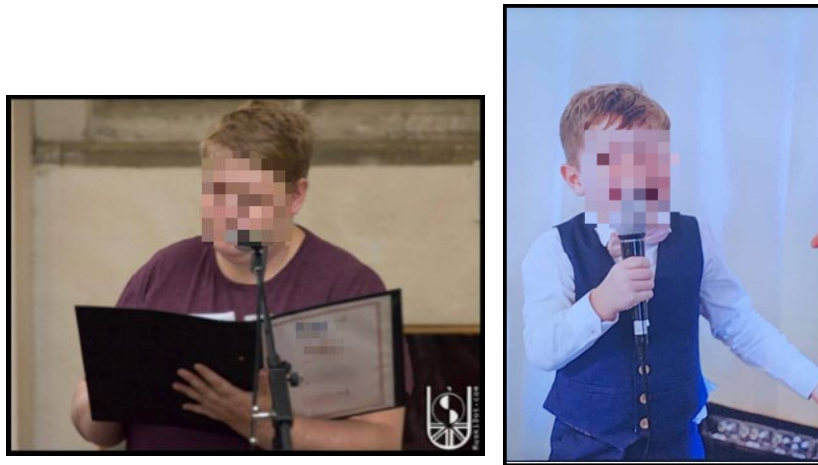
Figure 7. Theme 'Valued Social Roles'

The last theme identified was one of the meaning attached to photos which showed participants in important or valued positions. Sofia chose a photo of her nephew at a family wedding. Through the conversation the closeness of her family and importance of her role as an aunt became clear. Moreover, at the wedding she described being a central family member and had read out a reading during the ceremony. The images can be seen to demonstrate Sofia's important role within her family and the positive sense of self gained from this.

Heather's photo showed her reading out her poetry to a large audience at an LGBT event.

> Heather: Because poetry to me is really important. I write a lot of
>   poetry and I also read a lot of poetry out to like different
>   places like [event] and I think I've done Pride once (...)
>   Because of the wording and it pulls people in. And I like to
>   write poetry about how I feel and what's happening inside
>   me and that brings my emotions and everything out. And
>   I've written a few LGBT poems.

This held meaning for Heather, therefore, not just because of it being an LGBT event, but also because of her ability to write poems which connect with her internal world and emotions. She talked of being proud of her achievements when looking at the photo and pride at being able to move other people

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emotionally, "pull people in". In her interview, Heather talked about having a negative self-image and low self-esteem, she described usually struggling with being able to acknowledge pride in herself, but she was able to do so in this context:

> Heather: …proud of everybody really and myself. And that's hard to say that is. (…) That is really hard to say. Really hard to say I'm proud of myself but I suppose what I've done with Pride is really important.

These images were talked about with warmth and positive emotions; they clearly held importance for the participants and served as a reminder of positive things about themselves. Demonstrating valued and responsible roles in different environments, the images might be seen to serve as a counter to the stigma and stereotyping of people with intellectual disabilities as lesser, and the regular infantilising of people with intellectual disabilities as perpetual children or adolescents.

3.6.5. Photovoice Process

Using the photographs stimulated conversations, which explored aspects of participants' sexual identity and where this fit with other parts of their lives; where their values, the things they enjoyed and aspects of their identity and sexuality intersected.

Photovoice interviews seemed to flow easily and participants, at times, seemed more at ease or perhaps more confident within this interview (although it was also their second time speaking with the researcher). Taking Alex as an example (she was one of the participants who seemed to find talking about her sexuality and experiences the most difficult), in the first interview she regularly replied that she was "not sure" or she "did not know" in response to some of the interview questions. However, by the end of the second photovoice interview she was very talkative and requested for more involvement.

> Alex: This is a really good project and maybe I want to carry on… so what's part three?

4. DISCUSSION

4.1 Chapter Overview

In this chapter, I outline the main findings from the research in the context of the initial study aims. I look to situate the findings within the existing research in this area and evaluate the strengths and weaknesses of the study. A critical review of the research will consider the methodology and process of analysis against quality criteria; it will also include a reflection about my own role within the research. Finally, the chapter concludes with recommendations for future research, policy and clinical practice.

4.2 Summary: Situating the Research

This thesis aimed to explore the experiences of lesbian, gay and bisexual women with intellectual disabilities in relation to their sexual identity. It sought to provide insight into how women with intellectual disabilities described and understood their LGB identity, where they felt included and excluded in their day-to-day lives and if they had felt supported in their expression of same-sex attraction.

As seen in the introduction chapter, there is a limited body of research in this area, which has predominantly focused on men with intellectual disabilities. In the following section, the data will be considered in relation to the initial research questions and situated alongside existing literature to consider what this research adds.

4.2.1. LGB Women with Intellectual Disabilities' Sexual Identity and Sense of Self

Previous research has shown LGB women with intellectual disabilities to be an unrepresented and invisible group in society. This research corroborates this finding due to the sheer difficulty of recruiting participants in this area, combined with the isolation described by a number of participants. All of the women in this research project knew few, if any, other LGB women with intellectual

disabilities. As a consequence, many of the women described feeling isolated and alone with their sexual identity, "like I'm the only one". This mirrors a number of studies with people with intellectual disabilities in which participants described feeling abnormal, different and isolated: "it feels as if I actually come from another planet" (Abbott & Burns, 2007; Dinwoodie et al., 2016, p. 7; Elderton & Jones, 2011). Indeed, due to the absence of women in the literature, it seems that LGB women with intellectual disabilities are a hidden and marginalised group, even when compared to gay and bisexual men with intellectual disabilities, an already isolated population. Subsequently this can leave LGB women with intellectual disabilities to feel abnormal and different to everyone else, with few direct role models or others to identify with in relation to their sexual identity.

In contrast to a number of studies in which participants identified their minority sexual identities quite easily (Abbott & Howarth, 2005; Dinwoodie et al., 2016; Stoffelen et al., 2013), in this study a number of participants seemed to struggle to choose or label their experience with 'lesbian', 'gay', 'bisexual' or another term. On the one hand, it could be argued that this could be seen to indicate a general dislike or reluctance to use these labels, as has been the case in other research (Withers et al., 2001). However, additional uncertainty from some of the women hinted to a less certain sexual identity and perhaps an unfamiliarity with accepting or talking about their own needs, wants and wishes related to sex and relationships. Drawing on theory of minority sexual identity development (Cass, 1979, 1984), it could be argued that the women were in an early stage of identity development, still confused by their sexuality and where they fit in the world. However, it also alludes to the limited support LGB women with intellectual disabilities may have had to understand and talk about their sexual identity.

Research has shown that women with intellectual disabilities have regularly been thought of and treated as asexual, regardless of whether they identify as asexual or not. Fitzgerald and Withers (2013) described the difficultly women with intellectual disabilities generally have in developing a full adult identity and sexuality when others continue to infantilise them. Indeed women with intellectual disabilities have often lived in a state of "suspended adolescence",

which can be seen in many of their own self-descriptions not as women but as girls (Fitzgerald et al., 2013). This construction of women with intellectual disabilities is further influenced by heterosexist cultures and others' perceptions of non-heterosexuality in people with intellectual disabilities to be problematic (Abbott & Howarth, 2007; Young et al., 2012); thus, LGB women with intellectual disabilities may have less well-formed sexual identities in part because sex and relationships are still little spoken about, particularly non-heterosexual relationships and especially with women.

The process of forming a minority sexual identity for non-disabled LGB individuals has been much written about in research (Cass, 1979, 1984; Coleman, 1982; Markowe, 1996; Troiden, 1989). In Markowe's (1996) investigation into the process of identity formation in non-disabled LGB women, she found that women had a long time gap between first feelings towards someone of the same sex and identifying themselves as LGB; furthermore, becoming "aware of self as lesbian often began with negative or conflicting feelings" (p.196). Markowe (1996) argued that awareness and acceptance of lesbianism is affected by social representations of gender:

> "Coming out to self takes place within a social context that includes
> perceptions of people's views of lesbians as negative, a stereotype of
> lesbians as masculine, abnormal, aggressive and unattractive; and
> lesbian 'invisibility'." (p. 194).

Although attitudes may have evolved since her research, particularly with the advancement of LGBT rights, some of these stereotypes and perceptions may still impact on the coming out process for women who feel attracted to other women. Markowe proposed that the process of 'coming out to self' was usually achieved by experiencing strong emotional feelings towards a woman, combined with an awareness of same-sex relationships and a process of acceptance. Women with intellectual disabilities can be seen to be disadvantaged in all three areas: being less likely to be exposed to LGB environments and generally having more barriers to forming relationships, less likely to be aware of same-sex relationships and perhaps having greater

difficulty at accepting their sexuality given their asexual positioning by others and being in an already de-valued position in society.

A number of the women described needing great courage to talk to others about their sexuality and some described having help from family members and support staff to either recognise their attraction to women or to indicate that it was okay to identify as lesbian or to be in a same-sex relationship. Some of the participants in this study seemed to be initially less aware of same-sex relationships and non-heterosexual identities, or struggled to put language to their experience, which acted as a barrier to their self-identification as LGB. Similarly, other research has shown women with intellectual disabilities to regularly lack knowledge of non-heterosexuality, particularly in relation to lesbianism (Burns & Davies, 2011). For the women in this research who had support to recognise that same-sex relationships existed, it seemed to help them to recognise that an LGB sexual identity was personally relevant to them. This fits with Markowe's (1996) suggestion that an awareness of lesbianism as an option was a necessary part of 'coming out to self', and needed for lesbian identify formation. If these participants had not received support to realise that women could be attracted to and form relationships with other women, then it is possible that they may not have come out when they did, or perhaps not at all. With potential negative consequences for their mental health and well-being (Butler, 2012; Pistella, Salvati, Ioverno, Laghi, & Baiocco, 2016). Indeed, in some instances supportive others had helped participants to "name" their sexual or romantic feelings and this was important in helping to frame their feelings and start to develop a sexual identity.

Not enough is known about identity formation for women with intellectual disabilities who are LGB and how their sexual identity is integrated into other aspects of identity. Research suggests that being labelled with intellectual disabilities places a person in such a de-valued position in society that all other aspects of identity, such as gender, are obscured (Fitzgerald et al., 2013; McCarthy, 1999). This fits with the women's descriptions of their sexuality being almost incomprehensible to others who they felt saw their disability before all else. According to LGB identity formation theories, the last and optimal stage of identity development involves the integration of various aspects of the

person's self, including other minority identities (Cass, 1979, 1984). However, not enough is known about how this theory might relate to women with intellectual disabilities whose other identities may be dominated by the intellectual disability label.

4.2.2. Feeling Excluded in Society and the Impact on Identity

There were clear instances where these LGB women with intellectual disabilities felt unaccepted and excluded by society. Previous research with non-heterosexual people with intellectual disabilities has highlighted the difficulty of experiencing negative responses to both an intellectual disability and non-heterosexual identity (Abbott & Burns, 2007; Bennett & Coyle, 2007; Dinwoodie et al., 2016; Stoffelen et al., 2013).   This finding was echoed in this study, in which participants had regularly experienced discrimination and negative responses from others. For the women in this research, this included experiencing verbal abuse in the street and discriminatory and heterosexist responses from others; a finding which has been consistent across the board with people with intellectual disabilities who are LGBT (Abbott & Burns, 2007; Bennett & Coyle, 2007; Dinwoodie et al., 2016; Stoffelen et al., 2013). The women did not, however, recount more extreme instances of homophobic violence and aggression, which had been directed at LGBT people with intellectual disabilities in some of the previous studies which had mainly male participants (Abbott & Burns, 2007; Dinwoodie et al., 2016); thus suggesting that gender may play a role and perhaps LGB women with intellectual disabilities might be less at risk of violent attacks than gay men with intellectual disabilities.

Crucially, the minority stress model is relevant to LGB women with intellectual disabilities. The minority stress model (Meyer, 1995, 2013) identified three main ways in which stressors impact on an LGB individual (internalised homophobia, stigma and experiences of discrimination) and all three of these can be identified in the women's accounts. Participants spoke of feeling different and lesser than others, "who will have me?", a demonstration of the effects of societal negative attitudes turning inwards on the self. The women also spoke about feeling stigmatised and judged by their difference and they also spoke

about incidences of abuse and discrimination experienced from strangers and people they knew.

The women can be seen to occupy a number of intersecting "spoiled identities" (Goffman, 1963, p. 13). Minority stress stemmed from their LGB identity, disabled identity, or both. Thus LGB people with intellectual disabilities can be seen to occupy two highly stigmatised positions and encounter layered stigma and marginalisation (Meyer, 2003; Wilson et al., 2016). People with intellectual disabilities have been regularly seen to have low self-esteem caused by negative social attitudes to disability (Cambridge, 2006; Wilson, 2006). Women with intellectual disabilities in this research spoke of the stigma of having a disability, which they felt often obscured all other aspects of their identity. The women spoke of fears of being disbelieved about their sexuality, not taken seriously or disapproved of; which mirrored previous research in which participants talked about other people problematising their intellectual disability and/or their sexuality, and of not being deemed capable of knowing their own minds and their own sexuality (Dinwoodie et al., 2016).

Some of the women described especially difficult reactions from their families, which they perceived to be negative or unsupportive of their sexuality. Negative reactions from family, friends and peers can lead to negative mental health outcomes (Carman, Corboz, & Dowsett, 2012). A common finding in LGB research has shown that revealing an LGB sexuality to family members continues to be difficult and can expose individuals to prejudice and rejection (Denes & Afifi, 2014; Grafsky, Hickey, Nguyen, & Wall, 2018; Jhang, 2018; Pistella et al., 2016). People with intellectual disabilities can additionally be reliant on other adults in their lives, such as family and staff, to support them with gaining and maintaining relationships. Abbot and Howarth (2005) found that LGBT people with intellectual disabilities feared that their support would be removed or they would be denied access to things due to their sexuality. Within this context, managing the consequences of potentially negative reactions from individuals whom they may be dependent on, can be an even greater challenge.

Group identities are said to be essential for individual emotional well-being (Brewer, 1991). Furthermore, affiliation and group membership has been

shown to buffer the effects of minority stress (Meyer, 2013). However, LGB women with intellectual disabilities described being on the outside, unable to identify with other people labeled with intellectual disabilities or with other LGB non-disabled individuals. They described a large number of barriers to meeting LGB others and forming friendships and relationships. This is significant, as the process of building LGB friendships and networks has been shown to link with higher levels of self-esteem and lower levels of mental distress (Frable, Wortman, & Joseph, 1997); it has also been seen as vital to developing a positive sexual identity (Bennett & Coyle, 2007; Cass, 1979; Markowe, 1996). Currently, LGB women with intellectual disabilities are at higher risk of mental distress, given their likelihood at having reduced opportunities for affiliation with others and reduced social support networks, both factors that have been shown to reduce, or ameliorate, the impact of minority stress.

4.2.3. Feeling Included in Society and the Impact on Identity

Within the women's stories there were clear accounts of the importance of feeling accepted and visible. In contrast to the section above, participants described the places and people who accepted them as individuals. This included certain support staff and family members who played an integral part in helping them to have a positive self-identity and to be able to talk about their sexuality. Proactive support from others in these instances also helped the women to continue to construct their sexual identity.

A strong message from participants was the need to be seen and visible in society. LGBT Pride events held importance for a number of participants who saw this as an occasion to celebrate diversity and inclusivity. They desired for more LGBT venues and groups to be inclusive of all people and to think about the specific needs of people with disabilities. They also desired for specific spaces for people with intellectual disabilities who are LGBT. This was important in being able to identify with other people who they perceived to be more like them.

Apart from some research which has explored the effects of LGBT support groups for people with intellectual disabilities (Elderton & Jones, 2011; Tallentire

et al., 2016; Withers et al., 2001), there has been little research to date about areas where LGBT people with intellectual disabilities feel included and well supported. In this research, the areas of women's lives in which they felt accepted as an individual marked the areas where they felt happy and included. For some this was their family, for others supportive staff and support organisations and, for others, LGBT groups had an important role. Participants who were observed to feel the most accepted and were accessing the most LGBT affirmative and inclusive places, seemed to have the clearest sexual identity and spoke positively about relationships and their sexuality.

LGBT Pride events also featured strongly as a place of potential inclusion, where other LGBT people were visible and heterosexual people were seen to take a stand to support sexual diversity. Goffman (1963) noted that a characteristic which is denigrated and stigmatised in one context may be a source of pride in another; and this process can be seen in LGBT Pride events and the use of the rainbow flag. As the opposite of shame, pride has become central as a form of resistance against the shame and stigma attached to LGBT identities (Halperin & Traub, 2009; Taulke-Johnson, 2008). In the words of Howarth (2011) "identity is both restricted by and liberated by its very visibility" (p. 242). In contrast to confusion over the use of LGB labels and the language attached to their sexual identity, the women were able to strongly identify with the symbolism and celebration of LGBT Pride. However, in reality it was not always an inclusive environment due to lack of accessibility and the invisibility of people with disabilities.

Despite being given free reign to choose which photographs to represent their sexual identity and places of inclusion or exclusion; the women in this research all chose photographs depicting parts of their LGB identity which were wholly positive, such as them with family, friends, their partner or celebrating being at pride. During photovoice interviews, participants spoke more about valued social roles and the conversations led to clearer representations of a positive sense of self.   Perhaps even more significant that women with intellectual disabilities who have shown their awareness of being 'lesser' and experiencing layered stigma, chose to focus on their strengths and the spaces in which they felt their identity was accepted and embraced. Similarly research with people

with intellectual disabilities who had mental health diagnoses showed that, aware of their perception of incompetence, they used strategies to represent more positive social roles (Whittuck, 2014).

4.2.4. Psycho-Social Support that Women with Intellectual Disabilities Have Found Helpful in their Expression of Same-Sex Attraction

There is inevitable overlap between where LGB women with intellectual disabilities feel included and what has been helpful for them, in terms of what has enabled participants to feel a sense of acceptance and inclusion. The importance of being able to access the LGBT community, and other people who identify as LGB, was strongly articulated by participants. This mirrors conclusions made from a number of researchers who have argued about the importance of access to gay social contexts and networks for gay men with intellectual disabilities (Davidson-Paine & Corbett, 1995; Tallentire et al., 2016; Withers et al., 2001). Contact with LGBT contexts, culture and with other LGBT individuals may not only have a positive impact on self-esteem and psychological well being (Frable et al., 1997; Pistella et al., 2016), but it might also be imperative for LGB women to express their sexuality. Indeed, Markowe (1996) argued that the need for affiliation with other LGB women was so strong that it was designated high importance in the process of forming a non-heterosexual identity. Participants also felt able to speak more easily with female staff members who openly identified as lesbian, which echoes results from previous research with LGBT people with intellectual disabilities showing that they could talk about issues with LGBT staff that they thought was otherwise taboo (Stoffelen et al., 2013).

The need for supportive others, such as staff and family members, to take the lead in helping women with intellectual disabilities who express a minority sexuality to have a positive self-identity was evident in the women's accounts. A number of the women spoke of important people who had helped them to discuss their sexuality. Some of the women needed this to realise that it was acceptable for women to be attracted to other women. However, research with support staff has shown that staff were reluctant to take the lead in relation to sexuality and did not always see it as their role, particularly in relation to

minority sexualities (Abbott & Howarth, 2005). Furthermore, parents of people with intellectual disabilities have been seen to struggle to think of their sons and daughters as sexual beings (Evans et al., 2009; Garbutt, Boycott-Garnett, et al., 2010). This research suggests that it is vital, however, for family and support staff to proactively support women with intellectual disabilities with their sexuality and to include sexual diversity in sexual education and training, and in general conversations about, and representations of, sex and relationships.

4.3 Critical Evaluation of the Research

4.3.1. Limitations

This is one of very few studies exploring the experiences of LGB women with intellectual disabilities, as such, it provides much-needed and valuable findings to the literature on disability and sexuality. However, as with all research, there are some limitations and other aspects of quality that need to be considered.

The sample size of this research could be said to be relatively small for qualitative research. However, LGB people with intellectual disabilities are a very small population, often thought of as a minority within a minority (Bennett & Coyle, 2007). Indeed, investigating the experiences of this marginalised and hidden group in society has resulted in research with similar sample numbers (Dinwoodie et al., 2016; Withers et al., 2001). Furthermore, as detailed in the introduction, women with intellectual disabilities who identify as gay, lesbian or bisexual have been reported to be even harder to recruit (Abbott & Howarth, 2005); as such, with the exclusion of men with intellectual disabilities from this research, a small sample size was anticipated. However, the present sample provided rich data, which was further enhanced by the addition of photovoice interviews, on top of the researcher led interviews. Perhaps future research in this area, however, could consider using a grounded theory or a narrative analysis methodology, which would allow for more in depth analysis with smaller sample sizes, particularly if recruitment of participants continues to be difficult. Using a narrative analysis might be useful, for example, at being able to explore how early life experiences, and narratives about people with

intellectual disabilities as incompetent or non-sexual, might influence being able to communicate with others about an LGB sexuality.

The sample was also unique in some ways. All of the participants had proactive caregivers, family or support staff, that acknowledged, accepted and supported their non-heterosexual sexuality. Indeed, due to the recruitment methodology, five of the participants had been put in contact with the research project through support staff or family members, and one participant had volunteered when the researcher attended an LGBT support group. The findings, therefore, may not be representative of the broader population of LGB women with intellectual disabilities, some of whom are likely to be more isolated and in environments where they perceive homosexuality to be something negative, or not to be spoken about, where the possibility of identifying as LGB could be an even greater one. These women who are less well supported remain an extremely hard-to-reach group to recruit to research. Furthermore, although the sample represented a range of ages, there were no young adults, and so it does not include participants who may be grappling with emerging sexuality issues.

Using Skype video-calls was a flexible and adaptable approach to interviewing participants who were such a hard to reach population and geographically spread; nevertheless, it may have come with some costs. Developing trust and rapport in research interviews is highly important (DiCicco-Bloom & Crabtree, 2006), and particularly so with people with intellectual disabilities (Prosser & Bromley, 2012). Although rapport was still a high priority and could be established with participants through this method, doing interviews via a computer screen would inevitably add some barriers to the process. Indeed, it may have made the researcher's questioning or responses more cautious due to not being able to read as many non-verbal cues and, similarly, it might have made participants' responses more restrained.

4.3.2. Quality of the Research

There have been a number of different quality frameworks and guidelines created to assess the quality of qualitative research (Elliott, Fischer, & Rennie, 1999; Spencer & Ritchie, 2012; Treharne & Riggs, 2015; Yardley, 2000). Here

the quality principles outlined by Spencer and Ritchie (2012) were thought to be a helpful guide for evaluating the quality of this research, considering particularly: the contribution, credibility and rigour of the research.

4.4.2.1 Contribution: Contribution refers to the perceived value of the research findings to areas such as theory, policy, practice, methodological development or to the lives of individuals (Spencer & Ritchie, 2012).

With regards to theoretical impact, this research was unique in its exploration of the sexual identities of non-heterosexual women labeled with intellectual disabilities, a population that has been under-researched and under-represented. The study was also innovative in its use of photovoice to further understand the experiences of these women and to enable the participants to actively participate and engage in the research as more than just 'subjects'.

With regards to policy and practice, the research has led to clear recommendations for research (detailed below, in section 4.5). It has also pointed to areas of clinical practice that need improvement, concluding with recommendations for both services that support people with intellectual disabilities, and services that advocate for the LGBT community. An important part of the research impact and contribution lies in the dissemination of the research findings. The research will be fed back to participants and their supporters and there are plans to produce at least one academic journal article, and one accessible summary article from the research. It is hoped that some of the participants who have expressed an interest will be involved in co-producing the accessible version of the research findings for people with intellectual disabilities. This is important for a number of reasons, not least in that it privileges the voice of people with intellectual disabilities in research and ensures that the research is written up in a way that is accessible (Garbutt, Tattersall, Dunn, & Boycott-Garnett, 2010).

Lastly, it is hoped that the research had some impact and value for the individuals who took part, in being able to talk about their sexuality openly and honestly. As demonstrated in the research, this is an area of life that has often been invisible and unspoken about and so, by partaking in the research, it is

hoped that it gave participants the opportunity to reflect on their own experiences and the importance of their experiences. It is hoped as well that this may also help other women with intellectual disabilities in the future who might be questioning their sexual identity, people who may feel isolated, stigmatised or alone. In an article reflecting on his research with LGBT people with intellectual disabilities in the UK over a decade ago, Abbot (2015) commented that after the research:

> "…a woman with learning disabilities from Alaska got in touch to say that she had found our photograph stories on the internet and was thrilled that she might not be the only lesbian with learning disabilities in the whole world" (p.103).

Thus, demonstrating the potential impact research can have, when disseminated well, to marginalised and isolated groups in society.

4.4.2.2 Credibility: Here Spencer and Ritchie (2012) refer to the defensibility and plausibility of the research findings, including the ability to see how any claims have been concluded upon. Credibility can be assessed on the evidence presented within the research, including the extracts of data used, interpretive accounts, explanations of theories and the inclusion of diagrams and examples.

Within this research, data extracts were used to demonstrate each theme and subtheme, which allowed for an appraisal of the fit between the interpretation made and the data provided. Furthermore, a detailed account of the design, data collection and analysis process was incorporated into the research; including an example transcript and detailed audit trail of the thematic analysis process of theme development (Appendices 11-15). In addition, the research supervisor also reviewed transcripts and the initial codes and themes generated from the research data, thus, providing a credibility check.

4.4.2.3 Rigour:
Under this principle, Spencer and Ritchie (2012) invite researchers to consider the transparency of the research process, the defensibility of the design and

thoroughness of conduct. Transparency and reflexivity was assigned high importance during this research project. The researcher sought to critically reflect on her role and impact in the research, in both the methodology (section 2.8) and in the section below (4.4.3), as well as in a reflective diary kept throughout the project (Appendix 16). The values behind the research and decision-making processes during the recruitment and analysis stages have been explained. The researcher has also been transparent and carefully documented the research process, including a copy of relevant documentation such as information sheets, emails and consent forms.

4.3.3. Researcher Reflexivity

As outlined in the methodology chapter, the perspectives of researchers influence the research process. Within qualitative research it is important to be transparent and to critically reflect on the inter-subjective relationships between the researcher, the participants and the data (Yardley, 2000). The process of reflexivity seeks to make the researchers' role in developing interpretations more explicit (Stevenson & Cooper, 1997).

Here, I could consider a variety of aspects to my identity which may have overlapped or conflicted with the research area and participants accounts and experiences. In particular though, I occupied an insider perspective to identifying as a non-heterosexual female.

In some ways I shared similar experiences to some participants, such as fear of coming out and mixed responses to my sexuality from wider society. What struck me during interview and analysis stages, however, was the additional difficulty of negotiating this process when labeled with an intellectual disability. I felt a strong sense of injustice and sadness for participants who were the most isolated and alone in their sexual identity. Knowing the importance in my own life of having LGBT friends and being able to identify with other LGB women in my life, it left me with a feeling and wish to do something in order to connect these women with others. However, I was cautious not to attribute too much of my own emotions and experiences onto participants' accounts. In being able to reflect about these personal feelings with both the research supervisor and in a

reflective journal, I was able to create more distance with the accounts and to not neglect the supportive and positive aspects of individual's experiences that were also evident.

Upon reflection, I noticed also that participants spoke less about their sexual experiences. Whilst this was not the core aim of this research, I wonder if I could have probed more about this aspect of their experience, so that participants had the opportunity to speak about sexual experiences if they so wished. They may not have felt as able to talk about sex, a potentially more difficult or taboo topic, without it first being aired by me. I worried afterwards that perhaps I might also have been impacted by the social construction of women with intellectual disabilities as asexual, or felt uncomfortable raising the topic of sex due to my own personal discomfort. However, reflecting further into the interview process, I acknowledged that for some of the participants speaking about their sexual identity and relationship preferences alone felt novel and at times difficult. A few of the participants seemed to be speaking about it in detail almost for the first time. Furthermore, as acknowledged earlier, a majority of interviews were conducted via Skype video call, with potential added difficulty in communication and establishing rapport. Within this context, I was particularly cautious to try to take the lead from participants about what they felt able to share with a researcher. A way to allow for sex to be a more easily accessed topic of conversation in future might be to include it explicitly in the information sheet for participants at the start of the interview, by talking through all aspects of sex and relationships which could be talked about if they chose to. It remains an area of interest for future research; preferably explored in face-to-face interviews and with this additional prompt in the research information.

4.4 Implications and Recommendations

In order to effectively support women with intellectual disabilities who express a minority sexuality, their specific needs and experiences need to be understood. This research explored how LGB women with intellectual disabilities described and experienced their sexual identity and where they felt included and well

supported; it has clear implications, therefore, for both future research and support for women with intellectual disabilities which will now be explored below. One of the most notable aspects of the research, the near invisibility of LGB women with intellectual disabilities, has consequences for both clinical and research practice and so will be explored firstly. Followed by a look at others implications in these areas.

<u>4.4.1. Absence and Invisibility of LGB Women with Intellectual Disabilities</u>
LGB women with intellectual disabilities have been shown to be a hard to identify and hard to reach population. It seems likely that there are multiple interacting reasons for the absence and invisibility of women with intellectual disabilities who identify as non-heterosexual. Using the findings in this research together with previous research, I propose below some of the main barriers obstructing women with intellectual disabilities to develop or voice an LGB identity and, thus, to explain their absence in services and in research.

4.4.1.1 People with intellectual disabilities, especially women, are not sexual beings: Women with intellectual disabilities have rarely been supported to develop full adult and sexual identities, instead being treated as perpetual adolescents (Fitzgerald et al., 2013). In the words of one member of staff, reflecting back at their earliest support worker role:

> "I admit that at the time, I believed that individuals labeled with an ID [intellectual disability] did not have much interest in sex or sexuality or that it was preferable to limit discussion regarding these subjects to protect them, lest they interact in socially inappropriate [ways]" (Winges-Yanez, 2014, p. 110).

Support staff have viewed women with intellectual disabilities as more sexually innocent and uninterested in sex and relationships (Young et al., 2012). These ideas have served to deny women with intellectual disabilities access to sex education and accessible information about diverse sexualities (Burns & Davies, 2011; Garbutt, Boycott-Garnett, et al., 2010). Thus, the culture around

women with intellectual disabilities continues to limit discussion of sex, relationships and sexuality.

4.4.1.2 Support with sexuality is focused on protectionism and risk aversion: When support has been provided it has regularly been dominated by the avoidance of risk and protectionism, and within this domain, women with intellectual disabilities who are LGB may come very low down on the list of priorities. Indeed, the sexuality of women with intellectual disabilities who are attracted to other women is likely to be perceived as less risky than men with intellectual disabilities, both gay and straight, who have regularly been viewed as hypersexual or at risk of contracting HIV (Cambridge, 1997b; McCarthy, 1999); likewise, female same-sex interests are likely to be perceived as lower risk than heterosexual women with intellectual disabilities who might be more at risk of getting pregnant. Indeed, in Abbot and Howarth's (2005) research, they found that female same-sex relationships were far more hidden than relationships between men, partly due to relationships between women being assumed to be unproblematic and platonic. Thus, LGB women with intellectual disabilities may go unnoticed, ignored and neglected in support of their sexuality.

4.4.1.3 Restrictive and heterosexist cultures: The influence of heterosexism on support services and in wider society can be seen to limit the acceptability of non-heterosexuality for people with intellectual disabilities. Indeed one of the participants in this research commented on the lack of acceptance or consideration of sexual diversity when she rang organisations to try to organise an LGBT meet-up event: "Some people we rang up said "oh, none of our people are like that"" (Heather). This is concerning, as the attitudes of family and staff have been seen to be very influential on the views of people with intellectual disabilities (Healy et al., 2009; Noonan & Gomez, 2011).

A recent thesis which explored the role of support staff in supporting adults with intellectual disabilities with sex and relationships, highlighted the potential role that heteronormative staff cultures and attitudes may play in silencing some LGBT women with intellectual disabilities (Cifelli, 2017). In the words of one of the support worker:

"We have um, in one of my services at the moment we have a lady who is very, very confused about her sexuality and when I first started working there, she um, she told me that she does – she's a lesbian. "I am a lesbian but don't tell anyone". And I was like "why can't – why is that a secret?" and she was like "I don't want anyone to know" and then I realised that the culture in the service, not just from the staff but the other people – sort of they're boyfriend/girlfriend, very hetero you know what I mean, and she was sort of lost in that. And what's really sad is she's now, engaged to be married – to a gentleman." (Cifelli, 2017, p.58)

4.4.1.4 Women with intellectual disabilities are less aware of sexual diversity and have fewer positive representations of non-heterosexuality: Models of lesbian and gay identity formation describe the difficulty in overcoming initial internalised stigma and negative perceptions of non-heterosexuality. Vital in the process of developing an LGB sexual identity is an awareness of same-sex relationships and "lesbianism as an option" (Markowe, 1996, p. 194). However, due to the factors described above, women with intellectual disabilities are less aware of non-heterosexuality and, potentially, have much fewer positive representations of minority sexualities (Burns & Davies, 2011). People with intellectual disabilities generally have much smaller social networks (Borawska-Charko, Rohleder, & Finlay, 2017); furthermore, support staff, have been shown not to be open about their sexual identity with people with intellectual disabilities (Abbott & Howarth, 2007). This combination of reduced social opportunities and lack of openness makes it more unlikely that women with intellectual disabilities will encounter others who demonstrate sexual diversity and positive examples of same-sex relationships. Contact with other LGBT people has been shown to be important in beginning to identify with and develop a more positive view of a stigmatised identity (Clarke et al., 2010; Dietz & Dettlaff, 1997; Markowe, 1996). Without this, women with intellectual disabilities may never express their sexuality, or remain isolated and cut off.

In summary, therefore, due to the way women with intellectual disabilities are positioned in society they are rarely offered the same level of information about sex, relationships and sexual diversity. Often they have smaller social networks

and potentially fewer LGBT role models in their lives. As a consequence, a number of women with intellectual disabilities may never come to recognise same-sex attractions. Due to restrictive and heteronormative cultures, other LGB women with intellectual disabilities may stay in the closet and never talk about their sexuality, which may partly explain why LGB women with intellectual disabilities are such a hard to reach group in research.

Combining all these factors, it is not hard to see why so few women with intellectual disabilities come out as LGB, present to services, or take part in research; especially when combined with the lack of direct access to women with intellectual disabilities and risk averse and heterosexist services, which may gate-keep people from getting near the research process. Furthermore, it can also explain why women with intellectual disabilities who have identified as LGB continue to grapple with their sexuality, feel isolated and alone, are unrepresented and feel unaccepted by wider society and those closer to home. In order to support LGB women with intellectual disabilities to be able to develop positive sexual identities, and feel less abnormal and isolated in society, changes are needed to how women with intellectual disabilities are supported generally.

4.4.2. Implications for Clinical Practice

Helping all women with intellectual disabilities to have more knowledge of minority sexualities and more positive representations of LGBT lifestyles would seem imperative to supporting more women to develop a sexual identity. As described above, LGB women with intellectual disabilities face many barriers to developing or accepting their own sexuality. Women with intellectual disabilities in this research were aware of the negative discourses and representations of both disability and non-heterosexuality. These negative ideas and discourses could impede many women from accepting their own sexual desires. However, it has been shown that sex education can improve the perceptions and attitudes towards non-heterosexuality in people with intellectual disabilities (Lindsay, Michie, Staines, Bellshaw, & Culross, 1994). Women with intellectual disabilities need to be provided better sex education and accessible easy-read information about sexual diversity (McCann et al., 2016). Importantly,

information, education and support for people with intellectual disabilities should focus on more than just sexual health and consent but also on wants, needs, desire, pleasure, and ways to have, if wanted, consensual sexual and loving relationships. Furthermore, sex and sexuality should be voiced and spoken about in day-to-day life, rather than as a one-off training or "single inoculation model" which is likely to be an ineffective method of learning for the majority of people with intellectual disabilities (Murphy & Callaghan, 2004, p. 1356).

Clinical psychologists and other professionals working in community teams for people with intellectual disabilities need to be actively LGBT affirmative. An LGBT affirmative approach provides a positive framework which acknowledges all gender identities and sexual orientations as equally valid (Halpert, Reinhardt, & Toohey, 2007; Langdridge, 2007). In such an approach practitioners need to affirm sexual identities rather than reinforce experiences of stigma and marginalisation, by demonstrating an understanding, accepting, and supportive attitude toward minority sexualities. The British Psychological Society (BPS 2012) guidelines for working with Sexual and Gender Minority Clients, encourages psychologists to work affirmatively and self-reflectively with sexual and gender minority clients and for psychology training courses to include issues of gender and sexuality within their regular teaching, rather than a tokenistic inclusion LGBT issues. Working affirmatively and proactively, clinical psychologists working in community learning disability teams would be well placed to take the lead in delivering inclusive sexuality training to support staff, providers and families of people with intellectual disabilities.

Clinical psychologists need to move beyond the individualised approach to 'assessment and treatment' of people with intellectual disabilities resulting in therapy and interventions which internalise problems within individuals. Clinical psychologists have been complicit in problematising sexuality for people with intellectual disabilities through reactive capacity assessments and individualised interventions. Indeed, clinical psychology is not a neutral endeavour removed from wider social and political context, rather it is value-laden and can act to reinforce an unjust status quo and further marginalise individuals (Clarke & Peel, 2007). In the words of Kitzinger (1997), "what political choices are they

[psychologists'] making in focusing on the problems of the oppressed rather than on the problem of the oppressor?" (p. 213).

Here, community psychology, which focuses on social change and justice, could offer much to the support of women with intellectual disabilities who are further stigmatised by their sexuality. By locating problems in their social and cultural context, community psychologists instead focus on the strengths of people who have been marginalised by society (Nelson & Prilleltensky, 2010). Community psychology could provide a way to challenge the structures and social practices that stigmatise and discriminate women with intellectual disabilities who are non-heterosexual. However, currently community psychology practices are still largely on the periphery of services within the UK (Burton & Kagan, 2003). Indeed, despite the work of prominent researchers in this area, such as Burton and Kagan (2003), community psychology has rarely featured in the support of people with intellectual disabilities, and even less so, LGB people with intellectual disabilities. For instance, the BPS (2016) guidance on working therapeutically with people who have intellectual disabilities makes no mention of community psychology approaches at all. Thus, much more work needs to be done in this area to demonstrate the potential usefulness of community psychology in this area.

Although clinical psychologists have appeared largely absent from this field, activist and advocacy organisations have worked to push for the respect of rights for people with intellectual disabilities to have sex and relationships, no matter what their sexuality. For example, the Lancashire Friends and Relationships Group campaigned for the Care Quality Commission (CQC), who inspect all support provider organisations, to include inspection questions specifically on how organisations are supporting sex and relationships (Sharples, 2017). Another initiative, The Supported Loving Network[1] is a network of staff, organisations and people with intellectual disabilities who aim to share best practice amongst those who are proactively supporting and empowering people with intellectual disabilities to express their sexual identity through sexual and/or romantic relationships (Snell, 2018). Advocacy groups

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[1] For more information view: http://www.centreforwelfarereform.org/our-work/supported-loving.html

provide a space particularly designed to enable people with intellectual disabilities to voice opinions and speak for themselves, and therefore may provide an ideal setting to explore the topics of sexuality and relationships (Azzopardi-Lane & Callus, 2015).

4.4.3. Implications for Service and Policy Development

To influence barriers at a societal level requires clinical psychologists to actively engage in policy development. Policy work can engender change and therefore could be used to develop services to address the needs of LGB people with intellectual disabilities. Clinical psychologists could be instrumental at joining LGBT services, sexual health services and services for people with intellectual disabilities, which currently occupy separate silos. Services need to work together to ensure that support and LGB spaces are created specifically for people with disabilities. Work also needs to be done with LGBT venues and organisers of LGBT Pride events to think about reasonable adjustments for people with intellectual disabilities, such as, clear easy read information and physical accessibility. LGBT support groups for people with intellectual disabilities have shown many benefits (Elderton & Jones, 2011; Tallentire et al., 2016; Withers et al., 2001), but are currently far too few; joining with local services to provide LGBT friendly spaces and support groups for people with intellectual disabilities should be a high priority.

The visibility of support staff and other key people in the person's life who are openly LGBT played an important role for some of the women in normalising minority sexualities. Staff who identify with a minority sexuality should be supported to be open and 'out' to the people they support if they so wish; a conclusion also drawn by Abbott and Howarth (2007) and Bennett and Coyle (2007), who argued that it might help to increase the number of LGBT role models in the lives of people with intellectual disabilities. Sex and relationship policies within support organisations also need to be clearly LGBT affirmative and state how they propose to support the sexualities of the individuals they support. Training of staff to be confident in talking about sex, relationships and sexual diversity is imperative. Support staff also need to know the potential

importance of Pride and LGBT events for the LGB people they support and proactively support people to attend if they wish to.

4.4.4. Implications for Future Research

Researchers have typically neglected the intersection of sexuality and disability. Sexuality studies have largely neglected the sexuality of people with disabilities and disability texts have commonly failed to mention sexuality, a topic that continues to create anxiety (Butler, 2012; Rohleder & Swartz, 2012). In the words of Butler (2012), "the majority of texts that write about areas of social difference take a single-issue focus" (p.13).   This is problematic because it ignores the interaction between different identities and the layering of stigma and oppression on people who occupy two or more potentially devalued positions in society.

Not enough is known about the development of LGB sexual identity for women with disabilities. Models of sexual identity formation typically focus on non-disabled people (Cass, 1984; Coleman, 1982; Markowe, 1996). While these were drawn on in this research to try to understand what might be similar for LGB women with intellectual disabilities, more research is needed to explore the specific process of sexual identity development for LGB people with intellectual disabilities.

Photovoice was an accessible and helpful addition to the research. As described earlier, there was a 'felt' difference between the photovoice interviews and the researcher led interviews. Photovoice allowed for discussions of LGB women's sexual identities and other aspects of their life and identity to be woven together and discussion of the women's values and things most important to them. Indeed, unlike previous research which focused almost completely on the negatives aspects of LGB identity expression for people with intellectual disabilities, using photovoice provided a different lens and participants all chose pictures which related to where they feel accepted, included and happy. Future research is needed to evaluate if participants felt a difference between these two interview procedures and to explore how it was experienced for them.

Using a photo-elicitation method removed some of the challenges for researchers to use photovoice with people with intellectual disabilities. Photovoice had been seen to require "considerable investments in time and resources" (Wang & Burris, 1994, p. 183). However, by moving to a photo-elicitation method, utilising participants existing images, the process was much quicker than had been anticipated (Reavey, 2011). Participants tended to choose pictures quickly, so there was no big time lag between interviews. This changed the process of photovoice away from photo-production, as the participants did not actively take photographs related to the research topic. However, in the age of the smart phone, participants all had pictures readily available to them, which they related to their sexual identity and being LGB. Thus, by removing one of the biggest barriers to this participatory research approach, it is hoped that more researchers could consider photovoice methodology as an accessible and inclusive research tool.

Within the literature base on the experiences of LGB people with intellectual disabilities, there remain a number of even further hidden groups who are currently unheard from. For instance, women who may be questioning their sexuality, or may be expressing some non-heterosexual behaviours, but not identify as LGB. Also participants who are less able to communicate verbally and would usually be excluded from research for that reason (Fish, 2016). Ethnographic research may be useful in this area, as it has been shown to help enable people with less verbal communication or who may be less articulate to be able to participate in research (Tim Booth & Booth, 1996; Fish, 2016). Photovoice has also been used with people with intellectual disabilities who are non-verbal, where the photographs have been analysed instead of a spoken interview (Povee et al., 2014). Research is also absent from LGB people with intellectual disabilities from black and minority ethnic backgrounds. Here, the potential barriers of additional stigma and the different experiences of those from diverse cultural backgrounds need to be explored.

The recruitment of participants was extremely difficult. As described above, there are numerous barriers to women with intellectual disabilities identifying as LGB, which may partly explain their current absence from research. Combined

with the additional difficulties of researching a topic that might feel sensitive, personal or anxiety provoking to talk to a researcher about, and the necessity of accessing women with intellectual disabilities usually through others who can act as either supporters or gatekeepers. Until more women with intellectual disabilities are effectively supported with their sexual identity, whatever sexual orientation they may identify with, it is unlikely that many more women with intellectual disabilities will express or voice a non-heterosexual identity. Change might happen extremely slowly, as wider representations of non-heterosexuality in society, the media and within communities, filters down to people with intellectual disabilities. However, research in this area is likely to continue to be difficult until there are wider changes in attitudes towards, and support of, women with intellectual disabilities. Nevertheless, future research is needed, to vocalise, publicise and share the experiences of these women. Time and resources will be needed to invest in publicising and recruiting LGB women with intellectual disabilities. Partnerships with organisations working in LGBT and/or disability sectors might assist recruitment. Furthermore, a participatory and inclusive form of research may aid some women to feel more able to take part. In the words of a project worker who was looking to set up an LGBT group for people with intellectual disabilities:

> "We know from our experience last time it will be a slow-burner. So, to anyone thinking of starting a similar group the message is, do the groundwork, allow enough time for it to become established and get your LGBT service users on board – they are the best ambassadors to help spread the word" (Snell, 2018, p. 9).

4.5 Conclusion

LGB women with intellectual disabilities have been under-researched, unrepresented and little understood. Social constructions of the sexuality of women with intellectual disabilities have regularly served to keep sex and relationships off the agenda. Furthermore, non-heterosexual identities have been seen as even more problematic and largely viewed as irrelevant for women with intellectual disabilities. This research provides one of the first

focused explorations with women with intellectual disabilities who identify as lesbian, gay, bisexual or in a same-sex relationship. For these women who have expressed a minority sexuality, they face additional stigma and discrimination. Some participants described experiencing exclusion from their families, from wider society and from the LGBT community. However, there were also places where they felt well supported and valued. This research, thus, provides much-needed and valuable findings to the literature on disability and sexuality, and also on the use of photovoice with people with intellectual disabilities. The difficulty of recruiting participants, combined with the isolation and invisibility of LGB women with intellectual disabilities demonstrates how few women with intellectual disabilities are supported with their LGB sexual identity.

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6. APPENDICES

<u>Appendix 1. Literature review strategy</u>

The following search terms were used to retrieve literature related to people with intellectual disabilities and sexual minorities. The key terms were used in combination with the Boolean operators 'AND' or 'OR'.

- "Learning disab*"
- "Intellectual disab*"
- "Developmental disab*"
- "Intellectual impairment"
- "Mental retard*"
- "Mental handicap"
- "Mentally handicapped"
- "Mental deficiency"

AND

- "homosexual*"
- "lesbian*"
- "gay"
- "bisexual*"
- "transgender*"
- "transsexual"
- "queer"
- "LGBT*"
- "Sexual minorit*"

In addition the search was also conducted with Down syndromes, Prader Willi syndrome and Fragile X syndrome in place of intellectual disabilities but these did not return any additional studies. Limits applied to the searches included language as English and in peer-reviewed journals only.

Appendix 2. Table of core studies

Authors and Title	Country	Analysis	Sample	Aims	Key Findings/Recommendations
Withers et al, 2001. A Psychoeducational group for men with ID* who have sex with men.	UK	Content Analysis	5 men	Evaluate the effectiveness of the group according to: - The extent to which participants demonstrated improved psychological well-being in relation to their sexual identity; and - Levels of awareness of safety issues, with regard to partner choice and safe sex practices.	Themes: Increased accessing of 'gay' community resources by group members; aspects of group membership such as 'making new friends' highly valued; new references to sexual orientation and positive aspects of this; described less progress in relation to understanding safe sex and partner choice. Recommendations: for future support groups.
Bennett & Coyle, 2007. A minority within a minority: experiences of gay men with ID.	UK	IPA	10 men	Investigate how gay men with ID represented and/or developed a gay identity and how they navigated threats to identity from marginalized social positions	Themes: Developing a gay identity; stigma and intellectual disability/gay identity; social isolation/desire for affiliation with gay 'community' contexts; Sense of belonging; Restrictions of being in care. Recommendations: Services need to be more aware of the impact of staff attitudes about homosexuality; Need more staff training; gay-identified staff should be supported to support gay social contexts; clinical psychologists should take a lead in training of staff and setting up support groups for gay men with ID.
Abbott & Burns, 2007 What's love got to do with it?: experiences of LGB people with ID in the UK and views of staff who support them.	UK	Ground Theory	20 people [11 men 9 women]	To explore sexuality, coming out, responses from others, relationships, sex, harassment, experience of LGB groups/venues, support for the future, hope & dreams.	Themes: Talk about love; reluctance to come out; discrimination; social isolation; lack of support. Also discussed negative discourses of sexuality and ID; staff defensiveness; LGBT community unwelcoming; risks of loneliness, isolation and depression. Recommendations: Importance of love and relationships should be prioritised; Should be staff duty to support sexuality.
Stoffelen et al, 2013 Homosexuality among people with a mild ID: an explorative study on the lived experiences of homosexual people in the Netherlands with a mild ID.	Netherlands	Analysis not stated	21 people [19 men, 2 women]	Exploratory study. Research qu's: How do people with an ID who are LGB experience their daily lives? What positive/negative experiences do they encounter? What are their needs? What is their lifestyle like?	Themes: Sexual experiences; gay or lesbian identity; support; family; partner. High prevalence of negative sexual experiences/abuse. Not open about sexuality in all settings; need for support in finding a partner. Recommendations: Specific training programmes for people with ID on sexuality; training for staff to be more confident in discussing sexuality; prioritise the reduction and prevention of discrimination in the working and living environments of people with ID; Create and publicise meeting places for LGB people with ID.
Tallentire et al, (2016) Stories of people who have attended a LGBT support group in a secure ID service.	UK	Narrative analysis; participatory	9 people & 9 more co-researchers. [17 men, 1 woman]	Investigate what people's experiences were of attending an LGBT support group in a secure intellectual disability service. The support group was designed to talk about issues relating to LGBT sexuality and gender.	Themes/Story: Deciding to go to the group: identity and coming out; starting to attend the group: fear and name-calling; becoming able to be yourself when at the group; developing pride in who you are: this changes your life; wanting to help others with their sexuality: pride in achievements; wanting to carry on the work elsewhere: future direction in life. Recommendations: Continued investment in the LGBT support group; suggestions for the setting up of other groups; recommendations for future research such as the attitudes of staff and the views and needs of women.
Dinwoodie et al, 2016. Them two things are what collide together: Understanding the sexual identity experiences of LGBT people labelled with ID.	UK	IPA	5 people [3 men, 1 woman, 1 trans bisexual woman]	Explore how LGBT people with ID experience their sexual identities. (Also in relation to how see themselves, when coming out, strengths, role models and decisions to come out).	Themes: Living with abuse and discrimination; understanding sexualities; other's responses to intellectual disabilities and sexualities; navigating acceptance from others. Recommendations: Services should be unambiguously affirmative about LGBT identities. Staff should ask direct questions to facilitate those who want to come out. Psychologists should link with local services, offer training and create LGBT resource packs.

*ID = Intellectual disability. **LD= Learning Disability

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Appendix 3. Email template to organisations

Dear xxxxxx,

I'm contacting you as I hope that you or your organisation may be able to help.

My name is Fiona Rooney and I am a trainee clinical psychologist at the University of East London. As part of my course I will be completing a doctoral level piece of research exploring the experiences of women with learning disabilities who are attracted to other women.

Women with learning disabilities who are lesbian, gay or bisexual (LGB) are a hidden and marginalised group in society. LGB women with learning disabilities are almost entirely absent from research and lesbian sexuality is one of the least understood forms of sexual expression for women with learning disabilities.

My study involves interviewing women on their experiences of being gay and having learning disabilities. I have attached a flyer and an information sheet which contain further information about the research and what the process would involve for people who may be interested in taking part.

The study has received approval from the University of East London.

If you are able to, please let me know if you think there are any women supported by your organisation that may fit the criteria and might be interested in taking part.

For some people it may be too daunting to get in touch with a researcher whom they do not know. I'm very keen to try to break down any barriers to taking part and I can come to speak with an individual/group directly about the study to explain more.

If you feel it's appropriate, I could come to your organisation to meet with anyone who is interested so that it is in an environment in which they feel supported and familiar.

If you have any questions about my research, please do not hesitate to contact me.

Best wishes,
Fiona Rooney
Trainee Clinical Psychologist

Are you lesbian or bisexual and have a learning disability?

- I want to hear about the experiences of women with learning disabilities who date other women or are attracted to women.

- The study would involve me interviewing you to hear your story of what it is like to be lesbian and have a learning disability.

To find out more email Fiona at:
u1038944@uel.ac.uk

Or tell the person who told you about the research to get in touch with me. I can meet with you to tell you more about it!

University of East London
School of Psychology
Stratford Campus
Water Lane
London E15 4LZ

Information sheet

My name is Fiona Rooney. I am studying Clinical Psychology at the University of East London.

This letter is about my research study.

It has information about my research so that you can decide if you would like to take part.

What is the research about?

I want to hear about the experiences of women with learning disabilities who are lesbian or bisexual.

Women who date other women or are attracted to women.

I am interested in hearing about the places where lesbian and bisexual women with learning disabilities feel welcome and happy.

I would like to tell other people so that they learn what has been helpful for you and other women and do more of this.

What does the research involve?

If you would like to take part I will meet with you and ask you some questions about your life and about being a lesbian or bisexual woman.

I will record the interview and type it up on a computer.

I will also ask you to take photos in your life related to what we speak about. We will talk more about the types of photos you can take.

We would then meet up again to look at the pictures together and talk about them.

What will happen with the research?

I will also see what other women with learning disabilities say.
I will make a summary of the things people have told me.

I hope to write about the project in articles for psychology magazines. These magazines are often called journals.

I also want to make an easy read article for people with learning disabilities about what we find.

## What happens to the things I share? Will they be kept private?

When I write about the project I will not use your name, I will use a made up name.

I will not tell your family or the people who support you details of what we have talked about.

The only time I have to tell someone else the details of what you have told me is if you:
- talk to me about harming yourself or someone else
- or you are not safe.
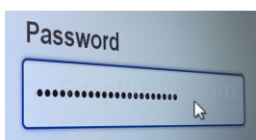
I will keep your information on computer equipment which has passwords to protect them.

Do I have to take part?

No. You do not have to take part.

Nothing will happen if you do not want to take part. It is your choice and no one else can make the decision for you.

If you say that you would like to take part, you can change your mind at any time.
You can tell me that you want to stop.

Up to three weeks after your interview, if you decide that you do not want to be in the project you can tell me and I will delete your information.

If you would like to take part I will ask you to sign your name on a consent form to say that I have told you this information. I will give you a copy of both forms.

You can ask me any questions.
Do you have any questions for me?

You can email me if you want to talk to me or ask any questions later. My email address is: u1038944@uel.ac.uk

If you have any questions or worries about how the project is happening then you can contact my supervisor. His name is Poul Rohleder.
Email: P.A.Rohleder@uel.ac.uk
Phone number is: 020 8223 6674

Or you can also contact the manager of the psychology committee at the University of East London.
Her name is: Dr Mary Spiller

Address: School of Psychology, University of East London, Water Lane, London E15 4LZ

Phone number: 020 8223 4004

Email: m.j.spiller@uel.ac.uk

Thank you for taking the time to hear about my project.
Fiona Rooney
Trainee Clinical Psychologist

Appendix 6. Interview schedules

Appendix 6.1. Schedule for Interview 1

- Welcome
- Explain purpose of the interview and what it involves
- Any questions?
- Go through information sheet and consent form
- Thank for taking part
- Any questions before start?

Initial exploratory questions and demographic details

- Age, type of accommodation, area live in, significant relationships, working? how like to spend your time?

Would you call yourself lesbian / gay / bisexual?
- If not how would you describe it?
- Would you say that you are attracted to women?

(Use the term the person has used for *LGB* throughout the rest of the interview – i.e. lesbian / gay / bisexual / attracted to women/ LGBT)

When did you realise that you are attracted to women?
Are you open about it with other people? Do you talk about it with other people?
How do you like to spend your time?
- Do you work?
- Do you go out/socialise?
- Do people at X know that you are *LGB*? How do they respond?

How do people respond to you being *LGB*?
- Do people react differently to you because you are *LGB*?
- Do you feel welcome as a *LGB* woman?

Are there times that you do not tell people that you are *X*?

Are there places you don't feel comfortable being *LGB*?

- When?
- Why do you not tell them?

Are you in a relationship at the moment?

- How did you meet them?
- How long together?
- If single - have you been in a relationship before?
             - do you want a relationship?
             - how easy is it to meet people to have a relationship?

Do you have friends who are *LGB*?

Do you go to places where people are mainly *LGB*?

- Can you tell me about them?
- How did you find them?
- Do other people with LD go?
- If no, do you know of any places where people go?
- Why do you not go?

Have you had any support with being *LGB*?

- Do you feel like you need support?
- Would have liked support in the past?
- What do you wish you had had support with?

Do you think there are particular things about being a woman with a learning disability who's *LGB* which are hard?

What do you think would be helpful for women with learning disabilities who are LGB?

- Do you wish things were different?
- How?

End of interview / debrief questions

How did you find the interview?

Which questions did you like?

Which questions were difficult?

Are there questions you think I shouldn't ask?

Are there any questions you wish I had asked?

Photovoice

- Explain the second interview and idea of taking pictures again

- Have a camera?

- Go through photovoice information sheet

- Invited to take or choose pictures which:

> - show where they feel included ⟦SEP⟧
> - show where they feel excluded ⟦SEP⟧
> - connect to them being LGB ⟦SEP⟧

- Explain not sexual/ explicit pictures/ nudity

- Need to get the permission of anyone else in the pictures.

Was there anything that we talked about last time which you have been thinking about or that you wanted to come back to today?

Would you like to talk me through some of the pictures you have taken?

What made you photograph that?

What do you see here?

How does this relate to your life?

Why was this important to you? Why was it important to photograph?

Does this show somewhere you feel included or excluded?

(Repeat above with other photos)

How did you find taking the pictures?

Was it hard or easy to take the pictures? Why?

Appendix 7. Consent form

UNIVERSITY OF EAST LONDON

Consent to participate in a research study

Experiences of lesbian and bisexual women with intellectual disabilities; Hearing from individuals through photovoice

I have read the information sheet about this research study, or it has been read to me. I have been given a copy to keep.

The purpose of the research has been explained to me.

I have been able to discuss the project and ask questions. All my questions have been answered.

I understand what Fiona Rooney plans to do in the research and how she will do it.

I understand that my information and what I say will remain confidential, which means other people will not see this information or be able to see my personal details.

Only the researcher and her supervisor will have access to information which can identify me, like my full name.

It has been explained to me what will happen once the research study has been completed.

I agree to take part in the research project.

Although I have agreed to take part, I understand that I can stop at any time and no longer be involved in the project.

I also understand that 3 weeks after my interview Fiona Rooney will include my words alongside other people's words so then I can no longer withdraw. My words will still be anonymous, meaning that it will not say my real name.

My Name

………………………………………………………………………………

My Signature

………………………………………………………………………………

Researcher's Name

………………………………………………………………………………

Researcher's Signature

………………………………………………………………………………

Date: ……………………
!

Appendix 8. Photo consent form

UNIVERSITY OF EAST LONDON

Consent to share photos as part of a research study

Experiences of lesbian and bisexual women with intellectual disabilities; Hearing from individuals through photovoice

I have been involved in a research study.

As part of the research, I took photos which related to the topic.

We spoke about the photos in an interview.

After the interview, I have agreed that I am happy for Fiona Rooney to include my photos when she writes about the research project.

I understand that this means that Fiona might use the photos in her thesis report about the research or in any articles for journals.

I have also got the permission of anyone else in my photos. I have taken out any photos that I (or anyone else) did not want to share.

I can change my mind at any point until Fiona has included the photos in her writing.

My Name

……………………………………………………………………………………

My Signature

……………………………………………………………………………………

Researcher's Name

……………………………………………………………………………………

Researcher's Signature

……………………………………………………………………………………

Date: ………………………

Appendix 9. UEL Ethical approval

Appendix 9.1. UEL ethics application

UNIVERSITY OF EAST LONDON
School of Psychology

APPLICATION FOR RESEARCH ETHICS APPROVAL

FOR RESEARCH INVOLVING HUMAN PARTICIPANTS

FOR BSc RESEARCH

FOR MSc/MA RESEARCH

FOR PROFESSIONAL DOCTORATE RESEARCH IN CLINICAL, COUNSELLING & EDUCATIONAL PSYCHOLOGY

*Students doing a Professional Doctorate in Occupational & Organisational Psychology and PhD candidates should apply for research ethics approval through the University Research Ethics Committee (UREC) and not use this form. Go to:
http://www.uel.ac.uk/gradschool/ethics/

If you need to apply to have ethical clearance from another Research Ethics Committee (e.g. NRES, HRA through IRIS) you DO NOT need to apply to the School of Psychology for ethical clearance also.
Please see details on www.uel.ac.uk/gradschool/ethics/external-committees.
Among other things this site will tell you about UEL sponsorship
Note that you do not need NHS ethics approval if collecting data from NHS staff except where the confidentiality of NHS patients could be compromised.

Before completing this application please familiarise yourself with:

The *Code of Human Research Ethics (2014)* published by the British Psychological Society (BPS). This can be found in the Ethics folder in the Psychology Noticeboard (Moodle) and also on the BPS website
http://www.bps.org.uk/system/files/Public%20files/code_of_human_research_ethics_dec_2014_inf180_web.pdf

And please also see the UEL Code of Practice for Research Ethics (2015)
http://www.uel.ac.uk/gradschool/ethics/

HOW TO COMPLETE & SUBMIT THIS APPLICATION

1. Complete this application form electronically, fully and accurately.

2. Type your name in the 'student's signature' section (5.1).

3. Include copies of all necessary attachments in the **ONE DOCUMENT** SAVED AS **.doc** (See page 2)

4. Email your supervisor the completed application and all attachments as **ONE DOCUMENT.** INDICATE '<u>ETHICS SUBMISSION</u>' IN THE SUBJECT FIELD OF THIS EMAIL so your supervisor can readily identity its content. Your supervisor will then look over your application.

5. When your application demonstrates sound ethical protocol your supervisor will type in his/her name in the 'supervisor's signature' section (5.2) and submit your application for review (psychology.ethics@uel.ac.uk). You should be copied into this email so that you know your application has been submitted. It is the responsibility of students to check this.

6. Your supervisor should let you know the outcome of your application. <u>Recruitment and data collection are **NOT** to commence until your ethics application has been approved, along with other research ethics approvals that may be necessary</u> (See 4.1)

ATTACHMENTS YOU MUST ATTACH TO THIS APPLICATION

1. A copy of the invitation letter that you intend giving to potential participants.
2. A copy of the consent form that you intend giving to participants.
3. A copy of the debrief letter you intend to give participants (see 23 below)

OTHER ATTACHMENTS (AS APPROPRIATE)

- A copy of original and/or pre-existing questionnaire(s) and test(s) you intend to use.

- Example of the kinds of interview questions you intend to ask participants.

- Copies of the visual material(s) you intend showing participants.

- A copy of ethical clearance or permission from an external organisation if you need it (e.g. a charity or school or employer etc.). Permissions must

be attached to this application but your ethics application can be submitted to the School of Psychology before ethical approval is obtained from another organisation if separate ethical clearance from another organisation is required (see Section 4).

Disclosure and Barring Service (DBS) certificates:

- **FOR BSc/MSc/MA STUDENTS WHOSE RESEARCH INVOLVES VULNERABLE PARTICIPANTS:** A scanned copy of a current Disclosure and Barring Service (DBS) certificate. A current certificate is one that is not older than six months. This is necessary if your research involves young people (anyone 16 years of age or under) or vulnerable adults (see Section 4 for a broad definition of this). A DBS certificate that you have obtained through an organisation you work for is acceptable as long as it is current. If you do not have a current DBS certificate, but need one for your research, you can apply for one through the HUB and the School will pay the cost.

  If you need to attach a copy of a DBS certificate to your ethics application but would like to keep it confidential please email a scanned copy of the certificate directly to Dr Mary Spiller (Chair of the School Research Ethics Committee) at m.j.spiller@uel.ac.uk

- **FOR PROFESSIONAL DOCTORATE STUDENTS WHOSE RESEARCH INVOLVES VULNERABLE PARTICIPANTS:** DBS clearance is necessary if your research involves young people (anyone under 16 years of age) or vulnerable adults (see 4.2 for a broad definition of this). The DBS check that was done, or verified, when you registered for your programme is sufficient and you will not have to apply for another in order to conduct research with vulnerable populations.

Your details

1. Your name: Fiona Rooney

2. Your supervisor's name: Poul Rohleder

3. Title of your programme: Professional Doctorate in Clinical Psychology

4. Title of your proposed research:
   Experiences of lesbian and bisexual women with intellectual disabilities;

   Hearing from individuals through photovoice!

5. Submission date for your BSc/MSc/MA research: May 2018

6. Please tick if your application includes a copy of a DBS certificate   X
                                                                                    (Appendix G)

7. Please tick if you need to submit a DBS certificate with this application but have emailed a copy to Dr Mary Spiller for confidentiality reasons (Chair of the School Research Ethics Committee) (m.j.spiller@uel.ac.uk)

8. Please tick to confirm that you have read and understood the British Psychological Society's Code of Human Research Ethics (2014) and the UEL Code of Practice for Research Ethics (See links on page 1)

X

2. About the research

9. The aim(s) of your research:

The proposed study is designed to explore the experiences of women with intellectual disabilities who have had, or would like to have, same-sex relationships.

The proposed research questions are:

- How do LBG (lesbian, gay or bisexual) women with intellectual disabilities experience their sexuality?
- What support have women with intellectual disabilities found helpful and unhelpful in their expression of same-sex attraction?
- Where do women with intellectual disabilities who are lesbian or bisexual feel included and excluded?

10. Likely duration of the data collection from intended starting to finishing date:

Data collection will start in May 2017 and finish by May 2018.

Methods

11. Design of the research:
(Type of design, variables etc. If the research is qualitative what approach will be used?)

The proposed research is qualitative, using Thematic Analysis.

The research will also use the method of photovoice. Photovoice was first outlined by Wang and Burris (1997). It is a method of participatory research where participant photos are incorporated into the research. Photovoice will involve asking participants to take photos related to the project and then using the pictures as a basis for individual interviews. Photovoice aims to enable the perspective of

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participants to be heard more authentically.   In this instance participants will be invited to take pictures which:

- show where they feel included
- show where they feel excluded
- connect to them being LGB

Participants will be asked not to take any photos of an explicit or sexual nature. They will also be asked to seek the permission of anyone else that they would like to be in their pictures.

12. The sample/participants:
(Proposed number of participants, method of recruitment, specific characteristics of the sample such as age range, gender and ethnicity - whatever is relevant to your research)

It is planned that 12 participants will be recruited. Participants will need to be over 18 and identify as female. They will have a diagnosed mild to moderate intellectual disability with capacity to consent. An intellectual disability will be demonstrated either through a formal psychology assessment report or through the receipt of support of a local health and social care team for people with intellectual disabilities (teams which requires individuals to have an intellectual disability before offering support). Participants will either identify as gay, lesbian or bisexual, or have had, or would like, a same-sex relationship. The participants will also need to have sufficient verbal communication to enable them to talk about their experiences, which will effectively mean that people will present with mild or moderate intellectual disabilities.

However, due to the potential difficulty of recruiting women with intellectual disabilities who are lesbian or bisexual, it is necessary to have a back-up plan if this proves too difficult. In this case the researcher intends to widen the study to also include men with intellectual disabilities who identify as gay or bisexual. Although broadening the research on the basis of gender will change some of the focus of the research, the experience of people with intellectual disabilities who are LGB remains an under-researched area. Furthermore the use of photovoice, a novel research method in this area, will provide a helpful addition to the literature. In this instance the criteria above will remain the same but both men and women will be included.

13. Measures, materials or equipment:
(Give details about what will be used during the course of the research. For example, equipment, a

questionnaire, a particular psychological test or tests, an interview schedule or other stimuli such as visual material. See note on page 2 about attaching copies of questionnaires and tests to this application. If you are using an interview schedule for qualitative research attach example questions that you plan to ask your participants to this application)

The research will involve semi-structured interviews and an interview schedule is attached with example questions (see Appendix A).

A recording device will be used to record the interviews which will then be transferred to two password protected USB sticks to protect confidentiality.

14. If you are using copyrighted/pre-validated questionnaires, tests or other stimuli that you have not written or made yourself, are these questionnaires and tests suitable for the age group of your participants?

N/A

15. Outline the data collection procedure involved in your research:
(Describe what will be involved in data collection. For example, what will participants be asked to do, where, and for how long?)

1. Once ethical approval has been granted, third sector and community organisations will be contacted regarding the study (see recruitment plan – Appendix B) and a key person/people in the organisation will be given an outline of the research. Preliminary contact has been made with some organisations and there has been interest from two organisations that support LGBT people with intellectual disabilities.
2. The researcher will gain permission from the relevant organisation to be involved in the study.
3. The researcher will also discuss practical arrangements, such as potential space for interviews and gather information about local services which may be useful for signposting.
4. If the organisation is happy to be involved then a main identified person in the organisation will inform any potential participants about the study or will invite the researcher to a meeting to explain the study in person.
5. The researcher will gather the minimum contact details of people who are potentially interested in being involved in the study.
6. The researcher will make contact with the individuals and explain the study further or answer any questions they may have. This could be over the phone or in person depending on the preference of the person. If the person is still interested a face-to-face appointment will be arranged.
7. The information sheet and consent form will be given to participants and explained (Appendix C and D). A brief conversation will take place with the person to check informed consent and to ensure that the researcher does not have any concerns about the person's capacity to consent (see further detail below).
8. Once consent is gathered interviews will last of approximately one hour long (depending on the participant).
9. At the end of the interview participants will be reminded about the photovoice element of the research.
10. Participants will be given instructions on taking photos and a time-frame, after which second interview will be arranged.

11. All interviews will be audio-recorded and transcribed. Throughout the interview stage the interview schedule will be reviewed and amended where necessary.
12. Participants will also have an opportunity to debrief after interviews and give any feedback (Appendix E)
13. Participants will be asked if they are happy for any of their photos to be included in the final thesis and/or any publications. If they are, then they will be given a consent form to sign (Appendix F)
14. Feedback sessions will be offered to participants to report findings of the study. This will also provide the opportunity to thank participants and offer a space to reflect on the experience of the interviews.

3. Ethical considerations

Please describe how each of the ethical considerations below will be addressed:

16. Fully informing participants about the research (and parents/guardians if necessary): Would the participant information letter be written in a style appropriate for children and young people, if necessary?

An accessible easy-read information sheet form will be used which is suitable for someone with an intellectual disability (see Appendix C). This will also be read to the individual if they have any difficulties in reading forms.

In order to check what the person has understood the researcher will then have a brief conversation with the participant, asking them to repeat back what they have understood about the research and giving them the opportunity to ask any questions.

17. Obtaining fully informed consent from participants (and from parents/guardians if necessary): Would the consent form be written in a style appropriate for children and young people, if necessary? Do you need a consent form for both young people and their parents/guardians?

It must first be assumed that all participants have the capacity to consent to take part; according to the principles outlined in section 1 of the Mental Capacity Act 2005 (MCA) an individual must be assumed to have capacity unless it is established otherwise. A preliminary discussion will take place with the organisation/person who knows the person with an intellectual disability to check whether they believe the person has capacity to consent.

Section 3 of the MCA 2005 outlines that a person is unable to make a decision if they are unable to do the following:
- understand the information relevant to the decision
- retain the information
- use or weigh the information as part of the process of making the decision
- communicate the decision (whether by talking, using sign language or any other means).

An accessible easy-read information consent form will be used which is suitable for someone with an intellectual disability (Appendix C). This form will form the basis of a discussion about the research project. By having a conversation with each participant (as detailed above), the researcher will be checking the four areas identified in the MCA (above) and where there is doubt that someone has the capacity to consent, they will not be invited to participate further. If the person is considered to have capacity and they consent to take part in the research they will be asked to sign a consent form (Appendix D).

However, it is understood that consent is a process and involves on-going

communication between the researcher and participants (Hughes & Castro Romero, 2015). During interviews and interactions with participants the researcher will continue to monitor participant responses and behaviour so as to check for any indication of tiredness, anxiety, reluctance or otherwise; the researcher will give participants opportunities to state their continued wish to participate in the research, to reschedule or to withdraw. The researcher will also request verbal consent to use the data collected after each interview.

18. Engaging in deception, if relevant:
(What will participants be told about the nature of the research? The amount of any information withheld and the delay in disclosing the withheld information should be kept to an absolute minimum.)

The proposed research does not involve any deception.

19. Right of withdrawal:
(In this section, and in your participant invitation letter, make it clear to participants that 'withdrawal' will involve deciding not to participate in your research and the opportunity to have the data they have supplied destroyed on request. This can be up to a specified time, i.e. not after you have begun your analysis. Speak to your supervisor if necessary.)

All participants will be informed that they have the right to withdraw anytime up to 3 weeks after their interview takes place, after which point the researcher will start to include their data in the analysis.

20. Anonymity & confidentiality: (Please answer the following questions)

20.1. Will the data be gathered anonymously?
(i.e. this is where you will not know the names and contact details of your participants? In qualitative research, data is usually not collected anonymously because you will know the names and contact details of your participants)

NO

21. If NO what steps will be taken to ensure confidentiality and protect the identity of participants?
(How will the names and contact details of participants be stored and who will have access? Will real names and identifying references be omitted from the reporting of data and transcripts etc? What will happen to the data after the study is over? Usually names and contact details will be destroyed after data collection but if there is a possibility of you developing your research (for publication, for example) you may not want to destroy all data at the end of the study. If not destroying your data at the end of the study, what will be kept, how, and for how long? Make this clear in this section and in your participant invitation letter also.)

The interviews will be audio recorded on a digital recording device and then copied onto a password protected USB stick to keep the information secure; this will be stored in a locked drawer. All contact details for participants will also be stored in the same way.

The audio recordings will be kept until the research is approved and passed by UEL. After this point they will be deleted. Transcriptions will be kept until publication of the results, up to 3 years after the study was conducted

22. Protection of participants:

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The study is not intended to cause any harm or distress to participants. There are no questions in the interview designed to draw out distressing memories or experiences. However, given the potentially sensitive nature of the topic, there is the possibility that participants may become upset by memories or feelings related to their sexuality or past. The researcher has nearly 10 years experience supporting adults with intellectual disabilities and will conduct the interviews in a sensitive manor. During the interviews participants will be allowed time to pause, to change topic or not to answer any questions. They will also be given the option to end the interview if they would like to. Information about local resources will also be given to participants with details of potential sources of support.

Confidentiality will be explained to participants prior to the interview. It will be explained that their details will not be shared with anyone other than the researcher and their supervisor. But it will also be made clear to participants that the researcher may need to break confidentiality if they are concerned for the safety of the participant or someone else that they speak about.

If the researcher has serious concerns about the safety of a participant, or a child or other vulnerable person whom they speak about, then the research may need to contact someone in the participant's support network or a relevant professional (for example, the police or relevant authority). This would only occur after discussion with the research supervisor and the researcher would always make every effort to discuss this with the participant first.

23. Protection of the researcher:

The majority of interviews will take place in a community setting. When the room is in the community/support organization known by a participant, there will be a contact person from the organization and the researcher will check about any arrangements for calling on support in case any difficulties occur.

Interviews will be conducted in these locations wherever possible. Only when a participant has difficulty travelling to another location (for example, due to their disability/lack of support) will interviews be conducted in the participant's home. If any interviews need to take place at a participants home then the researcher will attend the appointment accompanied by someone who will wait outside for them. Furthermore the research supervisor will be informed of the time and address of the appointment and will be in contact prior to and after the interview. The researcher is familiar with attending clients' homes as part of their clinical role in the NHS and will ensure that they have assessed the home environment on arrival and feel that it is safe to conduct the interview there. If

24. Debriefing participants:
(Will participants be informed about the true nature of the research if they are not told beforehand? Will participants be given time at the end of the data collection task to ask you questions or raise concerns? Will they be re-assured about what will happen to their data? Please attach to this application your debrief sheet thanking participants for their participation, reminding them about what will happen to their data, and that includes the name and contact details of an appropriate support organisation for participants to contact should they experience any distress or concern as a result of participating in your research.)

At the end of the study participants will be given an opportunity to have a feedback session to discuss the project and their contribution.

Participants will also be encouraged to ask any questions or raise any concerns at any point throughout the study.

25. Will participants be paid?   YES

If YES how much will participants be paid and in what form (e.g. cash or vouchers?)
Why is payment being made and why this amount?

It is hoped that internal funding will be obtained to offer a £10 voucher to participants to reimburse them for their time and any travel costs incurred. This is thought to be particularly important for people with intellectual disabilities who are a marginalized group in society and regularly receive no payment for participation in consultations and research.

For the photovoice element of the research, if a participant does not own a camera or a camera phone then an inexpensive digital camera (up to £25) will be given to participants for their use and will be offered to them to keep at the end of the research instead of a voucher.

26. Other:
(Is there anything else the reviewer of this application needs to know to make a properly informed assessment?)

4. Other permissions and ethical clearances

27. Is permission required from an external institution/organisation (e.g. a school, charity, local authority)?
                                                                        YES

Permission will be sought from any external organisations that help to facilitate discussions between the researcher and participants. The exact organisations will not be known until the recruitment process has started, after university ethical approval is granted and the study has been registered.

If your project involves children at a school(s) or participants who are accessed through a charity or another organisation, you must obtain, and attach, the written permission of that institution or charity or organisation. Should you wish to observe people at their place of work, you will need to seek the permission of their employer. If you wish to have colleagues at your place of employment as participants you must also obtain, and attach, permission from the employer.

If YES please give the name and address of the institution/organisation:

Please attach a copy of the permission. A copy of an email from the institution/organisation is acceptable.

In some cases you may be required to have formal ethical clearance from another institution or organisation.

28. Is ethical clearance required from any other ethics committee?

NO

If YES please give the name and address of the organisation:
Has such ethical clearance been obtained yet?   N/A
If NO why not?

If YES, please attach a scanned copy of the ethical approval letter. A copy of an email   from the organisation is acceptable.

PLEASE NOTE: Ethical approval from the School of Psychology can be gained before approval from another research ethics committee is obtained. However, recruitment and data collection are NOT to commence until your research has been approved by the School and other ethics committees as may be necessary.

29. Will your research involve working with children or vulnerable adults?*

YES

If YES have you obtained and attached a DBS certificate?   YES

If your research involves young people under 16 years of age and young people of limited competence will parental/guardian consent be obtained.

N/A

If NO please give reasons. (Note that parental consent is always required for participants who are 16 years of age and younger)

* <u>You are required to have DBS clearance if your participant group involves (1) children and young people who are 16 years of age or under, and (2)</u> 'vulnerable' people aged 16 and over with psychiatric illnesses, people who receive domestic care, elderly people (particularly those in nursing homes), people in palliative care, and people living in institutions and sheltered accommodation, for example. Vulnerable people are understood to be persons who are not necessarily able to freely consent to participating in your research, or who may find it difficult to withhold consent. If in doubt about the extent of the vulnerability of your intended participant group, speak to your supervisor. Methods that maximise the understanding and ability of vulnerable people to give consent should be used whenever possible. For more information about ethical research involving children see www.uel.ac.uk/gradschool/ethics/involving-children/

30. Will you be collecting data overseas? NO

Please note that ALL students wanting to collect data while overseas (even when going home or away on holiday) MUST have their travel approved by the Pro-Vice Chancellor International (not the School of Psychology) BEFORE travelling overseas.

http://www.uel.ac.uk/gradschool/ethics/fieldwork/

IN MANY CASES WHERE STUDENTS ARE WANTING TO COLLECT DATA OTHER THAN IN THE UK (EVEN IF LIVING ABROAD), USING ONLINE SURVEYS AND DOING INTERVIEWS VIA SKYPE, FOR EXAMPLE, WOULD COUNTER THE NEED TO HAVE PERMISSION TO TRAVEL

5. Signatures

TYPED NAMES ARE ACCEPTED AS SIGNATURES

Declaration by student:

I confirm that I have discussed the ethics and feasibility of this research proposal with my supervisor.

Student's name: Fiona Rooney

Student's number: u1038944 Date: 17/02/2017

Declaration by supervisor:

I confirm that, in my opinion, the proposed study constitutes a suitable test of the research question and is both feasible and ethical.

Supervisor's name: Poul Rohleder Date: 26/04/2017

Appendix 9.2. Notice of ethics review decision

REVIEWER: Mark Holloway
SUPERVISOR: Paul Rohleder
COURSE: Professional Doctorate in Clinical Psychology
STUDENT: Fiona Rooney

TITLE OF PROPOSED STUDY: Experiences of lesbian and bisexual women with intellectual disabilities; Hearing from individuals through photovoice

DECISION OPTIONS:

1. **APPROVED:** Ethics approval for the above named research study has been granted from the date of approval (see end of this notice) to the date it is submitted for assessment/examination.

2. **APPROVED, BUT MINOR AMENDMENTS ARE REQUIRED BEFORE THE RESEARCH COMMENCES** (see Minor Amendments box below): In this circumstance, re-submission of an ethics application is <u>not</u> required but the student must confirm with their supervisor that all minor amendments have been made before the research commences. Students are to do this by filling in the confirmation box below when all amendments have been attended to and emailing a copy of this decision notice to her/his supervisor for their records. The supervisor will then forward the student's confirmation to the School for its records.

3. **NOT APPROVED, MAJOR AMENDMENTS AND RE-SUBMISSION REQUIRED** (see Major Amendments box below): In this circumstance, a revised ethics application must be submitted and approved before any research takes place. The revised application will be reviewed by the same reviewer. If in doubt, students should ask their supervisor for support in revising their ethics application.

DECISION ON THE ABOVE-NAMED PROPOSED RESEARCH STUDY
(Please indicate the decision according to one of the 3 options above)

Approved, but minor amendments are required before the research commences

Minor amendments required *(for reviewer)*:

This is a carefully and sensitively designed piece of research but I have three reservations that should be addressed before research begins. Firstly I have never seen a sample of 8 for Thematic Analysis. My understanding is that Saturation Point (if there is such a thing) is around 15/16 participants. You need to increase the number of participants or change your qualitative approach to one requiring fewer participants. Secondly I think you should offer your participants the chance to review their transcripts before your analysis takes place. Thirdly I don't think you should interview participants in their homes and I don't think the precautions you have put in place are sufficient to safeguard you.

1

October 2015

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Major amendments required <mark>*(for reviewer)*</mark>:

ASSESSMENT OF RISK TO RESEARCHER *(for reviewer)*

If the proposed research could expose the researcher to any of kind of emotional, physical or health and safety hazard? Please rate the degree of risk:

☐ <mark>HIGH</mark>

☐ <mark>MEDIUM</mark>

☐ <mark>LOW</mark>

<mark>*Reviewer comments in relation to researcher risk (if any):*</mark> *Interviewing in participants' homes*

<mark>**Reviewer** *(Typed name to act as signature):* Dr Mark Holloway</mark>

<mark>**Date**</mark>: 24th May 2017

This reviewer has assessed the ethics application for the named research study on behalf of the School of Psychology Research Ethics Committee

Confirmation of making the above minor amendments *(for students)*:

I have noted and made all the required minor amendments, as stated above, before starting my research and collecting data.

Noting the concern about sample size, I have increased the sample size to 12. Moreover, each participant will be interviewed twice so there should be adequate data to conduct thematic analysis. To increase the sample size more than this could be prohibitive to the study as this is a very small population and an area in which recruitment to research is known to be difficult.

Giving participants copies of their transcripts is not thought to be appropriate in this instance as the transcripts will not be accessible to most people with learning disabilities as they will be long and difficult to read. However, as stated in the ethics application, each participant will be offered a debrief after their interview and asked again at this point whether they are happy for the conversation from the interview to be included in the research.

Interviews in participants homes will only be conducted as a last resort when it is extremely difficult for a person to attend another venue due to their disability and lack of support. In these instances, measures will be taken to ensure the researcher is kept safe which include the research supervisor having the details of the appointment and an agreed contact time after the appointment. Furthermore, following your recommendations the researcher will ensure that someone (such as a friend) attends the appointment with them and waits outside. The researcher is familiar with attending clients' homes as part of their clinical role in

the NHS and will ensure that they have assessed the home environment on arrival and feel that it is safe to conduct the interview there. A risk assessment has been completed as part of the research registration process.

Student's name *(Typed name to act as signature):* Fiona Rooney
Student number: u1038944

Date: 25/05/2017

(Please submit a copy of this decision letter to your supervisor with this box completed, if minor amendments to your ethics application are required)

PLEASE NOTE:

*For the researcher and participants involved in the above named study to be covered by UEL's insurance and indemnity policy, prior ethics approval from the School of Psychology (acting on behalf of the UEL Research Ethics Committee), and confirmation from students where minor amendments were required, must be obtained before any research takes place.

*For the researcher and participants involved in the above named study to be covered by UEL's insurance and indemnity policy, travel approval from UEL (not the School of Psychology) must be gained if a researcher intends to travel overseas to collect data, even if this involves the researcher travelling to his/her home country to conduct the research. Application details can be found here: http://www.uel.ac.uk/gradschool/ethics/fieldwork/

From: Mark Holloway
Sent: 01 June 2017 13:25
To: Poul A Rohleder; Psychology Ethics
Cc: Fiona ROONEY
Subject: RE: Ethics Application

Hi Poul

Thanks for sending through Fiona's revisions. This study now looks fine to me.

Best Wishes
Mark

From: Poul A Rohleder
Sent: 31 May 2017 22:01
To: Mark Holloway <M.R.Holloway@uel.ac.uk>; Psychology Ethics <psychology.ethics@uel.ac.uk>
Cc: Fiona ROONEY <u1038944@uel.ac.uk>
Subject: Re: Ethics Application

Dear Glen and Mark

Please find attached revisions from Fiona Rooney in response to the concerns you raised. I think they address them, so as I understand it is approval granted?

Thanks
Poul

Dr Poul Rohleder
Reader and Academic Tutor
Professional Doctorate in Clinical Psychology
School of Psychology
University of East London
Water Lane, Stratford
E15 4LZ, London

Email: P.A.Rohleder@uel.ac.uk

Appendix 9.4. Approval of request to amend UEL ethics application

UNIVERSITY OF EAST LONDON
School of Psychology

<div style="border:1px solid; text-align:center">

REQUEST FOR AMENDMENT TO AN ETHICS APPLICATION

</div>

FOR BSc, MSc/MA & TAUGHT PROFESSIONAL DOCTORATE STUDENTS

Please complete this form if you are requesting approval for proposed amendment(s) to an ethics application that has been approved by the School of Psychology.

Note that approval must be given for significant change to research procedure that impacts on ethical protocol. If you are not sure about whether your proposed amendment warrants approval consult your supervisor or contact Dr Mary Spiller (Chair of the School Research Ethics Committee).

HOW TO COMPLETE & SUBMIT THE REQUEST

1. Complete the request form electronically and accurately.
2. Type your name in the 'student's signature' section (page 2).
3. When submitting this request form, ensure that all necessary documents are attached (see below).
4. Using your UEL email address, email the completed request form along with associated documents to: Dr Mary Spiller at m.j.spiller@uel.ac.uk
5. Your request form will be returned to you via your UEL email address with reviewer's response box completed. This will normally be within five days. Keep a copy of the approval to submit with your project/dissertation/thesis.
6. Recruitment and data collection are **not** to commence until your proposed amendment has been approved.

REQUIRED DOCUMENTS

1. A copy of your previously approved ethics application with proposed amendments(s) added as tracked changes.
2. Copies of updated documents that may relate to your proposed amendment(s). For example an updated recruitment notice, updated participant information letter, updated consent form etc.
3. A copy of the approval of your initial ethics application.

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Name of applicant:	Fiona Rooney
Programme of study:	Professional Doctorate in Clinical Psychology
Title of research:	Experiences of lesbian and bisexual women with intellectual disabilities; Hearing from individuals through photovoice
Name of supervisor:	Poul Rohleder

Briefly outline the nature of your proposed amendment(s) and associated rationale(s) in the boxes below

Proposed amendment	Rationale
To give the option of conducting some interviews via Skype as opposed to face-to-face. Information and consent forms would be sent in advance and participants would be told to make sure they are in a private location where they feel comfortable talking about personal details (although they can also choose to have someone with them if they wish to, to help them feel at ease). The researcher would also be in a private room to ensure confidentiality. Liaison would be via the person with a learning disability, or more often via a support worker/someone supporting the person with a learning disability who told them about the study who can help to set up the Skype call and if necessary help with printing forms etc.	Recruitment of women with learning disabilities who are gay, lesbian and bisexual is potentially challenging due to low numbers of individuals being visible in services and within the population. Some participants may be identified who live very far from London and therefore the option of interviewing via Skype (if suitable for that individual) would allow interviewing to go ahead. This will also be particularly helpful for second (follow up) interviews using photovoice – as all participants will be asked to take photos in their lives and then a second interview will be conducted using the photos as a basis of discussion (see original study design). The photos would be emailed in advance so that both the interviewer and interviewee could look at the same picture simultaneously while talking via Skype.
The researcher would like to be able to publicise the research to third sector charity organisations via social media (twitter and	It has already been agreed that the researcher will contact these organisations via email with information about the study so that they

facebook).	can promote the research and identify/pass on the information to women with learning disabilities. Many of these organisations are now using social media, especially twitter, to share information, therefore sometimes a quicker and easier method would be to the study information (flyer and information sheet) via social media and ask if the organisation can re-tweet/re-post the information.

Please tick	YES	NO
Is your supervisor aware of your proposed amendment(s) and agree to them?	x	

Student's signature (please type your name):   Fiona Rooney

Date: 20/08/2017

TO BE COMPLETED BY REVIEWER		
Amendment(s) approved	YES	
Comments		
Please ensure that all necessary permissions from the charities are obtained with regard to the use of their social media platforms for recruitment purposes		

Reviewer: Mark Finn

Date: 31/08/17

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Appendix 10. Transcription Conventions Used

The following transcription scheme was adopted, which was adapted from Parker (Parker, 2005).

P	Indicates participant
I	Indicates interviewer
…	Indicates a short pause in speech
[inaudible]	Indicates speech was unclear and could not be transcribed
[ ]	Indicates when a comment has been added by the author, for example [brief interruption] or [P laughs]
-	Indicates unfinished word
" "	Indicates participant is giving an example of speech

Appendix 11. Example of transcript with initial codes

P: Yeah. Well I'm not very good at praising myself really

I: Yeah?

P: I'm not very good at that. I don't think much of myself.

I: Right

P: But um yeah

I: You're a bit hard on yourself?

P: Um. Yeah

I: And... well I'm pleased that you've been able to tell me about the things you are good at then, if you're quite hard on yourself mostly. What... so thinking about the topic area of what we're talking about. What do you... do you call yourself a lesbian, or gay, or do you identify as that?

P: Well I'm sort of torn between lesbian and bi. I think I might be bi more than anything.

I: Okay

P: But I'm more interested in women than I am men.

I: Okay

P: I don't really know what that makes me. I'm just me.

I: You're just you, yeah.

P: I'm just me.

I: And so if I used a word today, shall I use bi then?

P: Yeah

I: That's the best one? Although it is just you. That's the one we can use to describe...

P: Yeah

I: And so how long have you felt that way, or known that you're attracted to women?

P: Forever. But I've only just recently sort of come out because of (name) really. She was a lady, she's a lesbian and I felt I could talk to her. And I talked to her about how I felt. And it took me ages to get the courage to talk to her about how I felt and... she was pretty good support. We went for a walk along the fields. And we had a chat. She said that's okay and... and then I started getting involved in pride. And I felt I found my place really. I found that's where I belonged. I felt comfortable being there. I did pride without prejudice, I read some poems out there. And that's how I got involved with (another organisation) too.

I: What's that?

P: That's about domestic violence against girls and women.

I: Okay

P: And because I've been through a lot of domestic violence. I've been through quite a lot... emotional stuff as well. And that's why I was sort of reading my story out there.

I: Oh wow, so you read your story out to other women?

P: Yeah to try and give them a little bit of hope. And that there is hope. And that there is support there if they need it.

I: Yeah. And so going back to when you first able to talk to someone. Who was [person named]?

P: I didn't really know what she was at the start. I just worked with her with the [name] project, which was about mental health and wellbeing. But it...

I: Was that through here? Through [organisation]?

P: [Organisation] was involved in it.... I can't remember when I first met [name],

I: And that made it easier to talk to her?

P: Yeah I found her easy to talk to. And she was really good. But since then I've talked to people here as well. I talk mainly to [name] and [name] about how I feel and it gets confusing sometimes but I feel like I'm able now to speak out. My family don't want to know, they... my nanny and my aunty say it's just a phase and I said no it's always been there, I've never just, I've never been able to talk about it because I've been afraid of what my family would say. So I found the courage to say it. And she said "Oh don't be so silly. It's just a phase you're going through". And "okay", and left it as that, they didn't understand. My family isn't the easiest people to talk to anyway. So I don't really have much communication with them.

I: Okay. Was that already? Or was that after you told them, that you had less communication?

P: It was after that I had less communication with them.

I: Right.

P: They just said that its like a phase, and ... [noise interruption]. Yeah it's just a phase, something I'm going through, but I don't think it was.

I: Was that quite difficult to hear?

P: Yeah. I'll always seek from my nanny some reassurance and I don't get it. I don't get nothing like that. I haven't got a mum and dad. And so I seek guidance off my nanny but it's really difficult. It's really, really hard, she don't understand, she won't accept me. She wouldn't accept I've got learning disabilities, she wouldn't accept I've got mental health problems. She sees me as um, what do you call it, when... apart from everyone else. She don't want to hear it. She don't want to know how I feel. So I don't bother talking to her anymore.

Margin codes (right side, top to bottom):

- Attendance at pride events
- Dont feel accepted
- Worry about relationship
- Relationships confusing
- Isolated
- Negative experience of coming out
- Lack of accessible information, hard to find info
- What LGBT support is needed
- Attendance at an LGBT project
- Experience of LGBT culture
- Importance of love and relationships
- Unsure about LGBT identity labels
- LGBT sexual identity
- Coding Density
- Helped to realise se[xuality]

- Meaning of pride events
- Harder to be LGB with a LD
- Dont know other women with LD who are LGBT
- No places for LGBT & disabilities
- Barriers to coming out for women with LD
- Different to everyone else
- Fear in the community
- Good support
- Support from LGBT staff
- Positive experience of coming out
- Coming out to or being supported by someone else whose LGBT
- Lack confidence with relationships, finding a partner
- Abuse from male partners in the past
- Helped to realise sexuality or talk about for first time
- Coding Density

- Abuse from male partners in the past
- Different to everyone else
- Fear in the community
- Good support
- Positive experience of coming out
- Lack confidence with relationships, finding a partner
- Need support to find a partner or friends
- Feel accepted and included
- Hard to find a partner
- Importance of coming out
- Family difficulty accepting sexuality
- People see disability first, Stigma of LD
- Family relationships strained due to sexuality
- Coding Density

Appendix 12. List of initial codes

After the first round of coding, the following codes were identified:

1.	Abuse from female partner in the past
2.	Abuse from male partners in the past
3.	Attendance at an LGBT project
4.	Attendance at pride events
5.	Barriers to coming out for women with intellectual disabilities (ID)
6.	Coming out to someone who is LGBT
7.	Different to everyone else
8.	Difficulties in relationship due to disability
9.	Difficulty of coming out
10.	Don't feel accepted
11.	Don't know other women with IDs who are LGBT
12.	Experience of homophobia
13.	Experience of LGBT culture
14.	Family difficulty accepting sexuality
15.	Family relationships strained due to sexuality
16.	Family support of sexuality
17.	Feel accepted and included
18.	Female and male stereotypes and expectations
19.	Rainbow gay flag
20.	Good support with sexuality
21.	Hard to find a partner
22.	Harder to be LGB with an ID
23.	Helped to express sexuality
24.	Homophobia from church
25.	Importance of coming out
26.	In a relationship
27.	Interests and hobbies
28.	Interference in relationship
29.	Isolated
30.	Lack confidence with relationships, finding a partner
31.	Lack of accessible information, hard to find info

32.	LGBT friends
33.	Talk about LGB sexual identity
34.	LGBT world not welcoming, excluded
35.	Meaning of pride events
36.	How met a partner
37.	Need more places for LGBT & disabilities
38.	Need support to attend pride events
39.	Need support to find a partner or friends
40.	Negative experience of coming out
41.	Negative pride experience, feel excluded
42.	Not experienced negative reactions to sexuality
43.	Not in a relationship
44.	Others confuse gender and sexuality
45.	People see disability first. Stigma of ID
46.	Photovoice experience
47.	Positive experience of coming out
48.	Positive experience of pride events
49.	Realising sexuality
50.	Relationship experience
51.	Relationships are confusing
52.	Spending time together as a couple
53.	Staff not aware or supportive of people sexuality when have ID
54.	Support from LGBT staff helpful
55.	Support in relationship
56.	Unsure about LGBT identity labels
57.	Want to be in a relationship
58.	Want to make LGBT friends
59.	What LGBT support think is needed
60.	Worry about relationship
61.	Things that matter/values

Appendix 13. Example of coded data extracts

| Code	Extract
LGBT world not welcoming, excluded	I: What would be good about that? P: Well just having more out there and meeting people and making people feel… like sometimes they can belong in the world. Like because you get all sorts of crazy chicks who have really bad experiences and like we want them all to be okay. (Alex)
	P: Yeah in eh… like when they said they keep the… if you're in a gay bar and they said oh we'll just keep the music on low and then sort of deliberately turn it up or when like you're when people start shouting and your just in the middle of it and then you just walk away as it's not happening to you. (Alex)
	I: Do you ever go to places that are only for people who are LGBT? P: I've been to gay pride. But I think like if your disabled or learning difficulties it's really hard to be honest. Because if you're disabled whatever I think they like they haven't got nowhere to sit to join the parade. It nowhere to sit, like wheelchairs or something. They feel a bit left out. I: Is that something you've experienced? P: [Nods] (Cora)
	I: What happened when you went to pride? P: (Name) my partner has leg problem and she felt left out because there no where her to sit. We didn't know where it was. No one don't know where it is and that… I thought that not really nice. People like her feel bit left out. I: Because she has a physical disability? P: Yeah. I: Was that hard then?… what was that like having problems there? P: Bit upsetting, a little bit. That we wanted to join and have a good time. And a lot of people there don't have learning difficulties. Feel

	people who got learning difficulties want to go. (Cora)
	P: To accept them. It's really annoying that because we might have learning difficulties we feel like we are not accepted. Nowhere for us to go to make friends or anything. (Cora)
	…Well I said to you about the gay pride. Like I think they need to be like, let people who are LGBT with learning difficulties take part. (Cora)
	P: Yeah. It's a lesbian bar. It's quite small as well. I can't remember what it's called. It was quite small and I don't think they have people with wheelchairs. Not anyone there have people with wheelchairs in the club… Some places haven't got nowhere for people with wheelchairs or people who disabled, like a ramp or whatever. (Cora)
No place for LGBT and disabilities	P: Because there's no… there's not many places that do people with learning disabilities and LGBT. There's hardly anywhere really and no organisations that I know of do it. We want to be the first. (Heather)
	But it's going places to where people are, that's the hardest thing. That's the hardest thing. If I knew of anywhere. And I'm sure my support or [name] support would help me. But I just I don't know of any places so… (Heather)
	P: They wanted some support to go to pride and there was some easy read information people wanted about LGBTQ. There's lots of things people said, absolutely loads, so. But the main ones were easy read information and support to go to pride. And probably regular meet-ups with, at a bar or coffee or something like that, socialising. (Heather)
	…people with learning disabilities are the one in the middle, they need, they're the important people, they're the people that need things in the community you know. (Heather)
	I: So [name of group] is that something that you've set up? P: Yeah that's our group… Well after women's' group stopped,

	when you're past 25 and there's nothing going on. And I don't know it's a way to make friends and to make people feel safe… (Alex)
	There's nothing out there so that's why we did our own group. (Alex)
	…there should be more places like here, like (disability LGBT club). (Cora)
	… I feel like there's not a lot of places that are for us to go, like a gay club or whatever. People in wheelchairs. Like gay pubs or things like that. There should be places like wheelchair people like they would hang out with their mates and things. They need to think about people with wheelchairs as well, to get in. If they want to have a good time. (Cora)
Meaning of LGBT Pride events	Yeah, it's a celebration. Pride is a celebration of LGBTQ and it's open for all and it's where everyone's equal and everyone's the same as each other and accepting everybody for who they are really. It doesn't matter who you are, what race, what disability, what anything, it just to do with being equal. (Heather)
	Yeah I feel as one with everyone else and everyone is really friendly which is really nice. (Heather)
	P: She's transgender and she's really, really… she's one of my closest friends in pride. And we think pride is really important, to have pride because you definitely feel included with it. You definitely… there's no one left out, no one at all. And everybody's involved. I find that picture really good. That everyone's included, everyone's happy. You feel safe, you feel safe at pride. I: Right P: It's that safe feeling, even though there's loads and loads and loads of people. And I don't usually do loads and loads and loads of people but when I was there I actually felt quite safe. I felt like everybody was like a family sort of thing. It's really, really powerful. (Heather)
	And everyone's supporting each other and everyone's looking out for each other. It's really good and very equal (Heather)

	P: Yeah it is because a lot of people that are gay or so on, they still come, like if you're… even my mums been to watch me or help. Because when I was in it, like before my mum was in it with me, because obviously she's straight and married she was in it with me to support me. Because a lot of people who come to pride that aren't like obviously gay but they still come and have fun watching all of us march. (Sofie)
	P: Yeah because anybody can go really. Like I said my mum would go with me because she doesn't mind taking me. But anybody can go, anybody can go and watch, if you're straight or whatever. I: And why's that a good thing? P: Because it tells people that are like straight who we are and not to disapprove. Because it's not fair if they disapprove of gay people or bi because it's who we want to be. I: Yeah… so you think it's important for showing people? P: Yeah and we make a stand and show our rights. (Sofie)
	And I feel safe because I'm with my friends and I'm not being pushed in crowds and again I'm not being targeted… yeah because you're on a lorry and it's all women, oh no it's not all women actually it's mixture, it's a young people's group. Again makes you feel included and happy and… (Alex)
	Yeah friendships and stupid costume… just making a laugh and a joke about it and feeling safe on the lorry, not being pushed in the crowd. (Alex)
	(Place) gay pride. And the LGBT group and the workers are supportive as well …they're on there somewhere and there's loud music and just we can make a lot of friends and be a bit crazy. (Alex)
	I don't know just about everyone being equal I guess and safe and …(inaudible) (Alex)
	I: So gay pride was fun and it also meant something to you? P: Be happy with who I am.

	I: And did you say not feel alone? P: Yeah to see all LGBT people out there. (Cora)
	P: Because not have seeing other people out on the street... You can hold your partner hand or whatever. I: So you can hold their hand at pride P: And don't get judged… like homophobic or something. I: So you feel at pride you don't worry about holding hands? P: Yeah. (Cora)
	I: So pride is something different where you think everyone, everyone is… P: More friendlier. (Cora)

Appendix 14. Developing Thematic Map
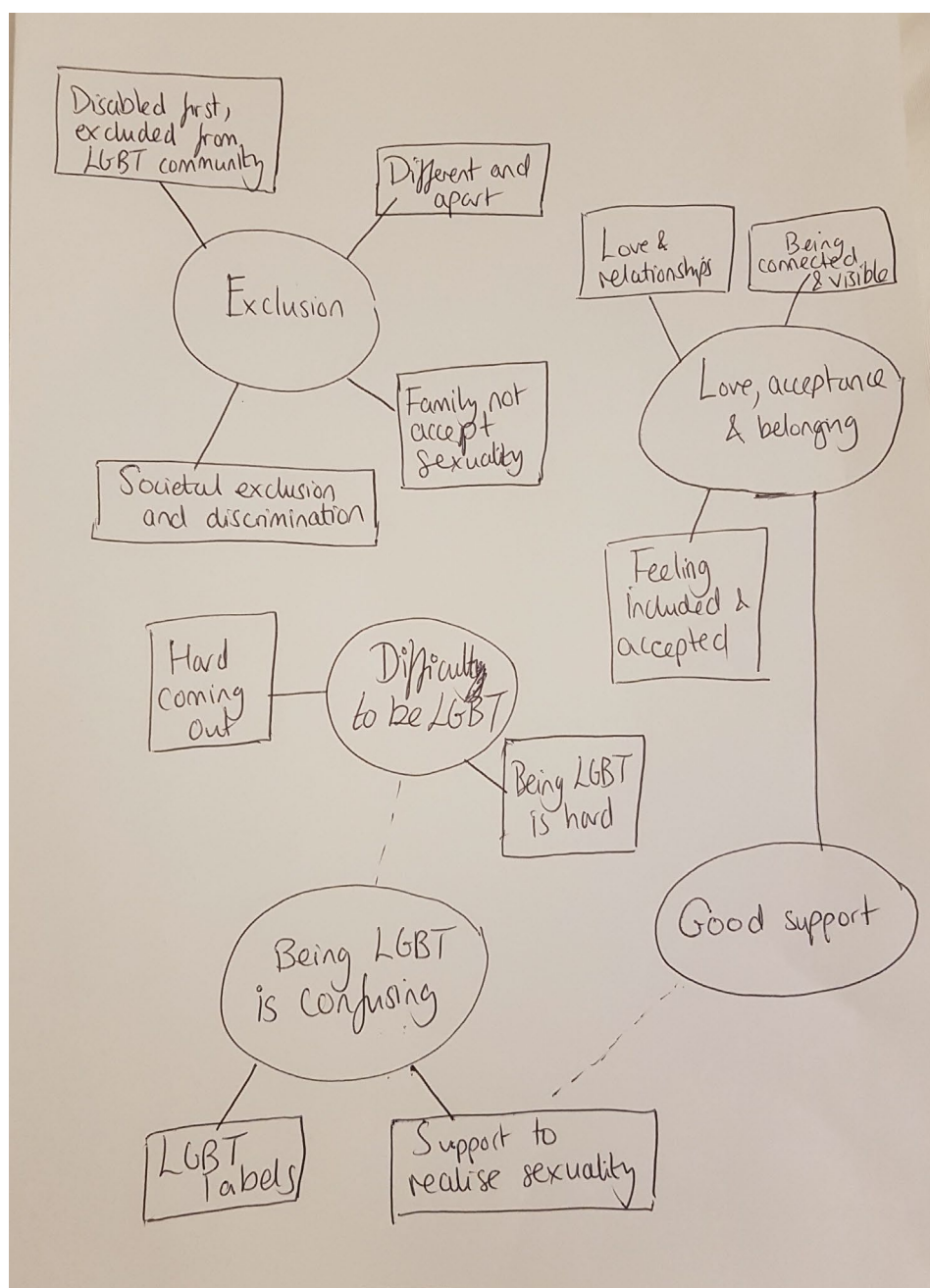
Appendix 15. Thematic Table with Theme Development including Codes

Code	Basic Theme	Global theme
Different to everyone else	The pain of feeling different	The Impact of Invisibility and Difference
Isolated		
Not fit in/judged by others	Judged by difference	
People see disability first. Stigma of LD		
No places for LGBT and disabilities		
LGBT world not welcoming, excluded	Experiences of exclusion and discrimination	
Family difficulty with sexuality		
Negative experience coming out		
Experience of anti-gay prejudice		
Fear in the community		
Unsure about LGBT labels	LGB identity as confusing	Non-heterosexuality as Difficult
Helped to express sexuality		
Difficulty of coming out	Barriers to coming out	
Hard to be LGBT	Negotiating an LGB Identity with a Disability	
Hard to find a partner		
Hard to make friends		
Lack confidence with relationships		
Relationships confusing		
Meaning of pride events	Visibility gives strength	Visibility and a Positive Sense of Self
LGBT culture		
LGBT staff support		
Having LGBT friends		
Feel accepted and included	A sense of belonging	
Importance of coming out		
Relationship meaning	The importance of romantic love	
Want a relationship		
In love		
Feeling well supported	Support as vital	
LGBT groups		
Family supportive of sexuality		
LGBT staff support		

The final thematic map can be found in the main body of the thesis, section 3.3

Appendix 16. Reflective Diary Excerpts

Excerpt 1:

Reflections on the difficulty of deciding between a female only focus or broadening to men as well. Female study is the real gap in the research - it's so under-studied - but have worries about the ability to recruit:

In my initial scoping and emailing of contacts about the potential study I was informed by two researchers I contacted about the difficulty they had in finding LGB women with learning disabilities for their study (which was national!). Discussion with DOS (research supervisor) and he suggested that broadening to included men or all disabilities (not just learning disabilities) might be preferable if recruitment will be such a challenge. Agreed to think about this further and come back to discuss again. I feel on the one hand relieved if this may prove too difficult, but on the other hand very disappointed as broadening the research has already happened and risks having a male focus as other research has shown.

Received an email back from another researcher in the field who was very positive about the aim of the research and the focus on women with learning disabilities. Emphasised the lack of research in the area and suggested that it would be really good to keep it as a female focus if I can. Buoyed on by this contact and by my own desire to try to continue with the initial research aim. The research conducted is older now (10 years old) so there's a possibility that it may be easier to recruit.

Excerpt 2:
Reflections on my own relationship to this research and in particular why I can sometimes feel a sense of discomfort or self-consciousness when talking about it:
When asked by others about my thesis I can feel my own reluctance or embarrassment about discussion my research area. I've come to question these feelings out of concern about my own prejudices (and possibly internalised homophobia as talked about previously in my journal). However, I feel that this response has also been building and is in no small part due to the response I get from people. In response to the answer to that question people seem to have a number of responses – namely, avoidance "Oh right" and change the topic, bemusement or amazement that this is something you could research or simply awkwardness and perhaps not knowing what to say or ask next. I in turn notice that I try to alleviate or pre-empt their awkwardness by saying firstly that it's "very niche". Only once or twice have I seemed to have a genuinely enthusiastic or interested response. I feel that I am experiencing just a small segment of the minority status and stigmatising response that people with learning disabilities must get in response to their sexuality… People can appear disinterested and uncomfortably with the research topic. It brings to mind ideas of therapeutic disdain and psychologists who specialise in Learning Disability services and the 'unsexiness'/'unglamorous' perceptions of others about working within learning disabilities.

Appendix 17. Photovoice example pictures

Participant 1 [2]
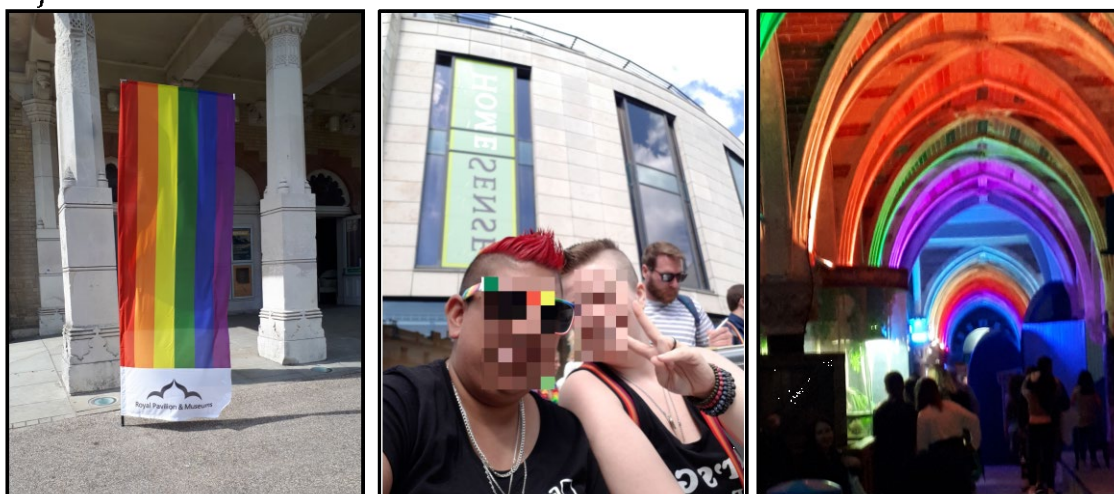
Participant 2

Participant 3

Participant 4