Sex and Relationships: The Role of Learning Disability Support Staff

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ABSTRACT

Sex and relationships with regards to people with learning disabilities is an important area of research for two overarching reasons; the promotion of social equality for people with learning disabilities, and the promotion of safety. Many people with learning disabilities have the support of paid staff to enable them to live independent lives. Support-staff's attitudes and opinions towards sex and relationships in relation to people with learning disabilities can have an impact on the type of support they provide.

This study sought to explore what informs support-staff understanding of their role with regards to provision of support around sex and relationships, how learning disability support-staff conceptualise their role with regards to providing this support, and what conflicts arise as a result of their adopted role.

The study employed a qualitative design, using semi-structured interviews with a sample of 11 support-staff from across South East England. A critical realist epistemology was adopted and a thematic analysis used to analyse the data.

Three overarching themes emerged; 'Definition of support work', 'Moral and value judgement', and 'Enablement and empowerment'. Support-staff discussed the changing nature of the role and how understanding of the overall support-staff role impacts on the type of provision towards sex and relationships. Support-staff identified the personal and value laden nature of decisions around sex and relationships, drawing on societal norms, family values and legislation to inform their role. Support-staff demonstrated a willingness to support people with learning disabilities with regards to sex and relationships and identified ways in which they could be enabled and empowered to do so, such as organisational changes, clear guidance and support from external professionals.

The findings have implications for clinical change in organisations and cross-professional working in this area. Further research could take a more action focused approach to enable and empower support-staff in the arena of sex and relationships.

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1. INTRODUCTION

This thesis considers how support-staff[1] of People with Learning Disability (PwLD) conceptualise their role with regards to providing support around sex and relationships. The thesis begins by exploring the importance of sex and relationships for PwLD, providing relevant context including the historical context in which PwLD have been supported. The researcher's understanding of both sexuality[2] and learning disabilities (LD) as social constructions are examined. The existing research on sex and relationships in the context of PwLD will be examined with attention paid to research examining the views of PwLD, parents of PwLD and a specific focus on the literature examining the views, attitudes and experiences of support-staff.

1.1 Sex and Relationships

Sex and relationships in the context of people with LD is an under researched area. This may be due to prevailing attitudes that people with LD are 'perpetual innocents', therefore, issues relating to sex and relationships are not appropriate or relevant to them (Murphy & Young, 2005). Research into this area is important, however, for two overarching reasons: safety and social equality.

1.1.1. Safety

Kitson (2010) argues that a lack of sex and relationship education has left PwLD vulnerable to abuse. Many PwLD are physically vulnerable to sexual and physical abuse as they may require persons to have intimate contact during personal care. People with LD may be socially vulnerable due to communication difficulties; being unable to articulate consent or report abuse. Peckham (2007)

[1] 'Support staff' refers to a range of possible job roles which may also be labelled as, for example, carer, support assistant or personal assistant. Throughout this thesis the term support staff has been used to refer to a person whose primary job role is to provide direct, non-specialist support to PwLD.

[2] 'Sexuality', unless otherwise stated, is used throughout to mean capacity for sexual feelings or sexual activity opposed to sexual orientation as in everyday parlance

suggests that PwLD are more at risk of sexual abuse and that the prevalence rates are higher than that of the general population.

Hollomotz (2011) argues that the sexual vulnerability of PwLD is not inevitable but is in part socially constructed. Whilst some impairments (e.g., physical disability or profound LD), may give rise to situations where PwLD require more intimate support, lack of education around what constitutes abuse and self-advocacy skills is what results in real sexual vulnerability (Cambridge & Carnaby, 2000). It is argued that lack of education and a societal assumption that PwLD are vulnerable is what actually renders people vulnerable. Doughty and Kane (2010) demonstrated that it is possible for PwLD to learn abuse prevention skills if they are given the opportunity to learn them. Notably, this study did not include anyone below the age of 21 or any men; men with LD can also be victims of sexual abuse and is should not be assumed that abuse prevention skills are relevant only to women.

Whilst the greatest risk is that of PwLD coming to harm from caregivers, there is also risk that support-staff may be placed in a vulnerable position in terms of being at risk of becoming the victims of sexual abuse from those they support due to lack of clear boundaries (Thompson, Clare & Brown, 1997).

1.1.2. Social Equality

People with LD experience inequality in many areas of their lives, such as health (Department of Health, 2013a) and socio-economic status (Emerson & Hatton, 2007). People with LD also face inequality with regards to sex and relationships; in the United Kingdom (UK) Valuing People (2001) and Valuing People Now (2009) aimed to address the inequalities experienced by PwLD. Amongst other areas, these papers highlight the importance of PwLD being able to form meaningful relationships, including those of a sexual nature and being able to access sex and relationship education.

Sexual rights are not explicitly mentioned in the UK Human Rights Act (1998), nor the European Convention on Human Rights. There is some difficulty in effectively defining sexual rights as there is a dual emphasis not simply on protection and

freedom from sexual coercion, violence and discrimination, which is arguably covered by existing human rights, but also on the right to a safe and pleasurable sex life. The Programme of Action of the International Conference on Population and Development in Cairo (United Nations, 1994) was an important shift in recognising sexual and reproductive rights and creating a cohesive definition. Presently, the World Health Organisation (2006) definition of sexual health emphasises a proactive approach to the physical, social and emotional aspects of sexuality, with an emphasis on the rights of *all* persons:

> …a state of physical, emotional, mental and social well-being in relation to sexuality; it is not merely the absence of disease, dysfunction or infirmity. Sexual health requires a positive and respectful approach to sexuality and sexual relationships, as well as the possibility of having pleasurable and safe sexual experiences, free of coercion, discrimination and violence. For sexual health to be attained and maintained, the sexual rights of all persons must be respected, protected and fulfilled.(p.5)

It is noticeable that The World Health Organisation (2010) do not make specific reference to the sexual health of PwLD but does focus on the sexual health of persons with physical disability, chronic illness and other groups. There is, however, focus on the interaction of individual and sociocultural factors as being key in defining individuals' sexual vulnerability and risk:

> The susceptibility of an individual to infection, physical disability or violence is determined not only by factors particular to that person, like his or her immune status, the presence or absence of a congenital disability, and his or her self-efficacy, but also by levels of risk and vulnerability and the ability to protect oneself. These factors are influenced by the family and community, as well as social, legal and political circumstances. (p.13)

Here, the World Health Organisation has identified that the locus of change to modulate vulnerability is not simply centred in the individual but can be altered through societal, legal and political change. In this way, changes in policy and

provision with regards to sex education and health provision can help balance the social inequalities PwLD currently face in this area.

In order to access sexual health services, PwLD need an understanding of what sexual health services do and an awareness of their own sexual wellbeing. Rohleder and Swartz (2012) found that young PwLD are often excluded from sex education and, where PwLD are included, the knowledge gained is often found to be poor (Jahoda & Pownall, 2014).

The Department of Health (2013b) found that young PwLD (16-24 year olds) do not have access to 'good' sex and relationship education; to be considered 'good', education should cover abuse, sexuality and consent, as well as provide practical information regarding contraception and safe sex.

In order to address social inequality, targeted intervention is needed to ensure PwLD are not left behind their peers in this area, particularly in the context of increasing numbers of young PwLD in mainstream schools as part of the inclusion agenda (e.g., Equality Act, 2010). The Children and Social Work Act 2017 makes sex and relationships education compulsory in all schools, and may assist in addressing inequality in sex and relationships education. However, the delivery of this education for PwLD must be accessible and meaningful and not simply delivered as part of a blanket approach.

The historic and continuing poor sex education for PwLD also has implications for those supporting PwLD in adulthood; it may be unclear how much, if any, sex and relationship education and/or experiences PwLD may have had. It may be difficult to assess both knowledge and capacity with regards to these decisions. Support-staff may be placed in the complex position of assessing capacity, assessing knowledge and advocating on PwLD's behalf in this area.

1.1.3. The Mental Capacity Act

The current mental capacity Act (2005) is designed to provide a legal framework for decision making processes for adults in the UK who are unable to make specific decisions for themselves. Capacity is considered decision specific, that

is, a person may lack capacity to make certain decisions but have capacity to make other decisions. The mental capacity act has particular relevance for PwLD as LD may impact on a person's capacity to make certain decisions. The act sets out five statutory principles, the first of which is the assumption of capacity,that is just because a person has a LD diagnosis, it should never be assumed that the person lacks capacity. The second statutory principle is that reasonable steps must be taken to support the person to be able to make the decision themselves e.g. by providing information. The third principle is that the person should be allowed to make an unwise decision. The fourth principle is that when a decision has to be taken on a person's behalf as they are deemed to lack capacity, then it should be made in that person's best interest. The fifth principle is that this decision must be the least restrictive in terms of the person's rights and freedom.

The Mental Capacity Act is used to guide informal and formal decision making; at times formal meetings with the individual, family and relevant professionals may be required to make decisions in a persons' best interests (e.g., where the person may live or regarding medical care). Decisions around a persons' sexuality should also be guided formally and informally by mental capacity decisions.
As previously established, sexual rights are human rights that must be balanced with capacity decisions. It must be stressed that a person's capacity to engage in a romantic or sexual relationship is not an indicator of whether that person is viewed as a sexual being. An individual may lack the capacity to engage in a sexual relationship but this does not mean that their sexual and reproductive rights should not be considered, whether this is their sexual education, their individual sexual expression (e.g., masturbation) or how the person is understood (e.g., sexual motivations).

1.2. Historical Context

Understanding how PwLD presently came to experience inequality with regards to sex and relationships has its beginnings in the development and understanding of LD which in itself is bound up with the increasingly prominent role of psychological knowledge (Rapley, 2004). Prior to the rise of psychological knowledge, PwLD were understood to be different based on religious, moral and

societal conceptualisations of difference. Pre-industrial Western societies would have based individual value on nobility and affluence. Post-industrial Western societies placed individual value on economic activity which left the poor, the sick, the elderly, the 'insane' and what we now refer to as PwLD lacking in social value. This gave rise to grouping such economically inactive persons in large scale institutions were conditions were generally dire.

Psychology, as an increasingly 'scientific' discipline became concerned with uncovering phenomena through scientific rigor. The development of psychometry assumed that a tangible phenomena 'intelligence' could be directly investigated through (neutral) experimental methods and meaningfully compared between individual persons.

Concurrent changes such as the introduction of universal education and the rise of psychometry meant children could be assessed and identified as being idiots, imbeciles, morons and feeble-minded. Social policy in the UK until around the 1930s was influenced by the growing eugenics movement and inaccurate theories regarding inheritance of LD. Research and psychometry was used to justify a set of beliefs that all forms of LD were heritable and that due to this heritable 'taint' (Shuttleworth & Potts, 1916) LD was on the increase. Learning disability was seen as a threat to society; it was believed that PwLD were responsible for poverty and crime, and it was therefore justifiable to prevent PwLD from marrying and procreating (Braddock & Parish, 2001). This was achieved through both segregation of PwLD into institutions, the prevention of marriage (Haavik & Menninger, 1981) as well as mass, forced sterilizations which took no account of the wishes or the capacity of the individual to make this decision. This practice continued in some European countries as late as the 1970s (Howard & Hendy, 2004).

People with LD were also viewed as a physical threat to the population in terms of being unable to control their sexual urges (Kerr & Shakespeare, 2002). Some research indicates that this view of PwLD, still pervades to this decade, particularly the view of men with LD as being unable to control their sexual desires (e.g., Young, Gore & McCarthy, 2012). Conversely, however, PwLD

have also been constructed as perpetual children; the concept of childhood itself being a construction laden with assumptions around sexual innocence (Jackson, 1992), meaning that knowledge regarding sex and relationships has been restricted for PwLD.

In the early 20th century, PwLD were mainly housed in large institutions and there was an emphasis on a custodial role of the institution. Following growing concerns about the conditions experienced in the large scale institutions, there was a move towards independence which was heavily influenced by Wolfensberger (1972) and the principles of normalisation. Nirje (1982) describes normalisation as promoting a way of life for PwLD which is as close to the norms of a given society as possible; this means promotion of independence, education, employment and relationships. Following the closures of large scale institutions and the promotion of normalisation principles, PwLD began to live more independently and there was a growing emphasis on the rights of PwLD to live as typical a life as possible (Ericsson & Mansell, 1996), which involved having a partner if so desired.

This approach to supporting PwLD continues, with recent emphasis on supporting people who have additional mental health problems, and whose behaviour poses a challenge to services, in the form of the Transforming Care agenda (NHS England, 2015). This specific group of PwLD may be further disadvantaged in their access to sex and relationships education and opportunities to make and sustain meaningful relationships. However, there is little legislation or guidance about how these rights might be realised.

The dramatic changes in support provision for PwLD have taken place in a relatively short period of time; arguably since the move towards community care in the 1980s. This means that many older PwLD and support-staff are likely to have experienced a lot of change in how they are supported and what support should look like. Wider reform to care provision for PwLD has unfortunately, often been motivated by serious case reviews (e.g., Death by Indifference, Mencap, 2007, and Transforming Care, NHS England, 2015), following the Winterbourne View abuse scandal. Whilst such cases highlight widespread organisational

deficits, their public nature also serves as a spot light on support-staff practice and it is unclear what impact such negative portrayal of support-staff may have.

1.3. Social versus. Medical Model of Disability

People with LD are usually conceptualised as vulnerable, which makes matters relating to sex and relationships problematic when considering safeguarding as balanced with human rights. Hollomotz (2009) highlights how differences in terminology, when referring to sexual experiences as applied to PwLD, conceptualises PwLD as vulnerable, and argues that this vulnerability is not inherent but, instead, arises as a result of social context when disability and sexuality are considered.

The individual or medical model of disability (Laing, 1971) situates disability as something inherent within the individual. It understands both physical disability and LD as caused by deficits (e.g., disease, trauma or illness), which arise within the individual, and directly cause difficulty for the individual in living their day to day life. This conceptualisation of disability results in a custodial approach where medical and professional experts provide care through medical treatment.

The social model of disability understands disability as an interaction between the individual and their social world. The Union of the Physically Impaired Against Segregation and The Disability Alliance (1975) distinguish between impairment and disability. Impairment is understood as, for example, lacking a limb or possessing a defective mechanism of the body. Disability is understood as the disadvantage which society places on that person by failing to take account of people who have additional physical and learning needs. For example, an individual may be impaired in that they cannot understand long, complex sentences but are rendered disabled by others failing to alter their communication style to convey a message. The social model of disability shifts the emphasis of change from the individual to society.

The knowledge that a person has a LD diagnosis leads to others interacting with that person in ways which assume a deficit. Dudley-Marling (2004) highlights the

reciprocal roles that are adopted when one member of a pairing is labelled as learning disabled; this leads to an individual conforming to a set of interactions which are expected when engaging with a person with a LD label and, in turn, that person with a LD conforming to expected responses due to this limited repertoire. These reciprocal social roles entrench PwLD as disabled, vulnerable and in need of support.

Rapley (2004) argues that PwLD do not necessarily always conform to expected responses but that the interaction style between support-staff and PwLD can be seen as falling into three categories: "(1) babying/parenting, (2) instruction giving, and (3) collaboration/pedagogy" (p.142). Such interactions must be borne in mind when considering sex and relationships for PwLD, as this will have an impact as to what extent PwLD are able to exercise their rights in this area. Additionally, this understanding of the interaction style highlights that the personal attributes of the supporting staff member may play a key role in influencing PwLD in this area.

1.4. Sexual Norms

Sexuality in the context of this thesis deliberately incorporates a broad definition. The World Health Organisation (2006) defines sexuality as:

> …a central aspect of being human throughout life encompasses sex, gender identities and roles, sexual orientation, eroticism, pleasure, intimacy and reproduction. Sexuality is experienced and expressed in thoughts, fantasies, desires, beliefs, attitudes, values, behaviours, practices, roles and relationships. While sexuality can include all of these dimensions, not all of them are always experienced or expressed. Sexuality is influenced by the interaction of biological, psychological, social, economic, political, cultural, legal, historical, religious and spiritual factors.(p.5)

Definitions can be considered to be individually and socially constructed in terms of what is expected and what is considered normal; sexual norms can vary widely at the cultural and societal level, as well as within individuals (Seidman, 2003).

In the context of LD, research (Jackson, 1992) indicates that sexuality is often not considered, with PwLD viewed as children who have been constructed as lacking in sexuality. When sexuality is considered in the context of PwLD, it is heteronormative and non-reproductive sexual practices which are considered most appropriate (Gill, 2015). This leaves PwLD who may have emerging sexual identities which differ from these norms at a greater disadvantage. There are higher rates of mental distress and suicidality amongst people from Lesbian Gay Bisexual Transgender Queer (LGBTQ) (e.g. Kelleher, 2009) communities and, by failing to acknowledge this intersectionality, PwLD may be at an even greater disadvantage.

In the UK, the use of social media and dating applications (‘apps’) is changing the way individuals form new relationships. Arguably, social norms are changing with an emerging difference between the use of ‘dating’ and ‘hook-up’ apps, one for individuals seeking a romantic relationship and the other purely for sexual activity.

Online safety is important for everyone, as is knowledge of apps and how they are used. These changing relationship norms have implications for PwLD and their support-staff; they may need a good understanding of technology and dating culture in order to support PwLD in this area. Support-staff could potentially be required to give or to support PwLD to obtain practical assistance with this use of technology (e.g. for those individuals who are not literate or have additional sensory impairment.)

As the construction of sexual norms operates on both an individual and societal level, support-staff may unintentionally project their personal values onto the PwLD they are supporting. Conversely, support-staff may also project default societal values (e.g., heteronormative ideas) onto PwLD due to lack of clarity as to what is constituted acceptable in LD environments.

1.5. Perspectives on Sexuality and People with Learning Disabilities

Knowledge and attitudes towards sexual practices of PwLD are likely to progress as PwLD age. Research which focuses on younger PwLD is likely to focus on individual, parental and educator perspectives as the guardians and custodians of young people.

Research pertaining to sex and relationships in adult PwLD is more relevant when considering both the views of the individual and their support-staff. It is increasingly common for adult PwLD to live separately to their families and to lead their lives as independently as possible. In this context, the views of the support-staff supporting PwLD can be considered important in affecting that persons experiences, particularly in the context of sex and relationships (Healy, McGuire, Evans &Carley, 2009[a]).

1.5.1.Family Perspectives

Studies which have examined family perspectives on sex and relationships in PwLD have shown that families generally have a more conservative and protective view towards sex and relationships than those of support-staff. Evans, McGuire, Healy and Carley (2009)[b] found that support-staff were more likely than family to have open discussions in this area. They found that 80% of family carers showed preference for their family member with LD to have low levels of physical intimacy with others (e.g., non-sexual).

However, family members also demonstrate real concern about social isolation and describe balancing their wariness of sex and relationships with the desire for their child's positive emotional and relational wellbeing. Foley (2012) found that a sample of parents of adults with Down syndrome describe themselves as "reluctant jailors"(p.305); they were deeply concerned about social isolation but also highly fearful of sexual relationships for their children. This study also indicated that parents initially viewed their children as asexual but gradually come to understand their children as sexual beings.

1.5.2. Perspective of People with Learning Disabilities

McCabe (1999) assessed the sexual knowledge and experiences of PwLD, people with physical disability and people without either learning or physical disability. Sexual knowledge related to several aspects; anatomy, contraception and menstruation. A hierarchy of knowledge and experience was found with people without learning or physical disability having the most knowledge, followed by people with physical disability and then PwLD. Of the PwLD who took part, 50% had not received any sex education and of those who had, most had not received information from family or friends.

Williams, Scott and McKechanie (2014) interviewed young PwLD regarding who they would approach for advice around sex and relationships, their experience of using these sources and who they would prefer to approach. It was found that young PwLD most commonly wished to discuss sex and relationships with their parents, followed by professionals (doctors and support-staff) and friends. Given McCabe's (1999) finding that most young PwLD were receiving information regarding sex from "other"(p.150) sources it would be helpful to determine whether this difference is due to the different geographical areas in which the studies were conducted with the Williams, Scott and McKechanie study being conducted in Scotland and the McCabe study being conducted in Australia, or the different timelines; the two studies were conducted fifteen years apart. Nonetheless, it is interesting to compare the findings that young PwLD would rather speak to parents about sex and relationships matters with the finding that most young PwLD actually receive this information from other sources. Where services needed to be accessed, PwLD wanted to attend mainstream services with appropriate adjustments made if required.

Jahoda and Pownall (2014) also compared the sexual knowledge of young PwLD and people without LD and examined the sources of information. It was found that non-learning disabled participants had superior knowledge and wider social networks, resulting in more access to sources of information about sex and relationships. A reverse pattern was found when gender differences were considered; female non-learning disabled students were better informed whereas the reverse was true in the LD group. This is in keeping with the aforementioned

conceptualising of female PwLD as vulnerable; lack of knowledge is likely to increase vulnerability and information may be kept from female PwLD due to the perception of innocence.

Healy, MacGuire, Evans and Carley (2009) [b] conducted focus groups to identify social and cultural barriers for PwLD to achieving sexual autonomy. The study found that all young PwLD had received some form of sex education and that this education had been retained best by individuals over the age of 18. Whether this was due to repeated presentation of sex education and increased experience was unclear, but has implications for the age at which education is introduced. The study also found that the attitudes of family and support-staff were very influential, with some participants unsure as to whether their romantic relationships were permitted by family or the service and, therefore, kept secret.

1.5.3. Educator Perspectives

Rohleder (2010) found that educators responsible for providing sex education to PwLD were ambivalent about this role and were concerned that providing sex education would actually cause harm and result in inappropriate sexual behaviour. In this study, this may have been due in part to the educators' perception of the organisation within which they worked. Educators were unclear as to (i) whether the organisation was in agreement with the content of the education, and (ii) unclear whether the organisation could foster a positive environment within which PwLD could exercise their rights to sex and relationships. This has implications for organisations in general where a consensus regarding what is permissible around sex and relationships is not always clear.

Grieve, McLaren and Lindsay (2006) evaluated learning resources used to support individuals with severe LD around sex and relationships. They found the resources to be overly complex and not suited to supporting people with more severe LD. They identified the need for research in this area to support the development of adequate educational resources.

A study in Sweden which examined parents and teachers views on internet use for sexual purposes by PwLD was carried out by Löfgren-Mårtenson, Sorbring and Molin (2015). The study used a focus group and analysed the data using thematic analysis. Three overarching themes emerged; the internet as an arena for expression of love and sexuality in the context of limited social networks, concern about the ability for PwLD to behave appropriately online, and concern around risk for PwLD and others. In general, professionals expressed more concerns with internet usage risk than parents, with parents expressing more concern about loneliness and isolation. Parents felt it was the duty of professionals to teach about internet safety. This raises possible areas of contention as to what constitutes the remit of the family and the remit of professionals. It is not necessarily part of the support-staff role to be a competent computer or internet user, and the support-staff in this study have clearly expressed their reservations regarding risk management in this area.

1.5.4. Summary

Research into the views of PwLD, parents and educators indicates that young PwLD have comparatively poor knowledge of sex and relationships matters compared to their non-learning disabled peers. Young people with LD experience barriers to accessing appropriate sources of knowledge regarding sex and relationships. Parents find themselves in the difficult position of wishing to protect their children who, due to their LD diagnosis, are conceptualised as vulnerable with regards to sex and relationships, but are also aware of the social isolation their children may face. Parents may struggle to find a balance between safety and promotion of emotional and relational wellbeing.

Those in the position of providing sexual education to PwLD may experience some ambivalence around their role and be concerned that providing such education will impact negatively on their students; making them more vulnerable. Research has found that the more commonly used available resources to educate PwLD around sex and relationships may actually be overly complex and ill-suited for the task. Educators fear that provision of education may cause more harm than good is perhaps more understandable if the educational resources are not fit for purpose. Educators and parents may face increasing challenges with

the development of new forms of technology which increase people's access to sexual and romantic relationships. With the views of PwLD, parents and educators in mind, we turn our attention to the views of paid support-staff.

1.6. The Role of Support-Staff

There is increasing preference for PwLD to live independently, which may involve living separately to family. As medical advances increase, PwLD are also living longer, meaning that the role of paid support-staff is becoming increasingly more prominent in PwLD's lives, as PwLD transition from family support to paid support in later life.

Paid support-staff may work in a variety of settings; some may support PwLD in a supported living environment, whereby they are bought-in to support someone living independently or in a shared home for a set number of hours. This type of support work can involve supporting someone with whatever it is they need additional help with. For some this may be accessing the community, support with budgeting, shopping and support around personal care. The Department of Health (2008) emphasises the support-staff role as promoting PwLD to have control and choice over these aspects of their lives rather than a custodial care role. Support-staff may work as part of a residential service, usually for PwLD who have higher support needs due either to physical needs or the severity of their LD. Others may work in day services; non-residential services which support PwLD, usually in the form of organised activities, promotion of independent living skills and preparing for employment or voluntary work.

Support-staff are not required to have any qualifications, although a National Vocational Qualification is helpful and prior experience of voluntary work in this area is desirable (National Careers Service, 2017). Support-staff should be given training by the employing organisation, but this can vary depending on the organisation providing the training in terms of content and quality.

Windley and Chapman (2010) asked support-staff what they felt the important aspects of their job were and what training they felt would enable them to fulfil

this role. They found that support-staff felt that improving PwLD's quality of life was the central part of their job and that they would value more training to do so, particularly for new support-staff. This study found that support-staff felt they mainly learned through "trial and error"(p.38) and the authors concluded that a rights focused, person centred approach may be the best approach to provision of additional training.

Brechin (1998) highlights that how staff view their role as support-staff can impact on the type of support that is provided. Support can be both disempowering to PwLD and foster dependency as well as being able to promote independence. Support-staff perception of their role and the role support-staff embody may be quite different; for example, support-staff may divert emphasis on promoting decision making if they feel service user safety is more important in a given scenario (Morris, 2004).

As the role of support-staff becomes increasingly prominent, it is the support-staff who carry the role of guardian and educator. There is evidence to suggest that the attitudes and practices of support-staff impact on the everyday lives of PwLD with regard to sex and relationships (e.g., Healy, MacGuire, Evans and Carley, 2009 [b]). There is, however, a paucity of research which focuses on support-staff and the provision of support around sex and relationships. In the following section, research which examines support-staff perception, experience and attitude to providing support around sex and relationships will be critically examined.

1.7. Literature Review

1.7.1. Search Strategy

Preliminary narrative literature searches were carried out between October-November 2015. These indicated that research focusing on support-staff of PwLD in the context of sex and relationships was not a well-researched area. A more systematic literature search was carried out from July 2016 – February 2017. The literature review was a scoping review which aimed to explore the following questions:

- What research has been carried out in relation to support-staff of PwLD in the context of sex and relationships?
- What perceptions, experiences and attitudes do support-staff have of providing support around sex and relationships?

The following databases were searched: PsychInfo, Cinahl, SCOPUS, Science Direct, and Google Scholar with no limits on date or country.

Additionally, a list of relevant journals was identified by carrying out two searches using the University of East London e-journals page. Searches for journals containing 'learning disability' and containing 'sex' were carried out. Please see Appendix A for a list of journals individually identified and searched due to relevance to subject area.

The following search terms were used: 'learning disability, mental retardation, mental handicap, Down syndrome, Prader-Willi syndrome, mental disability, developmental disability' AND 'sex*, relationships, intimacy, love', AND 'staff attitudes, carer attitudes OR perceptions OR experience'.

1.7.2. Inclusion Criteria

Quantitative and qualitative papers published in peer reviewed journals and published in the English language were included in this literature review. Research pertaining to the experiences and attitudes of support-staff in providing support to PwLD around sex and relationships was included. Due to the small number of research articles published in this area, the severity of the LD of the individuals supported and the nature of the support work (e.g., residential support or supported living) was not factored into the search criteria. As such the papers selected for review represent a breadth of experience from support-staff who may support people with very mild LD to experiences of support-staff who may support people with profound needs.

1.7.3. Exclusion Criteria

Papers published in non-peer reviewed journals and/or not written in English were not included in this literature review. Papers published in peer reviewed journals which were solely concerned with forensic experiences (e.g., sexual abuse and sexual offending), papers which were only focused on physical wellbeing (e.g., support around menstruation) and papers solely focused on the development, but not the support-staff experience implementation of sexual education, were not included for review.

1.7.4. Results

In total, 21 relevant papers were identified. The majority of studies identified employed a quantitative methodology (n=10), a smaller numbering employed a qualitative methodology (n=6), three papers used mixed methods and two critical review papers were identified. The following figure illustrates the literature search process.

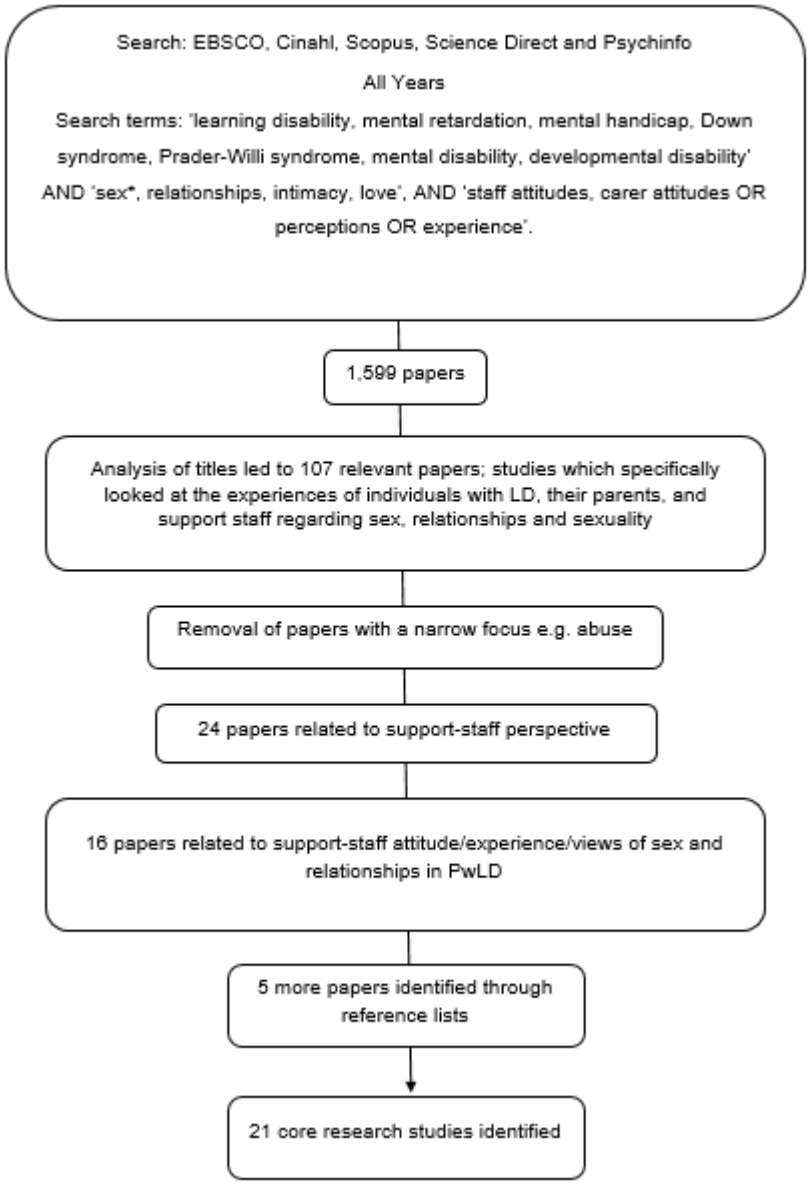

Figure 1. Literature Review Process

See Appendix B for an overview of the 21 papers identified.

1.8. Critical Review of Core Studies

Qualitative papers will be considered first, followed by quantitative, mixed methods, then critical review papers.

1.8.2. Qualitative Studies

Abbott and Howarth (2007) examined the views of support-staff in the UK towards the provision of support to lesbian, gay and bi-sexual PwLD. Seventy-

one interviews were carried out with support-staff from a variety of different services for PwLD. The majority of support-staff interviewed did not feel confident in providing support in this area. Support-staff identified some barriers to providing support which included lack of policy and guidance, lack of training and prejudice expressed by family and other support-staff. The study also found that support-staff were reticent to raise the subject of sex and relationships with service users unless this was explicitly raised by the service users first.

Young, Gore and McCarthy (2012) carried out semi-structured interviews with support-staff in the UK. They found that there were differences in the way support-staff viewed PwLD in relation to gender. Women tended to be viewed as sexually innocent with men seen as more sexually motivated. This may reflect the finding by Jahoda and Pownall (2014) that women with LD were much more poorly informed with regards to sex. Support-staff also felt that there were differences in motivations for sex between men and women, with the perception that women focussed more on romantic relationships or having a baby and the perception that men were more driven by sexual gratification. As a qualitative study there was a small sample size (n=10), seven of whom were female participants. Given the apparent influence of PwLDs gender on staff attitude, the gender of participants may have influenced the attitudes identified in the study.

In an North American study, Brown and Pirtle (2008) asked support-staff (n=40) to carry out a Q-sort methodology to examine their beliefs about sexuality of PwLD. This yielded four different belief systems: “advocates, supporters, regulators, and humanists” (p.59). Each belief system resulted in the individual viewing sexual education for PwLD in a different way, with humanists being the most strongly in promotion of human rights with regards to sexuality. The study hypothesised that personal belief systems could impact on the way support-staff approach education and support around sexuality for PwLD. However, the study does not directly examine how belief system impacts on practice. In addition, the study does not examine how support staff may form their belief systems but posits that cultural background and values from the support-staff’s family of origin may impact.

Yool, Langdon and Garner's (2003) study has been included in this literature review as although forensic staff are the participants, the study examines attitudes towards sexuality and PwLD in general, not just in forensic populations. The staff in this study also have direct experience of supporting PwLD. Four staff from a medium secure unit in the UK were interviewed regarding their attitudes towards sexuality. Staff were found to hold a mainly liberal attitude towards sexuality and PwLD. Less liberal attitudes were held towards relationships between clients, which may be expected in a forensic context given the presence of sexual offenders. It is suggested that attitudes may be biased by working with people who are either offenders themselves or PwLD who may be seen as vulnerable when placed alongside sexual offenders, indicating that staff values and experiences may shape the attitudes they hold towards providing support around sex and relationships. This study appears to have been conducted using an opportunity sample of forensic staff to investigate LD and sex and relationships and has a very small sample size (n=4). Therefore the validity of this study must be interpreted with caution.

Löfgren-Mårtenson (2004) carried out a study in Sweden which analysed the views of support-staff, parents and PwLD. The study employed interviews and observations and used a thematic analysis which drew upon a symbolic interactionist and social constructionist stance. The study aimed to describe and understand the enabling and disabling factors to express sexuality and form relationships for PwLD. Three overarching themes emerged: how meeting places are organised and defined; self-determination being difficult due to dependency on parents or support-staff; and as with other studies, attitudes and values of support-staff strongly influencing the behaviour and sexual expression of PwLD.

Previous research (e.g., Australian Research Centre in Sex, Health and Society, 2001) has identified the barriers which PwLD experience when obtaining good sexual health and an Australian study by Thompson, Stancliffe, Broom and Wilson (2014) builds on this, looking at the barriers as experienced by professional staff. All staff in this study worked directly with PwLD but in a teaching or clinical capacity. It was found that barriers fell into three categories: administration, attitude and experiences. This study complements existing

research on the view of PwLD as to the barriers they face, and adds an additional layer in highlighting barriers faced by support-staff trying to enable PwLD to experience good sexual health. The study used a grounded theory approach, with two phases, which drew on the experiences of 38 staff from different clinical backgrounds. This ensured a thorough approach to investigating the topic area, drawing on a variety of staff experience from different back grounds and paying attention to both individual and organisational factors. Phase one involved questions around policy, administration and provision in relation to sexual health and PwLD, Phase two involved an individual focus on clinical experience. This broad line of questioning led to the following recommendations: education, policy guidelines and explicit funding requirements as a way to address these barriers. They highlight the presence of policies aimed at protecting PwLD from sexual harm but a lack of guidance to promote safe sex and relationships practices.

1.8.2.1. Summary: Qualitative research has identified gender differences in the way support-staff view the sex and relationships of PwLD, with females being viewed as innocent and males more sexually motivated. This has implications for the way support-staff may support PwLD and what they may attend to in terms of the individuals' needs.

Support-staff operate using different belief systems with regards to sex and relationships, this belief system may be based on their working experiences (e.g., working in forensic settings) or may be based on personal values regrading sex and relationships. These belief systems are felt to have a strong influence on the views and behaviours of the PwLD they support. Support-staff experience barriers in promoting the sex and relationships health of PwLD; the barriers identified are similar to those reported by PwLD, but support-staff identify a further layer of difficulty in terms of organisational consensus regarding provision of support around sex and relationships, as well as lack of prominent focus in the area of sex and relationships.

1.8.3. Quantitative Studies

Study-specific attitudinal questionnaires which measured the attitudes of support-staff to sex and relationships in the context of PwLD were used in all quantitative

studies. Some of these studies used adapted attitudinal questionnaires originally designed for use with the general population.

Gilmore and Chambers (2010) assessed the views of LD support-staff and leisure industry employees working in Brisbane using the Attitudes to Sexuality Questionnaires (ASQ). They compared the ASQ (Individuals with an Intellectual Disability) and ASQ (Individuals from the General Population) to determine whether attitudes differed between support-staff and the general population (as represented by leisure industry employees) to PwLD. They also compared whether attitudes to sexuality in the general population differed to attitudes to sexuality in PwLD. Support-staff (n=169) and leisure industry employees (n=50) completed the questionnaires. Both groups were found to have a generally positive attitude to the sexuality of PwLD. Support-staff were found to be less positive about PwLD becoming parents than they were about other aspects of sexuality. Both support-staff and leisure industry employees were less positive about female PwLD engaging in sexual activity and both groups felt men with LD may possess less self-control with regards to sexuality. This study was one of the few studies which examined public perception of sexuality and LD. The study did not implement a measure of how much experience the public had of LD. There is a possibility that leisure industry staff who did complete the questionnaire (response rate 35%) did so due to having a motivation regarding their experiences of PwLD.

Meaney-Tavares and Gavidia-Payne (2012) carried out their study with the intention of targeting training to support-staff. This study also employed the ASQ (Individuals with an Intellectual Disability). Support-staff (n=66) working in Melbourne completed the questionnaire and attitudes were found to be generally positive. No significant difference was found in attitudes between male and female support-staff. Support-staff attitudes were found to be more positive towards women in terms of their sexual rights, sexual behaviour (non-pregnancy related), and self-control. Younger support-staff members reported more positive views towards sexual behaviour of PwLD than older support-staff members. Occupation was also a significant variable with managers holding more positive attitudes than support-staff.

Age of support-staff was found to be a significant variable in a study by Swango-Wilson (2008). In this North American study the perceptions of caregivers (n=87) regarding sex and relationships and PwLD were examined in relation to the implications this had on whether support-staff felt their organisation could support and participate in a sex education programme. Caregivers were a mix of family and non-family providers. The study used the Perception of Sexuality Scale and a demographic questionnaire. The study also found there to be some indication that age played a role in acceptance of sexual behaviours in PwLD, with younger people generally being more accepting. A weak positive correlation was found between attitude to sexuality in PwLD and perception of the ability to participate in a sex education programme. Caregivers were found to hold a different perception of acceptability of sexual behaviours for themselves vs. the acceptability of sexual behaviours for PwLD, with more heteronormative assumptions and less sexually intimate norms being found acceptable towards PwLD. The study found that support-staff perception of whether the organisation could deliver sex education was also influenced by how appropriate they felt the level of education was. This is indicative that in some services (e.g., for people with profound needs) it is not that support-staff are unwilling to deliver sexual support but that they do not see the relevance. The study concluded that caregivers need information and support in order to support PwLD around sex and relationships.

Another study which looked at both support-staff and family carer's perspectives was Cuskelly and Bryde (2004). This Australian study examined support-staff (n=62), parents and the general public attitudes towards the sexuality of PwLD. An attitudinal scale was specifically designed for this study, which used items from previously generated scales resulting in a questionnaire which addressed eight different themes, each of which had four or five questions pertaining to it. Age was found to be a significant variable, with those aged 60 or over demonstrating more conservative views. There was a significant difference between the view of parents and those of support-staff with support-staff holding more liberal attitudes towards sexuality. Both parents and support-staff

expressed less positive views about PwLD becoming parents than they did about other forms of sexual expression.

A Scottish study by Grieve, McLaren, Lindsay and Culling (2008) compared different professional groups and residential services on their attitudes towards sex and relationships and PwLD. Support-staff (n=188) completed the Sexual Attitudes Questionnaire (SAQ). Community support-staff were found to hold more liberal attitudes than those who worked in nursing homes. Support-staff held a more conservative view of male homosexuality, particularly support-staff working in nursing homes. Severity of LD was an independent variable and it was found that support-staff working in nursing homes held more conservative attitudes towards all people with LD regardless of the severity. Training was found to be a significant factor, with a positive correlation found between amount of training and positive attitudes towards sexuality and PwLD. This supports findings from studies (e.g., Yool, Langdon and Garner, 2003) indicating support-staff's individual work experiences may impact their overall view of sex and relationships in PwLD.

The impact of the type of service in which support-staff work on attitude was also found by Bazzo, Nota, Spresi, Ferrari and Minnes (2007). They examined social service (support-staff) providers (n= 216) attitude to sexuality of individuals with LD in Italy. The study used the Sexuality and Mental Retardation Attitudes Inventory, translated into Italian from the original English. Results indicated that on the whole social service providers showed a moderately liberal attitude to sexuality of individuals with LD. The type of service in which staff worked was found to be significant, with support-staff working in out-patient community settings showing significantly more liberal attitudes than support-staff working in residential and day centres. The study hypothesised that this may be due to level of interaction between support-staff and individuals in these services, with out-patient community settings offering support-staff less exposure to problematic expressions of sexuality. However, the individuals supported in each setting may vary in terms of the severity of their LD, with individuals with milder LD being supported in the community as opposed to residential facilities. The severity of an individual's LD may impact on their capacity to consent to sexual interactions and

thereby affecting the attitudes of the support-staff working with this group, as was the finding in the Grieve, McLaren, Lindsay and Culling (2008) study.

Parchomiuk (2012) also found that the profession of the staff member was a significant variable which impacted on attitude to sex and relationships and PwLD. A study-specific scale was given to special educational needs teachers, social workers, nurses and physiotherapists working in Poland in order to examine different professionals' attitudes to sexuality in people with disability; both physical and LD. From the description of the professional job roles, there appears to be some overlap with the profession 'nursing' and 'social work' which is similar to that of support-staff in the UK, therefore this study has been included in this literature review. Overall, staff indicated more acceptance of sexual practices in people who had physical disability than in PwLD. Social workers were the most accepting of sexual practices in PwLD with special educators indicating the least acceptance. This researcher hypothesised that this could be due to the difference in age of the PwLD, which social workers and special educators support. The findings of this study indicated that professionals found all manner of sexual practices to be more appropriate for people with physical disability than for PwLD, aside from sterilisation, which was felt to be more acceptable in relation to PwLD.

Pebdani (2016) further examined individual factors which may influence attitudes of support-staff working in group homes. Support-staff (n=71) in North America completed the ASQ (Individuals with an Intellectual Disability) and a demographics survey. The study found that personal factors such as having a family member who had a LD impacted positively on attitude. There were significant gender differences in attitudes towards sexual rights and the perception of the ability of PwLD to control themselves, with female support-staff having a more positive attitude. The study found that having in-service training improved attitudes to sexuality and PwLD. Gender and having a family member with a LD are difficult variables to control, however, it is of note that attending some form of training course improved attitudes to sexuality and LD.

In the Netherlands support-staff are given training on delivering sex education to PwLD. Schaafsma, Kok, Stoffelen, Van Doorn, and Curfs, (2014) investigated whether support-staff (n=163) were actually delivering this education and, if so, in what manner. The study found that only 39% of support-staff sampled delivered sex education and that, when they did, it was mainly delivered reactively. Of those who had delivered sex education, they reported a higher intention to do so again in the future, finding it easier and feeling more responsible for teaching sex education.

McConkey and Ryan (2001) examined what experiences support-staff had in supporting PwLD around sex and relationships and their confidence in managing them. The study was carried out in Northern Ireland. Support-staff (n=150) completed a questionnaire where they indicated whether they had ever experienced supporting PwLD in seven listed scenarios. The scenarios included - public masturbation, two scenarios around unwanted sexual advances, supporting PwLD to have sexual intercourse, support around contraception, support around relationship breakdown and same sex relationships. If support-staff indicated that they had experienced any of the scenarios, they were then invited to complete a Likert style questionnaire investigating their confidence in responding to the scenario. Around two-thirds of support-staff indicated that they had experience of managing at least one of the scenarios. The study found support-staff rated themselves as feeling more confident in managing a scenario if they had already managed one and that all support-staff feel they would benefit from further training and clear policy guidelines.

1.8.3.1. Summary: There were few quantitative studies (n=2) conducted in the UK which investigated support-staff views on sex and relationships and PwLD. Sex and relationships is an area where cultural and religious views may play a prominent role in shaping opinions, therefore, findings should be treated with appropriate caution when applying them across different countries.

The quantitative studies detailed here found age to be a significant variable affecting support-staff perception of sex and relationships in PwLD with the finding that younger support-staff generally held more liberal or positive attitudes.

The occupation of support-staff both in terms of their profession as well as their working context (e.g., working with people with more or less profound LD), had an impact on support-staff attitude to sex and relationships in PwLD. This was also found in qualitative studies. As in the qualitative studies, a difference between support-staff attitudes and family attitudes was found, with support-staff found to hold more liberal attitudes than parents. Both parents and support-staff expressed anxiety around reproductive sexual behaviour. Two studies found that having experience of working with sex and relationships in PwLD increased the confidence of support-staff in managing future situations; support-staff who had been able to deliver sex education, who had experienced managing a situation of a sexual nature, felt more confident in doing so in future. It was also found that the experience of attending a short training course on sex and relationships in PwLD resulted in support-staff expressing more positive attitudes towards this area; all studies which asked support-staff directly whether they would want further training in the area of sex and relationships were met with a positive response.

1.8.4. Mixed Methodology Studies

Evans, McGuire, Healy and Carley (2009) [b] carried out a study in the Republic of Ireland which examined support-staff and family carer perspectives on sexuality and personal relationships for PwLD. Support-staff (n=153) completed a Likert style questionnaire which also had a qualitative element. Comparison was made between support-staff and family perspectives and support-staff attitudes were found to be more in line with current developments in this area, i.e., more liberal attitudes, which is consistent with findings in other studies (e.g., Cuskelly & Bryde, 2004). This difference in approach could lead to difficulties in support provided and mixed messages received by PwLD. Around half of support-staff (53%) discussed sexuality with service users and of those who had participated in the study, 35% identified lack of training, 29% personal lack of confidence, 16% unclear organisational guidelines and 13% parental wishes as barriers to discussing sexuality. The majority of respondents (95%) expressed interest in training in sexual matters but only 12% had actually received any.

Gallagher (2011) investigated support-staff attitude and willingness to support around sex and relationships and PwLD with support-staff working across Glasgow. Thirty-four support-staff completed the ASQ (Individuals with an Intellectual Disability) and took part in a semi-structured interview designed to examine support-staff willingness to support in matters related to sex and relationships. Support-staff who held more positive attitudes to sex and relationships and PwLD were found to be more willing to give support in this area. No association between willingness and feelings of confidence in providing support around sex and relationships was identified, which perhaps indicates a training need.

As previous research has identified the effect of gender on attitudes to sex and relationships in PwLD, with more protective attitudes towards women with LD held, Christian, Stinson and Dotson (2001) carried out a study which examined the values support-staff had in relation to sex and relationships solely concerning women with LD. They conducted a survey in North America involving 43 support-staff; the survey included a qualitative element, a case scenario where participants wrote down how they would respond to a given scenario. The study found that the majority of participants felt comfortable in providing support to women around sex and relationships but not many had received formal training on how to do so. Many of the support-staff were relying on personal values to guide them in their decision making process in the absence of organisational guidelines.

1.8.4.1. Summary: As with the solely qualitative and quantitative studies, mixed methods papers found a difference in attitude between support-staff and family, with support-staff generally holding a more liberal view of sex and relationships matters. Mixed methods studies found an association between positive attitude to sex and relationships in PwLD and willingness to provide support in this area, however, willingness was not associated with confidence or comfort in this area, indicating a potential training need.

Support-staff who participated in mixed methods studies all expressed a wish for further training in this area. Support-staff reported using their own personal

values to guide their decision making in matters related to sex and relationships, as the organisations within which they worked did not set out a clear approach. This is indicative of not just a training need but also an organisational consensus regarding sex and relationships to increase support-staff confidence.

1.8.5. Critical Review Studies

Futcher (2011) carried out a critical review of the literature which examines support-staff and family attitudes to sexuality and PwLD. The review included literature published since the year 2000, including published journals, grey literature and books. Four key studies were identified and subject to analysis. Futcher found that lack of education for support-staff was a key theme throughout the literature. Support-staff training has been an element identified in the majority of studies cited in the current literature review, in line with Futcher's findings. The paper makes some recommendations as to how this may be facilitated including training on matters directly pertaining to the sexuality of PwLD but also training support-staff in leadership skills in order to facilitate decision making and coherent team decisions.

Cambridge, Carnaby and McCarthy (2003) provided an overview for service providers and those working directly with PwLD regarding common difficulties support-staff report when responding to masturbation and suggested optimal ways in which to respond. The study highlighted that there is often a conflation between masturbation and challenging behaviour; either with challenging behaviour being understood as an expression of frustration at being unable to adequately masturbate or the masturbatory behaviour itself being problematic (e.g. occurring in public or use of inappropriate objects). The overview highlights that often support-staff are guided by their own personal values and view of what constitutes sexual 'normality' in this area. The study advocated incorporating sexual policies into everyday support delivery, with the support required written into a person's individual plan/care plan. This recommendation followed the finding that support-staff would welcome clarity regarding organisational approach to providing support around sex and relationships.

1.8.5.1. Summary: Both critical review papers highlight that support-staff would welcome additional training around sex and relationship support provision. Training has been highlighted as a factor both in terms of content but also training in terms of leadership and policy making; i.e., an organisational approach to the provision of support around sex and relationships as opposed to individual decision making.

1.8.6. Overall Summary of Literature

The majority of research carried out regarding support-staff and their views on sex and relationships in PwLD has assessed attitudes and values, with some studies examining experience and willingness to provide support. Studies have been carried out across Europe, North America and Australia with under half of the studies identified being conducted in the UK (n=8). The studies comprised a majority of quantitative papers (n=10) with fewer qualitative papers (n=6), and few mixed methods (n=3) and critical review papers (n=2).

The studies indicate that LD support-staff have limited experience of training in issues pertaining to sex and relationships and would welcome additional training. The studies also indicate that many support-staff have not had experience supporting PwLD around sex and relationships and those who have feel more confident in managing these experiences in future. When support-staff have experienced managing sex and relationships issues, this has mainly been in a reactive manner, which means that sex and relationships related behaviours of PwLD may be more likely to be problematised and managed rather than being incorporated into the daily provision of support PwLD may require.

1.9. Rationale

Studies investigating the support-staff experience of providing support around sex and relationships to PwLD have mainly employed a quantitative methodology (n=10) and have investigated attitudes using an attitudinal scale, in several studies the same scale has been adopted; the ASQ. Over half of the studies detailed in the literature review (n=13) were conducted outside of the UK. As

discussed in the initial Introduction, cultural and societal factors can have a significant impact on views towards sexuality, therefore, studies carried out outside the UK may be limited in the generalisability to UK support-staff.

Studies (e.g. Cambridge, Carnaby & McCarthy, 2003) have identified that support-staff values play a role in the support which support-staff provide. Brown and Pirtle (2008) hypothesised what factors may inform support-staff values, but there is a gap in the literature in terms of studies investigating what may inform support-staff values with regards to sex and relationships.

Studies (e.g., Evans, McGuire, Healy & Carley, 2009 [b]) have indicated that support-staff feel a lack of confidence with regards to providing support around sex and relationships, however, studies have also found that support-staff indicate a willingness to provide support (e.g. Gallagher, 2011). It is not clear, however, what it is that are support-staff are willing to provide support around in matters pertaining to sex and relationships. In a sense, it is unclear as to how support-staff conceptualise their role with regards to support provision around sex and relationships.

As well as the impact of support-staff values on decision making, other studies (e.g., Thompson, Stancliffe, Broom & Wilson, 2014) have identified a lack of clarity and guidance in terms of the organisational approach to sex and relationships, and the majority of studies have identified a training deficit with regards to sex and relationships. Support-staff have also been found to be reluctant to raise the subject of sex and relationships with service users in the absence of an expressed need.

The knowledge that values differ from person to person and that support-staff have a lack of organisational guidance around sex and relationships indicates there may be fertile ground for conflicts to arise between support-staff values and organisational approach. The finding that support-staff are reluctant to raise the subject of sex and relationships with service users may be indicative of personal conflicts in decision making. Exploring what conflicts support-staff may experience when providing support around sex and relationships, a value-laden

topic, may help develop greater understanding of training needs and organisational support.

Whilst attitudes, opinions and views have been shown to impact on behaviour and have been investigated in the existing literature, no study has yet examined how support support-staff perceive their role in relation to the provision of support around sex and relationships for PwLD. Roles can be defined by how support support-staff perceive their position to be in relation to the PwLD and the wider context in terms of support provision. A person's understanding of their role with regards to a given situation will impact on how that person behaves and how that person is responded to. Perception of role has both an enabling and curtailing impact on behaviour and sets the boundaries for what that person feels is and is not permissible. Windley and Chapman (2010) found that, in general, support-staff view their overall role to be promotion of quality of life. The current research is interested in breaking this down and focusing on the distinct area of the support-staff's role with regards to sex and relationships, given it is an under-researched area and an area where conflicting cultural, social and moral norms may emerge.

The aim of this study, therefore, is to investigate what informs support-staff understanding of their role, how support-staff conceptualise their role with regards to sex and relationships and whether any conflicts arise.

1.10. Research Questions

1. How do support-staff conceptualise their role with regards to supporting PwLD around sex and relationships?
2. What informs support-staff conceptualisation of their role with regards to providing support to PwLD around sex and relationships?
3. What conflicts arise for support-staff as a result of the adopted role around supporting PwLD around sex and relationships?

2. METHODOLOGY

2.1. Overview

In this section, the epistemological stance of the research will be discussed in order to situate the research in context. The design, method, sample and mode of analysis of the data will then be described.

2.2. Epistemology

In order to situate the research in context, some discussion of the epistemological stance of the research is necessary. Epistemology has been defined by Blaikie (2000) as “the possible ways of gaining knowledge of social reality, whatever it is understood to be. In short, claims about how what is assumed to exist can be known” (p.8). Epistemology is concerned with how knowledge is gathered, acknowledging that knowledge is not static and can change based on the assumptions and theories knowledge is drawn from (Grix, 2002).

There are two extreme epistemological positions; realism or positivism and social constructionism. Studies which are scientific in nature, such as randomised control trials, adopt a realist position, that is, they posit that it is possible to obtain truth about the material world through direct, objective enquiry. Studies which rely on qualitative data fall farther along the spectrum towards social constructionism, that is, understanding the data as a product of the viewpoint of the researcher, the time, context and situation of the research and the way in which the data has been collected, which give a perspective on a topic but which does not represent a fixed reality. Social constructionism takes the view that knowledge is constructed through our interaction with the world and shaped by social processes, particularly language. Individuals construct different realities and interact with their world according to these constructions.

Critical realism combines elements of both realism and social constructionism in that it accepts that some material realities exist but that they cannot be known through direct enquiry as they are filtered through the understanding of the researcher and situation in time, place and context.

Critical realism has been adopted as the epistemological position in conducting this research. This was felt to be appropriate due to the nature of the research topic, question and methodology. Goodley and Lawthom (2005) give a useful overview regarding changes in epistemological thinking in studies pertaining to PwLD and it was felt that an epistemology which allows for elements of a constructional understanding of LD are most appropriate when considering this topic area. Learning disability and sexuality, as discussed in the Introduction are viewed by this researcher as social constructs. However, as discussed in the introduction, these concepts have very real impacts. People with LD have experienced discrimination and ill treatment in many areas since the construction of the LD label, particularly with regards to their sexual and reproductive rights which have been severely restricted in the form of segregation and sterilization. In this sense a critical realist approach to this subject area, which considers the social constructions of LD and sexuality, and the very real impact of sterilization and restriction, was considered appropriate.

This research seeks to examine how support-staff view their role when providing support around sex and relationships to PwLD. In this sense, the roles support-staff take on can be considered an individual social construction, which influences support-staff conduct in regard to sex and relationships. Critical realism allows the researcher to go beyond language and incorporate a layer of interpretation based on historical, cultural and social factors (Harper & Thompson, 2011). Critical realism allows acknowledgement of the participants' material realities whilst taking account of the impact that the researcher's and the participants' perceptions, beliefs and experiences may have on the data gathering and analysis processes and, as such, does not represent an ultimate truth (Willig, 2013).

2.3. Design

In order to answer the research question, a qualitative design was employed. The research questions are concerned with exploring participant's experiences and conceptualisations of their support-staff role; qualitative research methods are suited to exploring these type of questions as they allow for the generation of complex data, including experiences, reflections and conceptualisations. Quantitative designs tend to employ a more theory driven approach, with a pre-specification of the types of data the study will generate (Robson, 2011) and, as such, would not be appropriate to answer the research questions presented here.

2.4. Approach to Data Collection

Qualitative methodology allows for a range of approaches to data collection. Semi-structured interviews were chosen as the approach to data collection in this research for several reasons. Semi-structured interviews allow the researcher to adapt their line of enquiry to explore and expand upon areas of interest which emerge through the interview process. Given the sensitive nature of the research topic, individual interviews were felt more appropriate in order to minimise discomfort for participants and promote discussion. Given previous research has demonstrated the personal and value laden nature of support around sex and relationships, it was felt an individual data gathering approach rather than a focus group or group interview approach was most appropriate.

2.5. Recruitment

2.5.1. Participant Inclusion Criteria

Participants were all paid, non-NHS support-staff. 'Support-staff' refers to non-biologically related individuals whose primary job role is to provide direct support to people with LD in an assistive, non-specialised capacity, i.e., not therapists or educators. Support-staff may have had a variety of job titles. Participants were recruited across a range of work settings and worked with people with varying severities of LD. A relatively wide net was cast in terms of geographical location

covering Central London, Greater London and South East England in order to maximise potential recruitment, given the time limited nature of the thesis.

2.5.2. Recruitment Procedure

A three step approach described by MacDougall and Fudge (2001) was be employed; this involved a "prepare, contact and follow-up"(p.121) approach. Participants were recruited via their employers. Purposive and opportunity sampling was used to identify providers of LD support (including residential services, day services, supported living and residential colleges). The researcher's professional network (non-NHS), personal network and agencies the researcher was aware of through word of mouth, combined with a Google search for LD providers in the Greater London area, was used to establish a pool of LD providers who could be approached ("prepare"). Initial contact was firstly attempted via telephone. If the researcher was unable to speak to the organisation directly, or if organisations requested written information, which the majority did, an e-mail was then sent to the provider (see Appendix D). The e-mail included information about the project and a participant information sheet (see Appendix E). Providers were asked to contact the researcher by e-mail to confirm they were happy to have the study advertised to their support-staff ("contact").

The researcher then contacted the provider by e-mail and telephone several more times if they had not received a response. Some of the providers who responded and the individual participants themselves, where appropriate, were contacted post interview to advertise the study to additional support-staff ("follow-up").

Once providers contacted the researcher, recruitment was then carried out in the following ways;

- Providers would e-mail details of the study to their support-staff
- Providers would invite the researcher to meet with the support-staff team to give an overview of the study

- Providers would put a copy of the participants information sheet and poster in their staff rooms (see Appendix F)

In total, 25 organisations were approached. One declined to participate, six agreed to advertise to support-staff and the rest did not respond.
Although connections through the researcher's personal and professional network were used to identify organisations where participants could be recruited, none of the participants or the participants' direct supervisors were previously known to the researcher personally or professionally.

Once participants contacted the researcher, a time, date and location was arranged for the participant to meet the researcher to carry out the interview. In one case, an interview was carried out by telephone for the participant's convenience. Each participant was provided with a copy of the participant information sheet and given time to read it and ask questions. Each participant was then asked to sign a consent form (see Appendix G). For the telephone interview, the participant was sent an e-mail copy of the participant information sheet and consent forms and asked to write back to the researcher stating explicitly that they had given their consent.

All interviews were recorded using a Dictaphone and later transcribed by the researcher. Notes were made immediately after the interviews were conducted in order to capture initial impressions of the interview and used to support the Thematic Analysis (See Appendix H).

2.6. Participants

Table 1. Participant Information

Participants	Gender	Type of Organisation
Interviewee 1	Female	Residential
Interviewee 2	Female	Residential
Interviewee 3	Male	Supported living/Residential
Interviewee 4	Male	Day service
Interviewee 5	Female	Residential
Interviewee 6	Male	Residential
Interviewee 7	Female	Supported living
Interviewee 8	Female	Supported living
Interviewee 9	Female	Supported living
Interviewee 10	Female	Supported living
Interviewee 11	Male	Supported living

Based on the recommendations of Guest, Bunce and Johnson (2006) regarding saturation levels in qualitative interviews, the researcher attempted to recruit between ten to twelve participants. Eleven participants were recruited in total. Pilot interviews were included in the analysis, as the final interview format did not differ substantially from areas covered in the pilot interviews.

2.7. Ethical Approval

Ethical approval for conducting the study was sought from the University of East London (see Appendix I). Approval was sought to advertise the study to participants through their employers.

2.7.1. Informed Consent

Individual participants gave written consent to participate in the study. Participants were provided with written and verbal information regarding the

purpose of the study, duration and confidentiality arrangements. Participants were given the opportunity to ask questions before and after the interview and provided with verbal and written debriefing (see Appendix J). Participants were informed that their participation was entirely voluntary and that they could terminate the interview at any time and were free to withdraw their data up until February 2017. Participants were informed that their data would be kept confidential and that identifying information would be anonymised, except in the case of disclosure of unmanaged risk to the participant or others, in which case the relevant persons would need to be informed to manage risk.

The subject matter of this research may have at times been uncomfortable for participants to discuss but was not meant to be distressing. Sampling was deliberately self-selecting and participants were fully informed as to the nature of the study to avoid psychological distress. The researcher was aware that participants may have had personal negative sexual experiences or supported others who had, therefore, the researcher was fully transparent as to the purpose of the study and the questions asked. Participants were offered the opportunity to read the interview schedule if they wished and it was explained that due to the semi-structured design, the researcher may ask follow up questions which deviated from the schedule. The interview schedule left interpretation of the phrase ‘sex and relationships’ deliberately broad but this did at times elicit disclosure of experiences of a distressing nature (e.g., hearing service users disclose trauma and sexual violence).

One participant requested that the recorder be turned off during part of the interview as they had begun to discuss a highly sensitive topic. Another participant expressed a personal opinion then requested that this was not included in the transcript, these requests were respected.

2.7.2. Confidentiality

The recordings and transcripts were stored in password protected files, on a password protected computer of which the researcher was the sole user.

Interviews were anonymised at the point of transcription. Identifying audio recordings will be destroyed on completion of the study.
Participant identifying data was anonymised at the point of transcription; any identifying names of persons or organisations were removed and participants were given numbers as identifiers. It was made clear to participants that non-identifying quotations would be used in the write up of the study.

2.7.3. Dissemination

Dissemination to the organisations that have taken part in the research will be provided via an accessible report and/or delivery of a presentation dependent on organisational preference. There is intention for the study to be submitted to a peer-reviewed journal upon completion of the DClinPsych requirements.

3. RESULTS

3.1. Overview

This section will begin by providing an overview of how the data was analysed; describing the transcription and thematic analysis process. Presentation of the qualitative data will then be provided with use of quotes for illustrative purposes.

3.2. Transcription

Transcripts were produced using “Jefferson-lite” style transcribing (Poland, 2001, p.629) (see Appendix K) and analysed using thematic analysis (Braun & Clarke, 2006).

Jefferson-lite transcription involves using some of the standardised Jefferson notations (Jefferson, 2004) but not all. As thematic analysis was employed, it was not felt relevant to the transcription and analysis process to employ all notations which focused on the description of speech constructions, so notations which indicated the pace, overlap, emphasis, volume or latched speech were not employed in the transcription process. Whilst this meant that some of the interactional data was lost, for the purposes of this study this level of transcription was felt to be adequate.

The following table shows the transcribing conventions used within the transcripts.

Table 2. Transcribing conventions

Convention	Meaning
(.)	A full stop inside brackets indicates a micro pause
(0.2)	A number inside brackets denotes a pause, the number indicating the duration
[ ]	Square brackets denote a word substitution, usually to preserve anonymity
(( ))	Double brackets appear with a description inserted denotes some contextual information e.g. laughing
(h)	Laughter within the talk
[]	Overlapping speech

3.3. Thematic Analysis Process

Thematic analysis was used to analyse the data, as it is not wedded to any particular research or theory-driven paradigm (Braun & Clarke, 2006), making it compatible when employing a critical realist stance. Joffe (2011) argues that thematic analysis is suited to elucidating a group's conceptualisation of the subject of study; in this case, thematic analysis is well suited to determining support-staff's conceptualisation of their role with regards to sex and relationships. The aim of thematic analysis is to summarise themes and offer potential explanations, as opposed to generating novel theories to account for the findings in the data (Ryan & Bernard, 2000). Although the study involves interviewing participants about their experiences, the purpose of the study is to determine participants understandings of these experiences, not their lived

experience; lived experiences would be more suited to an interpretive phenomenological analysis (Smith, 1996).

The interview schedule (see Appendix C) was designed in such a way to prompt participants to offer descriptions of their experiences, give their opinions and explain their attitudes to the topic. In order to analyse latent and symbolic meaning from interview transcripts, thematic analysis must go beyond the cognitive information to which participants have access (e.g., opinions, attitudes) and focus on symbolic and latent meaning (Joffe, 2011).

As the research questions centred on the conceptualisation of support-staff role, a deductive analysis was applied in terms of identifying role conceptualisations which participants may offer. The researcher attended to the use of simile and metaphor as these were considered indicators of role conceptualisation (latent meaning), as well as use of verbs. As the research also sought to identify sources of values and conflicts for support-staff, the researcher was also open to inductive data which the interviews may yield.

The following steps were taken in the analysis process:

- In accordance with Braun and Clarke (2013), transcription was considered to be the beginning of the analysis process.
- Notes were made during transcription of any pertinent or striking elements.
- Once transcribed, the transcripts were read through in their entirety with any additional notes made on emerging themes.
- Transcripts were imported into Nvivo (Version 10 QSR International) coding software. Use of Nvivo software involves a coding process comparable to that of using highlighter pens and hand-written notes, however, it has the benefit of grouping the source material which aides the researcher during secondary level analysis when condensing codes into subthemes and themes, as it allows the researcher to review source material more readily than using traditional pen and paper highlighting. Nvivo software allows the research to code the transcripts using a digital

highlighter and to label the code. Nvivo also automatically records the number of sources (portions of text) and number of references (interviews) which each code corresponds to, making it simpler to identify codes which are most common amongst participants. Appendix L shows an example of the coding software. Appendix M shows an example of the coding process.

- Primary codes were created by summarising themes found in portions of text. The researcher employed a deductive stance in terms of actively identifying codes which corresponded to role conceptualisations (e.g., the use of simile and metaphor). The researcher was also open to inductive data during the first stage of the analysis. As such, the coding labels were largely descriptive.
- Each interview had multiple codes applied and a total number of 223 codes were identified during the primary analysis. These can be found in Appendix N.
- Appendix O shows an example of some primary codes and their corresponding source quotes.
- Following the primary analysis, the codes were reviewed and condensed. Codes which drew on only one source and one reference which could not be incorporated into a broader theme were discarded.
- The second phase of coding drew together primary codes which were conceptually similar. Coding moved from a descriptive account of the data to a more conceptual and analytical phase. Overarching themes were identified and subthemes within them brought together.
- There was a degree of overlap and interconnection between some of the initial codes and these were merged. This was done by re-reading the individual codes and looking for connections between the themes. Notes made immediately post interview, during transcription and during the first reading of the transcripts were drawn on to begin to identify overarching and sub themes within the data.
- See Appendix P for a visual representation of groupings.

3.4. Analysis

Following analysis, the data yielded three main themes with seven subthemes. These are shown in the table below.

Table 3. Summary of Themes

Theme	Subtheme
Definition of Support Work	Understanding of Learning Disability
	Changing nature of the role
Moral and Value Judgement	Socially constructed sexual norms
	Conflicts for support-staff
	Giving advice
Enablement and Empowerment	Facing fears
	Practical assistance

3.4.1. Theme One: Definition of Support Work

The first overarching theme is concerned with how support-staff understand their role in the provision of support to PwLD. This understanding incorporates two main elements which are support-staff understanding of the impact of LD and the changing nature of the support role. The first subtheme concerns support-staff understanding of the impact of LD and how understanding of LD and capacity may impact on decision making within support work. The changing nature of the support role refers to historical changes in the nature of support provision to PwLD from a more care oriented ‘doing to and doing for’ to a more support oriented approach where the emphasis is on independence and empowerment of the person; ‘supporting the person to’. This subtheme also incorporates the multitude of ways support is manifested and the roles support-staff take on; from traditional family roles such as ‘parent-child’, to ‘scaffolders’ and ‘protectors’.

3.4.1.1. Understanding of Learning Disability: Participant understanding of LD and how this affects the individuals they are supporting impacts on the type of support that they provide. The majority of participants spoke about the importance of a person centred approach:

> Interviewee 11: no size fits all because you should be person-centred to that person's particular place in the world, place in the universe and outlook, and also because everybody's disability is different, I mean yeah some things are the same or you see some things again and again but people's disability manifest in different ways, yeah show me that once, I get that it's sunk in or no I don't get that and we need to talk about it again or no I have no memory of talking about that at all. (p.11)

Participants also spoke about having a more general knowledge of commonalities experienced by PwLD or an autism diagnosis and how their behaviour may be misconstrued:

> Interviewee 11: because you do hear people say "oh she's exposing herself" she's not exposing herself, she's just chaotic, you know, she's just chaotic, that's what's happening here, you know, she's lost the thread of what she was at, something disrupted the routine and it just so happened that at this time she wasn't wearing clothes. (p.3)

In this example, the support-staff member draws the distinction between understanding sexualised behaviour (intentional nudity), which may be seen as offensive and problematic, and a behaviour which occurs as a result of a disrupted routine (accidental nudity). Knowledge that people with a diagnosis of autism can be reliant on routines, and may become distressed and behave in ways which may be considered unusual as a consequence, is important for support-staff in terms of providing appropriate support.

Some participants identified intention as being a tricky area when considering how to respond to service users. Some participants expressed their concern that some service users may try to have deliberately inappropriate sexual

conversations whilst others may have genuine interest and curiosity when asking sex related questions:

> Interviewee 5: If it is someone that genuinely had different intentions and does just want to explore that and needs that emotional support, that's a different conversation, that's my go to answer "it varies" ((laughs)) but, yeah, it's intention I think behind everything. It's a difficult sector to work in in terms of intentions, everyone is a quite fearful of repercussions of things. Especially when you get onto different topics like sex and money…(p.10)

The support-staff response would be very different depending on the perceived intention of the service user. Therefore, a good working relationship and understanding of that person is important.

Some participants highlighted the impact of the severity of the LD of the service user as impacting the type of support they may provide:

> Interviewee 1: …perhaps if you've only worked with people with very profound learning disabilities who can't verbally express that it's easier to slip into that paternal role…(p.5)

> Interviewee 11: …at the moment the clients I'm working with are probably the more severe learning disabilities with kind of higher level of communication needs, so before this setting I worked with people with much more mild learning disabilities or mild disabilities along with mental health issue or something else where (0.2) kind of like talking, exploring the facts of life, talking about the birds and bees, exploring people's feelings may have been a bit more fluid…(p.1)

All participants spoke about difficulties around mental capacity of the individuals they worked with. Whilst some argued that it is easier to support someone who has capacity:

> Interviewee 5: …if you're working with someone and they are able to tell you, I want a relationship, I want to meet people make friends, maybe end up in a romantic relationship, it's a bit easier. (p.1)

Others argued that the lack of control they had as support-staff when someone has the capacity to make (potentially bad) decisions could make the support-staff role difficult:

> Interviewee 1: It's quite difficult when you're working with people who have capacity to consent because you can't really do anything, unless you feel that they are being abused or being taken advantage of then you can't really get involved, you've got to be there to kind of mop[] clean up the pieces (.) and that was, that's the most frustrating part of that kind of job, you just have to give people the information and hope they make the right decision. (p.7)

Here, Interviewee 1 expressed their frustration at the lack of control support-staff have in this area. This subtheme has links to the theme of 'Giving advice', with participants expressing frustration at the lack of control they have in this area and the discomfort this can cause.

Regardless of whether an individual has capacity or not, support-staff found it easier to provide support when service users could verbally communicate their needs and wants:

> Interviewee 11: …you know some sets of circumstances there's a very, very clear need or wish and you can see, they're very clear in their communication and it's a relatively easy fix…(p.9)

Others expressed their concern that individuals who do not communicate verbally, or who do not make their needs clear through non-verbal skills, may miss out on having their sex and relationships needs addressed:

> Interviewee 5: Because I find as well if someone communicates non-verbally those kind of social goals tend to get missed a little bit more as well than if someone is verbally telling you, I want a relationship…(p.5)

Some participants reflected on the dilemma between assessing capacity and addressing a human need. Participants expressed being able to manage and support service users when they were able to express their needs, even if this meant undertaking capacity assessments and decisions in that persons best interest. Participants expressed uncertainty around introducing or assessing need in relation to sex and relationships in the absence of any indication of interest in this area from service users, and around where it is that knowledge of sex and relationships comes from:

> Interviewee 9: But then that's it, should we be thinking, should we start thinking, how much does she understand, what if she shows an interest in somebody, how would she show that interest, I think she can flirt you know, I think she can, I've seen her flick her eyelashes ((laughs)) so, does that mean then she has this, I don't know, is it innate in us? I'm going too deep here…(p.5)

This uncertainty may tap into a larger cultural understanding of sexuality and where it comes from. Whilst the body undergoes some biological changes during puberty, there may be an assumption that the desire for both sexual gratification and intimate relationships may appear at this time. The interaction between physiological changes, sexual education, cultural depictions of sexuality and peer learning culminate in an individual's sexual expression. As PwLD are often left lacking in formal sex education and peer interactions and having a LD may impact on understanding of cultural depictions, how much can a given individual with LD be expected to comprehend with regards to sexual expression and in particular the social art of flirting? The description of the service user by Interviewee 9 was reminiscent of how one may describe a small child as being flirtatious, which may further perpetuate the understanding of PwLD as eternal children.

3.4.1.2. Changing nature of the role: The majority of participants made reference to sex and relationships being "natural", "human" or "part of life". As a "part of life", the majority of support-staff felt that providing support in this area was something which would be incorporated into their job role:

> Interviewee 9: …we concentrate on the day to day, get an education, get enough skills for work and employment, looking after your body, looking after your home, your identity, get a good quality of life but nothing specifically to that. (.) Yeah ((laughs)) but I think [sex and relationships] should be actually, because it's massive and I think it would make a huge difference to somebody's life. (p.3)

Some participants reflected on the changes in practice which have occurred over the years regarding PwLD having sexual relationships. They highlight that services were not set up and, in some cases, are still not set up to promote an environment where PwLD potentially having sexual relationships is thought of:

> Interviewee 3: And I think staff struggle with that kind of stuff as well, 'cause I they're kind of like endorsing it 'cause by the same token although these people have got capacity, they've got a learning disability and you think like years ago you probably wouldn't have dreamed of supporting that and it's like most residential homes, you didn't have room for a double bed, you didn't find rooms in residential homes with double beds; all single beds, even now you do, I visited a residential home today; all single beds. You know, which still happens, it's not[] it's yeah so staff struggle with that because that's (.) years ago you're told you couldn't kind of support with things like that. (p.7)

Another participant who works with older PwLD reflected that for the individuals with whom they work, sex and relationships has not been a major feature of their lives. They reflected on the changing norms and environments in which PwLD were supported:

> Interviewee 6: I think it's just because it's kind of like the norm for them in the beginning, because they were not allowed or they don't see that they are allowed to enter into a relationship. Because some of them live with their parents and move into institutions and then now in residential and they are more like open to the community(.) because before like they were in the institutions and it was different(.) they're in a residential place now. (p.2)

Some participants highlighted the changing nature of the support-staff role in terms of both labelling from 'care-staff' to 'support-staff' and what this distinction may mean in terms of the support which is provided:

> Interviewee 5: So as we got more and more of those referral, that's when another service was set up, a more PBS [positive behaviour support] and autism service. And we would provide care so that was like put your carer hat on, take your carer hat off and put your support worker hat on. Because it's a different mind-set. So there were people we were working with who had profound LD, severe physical disabilities, and a lot of the stuff we were doing was around care, peg feeding and that sort of thing and then we were working with individuals who were at the complete other end of the spectrum. And everyone had such unique needs and goals. (p.7)

This distinction indicates a different type of support approach to persons with more profound LD, indicating they may need a more care oriented approach as opposed to promotion of independence. Whilst the level of support provided to individuals who have more profound needs may necessarily be more assistive, there is a danger that PwLD who have the most severe needs do not have their sexual and relationship needs recognised. Another participant, reflecting on training needs in their current service, a residential service for profound and multiply disabled individuals (PMLD), highlighted:

> Interviewee 1: …so we do touch on that and in services where it's pertinent I think there'd be further training, it's not pertinent here really.

> There's a support plan – two of the guys here like some alone time without any trousers on and that's fine. That's written into the support plan, people know to leave them alone if that's what they want to do. (p.9)

> …that's a difficult one isn't it. I think that some of the things here, 'cause people here have such profound needs it's not as pertinent here…(p.11)

The notion of 'pertinence' may result in further subdivisions of appropriateness based on the severity of someone's LD. Whilst there may be more complicated capacity decisions to consider, to deny any training around sex and relationships for support-staff working with PMLD people further instils the notion of the 'perpetual child' for this group of people.

Participants describe taking on a multitude of roles when supporting people around sex and relationships and drawing on a variety of sources. Over half of the participants made reference to supporting service users in a parental manner:

> Interviewee 1: It is a bit like being a parent to a teenager, isn't it, you've got to kind of let them go off and make their own mistakes but kind of have a little eye out.(p.5)

> Interviewee 8: obviously me being me, part of me and the way I am, because I am a mum as well. (p.7)

> Interviewee 10: so most of us are parents so we do understand, we always are maybe thinking from the perspective of a parent "what would you do if this was your child" if there was an issue. (p.3)

Other participants describe a two way process whereby service users treat support-staff in the manner that they would treat their mothers:

> Interviewee 1: I don't know what had happened but every single person that lived there, like the six people that lived there, they all had issues

> with their mothers. And I was just like surrogate mother and I was just abused from morning 'til night. And I phoned up my mum at the end of my first day and I was like "mum I'm so sorry for when I was a teenager" 'cause it was it was like slamming doors and "you're not my mum, I don't like you, you can't tell me what to do!!" I was like "I'm not telling you what to do, I'm just introducing myself!" (p.5)

Having a parent-child relationship with a service user may be indicative of a power differential between support-staff and service users. Whilst Interviewee 1 made the distinction in terms of parenting a teenager and the need for positive risk taking ("go off and make their own mistakes"), a parental approach may involve a level of control or permission seeking in PwLD which would further entrench both vulnerability and societal status as comparable to that of a child.

Participants also spoke about themselves as protectors of service users who they understood to be vulnerable. Participants expressed uncertainty between positive risk-taking and ensuring service users did not come to any harm:

> Interviewee 10: it would be something that I'd like to address to make sure she's safe and to make sure the person that she would probably open herself up to, it wouldn't be a person that would take advantage of her and you know, 'cause once she's in that situation who's to say how far it would go, so (0.2) I feel my role is more to make her comfortable in what she gets into but not to open it up to her because she's quite happy as she is without any other distractions. (p.1)

In this example, the participant describes their protective role as being most prominent. The notion of talking to this service user about sex and relationships is considered risky and goes against what it means to be a protector, therefore, delivery of sex education or introducing sex and relationships as a topic is not considered as part of the role of protector.

Some participants talked about taking a less direct approach to fostering knowledge around sex and relationships and instead view their role as setting up

environments where service users may be able to develop their knowledge of sex and relationships:

> Interviewee 7: If they want to have a boyfriend or a girlfriend there are different clubs they can go to. They have this [name of organisation] in [town] where basically they support them to make friends, then eventually it can lead to being boyfriend and girlfriend with support until they become independent until they can go out, most of them go out to the cinema, they go for meals and things like that and some of them eventually, they tend to live together. And even with that we still support them to be healthy and be able to live together like, just like me and you, it is like that. (p.1)

This 'scaffolding' approach (Wood, Bruner & Ross,1976) also extends to supporting service users with other life skills, such as emotional coping, and "lays the ground[work]" for that person to be able to have a successful relationship:

> Interviewee 4: So in that particular case you obviously have to acknowledge that and have regular meetings with that person, sort of emotional level meetings and work with that and also manage that, anxiety management, anger management or something like that in order to lay the ground for that possible future prospect, future relationship you know. So I think that is managed, I think that is well managed. Obviously that increases the possibility that in future that person has an independent and healthy relationship. (p.2-3)

3.4.2. Theme Two: Moral and Value Judgement

The second overarching theme concerns the nature of support work where sex and relationships are concerned. Many participants indicated their difficulty in decision making in this area as there are no definitive right and wrongs. Participants ideas around gender bias and heteronormative assumptions in relation to PwLD were apparent in some of the interviews. Participants indicated discomfort in talking about sex and relationships in general and acknowledged the personal difficulty in putting aside personal values when supporting someone

to engage in a behaviour that support-staff do not necessarily agree with. Participants also spoke of the dilemma of giving guidance and advice to PwLD, which due to the unique nature of the support-staff relationship, could mean that PwLD have their relationships micromanaged by support-staff.

3.4.2.1. Socially constructed sexual norms

This subtheme relates to how support-staff talk about sex and relationships. Some of the participants talked about sex and relationships as being a human right, both in terms of The Human Rights Act but also more generally as a basic human need:

> Interviewee 1: My friends are sick of me sharing stuff on Facebook about equal rights to relationships…(p.13)

> Interviewee 2: Sex is a human need, everybody has the right to have sex…as long as they're not being coerced.(p.2)

Some participants highlighted the recent portrayal of PwLD in the media, in television programmes such as The Undateables (Constable, 2013), as people interested in forming romantic relationships as a positive, but some expressed their concern that the media may sensationalise and alter the portrayal in unhelpful ways:

> Interviewee 1: …programmes like the Undateables are, as badly named as it is, it's great to kind of promote showing people in sexual relationships and having dating and going out and meeting people and I think that's really important. Like the only people you ever saw with disabilities on television were kind of saints or, and I think now to have like people on telly actively looking for love, and showing people that they're not just like sexless blobs sitting there, they wanna meet people, they want to do things, I think it's great. Maybe call it something different. (p.13)

> Interviewee 4: But I'm always a bit reluctant with TV. 'Cause they always want to get the most out of it, and they want to get the things that people – they would create – it's like the yellow press, it's not really objective, I don't know how to call it, it's more for the sensationalism. (p.9)

The concept of sex and relationships was deliberately kept open to participant interpretation. During a couple of the interviews, participants interpreted questions to be focused on PwLD solely having relationships with other PwLD. The way in which some participants spoke about specialist dating agencies for PwLD was indicative of not just assumptions that PwLD may only wish to be romantically involved with other PwLD but also that in order to form relationships, dating agencies would be the first avenue of enquiry:

> Interviewee 8: But we have not seen that at all coming from the female here, she is not interested in that way at all towards the male here. No interest at all, so we would be like, not horrified but really worried. (p.5)

> Interviewee 9: Plus I don't think there actually is enough out there, you asked if I knew what the options are I don't think there actually is enough, is it [name of agency]? They're a specific agency? (p.4)

Participants indicated that they themselves or others had the view that when it came to sex and relationships in relation to PwLD that there was a hierarchy of acceptable sexual behaviour. Participants found 'innocent' behaviour such as dating and holding hands acceptable but had more difficulty in thinking about more physically intimate sexual behaviour:

> Interviewee 10: okay things like apps and that it's not for them but to go on an innocent date and just chaperone them, you know they're young, they have a whole lifetime ahead of them, they need to have as much of a natural life as they can within their limitations and I think as a support worker you need to understand that. (p.4)

> Interviewee 11: I think you can perhaps look at people who are, who have learning disabilities and kind of treat them as very innocent, you know, treat them as very childlike and say ‘aw you know, you two are going to go and live together and you’ll read the paper and she’ll do the washing up’ because that’s how it looks in your head um and kind of think about wanting relationships, thinking ‘oh that’s nice, companionship, sharing, looking after each other’ and that’s really nice and we can think about that really quite nicely but there’s no part of two adults having sex in that picture…(p.5)

One participant expressed that they felt some organisations hold heteronormative assumptions which are impressed upon the PwLD being supported. As sexuality may be a very personal experience, the default to assume a PwLD is cis gender and heterosexual can result in this norm being foisted on PwLD regardless of their personal feelings:

> Interviewee 2: 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. (p.5)

Other participants shared their experiences of having made alterations to their organisation’s interview schedule to include a vignette around sex and relationships in the recruitment process. In the vignette the participant had deliberately specified that the (female) service user was seeking a same sex relationship but found that applicants responded in a heteronormative fashion:

> Interviewee 5: So we did have a few people write down I would support her to meet a boyfriend, and I very obviously made it clear that it was a

> female that she was seeking ((laughs)) so that was the reason I put that in. (p.4)

Participants identified reasons why they may hold the values they have towards supporting people with sex and relationships. Some participants identified the influence of their own families and their upbringing in influencing their values and morals. Participants spoke about this in such a way that indicated providing support around sex and relationships may be easier for support-staff who hold liberal values. One participant felt that provision of good support and support-staff's values towards sex and relationships and PwLD can be mutually exclusive:

> Interviewee 1: …I mean I'm quite lucky – I come from a family of like hippie lefties – my mum's a social worker and my dad's a therapist…(p.13)

> Interviewee 2: …see I have, me, I'm not bothered about sex because I have a lesbian sister and a transgender son[] brother in law so ((laughs)) so we're kind of, we're quite open about all things sexual in our house. But I, I've always been like that, before they came out and before that happened, and I think it's just to do with upbringing…(p.8)

> Interviewee 11: And I've got empathy for people who are fantastic workers but just say look we never did this when I was growing up, we never talked about this in my house this is not something that I am familiar with.(p.12)

Other participants identified factors such as age and religion to be key influences in affecting their values towards sex and relationships. There appeared to be an inherent assumption that younger people, and those without a religion may find provision of support around sex and relationships easier:

> Interviewee 1: they were all quite young and open minded on that team so it was quite nice 'cause they were all like 'yeah if he wants to' you

know, ‘if you want to have a boyfriend or a girlfriend then let’s get you a girlfriend’, that was really good. (p.4)

Interviewee 2: I think religion does come into it definitely um ‘cause we do have a high proportion of Christians, very staunch Christians or Muslim people in their group. But then it’s that thing of, you have to remind them, when they enter that house they have to leave all that at the door, because you’re not there for them, you’re there for the people you support, so unless the person they support is being religiously abusive or racially abusive, it doesn’t matter what we believe outside of that door ‘cause we’re there for those people, so you know, just deal with it. (p.3)

Participants identified individual factors such as family upbringing, age and gender, as well as cultural factors, such as media portrayal, as factors which influenced their support role with regards to sex and relationships. Participants also identified broader factors such as The Human Rights Act and Mental Capacity Act as influencing their stance. All participants expressed positive views about PwLD having romantic relationships, however, there was some acknowledgement of a hierarchy of acceptability with intimate sexual behaviour being talked about as more problematic than dating, which was seen as more innocent. Some participants indicated there may be heteronormative assumptions within the organisations they work for and some participants also indicated a ‘them and us’ divide, with the assumption that PwLD would only be attracted to other PwLD.

3.4.2.2. Conflicts for support-staff: This subtheme relates to some of the conflicts support-staff may experience when supporting PwLD around sex and relationships. These conflicts involve both internal conflicts in terms of support-staff putting aside their own needs or values when decision making, as well as service conflicts, where support-staff may feel the organisation does not share their personal values.

3.4.2.2.1. Internal Conflicts

Some participants argued that putting service users’ needs in front of support-

staff needs and accepting that everyone is different is very much part of the support-staff role:

> Interviewee 2: Also, I think it's to do, it's to do with being able to again, put them first and not see it through your eyes, see it through their eyes so, yeah, I might not like that but it doesn't make any difference. Yeah, I don't understand what he's got out from masturbating in a [shoe] but I'm not gonna, just 'cause it's not what I want doesn't mean it's wrong. And it's being open enough to say "people do weird shit" all the time. (p.8)

Some participants felt that it is the support-staff role to support service users to do what they chose, sometimes at the expense of support-staff wishes, as this is what support-staff are paid to do:

> Interviewee 1: it's very hard but it's what we're paid to do isn't it, as support workers, and I think the danger comes when you forget that that's what you're paid to do. I think you've got to remember that you're around to support people and what they want, not what you want. I think that's what it always comes back to and when I manage people that's what I always say to them, it's not about what you want, it's what they want. (p.4)

Other participants held conflicting views and felt that support-staff should be respected in their choices of what kind of support they feel able to provide:

> Interviewee 3: …some people thought it, um it wasn't what we do so they like challenged and said didn't want to do it, and some female members of staff don't do the forensic – the sex offender work because of personal reasons and that kind of stuff and you have to respect that. (p.4)

3.4.2.2.2. External Conflicts

Participants detailed some of the external conflicts they had experienced, in terms of being asked to carry out duties they did not want to, and uncertainty around the organisational approach.

Interviewee 2 gave an account of their team's discomfort in supporting a service user to keep her sex toy clean. The participant highlights that some support-staff may feel there is a distinction between sexual fluids and other bodily fluids and experience a greater level of discomfort in carrying out practical aspects of the support role due to the stigma placed on sexual fluids:

> And also that sex is private and that it's somehow (0.2) I remember someone saying "oh but it's so icky". And it was like how is that more icky than poo or vomit or (0.2) I think it goes back to a deep rooted thing that we have of being prudish. (p.1)

Another participant highlighted a situation where it has been suggested by other support-staff members that they support a service user to use sex workers. In this instance, the participant describes both their discomfort and the lack of decisive action with regards to this course of support, in that other support-staff are reluctant to document this suggestion:

> Interview 11: But I've also been nudged towards bringing male service users to a massage parlour that may not entirely be a massage parlour ((laughs)) it's kind of – what makes you think I know where this place is? I can go with them but I'm not entirely sure I understand what you're asking me to do, I'll tell you what, put it in an email and send it to me and I'll look into it. And the email never comes. (p.6)

Conflicts around provision of support for male service users accessing sex workers was raised by several participants. Some participants described direct experience of supporting service users who used sex workers, others described their anxiety and uncertainty as to whether this type of support was included in their support role. Use of sex workers appears to be conceptualised by support-staff as at the extreme end of the support provision support-staff are willing to provide.

Participants highlighted that often provision of support around sex and relationships for service users is overshadowed by other, more pressing matters:

> Interviewee 4: I'm sure the [organisation name] has to have the training, I'm sure I requested at the time but in the end you get busy, and in the end you kind of forget about it, but I'm sure they have to have training because it's such a big organisation, but I'm sure there has to be. (p.5)

> Interviewee 5: It just seems like things that, which are essential for us and we would prioritise just don't get prioritised. (p.5)

In these extracts, participants highlight that the provision of day to day support in the organisation can get in the way of attending specific training. In the second extract, Interviewee 5 expresses their frustration that sexual matters which are attended to for people without LD, do not get prioritised for PwLD.

3.4.2.3. Giving advice

Participants spoke about making many of their decisions relating to sex and relationships independently:

> Interviewee 4: But obviously she wouldn't have the initiative to tell you what she wants and what she lacks on this aspect, so what we come up with was these sessions and she agreed on that, she agreed on the process, I mean the key is, you know what can make her better in that so you can propose her and see if she agrees or not. (p.3)

In this extract, Interviewee 4 recounts proposing one to one sessions with a focus on relationships for a service user they had noticed appeared to be interested in forming a romantic relationship. This was done without consultation to external sources.

Other participants gave examples of advice or guidance they had given around sex and relationships, with some expressing uncertainty as to whether this was the right course of action:

> Interviewee 6: Like, for me, I have understanding about this, it's just, is it right for me, is it right if it's coming from me or should it be the professional, you know, like to discuss like contraception. (p.9)

In this extract, Interviewee 6 may be experiencing uncertainty as to which role they should take on; the desire to provide an environment where the service user can discuss contraception with a trusted support-staff member ('scaffolder') versus. safeguarding the service user against potentially inaccurate information ('protector').

Other participants recounted experiences of offering directive advice regarding sex and relationships without querying whether this was within the remit of the support-staff role:

> Interviewee 7: So what I advised was that the lady should go and stay at the man's place for three days or two days and the man can come over and stay for two days or three days for them to practice the minimum of living together. (p.8)

Some participants identified the unique insight they have into service users' private lives, with support-staff being privy to more intimate information than they would perhaps always feel comfortable with:

> Interviewee 7: I think some of them do that because they are free to talk about it. You can imagine, your customer saying to you "guess what? I had sex yesterday" and I'm thinking "all right ok, I'm sure you had a good time". You know, they talk about things that they feel they want you to know. (p.1)

Some participants also found themselves in the position of knowing sensitive information about a service user's partner, of which the service user was unaware:

> Interviewee 6: the girlfriend is supported by other people that works in our company as well, the new girlfriend. But we've heard she's got a boyfriend so it's tricky if we consider the person that we support, he found it in the end though and he'd say "they're only friends, I'm still the boyfriend" so we kind of were okay, if that's how he think so we just let him see it that way because it would upset him if he found out the truth. (p.4)

This unique positioning of the support-staff member to be privy to personal information regarding the service user but also be in a position where they can influence the service user's behaviour can result in the sex and relationship behaviour of service users being micromanaged by support-staff. In the example below, Interviewee 1 talks about supporting a service user to become pregnant:

> Interviewee 1: well, we'd got to the first stage where we were talking about, 'cause the [potential] mother in the couple was a smoker, well we said "you'll have to give up smoking if you get pregnant, so let's give up smoking first and that'll be the first stage and then we can start talking about the rest of it". (p.6)

Whilst this is arguably good health promotion and a GP would likely offer similar advice to any woman attempting to conceive, what is interesting is that the focus has been steered by the support-staff member from discussion of support around pregnancy to smoking cessation, which is arguably a far less complex scenario to support. Additionally, this could be construed as support-staff imposing a condition on the service user; 'if' the service user gives up smoking, 'then' they can consider pregnancy. In this sens, support-staff could be seen to be imposing a restriction, however well intentioned.

Other participants offered good relationship practice advice to service users. In the following extract, Interviewee 3 describes an example whereby a service user who has a girlfriend behaves in a way which may be hurtful to their partner. Support-staff then discuss this behaviour with the service user to explain the impact of this behaviour:

> Interviewee 3: But [name] likes the ladies and sometimes causes problems, he's sometimes a bit disrespectful and you, so we've had to support that sometimes. He always wants girl's phone numbers and he'll always be really flirty in front of [girlfriend's name] his girlfriend, so kind of after the fact you have to talk to him and say you've got a girlfriend if you don't want a girlfriend or relationship with [girlfriend's name], so we have those conversations but he knows what he's doing. (p.8)

In this example there is an element of teaching appropriate relationship behaviour, which could arguably fall within the remit of a support-staff. For individuals without LD who do not have support-staff, this learning may come from a variety of formal and informal sources (e.g., friends and family). In this example, the participant explains "but he knows what he's doing" indicating that in this situation the service user does not need to be taught appropriate behaviour but instead support-staff feel they need to let the service user know that they disapprove of his behaviour.

Another participant gives direct advice to a service user about how to manage a potentially difficult family situation; two service users are engaged to be married but the male service user has not told his family. The support-staff member gives direct advice as to how to navigate this situation:

> Interviewee 7: I spoke to this gentleman and said "now you need to take action because you are getting married to this lady that your family have never met", then I advised that maybe the best thing to do was to arrange maybe dinner or lunch with your girlfriend, yourself, your sister and your nephews, just sit down to do a little bit of introduction and see how it goes. (p.3)

The support-staff member presumably has the service user's best interests when giving this advice but is operating on their assumption about what is considered a norm when applied to marriage; that families should meet one another. Of course, many people have very different relationships with their own family and

their partner's family. However, when considered in the context of a potential power differential between support-staff and service user, the line between helpful suggestion, which the service user is permitted to disregard, and direct instruction may become blurred.

3.4.3. Theme Three: Enablement and Empowerment

The third overarching theme concerns enablement and empowerment of support-staff to carry out their support role with regards to sex and relationships. During the course of the interviews it became clear that support-staff were already providing a broad spectrum of support to service users with regards to sex and relationships, as identified in theme two, it is simply "part of life". Whilst participants described a broad range of experience, they also expressed a lot of uncertainty and fear around this area. Lack of certainty in decision making and having things go wrong or being accused of unprofessional behaviour was a big fear for participants. Paradoxically, although sex and relationships was viewed as "natural" and "just part of life", provision of support around this was felt to require specialist support and knowledge. Although most support-staff felt that they were best placed to deliver support, they did not necessarily feel they were best placed to plan this support, or to do this independently. Participants had many ideas about what support they would find most beneficial.

3.4.3.1. Facing Fears: Many participants indicated that in order to provide effective support around sex and relationships, specialist knowledge was required. There were varying expressions of why this may be the case. Some participants felt they were not qualified to make decisions and that this subject area required additional education. Others felt that the level of risk and responsibility surpassed their level and would feel more comfortable with someone with professional qualifications supporting them to do this work:

> Interviewee 10: I think we could deliver it but with guidance from someone else, I say support workers because we're around them most of the time, so if we're delivering it we should have direction from somebody so we know how to pitch it, so we're all kind of pitching it at the same level. (p.3)

> Interviewee 11: And where you are, I mean the hierarchy of social care I mean as a support worker, I think because you do a lot of menial things, a lot of very hum drum things, cleaning and this sort of thing, you can sometimes feel that I'm looking for someone above me, someone with letters after their name, a doctor or consultant or a social worker or an AMP or whatever, whatever trying to give me the guidance and empower me to do this thing because I'm worried if I do, I think I said befor, I'm worried that if I do it and it blows up in the face I'll be the one where there's all sorts of questions being asked of me. (p.7)

In this extract, Interviewee 11 also identified their fear of repercussions around decision making concerning sex and relationships.

There was the perception from some participants that other professionals were more likely to have specialist knowledge and be more able to support service users with certain elements, such as contraception, than the support-staff could:

> Interviewee 6: I guess I would educate them really, what are the [contraceptive] options and discuss it with them and maybe the GP, because the GP would have more knowledge and information. 'Cause for me I'd just be guessing or checking the internet, because if it's coming from a professional they are likely to listen as well. So I think that is the route I'm going to follow, so I would say "if you want to know more about this stuff to protect you or your girlfriend or boyfriend would you like to see the nurse or doctor and know more things about it". (p.9)

In this example, the participant suggests going to a GP for information. Whilst the researcher acknowledges a GP should have a good understanding of contraception, it is unlikely the GP will have specialist knowledge of how to communicate this information to an individual with a LD. This has implications for support-staff who may be seeking support from sources who may actually be poorly placed to aid in the sexual support of service users.

There were varying amounts of experiences and reports of confidence from the participants, with some having more experience providing sexual support than others. Participants who have regular experience of providing this support spoke confidently about their experiences, and highlighted the amount of time they had spent working as having a positive impact on their confidence:

> Interviewee 7: well I've been working with people with LD for over ten years, especially talking to them about how to look after themselves, sexual health topics sometimes, which we do talk about during support sessions. (p.1)

Many participants expressed fear around the topic of sex and relationships. One participant drew comparisons between sex and relationship and other areas of support work, highlighting a tendency to have a general fear of anything untoward happening to service users:

> Interviewee 5: I mean it's just that fear of the unknown that we get in every kind of area, you get it in terms of what if I go out with someone and they run into the road, so I think it's always about just having honest conversations. I think you need to have a staff team that aren't afraid to speak up and say those things because they can address them. So yeah, it's the same thing when it comes to relationships. (p.9)

This general fear of the untoward also feeds back into the role of support-staff as being protectors, being vigilant to potential risk.

Fear of being unable to or having to justify decision making around sex and relationship was raised by a majority of the participants. As discussed, sex and relationships is seen as an area where there are few definitive answers and opinion may vary as to what the correct course of action is. Support-staff expressed fear in justifying any decisions they had made with regards to supporting service users, due to fear that they would be seen as over-stepping boundaries or being inappropriate:

> Interviewee 2: I think again it's the fear. It's the fear element. Because you would have to justify why you allowed that to happen, do you know what I mean, why you thought that was acceptable. (p.6)

> Interviewee 3: I think it's 'I dunno what the right thing is' and I think it's- I think they're scared because if they're criticised by, say, a social worker or something like that or a family member raises it and says 'that's nothing to do with you, you shouldn't have done that, I don't want my daughter or my son to be doing that and you've supported it' and I think they're frightened of getting into trouble. (p.7)

> Interviewee 11: there's a little bit of (0.2) worrying I suppose that you'd support somebody into something that perhaps they don't fully understand all the ramifications of it, that that could come back to you, you know, a concerned outsider or someone could say "what?! Who said this was a good idea?! No!" (p.6)

This fear may stem from uncertainty around who should be making decisions around sexuality, as the extract from interview three highlights, there is a feeling from support-staff that parents have the final decision when it comes to decision making on behalf of service users.

3.4.3.2. Practical Assistance: Although participants felt that the role of directly supporting service users in matters relating to sex and relationships was within the role of support-staff, all participants felt that this should be with some form of support. Some participants identified the need for support-staff to be able to ask questions and foster a working environment where issues could be brought up and discussed without fear of embarrassment or recrimination:

> Interviewee 5: And it's like being able to have those conversations with staff and try to kind of, rather than expect them to deal with it, to provide that support and to start looking at issues like capacity and if there is anything that they're not comfortable with in relation to being able to support someone in those kind of areas, being able to look at and just

> have very honest conversations, what makes you uncomfortable about that, what are some of the concerns that you might have if you were in this situations and you had to make decisions. (p.1)

Other participants raised the importance of having good support from within the organisation, whether this be from fellow team members or managers, in providing supervision:

> Interviewee 9: …it's a good team as well, we can all talk about our sort of, how we feel in a situation, yeah, you're listened to and everyone's contribution is valued, everyone's input is really valued, so yeah, well supported, definitely. (p.3)

> Interviewee 10: yeah, I know that I would go to my manager, if there was something that needed addressing that obviously I couldn't address because it's over my head but, generally, yeah I do feel supported because, as I've said before this is a good team in that we talk, and so I don't feel the need to try and sort it out by myself, if I do not have the answer I know that I can take it further, upwards to my manager or I can talk to my colleagues. (p.3)

As well as support with practical guidance in terms of how best to support service users, participants also discussed the emotional impact of supporting service users with sex and relationships:

> Interviewee 3: And I didn't speak to that member of staff about it because I wasn't 100% sure but I think that's what happened but I also didn't want to upset that member of staff, as she felt really bad when that relationship broke down. (p.8)

In this extract, the participant discusses a fellow member of staff who supported two service users to enter into a relationship which had then broken down. The participant felt that this support-staff member may have encouraged the relationship and then felt bad when it had subsequently broken down. The

participant describes not being “100% sure” this had happened but, certainly, the support-staff member had some emotional investment in the service users relationship, which was then impacted when it broke down.

Another participant recounted the emotional impact of supporting a service user who had been raped. This was a service user who had capacity to make relationship decisions in a supported living environment, which the participant had been supporting them to do:

> Interviewee 1: But I think, when it gets a lot more complex, when there’s a lot more things going on, I think that’s when we need to – we definitely need debriefing as well. Sometimes things can be quite traumatic, I worked with – somebody I supported got raped and it was…yeah, pretty horrible. You need a lot of support and debriefing after that, it was quite hard to deal with… (p.9)

This participant describes being quite unsupported during this time, whilst trying to give the best possible support to the service user:

> Interviewee 1: yeah well, nobody else was really involved, it was just me and the person she disclosed it to, really, that took the burden of most of it. And I did a lot of debriefing with her to make sure she was okay. (p.10)

In this example, Interviewee 1 highlights the need for practical support for support-staff in terms of someone to provide debriefing and ongoing support.

The majority of participants were unaware that their role may involve some form of support around sex and relationships when they applied for the support-staff role:

> Interviewee 4: nope, job description, interview, person spec, there’s nothing mentioned at all. It’s even not mentioned in the induction. All personal stuff, it’s not mentioned at all. (p.5)

Other participants spoke about the changes they had managed to make to the recruitment process in order to both make support-staff aware that their role may involve support around sex and relationships and also to assess support-staff values:

> Interviewee 1: I think that when you're (.) when you're recruiting for a service like ours, that one, we always look for people who'd be quite kind of open to those kinds of questions. And if we saw anybody who'd be a bit kind of 'that's naughty, that's wrong' then we probably wouldn't have them there. (p.7-8)

This is indicative of practical changes required around the recruitment process for support-staff roles, with clearer indication that sex and relationships will form part of the job role.

Interviewee 5 offers a perspective on support provision to support-staff akin to a cycle; good staff support from the organisation leads to good service user support from support-staff, which leads to happier service users and fewer crises:

> The support that staff provide will only ever be as good as the support you're providing to those staff. So if you don't support your team and make them feel valued and supported, that's gonna reflect in the care or support they provide and you're almost setting yourself up for more work because then you're picking up the pieces and firefighting all the time, you're going to have families that are very upset and really crap quality care and high staff turnover. If you want to provide good care or good support you then you need to support your staff. (p.8)

The majority of participants spoke positively about their experiences of support from other professionals and from external organisations:

> Interviewee 4: so sexual relationship meetings and they were delivered by, not psychologist, behavioural coordinator and the key worker of that person we support. So that person is the key worker but hasn't had the

> training. But at least you have the behaviour coordinator there, so is the same person with the same values. And I think, I hope they have been trained for that. (p.6)

> Interviewee 8: that would be that and that was with the council, it was done quite well, they have access to all these people, all these outside agencies, I don't know what it's like now but at the time they did, phone calls here, call these people there, all these different agencies coming from all over, together as one, the social worker would call this person, we'd call that person. It was really good. (p.2)

The majority of participants either had experience of working with outside agencies such as local groups or the community LD team, or cited them as organisations they would approach if they felt a situation could not be managed within the organisation. Some participants felt that support from outside organisations was helpful in that it created a different dynamic with service users, one in which the service users may be more likely to take on new information in relation to sex and relationships:

> Interviewee 11: I think sometimes it's smoother and cleaner and clearer for that person to hear really important facts from the professional. We're going to a meeting and we're going to talk about this and this is this and that's that… Sometimes because you're close, it's not that the authority isn't there but (0.2) the weight, you know…(p.12)

In this extract, Interviewee 11 feels that due to the close relationship with service users, important information regarding sex and relationships may not be taken seriously, they highlight it is not the authority of telling a service user what to do but more the weight of the message being understood. So whilst participants felt that supporting service users around sex and relationships is very much within their role, there may be certain elements of support which are more suited to working collaboratively with external professionals.

A couple of participants spoke positively about the impact of external

professionals but commented on the lack of involvement the support-staff had with this work:

> Interviewee 8: we weren't a part of that to be honest, the whole process. It moved on from the manager and then the professionals, they all took over, people came in and out interviewing her, then they were going to the town hall for interviews, taking him, in the end they decided that she was giving consent, basically, and that she knew what she basically wanted so. And the family were involved, everyone was involved. I've not really been part of the whole process, just like watching it happen. (p.1)

> Interviewee 9: We didn't do a lot on our side, the psychologist had a lot of input. We sought help basically. (p.1)

The combination of professionals 'taking over' and the lack of consultation with support-staff in these instances, may serve to further entrench the notion that providing support around sex and relationships is not within the role of the support-staff. This has potentially negative consequences on support-staff in terms of devaluing their position, and also on service users, in terms of having limited access to appropriate support. Interviewee 6 comments on their feelings that support-staff should be trained in how to support service users in sex and relationship matters, highlighting the waiting time that might be needed to see professionals:

> …because if the situation is already happening it would be handy if we had the information to present to them, rather than waiting for an appointment that's not going to happen tomorrow, so I guess for me if that is um, it's not happening, you know, if the situation arises we would have a special training for it…(p.9)

4. DISCUSSION

4.1. Overview

This section considers the findings of the research in the context of the initial study aims. A critical review of the methodology will then be offered, highlighting limitations. Finally, a reflective account of the research process will be given, acknowledging the research's critical realist epistemology and the need to balance the position of the researcher with regard to the conclusions drawn from the research findings.

4.2. Discussion of Findings

This study sought to determine how support-staff conceptualise their role with regards to supporting PwLD around sex and relationships, to explore what informs support-staff understanding of their role and whether any conflicts arise for support-staff within this role. An inductive thematic analysis was carried out which yielded three overarching themes; 'Definition of support work', 'Moral and Value Judgement', and 'Enablement and Empowerment'. The key findings will now be discussed in the context of three research questions and existing literature.

4.2.1. How Staff Conceptualise their Role

Participants' conception of their overall role with regards to support work was seen to influence their understanding of their role with regards to sex and relationships.

Participants described the changing nature of their role in terms of historical developments. Some participants acknowledged the historical context of the late 20th Century, in that the physical environment for provision of support-work had altered; with a move from large scale institutions to community work. The support-staff role may historically have involved active discouragement of sexual practices and institutions were not set up to cater for privacy. Since the late 20th

Century, the support-staff role has moved from discouragement of sexuality to enablement regarding the rights of PwLD, driven by a change in societal views and rights based legislation (e.g., Valuing People, 2001). It was acknowledged by some participants that despite these changes, residential services for PwLD are still not physically set up to promote successful sex and relationships for PwLD (e.g., only providing single beds). Support-staff also reflected on a change in terminology in terms of the description of the support-staff role from carer to support-staff, emphasising a less custodial and more enabling approach to the role.

Three prominent conceptualisations of the support-staff role with regards to sex and relationships were found; the researcher has termed these protectors, parents and scaffolders, which are explored below.

The protector role involves prioritising safeguarding service users from harm. When adopting the role of the protector, there is potential for the support-staff to prioritise safety at the expense of positive risk tasking and emotional development. The protector role draws on a conceptualisation of PwLD as vulnerable in the arena of sex and relationships. Similar to the findings of Rohleder (2010), participants expressed ambivalence at promoting knowledge of sex and relationships to PwLD, as they felt this may expose service users to harm. In their role as protector, some participants were reluctant to introduce sex and relationship information, feeling that this could complicate and impact negatively on service users. The protector role may inhibit support-staff from proactively assessing provision of sex and relationship support to service users.

The parental role balances safety with positive risk taking. Previous research has indicated that actual parents of PwLD have quite different views around sex and relationships to support-staff (e.g.,Cuskelly & Bryde, 2004, Löfgren-Mårtenson, Sorbring & Molin, 2015), though participants spoke about providing support to service users in the same way they would support their own children. However parent-child relationships are not static and there is a degree of difference in parenting an infant versus. parenting a teenager. In some ways, this parallels the changing conceptualisation of support-staff from caring to promoting

independence. One participant made the inference that the support-staff role was akin to parenting teenagers; it involves care and worry but also positive risk taking; equipping people to make choices, hoping they make the right ones and being around to support when things may not go well. The parenting role may also involve an uneven power dynamic with support-staff adopting a powerful, parental role and infantilising the service user. Some service users may respond to staff adopting this role in a rebellious fashion, which could lead to negative outcomes.

The term ‘scaffolder’ comes from Wood, Bruner and Ross (1976) but is based on Vygotsky’s (1978) theory of the zone of proximal development which is described as:

> "the distance between the actual developmental level as determined by independent problem solving and the level of potential development as determined through problem solving under adult guidance, or in collaboration with more capable peers" (p.86)

In this case, ‘scaffolding’ support-staff fulfil the role of more capable peers by creating an environment where service users are able to learn sex and relationship skills and also by attending to skills in other areas. For example, one participant described supporting a service user with emotional regulation, with the knowledge that this will help when forming friendships and romantic relationships in future. The scaffolder may also identify groups or activities which can promote the service users’ experiences with regards to sex and relationships.

In the role of scaffolders, support-staff seize opportunities for incidental learning; support-staff can experience difficulties when weighing up the desire to impart information when it is relevant (e.g., in response to a service user request) versus. deciding whether they feel qualified to do so.

Most participants spoke about their overall role as supporting the service user to be independent and make choices about their life; a similar finding to that of Windley and Chapman (2010). Sex and relationships was understood to be

another element of life and, therefore, within the remit of the support-staff role. Gallagher (2011) found that support-staff willingness to provide support was not associated with confidence in this area. This highlighted that additional input is required for support-staff to feel confident providing support around sex and relationships. In this study, it was found that support-staff valued working environments where they felt able to ask questions and query decisions with the wider team around sex and relationships.

The role of other professionals may impact on support-staff conceptualisation of their role with regards to sex and relationships. Participants spoke positively about their experiences of working alongside other professionals, particularly if they felt the professional was qualified to make decisions and manage risk. Some participants described their experiences of working with other professionals as being uninvolved with the decision making processes. Support-staff described professionals from external organisations 'taking over' at times. Whilst participants did not frame this negatively, the researcher considers what impact this may have on support-staff; perhaps what is being communicated to support-staff in this instance is that they are not able to provide support around sex and relationships and someone else needs to do this for them. The consulting professionals may need to reflect on the type of work they do and how support-staff can be meaningfully involved in order to avoid undermining the contribution support-staff make towards support provision of PwLD and sex and relationships.

4.2.2. What Informs Staff in their Conceptualisation of their Role

This study found that providing support around sex and relationships draws on support-staff's morals and values. This finding aligns with that of Christian, Stinson and Dotson (2001), who found that support-staff were often guided by their own value judgements when making decisions around sex and relationships. Some participants spoke of morals and values being something they had incorporated from their upbringing and from the leanings of their own parents. Participants who had, for example, personal experience of homosexual and transgender family members described being more open to the possibility that the service users they support may need support exploring their sexuality and gender.

As well as family upbringing, participants gave accounts which suggest that the prevailing sexual norms within Western culture may have pervaded support-staff behaviour. A heteronormative stance was apparent in terms of organisational approach and also in terms of individual understanding. It is unclear why, in the absence of overt reporting of prejudice towards LGBTQ communities, PwLD should have heteronormative standards applied to them. Abbott and Howarth (2007) found that support-staff were not confident in providing support to LGBTQ PwLD, citing a training need and complexity in terms of support-staff and parental prejudice. Gill's (2015) finding that support-staff find heteronormative practices and non-reproductive sex more appropriate for PwLD could indicate that the motivations behind this heteronormative projection are likely to be multifactorial, and bound as much in constructions of capacity and LD as it is in understanding LGBTQ communities.

The majority of participants spoke about a lack of clear guidance within organisations with regards to providing support around sex and relationships and, as such, described defaulting to independent decision making based on personal value judgements. This highly individualised approach to support in this area could have negative implications for service users; potentially leading to inconsistency and mixed messages about what is and is not permissible. Previous research (e.g., Thompson, Stancliffe, Broom & Wilson, 2014) has indicated an absence of coherent organisational approaches to sex and relationships and the findings here echo this.

Legislation such as the Mental Capacity Act and Human Rights Act, as well as organisational safeguarding guidance, was cited as a means to inform the support-staff role around sex and relationships. The researcher considers what impact the current climate regarding attitudes and approaches to safeguarding against sexual abuse may have on support-staff. Initiatives such as 'Behind Closed Doors' (Mencap, 2001) have sought to protect PwLD from sexual abuse and promote awareness of capacity decisions. There is a possibility that providing training to support-staff around sex and relationships solely in the

context of safeguarding will have a disempowering impact on support-staff ability to support and promote sexuality as a means of enjoyment for PwLD.

Power dynamics between support-staff and service users may influence the support provided. Participants spoke about the unique insight they have into the sex lives and relationships of the PwLD they support. At times, this means support-staff may be privy to intimate and embarrassing details of their service users lives. Support-staff may also face the dilemma of what information they should share with service users, this is particularly pertinent for staff supporting two service users in a relationship with one another. Due to this positioning, and perhaps due to inherent power imbalances in the 'service user – support-staff dynamic', support-staff are uniquely placed to influence service user behaviour. Support-staff may intervene in relationships to settle arguments or to address poor behaviour within the relationship. As such, the line between support and teaching could become blurred, resulting in micromanaging the service user's relationship, which has the potential of resulting in an infantilising and disempowering experience for the service user.

Participants described the communicative ability of the people they supported as a key factor in providing support in this area. Participants described feeling more confident and able to manage situations whereby a service user could communicate their needs with regards to sex and relationships. This appeared to be regardless of capacity; expression gives rise to direction and a course of action (e.g., a capacity assessment or provision of support). Some support-staff indicated that supporting service users who had capacity to make their own decisions around sex and relationships was easier, as this gave support-staff direction as to how support could be provided. Other support-staff expressed their frustration and fear at the lack of control this gave support-staff in being able to protect service users, whom they viewed as vulnerable from sexual and relationship harm.

4.2.3. Conflicts in Supporting PwLD around Sex and Relationships

Participants acknowledged a dilemma in support provision, with some participants holding the view that their role is to put the service user first and support them in their choices, regardless of whether this contradicts the personal values of the support-staff. Other participants felt that support-staff values must be respected and that support-staff could reasonably refuse to provide support in some areas of support provision. The researcher noted the strength of opinion expressed by some of the participants with regards to ensuring the rights and needs of PwLD are met. Whilst the approach of "it's what we're paid to do" (Interviewee 1) could be understood as an uncompromising position when it comes to championing the rights of PwLD, there is also the possibility of alienating support-staff who may not conform to the same beliefs, and of shutting down potentially helpful conversations which would aide understanding in the wider team. Whilst to this researcher this view is undoubtedly held with the best of intentions, there is a possibility of this approach ultimately undermining the rights and need of PwLD by undermining the rights and needs of the support-staff. Cambridge (2012) has demonstrated that using a rights-based approach with support-staff can help bridge the gap between support-staff discomfort and service user preference.

Support-staff understood PwLD to be vulnerable with regards to sex and relationships but appeared conflicted as to whether sex education and discussion of matters related to sex and relationships would promote protection. Abbott and Howarth (2007) found that support-staff were reluctant to raise the issue of sex and relationships with service users, as the support-staff interviewed in this study also indicated. Conflicts emerged between different conceptualisations of the support role. Safety emerged as a hugely important factor, particularly when adopting the role of the protector. The tendency to adopt this role could conflict with other conceptualisations, such as the parent or the scaffolder where growth and positive risk taking feature as a priority. Protectors may have an exaggerated perception of harm and try to safeguard against uncontrollable eventualities such as emotional heartbreak of service users.

Support-staff may experience conflicts in the organisation within which they work. The researcher is curious about the support-staff experience of being able to refuse to carry out support or being given space to discuss and reflect before a decision is made with regards to sex and relationship support. Whilst it would be difficult to account for every conceivable duty within any job role, there is huge breadth of expectation when a job role is conceptualised as supporting someone to live their life. Whilst the work ethic of "it's what we're paid to do" (Interviewee 1) could be seen as a reasonable assertion when considering support work in the context of enabling PwLD's independence, devaluing the support-staff's needs and wants is unlikely to create a positive environment within which to deliver good support. Thompson, Stancliffe, Broom and Wilson (2014) identified support-staff barriers to the provision of good sexual health support. They identified the lack of focus and service approach to sex and relationships as a barrier and called for specific outcomes in this area within services and policy guidelines. The findings in this research indicate that support-staff in some organisations do not feel there is a service approach to sex and relationships and are unclear on policy or guidelines they should follow. Support-staff also highlighted that they and other professionals may have other, more pressing matters to attend to in the provision of support and, as such, good support around sexual health may not be prioritised. Drawing on Maslow's theory of motivation (Maslow, 1943), it may be that support-staff are overestimating the need for base level physiological safety at the expense of attending to psychological needs.

The emotional impact of the role of support-staff has been documented in research examining experiences of supporting PwLD who are in pain and who have experienced bereavement (e.g., Findlay, Williams, Baum & Scior, 2015; McEvoy, Guerin, Dodd & Hillery, 2010,). Emotional impact also appears to be a factor when providing support around sex and relationships to PwLD. Support-staff may find it difficult to support individuals who have had traumatic experiences such as sexual abuse as well as feeling some level of responsibility when relationships do not go well for the person they are supporting. Whilst support-staff view sex and relationships as just part of life, the embodiment of the role of protector can make it difficult to negotiate areas where service users may become hurt. Whilst safety is important and reasonable steps should be taken to

prevent PwLD from being abused, it is difficult, if not impossible to protect people from heartache. It can be hypothesised that support-staff would understandably find this difficult.

The finding that some support-staff do not feel decisions regarding sex and relationships is their decision to make, with some participants citing the parents of PwLD as the decision makers in this arena, has similarities with that of Löfgren-Mårtenson, Sorbring and Molin (2015), who found that support-staff feel parents should be the main decision makers with regards to internet usage for sex and relationship purposes. Support-staff at times felt conflicted about whether they should be offering advice and, at other times, offered advice without reflecting on motive. Nonnemacher and Bambura (2011) found support-staff could have both an enabling and inhibitory impact on service user decision making. This uncertainty as to who makes decisions, when an individual does not have capacity, may result in a lack of movement with regards to sex and relationship with no one confident to lead or to promote conversation around decision making. Whilst findings from this research indicate that more could be done to empower support-staff in their role, this raises the question of what else may be needed to empower other parts of the system.

The findings in this study indicate that many support-staff may already be providing a broad range of support to PwLD around sex and relationships, albeit on an informal and unsupported basis. Regardless of conceptualisation of how this support is provided, it is clear that sex and relationships is viewed as part of the lives of PwLD and, therefore, within the remit of the support-staff to provide assistance. What also emerged from the interviews is that support-staff need to be enabled and empowered to carry out this role effectively.

Enablement and empowerment can take many forms, whilst support-staff have valued cross-professional working with external organisations (e.g., charities and local LD teams), at times professionals have taken control which could result in feelings of powerlessness for support-staff. McConkey and Ryan's (2001) finding that support-staff who have managed a sexual scenario feel more confident in managing other sexual scenarios in the future indicates that collaborative cross-

professional working may enable support-staff to gain confidence in managing sexual scenarios, which may mean less demand for professional services.

4.3. Critical Review

4.3.1. Research Quality

Evaluating the quality of qualitative research which has a critical realist epistemology involves drawing on a different set of quality indicators than may be expected in quantitative, realist research. The concepts of reliability and validity of the research findings do not equate to the same expectations as in quantitative research; for example, qualitative research findings are viewed as a construction between the researcher and the data, therefore, are not expected to be replicable.

There are a number of frameworks for assessing the quality of qualitative research (e.g., Elliott, Fischer & Rennie, 1999; Miles & Huberman, 1994; Spencer & Ritchie, 2012 and Yardley, 2000). Agreement as to what constitutes good quality differs between frameworks and is dependent on epistemological stance. Miles and Huberman (1994) advocate checking with participants as to whether the researcher's findings represent the participants' intended message. This may be appropriate when employing a realist epistemology but would be a nonsensical quality indicator when employing a critical realist or social constructionist stance, as the data is constructed between researcher and participant, not harvested by the researcher from the participant.

Both Yardley (2000) and Spencer and Ritchie (2012) highlight that a qualitative study's impact or contribution is important in determining quality. The research should either generate new theory, contribute to current understandings or provide a deeper level of insight into the nuances of a particular group's experience. In this study, the researcher has attempted to explore in detail the role of the LD support-staff.

Elliott, Fischer and Rennie's (1999), Yardley (2000) and Spencer and Richie (2012), all indicate the importance of credibility or commitment in ensuring

qualitative research has validity. Credibility or commitment refers to two components; essentially, are the research findings believable and have the methods used to reach these findings been carried out in a sufficiently rigorous manner? In this study, many of the research findings have also been documented in previous research, indicating face credibility. The researcher has attempted to offer a detailed overview of the thematic analysis process and included extracts of raw data, coding process, primary codes and visual representations of thematic groupings, within the appendices, in order to aid the reader in assessing credibility.

Both Yardley (2000) and Spencer and Ritchie (2012) identify the importance of rigor as a quality indicator in qualitative research. Rigor can be considered an indication of reliability in qualitative research. The researcher attempted to make the means by which these findings were arrived at as rigorous as possible. Analysis involved line by line coding of the data and multiple readings of the transcripts to ensure familiarity with the data. Notes written immediately post interview were used as a reflective guide from the researcher when interpreting data from transcripts. An adherence to a critical realist epistemological stance has been demonstrated throughout the research via the analysis, going beyond the text, and a reflective account of the position of the researcher provided.

4.3.2. Study Limitations

This study employed a qualitative research methodology, as such, the sample size was small (n=11) and the data collection and analysis process was labour intensive and time consuming. The small sample size means that caution must be applied when generalising this study to a broader population.

The study necessarily employed a self-selecting sample; given the nature of the topic, participants had to be willing to discuss their experiences with the researcher. However, a self-selecting sample may have incurred some inherent bias; the recruitment phase involved a two-step process of firstly contacting organisations to gain permission to advertise, then advertising to support-staff members. Many of the organisations contacted (n= 18) did not respond to the researcher; there may have been some differences between organisations which

responded to the researcher and those who did not. Participants who volunteered to be interviewed may feel more comfortable in talking about matters of sex and relationships than those who did not volunteer and, as such, may not be an accurate representation of support-staff. Additionally support-staff who volunteered may have done so because they felt they had particular experiences around sex and relationships that they could share; this may have given over-representation to the finding that support-staff are already providing broad support around sex and relationships.

Due to the self-selecting nature of the research design, as well as the recruitment exclusion criteria, not all participants were employed at the same level; with some holding senior support roles and management responsibilities in addition to their direct support provision work. It may be that these participants represented a more confident population of support-staff, given their level of responsibility. Meaney-Tavares and Gavidia-Payne (2012) found that support-staff managers held more positive views than support-staff towards sex and relationships and PwLD; there is a possibility that findings around sex and relationships would have been drawn out if solely ground level support-staff were interviewed.

This study did not involve any PwLD or involve direct consultation with PwLD concerning what type of research may be useful. In LD research there is particular emphasis on service user involvement (Glasby, 2002). Hassiotis, Hamid and Scior (2015) found that PwLD's main research interests are inclusion, health and housing. This study relates to both the inclusion of PwLD in engaging in sexual activity and relationships and to sexual health.

This study was specifically concerned with examining the role of support-staff with regards to sex and relationships. The researcher, from their clinical position as a trainee clinical psychologist, focused on the role of the support-staff, hoping to gain insight into how support-staff view their role in order to shed light on cross-professional working. In valuing the role of the support-staff and the type of support they provide, this values PwLD and their rights in this area. Whilst support-staff were the main focus for the study, the wider reasons for examining support-staff role relates to the provision of support and experiences of PwLD.

Some caution must be applied when interpreting findings and applying to practice. This study asked participants directly about their experiences and is therefore, an account of what support-staff may talk about regarding the work they do. The study does not provide a direct account of practices in which support-staff actually engage or the impact of that support on service users.

4.3.3. Reflection on Role of the Researcher

Employing a critical realist epistemology has allowed the researcher to go beyond the data and add an additional layer of interpretation to generate themes. Some acknowledgement of the researcher's position should be reflected upon to put the findings in context.

The researcher acknowledges the potential impact their demeanour may have had on participants. The researcher has five years of pre-clinical training experience working in the LD field in both support-staff roles and advisory roles to support-staff, has completed further study in the field of LD and is enormously passionate about the rights of PwLD. Therefore, much of the researcher's first-hand experience and views will have influenced the interview process. Whilst shared experiences may have helped the researcher to generate a rapport with some participants, there is a danger that sharing experiences during the interview process may have discouraged participants from sharing some elements of their experiences.

Although the researcher was an external individual, in the sense that they were not employed by any of the organisations and did not work alongside the participants, the researcher has a sense of being an 'insider' in that they cared deeply about the issues being explored and could relate to many of the experiences, fears and dilemmas participants discussed. Whist this could have resulted in some bias in reporting, Coles (2015) argues that insider research, where the researcher has direct experience of the research problem, offers a unique perspective into the research being conducted.

The researcher is likely to have appeared as a relatively young, white, middle class female student which may have impacted on the research process. Sex and relationships was found to be considered a moral and value judgement, with sexual norms being constructed and bound up in culture, religion and societal assumptions. Previous research has indicated age to be an important variable in influencing attitude to sexual practices (e.g., Swango-Wilson, 2008). It is possible that due to the age, gender and cultural differences between the researcher and the participants, some key concepts may have been misunderstood or failed to be recognised as important themes.

Taking time to make some reflective notes following each interview was helpful in allowing time to reflect on initial overall impressions of the interview process. It was interesting to note the changes in perception immediately after the interview versus. the perception after having spent time analysing the transcripts. Missed opportunities in terms of line of questioning were identified and deepened understanding of the participants accounts were gained from repeated listening and analysis.

4.4. Implications and Recommendations

4.4.1. Clinical Implications

By understanding more about how support-staff conceptualise their role with regards to supporting PwLD around sex and relationships, this research has clinical implications for the provision of support for support-staff of PwLD which will be discussed below.

This research has indicated that support-staff do not have a homogenous conceptualisation of their role with regards to providing support around sex and relationships. Factors such as a lack of organisational clarity, lack of visibility of sex and relationship issues at the recruitment stage, and the prominence of other professionals in providing specialist support can make the role of support-staff unclear.

A clear organisational approach to supporting sex and relationships would help inform the support-staff role and act as a point of reference, as opposed to drawing on personal values. An environment whereby support-staff were able to address their fears and discuss matters of sex and relationship without embarrassment or fear of being reprimanded would promote discussion in this area.

Staff are generally willing, but do not feel confident in delivering this type of support. This has implications for LD support organisations in terms of empowering support-staff to feel confident in this area.

There is evidence to suggest (e.g., Spence Laschinger, Leiter, Day & Gilin, 2009) that staff empowerment has far reaching benefits, such as the reduction of burnout and staff retention. Kanter (1970) describes a framework for supporting organisational empowerment which involves four main tenets: access to information, support, resources and opportunities for learning. Support-staff in this study and previous studies have identified some of these tenets: having access to policy information and guidelines around sex and relationships, having a supportive team and manager to raise queries with, access to resources (e.g., easy read documents to support education), and opportunities for training in sex and relationships.

Participants spoke of being unaware that support around sex and relationships may be part of their job role, with participants sharing experiences of actively changing their organisation's interview schedule to include questions which would be sex and relationship focused. The role of support-staff is varied and may include a large number of duties unlikely to be easily quantified in a job description. However, given the moral and value laden nature of provision around sex and relationships, combined with the knowledge this area can be fear inducing for many support-staff, there appears to be a case for some acknowledgement of this area of support during the recruitment process for support-staff.

In their role as ‘protectors’, support-staff may require assurance that provision of support around sex and relationships will enable the support-staff to keep people safe. Whilst knowledge of safeguarding protocol and what constitutes sexual abuse is widely available, promotion of education for PwLD directly around sexual matters is less common, or where support-staff have experienced it, they may be ambivalent about its efficacy and fear that it will increase vulnerability in PwLD.

It is important to communicate a clear rationale that talking openly about sex and relationship matters and providing PwLD adequate sexual education has a protective focus, in that it enables PwLD to advocate and protect themselves against potential abuse. Some studies indicate that following an education programme PwLD do retain a substantial amount of sex and relationship related knowledge (Lindsay, Bellshaw, Culross, Staines & Michie, 1992) however there are few studies which have examined outcomes related to sex education (e.g., incidences of abuse, decreases in sexually transmitted infections).

The finding that cross-professional working is seen as a positive experience but that professionals can at times take over, instead of sharing knowledge and responsibility, indicates that more could be done to promote good practice. By employing a collaborative consulting process, both professionals and support-staff can pool their knowledge with the aim of empowering support-staff to feel confident in their role.

This research also has implications for service delivery. Presently, delivery of psychological support around sex and relationships takes the form of consultation with services, opposed to an embedded approach. It is possible that a changing organisational structure, where psychologists, or other trained staff, are embedded within teams may be a more effective model of delivery. This would allow for ongoing consultation and learning, and by employing psychology leadership skills, may help promote a service culture where open conversations around sex and relationships could happen.

At a policy level this study also has implications. Valuing People (2001) and Valuing People Now (2009) rightly identify the rights of PwLD to good sexual wellbeing. It would appear that there is some variability in consistency in which services support PwLD around sex and relationships. Having a policy either within or across service providers which explicitly identifies sexual and relationship needs of individuals as an area which must be supported would go some way to ensuring that these needs are considered.

4.4.2. Research Implications

This study was an exploratory study which examined how support-staff conceptualise their role with regards to support provision around sex and relationships. During the course of carrying out this work, several of the LD providers who agreed to participate indicated that they would like additional support in this area. Whilst it was made clear that the researcher was undertaking research as part of a doctoral thesis and, as such, was unable to consult on individual cases, this indicates a willingness from LD providers to be supported around sex and relationships.

The finding that support-staff view provision of support around sex and relationships as very much a part of their role, but not something they wish to undertake without support indicates, that a more action focused rather than exploratory approach to further research could be helpful. Harflett and Turner (2016) recommend that future research could focus on the impact of policy implementation, access to appropriate guides and resources as well as impact of support-staff training on the lives of PwLD.

In this study, support-staff highlight the desire to be enabled and empowered to carry out this role, and the participants in this study had many ideas about what supports are useful but do not have a vehicle with which to drive their ideas forwards. A social action approach could enable support-staff to come together to form policies, identify resources and develop training and explore the feasibility and efficacy of a unified approach to provision of support around sex and relationships.

Participants identified that cross-professional working, although helpful, may not always be a collaborative process, with some professionals felt to be ‘taking over’. Further research which examines consultancy models with regards to supporting support-staff around sex and relationships could be explored to identify approaches for cross-professional working.

This study, as well as previous research (e.g., Cambridge, Carnaby & McCarthy, 2003), has indicated that support-staff do not feel their organisations have a clear approach to sex and relationships. It is unclear why this may be; whether policy and guidance is absent or whether it exists and it is not being communicated to support-staff. A mixed methods approach incorporating an audit of LD providers’ sex and relationships policy/guidance and a qualitative element exploring support-staff understanding and experience of policy or guidelines may help shed some light on this uncertainty.

Participants acknowledged the emotional impact of supporting service users when they had experienced traumatic sexual violence, as well as the feelings of responsibility and sadness when service user relationships broke down. A study examining further the emotional impact of providing support around sex and relationships could provide insight into how support-staff cope and what supports they may need in order to fulfil this role.

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6. APPENDICES

Appendix A: Table of Journals Individually Searched

Journal Name	From Year	Number of hits	Number of relevant papers
Journal of Applied Research in Intellectual Disabilities	2000 - present	47	10
		213	8
Journal of Intellectual Disability Research	1998 - present	84	6
		401	N/A
		5	3
Journal of Intellectual & Developmental Disability	1996 - present	5	2
		39	12
		150	1
Journal of Intellectual Disability Research supplement	2010	0	0
		5	0
Journal of Policy and Practice in Intellectual Disabilities	2004 - present	20	0
		98	0
Journal of Mental Health Research in Intellectual Disabilities	2008- present	10	1
		22	0
Learning Disabilities Research and Practice	2001- present	2	0
		35	0
Intellectual and Developmental Disabilities	2012- present	7	0
		64	2

British Journal of Developmental Disabilities (Online)	1997 - present		
Research and Practice for Persons with Severe Disabilities: the journal of TASH.		0	0
	2002	52	0
British Journal of Learning Disabilities	2000	37	12
Advances in Sex Research (online)	1975	2	1
		18	0
Sex Education	2001	4	3
		19	0
Annual Review of Sex Research	1996	0	0
Sexuality and disability	1997	73	32

Appendix B: Overview of Literature Search Results

Qualitative

Author	Sample	Country	Design/Analyses	Conclusions
Brown and Pirtle (2008)	40 staff	USA	Q – Methodology	Identified four belief systems of family and support-staff: advocates, supporters, regulators, and humanists" (p.59). Personal belief system impacted on view of education
Yool, Langdon and Garner (2003)	4 staff	England	Semi-structured interviews; thematic analysis	Staff held liberal attitudes to PwLD and sexuality. Attitudes may be impacted by working with both vulnerable PwLD and sex offenders
Löfgren-Mårtenson (2004)	13 staff (plus 13 youths and 11 parents)	Sweden	Observations and interviews; thematic analysis	Three themes emerged; organisation and definition of meeting places; dependency on parents or support-staff impacting self-determination and attitudes and values impacting on behaviour of family and support-staff
V.R. Thompson, Stancliffe, Broom and Wilson (2014)	31 staff (8 service managers, 23 clinicians)	Australia	Semi-structured interviews; Grounded theory	Support-staff identified administration, attitude and experiences as barriers to provision of support around sex and relationships for PwLD
Young, Gore and McCarthy (2012)	10 staff	England	Semi-structured interviews	Gender differences in how PwLD were viewed; men with LD viewed as motivated by physical gratification and women with LD as motivated by romance and procreation
Abbott and Howarth (2007)	71 staff	England	Interviews	Staff did not feel confident supporting LGBTQ PwLD around sex and relationships. Staff identified barriers such as lack of policy and guidance, lack of training as well as prejudice expressed by family and other support-staff.

Quantitative

Author	Sample	Country	Design/Analyses	Conclusions
Bazzo, Nota, Spresi, Ferrari and Minnes (2007)	216 staff	Italy	Attitudinal scale	Support-staff showed a moderately liberal attitude to sexuality of individuals with LD. Type of service was found to have an impact with those supporting PwLD in the community having more liberal views.
Pebdani (2016)	71 staff	USA	Attitudinal questionnaire and demographic survey	Personal factors such as having a family member who had a LD impacted positively on attitude, as did being a female member of staff. Training was found to improve attitudes.
Swango-Wilson (2008)	87 staff	Alaska	Likert scale and demographic questionnaire	Younger support-staff were more accepting of sexual behaviour in PwLD. Perception of whether the organisation could deliver sex education was influenced by how appropriate the level of education was felt to be.
Grieve, McLaren, Lindsay and Culling (2008)	188 nurses and care staff	Scotland	Attitudinal questionnaire	Positive correlation between amount of training and positive attitude to sexuality and PwLD. Type of service was found to impact with community staff holding more liberal views than staff working in nursing homes. Support-staff held more conservative views towards homosexuality.
Parchomuik (2012)	98 staff	Poland	Semantic differential scale	Profession of staff impacted on attitude towards sexuality and PwLD. Compared attitudes towards physical and LD. All staff found sexual practices in people with physical disability more acceptable than in PwLD other than sterilisation which was more acceptable in PwLD.

Schaafsma, Kok, Stoffelen, van Doorn, and Curfs (2014)	163 staff	Netherlands	Online Questionnaire	Only 39% of support-staff sampled delivered sex education. When education was delivered it was mainly reactively. Staff who had delivered sex education expressed more confidence in delivering sexual interventions in future.
McConkey and Ryan (2001)	150 staff	Northern Ireland	Questionnaire	Two-thirds of support-staff had experience supporting PwLD around sexual interventions. Support-staff who had experience expressed more confidence in supporting sexual interventions in future. Staff welcomed clearer policy guidelines and training.
Cuskelly and Bryde (2004)	62 care staff (+ family members)	Australia	Attitudinal scale	Staff aged 60 or over held more conservative views. Support-staff held more liberal views than parents and both expressed less positive views about PwLD becoming parents than they did about other forms of sexual expression.
Meaney-Tavares and Gavidia-Payne (2012)	66 staff	Australia	Attitudinal scale	No significant difference in attitudes between male and female support-staff. Support-staff attitudes were more positive towards women in terms of rights and self-control but not towards pregnancy. Younger support-staff members reported more positive views. Managers held more positive attitudes than support-staff.
Gilmore and Chambers (2010)	169 staff (+ leisure industry employees)	Australia	Attitudinal Scale	Support-staff and general population held generally positive views towards PwLD and sexuality. Support-staff less positive about PwLD becoming parents. Some gender differences were found with men with LD being perceived as less in control of sexual behaviour and less

				positive views about women with LD engaging in sexual activity.

Mixed Methods

Author	Sample	Country	Design/Analyses	Conclusions
Gallagher (2011)	34 staff	Scotland	Attitudinal questionnaire and semi-structured interviews	Support-staff indicated willingness to support PwLD around sex and relationships but willingness was not associated with confidence in delivery of this support. Support-staff with more positive attitudes towards sex and relationships and PwLD were more willing to provide support.
Christian, Stinson and Dotson (2001)	43 staff	USA	Survey with some qualitative elements	The majority of support-staff felt comfortable providing support to women with LD around sex and relationships but few received formal training on how to do so. Support-staff were relying on personal values to guide them in decision making.
Evans, McGuire, Healy and Carley (2009)	153 staff	Ireland	Quantitative survey with qualitative element	Support-staff attitudes towards PwLD and sexuality that were more in line with developments in this area compared to parents. Around half of support-staff (53%) discussed sexuality with service users. Lack of training, personal lack of confidence, unclear organisational guidelines and parental wishes were identified as barriers to discussing sexuality. The majority of respondents welcomed training but few had received any.

Critical Review Papers

Author	Sample	Country	Design/Analyses	Conclusions
Futcher (2011)	Four key papers	UK	Critical Review	Lack of education for support-staff was a key theme throughout the literature. Recommends both training on sex and relationship content as well as leadership skills.
Cambridge, Carnaby & McCarthy (2003)	N/A	UK	Critical Review	Advocates incorporating sexual policies within the individual plan/care plan. Support-staff would welcome clarity regarding organisational approach to providing support around sex and relationships.

Appendix C: Interview Schedule

Bullet points indicate prompts if not already covered in answering the opening question

1. Can you tell me a bit about your experiences of supporting people with learning disabilities around sex and relationships?
2. Can you tell me about a specific experience where you feel the situation was managed well (by either you or another person)?
    - What happened?
    - What did you do?
    - How did you feel?
    - What did anyone else do?
3. Can you tell me about a specific experience in your job related to sex and relationships where you felt confused or conflicted about what to do?
    - What happened?
    - What did you do?
    - How did you feel?
    - What did anyone else do?
4. Can you think of a situation where the outcome went against what you felt to be the correct thing to do?
    - What happened?
    - Why did you feel this was not the right thing?
    - What, if anything did you do to influence this?
5. How supported do you feel in carrying out your job day to day with respect to sex and relationships?
    - Is it clear what you should and should not do?
    - What factors inform your decision making? (e.g. personal values, other people, legislation)
    - Who, if anyone do you seek support from?
6. Who do you feel should be responsible for supporting people with learning disabilities around sex and relationships?
    - With regards to delivering education?
    - With regards to making new relationships?
    - With regards to sexual expression? (e.g. masturbation, accessing contraceptives, accessing appropriate environments to engage in sexual expression)
7. What additional support, if any, do you feel staff need in order to effectively support people with learning disabilities around sex and relationships?
    - Supervision?
    - Education with regards to legislation/rights?
    - Support with delivering sexual education?

Appendix D: Example of E-mail sent to Organisations

Dear Sir/Madam,

My name is Ami Cifelli and I am a Trainee Clinical Psychologist at the University of East London.

I am in the process of recruiting participants to my doctoral thesis. I am interested in speaking to support workers who support people with learning disabilities about their experiences of providing support around sex and relationships.

At the moment I am contacting organisations who support people with learning disabilities to ask if it would be okay to advertise my study to their support workers; in some places I have put up posters in the staff room, in others an e-mail has been sent round advertising the study and I am also happy to visit your service and give an overview of the project at a staff meeting, if appropriate.

If staff wish to participate I can arrange a time and location convenient to them to meet and interview them about their experiences; the interviews last around an hour and are audio recorded. Participation is entirely voluntary and all information given will remain anonymous and confidentiality will be adhered to. I have attached a participant information sheet with gives more detailed information for your reference.

If this is something you are happy for your organisation to be involved in please do get in touch.

Many thanks in advance,

Ami Cifelli
Trainee Clinical Psychologist
University of East London

Appendix E: Participant Information Sheet

UNIVERSITY OF EAST LONDON
School of Psychology
Stratford Campus
Water Lane
London E15 4LZ

The Principal Investigator(s)

Ami Cifelli
Contact Details: u1438292@uel.ac.uk

Consent to Participate in a Research Study

The purpose of this letter is to provide you with the information that you need to consider in deciding whether to participate a research study. The study is being conducted as part of my Doctorate in Clinical Psychology degree at the University of East London.

Project Title

Sex and relationships: The role of learning disability support staff

Project Description

People with learning disabilities experience social inequality with regards to sexual expression and opportunity for romantic relationships. People with LD are often dependent on support staff to meet their day to day needs, including mediating their sexual and relationship needs. Support staff have the complex task of negotiating mental capacity decisions with the human rights of people with LD to attain good sexual health. Role theory suggests that an individuals' perceived role may influence their behaviour as they are likely to conform to the expectations that role demands. One factor which may influence support staff is their construction of their role with regards to sex and relationships. This study will use a qualitative research design, employing semi-structured interviews to examine the roles paid support staff who support people with learning disabilities adopt around sex and relationships.

You will be interviewed, at a time and place convenient to you, regarding your experiences of supporting people with learning disabilities around sex and relationships. It is acknowledged that this may be an uncomfortable area for people to discuss and as such participation in this study is entirely voluntary. Information will be provided regarding further avenues of support should you be affected by the content of the interviews.

The study will be written up as part of the dissertation element of the researcher's DClinPsych qualification and may also be submitted to an academic journal.

Confidentiality of the Data

Any identifying data you provide will be anonymised at the point of transcription – any identifying names of individuals or organisations will be given a pseudonym and participants will be given numbers. Quotations will be used in the write up of the study and this will be made clear to participants.

The interview recordings will be stored on a password protected laptop and backed up on an encrypted USB stick, both of which will remain in the researcher's home. Following completion of the study audio recordings will be erased but anonymised transcripts will be kept for journal submission for up to five years.

The only exception to confidentiality of your data is if a safeguarding concern should arise during the data collection or transcription process then confidentiality will have to be broken to ensure everyone's safety.

Location

Interviews will take place in a convenient location to you e.g. at your place of work. The researcher can arrange a time and date convenient to you. Please be aware that should we arrange to meet at your home, your name and address will be shared with the researcher's supervisor in keeping with the university's health and safety procedures.

Disclaimer

You are not obliged to take part in this study and should not feel coerced. You are free to withdraw up until 1st February 2017, after which point the researcher reserves the right to use your anonymised data in the write-up of the study and any further analysis that may be conducted by the researcher.
Should you choose to withdraw from the study you may do so without disadvantage to yourself and without any obligation to give a reason.

Please feel free to ask me any questions. If you are happy to continue you will be asked to sign a consent form prior to your participation. Please retain this invitation letter for reference.

If you have any questions or concerns about how the study has been conducted, please contact the study's supervisor [Poul Rohleder, School of Psychology, University of East London, Water Lane, London E15 4LZ. 02082234174. P.A.Rohleder@uel.ac.uk]

or

Chair of the School of Psychology Research Ethics Sub-committee: Dr. Mary Spiller, School of Psychology, University of East London, Water Lane, London E15 4LZ.
(Tel: 020 8223 4004. Email: m.j.spiller@uel.ac.uk)

Thank you in anticipation.

Yours sincerely,

Ami Cifelli

Appendix F: Poster

Interested in taking part in some research..?

I am a trainee clinical psychologist at the University of East London and I am conducting a study looking at support staff experiences of supporting people with learning disabilities and/or autism around sex and relationships.

Participation involves taking part in a 1:1, audio recorded interview about your work experiences. The interview will be confidential – all identifiable data will by anonymised.

If you would like to participate the interview can take place at a time and location convenient to you or by telephone.

For more details, or if you would like to participate please contact:

Ami Cifelli - u1438292@uel.ac.uk

Thank you for your interest

Appendix G: Consent Form

UNIVERSITY OF EAST LONDON

Consent to participate in a research study

Sex and relationships: The role of learning disability support staff

I have the read the information sheet relating to the above research study and have been given a copy to keep. The nature and purposes of the research have been explained to me, and I have had the opportunity to discuss the details and ask questions about this information. I understand what is being proposed and the procedures in which I will be involved have been explained to me.

I understand that my involvement in this study, and particular data from this research, will remain strictly confidential. Only the researcher(s) involved in the study will have access to identifying data. It has been explained to me what will happen once the research study has been completed.

I hereby freely and fully consent to participate in the study which has been fully explained to me. Having given this consent I understand that I have the right to withdraw from the study at any time without disadvantage to myself and without being obliged to give any reason. I also understand that should I withdraw after 1st December 2016, the researcher reserves the right to use my anonymous data in the write-up of the study and in any further analysis that may be conducted by the researcher.

Participant's Name (BLOCK CAPITALS)

…….

Participant's Signature

……..

Researcher's Name (BLOCK CAPITALS)

……..

Researcher's Signature

……

Date: ……..

Appendix H: Extract from Interview Journal

3rd August 2016

Reflections on Interview One

Interviewee had a broad range of support experiences relating to sex and LD – was surprised but pleased these experiences compared favourably to my own clinical experience in this field

Had an awareness of lots of legislation; Mental Capacity Act, issues around consent, Safeguarding, knowledge of the law around sex work – well informed; had taken initiative to educate [themselves] on some matters

Impressed by interviewee's enthusiasm and motivation in this area; is passionate about it and talked about those passions spilling over into personal life. Concern this might bias the sample if other interviewees are similar?

Talked about personal values but also being a professional – interaction between the two? Can the two be separated?

Personal values and morals might be opposed to support-staff duty of care? E.g. sex worker example

Talked about taking on the role of a 'parent of a teenager' – different to other types of parenting? Western construction of the "teenager"?

Talked about lack of relevance in PMLD populations, personally not sure how much I agreed – sex and LD rights should be for all, not just mild LD otherwise this is just further subdivisions?

"It's what we're paid to do" – is it? What impact does this attitude have? Might be a case of 'easy for you to say' if you happen to be liberal, non-religious etc.

Appendix I: UEL Ethical Approval Form

School of Psychology Research Ethics Committee

NOTICE OF ETHICS REVIEW DECISION

For research involving human participants
BSc/MSc/MA/Professional Doctorates in Clinical, Counselling and Educational Psychology

REVIEWER: Maria Castro

SUPERVISOR: Poul Rohleder

COURSE: Professional Doctorate in Clinical Psychology

STUDENT: Ami Cifelli

TITLE OF PROPOSED STUDY: Sex and Relationships: The role of learning disability support staff

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 not 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)

2. APPROVED, BUT MINOR AMENDMENTS ARE REQUIRED BEFORE THE RESEARCH COMMENCES

Minor amendments required *(for reviewer)*:

The length of time anonymized transcripts will be kept needs to be specified both in the application and Appendices A and D. Normally, these are kept for a maximum of five years.

In Appendix A, I would consider taking out the text referring to remuneration -there is no need to bring attention to this.

There are sentence structure and spelling errors (date instead of data).

Major amendments required *(for reviewer):*

ASSESSMENT OF RISK TO RESEACHER *(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:

- [ ] HIGH
- [ ] MEDIUM
- [x] LOW

Reviewer comments in relation to researcher risk (if any):

Reviewer *(Typed name to act as signature)*: Maria Castro Romero

Date: 08.06.16

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.

Student's name *(Typed name to act as signature)*: Ami Cifelli
Student number: U1438292
Date: 16th June 2016

(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/

Appendix J: Debrief Form

UNIVERSITY OF EAST LONDON

Debrief form

Thank you very much for agreeing to take part in this research. Please keep this information for your records.

Your Data:

The information you have provided will be used to inform a Doctoral Research Thesis in Clinical Psychology at the University of East London. The audio recording of your interview will be stored on a password protected computer and back up on an encrypted USB stick. The recordings will be transcribed using pseudonyms so that all identifiable data is removed prior to analysis. Quotations of the data you have shared may be used but it will not be possible to identify you as having said them in order to protect your anonymity. Audio recordings will be destroyed once the study has been submitted, the viva carried out and feedback received.
Your anonymised data may also be used in further dissemination in a peer reviewed journal.

Useful contacts:

Should you have any questions regarding the study at a later date, or if you wish to withdraw you can contact the researcher directly via e-mail : Ami Cifelli u1438292@uel.ac.uk
If you would like to raise any concerns or give feedback you can contact my supervisor via e-mail: Dr Poul Rohleder P.A.Rohleder@uel.ac.uk

Further support:

If you have been affected or wish to access further support around the issues discussed within the interviews you can speak to your line manager: [Provide specific contact information for senior personnel within each organisation]

You can also access support from your manager or internal Safeguarding Team if the study has made you think about situations you feel may be risky.

If you would like personal, confidential support you can contact the Samaritans: Tel: 116 023 or e-mail: jo@samaritans.org

Appendix K: Example Transcript

1: Um so can you tell me a bit about your experiences of supporting people with learning disabilities around sex and relationships

2: well um quite a lot actually, when I first was a support worker I supported someone that had a relationship with their boyfriend but went on to get married. Um and somebody else that lived in that same service had been married but was widowed. And I've worked in various different services with younger people who had some degree of sexual activity going on. The service that I worked in before I came to the service that I'm in now is young people who had lots of stuff around sex, relationships, consent, multiple sexual partners, sexually transmitted diseases, contraception, all of that. And then here you know there's some masturbation and things that we need to write support plans around and that seems quite a difficult thing to do, and quite a personal thing but we need to know how to give people structure, how to deal with things like that especially with people with profound and multiple disabilities.

1: yeah it sounds like you've got quite extensive experience[]

2: [] I do yeah that's why I said, when you said to me "oh no I can help you with that!"

1: thank you very much. Um (.) so you've mentioned, sort of, quite a lot of things there (.) um (.) can you tell me a bit about a sport of specific experience where you've sort of been involved in managing something that you feel has gone quite well

2: right – one, the place I was in before one of the people we supported, we um, found out he spent a large chunk of money on prostitutes

1: right

2: and it was quite a difficult situation because he had, he didn't realise it was against the law, and he had Asperger's so –

INTERRUPTION

-and um so he founded it very difficult that he could freely access something that wasn't legal. So we had to do a lot of discussion around things that were illegal but that the police weren't bothered about which was quite a difficult topic because when you've got Asperger's things are black and white, so we had to talk a lot about things that like… I think the way we kind of got his head round it was to talk about his brother who smoked dope, and to say well your brother smokes dope but the police might not want to arrest him but they'll want to arrest the person that's sold it to him. Kind of thing, 'cause that's what's more important to them, the police, that's what's more illegal. And I had to really know the law inside out'cause there was lots of questions about it and I didn't know it's actually not illegal to use prostitutes but it's illegal to approach somebody with the intention of paying for sex and it's illegal to solicit. But it's not, the actual act is not illegal and I had to talk to him a lot about that, I had to take him for STD tests, I

had to give him basically all the information and said to him look I can't say that you're not allowed to do this because you're your own person and you've got capacity and can make that decision. But here's the consequences, here's what could happen, here's what could happen, you could have a criminal record, you might be on a sex offenders register, you know all these things. And also as well about the differentiation between sex with a prostitute and sex in a relationship and how if he had a girlfriend it might not be the same as it would be with a prostitute and there's a lot more to it than just the actual act of sex, the in and outs, so to speak, it's about intimacy, all those kind of things, so it's quite a big project but it's certainly one of the sexual health pieces of work that I'm most proud of in my career definitely.

I: and when you were doing that, em, what kind of, was that a whole team approach of support or were you doing that quite independently

2: I did that quite independently. I mean I spoke to the nurse, the kind of community nurse and asked them for some help and they pointed me in the right direction but they couldn't really do a piece of work around it because he did have capacity and it wasn't like he was being taken advantage of but the main piece of advice was to tell him to bring condoms and tell him not to pay with a card(h) and ((laughs))

I: right okay…

2: kind of more practical advice on that, things I hadn't thought of

I: it sounded like you had to go and do quite a lot of digging

2: I did yeah, no, I did, I did because I knew he'd ask quite a lot of questions and I knew he'd be embar[] the more people that were involved the more kind of clammed up he'd get 'cause it's quite a personal thing and he kind of felt a bit embarrassed that he'd done it and not realised that it might not be proper. 'Cause as far as he was concerned he just wandered down Soho and knocked on a door. But he said "well a policeman saw me walking in!" and I was like "well…" that's….its by the by, it'.. it's.. they might not be interested in you today but might be interested in you tomorrow.

1: Mmm. And in terms of sort of your, sort of did you feel of your kind of duty of care or your remit to do that. 'Cause I'm thinking someone else in your position, supporting that guy, they might have had a different approach to it or…

2: no I think because I was managing that service at the time it kind of fell on me to lead

1: right

2: but I think I would rather I did it, I wouldn't want any moral, 'cause it's very hard to disengage your morals in these situations isn't it?

1: mmm

2: we did talk to him a lot about trafficking and how people who were prostitutes might not necessarily want to be prostitutes, how some people were tricked into it, coming into this country for it and – that was like the most moral it got, the rest of it was just stone cold facts which is what he needed really

1: yeah, ok. And can you think, the sort of flip question, can you think of a specific experience where you didn't feel things got managed well?

2: Um (0.2) the only situation where I feel things didn't get managed well is when the individual didn't want to take notice of the information that they're getting

1: right

2: which is within their remit. But it had quite a frustrating situation in the same service where somebody ended up in an abusive relationship with somebody who was a sex offender, and the more we kind of – what we did was – we were very kind of disapprov[] well we weren't disapproving but we were like, pointing out the dangers and pointing everything out and it just pushed her further into his arms I think and that was the biggest mistake we made and we had a lack of support from social services as at that point we wanted to put safeguarding in place. But we got a very hippy dippy social worker who said "sex offenders deserve love too" and….

1: right that sounds…

2: yeah it wasn't helpful. And she ended up moving in with him. And I don't know where she is. And it's quite upsetting to think about…but that wasn't managed. But I think if we'd been a bit more open and a bit less disapproving of him it might have made the relationship go a different way but then what she got was 'oh we're all against you' you know 'they're all against you – I'm the only one that loves you kind of thing'

1: right okay, so that was more a case of that's sort of the situation, it felt like you were trying to do what you wanted to do…

2: Yeah – I think, your instincts, it's the same when you have a friend in the same situation your instincts are telling you to get them to run but what you really need to do is just kind of be there for them and let them make their own mistakes. And be there. But then, it just isolates them further doesn't it, if you don't approve of the relationship and get all high and mighty about it, it just isolates them from another escape route.

1: mm. okay…have you ever been in the situation where (.) em (.) perhaps what you want to do or you sort of think the best way forward of supporting someone sort of conflicts with other staff members that you're working with. Sort of thinking about what you said about, coming back to moral judgements and things like that, and people might have different ideas about what should and shouldn't be allowed or how, you know, you should resolve a situation…

2: well masturbation is a big one. A lot of Christian people don't approve of it. And a lot of support staff are Christian so you, you always have quite a battle getting

people to see it as a natural thing that is part of what most of us do and its[] that's always been quite a battle of my – you know, people getting told to stop it, getting told it's naughty and it's dirty and getting all kinds of mixed messages about it and you're saying to them well it's not dirty, it's natural, it's normal. I mean I remember once someone asking me about 'self abuse' and I was like what, seriously, what are you talking about, people hitting themselves? They were like no no no getting quite serious about it, im like no – are you talking about masturbation? Yeeeeah.

1: and how have you managed situations like that?

2: I think you have to say – you just have to let people know that everybody's values are different and that it's not your house and it's not your decision

1: and is sort of taking – 'cause that sounds like quite a firm –

2: well it has to be, you have to advocate for people's rights don't you, when you're a support worker you always get asked if there are any moral issues that would stop you from doing your job and people always say no. And you say well remember when you were asked at interview this is one of your moral things, it's not – please don't tell people that its dirty, people don't tell people that it's wrong because when you find a 45 year old woman that's masturbating with rubber gloves 'cause she's been told it's dirty so often it's not nice to see

1: gosh…and that's sort of something that's quite specific to masturbation but in terms of sort of wider, service users beings friends with each other or more than friends with each other, have you come across anyone with sort of attitudes about whether people with – you know the sort of 'people with learning disabilities shouldn't be in relationships' or don't have capacity or…

2: Um so it's usually people's parents who find it difficult. Support staff are usually quite – it depends how innocent they feel it is, that people are always much more accepting of a companionship based relationship than a sexual one, I mean the team I worked with, with young people, the one I told you about with the guy using prostitutes, they were all quite young and open minded on that team so it was quite nice 'cause they were all like yeah if he wants to you know, if you want to have a boyfriend or a girlfriend then let's get you a girlfriend, that was really good but yeah people's family's are always quite difficult to get around and there's always um. But yeah I think a lot of people if they think it's innocent and it's all friends and holding hands it's quite sweet but then if you actually talk to them beyond that that it might be more than that that's when they start to get a bit – but it's usually because they're not married rather than they've got learning disabilities

1: oh really?

2: yeah

1: okay, so it's a sort of values thing rather than sort of – 'cause I was kind of wondering from a paternalistic sort of angle of like safety and that sort of thing but it seems to be more values or…

2: yeah, yeah, I think the parents are always more concerned about their and kind safety and being led astray and, but I think the support work[er] it's more about the person not being married. I remember getting that as an answer in an interview question I asked, one of the question I used to ask about sexual relationships and somebody had said 'well fornication…' I remember what they said 'I would tell them that fornication outside the sanctity of marriage is a sin to the Lord Jesus' ((laughs))

1: fair enough! That's a –

2: I was like 'right, okay, next question!'

1: very clear with where they stand there, okay

2: yeah but um it can be difficult yeah, you have to tell people that this is their life and doing what they wanna do and we don't have a lot of say in it. I mean I'm always of the of the same kind of, I suppose it's quite parental the way my parents were, I'd much rather know about it so that that I can help you than it's kept secret.

1: mmm, do you think that's something that's come from your sort of family upbringing?

2: I think it's got a lot to do with my upbringing but I think it's got to do with my professionalism as well. We can't be, we can't have those kind of moral judgements in our jobs. We've just got to get on with it. I've got my own feelings about men who use prostitutes but then I had to kind of put that aside when I was talking to this guy and, you know, this is what I, I can't tell you what I think but here are the facts

1: mmm. And I mean, what, was it the support from your team or um, is it how you value your job and what you do, I mean that's a pretty big thing to do really you know, if you've got a very strong moral judgement about something sort of putting that on the back burner and then thinking about 'okay what does the person need at this time?'

2: it's very hard but it's what we're paid to do isn't it, as support workers and I think the danger comes when you forget that that's what you're paid to do. I think you've got to remember that you're around to support people and what they want, not what you want. I think that's what it always comes back to and when I manage people that's what I always say to them, it's not about what you want, it's what they want

1: I think that's why I'm so interested in asking these questions, 'cause it's interesting what you've said there about 'that's what we're paid to do' I kind of wonder if everybody's idea is the same in terms of is that what they're paid to do

2: I don't think it is. I think some people still think they're straight of the care system, I think some people think they're some kind of surrogate mother to people, or father and you know get very like 'you can't do that, no no no that's wrong' and it's not, it's really not our job. And I think unless you work with very

independent young people with learning disabilities who will tell you ‘actually no, you can’t tell me what to do’ that you don’t really fully understand that. But when you’re told by someone, you know ‘fuck off I’m going to do it anyway’

1: ((laughs)) did – do you think there might be that impact, it sounds as if you’ve worked in a variety of different with a variety of different levels of learning disability and perhaps if you’ve only worked with people with very profound learning disabilities who can’t verbally express that it’s easier to slip into that paternal role

2: of course, of course it is, you’ve got to constantly check yourself out. I do it all the time. And I have to watch my language and my view point, and my [something] tongue. It is a bit like being a parent to a teenager, isn’t it, you’ve got to kind of let them go off and make their own mistakes but kind of have a little eye out. And when I started working with these young people I phoned my mum. The first day, I did my first day and I phoned my mum. ‘Cause they all had problems with their mothers, like every single one, I don’t know what had happened but every single person that lived there, like the six people that lived there, they all had issues with their mothers. And I was just like surrogate mother and I was just abused from morning til night. And I phoned up my mum at the end of my first day and I was like ‘mum I’m so sorry for when I was a teenager’ ‘cause it was it was like slamming doors and ‘you’re not my mum, I don’t like you, you can’t tell me what to do!!’ I was like ‘I’m not telling you what to do, I’m just introducing myself’

1: ((laughs))

2: but the little things that you don’t think about, like one of my jobs when I worked with the young people was to go round and delete everybody’s internet history once a week ‘cause they all had viruses and they were all watching porn,

1: okay – ((laughs))

2: somebody downloaded so much porn once that we had to get them an i-pad because they went through, through four laptops in a year, just downloading malware and clicking on things

1: oh my goodness. Wow. But then to me, some of the places that I’ve worked before, the fact that someone would be allowed to do that is kind of – heartening? In a way!

2: of course it is, it’s really great. I remember once having to calm down a member of staff ‘cause somebody was looking at red-hot, red-haired milfs, and was like ‘I’m a red hot, red haired milf!! That’s disgusting, I’m not having that!’ and that was the most annoyed she got with it because she was like ‘you can’t be looking at red hot red haired milfs, I’m a red hot red haired milf’

1: wow. And so what – obviously confidentiality and things like that – but I’m interested in what kind of organisation that was, was it a private, was it a supported living or –

2: it was a supported living service for a charity, like most of the organisations, most of the homes round here are owned by charities. The council subcontract charities to provide not for profit services, that's the way it works in L and G anyway.

1: and I'm quite interested in what – 'cause it's not just individuals I feel, you know it's a whole organisational approach that supports people, I feel like you don't just have one person that's there with the proactive views it's got to be everyone working together

2: no, that was the team that we had, we had a really team that was into people's rights. I know I spoke to one of the ladies that lived there a while ago and she'd just started internet dating

1: excellent

2: so she'd being going on dates and using the internet to chat to people

1: and I was wondering, did you get any particular training that sort of touched on that

2: we spoke to, in L we have quite a good community nurse who is really good to have a chat with and sort of touch base with, the organisation I was with at the time were quite proactive at talking about this stuff. We didn't get any specific training, I think there was the, I think L did have sex and relationships training back in the day, I don't know if they still have that but there's no money any more. That's when we used to have our own training department in L and we had loads of money. And we had one day I think where we'd all talk quite frankly. But I think that service was really special in that way and they opened another one up that was quite similar and it's all young people who want to talk about those kinds of things

1: yeah

2: and it's quite good 'cause they weren't afraid to ask. … the place that I left, there were a couple who were looking to have a baby at some point in the future. I need to keep in touch with them and see if that ever happens because they were quite excited about that idea

1: yeah and how was that being supported?

2: well, we'd got to the first stage where we were talking about, 'cause the mother in the couple was a smoker, well we said you'll have to give up smoking if you get pregnant so let's give up smoking first and that'll be the first stage and then we can start talking about the rest of it. But you know I think there's a plan in place for what would happen if she ever gets pregnant.

1: right

2: just what we would do, well what they would do, I don't work there anymore and kind of things that would need to be in place

1: and were their families involved with that?

2: well no, ‘cause one of them didn’t have any, well, they had a brother that was in prison, and the girl, the woman in the pair didn’t want her parents to know and we’ve got no right to tell them

1: mm, fair enough. Um, in your experience with sort of the people you’ve supported, did they have any sex education from school or college or anywhere, or was it something that you had to have conversations about

2: they had the basics. I don’t think their parents would have taught them as much as anyone else but they did do it. One of them had a class at college about relationships and stuff and there was a course on at the local college called friends and relationships about boundaries and appropriateness and things like that that a lot of people liked, but I felt you know, quite important about consent education and things like that, that was something I felt I needed to talk to people about ‘cause you know people with learning disabilities are always trained to say ‘yes’ aren’t they, don’t rock the boat, you know (.) be good, do what you’re told and I think consent education falls into that, they can be taught that they can say no and it’ll be all right

1: right. So you as sort of support staff and managing an organisation took that upon yourself to do?

2: yeah

1: Fantastic. Um, so that was one of the other areas I’m sort of interested in, so from the support staff point of view who should be responsible for supporting people around sex and relationships

2: I think it’s got to, I think it’s got to be if you want to, you have to use the mental capacity act and you have to, that has to be a whole team approach doesn’t it but I think you have to share that responsibility. It’s quite difficult when you’re working with people who have capacity to consent because you can’t really do anything, unless you feel that they are being abused or being taken advantage of then you can’t really get involved, you’ve got to be there to kind of mop – clean up the pieces, and that was, that’s the most frustrating part of that kind of job, you just have to give people the information and hope they make the right decision

1: okay

2: the right decision for them at the time but…

1: and if there was a scenario where you were supporting somebody and they um…say they didn’t have capacity but they were interested in sexual relationships, they were interested in masturbation but and you could tell that from that person’s behaviour but they might have questions about what’s going on with my body and that kind of thing. I mean do you feel that that’s something that should be as a member of support staff are you happy to facilitate ‘oh actually you know, I’ll sit you down, we’ll get a book and we’ll talk about it and whatever might be appropriate’

2: I would, I would take advice on that I think, I think I would get someone else involved I think I'd get a nurse involved, just for advice. It might be the best person to deliver that is you but I think that if …it's quite, you can leave yourself open to a lot of accusations if you don't do that properly and with the right kind of…that might not be involving people's parents and families but it might be involving other professionals, a person's manager and their social worker and just, sharing out that responsibility

1: and in terms of actual, 'cause I take your point actually, if you're having a conversation with someone and it's just you and that other person, things could be taken out of context and you could leave yourself open professionally –

2: "she told me to touch my willy" that kind of thing?

1: yeah, yeah. Um…in terms of do you feel that should actually be part of a support staffs role?

2: yeah

INTERRUPTION

2: I think (0.2) it should be. You should be able to answer questions that you are asked.

1: okay

2: I think that when you're – when you're recruiting for a service like ours, that one, we always look for people who'd be quite kind of open to those kinds of questions. And if we saw anybody who'd be a bit kind of 'that's naughty, that's wrong' then we probably wouldn't have them there. But I think that the bigger things, especially people who don't have capacity. 'Cause that's the thing if people don't have capacity you've got to be more careful 'cause you're, you know, you're taking the decision on their behalf, 'cause if people do have capacity and just wanna ask you a question. 'Cause some people as well, they don't give you a choice, they just come and give you information that you don't need to know! ((laughs)). Like one of the examples if the couple I told you about that were looking to have a baby, she was on antibiotics, she was on the pill but she had to take some antibiotics, so the doctor told them to use condoms until the antibiotics had finished and they um, we reminded them of this and they came upstairs to show us that they had used a condom…

1: oh well, just roll with that I guess…

2: we don't need to know! That's fine, that's between you two!

1: good that that advice had been followed!

2: yes. But, yeah, just that's a bit too much detail for me today…

1: sounds like you need to have quite a good sense of humour

2: oh god yes

1: definitely

2: apart from when it involves red hot red haired milfs

1: and what kind of additional support, if any, do you feel staff need in order to effectively support people with learning disabilities around sex and relationships. Sort of thinking do they need additional supervision, input from other professionals…

2: definitely, definitely. I think if people are having to have these types of conversation on a regular basis and they're not sure or they're not comfortable I think trainings a definite thing, it's a really good resource, lots of organisation, [name of organisation] and all that are quite specific in these things and they have quite good booklets to be able to talk to people.

1: [queries name of organisation]

2: the [name of organisation]. It's about sexual relationships and people with learning disabilities, so there's a lot out there. But yeah, I think people do need – a bit of debriefing as well If your key working someone whose obviously going through something and wants to have a certain kind of relationship. I think you definitely need to give them a bit of extra support and make sure they know what they're doing and just for you to check in as well and make sure everything's going in the right direction if you're not doing it specifically.

1: what you said before about um, you know, differences in mental capacity and it sounds like, the work you did with the man who was seeing prostitutes, you obviously went and education yourself about actually 'what is the law'. I guess mental capacity is obviously a really important one but I guess human rights as well –

2: yeeaah

1: in terms of, I can't remember myself if sex is an actual right but I think it's the right to relationships and meaningful relationships and things, and I wonder, you know my own experiences of when I was a support assistant – sort of food hygiene and health and safety – I don't recall being educated about the human rights act or mental capacity

2: no but it does come into our safeguarding training. The difference between sexual relationships and sexual abuse and how the mental capacity act is probably used to safeguard people from sexual abuse and someone's capacity can be the difference between, you know…I'm getting really annoyed at that film 'Me Before You', is that what it's called? Because basically it's sexual abuse – any, the sexual offenses act says that anyone who is in a paid position of care or unpaid position of care can't have a relationships with somebody that they're caring for even if they have capacity to have that relationship.

1: oh really? I didn't know that

2: yeah. So you know, it's illegal. It's illegal, it's rape! And you're romanticising it and putting Coldplay over it!

1: ((laughs)). Well I've learned something today, well two things – that and not to see that film.

2: well I think you knew that anyway. Yeah – so we do touch on that and in services where it's pertinent I think there'd be further training, it's not pertinent here really. There's a support plan – two of the guys here like some alone time without any trousers on and that's fine. That's written into the support plan, people know to leave them alone if that's what they want to do. But I think, when it gets a lot more complex, when there's a lot more things going on, I think that's when we need to – we definitely need debriefing as well. Sometimes things can be quite traumatic, I worked with – somebody I supported got raped and it was…yeah, pretty horrible. You need a lot of support and debriefing after that, it was quite hard to deal with. Hmmm.

1: and is. Is it okay to ask this question?

2: go on.

1: I mean one of the things when I've been doing reading about this is that is actually about safeguarding people to give them, people, education about sex and relationships as a way to keep them safe – was that a factor?

2: she – well, hmm. It's quite a difficult one 'cause this is someone who is kind of ignored by her parents and was very desperate to have somebody to love her and this guy came up to her in the street and said he would love her and look after her and all that stuff. And then she brought him home and she lied to the staff and said that he was a friend of her cousins and she knew who he was. She had a lot of sexual relationships I think but I don't think – she went with people that she kind of trusted and she brought this guy home and he raped her in her bedroom which wasn't…yeah. And it kind of got, he got found not guilty because she phoned him afterwards and…well she said that she phoned him to say, to ask him why he'd done it. Why he'd hurt her and why he'd abused her trust which I think is fair enough. If you've got learning disabilities and trying to make sense of things the first thing you want to do is ask people questions so yeah, it was quite horrific but I was with her. I was with her because she'd disclosed it to a member of staff but once you've disclosed it that person can't be involved in anything else 'cause that person has to preserve their testimony for court so I had to be with her through her hospital kind of examination and rape clinic examination and police interview, I had to be there when she told her parents. Yeah, it was quite horrible. But she knew about consent, but it just got to a thing with this guy who promised her everything, that he was going to love her and look after her and give her everything she ever wanted. Bit of a bastard really.

1: I mean, having to do all that for, obviously you were there to support her but who was there to support you through that 'cause that's – obviously you go to your work doing a support assistant job and that's something way at that the other end of the spectrum that you'd hope that you'd never have to do

2: my manage [] my manager at the time wasn't very helpful. She – LAUGH – she told me she used to work in Kosovo with female refugees and um that I should

get things put in perspective. Yeah, she didn't last long after that. Her manager was a little bit better and I was offered counselling but I didn't take it up in the end.

1: and was that a case of you had other members of the team that were supportive towards you…

2: yeah well nobody else was really involved, it was just me and the person she disclosed it to really that took the burden of most of it. And I did a lot of debriefing with her to make sure she was okay

1: um, I mean, that's probably not a situation that you'd sort of prepared for, for you to be able to know how to support her and what needs to be done and who you need to speak to, who kind of guided you through….

2: it was the police. The police were amazing. [team name] were just absolutely out of this world, they were brilliant, they explained everything to her, she had a dedicated named officer from the moment she, from the moment she reported it to the moment she was in court she had the same link person, it was absolutely brilliant.

1: wow

2: could not fault the police for what they did they were so good. And they were a lot more help than most people were to be honest. Which is not something you get to say very often is it?

1: no…

2: could not fault the police for the way they acted, yeah it was really good. But it just goes to show that with the best will in the world you can educate people on awareness and consent and then the wrong thing happens at the wrong time and you've got a rape case on your hands. But it was really uh, I don't want it to sound like a positive came from it but it opened up the conversation with the guys in the house, about who they brought back and why they brought them back, you know if you invite somebody back home do you know what they think they're getting, do you know what – do you know what they might think that means, you know the importance of knowing people before you bring them home and…so I, I would call it a silver lining on a very dark cloud, that opened up that conversation 'cause it put it into context – it's always something that happens to somebody else or happens on Eastenders but it was like no this happened in your house…

1: and how – I mean that sort of decision, was that made with the lady about telling people –

2: oh god yes yes yes –

1: Sorry, I didn't mean you were just blabbing it out!

2: no, we spoke to her about how much she wanted us to say and she said I don't want it to happen to anybody else so can you tell them everything and tell them to be careful who they bring home

1: right.

2: so…

1: I think again, I'm quite impressed actually about the breadth of your experience of this but also how thoughtful things have been in each case. And, my experiences with different organisations haven't always been the most positive and it always seems that something happens and you go 'I don't know who to talk to about this, I don't know who the next person – there isn't a policy in place, there isn't a you know, a lot of organisations now have like sex and relationships steering group so that if there is an issue, have you found that in your experience, have there been you know sort of avenues of okay this is how this gets talked about or…

2: not really no, I think it's more reactive to the certain situation. I mean, this is, [Avenues] is the biggest organisation I've worked for so this is the one with most formal kind of policies but everybody else I've worked for has been a bit rag tag and oh kind of we'll deal with that later kind of thing but – yeah there's always the biggest things are always the things there aren't a policy for though isn't there, the things like the big crises are the things that you never prepare for – that's the things that keen managers awake at night, like have I written a risk assessment for that?

1: yeah. And with um, 'cause you were saying about here and having it written into people's support plans about masturbation and things. That's an area I've found kind of an interesting one as I've found opinions are divided between that's that persons private experiences, that shouldn't be written down anywhere vs, well, yes it is but how would anybody know about it in order to support them unless it is written down. And –

2: well that was it, I mean I remember once – the woman that I told you about earlier that masturbated with rubber gloves (.) when the care commission came in they're going 'why are staff leaving rubber gloves in her room that's really unprofessional' and we kind of had to say, well they're hers and this is what she uses them for and they were like well we need to have that written down somewhere otherwise everybody's going to misinterpret that. And you know ( ) but staff have used them! ( ) off the floor! But yeah I think it's, I think it's a bit seedy and a bit not nice to have it all written down but I think it's necessary, I think people need to know. Because then, and also then you've got something to use on people who are making moral judgements as well. 'Cause you say well actually no that's in their support plan you need to leave them alone for five minutes so they can get that done

1: right

2: it gives you a framework to kind of tell people, actually it's not about morals it's about what's in the support plan and you need to follow the support plan

1: okay, right. Just check if there's anything we haven't covered, we covered quite a broad area quite quickly there um (0.5) I guess we kind of touched on it in

sort of various bits and saying here was the biggest organisation you've worked for but um, how supported in general do you feel, you personally feel and sort of how supported do you feel other staff feel to sort of carrying out your day to day job with respect to sex and relationships. Do you feel it's always clear as to what you should and shouldn't do?

2: that's a difficult one isn't it? I think that some of the things here, 'cause people here have such profound needs it's not as pertinent here but I think it's quite difficult especially when you're in supported living and people have got say quite a lot of capacity and they're able to come up with decisions themselves that's always really difficult 'cause there's not a framework and there's not a kind rule book 'cause you've got to make a decision on a day by day basis haven't you 'cause people (.) you can say to people is that wise, is that a good idea…you know have you thought about the consequences of this, have you thought about – they're still going to do what they want anyway.

1: yeah

2: you know, so it's it's I would say it, I know it's a bit of a woolly answer but I would say it depends on the service and the type of service and type of support that you are giving, 'cause if you're working with somebody for two hours a week in the community you know you can only (.) if they ask you a question about their love life or whatever you can only give them the best advice you can at the time and then hopefully fingers crossed no harm comes to them by the next time you've seen them. And somewhere like here – it's going to be very difficult for someone to come in and attack someone or. But then if you've got someone that's cannae enough to tell you that it's their cousins friend and they're coming over for a cup of tea and then they end up being raped it's a slightly different story isn't it. But then you've got the like, there was no staff in when it happened 'cause people could be left alone for a couple of hours and it was like 'well how could you let this happen?' I didn't let it happen, it wasn't me'

[interruption]

2: so well yeah, yes that's the things, there's no fixed answer to that, depends on the people you're supporting and what they need and want.

1: and have you ever, I realise we've sort of talked about people who are very – who sort of have capacity and are very able and people you work with here who might not have capacity. Have you ever had sort of experiences of people who fall in the middle –

2: yeah definitely

1: I'm just trying to sort of think about experiences or things I've heard people say about um, perhaps challenging or what's seen as challenging behaviour and it's sexual, or sexually challenging behaviour in terms of maybe stripping or inappropriate – what's considered inappropriate masturbation sort of things like that?

2: yeah, um I used to supported someone who was quite into masturbating and she also had challenging behaviour as well, or severe challenging behaviour and one day she was sort of inconsolable we did not know what was wrong with her, we did not know how to calm her down and it transpired that she'd used a can of deodorant to masturbate with and had lost the lid. So we had to take her to accident and emergency to take it out. So then how we responded to that was by buying her a vibrator which she thought was the funniest thing in the universe and never used it.

And the other one as well there was a married couple and she was, she was having a period of – she had some depression but she had a period of kind of mania in between that, like a psychotic episode, dunno what it was but she was making her husband have sex with her 4 or 5 times a day, he was at the end of his tether basically and we had to take her to get a sex toy as well. But the staff found that very difficult to deal with in that service

1: and that was someone that's married so clearly has capacity and understanding of that kind of thing. With the other lady who lost the lid, 'cause that – kind of, is obviously a risk issue. And you know it sounds buying a sex toy that was appropriate and you know wouldn't injure – how was that managed that you know she thought it was funny and didn't want to use it. How did you make sure that didn't happen again or…?

2: well we kind of said to her – 'cause she was deaf, if she didn't want to listen she'd just put her head to one side and just like cover her eyes and it was like 'look if you want to do that again what you did with the deodorant can' – we had to be very careful 'cause she was so embarrassed as well, she'd only told two or three people about it. 'this is what you use' we showed her how to use – well not actually show her how to use it – showed her how to turn it on, showed her where it went in the kind of very descriptive sense and she was just like 'look at the willy, look at the willy!'

But yeah um, trying to think of other situations I'm sure I've had one. There's a lot of kind of um misunderstandings –I used to work with somebody with a boyfriend at a day centre and she'd kissed him and she thought she was pregnant and we had to spend 24 hours kind of calming her down and letting her know that she wasn't – like ascertaining what had actually happened 'cause she'd kissed him in the toilet so obviously that's her pregnant and she was really distressed

1: and that kind of links back to that thing about education and that kind of quality of – because, I mean, you know, I'm sure you remember –

2: our school days, sex education

1: you didn't learn much from that –

2: no, you learn it from each other didn't you. There's not the same peer stuff

1: exactly and it's that kind of thing of there's not the same peer stuff you know that – more could be done to foster that but then someone is going to have to –

that's pretty valuable information that people need um and then is that, you know does that come down to support staff to fill that in at a later date –

2: I think it would yeah. I mean what happened was ( ) I don't think you're pregnant kind of thing, besides you're on the pill so you wouldn't get pregnant if you did have sex and it was quite a long conversation – she got there in the end. But in terms of like I've not directly worked with anyone who strips off or masturbates at people or that kind of thing but um I've heard of it, I haven't really got much experience with it

1: no, just sort of (.) you've covered a pretty broad spectrum there

2: yeah that's the kind of one the kind of dangerous sexual behaviour that's kind of a bit of as I've said people who are a bit promiscuous but not anybody who is kind of…no I'm trying to think (0.2) no (0.2) no I'm thinking really hard and I can't really think of anything like that as a challenging behaviour. No sorry.

1: no that's all right. One sort of final kind of question, I could be wrong but I'm getting the impression that it's something you feel quite passionately about and something you've taken an active interest in and done a lot of in your job – is it something that you sort of feel that you actively promote sort of outside your job as well like in conversations with friends and family, um as like sort of people with learning disabilities rights and relationship rights –

2: oh of course yeah. I mean I'm quite lucky – I come from a family of like hippie lefties – my mum's a social worker and my dad's a therapist, it's all like – well he was and he used to work with ex-offenders when I was a kid as well –

[INTERRUPTION]

So it's it's – we talk quite a lot and a lot of my friends are in the caring profession, nurses and stuff like that so we do chat quite a lot about stuff. Friends love hearing about what I get up to at work. Like what's the most bizarre thing you've done today – well…yeah that kind of thing. My friends are sick of me sharing stuff on Facebook about equal rights to relationships and that's where – as corny as programmes like the Undateables are, as badly named as it is it's great to kind of promote showing people in sexual relationships and having dating and going out and meeting people and I think that's really important. Like the only people you ever saw with disabilities on television were kind of saints or and I think now to have like people on telly actively looking for love, and showing people that they're not just like sexless blobs sitting there, they wanna meet people, they want to do things, I think it's great. Maybe call it something different –

1: yeah ((laughs))

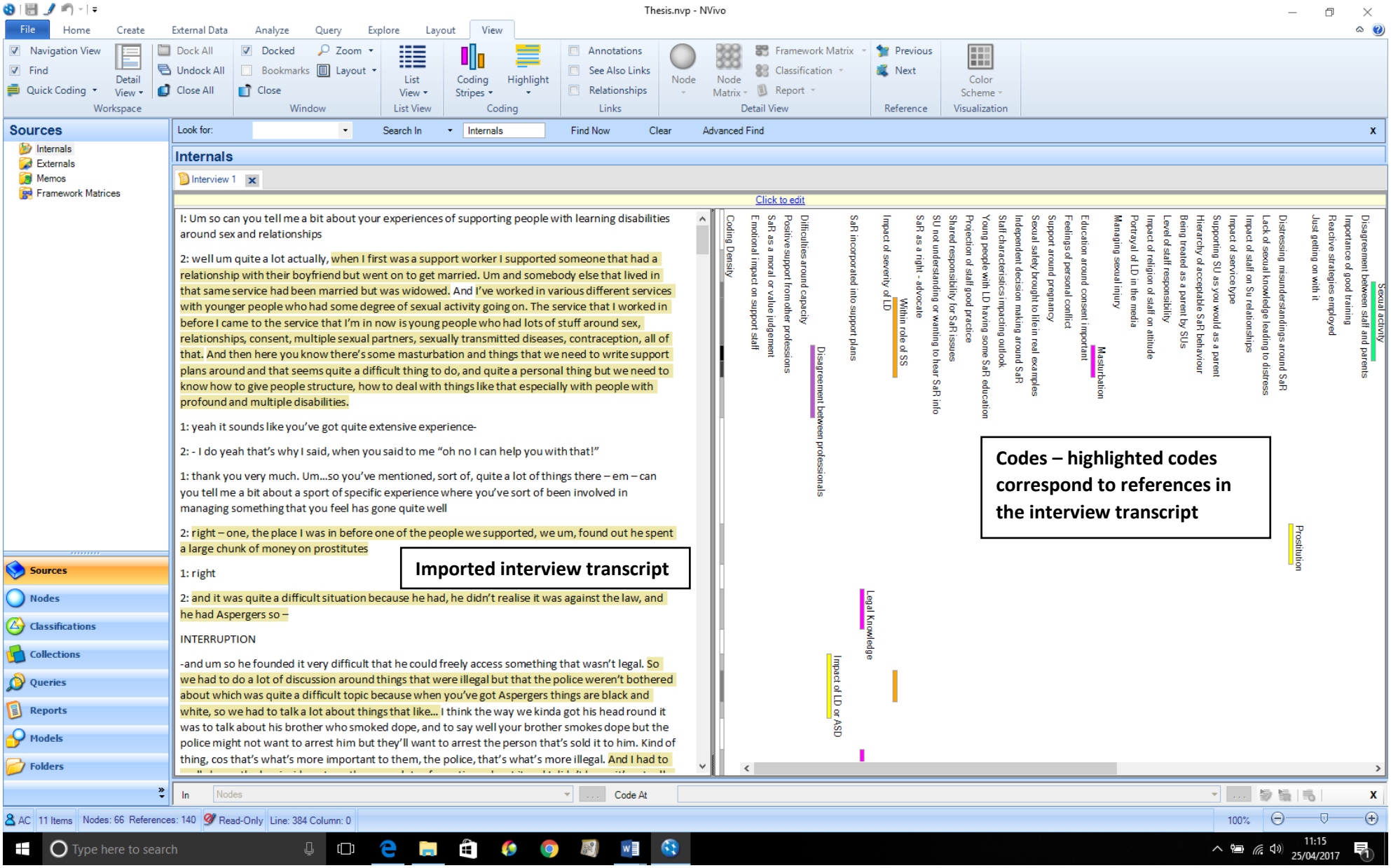
2: but apart from that I think it's really good

1: and is there anything else you'd like to say?

2: no I can't think of anything

NOT TRANSCRIBED

Appendix L : Extract from Nvivo coding



Appendix M: Example Coding

2: at the moment the clients I'm working with are probably the more severe learning disabilities with kind of higher level of communication needs so before this setting I worked with people with much more mild learning disabilities or mild disabilities along with mental health issue or something else where (0.2) kind of like talking, exploring the facts of life, talking about the birds and bees, exploring people's feelings may have been a bit more fluid (.) I mean there's a bit of power imbalance because you know the things and they may be a bit more cautious because they've been told not to talk about sex or body parts or any of these sort of things. So I've had a couple of experiences which are really really interesting um one specifically, I worked with a young man who had very very slight[] very mild LD but was also on the autistic spectrum but had a history of really kind of, behaviours which focused on gaining a reaction from other people, causing antagonistic[] upsetting other people, gaining powerful reactions. So he'd discovered that things around sex were very emotive, that there were words he could use that would really get a reaction from people. So along with the social worker and the psychologist, they kind of took the view that because these things were taboo, they were attractive and they got a reaction and also there wasn't a huge amount of understanding of the words he was using that he didn't(.) he just knew it for the reaction and the effect it got from others so in that instance we sat down and basically wrote a list of every word we could think of to do with sex, to do with sexual actions, to do with sexual organs, to do with verb and noun and try to divide it up into like doctors and nurses words, kind of proper word for a thing, then he had rappers words and then he had school words and then he had kind of everything else words and we kind of went through a big process of writing things down and deciding where that word went and then kind of joining them up. So that by the end of it he knew that wanking was masturbation	*Impact of severity of LD* *Power imbalance* *Sex and relationships as challenging behaviour* *Positive support from other professionals* *Shared responsibility for sex and relationship issues* *Importance of exploring cause of behaviour* *Within role of the support staff* *Pride or enjoyment in sex and relationship work*

Appendix N: List of Primary Codes

SaR = Sex and Relationships

SS = Support Staff

SU = Service user

1. Young people with LD having some SaR education
2. Working with someone with whom you may disagree
3. Within role of SS
4. Within role - with support
5. What would the person be doing if they didn't have LD
6. Wanting to provide more support
7. Vulnerable due to acquiescence
8. Value of planning and pacing - education
9. Having long, explanatory conversations
10. Value of joint working
11. Value of group SaR sessions
12. Universal drive to discuss sex
13. Uncommon for SU to bring up SaR issues
14. Types of SaR experiences
15. Supporting dating
16. Supporting a same sex couple
17. Support with contraception
18. Support around SaR and mental health
19. Support around pregnancy
20. Support around physical aspects of sexual health
21. Sexual activity
22. Sexual abuse
23. Purchasing sex toys
24. Providing support to arguing couples
25. Providing emotional support
26. Prostitution
27. Masturbation
28. Marriage
29. Managing sexual injury
30. Managing rape case
31. Looking at pornography
32. Laying the groundwork for a relationship
33. Internet dating
34. Forensic work
35. Education
36. Distressing misunderstandings around SaR
37. TV portrayal
38. Treating SU couples as you would any other couple
39. Training not given as not relevant
40. Tendency to medicalise SU's needs
41. Surprise at existing knowledge
42. Supporting SU as you would as a parent
43. Supporting SU as you would a friend
44. Difference between SU support and friends

45. Supporting as if you were a teacher
46. Support workers undervalued
47. Support staff know SU best
48. Support staff as facilitators
49. Support from other organisations
50. Support different to that of a sibling
51. Support around relationship breakdown
52. SU not understanding or wanting to hear SaR info
53. SU making sexual advances to staff
54. SU being failed by the system
55. Would like more opportunity to support SaR
56. People with LD living arrangements
57. Assumption that people with LD don't have sex
58. Staff prudishness
59. Staff needing to ask questions
60. Staff match making
61. Staff knowing personal info about relationship
62. Staff infantilising SU
63. Staff encouraging SaR activity
64. Staff characteristics impacting outlook
65. Staff family impacting on values
66. Staff age
67. Position in the team
68. Impact of service type
69. Impact of religion of staff on attitude
70. Staff as scaffolders
71. Staff as protectors
72. Staff as coaches
73. Staff as advisors
74. Staff arranging practical aspects
75. Staff adjustment to SaR work
76. Specific role in providing sexual support
77. Some things too difficult to prepare for
78. Slippery ground
79. Silo - PwLD going for other people with LD
80. Shared responsibility for SaR issues
81. Sexual safety brought to life in real examples
82. Service with SaR viewed as special
83. Specialist knowledge - level of risk
84. Specialist knowledge
85. Specialist available within organisation
86. Specialist - outsider delivering info
87. Service approach to SaR
88. SaR work interesting
89. SaR not the main focus when setting goals
90. SaR knowledge may make SU more vulnerable
91. SaR just part of life
92. SaR incorporated into support plans
93. Dilemma of care plans
94. Different approaches for staff comfort

95. SaR in the context of safeguarding
96. SaR in hierarchy of importance
97. SaR as sensitive topic
98. SaR as innate knowledge
99. SaR as challenging behaviour
100. SaR as a health matter
101. Respecting staff choice
102. Relationships as societal expectation
103. Reactive strategies employed
104. Querying SU understanding of relationship
105. Querying credentials of other professionals
106. PwLD limited ways to meet new people
107. Putting SU's needs before staff's
108. purpose of support worker role
109. Protection of vulnerable SU
110. Promotion of SaR
111. SaR as a right - advocate
112. SaR as a moral or value judgement
113. Projection of staff good practice
114. Professionals taking over
115. Professional boundaries - physical contact
116. Professional boundaries - conversations
117. Proactive strategies
118. Pride or enjoyment in SaR work
119. Power imbalance
120. Positive view of pornography use
121. Positive support from other professions
122. Positive risk taking
123. Portrayal of LD in the media
124. Pornography giving skewed education
125. Poor communication between professionals and support staff
126. Person centred approach to sex
127. Outside role of support staff
128. Other matters more pressing
129. NVQ includes SaR content
130. Not staff role to introduce sex education
131. Not my decision
132. No policies
133. More experience leads to greater confidence
134. Misconception that staff will get in trouble
135. Mental health difficulties interacting with SaR behaviour
136. Managing staff discomfort
137. Management of sexual advances
138. Male SU as knowledgeable in sexual matters
139. Making staff aware of expectations
140. Limitations of health professionals
141. Level of staff responsibility
142. Lack of training in SaR
143. Legal Knowledge
144. Importance of resources to enable conversations

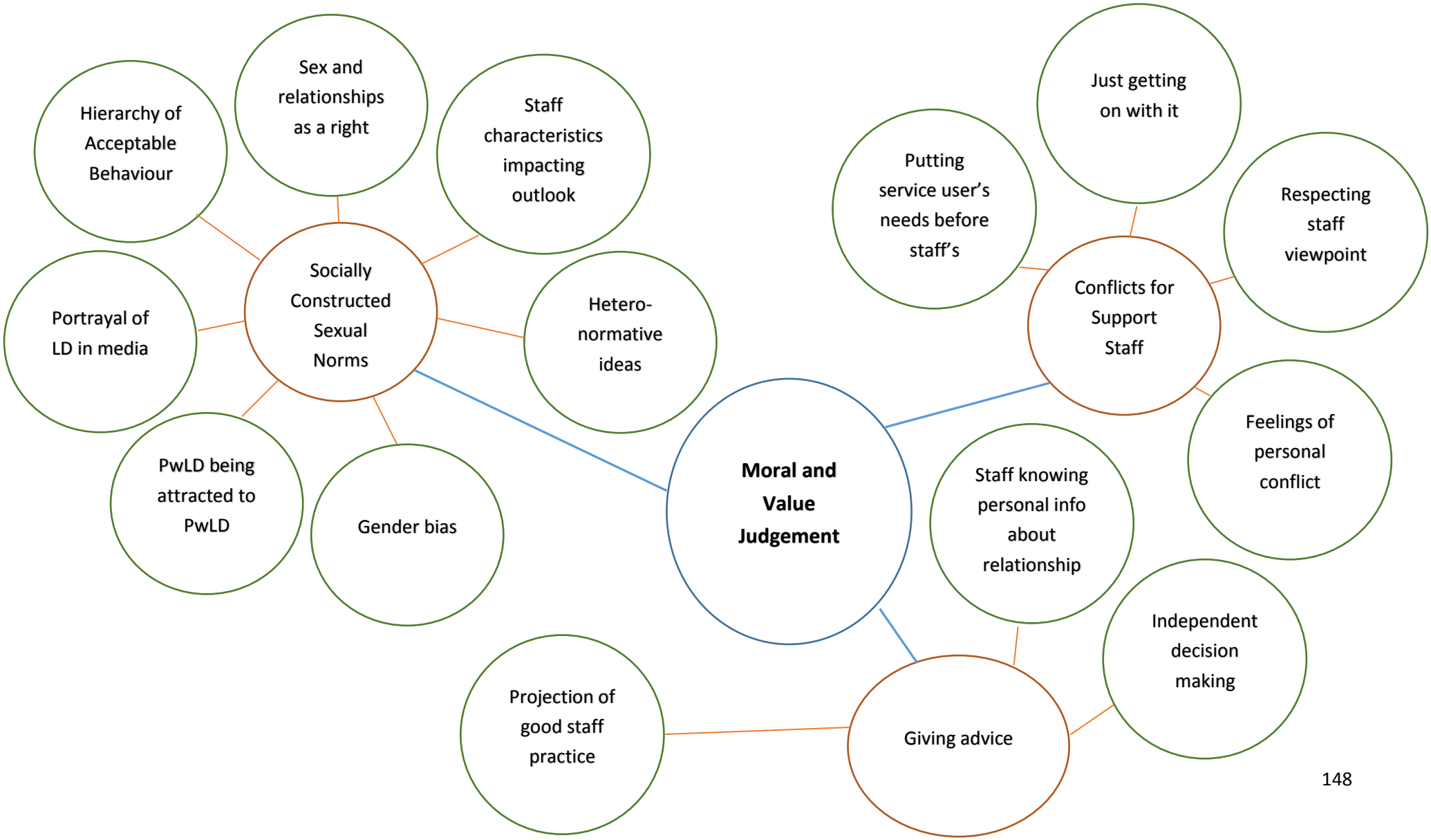
145. Lack of sexual knowledge leading to distress
146. Lack of joined up care
147. Lack of guidance
148. Lack of exploration around SaR matters
149. Lack of experience of SaR issues
150. Lack of education
151. Lack of peer SaR info sharing
152. Just getting on with it
153. Independent decision making around SaR
154. Inappropriate management
155. Importance of support or supervision
156. Importance of good training
157. Value of bespoke training
158. Some things cannot be trained
159. Not qualified to help
160. Importance of exploring cause of behaviour
161. Impact of staff on Su relationships
162. Impact of sexual abuse on staff perception
163. Impact of LD or ASD
164. Staff understanding of LD
165. Impact of severity of LD
166. Historical impact on current SaR functioning
167. Hierarchy of acceptable SaR behaviour
168. Heteronormative ideas
169. Helplessness
170. Having a sense of humour important
171. General relationship advice
172. Gender bias
173. Feelings of personal conflict
174. Fear that one SU may be abusing another
175. Fear of the unknown
176. Fear of SU being attracted to staff
177. Fear of justification of decisions
178. Unintended negative consequences
179. Fear of physical injury to SU
180. Fear of misinterpretations
181. Fear of being inappropriate
182. Family wanting relationship for the SU
183. Family unaware of nature of relationship
184. Family characteristics impacting on SaR attitude
185. Everyone being on the same page
186. Empathy with SU
187. Empathy for parents position
188. Emotional impact on support staff
189. Education as protection
190. Education around consent important
191. Easier with family support
192. Easier when SU can communicate needs
193. Discretion and privacy
194. Discomfort in talking about sex in general

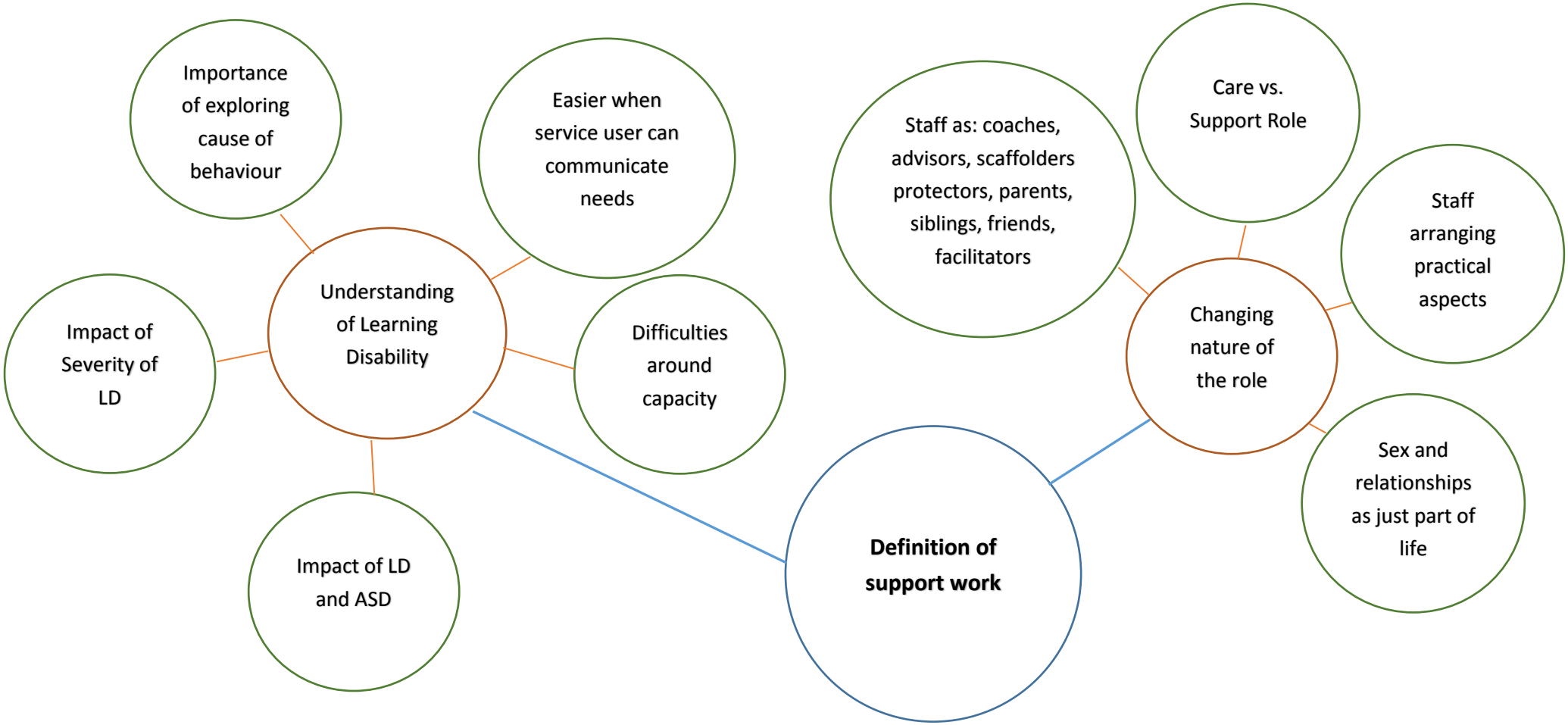
195. Discomfort around sexual fluids
196. Disagreement between staff and parents
197. Disagreement between professionals
198. Disagreement affecting team dynamics
199. Difficulty in everyone agreeing
200. Difficulty in escalating concerns
201. Difficulties around capacity
202. Different types of relationship
203. Difference in staff and parent opinion
204. Deprivation of liberty
205. Confidence in raising issues
206. Concerns behaviours will escalate
207. Complexity of Support staff role
208. Complexity of decision making around SaR
209. Legal restraints make things difficult for staff and SU
210. Difficulty in shared agreement for complex decisions
211. Complex relationship with staff
212. Clear guidelines
213. Clarity of the role of other professionals
214. Changing nature of the support staff role
215. Changing nature of LD
216. Care vs Support role
217. Burden of work
218. Being treated as a parent by SUs
219. Baseline assessment of sexual need
220. Assumption that Su will be attracted to other SU
221. Assessing staff in SaR at the recruitment stage
222. Ambivalence in doing relationship work
223. Age of SU impacting on SaR activity

Appendix O: Primary Codes and Supporting Quotations

Primary Code	Source	Quotation
Portrayal of learning disability in the media	Interview 1	…programmes like the Undateables are, as badly named as it is it's great to kind of promote showing people in sexual relationships and having dating and going out and meeting people and I think that's really important. Like the only people you ever saw with disabilities on television were kind of saints or and I think now to have like people on telly actively looking for love, and showing people that they're not just like sexless blobs sitting there, they wanna meet people, they want to do things, I think it's great. Maybe call it something different…
	Interview 4	Ahhh cool. It may be a good idea. But I'm always a bit reluctant with TV. 'Cause they always want to get the most out of it, and they want to get the things that people – they would create – it's like the yellow press, it's not really objective, I don't know how to call it, it's more for the sensationalism. But yeah that would be a good thing to, obviously all the propaganda that show how things work just take it out to society and expose it. Obviously there's gonna be people that once you talk about sex and relationships there's going to be people screaming like what are you doing, moral disapproval and there's always gonna be people like good you know, it's always gonna be like that, we are too many people LAUGHS but yeah that's it…
Impact of religion on staff attitude	Interview 1	…well masturbation is a big one. A lot of Christian people don't approve of it. And a lot of support staff are Christian so you, you always have quite a battle getting people to see it as a natural thing that is part of what most of us do…
	Interview 1	…I remember getting that as an answer in an interview question I asked, one of the question I used to ask about sexual relationships and somebody had said 'well fornication…' I remember what they said 'I would tell them that fornication outside the sanctity of marriage is a sin to the Lord Jesus' [laughs]
	Interview 2	…I think religion does come into it definitely um 'cause we do have a high proportion of Christians, very staunch Christians or Muslim people in their group. But then it's that thing of, you have to remind them, when they enter that house they have to leave all that at the door, because you're not there for them, you're there for the people you support, so unless the person they support is being religiously abusive or racially abusive, it doesn't matter what we believe outside of that door 'cause we're there for those people, so you know just deal with it…

Appendix P: Analysis Mind Maps




Importance of exploring cause of behaviour
Easier when service user can communicate needs
Staff as: coaches, advisors, scaffolders protectors, parents, siblings, friends, facilitators
Care vs. Support Role
Staff arranging practical aspects
Impact of Severity of LD
Understanding of Learning Disability
Difficulties around capacity
Changing nature of the role
Sex and relationships as just part of life
Impact of LD and ASD
Definition of support work


Fear of harm to the service user
Fear of getting into trouble
Fear of being unable to justify decisions
Not my decision
Facing Fears
Fear of being inappropriate with service users
Fear of the unknown
Sex and relationships requiring specialist knowledge
Enablement and Empowerment
Experience of positive support from other professions
Importance of team support and supervision
Support from outside organisations
Staff need to be able to ask questions
Practical Assistance
Clarity of the role of other professionals
NVQ includes sex and relationship content