What are the Experiences of People with Learning Disabilities, and their Support Workers, When Negotiating Access to Opportunities for Developing Relationships and Intimacy?

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Abstract

Introduction: People with learning disabilities (PWLD) are often described as "vulnerable" and needing protection. This contributes to a lack of involvement in decision making. Despite recent positive shifts in societal attitudes surrounding sex and PWLD, gaps between attitudes and practice remain (Shakespeare & Richardson, 2018). There is confusion about how to effectively support and empower PWLD to engage in intimate relationships whilst minimising potential harm. This study aimed to explore the experiences of PWLD and their support workers, when negotiating access to relationships and intimacy. The voices of PWLD were at the centre of this research.

Method: A qualitative methodology was used to explore the topic. Three PWLD and three support workers participated. It consisted of two parts: part one was data creation using prompt cards to facilitate discussion between PWLD and support workers and part two was a semi structured interview with individual participants using an Interpersonal Process Recall (IPR) framework. Data was analysed using a multi perspective Interpretative Phenomenological Analysis (IPA) approach.

Results: Personal experiential themes (PETs) and subthemes represented the experiences of each participant and were then analysed in the context of their pair (PWLD and support workers). Group experiential themes (GETs) were developed for the group as a whole, paying particular attention to any similarities or differences between PWLD and support workers. Four overarching GETs were: intersecting layers of vulnerability, navigating without a compass, the struggle for control and fearing negative consequences.

Discussion: This study provided each participant with a rare opportunity to safely discuss relationships and intimacy in a scaffolded space. The outcomes highlight a need for further education and guidance for both PWLD and support workers as the current lack of this contributed to parallel experiences of perceived vulnerability. This often led to avoidance and restriction of PWLD's right to engage in relationships and intimacy.

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Chapter 1: Introduction

This study offers insight into the negotiations involved when people with learning disabilities (PWLD) try to access relationships and intimacy, paying particular attention to the concept of "sexual vulnerability". It aims to address the question: *"What are the experiences of people with learning disabilities, and their support workers, when negotiating access to opportunities for developing relationships and intimacy?"*

Secondary aims are to understand what the experiences of PWLD and their support workers are regarding the concept of sexual risk and sexual vulnerability, and to understand why there may be differences, or similarities, in the experiences of PWLD and their support workers.

Note on Terminology

My interest and prior experience within the area of learning disabilities has contributed to a number of dilemmas with regards to the use of terminology in this research. When conducting the literature review, I often experienced discomfort with historical, and some current, use of language and terminology and wanted to distance myself from this as I felt it perpetuates the ongoing discourse surrounding learning disability. In this respect, to highlight my position, quotation marks ("") will be used to illustrate aspects of language, discourse, or terminology which I believe contributes to the largely negative discourse surrounding this topic. It also reflects language that I felt particularly uncomfortable using and did not align with my values or attitudes regarding PWLD. As part of centering PWLD in this research, I will include language used by participants and expert consultants. Quotation marks will also be used to illustrate quotes from the literature and as part of the results but these will be clearly distinguishable with the inclusion of references and page numbers.

Reflexivity

Owning one's perspective is important within qualitative research as it contributes to the credibility and trustworthiness of a study (Elliott et al., 1999). Recognising how my own experiences will influence what meanings I construct from the data (Nightingale & Cromby, 1999) will ensure transparency as part of the process. My reflections will be presented in boxes throughout the paper to offer transparency.

I am a 32 year old, white British female without a learning disability. PWLD have always been a part of my life: family friends and peers at school. I have always been aware of the inequalities facing PWLD and have therefore tried to be an advocate. Admittedly, an underlying function of “protection” likely motivated my facilitation of lunch time “safe” spaces for peers with learning disabilities, away from the bullying and ridicule they experienced on the playground. A secondary motivation was to advocate for equal opportunities and maximise their potential by empowering them to engage in similar aspects of school life such as becoming qualified peer mentors and sharing responsibility for facilitating lunch clubs.

I have voluntary and paid work experience in the area of learning disabilities. As an assistant psychologist in a community learning disability team (CLDT), my interest in how PWLD navigate, and experience, sex and relationships grew. I was frequently exposed to referrals for “inappropriate” sexual behaviour which separated into sexually “harmful” or sexually “vulnerable” behaviour. However, it was not uncommon for the two to overlap and this lack of clarity increased anxiety for support systems. This led to major developments within the service to support PWLD to lead healthy sexual lives (Doughty et al., 2017) and provided support to staff and families who were struggling with the complexities surrounding the issue. I wanted to understand the barriers to encouraging sexual self-determination for PWLD. I also wanted to understand how the contexts in which people are situated influence their experiences of sex and relationships, more specifically how power is used in these situations.

Now, as a trainee clinical psychologist, I feel privileged to be able to contribute to this understanding. I recognise that power will be present at multiple levels within the study and I am mindful of how this may impact data analysis. At the core, my power and privilege as a non-learning disabled, trainee clinical psychologist will be used to make sense of the experiences of negotiating access to relationships and intimacy for PWLD and their support workers. The results will inform future clinical practice regarding protecting the rights of PWLD to have relationships and sex whilst protecting them from harm. Similarly, my experiences will influence what sense I make of the experiences of both PWLD and support staff. The results could identify particular areas of need or that require further exploration. I will be mindful of how my power may be perceived by others and how this may impact engagement with the study.

Context: Terminology, Definitions and the Learning Disability Narrative

Terminology

“Learning disability” is the most widely used term within the UK (Walmsley & Johnson, 2003) when referring to individuals who have diagnosed intellectual disabilities as defined by the International Classification of Diseases (ICD-11) (World Health Organisation, 2019) or Diagnostic and Statistical Manual of Mental Disorders – V (DSM-V) (American Psychiatric Association, 2013). Therefore, learning disability will be used throughout this research. Some individuals reject the term as it is given by professional "experts" and can be experienced as oppressive (McLelland et al., 2012). Wehmeyer (2013) reflects on the shift away from "mental retardation" which referred to "defects" of the mind and "inferior" mental performance. This terminology reflects faults within the individual as opposed to society, therefore placing responsibility with the person. This shift meant that greater consideration was given to both individual difficulties *and* the context in which they are situated. This removed the "defect", or "fault" from within the person, situating it within the wider context (Wehmeyer, 2013). Regardless of this shift in terminology, the current diagnostic label remains firmly situated in the medical catalogues of "disorders" and "diseases": DSM-V and ICD-11, with the latter only recently (2015) removing the heading of "mental retardation". The label of learning disability is often given by professionals in contexts synonymous with unequal power distributions and thus contributes to the ongoing discourse of PWLD being limited in their abilities including self-advocacy (Beart, 2005; Petri et al., 2021; Pring, 2016) and potential for self-determination. Wehmeyer (2013) argues for it to be moved to the International Classification of Functioning, Disability and Health (ICF) (World Health Organisation, 2001) to reframe the perception of learning disabilities. Unlike the ICD-11, the ICF encompasses individual and societal aspects of functioning and disability. Whilst this could positively influence how learning disabilities are socially constructed, it could also exacerbate existing barriers to further opportunities and access to services, most of which is gained via a diagnosed "disorder" within a Western context.

Experts by experience and self-advocacy groups have previously been consulted regarding terminology and they identified "learning difficulties" as a preferred term (Holland, 2011) whereas "intellectual disability" is commonly used in academia. This led to somewhat of a dilemma during the initial planning stages of this research but it was decided that whilst the research centres PWLD, it also acknowledges that other areas such as academia use learning *difficulties* to relate to specific difficulties like dyslexia or dyspraxia (Public Health England, 2023). To avoid confusion and to align with terminology used clinically within the National Health Service (NHS) in the UK, "learning disability" will be used throughout this research (NICE, 2013, 2023). Participants' own language and terminology will be encapsulated in chapters 3 and 4 to ensure credibility of the research.

"Vulnerability" is argued to be a socially constructed term which comes with associated societal attitudes and beliefs. Throughout this research it will be argued that it is not individuals themselves who are "vulnerable" but it is the context in which they are situated which constructs their "vulnerability" (Martino, 2022). This supports the decision from the Office of the Public Guardian (2023) to shift terminology away from "vulnerable adult" to "adult at risk", emphasising the need to externalise "vulnerability" and blame outside of the individual. This study will offer further insight into whether the perception of people being "vulnerable" continues to dominate, or if society has started to take some accountability for this and therefore shares the burden of "vulnerability".

Definitions

Mencap (2023) define a learning disability as:

> A reduced intellectual ability and difficulty with everyday activities – for example household tasks, socialising or managing money – which affects someone for their whole life. People with a learning disability tend to take longer to learn and may need support to develop new skills, understand complicated information and interact with other people.

Data from Public Health England (2016) and the Office for National Statistics (2020) reveal approximately 2.16% of adults in the UK have a learning disability (Mencap, 2023) with an estimated world prevalence of 1-3% (Goli et al., 2020). According to the DSM-V (American Psychiatric Association, 2013), labelling someone with a learning disability is dependent on three factors; an assessed Intelligence Quotient (IQ) below 70, onset before the age of 18, and difficulties with adaptive functioning (NICE, 2015). These factors are assessed using standardised assessments which are completed by appropriately qualified clinicians (BPS, 2001; Carr & O'Reilly, 2007). It should, however, be noted that current assessments used to support this process such as the Wechsler Adult Intelligence Scale IV (WAIS IV) (Wechsler, 2008) and the Adaptive Behaviour Assessment System III (ABAS-III) (Harrison & Oakland, 2017) are not culturally generaliseable and are timebound (Webb & Whitaker, 2012). The debate regarding the usefulness of IQ as a measure is exacerbated by it being a largely Western concept. Even in Western populations, IQ scores only give an indication of "intelligence" in a particular context and are dependent on the assessor (Webb & Whitaker, 2012). It is argued that IQ lacks ecological validity as there is little evidence for the predictive element of "real-life" functioning (Webb & Whitaker, 2012). Categorising people in this way is reductionist and contributes to the perpetuation of the dominant discourse surrounding PWLD as being limited in their abilities. This is not to disregard the positives of being able to categorise a person's difficulties as it can offer a way to access further support and can both validate and provide a reason for a person's difficulties. Others have sought to move away from this view, instead perceiving difficulties as socially constructed (Nunkoosing & Haydon-Laurelut, 2012; Oliver, 2013; Rapley, 2004) and therefore regards people as being limited by their social context.

The construct of learning disabilities runs throughout history, but how society has both understood and responded to it has differed (Goodey, 2005). The introduction of intelligence testing after the first world war led to divisions in how assessments were used. France and Italy used them primarily for educational purposes and to contribute to progressive social reform (Binet & Simon, 1907) whereas Spain and America used them as part of the eugenics movement (Carson, 2007) to "eliminate" groups of people. These differing aims clearly demonstrate how phenomena cannot be understood separately from the contexts in which they sit.

Standardised assessments contribute to diagnosing a learning disability but the experience of having a learning disability is dependent on contextual interactions and can therefore only be understood in the specific context in which it is being experienced. People may have a range of developmental difficulties associated with sensory, motor, cognitive, linguistic and social areas of their lives (Carr & O'Reilly, 2007), however, it does not mean that every person with a learning disability will experience the same difficulties, or difficulties in each area. The unique and individual insights and voices of those living with a learning disability are rarely captured in the literature, something which is integral to this study.

Learning Disability Narrative

Historically, PWLD have been marginalised and perceived as "lesser beings". They have often been placed in institutions and asylums, separating them from the rest of society (NHS, 2013) due to concerns around the "threat that…incompetence was believed to pose" (Jenkins, 1999, pp.10-11). This reflects the dehumanisation of PWLD, placing blame within them rather than considering the influence of wider systems (Bronfenbrenner, 1979). The eugenics movement at the end of the 19th century (Rowlands & Amy, 2019) was an extreme response to such "problems" resulting in the forced sterilisation of many women with learning disabilities due to "concerns about the breeding of the feeble-minded" (Rapley, 2004, pp.47). Similarly, the dual purpose of institutionalisation was to protect society from these "criminal" and "defective" individuals whilst offering safe and stimulating spaces for them (Walmsley, 2005). This demonstrates a tendency for decisions to be made *for* PWLD, limiting their potential to develop self-determination due to lack of experience in decision making. There was no recognition that PWLD may want access to relationships or intimacy as has been highlighted in other research (Siebelink et al., 2006; Wheeler, 2007).

Nirje (1969) introduced the concept of "normalisation" in which the key principles were for PWLD to have as close to a "normal" life as possible including having access to similar opportunities that other "non-disabled" members of society had. The normalisation movement placed responsibility for change within wider society, not the individual. Society held responsibility to give PWLD the "normal" life experiences their other non-disabled counterparts had access to. Consequently it meant that PWLD were able to live in their own homes instead of being locked away in institutions or asylums (Williams & Nind, 1999). Wolfensberger (1972) influenced the UK's interpretation of normalisation, moving responsibility back to the individual, requiring them to fit in and align with the rest of society in order to be considered "normal". Fitting in with society would enhance their social image and would increase their own competencies which would in turn, offer greater opportunities for a "normal" life. However, Brown & Smith (1989) described the role power had within normalisation as it was, and is, powerful "experts" influencing society's perception of "normality". Diagnostic categories were created by the "powerful" and have been used to position and marginalise people in society. Despite the normalisation movement aiming to improve the lives of PWLD and develop their position as equally valued members of society, there continues to be a dominant discourse of "othering". This is further highlighted through the lack of consultation with PWLD during the normalisation movement. This power dynamic has resulted in PWLD being absent from decision making, particularly about their own lives. It would seem that whilst society has been given the responsibility to include PWLD in their own lives, the extent to which this happens is heavily controlled by others and the voices of PWLD are rarely heard.

In order to advocate and protect the rights of PWLD, The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD; United Nations, 2006) highlights the rights of disabled people, including PWLD, to have a family. Further support and protection of rights comes under the Mental Capacity Act (2005) which provides a legal framework for services to facilitate choice and support decision making where individuals may lack capacity. The Act states that capacity should always be assumed. It also advocates the rights of PWLD to have consensual sexual relationships and specifies, “a person is not to be treated as unable to make a decision merely because he makes an unwise decision” (Mental Capacity Act, 2005, p.19). Nevertheless, we continue to witness negative societal discourses as stated in a report for Mencap; that common misconceptions of PWLD include that they have severe disabilities, or are unable to do much independently (Scior & Werner, 2015), therefore decisions are often made for PWLD, especially surrounding accessing opportunities to develop relationships and intimacy. This suggests either a misunderstanding or misinterpretation of what a learning disability is.

Social Model of Disability

The social model of disability was introduced by the Union of the Physically Impaired Against Segregation (1976) in response to the individual model of disability. It argues that disabled people are not disabled by their impairments, but by society’s response to them (Oliver, 2013; Yokoyama, 2021). The model distinguishes between “impairment” and “disability”, describing an impairment as something unique to the individual such as cognitive functioning, whereas disability is society’s response (Burchardt, 2004). Finkelstein (2001, pg. 2) states, “Society is constructed by people with capabilities for people with capabilities and it is this that makes people with impairments incapable of functioning”.

Viewing PWLD with an individualistic lens locates any problem, or difficulty within the person, therefore relieving society of its responsibility to adapt. This becomes problematic in the context of relationships, intimacy and sex because it would argue that instances of sexual abuse are problems for individuals, not society. This raises the argument that society has a complicit role in the sexual abuse of PWLD because it regards risk and vulnerability as an individual issue, therefore seeing no responsibility to intervene. This links to the internalisation of vulnerability and perceiving PWLD as inherently vulnerable. The social model disagrees, arguing that if society can adapt and break down existing barriers then individuals would not be perceived as “disabled”, or “vulnerable”, instead they would be able to participate more fully, and safely, in life (Oliver & Barnes, 1998). Taking the focus of responsibility outside of the individual and externalising it to wider systems (Oliver, 2013) became the dominant way to explore issues of disability and difference, raising the profile of the rights of disabled people and attempted to overcome the barriers facing this population. This is also supported by the Mental Capacity Act (2005) and United Nations (2006) who provided legal frameworks to support and protect the rights of PWLD to safely access all areas of their lives. Necessary information and education should be available for PWLD to enhance their potential for self-determination and to make fully informed decisions (Skuban-Eiseler, 2022).

Vulnerability, Learning Disabilities and Sex

Vulnerability

"Vulnerability" is a term frequently used to define groups of people, although it repeatedly locates vulnerability within a person (Office of the Public Guardian, 2015).

Sellman (2005) describes "vulnerability" within the context of nursing, describing them as a person who is "susceptible to harm as a result of either a higher than normal exposure to risk or a reduced, sometimes absent, capacity to protect themselves" (pg. 2). He goes on to describe situations which may be more commonly associated with "vulnerable" people such as those in institutions, being reliant on others for care and who appear to require additional protection compared to the rest of society. He also considers the normalcy of being vulnerable day to day such as when sleeping. This highlights that we can never be completely free from the risk of being harmed. He further categorises vulnerability into "ordinary" and "extraordinary" (pg. 3), the latter of which would include PWLD; "those whose mental development does not match their physical development", (Sellman, 2005, pg.4). Whilst this may be true, it contributes to the "othering" of PWLD and could be argued to create an almost helpless discourse, again placing responsibility within the individual. This is furthered when it is stated that "ordinary people with ordinary vulnerabilities do flourish in the world", (Sellman, 2005, pp.4). This "blaming" perception of vulnerability has been recognised by the Office of the Public Guardian who have updated the terminology used in their safeguarding policies. They have replaced "vulnerable adult" with "adult at risk" to draw attention to the social influences on vulnerability, however, this does not equate to a generalised shift in societal attitudes, something highlighted in this study.

Brene Brown discusses vulnerability as "uncertainty, risk, and emotional exposure" (Brown, 2015, pp.34) and regards being "vulnerable" as something requiring courage. She describes it as an opportunity, not a limitation. This contrasts with the more commonly used definitions which perceive vulnerability as weakness and something requiring enhanced protection. Whilst many share Brown's stance on vulnerability, it assumes that people have the autonomy and self-determination to be vulnerable and to open themselves up for new opportunities whilst recognising the potential risks of doing so. Therefore, PWLD are unlikely to experience the positives of engaging with their own "vulnerability" due to the risk of increased restrictions rather than opening up opportunities. There is minimal encouragement for positive risk taking in the context of learning disabilities, especially when negotiating access to relationships and intimacy, therefore this area of life remains restricted and limiting.

As argued previously, the phenomena of "vulnerability" is experienced differently depending on the context in which it exists. For PWLD, vulnerability is often associated with an assumed need for protection and restriction by others (Lam et al., 2019), not to provide education, understanding and opportunities to enhance self-determination. Whilst there is growing literature regarding life experiences of PWLD, it is minimal. The current study strengthens the limited available literature by exploring the lived experiences of PWLD when trying to negotiate access to relationships, intimacy and sex (Brown & McCann, 2018; Turner & Crane, 2016). It complements the work done by McCarthy et al. (2022) who emphasise the rights of PWLD to experience all aspects of relationships, free from the restrictions imposed by their support networks. The current study also provides greater insight into the experiences of support workers and some of the contributing reasons for gatekeeping access to experiences or education (McCarthy et al., 2022).

Throughout this research, "vulnerability" will refer to the potential for experiencing harm and a person's ability to implement self-protective measures after having demonstrated an ability to recognise potential risks. It hopes to move away from perceiving "vulnerability" as a term which strengthens an existing discourse of weakness and reliance on others for protection, to a more dynamic term which highlights how the concept of vulnerability is navigated and negotiated. It will also highlight the fluidity of vulnerability so as to draw attention to the potential for individuals to learn ways of self-protection and to move away from a sense of "helpless vulnerability". This study will highlight the need for increased support and education surrounding relationships, intimacy and sex for PWLD *and* their support workers (de Wit et al., 2022). It hopes to contribute to changing how "vulnerability" is perceived and responded to.

Sexual Vulnerability

The World Health Organisation (WHO) (2015) regards having the right to engage in pleasurable sexual activities where individuals are free from coercion and violence as being central to positive sexual health. Similarly, the Human Rights Act (1998) and The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD; United Nations, 2006) recognise and respect the right of each person to a private family life, inclusive of intimate relationships.

Perceiving someone as "vulnerable" can influence the behaviours of others and can lead to over-protection or increase the risk of potential abuse. Moreover it locates blame and responsibility with the person (Office of the National Guardian, 2015). This is exacerbated within the learning disability population when it comes to sex and relationships as they have historically been regarded as “asexual” and “eternal children” (McCarthy, 1999). This perception assumes vulnerability and a need for protection whilst disregarding any normal, sexual urges and removing the possibility of shared decision making. The risk of oppression and restriction increases due to assumptions being made in the absence of any capacity assessment. There is an ongoing fear of doing something “wrong” if PWLD engage in sexual activity without a capacity assessment which could result in harm or abuse (Bates, 2019). The Mental Capacity Act (2005), however, clarifies that it should not be used to restrict or deny PWLD from accessing sexual relationships. As mentioned earlier, PWLD are at greater risk of sexual abuse and exploitation, often occurring in the context of unequal power relations with family or carers (Beadle-Brown et al., 2010; Majeed-Ariss et al., 2020; McCormack et al., 2005; O’Callaghan & Murphy, 2007; Reid, 2018; Sinason, 1992). However, it is important to understand the person as a whole, not just as their learning disability. If the intersecting parts of their identity such as gender and disability are deconstructed, then maybe the discourse surrounding perceived “vulnerability” can be challenged (Siller & Aydin, 2022).

It is important to carefully define “sexual vulnerability” due to a dominant narrative suggesting victims of sexual violence are in some way accountable for what happens to them (Wishart, 2003). The internalisation of personal responsibility mirrors historical narratives surrounding learning disability; the problem is within the person, not within society. Internalising responsibility for sexual abuse becomes increasingly problematic as it insinuates perpetrators are not accountable, therefore somehow justifying their offence. Consider the sexual abuse of young children or PWLD, they are unlikely to have accessed sexual education (Byrne, 2018) and therefore have large knowledge gaps in this area. Are we therefore expecting them to be accountable for what happens to them in cases of sexual abuse or violence, that the burden of being “vulnerable” should come down to the individual and not that of society? Wishart (2003) explains that there appears to have been little debate regarding the concept of vulnerability or how it can differ among contexts, despite it informing policies and guidance. This research aims to explore individual experiences and perceptions, of “vulnerability” and how they influence negotiations in a learning disability context. It is important to understand individual experiences in order to inform current clinical practice.

As mentioned briefly above, “vulnerability” can be understood in the context of intersecting variables. Intersectionality as a concept considers the many different identities we hold and how they interact to create disadvantage and exclusion

(American Association of Intellectual and Developmental Disabilities, 2022). The original concept of intersectionality arose to explore the layers of inequality faced by women of colour (Crenshaw, 1989). It has since expanded to include a breadth of socially constructed norms in which people are marginalised and discriminated against (Singer, 2023). These include race, gender, ethnicity, sexual orientation and socioeconomic status (Singer, 2023). Others have explored intersectionality as a way of understanding the heterogeneity of populations as opposed to using blanket approaches (Kuran et al., 2020). For example, culture is encompassed in the concept of sexual vulnerability due to the diverse populations in which we live. Some East Asian cultures are less likely to discuss sex and sexuality, whereas in Western culture it is much more prevalent in the media and it is this Western perception which is often used to establish "norm" and provide "acceptable" societal standards (Khoo, 2009). In some cultures, PWLD continue to be excluded from general society (Chou & Lu, 2011).

Considering intersecting parts of identity and experience during any work with PWLD would complement the social model of disability as it further extends the perception of difficulty and limitation being external to the person. It allows exploration of how other factors can contribute to barriers to social opportunities and the exacerbation of individual impairments (von Koettlitz, 2019). This study particularly considers the intersection of gender and learning disability, and how this influences negotiations between PWLD and their support workers when accessing opportunities for relationships, intimacy and sex.

Relationships and Intimacy for People with Learning Disabilities

Relationships and intimacy is an area of life that PWLD have been prevented from accessing. Historical perceptions of PWLD describe them as being limited in their cognitive abilities and there is a fear of limitations being passed onto younger generations, therefore, sex has often been denied. This contributes to an unhelpful belief that PWLD *are* "vulnerable" and need protecting (Office of the National Guardian, 2015). Whilst the literature demonstrates increased numbers of PWLD being sexually abused or exploited (Codd & Hewitt, 2021), it does not justify withholding the opportunity for positive sexual experiences. It does not mean that PWLD are always "vulnerable", in fact anyone can be vulnerable depending on their context.

PWLD have often been dehumanised, including being perceived as asexual and devoid of sexual needs (Azzopardi-Lane & Callus, 2015). Although it is now regarded as a human right, barriers continuously prevent people from being able to adequately, and safely, access relationships and intimacy. For example, there has been an increase in the availability of sexual education packages (Coleman & Sharrock, 2022) and a recognition that PWLD have desires to develop both intimate, and non-intimate relationships, but there is a disconnect between recognition and practical application. Whilst there is a lack of literature exploring this disconnect, it could be understood as a result of an ongoing belief that PWLD are inherently vulnerable to harm and abuse, therefore require protection from sex and relationships (Codd & Hewitt, 2021). It is also documented that staff continue to experience anxiety and uncertainty about *how* to support PWLD in this area (Bates et al., 2020; Grauerholz, 2000; Lam et al., 2019) despite it being expected from parents (Bates et al., 2020). The current study provides further insight into the disconnect by taking a multi perspective approach to understanding the experiences of both PWLD, and their support workers (Larkin et al., 2019). These experiences will contribute to the understanding of negotiating relationships, intimacy and sexual self-determination for PWLD.

Sex and sexual expression is a human right and the WHO stipulate that a person's sexual health is dependent on their ability to engage in sexual expression which meets the cultural norms and attitudes of their society, as well as abiding by the existing laws (World Health Organisation, 2015). The complexity surrounding sexual health is exacerbated for PWLD. Their ability to engage in sexual activity is dependent on a range of factors many of which are context dependent and are influenced by the dominant discourse of that particular context. As many PWLD receive support from carers or family, they are often the ones gatekeeping sex and relationships, acting as mediators between PWLD and their access. It is not well understood how these decisions are mediated or what contributes to the negotiations involved, something this study aims to address.

Despite recognising that the expression of sexuality and engaging in relationships contributes to an overall sense of self and well-being (World Health Organisation, 2015), there have been longstanding debates regarding how this applies to PWLD (Lofgren-Martenson, 2004; Winges-Yanez, 2014). Historically, they have tended to fall into one of two categories when it came to sexualised behaviours, "asexual" (Arias et al., 2009; Deeley, 2002) or "hypersexual" (Deeley, 2002), both of which contributed to two contrasting discourses surrounding the sexuality of PWLD; sexually "vulnerable" or sexually "risky". These words create a powerful, sexual binary in which PWLD are positioned by other, non-disabled people. Being labelled as "asexual" suggests there is no interest in sex which perpetuates the dehumanisation of PWLD and disregards their basic needs and human rights. In contrast, being "hypersexual" creates a sense of problematic sexual behaviour, especially in the context of learning disabilities, where it has often been assumed that individuals lack understanding, or basic skills to engage in healthy sexual relationships. Professionals working within Community Learning Disability Teams (CLDTs) have noticed people do not often fit onto a binary, making potential interventions increasingly complex. As a result of categorising PWLD as “asexual” or “hypersexual”, many countries, including the UK, have engaged in forced sterilisation programmes (Parmenter, 2001) whilst others prevented the marriage of PWLD (Haavik & Menninger, 1981). The sexual expression of this population has often been contextualised as sexually threatening (or deviant), sexually promiscuous, or too complex to manage (Hollomotz, 2011). As a consequence, PWLD have been excluded from information and education surrounding sex and relationships, their sexual needs ignored, and have often been sexually segregated in institutions (Furey & Niesen, 1994; McCarthy, 1999). These preventative measures contributed to increases in, largely undetected or underreported, instances of sexual abuse within institutions (Furey & Niesen, 1994). This was because the abuse was not being reported, or the victims did not recognise the abuse as abuse (McGilloway et al., 2020). Over time, a third way to categorise PWLD sexually was introduced – PWLD as sexual beings with sexual rights (Deeley, 2002).

Within learning disability services, as with other healthcare settings, sex and relationships continues to be a taboo subject (Perez-Curiel et al., 2023; Race, 2016) which results in higher levels of uncertainty and confusion for those in caring positions. The concerns surrounding the “sexual vulnerability” of PWLD has been strengthened by literature describing the increased risk of being sexually assaulted and/or exploited (Sinason, 1992), especially by people known to them (Beadle-Brown et al., 2010). Wishart (2003) describes the risk as most often being posed by men known to their victims, staff members, family members and men with learning disabilities. It can be particularly challenging for PWLD to report incidents of sexual abuse (McGilloway et al., 2020) if they have limited understanding that what is happening to them is abuse, if they have communication difficulties or because they acquiesce to others (Mencap, 2001). Despite there being an increase in reports of sexual abuse, the statistics remain inaccurate because cases are not followed through, or because they are not reported in the first place (Mencap, 1997; Mevissen & de Jongh, 2010).

With a shift towards recognising PWLD as sexual beings with sexual rights, attempts have been made to ensure equal opportunities to develop intimate relationships and engage in sexual behaviours are given. The Mental Capacity Act (2005) offers opportunities for professionals to assess the capacity of individuals where there are queries about a person's capacity. It aims to try and balance the dilemma of being overprotective and restrictive, while advocating their rights to sexual lives (McCarthy & Thompson, 2004). If an individual is assessed as lacking capacity to consent to sex, then there is a legal requirement to offer an appropriate intervention to increase their understanding. Whilst offering an intervention does not mean that capacity will be gained, it offers an opportunity to access education they may otherwise have missed out on. Receiving sexual education has been found to reduce the risk of sexual abuse and exploitation but is not sufficient (McGuire & Bayley, 2011; Singer, 2023). There are also questions surrounding the accessibility of such education (McGuire & Bayley, 2011; Stinson et al., 2002).

The British Institute of Learning Disabilities (BILD) developed an educational package to support PWLD in the area of sex and relationships (Sexual Knowledge and Understanding Assessment), which includes a capacity assessment (Dodd et al., 2015). Whilst it is positive that capacity can be assessed to maximise an individual's right to engage in sexual relationships, its use can be driven by power and an often subjective belief about what is right and wrong. The dominant discourse of PWLD being limited in their abilities, and needing continuous protection is therefore likely to influence decisions when assessing capacity, especially regarding decisions surrounding marriage or having children (Haavik & Menninger, 1981; Parmenter, 2001). It is therefore important to understand the experiences of individuals acting as mediators in the lives of PWLD, to better understand the decisions they make and why. This study captures the voices of support workers and reveals the influencing factors involved in negotiating access to sex and relationships.

As with the general population, not all PWLD will want to have a sexual relationship but there are differences with regards to the level of autonomy and opportunities they have to make such decisions (Wehmeyer, 2020). Chou et al., (2015) highlighted the limited opportunities that are available for PWLD to access intimate relationships despite them believing that they should have the same sexual rights as others. Understanding and enhancing self-determination with regards to sexual decision making for PWLD has often been neglected within research. Whilst there is limited understanding surrounding how decisions are made by PWLD, there is a recognition that the context in which PWLD are situated can influence their level of self-determination (Abery & Stancliffe, 2003; Rubio-Jimenez & Kershner, 2021). The lack of research exploring sexual decision making for PWLD likely reflects the limited opportunities they have to access these decisions. Often such decisions and choices are encapsulated within the legalities of the Mental Capacity Act (2005) and are driven by others wanting to protect PWLD from harm. Individuals in caring positions experience conflict, confusion and anxiety regarding the balance between safeguarding and protecting PWLD while advocating their right to have relationships - sexual or not (McGuire & Bayley, 2011; Rushbrooke et al., 2014). Whilst the implementation of policies and frameworks would offer necessary guidance and support to those in caring roles (Brown & McCann, 2019), it could also increase the risk of implementing restrictive practice (Bane et al., 2012). The introduction of guidance alone is unlikely to guarantee increased staff confidence when navigating sex and relationships for PWLD because there are other factors to consider such as personal values and beliefs (Finlay et al., 2008). It is repeatedly recommended that support staff need adequate training to support PWLD in this area of life and to enhance their confidence in doing so (Bates et al., 2020; Care and Quality Commission, 2019). Herbert et al. (2019) further highlight the need for training to happen in “safe” contexts due to the sensitive nature of the topic. This study illustrates an example of how this can be achieved.

The experiences of support workers when negotiating sensitive topics such as forming intimate relationships for PWLD is not widely captured within the literature. This study hears the voices of both support workers and PWLD whilst providing an opportunity to influence clinical practice, specifically regarding how safely scaffolded conversations and learning opportunities can influence self-determination and autonomy for PWLD.

Decision Making

Our day to day lives are made of up choices and decisions such as what to eat for lunch, what to watch on TV, or larger decisions which may impact our futures such as buying houses or choosing romantic partners (Curryer et al., 2020). Choice does not occur in the absence of positive outcomes, therefore, the decision itself, and potential impact of the decision need to be understood first (Ajzen, 1996). Future situations will be influenced by engagement in this behaviour. The outcome could lead to repetition of the same decision being made, or may trigger a re-evaluation to seek an alternative solution. For PWLD there is a lack of involvement in choice and decision making and are often exposed to limited information, particularly surrounding intimate relationship decisions. In this context, are they ever able to make informed decisions if they are kept from necessary information or if choices are skewed by others?

It is argued that depending on what type of decision is being made will influence what strategies are used: logic, statistics or heuristics (Gigerenzer & Gaissmaier, 2011). Logical and statistical strategies have been associated with "rational reasoning" unlike heuristics which have been linked with more spontaneous and "irrational" reasoning. Earlier decision making research that centred around mathematics and economics, focussed more on understanding decision making processes within the business and financial arenas. Much of this research highlights the use of risk calculations and consideration of the potential losses and wins people may experience (Rossiter, 2019). In this context it is believed that the focus of potential wins and losses influences decision making and, ultimately, behaviour (Tversky & Kahneman, 1981).

Not all decisions are regarded as "rational" and it is important to understand what influences those decisions. Some argue the speed in which decisions are made and the narrow lens of information used to inform decisions leads people to make "irrational" decisions (Tversky & Kahneman, 1981). Some decisions may be regarded as "rational" in one context and "irrational" in another and can be argued to be influenced by underlying belief systems (Nickerson, 2008). Belief systems held by individuals will always be regarded as more rational than the belief systems of others (Cavojova & Miksskove, 2014). It is important that this is understood further, especially in the context of learning disabilities. PWLD are often engaged in relationships with people holding more power, for example, support workers, or families and who act as mediators during decision making, gatekeeping access to areas of life. This study aims to understand what influences decision making from both groups in order to inform clinical practice.

Gaps in knowledge, education and experience are also argued to impact decision making with some arguing that this can contribute to "irrational" decisions being made (Stanovich, 2009). One could therefore assume that with appropriate education, individuals would be able to make more "rational" decisions. What is a "rational" decision and what would a "rational" decision look like? Perceiving the rationality of decisions appears to be from the context of the observer, not the decision maker. This raises potential for the "rationality" of decisions to be determined by individual beliefs, values and attitudes, particularly surrounding sex and relationships for PWLD. This is problematic as PWLD already live in an unequal and restricted society where important life decisions are held in the hands of others, particularly surrounding relationships and intimacy. The decision makers in the lives of PWLD also manage access to necessary education and knowledge whilst often preventing them from accessing experiential learning, instead prioritising safeguarding and protection (Lam et al., 2019). For this reason, PWLD are more likely to be blocked from making decisions in this context. Will PWLD ever be regarded as "rational" decision makers if they are continuously prevented or blocked from accessing education? This study provides further insight into how PWLD and their support workers negotiate access to relationships and intimacy. It shares the voices and experiences of both groups in the context of “vulnerability” which is rarely addressed in existing literature.

Decision Making Theories

Prospect Theory. Prospect Theory (PT) originated in 1979 (Kahneman & Tversky, 1979) as an attempt to offer rationale to why people failed to make “correct” decisions. It describes decision making based on the (inaccurate) evaluation regarding the probability of perceived losses and gains in relation to key reference points (their current context). PT has been used to understand the process of making what some may describe as “suboptimal decisions” and describes behaviour that is motivated by the possibility of loss (loss aversion) rather than gain (Tversky & Kahneman, 1981). PT suggests that risk aversion increases when faced with potential losses, whereas those who are more likely to experience loss become risk seeking (McDermott et al., 2008). PT has been critiqued for its’ focus on complex mathematics to explain the influence of risk, uncertainty, loss and gain attitudes on decision making (Rossiter, 2019). Others explain that PT fails to account for the value individuals place on decisions and behaviours, and the difficulty defining potential losses and gains (Kozegi & Rabin, 2007). Whilst PT can be used to make sense of individual decisions for support workers (loss averse) and PWLD (risk seeking) in the context of navigating relationships and sex for PWLD, it does not offer insight into the complex decision making processes and negotiations occurring within the supporting relationship. There is also limited information regarding how PT could be applied to decisions focused on intimacy and relationships other than using online dating apps (Gregorich, 2018).

Theory of Planned Behaviour. Theory of Reasoned Action (Ajzen & Fishbein, 1980) assumes that individuals each have the necessary resources, skills and opportunities to enable them to engage in chosen behaviours but this is not often accurate and rarely applies to PWLD (Ajzen, 1988; Beresford & Sloper, 2008). To account for this limitation, Ajzen (1988) extended TRA to incorporate perceived behavioural control as a factor to consider in decision making. Theory of Planned Behaviour (TPB) adds perceived behavioural control to individual attitudes and subjective norms. Perceived behavioural control considers the influence of internal factors (skills, ability, information, emotions) and external factors (opportunities and potential cooperation of others) and is believed to be directly linked to behavioural intent (Beresford & Sloper, 2008). PWLD experience barriers to accessing information surrounding relationships and intimacy which impacts the development of necessary skills needed to safely access this area. They are also often supported by others who restrict access to experiential opportunities and make decisions for them. This limits the extent to which they can engage in negotiations or shared decision making with others.

In April 2020, TPB was one of the most applied theories across a range of behaviours (Bosnjak et al., 2020) but it did not include shared decision making, or decisions around relationships and intimacy, other than condom use (Asare, 2015). It argues that behaviour is driven by intent, which is influenced by:

- Beliefs about the consequences of the potential behaviour
- Beliefs about the normative expectations of others regarding the potential behaviour
- Beliefs about what may help or hinder engagement with the behaviour.

Behavioural intent is stronger when there are favourable attitudes surrounding the behaviour, there are positive beliefs regarding normative expectations of others and there is greater perceived behavioural control present (Bosnjak et al., 2020). It is argued that all of these factors would be lacking for PWLD and therefore would not be sufficient to understand behaviours surrounding relationships and intimacy.

Shared Decision Making. Shared Decision Making (SDM) emerged in the 1980s (Brown & Salmon, 2019; Elwyn et al., 2012) with an aim to enhance patient centred care. It is commonly used in health contexts, placing patients and their values at the centre of decision making processes (Waldron et al., 2020). It requires open communication between healthcare professionals and patients via comprehensive and accessible information to provide a clear understanding of available treatment options (Charles et al., 1997). It aims to enhance decision making ability whilst recognising the rights of patients to make autonomous decisions (Danner et al., 2020) and protecting patient interests (Brown & Salmon, 2019). Elwyn et al. (2012) highlight the need for clinicians to be aware of guiding ethical principles and a need to accept that individual self-determination is a key goal to work towards using SDM. Relational autonomy is mentioned in Elwyn's paper, highlighting that our decisions will always be influenced by our interpersonal relationships (Mackenzie, 2008). They also highlight the barriers to SDM such as individuals lacking experiences of being involved in decision making processes and lacking health education and knowledge. Elwyn et al. (2012) suggest that to achieve SDM, individuals must be able to demonstrate autonomy and feel able to make choices. They argue that this can be done through providing information and supporting decision making processes. Supporting individuals to make health related decisions has barriers such as believing that clinicians would make “better” decisions, or some may experience fear and abandonment when placed in a “decision maker” role.

Applying SDM in the context of learning disabilities becomes challenging as it assumes an ability to develop autonomy and decision making skills, something PWLD are often prevented from accessing. They are also often kept from, or given limited access to the necessary information they would need in order to make informed decisions about relationships, intimacy and sex. Whilst SDM offers a positive framework in which to enhance person centred care, it both focuses on health related decisions and with populations where capacity is easily assumed.

A major limitation of the above theories is the assumption that individuals have autonomy and opportunities to make independent and fully informed decisions. The theories do not provide an understanding of the negotiations occurring within pairs where there is an ongoing unequal power distribution or where capacity may be questioned, nor do they provide understanding of decision making involving relationships and intimacy. The current study reveals the complexity of negotiations occurring when PWLD seek opportunities to access relationships and intimacy, and what drives individual decision making.

Learning Disabilities and Decision Making

Decision making in the context of learning disabilities has been an area of much debate over the years, particularly for decisions surrounding relationships and intimacy (Butler-Cole, 2017; Dukes & Maguire, 2009; Lyden, 2007). The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD; United Nations, 2006) clearly highlights the right of any disabled person to be involved in decision making. Despite this being enshrined in law, PWLD are often blocked from experiencing sexual relationships or from accessing appropriate and relevant information which would support decision making processes.

Theory of Planned Behaviour discusses the influence of subjective norms which is considered important within the field of learning disabilities. This is an important consideration due to the frequent reliance on others for support with day to day life (Curryer et al., 2015) and the historically limited opportunities they have to make decisions. Being reliant on others means that decisions are not only influenced by their own beliefs, attitudes and previous experiences, but also that of their support network (Curryer et al., 2020). Research has found that support for decision making is influenced by the context of decisions and how support staff prioritise such decisions (Bigby et al., 2022; Curryer et al., 2020) thus it could be argued that PWLD would have lower perceived behavioural control and are less likely to act on decisions.

Jenkins and McKenzie (2011) conducted a study which found that all three factors were significant predictors of encouraging healthy eating behaviours in PWLD. Whilst all factors were predictors, they found that the perceived attitudes of others were particularly important. Past behaviour is mentioned in Jenkins and McKenzie's (2011) paper as it is known to be powerful predictor of future intent, thus showing support for the efficacy of TPB. Martin et al. (2011) used an adapted version of Norman and Conner's (2005) TPB questionnaire to explore how much TPB could predict the behavioural intent of carers with regards to supporting physical activity in PWLD. They found that TPB could be used to explain the variance of carer's intentions. Their findings supported the work of others (Hagger et al., 2002) which demonstrated perceived behaviour control and attitudes were the most influential and predictive elements of intention. Other findings were in contrast (Jenkins & McKenzie, 2011), for example, Martin et al. (2011) found that subjective norms were not significantly predictive of behavioural intent. As with many studies exploring aspects of life for PWLD, Martin et al. (2011) omitted the voices of PWLD which would have offered a much needed layer to their work.

The Mental Capacity Act (2005) provides a legal framework which protects the rights of people to be involved in decision making as much as possible. Where individuals lack capacity, it is recommended that further information and education is provided which can enable them to gain capacity (Lyden, 2007). This becomes complex when considering capacity to engage in sexual relationships (Butler-Cole, 2017). Assessing capacity for sexual decisions is a confusing and anxiety provoking area but sexual consent capacity can be achieved if a person is able to understand what is proposed, the implications and they are aware they have a choice of whether to engage or not. Capacity is largely dependent on access to information and opportunity, something which is less widely available to PWLD (Fyson & Cromby, 2013) and contributes to interventions and restrictions being implemented to "protect" them (British Psychological Society, 2019; Butler-Cole, 2017). Though such restrictions are implemented to protect, they can deny the rights of PWLD in the absence of providing sexual education. The British Psychological Society (2019) provide a range of case examples to illustrate the potential outcomes of capacity assessments and what steps can be taken to mitigate enhanced risk.

Study Rationale and Aims

After considering the available literature, this study aims to capture a rich insight into the experiences of PWLD, and their support workers, when negotiating opportunities to access relationships and intimacy. The main research question asks:

“What are the experiences of people with learning disabilities, and their support workers, when negotiating access to opportunities for developing relationships and intimacy?”, with additional research questions:

- What are the experiences of PWLD and their support staff regarding the concept of sexual risk and sexual vulnerability?
- Why are the experiences different between PWLD and their support workers?

Chapter 2: Method

This chapter will describe the chosen methodology for the research, Interpretative Phenomenological Analysis (IPA). Interpersonal Process Recall (IPR) supported data collection. The method will outline the design, sampling and recruitment of participants, and will explain the ethical and risk considerations. It will finally explain the analysis.

Methodology

A qualitative approach was chosen for this research as there was no pre-determined hypothesis. This study aimed to capture individual experiences of sexual decision making and wanted to understand how people make sense of their experiences. The research sat within an interpretive, constructivist epistemological position because it sought to interpret the experiences of others and to make meaning from them. Discourse Analysis (DA) was initially considered as it would allow the exploration of participants' experiences from personal, social and political perspectives (Edwards & Potter, 1992) and would focus on the voices of PWLD, something often ignored in research (Scior, 2003). However, whilst DA would have offered useful insight into the potential influences of language use for this population it would not have provided in depth experiential accounts. As such, Interpretative Phenomenological Analysis (IPA) was selected as an appropriate method to answer the research questions. IPA argues that multiple perspectives can exist about the same phenomena and that individual realities are influenced by the context in which people are situated (Al-Saadi, 2014; Smith et al., 2022).

Interpretative Phenomenological Analysis (IPA)

IPA was selected as an appropriate methodology as it focuses on the in depth exploration of everyday experiences and the sense people make of them (Smith, 1996); what makes the ordinary experience extraordinary for people? It does not seek to produce generalisable findings or new theories which complements the aims of the research. Whilst IPA is not embedded in a particular theoretical model, nor does it seek to create generalisable results, it allows "theoretical transferability" into other, wider areas of pre-existing research (Smith, 2008) which this study aimed to achieve.

Researchers will never be able to access the first hand experiences described by participants, but IPA gets as close as possible to walking in their shoes (Smith & Osborn, 2008). Despite providing rich, detailed accounts of experiences, IPA requires researchers to make sense of participant's sense making – known as the double hermeneutic (Smith et al., 2022). This process enables researchers to take both an empathic and curious stance to give insight into the lived experience of the phenomena whilst exploring what it means to the person (Smith et al., 2022). This process increases the risk of being influenced by personal biases as researchers become “an inclusive part of the world they are describing” (Larkin et al., 2006; P.107) whilst making sense of it using their own subjective experiences.

IPA is appropriate for small sample sizes (Padgett, 2008) and places the individual as expert (Smith et al., 2022), something largely absent in the lives of PWLD. IPA is a dynamic process, allowing in-depth exploration of individual experiences, giving voice to under researched areas and often neglected populations, such as PWLD, therefore meeting the aims of the research. More recent extensions to IPA have seen the introduction of novel approaches, such as exploring phenomena from multiple perspectives (Larkin et al., 2019; Smith et al., 2022). Larkin et al. (2019) provide different ways in which multiple perspectives can be constructed, for example, examining cases in directly related groups (same experience but different views), indirectly related groups (people being linked by an underlying quality), families, teams and other cohorts (shared experience within a system), and dyads (shared and distinctive features of an experience which is important to two people). Research commonly explores individual experiences but it was important to widen this for the current research, to further understand what occurs during negotiations and decision making processes. The latter construction was therefore selected for the current research, to explore the experiences within a dyad. This would allow exploration of the experiences of negotiating access to relationships and intimacy from both the perspectives of PWLD, and their support workers.

The literature describes how challenging conversations surrounding relationships and intimacy can be for PWLD’s support networks due to balancing advocacy and safeguarding (Byrne, 2018). It has been noted that staff can unintentionally maintain unequal power dynamics through language use and can foster perpetual dependence on them for decision making (Rapley, 2004), as opposed to enhancing self-determination. A multi perspective approach to IPA will offer an in-depth insight into how PWLD, and their support workers make sense of, and negotiate, opportunities to access relationships and intimacy. Although each participant will enter this research from their specific context with one specific person, it will offer the opportunity to inform clinical practice, specifically with regards to enhancing self-determination for PWLD due to making sense of the experience from multiple perspectives (Smith et al., 2022).

IPA is informed by three key principles: phenomenology, hermeneutics and idiography (Smith et al., 2022), each of which will be explained below.

Phenomenology. Phenomenology focusses on understanding phenomena through individual experiences, creating space for different realities to exist (Willig, 2008). It encourages reflective engagement with lived experiences (Pietkiewicz & Smith, 2014) to further understand the sense people have made of phenomena and how their sense making influences their responses. It aims to strip back as much "noise" from experiences and reveal them in their natural form, free from clinical experimentation, interference and preconceived assumptions (Giorgi & Giorgi, 2008; Larkin et al., 2006).

Hermeneutics. Heidegger (1962) introduced the second principle, hermeneutics which relates to how we interpret the world (Bowie, 1998). It requires researchers to make sense of participant's sense making, known as the double hermeneutic (Smith & Osborn, 2008). The double hermeneutic is a layered approach to understanding phenomena; initially participants try to make sense of their experiences before researchers begin to understand individual experiences of phenomena through the eyes of participants.

Humans are sense making creatures and will always try to make sense of experiences and the world. IPA can be used to reveal hidden parts of experiences by bringing them to the forefront and supporting the interpretative experience. It creates an alliance between participant and researcher because both are engaging in the same sense making process (Smith et al., 2022). We cannot separate ourselves from existing assumptions as we jointly enter our participants' world, therefore, we must consistently employ reflexivity and transparency to acknowledge this influence.

Idiography. Idiography is a key influence in IPA, bringing the focus to the "particular", an individual's experience of the phenomena, not the phenomena itself (Eatough & Smith, 2017). It does not aim to uncover a unified and generalisable experience which can be applied to a particular population, instead, individual experiences are considered unique and valuable (Smith et al., 2022). By committing to focussing on the "particular", researchers aim to conduct in depth analysis to understand the detail of experiences. There is also a commitment to understand how the phenomena is understood by certain people in certain contexts (Smith et al., 2022).

Interpersonal Process Recall (IPR)

Interpersonal Process Recall (IPR) originated as a clinical supervision tool to support reflection and greater exploration of clinical practice for counsellors (Kagan & Kagan, 1990; Larsen et al., 2008). It facilitates reflection of recent memories and does not rely on memory recall (Janusz & Peräkylä, 2021). An intersubjective approach to IPR was used within this research as it draws attention to the conscious but unspoken experiences of individuals and does not require accurate recall of the event (Janusz & Peräkylä, 2021). PWLD regularly experience unequal power relations and may often feel unable to speak up, or they may not have the communication skills to be able to spontaneously offer their inner thoughts and feelings but IPR would allow them to share these. IPR allows the researcher and participant to review recordings and notice the unsaid which can prompt further discussion and co-creates sense making (Larsen et al., 2008; Macaskie et al., 2015).

IPR complements the multi perspective approach to IPA as it draws inner experiences to the forefront to support sense making. This was particularly important for this sensitive research topic and the use of IPR created a safe context to explore the experiences of both PWLD and their support workers (Kijak, 2013). The aim of IPR is not to explore the content of what is being said, but to reveal underlying thoughts and feelings being experienced at the time of the event, not when rewatching the video (Larsen et al., 2008). It is possible that other previous experiences are recalled and reflected on during this process which could add further insight into the sense making experience of the phenomena.

Method

Design

A qualitative design using semi-structured interviews was chosen to explore participants' experiences of negotiating access to opportunities for relationships and intimacy. The interviews were transcribed by an external, University approved transcriber and the final transcripts were analysed using IPA (Smith et al., 2022). Consideration was given to the use of focus groups as it could offer opportunity for people to come together and share experiences (Martino, 2022) thus increasing the level of information gained. However, it was felt that due to the nature of the topic that individuals may have felt uncomfortable in a group setting, something which was commented on by expert consultants. Quantitative methodologies were also considered but this would not have answered the research question as it would limit the extent to which experiences could be accessed.

It was important that PWLD were involved in the design of the study, helping to shape it and ensure an inclusive and meaningful approach was taken (Garcia Iriarte et al., 2014; Northway, 2000). PWLD have been excluded from research due to communication difficulties and/or the perceived "severity" of learning disability (Goodley, 1996; Atkinson, 1997; Lewis et al., 2020). Members of their support network are therefore often asked to comment on their behalf. While this can involve people who know the individual well, subjective views and beliefs are likely to contribute to an urge to protect PWLD thus offering somewhat of a distorted representation of views (Lloyd et al., 2006). This study will follow the principles of inclusive research outlined by Walmsley and Johnson (2003);

- It must address issues which really matter [to the research population] and ultimately leads to improved lives for them
- It must access and represent their views and experiences
- People with intellectual disability need to be treated with respect by the research community

A group of expert consultants with learning disabilities were recruited from a third sector organisation specialising in supporting PWLD to establish friendships and relationships. They contributed to the design of the study, the language and terminology used throughout the research and it is planned that they will provide consultation on the dissemination of findings. This ensured the study met the needs of, and was accessible to, PWLD as was recommended by Lewis et al., (2020). Consultation meetings with experts were held via Zoom and lasted for no longer than one hour. All consultants received payment for each part of their involvement.

Sampling

The literature recommends smaller sample sizes for qualitative research although offers no defined standards for how many participants are appropriate (Marshall et al., 2013). This is due to the in depth analysis required to get rich insights into participant's experiences of phenomena. Recommendations suggest a sample size of between 6-10 for Doctoral level research projects (Smith et al., 2022) is an adequate and manageable sample. There is an emphasis that more participants does not necessarily result in better quality research. With this in mind, and the intricacies of the research design, a minimum sample of six was aimed for; three pairs of participants. This was believed to be a sufficient number of participants in order to address the research question and provide rich insights into the understudied phenomena being explored (Cook et al., 2021).

Inclusion and Exclusion Criteria

Table 1 illustrates the inclusion and exclusion criteria for the research.

Table 1. *Summary of inclusion and exclusion criteria*

Inclusion Criteria	Exclusion Criteria
18 years or over.	Under 18 years of age.
Has a diagnosis of a learning disability as defined by the ICD-11. (This is not part of the inclusion criteria for staff or family members).	Does not have a diagnosed learning disability as defined by the ICD-11.
Is able to provide informed consent to participate in both parts of the study, including being video recorded.	Lacks capacity to provide informed consent to participate in the study.
Is able to engage in a conversation about sex and relationships.	Recent experience of sexual abuse or trauma.
Has a level of verbal communication to enable them to participate in both parts of the study.	Does not have a level of verbal communication which enables them to participate in both parts of the study.

Whilst there was an exclusion criteria of recent history of sexual abuse or trauma, it is likely that this would be more known for PWLD as they were accessing the recruitment service and lead clinicians held the power regarding who they believed met all criteria before approaching them to advertise the study. This was less clear for support worker participants who may choose to withhold information about their personal histories. After having spoken with support worker participants there may have also been the assumption that criteria did not necessarily apply to them as the general belief was that the research was to focus on PWLD. All participants were provided with contact details for the research team and further details for making complaints if necessary. An additional consideration is people not having disclosed previous abuse, or even recognising that situations may have been abusive. A comprehensives signposting document was given to all participants with information regarding local organisations specialising in this area. Future research using paired participants should ensure that all participants are clear that inclusion and exclusion criteria applies to them equally.

Recruitment

Participants were recruited purposively through a Community Learning Disability Team in Yorkshire. A member of the CLDT's psychology team was a gatekeeper for recruitment and offered field supervision as and when necessary. The narrow scope of the research and complexity of research design justified the requirement for fewer participants (Henry & Fetters, 2012; Malterud et al., 2016; Pietkiewicz & Smith., 2014). The CLDT referral criteria further narrowed the pool of potential participants, making recruitment challenging.

Figure 1 illustrates some of the key steps involved in the recruitment process. A more in depth version is included in Appendix F. After introducing the study in team meetings, consultations were offered to individual clinicians who had identified appropriate individuals on their caseloads. This offered an opportunity to clarify the inclusion and exclusion criteria and what was involved in the study. This recruitment strategy relied heavily on clinicians who were working in a busy and stretched service, therefore, this is likely to have impacted recruitment numbers. A range of strategies were employed to enhance recruitment and are discussed further in the strengths and limitations section in chapter 4. After clinicians met with potential participants and gave them the study advert (Appendix A), a consent to contact form was completed by the individual (Appendix A). The form was then kept in a secure place within the admin office at the recruitment site. Completed forms were collected from the recruitment site by the primary researcher and initial telephone contact was made with potential participants. Face to face introductory sessions were arranged with each person where easy read information sheets were provided (Appendix C) and an invitation to participate form for support workers (Appendix B) was given to participants. It was then their responsibility to approach a staff member with whom they had a good relationship with and who they wanted to participate in the research with them. The recruitment of support workers was led by PWLD in this research. On reflection, I wonder about the placement of power and if staff felt genuinely able to decline. All staff in this study valued their jobs and expressed a desire to do them well. However, it has been reflected that this may have hindered their ability to act on their honest feelings and decline participation in the research, feeling it was their "job" to do so. Future research using similar designs should ensure staff are given ample opportunity to discuss concerns and hesitations with researchers which is supported with additional information about declining and how the potential impact of power may leave them feeling obliged to participate. Where appropriate staff cannot be sourced, it may result in PWLD being unable to participate but would ensure fully informed consent continues to be gained from participants.

All equipment that would be used in the research (laptop, microphone, Dictaphone) was taken to introductory sessions to ensure individuals were given the opportunity to make fully informed decisions and to minimise any anxiety on the day of data collection. Conversation prompt cards (Appendix G) were also taken to give participants an idea of what conversations could cover. Participants were given one week to decide. Once agreed, a further discussion was had to clarify dates and times, and location of interviews. Location preference was identified by PWLD and was actioned in each case.

Clinicians highlighted 11 individuals they believed met inclusion criteria. Nine were approached by clinicians. Two declined further information whilst seven consented to further contact. Six met for further information. Four consented to participate in the research but one withdrew before commencing part one of the study. One participant wanted to participate but was unable to due to limitations in their personal support hours which highlighted the barriers to hearing the voices of PWLD in research as well as the daily restrictions being experienced. Three participants with learning disabilities completed all aspects of the study. This resulted in six semi-structured interviews being completed (three PWLD and three support workers). Whilst efforts were made to increase recruitment, the final number of participants was sufficient to meet the needs of a qualitative study using IPA (Smith et al., 2022).

Participants were male and female, aged in their early 20s to early 50s. All PWLD were receiving input from the recruitment site at the time of data collection. Staff participants were employed by third sector organisations or the NHS. Each pair had an existing relationship and had had the opportunity to discuss the research together prior to giving consent. Figure 2 shows the final recruitment numbers.

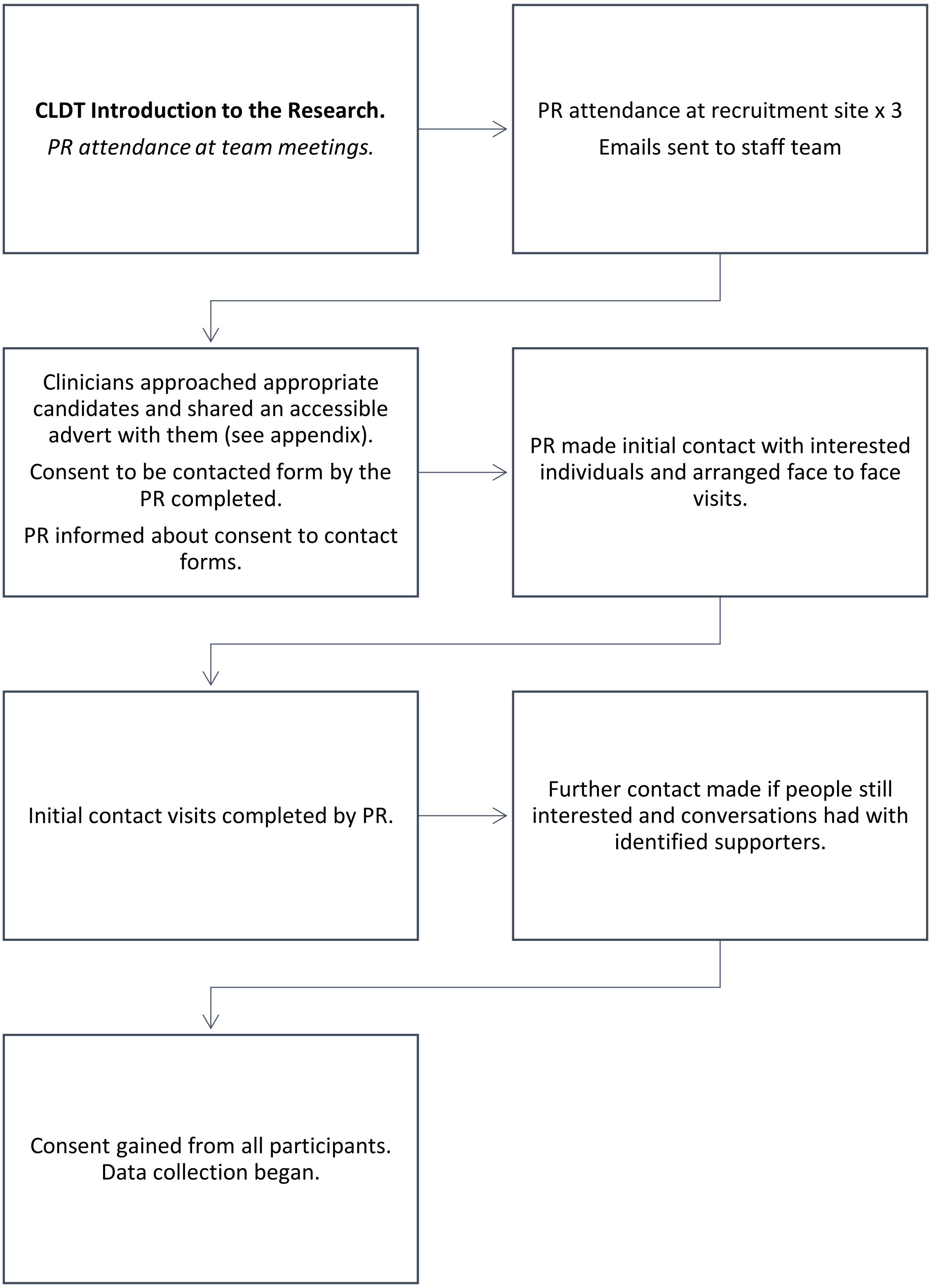

Figure 1. *Key Steps in the Recruitment Process*

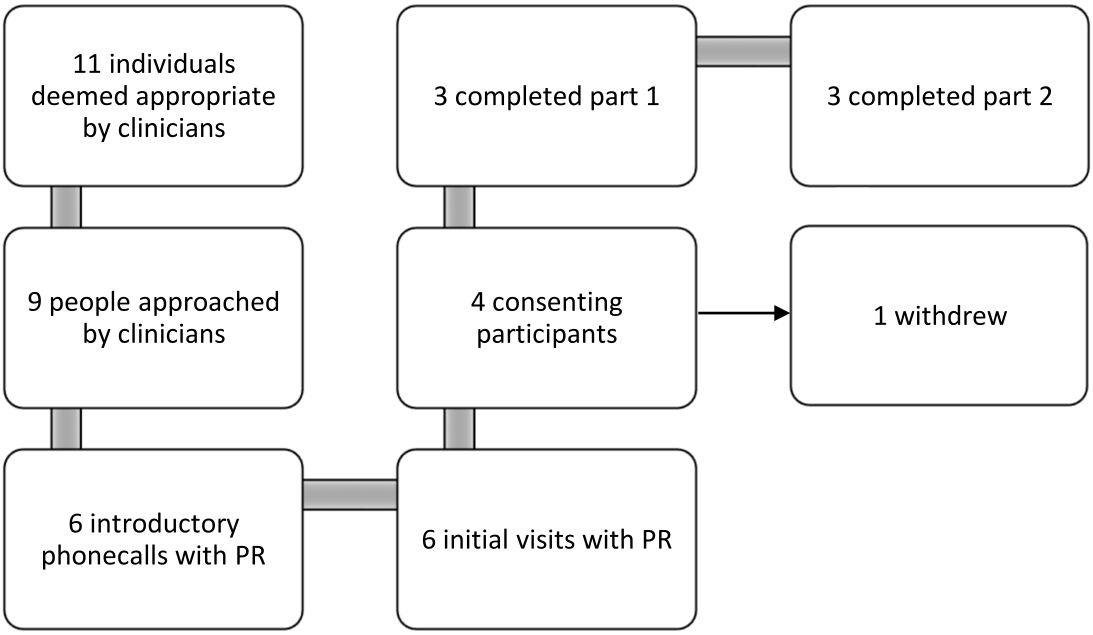

Figure 2. *Final Recruitment Numbers*

Ethical Considerations

Ethical Approval. Ethical approval for this research was granted by the Yorkshire and Humber - Leeds West REC (REC reference: 22/YH/0163). HRA and HCRW approval was granted on the 22nd September 2022 (Appendix E). Research and development approval was also sought and gained from the NHS recruitment site.

Capacity and Consent. Rolling consent was gained throughout the study to ensure it was regularly reviewed (Dewing, 2007). Comprehensive and accessible information sheets were provided (Appendix C) to ensure participants could make informed decisions and all participants signed a consent form (Appendix D). Individuals who lacked capacity to consent were not recruited. Capacity was initially assumed as per the Mental Capacity Act (2005) and because participants were identified by clinicians who knew them. Despite this, verbal and written explanations were given to participants during face to face introductory visits and they were asked to repeat back their understanding of the study. During this process, some individuals' capacity was uncertain but they decided not to participate due to their lack of understanding.

Privacy and Confidentiality. Conversations held during part 1 were video recorded using the record function on Microsoft Teams. The laptop was a Trust approved laptop and video recordings were saved to OneDrive which is an approved safe place to store confidential material. All videos were deleted immediately after participants completed part 2.

Interviews during part 2 were audio recorded using an encrypted Dictaphone obtained from the University of Leeds. Recordings were uploaded to the University of Leeds OneDrive after the interviews and were immediately deleted off the device. OneDrive is an approved safe place to store confidential material. It requires Duo Authentication to gain access which offers an additional level of security.

Data analysis involved transcribing the audio recordings. This was done via a University approved transcriber who signed a confidentiality agreement prior to receiving any recordings. The audio recordings will be kept for three years after the end of the study which meets the minimum requirement for the University. After three years, the videos will be deleted by a research coordinator who is part of the Leeds DClinPsy programme.

All participants were given the opportunity to select a pseudonym to reduce any power imbalances that may exist. It also supported the principles of participatory action research (Johnson & Walmsley, 2003). Where participants did not select one themselves, one was selected for them. Information such as age group, gender and living status is recorded in pen portraits in chapter 3 to situate the sample.

Research with "Vulnerable" Participants. Steps were taken to ensure individuals were not coerced into participation, for example, regularly reviewing consent and offering opportunities to withdraw. It was highlighted that there would be no negative impact on care if PWLD chose not to take part. There was a duty of care to report any concerns surrounding participant safety via supervisors and following the procedures of the recruiting service.

The research explored a sensitive topic with what is widely considered to be a "vulnerable" participant group: PWLD. Participants with learning disabilities were only recruited if they were accessing the recruitment site throughout their participation. This ensured that appropriate support was in place if any aspect of the research resulted in distress. Such support would include involvement of a lead clinician. Participants were not required to inform clinicians involved in their care about their participation in the research but the majority were keen to share their involvement as it was a new opportunity for them. Additionally, the primary researcher was available to discuss any immediate concerns and could signpost if needed. Advice was sought from the Trust safeguarding team about potential disclosure processes. In the event that a support worker participant made a disclosure, the Trust safeguarding team would be contacted for further advice and support.

The study was not designed to induce distress in participants but it could highlight areas of their lives where they feel they have less control. As such, it could trigger some potentially uncomfortable, or frustrating emotions. Similarly, the design of the study, being video recorded and watching this back may lead to some uncomfortable feelings and embarrassment for participants. As such, a safe space was provided, ensuring time was given before and after each part of the process.

Contact details of the wider research team was given to all participants and participants were encouraged to discuss any concerns or potential distress with clinicians involved in their care.

Consideration of Risk Issues.

Participants. As with any research involving interviews, there was an uncertainty surrounding what participants would share. Consideration was given to this and participants were given a signposting document including a range of local services. The recruitment site's safeguarding team were contacted prior to the start of the research to ensure all steps had been covered. Some participants shared accounts of historical abuse, or mental health difficulties which had already been responded to by appropriate agencies. There were no new safeguarding concerns that arose during this research.

Researchers. The University and recruitment site's lone working policy was followed, ensuring the field supervisor had details of where the primary researcher was conducting visits. There was also a check in and check out procedure via direct message to the field supervisor. The location of interviews meant staff were always present in the same building which offered a protective element.

Procedure

Part One

Part one of the study aimed to capture a naturalistic conversation between PWLD and their chosen support worker to generate data: a discussion about relationships, sex and intimacy. Due to the sensitive, "taboo" nature of the topic (Perez-Curiel et al., 2023; Race, 2016), and after advice from expert consultants, prompt cards were developed (Appendix G) which offered participants a scaffolded approach to initiating conversations. All participants used the prompt cards to structure the conversation and felt this created a safe space to navigate an unfamiliar, and embarrassing, topic (Kijak, 2013).

All participants were given the option of having the conversation without the primary researcher present but none chose this. It is unusual for researchers to share the initial experiences with participants, something which added an additional layer to interpreting experiences for the current study.

Consideration was given to the increased likelihood of social desirability bias (McCambridge et al., 2012) and the impact this design would have on natural flow of conversation (McLarty & Gibson, 2000). The strengths and limitations of this will be explored more in chapter 4. The conversation was video recorded on a Trust approved laptop using the record feature on MS teams. Videoing participants offered the opportunity for non-verbal communication to be captured (Rojas & Sanahuja, 2011) and created an opportunity for the researcher to ask further questions about this during part two (Henry & Fetters, 2012). It also provided participants with an opportunity to co-create research data.

Part Two

Part two of the research offered participants an opportunity to make sense of the experiences generated in part one through the use of IPR (Larsen & Flesaker, 2008). Previous studies have shown that staff can find the reflective process of IPR particularly helpful when thinking about their own clinical practice and can support the meaning making process (Haines, 2017).

After completion of part 1, the researcher reviewed videos at least twice to become familiar with the data and to identify key aspects of the conversation to explore further, particularly paying attention to interpersonal aspects and non-verbal communication (Cashwell, 1994). During part 2, the researcher reviewed pre-selected sections of the video back with individual participants. It was not possible to watch the full videos due to time restrictions.

Semi-structured interviews (Appendix H) were used to explore individual experiences. It can be common for others to speak on behalf of PWLD and influence sense making using their own interpretations (Haines, 2017; Ware, 2004). Therefore, participants who participated as a pair during part 1, were interviewed individually in part 2 to reduce the potential for social desirability. Shared control of pausing the video was offered to support the co-creative element of the research and to follow steps indicated as part of IPR (Cashwell, 1994; Larsen et al., 2019). Only two participants took control of pausing the video; one PWLD and one support worker. Pausing the video allowed deeper exploration of certain sections to support sense making for all participants. It reduced the potential for inequality and a shared experience of both participants and researcher trying to sense make at the same time.

To enhance accessibility of IPR and aide recall for people with potential cognitive differences (memory retention), it is recommended that interviews should be conducted as close to the event itself with some suggesting a maximum of 48 hours (Elliott, 1986; Rennie, 1990). The practicalities of this research meant that a maximum of one week was given to interview participants after the initial experience. This was reliant on availability, time needed for the video to be reviewed by the researcher prior to part two, availability of recording equipment and a private space to conduct interviews. Unfortunately, due to sickness, one participant exceeded the 1 week gap.

A strength of the current research design is the multiple perspective approach to analysis. Unlike more traditional IPA approaches, the current study created new experiences to explore, as opposed to relying on memories which can be difficult for some PWLD (Vicari et al., 2016). Being present for the initial experience and reviewing the videos with participants gave powerful insight into the level of shared understanding surrounding non-verbal communication and how this was used to negotiate conversations as well as how power was shared between individuals (Rojas & Sanahuja, 2011). Without the video, there would have been no awareness of any non-verbal gestures being used as a form of communication. This would have limited understanding and the level of interpretation that could be made. Whilst the research focussed on a sensitive topic, it reflected a naturalistic scenario as support workers are often the people who have to navigate similar conversations as part of their role.

Analysis

Data analysis required meaning to be created from the participant's meanings and was influenced by both my own, and wider supervisory team's experiences and knowledge, as well as individual stakes in the research. My aim was to highlight the ways in which interactions within contexts may help or hinder sexual self-determination for PWLD. Unlike more traditional IPA research, this study explored the same phenomena from multiple perspectives (Larkin et al., 2019). This created opportunities to reflect on the similarities or differences between themes whilst having the potential to influence clinical practice. Table 2 provides a step by step process of data analysis, as outlined by Smith et al. (2022).

Table 2. *Analysis Framework for Interpretative Phenomenological Analysis (Smith et al., 2022)*

Step	Aims	Implementation
1. Reading and re-reading	To immerse oneself in original data and ensure participant is the focus.	Audio recordings were listened to whilst reading transcripts. Transcripts were initially read at least twice.
2. Exploratory noting	To examine content and language, noting anything of interest. To gain growing familiarity with data. Start to see ways in which individuals talk, understand and think about the experience.	Exploratory notes were made in the margin of printed transcripts [Appendix I].
3. Constructing experiential statements	To consolidate researcher's thoughts. Shift to working with exploratory notes, rather than the transcript itself.	Exploratory notes were used as basis for creating experiential statements.
4. Searching for connections across experiential statements	To map how experiential statements fit together. Some experiential statements may be disregarded at this stage.	Experiential statements were printed and cut out. Statements were grouped together [Appendix J].
5. Naming the personal experiential themes (PETS) and consolidating and organising them in a table	Give a title to describe characteristics of the PETS.	I created titles for PETs which were refined through peer supervision.
6. Continuing the individual analysis of other cases	Moving onto the next transcript. Caution must be exerted, not to repeat ideas.	The same process was repeated for each participant.
7. Working with PETS to develop group experiential themes (GETS) across cases	Looking for patterns of similarity or difference across PETS in order to generate GETS. Aim is to highlight shared and unique features of the experience, not to identify a group 'norm'.	PETs were printed and cut up to look for unique and shared features of participant experiences.

REFLECTION

The topic of the study led to participants positioning me in a position of trust and expertise, someone who they believed could offer immediate support and guidance, even for participants who withdrew. This was also experienced by Martino (2022) who was placed into a role of “expert”. Similarly, the level of enthusiasm for participation was, at times, greater from staff perspectives, even family perspectives. This provided evidence that the research is needed. People wanted direct answers to support them navigating the area which placed me in an ethically challenging situation. Whilst my role was researcher, I found it difficult to separate the clinician part of me. This contributed to a pull to offer help and support which I believed would contribute to enhancing sexual autonomy for PWLD and reduce anxieties for staff. However, this would have been unethical in the context. I therefore provided signposting information and offered the opportunity to receive feedback upon completion of the project. This was warmly received and provided an anchor for me throughout the process. When I struggled with motivation, or lacked focus, I could always come back to the reason I was doing the research and it spurred me on.

Chapter 3: Results

The following chapter presents the results of the study. The structure of this chapter aims to offer insight into the sense making process from multiple perspectives.

Pen portraits for each participant will situate them within their context and the overall sample. Age ranges are provided for each participant and five of the six participants were white. Individual analyses will provide an opportunity to share in-depth and unique experiences of negotiating opportunities to access relationships and intimacy, and sense making surrounding this. Individual analyses will include Personal Experiential Themes (PETs) and sub-themes that emerged from the data. A further dyadic analysis will be provided for each pair. This will be followed by a group analysis for all participants to explore any shared, or distinct, group experiential themes (GETs). Quotes from participants are included throughout to ground the themes in the data.

During the interviews, participants shared different yet intersecting ways in which they perceived themselves and others to be vulnerable: gender, role in society and disability. The concept of intersectionality will be explored further in chapter 4, as a way of understanding how differing factors come together to increase the perception of sexual vulnerability for PWLD. Kimberle Crenshaw (1989, 1991) discussed the ways in which different aspects of inequality and marginalisation, such as race and gender, can come together to compound one another (Crenshaw, 1991). She particularly focussed on the tendency to focus on either race or gender in legal cases which failed to fully capture the experiences of black women. Crenshaw argues that human experiences need to be understood by attending to individual identities, not as people within homogenous groups. Davis (2008, p.68) also offers a definition of intersectionality and is applicable to participants in this research:

> The interaction between gender, race, and other categories of social difference in individual lives, social practices, institutional arrangements, and cultural ideologies and the outcomes of these interactions in terms of power.

Robbie

Robbie is a white British male in his early twenties. He lives in his own flat in supported accommodation and is proud of his living space. He receives minimal support and is independent with most of his daily living tasks: cleaning, shopping, cooking and travelling to the local area. Robbie regularly sees his parents, experiencing them as supportive and protective in one sense but overly controlling and restrictive in another.

Robbie supported the practical set up of the research; plugging in the equipment and helping decide where to position himself, his support worker and the laptop. He had given consideration about how to proceed with part 1 of the research, initially deciding that he would have the conversation whilst doing some ironing. He talked through his decision making, explaining that he would feel more comfortable talking about relationships and intimacy whilst doing something else, rather than it being a direct and potentially embarrassing conversation. However, on the day he decided against this, choosing to sit down and have a focussed conversation instead.

Robbie was eager to participate in the research because having a relationship and engaging in sexual decision making is an important area of life for him, albeit confusing and restricted; a source of ongoing frustration. The urgency with which he spoke made me wonder whether this research offered a rare opportunity for him to talk about relationships and intimacy. It was clear from speaking to Robbie that he was keen to have a girlfriend but that he also experienced many barriers to achieving this.

Frustration in Being Powerless

Robbie shared a real sense of feeling trapped and stuck in his current context which included frustrations about his learning disability, particularly how it can limit his understanding of social situations, and how this contributed to a reliance on others to safeguard him:

> When he pulls me back it means that I’m standing there and I’m far too close to her…so he has to pull me back. So when he gives me that signal that’s just to warn me…if he didn’t – if it were a girl…if he didn’t do that…then I would be all over her. I would be literally…like that constantly. (lines 182-200)

When Robbie describes having little choice and control over relationships and sexual decision making, he does so in a way that communicates frustration and powerlessness. His repetition in the following quote sounds almost desperate, like he is suffocating from all the rules and restrictions surrounding him which are preventing him from having the freedom to explore sex and relationships, “I can’t, I’m not able – I can’t do owt” (line 248). Using “able” communicates a belief that he lacks both power and opportunities to employ self-determination in this situation.

Whilst he describes being unable to talk to women, Robbie's repeated references to rules suggests he does not lack necessary skills but lacks opportunities. Social connection is important to Robbie as is highlighted in the following quote but he is not allowed to do this without additional support which limits this area of his life:

> And it, it, it hurts sometimes that I can't go out. But I, I do go out a lotta times, you know, I do…but when I see people that I know…the problem is that I can't speak sometimes…Well, I can speak…you know, I can speak and I'm very, ver – very chatting so and so but every time I see a girl it – I don't really wanna be speaking. .. Difference is if I speak to a woman on the street…then I wouldn't do – I wouldn't, you know, speak but it's just like, oh right, oh no, no, I can't… (lines 333-347)

Robbie clearly describes his frustration regarding the rigidity and relentless nature of the rules that have been implemented for him:

> What my mum went to do with [support staff] is to put the rules in to keep me safe. But then what actually happened is it were getting far too much, far too much. From then on it were a constant…so I'm not gonna do owt anyways. (lines 243-247)

He describes a limited understanding of why these rules (to stay away from strangers and unknown women), have been introduced "[mum] thinks I'm probably unsafe…because I'm vulnerable and they're not" (lines 275-277). He speaks about his own level of vulnerability in comparison with others but does not attribute it to any aspect of his learning disability, "My understanding is because – my understanding is that if I was out with somebody and they wasn't [vulnerable] they would take advantage of that"(lines 284-289). Robbie's sense of vulnerability has been internalised, likely through the narrative surrounding him which is evidenced in his difficulties explaining why he is vulnerable and how others may take advantage of him. He struggled to think of examples when others have taken advantage which again communicates his limited understanding of risk and vulnerability, "…just trying to think who…probably…who were it now? Er…er…who took advantage…I can't remember" (lines 302-303).

Robbie wants freedom but a combination of limited experiences of collaborative decision making and difficulties understanding the perspectives of others meant he is in a confused and helpless position:

> I tried to disagree in past, saying no, it's a completely different, it's my life. If I wanna meet this person and she wants to meet me, then there's no trouble. But when my dad says – when my dad said, erm, tried to have you know, relationship in the past and everything like that, but he kinda did say, oh like when people talk about [familiar female] it makes me even more aggressive...more don't wanna even talk. (lines 1384-1390)

In this quote, Robbie communicates desperation to have autonomy over sexual decisions but experiences hopelessness which means he gives up. There is evidence here that Robbie has attempted to experience relationships in the past but has been unsuccessful. Here, Robbie understands that his Dad uses the outcomes of these past experiences to inform his own decision making, to keep Robbie away from particular women with the aim of protecting both Robbie and the women. Robbie finds it difficult to reflect on the outcomes of his past decisions and how these could influence his future decisions, therefore experiences the rules as restrictive and unfair.

At the Crossroads of Living with a Learning Disability

Robbie's experiences have contributed to an internalised belief that PWLD are vulnerable and will be taken advantage of, as has been evidenced in his earlier quotes. Despite not explicitly linking his vulnerability to his learning disability, the sense he makes of rules and restrictions link to a sense of being "different" which he equates to being vulnerable. Robbie is also confused about the role of support workers, they can provide safety and protection but they can also take advantage and be overly controlling. Robbie seems torn between a life of greater control, autonomy and potentially less support, or a heavily controlled, restricted but safe life.

Torn Between Two Worlds. Robbie highlights his strengths and abilities, intentionally separating himself from other PWLD. This is understood in the context of his experiences of living with a learning disability as being largely negative; either being taken advantage of by others or being controlled due to people's perception of his vulnerability. During the research he acknowledged some of his difficulties "When I do get close to people...I don't know my own space..." (lines 11-13) but did not explicitly link these to risk or his own vulnerability. In situations involving young females, Robbie's behaviour was driven by decisions he made when "anxious": Interviewer – "And what, what helps you make that decision that you're too close?", Robbie – "Erm, possibly when I'm more anxious" (lines 59-61).

Here, Robbie uses the word “anxious” to describe his feelings but it is more likely that his experience is linked to being sexually aroused but lacks the language to describe this. He is also likely to be embarrassed talking about this with a young female.

When seeking support for sex and relationships, Robbie shares an assumption that his friends with learning disabilities will have limited, if any, sexual knowledge and are therefore unable to help, “If I spoke about it with my friends, I don’t think they would have no understanding of it. They would just say the word sex.” (lines 629-630). He describes these friends in an infantilising way, alluding to a degree of immaturity among them which is likely to be an internalised view of himself. He contrasts them with staff, who he believes are better able to support with sex and relationships, “if I talk about it with staff…they’re more mature, they’re more understanding” (line 644). Here, Robbie associates “maturity” with a perception of being developed and more able, therefore having more opportunities to make autonomous decisions. Robbie’s desire to align with people he believes are “mature” centres around an expectation that this would create new opportunities for autonomy and independence.

Whilst Robbie separates himself from other PWLD, regarding himself as more mature, he values spaces and events organised for PWLD as he feels more able to make friends in these contexts, “It can be quite difficult…and I do, I do make friends from like [organisation], I do do a lot of that” (lines 517-520). This highlights a recognition that he is “different” and struggles to connect with others who do not have a learning disability, something he wants to do.

Torn Between Potential Rejection or Safety and Restriction. “So then you miss your chances or don’t talk because if I talk then I’m just gonna get a horrible reaction back so I never talk.” (lines 1196-1197)

Robbie shares his preference of having a girlfriend without a learning disability “It makes the decision that I would go for the none one” (line 1293). This is contextualised as he goes on to explain his perception of dating someone with a learning disability, that it would be a limited and supervised relationship “erm, I think it’s the like they can’t do this or can’t do that” (line 1305). There is also an underlying perception of not being allowed to date someone else with a learning disability after previous negative experiences. Robbie had previously encountered frightening reactions from his parents when he engaged in what seems to be exploratory sexual behaviour with another female with a learning disability. He described a situation where sexual behaviour escalated, driven by sexual arousal and peer influence:

> ...It were building up, building up from the something going well and then probably one of my friends said, one of my friends said about, erm, about what has he, what has he been - what has he been doing. And then after that my mum was so flaming mad that I probably went to, erm – my mum dragged me outta the house. (lines 742-747)

His vague description of events communicates a belief that he should not be talking about this [sex] or it could be evidence of a knowledge gap, lacking the language to fully explain the situation and subsequent consequences or potential risks. This example had negative consequences for Robbie but it is uncertain if he fully understands the reasons for his mum's anger. He attributes her negative reaction as being linked to him and his girlfriend both having a learning disability and lacking sexual knowledge, not because they were underage or that he likely held more power as a male in the relationship "I didn't realise what I were doing and neither did she" (lines 736-737). Robbie did not explain if his friend shared information regarding laws and legislations surrounding sex and sexual behaviour such as consent which would have been important information given his age at the time (under 16). This again highlights a potential knowledge gap for Robbie.

The emotional impact of this experience has contributed to Robbie desperately wanting to avoid similar situations so he chooses to avoid speaking to females: "It got to a stage where I couldn't, like never again am I doing this, right, I'm not gonna even speak to a girl again. Er, it were hor – horrifying, let's just put it that way." (lines 780-784)

Despite stating an initial preference for dating someone without a learning disability because of the freedom this would involve, Robbie alludes to an underlying fear of being 'discovered' for having a learning disability when forming relationships, before being rejected or humiliated, "…erm, probably I'm too scared of what they're gonna say…they might say "oh, go away" (lines 569-574). Whilst Robbie fears rejection, he wants access to a relationship with someone without a learning disability as this would mean he has some autonomy over it. However, regardless of the decision Robbie would make, to have a girlfriend with or without a learning disability, he remains stuck in a powerless position whereby others make the decisions for him. It would either be to choose a girlfriend who has a learning disability and be prevented from accessing the relationship, or choose a girlfriend without a learning disability and experience rejection.

Being Denied Access to Sex and Relationships

Relying on Others Limits Opportunities. Robbie seemed conflicted about where he could seek support, initially stating "don't talk about it with my mum. And I don't talk about it with my dad. Do talk about it here because they're not here" (lines 220-223) but later said that he could ask "probably me – my mum or support workers" (line 1255). Whilst contradictory, the first statement refers to sex whereas the second refers to dating which indicates the level of depth he is comfortable sharing with his parents. Despite knowing he can seek staff support, he explains that the support he wants may not always be available to him. This is partly due to staff shift patterns, describing how difficult this can be to tolerate. He lacks alternative support such as friends or accessible information on the internet so feels he has no choice but to wait for an appropriate member of staff to come on shift. This communicates dependence on particular staff members which could impact staff well-being or increase pressure to be available for Robbie. Not having immediate access to information leads to a build of up confusion and anxiety for Robbie which negatively impacts his mental health:

> It depends what they've said and it depends whether the next person comes in on shift and it's that person what I wanna talk to about it. But then….I forget it two days later…but then I end up writing it down and it freaks me out from having two – leaving it two days later. (lines 381 – 390)

Robbie demonstrates sexual curiosity but the depth at which he feels he can explore this is determined by others. He shared a situation where he was in a sex shop with his dad. This was Robbie's first experience of seeing a sex toy and wanted to know more about it " 'Oh dad, what's that?' And me dad went, 'It's a sex toy'... 'can I buy it?' He went, 'no' " (lines 1500-1504). This experience allowed him to consolidate and contextualise a previous conversation with a friend "...from not knowing what it is, from then showing me on WhatsApp...and not really believing him that he had the sex toy, from then going to the place and actually seeing the sex toy" (lines 1518-1522). This is a striking example of the power of experiential learning for Robbie. Sharing this during his interview communicates a sense of safety and empowerment as he uses the space to give more detail about a topic he's usually prevented from accessing. He evidences this further as he goes on to provide specific details about the types of sex toys he saw, "They had different ones...small ones, different ones..." (lines 1533-1534). On reflection, there is a slight power shift here as Robbie takes on the role of expert, sharing his knowledge with me so I can better understand his experience. There is a level of excitement and eagerness to share this new found knowledge with me in the absence of shame or embarrassment. The response Robbie received from his dad feeds the narrative of PWLD being asexual and devoid of sexual urges and normalises a tendency to deny PWLD the opportunities to learn, withholding explanations. It also emphasises the discomfort experienced when talking about sex. Robbie's opportunities to expand his knowledge are limited by his dad's responses: Robbie – "So I picked it up, I went, "Dad, what's this?" He went, "Er, it's, just a toy", "Interviewer – "And was that end of conversation"?, Robbie – "That was the end of the conversation then". (lines 1565-1568).

Relying on Limited Available Information and Being Unable to Fill Knowledge Gaps. Robbie describes his "anxiety" in more detail, that being close to someone changes the feelings in his body, "So when it's getting close, close, close...that's fine but if it's someone that I know...really well...then it's alright...er, f-feelings in my body and what's going to happen" (lines 65-74). Robbie terms this as "anxiety" which evidences his limited language surrounding sex and relationships. His "anxiety" is better understood in this context as sexual arousal. Robbie's description of becoming sexually aroused is centred in negative consequences, linking to shame and embarrassment and experiencing it as "nerve-wracking...scary...and not very great" (lines 82-86), communicating that it is bad and should be stopped. His reliance on staff to intervene in situations where he lacks awareness surrounding the risks he may pose to others demonstrates knowledge gaps surrounding risks to others, and limitations in his ability to safeguard himself. He gives further evidence for this when he describes a risky situation involving social media, "I had a problem with [peer] with that social media incident...There was no staff there at the time to keep an eye on me" (lines 496-501).

Felicity

Felicity is a British female and is three years younger than Robbie. She is a support worker for PWLD, supporting Robbie on an infrequent basis:

> Robbie is older than me…so I don't know, I think maybe it sometimes feels a bit awkward because it's like the idea of explaining it to Robbie who's older than me, also he's a boy, so sometimes it's easier for males to talk about males to talk with males, isn't it…? (lines 38-53)

Throughout Felicity's account, she makes sense of her difficulties relating to Robbie by focusing on their differences: gender and experiences of living with a learning disability. These factors contribute to a lack of confidence to support

Robbie with sex and relationships and an increase of her own perceived vulnerability. Whilst they are similar in age, Felicity continues to focus on their differences, reflecting an "us" and "them" attitude, presenting herself as more able and better placed to understand the world around her as she does not have a learning disability.

Felicity values her job and wants to do it well but her young age limits both the life, and work experience she will have had. She shared little information about her personal life so this remains unknown. She demonstrates an awareness of the rights of PWLD to make their own decisions in life but struggles to balance this with her own sense of vulnerability when working with Robbie. Felicity participated in the research because Robbie wanted to use his support hours for it. She lacked the confidence or bravery to disagree with him because she feared potential negative consequences which could involve impacting her employment. There is another possibility that by disagreeing, or choosing not to participate, she would be denying Robbie of his right to choose how to use his support hours thus restricting his human rights and behaving unethically.

The Fear of Being Exposed and Vulnerable

Intersecting Layers of Vulnerability. Felicity describes her own vulnerability when working with Robbie, "As a young woman you feel a bit, you know, a bit uncomfortable" (lines 41-42), linking it specifically to being a woman, "Yeah, yeah, Robbie can be quite open about how he's feeling about, erm, girls or frustrations he has with the situation surrounding women or anything like that" (lines 80-82). The interchangeable use of "girls" and "women" suggests different experiences for Robbie. Felicity describes two contrasting situations for Robbie, one where he experienced "natural" feelings in response to being in the presence of "girls", and another where access to "girls" and relationships are blocked by what is assumed to be older "women". From Felicity's descriptions, it would seem that she is in the former category, one that may be at risk of Robbie's advances due to her age.

Felicity has an underlying fear of confusing Robbie or worries that he may misinterpret information such as her sending him "signals", which would increase her own vulnerability. This fear drives Felicity's decisions to block, or avoid discussions about sex and relationships, instead signposting Robbie to male members of staff who are less vulnerable than herself:

> But if he's asking me kind of questions that I think, actually you're probably best discussing this with somebody you know, erm, probably like a man to be honest,

> I’ll just say, “Oh well…” I’ll say, “It’s probably not best for me and you to talk about that, is it?” And he’ll kind of mumble, “No.” So it’s like he knows (lines 823-833).

Despite explaining that Robbie is older, Felicity describes him as a “boy” in the above quote which fits with the ongoing discourse of PWLD being perceived as eternal children. Using this term reveals an underlying belief that Robbie is naïve with regards to life experiences, particularly those involving sex and relationships and communicates her own perception of him as “childlike”. It also places her in a powerful position, something she is unlikely to recognise due to focusing on her own vulnerability as a young woman.

Felicity adds another layer of vulnerability, of being a staff member:

> As staff you feel a bit like, well, do I feel comfortable perhaps going in there on my own…it does make you a little bit wary sometimes of kind of the situations that you put yourself in …with Robbie (lines 469-475).

She fears Robbie misinterpreting her and consequently losing her job because of his tendency to report young, female support workers to management when confused and upset, “…there have been, erm, incidents with Robbie and other young female staff members, so for me talking about sex with Robbie is something that I would avoid. Just to avoid any sort of, you know, miscommunication” (lines 63-69). Whilst her sense of vulnerability centres around being female, there is also the responsibility and expectation that she should be able to offer information about a number of life situations and the risk this brings such as being misinterpreted.

Felicity repeatedly explains that sex and relationships “…can be quite a difficult one to navigate” (line 508) which links to a combination of lacking clear guidance whilst having a level of responsibility if something went “wrong”. She also fears making mistakes, “you want to make sure that you’re safe and that other staff are safe” (line 500). Felicity tries to mitigate any risk by avoiding discussions about sex and relationships to limit potential misunderstandings. When avoidance is not an option, she will often signpost Robbie to male members of staff who she believes are better placed to support him due to shared experiences of being male. Here, she recognises his right to a sex life and is facilitating this by signposting to others whilst protecting herself, “I’ll speak about relationships with Robbie because that, erm, feels like an appropriate topic, but I do avoid speaking about anything sexual with Robbie” (lines 251-255). This clear distinction between “appropriate” topics of conversation is an attempt to protect herself from being witness to Robbie’s potential for sexual arousal when discussing sex. This reflects either discomfort or a fear of him making sexual advances in the context of being sexually aroused.

Felicity’s uncertainty and anxiety regarding Robbie’s understanding and interpretation of information results in her needing him to understand and agree with her perspective, regarding it as “right” and as a way to safeguard herself “it’s very difficult to kind of explain things from a different perspective and have him understand it” (lines 244-245). Felicity seeks certainty and clarity, “my preferred technique obviously is to relay information back to Robbie” (lines 428-432) in an otherwise grey and confusing area of her role “we’ve kind of had to learn as we, as we go”(line 458). This technique reassures Felicity as it allows her to fact check with Robbie, to ensure she has understood him correctly and that there are no errors on her part. This places her in a less vulnerable position professionally.

Lacking Trust and Having a False Sense of Security. Felicity experiences feelings of confusion and frustration as she struggles to grasp the stark contrast in Robbie’s support needs, in that he needs close supervision when socialising with women, but not in other aspects of his life, “I think it’s frustrating because you do see how independent he is” (lines 120-121). She shares how she felt Robbie was being dishonest about some of his difficulties and how this contributes to her struggling to trust him, “But then also when he says he doesn’t know what he’s saying, I would personally – Robbie is very clever. He’s very intelligent and he’s very independent, so arguably I think he does know what messages he’s sending” (lines 214-219).

Having a Job To Do

Putting Your Values to One Side. Struggling to manage moral dilemmas was evident for Felicity when she explained:

> You’ve still got to do your job and such and…you know, you can't treat people any differently and things like that, and you wouldn’t want to anyway. Erm, it’s just one of the things you’ve got to do, so you just…you just do it, you just get on with it (lines 513-519).

She finds that supporting Robbie can be “a bit conflicting for me, because it’s kind of as – just kind of as a young woman…But then kind of as a support worker, having to understand that obviously Robbie has learning disabilities” (lines 35-49). In the following quote Felicity “others” Robbie by using “we”, suggesting that other staff, and myself, all perceive situations in the same way and therefore establishes a “correct” perception “he’s not gonna perceive it the same way that we do…"(lines 51-52). This assumption offers safety in the sense of not being alone in her perception of this.

Recognising Choice but Safeguarding Decisions. Felicity shares a need to balance Robbie's right for sexual self-determination with protecting him from potential exploitation, "if he's making those decisions and there are people making sure he's safe" (lines 715 – 717). During their conversation, Robbie shared his first experience of visiting a strip club whilst on holiday with male staff which Felicity regards as "quite typical I think of a [states age – early 20s] year old" (line 736), which is a validating and normalising statement. However, this validation contributes to her internal conflict as she had previously commented on Robbie's tendency to objectify women and regard them as possessions:

> Erm, it's his language for me. So when he says I would keep both of them... So saying I would keep both of them as opposed to kind of perhaps approach it like you and I would if, you know, us understanding that it's two people that make the decision to want a relationship. (lines 590-591)

She uses the research as an opportunity to ensure that it was Robbie's decision, asking him "who made the decision? You know, was it you or your support worker?" (lines 743-745). She feels the need to check that he has not been pressured into decisions "just checking that he's made that decision and that it wasn't that someone had kind of led him into it" (line 750).

Felicity shares an underlying, gendered stereotype as well as an infantilising attitude which is likely to influence her engagement with him, "he is a [states age, early 20s] year old boy, he is gonna be interested in things like…sex and women"(lines 704-708). Despite having a clear yet unspoken disagreement with Robbie's decisions, Felicity recognises his right to make his own decisions, encouraging autonomy and self-determination "even the support worker in me it's like, well, it's not for us to say what he does on his holidays…as long as he's safe" (lines 762-765).

Avoidance Prevents Opportunities for Growth. During part 1, Robbie dominated much of the conversation, using the space to reflect on previous, negative experiences in the context of sex and relationships whereas Felicity maintained a passive stance, contributing minimally to the conversation and reading the prompt cards to guide the conversation. Robbie speaks at length about being restricted by others, and his difficulties accessing relationships with females. His speech is quick and demonstrates enthusiasm for the topic, although mumbling through sections he feels uncomfortable with: talking about "sex", or during situations he felt vulnerable in, “And I just thought – I thought to myself, there’s summit not quite right. And there’s a group of lads saying hi and being all weird, not being great” (lines 1451-1455). This is an example of him feeling at risk due to the presence of unknown men who do not have a learning disability and Robbie struggling to make sense of the social context. His mumbling and increased rate of speech mirrored the anxiety he likely felt at the time.

Felicity utilised the prompt cards as a way to scaffold the conversation but did not elaborate much beyond these, only to ensure Robbie’s safety in the context of having made sexual decisions. She speaks quietly throughout the conversation but uses nodding and utterances to communicate that she was listening. Her posture avoided direct contact with Robbie, sitting on an angle and giving minimal eye contact. This communicates her sense of vulnerability and discomfort.

Finding Ways to Survive in Dangerous Territory

Felicity and Robbie reveal shared experiences of feeling awkward during part 1, particularly discussing sex. Their discomfort is demonstrated through intonation and clarity of speech; both mumbling the word “sex”. There is also a shared experience of confusion and uncertainty, both wanting guidance but being unsure of where to access this. This contributes to a sense of powerlessness for them both; Felicity being powerless regarding how she can safely guide the conversation to minimise her own vulnerability, and Robbie’s powerlessness regarding having his voice heard and gaining access to the world of sex and relationships.

Both fear the potential negative consequences surrounding “sex”, yet their individual experiences were distinct. Felicity’s fear links to Robbie misunderstanding her during conversations about sex and potentially putting her at risk, professionally and personally. Robbie’s fear relates to misreading situations, particularly the intentions of others, and experiencing negative reactions to his attempts to seek intimacy. Whilst distinct, their shared experiences of fear link to a perceived lack of control and powerlessness regarding potential loss of something important to them; Felicity’s job and having a sexual relationship for Robbie.

Unlike Robbie, Felicity demonstrates her ability to maintain control despite feeling vulnerable. Her decisions are driven by a need for survival, professionally and personally, so she chooses to take control and avoid conversations which may increase her vulnerability and ensures she retains her job. The decision to have the researcher remain in the room for part 1 lay with Felicity, “you know when you said before, you said do you want me to be in the room and I said yes, that’s because we were having the conversation about sex and relationships” (lines 313-317) meaning she could safeguard herself. Robbie however, is unable to implement survival strategies which allow him to engage meaningfully in all aspects of life. He is unlikely to gain control, instead being controlled by others.

Whilst Felicity perceives Robbie's difficulties as increasing his risk to others, Robbie perceives them as exacerbating his own vulnerability and the potential for people to take advantage of him. Here, I was struck by the need for there to be 'one truth' and one, almost justified, experience of vulnerability. Each find it hard to empathise with the other's perspective. This extends to how both family and staff perceive Robbie's vulnerability (and his risk to others), using it to control and restrict his life as a way to safeguard him. These responses result in Robbie being unable to access important areas of life: sex and relationships. His values remain unheard and there is an expectation that he should subscribe to the perspectives of powerful others in the system (staff and parents) to maintain the safety of himself and young women. Disagreeing with those in his support network places him in a vulnerable position of a different sort, one that involves greater restriction and control:

> Interviewer - Have you disagreed with your mum in the past?
>
> Robbie - Tried to, she wouldn't have it. I've even tried, right, I'm not gonna come to your house. And then she goes and dials (name) because there's a major big problem about it (lines 1345-1350).

Amelia

Amelia is a British female in her early twenties. She attends a work placement at an organisation for PWLD and chose to do the research there. Amelia lives in her own accommodation, receiving no staff support.

Amelia chose to participate in the research as it was a new experience for her. Staff were keen for her to participate as there were historical concerns surrounding her sexual vulnerability after being in abusive relationships and being exploited through online dating. A lot of work has been done with Amelia to understand the dangers of social media but current understanding surrounding risk and vulnerability seemed lacking. It is clear that Amelia values her work placement, giving her purpose and offering comfort being surrounded by staff that she can seek support from in a contained environment.

Amelia came across as quite shy, often mumbling and being led by the staff member who participated in the research with her. I noticed she seemed more relaxed and vocal during the initial introduction to the research and during part two, speaking more and sharing her opinions. This led me to consider the power dynamic taking place between Amelia and Ivy, something which will be explored further.

Amelia is currently in a relationship at the time of the research, with someone else with a learning disability and whose parents offer support to the couple. Amelia struggles to talk to her mother about issues surrounding sex and relationships.

Needing the Joy of Feeling Loved and Cared For

"I were just hoping for, like, one day he'd love me" (line 283).

Amelia repeatedly shares her desire to feel loved. This contributed to her previously remaining in exploitative relationships in the hope boyfriends would love her, "…I stayed with the guy because I loved him, even though I knew he didn't love me" (lines 271-272). She understands this to mean she was worthless, therefore continued acquiescing, hoping she'd experience love. Her acquiescence extends to staff, being driven by a want to avoid negative consequences and a need to feel cared for, "I just agree with what people say" (line 196). It could be said that Amelia, like other PWLD, perceives herself as unequal in relationships, assuming a powerless role and feeling unable to make decisions for herself.

Amelia also speaks about disagreeing with staff opinions regarding relationships, stating, "I could, but I wouldn't" (line 182) because of anticipated negative consequences such as receiving "the look" from staff. She is unable to describe the "look" or explain what it means but she worries about the negative context surrounding it, “I don’t know…I haven’t actually seen it but obviously they – obviously, like, thingy cos they don’t want the look” (lines 230-232).

Amelia describes feeling happy when she feels loved and cared for by her current boyfriend: “cos I know that he loves me…coz he tells me enough every day…I feel, like, happy” (lines 593-598). This is a new experience for Amelia and she wants it to continue so continues doing what others want her to do, taking more of a passive role in her own life in order to feel loved and happy. If she disagrees, there is a risk that her happiness, and boyfriend, could be removed by people around her.

Amelia has a desire to avoid loneliness and a need to feel cared for. She describes her use of online dating as a way of connecting with others “obviously they’re my friends so I’m not at all. But I don’t really meet anyone online any more” (lines 70-72). She explains this as if social media is her only way of accessing potential partners, “…I don’t really meet anyone online anymore...cos I’m seeing somebody now” (lines 71-74). Through lived experience, she has learnt the dangers of online dating, “because obviously some boys aren’t who they say they are. Like me ex, he, he wa, he was who he said he wa but he was a knobhead as well” (lines 74-78.) She chooses to continue using it to maintain friendships, mainly with males but did not explicitly say this during her conversation with Ivy due to a fear of it being stopped. Amelia gets her self-worth and value through her relationships with males, either friendships or romantic relationships, and this is more important to her than prioritising her own needs or her own safety, “But obviously then we split up, which I thought was a good thing cos (sighs) I wouldn’t have to give me money away any more” (lines 274-276). Whilst Amelia recognises the positives of this relationship ending, the decision was not hers, “He ended things” (line 292).

Risking Shame in Talking About Sex and Relationships

Needing to Talk About Sex and Relationships but it is Taboo. There are limited opportunities for Amelia to seek guidance and support about sex, “I’ve never talked about sex with anyone before” (line 416). She describes speaking to professionals in the context of reactive risk assessment and management interventions which came from someone external to her work placement “well, I had a lady come in who I used to talk about it with. But she were only person that I talked about sex with” (lines 420 -423). This, combined with a lack of normalised, everyday conversation surrounding sex and relationships and has created a belief that it should not be spoken about, it is taboo. Amelia is clear about her decision not to talk to family about sex and relationships. She does not mention speaking to her current boyfriend either which links with Amelia’s current view regarding sex, “it is important to me in a way but it’s not as well” (lines 402-404). She does not specify why they do not talk about it but it demonstrates some autonomy and self-determination. There is a presence of choice here and Amelia is able to communicate her views, something she was unable to do in previous relationships.

Despite having limited opportunities to talk about sex and relationships, Amelia shares a belief that staff are better positioned to offer helpful advice and to keep her safe in relationships, “[staff] been there when I’ve been so low and I like to know what people think before I think about getting into a relationship” (lines 167-169). She has a clear sense of who else she could talk to, “I talk to my friend (name) about it” (line 320), valuing the opportunity for peer support.

Struggling to be Honest About What is Important. Amelia shared uncertainty about how to navigate areas of life relating to having sex and having children, “And how would – how would you know? How would you decide [to have children]?” (Interviewer, lines 653-654) “Don’t know” (Amelia, lines 653-655). She describes a negative skew in the information she receives from others, especially as her sister has a young child “cos people say babies are hard work which I already know they are”(lines 657-658), and struggles to identify any positives. When asked if there were any good things about having children, Amelia could not provide any, “Don’t know” (line 667). There is a sense of frustration captured in this statement, an awareness that she is being kept from a balanced view of having children. In the second part of the interview I felt like Amelia being able to talk about sex and relationships with me was an opportunity for her to be honest about what is important to her, “I feel like one day I would want me own children” (line 650). She did not share this during her conversation with Ivy which means it is either a topic that is either not spoken about, or is discouraged but is important to her. There is a fluid nature to Amelia’s speech during her interview, a wondering out loud, rather than purely acquiescing with me or heavily monitoring her true thoughts and feelings. This was evidenced in the contrasting information she shares in part 1 and part 2.

Ivy

Ivy is a middle aged woman who holding a senior position in the organisation Amelia works in. She has worked with Amelia for several years and is aware of her difficult history within romantic relationships, where Amelia has been taken advantage of and exploited. Ivy continues to be impacted by the emotional content of what Amelia shares, becoming quiet and tearful at times. She communicates a strong urge to protect her from repeated experiences of abuse and exploitation which links to failing to protect her previously. Ivy communicates a desire to ‘get things right' both in terms of protecting other PWLD, and by ensuring she generates enough usable data for this research. It is difficult to get a sense of who Ivy is as she focusses more on Amelia and her experiences as opposed to reflecting on her own experiences and how this may influence her interactions and decisions with Amelia.

Anxiety About Navigating the Conversation

Ivy speaks in a vague and hesitant manner throughout her interview, repeatedly using the phrase "you know what I mean?", leaving sentences unfinished and checking things out with me "Does it make more sense now?" (line, 706). Whilst this makes it difficult to follow her flow and to step into her shoes, it provides evidence of her desire to protect Amelia and safeguard her information. There is a tentativeness in how she speaks and a need to know what Amelia has disclosed to others although this is not possible "I don't know if she's said in her [sessions] – cos I don't ask her" (lines 944-945). Ivy speaks openly about wanting Amelia to have taken control of the conversation, so she did not unintentionally put her in an uncomfortable position "that was going on for me…I knew what I wanted to say…but because of – of Amelia, and um, I didn't know how much she wanted to divulge" (lines 728-730). It is important for Ivy to highlight how staff can be impacted by the experiences of PWLD, "I'm trauma-ed (laughs), so I don't know what she's— You know what I mean?" (lines 984-985). Her vague descriptions combined with periods of laughter throughout her interview communicate discomfort and uncertainty, using it as a protective strategy.

Lacking Confidence and Perceived Incompetency

Ivy enters the conversation feeling unprepared and out of her depth, putting pressure on herself and Amelia to "perform", "I really had not had a chance to think about it…I'd think, oh my days, was there something else I was supposed to ask?" (lines 1824-1828). When watching the video I notice Ivy repeatedly checking the prompt cards which suggests a level of reliance on them to scaffold the unfamiliar and anxiety provoking conversation.

Ivy has an expectation that she should know how facilitate a conversation about sex and relationships, "It's hard sometimes to think of the qu – … how can I word this now" (lines 715-720), feeling that she should be able to provide enough quality data for the research, "if I prompted a lot more, yeah? She'd say. But that's not good for your (laughs) your research" (lines 931-936). This leads to her focussing on Amelia's "performance" more than reflecting on her own experiences of the conversation, "how long did she do?" (line 1741). This connects to a fear of being judged if Amelia "performs" inadequately. She is uncomfortable reflecting on her role in the conversation with Amelia, often taking control and redirecting the conversation, allowing her to avoid being exposed to what she may have done “wrong”. Laughter is present again as she tries to hide her discomfort, “Is there anything that you noticed in watching yourself back in how you navigated the conversation?” (Interviewer, lines 1863-1864), “Hmm, I don’t know. I don’t (laughs softly)” (Ivy, line 1865).

Ivy alludes to a level of vicarious trauma throughout her interview, “sometimes for staff, it’s a little bit difficult as well” (lines 1507-1508). She describes an urgency for external support to manage safeguarding concerns which had impacted Amelia’s mental health, “She says, “I’ve got so much in there,” and it was how it was making her feel…There’s no point looking after herself… It – it was all – honestly, it were just like – I’m like, no, we need – we need some help here” (lines 912-920). It is not just the unfamiliarity of having the conversation, but the potential of being emotionally impacted by it that contributed to Ivy’s anxiety and exacerbated underlying feelings of incompetence. Ivy’s explicit request for help suggests this is not something widely available to her and other staff which increases the pressure and burden to get things “right”. If not, she, and other staff are likely to be left alone with difficult feelings thus impacting their own mental well-being and sense of competence.

Being in the Spotlight

I was struck by Ivy’s discomfort surrounding the presence of myself and being video recorded, “it was really hard cos it – it – it didn’t feel as natural” (line 30). She repeatedly mentions the presence of the camera and feeling unable to speak freely, fearing negative consequences. She is particularly conscious about what hidden thoughts and feelings are revealed through her facial expressions, “I keep saying that half the time I need to fix me face and I need to fix me expressions coz I do give a lot away…if it’s somebody else looking on, you know what I mean?” (lines 839-841). This links to a fear of being judged and negatively evaluated in a context of wanting to get things right and “perform” well.

Ivy mentions numerous, unsuccessful attempts to engage Amelia in conversation and seeks reasons for this, to justify her perceived failure and to safeguard her professional role “and like you said, she weren’t well that day anyway” (line 548). Here, she draws me into her justification for Amelia’s “poor performance”, to share the burden and deflect blame away from herself.

Carrying the Weight of Responsibility to Protect Them

Struggling with the Shame of not Having Control and Responsibility. Ivy hopes that participating in the research will offer an opportunity to explore Amelia's current position surrounding sex and relationships. Taking part in the research gives Ivy an opportunity to explore some more anxiety provoking topics with Amelia but also leaves her with more questions and uncertainty, "I just wanted to hear how she you know, how Amelia thought and felt about that" (lines 1451-1456). This links with her need for control in order to protect and safeguard Amelia.

Ivy describes instances where she has been unable to control, and protect, PWLD which has left her with feelings of guilt and shame, especially considering her management position. Her management position assumes a responsibility, and ability, to safeguard PWLD from abuse and exploitation. A poignant moment for Ivy is reflecting on when Amelia did not disclose an abusive relationship to staff until much later, when her mental health had been significantly impacted. Amelia's withdrawal left Ivy feeling helpless. Her repetition in the following quote communicates disbelief and shame at failing to notice what was happening for Amelia:

> Interviewer – "…if something had happened and she wasn't able to say no or – would she would she be ab' – would she come to you and tell you?"
>
> Ivy – "she didn't"
>
> Interviewer – "right."
>
> Ivy – "she didn't"
>
> Interviewer – "yeah, gosh"
>
> Ivy – "she didn't. she – she really didn't" (lines 998-1008).

This helplessness is perpetuated when Amelia does not provide what Ivy believes to be "correct" answers to specific questions, "she didn't say that she could talk to the staff either. Hmm, yeah. So there's – there's still some work that needs to be done with her, really" (lines 976-980). Ivy communicates a need for Amelia to know how to access support, to ensure she does not suffer like she has previously. There is also a need for her to feel safe and protected which will make Ivy feel like she is doing her job well.

Ivy experiences powerlessness and fear about letting go of protective responsibility and giving it to others, "But, you know, if they've got parents and carers and – and stuff, the responsibility sort of, like, lies……you know, um, but for – for the majority, it – it's not an issue. It's not something that comes up often" (lines

1511-1517). Again, there is hesitancy in what Ivy says and she trails off, not finishing sentences which is likely driven by a fear of saying something wrong. In this quote she also shares a common perception, that PWLD are asexual and are disinterested in sex and relationships, as she specifies it is an uncommon issue. Sharing responsibility with others is particularly challenging for Ivy when parental decisions are in conflict with her own beliefs about what is right and safe for PWLD, "mum would phone and tell us stuff that wasn't you know, to protect so that she could still go and do what she was doing" (lines 626-629). She experiences helplessness because she feels a need to protect and prevent sexualised behaviours, but having no voice to do this "we had an experience and (gasps) you know, when you've got to phone the – the mum and…and – and it's, "Oh no, it's okay. You know, they've got prote…" and it were just so— Do – do you know what I mean?" (lines 1501-1506). Ivy's discomfort and underlying beliefs surrounding sex and PWLD are shared in this quote as she again, does not finish sentences and seeks reassurance that I understand, so she can avoid giving further details for fear of doing something wrong. It also seems as though Ivy is feeling unsafe and uncomfortable because she questions her own beliefs which are in direct contrast to those of parents.

Influencing People to Make 'Good' Decisions. Ivy finds it challenging to manage situations where she lacks control, or feels incompetent. Her desire to protect PWLD from harm is clearly communicated in her attempts to implicitly influence decisions specifically surrounding sex and relationships "we can't stop you, you can make choices, you can make decisions, but we can help support in thinking…in good decisions" (lines 584-588).

There is an unmistakable relaxation both in content of speech and body language when Ivy describes Amelia's current relationship status "I just love to see her when her face is relaxed" (line 1269). This perhaps links to her knowing Amelia's boyfriend and having some degree of control and supervision over the relationship. I wondered if her sense of comfort comes from knowing that preventative measures and restrictions can be implemented proactively rather than reactive strategies. When she mentions the relationships being "easy" (line 964) for Amelia, it is likely that it also makes her job easier as she has greater ability to protect, "the chappy that she's with now, she's um – cos it's all really, really above board and you know, um, easy for her" (lines 961-964). Ivy's use of "chappy" here suggests there are no concerns about the relationship and that he is a likeable man. The use of "chappy" in the context of learning disabilities however, also connotes a boyish perception, almost child-like, linking to the historical narrative of PWLD being eternal children.

When discussing having children in part 1, Ivy presents what she believes to be negative consequences of having children whilst neglecting any positives “she’s well aware that it’s not easy” (line 1442) which seems to be an attempt to influence any future decisions. Ivy reflects on the anxiety she experienced when other PWLD expressed interest in having children after receiving an education session “it’s quite frightening” (line 1475). Again, this links to wider beliefs that PWLD should be protected from having children, especially women.

Fear of Crossing the Line. The possibility of rupturing the relationship is at the forefront of Ivy’s mind when navigating this new topic, “it’s taken a long time for her to get that comfortable” (lines 33-34) and she fears being unable to protect Amelia, ultimately letting her down. Ivy is mindful about the delicate balance of giving control to Amelia but feeling a pressure to safely scaffold and guide the conversation “not sort of like overstepping the mark and stuff like that” (lines 1580-1581).

Treading on Eggshells to Avoid Doing Something Wrong

There is a shared sense of embarrassment and uncertainty during the conversation, neither wanting to take control. Ivy shares her frustration with Amelia’s limited engagement, at times communicating a feeling of being lost and almost helpless as she tries to move the conversation forward. Amelia rejects the offer of control from Ivy, instead remaining quite passive and somewhat happy to be led. This mirrors her tendency to acquiesce because it’s easier and there is less potential to do things or say things others may perceive as wrong. Whilst Amelia’s silence and lack of vocalised contributions resulted in frustration and anxiety for Ivy, she was able to demonstrate an ability to control the conversation, to avoid talking about certain topics by shrugging or staring intently at Ivy. This provides evidence that PWLD are able to *take* control when they want to although it is more likely that it will be framed as “uncooperative”, or “passive”. Examples like this need to be highlighted and shared with both PWLD and their support networks as positive, and successful attempts to take control, demonstrating autonomy and self-determination.

After interviewing Amelia and Ivy separately, I noticed there is a shared experience of hiding, or an avoidance of acknowledging, Amelia’s hopes for the future, such as having sex and having children. Whilst Ivy praises Amelia for giving what she believed to be “appropriate” answers to certain questions surrounding sex and having children, Amelia shares different answers during her individual interview. This indicates that Amelia wants to preserve the relationship, not wanting to upset Ivy, or to do anything that may lead to Ivy being disappointed with her. She holds onto the need to feel loved and cared for and therefore hides her underlying hopes and wishes. There seemed to be a reluctance to be honest with each other for fear damaging the relationship. This was evidenced in Ivy's hesitancy when speaking, leaving long pauses to assess Amelia's reaction, and Amelia's unclear speech, mumbling answers to questions and waiting to gauge Ivy's response. Ivy's presentation remained tentative and uncertain throughout both parts of the research but Amelia's differed, she was more vocal and free in her speech during part 2. The fear of getting something wrong was present for both Ivy and Amelia, which was exacerbated with the presence of a camera for Ivy, and with the presence of Ivy for Amelia.

Both speak about "vulnerability" and how this is experienced. Amelia regards her own vulnerability as being linked to her need to feel loved and doing what others want, "Um just used me for money, mainly" (line 267). Ivy interprets Amelia's vulnerability as risky and something she needs protecting from. She believes that Amelia does not have the skills to safeguard herself, therefore others need to do this for her. Ivy alludes to her own vulnerability which centres around professional conduct and risk:

> I think only because, you know, with being careful with some of the things that I've said…you know, um…you know, all this confidentiality and, you know, all the—Yeah. So, um, yeah, just very aware of – of – of (name)…and not sort of like overstepping the mark and stuff like that. (lines 1571-1581)

Amelia and Ivy relax noticeably when Amelia speaks about her current relationship, both laughing and smiling. There is a shared sense of safety and containment which contributes to reduced anxieties. For Amelia, this relationship is a new and positive experience of being loved and cared for which makes her feel "happy". She demonstrates this in her body language when describing how she felt; looking out of the window and smiling. This is mirrored by Ivy when watching the same clip back. Ivy's reduced anxiety links to the relationship being with another PWLD and her knowing the person, knowing that he is a good person who is not perceived as risky. The positivity of this new relationship, whilst shared, is experienced differently by Amelia and Ivy because it means different things to each; Amelia feels loved and cared for whilst Ivy knows she is safe and protected as there is additional oversight given by his parents.

Shirley

Shirley is a British female in her early 50s. She lives independently in her own accommodation and receives support from a family member when needed. This support is usually linked to shopping and finances as she struggles to understand this. Shirley has previously had support workers help her with daily tasks due to difficulties with her mental health. Shirley enjoys being in a long term relationship with her boyfriend and was keen to participate in the research. She is often involved with other opportunities in her local Community Learning Disability Team (CLDT), explaining that her involvement makes her feel valued and purposeful, contributing to her experience of "being human".

Shirley chose to participate in the research at a CLDT base she is familiar with and it is clear that she finds this a safe space to be. Most of the staff know her and take time to speak to her when she comes into the building "I like coming here, I look forward to me Mondays when I come here (lines 948-949)".

During the research Shirley shares gratitude for being asked to participate but also demonstrates anxiety regarding some of what she shares and how it may be perceived by myself and others.

In the initial introductory session, Shirley shared the importance of the research and how it relates to her understanding of the World. She described difficulties trusting the police because of recent news stories regarding sexual abuse perpetrated by officers. Throughout her participation, there was a clear passion for equality and access, wanting to be part of something that could be used to influence positive change for PWLD, "I think there should be more, more out there for people with learning disabilities and mental health, there should be more advice and more support for people" (lines 1341-1343).

Wanting Freedom, Control and Autonomy Over My Life

Being Powerless and Worthless to People. Shirley repeatedly mentions feeling 'less than' and not feeling like she is treated as a human being, "She just talks to me as if I'm stupid, if I was a – if I'm an invalid or something" (lines 334-335). She describes feeling worthless, invisible and without a voice. She also describes feeling like a child, "It's embarrassing when you've got a stupid support worker round with you" (lines 741-742). She makes numerous references to needing to "…know better than this, I need to act me age" (line 600-601) which communicates an internalised expectation that she should make better decisions due to her age but also that she is perceived as "childish" and unable to make "good" decisions.

Shirley communicates powerlessness as she seeks clarity and reassurance regarding her right to make decisions, “Is it my decision” (lines 168-169). She feels trapped, unable to leave her situation and take control, “I shouldn’t have to, I shouldn’t have to do what [family member] tells me to do, should I?” (lines 505-506). Shirley repeatedly asks for permission regarding her right to make decisions which communicates a need for validation and reassurance from someone without a learning disability, “I’ve got enough pressure and I don’t need, I don’t need [partner]’s pressure and [family member]’s pressure, do I?” (lines 464-466). Her lack of certainty here highlights the limited opportunities she has to make autonomous decisions. When she is faced with opportunities to make decisions she experiences confusion and anxiety in case she does something wrong. Shirley feels frustrated when people ignore her views and make decisions for her, desperately wanting to be heard and validated. She sometimes communicates her desperation through anger and threats “I’ll cause a riot” (line 255). She describes the emotional impact of being excluded from decision making and feeling forced to do things she does not want to, such as being told to move some of her belongings, “I’ll be heartbroken if they go out of me flat” (lines 254). In the context of sex and relationships, it is more likely for that Shirley will agree with the decisions being made for her in the hope it will result in more opportunities for her. Previously this linked to her hope of getting a boyfriend.

Shirley explains how others make assumptions about her and the support she needs. After receiving support during a mental health struggle, Shirley experienced difficulties navigating her way out of it, leaving her feeling stuck, controlled and angry, “I felt safe at first but I got a bit. I got a bit brassed off with it in the end” (lines 716-717). She previously felt exposed, judged and lacking privacy when she had external support, “Come to your house and they’re looking, looking around your home as if it’s dirty, looking through me letters” (lines 660-662). There was no opportunity for Shirley to be independent when she had support workers and she felt powerless to change this, “I says to her, I says “Excuse me, I know when I want to clean me own house up”…so she carried on dusting” (lines 793-…797). This links to Shirley’s internalised belief that she does not matter to others and is powerless to take control of her own life.

Shirley feels that PWLD are treated as “less than” and not as “human beings”. She speaks about her experiences of feeling ignored and controlled by family and previous support workers. There is a sense of frustration as she contrasts this with the people currently in her life that listen to and respect her. Shirley regards people working in the CLDT, a group she now associates me with, as safe and trustworthy people who validate her experiences, “You people don’t treat me like that, you treat me like a human being. You don’t say, do this, do that, control me life” (lines 750-752). She experiences the CLDT as a place she can express her views, make decisions and demonstrate self-determination. Shirley links the opportunity to make decisions and demonstrate self-determination with being human which clearly communicates her appreciation of person centred working. By contrasting her experiences, she communicates her sense of injustice that PWLD continue to be treated unfairly by some members of society.

She regards having a learning disability as limiting due to the increased likelihood of being controlled by others in more powerful positions, “I don’t want people going through same experience, I don’t like – it’s awful for somebody like with a d – with a learning disability” (lines 1334-1336). She separates herself from peers who she regards as having “worse” learning disabilities, reflecting on her own privilege at being able to make some decisions in life,“…some people haven’t got the freedom like I’ve got” (lines 1366-1367). Perhaps this is an attempt for Shirley to remind herself of the decisions she can make and to act on her self-determination.

Taking Power and Control. Shirley provides examples of when she has been able to make decisions about sex and relationships and how this makes her feel. Sharing this with me changes her whole demeanour during the interview, smiling and speaking with more confidence and autonomy. At one point in the interview, Shirley turns to me, smiles and say:

R – “I felt good about that one”

I – “Okay”

R – “Yeah”

I – “Why, why so? What, what did you feel good about?”

R – “Erm, I could, I could tell Charles about if when it’s the time to live with [boyfriend], when it’s the time when I can move in” (lines 123-128).

This relates to her telling Charles (support worker) that she does not feel ready to live with her boyfriend yet. The joy she communicates in her body language is powerful and highlights the rare opportunities she has to assert herself or her views. When she reflects on another part of the video, she again seems surprised that she looks happy, “…that were great and all…because I seem happy on there, don’t i…because I met up with [boyfriend]…” (lines 1200-1206). This emphasises how much she values her relationship and enjoys spending time with her boyfriend.

Feeling safe is important for Shirley “I want to be safe when I’m out” (line 564) and she has autonomy to decide how she does this, “I need to go home on me own, I want to be safe…so I get a bus up to where I live instead of walking up. To keep myself safe” (lines 567-571). Despite being able to make some decisions, she feels there is not enough information for PWLD to learn how to safeguard themselves when accessing the community and exploring relationships, “…there should be more, more out there for people with learning disabilities and mental health, there should be more advice and more support for people…to be safe when they’re out and about” (lines 1341-1346). This is particularly important for Shirley as she has lived experience of both a learning disability and mental health difficulties. Through advocating for this, it communicates how lost and confused she was when she experienced her own difficulties, and how scary it was for her. Here, she demonstrates an awareness of how a deterioration in mental health contributed to an increased vulnerability and now feels a need to protect others from going through the same experiences. She understands that she lacked appropriate information at the time and feels this is something that urgently needs to change.

Shirley describes accepting some of her own vulnerabilities and wanting support around these but clarifies it should not lead to assumptions of needing support in all areas of life. She distinguishes between being supported and being excluded from decision making when she reflects on the support she receives from the CLDT, “you don’t control me life, you don’t, you don’t tell me what to do, you only advise me” (lines 758-759).

Whilst Shirley has felt stigmatised and judged for past decisions and expects negative reactions from others, she is able to talk about these experiences with Charles, giving her a new experience, free from judgement “…at first I thought, Charles’ll be a bit annoyed about it but he wasn’t” (lines 1001-1002). This demonstrates the importance, and value, of experiential learning. Through having a new experience, Shirley is able to challenge her existing beliefs surrounding reactions of others. For this particular scenario, it could contribute to a shift in Shirley’s sense of self.

Being Angry About the Vulnerability of Being a Woman

Shirley is acutely aware of the risks facing women. She describes powerlessness and relentless objectification when in the presence of men, wanting respect and to be valued for more than her body:

> I can’t, I can’t stand the way people say to me, like that idiot on bus, like you’ve got nice legs…years ago that wouldn’t have bothered me but now it, it upsets me,

> breaks me heart and hurts me…it breaks me heart, hurts me feelings. I always think, you dirty old man…why can't you talk normally instead of having sex brought into it? (lines 1128-1138).

Repeated negative experiences throughout Shirley's life have contributed to a stereotyped, and unsafe view of men, "Dirty men what's out there. Yeah, what, what can't keep their, can't keep their bodies to themselves" (lines 14-17). Understandably, Shirley feels more comfortable talking to women about personal issues, commenting on the positives of having shared experiences "because us women sorta go through same thing really, we've got the same bodies and that, haven't we, us women" (lines 57-59).

Early sexual experiences have left Shirley feeling used and worthless, creating expectations of what sex will be like in the future, possibly meaningless and lacking love, "The lads when I met them on one night stands…they were out for one thing weren't they" (1031-1033). For PWLD, a lack of alternative experiences will mean this narrative is continued; sex is bad, sex is unsafe. Shirley does not speak about any other sexual relationships other than ones she has felt used and exploited in.

Shirley reflects on the risks of having sex, such as catching sexually transmitted infections (STIs), something she says she would not have known when younger. Her parents made the decision to give her oral contraception at age 16, something she disagreed with but went ahead because she hoped it would result in her being "allowed" to have a boyfriend:

> Shirley - "Me mum and dad, me mum and dad put me on the pill anyway…to keep me safe"
>
> Interviewer – "Yeah. And did you agree with the decision at the time?"
>
> Shirley – "Not really. Not at the time…because I wanted a boyfriend…at the time I were upset because me mum and dad wouldn't let, wouldn't let me have a boyfriend at that age" (lines 1049-1072).

Her parents had not previously "allowed" Shirley to have a boyfriend due to her perceived vulnerability and Shirley's likelihood to acquiesce in the hope it would result in a relationship, "I were too vulnerable…I always say yes to everything instead of no" (line 1081). There seems to be an increased risk of potential abuse and exploitation for Shirley but her desire to have a boyfriend was more important at the time so she continued to engage in unsafe relations. Her parent's decision reflects a belief that women with learning disabilities "should" be protected from having babies and that contraception is an acceptable way to prevent pregnancy. From the limited information Shirley shares, it can be argued that her parents were not denying her the right to a sexual life but they were denying her the right to a healthy sexual life.

Charles

Charles is a middle-aged male, working in healthcare. On occasion, he has supported Shirley as part of his role and takes time to speak to her when she attends appointments. Charles asserted that the research gave him a novel opportunity to discuss sex and relationships in a more scaffolded way. He speaks passionately about advocating for PWLD and maximising their autonomy as opposed to limiting and controlling them. He also shares a belief that PWLD need an element of protecting and safeguarding but hopes they can collaboratively enhance their self-determination.

Misplaced Understanding of Vulnerabilities

Charles shares his concerns about how often Shirley needs to reflect on her own vulnerability due to having support around her, "has she needed to reflect on her own vulnerabilities…she has a safety net around her in her sister, yeah, and she, she's in – she's in what we call is a safe relationship with her partner" (lines 1004-1008). Charles believes that Shirley needs to understand the factors contributing to her own vulnerability because relying on others limits her ability to truly understand potential risks and to safeguard herself against them. He also shares concerns about her being subjected to peer pressure, "its about her understanding the whole situation…was it the fact that she was with someone but some-someone was putting her under peer pressure?...or she felt she had to fit in?" (lines 470-491). This relates to Shirley's historical tendency to engage in casual sexual relationships but highlights an important aspect of capacity and consent.

Charles experiences reassurance when Shirley reflects on the vulnerabilities of women working in the sex trade whilst considering what this means about her own vulnerability. She does not disclose personal experiences of working in the sex trade but shares the experience of being exploited for sex. Charles focusses on the fact that Shirley is able to discuss choice, recognising she is in a privileged position where she can advocate choice within her own relationship:

> She categorised these, these ladies into vulner – vulnerable ladies, she may have thought the fact is she's in a stable relationship, she has a choice of where she

> goes with this relationship….so they are vulnerable because they don't have, they don't have them choices. (lines 862-868)

Charles reflects on anyone's potential to be vulnerable in the current societal context and that it is hard to minimise this risk. He tries to unpick factors contributing to vulnerability and discovered it is everywhere, even within what society assumes to be trusted establishments "there's so many things all things all at the moment, isn't it, because you've got the police, haven't you, there's so many things going wrong, even the police…" (lines 671-678). This communicates a sense of helplessness and uncertainty about how to protect and safeguard more vulnerable members of society.

Empowering PWLD to Experience Life to the Full

"Why does a person with learning disability have to try so hard for relationships? Why does a person with a learning disability feel that they've, they've got to please everybody" (lines 1272-1275).

Advocating for Experiential Learning. Charles shares his frustration that PWLD are kept from accessing information and experiential learning opportunities regarding sex and relationships, commenting on some of the outdated and inappropriate resources, "It's a training video, where he was putting a condom on a banana…and thinking that was safe sex because that's how it was explained to the person" (lines 586-590). He argues that without accessible information, PWLD are prevented from being able to make informed decisions about sex and relationships which leaves him feeling uncomfortable and somewhat angry:

> I think maybe people can be quite squeamish when it comes to people with learning disabilities…can we really show him the, the female genitalia, can we show him the male genitalia? Well, yeah, if it's – if it's something that, that gives them a sound knowledge… (lines 597-602).

Charles speaks about a range of options for acquiring information about sex and relationships, "you've got so many resources, you've got the internet, libraries, you've got sexual health clinics…sexual health nurses you know…your GP, health visitors" (lines 551-556*)* but recognises the limitations surrounding the quality of information for PWLD, "whether that be the right advice, whether that be the wrong advice, Shirley has to go with the advice that she's given" (lines 55-56). Due to his role, Charles likely has an expectation that he should be able to offer appropriate and accessible information to PWLD but he experiences anxiety about how easily it could be misunderstood and therefore being at risk of blame, "It'd make me feel pretty bad the fact that I have given someone information and thinking, oh, I've given that information, look what's happened" (lines 629-632).

Charles highlights the powerful nature of learning through experience and how this can inform future decision making "lived experiences. It's an ed – that's an educator in its own really isn't it?" (lines 808-809) . He normalises making mistakes "we all make mistakes in life, don't we?" (line 322), explaining that we cannot always avoid making poor decisions, but that we need the experience and the benefit of hindsight to be able to reflect on choices, "you know, we, we might make decisions and we think they're all right but then suddenly they're not" (lines 283-284). Despite normalising making mistake, he alludes to this being less acceptable for PWLD. Charles regards his participation in the research as a unique learning experience for himself, providing evidence for his earlier statements about experiential learning, "I quite enjoyed it, you know, because it's-its made me reflect on my own learning, my own style of learning, my own understanding of…of what relationships are" (lines 1141-1146).

Empowering People not Restricting Them. Charles speaks passionately about PWLD being entitled to make their own decisions in life, "…she's entitled to make those decisions. And those decisions need to be made from her" (lines 28-30). He maintains this view regardless of whether he, or others, agree with the decisions "they're entitled to make those unwise decisions" (lines 761-762). He struggles to comprehend how, and why, other people take control of decision making from PWLD, "it took me back a little bit thinking…everybody's entitled to make their decisions" (lines 36-40).

Charles begins to challenge the dominant narrative surrounding PWLD as he emphasises the need for them to know that they are 'allowed' to make decisions for themselves, "it's about promoting that decision and respecting the decision that Shirley's saying" (lines 140-141). He repeatedly communicates a sense of disbelief that power is not held by the person.

Charles feels strongly that conversations about sex and relationships should be normalised for PWLD as they can be powerful opportunities to learn about sexual safety whilst nurturing self-determination:

> It's giving them the tools to go forward and saying, right, this can't be right, because I've had that conversation with Charles…and Charles says that, you kno, you sho – this shouldn't be happening, well, this is happening, so is it right? (lines 257-262).

Charles acknowledges the powerful position staff hold with regards educating PWLD in the area of sex and relationships. Instead of protecting via control and restriction, PWLD could have the opportunity to make informed and sometimes unwise decisions.

Using the Position of Privilege to Open the Doors of Opportunity. Privilege is something Charles spoke about often and this centred around being trusted with information Shirley may never have shared with anyone before. Being involved in the research means that a unique opportunity is offered to discuss an area of life that is usually off limits to PWLD, "It's probably an honour as well, the fact is that this person trusts you, and opens up and tells you exactly intimate details of a person's life" (lines 1116-1118).

Charles also reflects on being able to make his own decisions about relationships which he usually takes for granted, "where you and I can make friendships and those friendships carry on" (lines 523-525). He highlights his ability to exercise his human right to have a private life without supervision or monitoring:

> The choices I had were a lot greater than what a person with a learning disability had, you know, in, in relationships. No one was taking me to the, to the cinema, sitting behind me making sure, you know…are they relationships with two people or are they third party relationships? (lines 1168-1181).

Navigating Dangerous Territory

Charles describes sex and relationships as unnerving territory to explore, being full of unknown dangers and the pressure to protect both himself and PWLD, "It's just – it's a minefield. A minefield…it's about making sure that when you're delivering – if you're delivering awareness or you're having them discussions, that when you have those discussions that you're giving the right information across" (lines 617-623).

He shares discomfort and uncertainty about managing complex situations which may arise as a result of initiating conversations about sex and relationships "having those conversations, it could open up a can of worms say" (lines 244-245). He wonders about his level of training and doubts his competency to support particular aspects of conversations, "are you trained to be in a position to offer Shirley support round that…well, no, so you need to sorta think…" (lines 413-416). It is apparent there is a fear that he is unable to contain complex situations that could possibly cause harm to PWLD.

Empowering Others to Make Informed Decisions

Shirley and Charles allude to the discussion of sex and relationships as being taboo. Shirley clearly communicates this as she whispers when speaking about things she believes should be "private", and Charles shares his shock when Shirley mentions the menopause. There is a real sense that sex and relationships should not be spoken about, influenced more by their gender differences. Both share a belief that more personal aspects of life are better discussed with someone of the same gender, attributing this to shared experiences yet Shirley feels able to discuss the topic with Charles in the context of research.

There is a strong theme of enhancing self-determination and autonomy present for both Shirley and Charles. They share frustrations that PWLD are often blocked from decision making, particularly surrounding more intimate areas of life such as sex and relationships. There is also a shared recognition that appropriate information and support need to be given to PWLD to enhance their decision making skills. After either witnessing, or having experienced ineffective and restrictive decision making for PWLD, they ultimately agree that decision making responsibility should lay with the individual, and it is the responsibility of others to provide accessible and accurate information to support this process.

Both recognise "vulnerability" but conceptualise it differently. Whilst Charles shares his concerns surrounding Shirley's level of understanding and ability to safeguard herself, Shirley gives examples of how she is actively making decisions to enhance her safety in the community. She also separates herself from other PWLD, recognising her greater level of freedom and autonomy whereas Charles regards this as a demonstration of her limited understanding surrounding her own vulnerability and the risks this could bring.

There is a shared experience of privilege, both regarding themselves as lucky to have as much autonomy as they do and reflect on those who are less able to be actively involved in their lives. This is a powerful reflection as it seems to dilute any power imbalance present within the dyad. Much of the content from part 1 centres around female vulnerability, how Shirley safeguards herself, and the frustration she experiences when people make decisions for her. This is not a shared experience for Charles thus created a power imbalance, as well as him being male and a staff member. Coming together to recognise their individual positions and privileges creates a shared experience, one that is likely to have validated Shirley.

Group Experiential Themes

During individual case analysis a number of GETs were identified and are illustrated in Table 3.

Table 3. *Group Experiential Themes for All Participants*

GETS	Subthemes	Robbie	Amelia	Shirley	Felicity	Ivy	Charles
Intersecting layers of vulnerability	Being blocked from						
	- important learning	X	X	X	X	X	X
	- information	X	X		X	X	X
	Needing to get things right		X		X	X	X
	Feeling used and exploited	X	X	X	X		
Navigating without a compass	Feeling lost and alone	X	X		X	X	X
	Lacking direction and support	X	X	X	X	X	X
Surviving by avoiding		X	X	X	X	X	
The struggle for control	Being controlled	X	X	X			
	Giving control	X	X		X	X	X
	Taking control	X		X	X	X	X
Fearing negative consequences		X	X	X	X	X	X

Intersecting Layers of Vulnerability

All participants described a parallel experience of feeling vulnerable. Whilst distinct in their experiences, participants' accounts highlight the complexity, and intersectional nature of vulnerability. Within this theme are subthemes of: *being blocked from important education and information, needing to get things right,* and *feeling used and exploited.*

The way in which vulnerability is spoken about differed: either speaking explicitly, particularly regarding sexual vulnerability, or implicitly. For participants in this research, their vulnerability seems to be contextualised in the actions and decisions of others, contributing to powerlessness and helplessness. This is paralleled in terms of PWLD feeling powerless to staff and staff feeling helpless in the context of their organisation.

Being Blocked from Important Education and Information. Participants believe informed and safe decisions can be made in the context of adequate and accessible information although the majority experience limited, or inadequate, information contributing to poorer decisions. This is the same for both staff and PWLD. Charles explains PWLD often end up with no, or inaccurate representations of information and lack experiential learning opportunities as he commented on available resources such as a training video (Hole et al., 2022), "and that's how they demonstrated it, say, oh well, this is safe sex. If you put this condom on the banana, it's safe. Well it's not safe is it?..." (lines 592-594). Charles believes inaccurate representations of important information places both PWLD and staff at risk, which contributes to increased anxiety and pressure for him to provide accurate information to ensure the safety of PWLD. Ivy shares increased pressure to safeguard PWLD through needing to offer accurate information but found this challenging when it conflicts with families' views, "So trying to speak with Mum and say, you know, this is not— Cos we're not here to judge. We're here in a supporting way" (lines 632-633). I believe Ivy is trying to communicate that she holds different information, likely resulting from her professional role, which she believes will better protect Amelia. Shirley describes wanting to safeguard herself rather than rely on others to manage her vulnerability "Tell me to be safe and that's it. You don't tell me do this, do that" (lines 761-762). This suggests that she wants access to information and education which will equip her to make informed decisions about relationships and intimacy, without people making decisions for her. It will make her feel "human".

Feeling Used and Exploited. This subtheme occurs both in the context of being taken advantage of due to having a learning disability and also in the context of being female. PWLD share experiences of having been exploited and taken advantage of because others perceive them as vulnerable. This has contributed to internalised beliefs of being vulnerable and powerlessness to make changes. This is similar for women in the group as Felicity describes the potential for her to be used, "when he's upset or when a person, or a woman in particular has upset…he will relay information that isn't quite true" (lines 246-249).

Whilst these experiences are distinct, they highlight the increased and intersectional nature of vulnerability within the context of sex and relationships for PWLD. As Crenshaw (1989) and Davis (2008) highlighted, it is necessary to give attention to the unique ways in which people are marginalised as opposed to using blanket assumptions and stereotypes. For PWLD, there are varying inequalities facing them which can exacerbate vulnerability such as being female, living with a disability, and poor access to information and healthcare.

Navigating Without a Compass

Feeling Lost and Alone. There is a strong sense of uncertainty and feeling lost within the topic as participants often regard it as "taboo", feeling embarrassed and not knowing how to initiate the conversation, "Just feel embarrassed about some…sometimes…cos I've never talked about sex with anyone…" (Amelia, lines 412-416), "it could be a bit embarrassing at first" (Shirley, line 11). There is hesitation and wanting the other person to take control, "I wanted Robbie to lead it obviously because it's a conversation about sex and relationships" (Felicity, lines 11-13*)* which is likely to be representative of life outside the research context; feeling uncomfortable raising sex and relationships, placing responsibility with others. The research provides a rare, yet somewhat scaffolded opportunity for them to discuss sex and relationships with people they worked with.

Lacking Direction and Support. Whilst PWLD identify sources of support and information, they do not seem to actively seek this, or if they do, there is a disconnect between the availability of support and the willingness of people to provide it. This links to the lack of clarity and guidance surrounding this area for PWLD, leaving staff feeling incompetent and ill equipped to provide support. Unlike staff who have the ability to "kind of had to learn as we, as we go" (Felicity, line 458), PWLD are often prevented from having experiences that could offer insight and education, therefore remaining lost. Despite these distinct differences, there are parallels within both groups: wanting access to experiential learning but being blocked from it. A compensatory strategy is therefore experiential avoidance; if we don't talk about it, nothing bad can happen which maintains the status quo.

There is also uncertainty about which route to take because of inner conflict. For PWLD, this links to wanting help and support but not wanting to be controlled.

Staff experience more conflict between their own values and beliefs. Some speak of having to put these to one side in order to do their job and support PWLD whilst others may not recognises how their beliefs and values influence their attitudes to sex and relationships for PWLD. Ivy gives insight into her underlying attitudes towards sex and relationships when she says "there is some things that should be kept private, um, you know" (Ivy, lines 1672-1673). This is likely to influence the way she approaches any conversation involving sex and relationships, not just when supporting PWLD.

Surviving by Avoiding

There is a sense of needing to get things "right" in order to survive and maintain employment for staff. Felicity and Ivy use avoidance as a survival strategy. By not speaking about sex with PWLD, they cannot provide inaccurate information, be misinterpreted, or "encourage" anyone to engage in sexual activities. However, by avoiding such conversations, it becomes a belief that sex either is not important to PWLD, or is not an active part of their life therefore does not need discussing. This means is it not discussed because it is not a problem but by not discussing it, it becomes a problem because PWLD enter intimate relationships with incomplete, or inaccurate information.

Robbie puts a lot of effort into avoiding the topic of relationships and intimacy day to day. This tends to be when in the presence of certain people such as young female staff, or his parents. Nevertheless his attempts to avoid contribute to increased desires and frustrations. He is almost at bursting point when he feels unable to talk to staff about his difficulties which subsequently impacts his mental health and leads to an increase in unsafe behaviours (using social media). Whilst he cognitively tries to avoid thinking about sex, he finds it near impossible to avoid physical responses to arousal, leaving him with little outlet.

The Struggle for Control

There is a strong theme of control across all participants although there are distinct experiences within this: *being controlled*, *giving control* and *taking control***.**

Being Controlled. For PWLD, there is a palpable experience of being controlled by others. There is a powerlessness and frustration linked to this as Shirley explains, "I told her to F off and leave me alone. I don't need it…she ignored it" (lines 770-774). Robbie describes wanting help but recognising this would result in him losing his autonomy, "I don't know what I'm gonna do yet, who knows, but if I get my mum involved, she'll have a complete, let's take control of him" (Robbie, lines 1329-1331). Most participants with a learning disability and one staff member recognise that the rights of PWLD are often taken away and inaccurate assumptions made about their capacity and ability to be independent "…she thought I couldn't cook me own food, she – I started making scrambled eggs for myself…and…came over to the pan and took over, when I were trying to make me own tea" (Shirley, lines 765-769). Being controlled extends to making decisions about sex and relationships. Amelia describes being exploited in previous relationships, "but also boyfriends I've gone out with…they used to take my money…just used me for money" (lines 257-267) and Shirley mentions the challenges she faced when trying to engage in a relationship with her now, boyfriend:

> I didn't like it with the support workers were just coming out with me when I were out with (name), I hated it. There were no personal, there were, there were no personal business towards us when I had support workers with me all the time (lines 652-656).

Giving Control. Staff want to protect and safeguard PWLD, feeling unable to give control to them as they believe it is the only way to keep them safe, "…we can't stop you, you can make choices, you can make decisions, but we can help support in thinking…" (Ivy, lines 584-586). Ivy explains not knowing what they were up to impacts her ability to control, especially if they decide to have children, "…we don't know how – how would they be supported with that…?" (line 1482). Considering sex and relationships in a context without supervision or control, staff feel powerless and uncomfortable which is a direct contrast to PWLD. There are moments when staff attempt to give control to PWLD, for example, to guide the conversation but this opportunity is not always taken, being influenced by an internalised belief that PWLD should not have control over their lives. Within this is a fear of PWLD making unwise decisions if control is given to them. This then exacerbates the fear of professional consequences.

Taking Control. PWLD want to be empowered to make autonomous decisions and to protect and safeguard themselves, "I use me common sense when I'm out, I keep myself safe and secure…" (Shirley, lines 588-589). Shirley gave examples of taking control, experiencing joy and happiness after doing so "So I rang, I rang the management up and complained" (line 726). Amelia also demonstrated an ability to take control and direct the conversation through her body language and minimal contributions.

Fearing Negative Consequences

Across participants there is a central theme of fearing negative consequences such as fearing judgement at multiple levels: individual, organisational and societal. This fear increases the temptation to avoid the topic for all participants and thus provides protection for all. However, despite offering safety and protection, avoidance prevents experiential learning and the possibility of having positive experiences. Avoidance is certain and predictable whereas embracing a degree of vulnerability to do something different brings uncertainty and risk.

For PWLD there is a particular fear of being "told off" or having support withdrawn, "I went to myself, Robbie, don't say a word…erm, probably I would a got told off", (Robbie, lines 943-948). Here, Robbie describes a situation where he would be punished for expressing his views relating to sex and relationships and therefore chooses to retain support and positive relations with others over meeting his need for a relationship sexual or otherwise.

Staff are primarily concerned with losing their jobs if they disrupt the relationships they have with PWLD either by saying something the person does not like, or by breaching confidentiality "…being careful with some of the things I've said…you know, um…you know, all this confidentiality" (Ivy, lines 1571-1576).They attempt to keep their own morals and values hidden to avoid impacting PWLD negatively although these occasionally seeped out into their actions. There is also a fear of PWLD misinterpreting information, or staff unintentionally sharing inaccurate information, "yeah, if you give them the information and that information's incorrect, you're thinking, right, okay, why was I given this role…?" (Charles, lines 639-641). The need for stability and clarity is important for staff but is something they lack. They share a belief that if sex and relationships is not raised by the person themselves, then it does not need to be discussed, it is safer to leave it unsaid. Whilst Charles agreed that it had not previously occurred to him that sex and relationships should be discussed with PWLD as part of his role, he strongly believes that more conversations should take place and that it is important for everyone to find ways to do this. Ivy and Felicity choose to signpost to other professionals therefore mitigating their own risk and vulnerability.

REFLECTION

I valued the supervisory process throughout this research but particularly for Robbie’s experiences. Supervision helped me to realise that I was continuing to perpetuate a narrative of PWLD being asexual and that sex for them is taboo, it shouldn’t be spoken about. This was highlighted by my supervisors who noticed my analysis lacked detail and when reviewing comments I noticed that I had avoided providing an in depth analysis regarding Robbie’s sexual arousal. I instead used his interpretation of “anxiety” and went with this. I was surprised and disappointed that I had done this but then experienced joy at being able to revisit his narrative and focus on sharing his story.

I believe my initial decision was driven by a felt need to protect him from further being regarded as a sexual risk and to shift the narrative of male PWLD as being sexual predators. However, in doing this I failed to communicate an important part of his experience: that the rules and restrictions prevented him from accessing sex and relationships and also contributed to him feeling shame and embarrassment regarding his sexual needs.

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Chapter 4: Discussion

The primary research question for this study was "What are the experiences of people with learning disabilities, and their support workers, when negotiating access to opportunities for developing relationships and intimacy?". Additional research questions were:

- What are the experiences of PWLD and their support staff regarding the concept of sexual risk and sexual vulnerability?
- Why are the experiences different between PWLD and their support workers?

A multi perspective IPA design (Larkin et al., 2019) provided a novel opportunity to understand individual experiences of decision making and how these were negotiated within pairs (PWLD & support worker), and across groups of participants. A level of difference was anticipated surrounding the experiences between PWLD and support workers. Part 1 was instrumental in highlighting the difficulties experienced when engaging in decision making processes for PWLD and support workers. It highlighted a lack of collaborative decision making contrary to recommendations in the Mental Capacity Act (2005). Instead, participants reflected on historic accounts of sexual decision making, either having decisions made for them, or making decisions for people/influencing their decisions. This forms the basis of this research. The extent to which experiences of negotiating decision making could be explored within this study was limited but reflects everyday life for many PWLD (Nonnemacher & Bambara, 2011). The multi-perspective design of the study created opportunities for participants to reflect on the immediate feelings and reactions they experienced in relation to the content and to begin further consideration of the dilemmas they face in similar situations thus informing clinical practice.

How do Identified Group Experiential Themes (GETs) Compare Between PWLD and their Support Staff?

There were four Group Experiential Themes (GETs) identified within the research, each of which will be discussed in turn: intersectional vulnerability, navigating without a compass, the struggle for control and fearing negative consequences.

Intersectional Vulnerability

All participants with a learning disability held internalised beliefs that they are vulnerable. Their beliefs are rooted within societal discourses surrounding PWLD (Logeswaran et al., 2019; Rushbrooke et al., 2014) and their immediate support networks. This is highlighted throughout Ivy's account where she communicates her belief that PWLD are safer in the presence of staff or with ongoing support from family. Felicity also shares a belief that PWLD are vulnerable within this context, "And kind of how vulnerable they are in terms of their understanding of sex and relationships" (lines 138-139). Vulnerability as a multi-layered or intersectional concept had not been considered when developing the study but it became clear throughout the process that it should be conceptualised in this way, not as a 'one size fits all' approach. Despite recommending person-centred and least restrictive care (Mental Capacity Act, 2005) this was not something experienced by participants. Conceptualising vulnerability intersectionally offers a framework for support workers to tailor their care in a person centred way and would support the attempt from the Office of the Public Guardian (2015) to externalise the concept of "vulnerability" to wider society. Despite the attempt to shift how vulnerability is perceived, the results illustrate a shared belief among participants that PWLD *are* vulnerable, but what this meant for each person is less clear. Shirley and Robbie attempt to separate themselves from the "disabled minority" and develop an identity of being more able (Corr McEvoy & Keenan, 2014; Logeswaran et al., 2018;). This process is also paralleled in staff participants who explicitly associate themselves with other staff, including me, "He's not gonna perceive it the same way that we do" (Felicity), conceptualising "us" as the powerful, and all knowing, majority.

Vulnerability as a concept is rarely deconstructed which limits the extent to which individual and intersecting variables can be explored to help understand how someone can be more, or less, vulnerable (Vikery, 2018). Baisasu (2020) speaks about changing the narrative surrounding vulnerability from one of negativity and protection, to one of risk taking and empowering opportunities. The Office of the Public Guardian also shares a commitment to empowering others whilst protecting them from abuse (2015).

Participants reflect on several ways people can experience vulnerability which is supported by Siller and Aydin's (2022) discussion regarding hidden and neglected areas of inequality. Whilst their findings are situated in the context of COVID-19, they use the concept of intersectionality as a lens with which to critique other literature linked to social inequality. Participants in this study specifically reference their experiences of being female, having a learning disability and being young. Whilst Siller and Aydin’s work focusses on the experiences of marginalised groups during COVID 19, they argue that people themselves are not inherently vulnerable, but their vulnerability is a product of the structures and systems in which they are contextualised. This is supported by Martino, (2022) who explains the everyday barriers experienced by PWLD is what contributes to them being “vulnerable”. Examples include being prevented from making autonomous decisions. The findings from this study support this as participants with LD feel unable to make autonomous sexual decisions, largely driven by a fear of negative consequences. Amelia particularly wants the opinion of staff before making any decisions. Whilst this is regarded as “normal”, to seek advice from others, it feels more like she is seeking permission to act on her decisions. Theory of Planned Behaviour (TPB) would describe this as Amelia lacking perceived control of behaviour, instead focussing on the attitudes of others, however it does not offer insight into any negotiations occurring in this context. TPB does not allow an in-depth understanding regarding the decisions being made or how the PWLD in this study negotiate their positions. Similarly, considering Shared Decision Making, Amelia is not centred in the decisions, she is reliant on approval from others meaning any decisions would be influenced by the attitudes and beliefs of Ivy. This is further supported by Ivy’s approval of Amelia’s current boyfriend. Amelia expresses happiness because she feels loved but also that her decision has received approval from important people in her life, such as Ivy. Neither TPB or SDM provide enough understanding regarding these complex decisions and how independent decision making processes come together in such negotiations.

Katsulis (2008) describes how greater sexual autonomy is afforded to males, placing them in a powerful position within sexual encounters and contributing to the perception of women being sexually naïve and vulnerable (Young et al., 2012). This is evidenced in Shirley’s narrative and her repeated association with “girls”, not “women”, suggesting an internal belief of being immature and less informed, “They were treating me like, like them two girls. Qui-quick jump and that’s it” (Shirley, 1038-1041).

Stanovich (2009) explains the necessity of having adequate education, knowledge and experiences to support decision making. For PWLD, they are rarely given equal access to appropriate sex education, they are blocked from necessary information and have limited, if any alternative resources to fill in the gaps thus increasing their vulnerability (Eastgate et al., 2012). Similarly, for many PWLD, there is a reliance on staff to fill in the gaps which can also increase their vulnerability to abuse. For Robbie, relying on his dad to provide further information about sex toys resulted in his knowledge gap being maintained. He demonstrates an eagerness to learn more which previously resulted in him being in risky sexual situations using social media. For Amelia, she receives skewed information regarding having children. Shirley previously lacked knowledge surrounding STIs but continued to engage in risky sexual behaviours because her parents had put her on the pill to prevent pregnancy. Eastgate et al. (2012) discussed concerns about PWLD accessing other means of experiential learning such as accessing pornography or sex workers, something which was observed in Robbie's account as he utilised sex clubs as a way of learning and experiencing sexualised environments. Capacity needs to be considered as Series (2015) highlights that lacking necessary information regarding sexuality can lead to being regarded as incapacitous. However, this can shift over time (McGuire & Bayley, 2011) with access to appropriate education and knowledge, but this is limited for PWLD, making it difficult to "prove" their capacity. It is therefore argued that the rights for PWLD remain unmet and, in some cases, are being unnecessarily deprived of their liberty due to capacity, or lack of, being treated as something fixed and unmovable. This means efforts are rarely made to introduce positive risk taking to learn from experiences, whether they be positive or otherwise. There seems to be an underlying belief that PWLD need to be protected from any potential of negative outcomes, therefore prevent access to experiences.

There is an increased prevalence of sexual abuse and exploitation within the learning disability community which is evidenced throughout the stories in this research. All participants with a learning disability had experienced sexual abuse either directly or indirectly due to a combination of wanting a romantic partner but having limited understanding of their rights and laws surrounding sex. These factors contribute to negative experiences of sex and relationships, negatively skewed attitudes towards it and a belief that it is "bad" and should not, or cannot, be engaged in. The negativity associated with sexual situations leads to avoidance of sexualised behaviours for Robbie, Amelia and Shirley. The absence of experiential learning also limits their ability to make fully informed decisions because there is a scarcity of alternative, positive outcomes (Ceschi et al., 2019). Martino (2022) advocates for the sharing of sexual stories and is something that should be encouraged within the learning disability community. There is a stark absence of positive sexual stories which skews the perceptions PWLD, families, and staff have, though this is beginning to shift. Staff participants lack knowledge and guidance for supporting PWLD in this area of life and any experiences they have had to support people are often situated in risk related contexts. This contributes to an increased tendency to restrict opportunities rather than look for ways to facilitate understanding and access to experiential learning.

An unexpected outcome of the research was the degree to which staff experience vulnerability. It was assumed that because of the power differences, and existing research demonstrating the perpetual control of PWLD, staff would be comfortable in taking control of the conversation in part 1 and scaffolding decision-making processes for PWLD. Some discomfort and embarrassment was expected (Kitson, 2021) but not a parallel experience of vulnerability. It was not expected that support workers would experience vulnerability, due to their powerful position as people without learning disabilities and as staff. Whilst vulnerability was a parallel experience, staff experiences linked more to their fear of professional repercussions, doing something "wrong" and being negatively evaluated by others, rather than feeling powerless and controlled by others.

Overall, there are shared experiences of vulnerability present throughout all individual accounts, but each remain unique. Whilst unexpected, this finding gives further evidence for the need for an intersectional approach to understanding vulnerability. Understanding vulnerability in this way will increase understanding of the associated consequences for both support workers and PWLD, that have been highlighted in this study: restriction, protection and avoidance. It gives insight into why support workers may engage with certain consequences and how PWLD experience them.

Navigating Without a Compass

Each participant experiences the topic as uncertain and embarrassing which has been reported elsewhere (Kitson, 2021). Despite having consented to take part, none held a clear direction of how to guide the conversation forward during part 1. There is an openness to discussing sex and relationships and a recognition of it being a human right, but uncertainty creates a cloud which is difficult to navigate through. All staff reflect on expectations that PWLD should raise the topic, therefore do not think to initiate conversations. They describe a lack of training which would provide them with the foundation from which to offer support and guidance. This explains why staff participants are less confident and more hesitant with regards to supporting PWLD with sexual decision making and reiterates recommendations for increased staff training (Grieve et al., 2009; Healy et al., 2009).

Many PWLD want access to sex, relationships and dating (May & Simpson, 2000) but lack accessible information surrounding it (Chivers & Mathieson, 2000). Sources of information are limited, or inappropriate, and the participants in this sample seem to rely on opportunistic sources of information (Hollomotz, 2011), such as being exposed to sex toys, or through lived experiences.

This research provides supporting evidence that PWLD continue to experience barriers to autonomous sexual decision making (Hingsburger, 1995; Oloidi et al., 2022; Rushbrooke et al., 2014). Byrne (2018) explains that PWLD are also less likely to have sexual education. In this sample, limited education usually came from parents or staff, with inconsistent school experience; Amelia had not received sexual education at school whereas Robbie had. This reflects a continued belief that women with learning disabilities need protecting from sex (Perez-Curiel et al., 2023). The availability and quality of sex education for PWLD can result in knowledge gaps, especially surrounding consent and sexual pleasure (Frawley & Wilson, 2016; McCarthy et al., 2021; McGuire & Bayley, 2011).

Staff often experience a dilemma when supporting PWLD with relationships and intimacy as they recognise the right for sexual relationships but struggle to balance this with the various risks and pressures involved (Charitou et al., 2021). Charles addresses this when he recognises the desire to protect PWLD but also that this involves potential risks such as people making "unwise" decisions, but that these risks could be minimised through comprehensive and accessible education.

The Struggle for Control

The findings from this study support existing literature surrounding a perceived need to protect PWLD (Ryan & McConkey, 2000). There is a stark contrast in the experiences of sexual decision making between PWLD and their support workers. Staff exert power and control to make decisions for PWLD, fuelled by a belief that their role is to protect them from abuse and exploitation (Deeley, 2002) whilst PWLD feel powerless and excluded from decision making processes (Strnadová, 2015). Despite staff making decisions they believe are to protect PWLD, PWLD experience them as suffocating and controlling (Jingree, 2015). A delicate balance needs to occur to enhance the sexual autonomy for PWLD whilst safeguarding them against potential harm, as there is a risk of neglecting and violating their human rights. Staff struggle with the thought of giving control to others as it means vulnerability may increase for both themselves, and PWLD. All staff compared the participants in the research to other PWLD they support. They share examples of providing increased involvement and protection for people they regard as being more vulnerable due to their level of learning disability (Lafferty et al., 2012). However, the Mental Capacity Act (2005) should underpin all decisions made for PWLD, ensuring that capacity is assumed (Dowling et al., 2019). This is particularly difficult for some staff as they experience discomfort when considering positive risk taking, or the potential for PWLD to make unwise decisions (Brown & McCann, 2018). It becomes complex when trying to differentiate between unwise and incapacitous decisions (Dowling et al., 2019; Williams et al., 2012) as the two have become synonymous over time, resulting in increased restrictions for PWLD. There is a fear of developing autonomy in case it increases the possibility of making "unwise" decisions. This fear leads to avoidance, but as is seen in Shirley's experiences, she learned from past situations and was able to make "wise" decisions (Dowling et al., 2019) such as not seeking multiple sexual relationships on nights out. Amelia also shares her negative experiences with peers as a form of peer-to-peer education to increase awareness and ability to make informed, "wise" decisions (The Young Women's Movement, 2023). This provides evidence to stop preventing access to sex and relationships for PWLD and enhance opportunities to receive necessary information that can enable them to make informed decisions, "wise" or "unwise". Charles strongly advocates for this and hopes to use his power and privilege to empower PWLD to take more control over their sexual lives.

There is a strong experience of feeling controlled for PWLD and being excluded from collaborative decision making regarding sexual decisions. Despite a negative skew to their experiences, there are pockets of hope and positivity, especially within Shirley's stories. All staff acknowledge the importance of sex and relationships for PWLD and want to enhance this area of life for them but struggle to know how to do this.

Fearing Negative Consequences

For staff, there is a fear of increasing both sexual risk and vulnerability by raising the issue of sex and relationships (Lumley & Scotti, 2001). There is a tendency to avoid or deprioritise it as it "is rarely an issue" (Ivy), or because it could become an issue (Shakespeare et al., 1996). Ivy describes the fear she experienced after facilitating an educational session for PWLD, "Then afterwards it was like "Oh you know, I can have a baby"". Whilst Ivy's decisions to avoid such conversations are likely driven by a desire to protect, preventing access to education contributes to increased sexual exploitation (Byrne, 2018) as was the case for both Amelia and Shirley. Shirley particularly, was previously unaware of STIs but had been put on the contraceptive pill to prevent pregnancy (Wiseman & Ferrie, 2020).

Staff particularly fear professional repercussions if they involve themselves in sexual decision making in the absence of clear guidance (Maguire et al., 2019; Martino & Perreault-Laird, 2019; Pariseau-Legault et al., 2019). Ivy specifically mentions "crossing the line" in relation to her relationship with Amelia but this also links to a professional line where there would be professional consequences

(Maguire et al., 2019; Martino & Perreault-Laird, 2019). Felicity comments on a tendency to signpost individuals to other members of staff to avoid the possibility of negative consequences and blame (Maguire et al., 2019; Oloidi et al., 2020).

How Do PWLD and Support Workers Experience the Concept of Risk and Sexual Vulnerability?

Sexual risk is considered more by staff participants, and PWLD allude to a parental recognition of sexual risk posed by others. Shirley comments on the importance of experiential learning as she was able to recognise the risks of engaging in sexual relationships such as sexually transmitted infections (STIs). She explains that she would not have known this previously which highlights the need for greater education and supports findings from Borawska-Charko et al. (2017). Shirley's parents decided to put her on the contraceptive pill but she did not mention other contraception methods such as condoms which would also protect her from STIs. This demonstrates prioritising pregnancy prevention over sexual health because of an underlying belief that PWLD lack the skills to be good parents (Swain & Cameron, 2003). Similarly, a socio-cultural lens would suggest that "disabled" women are unable to become effective homemakers or mothers due to their limitations (Begum, 1992). In Shirley's case, it happened over 40 years ago, which would be reflective of societal beliefs and quality of sexual education at that time (Hollomotz, 2011). Attitudes are generally more positive now (Bazzo et al., 2007) and have been influenced by the introduction of the UN Convention on the Rights of Persons with Disabilities (2006) but there remains a disconnect between attitudes and beliefs, and practice (Maguire et al., 2018; Shakespeare & Richardson, 2018). The improved attitudes and acceptance surrounding the sexual rights of PWLD is not enough to influence positive change in the sexual lives of PWLD as it occurs in the context of fear and uncertainty (Shakespeare & Richardson, 2018). There continues to be an emphasis on preventing PWLD from having sex for fear of them, particularly women, becoming pregnant. This is evident throughout Ivy's account.

The common way of managing sexual risk within this sample is to avoid sex completely. Both staff and PWLD avoid talking about it, or do not seek guidance for it, and PWLD avoid engaging in it. This is despite recognising it as a human right and being entitled to experience it (Maguire et al., 2018). The PWLD in this sample regard sex as a risk, either of being abused or exploited, or because they will receive negative consequences from others.

All PWLD included in this research are able to speak to the concept of vulnerability, all regard themselves as vulnerable though this is more generally, not specifically in relation to sexual vulnerability. However, there are limitations to the depth of explanation and contextualisation to justify these beliefs. For example, Shirley is able to understand the vulnerabilities of women working in the sex industry and how she has greater choice and autonomy than them, but she struggles more to understand the factors contributing to her own vulnerability. Björnsdóttir et al. (2015**)** extends Meyers' (2010) feminist conceptualisation of internalised oppression to PWLD, explaining how an internalised form of oppression can contribute to difficulties developing autonomy for future decision making. They often remain stuck in powerless positions due to government decisions (Jingree, 2015), misuse of the MCA (Shakespeare & Richardson, 2018; Willner et al., 2011) and difficulties in getting their voices heard.

The female participants in this research are aware of their vulnerability and how this had contributed to abuse and exploitation previously. Shirley understands her vulnerability as a woman and how this leads to increased unwanted attention from men, something commonly experienced by women in general (Hollomotz, 2011). Similarly, Felicity is acutely aware of her vulnerability as a female supporting Robbie. Whilst her experience links to being female, it is specific to the context she works in and is a result of historical incidents involving Robbie which informs her opinion. Consideration is given to the potential for sex to be used as a survival strategy or for freedom for PWLD. It seems at times that engaging in sexual behaviours could open potential opportunities for other important areas of life that is otherwise restricted such as experiencing love and care, "I were just hoping for, like, one day he'd love me" (Amelia, line 283). Shirley and Amelia recognise that experiencing love is subjective and is not reliant on engaging in, what they regarded as unpleasant, sexual relationships (Murotmusaev, 2021), but can be a result of feeling happy and positive because of the other person. Similar findings were reported in McCarthy et al's. (2021) study.

How Do PWLD and Their Support Workers Make Sense of the Concept of Risk and Sexual Vulnerability During Sexual Decision Making?

Whilst there is an absence of immediate decision making within this research, pairs use their participation as opportunities to reflect on past experiences and to consider what might contribute to future decision making. There are distinct differences between PWLD and staff in the perception of 'decision making' and what influences this. There is a strong theme of wanting greater control and autonomy over their lives, particularly for Robbie and Shirley. For staff, there is a shared desire to protect PWLD from sexual relationships and a strong sense of hesitancy and uncertainty about navigating this area of life. This leads to increased avoidance of raising the topic with PWLD (Krebs, 2007).

There is a tendency to evaluate the cost and benefits of the decisions being made, with a particular focus on the costs for support workers. For PWLD there is a desire to experience the benefits associated with sex and relationships but their previous experiences draw attention to the risks and leads to avoidance rather than seeking new experiences. Whilst PWLD want information and education regarding sex and relationships, which could contribute to reducing their vulnerability and enhancing sexual determination (Swango-Wilson, 2008), staff consider it a risk as it exists in a confusing and potentially dangerous context. This provides evidence in support of Tversky and Kahneman's Prospect Theory (1981), both groups seeking to avoid perceived losses. However, the complexity of mathematically weighing up information (Rossiter, 2019) in the context of prospect theory is less likely to occur here given the cognitive difficulties that can often be experienced by PWLD. There is more occurring within the relationships than loss aversion.

Theory of Planned Behaviour (TPB) can be used to understand the individual decisions being made by both PWLD, and staff by exploring the three key concepts: attitudes, subjective norms and perceived behavioural control. These concepts apply to both groups: is the decision important to the person or would the potential outcomes be socially acceptable for someone with a learning disability (attitudes), the perceived subjective norms of people offering daily support to PWLD (and of the employers and managers of paid support workers for PWLD), and how much control people believe they have to implement decisions. These factors influence whether behaviours will occur and will impact how much systems around individuals influence their lives, particularly in the areas of choice and decision making (Jackson & Jackson, 1998; Rodgers, 1998). Belief systems and attitudes influence the types of interactions people have, especially in this context. For PWLD, it is likely that the contexts they find themselves in are largely sex-negative (Race, 2016), influenced by the beliefs and attitudes of staff rather than PWLD. Tarnai (2006) explains that the problem of sexual expression does not lie with the individual, but those in their support network. The struggle to be heard was present in this study as both staff and PWLD believed their perspectives were "correct" and more rational than the other (Cavojova & Mikssove, 2014).

Overall, decisions are often driven by fear, or are reactive responses to instances of abuse or exploitation as was also found by Schaafsma et al. (2015). Staff responses are usually to risk manage situations and increase restrictions. In this study, restrictions were welcomed by PWLD but are also resented (Fulford &

Cobingo, 2018) as is clearly described by Robbie and Shirley. There is a lack of preventative, normalising discussions mentioned throughout the research which indicates that it remains taboo (McInnes, 2003). It is difficult to use the existing theories to understand the experiences of shared sexual decision making in this research because the evidence demonstrates that this did not happen. Therefore, the within pair decision making processes remain unexplored. However, the research shines a spotlight on individual decision-making processes, which can be understood using PT and TPB. Decision making is largely influenced by loss aversion for staff and the level of perceived control impacts how much PWLD were willing to disagree with decisions. This is present in all the accounts for participants with learning disabilities, all stating that they rarely disagree with family/staff. These theories can only be used to understand the experiences of isolated decision-making processes because collaborative decision making does not occur within this sample. This would be a recommendation for future research.

Strengths and Areas for Future Development

Whilst areas for development have been identified within this research, there are important strengths to be acknowledged. The following section will explore these individually: *topic, recruitment, method and methodology, and analysis.*

Topic

The topic of negotiating access to relationships and intimacy for PWLD is an under researched area but is something important in the lives of many PWLD. This was reflected in the enthusiasm both expert consultants and participants with learning disabilities demonstrated with regards to the study. All the participants with learning disabilities were keen to participate but experienced hesitation due to the lack of opportunities they have day to day to discuss relationships and intimacy, and the lack of guidance they receive from support workers. This uncertainty, discomfort and anxiety was also reflected in the support workers which is likely to have impacted engagement (Deffew et al., 2022). Ivy admitted not really thinking about sex and relationships as something she needed to speak about with PWLD, despite being acutely aware of the increased likelihood of them experiencing abuse. This links to an ongoing belief that PWLD are less likely to have sexual needs (Maguire et al., 2019). The need to protect professional vulnerability was a barrier to a relaxed and exploratory discussion.

Despite the discomfort and embarrassment experienced, all participants recognised the importance of discussing sex and relationships with PWLD and were keen to have more scaffolded opportunities to do this.

Recruitment

This study explores a limited sample size though meets the recommendations (6-10) for a Doctoral Level IPA study as outlined in Smith et al. (2022). The small sample size reflects both the complexities of the study design as is described by Henry and Fetters (2012), and recruitment difficulties; reliance on clinicians to consider cases and make initial contact with potential participants, the necessity of having an appropriate staff member to be both available and consenting, and capacity. The latter was further complicated by shift patterns and the willingness of individual staff members to discuss sex and relationships with a service user due to cultural beliefs or discomfort (Deffew et al., 2022). Some individuals had been identified as meeting the inclusion/exclusion criteria but during initial contact, they were found to lack capacity and were not included in the study.

Steps taken to enhance recruitment involved multiple follow up emails with the whole team and individual clinicians, some of which were not always responded to due to demand and priorities within clinical roles. I visited the recruitment site and spent three full days to speak to staff about potential participants and to clarify inclusion/exclusion criteria. Other barriers related to identified individuals being in a mental health crisis or experiencing ongoing systemic difficulties. One participant had to decide how to use their personal support hours and decided to prioritise their deteriorating physical health over participating in the research. This highlighted the barriers PWLD face on a daily basis. Other potential participants were apprehensive about being video recorded but said they would value discussing the topic.

Participants in this research reflect a self-selected sample, therefore results are more likely to be skewed so cannot be generalised. The sample offers limited information regarding immediate experiences of decision making for PWLD where their supporters have either negative perceptions of sex and relationships for PWLD or do not recognise the importance of having such discussions. Similarly, the research does not capture the experiences of PWLD living with 24/7 support, or family member, nor does it offer a religiously or culturally diverse insight. Future research would benefit from a more diverse sample to further understand these unexplored areas.

Method and Methodology

The design of the study aimed to create a fresh and topically focussed experience to reflect on in part 2. The addition of video meant there would be visual and audio prompts to support experiential recall as traditional IPA relies on the ability to access past experiences, something that can be challenging for PWLD (Larsen et al., 2008; Smith et al., 2022). Part 1 aimed to generate an experience of collaborative sexual decision making between participants, however, it gave insight into the isolated experiences of sexual decision making. It also enabled participants to reflect on past experiences of sexual decision making and prompted further reflection of theses (Larsen et al., 2008). The level of avoidance demonstrated by staff during part 1 was also not anticipated. These unforeseen circumstances made it difficult to answer the initial research question. However, through the use of IPR, it allowed participants to reflect on past experiences and what sense they made of them. The research also provided evidence to suggest that PWLD continue to be excluded from collaborative decision-making surrounding sex and relationships, often having decisions made for them, or being implicitly influenced to make certain decisions.

The design of the study allowed for individuals to change their mind and withdraw, even after part 1 had already taken place. This was a strength of the design as it allowed PWLD to take control and make a decision, not to participate under acquiescence. It should be recognised that due to PWLD being socialised into compliance, there remains the potential for acquiescence during their interviews (Hollomotz, 2018; Stalker, 1998). Other unintended events occurring outside of the research project also impacted the start of recruitment.

Having expert consultants contribute to the design of the study further strengthened the credibility, ensuring it would be both accessible and meaningful to the target population (Williams, 2020). The experts were paid for their time which contributed to feeling purposeful and valued. This added to their overall experience of what it means to be human (Modini et al., 2016) and offered them a rare opportunity to be paid for their time and expertise (Ellenkamp et al., 2016; Tarvainen & Hänninen, 2022).

Use of both video and audio recording possibly increased the risk of withholding information (Williams, 2020). For 2 of 3 dyads, I believe this had minimal impact. One dyad experienced the presence of both myself and laptop as strange and somewhat invasive. They felt unable to speak at ease and I wondered if the conversation felt more like a ‘performance’ than free flowing dialogue, thus increasing exposure and fear of being negatively judged. Nevertheless, I believe my presence and recording of part 1 enabled me to share the experience with them, albeit from an observer's position. This is unusual for an IPA study (Smith et al., 2022) and I believe this strengthened the design. Whilst I hoped to be unobtrusive in the various settings, I was exposed to various behaviours, the atmosphere and other factors which will have informed the double hermeneutic process and contributed to my sense making. The use of IPR enabled at least three of the six participants to reflect on their own behaviour and I believe without this, it would have been difficult to access these reflections, or pick up on non-verbal communication. Unresponsiveness could be explored which was often due to an unwillingness to answer questions in part 1 rather than being unable to (Lesseliers et al., 2009). Whilst participants were offered control of pausing the video, and shown how to do this, only two did; one staff member and one PWLD. This could reflect the perception of who holds the power and control within the research, something I tried to minimise as much as possible in the design and approach to the study.

One participant extended the maximum one week gap between parts one and two of the study due to illness. Potential impact on recall of the experience was minimised with having the video recording to refer back to (Smith et al., 2022).

In order to enhance credibility of the research, Elliot et al's. (1999) guidelines for qualitative research was used and is illustrated in [Table 4].

Table 4. *Guidelines for Reviewing Standards of Qualitative Research (Elliott et al., 1999)*

Guidelines for Reviewing Standards of Qualitative Research	
Owning one’s perspective	This was done in the reflexivity section at the beginning of this report. Reflections were also added in throughout the body of the report.
Situating the sample	The sample was situated within the methods section and by offering brief pen portraits for each participant. I was mindful of balancing this with the need to maintain anonymity of participants where possible.
Grounding in examples	Direct quotes were identified from the transcripts that supported the analysis of data.
Credibility checks	Themes were discussed with project supervisors who both have clinical experience working within learning disabilities and through peer supervision with another DClin trainee conducting IPA.
Coherence	I sought feedback from supervisors on the flow and coherence of the writing. Tables and figures have been used where appropriate.
General. Vs. specific task	The use of IPA enabled specific insights into individual experiences whilst offering a general oversight regarding the phenomenon of sexual decision making.
Resonating with readers	There is research by other PWLD captured within this study highlighting the importance of hearing the voices of PWLD (Corr McEvoy, 2014). I have been mindful of the language and terminology used throughout the research. I chose words and terms that participants used to described their experiences and what is included within the literature. I also used quotation marks where I used terminology that I found ethically or morally questionable. I have been mindful to not overintellectualize the content, avoiding the use of jargon where possible and keeping the reader in mind. Expert consultants will be contacted to support the dissemination of results to relevant organisations and other PWLD.

Analysis

IPA was identified as an appropriate method of analysis as it would provide in depth accounts of sexual decision making. Whilst it was anticipated that the design may result in some barriers to 'free conversation' in part 1, these were underestimated. Being video recorded and having myself present in the room for part 1 led to some participants feeling like they were unable to interact normally. I believe this will have negatively impacted the ability to capture a natural experience and may have contributed to participants, particularly staff, behaving in what they believed to be a socially desirable manner. Whilst this is regarded as a limitation, the design and topic is a strength as it provided a novel experience for all participants to reflect on the otherwise limited opportunities they have to discuss sex and sexual decision making. All participants explained that it was the first time they had spoken about sex or sexual decision making with their particular pair and enabled them to reflect on past experiences, using these reflections to consider future decisions.

IPA is dependent on how much information a participant wishes, and is able to, share with a researcher. In this study, some participants withheld aspects of their experiences due to fears of being judged. This was observed in Felicity and Ivy's interviews as they either focussed on their professional role as a form of protection from revealing hidden beliefs and attitudes, or focussing on the performance of the other participant to deflect attention from themselves, "How long did she do?" (Ivy, 1741). Others were unable, or unwilling to fully communicate their experiences which was demonstrated when Robbie and Amelia did not finish sentences or chose not to elaborate on certain points (Amelia tended to shrug or say "I don't know"). This resulted in more interpretation from the researcher, in order to make sense of their experiences.

Overall, a key strength of this study was that it centred PWLD throughout the entire project. It met the aim of sharing their voices which also provides a significant contribution to the literature.

Implications

Implications for Participants and Expert Consultants

By participating in this research, individuals were given the opportunity to talk about something they rarely get chance to (Martino, 2022). They were able to do it in the context of research which offered a degree of safety and protection. For PWLD it was particularly important for them to have their voices heard; this was the same for participants and expert consultants. Whilst the literature lacks the voices of PWLD, there was a sense of support workers wanting their voices to be heard in this research too. They specifically mentioned having limited training and guidance which they believed would equip them with the confidence they need to support negotiating access to relationships and intimacy for PWLD. Charles draws attention to the dangerousness of the area in the absence of direction.

Clinical Implications

This study contributes to the limited literature surrounding the experiences of negotiating access to relationships and intimacy for PWLD. It has a number of clinical implications: how to open up much needed conversations, a need for reflective opportunities for staff, and unmet training needs including practical application of the MCA (Willner et al., 2011) when negotiating access to relationships and intimacy for PWLD.

All participants experienced embarrassment and lacked confidence to initiate the conversations, not wanting to exacerbate any discomfort. This study highlights the importance of creating a safe and scaffolded environment in which to have such conversations. Combining physical prompts (Appendix G) with a curious and non-judgemental approach to interviews meant that a naturalistic experience could be captured and explored from individual perspectives. Each pair had seen the prompt cards prior to part 1 but staff decided the order in which they would ask questions. Whilst staff asked direct questions as written on the cards, further discussion was elicited as participants were able to reflect on past experiences and engage in a more fluid and dynamic conversation. Some participants struggled to speak freely thus the prompt cards were more heavily relied on. This emphasises both the versatility and necessity of resources such as prompt cards to safely scaffold conversations. Without the cards it is uncertain if conversations would have elicited as much information due to them being sensitive and unfamiliar. Having had input from expert consultants meant the cards particularly resonated with PWLD. Shirley noticed that the depth of conversation was influenced by the questions on the cards and this felt ok for her but it also highlights the flexibility in which they can be used. Developing a resource pack of prompt cards would enhance the potential for future collaboration in facilitating similar conversations. This research demonstrated a tendency for support workers to take control of what questions would be asked in what order, therefore it would be recommended that pairs take it in turns to choose questions or even turn cards face down and randomly pick them. This would reduce power imbalances and create an informal yet structured space to explore sensitive topics. The content of discussions could reveal knowledge gaps and areas for further development. Such cards should not be used solely as a reactive strategy, but more as an ongoing clinical tool to normalise discussions. This could then enhance collaboration and involvement for PWLD in negotiations and decision making processes.

The use of IPR provided staff with an opportunity to reflect on their clinical practice in a novel way – watching themselves on video. Not only did IPR offer an aide memoire for conversation content but it allowed staff to consider their emotional responses to the content and how this influenced their future decisions. Felicity was able to recognise how she made sense of Robbie's comments about "keeping" women through her own experience of being a young woman and felt uncomfortable about this, prioritising the safety of "vulnerable" women over Robbie's sexual autonomy. Ivy was able to use the video to pay attention to her body language and facial expressions. This increased Ivy's anxiety about getting something "wrong", or being exposed. Whilst Ivy's willingness to reflect was limited in this study, it emphasises the potential for continued use of IPR. Charles found it particularly helpful as it allowed him to reflect on his own beliefs and understanding of the topic. IPR also benefitted the participants with LD. Robbie used it as an opportunity to guide the interview, sharing control of pausing the video thus demonstrating how empowering this method can be. Shirley and Amelia used the process to identify sections where they had experienced positive feelings and really focussed on these, "I felt good about that one" (Shirley). Regular reflection using IPR would reveal any patterns and could support greater understanding of clinical practice, particularly of decision-making processes.

The outcomes of this research demonstrate a tendency to avoid decision making in this context. Relationships and intimacy remains a grey and taboo area for both PWLD and supporting staff in this sample. The discomfort and uncertainty experienced by staff particularly, indicates a need for focussed training (Grieve et al., 2008; Hollomotz, 2009). The lack of direction and guidance experienced by staff impacted their confidence in their ability to safely navigate conversations about sex and relationships with PWLD. The clear lack of confidence and guidance revealed an unexpected and hidden yet important outcome: support workers' experiences of vulnerability. The fear and uncertainty surrounding it led to avoidance, ultimately increasing potential vulnerability. Staff both implicitly and explicitly communicated a need for more training and guidance in their interviews, "we're making it up as we go along (Felicity)", "are you trained to be in a position to offer Shirley support round that, well, no…" (Charles).

This study has demonstrated that PWLD continue to be excluded from decision making processes, especially sexual decisions. Support staff believe they need to protect PWLD by making decisions for them, or by withholding information and education. This was illustrated in the current study when Ivy expressed her anxiety when a "training" course was given to PWLD about relationships and children. She also did not raise the topic with Amelia as she was not currently engaged in a sexual relationship. Robbie experienced restrictions but had limited understanding about the complexities of this. This could link to his limited understanding and the extent to which others have tried to address knowledge gaps is unclear. Whilst restrictions are often implemented in the context of safeguarding and protection, it unintentionally contributes to the perceived vulnerability of PWLD (Martino, 2022). The tendency to prioritise protection over enhancing sexual autonomy reflects either a poor understanding or misunderstanding of the practical application of the MCA. Furthermore, there is a risk of breaching article 8 of the Human Rights Act (1998) if PWLD are prevented from accessing relationships, sexual or otherwise and if they are not supported to gain capacity. These examples suggest a need for further training on both the MCA and Human Rights. Training would benefit from a range of complex scenarios which are reflective of staff experiences. It would be important to include both staff and PWLD in the development of training packages to ensure it addresses the uncertain areas.

Research Implications

This study provides a framework on which future research can be built. It demonstrates inclusive research as outlined by Walmsley & Johnson (2003) and is led by PWLD.

Future research should capture the experiences of family members during sexual decision making. Some of the findings from this study contrast existing literature as it tended to be staff that experienced more hesitancy and uncertainty compared to family members. At least two families were described as having open and liberal approaches to their child’s sex life, something which resulted in heightened anxiety for staff. Where family are actively involved in the lives of PWLD who receive support from staff, it would be beneficial to reproduce this study with all three groups: PWLD, staff and family. This would offer greater insight into the complexities of decision making and would reveal potentially hidden barriers.

It would be recommended that similar, novel, and multi perspective approaches to research are used for this area. Even though this study was designed to gain insight into the shared decision making process, it highlighted the difficulties researching this area and the barriers to participation. Future research would benefit from a longitudinal approach. It would be interesting to follow pairs of participants through a journey of sexual decision making, supported by the use of IPR, and other models such as Kolb’s Experiential Learning Cycle (1984). Not only would this offer helpful insight into what can facilitate and hinder collaborative decision making but it would inform clinical practice and could result in a framework for use in similar situations. It would enable clinicians to reflect on experiences, what they have learnt and trying other ways of approaching the topic (Kolb, 1984) in a safe and hopefully contained way.

The dynamic between Robbie and Felicity highlighted the difficulties future researchers may face when exploring this topic in mixed gendered pairs. Due to staffing difficulties, Robbie participated in the research with a young, female support worker which led to uncomfortable feelings for both. This could potentially have impacted how freely they both engaged in part 1 and highlights the necessity of giving enough time to consider appropriate pairing to ensure protection of all participants. In this instance, I remained present in the room to offer a layer of protection for both participants. Whilst the pairing was not ideal, it offered insight into how such conversations may occur within some dyads, in this example between a young female support worker and a young male with learning disabilities. In such situations there may be increased experiences of vulnerability, often influenced by where the power is held in the relationship.

With regards to further understanding the decision making processes, it would be helpful to gain further insight into the perceived risks and gains used to negotiate and weigh up decisions. This would offer insight into how people negotiate risks within similar relationships, where there is an imbalance of power. It also would be interesting to explore the potential application of Shared Decision Making in this context. It is likely that further clinical developments, such as enhanced staff training, would need to be observed prior to engaging in SDM in this particular context. Staff would need to have a good level of confidence and information to be able to share with PWLD and a comprehensive understanding of the Mental Capacity Act (2005) and how it is applied to scenarios involving relationships and intimacy. There needs to be a recognition that PWLD are entitled to be involved in decision making processes and to make unwise decisions if they have capacity. Much of the existing research into SDM focusses on health treatment options therefore further research would be needed to understand if SDM could be applied in the context of negotiating access to relationships and intimacy for PWLD.

Conclusion

The outcomes of this study unexpectedly highlight a parallel experience of perceived vulnerability for PWLD and support workers. PWLD repeatedly experience barriers when trying to access relationships and intimacy which is centred around a continued internalised belief that PWLD are “vulnerable” and need protecting. This challenges the recent changes in terminology from “vulnerable adult” to “adult at risk”. Despite moving to “adult at risk” as a way of externalising vulnerability, people regularly working with PWLD in sensitive contexts continue to regard them as inherently vulnerable. PWLD in this sample also perceive themselves as vulnerable. This results in unequal access to education and information for PWLD thus contributing to increased vulnerability and risk. A lack of training and knowledge sharing for staff supporting PWLD creates confusion, uncertainty and anxiety which ultimately leads to avoidance of discussing relationships and intimacy. It is difficult for staff to act on their beliefs that PWLD have a right to sexual relationships because of a lack of existing guidance to empower sexual determination thus heightening their perceived vulnerability. Thus by protecting PWLD from harm, staff are unintentionally denying them of their human rights. This study has emphasised the need for further research surrounding the processes of sexual decision making for PWLD and their wider support network.

This study provides evidence to encourage sensitive conversations to happen. It highlights how important, both PWLD and support workers, feel it is to have conversations about relationships and intimacy but also how embarrassing and anxiety provoking it can be. There is a fear of negative repercussions and this results in avoidance. There is an uncertainty about how to start conversations because they rarely happen, mostly in the context of reactive risk management scenarios. Through participating in this research, all participants were able to navigate sensitive conversations with the support of prompt cards despite feeling embarrassed and uncomfortable at times during part 1. The addition of part 2 gave participants opportunity to reflect on internal experiences that arose during part 1 and offered the opportunity to explore these further. This illustrates the importance of creating structured guidance to facilitate such conversations. The outcomes recommend staff taking an initial lead, to invite PWLD to have conversations about relationships and intimacy, to begin to shift the narrative to a positive and safe discussion. Once the option is available, PWLD should then be encouraged to take control by sharing navigation of conversations. Further training for support workers should involve how to initiate sensitive conversations, encouraging the use of resources, such as prompt cards, where appropriate.

More research is needed to understand how decision making processes, and negotiations, occur in supportive relationships between PWLD and their support workers. Current theories, such as Prospect Theory, Theory of Planned Behaviour, and even Shared Decision Making, fall short of helping us understand how decisions are reached for PWLD in the context of accessing relationships and intimacy. Existing theories could be used to understand individual decision making processes but these rarely address intimate decisions as mentioned in this study.

Key recommendations for Clinical Practice

The clinical implications of this research has resulted in a number of recommendations for future clinical practice. The recommendations apply to all individuals who support PWLD within this context:

- Take an intersectional and interdisciplinary approach to deconstruct individual experiences of vulnerability (Martino, 2022; Siller and Aydin, 2022; Vikery, 2018). This recognises the individual nature of “vulnerability” and will encourage deeper thinking about what contributes to the perception of being “vulnerable”.
- Increase the amount of training offered to staff regarding sex and sexuality for PWLD (Deffew et al., 2022). This should encompass the practical application of the MCA to sexual decisions (Willner et al., 2011) and reiterate article 8 of the human rights act

(Rushbrooke et al., 2014). Case examples should be used to ensure training resonates with staff (Herbert et al., 2019) and training should be co-produced with both staff and PWLD (Deffew et al., 2022). Within this it will be important to highlight examples of positive sexual experiences to support a shift in narrative for both PWLD and staff. This could be strengthened through having PWLD as co-facilitators (Corr McEvoy, 2014; SCIE, 2007).

- Develop resources for staff to use to scaffold conversations. The prompt cards in this study were highly beneficial and created a rare opportunity for conversations surrounding relationships and intimacy to happen. Resources should be developed in collaboration with PWLD and staff to ensure they are both meaningful and accessible.
- Encourage the use of Interpersonal Process Recall as a reflective tool. This would require appropriately trained staff being able to facilitate supervision spaces. It may be necessary to network with external organisations to seek appropriate supervision. Alternatively, other models could be used to encourage reflection such as Kolb's Experiential Learning Cycle (Kolb, 1984). This would encourage reflection regarding how negotiations are made and what drives decisions.
- Remember that PWLD are "human beings" and should be empowered to enhance their ability to make informed decisions about their rights (Corr McEvoy & Keenan, 2014), including sex and relationships (Rushbrooke et al., 2014). Safe spaces to discuss this should be created and initially it will be staff responsibility to invite PWLD to engage in these conversations. Appropriate information and education should be available in these spaces in order to fill existing knowledge gaps (Björnsdóttir et al., 2015). This will shift the narrative of sex and relationships as being taboo and something that requires intervention, to something that is a basic human need and can be explored safely.

All participants valued being involved in this research and appreciated the opportunity to safely test having conversations about relationships and intimacy. To conclude this research, important points raised by PWLD during their participation will be shared:

- Robbie emphasises the need for full information about relationships and intimacy. He is often provided with limited information but wants to know more.
- Amelia speaks about being given skewed information, such as the bad things about having children. It is important to provide balanced information so people can make choices and fully informed decisions.

- Shirley believes that more information needs to be available for PWLD. She feels strongly that PWLD should be treated as human beings, and this means being given access to information and being empowered to make autonomous decisions.

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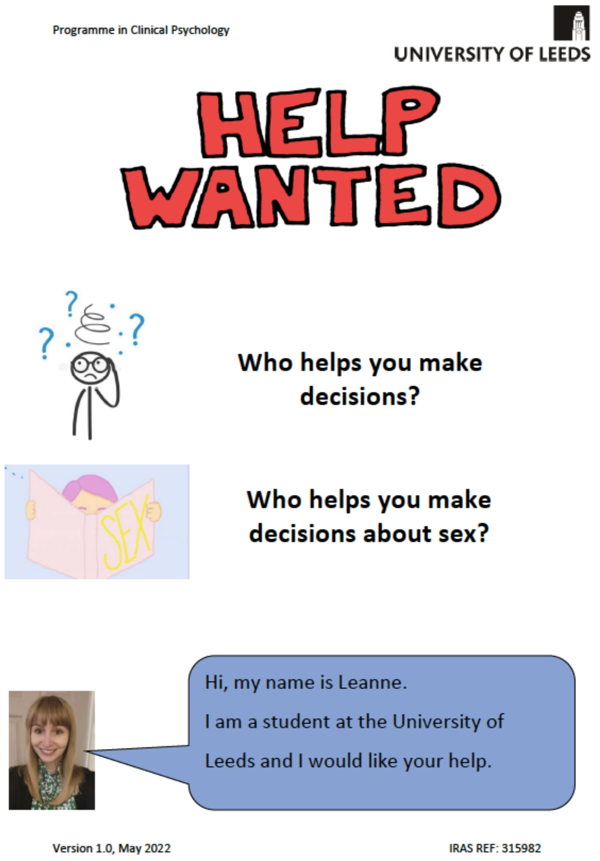
Appendix A: Recruitment Advert



Programme in Clinical Psychology

UNIVERSITY OF LEEDS

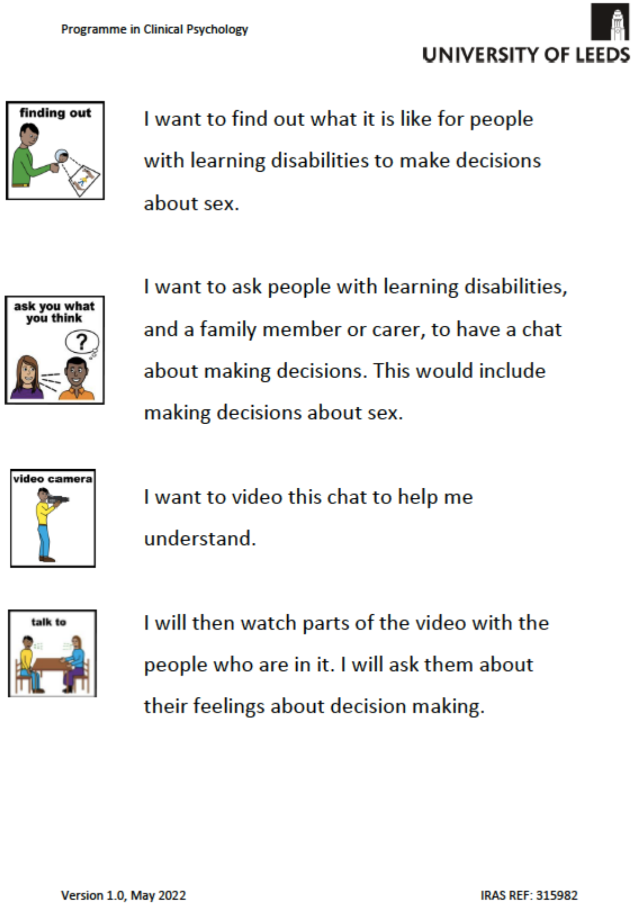
Who helps you make decisions?

Who helps you make decisions about sex?

Hi, my name is Leanne.
I am a student at the University of Leeds and I would like your help.

Version 1.0, May 2022

IRAS REF: 315982



Programme in Clinical Psychology

UNIVERSITY OF LEEDS

I want to find out what it is like for people with learning disabilities to make decisions about sex.

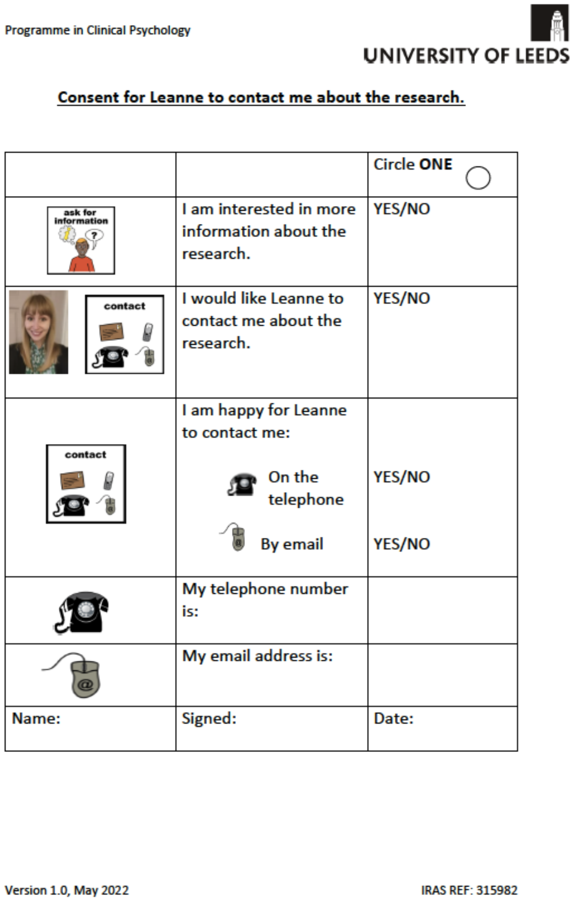
I want to ask people with learning disabilities, and a family member or carer, to have a chat about making decisions. This would include making decisions about sex.

I want to video this chat to help me understand.

I will then watch parts of the video with the people who are in it. I will ask them about their feelings about decision making.

Version 1.0, May 2022

IRAS REF: 315982



Programme in Clinical Psychology

UNIVERSITY OF LEEDS

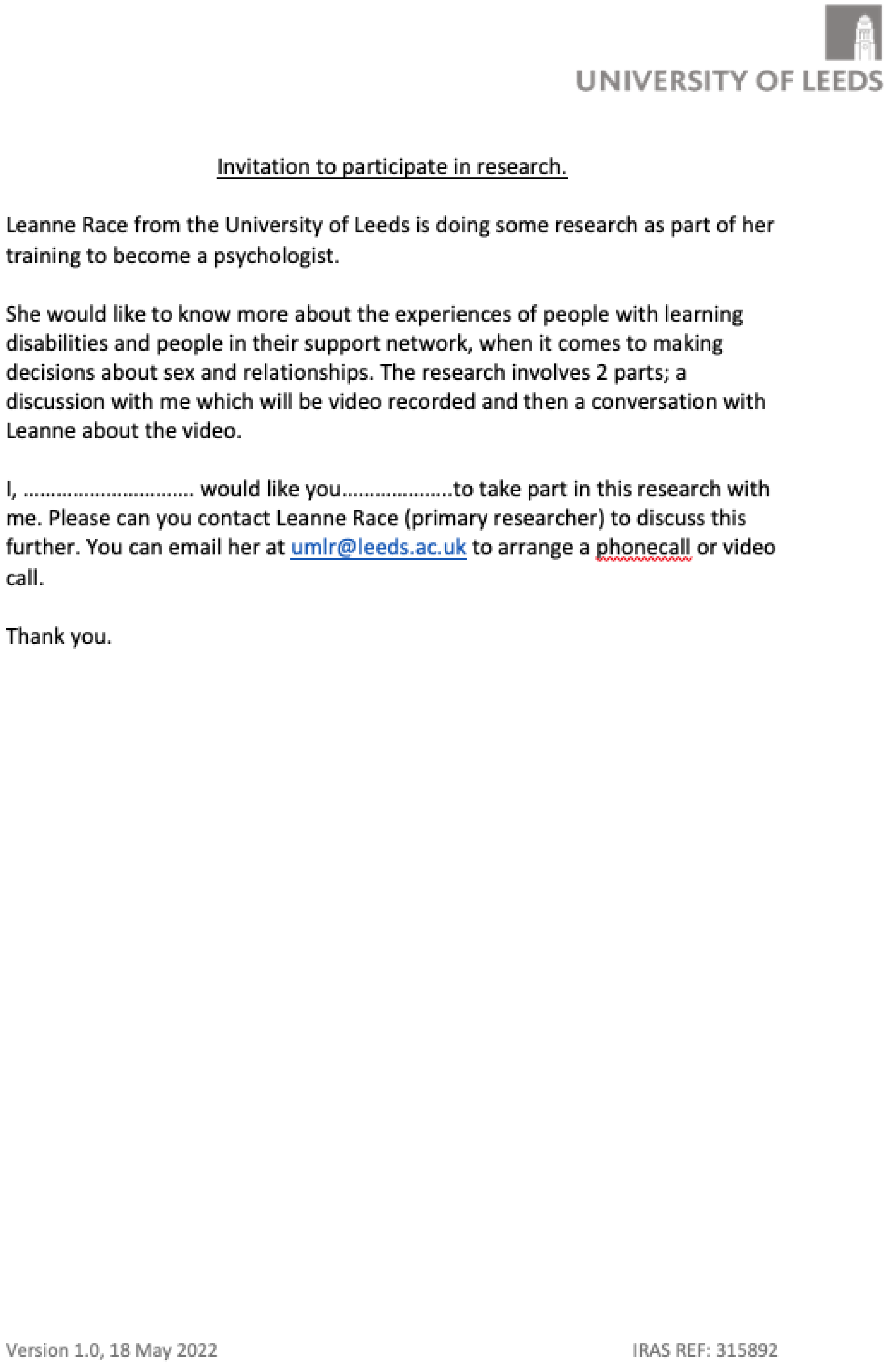
Consent for Leanne to contact me about the research.

		Circle **ONE** ○
	I am interested in more information about the research.	YES/NO
	I would like Leanne to contact me about the research.	YES/NO
	I am happy for Leanne to contact me: ☎ On the telephone By email	 YES/NO YES/NO
☎	My telephone number is:	
	My email address is:	
Name:	Signed:	Date:

Version 1.0, May 2022

IRAS REF: 315982

Appendix B: Invitation to Participate for Support Workers



UNIVERSITY OF LEEDS

Invitation to participate in research.

Leanne Race from the University of Leeds is doing some research as part of her training to become a psychologist.

She would like to know more about the experiences of people with learning disabilities and people in their support network, when it comes to making decisions about sex and relationships. The research involves 2 parts; a discussion with me which will be video recorded and then a conversation with Leanne about the video.

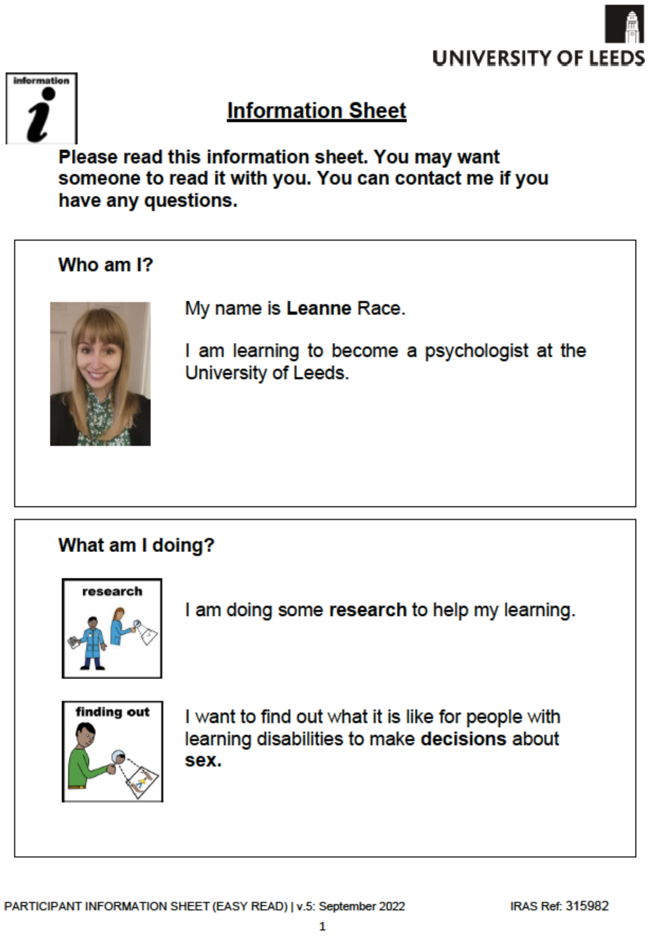
I, ………………………… would like you………………..to take part in this research with me. Please can you contact Leanne Race (primary researcher) to discuss this further. You can email her at umlr@leeds.ac.uk to arrange a phonecall or video call.

Thank you.

Version 1.0, 18 May 2022 IRAS REF: 315892

Appendix C: Information Sheets

C: Easy Read Information Sheet



UNIVERSITY OF LEEDS

Information Sheet

Please read this information sheet. You may want someone to read it with you. You can contact me if you have any questions.

Who am I?

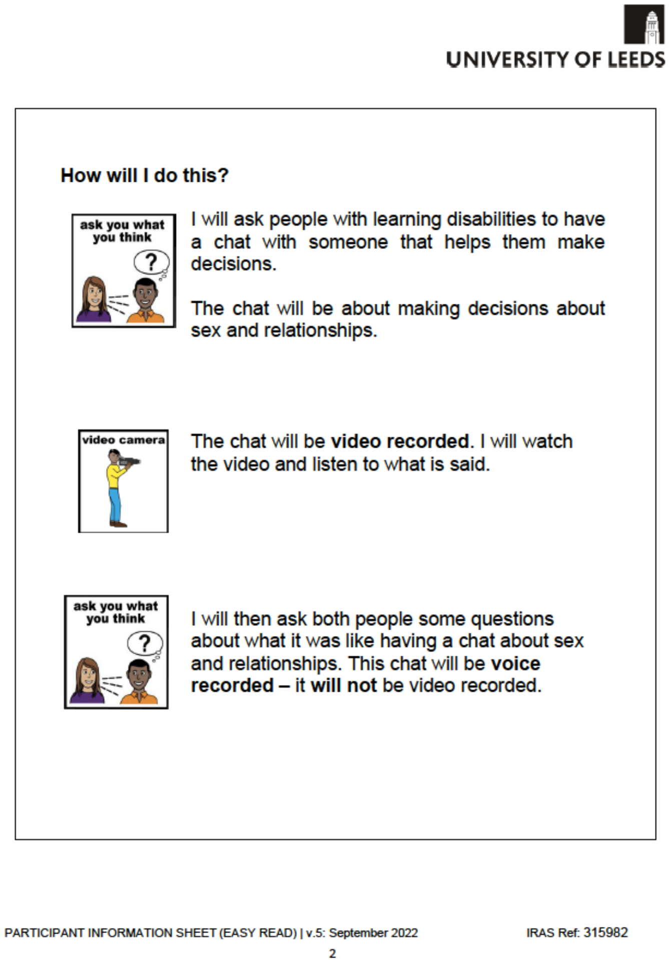
My name is **Leanne** Race.

I am learning to become a psychologist at the University of Leeds.

What am I doing?

I am doing some **research** to help my learning.

I want to find out what it is like for people with learning disabilities to make **decisions** about **sex.**



UNIVERSITY OF LEEDS

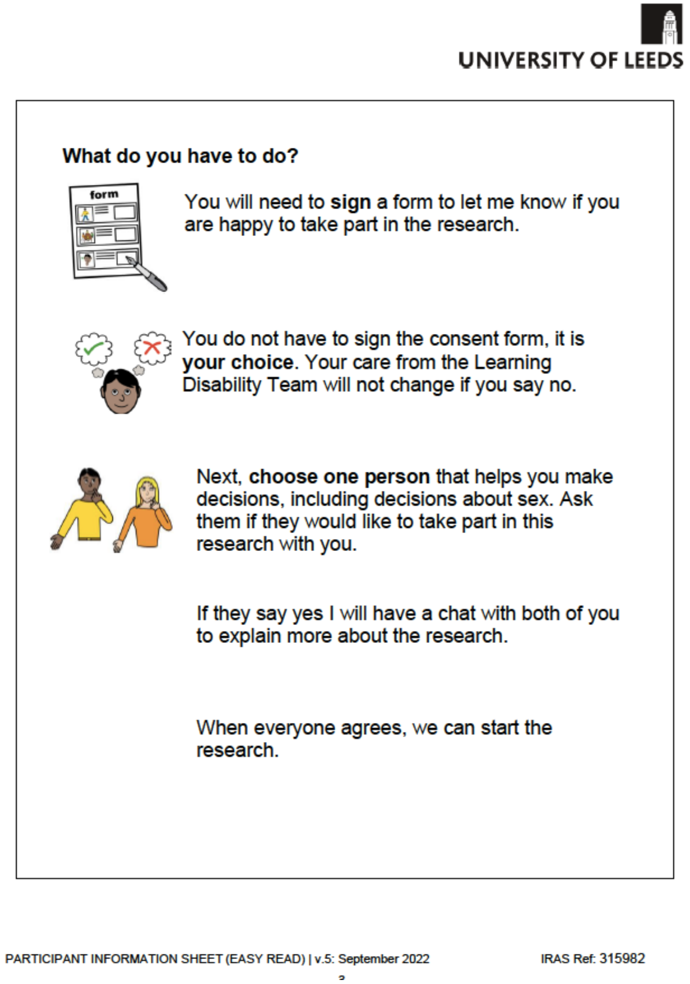
How will I do this?

I will ask people with learning disabilities to have a chat with someone that helps them make decisions.

The chat will be about making decisions about sex and relationships.

The chat will be **video recorded**. I will watch the video and listen to what is said.

I will then ask both people some questions about what it was like having a chat about sex and relationships. This chat will be **voice recorded – it will not** be video recorded.



UNIVERSITY OF LEEDS

What do you have to do?

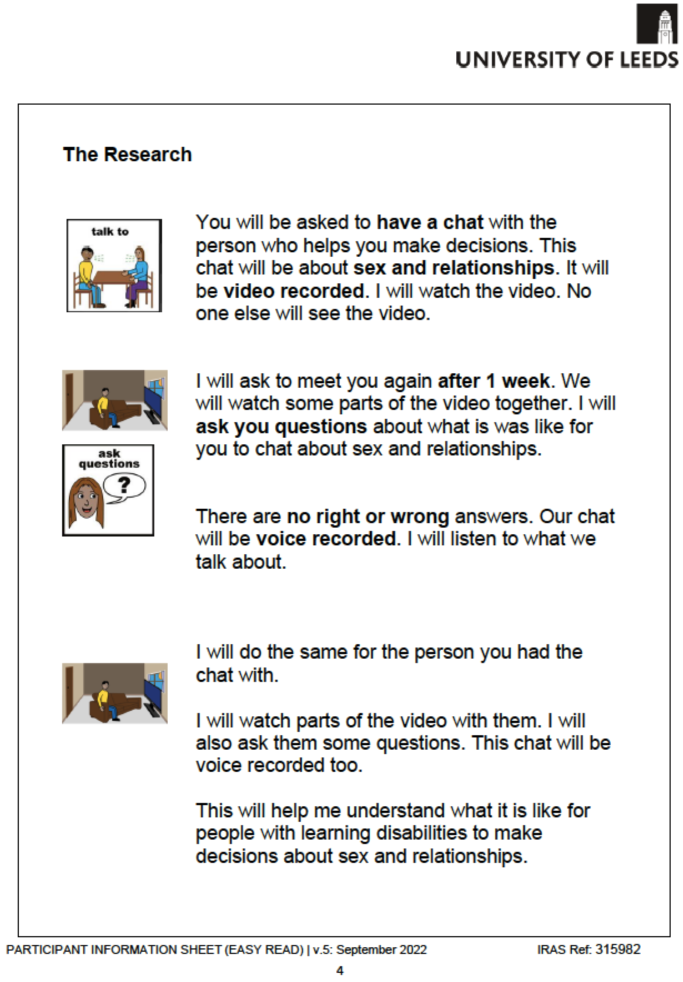
You will need to **sign** a form to let me know if you are happy to take part in the research.

You do not have to sign the consent form, it is **your choice**. Your care from the Learning Disability Team will not change if you say no.

Next, **choose one person** that helps you make decisions, including decisions about sex. Ask them if they would like to take part in this research with you.

If they say yes I will have a chat with both of you to explain more about the research.

When everyone agrees, we can start the research.



UNIVERSITY OF LEEDS

The Research

You will be asked to **have a chat** with the person who helps you make decisions. This chat will be about **sex and relationships**. It will be **video recorded**. I will watch the video. No one else will see the video.

I will ask to meet you again **after 1 week**. We will watch some parts of the video together. I will **ask you questions** about what is was like for you to chat about sex and relationships.

There are **no right or wrong** answers. Our chat will be **voice recorded**. I will listen to what we talk about.

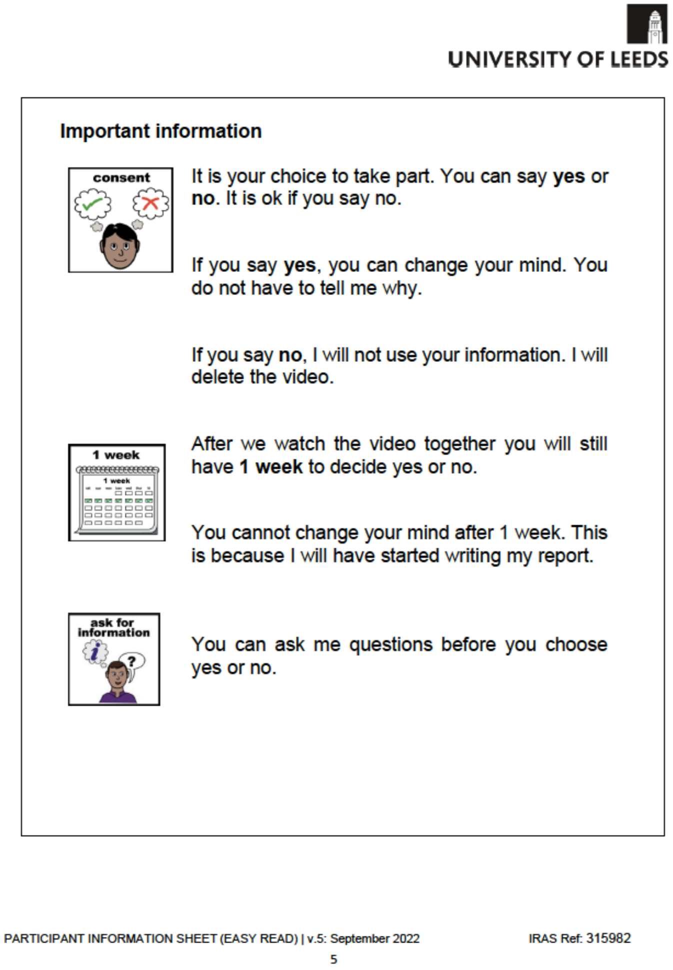
I will do the same for the person you had the chat with.

I will watch parts of the video with them. I will also ask them some questions. This chat will be voice recorded too.

This will help me understand what it is like for people with learning disabilities to make decisions about sex and relationships.

PARTICIPANT INFORMATION SHEET (EASY READ) | v.5: September 2022 IRAS Ref: 315982

4



UNIVERSITY OF LEEDS

Important information

It is your choice to take part. You can say **yes** or **no**. It is ok if you say no.

If you say **yes**, you can change your mind. You do not have to tell me why.

If you say **no**, I will not use your information. I will delete the video.

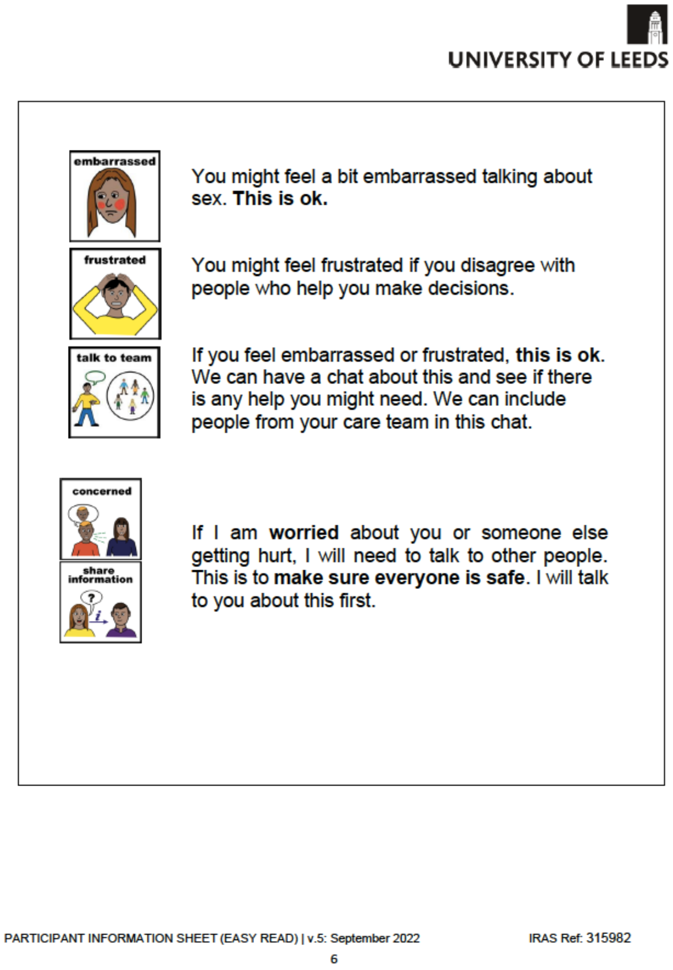
After we watch the video together you will still have **1 week** to decide yes or no.

You cannot change your mind after 1 week. This is because I will have started writing my report.

You can ask me questions before you choose yes or no.

PARTICIPANT INFORMATION SHEET (EASY READ) | v.5: September 2022 IRAS Ref: 315982

5



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You might feel a bit embarrassed talking about sex. **This is ok.**

You might feel frustrated if you disagree with people who help you make decisions.

If you feel embarrassed or frustrated, **this is ok**. We can have a chat about this and see if there is any help you might need. We can include people from your care team in this chat.

If I am **worried** about you or someone else getting hurt, I will need to talk to other people. This is to **make sure everyone is safe**. I will talk to you about this first.

PARTICIPANT INFORMATION SHEET (EASY READ) | v.5: September 2022 IRAS Ref: 315982

6

If you say yes

I will keep your name **private** and **confidential**. It will be a **secret**. You can choose a different name I can use when I write my report.

I will **not share** the **videos** with people. I might let other people from the research team listen to the voice recordings to help me understand.

I will watch the videos and will write a **report** about them. I will use some of what you talk about. This is to help other people learn about making decisions about sex. I will **not include** your private and confidential information.

You will have the **choice** to read a **short report** of the research after it is finished. This can be sent to you.

Videos and voice recordings will be kept in a **private** place on a University of Leeds computer network. No one else will have the password for the computer being used or for the University of Leeds computer network.

Videos will be deleted after I have written a report about my research.

Voice recordings will be kept on the computer network for 3 years. They will be **deleted after 3 years.**

Other information

This website has more information about how I might use your information in my research www.hra.nhs.uk/patientdataandresearch.

The University of Leeds has a document explaining privacy and research. This has been included with this information sheet.

The research team

If you would like to contact anyone about this research, the people you can contact are:

Leanne Race (primary researcher)
Leeds Institute of Health Sciences, School of Medicine
University of Leeds, Clarendon Way, Leeds, LS2 9LN
umlr@leeds.ac.uk
0113 3430815

Dr Andrea Hollomotz (research supervisor)
Social Sciences Building, University of Leeds, Clarendon Way, Leeds, LS2 9LN
a.hollomotz@leeds.ac.uk
0113 3437298

Dr Tom Isherwood (research supervisor)
Leeds Institute of Health Sciences, School of Medicine
University of Leeds, Clarendon Way, Leeds, LS2 9LN
t.m.isherwood@leeds.ac.uk
0113 3430815

Who can I contact if I have a complaint?

If you want to complain about how researchers have handled your information, you should contact the research team. If you are not happy after that, you can contact the Data Protection Officer on dpo@leeds.ac.uk.

If you are not happy with their response or believe they are processing your data in a way that is not right or lawful, you can complain to the Information Commissioner's Office (ICO) (www.ico.org.uk or 0303 123 1113).

Thank You

Thank you for reading this information sheet. It is yours to keep.

Word Meanings

Confidential
Information that is confidential is meant to be kept secret or private

Consent
When you say that you agree to something happening, you are giving your consent.

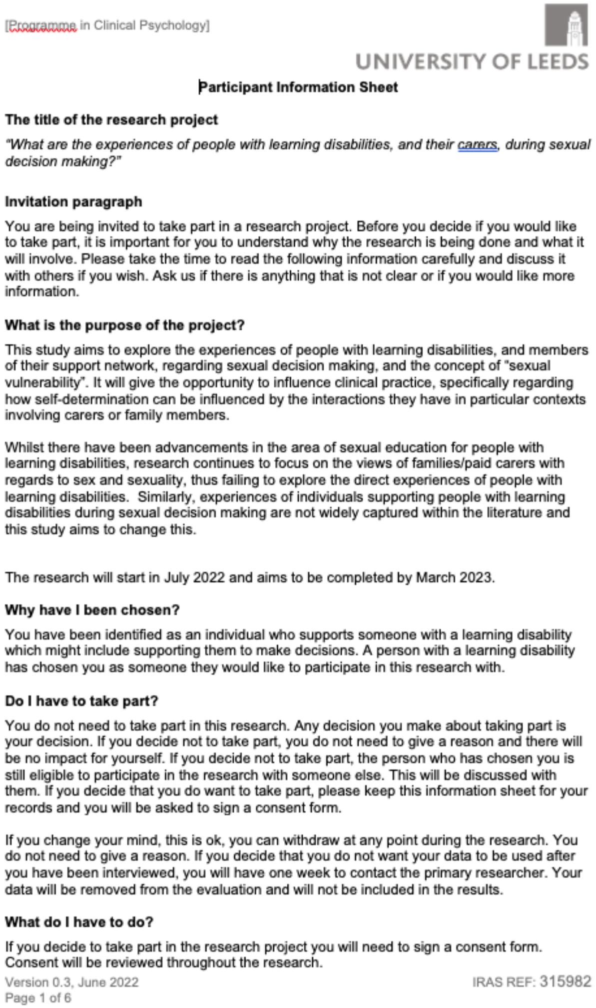
When you give your consent, it is only for what you have been asked about at that time.

You will be told everything you need to know. You must be given enough information to help you decide.

Psychologist
A psychologist is someone who talks to people about their thoughts and feelings.

Research
Research helps us understand different things. It involves collecting information from people about different topics.

C: Written Information Sheet



Participant Information Sheet

The title of the research project

"What are the experiences of people with learning disabilities, and their carers, during sexual decision making?"

Invitation paragraph

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

What is the purpose of the project?

This study aims to explore the experiences of people with learning disabilities, and members of their support network, regarding sexual decision making, and the concept of "sexual vulnerability". It will give the opportunity to influence clinical practice, specifically regarding how self-determination can be influenced by the interactions they have in particular contexts involving carers or family members.

Whilst there have been advancements in the area of sexual education for people with learning disabilities, research continues to focus on the views of families/paid carers with regards to sex and sexuality, thus failing to explore the direct experiences of people with learning disabilities. Similarly, experiences of individuals supporting people with learning disabilities during sexual decision making are not widely captured within the literature and this study aims to change this.

The research will start in July 2022 and aims to be completed by March 2023.

Why have I been chosen?

You have been identified as an individual who supports someone with a learning disability which might include supporting them to make decisions. A person with a learning disability has chosen you as someone they would like to participate in this research with.

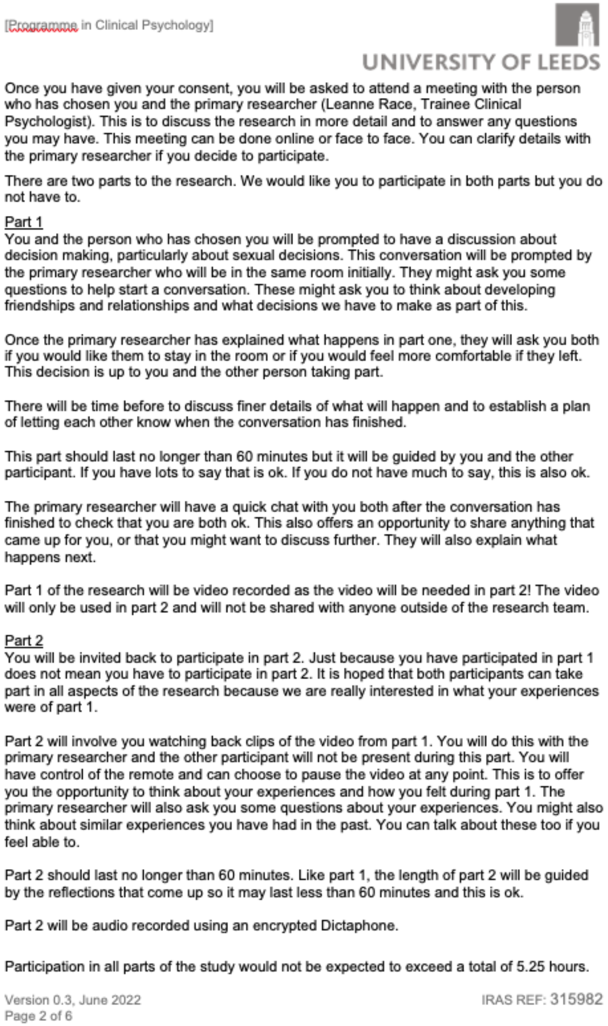
Do I have to take part?

You do not need to take part in this research. Any decision you make about taking part is your decision. If you decide not to take part, you do not need to give a reason and there will be no impact for yourself. If you decide not to take part, the person who has chosen you is still eligible to participate in the research with someone else. This will be discussed with them. If you decide that you do want to take part, please keep this information sheet for your records and you will be asked to sign a consent form.

If you change your mind, this is ok, you can withdraw at any point during the research. You do not need to give a reason. If you decide that you do not want your data to be used after you have been interviewed, you will have one week to contact the primary researcher. Your data will be removed from the evaluation and will not be included in the results.

What do I have to do?

If you decide to take part in the research project you will need to sign a consent form. Consent will be reviewed throughout the research.



Once you have given your consent, you will be asked to attend a meeting with the person who has chosen you and the primary researcher (Leanne Race, Trainee Clinical Psychologist). This is to discuss the research in more detail and to answer any questions you may have. This meeting can be done online or face to face. You can clarify details with the primary researcher if you decide to participate.

There are two parts to the research. We would like you to participate in both parts but you do not have to.

Part 1
You and the person who has chosen you will be prompted to have a discussion about decision making, particularly about sexual decisions. This conversation will be prompted by the primary researcher who will be in the same room initially. They might ask you some questions to help start a conversation. These might ask you to think about developing friendships and relationships and what decisions we have to make as part of this.

Once the primary researcher has explained what happens in part one, they will ask you both if you would like them to stay in the room or if you would feel more comfortable if they left. This decision is up to you and the other person taking part.

There will be time before to discuss finer details of what will happen and to establish a plan of letting each other know when the conversation has finished.

This part should last no longer than 60 minutes but it will be guided by you and the other participant. If you have lots to say that is ok. If you do not have much to say, this is also ok.

The primary researcher will have a quick chat with you both after the conversation has finished to check that you are both ok. This also offers an opportunity to share anything that came up for you, or that you might want to discuss further. They will also explain what happens next.

Part 1 of the research will be video recorded as the video will be needed in part 2! The video will only be used in part 2 and will not be shared with anyone outside of the research team.

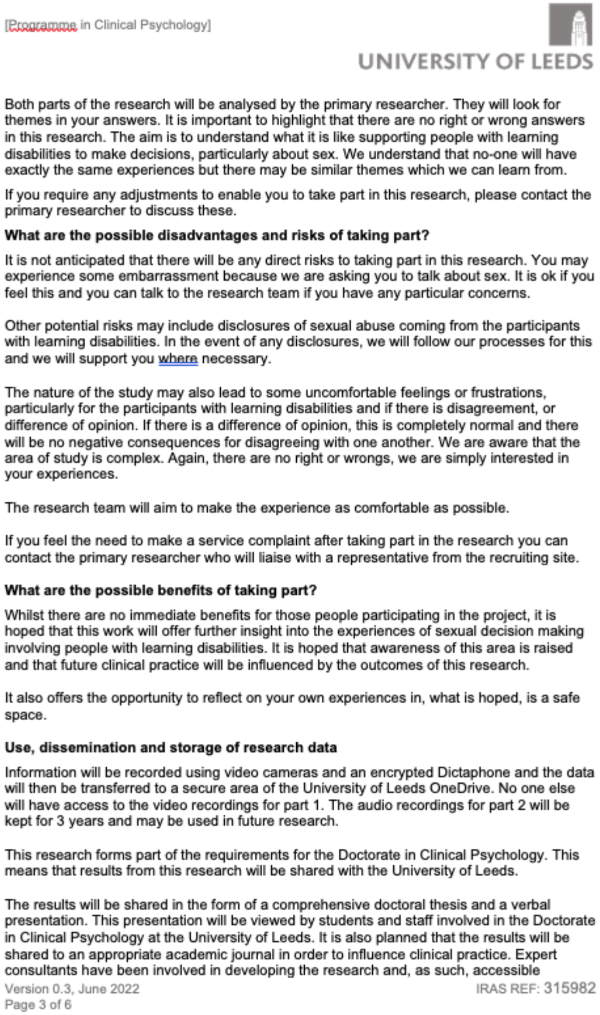
Part 2
You will be invited back to participate in part 2. Just because you have participated in part 1 does not mean you have to participate in part 2. It is hoped that both participants can take part in all aspects of the research because we are really interested in what your experiences were of part 1.

Part 2 will involve you watching back clips of the video from part 1. You will do this with the primary researcher and the other participant will not be present during this part. You will have control of the remote and can choose to pause the video at any point. This is to offer you the opportunity to think about your experiences and how you felt during part 1. The primary researcher will also ask you some questions about your experiences. You might also think about similar experiences you have had in the past. You can talk about these too if you feel able to.

Part 2 should last no longer than 60 minutes. Like part 1, the length of part 2 will be guided by the reflections that come up so it may last less than 60 minutes and this is ok.

Part 2 will be audio recorded using an encrypted Dictaphone.

Participation in all parts of the study would not be expected to exceed a total of 5.25 hours.



Both parts of the research will be analysed by the primary researcher. They will look for themes in your answers. It is important to highlight that there are no right or wrong answers in this research. The aim is to understand what it is like supporting people with learning disabilities to make decisions, particularly about sex. We understand that no-one will have exactly the same experiences but there may be similar themes which we can learn from.

If you require any adjustments to enable you to take part in this research, please contact the primary researcher to discuss these.

What are the possible disadvantages and risks of taking part?

It is not anticipated that there will be any direct risks to taking part in this research. You may experience some embarrassment because we are asking you to talk about sex. It is ok if you feel this and you can talk to the research team if you have any particular concerns.

Other potential risks may include disclosures of sexual abuse coming from the participants with learning disabilities. In the event of any disclosures, we will follow our processes for this and we will support you where necessary.

The nature of the study may also lead to some uncomfortable feelings or frustrations, particularly for the participants with learning disabilities and if there is disagreement, or difference of opinion. If there is a difference of opinion, this is completely normal and there will be no negative consequences for disagreeing with one another. We are aware that the area of study is complex. Again, there are no right or wrongs, we are simply interested in your experiences.

The research team will aim to make the experience as comfortable as possible.

If you feel the need to make a service complaint after taking part in the research you can contact the primary researcher who will liaise with a representative from the recruiting site.

What are the possible benefits of taking part?

Whilst there are no immediate benefits for those people participating in the project, it is hoped that this work will offer further insight into the experiences of sexual decision making involving people with learning disabilities. It is hoped that awareness of this area is raised and that future clinical practice will be influenced by the outcomes of this research.

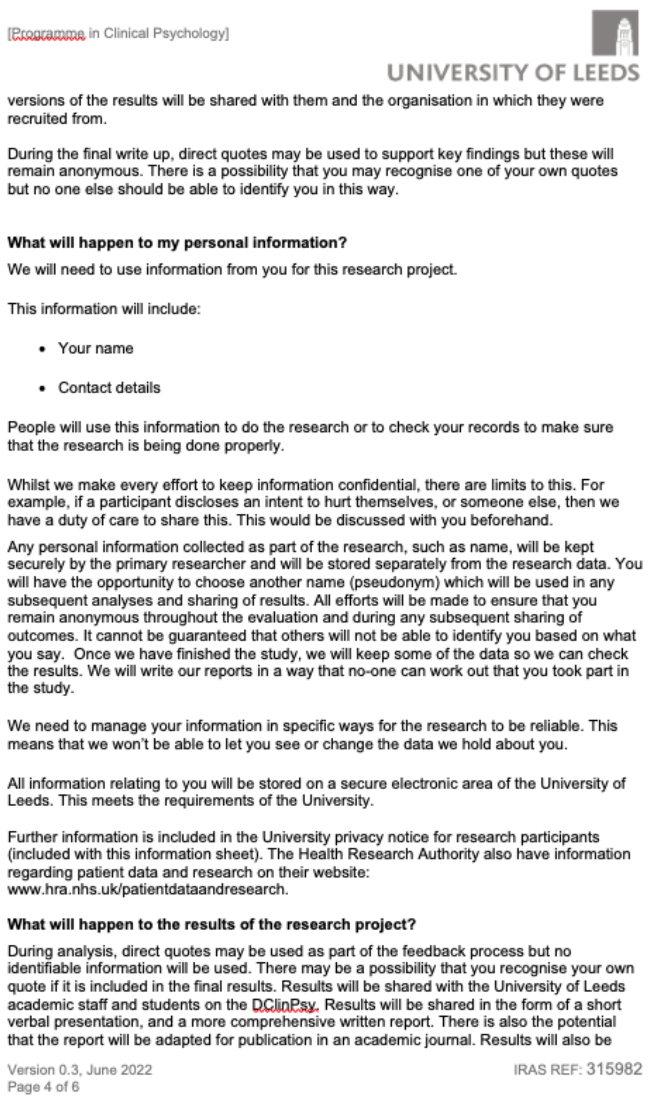
It also offers the opportunity to reflect on your own experiences in, what is hoped, is a safe space.

Use, dissemination and storage of research data

Information will be recorded using video cameras and an encrypted Dictaphone and the data will then be transferred to a secure area of the University of Leeds OneDrive. No one else will have access to the video recordings for part 1. The audio recordings for part 2 will be kept for 3 years and may be used in future research.

This research forms part of the requirements for the Doctorate in Clinical Psychology. This means that results from this research will be shared with the University of Leeds.

The results will be shared in the form of a comprehensive doctoral thesis and a verbal presentation. This presentation will be viewed by students and staff involved in the Doctorate in Clinical Psychology at the University of Leeds. It is also planned that the results will be shared to an appropriate academic journal in order to influence clinical practice. Expert consultants have been involved in developing the research and, as such, accessible



versions of the results will be shared with them and the organisation in which they were recruited from.

During the final write up, direct quotes may be used to support key findings but these will remain anonymous. There is a possibility that you may recognise one of your own quotes but no one else should be able to identify you in this way.

What will happen to my personal information?

We will need to use information from you for this research project.

This information will include:

- Your name
- Contact details

People will use this information to do the research or to check your records to make sure that the research is being done properly.

Whilst we make every effort to keep information confidential, there are limits to this. For example, if a participant discloses an intent to hurt themselves, or someone else, then we have a duty of care to share this. This would be discussed with you beforehand.

Any personal information collected as part of the research, such as name, will be kept securely by the primary researcher and will be stored separately from the research data. You will have the opportunity to choose another name (pseudonym) which will be used in any subsequent analyses and sharing of results. All efforts will be made to ensure that you remain anonymous throughout the evaluation and during any subsequent sharing of outcomes. It cannot be guaranteed that others will not be able to identify you based on what you say. Once we have finished the study, we will keep some of the data so we can check the results. We will write our reports in a way that no-one can work out that you took part in the study.

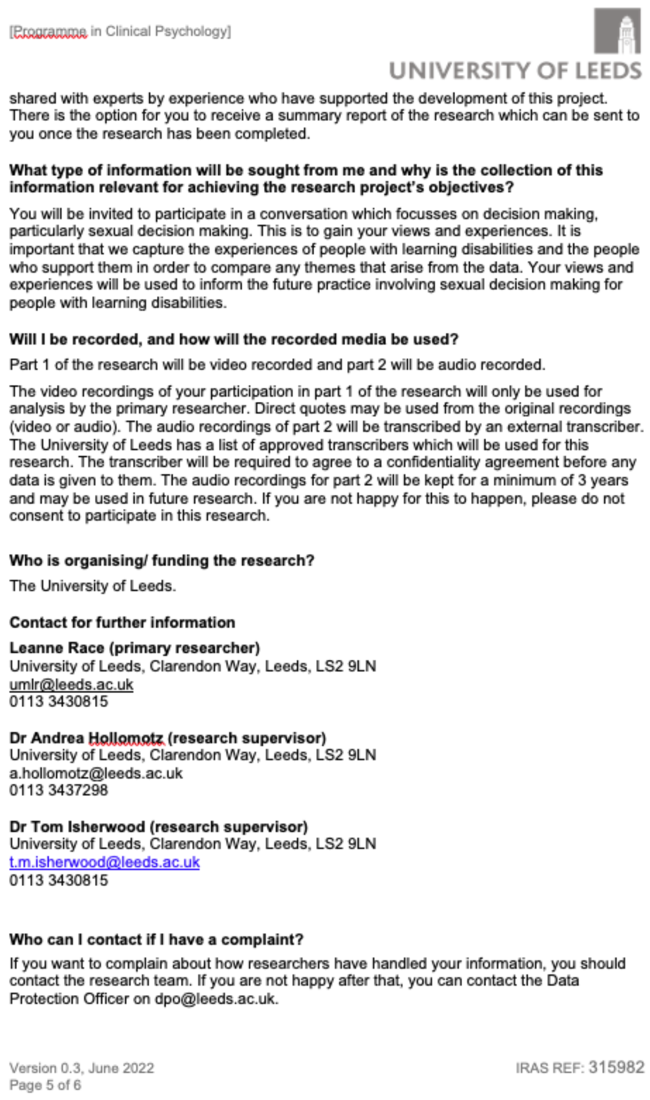
We need to manage your information in specific ways for the research to be reliable. This means that we won't be able to let you see or change the data we hold about you.

All information relating to you will be stored on a secure electronic area of the University of Leeds. This meets the requirements of the University.

Further information is included in the University privacy notice for research participants (included with this information sheet). The Health Research Authority also have information regarding patient data and research on their website: www.hra.nhs.uk/patientdataandresearch.

What will happen to the results of the research project?

During analysis, direct quotes may be used as part of the feedback process but no identifiable information will be used. There may be a possibility that you recognise your own quote if it is included in the final results. Results will be shared with the University of Leeds academic staff and students on the DClinPsy. Results will be shared in the form of a short verbal presentation, and a more comprehensive written report. There is also the potential that the report will be adapted for publication in an academic journal. Results will also be



shared with experts by experience who have supported the development of this project. There is the option for you to receive a summary report of the research which can be sent to you once the research has been completed.

What type of information will be sought from me and why is the collection of this information relevant for achieving the research project's objectives?

You will be invited to participate in a conversation which focusses on decision making, particularly sexual decision making. This is to gain your views and experiences. It is important that we capture the experiences of people with learning disabilities and the people who support them in order to compare any themes that arise from the data. Your views and experiences will be used to inform the future practice involving sexual decision making for people with learning disabilities.

Will I be recorded, and how will the recorded media be used?

Part 1 of the research will be video recorded and part 2 will be audio recorded.

The video recordings of your participation in part 1 of the research will only be used for analysis by the primary researcher. Direct quotes may be used from the original recordings (video or audio). The audio recordings of part 2 will be transcribed by an external transcriber. The University of Leeds has a list of approved transcribers which will be used for this research. The transcriber will be required to agree to a confidentiality agreement before any data is given to them. The audio recordings for part 2 will be kept for a minimum of 3 years and may be used in future research. If you are not happy for this to happen, please do not consent to participate in this research.

Who is organising/ funding the research?

The University of Leeds.

Contact for further information

Leanne Race (primary researcher)
University of Leeds, Clarendon Way, Leeds, LS2 9LN
umlr@leeds.ac.uk
0113 3430815

Dr Andrea Hollomotz (research supervisor)
University of Leeds, Clarendon Way, Leeds, LS2 9LN
a.hollomotz@leeds.ac.uk
0113 3437298

Dr Tom Isherwood (research supervisor)
University of Leeds, Clarendon Way, Leeds, LS2 9LN
t.m.isherwood@leeds.ac.uk
0113 3430815

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If you want to complain about how researchers have handled your information, you should contact the research team. If you are not happy after that, you can contact the Data Protection Officer on dpo@leeds.ac.uk.

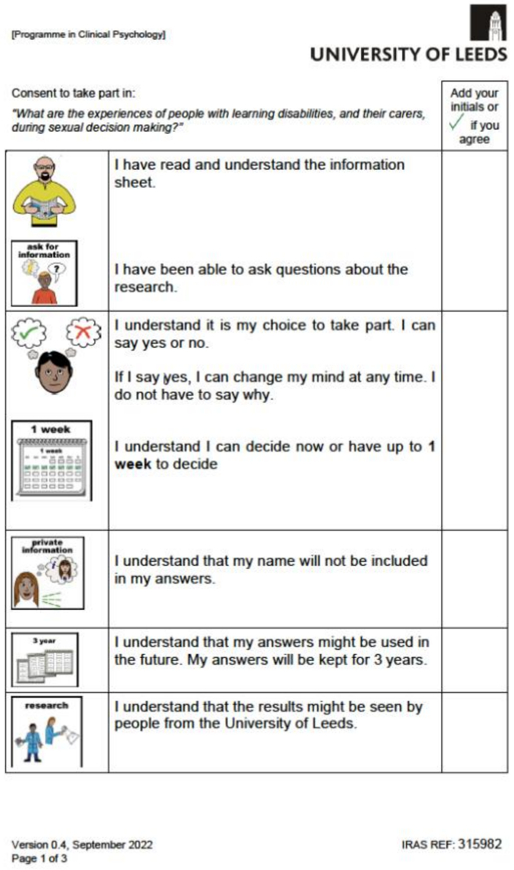
If you are not happy with their response or believe they are processing your data in a way that is not right or lawful, you can complain to the Information Commissioner's Office (ICO) (www.ico.org.uk or 0303 123 1113).

This information sheet is yours to keep. A copy of your signed consent form will also be given to you for your records.

Thank you for taking the time to read through this information and for considering participating in this research.

Appendix D: Consent Forms

D: Easy Read Consent Form



[Programme in Clinical Psychology]

UNIVERSITY OF LEEDS

Consent to take part in:

"What are the experiences of people with learning disabilities, and their carers, during sexual decision making?"

		Add your initials or ✓ if you agree
	I have read and understand the information sheet. I have been able to ask questions about the research.	
	I understand it is my choice to take part. I can say yes or no. If I say yes, I can change my mind at any time. I do not have to say why. I understand I can decide now or have up to **1 week** to decide	
	I understand that my name will not be included in my answers.	
	I understand that my answers might be used in the future. My answers will be kept for 3 years.	
	I understand that the results might be seen by people from the University of Leeds.	

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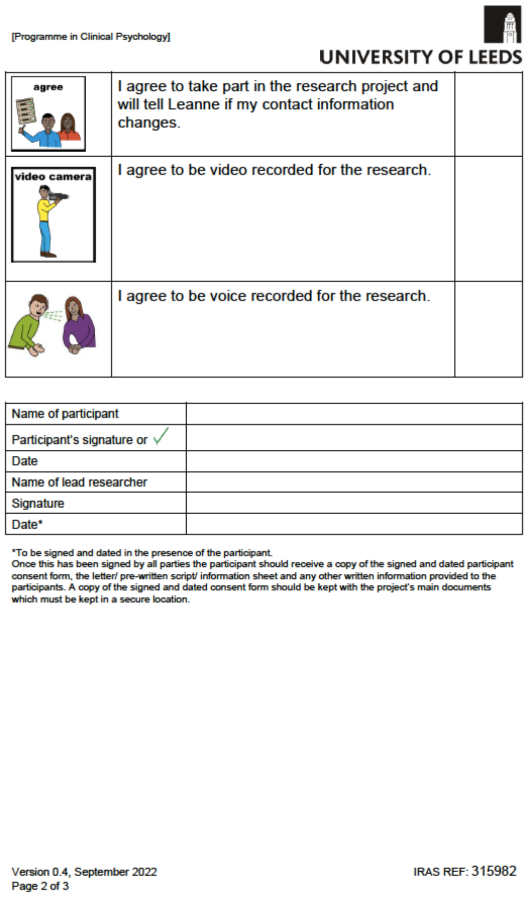
Page 1 of 3

IRAS REF: 315982



[Programme in Clinical Psychology]

UNIVERSITY OF LEEDS

	I agree to take part in the research project and will tell Leanne if my contact information changes.	
	I agree to be video recorded for the research.	
	I agree to be voice recorded for the research.	

Name of participant	
Participant's signature or ✓	
Date	
Name of lead researcher	
Signature	
Date*	

*To be signed and dated in the presence of the participant.
Once this has been signed by all parties the participant should receive a copy of the signed and dated participant consent form, the letter/ pre-written script/ information sheet and any other written information provided to the participants. A copy of the signed and dated consent form should be kept with the project's main documents which must be kept in a secure location.

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Page 2 of 3

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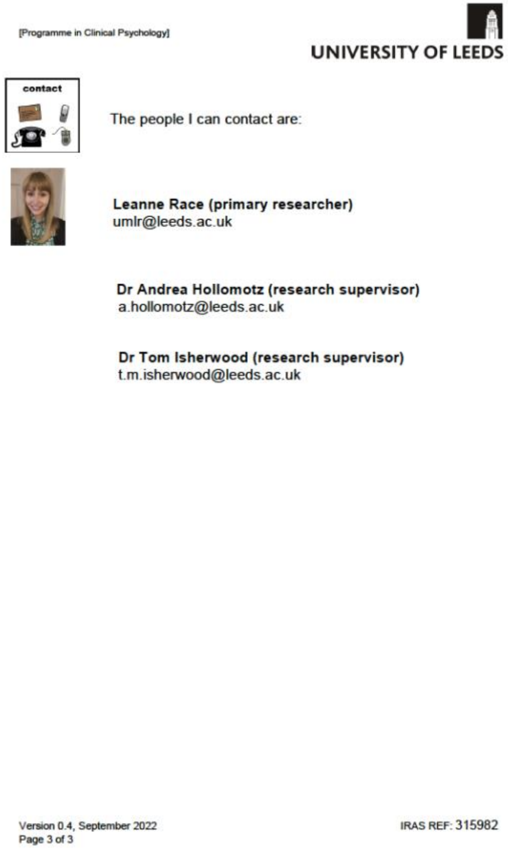

[Programme in Clinical Psychology]

UNIVERSITY OF LEEDS

The people I can contact are:

Leanne Race (primary researcher)
umlr@leeds.ac.uk

Dr Andrea Hollomotz (research supervisor)
a.hollomotz@leeds.ac.uk

Dr Tom Isherwood (research supervisor)
t.m.isherwood@leeds.ac.uk

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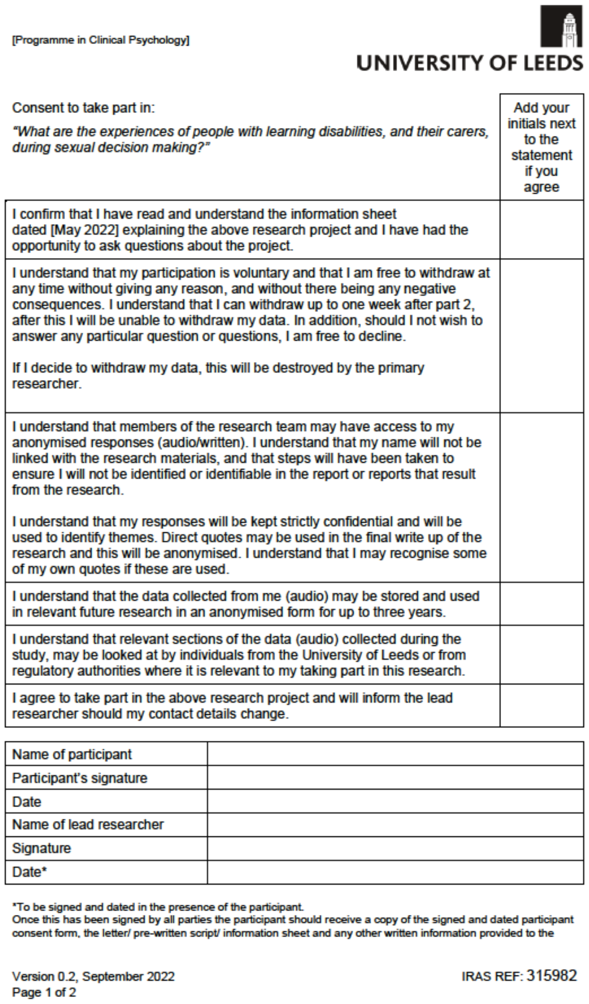
D: Written Consent Form



[Programme in Clinical Psychology]

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Consent to take part in: *"What are the experiences of people with learning disabilities, and their carers, during sexual decision making?"*	Add your initials next to the statement if you agree
I confirm that I have read and understand the information sheet dated [May 2022] explaining the above research project and I have had the opportunity to ask questions about the project.	
I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, and without there being any negative consequences. I understand that I can withdraw up to one week after part 2, after this I will be unable to withdraw my data. In addition, should I not wish to answer any particular question or questions, I am free to decline. If I decide to withdraw my data, this will be destroyed by the primary researcher.	
I understand that members of the research team may have access to my anonymised responses (audio/written). I understand that my name will not be linked with the research materials, and that steps will have been taken to ensure I will not be identified or identifiable in the report or reports that result from the research. I understand that my responses will be kept strictly confidential and will be used to identify themes. Direct quotes may be used in the final write up of the research and this will be anonymised. I understand that I may recognise some of my own quotes if these are used.	
I understand that the data collected from me (audio) may be stored and used in relevant future research in an anonymised form for up to three years.	
I understand that relevant sections of the data (audio) collected during the study, may be looked at by individuals from the University of Leeds or from regulatory authorities where it is relevant to my taking part in this research.	
I agree to take part in the above research project and will inform the lead researcher should my contact details change.	

Name of participant	
Participant's signature	
Date	
Name of lead researcher	
Signature	
Date*	

*To be signed and dated in the presence of the participant.
Once this has been signed by all parties the participant should receive a copy of the signed and dated participant consent form, the letter/ pre-written script/ information sheet and any other written information provided to the

Version 0.2, September 2022
Page 1 of 2

IRAS REF: 315982

[Programme in Clinical Psychology]

UNIVERSITY OF LEEDS

participants. A copy of the signed and dated consent form should be kept with the project's main documents which must be kept in a secure location.

Contact details for the research team are as follows:

Leanne Race (primary researcher)
umlr@leeds.ac.uk

Dr Andrea Hollomotz (research supervisor)
a.hollomotz@leeds.ac.uk

Dr Tom Isherwood (research supervisor)
t.m.isherwood@leeds.ac.uk

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Appendix E: Ethical Approval

Ymchwil Iechyd a Gofal Cymru
Health and Care Research Wales

NHS
Health Research Authority

Email: approvals@hra.nhs.uk

Dr Tom Isherwood
University of Leeds
Clarendon Way
Leeds
LS2 9LNN/A

22 September 2022

Dear Dr Isherwood

HRA and Health and Care Research Wales (HCRW) Approval Letter

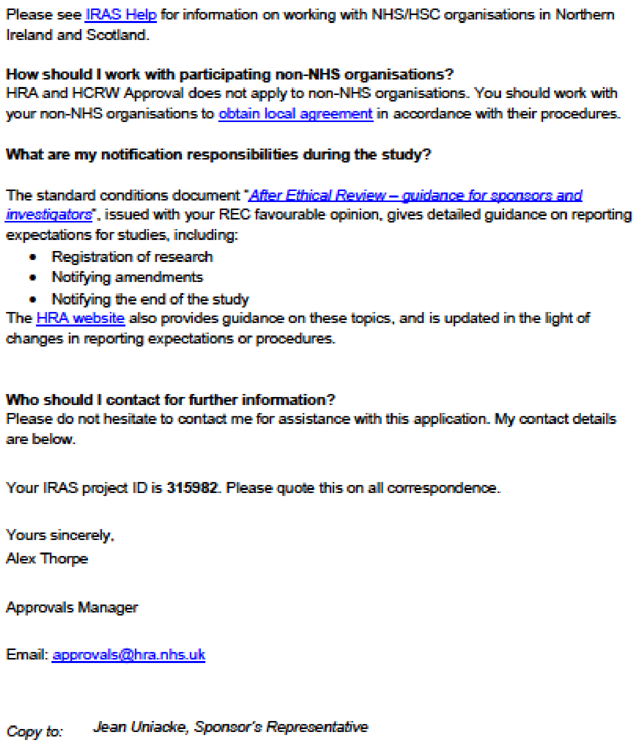
Study title: **Whose decision is it anyway? A qualitative exploration of sexual decision making for people with learning disabilities and their support network.**
IRAS project ID: **315982**
Protocol number: **n/a**
REC reference: **22/YH/0163**
Sponsor **University of Leeds**

I am pleased to confirm that HRA and Health and Care Research Wales (HCRW) Approval has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications received. You should not expect to receive anything further relating to this application.

Please now work with participating NHS organisations to confirm capacity and capability, in line with the instructions provided in the "Information to support study set up" section towards the end of this letter.

How should I work with participating NHS/HSC organisations in Northern Ireland and Scotland?
HRA and HCRW Approval does not apply to NHS/HSC organisations within Northern Ireland and Scotland.

If you indicated in your IRAS form that you do have participating organisations in either of these devolved administrations, the final document set and the study wide governance report (including this letter) have been sent to the coordinating centre of each participating nation. The relevant national coordinating function/s will contact you as appropriate.



Please see IRAS Help for information on working with NHS/HSC organisations in Northern Ireland and Scotland.

How should I work with participating non-NHS organisations?
HRA and HCRW Approval does not apply to non-NHS organisations. You should work with your non-NHS organisations to obtain local agreement in accordance with their procedures.

What are my notification responsibilities during the study?

The standard conditions document "*After Ethical Review – guidance for sponsors and investigators*", issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:

- Registration of research
- Notifying amendments
- Notifying the end of the study

The HRA website also provides guidance on these topics, and is updated in the light of changes in reporting expectations or procedures.

Who should I contact for further information?
Please do not hesitate to contact me for assistance with this application. My contact details are below.

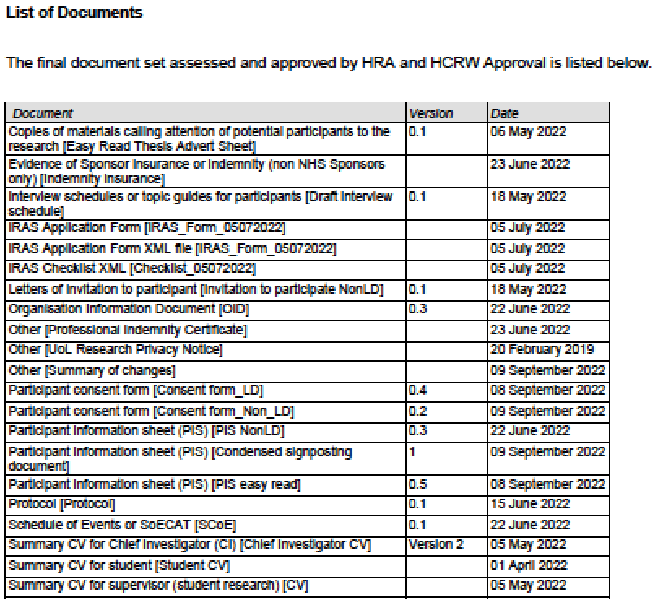
Your IRAS project ID is **315982**. Please quote this on all correspondence.

Yours sincerely,
Alex Thorpe

Approvals Manager

Email: approvals@hra.nhs.uk

Copy to: *Jean Uniacke, Sponsor's Representative*

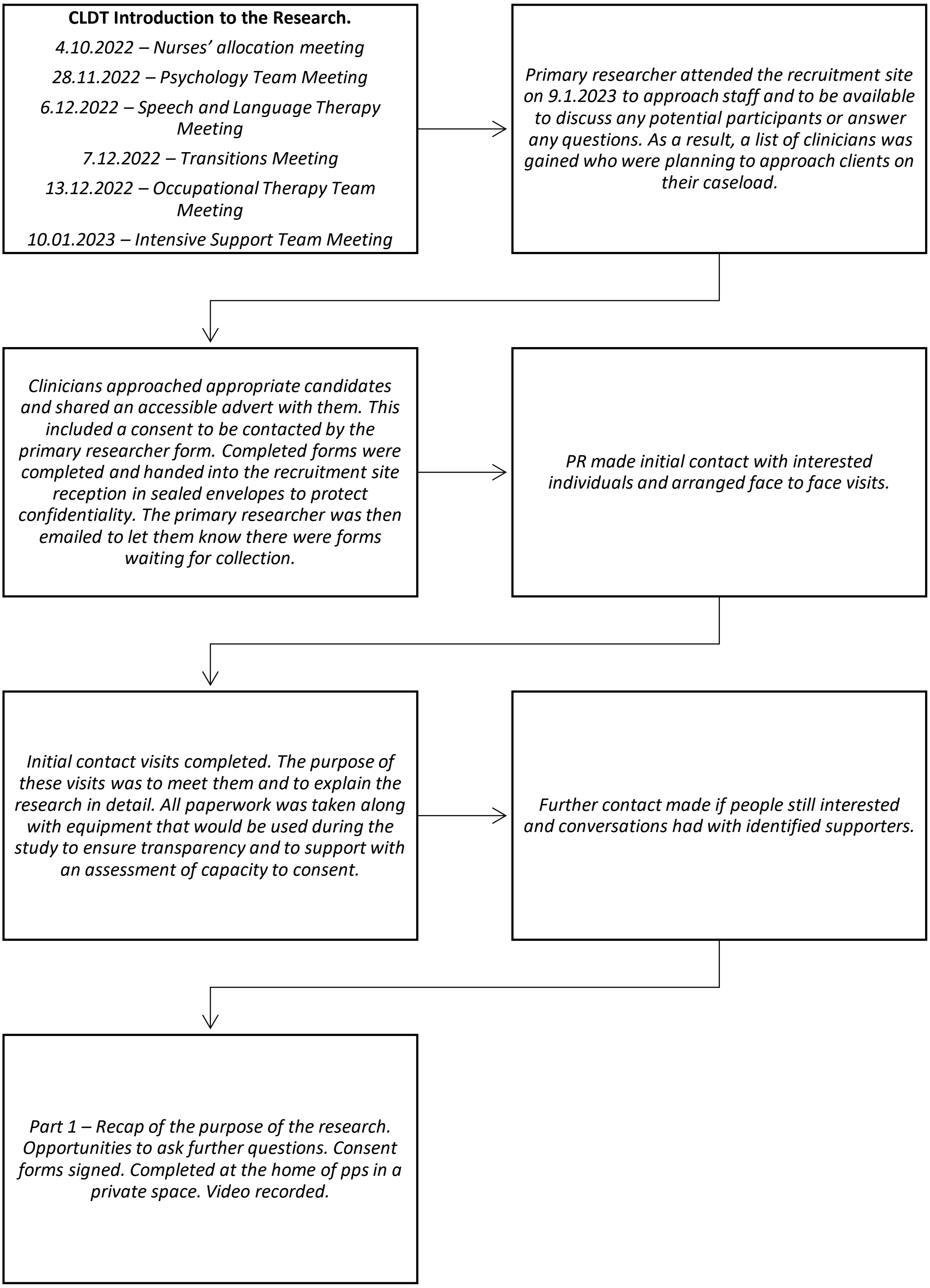


List of Documents

The final document set assessed and approved by HRA and HCRW Approval is listed below.

Document	*Version*	*Date*
Copies of materials calling attention of potential participants to the research [Easy Read Thesis Advert Sheet]	0.1	06 May 2022
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Indemnity Insurance]		23 June 2022
Interview schedules or topic guides for participants [Draft Interview schedule]	0.1	18 May 2022
IRAS Application Form [IRAS_Form_05072022]		05 July 2022
IRAS Application Form XML file [IRAS_Form_05072022]		05 July 2022
IRAS Checklist XML [Checklist_05072022]		05 July 2022
Letters of invitation to participant [Invitation to participate NonLD]	0.1	18 May 2022
Organisation Information Document [OID]	0.3	22 June 2022
Other [Professional Indemnity Certificate]		23 June 2022
Other [UoL Research Privacy Notice]		20 February 2019
Other [Summary of changes]		09 September 2022
Participant consent form [Consent form_LD]	0.4	08 September 2022
Participant consent form [Consent form_Non_LD]	0.2	09 September 2022
Participant information sheet (PIS) [PIS NonLD]	0.3	22 June 2022
Participant information sheet (PIS) [Condensed signposting document]	1	09 September 2022
Participant information sheet (PIS) [PIS easy read]	0.5	08 September 2022
Protocol [Protocol]	0.1	15 June 2022
Schedule of Events or SoECAT [SCoE]	0.1	22 June 2022
Summary CV for Chief Investigator (CI) [Chief Investigator CV]	Version 2	05 May 2022
Summary CV for student [Student CV]		01 April 2022
Summary CV for supervisor (student research) [CV]		05 May 2022

Appendix F: Detailed Flow Chart of Recruitment



CLDT Introduction to the Research.

4.10.2022 – Nurses' allocation meeting

28.11.2022 – Psychology Team Meeting

6.12.2022 – Speech and Language Therapy Meeting

7.12.2022 – Transitions Meeting

13.12.2022 – Occupational Therapy Team Meeting

10.01.2023 – Intensive Support Team Meeting

Primary researcher attended the recruitment site on 9.1.2023 to approach staff and to be available to discuss any potential participants or answer any questions. As a result, a list of clinicians was gained who were planning to approach clients on their caseload.

Clinicians approached appropriate candidates and shared an accessible advert with them. This included a consent to be contacted by the primary researcher form. Completed forms were completed and handed into the recruitment site reception in sealed envelopes to protect confidentiality. The primary researcher was then emailed to let them know there were forms waiting for collection.

PR made initial contact with interested individuals and arranged face to face visits.

Initial contact visits completed. The purpose of these visits was to meet them and to explain the research in detail. All paperwork was taken along with equipment that would be used during the study to ensure transparency and to support with an assessment of capacity to consent.

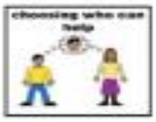
Further contact made if people still interested and conversations had with identified supporters.

Part 1 – Recap of the purpose of the research. Opportunities to ask further questions. Consent forms signed. Completed at the home of pps in a private space. Video recorded.

Appendix G: Prompt Cards for Part 1

What do you need to think about when making friends/relationships?

Who helps you make decisions?



How do you decide who to be friends with/be boyfriend/girlfriend with?

What decisions to you have help with?

Are relationships important to you?

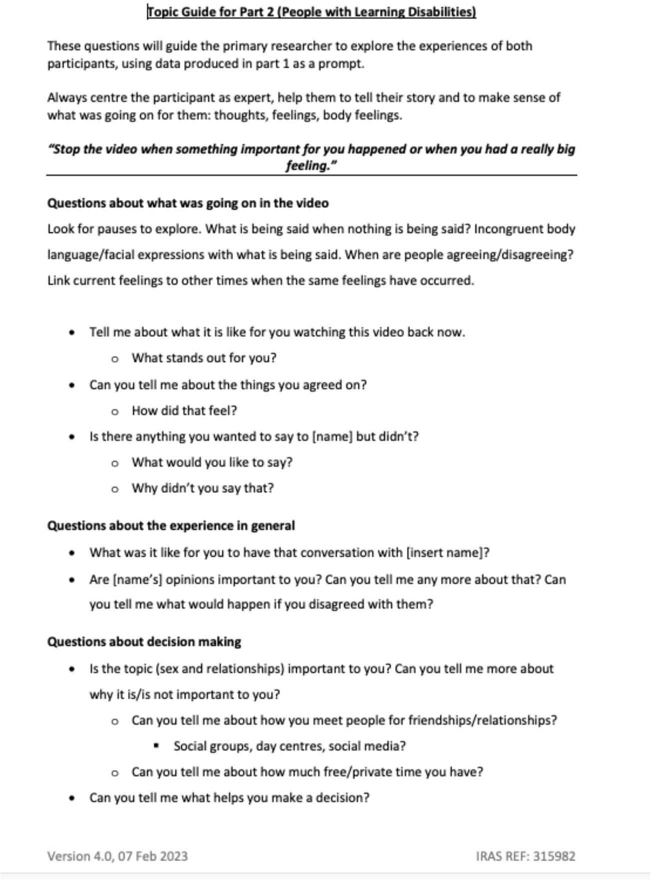
Where can you meet friends/boyfriends/girlfriends?

Is having sex important to you?

What opportunities do you have to talk about sex and make decisions about it?

Appendix H: Interview Guide

H: People with Learning Disabilities



Topic Guide for Part 2 (People with Learning Disabilities)

These questions will guide the primary researcher to explore the experiences of both participants, using data produced in part 1 as a prompt.

Always centre the participant as expert, help them to tell their story and to make sense of what was going on for them: thoughts, feelings, body feelings.

"Stop the video when something important for you happened or when you had a really big feeling."

Questions about what was going on in the video

Look for pauses to explore. What is being said when nothing is being said? Incongruent body language/facial expressions with what is being said. When are people agreeing/disagreeing? Link current feelings to other times when the same feelings have occurred.

- Tell me about what it is like for you watching this video back now.
  - What stands out for you?
- Can you tell me about the things you agreed on?
  - How did that feel?
- Is there anything you wanted to say to [name] but didn't?
  - What would you like to say?
  - Why didn't you say that?

Questions about the experience in general

- What was it like for you to have that conversation with [insert name]?
- Are [name's] opinions important to you? Can you tell me any more about that? Can you tell me what would happen if you disagreed with them?

Questions about decision making

- Is the topic (sex and relationships) important to you? Can you tell me more about why it is/is not important to you?
  - Can you tell me about how you meet people for friendships/relationships?
    - Social groups, day centres, social media?
  - Can you tell me about how much free/private time you have?
- Can you tell me what helps you make a decision?

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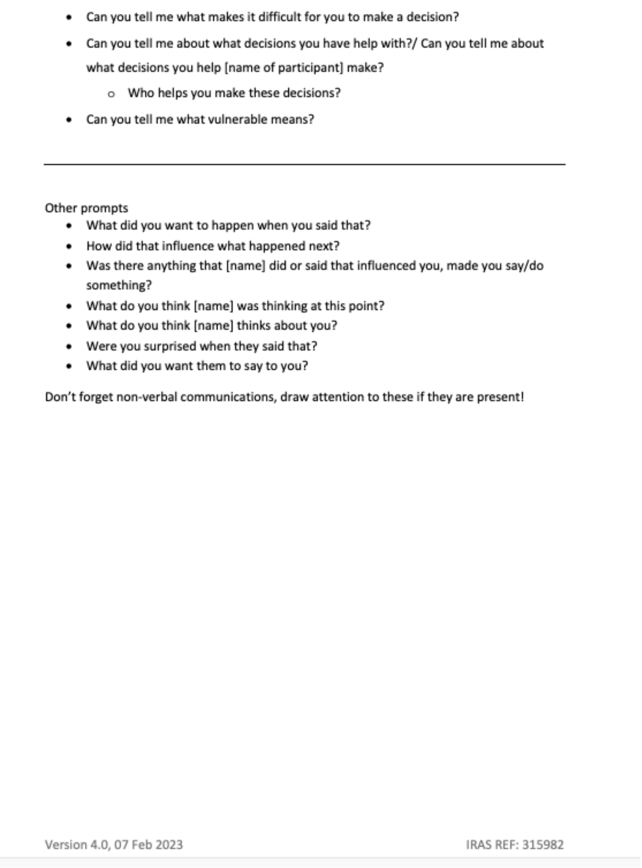


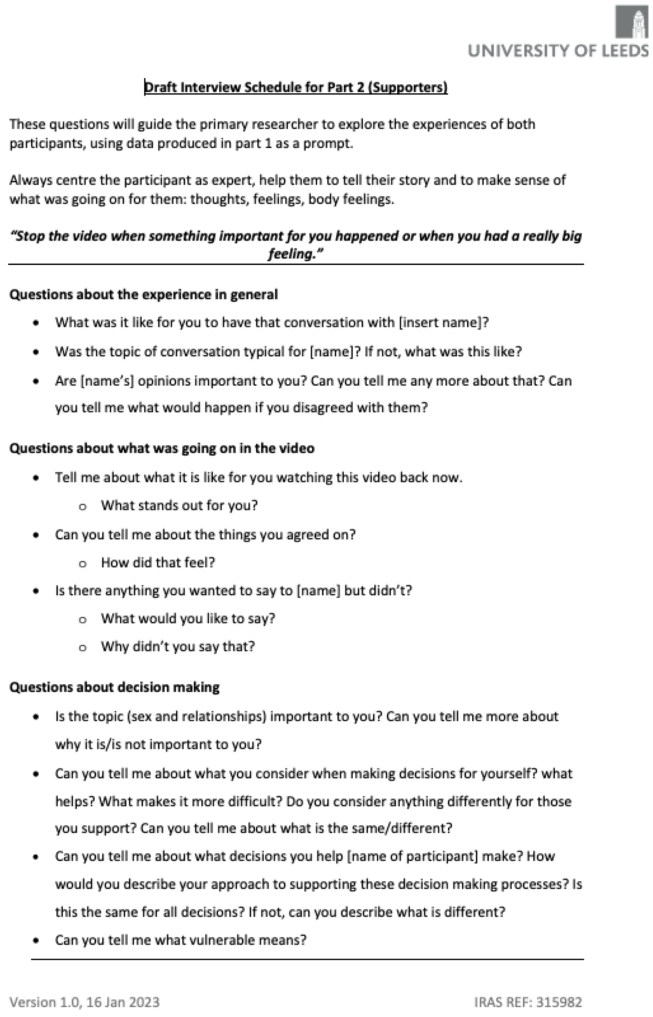
- Can you tell me what makes it difficult for you to make a decision?
- Can you tell me about what decisions you have help with?/ Can you tell me about what decisions you help [name of participant] make?
  - Who helps you make these decisions?
- Can you tell me what vulnerable means?

Other prompts
- What did you want to happen when you said that?
- How did that influence what happened next?
- Was there anything that [name] did or said that influenced you, made you say/do something?
- What do you think [name] was thinking at this point?
- What do you think [name] thinks about you?
- Were you surprised when they said that?
- What did you want them to say to you?

Don't forget non-verbal communications, draw attention to these if they are present!

Version 4.0, 07 Feb 2023 IRAS REF: 315982

H: Support Workers



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Draft Interview Schedule for Part 2 (Supporters)

These questions will guide the primary researcher to explore the experiences of both participants, using data produced in part 1 as a prompt.

Always centre the participant as expert, help them to tell their story and to make sense of what was going on for them: thoughts, feelings, body feelings.

"Stop the video when something important for you happened or when you had a really big feeling."

Questions about the experience in general

- What was it like for you to have that conversation with [insert name]?
- Was the topic of conversation typical for [name]? If not, what was this like?
- Are [name's] opinions important to you? Can you tell me any more about that? Can you tell me what would happen if you disagreed with them?

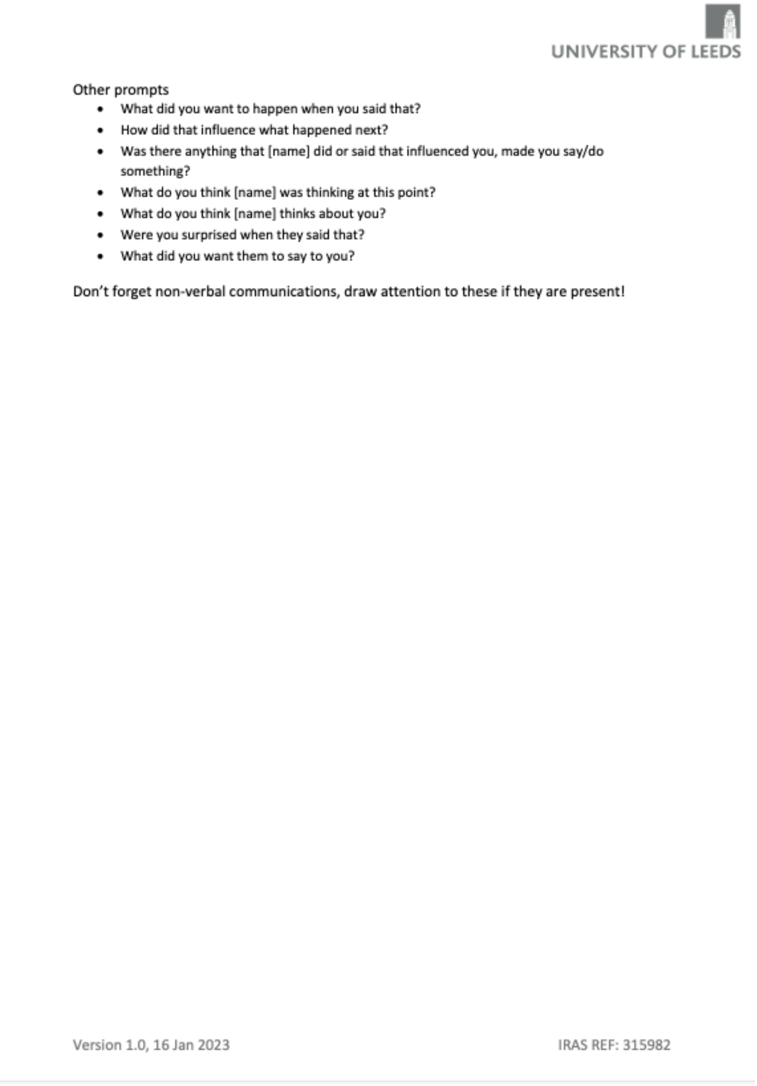
Questions about what was going on in the video

- Tell me about what it is like for you watching this video back now.
  - What stands out for you?
- Can you tell me about the things you agreed on?
  - How did that feel?
- Is there anything you wanted to say to [name] but didn't?
  - What would you like to say?
  - Why didn't you say that?

Questions about decision making

- Is the topic (sex and relationships) important to you? Can you tell me more about why it is/is not important to you?
- Can you tell me about what you consider when making decisions for yourself? what helps? What makes it more difficult? Do you consider anything differently for those you support? Can you tell me about what is the same/different?
- Can you tell me about what decisions you help [name of participant] make? How would you describe your approach to supporting these decision making processes? Is this the same for all decisions? If not, can you describe what is different?
- Can you tell me what vulnerable means?

Version 1.0, 16 Jan 2023 IRAS REF: 315982



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Other prompts

- What did you want to happen when you said that?
- How did that influence what happened next?
- Was there anything that [name] did or said that influenced you, made you say/do something?
- What do you think [name] was thinking at this point?
- What do you think [name] thinks about you?
- Were you surprised when they said that?
- What did you want them to say to you?

Don't forget non-verbal communications, draw attention to these if they are present!

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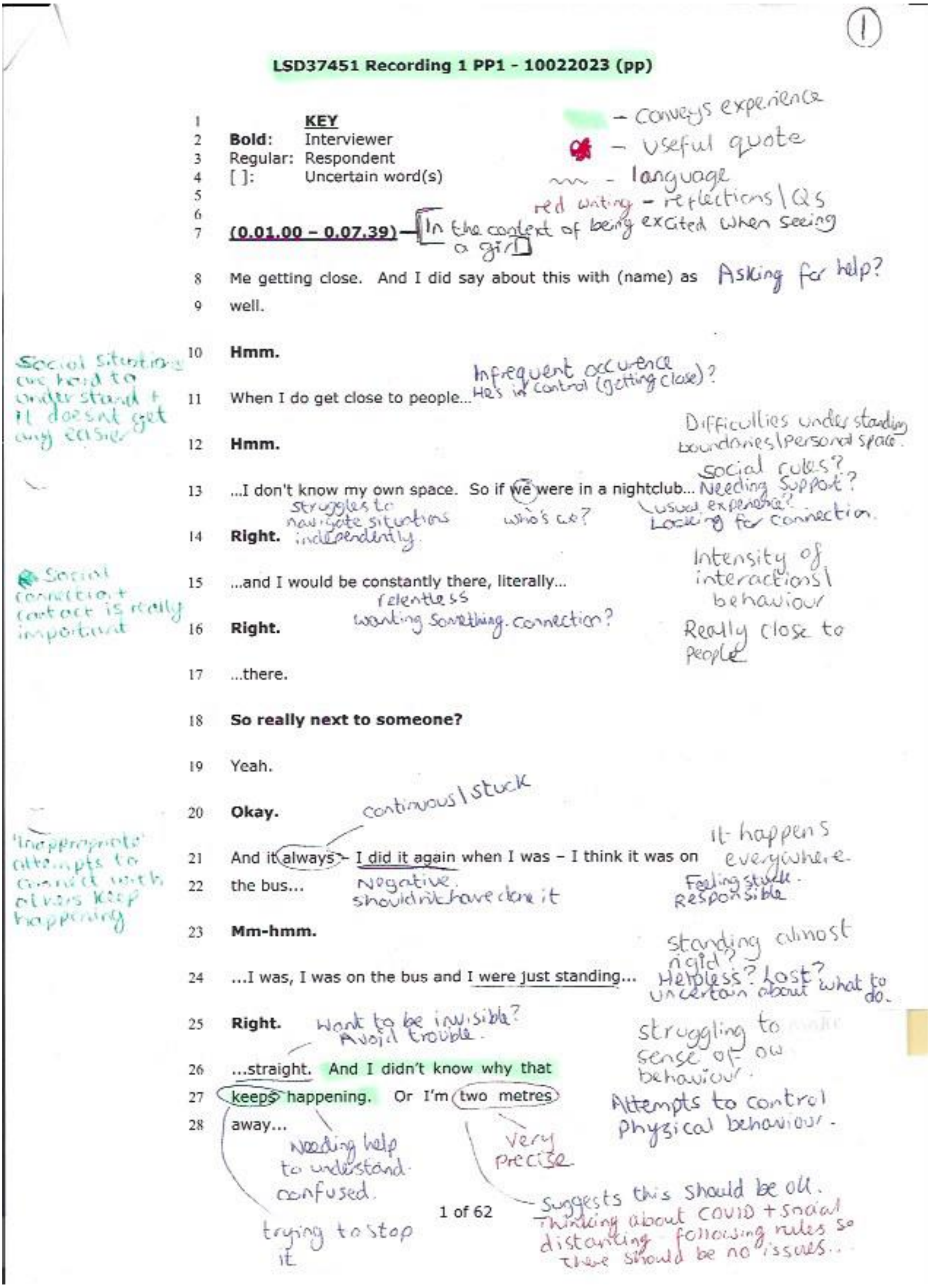
Appendix I: Analysis of Transcript Example



①

LSD37451 Recording 1 PP1 - 10022023 (pp)

KEY
Bold: Interviewer
Regular: Respondent
[ ]: Uncertain word(s)

🟩 – Conveys experience
✱ – useful quote
〰 - language
red writing - reflections|Qs

(0.01.00 – 0.07.39) – [In the context of being excited when seeing a girl]

Me getting close. And I did say about this with (name) as well.

Asking for help?

Hmm.

When I do get close to people...

Infrequent occurence
He's in control (getting close)?

Social situations are hard to understand + it doesnt get any easier

Hmm.

Difficulties understanding boundaries|Personal space.

...I don't know my own space. So if we were in a nightclub...

who's we?

social rules?
Needing support?
usual experience?
Looking for connection.

struggles to navigate situations independently

Right.

...and I would be constantly there, literally...

Intensity of interactions|behaviour

Really close to people

relentless
wanting something. connection?

✱ Social connection + contact is really important

Right.

...there.

So really next to someone?

Yeah.

Okay.

And it always – I did it again when I was – I think it was on the bus...

continuous|stuck

Negative.
shouldn't have done it

it happens everywhere.

Feeling stuck.
Responsible

'Inappropriate' attempts to connect with others keep happening

Mm-hmm.

...I was, I was on the bus and I were just standing...

standing almost rigid?
Helpless? Lost?
uncertain about what to do.

Right.

Want to be invisible?
Avoid trouble.

...straight. And I didn't know why that keeps happening. Or I'm two metres away...

struggling to make sense of own behaviour.

Attempts to control physical behaviour.

Needing help to understand.
confused.

trying to stop it

very precise

Suggests this should be ok.
Thinking about COVID + social distancing following rules so there should be no issues..

LSD37454 Recording 4 PP 2 - 27022023 (staff)

Difficult - Unnatural context.

It – it was really hard cos it – it – it didn't feel as natural, cos
when – when it's just (name) and myself, you know.

Different having an extra person there - judged? assessed?

This experience felt different + more difficult.

Yeah.

Didn't give time to build rapport with me!

Er, but saying that, it's taken a long time for her to get that
comfortable…

Despite it feeling unnatural it was still positive for her.

Time to build trust

Okay.

…um, as well, because of the kind of, um, person that she,
um – that she is.

Fixed, won't change. issue(?) is with her.

Individual personalities/ tendencies.

Yeah.

Um, so having someone new… Bringing me into it

Unfamiliar people

Hmm.

…in the room as well, cos you notice she – she – she kept like
that at first.

Clear sign

Sense of being trapped? out numbered?

Body language communicated feelings.

My presence an impact

Yeah.

And right towards the end, you could see her starting to
relax…

indicates how long it can take to feel comfortable in new situations

shows the time it takes to feel comfortable

Yeah.

Unknown for both people. Expectations?

…more, you know. But, um, I think it's a little bit of the
unknown here as well…

Uncertainty. How to navigate. What to say?

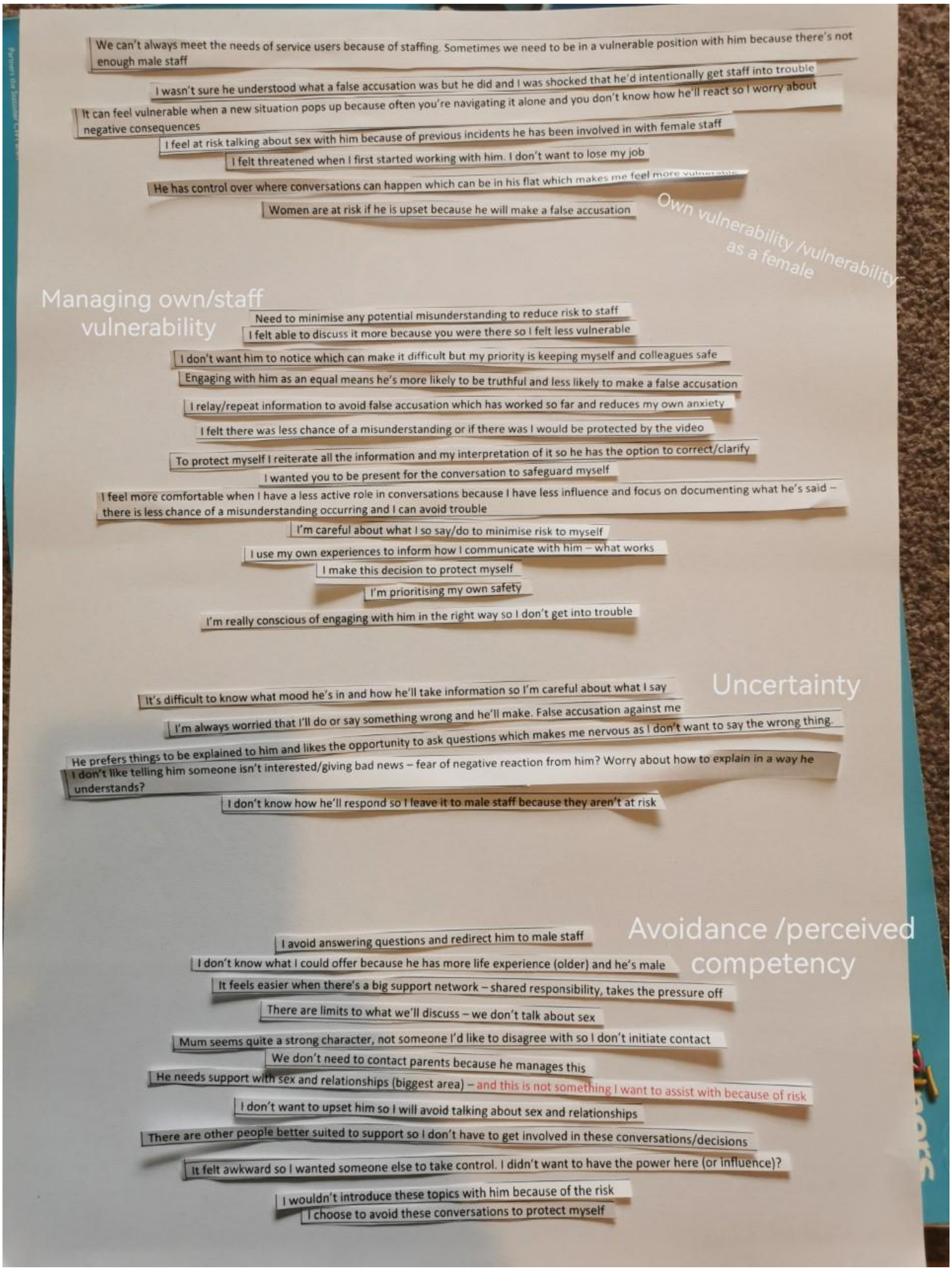
New topic of conversation

New experience

Hmm.

…you know, um—

Appendix J: Developing Personal Experiential Themes



We can't always meet the needs of service users because of staffing. Sometimes we need to be in a vulnerable position with him because there's not enough male staff

I wasn't sure he understood what a false accusation was but he did and I was shocked that he'd intentionally get staff into trouble

It can feel vulnerable when a new situation pops up because often you're navigating it alone and you don't know how he'll react so I worry about negative consequences

I feel at risk talking about sex with him because of previous incidents he has been involved in with female staff

I felt threatened when I first started working with him. I don't want to lose my job

He has control over where conversations can happen which can be in his flat which makes me feel more vulnerable

Women are at risk if he is upset because he will make a false accusation

Own vulnerability /vulnerability as a female

Managing own/staff vulnerability

Need to minimise any potential misunderstanding to reduce risk to staff

I felt able to discuss it more because you were there so I felt less vulnerable

I don't want him to notice which can make it difficult but my priority is keeping myself and colleagues safe

Engaging with him as an equal means he's more likely to be truthful and less likely to make a false accusation

I relay/repeat information to avoid false accusation which has worked so far and reduces my own anxiety

I felt there was less chance of a misunderstanding or if there was I would be protected by the video

To protect myself I reiterate all the information and my interpretation of it so he has the option to correct/clarify

I wanted you to be present for the conversation to safeguard myself

I feel more comfortable when I have a less active role in conversations because I have less influence and focus on documenting what he's said – there is less chance of a misunderstanding occurring and I can avoid trouble

I'm careful about what I so say/do to minimise risk to myself

I use my own experiences to inform how I communicate with him – what works

I make this decision to protect myself

I'm prioritising my own safety

I'm really conscious of engaging with him in the right way so I don't get into trouble

Uncertainty

It's difficult to know what mood he's in and how he'll take information so I'm careful about what I say

I'm always worried that I'll do or say something wrong and he'll make. False accusation against me

He prefers things to be explained to him and likes the opportunity to ask questions which makes me nervous as I don't want to say the wrong thing.

I don't like telling him someone isn't interested/giving bad news – fear of negative reaction from him? Worry about how to explain in a way he understands?

I don't know how he'll respond so I leave it to male staff because they aren't at risk

Avoidance /perceived competency

I avoid answering questions and redirect him to male staff

I don't know what I could offer because he has more life experience (older) and he's male

It feels easier when there's a big support network – shared responsibility, takes the pressure off

There are limits to what we'll discuss – we don't talk about sex

Mum seems quite a strong character, not someone I'd like to disagree with so I don't initiate contact

We don't need to contact parents because he manages this

He needs support with sex and relationships (biggest area) – and this is not something I want to assist with because of risk

I don't want to upset him so I will avoid talking about sex and relationships

There are other people better suited to support so I don't have to get involved in these conversations/decisions

It felt awkward so I wanted someone else to take control. I didn't want to have the power here (or influence)?

I wouldn't introduce these topics with him because of the risk

I choose to avoid these conversations to protect myself