Adults with learning disabilities' experiences of disclosing abuse, who access Community Learning Disabilities Teams, in Southeast England, UK.

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List of Acronyms in alphabet order

Term	**Acronym**
ACE/s	Adverse Childhood Experience/s
BPS	British Psychological Society
CASP	Critical Appraisal Skills Programme
CDC	Centers for Disease Control and Prevention
CLDTs	Community Learning Disability Team/s
CSA	Childhood Sexual Abuse
HRA	Health Research Authority
ID	Intellectual Disability
IPA	Interpretative Phenomenological Analysis
IRAS	Integrated Research Application System
LD/s	Learning Disability or Learning Disabilities
MDT	Multidisciplinary Team
NHS	National Health Service
NICE	National Institute for Health and Care Excellence
NIHR	National Institute of Health Research
PISs	Participant Information Sheet/s
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-Analyses
PTMF	Power Threat Meaning Framework
PTSD	Post-Traumatic Stress Disorder
REC	Research Ethics Committee
SCR	Survivor Centred Recovery
SLT	Speech and Language Therapist
SRT	Shame Resilience Theory
UK	United Kingdom
USA	United States of America
WHO	World Health Organization

Abstract

Background: There is a high prevalence of abuse experienced by the learning disability (LD) population, with a clear impact of abuse on individuals. Several theoretical frameworks support the importance of disclosure in the recovery process, with regards to shifting self-blame and guilt and creating new narratives for these experiences. The key facilitators and barriers to disclosure and responses received have been studied for individuals without LDs, however there is a paucity of research in this topic area for the LD population.

Rapid Review: A rapid review of the experiences health and social care professionals working with adults with LDs who have been abused highlighted variability in the care provided to this cohort. This was due to differences in the implementation of policy and procedures, the influence of relationships between professionals, service users and their families, perceptions of LDs, and clinicians' own knowledge and thresholds, and confidence in their clinical expertise.

Aim and Method: The aim of the empirical study was therefore to explore adults with LDs' experiences of disclosing abuse. Semi structured interviews were conducted remotely, due to COVID-19, with five participants with LDs who had experienced historical abuse and were open to Community Learning Disability Teams (CLDTs) in Southeast England, UK. A reflexive thematic analysis was used to analyse the data.

Results and Conclusions: Four themes were generated 'Abuse is discovered not disclosed', 'Exposure of the abuse triggers a set response', 'Carrying the burden of what happened' and 'Finding a way out', under the overarching theme of 'The journey of disclosure'. The themes suggested disclosure occurred on a non-liner timeline, not at one timepoint, with abuse not being disclosed but identified by others, a lack of power and control over the process for participants and the importance of accessing the right support.

Facilitators and barriers were identified, some unique to those with LDs, such as the influence of clinicians’ knowledge, or lack of, not only about abuse but also LD on the identification of abuse e.g., the role of diagnostic overshadowing, and the potential additional complexity of relationships for adults with LDs. Other facilitators and barriers were in line with previous research for those without LDs, such as trust, being listened to and believed. Several areas for future research are highlighted, such as the experiences of adults with LDs who may have different communication abilities e.g., use of augmented technology, adults with LDs from Black and Asian racialised communities who experiences of abuse and disclosure may be different, and further exploration of the experiences of disclosing specific types of abuse. The clinical and policy implications are discussed, such as reinforcing the need for professionals to receive training in the area of supporting individuals with LDs to disclose abuse and responding appropriately.

Introduction

This introduction provides an overview of structure of the thesis, as well as outlining the impact of the COVID-19 pandemic on the study.

Thesis Overview

At the centre of this thesis is the voice of people with LDs. Historically, their views and experiences have not been heard within society. Despite some shifts in the detrimental attitudes towards individuals with LDs, they still remain largely stigmatized by society. This ultimately creates a context where abuse and hate crimes can occur without question or challenge. Evidence does suggest the occurrence of abuse experienced by the LD population is high, albeit with challenges in establishing its overall prevalence, and the detrimental impact of abuse on a person's wellbeing. Furthermore, theoretical frameworks posit the key role disclosure plays in recovery from abuse. Therefore, the experiences of adults with LDs of disclosing abuse is an important topic to explore to ensure the best care is provided to them during the disclosure process.

A review of the current research literature highlighted the experiences of the general population on disclosing abuse had previously been investigated. Yet despite the aforementioned position for individuals with LDs in relation abuse and its disclosure, there is a scarcity of research on their direct experiences of disclosure. Therefore, in this thesis, to address this research gap, the researcher completed a qualitative rapid review and empirical study. The rapid review explores the health and social care professionals' experiences of working with adults with LDs who had been abused, as the relational phenomenon of disclosure is recognised and to provide information to deepen the understanding of the empirical study's findings.

The empirical study explored the direct experiences of adults with LDs of disclosing abuse recruited from Community Learning Disability Teams (CLDTs) in Southeast England, UK. Specifically, it intends to examine the contexts of the disclosures, the facilitators and barriers, the responses given, and the impact the experience of disclosure had on these adults. The involvement of CLDTs in the process of disclosing abuse is also considered. A qualitative research method was used as this aligned with the researcher's critical realist approach. Semi- structured interviews were conducted via video conferencing software, due to the COVID-19 pandemic, to gather in-depth information on the participants' experiences of disclosing abuse. The approach also offered flexibility to meet the research aim and participants' varying needs. A reflexive thematic analysis was completed, to create themes to capture a nuanced understanding of adults with LDs' experiences of disclosing abuse. Respondent validation was also carried out to ensure the themes were reflective of participants' accounts. The results of study informed clinical and policy implications and recommendations and identified areas for future research.

Overview of Chapters

Chapter One: Literature Review

The chapter begins by presenting our understanding of the concept of 'learning disabilities', alongside the impact of policy and theoretical perspectives on both the concept and care provided to the LD population. Next, the chapter presents the definitions of abuse and prevalence rates of abuse for people with LDs, and the challenges in establishing this. It then proceeds to outline the impact of abuse, including on mental health, and the theoretical and psychological models. Theories relevant to disclosure; the Survivor-Centred Recovery (SCR) theoretical framework (Chouliara et al., 2014), Shame Resilience Theory (SRT) (Brown, 2006), Childhood Sexual Abuse (CSA) Healing Model (Draucker et al., 2011) and the Power Threat Meaning Framework (PTMF) (Johnstone et al., 2018) will then be discussed. This will be followed by the examination of the current research literature on experiences of disclosing abuse for the general and LD populations. The content of this chapter situates the study in the context of the current research literature and relevant theory on the topic of LD, abuse, and disclosure.

Chapter Two: Qualitative Rapid Review

The chapter consists of a rapid review which qualitatively synthesises identified studies to answer the question 'What are the experiences of health and social care professionals working with adults with LDs who have been abused?' This research question was chosen as it has not been previously explored qualitatively, due to the relational aspect of disclosure and it will provide additional context in which in to understand the empirical study's findings, particularly the participants' interactions and experiences of professionals in the disclosure process. In addition to, highlighting areas of training and learning for health and social care professionals working with adults with LDs and the disclosure of abuse.

Chapter Three: Empirical Study

The chapter presents the empirical study conducted. It begins with outlining the rationale for the study, its aims and the research question.

Next the study's method is described. This research used an exploratory qualitative research approach grounded in a critical realist framework, to explore adults with LDs' experiences of disclosing abuse. This chapter outlines this approach in more detail, including researcher's ontological and epistemological positions. This demonstrates the rationale for the qualitative methodology, research design, procedure and data analysis that was adopted. These are then presented in detail to allow replicability of the study along with the ethical considerations and discussion on validity and reliability of the research.

This is followed by the results of the empirical study. Firstly, to provide a context in which to place these findings the demographics of study sample are reported. Secondly, the themes generated from the thematic analysis are outlined, alongside verbatim extracts from the participant interviews. To ensure anonymity, participant and researcher chosen pseudonyms are used and any potential identifiable information redacted.

Finally, the chapter ends with a discussion and critical appraisal of the empirical study and findings and demonstrates the research's novel contribution to the literature on disclosure experiences within the LD population. The main findings will be discussed in relation to the aims of research and their relationship with relevant literature and theory presented in the previous chapters. The strengths and limitations of the research will be discussed and suggestions for the future research will be proposed.

Chapter Four: Clinical and Policy implications, Recommendations and Personal Reflections

The chapter comprises the clinical and policy implications and recommendations derived from the empirical research findings and other sections, to demonstrate the contribution of the research to the topic area and clinical practice. The researcher will then provide an overview of their own reflections on conducting the research, to ensure transparency in highlighting how their position as researcher may have impacted on the study and its findings. This is followed by plans for dissemination of the research and the conclusion.

Impact of COVID-19

To situate the research's procedure and its subsequent findings it is important to highlight this research was completed during the COVID-19 pandemic. The COVID-19 pandemic significantly impacted on the design and timescales of the study, including on ethical approval, recruitment, and data collection.

Due to the ever-changing picture of COVID-19, e.g., social distancing restrictions, it was agreed to initially proceed with the research with the addition of remote procedures, alongside the face-to-face procedures. This required the development of remote participant information sheets (PISs), remote consent forms and a remote risk management procedure. This was to ensure compliance with any UK Government guidance, the University of Essex's requirements and participating trusts' policies.

The best practice guidance from the British Psychological Society (BPS, 2020) on conducting research with human participants during COVID-19 and extensive liaison with key stakeholders, such as the participating services and their trusts' Research and Development Departments, University of Essex's Ethics Department and academic supervisors, when developing the remote procedures was undertaken, including the development of remote data collections tools. The potential impact of conducting the research remotely with staff and participants was also carefully considered in terms of the increased burden on staff workload and accessibility to online platforms for adults with LDs. In addition, COVID-19 research was also given a priority by HRA/REC committees for approval.

At point of recruitment, following UK Government guidance, the University of Essex's protocols and the two recruiting trusts' requirements the decision was made to conduct the study entirely remotely, including recruitment and data collection, therefore only information on the remote procedure and copies of remote data collection tools will be included in this thesis.

The researcher also acknowledges the limitation of a sample size of five, that arose due to the aforementioned impact of the pandemic. It is noted that a sample size of five means there is only limited transferability of the findings, and the nuances of disclosing abuse cannot be fully explored. However, the participants who took part in the study generously shared their own experiences of disclosing abuse, to provide an initial exploratory account within the context of the study sample to add knowledge and understanding to the field and demonstrates the need for further research.

1. Chapter One: Literature Review

1.1 Chapter Overview

This chapter provides an overview of literature and theory on LD, abuse and disclosure, which provides a context in which to place the study. It highlights a gap in the literature of the direct qualitative experiences of adults with LDs of disclosing abuse. This is an important topic to explore as a qualitative approach allows for a nuanced and in-depth understanding of these experiences and informs the support needed for disclosure, including indicating areas of training for clinicians to deliver the best care. The chapter starts with outlining the historical and current conceptualisation of 'learning disabilities' and the care provided to the LD population, this is followed by definitions of and prevalence of abuse in the LD population, its impact and theoretical and psychological models of abuse. Next, relevant disclosure theories are outlined, and experiences of the general and LD population of disclosing abuse are discussed. This is followed by chapters presenting the rapid review and empirical study to address the research gap.

1.2 LD Definitions and Provision of Care

1.2.1 The Historical Conceptualisation of the Term of 'LD', and its Impact for those with LDs and their Care in the United Kingdom (UK)

This thesis takes the stance that the concept of LD is one that is socially constructed, meaning those considered to have a LD has changed over time (Trent, 2016; Wright & Digby, 1996), and varies across countries and cultural contexts (Emerson & Hatton, 2007; Jenkins, 1998). Moreover, as Wendell (1989, p.108) articulated "how a society defines disability and whom it recognises as disabled are of enormous psychological, social, economic and political importance, both to people who identify themselves as disabled and to those who do not but are nevertheless given the label". Hence, the terms used by services, professionals, the public, and those with LDs have direct implications on the lives of people with LDs, and their inclusion in society (Cluley, 2017).

As early as the 13th century the terms used to label people with LDs have been utilised in the legal system, and medical and social welfare policies (Gates & Mafuba, 2016; Rushton, 1996). This meant people with LDs could have their rights restricted, be segregated from society and placed within institutions receiving extremely poor care (Atkinson, 1997; Baum & Lynggaard, 2006; Digby, 1996). From the 1970s onwards, the influence of the ‘Normalisation (Social Role Valorisation)’ principles (Nirje, 1969; Wolfensberger, 1983; Wolfensberger & Tullman, 1982) the disability rights and self- advocacy movements, and the social model of disability can be seen in legislation and policy, such as the Department of Health 2001 White Paper, Valuing People: A new strategy for people with learning disabilities, with community multidisciplinary team (MDT) person centred care as the main focus (Atkinson, 1997; Department of Health, 1971, 2001; Gates & Mafuba, 2016; Porter & Lacey, 2005; Webb 2014). This included the development of CLDTs to provide person-centred interdisciplinary care from a range of specialities to support people with LDs to actively engage in meaningful and respected community activities (The subject, 2019). Yet it is important to note recent figures suggested 3,870 people with LDs or autism were in hospitals, with 36% having been in hospital for over two years (Mental Health Dataset, 2019).

1.2.2 The Contemporary Understanding of the Term ‘LD’ in the UK

It is difficult to establish the exact number of people with LDs living in the UK. However, it is estimated there are approximately 1,130,000 adults with a LD in the UK (Mencap, 2020). Two of the most widely used definitions in the UK for LD are those outlined in the Department of Health 2001 White Paper and the World Health Organisation (WHO, 2020) definition of intellectual disability (ID).

The Department of Health 2001 White Paper states:

“A learning disability is “a significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence), with a reduced ability to cope independently (impaired social functioning), which started before adulthood, with a lasting effect on development.” (Valuing People White Paper, Department of Health, 2001, p. 14)

The paper also states the presence of an IQ below 70, is not sufficient evidence to decide whether an individual should be provided with additional health and social care support, and an assessment of adaptive functioning should also be carried out (Department of Health, 2001). The WHO (2020) definition is similar but attempts to incorporate social factors and the impact of the environment.

Webb and Whittaker (2012) provide further comment on the classification of LD as they call into question the reliability, validity, and utility of IQ assessments and scores as well as measures of adaptive functioning to define LDs (Webb & Whittaker, 2012; Whittaker, 2008a, 2008b).

The BPS (2000) categorises LD into two levels of impairment based on IQ scores; significant impairment of intellectual functioning, based on an IQ of 55-69, and severe impairment of intellectual functioning based on an IQ of 55 and below. The term “intellectual disability” has started to be increasingly used in LD policy, research and practice (Cluely, 2017). The term is used both within the DSM-V and ICD-11 and is adopted more internationally (Cluley, 2017). There is debate as to whether or not the ID term should be more widely used within the UK, with some arguing it will create a more open dialogue with researchers across the world and mainstreaming the term is positive, whereas others are more sceptical about the term and its potential negative connotations (Baum & Lynggaard, 2006;

Cluley, 2017; Gates & Mafuba, 2016). Throughout this thesis, the term learning disability (LD) will be used.

As demonstrated by the above literature on the conceptualisation of LD, the researcher acknowledges ‘learning disability’ to be a social construct. Therefore, for the purpose of this study, the definition of LD is not based on an IQ score or ‘level’ of LD. Participants will be recruited based on being open to a CLDT, therefore registered as having a LD by their team and to have the ability to take part meaningfully in a verbal interview, assessed by a clinical member of the CLDT. The researcher acknowledges this inclusion criteria will likely mean individuals who are identified to have a mild or mild-moderate LD will be recruited.

1.3 Abuse

1.3.1 Definition of Abuse

The definition and categorisations of abuse are multifaceted and vary within and between countries as well as globally (Northway, Jenkins et al., 2013).

Specifically, within the UK, the definition used by policy documents in England and Wales; No Secrets (Department of Health, 2000, p.9) and In Safe Hands (National Assembly for Wales, 2000, p.14) respectively, stated the same definition of abuse “a violation of an individual’s human and civil rights by any other person or persons”. Yet in terms of categorisations of abuse, both highlighted physical, sexual, psychological, financial and material abuse, with In Safe Hands (National Assembly of Wales, 2000) identifying also neglect, and the No Secrets (2000) naming neglect and acts of omission, in addition to discriminatory abuse. No Secrets (2000) was later repealed by Care Act (2014), and in the Act and related publications there does not appear to be a starting definition for abuse as previously stated in No Secretes (2000). The Act also categorises abuse introducing additional types, such as modern-day slavery, organisational abuse, self neglect and domestic violence. It also notes “local authorities should not limit their view of what constitutes abuse or neglect, as they can take many forms and the circumstances of the individual case should always be considered” (Care Act, 2014, 14.17). Furthermore, organisations such as the NHS (2022) categorise for the public information abuse as sexual, physical, psychological, domestic, discriminatory, financial and/or neglect.

Moreover, variations in conceptualisation of abuse can be seen when the definition of abuse is considered globally. The WHO (2002) encompasses all abuse within their definition of violence below, with acts of violence being physical, sexual, psychological and deprivation or neglect in nature; “The intentional use of physical force or power, threatened or actual, against oneself, another person, or against a group or community, that either results in or has a high likelihood of resulting in injury, death, psychological harm, maldevelopment or deprivation” (WHO, 2002, p. 5).

A sub-category of this violence is ‘interpersonal violence’, defined as “violence between family members and intimate partners and violence between acquaintances and strangers that is not intended to further the aims of any formally defined group or cause” (WHO, 2004, p.x). Furthermore, child abuse and neglect, intimate partner violence and abuse of elderly, stranger rape and sexual assault are recognised within this subcategory (WHO, 2004).

Other terminology to describe and categorise abuse is used by Centers for Disease Control and Prevention (CDC, 2022). The Centers’ Adverse Childhood Experience (ACE) study conducted in 1998 categorised these experiences into three types of abuse, neglect and household challenges, which included emotional, physical and sexual abuse, emotional and physical neglect and witnessing intimate partner violence or domestic violence (CDC, 2022). It was highlighted that data collected on ACEs, focused predominately on the experiences of participants from white middle- and upper-class backgrounds and within the home setting (Cronholm et al., 2015). Further research by Cronholm et al., (2015) and Finkelhor et al., (2013) advocated for the inclusion of other ACEs including racism, discrimination, peer rejection, peer victimization, bullying and community violence.

There are also differences in cultural norms on what actions or behaviours may be considered abuse in one culture but not in another (Northway, Jenkins et al., 2013). Cultural norms may also be considered as justifications for certain practices that facilitate violence, as well as culture being a protective factor to experiencing violence (WHO, 2002). The legal positions of what acts are considered abuse may also differ (Cambridge et al., 2006).

The ever evolving and varying conceptualisation of abuse is important as it allows for recognition of situations not previously considered harmful to be recognised as so, thus supporting appropriate action is taken. In turn the differences in definitions and categorisation of abuse can produce a subjective and possible ambiguous picture of how abuse is operationalised. It can impact on how different organisations may understand and decide what is abuse, and therefore the safeguarding decisions that are made (Northway, Jenkins et al., 2013).

It is without saying that everyone with a LD should be treated with respect and receive appropriate care. A question to consider is when does care being received classify as abusive and safeguarding procedures initiated versus being poor care and alternative action such as providing further training to staff being offered. This may be difficult to determine in consideration of the aforementioned challenges in defining abuse. Therefore, it would be important for clinicians to carefully consider this within the policy and legislation guidance and listening to the voice of the individual with a LD and their family as to their understanding of the situation.

For the purpose of the empirical study, its focus will be on interpersonal abuse, therefore the definition of abuse chosen is the WHO’s (2004) sub-category of violence ‘interpersonal violence’ and the categories of abuse set out by the NHS (2022), which are physical, sexual, psychological, financial, domestic, discriminatory and social abuse, and neglect, as the study is based in the UK and participants will be recruited from NHS services. Participants taking part in the study identifying and narrating their experiences as abuse.

1.3.2 Prevalence of Abuse in the General and the LD population

The prevalence of abuse in the general and LD populations experience is a challenge to determine due to various reasons, and therefore should be viewed with caution.

For both populations, the aforementioned impact on the variations in conceptualisation of abuse within countries and globally, as well as revisions to legislation and policy on whether abuse is recognised as so by professionals can influence what is officially reported (Northway, Jenkins et al., 2013).

Specifically in relation to the LD population the prevalence of abuse can be impacted on who is considered to have a LD. Northway, Jenkins et al. (2013) posited the example of an older adult with Down Syndrome, who may be classified as being elderly or experiencing mental health difficulties, or have a LD, with different services categorising this individual in different ways. Furthermore, there may be individuals who are not recognised as not having a LD but do so and who have experienced abuse, as evidence suggests there are individuals with a mild LDs accessing mainstream services (Alborz et al., 2005).

It is also important to note that the official statistics only include those incidents of abuse that have been identified, investigated, and reported (Northway, Jenkins et al., 2013). Individuals with LDs may be less likely to be believed and individuals may withdraw their reports of abuse as they are concerned about the ramifications of doing so, therefore even if abuse has occurred it will not be included in the official statistics (Joyce, 2003; Magill et al., 2010). Furthermore, professionals' or services' differing interpretations of definitions of abuse in policies, their varying assessment, approaches and thresholds of what is abuse can cause discrepancies in what is recorded as abuse and therefore impact the official statistics (Collins, 2010, McCreadie et al., 2008). For example, Joyce (2003) suggested in services peer-to-peer aggression may considered as challenging behaviour, therefore not recorded as abuse. Finally, safeguarding actions and policy implementation may also have an impact of prevalence rates of abuse reported for people with LDs, for example an increase in reported incidents of abuse could reflect a policy is successfully being implemented to recognise abuse or conversely there are failures in safeguarding procedures (Northway, Jenkins et al., 2013).

Despite these limitations, literature highlights the prevalence of abuse in the LD population. The recent figures and exposés of inpatient LD hospitals suggest that although significant improvements have been made, the legacy of the aforementioned poor care and abuse experienced by people with LDs still remains. The WHO highlighted that people with disabilities are at a higher risk of experiencing abuse than the non-disabled population, with individuals with LDs in particular at a greater risk of experiencing abuse in comparison to those with other disabilities (Horner- Johnson & Drum, 2006; Hughes et al., 2012; Jones et al., 2012).

Evidence of this abuse can be found in the UK across a number of settings and has been highlighted through various forums. As previously mentioned, two BBC Panorama broadcasts have exposed abuse taking place at two inpatient hospitals, Winterbourne View and Whorlton Hall. Several studies have also highlighted the verbal, physical, financial, psychological, and sexual abuse, as well as hate crimes that this population experience in the community, supported living and residential care (Beadle-Brown et al., 2010; Cambridge et al., 2006; Gravell, 2012).

Beadle- Brown’s study (2010) which analysed the data from 1,926 adult protection referrals to two local authorities in Southeast England, UK, over seven-year period, found physical abuse was the most common type of abuse for this population. The abuse was most likely to have taken place in a residential setting by a member of staff, which was reflective of the living situation for the participants with the majority not living in their own homes (Beadle-Brown et al., 2010). The limitations of study are the data was only collected from two local authorities in a specific area of England. Therefore, these finding may not translate to other areas, which is of note given the aforementioned variation in services’ thresholds to abuse. Nevertheless, the findings were in line with previous research in terms of trend of abuse identified (Beadle-Brown et al., 2010; Brown & Stein 1998, 2000).

Gravell (2012) interviewed 67 adults with LDs, of which 62 reported in the community experiencing abuse, harassment, and related crime. They reported this was most likely to occur when they were in their local area e.g., in parks, on the street and public transport, but also within close proximity to their homes (Gravell, 2012). Perpetrators were most likely to be local residents and neighbours, they also included those who befriending people with LDs to take advantage of them (Gravell, 2012). The types of abuse included physical violence, verbal assaults on their identity e.g. insults and taunting, as well as financial abuse, psychological and sexual abuse (Gravell, 2012).

Further, recent systematic reviews continue to illustrate the prevalence of abuse within the LD population (Bowen & Shift, 2019; Tomsa et al., 2021). Tomsa et al. (2021) completed a systematic review and meta-analysis of 25 articles into the prevalence of sexual abuse for adults with LDs, which indicated one in three adults with LDs has experienced sexual abuse in adulthood, with the UK having the highest prevalence (34.1%), and the most common perpetrator being an individual with a LD. It was also noted the prevalence was higher in males, for those who were institutionalised and increased from mild to severe levels of LD, decreasing at profound levels (Tomsa et al., 2021). The limitations of the review include methodological issues, such as focusing only on sexual abuse and convenience sampling participants from services used within studies, therefore the studies may not be representative of the whole population. The studies selected identified sexual abuse occurring in adulthood, however the studies acknowledged the prolonged nature of sexual abuse, which may have begun in childhood (Tomsa et al., 2021). Bowen & Shift (2019) noted caution in the interpretation of their findings due to the poor-quality studies included in the review, which highlighted participants with LDs' experiences of partner violence included physical, emotional, and sexual violence with consequences of serious injury and impact of psychological wellbeing.

To summarise, it is difficult to know the extent of abuse, including the type, setting it occurs in and who are perpetuators, through the data on its prevalence due to the aforementioned issues. However, these studies have undoubtedly illustrated this in an experience for many people with LDs, which will understandably have an impact upon them.

1.3.3 The Impact of Abuse

It is well known abuse has an impact on individuals' mental health and wellbeing, as well as on their physical health, their family, service use and the economy (Holt et al., 2008; Safelives, 2016; Spencer, 2000; Springer et al., 2007). ACEs, some of which can be extended into adulthood, such as abuse, have been shown long term impact on negative life and health outcomes, and include physical injury, infectious diseases, chronic disease, mental health, maternal health, risk behaviours such as alcohol and drug abuse and opportunities e.g., education, employment and income (CDC, 2021).

It can therefore be argued considering the increased prevalence of abuse within the LD population compared to the general population, it is likely the LD population will be no expectation to these outcomes. There is extensive evidence that individuals with LDs as a cohort have a shared experience of humiliation, shame, symptoms of or a diagnosis of post-traumatic stress disorder, self-harm, suicidal ideation and behavioural changes in relation to abuse (Brown & Beail, 2009; Gravell, 2012; Morgart et al., 2021; Murphy et al., 2007; Roberts & Hamilton, 2010; Rowsell et al., 2013; Sequeria & Hollins, 2003). Overall, it is estimated 40% of individuals with LDs experience mental health difficulties (Mencap, 2018), and a report by Public Health England (2015) indicated that between 2014-2015, 98,005 outpatient consultations and 12,335 inpatient consultations classified under LD psychiatry were completed. Moreover, the mental health difficulties experienced by individuals with LDs may not always be recognised as so due to diagnostic overshadowing, which includes not recognising trauma as a potential contribution to their mental health or attributing their difficulties to a physical health issue (National Institute for Health and Care Excellence [NICE], 2016). This could mean extended distress and further re-traumatisation for an individual with a LD if the underlying cause of their mental health difficulties are not recognised and inappropriate support provided. Undoubtedly, physical health can also impact on mental health, as well as the level and aetiology of a LD, biological components such as prescribed medication and pain (NICE, 2016).

Furthermore, intersectionality plays an important role here in how other factors may further contribute to this group's poor mental health and wellbeing, reduced social mobility and increased exclusion (Emerson & Gone, 2012). Individuals with LDs are more likely to be of a lower social economic position and experience poverty (Emerson, 2012), which may impact on the resources available to manage the impact of the abuse. Gender inequalities also affect both men and women with disabilities, alongside not often being considered 'gendered individuals', which can impact on their opportunities for relationships and sexual expression (Emerson & Gone, 2012), which may be further exacerbated by their risk to experience sexual abuse. Individuals with LDs from racialised communities often experience stigma from having a learning disability, as well racism, and experience inaccessible, inadequate and a lack of culturally sensitive services (Emerson & Gone, 2012), which may have significant impact on the support they receive following disclosure of abuse. Finally, those with LDs also experience ‘disablism’; discrimination associated with their disability (Emerson & Gone, 2012).

Taking into consideration of the impact of abuse, alongside other factors influencing a person with a LD’s life, a systematic understanding of their difficulties and the identification of abuse is imperative to ensure appropriate care is received.

1.3.4 Theoretical Understanding of the Impact of Abuse

The literature presented so far has demonstrated that abuse and its impact is multifaceted, occurring in relationships and by systems. With several psychological theories to explain why abuse impacts on mental health and wellbeing, this section will present Attachment Theory, Ecological Systems Theory (Bronfenbrenner, 1989 as cited in Campbell et al., 2009) and Narrative Theory. Each theory contributes to providing an underpinning to understanding the impact of abuse through the aforementioned relational and systemic nature in which it is experienced.

1.3.4.1 Attachment Theory.

With the interpersonal aspect of abuse and its occurrence within relationships, Attachment Theory was considered valuable in providing theoretical understanding for the impact of abuse, particularly considering people with LDs often have multiple and sometimes complex relationships with peers, family and professionals where abuse can occur. Attachment theory identified that children who experience inconsistent or unresponsiveness parenting from their caregivers or adults who experience unavailability of an attachment figure e.g., their partner, including abuse, can develop an insecure attachment style, negative internal working models of the self, others and relationships, as well as maladaptive coping strategies for emotional regulation and social interactions (Riggs, 2010; Riggs & Kaminski, 2010; Shaver & Mikulincer, 2009 In adults, this is specifically secondary attachment strategies such as deactivation and hyperactivation, i.e., inhibiting needs to remain in close proximity to the attachment figure vs acting on this inclination (Riggs, 2010; Shaver & Mikulincer, 2009). As a result, this places individuals at an increased risk of presenting with psychological difficulties across the life span (Riggs, 2010; Riggs & Kaminski, 2010). The theory clearly demonstrates the impact of abuse on relationships, however, does not identify the influence of wider systems on the impact of abuse.

1.3.4.2 Bronfenbrenner's Ecological Systems Theory.

Bronfenbrenner's (1989 as cited in Campbell et al., 2009) ecological systems theory goes beyond the individual and relationships and can be applied to examine how the different system factors within the model influence an individual's mental health outcome following abuse, as demonstrated by Campbell et al. (2009) for a sexual assault. Campbell et al. (2009) when using this model found that alongside a person's characteristics and the nature of the assault itself at the individual levels, positive and negative responses following disclosure (e.g., from family and friends) at microsystem level and seeking help from the legal, medical and support services e.g., community mental health teams at the meso/exosystem level, all contributed to the individual's recovery (Campbell et al., 2009). Women were also impacted by factors at the macrosystem level, such as rape myths and institutionalised racism, creating a context which made recovery difficult (Campbell et al., 2009). At the chronosystem level in cumulative trauma and re-victimisation throughout life impacted on their mental health e.g., experiences of depression, anxiety and Post Traumatic Stress Disorder (PTSD) (Campbell et al., 2009). Self-blame was also seen as a meta-construct derived from and developed by several of the levels in the model, e.g., being blamed for the abuse at microsystem and meso/exosystem and internalized sociocultural beliefs increased self-blame (Campbell et al., 2009). The application of this theory to the experience of those with LDs allows broader consideration of the systemic factors contributing to impact of abuse e.g., at the chronosystem level with the aforementioned historical trauma held by the LD population as collective and reflects the systems people with LDs may find themselves within e.g., health and social care services.

1.3.4.3 Narrative Theory.

Narrative theory posits as humans we create stories through our experiences. These stories are dependent on how we have sequentially linked certain moments and the interpretations and the attributed meanings we place upon on them (Morgan, 2000). They do not occur in isolation and are influenced by the broader social context e.g., gender, class, race, culture and sexual orientation (Morgan, 2000). Stories can consist of ones about ourselves, our strengths, and our difficulties, with families and communities also holding stories about themselves (Morgan, 2000). The stories which are dominant can powerfully influence a person in their present but also their actions in the future (Morgan, 2000). This theory applied to an individual’s experience of abuse may suggest a dominant negative story regarding themselves could develop, as reflected by evidence on individuals with LDs experiencing mental health difficulties and self-blame following abuse (Bennett et al., 2013; Brown & Beail, 2009; Gravell, 2012; Morgart et al., 2021; Murphy et al.,2007; Northway, Melsome et al., 2013; Roberts & Hamilton, 2010; Rowsell et al., 2013; Sequeria & Hollins, 2003). The aim of narrative therapy is re-authoring to find alternative stories, which brings to the fore the disclosure of abuse to support recovery (Morgan, 2000).

1.4 Disclosure

1.4.1 Theoretical Frameworks for Disclosure

Disclosure is defined as “the act of making something known or public that was previously secret or private” (Oxford Learner’s Dictionaries, 2022). This concept in relation to abuse becoming known has been posited by the Survivor-Centred Recovery (SCR) theoretical framework (Chouliara et al., 2014), and Childhood Sexual Abuse (CSA) Healing Model (Draucker et al., 2011). In addition, the Shame Resilience Theory (SRT) (Brown, 2006) and the Power Threat Meaning Framework (PTMF) (Johnstone et al., 2018) also contribute to understanding of disclosure. The overarching concept that can be taken from each of these theoretical frameworks is the disclosure of abuse or a deeper understanding of it and its impact, can improve wellbeing.

1.4.1.1 Survivor-Centred Recovery (SCR) Theoretical Framework and CSA Healing Model.

The SCR theoretical framework is informed by the lived experiences of those who had experienced childhood sexual abuse to create a theoretical model of personally meaningful recovery focusing on five areas The Affected Self, Factoring Hindering Recovery, Factors Enhancing Recovery, Hurdles of Recovery and The Recovering Self (Chouliara et al., 2014). The model has similarities to Draucker et al.’s (2011) theoretical model of healing from childhood sexual abuse also developed from the experiences of adults who had experienced sexual abuse in childhood. Both models posit disclosure of abuse as the most important stage in the recovery process (Chouliara et al., 2014; Draucker et al., 2011)

The CSA model proposes a four-stage liner model of healing which involves ‘Grappling with the Meaning of CSA’, ‘Figuring out the Meaning of CSA’, ‘Tackling the effects of CSA’, and ‘Laying Claims to One Life’ (Draucker et al., 2011). At each stage, the disclosure of CSA is considered and the impact of the stage of healing upon this.

In the first stage, ‘Grappling with the Meaning of CSA’ abuse was often not disclosed to due participants avoiding thinking about it, experiencing feelings of shame, being concerned they would be would not be believed or blamed, not having a supportive person to disclose to or wanting to protect the perpetrator or family (Draucker & Martsolf, 2008; Draucker et al., 2011). This resulted in their understanding of their experience of abuse remaining the dominant narrative. If the abuse was disclosed, this was not done directly e.g., via notes, and arbitrarily (Draucker et al., 2011). This shifted slightly in the second stage of healing ‘Figuring out the Meaning of CSA’ as participants gained meaning of the CSA, they would often disclose to someone they considered to be safe and in sharing their experience they achieved a more complex understanding of the abuse (Draucker et al., 2011). They often spoke about the experiences with a mental health professionals or close family and friends. In ‘Tackling the effects of CSA’, the disclosure of abuse was to affirm their new understanding of it, as they spoke about the abuse it confirmed to them they were not to blame and it did not have to influence their future life (Draucker & Martsolf, 2008; Draucker et al., 2011). They also began to share this understanding with others to help them achieve a similar position. This moved one step further in the final stage ‘Laying Claims to One Life’ they share this new perspective of abuse more widely e.g., in the media and to services, and disclosed abuse mainly to help others (Draucker & Martsolf, 2008; Draucker et al., 2011). The value of this theory is its conceptualisation of the importance of meaning making in the healing process, reflective of concepts of the aforementioned Narrative theory, and later the Shame Resilience Theory and the Power Threat Meaning Framework.

However, in comparison the SCR theoretical framework further explains how the processes of disclosure impacts on recovery, focuses on the influence of emotions, and encapsulates recovery as having “forward to backward processes”, not following set stages (Chouliara et al., 2014, p.76). The framework posits through disclosure helplessness and hopelessness can reduce, alongside the shame and blame moving away from the individual who has experienced abuse (Chouliara, et al., 2014), which will further explored later in Shame Resilience Theory. However, it acknowledges due to recovery being non-linear shame and guilt can increase with disclosure (Chouliara, et al., 2014).

Furthermore, in the SCR theoretical framework, some aspects of the aforementioned themes of The Affected Self, and Factors Hindering Recovery can impact upon the act of disclosure (Chouliara et al., 2014). Barriers to disclosure included in the Affected Self were themes of self-blame or responsibility including for the abuse, and within Factors Hindering Recovery ambivalence about recovery and disclosure, including concerns about consequences of disclosure (Chouliara et al., 2014).

Other areas of model include Factors Enhancing Recovery and The Recovering Self, which identified following disclosure individuals establishing inner strengths, and the aforementioned shifting of blame and increasing confidence, self-acceptance and embracing their vulnerability supported their recovery (Chouliara et al., 2014). Finally, the area of Hurdles of Recovery identified the challenge for individuals of acknowledging the process of recovery will be ongoing, and unhelpful responses to disclosure and wishing to protect others at times impeded or delayed disclosure (Chouliara et al., 2014). The model also acknowledges the impact of significant positive and negative life events on recovery (Chouliara et al., 2014).

The SCR framework overall, presents that to facilitate recovery, support and validation is required to address these feelings of blame and shame (Chouliara et al., 2014; Read et al., 2007).

Both the SCR and CSA Healing Frameworks add value to the literature in highlighting the importance of disclosure in the recovery process and that it is complex and multidimensional. Both also draw on the personal experience of abuse and highlight approaches healthcare professionals should adopt in supporting the disclosure of CSA (Chouliara et al., 2014; Draucker et al., 2011). The clear limitation of these theories is their contribution to understanding disclosure and recovery for other types of abuse and abuse occurring in adulthood, as both focus on CSA. Their transferability more broadly is also impacted by methodological issues such as limited variability in samples with regards to participants' demographics, including ethnicity, socio-economic status and geographical location, as well as their stage of recovery. Nevertheless, both studies contribute insightful and rich perspectives on disclosure.

1.4.1.2 Shame Resilience Theory (SRT).

The SRT supports this idea of the positive aspect of shifting of shame proposed in the SCR framework and CSA Healing models (Brown, 2006). The SRT was developed through interviewing 215 women to create a novel theory of understanding shame and its impact specifically on women. It posited shame is a psycho-social-cultural construct and experienced as a 'web' of conflictual and competing expectations of how women should be, as result of powerful sociocultural expectations for women (Brown, 2006). At the centre of web are feelings and realities of being trapped, powerless and isolated. The theory states that shame resilience is on continuum, and to increase shame resilience involves moving towards connection, power and freedom via the impact of four subcategories of shame resilience, including 'Speaking Shame' (Brown, 2006). This category proposes when someone is unable to express their shame experiences, they are unable to externalise it through naming and understanding it (Brown, 2006). This can lead them to think the shame should be kept secret, contributing to those feelings of powerlessness, and being isolated and trapped (Brown, 2006), a position the LD population may already feel they are placed within in society. Despite this theory not being linked directly to abuse experiences, the role of shame as result of abuse and in disclosure process is documented above. The theory is useful in highlighting the complexity of the experiences of shame and the strategies to support individuals to move away from shame, and this understanding can be utilised by therapists to support women and those who have experienced abuse.

1.4.1.3 The Power Threat Meaning Framework (PTMF).

The PTMF (Johnstone & Boyle, 2008) proposes a shift away from a focus on diagnosis “what is wrong with you” (p.9), to one of understanding people’s experiences. The framework suggests similarly to aforementioned models of SRT and CSA Healing Model, having a deeper understanding of “what has happened to you” (Johnstone & Boyle, 2008 p.9), can improve an individual’s emotional wellbeing. This is achieved by considering four factors, firstly through the operation of power in individuals’ lives e.g., coercive power which could be abuse, as well as those with a LD, the role of biological or embodied power (Johnstone & Boyle, 2008). This is followed by the threat this power poses, thus in context of abuse how did the abuse affect the individual, for example, e.g., losing their identity or feeling emotionally unsafe or overwhelmed, and any circumstances that influenced the level of the impact of the threat e.g., age at which the threat occurred, severity and longevity of the threat (Johnstone & Boyle, 2008). Next is the meanings individuals attached to their experiences e.g., feeling trapped, helpless, isolated or responsible (Johnstone & Boyle, 2008). Finally, how individuals responded to the threats; how did they survive, includes flashbacks, distrust of others, emotionally distancing from others or avoiding threat triggers (Johnstone & Boyle, 2008). The model also considers the power resources ‘strengths’ individuals can access e.g., supportive network, skills and valued parts of their identity (Johnstone & Boyle, 2008).

In sum, each of these theoretical models provides a framework in which to understand the importance and role of disclosure in the context of experiencing abuse and the recovery process, with some highlighting the barriers and facilitators to disclosure. For the purpose of this study, the SCR theory will provide the main framework in which place the disclosure process, as it broadens the conceptualisation of disclosure into how it influences recovery and the potential fluidity of disclosure process i.e., not following set stages, reflecting the complexity of disclosure as highlighted by the research literature. However, given the overlapping, e.g., themes of shame, and unique contributions of each theoretical model discussed, the thesis will also draw on the other frameworks and models presented above to understand the disclosure process for adults with LDs.

Nevertheless, it is important to note the apparent gap in these theories, albeit the PTMF, is the consideration of the perspectives of adults with LDs who have experienced abuse, joint disclosure i.e., disclosure by individuals and a family member together, or the impact of abuse becoming known through its identification by someone else, all of which may present differently in the experiences and processes for disclosure and recovery.

1.4.2 Disclosure of Abuse and Response Experiences

As the aforementioned evidence and theory indicates disclosure is important part of the recovery process, and there is literature which has explored the experience of disclosure for the general population and is limited within the LD population.

1.4.2.1 General Disclosure.

Literature reviews and studies have been conducted to explore the experience of adults without LDs in the process of disclosing abuse, including the factors which act as facilitators and barriers to disclosure. The facilitators to disclosure included escalating abuse, safety of children, geographical distance from the perpetrator, and media stories of well-known people disclosing abuse (Femi-Ajao et al., 2018; Tener & Murphy, 2015). Individuals identified having a trusting relationship with the person they chose to disclose to and receiving high levels of social support also helped (Femi-Ajao et al., 2018; Tener & Murphy, 2015). Other facilitators to disclosure included becoming aware of or acknowledging the event/s were abuse, and having the language to define it, which gave meaning to and a sense of control over these events, as well as the higher frequency and severity of abuse and attributed meaning to abuse (Sylaska & Edwards, 2014; Tener & Murphy, 2015).

The barriers to disclosure included those linked to the social systems around the individual; interpersonal relations, the environment, society and culture (Alaggia 2010; Sivagurunathan et al., 2019; Tener & Murphy, 2015, Ullman, 2002). These included concerns about how others would react; not being believed and rejected, or themselves or their loved ones being hurt, in addition to fears around losing their current lives, their identity and family, bringing scandal to their community and religious-related barriers e.g., forgiving perpetrator (Femi-Ajao et al.,2018, Ullman, 2002). Social scripts, for example in relation to gender also added to the dilemma of disclosure, e.g., masculine norms for men like self-protecting (Easton et al., 2014). Moreover, questioning if what happened constituted abuse, immigration status, difficulties with language and interpretation, and unsupportive attitudes of staff and access to services (Femi-Ajao et al., 2018; Tener & Murphy, 2015) also contributed as barriers to disclosure. Shame, guilt, blame, anxiety, denial, and lack of choice also impeded on the decision to disclose, as well as there being consequences of the disclosure itself (Alaggia et al., 2019; Tener & Murphy, 2015).

The responses individuals received were positive and negative. The positive responses included the person they disclosed to being calm, responsive and accepting, with negative responses encompassed by the person not believing them or dismissing or minimising the abuse (Tener & Murphy, 2015). The type of response received also impacted on a person’s wellbeing and the likelihood of them telling their story again i.e., if they received a negative response this would impede on sharing their story again, and a positive reaction associated with better psychological health outcomes (Sylaska & Edwards, 2014; Tener & Murphy, 2015, Ullman, 2002).

It is important to note these studies have primarily focused on the disclosure of childhood sexual abuse and domestic violence or intimate partner violence. Although there will be likely commonalities in the experiences of disclosing other types of abuse, the nuances of disclosing other categories of abuse may not be represented. Nevertheless, these studies illustrate facilitators and barriers of disclosure are multi-layered and can be conflicting, and the responses received from others impact on an individual's wellbeing going forward.

1.4.2.2 Disclosure in Healthcare Settings.

There have also been several literature reviews that have focused specifically on the experiences of individuals without LDs disclosing abuse to services. This research is useful given the support people who have been abused may need from these settings once abuse has been disclosed e.g., psychological therapeutic support or physical health intervention as a result of the abuse, in addition to being settings in which abuse may be disclosed or identified. The settings in which studies took place included primary care, mental health services, clinics and accident and emergency departments. Facilitators and barriers to disclosure were similar to those for general disclosure; facilitators included professionals being non-judgemental and supportive and tailoring their approach, and barriers to disclosure included clients' feelings of fear, shame and guilt, as well as staff attitudes (Feder et al., 2006; Havig, 2008; Robinson & Spilsbury, 2008; Snyder, 2016; Trevillion et al., 2014). This population also wished for appropriate action and support to be offered following abuse, e.g., referrals to mental health services (Read et al., 2018a; Robinson & Spilsbury, 2008; Trevillion et al., 2014). Similarly, to general disclosure, these studies focused on sexual abuse occurring in childhood and adulthood, and intimate partner violence and domestic abuse.

Nevertheless, they do provide valuable information for clinicians to be aware of and consider in their practice.

1.4.3 Trauma Informed Care, including Training Programmes for Staff

There is also a growing interest in trauma informed approaches and argument for them to inform the structure and delivery of mental health services to improve how services meet clients' needs that foster empowerment and do not retraumatize (NHS Scotland, 2021 Sweeney & Taggart, 2018). Trauma informed approaches are considered to be driven by five key principles: safety, trustworthiness, choice, collaboration and empowerment (NHS Scotland, 2021). Sweeny and Taggart (2016) adapted the principles further, and specifically outlined a principle of inquiring about trauma with sensitivity, with an acknowledgement that staff are then prepared with the knowledge of how to respond (Read et al., 2007).

In the UK, a one-day training programme was held to address staff concerns about working with individuals who had experienced abuse, and to develop their skills in asking and responding appropriately to disclosure. This resulted in staff reporting they felt more confident in routinely enquiring about abuse and in their knowledge in working with abuse (McNeish & Scott, 2008). A staff training programme in New Zealand which focused on ways of asking about and responding to abuse, found that clinicians reported improvements in their confidence, changes in their beliefs and clinical practice as a result of the training (Cavanagh et al., 2004). However, these training programmes differed in how they trained staff to enquire about abuse; the UK model trained staff to ask about abuse in general whereas the New Zealand model trained staff to ask about specific events (Read et al., 2018b). In support for the New Zealand training, it was argued people who have experienced abuse may not define it as abuse and asking questions about specific events identified a greater number of abuse experiences (Read et al., 2018b). This may be significant to the LD population who may require more concrete questions regarding abuse to ensure it is identified. A further study by Johnson and Yee (2019) which focused on a LD population, evaluated staff perceptions to training and communication tools to support adults with LDs to report abuse and neglect, which indicated that despite training staff were not confident using the tools with clients. This was partly explained by their limited knowledge and skill set in using augmentative and alternative communication and limited support post training (Johnson & Yee, 2019). It is important staff receive training on abuse as there is research to suggest people with LDs and autism may be less likely to or wait longer periods of time to disclose abuse (Carrigan & Allez, 2017), or for it be identified by chance (Rowsell et al., 2013). In addition, with regards to mental health in general clinicians report a lack of knowledge regarding this and training in this area being beneficial (Woodward & Halls, 2009). Overall, trauma informed services should work in a way that staff engagement with patients promotes recovery, staff understand that varied responses to different types of trauma may be required, and that clinical practice does not re-traumatise service users, either via the use of force, or lack of acknowledgment of the abuse or its impact (Read et al., 2018b).

1.5 LD Research

French and Swain (2006, p. 384), described the "voices of disabled people themselves are largely absent in disability history in general" (p. 384). It is evident from the literature that the experiences of those with disabilities, and more specifically individuals with LDs, are rarely heard on the issue of the disclosure of abuse, with the research community itself criticising the lack of research (Porter & Lacey, 2005). The focus has been research 'on' people with LDs and their stories being "owned and documented by those in power" (French & Swain, 2006, p. 384; Munford et al., 2008). People with LDs often experience being highly scrutinised, but their voices remain unheard, with little power to make changes to the services that directly affect them (Munford et al., 2008). It is also important to acknowledge that previous research, particularly with a medical model focus, has contributed to the oppressive legislation and policies of the past, and invisibility of those with LDs.

The lack of research may be due to abuse being seen as a sensitive topic (McGarry, 2010), as well as the LD population being seen as a vulnerable group in research (Iacono, 2006). However, Jurizten (2011), as cited in Northway, Melsome et al. (2013) proposed by not researching the abuse, the subsequent support and services this cohort receive remain unquestioned, which potentially places them at further risk. Therefore, there has been a move to conduct more inclusive and participatory or emancipatory research with people with LDs (Nind, 2008).

A three year-participatory study by Bennett et al., (2013) aimed to address this issue. The project included the involvement of people with LDs at every stage of research including the formulation of the research idea, data collection, analysis and dissemination. The study aimed to gain an insight into the views and experiences of people with LDs on abuse via focus groups, individual interviews and questionnaires, and make recommendations on how best to support this group following disclosure and to prevent further abuse (Bennett et al., 2013). Participants were able to identify the negative impact of abuse, including the emotional reactions they may experience, which could be hard to articulate and may impact on disclosure (Northway, Melsome et al., 2013). These included blame, embarrassment, fear, anger, bitter, disgust and paranoid (Northway, Melsome et al., 2013). Participants also held a sense of disbelief and injustice about abuse occurring, as well as enduring impact of abuse and its impact on suicidal ideation for some (Northway, Melsome et al., 2013). When asked what did people do about the abuse, some indicated nothing, asked for it stop or reported it officially e.g., via a hate crime report or to someone they trusted, and noted they did not always receive a positive response from those they reported it to e.g., not supporting them to take further action (Bennett et al., 2013). When disclosing abuse, participants wanted to be listened to, believed, and appropriate actions to be taken and support given, including being informed what is happening and greater access to counselling following abuse (Bennett et al., 2013). Additionally, participants were able to identify different categories of abuse, with sexual abuse commonly considered by participants as the most severe type of abuse, although there were differing perspectives with some identifying emotional abuse as also being difficult, and others finding it hard to answer the question (Northway, Melsome et al., 2013). These differences and difficulties highlighted the subjective nature of abuse, and the idea some individuals may be being abused but not realise it, or feel they are being abused but others did not feel it met the threshold, nevertheless both experiences would have detrimental effects on an individual's psychological wellbeing (Bennett al., 2013; Northway, Melsome et al., 2013b). Despite not focusing specifically on disclosure, this study provides an overview of adults with LDs' understanding of abuse and reflects some of experiences of general population when disclosing abuse. The authors of the study acknowledge the limitations with regards to recruiting only participants with mild and moderate LDs, and from self-advocacy organisations, therefore their experiences and understanding of abuse may differ from those outside these groups e.g., those with severe LDs (Bennett et al., 2013).

Some studies have been conducted to specifically explore the views and experiences of disclosing abuse for individuals with disabilities, including those LDs or defined as having 'cognitive difficulties', and the experiences of other stakeholders involved in their care on disclosing abuse (Curry et al., 2011; Fraser-Barbour et al., 2018; Hollomotz, 2012; Joyce, 2003; Plummer & Findley, 2012; Powers et al., 2008; Powers et al., 2009). The studies highlighted specific barriers and facilitators to and responses received when individuals with LDs disclose abuse, including to healthcare professionals and the criminal justice system. The studies highlighted barriers were a fear of losing their independence or conversely being dependent on others, communication; power imbalances and being misunderstood, people with LDs understanding what is abuse, professionals' lack of knowledge in recognising LD, abuse and how best to support people who have been abused, lack of joint working between services and resources, misconceptions about capacity and credibility of people with LDs' reports of abuse, and their identity and character (Curry et al., 2011; Fraser-Barbour et al., 2018, Hollomotz, 2012; Joyce, 2003; Plummer & Findley, 2012; Powers et al., 2008; Powers et al., 2009). This was alongside similar facilitators and barriers to disclosure for the general population as previously mentioned such as the reaction on perpetrator e.g., escalation of violence, being (or not being) believed and blamed, embarrassment, cultural norms, importance of having a trusting relationship with the person they disclose to or significant contact with them, and receiving support (Plummer & Findley, 2012; Joyce, 2003; Powers et al., 2009.) The participants did not always receive positive response, with delayed or no action taking place, or not taken seriously (Hollomotz, 2012; Joyce, 2003).

These studies provided useful information in understanding the disclosure experience for adults with LDs who have been abused. Although several of studies only focused on sexual abuse, experiences of women or men, other stakeholders' points of view and the use of the term 'cognitive difficulty' made it difficult to identify the specific nature of the cognitive difficulty i.e., a LD or acquired brain injury, or disclosure was not primary focus on the study.

1.6 Summary of Literature Review and Conclusion

The literature review aimed to provide an overview of the current research and theory on LD, abuse and disclosure, to identify the gaps in the current literature and provide a context in which to situate the overall thesis. It highlighted that research can be successfully conducted with people with LDs, to provide rich data that could inform future policy. Yet there is a clear gap in the literature on people with LDs' own experiences of disclosing abuse across a broad range of types of abuse This is despite the literature indicating the detrimental impact of conceptualisation of LD throughout history on the care people with LDs received, a high prevalence of abuse within this cohort, albeit with some issues in determining exact figures, and the impact abuse has upon an individual's wellbeing. Several theoretical frameworks highlighted the importance of disclosure in the recovery process, and research highlighted the facilitators and barriers for the general population, including those specific to health care settings. This literature does provide useful insight, although is limited as it has predominately focused on sexual abuse, those without a LD or other stakeholders' perspectives. To address this research gap, a qualitative rapid review of health and social care professionals' experiences of working with adults with LDs who have been abused and an empirical study on the direct qualitative experiences of adults with LDs of disclosing abuse were completed, which are presented in the following chapters. The rapid review was completed to recognise the relational aspect of disclosure, that it is an interaction between individuals, in which each perspective will inform the other, providing some of the clinical and policy implications of the thesis, e.g., training required for clinicians. The rapid review also utilised secondary data of professionals' experiences as this research literature was available, whereas the qualitative empirical study on the subjective experiences of adults with LDs of disclosing was required due to the lack of research in this area. Furthermore, in conducting the study it adds further evidence for the successful and beneficial involvement of adults with LDs in the production of research.

2. Chapter Two: Qualitative Rapid Review

Health and social care professionals’ experiences of working with adults with LDs who have been abused

2.1 Chapter Overview

This chapter outlines the qualitative rapid review which explores the health and social care professionals’ experiences of working with adults with LDs who have been abused. The review was conducted as this topic had not previously been synthesised qualitatively, and more importantly due to the relational phenomenon of disclosure and to provide additional narratives and information in which to understand the experiences of adults with LDs on disclosing abuse. The chapter provides detailed information on how the researcher conducted the rapid review, the themes generated, and the strengths and limitations of the review.

2.2 Method

2.2.1 Design

The aim of the review is to explore health and social care professionals’ experiences, therefore a qualitative design was considered to be the most appropriate, as this methodology can capture the nuances and idiosyncrasies of individuals’ experiences (Taylor, 2005). The reporting of the review was guided by the PRISMA (2020) statement checklist for systematic reviews, to ensure accuracy and transparency of the process (Sarkis-Onofre et al., 2021).

The review would be considered a rapid review within the definition proposed by Cochrane informed by a study conducted by Hamel et al. (2021):

“A rapid review is a form of knowledge synthesis that accelerates the process of conducting a traditional systematic review through streamlining or omitting specific methods to produce evidence for stakeholders in a resource-efficient manner." (Garritty et al., 2020, p. 1).

In the case of this review, it was completed solely by the researcher, using rigorous, transparent systematic methods in a time-efficient manner whilst ensuring rigor in the selection of studies and their appraisal (Hamel et al., 2021). Although this review was not completed at the direct request of stakeholders e.g., health care professionals, Hamel et al. (2021) proposed this definition can be used when the review is to inform policy practice and meet the needs of consumers. This was an aim of this review, for the findings to contribute to the literature on how health and social care professionals manage disclosure; identifying strengths in practice and inform areas for improvement that will benefit clinicians and service users.

2.2.2 Search Strategy

A search of the three main systematic databases (PROSPERO, Cochrane Library and Journal of Systematic Reviews) confirmed a systematic review addressing the same question had not been previously completed. CINAHL Complete, PsychInfo, PsychArticles and MEDLine, were searched from their start dates to May 2021 for peer reviewed, English language, published journal articles on EBSCO Host. Following this, SCOPUS was searched to identify any other relevant title and abstracts.

The search strategy and inclusion and exclusion criteria were informed by utilising the SPIDER tool (see Appendix A). A scoping search of the four databases was completed and based on those results, the search terms were further defined, piloted and amended accordingly. The U.S. National Library of Medicine's Medical Subject Headings online resource (2018) was searched to identify any alternative phrases or words for the search terms. Truncation, quotation marks and Boolean operators 'OR' were applied to the separate groups of terms, and 'AND' applied to combine them (see Appendix B for the search terms).

2.2.3 Inclusion and Exclusion Criteria

The inclusion criteria were studies which: a) explored the experiences of health and social care professionals experiences working with adults with LDs who have been abused or abuse is suspected b) recruited health and social care professionals working with adults with LDs, or the experiences of health and social care professionals could be extracted c) utilised qualitative methodology and analysis, or if a mixed methods approach was used qualitative data could be extracted d) peer-reviewed in the English language e) were published in any time period and geographical location.

The exclusion criteria were studies which a) the experiences of health and social care professionals could not be disaggregated from the experiences of other participants in the study e.g. service users b) focused on work with children and young people with LDs c) focused on trauma not interpersonal in nature e.g. car accident d) evaluated the outcomes of specific interventions to support once abuse disclosed or tools for disclosure e) were commentary or reflective journal articles by clinicians.

For the purpose of this literature review, terms relating to abuse, trauma and adverse events have been combined in the search criteria, to reflect their overlapping nature and how they are used interchangeably within the research literature. Similarly, ‘autism’ was included due to the co-morbidity of LD and autism diagnoses. ‘Working with’ is broadly defined to acknowledge the diversity of specialities that are represented within health and social care profession e.g., nursing, psychiatry, psychology, occupational therapy, physiotherapy and social work etc, and the different duties within these roles e.g., psychological therapy and safeguarding assessment etc. The term ‘experienced abuse’ is also defined as disclosed or suspected abuse to highlight the differing responsibilities and duties within the health and social care professionals’ roles.

2.2.4 Screening

The articles generated from the search on EBSCO host were exported to Mendeley, and duplicates removed. The titles, then abstracts of the articles were screened against the inclusion and exclusion criteria. Following this the reference list of these articles and any relevant systematic reviews that were returned in the main search were then forward and backward cited to identify any additional potential articles. Finally, the full texts of all the articles were assessed for eligibility using the inclusion and exclusion criteria and seven papers were deemed suitable for the review.

2.2.5 Quality Appraisal

The quality of articles were evaluated using the Critical Appraisal Skills Programme Qualitative checklist for Systematic Reviews (CASP, 2018). The CASP (2018) comprises of 10 questions (responses: yes, no, or can't tell), set across three broad sections; Section A: Are the results of study valid?, Section B: What are the results? Section C: Will the results held locally?, on which each article was evaluated upon. As there is no current agreement on the inclusion of poor-quality studies in qualitative syntheses (Atkins et al., 2008), all studies irrespective of quality were included in the analysis.

2.2.6 Data Extraction and Synthesis

To systematically review the qualitative studies, data from the studies was synthesised using Thomas and Harden's (2008) thematic synthesis approach. An approach informed by Braun and Clarke's (2006) thematic analysis approach. Firstly, data was extracted from the studies; data was considered to be any text found under the headings 'results' and 'findings' specifically addressing the review question. The studies which included the experiences of health and care professionals and other stakeholders e.g., services users or police (Jenkins et al., 2007; O'Malley et al., 2019), only the findings from health and care professionals were extracted when clearly distinguishable from the experiences of the other stakeholders. Electronic copies of all the studies were available and imported into NVivo 12 for analysis.

To analyse the findings, a three stage process (Thomas & Harden, 2008) was followed 1) development of codes via line by line coding of the data 2) developing descriptive themes from the codes 3) creating analytic themes. The relevant text was inductively coded line-by-line. Each sentence could have one or more codes depending on its meaning and content derived. All the codes were checked for consistency and merged when multiple codes addressed the same idea. The descriptive themes were developed through grouping of the codes derived in stage 1 to facilitate the identification of patterns in the data. Next, to go beyond these descriptive themes, the analytic themes were developed by interpreting the meaning of the data to provide narrative descriptions for the themes that answered the review question.

2.2.7 Reflexivity

The qualitative synthesis aimed to explore the experiences of health and social care professionals working with adults with LDs who have been abused. The researcher who completed this review is a Trainee Clinical Psychologist, who has experience working with adults with LDs who have experienced abuse and is a health professional themselves. Therefore, these experiences may have influenced the interpretation of the data and should be held in mind when considering the conclusion of this review.

2.3 Results

2.3.1 Search Results

A total of 1,055 were initially identified from the search of the four databases, and 598 once duplicates removed. Through screening the articles at title, 340 were excluded, then 238 were excluded after abstract screening. The remaining articles were forward and backward cited, and a further seven articles were identified. Finally, 28 were screened at full text, and 21 excluded, thus a total of seven articles were included in the review. Figure 1 outlines this process in the PRISMA flowchart.

The key characteristics for each study can be found in Table 1 below. The experiences of approximately 160 health and social care professionals were collected, this is a close estimate as not all studies involving other stakeholders e.g., police, did not specify numbers for each profession (Jenkins et al., 2007). The health and social care professionals that took part included nurses, clinical psychologists, support workers, social workers, and other allied health care professionals. They worked in various settings; inpatient, CLDTs, a residential service and a trauma informed day programme, working with adults with LDs and/or autism. The exact numbers of individuals supported by the clinicians in the studies could not be identified, albeit the O'Malley et al., (2019) study which noted six service users gave consent for the professionals working with them to be interviewed. The studies also did not all explicitly state the types of abuse experienced by those under the care of their services but those noted by clinicians included sexual, physical and psychological abuse, from family members, peers and other professionals or services, either directly or by proxy in allowing abuse to continue. The studies were conducted predominately in UK, as well as the USA, Norway and Ireland.

2.3.2 Quality Appraisal

The CASP (2018) was applied to evaluate the trustworthiness, results and relevance of the seven studies (see Appendix C for Table of overview of the quality appraisal for each study in relation to three sections of the CASP, 2018 checklist). The quality criteria for trustworthiness were based on credibility, dependability, transferability, and conformability (Guba and Lincoln, 1985 cited in Korstjens & Moser, 2018). In relation to the credibility, the level of confidence in the 'truth' and findings being a representation of participants experiences (Korstjens & Moser, 2018), this was demonstrated in the majority of studies as analyst triangulation was implemented by using multiple researchers to complete and review the analysis (Hodges & Northway, 2019; Jenkins et al., 2007; Kildahl et al., 2020, O’Malley et al., 2019, O’Malley et al., 2020, Truesdale et al., 2019). It was unclear whether analyst triangulation was implemented in the Keesler (2016) study, but it was noted ‘member-checking’ was completed. This was completed by Truesdale et al. (2019). With regards to dependability and confirmability, the majority of the studies provided sufficient detail of the research steps; recruitment, data collection and analysis (Hodges & Northway, 2019; Keesler, 2016; Kildahl et al., 2020; O’Malley et al., 2019; O’Malley et al., 2020; Truesdale et al., 2019), facilitating their replication, with three of studies explicitly noting the researcher’s background may have influenced their relationship with the research and the research process (Keesler, 2016; Kildahl et al., 2020; O’Malley et al., 2019). Finally, it was hard to critically appraise the transferability of the studies’ findings to other contexts, as they were conducted across various settings. Nonetheless, all the studies provided rich information on health and social care professionals’ experiences of working with adults with LDs who had been abused or suspected abuse.

Figure 1.

PRISMA 2020 Flowchart for the rapid review

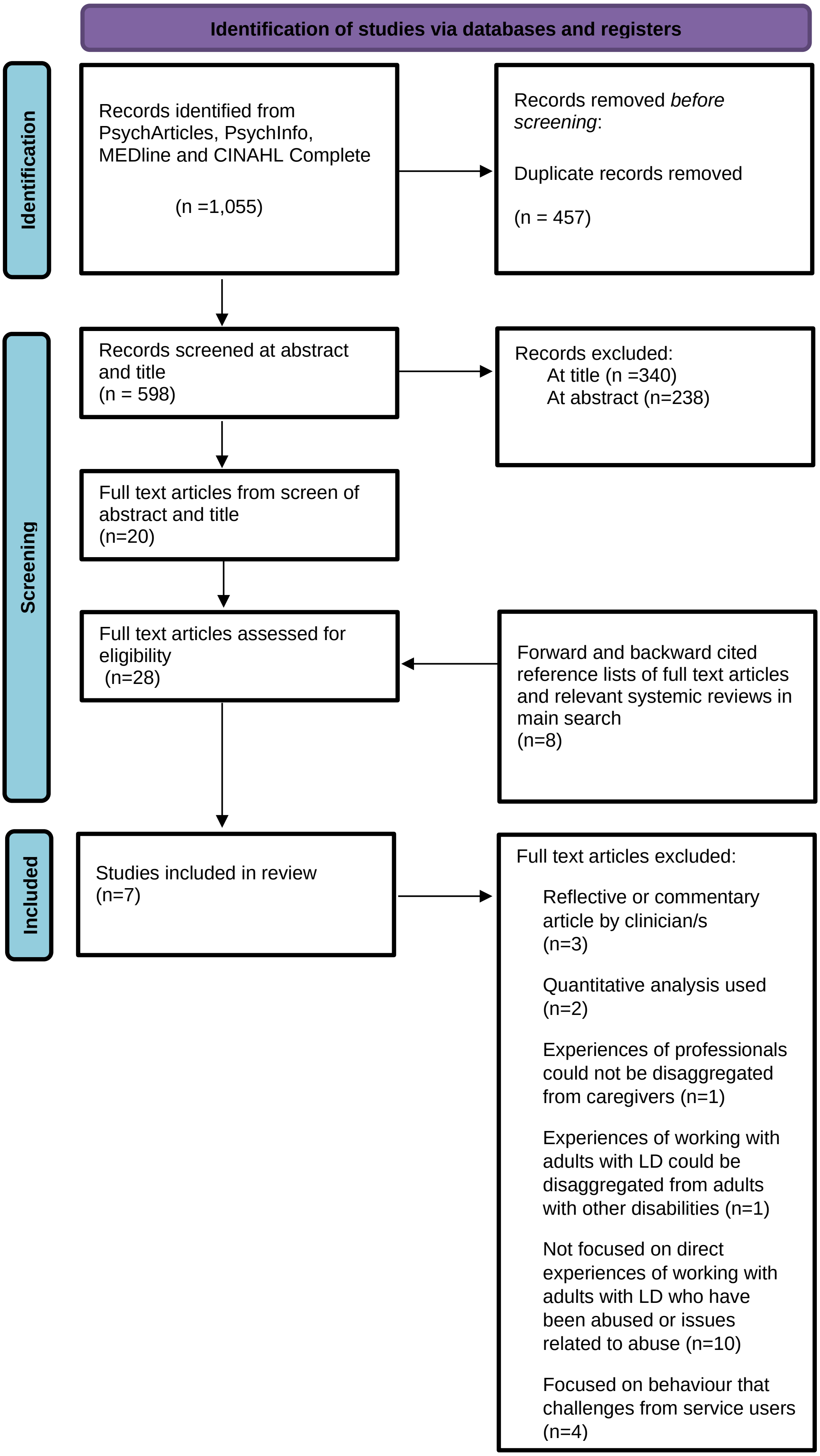


Table 1.

Overview of studies included in the rapid review

Study	Aims	Participants and Setting	Sample Size	Data collection and Analysis	Country
Hodges & Northway (2019)	To explore nurses and social workers' decision making when safeguarding adults with LDs	LD nurses and social workers working in Community Learning (intellectual) Disability Teams	25	Semi-structured interviews and Thematic analysis/Grounded theory	Wales, United Kingdom
Jenkins et al., (2007)	To explore how nurses respond to the abuse of adults with LDs, and within the context of zero tolerance policy on abuse (part of a larger two-year study)	Direct care staff in the NHS, social care, voluntary and private care sectors and police or social care abuse investigators	70 (inclusive of police as could not separate them from the main sample)	Focus groups and Thematic Analysis (part of a larger two-year study)	Wales, United Kingdom
Keesler (2016)	To explore staff views and understanding within a trauma informed day services for individuals with LDs	Staff employed at a trauma-informed day programme or had been employed and promoted to other programmes in the organisation	20	Semi-structured interviews (part of a larger mixed-methods study)	USA
Kildahl et al., (2020)	To explore clinicians' experiences of failing to identify abuse for a service user with a LD and autism in their care	Clinical psychologist, psychiatrist, LD nurses, mental health nurse working in an inpatient ward	5	Semi-structured interviews and Interpretative Phenomenological Analysis	Oslo, Norway

O'Malley et al., (2019)	To establish what support is available to adults with LDs who have experienced sexual abuse, and how this is experienced by service users and professionals	Key worker and psychologists working in a community based and residential service Service users who accessed the service	9 interviews with professionals completed in total 6 services users consented for their psychologist to be interviewed, three consented for their key worker to be interviewed too, and two consented to direct interview	Factual descriptive analysis followed by a concept one (thematic analysis) Qualitative data specific to professionals; psychologist and key workers, could be extracted from the findings	Ireland
O'Malley et al., (2020)	To explore how clinical psychologists support individuals with LDs who have been sexually abused and their views on therapeutic interventions	Clinical psychologists working in an adult intellectual disability service	6	Semi-structured interviews and Thematic analysis	Ireland
Truesdale et al., (2019)	To explore health care professionals' perceptions on service provision for individuals with LDs and traumatic stress	Clinical psychologists, psychiatrists, nurses, allied health professional and social workers working in a specialist intellectual disability service	25	Semi-structured interviews and Thematic analysis	UK

2.3.3 Thematic Synthesis

A thematic synthesis led to the generation of five themes, and 12 subthemes encompassed under one overarching theme (see Table 2). The occurrence of each theme across the seven studies can be seen in Table 3.

Table 2.

Overview of themes in the rapid review

Overarching Theme: Variability in practice- meeting individual client's needs or creating inequitable care for the majority?

Themes	Subthemes
1) 'We have to make it work'	Let's adapt and create approaches We don't always have what we need
2) 'Navigating the complexity of my different roles and the consequences'	Client and Family- It's the relationship that matters MDT working- It is better to work together
3) 'Perceptions and impact of LDs'	Holding assumptions about the service user I want the best for my client
4) 'What is abuse and what does it do?'	Unmasking abuse What meets the threshold? It impacts us all
5) 'Trusting my clinical expertise or seeking guidance'	-

Table 3.

Occurrence of themes in each study in the rapid review

	Study						
	Hodges & Northway (2019)	Jenkins et al., (2007)	Keesler (2016)	Kildahl et al., (2020)	O’Malley et al., (2019)	O’Malley et al., (2020)	Truesdale et al., (2019)
Themes							
Overarching theme	*	*	*	*	*	*	*
Theme 1	*	*	*	*	*	*	*
Theme 2	*	*	*	*	*	*	*
Theme 3	*	*	*	*	*	*	*
Theme 4	*	*	*	*	*	*	*
Theme 5	*	*	*		*	*	*

2.3.3.1 Theme One: ‘We have to make it work’.

This first theme captures an inevitable flexible, yet stoic stance participants held to ensure the delivery of care and treatment. This theme is divided into two sub themes; ‘Let’s adapt and create approaches’ and ‘We don’t always have what we need’.

Practitioners referred to adapting their practice in terms of their ‘style’; communication e.g., introducing visual aids and art-based tools and the session structure e.g. offering more breaks and shorter sessions (O’Malley et al., 2020; Truesdale et al., 2019) to the interpretive application of legalisation and policy (Hodges & Northway, 2019; Jenkins et al., 2017) as well as specifically modifying assessment and intervention approaches that had an evidence base within the general population e.g. CBT, DBT, Mindfulness, Psychodynamic Psychotherapy, Trauma-informed models (Keesler, 2016, O’Malley et al., 2020; Truesdale et al., 2019). One participant from the O’Malley et al. (2020) study illustrates this and their commitment to adapt their practice:

> “A lot of people just kind of automatically go ’oh you can’t really do therapy with people with ID’, or ‘what? You do CBT? What? You do psychodynamic therapy?’ […] I think that’s absolute rubbish […] I think it’s just a reason to exclude people. It’s a reason not to try and adapt your practice.” (O’Malley et al., 2020, p. 63)

This adaption of practice was influenced in part by the lack of an evidence base, which was viewed by some participants as detrimental or the status quo in LD services (Hodges & Northway, 2019; O’Malley et al., 2020; Truesdale et al., 2019). One participant from Truesdale et al.’s (2019) study reflects this:

> “I think the problem with learning disability services, we try and do things, we try and kind of adapt what mainstream are doing. But I think we're really behind the times when it comes to trauma.” (Truesdale et al., 2019, p.1441)

Whereas for others it was seen an opportunity to adopt novel or experimental approaches e.g., eidetic psychotherapy (O'Malley et al.,2018; O'Malley et al., 2020). In adapting their practice, professionals hoped for a range of outcomes and the process by which these were achieved varied, but ultimately there was a consensus person-centred care was the most important factor in practice (Hodges & Northway, 2019; Keesler, 2016; O'Malley et al., 2019; O'Malley et al., 2020; Truesdale et al., 2019):

"Person-centred … they should be tailored to the patient … they've got to take account of the person's intellectual disability. They've got to be at the pace that the person can cope with. Communication issues are obviously going to be crucial, you know, all the descriptions have got to be at a level that the person can understand.*"* (Truesdale et al., 2019, p. 1440)

Noting the aforementioned lack of evidence base, participants also highlighted other aspects of their work where there was 'lack of' what was needed and how it impacted on delivery of person-centred care. Some participants referred to this being the availability of 'resources' (Keesler, 2016; Jenkins et al.,2007; O'Malley, 2020; Truesdale et al., 2019), as illustrated in a quote from the Jenkins et al. (2007) study:

"Unless it's the top end of abuse, you know, the physical, sexual, then unfortunately there is no resources there where they are flagged up – nothing ever changes." (Jenkins et al., 2007, p. 3045)

Whereas others spoke more specifically about a lack of policy and legislation (Hodges & Northway, 2018, O' Malley et al., 2020), time (Truesdale et al., 2019), supervision and support, (Keesler, 2016; O Malley et al., 2020, Truesdale et al., 2019), training (Truesdale et al., 2019) and funding (Jenkins et al., 2007; Truesdale et al., 2019). Practitioners also located an absence within themselves in terms of their expertise or knowledge in working with abuse (Keesler, 2016, Kildahl et al., 2020; O'Malley et al., 2020; Truesdale et al. 2019), a lack of choice, validation, opportunity or justice for their clients currently or during their lives (Jenkins et al., 2007; Keesler, 2016; O'Malley et al., 2019; O' Malley 2020).

The sense of deficiency was also extended to an organisational level e.g., the service environment, both physical, e.g. "small hallways (impact on safety)" (Keesler, 2016, p.489) and care pathways, protocols and structure, e.g. "fragmented referral system" (Truesdale et al., 2019, p.1439), which impacted not only practitioners' abilities to meet clients' needs, but to develop their own expertise (Hodges & Northway, 2019; Jenkins et al., 2007; Keesler, 2016; Kildahl et al., 2020; O'Malley et al., 2020; Truesdale et al., 2019).

As with adapting approaches, some participants saw the lack of what was needed as just what occurred in services and 'making do', whereas others noted the benefits to having more and the need for it. This included training, support and supervision to ensure practitioners are better able to support clients and achieve the best outcomes as practitioners feel more supported themselves and having increased knowledge to deliver this care (Hodges & Northway, 2019; Keesler, 2016; O'Malley et al., 2019; O'Malley et al., 2020; Truesdale et al., 2019).

2.3.3.2 Theme Two: 'Navigating the complexity of different roles and the consequences'.

This theme relates to the professionals' navigating the roles they hold within their practice with others and the significance of doing so. Two subthemes encapsulate this; 'Client and Family: It's the relationship that matters', and 'MDT working- It is better to work together'.

Professionals spoke about developing an individual relationship with service users to facilitate communication, a client's recovery, sense of security and confidence in therapy, alongside staff's own confidence to protect clients from abuse and report it (Hodges & Northway, 2019; Jenkins, 2007; Keesler, 2016; O'Malley et al., 2019; O'Malley et al., 2020). This is demonstrated by a social worker in Hodges & Northway (2018) study:

“…you need quite a close relationship with that person for them to tell you what’s going on and to feedback.” (Hodges & Northway, 2019, p.442)

It was acknowledged establishing a therapeutic alliance, and trust and rapport within the relationship was important and a key aim (Hodges & Northway, 2019; Keesler, 2016; O’Malley et al., 2019; O’Malley et al., 2020), particularly in cases where service users had experienced invalidation or absence of trust throughout their lives (O’Malley et al., 2020). One practitioner in the O’Malley et al. study (2019) also spoke about practitioners also needing to be able to trust their clients. The contributing factors to a positive relationship were good communication, active listening, being aware of one’s own beliefs and assumptions, getting to know the client and providing consistency and predictability (Keesler, 2016; O’Malley et al., 2020). The significance of the practitioner- service user relationship is highlighted in the O’Malley et al. (2020) study:

“No matter what model you throw out there it’s the relationship. Em… It’s the trust. It’s the boundaries that hold the person. It’s the being there from week in to week out.” (O’Malley et al., 2020, p. 61)

Staff also addressed the dilemmas they face when the abuse has perpetuated by another service user in terms of duty of care to both parties, protecting the client who is experiencing the abuse and consideration of the perpetrator's capacity to understand their actions, and in turn how to respond to the abuse (Jenkins et al., 2007). This is highlighted by a situation faced a practitioner in Jenkins et al. (2007) study:

“I am sorry, I am going back to the client situation with another client. If I had that situation in my house, that my husband was hitting me, and I would want him out of the house today, now this minute. I wouldn’t want him out of the house in probably three to four months because it is expensive to re-home him.” (Jenkins et al., 2007, p. 3044)

This situation in which the abuse has occurred between two services users or by the service itself also impacted on the trust the service user held for the staff member, for example in the O'Malley et al. (2020) study one practitioner noted the client did not want to speak to them as the service user was aware the practitioner knew the person who had abused them.

Moreover, practitioners reflected on the complexity of the relationships with service users' families, this included how this may impact on how they responded to suspected abuse from a family member (Hodges & Northway, 2019; Jenkins et al., 2007; Kildahl et al., 2020; O'Malley et al., 2020) some spoke of not considering abuse given the family context, and a staff member from Kildahl et al.'s (2019) study reflected on this in hindsight:

"We should have thought of trauma. I don't think we even considered it, because we thought that he had a fantastic mother and father and it had been very safe for him. We just assumed there wasn't any." (Kildahl et al., 2020, p.197)

Others identified their own internal conflicts, similarly to when a service user had caused the abuse, in what would be the best course of action when abuse is reported or suspected to have been perpetrated by the family (Hodges & Northway, 2019; Jenkins et al., 2007). There were concerns regarding the impact of investigating the abuse claims or taking action on their relationship with families which could impacted upon if they did so, more so than their relationship with the service user, highlighted by a practitioner in Hodges & Northway's (2018) study:

"It's complicated though, cos you've got to have a kind of working relationship with people, you know, and there's got to be an element of trust, you've got to develop a rapport to an extent, but obviously you have to stand back on occasions and think, am I compromising my practice here, am I not advocating on a person's best behalf, because you can get drawn in with families." (Hodges & Northway, 2019, p. 441)

Some staff also identified the difficulty in how much the family should know and be involved in decisions and its impact on the client:

“The parent herself was unwilling to bring them to court because that was going to be another 2 or 3 years and bringing everything back. And her daughter was already very, very traumatised by the whole thing.” (O’Malley et al., 2020, p. 64)

Alongside their relationships with service users and family members, professionals also reflected on their working with the MDT colleagues and in the wider network. Clinicians recalled working with a variety of professionals, including social workers, nurses and clinical psychologists (Keesler, 2016; Hodges & Northway, 2019; O’Malley et al., 2020; Truesdale et al., 2019). There was preference and value seen in working together as an MDT across the time points in a service user’s care e.g., assessment and intervention, as the different specialities brought different skills which benefited the service user (Keesler, 2016; Hodges & Northway 2018; Truesdale et al., 2019. This is illustrated by a Clinical Psychologist in Truesdale et al.’s (2019) study:

“A multidisciplinary approach is probably the best way because often it's about building relationship with the clients … a multidisciplinary approach where you know you've got a team working together and there's communication within the team, then at different points in that client's journey to kind of recovery from trauma, you've got maybe different people working who've got a different skill set, so that their needs can be met." (Truesdale et al., 2019, p. 1440)

There was a sense that working together as an MDT and having support from colleagues was also not only beneficial to the outcomes for service users, but for professionals within the teams too in terms of work pressures and comradery (Keesler, 2016; Hodges & Northway, 2019; O’Malley et al., 2020). These benefits appeared to be fostered through trust and collaborative working within the team, with certain approaches such as trauma informed care facilitating this, as demonstrated by those participants in Keesler's (2016) study:

"We all work together; we always are lending a helping hand.. . It makes the work day a lot easier knowing that you have a great team set up where you are all working together." (Keesler, 2016, p. 486)

Working with professionals outside of your immediate team or organisation were also welcomed. A participant in the O'Malley et al. study (2020) spoke positively of a recently introduced initiative that would encourage more joined up working with therapists outside of her team:

"The roll out of these MHID [mental health in ID] teams [is] a real opportunity for therapists who are working in ID to get together […] Because usually, we've been kind of working in isolation." (O'Malley et al., 2020, p. 486)

Nevertheless, MDT working did not come without challenges including conflicting ideas with regards to the best appropriate to support clients, as well as predicaments regarding whistleblowing colleagues or services one worked in and how these situations were managed (Jenkins et al., 2007; Keesler, 2016). A participant in Keesler's (2016) study recalled the difficulties between members in team and within the wider service when the trauma informed care approach was first introduced:

"We had a couple staff in the beginning that did not necessarily fit into the model we were trying to build and it wasn't something that they felt comfortable in and they chose to leave." (Keesler, 2016, p. 488)

A participant working in health and social services in the Jenkins et al. study (2007) described the deliberation process of considering whether to 'protect' staff members or carry out their duty regarding possible abuse due to concern for themselves or staff members and the services who may be perpetuating abuse.

"What I am trying to say is, although we all know that we should be disclosing any sort of abuse that we come across, there is a duty there for us to disclose, but I do think that some abuse is being held back because staff are unsure how they are going to be treated, so I do feel that they need protecting as well, members of staff." (Jenkins et al., 2007, p. 3046)

Participants also spoke about the scope of MDT decision making and the influence of the role of their managers which will be discussed in later themes.

2.3.3.3 Theme Three: 'Perceptions and impact of LDs'.

This theme encapsulates how professionals and others view the service user. These beliefs influenced whether the service user was truly understood and seen, which ultimately impacted on the care (Jenkins et al., 2007; Kildahl et al., 2020; Keesler, 2016; O Malley 2018; O'Malley et al., 2020, Truesdale et al., 2019). This theme is reflected within the two sub-themes 'Holding assumptions about the service user' and **'**I want the best for my client'.

Professionals spoke about the general assumptions either held by themselves or others about people with LDs. These included those on communication ability, capacity, skills and interpersonal style (Jenkins et al., 2007; Kildahl et al., 2020; Keesler, 2016; O Malley 2018; O'Malley, 2020, Truesdale et al., 2019).

A practitioner in O Malley et al.'s (2020) study spoke of the perceived lack of reliability of people with LDs to recall what had happened to them, and this was expanded on by a Clinical Psychologist in Truesdale et al.'s (2019) study who shared this impacted on their ability to engage in trauma therapy.

"People with ID aren't seen as good historians […] Like lots of people, they struggle with memories of upsetting things… Traumatic things… So you have that coupled with somebody who would tend to struggle with saying what they did last week." (O'Malley et al., 2020 p. 62).

"I mean it works better for people with mild or moderate intellectual disabilities and obviously anyone whose borderline learning disabilities. They are all very capable of doing this, when you get to the lower end of the moderate intellectual disability severe and profound, you're suddenly very limited in what you can do because I wouldn't generally be working directly with the person they'd be working more systemically, they have more trouble seeing insight and remembering things." (Truesdale et al., 2019, p. 1442)

There was also a general concept of people with LDs not being able to communicate well, particularly when nonverbal (Kildahl et al., 2020; O'Malley et al., 2020; Truesdale et al., 2019). A professional in Kildahl et al.'s (2019) study described their experience of finding it hard to understand a client they were working with:

"It was often challenging, as he had a distinctive way of speaking. It wasn't always easy to get answers to the questions you asked." (Kildahl et al., 2020, p. 197)

Alongside their own perspectives of service users, clinicians also hypothesised how those with LDs may feel and how this might differ from the perception of professionals as demonstrated in O'Malley et al.'s (2018) study:

"Megan's key worker described: After she had had appointments and stuff, she'd be teary [...] she wouldn't really go into specifics she'd just say that she didn't like talking about that kind of thing. In contrast, the psychologist described: We passed through that [difficult] phase very quickly—it was not very painful." (O'Malley et al., 2019, p. 109)

Overall, these assumptions often created a narrative that people with LDs were seen as challenging to work with, passive or lesser than others, thus placing lack of progress or poor outcomes as being the fault of service users, rather than clinicians or services. (Jenkins et al., 2007; Kildahl et al., 2020; Keesler, 2016; O Malley 2018; O'Malley et al., 2020, Truesdale et al., 2019).

In contrast, clinicians also expressed wanting the best for their clients and the active role they played as practitioners in ensuring this (Hodges & Northway, 2019; Jenkins et al., 2007; Keesler, 2019; O'Malley et al., 2019; O'Malley et al., 2020; Truesdale et al., 2019). Practitioners identified the importance of being mindful of their own aforementioned assumptions about people with LDs and challenging or reframing these to ensure a holistic understanding of the client is achieved to support them (Keesler, 2019; O'Malley et al., 2020). This captured by clinicians in Keesler's (2019) study and O'Malley et al.'s (2018) study:

"….It is not trying to make someone who is bad better. It is trying to help someone be the best person they can be.. .It is more about learning about the individual...their needs.. .their backgrounds so that you will be able to help them instead of cause more trauma." (Keesler, 2019, p. 486)

"The most important issue that we have to learn out of all this experiences… That we do not see people with learning disability as carrying an emotional baggage […] We should be able to empathise with them, and be able to support them, and be able to trust them." (O'Malley et al., 2019, p.110)

There were shared and differing ideas of what 'the best' meant amongst clinicians, some focused on the care delivered, including person-centred care as previously mentioned (Jenkins et al., 2007; Truesdale et al., 2019). A practitioner in Jenkin et al.'s (2007) study spoke of the importance of questioning inclusivity within patient's care during the decision making process, whereas a clinician in O'Malley et al.'s study (2020) considered how best to support client's at the end of therapy:

"…and the client isn't even aware that the vulnerable adult strategy meeting's going on; then things are being taken forward and I think, 'Where is there person-centred planning around this." (Jenkins et al., 2007, p. 3044)

“I’m not going to abandon. Because that’s retraumatising. So I have to be really careful with people who have been abused about how we finish […] Around them taking control of that […] you’re guiding them towards feeling that they are making that decision.” (O’Malley et al., 2020, p. 63)

Others conceptualised this as being the outcomes for the clients (Keesler, 2016; Hodges & Northway, 2019), as illustrated in Keesler’s (2016) study:

“The importance of teaching (e.g., coping skills and emotional self-regulation), relationship building and understanding individuals were seen as critical components to helping individuals progress ‘further and faster’” (Keesler, 2016, p. 496)

2.3.3.4 Theme Four: ‘What is abuse and what does it do?’

This theme demonstrates the multi-layered aspects of abuse in terms of awareness, definition and recognition, and its impact and how these influence the responses service users received from clinicians. It is summarised across the three sub-themes of, ‘Unmasking abuse’, ‘What meets the threshold? and ‘It impacts us all’.

Professionals reported on the different types of abuse e.g., sexual, psychological, and physical, that occur and those who are the perpetrators. This included service users’ peers, but often those in positions of power such as family members, carers as well as services, institutions, and clinician themselves, either directly or by proxy through allowing abuse to pervade (Jenkins et al., 2007; Keesler, 2016; Kildahl et al., 2020; O’Malley et al., 2020). This is reflected in a quote from Susan, a clinician, in O’Malley et al.’s (2020) study, who recalled a client’s experience of returning to a service where the perpetrator continued to be:

“She was still being retraumatised - that’s why she wouldn’t come in to any of the services. So I could understand that. It was not avoidance in terms of the memory, it was avoidance in terms of - it could happen again! Because he was still in those environments.”

(O’Malley et al., 2020, p. 61)

However, clinicians also acknowledged the awareness and detection of abuse was not always straightforward. This risked detrimental effects e.g., untreated trauma or continued abuse, to service users who may not readily share themselves that they had been abused (Kildahl et al., 2020; Truesdale et al., 2019). There were several factors that contributed to why abuse may not have been recognised or considered by practitioners. They reflected when people with LDs are initially referred to the service trauma as a result of abuse was often not cited as the reason for referral (O’Malley et al., 2020; Truesdale et al., 2019).

“I have had people whereby they have been referred for anger management or challenging behaviour and then you realise actually the persons had a horrific childhood where they've been beaten and various other negative life events.” (Truesdale et al., 2019, p. 1439)

Clinicians also identified themselves as not recognising a client’s presentation was the result of abuse through lack of knowledge and diagnostic overshadowing which impeded on them further investigating or asking questions of service users’ presentations (Kildahl et al., 2020; Truesdale et al., 2019). Two practitioners in the Kildahl et al. (2020) study reflected retrospectively on their team not identifying a service user who had experienced sexual abuse, attributing his symptoms to autism and his mood.

“He had quite a few symptoms. We understood them differently, but they probably were associated with trauma. We were too quick to find an explanation. I think we explained too much by his autism.” (Kildahl et al., 2020, p. 198)

“I’ve thought about afterwards how he was very rarely happy” [5]. At the time, this was attributed to a mild depressive disorder.” (Kildahl et al., 2020, p. 199)

Furthermore, professionals reported how well they knew a client or their intuition were also determining factors in how they were able to identify their service user was experiencing abuse.

“Some members of the team have worked with particular individuals for many years, um, I tend to rely heavily on their past experience. You know sometimes you can think ah I know that person, they’re always like that and possibly its familiarity.” (Hodges & Northway, 2019, p.442)

“Things like that tell you, you know, gut feelings.” (Hodges & Northway, 2019, p.441)

Alongside becoming aware of abuse, clinicians appeared to subjectively decide thresholds as to what would be considered abuse, and thus what action or no action needed to be taken (Hodges & Northway 2019; Jenkins et al., 2007 Keesler, 2016, O’Malley et al., 2020). Professionals spoke about services being either under sensitive or overly sensitive during the safeguarding decision process (O’ Malley et al., 2020). One clinician reflected on her experience of reporting her concerns to the safeguarding team and her colleagues’ reactions, and another on how services differ in their implementation of policies and procedures (O’Malley et al., 2020):

“When I refer something to the safeguarding person, em, other people were saying, like, ’oh, you know, people might feel that’s kind of punitive, do you really need to do that?’ and I’m kind of like.. Well, yeah!” (O’Malley et al., 2020, p.62)

Others spoke of the influence of certain circumstances on whether they would consider abuse or if action needed to be taken e.g., the frequency of incidents or severity of consequences for the service user (Hodges & Northway, 2019; Jenkins et al., 2007). A clinician in Hodges & Northway’s (2018) study describes a scenario in which she decided to act following numerous concerns of abuse:

“Yes, sometimes if you go to an organization they can say that was just a one off, just a blip. But sometimes there are a number of blips and then you think right there have been too many single incidents so you raise a POVA [Protection of Vulnerable Adults] then." (Hodges &Northway, 2018, p. 440)

Capacity was also considered a factor to consider in the decisions as to whether abuse had occurred and how to respond when abuse had been perpetuated by an individual with a LD (Jenkins et al., 2007).

"'Capacity', it is a good word, isn't it? It is a person's capacity, regardless of the fact that the person has had their hair pulled out in chunks, and that person who did it didn't have the capacity to know what they would do. The other person who has had their hair pulled out in chunks is still there, ... so capacity is a good thing to throw up." (Jenkins et al., 2007, p. 3045)

The final consideration for abuse was understanding its impact on individuals who had experienced abuse, this was part demonstrated in the previous subtheme which acknowledged clinicians noticed the consequences of abuse on clients' wellbeing, even if they did not attribute this to abuse. Nonetheless, clinicians were also able to describe a range of difficulties experienced by individuals as a result of abuse, including flashbacks, negative thoughts about themselves and others, anxiety, symptoms similar to PTSD, attachment issues, and their interactions with staff (Jenkins et al., 2007; Keesler, 2016; O Malley et al., 2018; O'Malley et al., 2020; Truesdale et al., 2019). This was noted by a clinician in Keesler's (2016) study:

"The effects of being institutionalized are so easy to see in them. They will come at you with their arms already in the pose for a (restraint)...You don't even have to do anything to put them into an intervention which is sad to me that that is their automatic response." (Keesler, 2016, p. 485)

Clinicians also noted the toll of working individuals who had been abused on themselves (Keesler, 2016; O'Malley et al., 2020. One psychologist described their experiences of vicarious trauma "When you're with somebody, there's counter-transference issues, but there's also vicarious traumatisation […] I think that supervision is about safe practice." (O' Malley et al., 2020, p. 64).

2.3.3.5 Theme Five: 'Trusting my clinical expertise or seeking guidance'.

This theme reflects the dilemma faced by professionals with regards to conviction in their clinical expertise or seeking guidance when working with individuals with LDs who had experienced abuse. Some professionals conveyed feeling competent in their roles based on their training and clinical experience (Hodges & Northway, 2019; Keesler, 2019). A clinician in Hodges & Northway's (2018) study encapsulates this when describing the process of making a safeguarding decision:

> "Everybody has got background, everybody has got experiences, everybody does practice; you know so it all impacts… I might feel like that but what am I basing that feeling on and have the picture in front of me is this and that is why I need to be risk assessing." (Hodges & Northway, 2019, p. 441)

Confidence also interplays with this sense of competence for clinicians with it influencing their commitment to undertake their roles and responsibilities with autonomy and self-assurance (Jenkins et al., 2007; Kildahl et al., 2020). Therapists demonstrated confidence in their rationales and clinical expertise to adapt interventions to support the needs of individual with LDs when faced with the necessity to do so (O'Malley et al., 2018; O' Malley et al., 2002; Truesdale et al., 2019):

> "Every individual who walks in the therapeutic session is a different person altogether. So it is a very creative work." (O'Malley et al., 2020 p.61)

Others spoke of feeling confident when supported by their managers to carry out their roles with flexibility and how this resulted in better care for clients too:

“Management has empowered us to be confident in the way we do our job and we provide empowerment for the individuals to do whatever they have their mind set on.” (Keesler, 2016, p.487)

Whereas as others described a more didactic relationship with management in seeking support to ensure confidence in their choices regarding client’s care, and often apparent at the initial safeguarding decision stage, as illustrated by clinicians in Hodges & Northway’s (2018) study:

“I’d discuss it with my manager absolutely definitely, somebody with a lot more experience or senior practitioner whoever.” (Hodges & Northway 2018, p. 441)

“I wouldn’t want to be the person who draws the line in the sand.” (Hodges & Northway 2018, p. 442)

This raised the question who is overall responsible for a service user’s care? For some this was seen as a collective decision, reflecting the preferences for MDT working highlighted in a previous subtheme (Keesler, 2016; Truesdale et al., 2019). Whereas in safeguarding decisions in particular, social care were seen to hold overall responsibility for the final decision even if they did not agree with this (Hodges & Northway, 2019):

“…even if my manager was unsure he would go to the social services manager.”

(Hodges & Northway, 2019, p. 443)

It is noteworthy that those who perhaps felt more confident were therapists delivering therapeutic intervention following disclosure, and those who sought guidance were professionals making safeguarding decisions. This may reflect the different types of work, with professionals making safeguarding decisions feeling more time pressure and that more was at stake e.g., removal of service user from their family home, or an impact on their relationships with families, or consequences for their colleagues or services, therefore collaborative decision making is important. Whereas the therapist may be afforded more time and their adaptive practice holds less risk.

2.3.3.6 Overarching Theme: 'Variability in practice- meeting individual client's needs or creating inequitable care for the majority?'

Overall, it was clear across all the studies there was variability in the practice delivered by clinicians. The lack of neutrality or subjectivity in how services respond to disclosures and support offered to those who had been abused, afforded both person centred care and inconsistencies in standards of care for service users (Hodges & Northway, 2019; Jenkins et al., 2007, Keesler, 2016; O'Malley et al., 2019; O'Malley et al., 2020; Truesdale et al., 2019). This places clinicians and services in positions of power in terms of the delivery of care, one that a participant in O'Malley et al.'s (2020) study indicated people with LDs are aware of:

> "People with ID tend to be quite aware of the power differentials. You know - they'll want to agree; they'll want to keep the system going. They'll want to do what they're supposed to do." (O'Malley et al., 2020, p .64)

2.4 Discussion

2.4.1 Summary of Findings and Links to Previous Literature

The qualitative rapid review aimed to qualitatively synthesise health and social care professionals' experiences of working with adults with LDs who have been abused or abuse is suspected. The findings suggest overall there is variability in the care provided to adults with LDs who have experienced abuse or abuse is suspected, with contributing factors highlighted in each theme; 'We have to make it work'; varying ways policies and procedures are implemented, 'Navigating the complexity of my different roles and the consequences'; the influence of the relationships professionals have with service users and their families, ‘Perceptions and impact of LDs’; the perceptions clinicians hold about individuals with LDs, both positive and negative, ‘What is abuse and what does it do?’; clinicians’ level of awareness and thresholds to abuse, and ‘Trusting my clinical expertise or seeking guidance’; clinicians’ confidence in their own clinical expertise. Ultimately these place people with LDs at a disadvantage as power is held with professionals and more broadly services. It highlights a gap in the research to hear from those who are receiving these services to inform how they can be improved to best meet their needs.

The variability in care as the result of the adaptations of approaches, differences in how policies and procedures are implemented and thresholds for abuse, could be reflective of and reinforce the issues presented in Chapter One on defining and categorising abuse e.g., differing definitions within countries and globally. The varying definitions of abuse may also impact on findings that some professionals lacked confidence in their own abilities and knowledge of how to respond to abuse. This is line with previous research in Chapter One, which indicated that professionals working adults with and without LDs who had been abused, did not feel in confidence in how to best respond, but following training this improved (Cavanagh et al., 2004; Johnson & Yee, 2019; McNeish et al., 2008). Furthermore, the review adds to the concept of relationships playing an important role in disclosure and responding to abuse, and how they could act as both facilitators and barriers, depending on if they are positive or negative. Professionals in the review identified how their relationships with clients and families may impact on them recognising (or not) or acting (or not) on concerns regarding abuse, and the literature in Chapter One, highlighted facilitators to disclosure is a trusting relationship with the person they disclosed too (Tener & Murphy, 2015). Finally, Chapter One highlighted the detrimental historical and still current views of people with LDs, which is important to note given the influence of professionals’ perceptions on the care provided to this cohort highlighted in the review. The implications of this review will be addressed in Chapter Four, alongside the main findings from the empirical study.

2.4.2 Strengths and Limitations

The current rapid review successfully synthesised the experiences of health and social care professionals working with adults with LDs who have been abused or abuse is suspected. As the first qualitative literature review focusing specifically on the topic it provides several themes to deepen the understanding of these professionals' experiences. The studies were identified using rigorous structured and systematic steps. The databases used in this rapid review were chosen following consultation with the University of Essex’s Subject Librarian and feedback from an academic assignment. However, it is important to note a limitation of this review is the qualitative databases of Web of Science, Social Science citations and Scopus were not searched, which may have highlighted papers not identified in the databases that were used in this review. Another limitation is the broad inclusion criteria for professionals working within health and social care who will work in varying roles and settings, as well as the studies being conducted in different services and countries which may impact its transferability. The review was also completed without a second reviewer and by a single researcher, with experience working in healthcare settings, which may have increased the risk of researcher bias.

2.5 Conclusion

The combination of the two reviews highlighted a gap in research with regards to the direct subjective experiences of adults with LDs on the disclosure of abuse to be able to understand the disclosure experience for this cohort beyond clinicians and other stakeholders’ perspectives. The researcher decided to address this gap by conducting a qualitative empirical study, utilising semi-structured interviews and reflexive thematic analysis to explore adults with LDs’ experiences of disclosing abuse, recruited from CLDTs in Southeast England, UK.

The researcher also completed consultation with an established LD drop-in group on the research, including the development of the research materials, to provide further evidence adults with LDs can successfully be involved in the production of research.

3. Chapter Three: Empirical Study

3.1 Chapter Overview

This chapter presents the qualitative empirical study on adults with LDs' direct experiences of disclosing abuse to contribute to addressing this identified gap in the research literature. The chapter outlines the rationale and aims of the study, followed by a detailed account of method, including analysis, to support transparency and replicability. The results are then provided, and the chapter concludes with a discussion and critical appraisal of the study and the results, highlighting its contribution to the research literature.

3.2 Rationale for Current Study

In light of the high prevalence of abuse in the LD population, its impact on their mental health and wellbeing, and the importance of disclosure in recovery and the inconsistencies in services being provided to this population, as highlighted in Chapter One and Chapter Two, there is a clear need to ensure professionals working with the LD population, who arguably may be at greater to abuse and its impact, have an understanding on how best to support and respond to the disclosure of abuse. As highlighted by the paucity of research, the LD population are seldom heard within the literature, and in the topic of area of abuse, including their facilitators and barriers to disclosure. Therefore, by developing this study in conjunction with people with LDs and asking them directly about their experiences of disclosure, this will provide further insight into this area and begin to address this gap in research literature, as well as reinforce the involvement of the LD population in research is possible. This research also hopes to inform recommendations for professionals working in CLDTs, and other support services on the facilitators, barriers, and responses to abuse disclosure for people with LDs. As previously mentioned, for the purpose of the empirical study, abuse is defined as interpersonal in nature and physical, sexual, psychological, financial, domestic, discriminatory and social abuse, and neglect (NHS, 2022), with participants taking part in the study identifying and narrating their experiences as abuse. Further, it is likely people with LDs are potentially exposed to a wide range of abusive experiences and the need for a broad definition is therefore appropriate.

3.3 Aims, Research Question and Outcomes

3.3.1 Aims

To explore in greater depth using qualitative methods:

- The experiences of adults with LDs on disclosure of abuse, including identifying the context, facilitators and barriers to disclosure, and the responses received.
- The experiences and views of adults with LDs on how CLDTs and other support services can support disclosure, and on how these services should respond
- To develop recommendations for professionals and services working with adults with LDs on how to enquire about and respond appropriately to the disclosure of abuse

3.3.2 Research Question

What are the experiences of adults with LDs on disclosing abuse?

3.3.3 Outcomes

This study will contribute to the understanding of the experiences of adults with LDs on disclosing abuse, and the support that may need to be provided. As a result, it will hopefully inform recommendations for best practice for professionals working with adults with LDs regarding how to enquire about and respond appropriately to abuse disclosure. Throughout adults with LDs will be involved in the development of the research, as well as the respondent validation of the findings and dissemination.

3.4 Method

3.4.1 Philosophical Framework and Research Paradigm

Research is inevitably informed by the philosophical framework that underpins it. This framework is organised by a set of beliefs and assumptions about knowledge development, often defined as ontology; the nature of reality, and epistemology; the nature of human knowledge (Jackson, 2013), both represented on a continuum with two polarised ends: one of positivism and one of interpretivism. Through the researcher identifying their own ontological and epistemological positions a coherent and consistent methodology and procedure is applied to the research process, which ensures transparency, meaningful interpretation, and high-quality research (Twining et al., 2017). Therefore, the following section is written in the first person.

3.4.2 Researcher's Ontological and Epistemological Positions

In terms of my own ontological position, I place myself in the middle of the continuum, within the position of critical realism. I assume that a reality exists, but that it has been moulded by "social, political, cultural, economic, ethnic and gender values" (Guba & Lincoln, 1994, p. 109). In terms of this study, it feels important to take a realist stance towards abuse; in acknowledging that the abuse that has occurred is real. However, individuals will have different viewpoints based on their experiences. I also acknowledge that qualitative research cannot be unbiased, as the role of my own beliefs will impact on the interpretations of the data. Similarly, to my ontological position, I place myself in the middle of epistemological continuum. I hold a stance of contextualised constructionism, that all knowledge is contextual (Madill et al., 2000). It posits that there can be different meanings for the same phenomenon (Madill et al., 2000). This fits with the topic under investigation; exploring the views of adults with LDs on how best to support them to disclose abuse and the responses required from CLDTs and other services. A qualitative methodology was utilized by the study to ensure an in depth understanding of the participants' views and experiences, to inform recommendations for professionals and services (Chenail, 2011). The axiology of the research i.e., the researcher's positionality to the research will be discussed in Chapter Four.

3.4.3 Service User Consultation

The involvement of service users within the health and social care research processes is encouraged by ethics committees, the National Institute of Health Research (NIHR, 2021) and within the wider literature (Minogue et al., 2005; Beresford, 2013). The NIHR recommends one level of involvement is through consultation, which involves asking service users for their views on various different aspects of the research, such as prioritizing research questions, design and management and dissemination of findings (NIHR, 2021). Through actively involving service users in this way and the expertise by experience they bring, it is argued their involvement contributes to improving the accessibility of the research and its impact by strengthening research-practice links (Pandya-Wood et al., 2017). Therefore, the researcher it felt crucial to ensure adults with LDs were included in developing the research, and even more so given the evidence that their views are rarely heard. Studies have also demonstrated involving adults with LDs in the research process is invaluable and contributes to the research being relevant (Minkes et al., 1995). They bring their own life experiences which is imperative in trying to understand their experiences, and how any difficulties they experience can be addressed (Northway, Melsome et al., 2013).

The NIHR guidelines (2018), informed the process on consultation with a local LD service user drop-in group within one of the participating trusts. The group met weekly to socialise and focus on a specific topic for discussion facilitated by occupational therapists and support workers. The researcher and the second academic supervisor met with group on three occasions, prior to the COVID-19 pandemic, to consult directly on the development of the research idea, the data collection tools and dissemination. In the first meeting, the researcher and the second academic supervisor provided psychoeducation on emotions, and how we feel, think, behave can been impacted on by our past experiences, and the group identified these experiences could be parents splitting up or being bullied, and we then introduced the research idea. In the following two sessions initial designs of the data collection materials, including consent forms, were presented, as well as the interview schedule. Both the PIS and the consent forms were adapted from forms developed by a previous trainee clinical psychologist on the University of Essex Clinical Psychology Doctoral Programme for placement purposes, and those used in a study with adults with LDs by Bennett et al. (2013).

The service user drop-in group proposed language and visual aids that could be used within the data collection tools to ensure they were accessible to participants, e.g. providing feedback on the images used to support the text in the documents, suggesting both photo and picture versions of the consent forms and PIS to meet participants differing needs and preferences, as well as preferred locations for the interview e.g. in their own home as participants may feel more relaxed or in a café as this was considered more neutral. The group also identified prompts for the interview schedule guide, through a discussion about the interview questions e.g., trusting the person and building rapport with person you disclose to would facilitate disclosure. A copy of the consultation can be found in Appendix D. The staff facilitating the service user drop-in group also provided feedback on the data collection tools during discussions with the wider group.

Other key stakeholders who were consulted on the research were a Senior Speech and Language Therapist (SLT) from the School of Health and Social Care at University of Essex, who advised defining abuse with participants at the beginning of the interview to help orientate participants to the interview questions that would follow. Please see Appendix E for a copy of the consultation log.

3.4.4 Service Context

The current research was conducted in CLDTs across two NHS trusts in Southeast England, the details of which will not be given to maintain anonymity. The services provide specialist healthcare to adults with LDs. Each service includes a MDT of psychiatrists, psychologists, nurses, occupational therapists, physiotherapists, art therapists, SLTs and support workers. Given the topic of area of abuse, participants were recruited from CLDTs to ensure the appropriate support was available if required.

3.4.5 Ethics

The research was conducted in accordance with guidance outlined in the code of human research ethics set out by the BPS (2014).

3.4.5.1 PIS.

The BPS (2014) states for participants to make an informed decision regarding their participation a study i.e., their informed consent, they must be provided with sufficient information about the study, that is in an accessible and comprehensible format for the participant. To address this, participants were provided with an information sheet (see Appendix F, for photo and pictures versions of the PIS form) which provided an overview of what the research was about, what it would involve, and their right to withdraw at any time. The principle of respect for autonomy and dignity of individuals set by the code (BPS, 2014) states that vulnerable populations should be given sufficient opportunities to understand the research. Therefore, in line with this guidance participants were given two occasions to read and go through the information sheet; prior to being contacted by the researcher and prior to the starting the interview. Following reading the sheet, participants were asked to complete a form to indicate they understood the research and the opportunity to ask any questions.

3.4.5.2 Consent Forms.

Once participants had been provided with and understood the information about the study, they were asked if they consented to take in the study via two consent forms. The consent forms included a consent to contact form and consent to take part form (see Appendix G, for photo and pictures versions of the consent forms). The REC committee requested an explicit statement be added to both consent forms to indicate the researcher would be aware of the type of abuse the participant had experienced. The participants were also invited to decide on their own pseudonym and to take part in respondent validation once the interviews were analysed.

In the study, informed consent was considered as an "on-going process constantly under review and negotiation" (Abrahams, 2007, p. 241), with participants asked if they consent to take part at each key stage of the study. Participants were also asked verbally if they consented once the recording for the interview had begun. The researcher discussed with participants at beginning of the interview how best they would wish to communicate, if they did not want to answer a particular question or stop the interview at any time, which included the use of a stop card to present to the researcher. At each stage, participants were invited to have a member from their support network present if they wished.

Both the PIS and consent forms were also accompanied by visual aids to support them to answer the questions if needed (see Appendix H), and copies provided to participants via email.

3.4.5.3 Risk of Harm.

The risk of harm involves considering a range of potential risks to an individual as a result of their participation in the study. Participants must be made aware of the potential risks involved to help inform their decision as to whether or not to participate. If risks are identified, protocols for risk management must be developed to manage or minimise the risks (BPS, 2014). Some participants may find talking about abuse distressing. Although, the study did not ask explicitly ask participants directly about their experiences of abuse, it was considered that participants may discuss this in the context of the questions asked or a small possibility that participants may disclose new abuse.

In order to manage any potential distress, a remote risk management protocol was developed to manage this and followed. A member of the clinical team and the second academic supervisor working in one of services were contactable by telephone at all times during the interview. If a participant showed any signs of distress, the researcher was able to contact a member of the clinical team or the second academic supervisor along with the participant, to discuss continuing the interview or any other concerns that had arose. If a participant disclosed any risk, as above the researcher informed the participant, they would need to share this information with the clinical team, who would implement the trust safeguarding procedures. If the researcher felt the participant needed to be speak with a member of the clinical team as a result of the interview, the clinical team would be contacted, and the researcher would remain with the participant on telephone or video call until they were able to contact the participant e.g., join the video call. If the researcher assessed that the participant was at immediate risk, the emergency services would be contacted.

The participants that took part in the study did not show significant signs of distress, but three participants requested to check in with their clinician following the interview. For the remaining two, one had the clinician present throughout, and another their family members.

3.4.5.4 Information about Seeking REC Approval.

Ethical approval was initially sought and gained via the Integrated Research Application System (IRAS) from the Health Research Authority (HRA) and the Research Ethics Committee (REC), with feedback incorporated from REC meeting (see Appendix I and J). The REC ethical approval number was 20/LO/1015 and the IRAS protocol number was 266493. Following this, the participating NHS Trusts' approval was obtained. Final approval was gained from the University of Essex Ethics Committee, as the study contributes to the fulfilment of a Doctorate in Clinical Psychology, which the researcher is undertaking. The University of Essex Ethics Committee ethical approval number was ETH2021-0310. A non-substantive amendment was made to the PISs to change researcher's year of study and to extend the study end date due to aforementioned impact of COVID-19.

3.4.6 Materials for Data Collection

3.4.6.1 Demographic Information Sheet.

The demographic information sheet (see Appendix K) was completed with each participant on the interview day, prior to starting the interview. To balance the sensitive nature of information being sought and to situate the sample, open ended questions were asked to gather information on gender, age and ethnicity (Dobosh, 2018; Hughes, 2016). This information on the demographic characteristics of the sample also provided a deeper context within which to interpret the interviews (Dobosh, 2018).

3.4.6.2 Definition of LD and Abuse to be used in the Empirical Study.

For the purpose of this study, 'learning disability' is acknowledged to be a social construct. The participants were recruited based on being open to a CLDT, to be registered as having a LD by the team and to have the ability to take part meaningfully in a verbal interview. This was established by a clinical team member within the service when considering eligibility.

As noted, for the purpose of this study, abuse will be interpersonal in nature and encompass physical, sexual, psychological or emotional abuse, financial abuse, domestic abuse and discriminatory abuse, as outlined by the NHS (2022), and take a broader perspective to include experiences such as bullying, that have taken place in childhood or adulthood. The participants will also name their experiences to be abuse.

3.4.6.3 Interview Schedule Guide.

An interview schedule was developed as semi-structured interviews were considered the most appropriate method to use within the current research's critical realist research paradigm and study sample for the following reasons. Semi-structured interviews have been successfully used in previous studies with adults with LDs (Smith & McCarthy, 1996; Walter-Brice et al., 2012). It is also a useful method for data collection when using thematic analysis (Braun & Clarke, 2013). Individual interviews were chosen over focus groups due to the sensitive nature of the research topic. They create an environment where individuals feel comfortable to discuss topics they may have not raised in a larger group (Adams, 2015; Gaskell, 2000). Individual interviews also allow the participants to speak and be heard (Reid et al., 2005), which is a fundamental part of this research. Another advantage is they allow the researcher to build rapport with the participants, a factor which is highlighted to be important when working with and conducting research with individuals with LDs (Reid et al., 2005; Nind, 2008). The flexibility of semi-structured interviews also permits the exploration of the information that is pertinent to participants, facilitating novel data collection (Gill et al., 2008). Semi-structured interviews also provide the participant with time and support (e.g., via prompts) to express their views and experiences. Thus, the approach allows the interviews to be tailored to the possible varying communication abilities of a sample, including incorporating the participants' own language into the questions during the interview (Willig, 2008).

The interview schedule can be found in Appendix L. Taking into consideration recommendations from the SLT and the literature on interviewing adults with LDs, the initial part of schedule aimed to provide participants with a concrete frame of reference through sensitively clarifying with participants the type of abuse they had experienced. This was facilitated through the use of prompt cards for the abuse they had experienced (see Appendix M). This provided an opportunity for the researcher to reflect with participants that abuse is not something that is ever someone's fault, and they would not be asked for details of what happened to them. This also allowed the researcher to further build rapport with participants following completing the demographic information sheet and consent forms.

This was followed by more specific questions about their experiences of disclosing abuse, including facilitators and barriers to the disclosure of abuse and how services can best respond. These questions had to strike a balance between being open ended and not leading, and a need for the questions to meet a level of explicitness, to ensure they were accessible to the participants. The use of descriptive questions such 'How did you feel….?' And 'How did they respond?' were helpful in this sense. The use of prompts also invited the participants to elaborate on what they have said or re-engage with the interview (Ryan et al., 2009). The interview ended with a debrief; the researcher assessed for any signs of distress and confirmed if the participant wished to speak with their clinician. The aforementioned stop card could also be used by participants to indicate they did not wish to answer certain questions or end the interview (see Appendix N) and visual aids for each question could be used by the researcher to support the participants' comprehension of the questions if needed (see Appendix O).

Previous systematic reviews on the disclosure of abuse in non-LD populations to health care services and the interview schedule and findings from a three-year participatory study by Bennett et al. (2013), highlighted areas of interest to be included in the schedule e.g., barriers and facilitators to disclosure (Feder et al., 2006; Havig, 2008; Robinson & Spilsbury, 2008; Snyder, 2016; Trevillion et al., 2014).

Consulting with the service user group also allowed for the identification of any difficulties that may have arisen during the interviews, e.g., in the wording of questions (Smith & Osborn, 2003), and prompts for the questions. Throughout the interviews the researcher was aware of acquiescence, unresponsiveness and recency in participants' responses, seeking clarification from participants when needed, and adapting questions to meet the participants' communication needs where necessary. The researcher drew on their clinical skills and experience to do this.

3.4.7 Recruitment

3.4.7.1 Inclusion and Exclusion Criteria.

Participants were eligible to take part in the current research if they met the following criteria. Participants were required to be open to one of the CLDTs recruitment sites and registered as having an LD by the service. The age range was 18 and over, with no upper age limit. The participant needed to be able to take part meaningfully in a verbal interview; communicate verbally and understand the concepts to be discussed within the interview. The above was determined by the clinical team member/s working closely with the individual. With regards to capacity to consent, participants were required to have capacity to make their own decision as to whether or not to take part in the study, this was also informed by the clinical team member/s working closely with the individual before asking if they were interested in taking part in the study, in addition to the participant's understanding of the PIS. The principles of the Mental Capacity Act (MCA, 2005) were applied when assessing capacity, including that an individual is assumed to have capacity unless proven otherwise.

The participants had to have experienced historical abuse and had disclosed and discussed/processed the abuse with their service alongside their mental health to be in a reasonable state at the time of the study. This was considered important to ensure participants had the support and strategies in place to talk about the experiences. Both of these criteria were assessed by the referring clinician.

In terms of the abuse being defined as historical, there was no specific lapse in time from when the abuse occurred to when the participant took part in the study, but participants were not included in the study if the abuse was current, events related to the abuse were ongoing e.g., court proceedings or police investigations, or discussing the disclosure experience would cause any undue or increased distress to the participants. This was assessed by the recruiting clinical team member, whose priority was to minimise the likelihood of any participant becoming distressed.

3.4.7.2 Sampling and Intended No. of Participants.

Participants were recruited from NHS CLDTs, located in Southeast England, UK. The setting of NHS CLDTs was considered appropriate due to the prevalence of abuse in the LD population, the associated negative impact of abuse on wellbeing, and use of mental health services by the LD population. Participants were recruited via purposive sampling. This type of sampling ensures information dense cases are identified and selected (Patton, 2002), to ensure the aim of gaining an in depth understanding of the participants’ views on the disclosure of abuse and how services can best respond is met. There is limited data nationally on the number of adults accessing community learning disability services, and their demographic information, including ethnicity. There is an estimated 530,000 men and 375,000 women with a learning disability in the UK (Emerson et al., 2012). This is an approximate ratio of 1.76:1.25. The study will aim to recruit a sample that reflects these figures.

The recommended sample size for thematic analysis for a professional doctorate project is 6-15 (Terry et al., 2017). Based on this, the study aimed to recruit 10 participants, prior to COVID-19 pandemic, and a total of five participants were recruited.

3.4.8 Procedure

Remote procedures required the recruitment and interview process being conducted via phone call and video conferencing software.

3.4.8.1 Recruiting Participants.

The researcher approached a team in one of the trusts to provide information about the study and participant eligibility criteria. The second academic supervisor, who worked in one of the teams in the other trust, also liaised with the clinical teams across their trusts' sites to provide them with the study information and the participant eligibility criteria. The clinical team members then gathered a list of potential participants who met the eligibility criteria. The academic supervisor and psychology team were also able to identify eligible participants.

In both services, a psychology team member (or another member of the clinical team if more appropriate) then contacted any potential participants via a telephone or video appointment to inform them of the study. At this appointment (or their next appointment if contacted via telephone), the participant was shown and provided a copy of PIS and consent to contact slip electronically. The psychology team member (or another member of the clinical team if more appropriate) read the PIS with the participant, then asked if they would like to take part in the study. If they wished to do so, the participant completed the consent to contact slip or by proxy via the clinician. These were then securely sent to the researcher via email.

Following the appointment, if consent to contact was given, the researcher contacted the participant via telephone, email or via the clinician if considered in best interests of the client, to ask if they would like to take part, and to book a meeting to obtain informed consent and complete the interview. If they agreed, the researcher arranged a video call to go through the PIS again, answer any questions, and complete the consent form and the interview.

Participants were provided with a £10 monetary voucher for Amazon or One4All as a token for their participation, which was sent to them via email by the researcher or in the post. This figure was derived from previous studies which provided a monetary incentive for participation.

3.4.8.2 Conducting Interviews.

The interviews were audio recorded using video conferencing software and a Dictaphone and transcribed as soon as possible following the interview. The participants were informed the interview would be 45-60 minutes and with checks in by the researcher at regular intervals. Time was factored into the research to complete the interviews across two contacts, if required, but all participants were able to be complete the interview in one contact. The researcher also completed an interview summary following each interview to capture their initial reflections and thoughts on the interview e.g. what role did the participant take and topics of focus for the participant, alongside the researcher's considerations for future interviews based on the information from the interview e.g. questions to pursue in the following interview, their researcher's interview style, and finally how valuable the interview was based on scoring system of 0-10 (see Appendix P for a copy).

3.4.9 Data Processing and Analysis

3.4.9.1 Transcription.

The interviews were transferred from Zoom or MS Teams and the Dictaphone to a personal computer and encrypted. The interviews were transcribed orthographically recording spoken words and features e.g., laughter, pausing and overlapping speech, and minimal punctuation was used to accurately reflect the spoken language. The orthographic transcription notation system (Braun and Clark, 2013 adapted from Jefferson, 2004) was implemented to transcribe the interviews to ensure consistent transcription across the interviews. The transcripts were then anonymised using the participant or researcher selected pseudonyms and any identifiable information redacted or removed. The transcripts were then transferred into NVivo 12 for analysis.

3.4.9.2 Data Analysis.

There are different methods for data analysis within a qualitative methodology, including Interpretative Phenomenological Analysis (IPA), and three types of thematic analysis: Coding Reliability, Codebook and Reflexive.

3.4.9.2.1 IPA.

IPA is an approach seeks to explore how individuals make sense of their personal and lived experiences (Pietkiewicz & Smith, 2014). It considered useful in exploring experiences that are complex and emotive (Smith & Osborn, 2015), therefore could be considered appropriate to apply in the topic area of abuse. IPA has three main theoretical foundations. The first is phenomenology, proposed initially by Husserl, which focuses on how individuals themselves articulate their experiences as opposed to understanding the experience or phenomena based on pre-existing preconceptions or criteria (Pietkiewicz & Smith, 2014). The second is hermeneutics, in that participants are trying to make sense of their own experiences, and in turn the researcher aims to make sense of the meanings the participants attached to their experiences (Pietkiewicz & Smith, 2014). The third is idiography, in that each individuals' experience will be looked at in detail (Pietkiewicz & Smith, 2014). Given this focus approach IPA has been used on single case studies or homogenous small samples (Pietkiewicz & Smith, 2014).

The current research does not aim to generate detailed meaning attached to each experience, but to initially outline and interpret adults with LDs' experiences of disclosing abuse, to identify the facilitators and barriers to disclosure and elicit their views on and recommendations for the care they received. This was supported by a discussion the researcher had about their study at an external teaching on IPA, with the presenters indicating thematic analysis would be more appropriate for this reason. In addition, the LD population are not a homogenous group and the experiences of disclosure of abuse may differ. Therefore, the idiographic focus of this approach may not be appropriate for this study.

3.4.9.2.2 Thematic Analysis.

Braun and Clarke (2019) propose there are three types of thematic analysis: Coding Reliability, Codebook and Reflexive. These approaches can be viewed on a continuum with coding reliability at one end to reflexive approaches on the other.

3.4.9.2.2.1 Coding Reliability.

Coding reliability (Boyatzis, 1998; Guest et al., 2012) considers coding as identifying evidence for pre-existing themes within the data. A codebook or coding framework is applied to the data by multiple coders to reduce bias, with codes confirmed as reliable and final if there is a high level of consensus i.e., inter-rater reliability between the coders (Braun & Clarke, 2020a, 2020b). The approach is considered be a ‘small q’ qualitative (Kidder & Fine, 1987 as cited in Braun & Clarke, 2020b); using a qualitative method with a positivist philosophy and valuing reliability and replicability (Braun & Clarke, 2020a, 2020b).

3.4.9.2.2.2 Codebook.

Codebook approaches (King & Brooks, 2018; Ritchie & Spencer, 1994) sit somewhere between coding reliability and reflexive thematic analysis on the continuum. It represents qualitative research values but uses a structured approach similar to coding reliability applying a codebook or coding framework (Braun & Clarke, 2020b). However, less emphasis is placed on establishing reliability and consensus, with the codes being able to be developed throughout the analysis and the codebook implemented to record the evolving analysis (Braun & Clarke, 2020b).

3.4.9.2.2.3 Reflexive.

Reflexive thematic analysis fully embraces qualitative research values and methods (Braun and Clarke, 2019), described as the 'Big Q' (Braun and Clarke, 2020a; 2020b. The researcher is considered to play an active role; engaging reflectively, reflexively and thoughtfully with the data and analysis (Braun and Clark, 2019), and generating the themes. The analysis can be either inductive or deductive, within theoretical flexibility of the approach, identifying the shared patterns of meanings within the data (Braun and Clarke, 2019).

Taking into consideration the above approaches, reflexive thematic analysis was considered appropriate for the current research as it in line with the critical realist position, allowing for generation themes from the data to capture a nuanced understanding of adults with LDs' experience of the disclosure of abuse.

An inductive and deductive reflexive thematic analysis was completed informed by Braun and Clarke's (2006, 2013) six stage process:

1) Familiarisation with the data and dataset (i.e., each interview transcript and all the transcripts together) and writing familiarisation notes
    - reading and re-reading the data and making notes to identify items of interest, through critical and analytical questioning of and engagement with the data e.g., the researcher asking what assumptions they bring to the analysis.

2) Systematic data coding
    - generating researcher derived codes or latent codes identifying implicit meanings in the data, ensuring equality in the coding of the data e.g., same about time dedicated to coding each transcript. This stage was completed two times.
3) Generating initial themes from coded and collated data
    - clustering similar codes into candidate themes with each theme having a key central organising concept i.e., shared patterns of meaning, to capture the most important patterns in the data to answer the research question.
    - starting to create a visual map of the themes and the relationships between them.
4) Developing and reviewing themes
    - re-reading the coded and collated data and the whole dataset to ensure the themes represent the meaning within the dataset, collapsing themes together or removing themes where necessary.
    - confirming candidate themes and finalise visual map.
5) Refining, defining and naming themes to capture key idea of each theme
6) Writing the report

The quality of thematic analysis was assessed and met the Braun and Clarke (2006, 2013) 15-point checklist of criteria for good thematic analysis, which met all criteria points (see Appendix Q). The themes were discussed with researcher’s supervisors and respondent validation was sought from one participant, which is discussed below.

3.4.9.3 Respondent Validation.

At the end of each interview, participants were asked if they would like to later comment on their interview transcript, and if the themes reflect the topic being studied. This was a means to facilitate respondent validation to enhance validity of the study (Long & Johnson, 2000), and would be communicated to the participants in an accessible way. All participants agreed to respondent validation. Respondent validation was sought from one participant, given delays to the project at the point of respondent validation some participants were no longer open to the CLDTs or clinicians assessed it would not be appropriate to approach clients, therefore there were no contacted to not cause any undue distress or due to management of risk. The researcher completed a video call with the participant to feed back the results via an easy-read document, which they presented via the share function on the computer. A copy of the document can be seen in Appendix R. The participant reported they felt the results reflected their experiences.

3.4.9.4 Assessment of Quality.

Yardley (2000) proposed four criteria to consider when assessing the quality of qualitative research in health research.

1) Sensitivity to context; an awareness and understanding of the current research literature in the topic area and socio-cultural context of the research.
2) Commitment and Rigour; commitment refers to extensive engagement in the topic, competence in research skills and immersion in the study data, and rigour refers to comprehensive data collection and analysis.
3) Coherence and Transparency; coherence considers the match between the research question and the philosophical framework and methodology, including analysis and transparency refers to the detailed information provided to replicate the study as well as the researcher’s own influence.
4) Impact and Importance; relate to a research’s impact and utility in the research literature and in practice, both clinically and policy.

The researcher endeavoured to conduct the current research to meet these criteria, and an appraisal of this is outlined in the discussion section of this chapter, and Chapter Four with regards to impact and importance.

3.4.10 Data Security

3.4.10.1 Confidentiality and Anonymity.

Confidentiality is protecting the privacy of the participant and their information. Anonymity means any identifiable information is removed or replaced to ensure the participant is non-identifiable. The consent to contact forms, consent forms and demographic information sheets were sent via email securely and stored as password documents on the researcher's personal computer. The information from the demographic sheets was stored in a password protected Excel spreadsheet on the University Essex secure drive. The above information will be held securely at the University of Essex for five years.

The interviews recordings transferred to a personal computer and encrypted. The participants were aware the interviews would be audio recorded and the recordings would be deleted afterwards. The interviews were transcribed shortly after taking place and all identifiable information was removed. Once anonymised, the transcripts were held securely for analysis on the researcher's personal laptop and on the University of Essex secure drive. Participants gave or were allocated a pseudonym. At the end of the study, the transcripts will be deleted from the researcher's personal computer and will be held securely at the University of Essex for five years. The study's confidentiality and anonymity procedures comply with the requirements of the General Data Protection Regulation (EU) 2016/679 (GDPR) and the Data Protection Act 2018 (DPA, 2018) with regards to the collection, storage, processing and disclosure of personal information.

3.4.11 Feedback to Participants and Other Stakeholders

On completion of the Doctorate in Clinical Psychology, the thesis can be accessed via the University of Essex's library website. The clinical teams in the LD service host sites will be provided with a written summary of the study. They will also be offered an oral presentation of the study's results. The service user LD drop-in group at one of the participating trusts will also be informed of the study's results and consulted on how to disseminate the results of the study to participants. This may take the form of an easy read information sheet or video. The researcher aims to submit the research to one of the following journals and forums for consideration for publication, Journal of Intellectual Disability, Disability and Society, Tizard Learning Disability Review, The British Psychological Society Clinical Psychology Forum and British Journal of Learning Disabilities. A poster and/or presentation will be submitted to the following conference for consideration; The Faculty of People with Intellectual Disability Annual Conference.

3.5 Results

3.5.1 Study Sample

A total of eleven service users were identified as potential participants by the clinicians at the CLDT recruitment sites. Of these, five were unable to be recruited due to the workload of clinicians and their time constraints on supporting recruitment. One person who consented to take part had restricted availability, and an interview slot could not be arranged prior to the recruitment stage closing.

In total five participants were recruited to the study, their demographic information was gathered via a self-report questionnaire each participant was supported to complete on the day of the interview and they were invited to choose their pseudonym. Prior to commencing the interview, 'communication cards' summarising different types of abuse were also discussed with participants to confirm the type/s of abuse they had experienced.

Participants were informed they could have a member of their support network with them during the interview. The participants were as follows:

Unicorn was a 33-year-old woman, who had experienced historical physical, sexual, emotional and psychological abuse. She chose her own pseudonym and was the first participant to be interviewed.

Harley Quinn was a 26-year-old woman, who had experienced historical sexual abuse, and was the second participant to be interviewed. She also chose her own pseudonym, and the therapist she was working with at the time joined for the duration of the interview.

Jane Doe was the third participant. She was a 32-year-old woman, who had experienced physical, emotional and psychological abuse. She described experiencing victimisation throughout her life and was joined by her partner for the interview.

Luke was a 31-year-old man, who had experienced historical emotional and physical abuse, through an experience of bullying at school. He chose for the researcher to decide on his pseudonym and was the fourth participant to take part.

Paul was the last participant to be interviewed. He was a 59-year-old man, who had experienced financial and sexual abuse. He chose his own pseudonym and asked for two members of his family to be present during the interview.

All the participants were White British and currently receiving psychological therapeutic support or had done so in the past from their CLDT. Table 4 below provides a summary of participants demographic details and abuse they experienced.

Table 4.

Demographic Information and Type of Abuse of Study Sample

Pseudonym	Age	Gender	Ethnicity	Type of Abuse
Unicorn	33	Female	White British	Physical, Sexual and Emotional and Psychological Abuse
Harley Quinn	26	Female	White British	Sexual Abuse
Jane Doe	32	Female	White British	Physical*, Emotional and Psychological Abuse
Luke	31	Male	White British	Emotional and Psychological Abuse
Paul	59	Male	White British	Financial and Sexual Abuse

*identified during interview (historical and already disclosed)

3.5.2 Thematic Analysis

Through reflexive inductive and deductive thematic analysis of the five interviews, one overarching theme, four themes and were constructed. Table 5 outlines the themes.

Table 5.

Themes of the thematic analysis for the empirical study

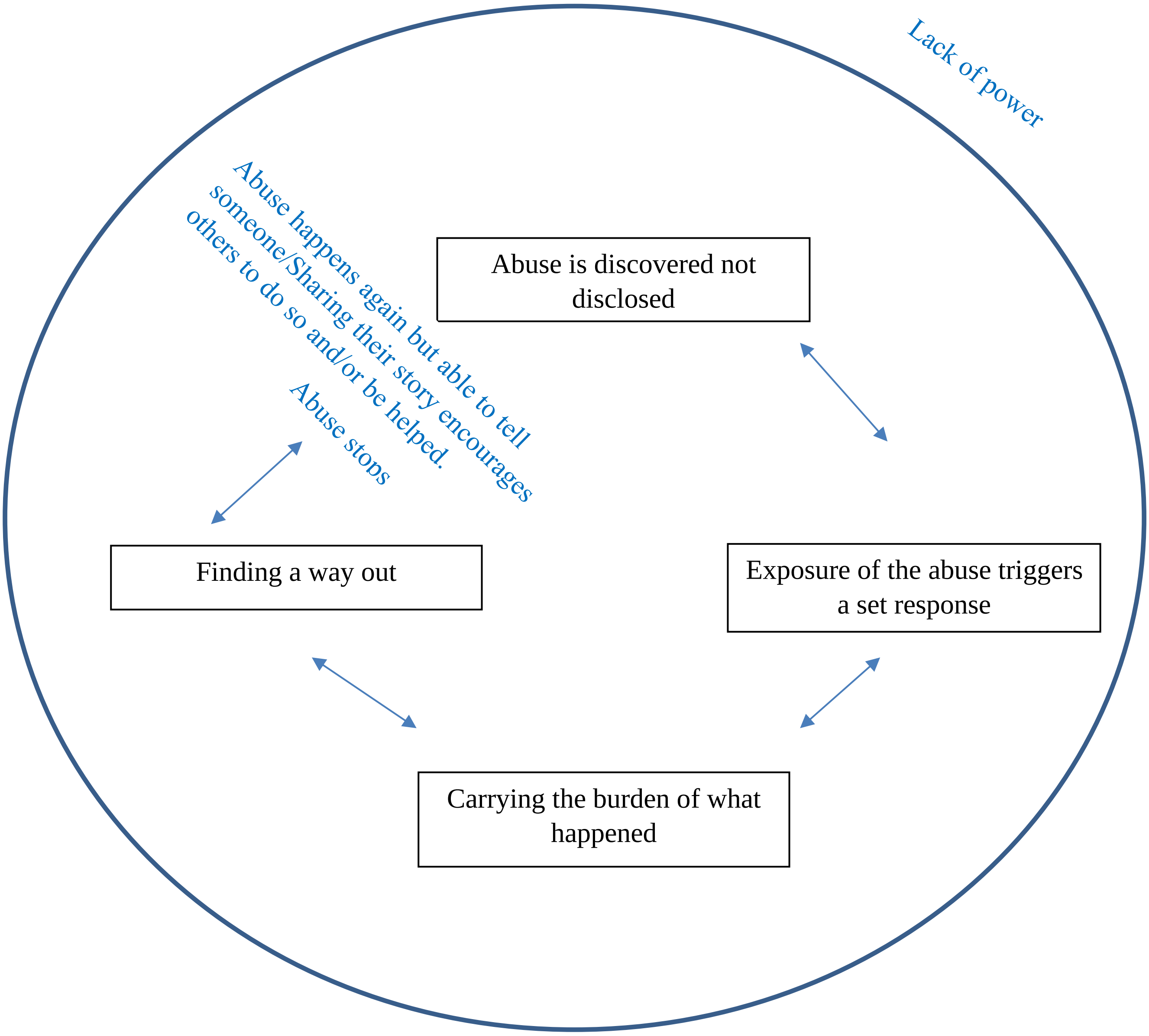
Themes	Overarching theme: The journey of disclosure
Abuse is discovered not disclosed	
Exposure of the abuse triggers a set response	
Carrying the burden of what happened	
Finding a way out	

3.5.2.1 Overarching Theme: ‘The journey of disclosure’.

It was clear from participants’ accounts that a timeline of their disclosure experiences could be mapped. This starts with the abuse first being identified to receiving therapeutic support through to sharing their experiences, with each theme representing a different stage along their journey. The timeline was not completely linear in nature with participants’ experiences overlapping between the stages or moving backwards and forwards between them e.g., participants finding support helpful (finding a way out) but continuing to experience flashbacks of the abuse (carrying the burden of what happened). Participants also reflected that even though they may have found ‘a way out’ there was a risk or reality of abuse happening again, but as they saw the benefits in disclosing to others, they may disclose abuse before its coincidental identification by others They also spoke about their hopes of talking about their abuse would mean others may be able to be helped or tell their stories. The concept of power is also interwoven into this timeline i.e., the lack of power participants may have over this process. The overarching theme is represented in the Figure 2.

Figure 2.

Visual representation of Overarching theme: The journey of disclosure



3.5.2.2 Theme One: 'Abuse is discovered not disclosed'.

The timeline begins with the circumstances in which the abuse becomes known. These situations were characterised by the abuse being seen by others either directly or via signs to indicate it may have or be taking place coincidentally. This led these 'observers' to directly ask participants if they had been abused or acknowledge they had witnessed what had happened, prior to participants themselves disclosing the abuse.

Participants found themselves in scenarios where the abuse (and at times themselves) was on display for others to observe eliciting a sense of vulnerability and exposure for the participants. This is demonstrated by Jane Doe and Unicorn who spoke about their abuse becoming visible through others noticing the physical indicators of the abuse. Jane Doe explains how her mother noticed the bruises, which led her to confirm the abuse had occurred. Unicorn reports a similar account in which these indicators of abuse were on display when admitted to A&E.

> "So my mum was the first person because my mum noticed it [bruises], then my mum took me to the doctors like and then every day the doctor had to see me to see how many bruises I got" (Jane Doe)

> "And the (.) the person that was on the charge of the social worker side erm the hospital has rang them (.) had rang the social worker to say statement said like you know I was literally bruised and battered all over the place erm which I found really hard to (.) to discuss that with the hospital people" (Unicorn)

Although for some participants the signs of abuse were perhaps less tangible to observe. Harley Quinn reports how the person she spoke to about the abuse had queried a subtle change in how she usually presented. For Paul the visibility of the abuse he experienced built up over time, perhaps influenced by him not wanting others to find out, with him reaching a juncture where he described no longer being able to hide what was happening.

> "Because [name of person disclosed to] knew I wasn't really myself so she knew something was wrong and I said I had to show her something I think and when I showed her she called police" (Harley Quinn)

> "He found out cos (.) he asked me where's your money gone Paul where's your money gone, and I wouldn't get any peace so I told the truth", "I couldn't hide it [the abuse]" (Paul)

Others directly witnessing the abuse also featured. Luke describes how his friend saw what happened and supported him to share what had occurred:

> "Erm I think she was very supportive like the lady that saw it" (Luke)

> "So that she encouraged to me this is not right you need to say something" (Luke)

3.5.2.3 Theme Two: 'Exposure of the abuse triggers a set response'.

The second theme encompasses the initial period shortly after the abuse is identified. It brings together participants' experiences of what happened at this point on the timeline and reflects an overall perception from participants that a certain pathway is followed, constructed from both their own, others and societal expectations and norms.

Participants outlined those involved in the process and their assigned or adopted actions. The people participants disclosed the abuse to or subsequently spoke to initially after the disclosure, included family members and friends as well as professionals such as doctors, teachers, social workers, the police and council workers, often multiple people were involved, each one following their set roles and responsibilities.

Family and friends were often the first people participants told about the abuse. This then placed them in a position of informing others, often statutory services, that the abuse had occurred. Jane Doe described once her mother was aware of the abuse she contacted their GP and Jane's school to report this:

"She asked me where's the bruise and I said I was getting bullied at school and then she was like okay I'm going to ring the the doctors and see if the doctors can she did like she did speak to the school…" (Jane Doe)

Participants' experiences of how their family and friends responded to the abuse were denoted by a sense of dutifulness to provide love, containment, safety and protection, reflective of the societal narrative of what a family unit should do for its members.

Harley Quinn demonstrates this when recalling how a family member supported her whilst she was waiting for the police to arrive.

"She was like really understanding errm and she's trying to keep my mind off it until the police came so (.) she had like animals that I really love so she just like let me like yeah kind of showed me around and thats" (Harley Quinn)

The assumed unconditional nature of these duties were illustrated by Paul's experience of despite an acrimonious relationship with his brother, he was still there to help him, and Jane Doe's mother's perseverance to ensure her daughter received the support she needed.

"I thought we [Paul and his brother] was enemies well sounding like we were enemies like I didn't wanna be enemies and when he came round I wanted him to come around and see the guy so he could have a go at the guy and sling him up" (Paul)

"…the school wasn't doing nothing about it so that's why she said that she was intervening to speak to the doctor and that's when the doctor kept checking me" (Jane Doe)

Yet for Unicorn, this expectation was not met as she spoke about her family's dismal experience of her abuse experience.

"Talking to (.) family members that (.) kind of been telling me don't report it you just need to like forget it and move on" (Unicorn)

This provision of support also expanded to those working in pastoral care roles, perhaps akin to the relationships participants had with their family or friend or their roles being seen as to provide care. Luke shared the support he received from a teacher at school, who supported children and young people with additional needs.

"I have a special needs person erm a person looking after me as well so she was also involved because she deals with most of the bullying which is erm part of her job so" (Luke)

The involvement of professionals was then considered the next step in the process. The role and responsibilities of professionals were considered by participants as an expectation that those working within health, social care, educational and criminal justice systems should help others, mirroring these services' message this is their role to society as a whole. Harley Quinn illustrates both these concepts when describing what services can do to support those who have experienced abuse.

"Police can help NHS can help (.) counselling to help, social can help communities family friends and erm (.) I was about to firefighters but they don't really help they just put out the fires (small laugh) (short pause) I'm trying to think like family, friends all that erm (.) (sigh)" (Harley Quinn)

This help was largely conceptualised as pragmatic; professionals acting within their assigned roles following policy, guidelines and within the parameters of their role. This included experiences of police arresting the perpetuators of the abuse, social worker finding alternative school arrangements and teachers following policy on bullying.

“Only tell the police…Arrest them or something” (Paul)

“…then she I think they got social services involved as well…And then in the end the social worker moved to me the school I was at originally where I wasn’t’ getting bullied” (Jane Doe)

“…so what he did he sent me down to (.) I think the head of the year I think it was to identify who it was and then not only got the head the head of year involved but also got the I have special needs person erm a person looking after me as well” (Luke)

Participants' experiences suggested the predominant purpose of these actions by professionals were to prevent further abuse or to stop the abuse yet it was their role, as participants, to confirm the abuse had happened for others to take these actions.

Harley Quinn described feeling *“good”* after telling others about the abuse she had experienced and reflected the abuse would continue if she did not share the information.

“Good coz then they can start taking action…If you don’t take action it’s just going to carry on” (Harley Quinn)

Luke further illustrates this concept when describing his reasoning for sharing he had been bullied.

“To be honest I just felt I had to say something like if I’ve gotta be honest with you that's probably the only reason…Because he may the person may hurt me again” (Luke)

When Paul spoke about his experience of disclosing the abuse to his family and professionals, he saw this not only a way to stop the abuse happening to him but also to others.

“ Erm tell social services and told the police and [inaudible] something won’t happen to others and have it stopped” (Paul)

Overall, everyone is seen to have a role and responsibility in the pathway following the disclosure with the shared aim of making the abuse stop, yet it is important to note participants' sense of control over this pathway and the processes within it. With a seemingly set route for what occurs directly following the disclosure; starting with individuals and their family then professionals, the potential impact could be that those who have been abused have little autonomy and active participation in choosing the route and its direction. This creates the sense that once the disclosure process is triggered, care is done to individuals as opposed to with them. This was demonstrated by the participants in the study, alongside the associated feelings this generated. Unicorn describes when she arrived at the hospital, how she was excluded from the process of how she told her story, and the subsequent impact this had on her being able to tell her own narrative of what happened at that time and what she had to share. This evocated a sense of exposure, perhaps similar to the experience of when the abuse was first discovered

"I think it was a bit of (.) it's a bit of it was quite difficult to explain to them because they were like (short pause) they were (.) asking the ambulance crew all the information… erm instead of asking me the one that's been through it (.). and then that (sigh) was the physical abuse (.) and then ended up having to go through (.) the (.) sexual abuse because and was with [perpetuator description]" (Unicorn)

This experience also created a sense of vulnerability and fear. Harley Quinn explains how the initial presence of police shortly after the abuse incident was difficult, resulting in an outward expression of upset and a compelled need to physically distance herself from the situation, highlighting how distressing the disclosure process can be.

"Yeah yeah so when the police got to [name of person disclosed to] house it was harder any way because it literally just happened so I put myself right in the corner of the sofa…Shaking, crying h-um" (Harley Quinn)

Feelings of frustration of not having control over what happened when professionals found out about the abuse were also reported. Paul demonstrated this feeling, possibly underpinned by his concern as to what may happen to the security and independence of his current living situation.

“[Thought] I’d been let off the hook…Be forgiven straight away but nah the police had to get involved…Social worker got involved and I nearly got kicked out my flat because of it” (Paul)

Action as well as inaction from professionals also created similar feelings to those above. It was clear from Jane Doe’s experience these feelings can intensify when individuals are reliant on others to believe them and take action, yet professionals do not fulfil their expected role. Jane Doe described the longevity of her encounters with the police and the council to acknowledge the abuse she was experiencing and what and when action needed to be taken.

“I would say that one was the hardest because police didn’t do nothing and the council kept getting reports in from the police…And erm (sigh) constantly getting smashed windows breaking our slabs and stuff that they've got that's when the council decided two years was enough because they ended up moving us” (Jane Doe)

The above situations are embedded with feelings of powerlessness, which is in contrast to Luke’s experience, although potentially exposing for him, he described how he was directly instructed and complied with what he was told to do by the teachers which gave him a sense of “hope” and predictability to a situation which felt uncontrollable.

“Erm like I think I was still the same a bit shaking and upset because of everything that happened but I didn't feel erm I still thought I’ll just listen [to the teachers] go downstairs and do it so (.) gave me that little hope that I can go down and sort things out.” (Luke)

3.5.2.4 Theme Three: ‘Carrying the burden of what happened’.

The third point on the timeline represents the effects of abuse on individuals, the ‘weight’ participants were left holding. This theme’s placement on the timeline at this point illustrates the impact of abuse remains once it has been shared. However, it is acknowledged the impact will have been present prior to and likely played a part in impeding disclosure.

Participants’ accounts encapsulated the varying level of juxtapositions they experienced of holding responsibility for the abuse occurring alongside an understanding that they were not blame for what happened. They expressed their thoughts and beliefs as to who was to blame for abuse in trying to navigate why the abuse occurred and what this means in terms of the risk of further abuse in the future.

With regards to the position participants held about their own sense of responsibility for the abuse happening, participants demonstrated a need to confess a ‘wrongdoing’, explicit statements of blame or associated feelings such as shame, guilt and being a burden.

During the interview when the researcher reminded participants they were not to blame for the abuse, Unicorn expressed this was not how she felt, and Harley Quinn spoke about feeling reassured when it was communicated to her she was not to blame at the point of disclosure.

“(.) See I blame I must admit I do blame myself” (Unicorn)

“(Sigh) no I just felt that I had done something so I just told [name of person disclosed to] and [name of person disclosed to] said I’ve done nothing wrong others so” (Harley Quinn)

For Paul, his sense of blame was conveyed through his feelings of shame and guilt about the abuse and not wanting others to find out beyond his family.

"No he found out and I had to tell the truth because I will feel horrible I felt ashamed I felt guilty and.." (Paul)

"No I made him I kept it a secret" (Paul)

Participants expanded on this sense of responsibility further through indicating it was aspects of their own personhood as the reasons the abuse occurred. This created a complex picture as the responsibility was interwoven with core aspects of the participants' identities as well as their wants and desires, developing self-stigmatization.

Paul spoke about his Christian faith influencing his decision to want to help the perpetuator. Both himself and Harley Quinn also spoke of their wish for friendship and relationships and the associated love and acceptance, as contributing to the abuse taking place.

"Yeah cos go go to church and all that and oh you'd be helping him you'd be showing him love and support" (Paul)

"And out in the street I see them with their mates with their friends talking and I thought l want what they got it took I don't care how it happened I just wanted friendship and that's how it happened" (Paul)

Individuals with LDs often feel they are not entitled (or excluded from) from friendships and intimate relationships that they observe people enjoying in wider society and captured a construct held by society that a goal in life is to have successful friendships and intimate relationships. This creates a level of complexity within the individual and perpetuator relationship as the abuse may be downplayed as exemplified by Paul.

"He wasn't horrible and liked kills me or hurts me that he only hurt me financially you wouldn't say if you don't give me $1,000,000 I'm gonna put your head down or anything like that" (Paul)

Jane Doe conveyed she was to blame for the abuse as other schools would not enrol her and only one school would accept her, and this is where she was bullied.

"I could understand where she was getting angry and frustrated because she should it shouldn't have happened but… no other school would have took me on and then erm so she said (inaudible) I had to go to that school" (Jane Doe)

Participants also expressed they felt it was their own naivety was in part the reason for them experiencing abuse, raising the question if the abuse could happen again in the future. Luke described feeling shocked the abuse had occurred.

"(.) Erm just by the shock of everything that occurred on that day when I was being bullied yeah" (Luke)

The sense of risk for the recurrent of abuse was also amplified through participants' accounts that others were shocked the abuse had occurred.

"They would just like (.) gobsmacked really they didn't really they was 'oh I'm so sorry for what you've been through' (.) but it's kind of hard at the moment" (Unicorn)

Most strikingly, Harley Quinn explicitly linked having a LD to her naivety and ability to notice the signs of potential abuse.

" so I was foolish and kind of followed with the perpetrator and I didn't know it's going to happen until the day, so people with disabilities say ' o I am moving with you, or you know anything like that they think that's the right thing (.)" (Harley Quinn)

However, participants were also able to hold the alternative perspective that they were not to blame for the abuse happening. This was demonstrated through their accounts explicitly stating that they knew when the abuse occurred that it was wrong and that it shouldn't have happened, as illustrated by Luke when he was asked why he decided to tell the teachers about the abuse.

“Erm I think what happened to me was wrong so….I was very upset about it as well so we just went straight teacher said this happened and it was dealt with” (Luke)

Participants were also clear they should receive justice for what happened to them and the perpetrator should be held accountable for what they had done, such as acquiring an apology or the involvement of the criminal justice system. Harley Quinn reflects on her relief of her perpetrator going to prison.

“At least that I know that he's in prison that’s all that matters to be at the moment that he's in prison” (Harley Quinn)

Participants also reflected a sense of self resignation or inevitability that the abuse will always happen, and therefore is out of their control and always in hands of the abuser.

“because like all through my life I've had victimization all through my life” (Jane Doe)

“I'm out and I'm where at somewhere and people might some people are not nasty most people are alright but most people saying out of the way fat git get out the way that’s whats happened to me in the past when I was in the shops” (Paul)

This juxtaposition between ‘I am to blame’ or ‘not to blame’ is intricate and multifaceted, as the inevitability of the abuse could have also been felt by participants as a result of who they are. Ultimately, making sense of who was to blame leaves participants in a position of uncertainty, as if there is no clear answer if they will have the ability to stop abuse or see it coming next time, thus creating a sense of the world as an unsafe place. This dilemma is articulated by Harley Quinn when making sense for herself why abuse may happen and conveys the ongoing dilemma.

“people with learning disabilities know what is right and wrong but the abuser will manipulate them. Some people are scared to tell anyone because they feel like they're in the wrong or they feel like they shouldn’t put themselves in a situation, people with disabilities they know what's right and wrong so whatever (.) they know what right and wrong is but sometimes they feel like they’re doing the right thing… getting a relationship with someone who live somewhere else and you know when they tell someone people are happy for them, but it's kind of more difficult because you don't know what's going to happen… if they do live there, you know you haven’t got any family or friends support you so when people (.) like telling someone oh yeah you know gonna live somewhere else yeah that's fine, but they haven't got anyone to support them, so you know telling the police, yes its alright, but then you're putting yourself in a situation, but you don't know and that person is actually going to hurt you're not so but like how I kind of done and moved in with that person I didn't know they were going to abuse me until that time, so you know, and when people with disabilities, they kind of can always be in what's the word manipulated it is that word” (Harley Quinn)

Furthermore, when participants recalled their accounts of the impact of abuse upon them, there was a shared narrative of an endurance of these experiences, yet derived from idiosyncratic and personal stories tied to each participant, with only themselves knowing what it was like and the toll it had taken.

Many participants spoke of the impact of abuse being held within their bodies and minds, as conveyed through their mental health and emotions, immediately after the abuse and in the long term. Unicorn shared the trauma she experienced from the abuse and its impact on her mental health.

“So its kind of (.) obviously with mental and physical abuse I I hold all my struggling to still struggling to cope with them the trauma and stuff that was caused (.) and obviously (.) it’s made my obviously mental health deteriorate obviously cos of what happened you know” (Unicorn)

Participants also reported experiencing flashbacks and nightmares as a result of abuse. Jane Doe explains how her experiences of nightmares and flashbacks led her to feel outside of reality.

“Because some nights when I keep talking about the past I have nightmares and flashbacks and stuff like that so that's why I'm trying I gotta try to figure out it's not real if that makes sense” (Jane Doe)

Moreover, participants spoke about their conscious efforts to not express their emotions associated with abuse or to try and forgot about it. Luke described himself and others “bottle it all up”. There was a sense that these emotions were perceived to be a risk, dangerous in some way to the participants’ mental health, as well as impacting their self-esteem and were a burden to others, and participants distanced themselves from emotions to keep themselves safe.

Unicorn reflected she had worked with a clinician in the CLDT to express her emotions safely and how she tries to forget about the abuse and at the same time acknowledges this is hard to do.

“But I'm gonna ask (.) [name of clinician] if she can get [name of other clinician] to help work out a plan on how to so I can get my emotions out but in a safe (.) in a safe way” (Unicorn)

“((overlap)) It is really difficult to kind of forget….And move on but it’s (short pause) hard for me (.) to process it all” (Unicorn)

Thus, this internal connection to abuse for participants through their bodies and minds, thus created a sense that the abuse was difficult to escape from. Harley Quinn used a powerful metaphor of being trapped in a cage to describe her experiences of flashbacks. She reflects how her own mind deceives her, which solicits the idea if participants can trust their own bodies.

“Your mind playing tricks on you because you literally cannot get out of it because you're stuck in (.) you stuck in this cage that you’ve got all the keys on the floor but you don't know which key to unlock the cage so you're kind of stuck in a cave trying to figure out what key so kind of the same as a flashback you cannot get out of it until you find the right key” (Harley Quinn)

Along with what participants were left holding following the abuse, participants also experienced losses as a result of abuse and within the disclosure process. These included loses to their finances, their life choices and ultimately their own sense of self and quality of life.

Paul explained how the financial abuse he was subjected to left and continues to leave him in financial difficulty, impacting on him losing his independence and things in he values deeply.

“I would have lost my flat and go to a group home And I wouldn’t want to lose my flat and lose my animals” (Paul)

“And I I ended up not all ended up not going without going without myself empty pocket not going going without now I gotta learn to cope with that now” (Paul)

Participants’ loss was also expressed through a requirement for them being the one to change as a result of the abuse e.g., changing the style of the clothes they wore or moving properties, creating a loss of stability in their lives. Jane Doe spoke of her experiences of having to move school as well as home multiple times to get away from the abuse and a felt sense of unfairness of having to do so.

"… we kept moving because we kept getting problems they should have realised that it's going to happen where we go, so they should put us somewhere where it's quiet and start in the middle of nowhere they should have put us in their first instead of moving us to different places" (Jane Doe).

Participants also shared losing parts of themselves, e.g., their independence, confidence, and trust in others, which impacted on their quality of life. Harley Quinn described how she lost all aspects of herself through the perpetrator gradually taking these away from her as they gained more and more control.

. "...they can take everything away from you, so if you take your lifestyle away for you, they can take your personality away from you, your confidence you any control you had they take that away from you so you're literally basically hopeless and worthless because you've got nothing to stand up for got no control that you can stand by but no personality, no confidence with you you're just kind of stuck stuck you're kind of stuck in a cage but all the keys are wrong, so you can't even get out of it" (Harley Quinn)

Harley Quinn later described this experience as leading people, including herself, to put their 'shields' up to protect themselves from others, thus from potential abuse. This was not too dissimilar to participants attempting to distance themselves from their emotions. Moreover, she reflected how having one's shields up prevents you from making social connections e.g., friendships and intimate relationships, with individuals having to weigh up the cost and benefits of this.

"Kind of kind of got two paths you can have path of always shield up and you have friends, but not very many and never have relationships or put a shield down you have loads friends and or actually have a relationship" (Harley Quinn)

Overall, across this theme there is a pattern of participants being trapped by and being unable to escape their abuse experiences. From questioning the inevitability of the abuse when trying to make sense of their experiences, to the trauma held within participants’ bodies and minds and the things they have lost, it raises the idea of will the abuse ever stop either directly or indirectly as the perpetrator continues to have control through participants carrying burden of what happened to them.

3.5.2.5 Theme Four: ‘Finding a way out’.

This theme represents the final stage of the timeline, it draws together what helped participants to navigate out of being trapped by the abuse and positively move forward. As noted in the theme above there is cross over within the stages, thus this theme illustrates what helped participants after their disclosure but also to facilitate it, and conversely the barriers.

Participants’ experiences illustrated the closeness or commonality to the person they disclose to or seek support from is important. As outlined in first and second themes participants confirmed abuse had occurred with those they were close to them, including parents, friends and relatives. These relationships are often associated with inherent safety, trust and support, all of which were conveyed by the participants. When discussing her experiences and views on what can be helpful for people who had been abused Jane Doe spoke of sharing your experience with friends who you can the trust and offer support.

“And just like tell tell peo- tells like friends that you can trust and stuff like that since they can help you as well” (Jane Doe)

This closeness or familiarity was also conceptualised as creating a sense of ease in which participants were able to share their experiences of abuse. Paul reflected how closeness to others made it easier for him to speak to others about the abuse, when asked what supported him to do so.

“When they asked me why come round for and I told my best [name of relative] like a sister like a friend and even a partner is like a friend it’s like a cousin like or it's easy to tell family who I got to know” (Paul)

Both these participants also reflected a loss of someone close to them who they would have spoken to about the abuse and its impacts. Jane Doe reflected on this loss and on building on existing relationships to support her:

"That's the one [her mother] normally talk to if I've got problems or anything speak to but [name of partner]'s mum been amazing she's taking taking over which is she not actually taking over but she can understand" (Jane Doe)

Even within less familiar relationships other commonalities supported participants to share what had happened. Unicorn described feeling more comfortable speaking with a female police officer and Harley Quinn with a female relative, reflecting the narrative or some lived experience that women are safer together and able to trust one another given their shared gender identification.

"Made it easier when it was erm a police lady not a man…because obviously it's hard to tell men (.) or policeman what actually went on during (.) that" (Unicorn)

"Because she was like a female so any part I needed to show her she wouldn't mind so" (Harley Quinn)

Trusting relationships could also be built between participants and other figures when a comparable level of knowingness to that of their friends and family had been established. Paul spoke of a clinician being like a friend who he could talk to, and the group support he accessed being like a "club".

"Erm because she was like a friend like art therapy and I am able to talk when we were doing a drawing and talking at the same makes its (.) its like a club time its helps" (Paul)

Familiarity with or expectations of certain professions' roles also aided participants' willingness to speak to others about their experiences. Luke recalled perceiving the teacher would help resolve the abuse as this was within their job role helped him to talk about the abuse incident.

“I think he takes his job seriously that bullying is not acceptable just get downstairs and sort it all out” (Luke)

Participants’ accounts also demonstrated themselves and their experiences of abuse being recognised and understood by others as vital; the concept of being seen, heard and valued. Participants shared descriptions of those they shared their abuse story with and how they listened to what they had to say. Luke described alongside one teacher spending the time to listen about what had happened, another teacher advocated for him.

“Erm like he’s very friendly towards me he was erm (.) oh he was encouraging erm he would listen as well so yeah” (Luke)

“She really like came up to really stood up for me make sure to (.) like sort him out really” (Luke)

Professionals tailoring their approaches to the participants’ needs also communicated these principles. Unicorn explained the police officers interviewing her took into consideration that she had a LD and adapted their procedures accordingly.

“They took into that I have learning difficulties and they kind of (.) took the statements and and that slowlier so then so they need not too overwhelming” (Unicorn)

Harley Quinn added to this by reflecting on the importance of professionals pacing their exploration of the abuse with someone e.g., taking their time and using their initiative to learn about the person’s experience.

“… and the counsellor wants to take it slowly just doing it and not jump into the deep end that's that's what makes us much more worse and if they know about it before and they don't know much about it all all the counsellors can do is just research about it so they can see how they can work with the person not to jump into it (.) because if they research it then they know how to (.) approach that person" (Harley Quinn)

Ultimately these experiences represent to participants that others understand them and their experiences of abuse, mirroring the aforementioned value of proximity and familiarity participants held for others. Moreover, it was felt professionals, as well as family and friends, holding this level of understanding, facilitated the best standard of care to be delivered to meet each individuals' needs.

Unicorn described how clinicians understanding her and the impact of abuse on her mental health, enabled them to give her choices to support her in crisis.

> "So the staff then got options give me the options to come (.) gives you options and then (.) they would do (.) give me the choice of what say to get rid of get me out of that panic" (Unicorn)

Harley Quinn explained if practitioners have an in-depth understanding of how the service users usually present, they will be able to notice subtle and nuanced changes and explore these further with the service user to support them, indicating the benefits of establishing a strong therapeutic relationship.

"So they know what to look out for if one day they are alright but the next day they're not or next week when I have the like me and [name of clinician] have a catch up on every Thursday and they're not themselves so they can kind of look out for what is" (Harley Quinn)

Participants also shared the importance of reassurance. Jane Doe's account of this was in relation to one team validating her experience and reassuring her of the reduced likelihood of abuse happening again.

“Because like with the learning support team like with the mental health team they didn't exactly do anything they just said like it's normal for it to happen and it could happen again sort of thing and and that's what's that's what was playing on my mind it could happen again sort of thing and with [name of other clinician] [name of other clinician]'s understand [name of other clinician] understand what was going on in because it was one of them things it could happen, but it's not unlikely could happen” (Jane Doe)

Fundamentally, other’s understanding of participants' experiences contributed to them feeling believed, which gave participants the self-empowerment and belief to share their story. Unicorn recalled how completing a Tree of Life, a strengths based narrative therapy approach (Ncube, 2006) with her clinician facilitated her confidence to share her story with her support staff and start to move forward.

“I felt braver at the in the middle of the session with [name of clinician] to do a family not family tree a tree of life and then we done like a storm we done like a storm project which it’s like with everything that went on how how was I at the first beginning and how I'm here at the moment…And erm that really make me feel brave enough and that to write a letter (.) and the obviously writing the letter with my staff actually helped me to kind of feel proud that I've made that first step” (Unicorn)

Harley Quinn described how the police officer being understanding helped her to complete her witness statement which was imperative to taking forward a criminal charge.

“Yeah were understanding actually helped me feel confident enough to do the the statement” (Harley Quinn)

Overall, these accounts demonstrate the importance of clinicians actively listening to service users and faithfully understanding them and their experiences to facilitate service users to share their stories and to move towards in processing their experiences. As summarised by Luke "… just listen basically and that understand what someone's going through".

Participants endorsed the benefits of talking about their abuse with others. Their experiences of being invited to and being able to share their story was a powerful tool in managing the impact of the abuse. It appeared to create a sense of relief for participants; lifting the burden they had been carrying illustrated in theme three. This is conveyed by Paul who articulated feeling a weight had been lifted off his shoulders, as well as relieved, following confirming he had been abused

"Erm (.) I feel relieved I told the truth I felt better and I felt relieved like life is like a jigsaw….I don't wanna put I don't have to put up with it anymore…I have to tell someone even if its I'm even though it's hard…" (Paul)

Luke reflected by talking with his therapist and not bottling up how he felt this had helped.

"That if you bottle it all up that (.) we we get worse in health if I be honest with you that has happened to me but if I'll be honest with you but I managed to open up so that is helpful" (Luke)

Talking about their experiences also facilitated participants to be active contributors to ensure they received the right care that met their needs e.g., through the creation of hospital passports, a document containing key information about a patient for all hospital staff, to ensure the patient is supported appropriately. This is somewhat in contrast to the lack of control they experienced over their care at the point of and initially after disclosure. Participants often reflected positively on therapy they received, noting it empowered them to know what helps their emotional wellbeing, including acquiring a range of self-soothing skills e.g., painting, art or going for a walk.

Jane Doe explained how working with the therapist specifically in the CLDT she had developed a range of coping strategies to support her in her goal to be leave her home, alongside acknowledging the helpfulness of medication.

"I did have another therapist and she basically told me that stuff to do so I can go out…..Hmm like using fidget toys erm like a card that got tells you different colours to find and that seems to help" (Jane Doe)

"It's not just like [name of other clinician] it's the psychiatrist and giving me the right medication to control my anxiety….And like (.) erm it's there really more helpful than the than the mental health team itself than the than the mental team itself" (Jane Doe*)*

Participants also appreciated the varied therapeutic interventions CLDTs offered, including those which facilitated them to open up using alternative methods e.g., art.

"Yeah I would recommend I would recommend art therapy to (.) anyone that struggles with learning disabilities to express their concerns" (Unicorn)

Through sharing what had happened to them, participants also regained control over their experience of abuse. It provided participants with opportunities to create their own narrative about the experience and a sense of ownership over their future. Harley Quinn described in sharing her story with her allocated nurse helped give her permission to leave abusive relationships in the future.

"That anything that happened, if you like with abuse or anything about relationships, you can just you know trying to help but if it doesn't work and just walk out it…" (Harley Quinn)

Participants also hoped in opening up about their experiences this would help other people with LDs or additional needs to disclose abuse and talk about their experiences or prevent further abuse from happening. Harley Quinn suggested a number of alternative methods, e.g., pictures, people with additional needs could use to be supported in disclosing their experiences of abuse, if they would find talking about the abuse too difficult or they are unable to communicate verbally.

“What about if someone is too scared to talk and the only I can think of is pictures they can try of.let the police know or whoever knows can erm take erm take erm print pictures put into a from beginning to end, so they don't have to talk they can just move pictures around and tell you the story if they're too scared to tell you, or they can write down” (Harley Quinn)

Participants advocated people who experienced abuse should be able to access therapy to help manage with the impact of abuse, as illustrated by Unicorn.

“(.) That have got learning difficulties or any under or any health conditions I would would recommend getting counselling through your doctors (short pause) that was all cause it was going to say on that one (short pause) because it was qui- quite erm traumatizing” (Unicorn)

However, it is important to note when explicitly asked if there was anything unhelpful CLDTs had done in response to the abuse, the majority of participants said there was not, raising the question if this reflects the position individuals with LDs are routinely placed, that is to not to speak up against or disagree with the systems supporting them. This and other reasons will be explored further in the discussion section of this chapter.

In addition, across this theme there was a reality and a fear for participants of not being understood, being able to talk or listened to. Participants expressed the harm that could be caused if they were not understood or supported to share their story e.g., not receiving the help themselves and others needed. Luke reflected if this had happened for him the abuse would have likely continued.

“Just my friend being there I’ll be honest….That she realized what happened just said like lets go and sort this out tell the form tutor and just without their support it just won’t you know it just won’t have been solved to be honest with you” (Luke)

Jane Doe explained she had to wait for the mental health team to decide to complete an assessment as opposed to listening to what she had said, before receiving treatment.

“Erm the mental health team…I spoke to them about it but they didn't do nothing and then I had to do an assessment and then that’s when they said I had agoraphobia for about nine years” (Jane Doe)

Unicorn and Paul described the negative reactions they received, disbelief and anger, respectively, when they told others about the abuse and how this impacted on them.

“At first they didn't (.) believe what I was saying (.) erm which obviously I was like erm I was a burden for trying to tell someone how what happened (.) so it kind of makes it really might be quite difficult” (Unicorn)

“It made me feel like I was a bad boy a naughty boy at school you know when you get told off when you was at school and you get say oh if you're bad you put the dunces hat on your head and you go into a corner makes you feel stupid” (Paul)

Harley Quinn expressed her concerns of the unpredictability of how others will respond, with the decision in their hands to believe or not believe the service user as a result of others not always being truthful about abuse happening, this further illustrates the potential vulnerability of people with LDs in services and wider afield.

“Cos some people say it they just want sympathy but when someone actually went through it so it's kind of you believe them or you don't but for some people lie about it and some people don't so it's a shock that actually happened but you can be shocked when someone lies to you about it as well so its kind of stuck in a situation which is you go for believe or is it just a lie” (Harley Quinn)

Nevertheless, all participants were also in agreement that CLDTs should ask people with LDs if they have experienced abuse to ensure the abuse is stopped and appropriate support can be provided, as illustrated in the final reflections from the participants:

“Yeah I reckon I reckon it would be erm a good (.) step forward because it took me until I was 25 to get counselling with [name of clinician]...I think it might be a good step forward for them to have the confidence to tell people about what they've been through” (Unicorn)

“Erm-um (.) I think they should when they assess it I think they should so they can actually be aware of what has happened so they can kind of (.) tweak well not kind of tweak how they work but kind of just be more careful" (Harley Quinn)

“Erm cos it in case it happens to others” (Paul)

“Because erm (.) because then if someone's going through it then they can speak up and say yes I have then it will be a lot easier for them not just to say it just like some for encouragement…” (Jane Doe)

“Yeah I think they should like ask if there is things going on in their lives like they need to talk about because you know we shouldn't keep it to ourselves…” (Luke)

3.6 Discussion

3.6.1 Research Aim

The current research aimed to explore adults with LDs experiences of disclosing abuse, considering the context, facilitators and barriers and responses received. Five adults with LDs were interviewed, who spoke openly about their experiences of disclosure. A reflexive thematic analysis generated one overarching theme and four themes relating to these experiences. The research met the above aim and the main findings; abuse is discovered, power and control and accessing the right support helps, and how these and each theme informs the facilitators and barriers to disclosure and how best to respond, are presented below.

3.6.2 Main Findings

3.6.2.1 Abuse is Discovered.

The current research indicates that adults with LDs may be less likely to disclose abuse, and abuse more is likely to be discovered by others. In terms of how abuse was discovered this appeared to vary for the different types of abuse. For those who had experienced physical abuse it was noticeable signs of abuse, such as bruising, or witnessing what had occurred, whereas for the signs of sexual abuse and financial abuse these were less tangible and built up over time, then others questioning individuals directly if they had been abused. The clinical implications of this will be discussed in Chapter Four. Furthermore, it was expected from previous research that the act of disclosing abuse e.g., talking to someone for the first time about the abuse, would be considered within the context of one time point, however this was not the case as participants accounts generated a non-linear timeline and context in which to situate the disclosure process broadening the original definition of disclosure that was considered.

Nevertheless, the discovery of abuse is in line with the literature that indicated people with LDs and autism may be less likely to or wait longer periods of time to disclose abuse (Carrigan & Allez, 2017), or it be identified by chance (Rowsell et al., 2013). The current research finding is also noteworthy given previous research presented in Chapter One indicated variability in definitions of abuse both within countries and globally, suggesting this lack of certainty and vagueness could impact on how abuse is categorised by services and the clinical decisions made when assessing safeguarding concerns of abuse (Northway, Jenkins et al., 2013). This corroborates with findings of the thematic synthesis in Chapter Two which highlighted professionals reported the identification of abuse was not straightforward due to misinformation on referrals, their knowledge about abuse and how its presents in adults with LDs and the setting of their own and service thresholds for what would be considered abuse, including their relationship with and perceptions of service users and their families. Previous research highlighted in the Chapter One also indicated prior to receiving specific training professionals did not feel confident in assessing and investigating potential abuse further with services users. This was also identified in the thematic synthesis in Chapter Two, with differing levels of confidence amongst professionals regarding making safeguarding decisions and delivery of care. This current research finding in conjunction with those in the previous research could have a significant impact on people with LDs who are experiencing or have experienced abuse in terms of their safety, access to the support they need and preventing further abuse, as the variability in awareness and detection by professionals may mean abuse is not being readily identified.

3.6.2.2 Power and Control.

The current research indicates the adults with LDs primarily had a lack of autonomy and control over the disclosure process. This was exemplified by their experiences of a set process to disclosure which was often dictated to them by others and a reliance on others to carry out their roles and responsibilities to ensure the abuse stopped. This reinforces the historical narrative and context of the medical model, highlighted in Chapter One that professionals are perceived as the experts in care delivery, yet this is in contrast to the accounts provided by professionals in the rapid review and previous research highlighted in Chapters One and Two, who collectively described feeling they lacked knowledge and expertise on how to support with disclosure or decisions regarding safeguarding. This is of interest as this stage of the disclosure journey where participants felt a lack of control in their care, may mirror clinicians' own apprehensions or the variability in definitions of abuse as discussed in the previous main finding. Interestingly of the four participants, although Luke noted the process of disclosure was dictated by others, he was only one who reported an overall positive experience of the set process of disclosure, in comparison to the other participants. This could be for several reasons including, Luke was the only participant to have the abuse directly witnessed and contained within the school setting, which lead to immediate action to be taken and was perceived to be resolved in a relatively short of time. This was in contrast to the other participants' experiences, which may have further impacted on their feelings of powerlessness due to the longevity of the process. Moreover, the other participants had multiple professionals involved e.g., social workers, health care professionals, police, and multiple steps within their disclosure e.g., police interviews and going to court, possibly creating more scenarios participants did not have control over and less joined up working between professionals, therefore impacting on how the disclosure process was managed.

Nonetheless, all the participants in the current study were not consulted in the disclosure process. This could also reflect the application of the wider societal narrative and assumptions held by clinicians that individuals with LDs are passive or less than others into their practice, as noted in the aforementioned thematic synthesis in Chapter Two, as well as individuals with LDs resignation to the power differentials in their care (O'Malley et al., 2020). Furthermore, this current finding does not reflect the standards of care outlined in the Department of Health 2001 White paper, with regards to increased autonomy and control in decision making, and at odds with professionals' desire to do the best for their clients as outlined in thematic synthesis in Chapter Two.

The second aspect of power and control to consider is the current research's finding that adults with LDs experienced a sense of feeling trapped as illustrated in theme 'Carrying the burden of what happened' in trying to make sense of who was to blame for the abuse and the impact of abuse on their mental health and quality of life with regards to the inevitability of abuse never ending. This finding indicates that adults with LDs who have experienced abuse find themselves stuck between the polarised position of feeling they are to blame versus another is to blame. This current finding maps onto the Survivor Centred Recovery (SCR) framework (Chouliara et al., 2014) as participants were able to partly hold the position they were not to blame and reported a sense of relief once they had confirmed the abuse had occurred, which could be perceived as reduction in helplessness and hopelessness as proposed by the framework. Yet the model also suggests with disclosure shame and guilt can increase, which could represent the self-stigmatisation participants placed on themselves and the position they held that they were to blame for the abuse occurring. Interestingly, the Shame Resilience Theory (SRT) proposes that when someone is unable to express their shame experiences they are unable to externalise it (Brown, 2006), leading to feeling powerless, isolated and trapped (Brown, 2006). Despite the participants sharing 'their shame experience' they remained within in the position of feeling trapped, it could be hypothesised that this is due to the resolved uncertainty that the abuse may come back and the possible causal role they play in this, in addition to re-traumatisation due to the lack of control over the disclosure experience mirroring their abuse experiences. This could also reflect that the impact of the abuse means participants' dominant stories, a concept of Narrative Theory (Morgan, 2000) remain that they are to blame or they are at risk of being abused again.

Participants also expressed feeling trapped by the impact of abuse through the ongoing trauma experiences and personal losses. The Power Threat Meaning Framework (PTMF, Johnstone & Boyle, 2008) could provide an explanation for the impact on adults with LDs who have been abused in terms of the experiences of trauma, feeling trapped and wanting to distance themselves from other feelings. The meaning for adults with LDs to the threat of abuse or its inevitability, is that they are trapped or unsafe, and their response to this threat is flashbacks, nightmare, distrust of others, emotional defences, all described as consequences of abuse by participants in the study. A layer of complexity to add to this would be their diagnosis of a LD and the embodied power this operates in their lives. Both the PTMF (Johnstone et al., 2018) and Bronfenbrenner's ecological theory (1989 as cited in Campbell et al., 2009) also support the transgenerational trauma of experiencing abuse for adults with LD, as participants within the study highlighted an awareness of abuse occurring to their peers and their desire to help. There are similarities between participants with regards to the impact of the abuse, e.g., both Jane Doe and Harley Quinn experienced flashbacks, but these were not linked to experiencing a specific type of abuse. This reinforces the importance of recognising and supporting people with their individual experiences of abuse in their recovery, as suggested by theoretical frameworks for the impact of abuse and disclosure presented in Chapter One.

3.6.2.3 Accessing the Right Support Helps.

The current research indicates adults with LDs who have experienced abuse value professionals taking the time to actively listen, giving choices, tailoring approaches, building a trusting relationship, and offering reassurance as this illustrates to them that professionals understand and believe them, which empowers them to share their abuse story. Moreover, the current research suggests having the power to share their abuse story facilitates adults with LDs to be actively involved in their care and develop skills to manage the impact of abuse. This is in line with policy and guidelines on delivering person centred care and making adjustments to meet service users' needs and service users being actively involved in their care (The NHS and Community Care Act 1990 & Department of Health 2001 White Paper). These positive experiences of care for participants were noted to be later stages of the disclosure, particularly in accessing therapy. This may be explained by the findings from the thematic synthesis in Chapter Two which demonstrated psychologists and therapists may have felt more confidence in their clinical expertise or afforded the space to adapt their practice, as opposed to the professionals making the safeguarding decision, earlier on in the timeline.

3.6.3 Context, Facilitators and Barriers to Disclosure and Responses Received

3.6.3.1 Context.

One of the main findings that abuse is discovered, alongside the overarching theme that illustrated the journey of disclosure, indicates as previously mentioned the context of disclosure for adults with LDs may not take place at one time-point, but on a non-linear timeline, with experiences of a set process being followed, the significant impact of abuse and trying to find a way out. The participants' accounts also indicated the initial context of disclosure is likely to be with those with whom they have close proximity to and familiarity with i.e., family and friends, or professionals they have established strong relationships who they can trust.

3.6.3.2 Facilitators and Barriers to Disclosure and Responses Received.

The summarised main findings and the four themes contribute to understanding the facilitators and barriers to the disclosure process of abuse for adult with LDs, as presented in

Table 6, and the responses received. The clinical implications and recommendations of the facilitators and barriers will be discussed in Chapter Four.

It can be argued the facilitators and barriers to disclosure can inform one other i.e., if a barrier is addressed the outcome of this would likely serve to facilitate disclosure, which is the case for several of the facilitators and barriers outlined in Table 6.

One of facilitators to disclosure appears to be for others to ask individuals with LDs has abuse happened to them, and would be further aided by family and professionals working in CLDTs being knowledgeable about the signs of abuse. Therefore, a barrier to disclosure could be staff with limited understanding of how abuse and its impact presents in adults with LDs or hold differing thresholds for abuse, who may not identify or consider abuse is occurring or occurred. This is reflective of similar accounts from professionals highlighted in the literature in Chapter One and Two.

Another facilitator to disclosure would be the belief that following the abuse becoming known professionals have a responsibility to ensure it stops to the individual and possibly others and the perpetrator will be held accountable. A barrier to disclosure would receiving a negative response from others e.g., family dismissing abuse or not sharing it further with professionals, as well as not feeling in control of the disclosure process, eliciting feelings of fear and vulnerability, which may deter individuals from disclosing further information as it does not feel safe to do so. This reduced likelihood of an individual sharing their story again if they received a negative response from disclosure, was in line with literature highlighted in Chapter One.

Table 6.

List of Facilitators and Barriers to disclosure from the empirical study

Theme (Main finding)	Facilitators / Barriers
Abuse is discovered not disclosed (Main finding: Abuse is Discovered) (Main finding: Power and Control)	Facilitators • Professionals working with adults with LDs who are knowledgeable about signs of abuse • Opportunities for disclosure are offered Barriers • Adults with LDs may not be able to disclose without support • Clinicians may not recognise abuse, e.g., due to a lack of knowledge about signs of abuse or hold varying threshold as to what is abuse • Coincidental nature of how abuse witnessed
Exposure of the abuse triggers a set response (Main finding: Power and Control)	Facilitators • Perceiving professionals will follow their roles and responsibilities • Abuse will stop for individual and protect others • Perpetuator will be held accountable • Close relationship with family or professionals/trust in the wider system Barriers • Families may dismiss abuse or not tell professionals that it has occurred • Not having control and negative experiences leading to feeling vulnerable, fear and frustration • Inaction by professionals
Carrying the burden of what happened (Main finding: Power and Control)	Facilitators • Knowing the abuse was wrong and the individual is not to blame • Individual receiving justice for abuse occurring Barriers • Individual feeling to blame and experiences of guilt and shame • Abuse occurring within complex relationships • Trying to distance oneself from impact of abuse • Inevitability of abuse; feeling trapped
Finding a way out (Main Finding: Accessing the Right Support Helps) (Main finding: Power and Control)	Facilitators • Proximity and familiarity to person they disclose to • Being seen, heard and valued; believed • Others asking about abuse • Tailoring support to individual e.g., communication style, active listening, reassurance, giving choice • Adults with LDs having an active involvement in care Barriers • Minimal proximity and familiarity with those in their network • Individual not being believed; abuse not recognised by others • Individual feeling there is an unpredictability of what will happen following disclosure

The impact of abuse could also directly contribute as a barrier to disclosure. Participants spoke of feeling to blame for the abuse occurring, eliciting feelings of shame and guilt. This was similar to a barrier identified in the previous research literature in Chapter One, as well as being outlined in the Draucker et al.'s (2011) CSA Healing Model. In addition to feeling abuse is inevitable serving as barrier as it may also be considered that disclosing would not make a difference to the abuse stopping or happening again, and individual continuing to feel trapped. Participants also spoke about distancing themselves from their abuse experience by either not thinking about it or the associated emotions, to order to protect themselves, which links in with Draucker et al.'s (2011) CSA Healing Model. This could be considered a barrier as disclosure would bring the abuse to the fore, making the individual vulnerable and unsafe. Moreover, it was highlighted abuse can occur in complex relationships. This could be a barrier for individuals as it not only contributes to the narratives and the role of power from the perpetrator that the individual is to blame, but they may not wish to lose their relationship or for the perpetuator to be reprimanded if abuse is disclosed. For example, it may lead to relationships endings or the individual having to move from their family home. These relationships and their perceived stability are considered as social goals of society and may be even more significant to an individual with a LD who may not feel they are not entitled (or excluded from) from friendships and intimate relationships. The counter to these barriers would participants recognising they are not to blame e.g., being knowledgeable about what abuse is, the perpetrator facing justice, and professionals and family, where appropriate, helping the individual through the loss of the relationship and providing a supportive network.

It is clear accessing the right support, with clinicians believing participants, listening to them, providing choice and tailoring care, and building trust contributed as facilitators to disclosure, which were also documented facilitators identified in the previous literature outlined in Chapter One. Alongside clinicians having these attributes, facilitators could also be professionals ensuring they provide multiple opportunities to ask about disclosure and service users having active involvement in their care.

It can be reasonably argued these attributes in clinicians can facilitate adults with LDs to share their abuse experiences, then the opposite to these attributes can likely be considered barriers. The current research did indicate adults with LDs are also concerned or have experienced not being believed or understood e.g., others being angry, which is consistent with barriers to disclosure reported in previous research noted in Chapter One.

Therefore, if disclosure is considered within a broader timeframe, these findings are in line with the majority of facilitators to disclosure for those with and without LDs, highlighted in previous research noted in the Chapter One. The findings also mirror the categorisation of positive responses to disclosure for both populations, including that a positive experience can encourage people to tell their story.

Finally, the current age and gender of the participants, or type of abuse they experienced did not explicitly appear to influence the perceived facilitators and barriers to disclosure, or their impact. The small sample size may have impacted on identifying these associations, as previous research in Chapter One and Campbell et al’s (2006) study highlighted the effect of social scripts e.g., in relation to gender, on the impact of abuse and disclosure. The age of which the abuse took place was not collected, therefore, to discern if this affected the disclosure process cannot be commented upon and will be an important consideration for future research.

3.6.4 Summary of Findings

The current research reflects the complexity of the disclosure journey for adult with LDs who have experienced abuse, starting at the discovery of abuse to accessing support. Adults with LDs are negotiating fundamentally powerful systems, perceptions of LDs and impact of the abuse itself. Overall, the current research broadly supports findings from previous research on general disclosure experiences, with facilitators being those that foster a safe environment to disclose abuse, whilst contributing a critical understanding of the disclosure experience for people with LDs who have been abused from their direct lived experience.

3.6.5 Strengths and Limitations

3.6.5.1 Adults with LDs' Experiences of Disclosing Abuse.

This research is novel in exploring adults with LDs' experiences of disclosing historical abuse. Previous research had focused predominantly on the experiences of people without LDs disclosing abuse generally and within healthcare settings, identifying facilitators and barriers to disclosure (Alaggia 2010; Alaggia et al., 2019; Cavanagh et al., 2004; Digman, 2021; Easton et al., 2014; Feder et al., 2006; Femi-Ajao et al., 2018; Havig, 2008; McNeish & Scott, 2008; Read et al., 2018a; ; Read et al., 2018ab; Robinson & Sailsbury, 2008; Sivagurunathan et al., 2019; Snyder, 2016; Tener & Murphy, 2015; Trevillion et al., 2014). There has been some research specifically focusing on adults with LDs on the topic of abuse but not solely on disclosure experiences or have been from the perspectives of health and social care professionals or carers (McGilloway et al., 2020; Bennett et al., 2013; Northway, Melsome et al., 2013). Previous studies, noted in the Chapter One, have identified the apparent gap in literature with regards to the views of adults with LDs on disclosure, thus the current research contributes in-depth qualitative data on this topic area and insight into the lived experiences of adults with LDs which as mentioned are often absent in the mainstream literature, despite being most at risk to abuse. It is important to highlight, the current research, in spite of these strengths, does not propose to illustrate a complete narrative of adults with LDs experiences of disclosure, alongside acknowledging participants provided retrospective accounts of their disclosure experiences, meaning their memory of certain events have may been reduced or differed. Nonetheless, the research serves as an initial exploratory account within the context of the study sample who provided rich information about their lived experiences of disclosure and adds knowledge and understanding to the field of disclosure for the LD population and demonstrates the need for further research.

3.6.5.2 Research Paradigm and Methodology and Inclusivity.

Historically, as noted in Chapter One, the research with the LD population has been positivist in which people with LDs have been objectively studied, leading to clear oppressive legislation and policy and their own voices missing from the research literature and society as a whole. Walmsley (2001, p. 188) states those with disabilities "were tested, counted, observed, analysed, described and frequently pathologised, but never asked for their views". In light of this, the researcher applied a critical realist position to underpin the research; the realist ontological position acknowledged the reality of abuse for adults with LDs, and the interpretivist epistemological position facilitated the contribution of subjective and contextualised understandings and knowledge from the lived experiences of disclosure for adults with LDs.

Semi-structured interviews are useful qualitative data collection tools as they allow for the exploration of lived experiences, are flexible with regards to questions asked and accessible e.g., tailoring language to meet participants needs. However, it is important to note their limitations with regards to breadth, in that semi-structured interviews only allow for smaller sample sizes, compared to qualitative or quantitative survey studies, there is a lack of anonymity in the interview which may deter how much information participants share, as well as their external validity due their unique nature, and the influence of the researcher's own assumptions and beliefs on the interpretation of the data (Braun & Clarke, 2013; Diefenbach, 2009). To ensure the quality of interviews the researcher completed the aforementioned interview summaries following each interview, which considered their initial reflections, considerations for future interviews and how valuable the interview was on a scale 0-10. The issues of the researcher’s positionality and reflections on completing the thesis are discussed in Chapter Four.

It is acknowledged that LD research has grown to become more inclusive in terms of active participation of those with LDs in the research process from study development to analysis to dissemination. The researcher endeavoured to involve people with LDs in the study process as demonstrated by meeting with the drop-in CLDT group and member checking, yet the researcher holds in the mind the reality that they are the one in the position to interpret the information and convey the participants’ experiences and the responsibility to do this justice, which is discussed further in Chapter Four. The drop-CLDT in group were in agreement with the research topic, which reinforced the need to conduct the research, however it is acknowledged that the people with LDs were not directly involved in identifying the research topic.

3.6.5.3 Study Sample and Sample Size.

There remains no definitive consensus on the sample size for qualitative research studies with Patton (2002, p. 244) stating “there are no rules for sample size in qualitative inquiry*”.* Although, it has been suggested sample size of 6-15 participants for thematic analysis is appropriate (Terry et al., 2017), and it is acknowledged the current research only recruited five participants. Despite being just below the proposed ‘cut-off’ it felt important to consider the possible explanations as to the smaller sample size for the study. Firstly, the recruitment took place during the COVID-19 pandemic which significantly increased pressure and demand on all NHS staff. The clinicians in CLDTs were integral in supporting both the initial stages of recruitment and the interview process given their established relationships with participants and the remote nature of the recruitment as a result of the pandemic. The aforementioned effects of COVID-19 on the NHS may have understandably impacted on clinicians’ capacity to support recruitment. This being both practically and mentally in terms of their increased workload and required adaptations to support adults with LDs who were and are considered extremely vulnerable to the effects COVID 19 e.g., risk of infection and death, as well other factors impacting the LD cohort e.g., accessible information and resources, social connectivity and the mental health impact (Courtenay & Perera, 2020; Williamson et al., 2021). Secondly, prior to the COVID-19 pandemic pre-existing barriers to recruitment of adults with LDs through stakeholders as ‘gatekeepers’ to participants were also highlighted; protection of the self and others, institutional factors e.g., hierarchical structures and administrative issues, and research factors e.g., aversion towards and misconceptions about research, all of which were likely to have been amplified by COVID-19 (Williams, 2020).

The UK Government guidance and University of Essex’s Research requirements also lead to the recruitment and interviews being conducted entirely remotely. This meant face to face interaction with clinicians that may have traditionally prompted clinicians to consider recruitment did not occur, such as the researcher attending recruitment sites in person as a visual reminder of the study. To attempt to mediate the above, the researcher implemented strategies adapted from the organisational, values and practice design principles identified by Boaz at el., (2018) to engage clinicians in the recruitment process and recommendations from Williams (2020) paper on exploring gatekeepers’ barriers in research with adults with LDs. The researcher ensured they outlined to clinicians the objectives and requirements of their involvement in the recruitment process, including development of a clinician checklist and electronic copies of research materials, attended team meetings as well as offering to meet clinicians individually to discuss suitable cases, consent processes and how participants would be supported, which contributed to building rapport with the clinicians. The researcher also identified their shared goals with clinicians for the outcomes of the research to contribute to improved care for adults with LDs, in addition to extending the timeframe for the recruitment stage.

Another limitation to consider is the sample homogeneity in terms of ethnicity and verbal communication ability. All participants were White British, therefore experiences of other forms of abuse such a racial trauma will have been missed. It is also important to acknowledge the systemic racism documented within society and institutions who are involved in disclosure processes e.g., NHS and criminal justice system, and the specific experience of racial trauma, and how this may impact individuals from racialised communities' experiences of disclosure (Emerson and Gone, 2012). A number of the participants were also not familiar with the term ethnicity. This was explored with the participants via the prompts for this question on the demographic information sheet. Therefore, the researcher must acknowledge the influence of their own understanding of ethnicity on supporting participants to answer this question. With regards to communication, one of the inclusion criteria was participants had the ability to verbally communicate to take part in an interview, given the timeframe to complete the doctoral thesis and the researcher's own skill set. Yet undoubtedly individuals with LDs who have more severe communication difficulties will have different experiences of abuse and disclosure. These issues with the sample are further addressed in future research section. Despite the aforementioned issues raised with the sample and its size, including those within the context of COVID-19, the sample does reflect the experiences of disclosure for the five adults with LDs who were recruited. Moreover, it supports the arguments that those within the LD cohort, whose voices have previously been neglected from research and viewed as being unable to meaningfully take part in research, can successfully take part in research, even on a sensitive topic area, with appropriate adaptations.

3.6.5.4 Virtual Interviews.

As discussed, the interview process could not be conducted face to face in accordance with aforementioned UK Government guidance and the University of Essex's Research requirements in response to COVID-19. The researcher was able to adapt and include remote procedures for interviews within their study protocol in case of this possibility. This included electronic easy read PISs and consent forms and conducting the interviews via video conferencing software. On PIS, the researcher introduced themselves, including with a photo, to indirectly begin to build rapport with the participants. This is an important step within any research study but considered pertinent when completing research with adults with LDs and when unable to meet face to face. This step was followed by contacting the participants by telephone or email to arrange an interview date if they were interested to take part. There were recognisable benefits to the interview taking place virtually as it provided participants with flexibility for the time and place the interview took place (Opdenakker, 2006) with all participants choosing their own homes. Although irrespective of face to face or remote protocol, participants were invited to have a member of their support network or clinician present during and/or following the interview. This was experienced as more streamlined as multiple members of the support network e.g., family members and clinicians, could simultaneously join the call when needed which may have been an additional logistical challenge if the interviews were conducted face to face.

The aforementioned importance of building rapport with participants was also supported using video conferencing software, which is vital when discussing potentially sensitive and emotive topics, such as abuse, as both the researcher and participant were able to see each other's faces and expressions (McGrath et al., 2019). However, virtual interviews likely impeded other features of communication, such as the researcher's ability to assess non-verbal cues for distress or fatigue. The researcher aimed to address this unescapable limitation by ensuring they checked in with participants throughout, agreeing how they would communicate if they wished to not answer a question or end the interview, and prearranged support from a clinician in their CLDT to be available during and after the interview, if required.

3.6.5.5 Definition of Abuse.

The broad operationalisation of abuse for the purposes of the research allowed for the study of a breadth of lived experiences of abuse and disclosure and drew together the shared aspects of participants' stories. These informed the development of general recommendations for services to support adults with LDs who have experienced abuse, yet it is acknowledged that different types of abuse hold their own specific experiences which will in turn influence disclosure experiences and require more specific recommendations within a general framework. These will be discussed in Chapter Four.

3.6.5.6 Participants' Responses.

It felt important to acknowledge what has not been said by participants within the interviews. When explicitly asked if others, particularly CLDTs, did anything unhelpful within the disclosure process, the majority of participants answered No. On reflection, there may be a number of reasons for this. Firstly, the participants were recruited from their CLDT and currently remained open to them, therefore it may have been that participants felt unable to be critical of the support they received given this context and concerns how it may have impacted their care if they had done so, despite reassurances from the researcher. It is also acknowledged the inclusion of supporters, such as family members or clinicians, during the interviews may have impacted on participants for similar reasons in that they may felt unable to critically voice their experiences that involved their family or clinicians. Nonetheless, the inclusion of supports was considered of benefit, with participants expressing they were pleased their family members or clinicians could join for the interview. Secondly, it may have been the participants who had a positive experience of the CLDT that agreed to take part, and perhaps those who had a less positive experience were not considered by clinicians. Thirdly, the lack of criticism for CLDTs within the interviews may have reflected participants experience of clinical interactions within the CLDT i.e., considered the interview space to be a clinical one, not research, especially given their awareness of the researcher's role as a Trainee Clinical Psychologist and support from the clinicians within these teams in recruitment and the interview process. Fourthly, participants' accounts of a positive experience within CLDT, particularly therapy, may have been likely due to these services and/or therapists' understanding of the importance of supporting disclosure and working through its impact, which facilitated participants to receiving an appropriate and containing response. Finally, recruiting from within clinical services means the accounts of those who have not received care from a CLDT, whose experiences may have differed, has not been covered. These issues should be addressed in future research.

3.6.6 Yardley's Criteria of Quality Assessment

In the light of the above strengths and limitations, Yardley's four criteria for quality research are considered.

3.6.6.1 Sensitivity to Context.

One aspect of sensitivity to context is an awareness and understanding of the current research literature in the topic area (Yardley, 2000). The researcher considered the literature in each key aspect of the study; LD, abuse and disclosure, alongside a rapid review to further explore health and social care professionals' experiences of working with adults with LDs disclosing abuse to contribute to and situate some of the study's findings. The socio-cultural context of research, including the researcher's own influence on the research, is also important to consider in the sensitivity to context. The researcher addresses this in Researcher's Positionality in Chapter Four of the thesis.

3.6.6.2 Commitment and Rigour.

In regards to commitment, the methodology of thematic analysis required the researcher to immerse themselves in the data demonstrated through conducting the interviews, transcription of the data and the analysis, and the research literature, alongside an extensive engagement in topic area as noted above. It is noted the limitations in sample size do impact on the rigour on the study, however the data that has been collected provided a rich information on topic area to meet the aims of initial exploratory study.

3.6.6.3 Coherence and Transparency.

The research question considering the lived experienced of adults with LDs and the qualitative methodology applied to explore this is in line with the critical realist philosophical framework. The thesis has also provided sufficient information to replicate the study.

3.6.6.4 Impact and Importance.

The research contributed to the research literature, as well as having clinical and policy implications, which are discussed in Chapter Four.

3.6.7 Further Research

As noted, the current research is an exploratory study illustrating preliminary themes of the abuse disclosure experiences of adults with LDs. It supports the need for further research in this topic area to inform clinical practice and policy. Firstly, research is required to further explore the experiences for people with LDs, not only in light of the current research’s sample size but its homogeneity in terms of ethnicity and communication, and the overall heterogeneity of the LD population itself. It is known individuals with LDs have different strengths and needs in terms of their cognition and communication e.g., communicating nonverbally and using augmented communication tools. Therefore, research into their experiences is warranted given their likely different experiences of how they communicated abuse had occurred, the abuse itself and their increased risk to it, as well as staffs' confidence in implementing augmented communication tools. The experiences of disclosure for individuals with LDs from Black and Asian racialised communities should also be further explored, as previously mentioned their experiences of disclosure may be different. Other aspects of intersectionality of identity for individuals with LDs could also be explored e.g., gender and sexual orientation, and must be considered when interpreting the results of future research.

Secondly, further research could be to explore individuals with LDs' experiences of disclosing specific types of abuse e.g., sexual, financial, psychological, physical or discriminatory, as well as a focus on the specific settings in which the disclosure occurred e.g., with health care professionals, police or social care. The current research highlighted the various abuses that occurred and the settings in which they were disclosed, and the subsequent experiences of this. The research focusing on these specific areas could inform clinical and policy recommendations, including specific training around different skill sets needed within such areas or further support the role of multiple agencies working in the disclosure process. The current research was also cross-sectional by focusing on participants' retrospective accounts of disclosure and for some current experiences of support at the point of the interview. Therefore, a longitudinal study exploring experiences shortly after disclosure then a period of time following this may be helpful in further informing guidelines to support individuals during this time.

Finally, it will be important for future research to continue to focus on the lived experiences of adults with LDs and participants' involvement in research. The current research was enriched by this in terms of adding experiential knowledge to the evidence base as well as informing recommendations for some of the services accessed by the LD population. The NIHR (2014) recommends the service user involvement within research; it argues it is not only ethical to do so but strengthens the credibility and validity of the research and contributes to more relevant research to meet service user's needs and improved translation into clinical healthcare practice (Beresford, 2007, Department of Health, 2006; Staley & Minogue, 2006). This is particularly pertinent given the concerns raised about the healthcare people with LDs received for several years (Mencap, 2007). The aforementioned Equality Act (2010) states services are required to make adjustments to ensure disabled people have equal accessibility to care. Northway (2021) argues this standard should be transferred across to service user involvement in research and researchers must work creatively to deliver successful research in partnership with individuals with LDs (Blunt, 2012 as cited in Durell, 2016; Building Bridges Training Research Group, 2014 as cited in Durell 2016). Tuffrey-Wijne et al. (2020) also delivered a course to train individuals with LDs to be researchers with positive outcomes. Therefore, further research should endeavour to have individuals with LDs actively involved in all aspects of research, as "this leads to better research, better data and the chance of real change" (Learning Difficulties Research Team, 2006 as cited in Durell, 2016).

4. Chapter Four: Clinical and Policy Implications, Recommendations and Personal Reflections

4.1 Chapter Overview

The chapter includes the implications, both clinical and policy, and the recommendations generated from the empirical study, literature review and rapid review, to inform how care can be best delivered to adults with LDs who have experienced abuse. This is followed by the researcher’s own personal reflections on completing the research to provide transparency, then plans for dissemination and the conclusion are outlined.

4.2 Implications and Recommendations

4.2.1 Clinical

The current research provides informative accounts of the disclosure experiences of adults with LDs, and the subsequent support they received from CLDTs. From these accounts a number of key recommendations can be identified to inform the practice of professionals working with adults with LDs in broader contexts, and more specifically in CLDTs.

Firstly, the current research implies that adults with LDs may be less likely to disclose abuse, and there is a responsibility for professionals working with this cohort to be able to recognise abuse and support disclosure. Therefore, the current research recommends that professionals are provided with specific training to effectively understand what abuse is, appropriately assess the signs of all types of abuse in individuals with LDs given how variations in how these may present for the different types of abuse and respond accordingly. Once equipped with this awareness and knowledge, professionals should ask service users directly if they are or have experienced abuse. Staff should ask specific questions about events of abuse e.g., ‘Has anyone ever taken money or things that do not belong to them from you without your permission?’ or ‘Has anyone ever touched your private parts or anywhere else on your body, and you did not want them too?’. This reinforces findings from previous research which indicated follow training and education programmes on abuse, clinicians felt more confidence to ask services users about abuse, with specific questions yielding a higher identification of abuse (Cavanagh et al., 2004; McNeish & Scott, 2008; Read et al., 2018b). Staff should also be offered follow up support post training as lack of such support can minimise confidence levels, which would impact the implementation of the above into practice (Johnson & Yee, 2019). This would also support the findings of the rapid review which highlighted professionals may hold varying definitions and thresholds of abuse alongside differing levels of knowledge about the signs of abuse. As family and others in the participants’ support networks were the initial points of contact for the disclosure, this training could also be extended to them.

Secondly, the current research implies a facilitating factor for adults with LDs in sharing their abuse story, is a positive and trusting relationship with the person they share their story with and feeling understood by them. Therefore, the current research recommends alongside the clinical skills outlined above, staff need to build rapport and strong working relationships with service users. This could be facilitated through staff proactively seeking to learn about who the service user is e.g., engaging in ‘problem free talk’ with clients; asking about their significant interests. This would also benefit staff in challenging any preconceptions they may have about adults with LDs, which can impact on care delivered as demonstrated in current research’s rapid review. Depending on the level of the risk to the service users, it is recommended staff get to know the service user and build this relationship with them prior to enquiring about abuse, as not doing so can impede how open service users are (Weise et al., 2018). A good understanding of the service user may also enhance clinician’s ability to assess for the signs of abuse, as nuanced changes in the service user’s presentation may be more obvious. This is further supported by the research literature discussed in Chapter One, which also indicated a trusting relationship was an important facilitator in disclosure, as well as the rapid review which indicated the relationship between clinicians and service users and their families played a role in the identification of abuse. Together, these first two recommendations will provide a holistic approach to identifying abuse and supporting disclosure.

Thirdly, the current research implies adults with LDs have a lack of control over the disclosure process. Therefore, the current research recommends that the regaining of control for service users is addressed at level of service delivery. It promotes that care is delivered in collaboration with service users, ensuring they are actively involved in decision making and provided with choices. This should be embedded into day to day practice, as well as adults with LDs who have experienced abuse being involved directly in leadership, service delivery and development as experts by experience to inform and guide practice on supporting this cohort through disclosure. This is line with principles of trauma informed care, an approach already campaigned by those working in services for the LD population (Goad, 2022; Keesler, 2014; Skelly, 2021), as well as the NHS long term plan (2019), the Department of Health 2001 White Paper and the NHS Scotland Knowledge and Skills Framework for Psychological Trauma (2017).

Finally, the current research implies that adults with LDs benefit from talking about their experiences of abuse, especially within a therapeutic setting. Therefore, the current research recommends services need to ensure they are providing and adapting appropriate therapeutic approaches to support those with LDs who have experienced abuse with the impacts of abuse, and the subsequent trauma. This recommendation is relevant to all services providing therapeutic support, as individuals with mild LDs may be seen by mainstream services. The recommendation is substantiated by the aforementioned Equality Act (2010) stance on adjustments care to ensure equality in accessibility to care. This was supported by the findings of the rapid review which indicated clinicians found adapting their approaches, particularly in therapy, best met their clients’ needs. The current research highlighted a common response to experiences of abuse for adults with LDs who have been abused may be self-blame, with abuse often occurring within complex relationships adding further confusion. Other responses include flashbacks, nightmares, poor mental health and emotional wellbeing. Therefore, current research recommends trauma informed therapy should include psychoeducation on what is abuse for individuals with LDs, an emphasis on processing the trauma and helping individuals to move on from their experiences, alongside services being more active and timely to offer support around the emotional consequences of abuse. The participants were also aware the abuse was wrong; therefore, services could offer information around keeping safe. These recommendations reflect some of the principles of trauma informed care outlined in Chapter One.

Furthermore, the research would support the changes to policy outlined in the House of Commons Library report (2021) on supporting with people with LDs, which highlights that by 2023/2024, all patients’ records will flag when a person has a LD, as well as ensuring mandatory training is provided to all health and social care staff, delivered in partnership with people with LDs and their families. This would reinforce appropriate support is provided to individuals with LDs to facilitate disclosure and responses provided, including adaptions to therapy, even for those not seen within dedicated LD services.

4.2.2 Policy

There are already several policies, legislation, guidelines and initiatives to ensure adults with LDs receive high quality care more broadly, and specifically in relation to abuse and trauma. The NHS long term plan (2019) has a strong focus on improving care for people with LDs, including supporting the whole NHS to make reasonable adjustments to provide equitable access to, experiences and outcomes from care and treatment. In addition, the plan recommends working together with people with LDs and their families to listen and understand their needs, as well as promote the strengths and insight of those with lived experiences within their work. Other areas of the plan lay out aims for personalised care for all patients, and trauma informed care for adult mental health services. Overall, this focus of The NHS long term (2019) echoes the aims of other initiatives, guidelines and policy, of which this list is not exhaustive:

- Getting it Right for People with Learning Disabilities Charter (NHS England, 2019)
- The Service model for all commissioners of health and social care services (2015) for supporting people with a learning disability and/or autism who display behaviour that challenges, including those with a mental health condition (Local Government Association, Directors of ADAS Adult Social Services & NHS England, 2015)
- Treat me Right! (Mencap, 2004)
- ‘Right to be heard’: The Government’s response to the consultation on learning disability and autism training for health and care staff (Department of Health and Social Care, 2019)
- Core Capabilities Framework for Supporting People with a Learning Disability (Skills for Health, Health Education England & NHS England, 2019)
- Ask, Listen Do pledge (NHS England, 2022)
- Trauma support (The Challenging Behaviour Foundation, 2022)
- The Trauma informed practice toolkit (NHS Scotland, 2021)

However, the current research, research literature presented in Chapter One and the rapid review implies there is a discrepancy between the plethora of policies for best practice and some of the lived experiences of service users with LDs and service delivery. As the aforementioned recommendations are not entirely novel, this suggests a failure or disparity in the implementation of policies to support adults with LDs accessing services who have experienced abuse, and prioritisation of their care. Yet this not new or unexpected within the LD sector, evidenced by the slow delivery of the Department of Health Transforming Care Programme (2012) in response to the Winterbourne failings and the recent health inequalities for people with LDs highlighted by COVID-19 pandemic and the care they received (BBC 2020, Courtenay & Perera, 2020, Open Access Government, 2021).

As Northway, Davies et al. (2007, p. 86) stated "Policies Don't Protect People, It's How They Are Implemented". Therefore, the current research recommends improvements in the national consistency of the policies and guidance available, as well as efforts at a local level to engage all local stakeholders, consider the perceptions of LDs in local-decision makers that may influence implementation, and adaption of implementation tools, such as Standard Operating Procedures (SOPs), to fit with needs of local LD populations to ease policy implementation. In addition to monitoring policy implementation and evaluating its effectiveness. There are understandable barriers to policy implementation, such as significant workforce gaps that need to be addressed (NHS Providers, 2022). Again, this is not a new proposed task, but not one that can be ignored as variability in the quality of care to adults with LDs who have experienced abuse will continue to pose a threat to those vulnerable to abuse and its impact.

4.3 Researcher's Positionality and Personal Reflections

The axiology i.e., the researcher's positionality encompasses different aspects of oneself and experiences, as reflected in the Social GRRRAAACCEEESSS developed by Roper-Hall (1998 as cited in Totsuka, 2014) and Burnham (2012). Positions can include but are not exclusive to; age, gender, race, sexual orientation, nationality, ability, appearance, class, culture, education, employment and spirituality (Burnham, 2012). Through reflexivity, the researcher-participant relationship can be managed with regards to ethics, power relations and data collection that will be influenced through this dyad. Ultimately, the researcher positionality within the research; their familiarity or unfamiliarity to the research topic and experiences of participants, will impact the overall research process, which brings both benefits and challenges. Therefore, articulation of the researcher positionality is important in any research to allow the reader to make sense of the research findings within the context of the researcher's identity, and as such the following section will be written the first person (Holmes, 2020).

At the time of writing, I identify as a 32-year-old, White-British heterosexual cis-gendered woman, and grew up in North-West England. I have BSc and MSC in fields of psychology. Prior to training, I worked for seven years in voluntary, third sector and NHS inpatient and outpatient mental health services in various roles, with predominately children, adolescents, and families, including individuals with LDs. Whilst on training, I have had experience working with adults with LDs and their wider networks in a CLDT. Within my clinical roles, I also have experiences working in service user-involvement and service transformation projects. In my practice, I take an integrative, curious and collaborative approach when working with clients and their families to best meet their needs. These experiences I have further highlighted to me the power imbalances within services, including access, and in society, for individuals with LDs and their families, most recently demonstrated by the treatment of people with LDs during the COVID-19 pandemic (BBC, 2020; Courtenay & Perera, 2020; Open Access Government, 2021). As mentioned, individuals and collectively as a group, the LD cohort's voice is not heard within society, which is reflected by the dearth of research literature which directly involves hearing the experiences of this population. These experiences and beliefs undoubtedly influenced my choice to undertake a thesis focusing on the views of individuals with LDs about the disclosure of abuse.

Reflecting on the process of conducting the research, the personal challenges were acknowledging that although I consulted with people with LDs and other stakeholders about the research, the timeframe and requirements of completing thesis for my degree, did not allow me to involve people with LDs in the co-production of study as I would have wished. I also continually considered how much my own beliefs influenced my interpretation of the lived experiences of the participants, attempting my best to convey their experiences and hoping to do justice to the experiences they had shared with me.

In undertaking this research, I have been provided with several learning opportunities which I hope will prove helpful in my career as a Clinical Psychologist. Firstly, it has helped me to understand the process of, and how to successfully apply for NHS ethical approval, including presenting at REC ethics committees. I have been able to develop my skills in confidently discussing my research project, incorporating feedback from other stakeholders, recording and justifying key decisions, and critically appraising my own research’s strengths and areas for improvement. Secondly, it has further developed my skills in working with people with LDs; considering communication, decision making, how to proactively involve them within research as participants as well as supporting to develop research ideas and materials. Thirdly, I have further developed my skills in thematic analysis to consider the latent themes within the data and create themes around a central organising concept, not just at the surface or semantic level of the data. Finally, it has further reinforced to me the contribution of direct experiences to inform service evaluation, development and delivery is invaluable, which I will bring into my clinical practice.

4.4 Plans for Dissemination

The plans for dissemination, include sharing the results with participants and other stakeholders as outlined in Chapter Three. The researcher intends to submit the research to one of the following journals and forums for consideration for publication; Journal of

Intellectual Disability, Disability and Society, Tizard Learning Disability Review, The British Psychological Society Clinical Psychology Forum and British Journal of Learning Disabilities. A poster and/or presentation will be submitted to the following conference for consideration; The Faculty of People with Intellectual Disability Annual Conference. The researcher will also consider co-producing a poster with people with LDs, to guide clinicians and others working with people with LDs on how best to support people with LDs to talk about abuse or possible other adverse experiences.

4.5 Conclusion

In summary, the current research makes a novel and a significant contribution to the understanding of the disclosure of abuse for adults with LDs. The main findings illustrate that disclosure does not occur at a single time point but instead is experienced as a non-linear journey for adults with LDs. Other important findings are that abuse is discovered not disclosed, that there is a lack of power and autonomy over the disclosure experience, yet sharing the abuse experience can lead to accessing the necessary help and support, as well as other facilitators and barriers to disclosure. This research demonstrates that adults with LDs can successfully take part in and make valuable contributions to the research field. The current research champions the need for adults with LDs' voices to be heard and action taken clinically, in both policy and research, to address the stark inequalities in care that remain, to best meet the needs of all those with LDs.

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Wright, D., & Digby, A. (1996). *From idiocy to mental deficiency: Historical perspectives on people with learning disabilities.* Routledge.

Yardley, L. (2000). Dilemmas in qualitative health research. *Psychology and Health*, *15*(2), 215-228. https://doi.org/10.1080/08870440008400302

6. Appendices

Appendix A

SPIDER Tool

Sample- Adults with disabilities who have experienced abuse in their childhood or adult life
Phenomenon of Interest - Experiences of disclosing abuse
Design- Interview or focus group
Evaluation- Views and Experiences
Research – Qualitative

Appendix B

Search Terms

1. “psychiatr*” OR “psycho*” OR “nurs*” OR “social work*” OR “occupational therap*” OR “family therap*” OR “art therap* OR “physiotherap*” OR “support work*” OR “behavio#r* specialist*” OR “speech and language therap*” OR “care work*” OR “therap*” OR “counsell*” OR “professional*” OR “staff” OR “clinician*” OR “practitioner*”
2. disabi* OR “learning disabi*” OR “intellectual disabi*” OR “learning disorder*” OR “intellectual disorder*” OR “cogniti* disabi*” OR “cogniti* disorder*” OR “neurodisabi*” OR “neurodevelopment* disorder*” OR “intellectual developmental disorder*” OR “learning difficult*” OR “autis*”
3. abus* OR neglect* OR maltreat* OR mistreat* OR trauma OR "sexual abuse" OR "physical abuse" OR "emotional abuse" OR "psychological abuse" OR "financial abuse" OR "material abuse" OR violence OR assault OR molest* OR "adverse event*" OR discriminat* OR "hate crime*" OR bully* OR prejudice OR "modern day slavery" OR “traffick*”
4. interview* OR “focus group*” OR qualitative OR “mixed methods”
5. #S1 AND #S2 AND #S3 AND #S4

Appendix C

Quality Appraisal of studies using the CASP (2018) Checklist

Section and Question		Study						
		Hodges &Northway (2019)	Jenkins et al., (2007)	Keesler (2016)	Kildahl et al., (2020)	O'Malley et al., (2019)	O'Malley et al., (2020)	Truesdale et al., (2019)
Section A: Are the results of the study valid?	Q1: Was there a clear statement of the aims of the research?	Yes	Yes	Yes	Yes	Yes	Yes	Yes
	Q2: Is a qualitative methodology appropriate?	Yes	Yes	Yes	Yes	Yes	Yes	Yes
	Q3: Was the research design appropriate to address the aims of the research?	Yes	Yes	Yes (signposted)	Yes	Yes	Yes	Yes
	Q4: Was the recruitment strategy appropriate to the aims of the research?	Yes	Yes	Yes (signposted)	Yes	Yes	Yes	Yes
	Q5: Was the data collected in a way that addressed the research issue?	Yes	Yes	Yes	Yes	Yes	Yes	Yes
	Q6. Has the relationship between researcher and	Can't tell	No	Can't tell	Yes	Yes	No	No

	participants been adequately considered?				(in detail)			
Section B: What are the results?	Q7: Have ethical issues been taken into consideration?	Can’t tell	Yes	Yes	Yes	Yes	Can’t tell Ethical approval sought no further detail)	Yes
	Q8: Was the data analysis sufficiently rigorous?	Yes	Can’t tell	Yes	Yes	Yes	Yes	Yes
	Q9: Is there a clear statement of findings?	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Section C: Will the results help locally?	Q10: How valuable is the research? (Was this considered by the researchers?)	Yes	Yes	Yes	Yes	Yes	Yes	Yes

Appendix D

Service User Drop in Group Consultations Log

Session number/Date	Attendance, Activities and Points raised
Session 1- Tuesday 18th July 2019	The session was attended by approximately 12 service users (11 male, 1 female) and 3 staff facilitators. Activities and Points Raised: 1. Psychoeducation a) Emotions We showed the group emoticon faces which expressed different emotions. The group were able to identify a range of emotions, including one expression can mean different things to different people b) Links between emotions, thoughts and behaviours We discussed the links between emotions, thoughts and behaviours. The group appeared to understand this, and were able to say what their emotions, thoughts and behaviour would be in different situations c) Links between E, T, Bs and past experiences We explained that difficult past experiences can influence how we feel, think and behave now. The group were able to identify what these experiences may be; parents splitting up, being bullied 2. Brief Introduction to Research We briefly introduced the research, and we discussed what people may want from services when being asked about difficult past experiences

	3. How should professionals approach talking about abuse to people with LD? Points raised: · Approach should match individuals' preferences. -There was discussion that some people may want to be asked straight away, and others may want to build a relationship with the professional before being asked - Importance of building trust/being someone they know · Complete a timeline of events · Should be referred on for help We agreed with the group we would develop some information sheets about the research and look at these together in 5 weeks' time.
Session 2- Tuesday 23rd July 2019	The session was attended by approximately 12 service users (10 males. 2 females) and 2 staff facilitators. The aim was to received feedback on the information sheet and consent forms that have been developed by the research. Handouts of forms and sheets provided. We also re-capped the previous session. Discussion points and feedback received: · Like font and good size; accessible · The term learning disability is used in the forms. A number of service users shared they identified as having a learning difficulty or mental health disorder. We discussed the option of having a number of different terms on the sheet to capture different preferences. · Mixed views on the preferences for drawing and photos. Discussed the possibility of designing two information sheets/consent forms and asking participants on their preferred choice

	· The group confirmed they understood the confidentiality section of the form, and liked the pictures · For questions with not sure, yes, or no responses, the group suggested emojis to support this text as opposed to thumbs up and thumbs down · The group felt it helpful to have the not sure option as it would give participants an opportunity to explain why this may be, as may be a number of reasons e.g. they do not understand or not sure what is being asked. Suggested a box to add an explanation could be helpful. · We discussed if we should ask participants only about the disclosure abuse or other adverse experiences. Some group members indicated a preference that participants should be asked about other adverse experiences (ACEs), including a lack of opportunities. · We discussed if we should offer to see participants in their own home. There a split in preference. 7 service users voted for the research interview to take place in the participants' home, stating that this may be more relaxed. 5 service users voted for the interview to take place in a neutral place e.g. coffee shop · The group expressed an interest to help develop the interview questions
Session 3- Tuesday 10th September 2019	The session was attended by approximately 12 service users (11 males. 1 females) and 4 staff facilitators. Both staff and service users contributed to the discussion. The aim was to received feedback on interview schedule. We also re-capped the previous session. Discussion points and feedback received: Interview Questions 1. What do you think abuse means? Should we use pictures?

	- Yes, have pictures, like a man hitting someone would make it easier - Photographs better - Pictures all the way through to go with wording Should we use the word abuse or hurt? - Maybe not understand abuse. Hurt- tends to mean physical abuse. Probably more think ‘hurt’ is better word. Maybe use both 2. What would help a person tell someone in this service if they have been hurt / abused? Possible prompts: Should someone in the service ask them? Who might this be? Or is it better to wait until the person feels Ok to tell the service? - Difficult for people to comment on - People prefer to tell someone they know How might they ask the question? - Just asking if the person is alright When should they ask? - Give time- so people don’t feel rushed Where should they ask? - Think home- feel more comfortable, but opportunity to speak outside What could the service do to help ? What might the professional be like? Offer telephone or face to face discussion Do the group have any other ideas about things that would make it easier? - Telling parents - Someone to advocate - Trusting person - Gentle questions prefer ‘take your time’ - Not direct Q straight away e.g. are you worried about something - Build rapport

- Have different options for different people
- Staff can tell if something is wrong

3. What would make it hard for a person to tell someone in this service if they have been hurt / abused?

- Frightened to tell new member of staff
- People not showing an interest
- Type of person- might not feel comfortable if someone looks unfriendly
- Age, position of power
- Consequences

4. If a person has been hurt / abused, they may need support.

What could the service do to help?

- Counselling to get advice
- Someone to listen- sharing problems
- Be containing- don’t leave person hanging
- Ongoing support; during and after
- Keep communication open

What wouldn’t help or make things worse?

- Rude/annoying if can’t be seen when need to speech
- Services being disrespectful
- Being fobbed off- need to be taken seriously

Appendix E

Consultation Meeting with Sarah Sherratt, Practice Education Lead Lecturer (Adults) Speech & Language Therapy, School of Health and Social Care, University of Essex

Date: Tuesday 3rd December 2019

Sarah and I discussed the rationale and aims of the research. Sarah reviewed the study information sheets and discussed the study protocol.

Sarah comments:

-It will be important to clearly orientate the participants to the purpose of the interview/how to set the context for participants at the beginning of the interview so they are clear on what they are being asked. i.e. that I will be asking them questions about when they told someone about the abuse, not about the abuse

- One possibility of doing this would be to provide an example question- we discussed that this could be leading- queried if another example could be used- but would this be too abstract?
- Ensuring participants understand the operationalization definition of abuse used by the study- queried language used on the study information sheet ‘People with learning disabilities are sometimes hurt by other people, This is sometimes called abuse’. Sarah queried that participants may talk about events that may not be considered abuse e.g. minor disputes within group homes. Queried whether to say in interview ‘I am asking you because.. [x happened to you]
- Developing a social story about how the research will be conducted to use with participants

-Respondent validation

- Sarah suggested that video recording participants instead of audio recording them may support them to recall what they said.

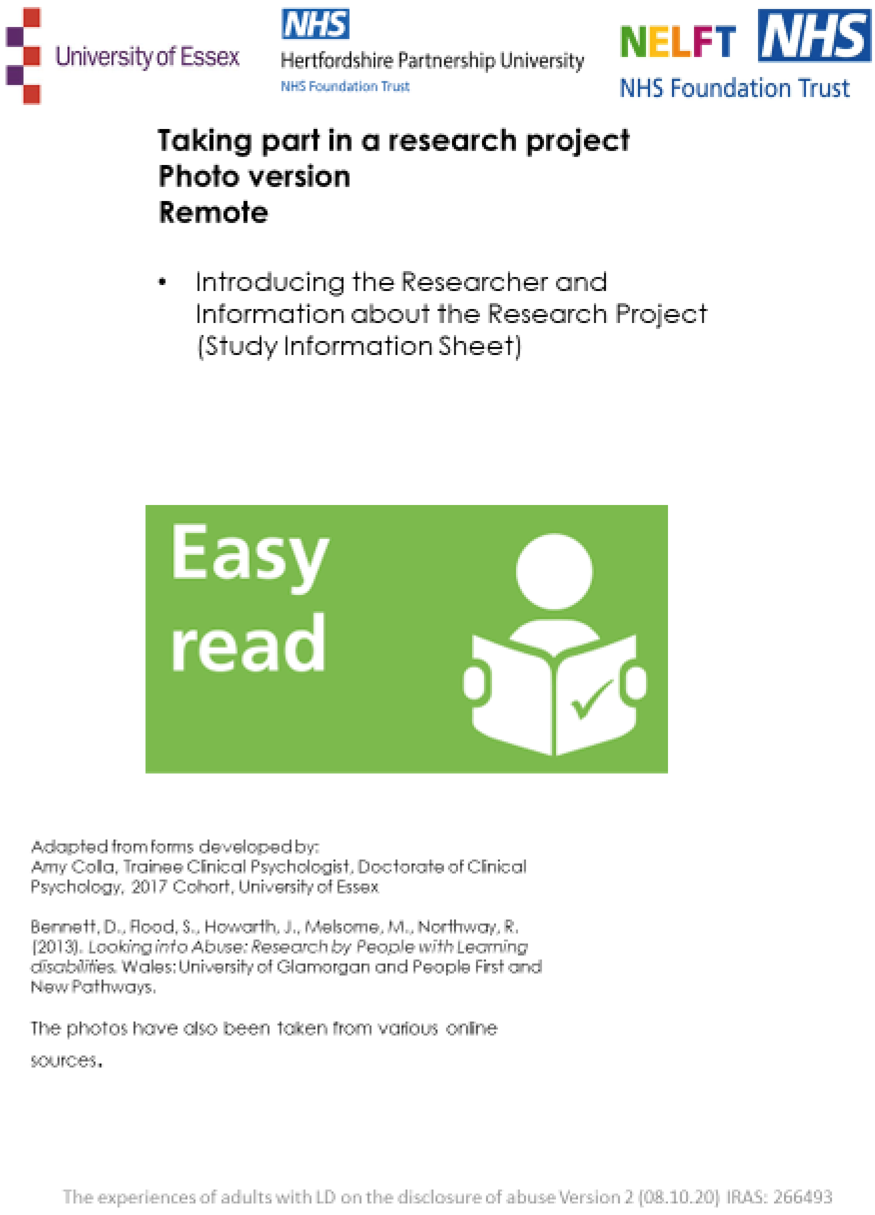
-Other

- Sarah discussed as participants will have discussed abuse with community learning disability term, they will likely have the language used to discuss abuse e.g. disclosure, abuse.
- Sarah provided information on other helpful resources: Respond; an online/phone line who did some work around LD and abuse; Makaton; references. Course around sign and symbols linked to abuse, and ACE.

Appendix F

Participant information sheet

Photo (remote)



Taking part in a research project
Photo version
Remote

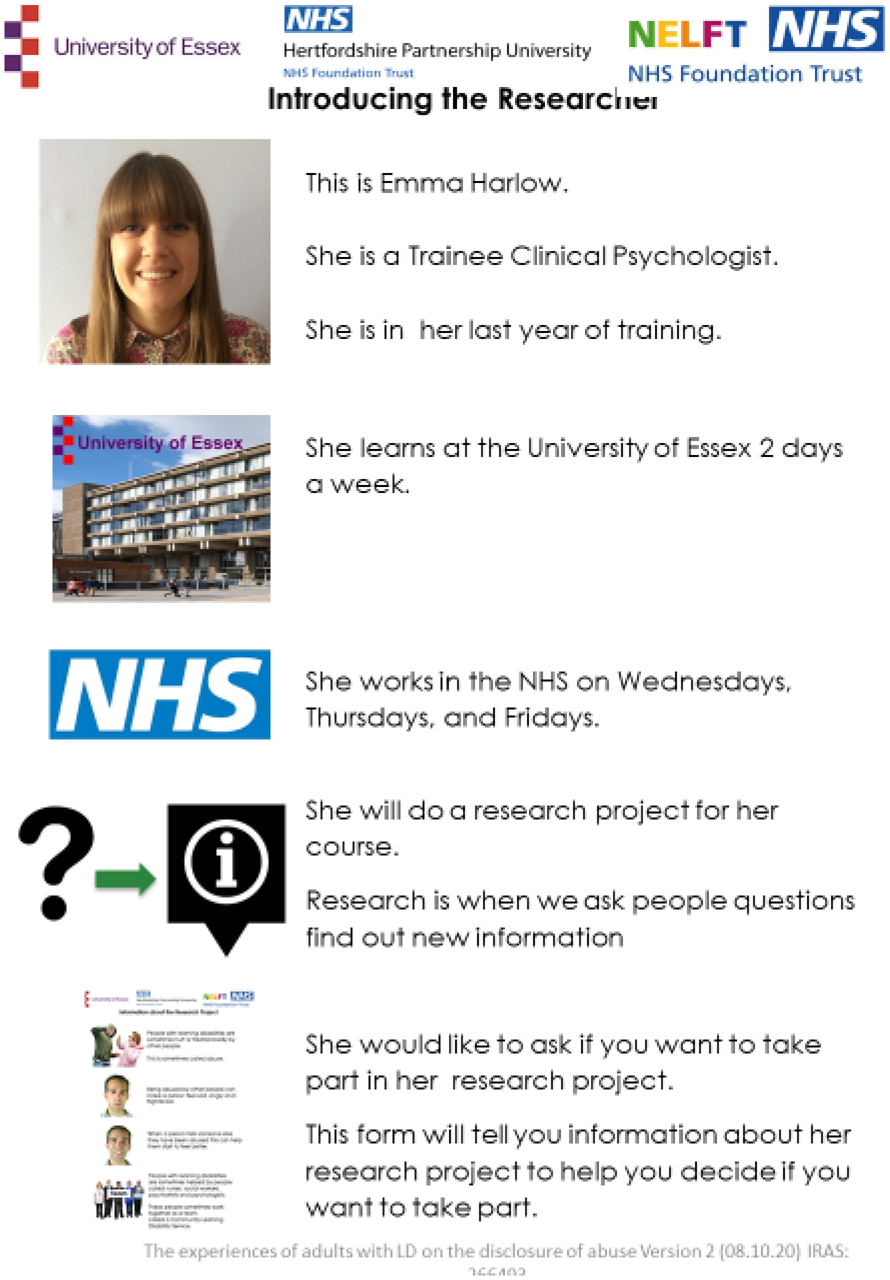
- Introducing the Researcher and Information about the Research Project (Study Information Sheet)

Adapted from forms developed by:
Amy Colla, Trainee Clinical Psychologist, Doctorate of Clinical Psychology, 2017 Cohort, University of Essex

Bennett, D., Flood, S., Howarth, J., Melsome, M., Northway, R. (2013). *Looking into Abuse: Research by People with Learning disabilities.* Wales: University of Glamorgan and People First and New Pathways.

The photos have also been taken from various online sources.

The experiences of adults with LD on the disclosure of abuse Version 2 (08.10.20) IRAS: 266493



University of Essex

NHS Hertfordshire Partnership University NHS Foundation Trust

NELFT NHS Foundation Trust

Introducing the Researcher

This is Emma Harlow.

She is a Trainee Clinical Psychologist.

She is in her last year of training.

She learns at the University of Essex 2 days a week.

She works in the NHS on Wednesdays, Thursdays, and Fridays.

She will do a research project for her course.

Research is when we ask people questions find out new information

She would like to ask if you want to take part in her research project.

This form will tell you information about her research project to help you decide if you want to take part.

The experiences of adults with LD on the disclosure of abuse Version 2 (08.10.20) IRAS:

University of Essex

Hertfordshire Partnership University
NHS Foundation Trust

NELFT NHS
NHS Foundation Trust

Information about the Research Project

People with learning disabilities are sometimes hurt or treated badly by other people.

This is sometimes called abuse.

Being abused by other people can make a person feel sad, angry and frightened.

When a person tells someone else they have been abused this can help them start to feel better.

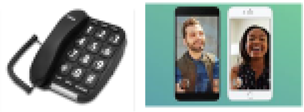
People with learning disabilities are sometimes helped by people called nurses, social workers, psychiatrists and psychologists.

These people sometimes work together as a team called a Community Learning Disability Service.

University of Essex | Hertfordshire Partnership University NHS Foundation Trust | NELFT NHS Foundation Trust

This research will ask people with learning disabilities questions about the **first** time they told someone they had been abused.

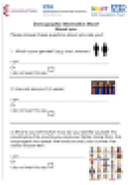
For example, who did they tell, what made it easier for them to tell this person about the abuse and how might services help someone if they have been abused. You will not be asked for stories about the abuse that happened to you.



Emma will call on the telephone or on a video call- you can decide. You can have a support person with you.

Before the call, the team will tell Emma about the type of abuse you experienced, but they will not tell her lots of information about it.

What will happen on the call?:



You will complete a form that asks for information about you, for example your age and ethnicity

You will do an interview with Emma that she will record. This will take 45 to 60 minutes/1 hour. Emma will delete the recording once she has written down what was said.

Abuse is a subject that can upset some people. Your team can help you if you are upset or need someone to talk to.

Emma will keep anything you tell her safe and private. However, if you tell Emma that you or someone else is being hurt. Emma will talk with you about who she needs to tell.

Alison and Andrew, who are teachers at the University of Essex, will help Emma with her project. Only Emma, Andrew and Alison will see or hear what you told Emma.

Emma will do a report on what she finds out. Emma will use what you have said in the report.

MY NAME

✖

However, Emma will not use your name. This means no one will know that you said anything.

If you decide to take part in the project, Emma will tell you what she finds out. Emma will also tell other people with learning disabilities, carers and professionals what she finds out. She will use journals and conferences.

A group of people with learning disabilities will help Emma with her project.

You can stop doing the research at anytime. You do not have to give a reason. This is ok. It will not change the care you receive from the service.

Once the study has finished, the information you gave will be stored safely at the University of Essex for 5 years, in case the research team need to check it. If you want to know more about this, you can ask Emma any questions.

University of Essex

NHS Hertfordshire Partnership University NHS Foundation Trust

NELFT NHS NHS Foundation Trust

OR

If you take part in the project, you will get a £10 Amazon gift card OR £10 One4all gift card.

You will choose which gift card you get.

Thank you for your time

Emma Harlow, Alison Spencer and Andrew Bateman

University of Essex

NHS Hertfordshire Partnership University NHS Foundation Trust

NELFT NHS Foundation Trust

Information about the Research Project
Reporting Concerns and Complaints

If you have any concerns or complaints about the study you or someone who supports should follow these steps.

1. If you have any concerns about any part of the study or you have a complaint about the study, the first person to contact is the researcher, Emma Harlow by email: eh18852@essex.ac.uk

2. If you are still concerned, you think your complaint has not been dealt with or you feel that you cannot speak to Emma, please contact Emma's supervisors, Dr Andrew Bateman or Dr Alison Spencer, by email.

Andrew's email: a.bateman@essex.ac.uk

Alison's email: as16018@essex.ac.uk

3. If you are still not happy, please contact the University's Research Governance and Planning Manager, Sarah Manning-Press by email. Please include the project number in your email: 266493

Sarah's email: sarahm@essex.ac.uk

PALS
Patient Advice and Liaison Service

If you do not want to contact Emma, her supervisors or Sarah, you can contact your local Patient and Advice Liaison Service (PALS) on: (insert PALS details linked to relevant trust). They are not part of the research team.

The experiences of adults with LD on the disclosure of abuse Version 2 (08.10.20) IRAS: 266493

University of Essex
NHS Hertfordshire Partnership University NHS Foundation Trust
NELFT NHS NHS Foundation Trust

Information about the Research Project

Name………………………….. **Date………………………..**

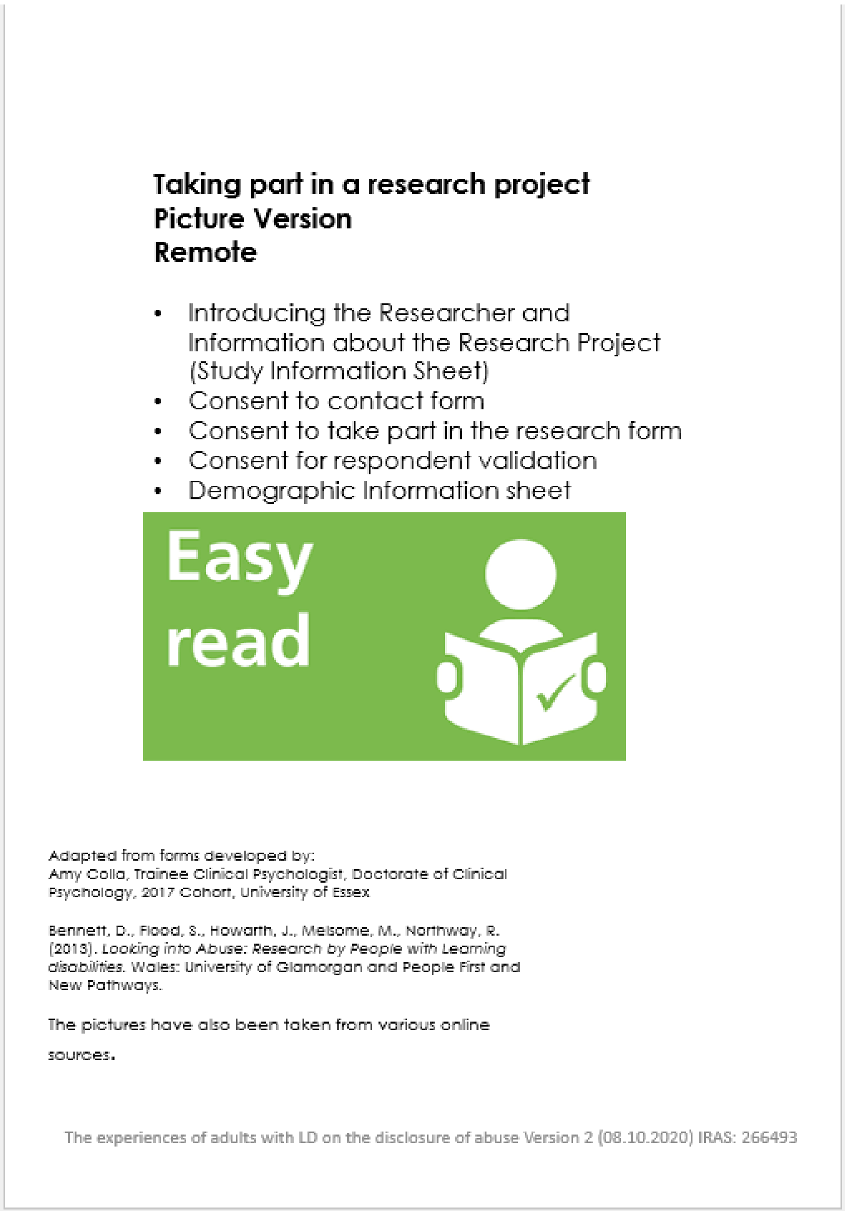
I understand what the project is about.

○ Yes ○ No ○ Not sure

You will receive a copy of this form

The experiences of adults with
LD on the disclosure of abuse
Version 2 (08.10.20) IRAS:
266493

Picture version (remote)



Taking part in a research project
Picture Version
Remote

- Introducing the Researcher and Information about the Research Project (Study Information Sheet)
- Consent to contact form
- Consent to take part in the research form
- Consent for respondent validation
- Demographic Information sheet

Easy read

Adapted from forms developed by:
Amy Colla, Trainee Clinical Psychologist, Doctorate of Clinical Psychology, 2017 Cohort, University of Essex

Bennett, D., Flood, S., Howarth, J., Melsome, M., Northway, R. (2013). *Looking into Abuse: Research by People with Learning disabilities.* Wales: University of Glamorgan and People First and New Pathways.

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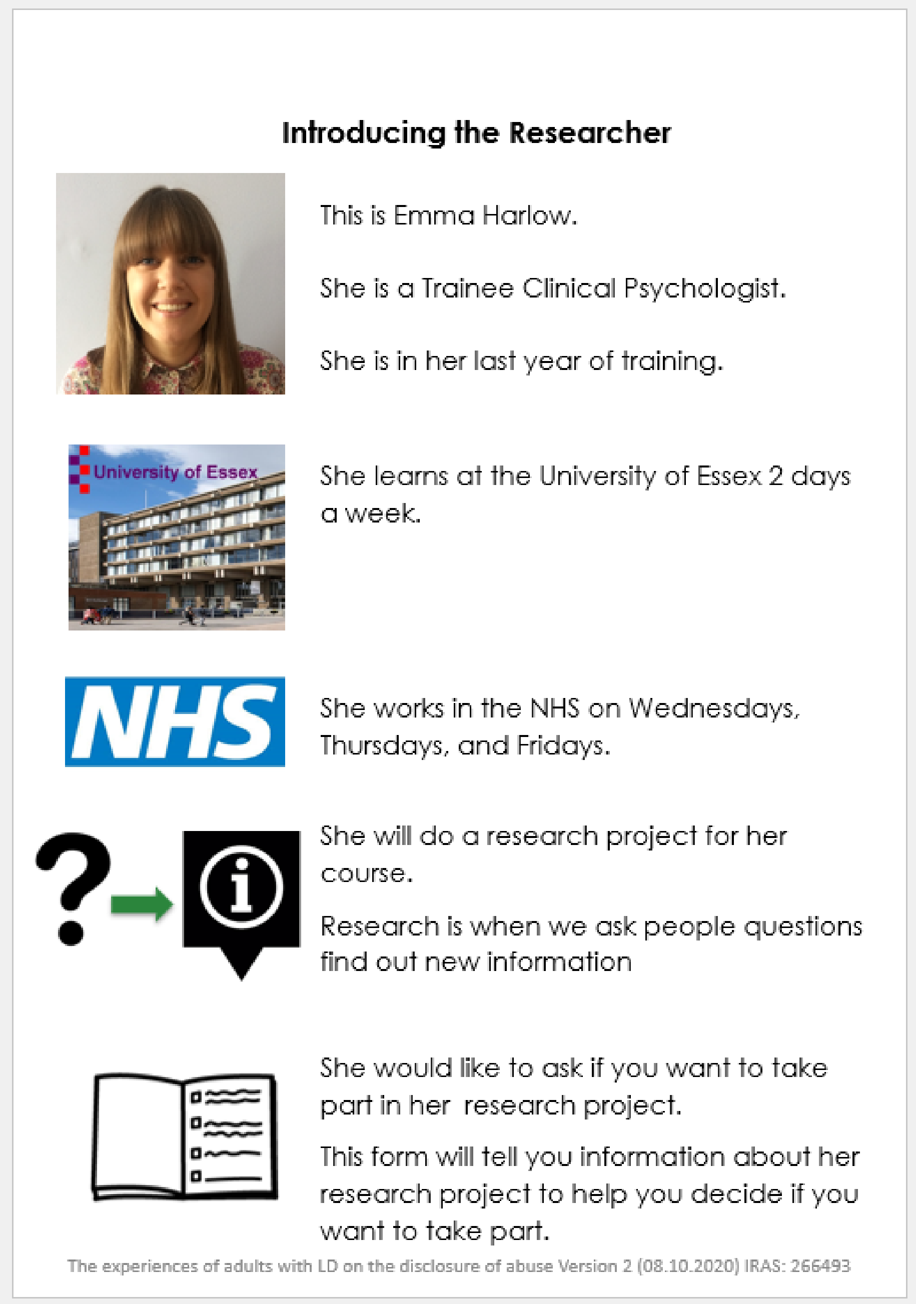

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She is in her last year of training.

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She will do a research project for her course.

Research is when we ask people questions find out new information

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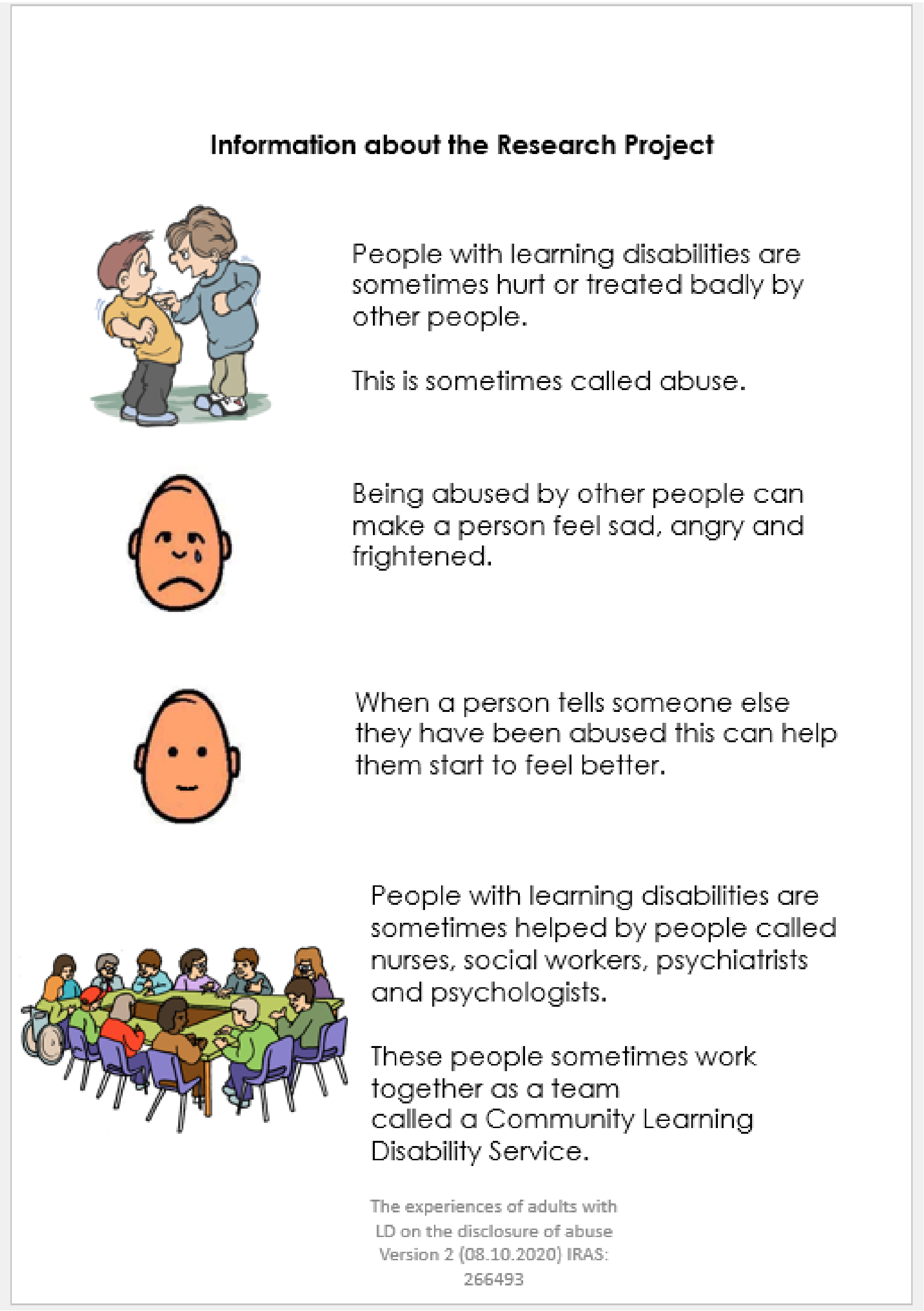


Information about the Research Project

People with learning disabilities are sometimes hurt or treated badly by other people.

This is sometimes called abuse.

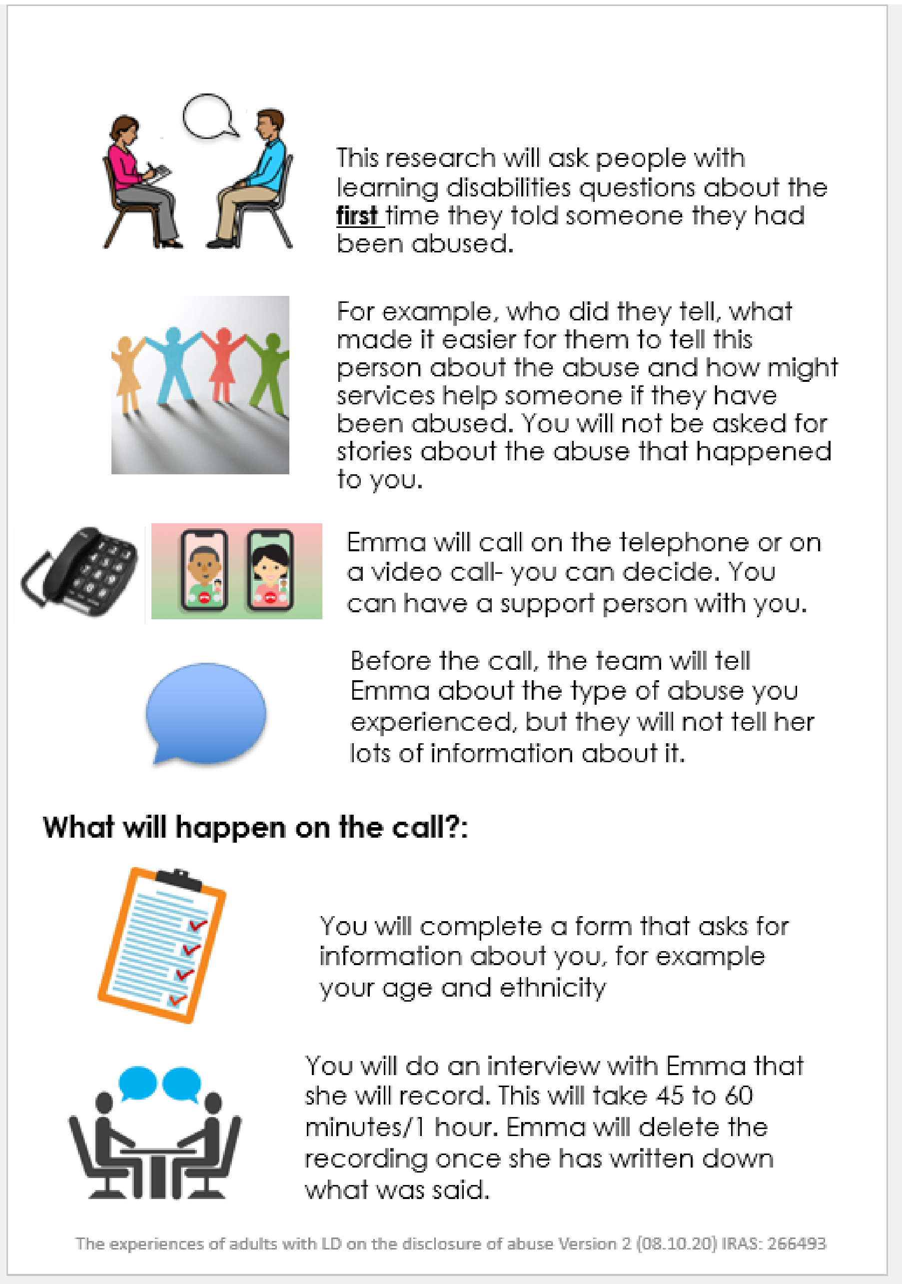
Being abused by other people can make a person feel sad, angry and frightened.

When a person tells someone else they have been abused this can help them start to feel better.

People with learning disabilities are sometimes helped by people called nurses, social workers, psychiatrists and psychologists.

These people sometimes work together as a team called a Community Learning Disability Service.

The experiences of adults with LD on the disclosure of abuse
Version 2 (08.10.2020) IRAS: 266493



This research will ask people with learning disabilities questions about the **first** time they told someone they had been abused.

For example, who did they tell, what made it easier for them to tell this person about the abuse and how might services help someone if they have been abused. You will not be asked for stories about the abuse that happened to you.

Emma will call on the telephone or on a video call- you can decide. You can have a support person with you.

Before the call, the team will tell Emma about the type of abuse you experienced, but they will not tell her lots of information about it.

What will happen on the call?:

You will complete a form that asks for information about you, for example your age and ethnicity

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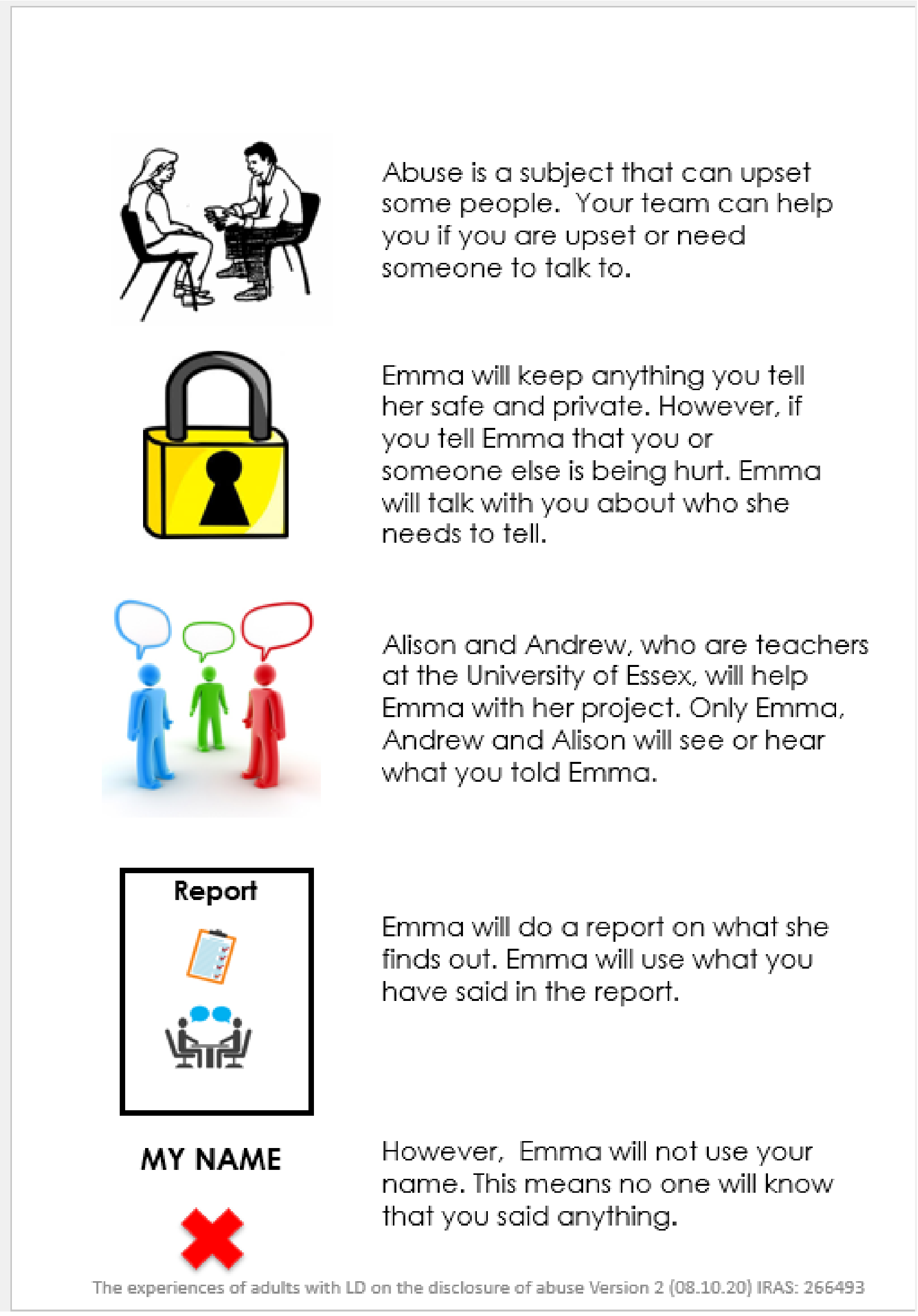

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Alison and Andrew, who are teachers at the University of Essex, will help Emma with her project. Only Emma, Andrew and Alison will see or hear what you told Emma.

Report

Emma will do a report on what she finds out. Emma will use what you have said in the report.

MY NAME

However, Emma will not use your name. This means no one will know that you said anything.

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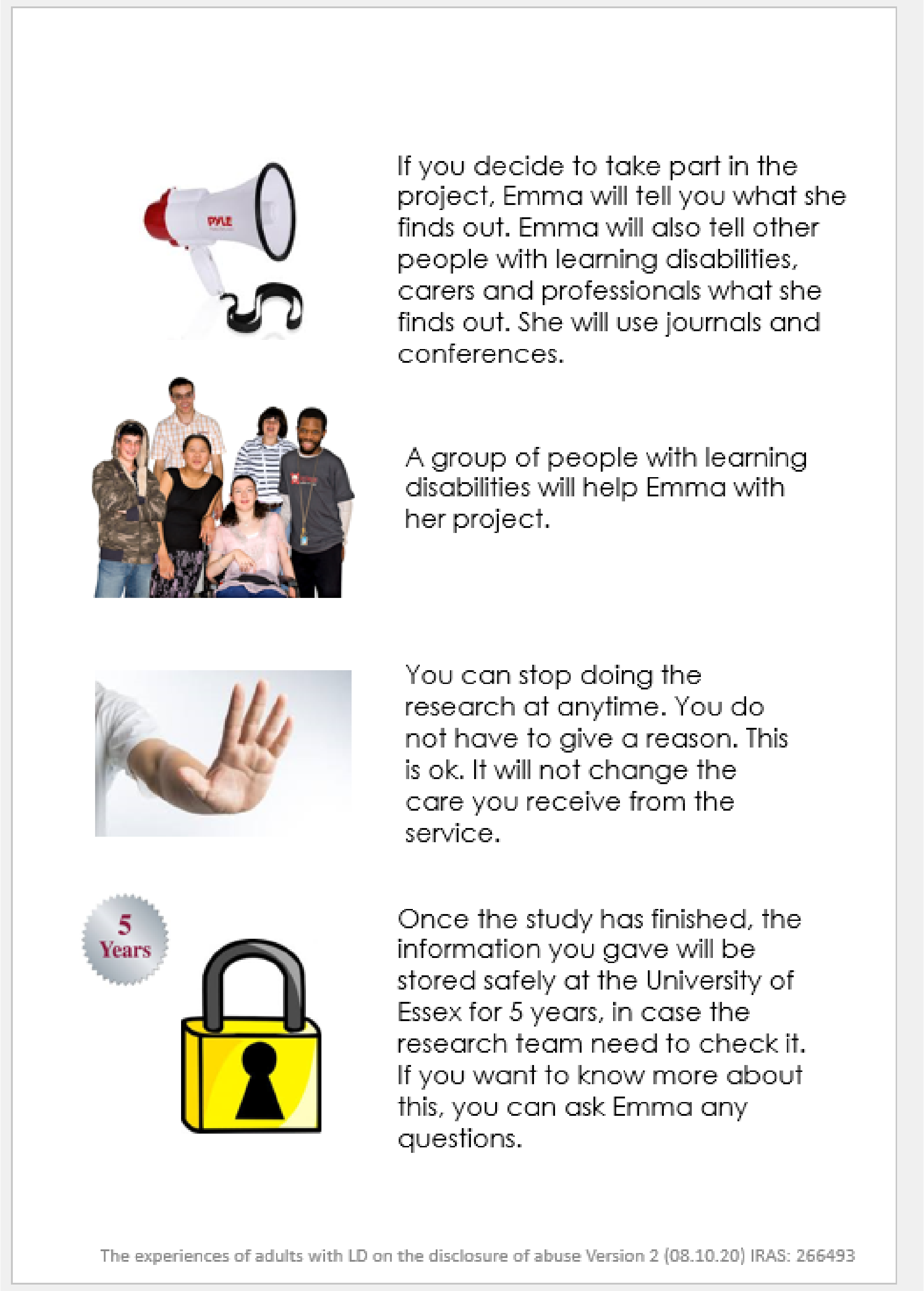
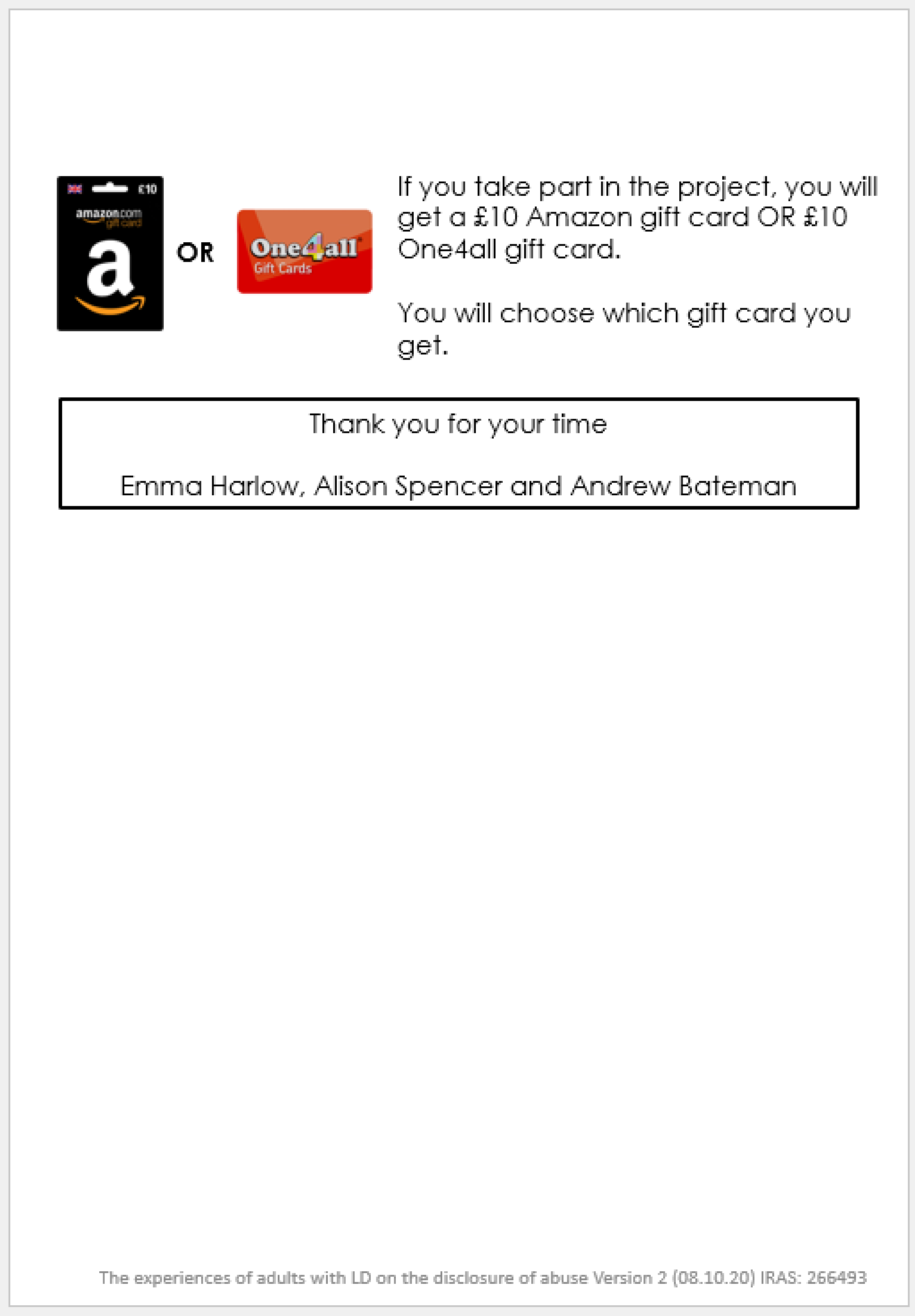


If you decide to take part in the project, Emma will tell you what she finds out. Emma will also tell other people with learning disabilities, carers and professionals what she finds out. She will use journals and conferences.

A group of people with learning disabilities will help Emma with her project.

You can stop doing the research at anytime. You do not have to give a reason. This is ok. It will not change the care you receive from the service.

Once the study has finished, the information you gave will be stored safely at the University of Essex for 5 years, in case the research team need to check it. If you want to know more about this, you can ask Emma any questions.



OR

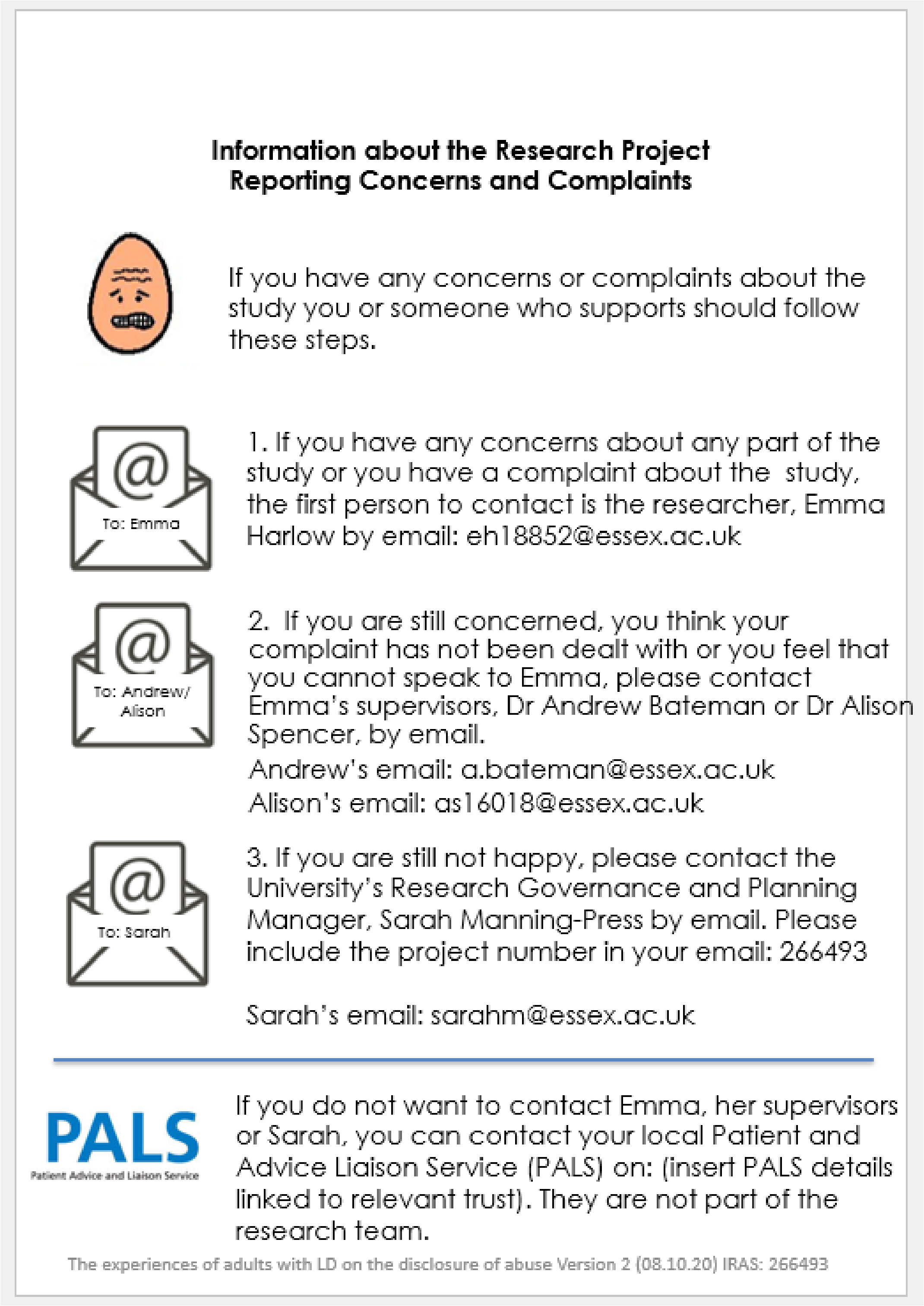
If you take part in the project, you will get a £10 Amazon gift card OR £10 One4all gift card.

You will choose which gift card you get.

Thank you for your time

Emma Harlow, Alison Spencer and Andrew Bateman

The experiences of adults with LD on the disclosure of abuse Version 2 (08.10.20) IRAS: 266493



Information about the Research Project
Reporting Concerns and Complaints

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2. If you are still concerned, you think your complaint has not been dealt with or you feel that you cannot speak to Emma, please contact Emma's supervisors, Dr Andrew Bateman or Dr Alison Spencer, by email.

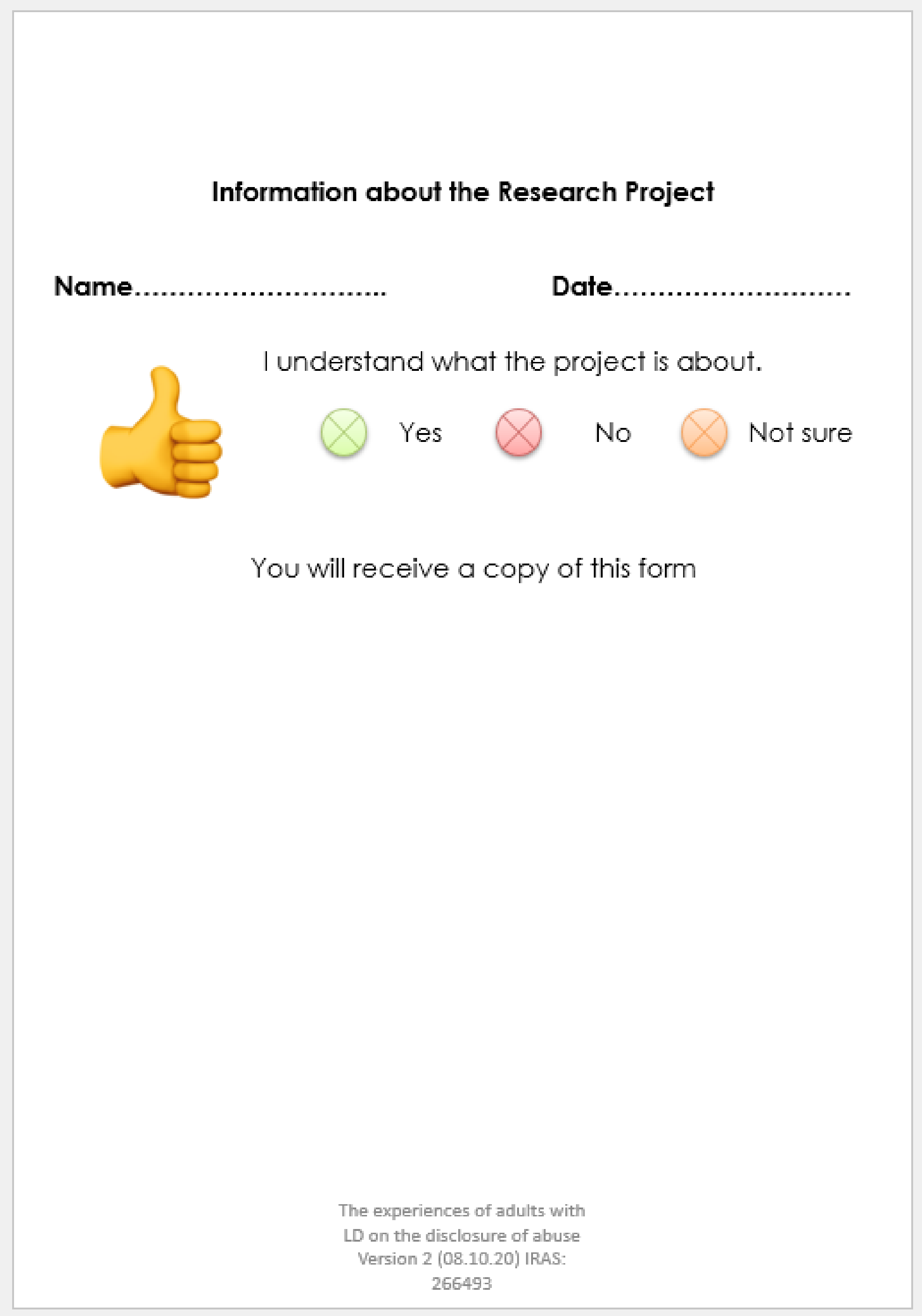
   Andrew's email: a.bateman@essex.ac.uk
   Alison's email: as16018@essex.ac.uk

3. If you are still not happy, please contact the University's Research Governance and Planning Manager, Sarah Manning-Press by email. Please include the project number in your email: 266493

   Sarah's email: sarahm@essex.ac.uk

If you do not want to contact Emma, her supervisors or Sarah, you can contact your local Patient and Advice Liaison Service (PALS) on: (insert PALS details linked to relevant trust). They are not part of the research team.

The experiences of adults with LD on the disclosure of abuse Version 2 (08.10.20) IRAS: 266493



Information about the Research Project

Name............................ **Date**..........................

I understand what the project is about.

⊗ Yes ⊗ No ⊗ Not sure

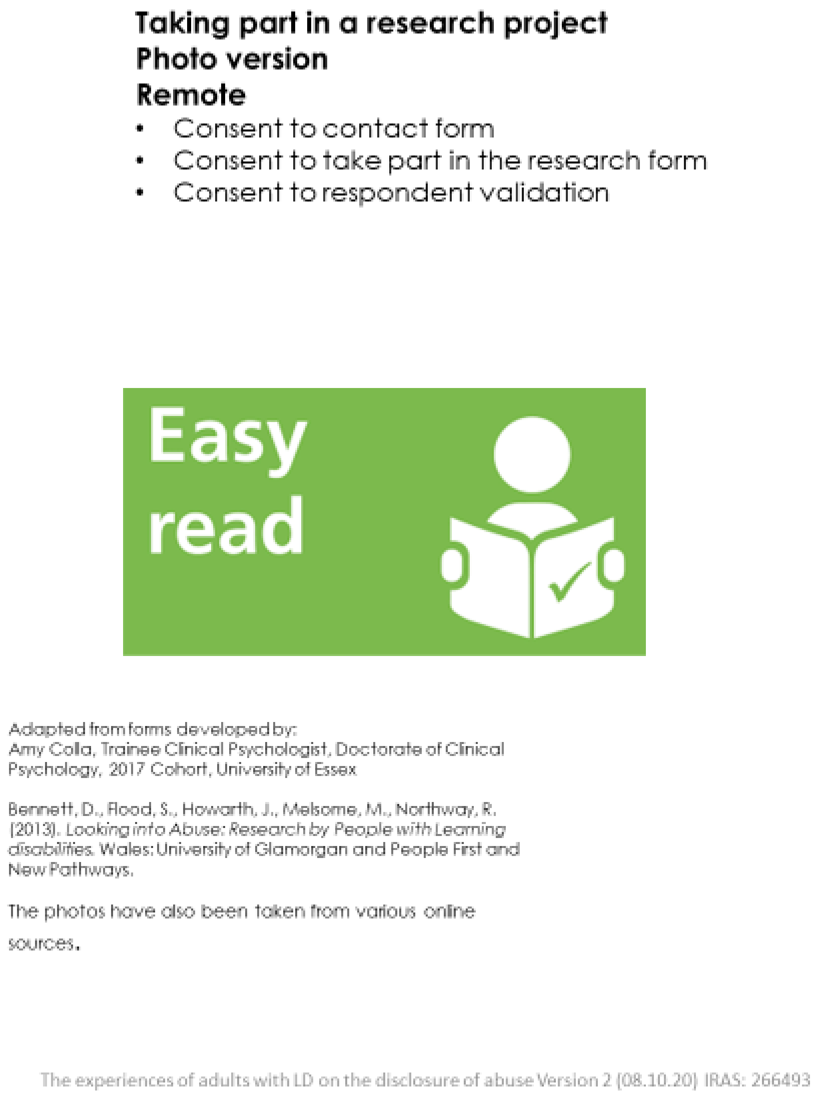
You will receive a copy of this form

The experiences of adults with
LD on the disclosure of abuse
Version 2 (08.10.20) IRAS:
266493

Appendix G

Participant consent to contact and take part forms

Photo (remote)



Taking part in a research project
Photo version
Remote

- Consent to contact form
- Consent to take part in the research form
- Consent to respondent validation

Easy read

Adapted from forms developed by:
Amy Colla, Trainee Clinical Psychologist, Doctorate of Clinical Psychology, 2017 Cohort, University of Essex

Bennett, D., Flood, S., Howarth, J., Melsome, M., Northway, R. (2013). *Looking into Abuse: Research by People with Learning disabilities.* Wales: University of Glamorgan and People First and New Pathways.

The photos have also been taken from various online sources.

The experiences of adults with LD on the disclosure of abuse Version 2 (08.10.20) IRAS: 266493

Consent to contact form

Name:...........................
Date:............................

Important

This form asks for your permission for some things

You do not have to say yes.
It is OK to say no.

It is OK to say you are not sure.

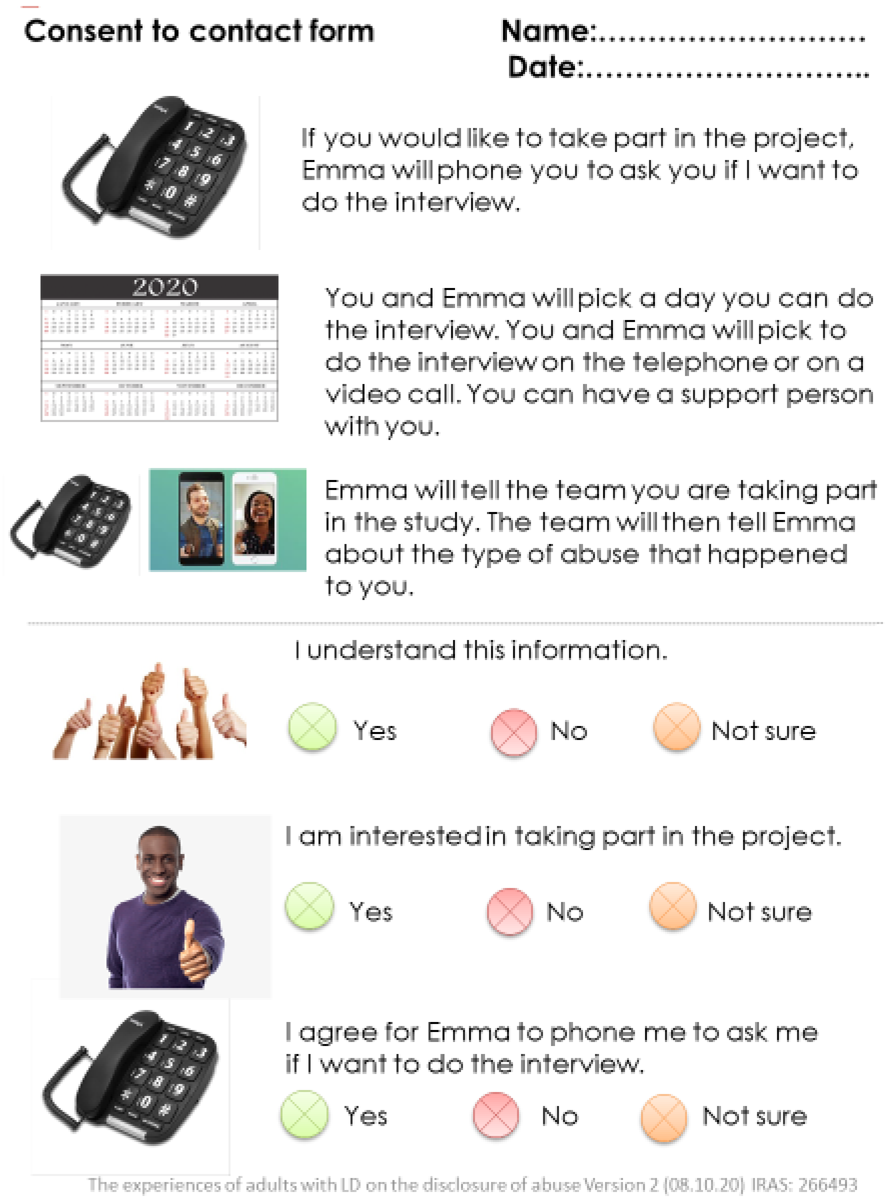
It is OK to ask for time to think about it.

Your treatment will be the same if you say yes or no.

I understand this information.

○ Yes ○ No ○ Not sure

The experiences of adults with LD on the disclosure of abuse Version 2 (08.10.20) IRAS: 266493



Consent to contact form

Name:............................
Date:............................

If you would like to take part in the project, Emma will phone you to ask you if I want to do the interview.

You and Emma will pick a day you can do the interview. You and Emma will pick to do the interview on the telephone or on a video call. You can have a support person with you.

Emma will tell the team you are taking part in the study. The team will then tell Emma about the type of abuse that happened to you.

I understand this information.

⊗ Yes ⊗ No ⊗ Not sure

I am interested in taking part in the project.

⊗ Yes ⊗ No ⊗ Not sure

I agree for Emma to phone me to ask me if I want to do the interview.

⊗ Yes ⊗ No ⊗ Not sure

The experiences of adults with LD on the disclosure of abuse Version 2 (08.10.20) IRAS: 266493

Consent to contact form

Name:……………………….
Date:………………………..

I agree for the team to tell Emma about the type of abuse that happened to me.

⊗ Yes ⊗ No ⊗ Not sure

Name:…………………………………..
My phone number:……………………………………………………..
Emma will call you on this phone number

Sign:……………………………………….. Date:……………………

You will receive a copy of this form

The experiences of adults with
LD on the disclosure of abuse
Version 2 (08.10.20) IRAS:
266493

Consent to take part form

Name:………………………
Date:………………………..

Important

This form asks for your permission for some things

You do not have to say yes.
It is OK to say no.

It is OK to say you are not sure.

It is OK to ask for time to think about it.

NHS

Your treatment will be the same if you say yes or no.

I understand this information.

○ Yes ○ No ○ Not sure

The experiences of adults
with LD on the disclosure
of abuse Version 2
(08.10.20) IRAS: 266493

Consent to take part form

Name:……………………….

Date:………………………..

I understand what the project is about.

○ Yes ○ No ○ Not sure

I agree to be interviewed by Emma.

○ Yes ○ No ○ Not sure

I agree for the interview to be recorded (changed from what I say recorded)

○ Yes ○ No ○ Not sure

Emma will listen to recording again and write down all the information from it. Emma will then delete the recording.

If we do a video call, Emma will also delete the video.

Consent to take part form **Name:............................**
Date:............................

I understand that all the information I give will be kept safe and private. Emma, Andrew and Alison will not share it with anyone else.

○ Yes ○ No ○ Not sure

MY NAME
✖

I agree that anything I say can be used in the report. My name will not be used.

○ Yes ○ No ○ Not sure

Emma will use a secret name for me. This means no one will know I said anything. It is like wearing a disguise. I can pick my own secret name.

My secret name is:

____

○ Not sure ○ Emma can choose

Consent to take part form **Name:............................**
Date:............................

(Complete as applicable)

If I agreed for the team to tell Emma about the abuse that happened to me, I understand Emma now knows this information.

⊗ Yes ⊗ No ⊗ Not sure

If I did not agree for the team to tell Emma about the abuse that happened to me, I understand Emma does not know this information.

⊗ Yes ⊗ No ⊗ Not sure

Sign:... Date...........................

You will receive a copy of this form

Consent to Respondent Validation

Name:……………………..
Date:………………………..

When Emma is writing her report she will look at all the information that people who took part in the study told her.

She will work out what information is important and interesting to tell other people about. Emma would like to check with some of the people who took part in her study that they think this is important and interesting information too.

If you want to do this with Emma, she will send you the information in the post or by email, then call you on the telephone/video call to talk about it.

Emma will tell the team she has contacted you.

I understand this information.

⊗ Yes ⊗ No ⊗ Not sure

I am interested in checking the information with Emma

⊗ Yes ⊗ No ⊗ Not sure

The experiences of adults with LD on the disclosure of abuse
Version 2 (08.10.20) IRAS: 266493

Consent to Respondent Validation

Name:……………………..
Date:………………………..

I agree for Emma to phone me to arrange a time to check the information with me, after the interview.

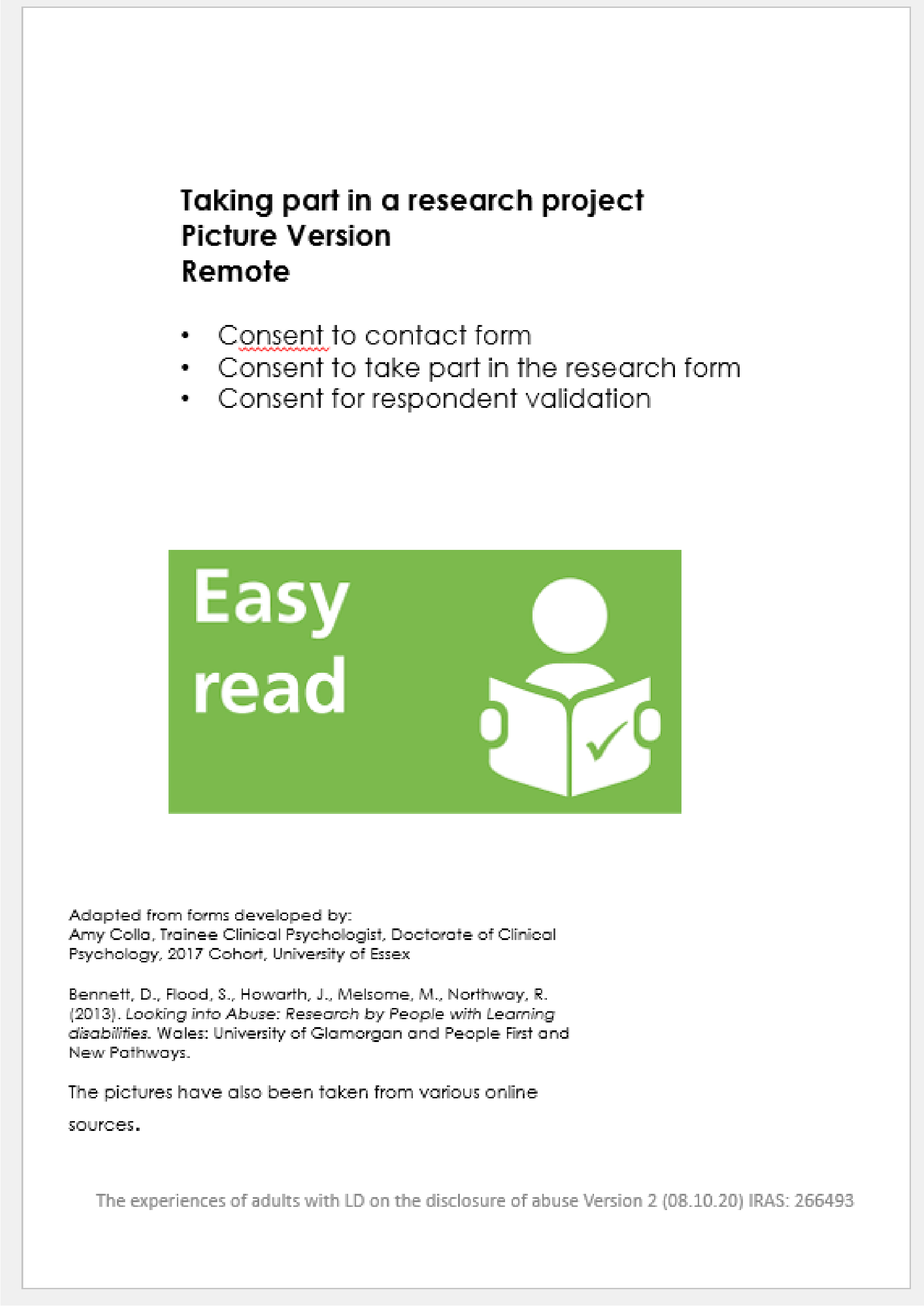
⊗ Yes ⊗ No ⊗ Not sure

Sign:………………………………………… Date………………………..

You will receive a copy of this form

The experiences of adults with LD on the disclosure of abuse Version 2 (08.10.20) IRAS: 266493

Picture (remote)



Taking part in a research project
Picture Version
Remote

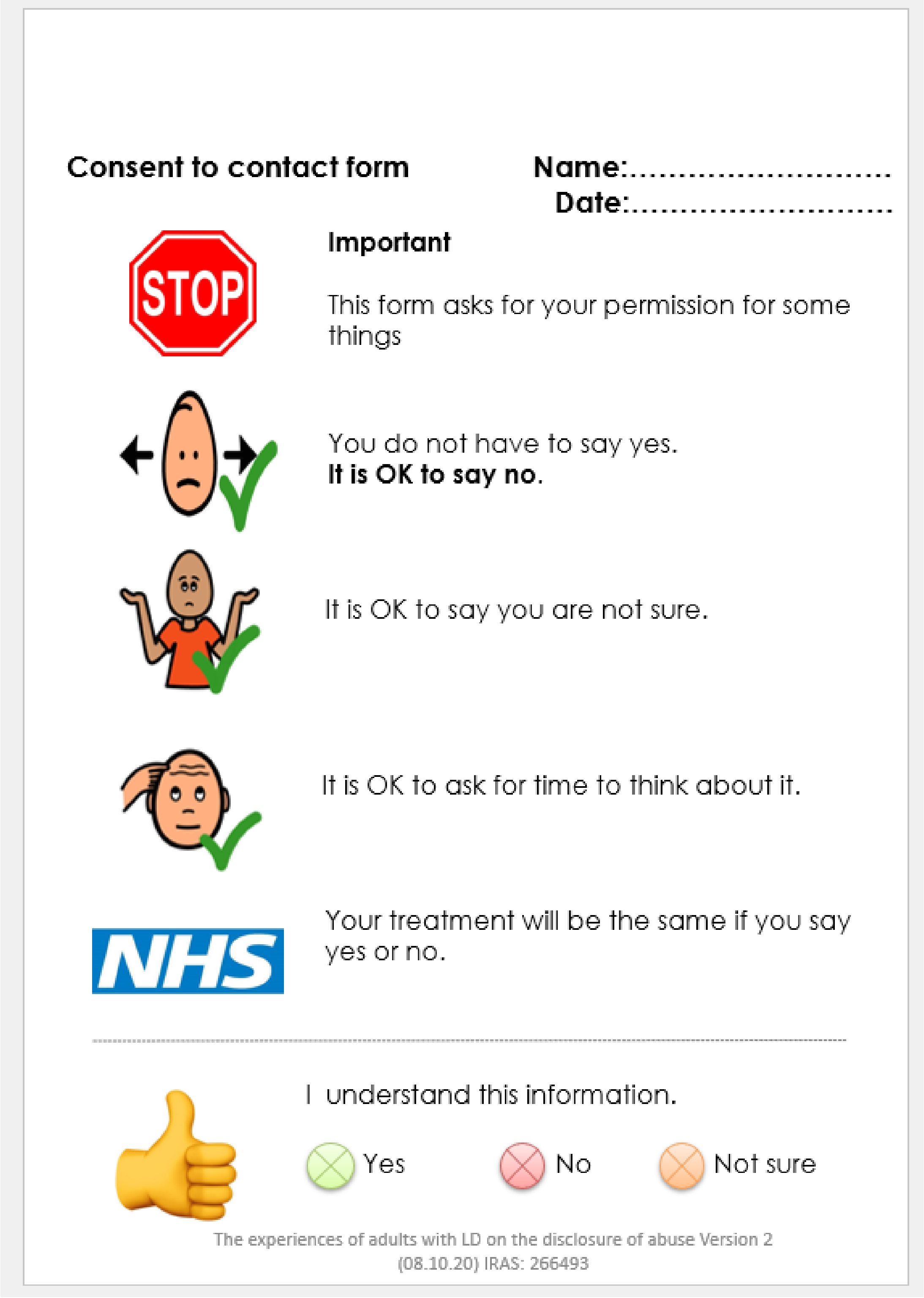
- Consent to contact form
- Consent to take part in the research form
- Consent for respondent validation

Adapted from forms developed by:
Amy Colla, Trainee Clinical Psychologist, Doctorate of Clinical Psychology, 2017 Cohort, University of Essex

Bennett, D., Flood, S., Howarth, J., Melsome, M., Northway, R. (2013). *Looking into Abuse: Research by People with Learning disabilities.* Wales: University of Glamorgan and People First and New Pathways.

The pictures have also been taken from various online sources.

The experiences of adults with LD on the disclosure of abuse Version 2 (08.10.20) IRAS: 266493



Consent to contact form

Name:..........................
Date:..........................

Important

This form asks for your permission for some things

You do not have to say yes.
It is OK to say no.

It is OK to say you are not sure.

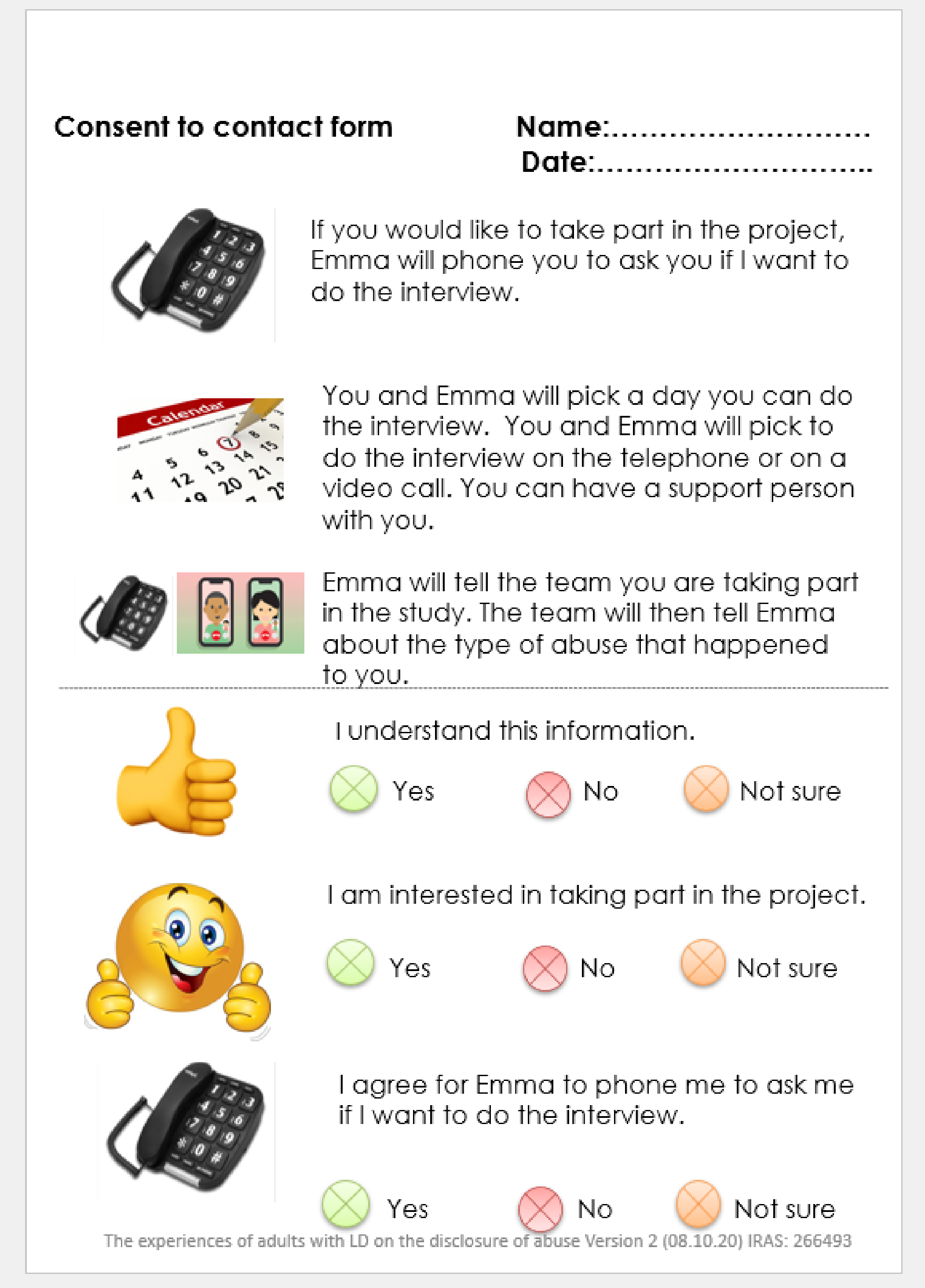
It is OK to ask for time to think about it.

Your treatment will be the same if you say yes or no.

I understand this information.

⊗ Yes ⊗ No ⊗ Not sure

The experiences of adults with LD on the disclosure of abuse Version 2 (08.10.20) IRAS: 266493



Consent to contact form

Name:..........................

Date:............................

If you would like to take part in the project, Emma will phone you to ask you if I want to do the interview.

You and Emma will pick a day you can do the interview. You and Emma will pick to do the interview on the telephone or on a video call. You can have a support person with you.

Emma will tell the team you are taking part in the study. The team will then tell Emma about the type of abuse that happened to you.

I understand this information.

⊗ Yes ⊗ No ⊗ Not sure

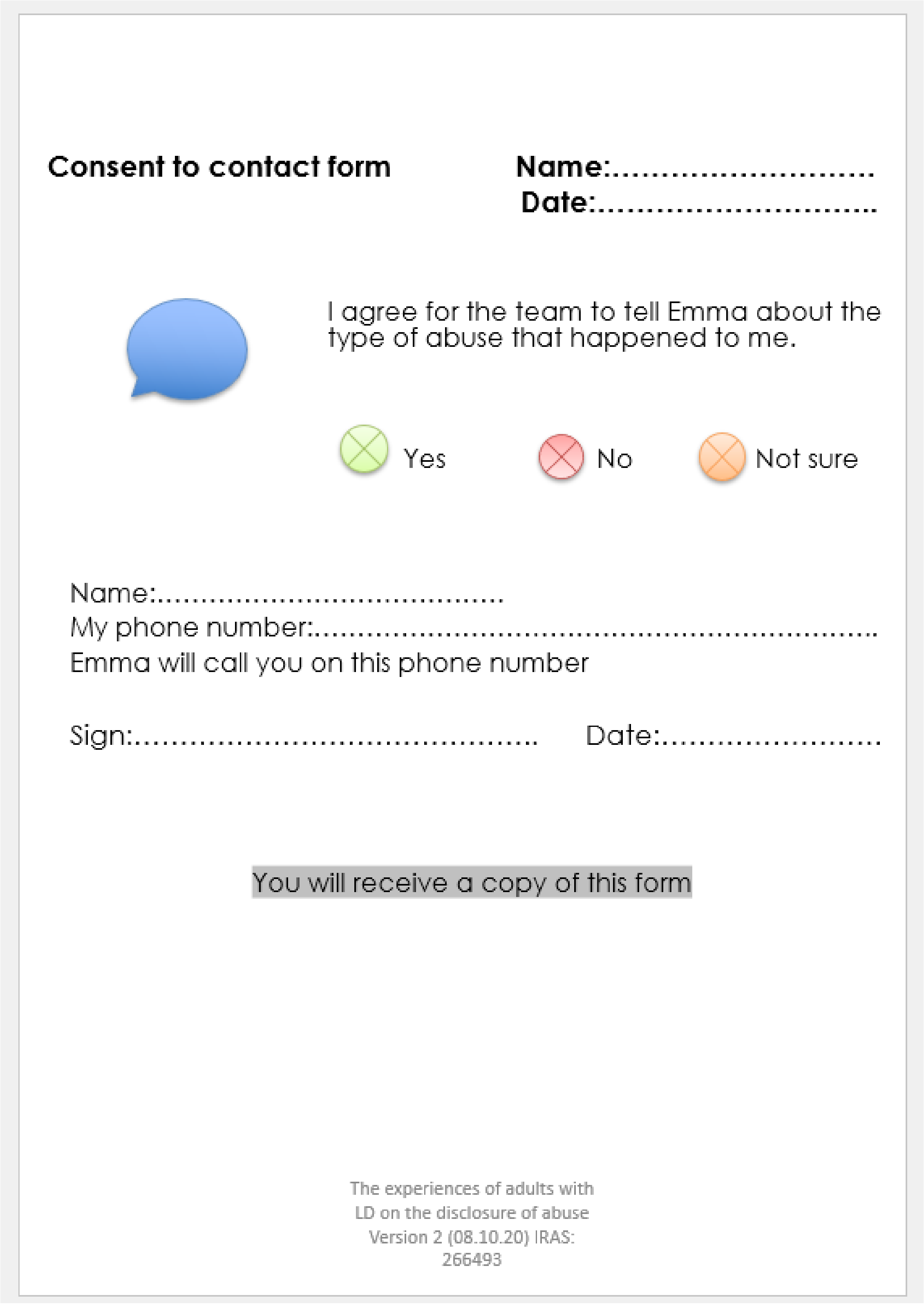
I am interested in taking part in the project.

⊗ Yes ⊗ No ⊗ Not sure

I agree for Emma to phone me to ask me if I want to do the interview.

⊗ Yes ⊗ No ⊗ Not sure

The experiences of adults with LD on the disclosure of abuse Version 2 (08.10.20) IRAS: 266493



Consent to contact form

Name:..........................
Date:............................

I agree for the team to tell Emma about the type of abuse that happened to me.

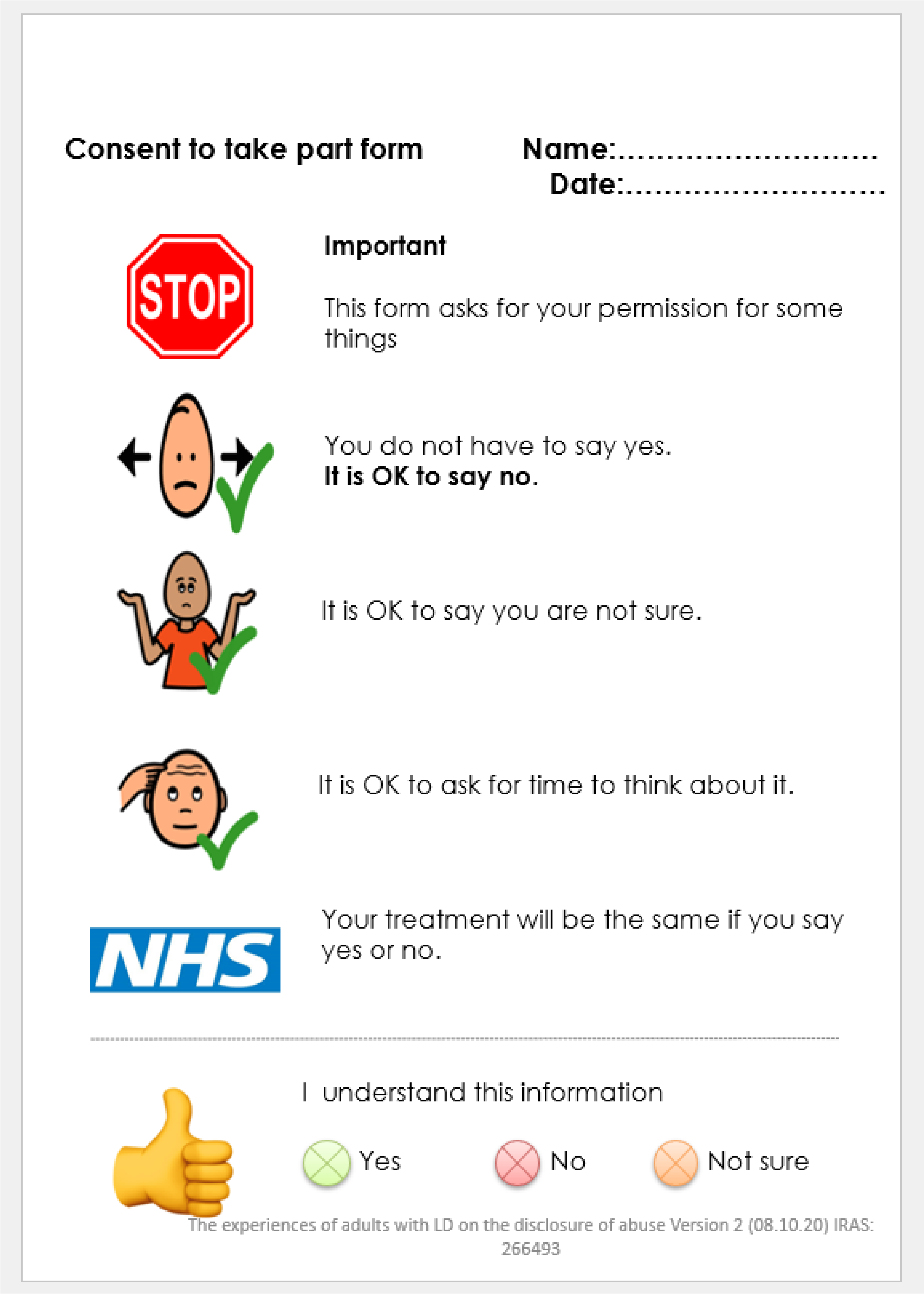
☒ Yes ☒ No ☒ Not sure

Name:......................................
My phone number:...
Emma will call you on this phone number

Sign:... Date:.......................

You will receive a copy of this form

The experiences of adults with
LD on the disclosure of abuse
Version 2 (08.10.20) IRAS:
266493



Consent to take part form

Name:...........................
Date:...........................

Important

This form asks for your permission for some things

You do not have to say yes.
It is OK to say no.

It is OK to say you are not sure.

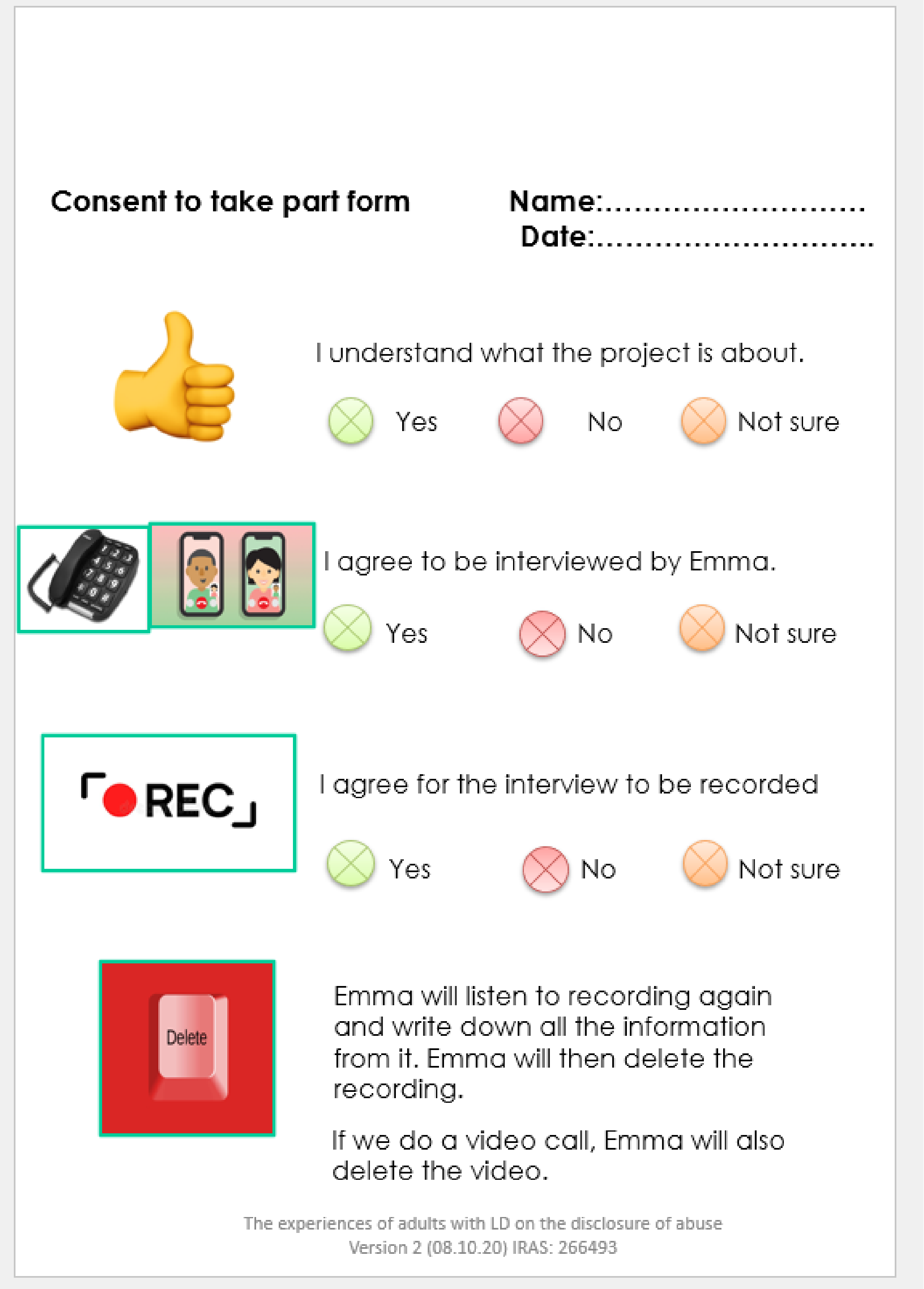
It is OK to ask for time to think about it.

Your treatment will be the same if you say yes or no.

I understand this information

⊗ Yes ⊗ No ⊗ Not sure

The experiences of adults with LD on the disclosure of abuse Version 2 (08.10.20) IRAS: 266493



Consent to take part form

Name:……………………….

Date:………………………..

I understand what the project is about.

○ Yes ○ No ○ Not sure

I agree to be interviewed by Emma.

○ Yes ○ No ○ Not sure

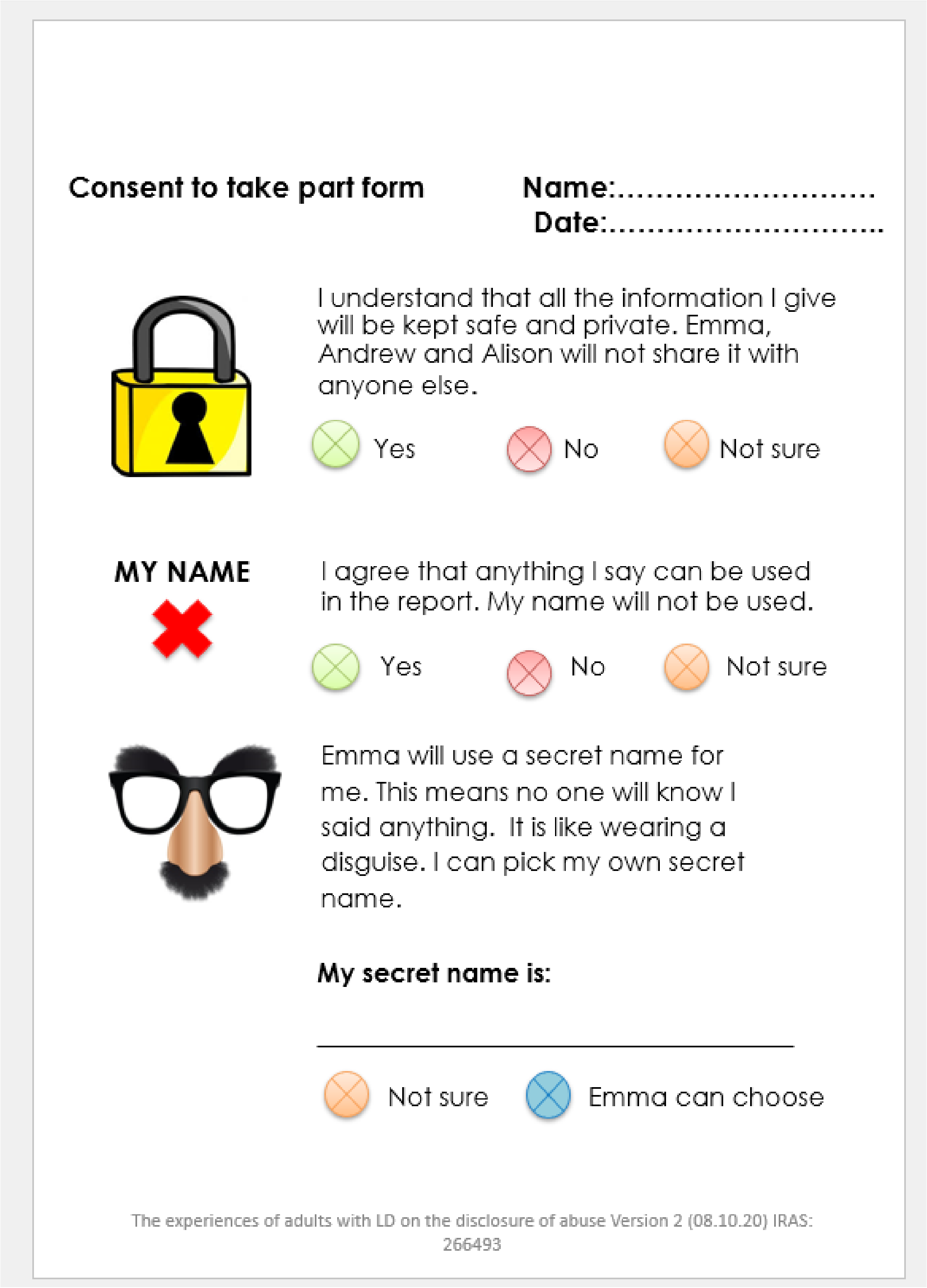
I agree for the interview to be recorded

○ Yes ○ No ○ Not sure

Emma will listen to recording again and write down all the information from it. Emma will then delete the recording.

If we do a video call, Emma will also delete the video.

The experiences of adults with LD on the disclosure of abuse
Version 2 (08.10.20) IRAS: 266493



Consent to take part form **Name:……………………….**
Date:………………………..

I understand that all the information I give will be kept safe and private. Emma, Andrew and Alison will not share it with anyone else.

○ Yes ○ No ○ Not sure

MY NAME

I agree that anything I say can be used in the report. My name will not be used.

○ Yes ○ No ○ Not sure

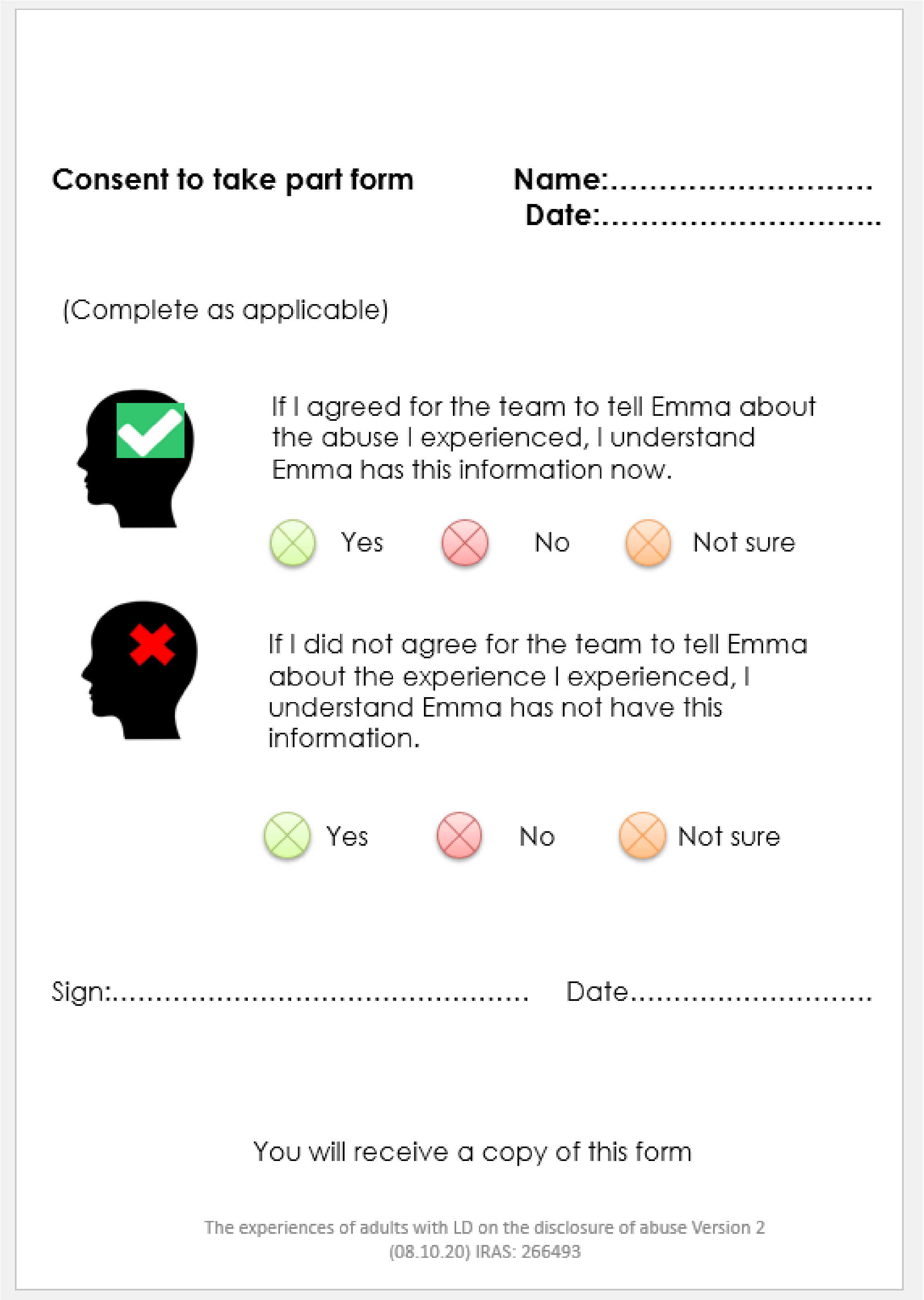
Emma will use a secret name for me. This means no one will know I said anything. It is like wearing a disguise. I can pick my own secret name.

My secret name is:

____

○ Not sure ○ Emma can choose

The experiences of adults with LD on the disclosure of abuse Version 2 (08.10.20) IRAS: 266493



Consent to take part form

Name:..........................
Date:............................

(Complete as applicable)

If I agreed for the team to tell Emma about the abuse I experienced, I understand Emma has this information now.

⊗ Yes ⊗ No ⊗ Not sure

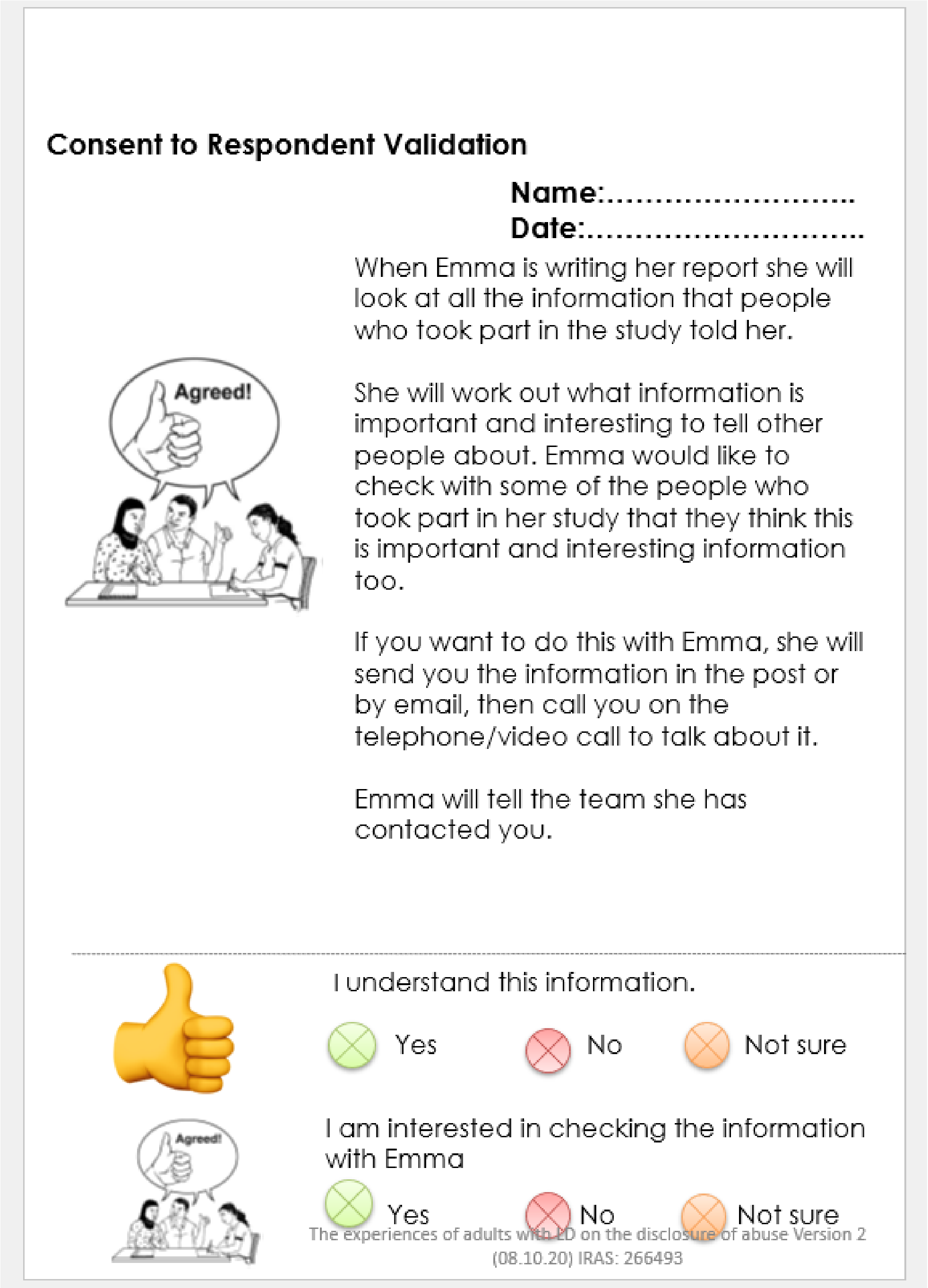
If I did not agree for the team to tell Emma about the experience I experienced, I understand Emma has not have this information.

⊗ Yes ⊗ No ⊗ Not sure

Sign:.. Date...........................

You will receive a copy of this form

The experiences of adults with LD on the disclosure of abuse Version 2
(08.10.20) IRAS: 266493



Consent to Respondent Validation

Name:……………………..
Date:………………………..

When Emma is writing her report she will look at all the information that people who took part in the study told her.

She will work out what information is important and interesting to tell other people about. Emma would like to check with some of the people who took part in her study that they think this is important and interesting information too.

If you want to do this with Emma, she will send you the information in the post or by email, then call you on the telephone/video call to talk about it.

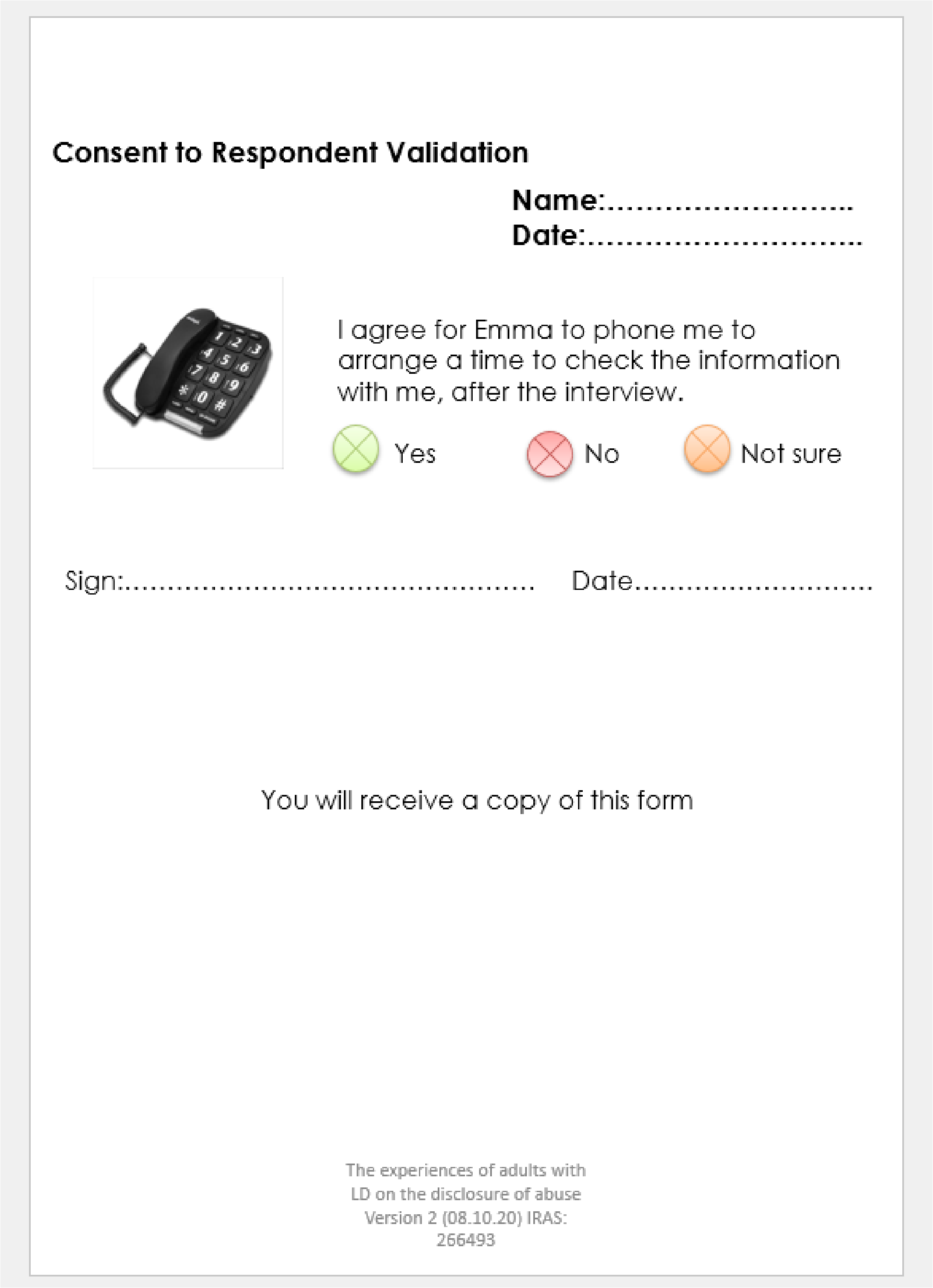
Emma will tell the team she has contacted you.

I understand this information.

⊗ Yes ⊗ No ⊗ Not sure

I am interested in checking the information with Emma

⊗ Yes ⊗ No ⊗ Not sure



Consent to Respondent Validation

Name:……………………..
Date:………………………..

I agree for Emma to phone me to arrange a time to check the information with me, after the interview.

⊗ Yes ⊗ No ⊗ Not sure

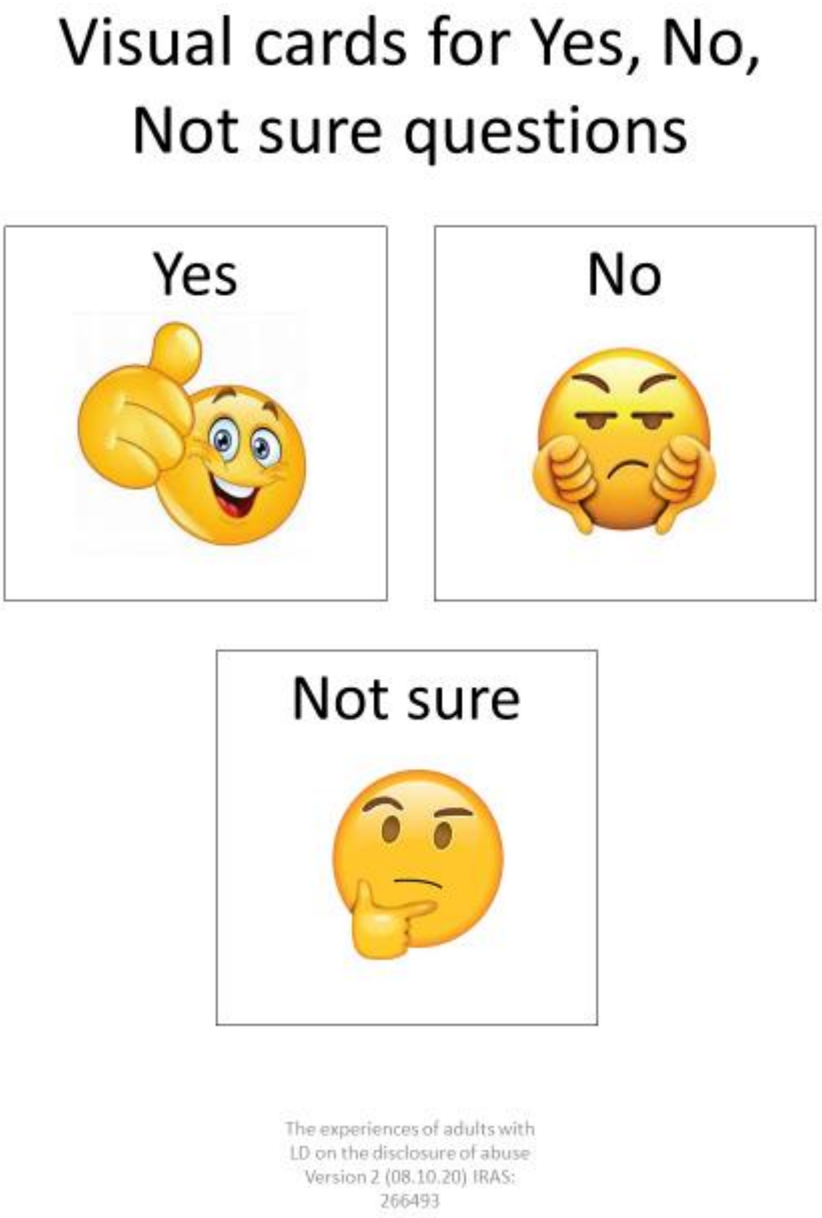
Sign:…………………………………………. Date………………………

You will receive a copy of this form

The experiences of adults with
LD on the disclosure of abuse
Version 2 (08.10.20) IRAS:
266493

Appendix H

Visual aids to answer the questions on PIS and consent forms if required



Visual cards for Yes, No, Not sure questions

Yes

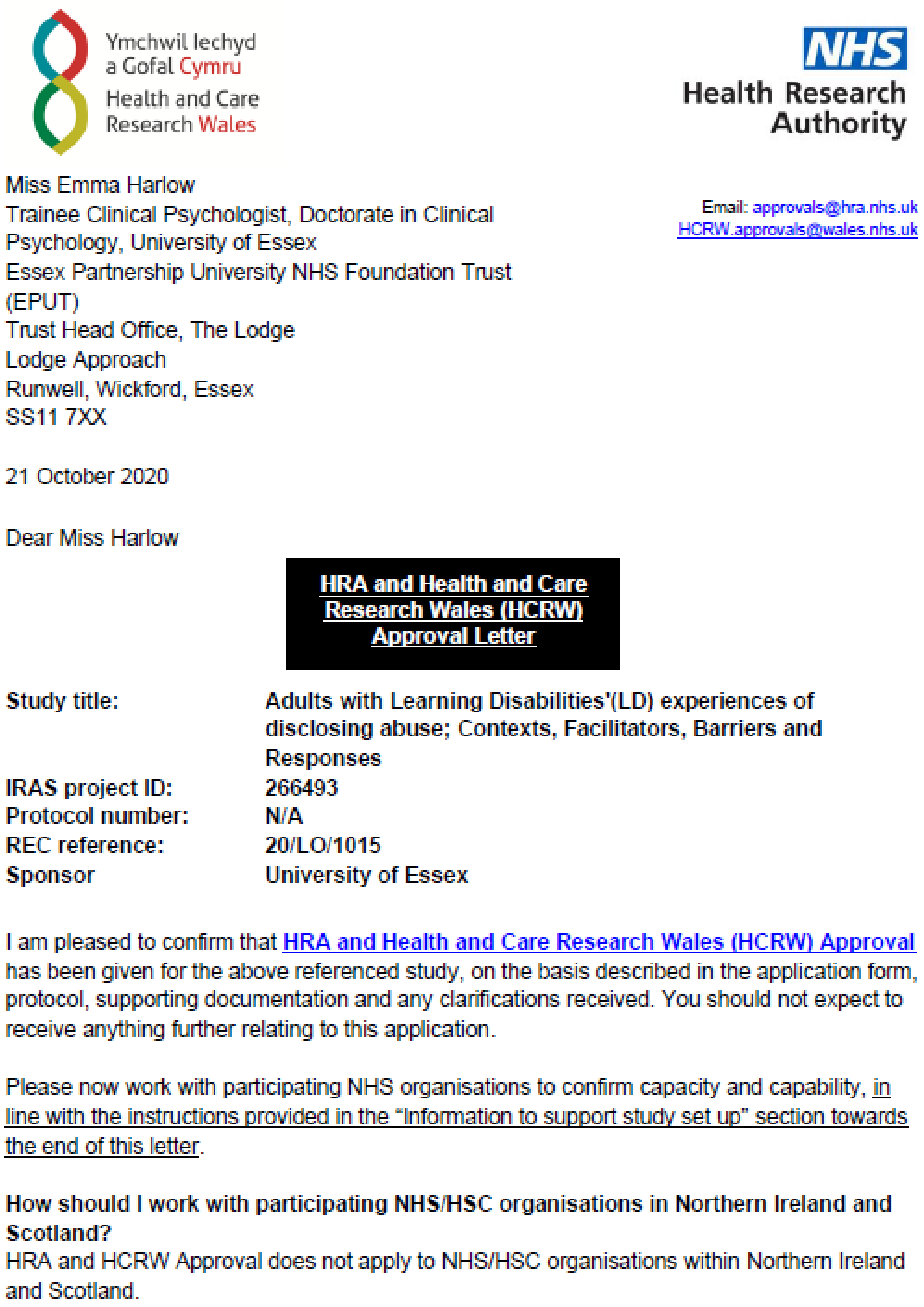
No

Not sure

The experiences of adults with LD on the disclosure of abuse Version 2 (08.10.20) IRAS: 266493

Appendix I

HRA Approval



Ymchwil Iechyd
a Gofal Cymru
Health and Care
Research Wales

NHS
Health Research
Authority

Email: approvals@hra.nhs.uk
HCRW.approvals@wales.nhs.uk

Miss Emma Harlow
Trainee Clinical Psychologist, Doctorate in Clinical Psychology, University of Essex
Essex Partnership University NHS Foundation Trust (EPUT)
Trust Head Office, The Lodge
Lodge Approach
Runwell, Wickford, Essex
SS11 7XX

21 October 2020

Dear Miss Harlow

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

Study title:	**Adults with Learning Disabilities'(LD) experiences of disclosing abuse; Contexts, Facilitators, Barriers and Responses**
IRAS project ID:	**266493**
Protocol number:	**N/A**
REC reference:	**20/LO/1015**
Sponsor	**University of Essex**

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 **266493**. Please quote this on all correspondence.

Yours sincerely,
Christie Ord

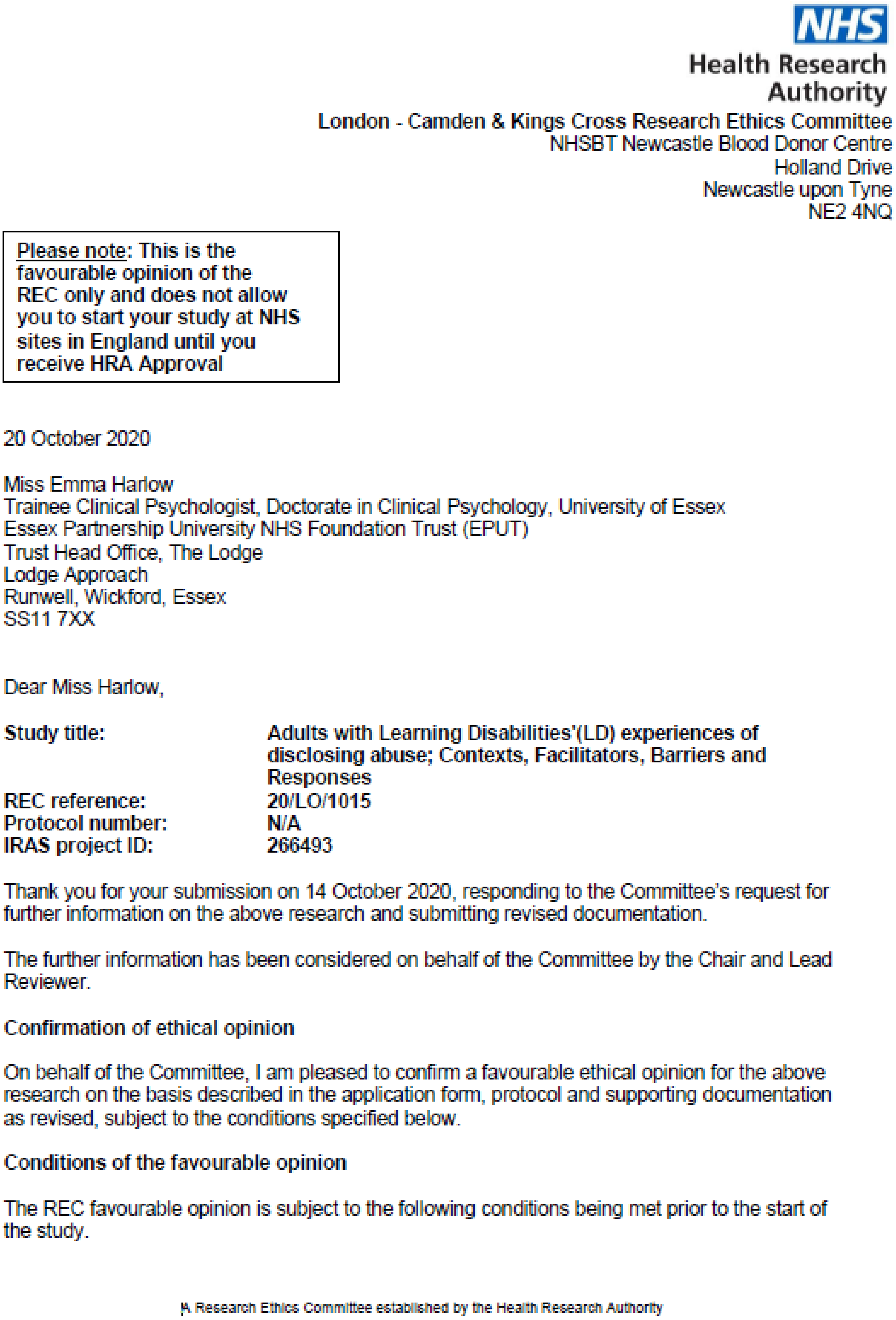
Approvals Specialist

Email: **INSERT for nation of sender** approvals@hra.nhs.uk
HCRW.approvals@wales.nhs.uk

Copy to: *Ms Sarah Manning-Press*

Appendix J

REC approval



Health Research Authority
London - Camden & Kings Cross Research Ethics Committee
NHSBT Newcastle Blood Donor Centre
Holland Drive
Newcastle upon Tyne
NE2 4NQ

Please note: This is the favourable opinion of the REC only and does not allow you to start your study at NHS sites in England until you receive HRA Approval

20 October 2020

Miss Emma Harlow
Trainee Clinical Psychologist, Doctorate in Clinical Psychology, University of Essex
Essex Partnership University NHS Foundation Trust (EPUT)
Trust Head Office, The Lodge
Lodge Approach
Runwell, Wickford, Essex
SS11 7XX

Dear Miss Harlow,

Study title:	**Adults with Learning Disabilities'(LD) experiences of disclosing abuse; Contexts, Facilitators, Barriers and Responses**
REC reference:	**20/LO/1015**
Protocol number:	**N/A**
IRAS project ID:	**266493**

Thank you for your submission on 14 October 2020, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair and Lead Reviewer.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Conditions of the favourable opinion

The REC favourable opinion is subject to the following conditions being met prior to the start of the study.

Confirmation of Capacity and Capability (in England, Northern Ireland and Wales) or NHS management permission (in Scotland) should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).

Guidance on applying for HRA and HCRW Approval (England and Wales)/ NHS permission for research is available in the Integrated Research Application System.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of management permissions from host organisations

Registration of Clinical Trials

It is a condition of the REC favourable opinion that **all clinical trials are registered** on a publicly accessible database. For this purpose, 'clinical trials' are defined as the first four project categories in IRAS project filter question 2. Registration is a legal requirement for clinical trials of investigational medicinal products (CTIMPs), except for phase I trials in healthy volunteers (these must still register as a condition of the REC favourable opinion).

Registration should take place as early as possible and within six weeks of recruiting the first research participant at the latest. Failure to register is a breach of these approval conditions, unless a deferral has been agreed by or on behalf of the Research Ethics Committee (see here for more information on requesting a deferral: https://www.hra.nhs.uk/planning-and-improving-research/research-planning/research-registration-research-project-identifiers/

As set out in the UK Policy Framework, research sponsors are responsible for making information about research publicly available before it starts e.g. by registering the research project on a publicly accessible register. Further guidance on registration is available at: https://www.hra.nhs.uk/planning-and-improving-research/research-planning/transparency-responsibilities/

You should notify the REC of the registration details. We will audit these as part of the annual progress reporting process.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

After ethical review: Reporting requirements

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study, including early termination of the study
- Final report

Summary CV for Chief Investigator (CI) [Summary CV]	V1	21 July 2020
Summary CV for supervisor (student research) [Summary CV- 1st Supervisor]	V1	21 July 2020
Summary CV for supervisor (student research) [Summary CV- 2nd Supervisor]	V1	21 July 2020

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/

HRA Learning

We are pleased to welcome researchers and research staff to our HRA Learning Events and online learning opportunities– see details at: https://www.hra.nhs.uk/planning-and-improving-research/learning/

IRAS project ID: 266493 Please quote this number on all correspondence

With the Committee's best wishes for the success of this project.

Yours sincerely,

Katie Arnold
Approvals Officer
P.P
Mrs Rosie Glazebrook
Chair

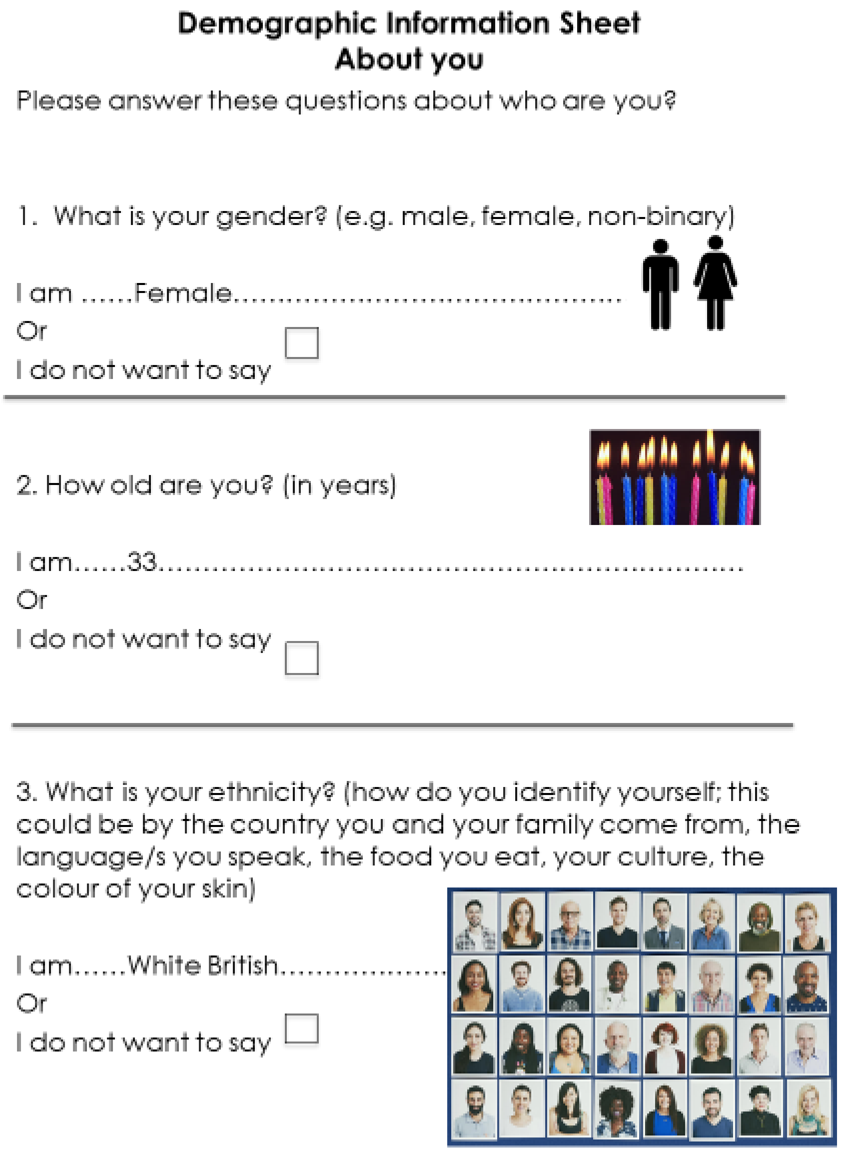
Email: CamdenandKingsCross.REC@hra.nhs.uk

Enclosures: "After ethical review – guidance for researchers"

Copy to: Ms Sarah Manning-Press

Appendix K

Demographic Information Sheet



Demographic Information Sheet
About you

Please answer these questions about who are you?

1. What is your gender? (e.g. male, female, non-binary)

I am ......Female..
Or
I do not want to say ☐

2. How old are you? (in years)

I am......33..
Or
I do not want to say ☐

3. What is your ethnicity? (how do you identify yourself; this could be by the country you and your family come from, the language/s you speak, the food you eat, your culture, the colour of your skin)

I am......White British....................
Or
I do not want to say ☐

Appendix L

Interview Schedule- Remote

Adults with Learning Disabilities' (LD) experiences of disclosing abuse; Contexts, Facilitators, Barriers and Responses

INSTRUCTION:

Both the CI and the participant will have copies of the study information sheet, consent form, demographic information sheet and the visual aids for the interview.

Once the CI and participant have introduced themselves, the CI will ask the participant if they are happy for the recording to begin. ‘I will now start recording *(Start recording)*. Are you happy to be recorded? *(If the participant declines to be recorded, stop recording, and explore the participant’s reasons why they wish to do so. If they still do not want to be recorded terminate the interview)*

THEN COMPLETE THE CONSENT FORM AND DEMOGRAPHIC INFORMATION SHEET

Prompt participants to the relevant communication aids throughout (if appropriate)

- Prior to commencing the interview, the CI will read and discuss the information sheet together, to ensure the participant has understood what the research is about.
- Throughout the interview to establish respondent validation the CI will summarise to clients what they have said, and ask; have I understood you correctly? is this what you meant?
- The term abuse may be tailored to each participant e.g. abuse, really bad things that have happened to you/or their own term.
- Prompt cards for each question will be used (see Appendix C in document).
- This interview has been developed using the interview conducted in the study by Bennett, Flood, Howarth, Melsome and Northway (2013)- Looking into Abuse: Research by People with Learning Disabilities, and resources on abuse from the Mencap website and East Riding Safeguarding Board’s Easy-Read guide to understanding and reporting abuse. The photos have also been taken from various online sources.

Introduction (To facilitate engagement and build rapport with the participant)

Now we have read the information sheet together and we have completed the consent form, and the demographic sheet, we will start the interview.

We are going to do the interview for 45 to 60 minutes (or state time e.g. 12:00-13:00) you can stop the interview any time or chose not to answer a question. You do not have to give a reason. This is ok. It will not change the care you get from the service. How would you like to tell me you do not want to answer a question or stop the interview? (Also offer the stop card- if via video call-see appendix A, you can also show me the stop card at any time you do not want to answer a question or stop the interview)

As you are taking part in the study I know you have lived through/experienced abuse (/ some really bad things have happened to you). The team/(name of staff member) have told me what types of abuse/bad things that have happened to you. I will not ask any more questions about the abuse (/really bad thing/s) that have happened to you. Today I am going to be asking you questions about the **first** time you told someone you had been abused (/about the really bad thing/s that happened to you), and the help you got. Anything you tell me I will keep safe and private. But if you tell me that you or someone else is being hurt. I will talk with you about who I need to tell.

I will do a report on what I find out from the study. I will use what you have said in the report. However, I will not use your name. This means no one will know that you said anything. Its ok to take your time to answer the questions. Don’t worry if you cannot answer some questions. I just want you to say what you think, there is no right or wrong answer.

1. Abuse definition (To orientate the participant to the definitions of abuse used by the study, and the study's focus on disclosure)

The team/(name of staff member) have told me what types of abuse/bad things that have happened to you. I have some cards which explain the different types of abuse/the bad things that happened to you. The team/(name of staff member) told me you experienced X abuse.

Abuse (/it) can be when someone hurts you or treats you badly or when someone does or says things to make you upset or frightened. Abuse (/really bad things) can happen anywhere; at school, at home, in hospital or out in the community.

I would like you to look at the card with the picture of [describe picture] and the title [type of abuse].The CI read out description, see Appendix B in document. Check with the participant this is their understanding of what happened to them too. Then add, Abuse (/really bad things) can happen to anyone, Abuse (/bad things happening to someone) is always wrong, and it is not your fault.

*If participants talk about the abuse they experienced in detail, acknowledge this and respectfully remind participants you do not need to know about the details of the abuse.

2. Disclosure Experiences

Now, I will ask you questions about the **first** time you told someone you had been abused (/about the really bad thing/s that happened to you).

a) **Who** was the **first** person you told that you had been abused (or the participant's own term)?

Prompts: friend, [family member; mum, dad etc.], [professional; nurse, social worker etc.] did you tell more than one person? e.g. both parents, another professional

b) **Where** did you tell them?

Prompts: at home, at the day centre, at school, at the service building; face to face or over the telephone, or text message or other social media messaging app?

c) After the abuse (or the participant's own term) happened, **how long** did you wait until you told them what had happened?

- Prompts: shortly after, months, years after it happened?

Why did you wait x amount of time?

- Prompts: fear of consequences; personal factors e.g. shame/blame/not believed/anticipated response and contextual factors e.g. something happening to abuser/would you get in trouble/didn't see it as abuse?/lose family? lose independence? didn't know how to explain it?

Was this the first time you had tried to tell someone about the abuse?

d) **Why** did you tell them?
Prompts:

- learnt it was a bad thing to be happening/have happened and shouldn't be happening/have happened? wanted the abuse to stop? felt scared? felt sad? felt angry? media story of abuse? moved away from abuser? abuse had stopped? to help you feel better?
- If the participant's response is 'they asked me' (or similar); when did they ask; an appointment?; did they explain why they asked you; did you seem unhappy?
- If the participant's response is 'they found out'; how did they find out; did someone else tell them?
- If the participant begins to talk about factors related to question e; move to this question

e) **What made it easier** to tell this person/s about the abuse (or term used by participant)? Prompts:

- qualities of the person you told; trustworthy? friendly? supportive? non-judgemental? listened? demographics; age, gender, ethnicity, culture? (participant's and person/s they disclosed to) social norms? religion?
- contextual factors; felt safe? the abuse had stopped? other people were being abused by them; needed to protect them? other people were at risk e.g. children, siblings? did they make sure it was private (e.g. in a room where no one else could hear us)? lots of time to talk? would believe you? would they help you?

f) **What made it harder** to tell this person/s about the abuse (or participant's own term)? Prompts:

- qualities of the person you told; untrustworthy? unfriendly? unsupportive? judgemental? did not listen? demographics; age, gender, ethnicity, culture? (participant's and person/s they disclosed to), social norms? religion?
- contextual factors; felt unsafe? the abuse was still happening? threatened by the abuser? consequences of the disclosure; children being taken away, lose your independence/identity/family/abuser? abuser would get in trouble? would others judge you (stigma)? worried you would upset others/bring shame to others? did you feel embarrassed (shame)? would you be blamed? It wasn't private; someone may overhear/ others would find out? felt rushed? they wouldn't believe me? they wouldn't help me? wasn't sure if it was abuse-accuracy of memory or understanding? didn't know how to explain it? how it would make you feel to disclose? previous bad experience of trying to disclose? worried abuse would get worse/you or someone else would be killed or hurt? admitting it was abuse?

g) **How did the person/s respond** (what did they do) when you told them? Prompts: kind? helpful? shocked? sad? referred you to a service for help?

- If participants begins to talk about factors related to question h; move to this question

h) **What was good,** or helpful about the way they **responded?**

Prompts: they listened? they believed you? they were kind? they were non-judgemental? they kept me safe? they told X, Y, Z/helped you tell X, Y, Z? e.g. parents, police, they supported you? they referred you to counselling? they did not rush you? asked' gentle' questions about it?

i) **<u>What was bad</u>**, or unhelpful about the way **<u>they responded?</u>**

Prompts: they didn't listen? they didn't believe me? (what happened when they didn't believe; what did you do? did you tell someone else? how long did you wait to tell someone else?. If yes also explore this disclosure with question a-h), were unkind? they judged you? they blamed you? they asked lots of questions? you felt rushed?

j) **<u>How did it make you feel</u>** after telling [insert person name] about the abuse (the participant's own term)? and **<u>why?</u>**

Prompts: Happy, sad, scared, relieved, worried? could now get/not get help?

k) **<u>What happened after you told them?</u>**

Prompts: Referral to services? Moved house? Went to the police?

l) Before telling this person/s **<u>had you ever tried to tell anyone else</u>**?

Prompts: who? where? why? what stopped you?

3. <u>Experiences of CLDT teams</u>

As part of your care with the team (CLDT), you told or the team were told about the abuse (or the participant's own term) you had experienced. I would now like to ask you questions about your experiences of talking about the abuse (or the participant's own term) with the team. The answers you give me will not affect your care in anyway, and the team will not know it was you who gave me these answers. Remember there are no right or wrong answers.

(if a member of the team was the first person the participant disclosed the abuse to questions 2a-2l will have been followed. The participant will then only be asked questions related to their views on how people can be supported by services, and how services can respond (questions 4a-4c).

a) **What made it easier** to tell the team/[name of the team member] about the abuse (or term used by participant) ?

Prompts:

- qualities of the person you told; trustworthy? friendly? supportive? non-judgemental? listened? demographics; age, gender, ethnicity, culture? (participants and person they disclosed to)
- contextual factors; felt safe? the abuse had stopped? did they make sure it was private (e.g. in a room were one else could hear us)? lots of time to talk? They believe you? they would help you/you wanted help?

b) **What made it harder** to tell the team/[name of the team member]?

Prompts:

- qualities of the person you told; untrustworthy? unfriendly? unsupportive? judgmental? did not listen? demographics; age, gender, ethnicity, culture? (participant's and person/s they disclosed to)
- contextual factors; felt unsafe? the abuse was still happening? threatened by the abuser? consequences of talking about it; children being taken away, lose abuser/ abuser would get in trouble? relationship with abuser? would others judge you (stigma)? did you feel embarrassed (shame)? would you be blamed? It was private; someone may overhear? felt rushed? they wouldn't believe you? they wouldn't help you?

c) **What was good, or helpful about what the team**/[name of member of staff] did when you talked the abuse (or term used by participant) with them?

Prompts: Refer you to therapy?, Support you in other ways? move house, tell the police?

d) **What was bad, or unhelpful about what the team/**[name of member of staff] did when they when you talked the abuse (or term used by participant) with them?

Prompts: Did not give you the help you need? e.g. therapy?, Did not support you in other ways? move house, tell the police?

4. Views on disclosure

These questions ask for your opinions/views on how the community learning disability team, could help other people with learning disabilities who may or may not have been abused?

a) **Should professionals ask** people with learning disabilities if they have been abused/really bad things have happened to them, to find out if this has ever happened to them?

If either a yes or no response
-Why?
-When should they ask them? e.g. first appointment, at home
-Should they ask more than once?

If a person has been abused/bad things have happened to them, they may need support.

b) What could the service do to help?
Prompts: Counselling? Containing? Ongoing support, during and after? Communication- keep communication open? Listen?

c) What would not help or make things worse?
- Prompts: Professionals being disrespectful?, Not taken seriously?, Not being able to access the service?

6. De-brief

We have now come to the end of the interview. Thank you for answering the questions. Is there anything else you would like to say or ask?

If consent given for respondent validation for analysis on the consent form, explain this again - and explain you will contact them to check the findings.

Establish if the participants is feeling ok following the interview. If distressed, follow the study’s risk protocol. If safeguarding concerns e.g. disclosure of abuse, follow the study’s risk protocol.

Appendix M

Prompt cards for type of abuse used the in interviews

Physical Abuse:

Physical Abuse

When someone hurts your body e.g. hitting, pulling your hair, kicks you

Sexual abuse:

Sexual Abuse

When someone touches your private parts or other parts of your body in a way you do not like or want. It is also when someone makes you do sexual things that make you sad, angry or frightened e.g. makes you touch them, has sex with you when you do not want them to

Psychological or Emotional abuse:

Psychological or Emotional Abuse

When people talk to you in unkind ways, say bad things to hurt your feelings and shout at you e.g. stop you from seeing other people, shout at you, blaming you when it’s not your fault

Financial abuse:

Financial Abuse

When people take your money or things which belong to you without asking e.g. steals your money and belongings

Domestic abuse:

Domestic Abuse

When you are being threatened by someone in your family or by someone who you live with e.g. your carer or flat mate, and can include sexual, psychological or emotional, physical, neglect or financial abuse

Discriminatory abuse:

Discriminatory Abuse

When people treat you badly because: your skin colour is different, you follow a different religion, you have a disability, your sexuality, you speak a different language, your age and your gender

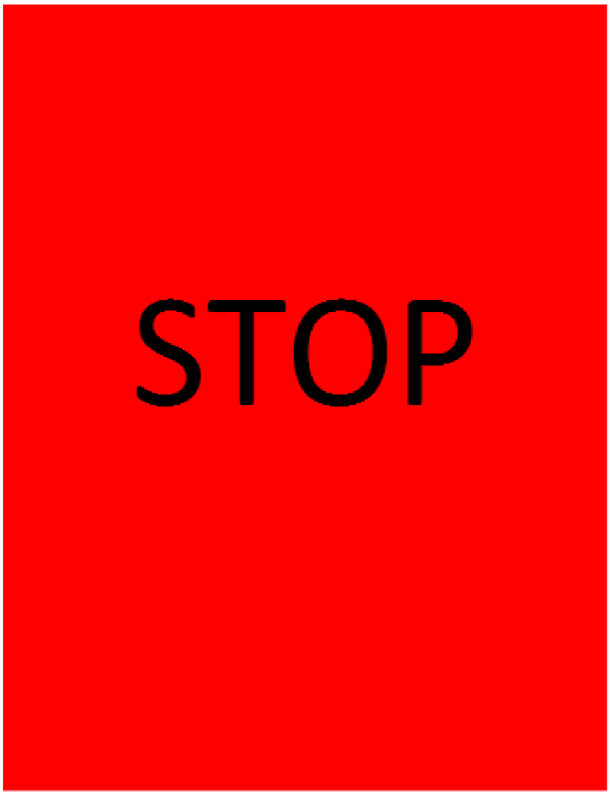
Neglect:

Neglect

When people who are there to help you do not look after you properly e.g. not giving you enough food, not having clean clothes to wear, not washing someone or supporting them to wash

Appendix N

Stop Card



Appendix O

Visual aids for questions

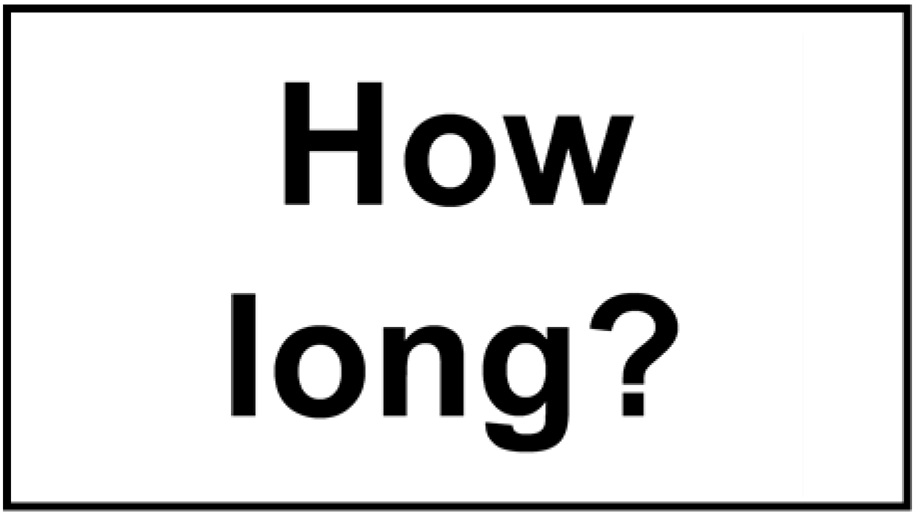
Question 3a:

Who?

Question 3b:

Where?

Question 3c:

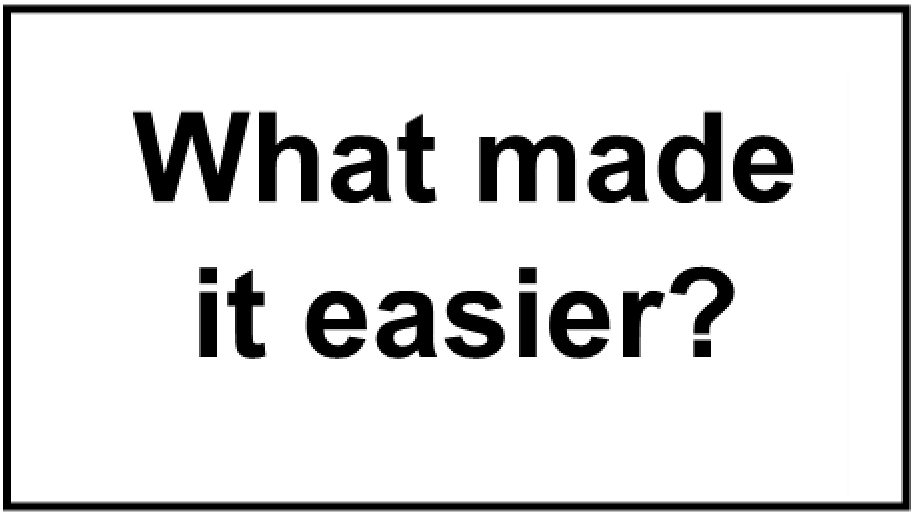


How long?

Question 3d:

Why?

Question 3e and 4a:



What made it easier?

Question 3f and 4b:

What made
it harder?

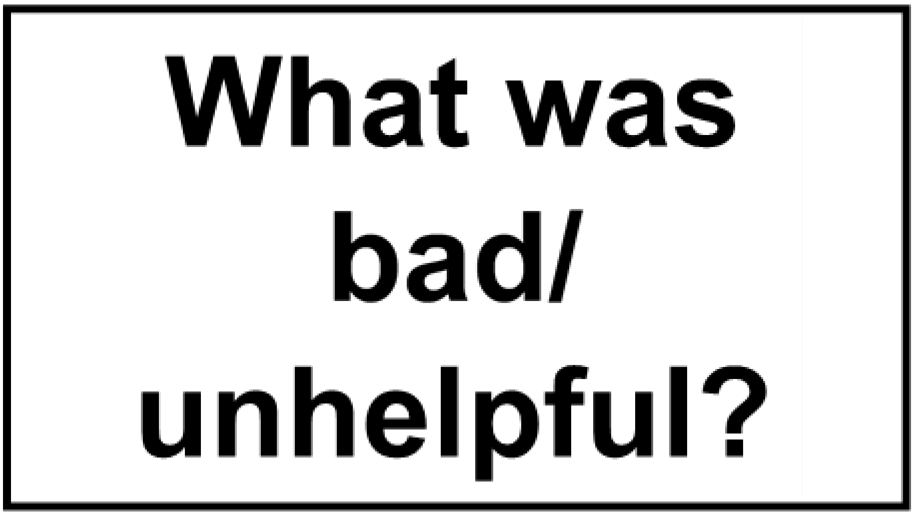
Question 3g:

How did
they
respond?

Question 3h and 4c:

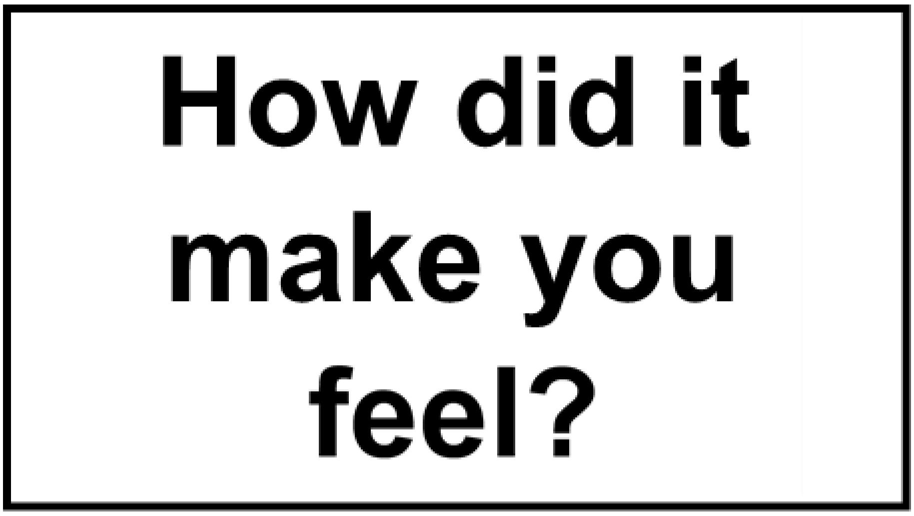
What was
good/
helpful?

Question 3i and 4d:



What was
bad/
unhelpful?

Question 3j:



How did it make you feel?

Question 3k:

What happened after?

Question 3l:

Had you tried to tell someone before?

Question 5a:

Should professionals ask?

Question 5b:

To help?

Question 5c:

Not help or make things worse?

Appendix P

Interview Summary

Interview Summary:

Questions to consider:

What was the interviewee like?

- **What role did they take in the interview?**
  - How did this influence their responses?
  - Did this limit the information you obtained from them?
- **Were there any particular non-verbal reactions?**
- **What did the interviewee talk about mostly:**
  - Note any key examples or particular themes which you can already identify
  - What did they feel most comfortable talking about
- **Any follow up questions to pursue in the next interview(s)?**
- **Overall how valuable was the interview? (1-10)**

Score:

Appendix Q

Braun and Clarke's (2006) 15-point quality criteria checklist for thematic analysis
(Table in Braun and Clark, 2013, Successful Qualitative Research, a practical guide for beginners, SAGE, p.287)

Process	No.	Criteria
Transcription	1	The data have been transcribed to an appropriate level of detail, and the transcripts have been checked against the tapes for 'accuracy'
Coding	2	Each data item has been given equal attention in the coding process
	3	Themes have not been generated from a few vivid examples (an anecdotal approach), but instead the coding process has been thorough, inclusive and comprehensive
	4	All relevant extracts for each theme have been collated
	5	Themes have been checked against each other and back to the original data set
	6	Themes are internally coherent, consistent and distinctive
Analysis	7	Data have been analysed- interpreted, made sense of- rather than just paraphrased or described
	8	Analysis and data match each other- the extracts illustrate the analytic claims
	9	Analysis tells a convincing and well-organised story about the data and topic
	10	A good balance between analytic narrative and illustrative extracts is provided
Overall	11	Enough time has been allocated to complete all phases of the analysis adequately, without rushing a phase or giving it a once over-lightly
Written report	12	The assumptions about, and specific approach to, thematic analysis are clearly explicated
	13	There is a good fit between what you claim to do, and what you show you have done- i.e., described method and reported analysis are consistent
	14	The language and concepts used in the report are consistent with the epistemological position of the analysis
	15	The researcher is positioned as *active* in the research process; themes do not just 'emerge'

Appendix R

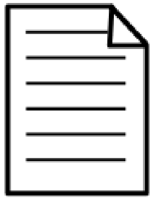
Respondent Validation Document

Feedback sheet to for member checking

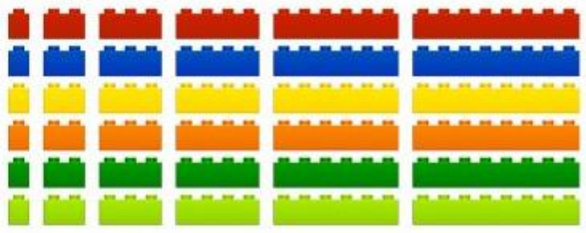
Analysis

1. I wrote out all the questions and answers people told me into five transcripts

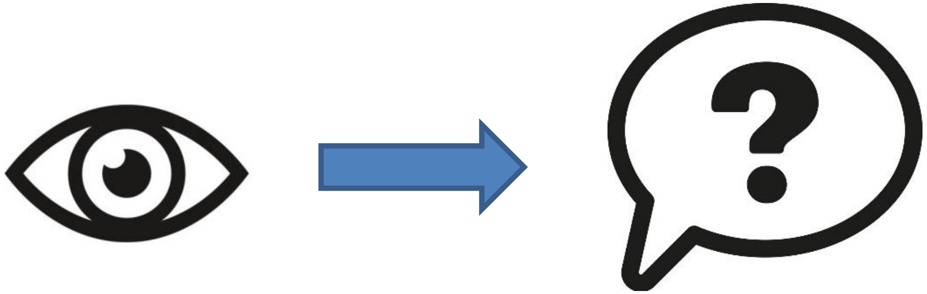
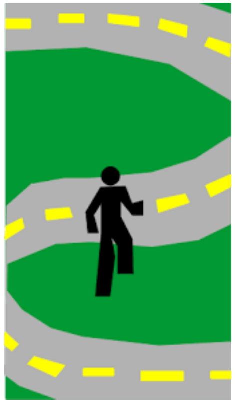
   (one for each person)



2. I put together the answers that were similar to make themes- like organising Lego; all the red bits together.



For example, all the answers about what helped people when people told someone they had been abused

Theme
Theme one: Abuse is witnessed not disclosed
Other people see the abuse happen or see the signs of abuse, like bruises Then ask the person, ‘have you been abused?’ or ‘what happened? 
Theme two: There is a set process to disclosure
Once you have told someone who you have been abused certain things will happen e.g., the police are called It’s a like a path being followed 

1. **Everyone plays a role and has responsibilities**

   Examples:

   The social worker will help me find somewhere new to go to school

   The teacher will tell off the person who bullied me

   I have to tell people what happened

2. **The abuse will stop when I disclose**

3. **How much control do I have in how this happens and how I tell my story?**

   Examples:

   Other people took charge
   Other people made decisions

   This could be good or bad

Theme three: Carrying the burden of what happened

How the person was affected by the abuse

Carrying the weight of what happened to me

Feeling trapped

1. Sense making of the experience

Holding responsibility for what happened

vs.

It shouldn’t have happened/not my fault

vs.

2. The consequences I endure due to the abuse

- Individual experience
- World is unsafe

- Will the abuse stop? The abuser still has control

- In our bodies and minds e.g. flashbacks and hard emotions

- Losing parts of me e.g. my personality, confidence

Theme four: Finding a way out

What helped people:

- To feel less trapped
- To tell their story
- To feel better

1.Proximity and familiarity

- It helps if I am close or know the person I disclose the abuse to or talk to the abuse about

2.Seen, Heard, Valued

- It is helps when people understand me and what happened to me
- It makes me feel safe, empowers me, makes me feel confident
- This helps me share what happened and get the help I need

- Sometimes this doesn’t happen (even though it should)
- Working together as a team is good

3.Open up

- Talking helps to:
- Stop the abuse
- Feel relief (stop carrying the weight)
- Gives me skills- empowers me to know what helps and regain power
- Support other people
- BUT- it can be hard to talk or people might not listen