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Exploration of sexuality and the sexual lives of adults with intellectual disabilities using Interpretative Phenomenological Analysis and Thematic Synthesis

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Thesis Abstract

Adults with intellectual disabilities have historically faced various challenges and barriers in developing romantic or sexual relationships despite expressing their desire to have these connections (Arias et al., 2009). Family members and staff play an instrumental role in enabling individuals with intellectual disabilities to have access to opportunities to meet others and impart sexual knowledge and help fulfill their sexual and romantic needs (Rushbrooke et al., 2014). The importance of the role of family members and staff has resulted in growing interest and body of research on their perceptions, attitudes, and views when supporting individuals with intellectual disabilities (Rushbrooke et al., 2014).

As adults with intellectual disabilities often report feelings of loneliness and isolation, the internet is a powerful tool to meet others and fulfill sexual, romantic, and intimate needs. However, some individuals with intellectual disabilities may need support from family members or staff to access the internet. A systematic review was conducted to explore, collate, and critically apprise qualitative research regarding internet use for sexual purposes. Thematic synthesis (Thomas & Harden, 2008) was utilised to analyse the included studies. Three superordinate themes were identified: (a) 'Navigating the online world: Norms and Netiquettes', (b) 'Exploring and expressing intimacy', and (c) 'My identity and the internet: The Digital Me'. The current literature is discussed alongside these findings. Recommendations are made for future clinical and research practice.

The sexual lives of adults with intellectual disabilities who identify as LBGTQ+ were explored by understanding the perspectives, attitudes, and views of paid (support staff) and unpaid (family members) carers. The study interviewed six carers, with the data analysed using Interpretative Phenomenological Analysis (Smith & Osborne, 2008). Four themes were identified: (a) 'Journey of coming out', (b) 'Minority in a minority, (c) 'Protection and possibilities', and (d) 'Access to similar others'. The findings emphasised the importance of adults with intellectual disabilities having access to others with similar experiences and queer friendly spaces. The results highlighted the importance of sexual education for adults with intellectual disabilities around sexuality and identity, and training for both staff and family members to improve knowledge and confidence in supporting sexuality and sexual expression. Suggestions for future research are discussed alongside clinical implications, such as the impact of LGBTQ+ groups for adults with intellectual disabilities on psychological well-being and identity.

Thesis Lay Summary

Research has shown that although adults with intellectual disabilities desire romantic and sexual relationships, they face challenges and barriers to developing these. Family members and staff are an important source of support to enable adults with intellectual disabilities to create opportunities to meet others and fulfill their romantic and sexual needs.

Adults with intellectual disabilities can use the internet to meet others, explore their sexuality, and meet their sexual needs. However, some individuals need support from family members or staff to access the internet. A systematic review was conducted to review the quality of qualitative studies in this area. The findings of these studies were analysed, and three main themes were found: (a) ‘Navigating the online world: Norms and Netiquettes’, (b) ‘Exploring and expressing intimacy’, and (c) ‘My identity and the internet: The Digital Me’. The findings are discussed alongside other research in the area and are used to make recommendations for future research and clinical practice.

The experiences of adults with intellectual disabilities who identify as LGBTQ+ were explored by understanding the experiences and attitudes of family members and staff who support them. Six participants were interviewed about the sexual and romantic lives of the adult they support. These interviews were then analysed, and four main themes were identified: (a) ‘Journey of coming out’, (b) ‘Minority in a minority, (c) ‘Protection and possibilities’, and (d) ‘Access to similar others’. The results suggest that it’s crucial adults with intellectual disabilities have access to others with similar experiences. They highlighted the importance of sexual education for adults with intellectual disabilities around sexuality and identity, and training staff and family members to improve knowledge and confidence in supporting sexuality and sexual expression. Further research suggestions are discussed alongside recommendations for clinical practice.

Journal Article 1: Systematic Review

The use of the internet for sexual and intimate purposes by individuals with intellectual disabilities: A systematic review and thematic analysis

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1. Abstract

Background: The expression of sexuality is integral to being human, and adults with intellectual disabilities access the internet to express their sexuality through chatting with others, looking at sexual content, or meeting others online to pursue a sexual or romantic relationship (Löfgren-Mårtenson, 2008). The review aims to explore the views and experiences of adults with intellectual disabilities, their families, and staff regarding accessing the internet for sexual and intimate purposes.

Method: Six primary studies published in the English Language were identified from electronic database searches (PsycINFO, EMBASE, MEDLINE, ASSIA, CINAHL, and SCOPUS), which were rated against inclusion and exclusion criteria, as well as quality criteria. Findings were analysed using thematic synthesis (Thomas & Harden, 2008).

Results: Three analytic themes were identified: (a) 'Navigating the online world: Norms and Netiquettes', (b) 'Exploring and expressing intimacy', and (c) 'My identity and the internet: The Digital Me'.

Discussion: Examination of the themes highlights that many adults with intellectual disabilities use the internet for sexual purposes and have positive experiences of accessing the web. Several barriers to accessing the internet were identified, such as safeguarding concerns and cyber-etiquette. Professionals and family members highlighted concerns regarding risk and vulnerability. It is recommended that services have clearer policies around supporting adults to access the internet for sexual purposes, and training and education around safe use for both adults with intellectual disabilities and those who support them.

Keywords: Intellectual Disabilities, internet, sexuality, relationships, thematic synthesis

Word Count: 11,115

Conflicts of interest: None.

2. Introduction

For over two decades, the internet has transformed how people communicate and interact with others and has become an integral part of daily life (Chen & Wellman, 2005; Reid & Boyer, 2013). The use of the internet has enabled individuals to grow, maintain, and develop friendships together with sexual and romantic partners (Cooper et al., 2003; Döring, 2009; Raacke & Bonds-Raacke, 2008; Whitty & Carr, 2006). The increase in sexual material available on the internet has also enabled individuals to engage in various online activities including reading and watching erotica, buying sex products, and arranging and meeting potential love interests offline (Cooper et al., 2003; Fisher & Barak, 2000; Shaughnessy et al., 2017). Anonymity, virtual proximity, and typing rather than talking have altered sexual scripts that have previously been defined through face-to-face interactions (Gagnon & Simon, 2005). This in turn has evolved sexually related online activities, which incorporates all sexually related content and activities that take place via the internet (Leiblum & Doring, 2002).

However, despite increasing internet consumption for sexual and intimate purposes (Rietmeijer et al., 2001), accessing cyberspace remains largely inaccessible for individuals with intellectual disabilities (Chadwick et al., 2013a; Stendal, 2012). Many individuals with intellectual disabilities are socially isolated, and internet-based tools enable access to social opportunities and community contact (McVilly et al., 2006; Löfgren-Mårtenson et al., 2015), in addition to gaining access to romantic and intimate resources (Löfgren-Mårtenson, 2008, 2009). The use of the internet also allows for the exploration of sexual identity and expression through the use of adult websites and purchasing products from online sex shops (Batey & Waine, 2015; D’Aubin, 2007; Dobransky & Hargittai, 2006; Jaeger, 2012). However, the limited access to the internet by individuals with intellectual disabilities reflects the experience of social exclusion faced within society (Batey & Waine, 2015; Shakespeare, 2008).

The expression of sexuality is an integral and significant part of being human (Krebs, 2007; Matich-Maroney et al., 2005). However, despite developments in social care and policy encompassing a more person-centred and inclusive approach (Thompson et al., 2007), adults with intellectual disabilities still experience barriers to expressing their sexuality (Brown & McCann, 2018; Shakespeare, 2013). Stereotypical beliefs held by non-disabled individuals centre around the perceived asexuality of adults with intellectual disabilities (Brown, 1994; Di Giulio, 2003; Franco et al., 2012; Goggin, 2009), which further impacts the opportunities for individuals to develop fulfilling sexual and intimate relationships.

Evidence suggests that adults with intellectual disabilities have limited access to technology and often rely on family or support staff assistance to access the internet (Tanis et al., 2012; Wehmeyer et al., 2008). Although there has been an ideological shift in services towards inclusivity and a person-centred approach, views held by those who support adults with intellectual disabilities remain a barrier to sexual expression (McGuire & Bayley, 2011). Although family members and staff acknowledge that sexual expression is essential to wellbeing and fulfilment, restrictive and prohibitive approaches are still implemented in various aspects of support (McGuire & Bayley, 2011). Professionals and family members often hold views regarding the perceived risk involved with individuals with intellectual disabilities accessing the internet, particularly regarding sexual abuse or easy access to pornography (Löfgren-Mårtenson & Mansson, 2006; Löfgren-Mårtenson et al., 2015). Those who support individuals with intellectual disabilities feel a sense of responsibility to protect them from harm, which often manifests through forms of control (McGuire & Bayley, 2011). This, in turn, can impact the sexual autonomy of adults with intellectual disabilities. Difficulties in accessing the internet may further act as a barrier to the exploration and expression of sexuality by adults with intellectual disabilities, which may result in fewer opportunities for individuals to find information about sex, engage in sexual experiences, and develop intimate and sexual relationships (Lazar & Jaeger, 2011; Swango-Wilson, 2010). These barriers can include the design, layout, and navigability of internet sites, or incompatibilities with assistive technology to access software (Lazar & Jaeger, 2011). Family members can place further restrictions on internet use, such as time limits and firewalls to block websites with sexual content (Lathouwers et al., 2009). Thus, others often decide what is safe and acceptable to access online for adults with intellectual disabilities (Seale, 2003).

Adults with intellectual disabilities have expressed their desire to have increased control over their sexual and intimate lives (Arias et al., 2009). However, some may experience practical obstacles when attempting to meet others in the community, such as accessing travel or public transport (Bernert, 2011; Turner & Crane, 2016). Furthermore, others may hold attitudes and views related to low self-worth, holding the notion that they do not have a right to experience intimate relationships or express their sexuality (Bane et al., 2012). The internet may provide increased opportunities for adults with intellectual disabilities to seek a partner or access sexual content (Löfgren-Mårtenson, 2008).

Although access to the internet provides adults with intellectual disabilities with an avenue to explore and express their sexuality, there is the potential for problematic use of the web, such as accessing illegal pornography or engaging in illicit activities online (Batey & Comer, 2013). Some adults with intellectual disabilities may engage in inappropriate sexual contact online, however, there are limited initiatives or interventions that actively target problematic use of the internet within this population. Psycho-education interventions around using the internet safely may promote independence, reduce vulnerability, and aid in understanding in what is appropriate or inappropriate to access online (Batey & Comer, 2013). Providing information on issues related to internet offending, how the internet is monitored, and the consequences of accessing illicit materials may improve confidence in adults with intellectual disabilities and enable informed and safer choices online (Batey & Comer, 2013).

A systematic review explored the use of social media and people with intellectual disabilities (Caton & Chapman, 2016), which highlighted the positive experiences of internet-based sites such as the increased opportunity to meet others and an avenue to express identity (Caton & Chapman, 2016). However, safety and safeguarding concerns were highlighted, including sexual threats (Holmes & O'Loughlin, 2014) and the use of pornographic images and films (Löfgren-Mårtenson, 2008). In response to this, there was evidence that family members and staff who supported individuals with intellectual disabilities occasionally banned sites that contained pornographic content or monitored the use of the internet (Löfgren-Mårtenson, 2008; Seale, 2007). The review highlights the ethical dilemma and conflicts of interest faced by family and health professionals who may wish to promote independence while protecting from harm. Within one study included in the review, young adults with intellectual disabilities were able to identify and describe various strategies that they should follow to stay safe online (Löfgren-Mårtenson, 2008). For instance, telling someone if they were going to meet someone they met online and making sure they had a way to contact for help if needed. However, they also disclosed that they had arranged meetings with strangers within their own homes. This may have arisen as part of the individual's longing for a partner (Löfgren-Mårtenson, 2008).

The review highlighted that research within the area of internet use by adults with intellectual disabilities remains weak, with small sample sizes (Caton & Chapman, 2016). Some of the included studies within the review gave no details of the sample size of participants or demographics (McClimens & Gordon, 2008, 2009). Some papers did not specify the specific analysis or methodology (McClimens & Gordon, 2008, 2009). Recruitment methods within the selected research studies, such as snowballing techniques (Löfgren-Mårtenson, 2008) likely resulted in participation by adults with intellectual disabilities who already used social media and the internet (Holmes & O'Loughlin, 2014; Kydland et al., 2012; Seale, 2001, 2007; Seale & Pockney, 2002). Therefore, the experiences of adults with less experience or interest in using the internet were underrepresented. Most participants included within the studies appeared to have a mild intellectual disability, which may not represent the population's experiences. Internet use for sexual purposes may be affected by the severity of intellectual disability and individual support needs (Caton & Chapman, 2016).

3. Rationale for the Current Review

Previous research has highlighted the use of the internet and information and communication technology (ICT) by individuals with intellectual disabilities (Chadwick et al., 2013a, 2013b) or the use of social media (Caton & Chapman, 2016). However, research on the use of the internet by people with intellectual disabilities for sexual or intimate purposes remains limited.

The present review aims to provide a review and synthesis of existing qualitative research on the use of the internet for intimate and sexual purposes by adults with intellectual disabilities. To date, there is no systematic review or synthesis of studies exploring the use of the internet by adults with intellectual disabilities for sexual and intimate purposes. The current review aims to identify, summarise, and critically assess the available research on the experiences of views of adults with intellectual disabilities and those who support them.

The present review aims to explore the research questions: 1) What are the experiences of adults with intellectual disabilities and those who support them in accessing the internet for sexual and intimate experiences? 2) What barriers are there for adults with intellectual disabilities who want to access the internet for sexual and intimate experiences?

4. Method

4.1 Search Strategy

The systematic search was conducted using the databases PsycINFO, EMBASE, MEDLINE, ASSIA, CINAHL, and SCOPUS. The search terms were developed through reviewing the current literature and discussion with a librarian. These were as follows: *((learning AND disab*) OR (intel* AND disab*) OR (mental* AND retard*) OR (develop* AND disab*) OR* *intellectual disability OR LD OR (intellectual* impair*) OR (mental* AND handicap)) AND (internet OR web OR online OR cyber* OR digital) AND (love OR intimacy OR relationships OR sex* OR porn* OR dating).* The identified search terms were used to conduct a systematic electronic search in November 2021. Citation tracking and checking of references from related journal articles identified in the search were also performed. Further searching was conducted using Google Scholar to scope and locate studies that may have been missed. The researcher also contacted experts in the area to ascertain if any other papers had been missed. This was in acknowledgement that effective identification of qualitative research through database searches depends on the database indexing practices and clarity of research titles and abstracts (Evans, 2002). The grey literature search included Google searches that utilised a combination of terms used within the database literature review, and further citation tracking and contacting of experts. Grey literature that met inclusion criteria were included.

4.2 Inclusion and Exclusion Criteria

Papers were included within the review if they described a primary research study exploring the internet use of individuals with intellectual disabilities over sixteen years old for sexual or intimate purposes. This included the views of individuals with intellectual disabilities, their family members, educational staff, and healthcare workers. Sixteen years of age was included as a cut off due to some professionals working in an educational setting with students attending college who had this age range. Papers were included if they were published in an English-language peer-reviewed journal between 2000 (the development of Web 2.0) and November 2021 (the date of the search). This time frame has been used in similar systematic reviews on the use of the internet by people with intellectual disabilities (Caton & Chapman, 2016). Only qualitative papers were included that explored the experiences of adults with intellectual disabilities, or their family members or professionals who support them.

Articles were excluded if they described the use of the internet in a broader study on ICT use, if individuals were using the internet for illicit sexual activity or offending behaviour, or if the individuals involved in the study were less than sixteen years of age. Papers were also excluded if there was no direct reference to romantic or sexual activity and the internet. The term “intellectual disability” was used to cover presentations ranging from mild to severe, as per the categories used within the International Classification of Diseases-10 (ICD-10; World Health Organisation, 2004) and Diagnostic Statistical Manual-5 (DSM-5, American Psychiatric Association, 2013) systems, due to studies often not specifying the severity of intellectual disability of participants or service users. The first author screened the titles and abstracts of the studies identified by the search to determine eligibility. Figure 1 provides further details of the selection process.

4.3 Data Extraction

Descriptive data were extracted from the selected papers by the main author. They included the author, year of publication, country of origin, title, aim, setting, demographics, sampling, data collection, analysis, themes, and limitations. The full text of the selected studies was transferred to NVivo software (Version 1.5.1., released in July 2021) for synthesis.

4.4 Quality Appraisal

The Critical Appraisal Skills Programme (CASP) qualitative tool (2019) was utilised within the present study to guide and assess the quality of included articles (see Appendix 2), as recommended by guidance outlined by the Cochrane Qualitative Research Methods Group. The CASP is a ten-question checklist-based framework utilised to consider the appropriateness of study design, risk of bias, choice of outcome measures, sample, recruitment, findings, and generalisability. It is widely utilised within the quality appraisal of qualitative research (Noyes et al., 2018). As introduced by Butler, Hall and Copnell (2016), global quality ratings and a numerical scoring system were used to compare ratings between the lead researcher and a second independent researcher (KH). This was utilised as CASP does not have an available system in which ratings can be categorised. Papers selected within the review were rated “low”, “moderate”, and “high” based on CASP criteria. The second independent researcher independently reviewed all six of the selected papers using the same quality criteria to minimise the potential for error and improve rigour. This process indicated an 87% inter-reviewer agreement. The kappa coefficient was calculated to account for the probability of agreement occurring by chance, with the calculated value (κ = .59) indicating a satisfactory level of agreement (McHugh, 2012). Disagreements in ratings were resolved through discussion. The assigned scores and ratings are demonstrated in Table 1.

4.5 Data Synthesis

Thematic synthesis (Thomas & Harden, 2008), framework synthesis (Carroll et al., 2011), and meta-ethnography (Campbell et al., 2011) are frequently used approaches for qualitative evidence synthesis. This is highlighted in the Cochrane Qualitative and Implementation Methods Guidance (Noyes et al., 2018). From this guidance, thematic synthesis was described as the most appropriate analysis method and was selected as the preferred data synthesis method for the present study. The approach allows for exploration of the findings of the selected studies and identifies recurrent themes, thus deepening the understanding of the topic and generating new insight (Thomas & Harden, 2008). Framework synthesis was considered due to its application within reviews with complexity within the framework, including theory representation. However, no suitable conceptual framework could be identified, and in the absence of this, there is a risk of data being forced into a framework for expedience (Carroll et al., 2011). Meta-ethnography was deemed inappropriate for the present study due to its complex methodology and synthesis process and inadequate reporting guidelines (Campbell et al., 2011).

As proposed by Thomas and Harden (2008), thematic synthesis follows three steps; line-by-line coding of the text to generate codes, the organisation of codes into descriptive themes, and the development of analytical themes. The coding process included data within the studies which were labelled ‘results’ or ‘findings’, and both themes identified by authors and verbatim quotes were used within the synthesis. Codes identified within the data were arranged into descriptive themes by creating new themes and assimilation of existing themes, which were incorporated into higher-order analytical themes (Thomas & Harden, 2008). New interpretive constructs or explanations are represented within these analytical themes, although the development of descriptive themes aligns closely with the primary studies’ themes.

4.6 Researcher Reflexivity

Throughout the review process, the main researcher held awareness of the impact of prior beliefs or prejudices that may influence the interpretation of the data, which may impact on research processes (Smith & Osborn, 2008). Awareness and commitment to reflexivity allow for potential biases to be acknowledged and the researcher’s understandings and development of interpretations of data explicit and accounted for (Stevenson & Cooper, 1997). The main researcher holds strong views on the rights of individuals with intellectual disabilities to have access to means to fulfill their sexual or romantic needs. They held expectations that current literature would highlight the restrictions and boundaries for adults with intellectual disabilities. Whilst conducting the review, the main researcher was concurrently investigating the views and experiences of family members and support staff on the sexual and romantic lives of adults with intellectual disabilities who identify as LGBTQ+. This may have influenced the present synthesis, particularly regarding areas pertaining to risk, vulnerability, and protection of individuals with intellectual disabilities. Throughout the research process, the researcher managed expectations, personal views, and the influences of their own beliefs on the interpretation and synthesis of data through discussion in supervision and the use of a reflective diary. The researcher noted the desire to construct a positive narrative of internet use for adults with intellectual disabilities, however, reflection on personal feelings and credibility checks ensured the interpretations were not a projection of the researcher’s views and beliefs. The researcher continued to work with individuals with intellectual disabilities in a clinical capacity throughout the review process. They remained aware of the impact this may have had on the interpretation of data within the thematic synthesis of the selected papers.

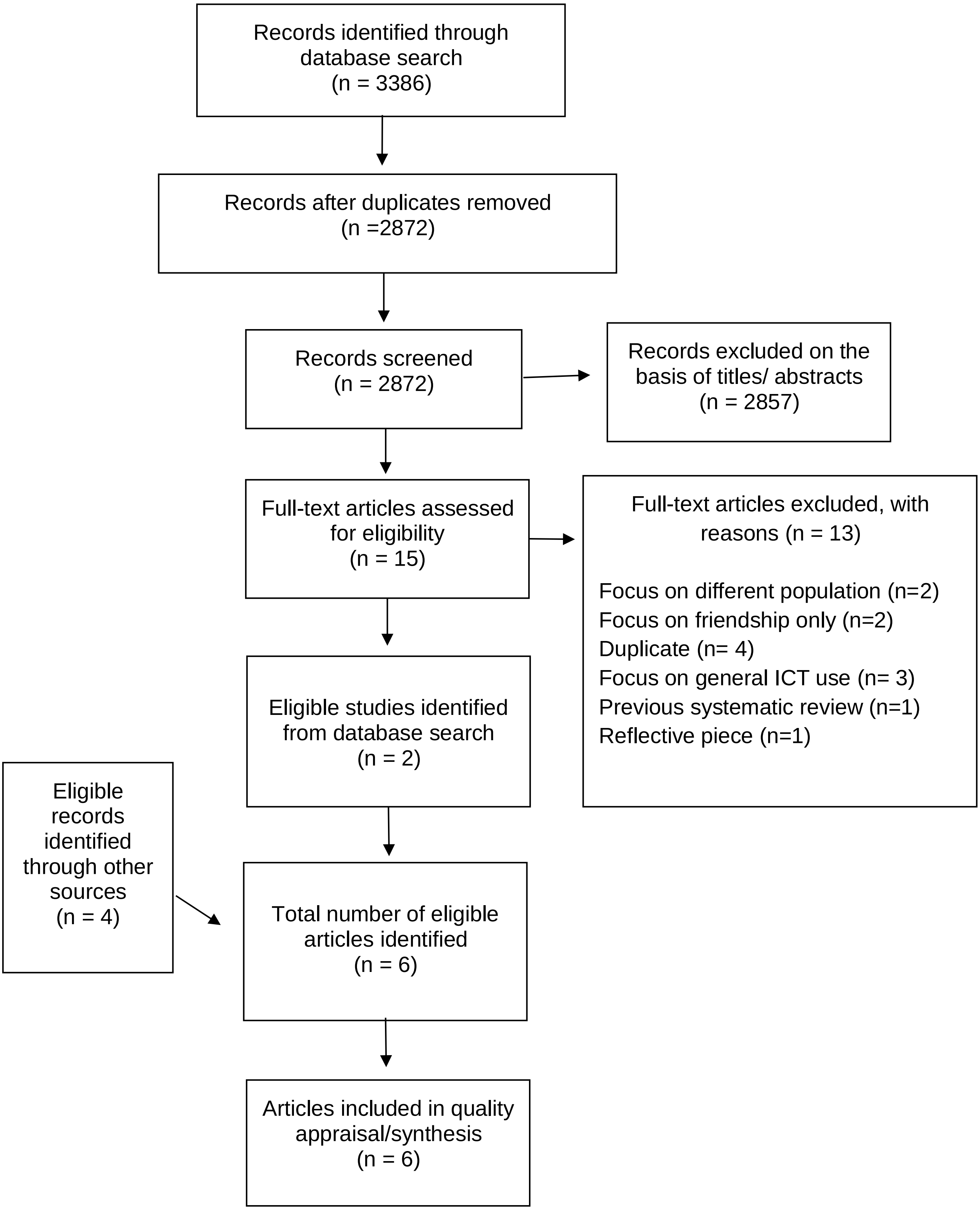
5. Results

5.1 Screening Process

The screening process followed the recommended stages within the Preferred Reporting Items for Systematic Reviews (PRISMA) protocol (Moher et al., 2009). These stages are represented in Figure 1. Following an initial search across the selected databases, 3386 papers were identified. These papers were exported to Covidence software to assist with the screening process and identifying duplicate papers. From the original papers identified, 514 were removed as duplicates, resulting in 2872 papers screened for relevance. Following the screening, 2857 papers were excluded based on their titles or abstracts. The full text was screened if the abstract did not contain sufficient information. The remaining 15 records were reviewed in full text and matched against the eligibility criteria.

Two records were deemed eligible, and 13 papers were excluded due to failure to meet the inclusion criteria (see Appendix 3 for further details). Papers were excluded due to duplication, focusing on general ICT use, the use of the internet for friendships only, and the incorrect population. Four further papers were identified through a manual search conducted by the main author, resulting in a total of six papers. A review of the articles indicated that two of the papers originated from the same primary research. Both papers were included within the review due to differences in the interpretation of participant’s accounts and development of key themes across both studies.

Figure 1. Search Process Flowchart based on the PRISMA group (Moher et al., 2009)



5.2 Quality Appraisal

Four studies were allocated with a “high” global quality rating (Darragh, 2019; Darragh et al., 2017; Lines et al., 2020; Löfgren-Mårtenson, 2008). Two received a “moderate” global quality rating (Löfgren-Mårtenson et al., 2015, 2018), with no papers receiving a “low” global quality rating. The lower ratings were often attributed to a lack of detail within ethical procedures and reflection from the researcher in relation to critically examining their own role and potential bias within the study. It is recommended with the scoring system proposed by Butler and colleagues (2016) that studies that receive a global quality rating of less than six be excluded from the review. Within this review, no studies received a score of six or lower, therefore none were excluded following the critical appraisal.

5.3 Characteristics of Included Studies

The extracted information from the selected papers included within the review can be found in Table 2. The six studies used qualitative methodology, with five using interviews for data collection and one study utilising a focus group to collect data. Of the five studies that indicated that they used interviews, four described the use of a semi-structured interview proforma, with one not including detail on the interview approach. In terms of qualitative methods used, interpretative phenomenological analysis, thematic analysis, and interactionist methodology were utilised across the studies. Three studies were conducted within Sweden, two in Australia and one in the United Kingdom.

Across the studies, a total number of 33 professionals participated. This included support workers, teachers, teaching assistants, and other professions not specified. A total number of 5 parents participated across studies, with 40 individuals with intellectual disabilities.

Table 1. Quality Ratings Table

	Quality Criteria											
Articles (First Author & Year)	(1) Aim	(2) Methods	(3) Design	(4) Recruitment	(5) Data Collection	(6) Researcher role	(7) Ethics	(8) Analysis	(9) Findings	(10) Value	**Total Score**	**Global Rating**
Darragh (2017)	0.5	1	1	1	1	1	1	1	1	1	9.5	High
Darragh (2019)	1	1	1	1	1	1	1	1	1	1	10	High
Lines (2020)	1	1	1	1	1	1	0.5	1	1	1	9.5	High
Löfgren-Mårtenson (2008)	1	1	1	1	1	1	1	0.5	1	1	9.5	High
Löfgren-Mårtenson, (2015)	1	1	0.5	1	0.5	0.5	1	1	1	1	8.5	Mod
Löfgren-Mårtenson (2018)	1	1	1	1	0.5	0.5	1	0.5	1	1	8.5	Mod
Scoring system: Yes- 1 point Unsure- 0.5 points No- 0 points **High Quality:** Scores 9-10 **Low Quality:** Less than 7.5 **Moderate Quality:** Scores 7.5-9 **Exclude:** Less than 6												

Table 2. Summary of Included Studies

Author(s) and Year	Focus of Study	Country	Number and Type of Participants	Methods and Type of Analysis	Key Qualitative Findings
Darragh (2019)	Experiences of adults with intellectual disabilities on accessing the internet to explore sexuality and develop relationships	Australia	30 individuals with a diagnosis of an intellectual disability	Semi-structured interviews Thematic analysis	Adults with intellectual disabilities use the internet for various reasons, including exploring and expressing intimacy and engaging in sexual behaviours. Participants also provided their views on others sending and receiving explicit content, and the barriers to accessing the internet. The findings also highlighted the use of the internet for online dating and accessing pornography.
Darragh et al. (2017)	Explore how people with intellectual disabilities access the internet to form relationships and express sexuality	Australia	30 individuals with a diagnosis of an intellectual disability	Semi-structured interviews Interpretative Phenomenological Analysis	Adults with intellectual disabilities described using the internet to create new friendships, maintain existing friendships, and explore and express sexuality. They described a range of devices to access the internet to be socially and sexually active. Adults accessed sexually explicit material either as an individual or within a couple. Few participants used the internet in a way that appeared to put them at risk of exploitation.
Lines et al. (2020)	Support worker’s understanding of their role in supporting adults with intellectual disabilities to access the internet for intimate purposes	United Kingdom	Eight support workers across three organisations	Semi-structured interviews Thematic analysis	Support workers described being faced with organisational dilemmas, the expectations of support, and having reflective and protected space to voice concerns. Support workers agreed that adults with intellectual disabilities should access the internet for sexual purposes. However, they did not feel confident in supporting this due to a lack of policy and guidance. The study highlighted the importance of policy implementation.

Author(s) and Year	Focus of Study	Country	Number and Type of Participants	Methods and Type of Analysis	Key Qualitative Findings
Löfgren-Mårtenson (2008)	Experience of young adults with intellectual disabilities and staff on using the internet for romantic purposes	Sweden	Ten young people with intellectual disabilities and twelve staff members	Semi-structured interviews Interactionist perspective	Young adults described the use of the internet as a positive arena where they could develop romantic relationships and socialise with others whilst presenting themselves without mentioning their disabilities. However, staff members held contradictory views and tended to focus on the risks involved in using the internet such as exploitation.
Löfgren-Mårtenson et al. (2018)	Exploring the perspectives and experiences of professionals when supporting young people with intellectual disabilities in accessing the internet	Sweden	Seventeen professionals working within schooling systems for young people aged 16-21	Semi-structured interviews Grounded in the theoretical framework of sexual script theory (Gagnon & Simon, 2005)	Findings highlighted that the professionals experienced challenges when supporting young people with intellectual disabilities to access the internet and felt a conflict between being controlling and permissive. Professionals highlighted the lack of strategies or policies available that could guide them in supporting young people and the internet.
Löfgren-Mårtenson et al. (2015)	Exploration of the views of parents and professionals on the internet use of young people with intellectual disabilities for sexual purposes	Sweden	Eight professionals working within secondary schools for those aged 18-20 and five parents	Five semi-structured focus groups Thematic analysis	Parents and professionals viewed the internet as an arena for risk and vulnerability, and for love and sexuality. Young people with intellectual disabilities were seen as more vulnerable than other youth accessing the internet. However, parents viewed their children as lonelier than their peers and viewed the internet as a positive tool for developing and maintaining relationships.

5.4 Thematic Synthesis

Within the included studies, the coding process yielded 51 codes (Appendix 5). A total of ten subordinate descriptive themes were developed from the codes. Consistent findings were reported across the selected articles included within the review, and therefore are likely to reflect the data.

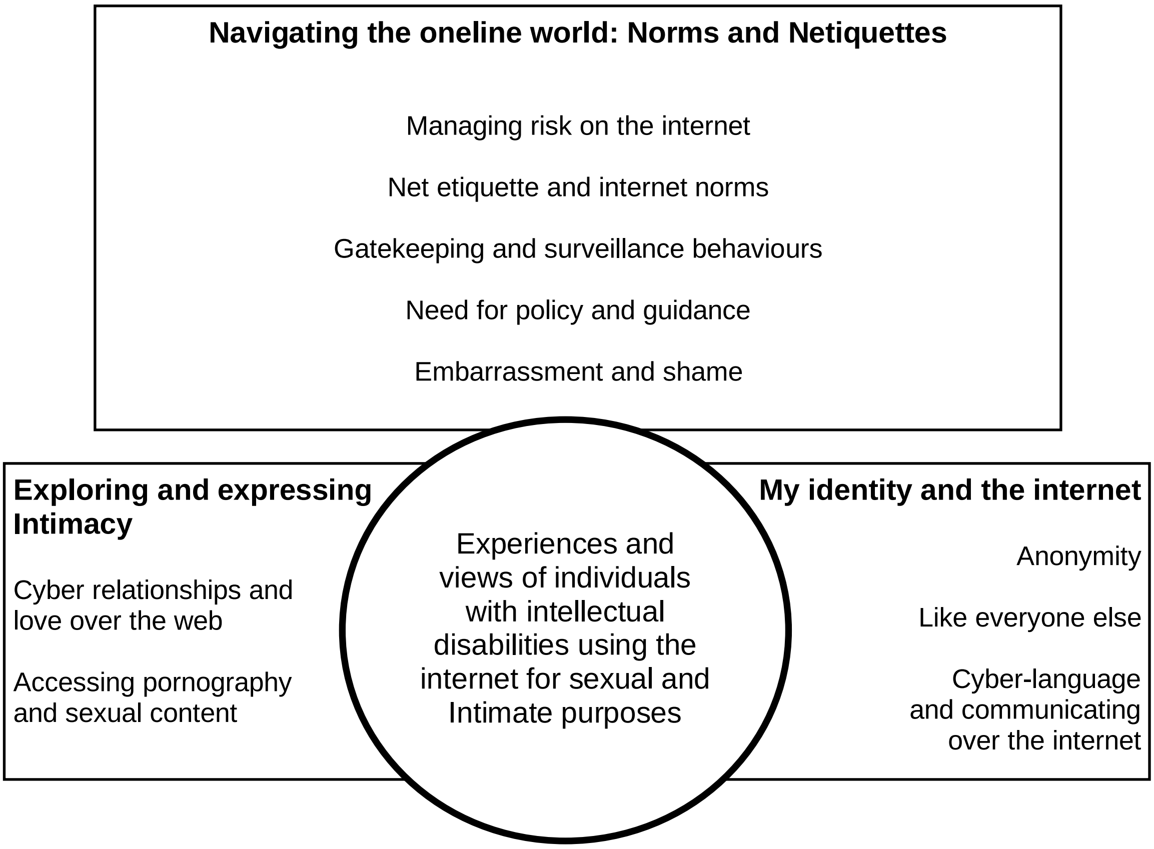
The researcher began coding of text ‘line-by-line’, and these codes were structured as free codes without a hierarchical structure. This coding enables the translation of concepts from one study to another (Thomas & Harden, 2008). These codes were then developed into descriptive themes through examining similarities and differences across codes. Descriptive themes derived from the analysis can be similar to existing themes within the original studies; however, thematic synthesis enables the exploration of themes beyond what is within the original content (Thomas & Harden, 2008). Abstract themes were developed from the descriptive themes by inferring the experiences of the professionals, parents, and individuals with intellectual disabilities interviewed within the studies regarding the use of the internet for sexual and intimate purposes. Consideration was given to how individuals with intellectual disabilities use the internet for sexual and intimate purposes, alongside perceptions of risk and barriers that may be present that may prevent access to the internet.

This process resulted in the creation of three abstract and analytical themes. These abstract and analytical themes are: (a) ‘Navigating the online world: Norms and Netiquettes’, (b) ‘Exploring and expressing intimacy’, and (c) ‘My identity and the internet: The Digital Me’. From these abstract and analytical themes, ten subordinate themes were identified. The superordinate and subordinate themes are illustrated in Table 3, alongside contributions from the selected papers.

Table 3: Superordinate and subordinate themes with contributions

	Navigating the online world: Norms and Netiquettes					**Exploring and expressing intimacy**		**My identity and the internet: The Digital Me**		
Articles (First author & year)	Managing risk on the internet	Net etiquette and internet norms	Gatekeeping and surveillance behaviours	Need for policy and guidance	Embarrass-ment and shame	Cyber relationships and love over the web	Accessing pornography and sexual content	Anonymity	Like everyone else	Cyber-language and communicating over the internet
Darragh (2019)	X		X		X	X	X	X		X
Darragh (2017)	X	X	X			X	X			X
Lines (2020)	X		X	X		X	X		X	
Löfgren-Mårtenson (2008)	X	X	X	X		X	X		X	X
Löfgren-Mårtenson (2018)	X	X	X	X		X	X	X	X	X
Löfgren-Mårtenson (2015)	X	X	X		X	X	X		X	X

Figure 2. Superordinate and subordinate themes



5.4.1 Navigating the online world: Norms and Netiquettes

The included studies highlighted a conflicted discourse between the rights of individuals with intellectual disabilities to access the internet for sexual and intimate purposes and balancing the potential risks that accessing the internet poses. Several barriers were identified throughout the papers that may prevent individuals with intellectual disabilities from accessing the internet for sexual and intimate purposes. These barriers ranged from the actions of others around them, such as gatekeeping or surveillance behaviours from family members or professionals, and personal obstacles such as feelings of shame.

Subtheme 1: Managing risk on the internet

Professionals, parents, and individuals with intellectual disabilities within the six studies emphasised the potential risks of accessing the internet (Darragh, 2019; Darragh et al., 2017; Lines et al., 2020; Löfgren-Mårtenson, 2008; Löfgren-Mårtenson et al., 2015, 2018).

The risks associated with accessing the internet were often expressed alongside the view of the perceived vulnerability of individuals with intellectual disabilities. These risks included meeting with someone off the internet they did not know, being exploited sexually, or accidentally accessing illicit material. Professionals and parents are often presented with a conflict between mitigating risk and protecting from harm whilst also allowing for autonomy, with one professional stating: *“my role would be to facilitate somebody to be able to do what they wanted to do, to get their wishes, but to keep them safe from underlying harm that might come their way due to their vulnerabilities”* (Lines et al., 2020, p. 7).

However, although individuals with intellectual disabilities acknowledged the potential risks involved with accessing or meeting people off the internet, they expressed considerable judgement in managing and mitigating the risks involved: *“If I want to meet someone I’ll try and wait awhile to meet them because I would rather get to know them first just in case they may be a paedophile or anything”* (Darragh et al., 2017). Frequently, the individuals had developed cyber safety practices through their own intuition or modelling behaviour from those around them, such as friends or siblings, rather than through formal education. Individuals expressed how they would manage risks when meeting someone off the internet, such as having their phone on them, meeting in a public place, or asking for help if they felt unsafe. However, despite an understanding of how to handle the potential risks of meeting someone off the internet for romantic or sexual purposes, some women with intellectual disabilities entered situations that contradicted their statements, meeting with strangers for the first time within their home: *“She went away once to meet this guy and then she stayed there during the weekend! And I mean…now she is doing it again, even though she surely learned a lesson last time.”* (Löfgren-Mårtenson, 2008, p. 133). However, risk can be perceived within social and cultural contexts (Löfgren-Mårtenson, 2008), and individuals with intellectual disabilities may not deem the risk of potentially be endangered as seriously as being isolated or not being able to access romantic or sexual relationships.

Löfgren-Mårtenson (2008) identified that young people with intellectual disabilities who accessed the internet felt confident in staying safe, with more positive views being expressed than those who worked or cared for them. The understanding and perceptions of risk on the internet differed (Löfgren-Mårtenson, 2008). Lines, Combes and Richards (2020) identified strategies applied by support staff to reduce risk and highlighted the conflicted moral positioning of staff when supporting romantic relationships developed on the internet. Support staff recognised the importance of accessing romantic and sexual relationships, with managing risk being on a continuum of direct and intrusive support to monitoring the use of the internet: *"It's their choice really, the only thing I can do is to make sure they come back safe, and when they come back that they feel comfortable talking about their experience."* (Lines et al., 2020, p. 7).

Subtheme 2: Net etiquette and understanding internet norms

Four of the papers referenced social norms on the internet (Darragh et al., 2017; Löfgren-Mårtenson, 2008; Löfgren-Mårtenson et al., 2015, 2018), and how individuals with intellectual disabilities navigate these. Due to their limited ability to understand internet norms and conduct, individuals with intellectual disabilities can find difficulty following 'netiquette' rules (Bergman, 1999), therefore becoming more vulnerable to bullying, sexual assault, or sexual risk. Young adults with intellectual disabilities were persuaded to undress via web cameras, believing that this may increase their popularity and gain friendships and partners with other young people without intellectual disabilities. One teacher described: *"Many might not have such a large social network and if you have it online, it is great. However, they do not know who the others are…They [the youths with intellectual disabilities] are often gullible and credulous and can then be made to do things that they do not really want to. When you have a [intellectual] disability, then you are more* *vulnerable."* (Löfgren-Mårtenson et al., 2018, p. 56). As a result, professionals and parents may utilise controlling or protective actions to protect individuals with intellectual disabilities, including banning sites that include sexual content or giving fixed timeframes of when they can access the internet.

Some studies highlighted that some young adults with intellectual disabilities are motivated to learn about norms and social codes in cyberspace to gain more social, romantic, and intimate contacts online. However, teachers, siblings, or friends may act as internet role models for individuals with intellectual disabilities. Teachers reported educating young adults regarding boundaries and the internet, such as not writing things with sexual meanings in a public forum, publishing intimate photos without consent, or expressing feelings of love to individuals on the internet they have not met: *"Well, it is difficult [for them] to have some kind of sense of what is proper to write or not. For example, this thing with "I love you"…They express anything in some of…well, other youngsters can do that also…but these kids, they write anything without thinking…"* (Löfgren-Mårtenson et al., 2015, p. 538).

Subtheme 3: Gatekeeping and surveillance behaviours

The theme of gatekeeping and surveillance behaviours from professionals and family members emerged across all the six papers (Darragh, 2019; Darragh et al., 2017; Lines et al., 2020; Löfgren-Mårtenson, 2008; Löfgren-Mårtenson et al., 2015, 2018). Individuals with intellectual disabilities expressed that family members would check their electronic devices to see what they had been accessing or monitor their social media accounts to see who they had been speaking to. Some family members denied individuals access to the internet for sexual or intimate purposes and implemented firewalls or blocks so adult content could not be accessed. Family members often cited safety concerns, with one informant detailing: *"My mum won't let me use Facebook for safety reasons."* (Darragh et al., 2017, p. 6); however, they were unable to expand on what those safety reasons were.

From papers that interviewed professionals, there appeared to be a continuum of views in terms of supporting people with intellectual disabilities to access the internet, from controlling to being more permissive (Lines et al., 2020; Löfgren-Mårtenson et al., 2018). Some professionals advocated for restrictive rules, whereas others expressed more faith that people with intellectual disabilities use the internet safely. These attitudes were not related to professional position, age, or gender, but possibly from a more individual standpoint with associated views on risk factors, such as sexual assault or bullying (Löfgren-Mårtenson, 2008). Staff reflected on the individual differences and distinctions between opinions regarding the role of a support worker: *"I feel like it's one of the extra things, like above and beyond, you know, it's part of our role to make sure they're safe and supported in everyday decision…I feel like any really good support worker strives to do (support with sexual relationships), cause it's part of the empowering them, isn't it?"* (Lines et al., 2020, p. 5).

Subtheme 4: Need for policy and guidelines

Three papers discussed the need for policies and guidelines for professionals working with adults with intellectual disabilities to access the internet (Lines et al., 2020; Löfgren-Mårtenson, 2008; Löfgren-Mårtenson et al., 2018). It was acknowledged that some professionals experienced a shift in attitude, mainly due to a societal normalisation process. Furthermore, as professionals increased their access to the internet, their view of the internet changed to become more positive (Löfgren-Mårtenson et al., 2018). Professionals expressed a lack of strategies when working with adults with intellectual disabilities who wish to access the internet for intimate purposes. It was highlighted that a continued need for education, policy, and guidelines is needed for staff to manage ethical dilemmas or conflicts (Lines et al., 2020), reducing the need for surveillance or gatekeeping behaviours. Dilemmas around support for using the internet for intimate purposes and making decisions related to the policy were discussed by staff: *"It's a* *minefield isn't it, getting somebody to the point where they're able to access that, but safeguarding them, you know, keeping them safe, and also keeping other people safe."* (Lines et al., 2020, p. 7).

Subtheme 5: Embarrassment and shame

Two of the papers highlighted that some individuals with intellectual disabilities might not choose to access the internet for sexual or intimate purposes due to internalised shame or embarrassment (Darragh, 2019; Löfgren-Mårtenson et al., 2015). Some views held by individuals with intellectual disabilities regarding accessing the internet for sexual purposes or pornography were negative. Some respondents said it was wrong or inappropriate: *"I think it's just you know uncalled for like people out there like to look at pornographic stuff and I just don't do that stuff, I'm not like that person. I'm a good boy."* (Darragh, 2019, p. 109). Individuals with intellectual disabilities may also choose not to access explicit or sexual content due to self-consciousness regarding their body image, or feelings of inadequacy regarding their physical attractiveness. One respondent expressed discomfort with accessing intimate photos online, reporting: *"Umm because it kinds of puts me, it feels like it puts me down because of the way I look. Umm but anyone's got their own sizes and what not but I don't. I feel this insecurity thing for me. Umm I don't feel pretty enough yet."* (Darragh, 2019, p. 107).

5.4.2 Exploring and expressing intimacy

The included studies described and explored the internet use by people with intellectual disabilities for sexual or intimate purposes. The use of the internet for such purposes was often to develop and maintain romantic or sexual relationships, meet people off the internet, or access sexual content such as pornography.

Subtheme 1: Cyber-relationships and love over the web

Professionals, parents, and individuals with intellectual disabilities within the six studies discussed the use of the internet to meet and develop romantic, sexual, and intimate relationships (Darragh, 2019; Darragh et al., 2017; Lines et al., 2020; Löfgren-Mårtenson, 2008; Löfgren-Mårtenson et al., 2015, 2018). The adults within the studies expressed the importance of the internet in finding a partner, both to pursue online or with the potential to meet in real life. The internet was viewed as a positive social arena that created possibilities of meeting a partner: *"When I was 17 I decided to get a boyfriend through the internet. That's the right place if you want to shag a partner!"* (Löfgren-Mårtenson, 2008, p. 130). Informants within the selected studies also stated they had used the internet to flirt with others and express their sexual attraction. Young adults with intellectual disabilities detailed their desire to use social media platforms to talk to others and arrange to meet in real life, expressing their desire to develop friendships and relationships with others without an intellectual disability.

Young adults in some studies (Löfgren-Mårtenson, 2008; Löfgren-Mårtenson et al., 2018) expressed difficulty in developing a relationship in real life. However, they had engaged in online relationships, in which their interactions only exist on the web: *"I have my best friends on the Net…and a girlfriend. But I have never met them."* (Löfgren-Mårtenson, 2008, p. 132). Professionals acknowledge that these relationships are experienced as equally real as any other relationship, although they acknowledged some young adults with intellectual disabilities may find difficulty in understanding the other person's needs and feelings, leading to conflict: *"I have pupils who…only have net relationships…and they write to each other…and then suddenly…they are sitting by the computer crying…and in despair…because now it is over…the other partner broke up…and…really, they have never met outside of cyberspace!"* (Löfgren-Mårtenson et al., 2018, p. 538). However, the internet provides individuals with intellectual disabilities with opportunities to develop romantic and intimate relationships that they may otherwise not have access to.

Subtheme 2: Accessing pornography and sexual content

The views on accessing pornography differed among individuals with intellectual disabilities, their family members, and professionals. All six studies found that individuals with intellectual disabilities accessed pornography or sexual content online (Darragh, 2019; Darragh et al., 2017; Lines et al., 2020; Löfgren-Mårtenson, 2008; Löfgren-Mårtenson et al., 2015, 2018). Parents of young people with intellectual disabilities expressed worry about their children accessing pornographic websites, citing that they may not understand what they are accessing or may lack the maturity to discuss sex and sexuality on the internet (Löfgren-Mårtenson et al., 2015). Teachers highlighted concerns regarding the influence of viewing pornography on young people's views on gender and sexuality. However, they acknowledged that internet use for individuals with an intellectual disability is more limited and restricted in comparison to other young people (Löfgren-Mårtenson et al., 2018).

However, some adults with intellectual disabilities described accessing the internet for pornography or erotic content as a positive experience. It allowed them to feel more confident in their sexual or intimate relationships with others in real life: *"I did used to look at porn and all that just to get ideas, like to do things with my girlfriend and all that at the time"* (Darragh, 2019, p. 104). Others highlighted that accessing pornography or erotic content allowed them to express their sexuality in a safe environment. It did not involve having to meet another person, with the following extract from an informant explaining why he used the internet: *"That is the main reason that I use the internet…to be able to do it. I don't want to get in contact with them. Just look at them. It is very exciting to enter the "underworld" and to see what they are doing!"* (Löfgren-Mårtenson, 2008, p. 132).

People with intellectual disabilities expressed some concerns in terms of accessing pornography. They felt if a family member or staff member found out, their ability to access the internet would be stopped or restricted. It highlighted the disparity of views on viewing erotic content online: *"I'll get told off by mum if I do that. Mum says don't go onto any of the…those things, yeah."* (Darragh, 2019, p. 105). However, some family members were supportive of respondents accessing pornography online, although encouraged accessing this within a private space, with one respondent explaining he watched pornography: *"Only in my room in a private place. In a private place and only at night-time…and not in front of people".* (Darragh, 2019, p. 104). Other respondents expressed they did not watch pornography or look at erotic content as a form of respect for their partner.

5.4.3 My identity and the internet: The Digital Me

Another theme that arose within the papers was the formation and development of identity through accessing the internet. Individuals with intellectual disabilities can present themselves in the way they want to over the web, enabling a feeling of fitting in and being 'normal'. This provided them with a social arena to express their personality, opinions, or views without the judgement of others. The three sub-themes, anonymity, feelings of being like everyone else, and communication over the internet, impact this central theme.

Subtheme 1: Anonymity

Two papers (Darragh, 2019; Löfgren-Mårtenson et al., 2018) reported anonymity as an essential factor when individuals with intellectual disabilities access the internet for sexual or intimate purposes. Individuals with intellectual disabilities may flirt or engage in sexual conversation with others online, as these net relations frequently stay on the internet and remain anonymous. Remaining anonymous online allows individuals to explore and experiment with their sexuality in ways that they may not be able to do in real life and provides a form of separation from their actions to their identity (Delmonico & Griffin, 2011). Anonymity also enables connections between people who may not meet in other circumstances.

Subtheme 2: Like everyone else

Four of the papers expressed a theme in terms of adults and young people with intellectual disabilities using the internet to feel like everyone else (Lines et al., 2020; Löfgren-Mårtenson, 2008; Löfgren-Mårtenson et al., 2015, 2018). Some respondents expressed that they did not mention their intellectual disability when accessing the web (Löfgren-Mårtenson, 2008), with the internet facilitating opportunities to present in a manner of their choosing and projecting a preferred identity, even if this differs from the identity presented offline. This allowed the individuals to escape the stigma associated with intellectual disability (Löfgren-Mårtenson, 2008). Using the internet enables individuals to socialise with others beyond the control or supervision of staff or family members and allows for a private space where they can escape the control of the surrounding world (Löfgren-Mårtenson, 2008).

Parents and professionals acknowledge that accessing the internet is essential for individuals with intellectual disabilities, particularly social media sites, as these sites are visited and used by those without an intellectual disability. It was also recognised that young people accessing the internet to find a partner and express their sexuality allowed them to generate feelings of being ‘normal’ and experiencing similar life events to that of their peers: *“It seems to be a way of feeling recognition somehow…to show who you are and…how many girls and boys you have met…how much sex you have. Again, it is this thing about being “normal”!”* (Löfgren-Mårtenson et al., 2015, p. 537). Support staff also acknowledged their role in supporting the use of the internet for individuals they work with: *“I think that would be, one of the best things you could possibly do to make somebody feel that there is actually an existence outside of their unit, their support, living in a home.”* (Lines et al., 2020, p. 4).

Subtheme 3: Cyber language and communicating over the web

Five of the papers explored language and communication over the internet as both a barrier and facilitator to making friendships and relationships, chatting with others, and expressing sexuality (Darragh, 2019; Darragh et al., 2017; Löfgren-Mårtenson, 2008; Löfgren-Mårtenson et al., 2015, 2018). For individuals with intellectual disabilities, cyber language is seen as advantageous as it does not rely on correct spelling or grammatical references, and feelings, emotions, or views can be expressed using pictures, symbols, or emoticons. One respondent reflected on the advantages of communicating over the internet: *"The only problem I have on the Net is with spelling. But that doesn't matter because the girls understand me anyway. That shows how kind they are to me."* (Löfgren-Mårtenson, 2008, p. 130).

However, cyber language may contain subtle codes, references, or social norms that may be difficult to understand or recognise, making communication over the internet difficult for some individuals with intellectual disabilities (Löfgren-Mårtenson et al., 2018). Professionals reflected on the support they have provided to young people with intellectual disabilities due to misunderstandings on the internet due to communicative limitations: *"Sometimes misunderstandings take place, and that happens quite often. Sometimes they express themselves [in weird ways] and don't really understand what they've said or what is written online. They are asking for help to find out about these problems."* (Löfgren-Mårtenson et al., 2018, p. 8). Cyber-language or communicating over the internet is problematic due to the lack of body language, with written words the only source of interactions. Family members also recognised the importance of body language when communicating; *"Because you are supposed to interpret…interpret faces…and feelings…feelings of warmth…or…well, you get so much more information when you talk to people (in real life) instead of wondering" Is this what she meant?"* (Löfgren-Mårtenson et al., 2015, p. 537). Communicating over the internet also brings difficulty in gauging and understanding others' intentions or what information is shared by others is false.

The internet also provides a social arena for individuals with intellectual disabilities to make or maintain friendships, mainly if some are socially isolated and the internet is their only contact network (Löfgren-Mårtenson et al., 2018). Some of the respondents described feelings of loneliness. The internet enabled the ability to communicate with others, arrange social events and activities, and expand networks and social circles.

6. Discussion

The present review explored the views, attitudes, and experiences of the use of the internet for sexual and intimate purposes by individuals with intellectual disabilities. The review identified six qualitative studies (Darragh, 2019; Darragh et al., 2017; Lines et al., 2020; Löfgren-Mårtenson, 2008; Löfgren-Mårtenson et al., 2015, 2018) that explored the views and experiences of individuals with intellectual disabilities, family members, educational professionals, and support staff. Barriers to accessing the internet for sexual and intimate purposes were also identified. These papers were quality appraised before findings were analysed using thematic synthesis. The process of synthesis resulted in three superordinate themes being identified: (a) 'Navigating the online world: Norms and Netiquettes', (b) 'Exploring and expressing intimacy', and (c) 'My identity and the internet: The Digital Me'.

Although synthesis findings provide an insight into the use of the internet for sexual and intimate purposes by individuals with intellectual disabilities, several methodological issues were raised concerning the selected articles included within the systematic review. The selected studies received moderate to high global quality ratings (Butler et al., 2016) following quality appraisal, however the number of informants within the studies consisted of small sample sizes. Individuals with intellectual disabilities who have an interest or knowledge regarding the internet were likely to be over-represented in the sample within the studies. Sourcing participants from a limited number of organisations, services, or educational institutions may have provided a limited and unrepresentative view of the use of the internet for intimate and sexual purposes for adults with intellectual disabilities.

The participants across the studies appeared to have a diagnosis of a mild intellectual disability, and it is likely the severity of intellectual disability would impact the experience of using the internet for sexual or intimate purposes. This has also been highlighted regarding research on internet use by individuals with intellectual disabilities more generally (Caton & Chapman, 2016). Authors within the studies often did not provide detail regarding their reflexivity and their own experiences and biases, which may have impacted the interpretation of qualitative data (Löfgren-Mårtenson et al., 2015, 2018). However, the selected studies revealed similarities in themes, with the thematic synthesis grounded in examples and themes across the articles.

The findings of the synthesis indicate that individuals with intellectual disabilities access the internet for sexual and intimate purposes, such as flirting and chatting to others online, engaging in online relationships, meeting others from the internet, and accessing pornography or sexual content (Darragh, 2019; Darragh et al., 2017; Lines et al., 2020; Löfgren-Mårtenson, 2008; Löfgren-Mårtenson et al., 2015, 2018). Family and professional perceptions and attitudes of individuals with intellectual disabilities accessing the internet for intimate purposes varied, with views on a continuum from encouraging to restrictive and controlling (Lines et al., 2020; Löfgren-Mårtenson et al., 2015, 2018). This is similar to findings regarding the views and attitudes of carers and staff when supporting adults with intellectual disabilities with sexuality and sexual relationships more generally (Grieve et al., 2009; Saxe & Flanagan, 2014).

Although professionals and family members expressed the right for adults with intellectual disabilities to express their sexuality and embraced the normalisation discourse, concern was also raised about the possibility of being taken advantage of online or being at risk of exploitation. Sexual expression continued to be seen as a source of risk and vulnerability by both family members and professionals (Löfgren-Mårtenson, 2008), similar to findings of previous research regarding sexuality and adults with intellectual disabilities (Rushbrooke & Murray, 2014). However, the view of risk can be perceived as a result of social processes (Löfgren-Mårtenson, 2008), with people with intellectual disabilities expressing that a more prominent risk lies in not being able to access the internet and therefore have limited access to developing sexual or intimate relationships (Löfgren-Mårtenson, 2008). Adults with intellectual disabilities demonstrated the ability to identify, assess, and formulate strategies to mitigate online risk. The use of the internet continues to have a dichotomous view, acknowledging that although the internet provides a social arena to make new friends or relationships, it also lends to disappointment or conflicts (Löfgren-Mårtenson, 2008).

The review highlights the importance of the internet for individuals with intellectual disabilities to develop and express their identity. Using the internet provides a space where individuals do not have to mention or discuss disabilities and can remain visually anonymous (Cromby & Standen, 1999). The internet offers a social arena to feel included and having access to the internet may enable coping strategies to manage negative stereotypes, attitudinal biases, and social and physical exclusion (Chadwick et al., 2013b). Such findings are consistent with current research regarding internet use and adults with intellectual disabilities, highlighting the importance of the internet and social media in providing a means to express a social identity (Caton & Chapman, 2016).

The review corroborates the barriers to accessing the internet by individuals with intellectual disabilities identified by other researchers (Caton & Chapman, 2016; Chadwick et al., 2013a, 2013b; McKenzie, 2007). The review highlights the importance of examining barriers to accessing the internet for individuals with intellectual disabilities and reducing these to enable adults to develop relationships and express their sexuality. Adults with intellectual disability may mirror or express repressive societal beliefs and attitudes from their family members or caregivers, describing accessing or viewing sexual content on the internet negatively. Some family members and professionals within the studies applied restrictive measures or surveillance behaviours in an attempt to mitigate risk; however, this denies the opportunity for individuals to express their sexuality or intimacy online.

Professional views on the internet and the use of restrictive practices appear to be influenced by a lack of policy or guidance. This finding is widely consistent with existing research that there continues to be a lack of training or policy implementation in services that support adults with intellectual disabilities (Evans et al., 2009). The absence of clear policies creates uncertainty and leaves professionals with moral dilemmas between the wish to support the sexuality of those they work with while also protecting them from harm. This could result in restrictive measures being implemented or the delivery of inconsistent messages for individuals with intellectual disabilities. This would align with current research on individuals with intellectual disabilities, highlighting that professionals' approach toward sexuality and intimacy is inconsistent (English & Tickle, 2018).

There is conflicting evidence regarding the level of internet use among individuals with intellectual disabilities within the studies identified within the review. Current research indicates lower levels of internet use by people with disabilities and people without disabilities (Guo et al., 2005). However, it is noted that the participants within the selected studies tended to be younger, and therefore are more socialised to internet use and have had greater opportunity to access computers and the internet than previous generations (Margaryan et al., 2011). The selected studies included small, unrepresentative samples, which may not accurately reflect the use of the internet by people with intellectual disabilities more generally.

The findings of this review support a growing body of literature regarding the sexuality and sexual expression of adults with intellectual disabilities. It is evident from previous research that people with intellectual disabilities experience barriers to accessing technology (Batey & Waine, 2015; Shakespeare, 2008) and are often infantilised or viewed as asexual (Brown, 1994; Franco et al., 2012; Murphy, 2003; Sweeney, 2007).

6.3 Strengths and limitations

At present, there is no overview or quality appraisal of the available research that explores the use of the internet for individuals with intellectual disabilities for sexual or intimate purposes. The thematic synthesis enabled the amalgamation of views and perspectives from individuals with intellectual disabilities and parents or the professionals they work with from multiple studies. Exploring these views and perspectives highlighted barriers to accessing the internet, identity when using the web, and the interplay of these factors when using the internet for intimate purposes.

A potential limitation of the current review concerns issues that commonly arise when searching for qualitative literature in electronic databases. There is a risk that relevant studies may be missed during the database search (Evans, 2002). Although measures were utilised to minimise this, such as contacting other researchers and conducting a manual search, the potential for error remains. The current review included grey literature, with a doctoral thesis as one of the included studies (Darragh, 2019). The inclusion of grey literature may limit the quality of the review due to the lack of a process of peer review; however, including unpublished research may have offered enrichment or further depth to the analysis and reduced publication bias (Paez, 2017). A strength of the current review is the inclusion of a second reviewer, which optimised the value of the critical appraisal of the selected studies and ensured a more balanced result.

In the present review, a variety of databases were searched alongside a manual search of reference lists to ensure relevant papers had not been missed. The database search utilised broad search terms, with the comprehensiveness of the search having significant implications on the validity of the review (Hemingway & Bereton, 2009). However, it is possible that some relevant papers may have been missed due to a wide range of search terms and the breadth of the area of internet use for sexual purposes.

The present review amalgamated views and perspectives from several groups, including individuals with intellectual disabilities, family members, and professionals. These groups may have various training or education about sex and sexuality, and it may have been beneficial to analyse the data separately to identify themes within groups. However, due to the limited number of available research literature on the subject, this was not possible. Furthermore, there may be a risk of social desirability bias when conducting interviews and bias when recruiting participants for qualitative research. Parents or professionals with more openly negative or discriminatory views on the use of the internet for sexual purposes may be under-represented in the current review and within the literature overall due to exclusion by self-selection (Robinson, 2014). Those with more liberal views and beliefs may be more open to participating in a study regarding sexuality.

Another limitation of the current review is that it only included papers written in English. Therefore, there is the risk that valuable findings from papers written in other languages may have been missed or overlooked (Liberati et al., 2009). The research papers included in the present review have generally used small samples, which may impact on generalisability of findings. Future research within the area may benefit from utilising a more robust methodology and developing clear theoretical models, such as models relating to interdependence and autonomy (Seale, 2007) or the social model of disability (McClimens & Gordon, 2008, 2009).

The researcher’s views and experiences may have impacted on the thematic synthesis of the selected articles. The principal researcher utilised structures professionally in terms of supervision to manage factors that may have influenced the synthesis and interpretation of findings. The researcher also used a reflective diary to reflect on potential biases throughout the research process. However, there is still debate regarding the trustworthiness of qualitative data more generally (Elo et al., 2014), and the present review included only qualitative articles. The thematic synthesis methodology applied within the review offers a transparent synthesis of the selected studies. However, it may be of benefit to include studies that utilise quantitative methods in future research.

The selected studies explored the use of the internet by individuals with intellectual disabilities who were both within a current relationship and unpartnered, providing insight into the decisions made on what content was deemed appropriate to access. Two studies highlighted that partnered adults with intellectual disabilities were mindful of viewing pornography or explicit content in terms of their partner’s wishes in how, where, and what material was accessed (Darragh, 2019; Darragh et al., 2017). However, none of the selected studies included sexually diverse participants, therefore, the use of the internet by individuals with intellectual disabilities who identify as lesbian, gay, bisexual, or transgender was not explored.

6.1 Implications for individuals with intellectual disabilities

The review highlights that some individuals with intellectual disabilities used the internet to express their sexuality, in addition to being a social arena to develop relationships and explore their identity (Löfgren-Mårtenson, 2008). As adults with intellectual disabilities may be at greater risk of social isolation and increased stigma (Batey & Waine, 2015; Jaeger, 2012), the internet provides means to engage with others socially.

The review highlights that the views of family members, carers, or professionals regarding sexuality and sexual expression and the use of the internet can affect individuals with intellectual disabilities. This can be both on an individual level, in terms of internalised shame or developing the notion that sexual expression is wrong, and within the broader context of restrictive or gatekeeping practices. Individuals who internalise negative views on expressing their sexuality may then refrain from accessing the internet for sexual purposes or avoiding romantic or sexual relationships (English & Tickle, 2018; Rushbrooke et al., 2014). Individuals with intellectual disabilities may also choose to hide or engage with sexuality in secrecy, potentially putting themselves at greater risk.

6.2 Implications for professionals and family members

Research has emphasised the ethical dilemmas support staff and professionals face when managing risk and privacy when supporting adults with intellectual disabilities to access the internet (Chadwick et al., 2013b; Lines et al., 2020). The findings of the review highlight the need for clear policies to support individuals with intellectual disabilities to access the internet for sexual or intimate purposes and consistent policies within organisations that support individuals and prevent the violation of human rights, in addition to alleviating concerns regarding accountability (Lines et al., 2020). Without a clear policy, decisions around support may be influenced by staff's individual beliefs and values rather than best practices (Lines et al., 2020). The policy should emphasise that decisions should be made to promote empowerment in adults with intellectual disabilities, rather than focusing on decisions around risk and capacity.

The implications of the review findings suggest the need for a clear and structured education programme that is available for all family members and professionals that support individuals with intellectual disabilities to use the internet for sexual purposes. The programme should incorporate views from individuals with intellectual disabilities and highlight their ability to navigate the internet safely and explore sexual relationships in a safe manner (Darragh et al., 2017). Opportunities for reflective practice should be provided alongside training for staff to challenge the societal belief that adults with intellectual disabilities are more childlike or vulnerable (Franco et al., 2012, Sweeney, 2007). A change in societal attitudes, beliefs, and views regarding sexuality and disability is required to support the human rights of people with intellectual disabilities (Darragh et al., 2017).

6.4 Research recommendations

There remains a perceived view of adults with intellectual disabilities being at heightened risk or vulnerability when accessing the internet, which prompts consideration of the ‘digital divide’ (Chadwick & Wesson, 2016). Further research and practice work would be beneficial to reduce misconceptions or prejudicial assumptions about the reduced ability to identify or mitigate risk online for people with intellectual disabilities. Further research may focus on family member or professional views and the reasons they may apply surveillance or gatekeeping behaviours and explore what processes may need to happen for individuals with intellectual disabilities to access the internet for sexual use. It may also be helpful to explore the responses of family members or professionals if an adult with an intellectual disability wishes to engage in more risky behaviour online.

The studies within the current review explored the experiences of individuals with intellectual disabilities who have already accessed the internet. Future research should examine the experiences of individuals with intellectual disabilities who do not use the internet frequently and face exclusion from the internet, such as experiencing less support or requiring higher levels of support. Further to this, future research should explore the mechanisms behind gatekeeping behaviour by family members or staff, and the effect of this on the self-determination of individuals with intellectual disabilities when accessing the internet for sexual purposes.

No research to date explores the use of the internet for sexual or intimate purposes for individuals with intellectual disabilities who identify as lesbian, gay, bisexual, transgender, or queer+ (LGBTQ+). Given the evidence of the prevalence of negative or discriminatory views or attitudes towards the sexuality of individuals with intellectual disabilities (McCann et al., 2016; Smith et al., 2022), future research on how these attitudes impact the use of the internet for sexual or intimate purposes may be helpful to explore. It may also be beneficial to explore views on sexuality and the internet based on gender, as these are often influenced by the socialisation process (Gagnon & Simon, 2005).

7. Conclusion

With the shift in focus of using the internet in daily life, access to the internet is essential. Adults with intellectual disabilities increasingly use the internet for sexual and intimate purposes, such as consuming sexual content, chatting and flirting with others online, and developing romantic relationships. Professionals and family members may need to support adults with intellectual disabilities to access the internet; however, restrictive or surveillance behaviours may be used due to the perceived risk or vulnerability. The present review provided an overview, quality appraisal, and synthesis of qualitative research in this area. Despite the identified limitations, the review offers further insight into the use of the internet and is the first qualitative synthesis of findings. From the synthesis, the internet provides a positive platform for adults with intellectual disabilities to explore their sexuality and access romantic and intimate relationships.

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Journal Article 2: Empirical Paper

The sexual and romantic lives of adults with intellectual disabilities who are LGBTQ+: Experiences, attitudes, and influences of paid and unpaid carers

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1. Abstract

Background: There is a growing body of research exploring the sexual and romantic lives of adults with intellectual disabilities (McCann et al., 2016). However, the experiences of those identifying as LGBTQ+ remain limited, particularly regarding how family members and support staff views influence the support and development of sexual identity and sexual relationships.

Method: This study aimed to explore how the views and experiences of paid (support staff) and unpaid (family members) and how they relate and influence the support provided to adults with intellectual disabilities who identify as LGBTQ+. Six participants were interviewed, and data was analysed using Interpretative Phenomenological Analysis (Smith & Osborne, 2008).

Results: Four superordinate themes were identified: (a) ‘Journey of coming out’, (b) ‘Minority in a minority, (c) ‘Protection and possibilities’, and (d) ‘Access to similar others’.

Conclusions: Findings suggested that participants held a largely positive and liberal stance on non-heterosexual identities. Adults with intellectual disabilities who identified as LGBTQ+ experienced a journey of self-acceptance, receiving acceptance from others and experiencing discrimination and self-stigma. Lack of sexual education and training for staff and family members was a common theme and highlights the need for further provision to support family members and staff in building knowledge and confidence in supporting sexual and romantic relationships. Clinical and research implications are suggested, such as the impact of LGBTQ+ groups for adults with intellectual disabilities on psychological well-being.

Keywords: LGBTQ+, sexual, romantic, Intellectual Disabilities, experiences, family, staff

Word count: 13,239

Conflicts of interest: None

2. Introduction

Sexuality is an integral and central part of being human and incorporates aspects such as intimacy, gender identity, and sexual orientation (Krebs, 2007). Adults with intellectual disabilities have expressed similar experiences, needs, and desires for relationships and intimacy as adults without intellectual disabilities (English & Tickle, 2018; Whittle & Butler, 2018). However, despite the psychosocial benefits of sexual and romantic relationships (Braithwaite et al., 2010), individuals with intellectual disabilities have been historically viewed as being asexual and can face significant challenges when developing and maintaining intimate relationships (Arias et al., 2009; English et al., 2018; Fulford & Cobigo, 2018). Sexual expression may remain inaccessible for some due to lack a of privacy, lack of knowledge regarding sex, and fewer opportunities to express sexuality (Cuskelly & Gilmore, 2007).

Disability movements have moved towards promoting human rights and equality (Verdugo et al., 2012). The changes in policy and legislation within the United Kingdom, such as 'Valuing People Now' (Department of Health, 2009) and 'The Keys to Life' (Scottish Government, 2013), alongside shifts in societal perspectives, have influenced the development of increased independence and social inclusion (Culham & Nind, 2003). The principles of normalisation have highlighted the right of individuals with intellectual disabilities to experience romantic and intimate relationships and express their sexual needs according to societal norms (Aunos & Feldman, 2002). However, although services that support individuals with intellectual disabilities have an increased awareness of the importance of the sexual and romantic needs of their service users, there continues to be a lack of implementation of policies and continued barriers to the fulfilment of sexual expression (Evans et al., 2009; Blanchett & Wolfe, 2002; McCarthy, 2014; Wilson et al., 2018). Research within the area of sexuality continues to have increased focus on sexual abuse and exploitation of individuals with intellectual disabilities (Thompson & Brown, 1997) and sexual behaviours that challenge or cause risk (Cambridge et al., 2003; Evans et al., 2009; Haynes, 2016), with sexual expression and sexuality often overlooked.

There has been an emergence of research regarding the sexuality and romantic lives of individuals with intellectual disabilities (Rushbrooke et al., 2014); however, the current literature mainly focuses on heterosexual perspectives, with the support needs and experiences of adults who identify as lesbian, gay, bisexual, transgender, or queer (LGBTQ+) often underrepresented (Abbot, 2015). Individuals with intellectual disabilities who identify as LGBTQ+ experience stigma, prejudice, and discrimination due to disability and sexual orientation, resulting in further barriers to developing romantic and sexual relationships due to social exclusion and marginalisation (Jones & Magowan, 2010; Wilson, 2006). Further to this, few research studies have explored the experiences of lesbian and bisexual women with intellectual disabilities (Stoffelen et al., 2018).

Individuals who identify as LGBTQ+ are more likely to experience psychological distress than their heterosexual or cisgender counterparts, in addition to loneliness, sexual problems, and an increased risk of sexual violence (Clarke et al., 2010). Research into health issues and experiences among LGBTQ+ individuals with an intellectual disability is limited (Duke, 2011; McCann et al., 2016; Fraley et al., 2007). A literature review highlighted that increased awareness and understanding of LGBTQ+ individuals with intellectual disabilities is needed to reduce stigma and discrimination and improve health consequences (McCann et al., 2016). Individuals with intellectual disabilities voiced that they often feel unrepresented within healthcare services, and often experience stigma when developing romantic or sexual relationships. The review authors recognised the diversity of sexuality and the broader spectrum of identities. However, these usually are not explored and remain underrepresented within the literature (McCann et al., 2016).

Barriers remain for individuals with intellectual disabilities in developing and maintaining intimate and romantic relationships, including opportunities to meet others and a lack of sexual knowledge of safe sex practices (Eastgate et al., 2012; Whittle & Butler, 2018). Views and attitudes regarding sexuality and sex can be shaped by parental influence due to fewer opportunities in acquiring sexual knowledge through peer interaction (Jahoda & Pownall, 2014; Johnson et al., 2002; Szollos & McCabe, 1995). Social and sexual autonomy may be impacted further by remaining in the family home. Adults with adults with intellectual disabilities often receive continued support and involvement from their parents throughout their lives (Kelly et al., 2009).

Although family carers have expressed their want for their children with intellectual disabilities to have the same opportunities to develop sexual and romantic relationships, concerns regarding safety and perceived vulnerability are commonly raised (Lafferty et al., 2012). Perceptions around vulnerability and safety may lead to restrictions on freedom and may prevent adults with intellectual disabilities from the freedom to develop or maintain romantic relationships (Haynes, 2016). Further to this, although family carers may be in support of the development of intimate relationships or partnerships, it has been suggested that they may have reservations if this is with a member of the same sex (Blyth, 2010; Blyth & Carson, 2007; Carson & Docherty, 2002). A small body of research postulates that family caregivers may hold more conservative views regarding same-sex relationships than support staff (Cuskelly & Bryde, 2004). However, this finding may be confounded by the relatively younger age of support staff in their sample.

Research that has focused on the views of support staff suggests that they may hold liberal attitudes towards sexuality and intimate relationships (Cuskelly & Bryde, 2004; Drummond, 2006; Gilmore & Chambers, 2010; Tamas et al., 2019). However, several factors may influence these views, with older staff members tending to hold more conservative opinions than younger staff members (Aunos & Feldman, 2002; Karellou, 2003). Further, differences between views have been observed between inpatient and residential staff (Bazzo et al., 2007) and female staff carers (Löfgren-Mårtenson, 2004), who often have the least liberal sexual attitudes. Another consideration is that caregiver views on intimacy and relationships may be unrepresentative within the current literature, as participants taking part in research around sexuality may hold more liberal perspectives (Kaats & Davis, 1971).

A recent systematic review (Charitou et al., 2020) explored the views and perceptions of staff towards the sexuality and relationships of individuals with intellectual disabilities. Despite staff expressing an understanding of the importance of sexual expression and supporting service users with sexual needs, this was also perceived as a possible area of risk and vulnerability (Grace et al., 2020). Due to the interplay of factors, staff often respond to sexuality and relationships with conflicting views (Abbott & Howarth, 2007), balancing organisational policies with personal, religious, and ethical beliefs. Although opinions were not openly discriminatory, staff often voiced concerns and caution around sexual expression, and acknowledged that negative attitudes were prevalent amongst other staff members (Abbott & Howarth, 2007; Parkes, 2006; Thompson et al., 2014). These factors may act as barriers to adults with intellectual disabilities exploring and developing relationships, particularly with members of the same sex (Charitou et al., 2020).

The views and attitudes of paid and unpaid carers towards sexuality and relationships of individuals with intellectual disabilities can impact their ability to express their needs and desires for intimacy (Charitou et al., 2020). If sexual expression is discouraged or not discussed by family members or support staff, then this may reinforce the notion that sexuality or sexual activity is dangerous or forbidden (Grace et al., 2020; Kelly et al., 2009). Therefore, individuals with intellectual disabilities may refrain from seeking support or education around sex or engaging with their sexuality in situations where they are more likely to receive negative consequences (Charitou et al., 2020).

A limited body of qualitative research has explored family caregivers' views, experiences, and perspectives regarding their adult children's romantic and intimate lives with intellectual disabilities (Gürol et al., 2014; Pownall et al., 2011). A qualitative meta-synthesis (Rushbrooke et al., 2014) explored the challenges and difficulties experienced by family carers and support staff. Caregivers, both paid and unpaid, highlighted uncertainty and lack of confidence regarding sexuality. Although the presumption of adults with intellectual disabilities being asexual was not a pervasive view, sexual identity and attraction were often presumed as heterosexual, with homosexual attraction and acts seen as experimentation (Abbott & Howarth, 2003). This aligns with current literature which highlights the experiences of individuals with intellectual disability who have expressed attraction to an individual of the same sex have often had their experiences delegitimised, with family members or staff describing their sexuality as a 'phase' or due to confusion (Toft et al., 2019). This perceived heteronormative view of sexuality in adults with intellectual disability further impacts the barriers to those who identify as LGBTQ+ who wish to develop sexual or romantic relationships. Although family caregivers and support staff express positive regard towards sexual expression, it is often perceived as conditional with limitations (Rushbrooke et al., 2014).

The meta-synthesis (Rushbrooke et al., 2014) provides insight into the experiences of adults with intellectual disabilities and their sexual and romantic lives; however, heterosexual and heteronormative views were disproportionately represented within the research studies, detracting from the experiences of adults who identify as LGBTQ+. Staff views were also disproportionately represented within the studies compared to family members, highlighting a gap in the literature (Abbott & Howarth, 2007; Carnaby & Cambridge, 2002; Hamilton, 2009; Lockheart et al., 2009; Löfgren-Mårtenson, 2008; Taggart et al., 2010; Wilson et al., 2009; Yool et al., 2003). The studies did not report or explore the sexual orientation and identity of paid staff members and family caregivers. As sexual orientation may influence views and perspectives of the sexual lives of adults with intellectual disability, this may be an important demographic characteristic to include within future research and analyses.

Although there have been few studies exploring the views of family caregivers (Brown & McCann, 2018), the perspectives and experiences of adults with intellectual disabilities who identify as LGBTQ+ have been investigated. A systematic review (McCann et al., 2016) highlighted that sexuality is often perceived as an essential and integral part of identity; however, some adults with intellectual disabilities found difficulty accepting their sexual orientation. Some individuals expressed that they felt unrepresented or unsupported in services for adults with intellectual disabilities, which highlighted the need for inclusive and appropriate education and training for staff and family members around sexuality and expression (McCann et al., 2016). Studies have focused on the experiences of homosexual males, with the views and experiences of lesbian and transgender individuals underrepresented (Cambridge, 1996; Edmonds & Collins, 1999; Elderton et al., 2014; Stauffer-Kruse. 2007; Withers et al., 2001). This is reflected within the broader evidence base, with the voice of lesbian and bisexual women often unheard (Stoffelen et al., 2018). It is worth noting that McCann and colleagues (2016) found significant limitations in the robustness of the selected studies, particularly in small sample sizes, weaknesses in methodology, and lack of transparency in analysis.

3. Rationale for the present study

There remains limited qualitative research that explores the views, experiences, and perspectives of family caregivers and support staff regarding supporting adults with intellectual disabilities who identify as LGBTQ+. Given the spectrum of non-heteronormative sexual orientations, and the importance of sexuality on wellbeing (Hull, 2008), this study aims to offer insight into the experiences of sexual minorities within the disability populace. The exploration of experiences aims to highlight the potential impact of views and attitudes on developing romantic and sexual relationships for adults with intellectual disabilities, and gain insight into barriers and facilitators of support. The key areas of exploration would pertain to the expression of the sexuality, intimate and romantic relationships, parenthood, sex education, and support needs.

The achieve the study aims, the research employed a qualitative design to explore the experiences, views, and attitudes of family members and support staff on the sexual and romantic lives of adults with intellectual disabilities who identify as LGBTQ+. The aim was to analyse perspectives on sexual expression, intimate and romantic relationships, bodily autonomy in terms of sexual health and parenthood, and sex education.

The use of family members and support staff were chosen due to their prominent role in supporting and enabling adults with intellectual disabilities access to social opportunities to meet others and sex education and supporting or preventing relationships. Furthermore, family members may considerably influence views and attitudes towards non-heteronormative sexual orientations. It is important to examine the views and attitudes of family members and support workers to identify barriers or facilitators to support, which can be targeted within training or psychoeducation within this group. Although it is vital to hear the voice of adults with intellectual disabilities within sexuality research, exploring potential gatekeeping behaviours or existing pejorative attitudes is an important focus to promote and enable sexual expression within this population.

The principal research question is 1) what are the attitudes, views, and experiences of paid and unpaid caregivers in relation to the sexuality of adults with intellectual disabilities who identify as LGBTQ+? To understand how paid and unpaid caregiver’s attitudes, views, and experiences influence support, further research questions were identified: 2) What are the sexual needs and experiences of adults with intellectual disabilities that identify as LGBTQ+, from the perspective of paid and unpaid caregivers? 3) Do the attitudes, views, and experiences of paid and unpaid caregivers act as barriers to support, education, and the development of interpersonal relationships?

4. Method

4.1 Design

This study employed a cross-sectional qualitative research design, recognised for collecting and assimilating data relating to lived experience. The qualitative study used semi-structured interviews to facilitate an in-depth exploration of the experiences of paid and unpaid caregivers when supporting an adult with an intellectual disability who identifies as LGBTQ+.

Interpretative Phenomenological Analysis (Pietkiewicz & Smith, 2014; Smith, 1996; Smith et al., 2009; Smith & Osborne, 2008) was chosen due to its flexibility in exploring the phenomena studied (Lincoln & Guba, 1985), with the researcher gaining an understanding of the phenomena from the perspective of the participant (Darragh et al., 2017; Delaney, 2003) and developing an understanding of the experience and meaning held by participants (Lester, 1999). Utilising Interpretive Phenomenological Analysis is aligned with the researcher's epistemological stance, as it enables the researcher to analyse unique perspectives and understand lived experiences without seeking objectivity (Smith & Osborn, 2008).

4.2 Principal researcher

The principal researcher has been employed in various roles working directly with individuals with intellectual disabilities and takes a social constructionist epistemological position (Gergen, 1985). The principal researcher holds strong views on the rights of individuals with intellectual disabilities and the rights of individuals who identify as LGBTQ+. The researcher believes that paid support workers and caregivers working with adults with intellectual disability should enable people to achieve their desires and goals and holds expectations of support workers to support the rights of those they are supporting.

4.3 Procedure

4.3.1 Ethical considerations

The University of Edinburgh Ethics Committee granted ethical approval for the study in February 2021 (Appendix 6 and Appendix 7). Further to this, ethical approval was granted by the Research Ethics Committee (REC) as part of the Health Research Authority (HRA) in November 2021 (Appendix 9), and Research and Development (R&D) approval was provided by NHS Lanarkshire, NHS Lothian, and NHS Greater Glasgow and Clyde health boards. The researcher considered further ethical issues regarding the sensitive nature of the study topic and the confidentiality of the participants. During the recruitment process, relevant permissions from third sector organisations were sought when required. A protocol pertaining to managing risk information or participant distress was developed, which included conducting interviews within working hours and informing supervisors of the time and date of interviews so they could be contacted if needed. Participants were provided with a brief sheet following the interview. The researcher included a list of local and national services that offer psychological support and support for individuals who identify as LGBTQ+.

4.3.2 Recruitment

Participants were recruited using several methods. Organisations and support services across the United Kingdom were found online and information was sent to the service manager via email. The information contained the Participant Information Sheet and a digital poster that had the researcher’s contact details. The researcher followed up contact with the organisations via telephone. In addition to this, a poster containing information about the study was shared on social media (i.e. Twitter, Facebook), which included an electronic link that participants could follow to the Participant Information Sheet and consent form. Participants could then complete the consent form and provide their email address or telephone number for the researcher to make contact if they wished to participate. Using social media platforms to recruit enabled the utilisation of a snowball subject recruitment to access additional potential populations. All participants that took part in the study contacted the researcher through email or social media to express their interest in participation. They were then sent a link to the Participant Information Sheet and consent form, which they completed before the interview.

Service managers and clinicians across three National Health Service (NHS) health boards within Scotland were contacted via telephone and email. Participant Information Sheets, consent forms, and recruitment materials were sent to these clinicians. They were encouraged to review their caseloads to identify adults with intellectual disabilities who identify as LGBTQ+ and contact them to share information regarding the study. If the service users and family members showed interest in participating in the research, their contact details were to be shared with the researcher. The researcher's contact details were also provided to the potential participant so they also may make contact. No participants were successfully recruited through the NHS health boards that were contacted.

Participants met the following criteria to partake in the research; they supported or cared for an adult older than 18 years old with a mild or moderate intellectual disability, they were fluent in English and could provide informed consent. No formal evidence of a diagnosis of intellectual disability was required. The severity of the intellectual disability of the individuals was based on the participant's self-reports. Table 1 details the inclusion and exclusion criteria for participant eligibility.

Table 1. Inclusion/exclusion criteria for participation

Inclusion Criteria
Eighteen years of age or older. No upper age limit.
Supported or provided care to an adult, aged eighteen years or older, with a diagnosis of an intellectual disability and disclosure of an LGBTQ+ label, questioning, or a non-heterosexual identity
Speak fluent English
Able to provide informed consent

4.3.3 Participants

Five staff members across three services within the United Kingdom and one family member completed semi-structured interviews. Table 2 shows the demographic data for all participants.

Pseudonyms were given to maintain anonymity. Ages ranged from 28 to 57 years old. Participants were two males, three females, and one non-binary identifying person. Table 3 summarises individual participant characteristics, whilst maintaining anonymity regarding sexual orientation and level of education.

Table 2. Participant demographics

Characteristics	Description	N=6
Gender	Male	2
	Female	3
	Non-binary	1
Age	18-24	0
	25-40	4
	41-60	2
Highest level of education	Highers or equivalent	2
	Undergraduate	3
	Postgraduate	1
Sexual orientation	Heterosexual	4
	Homosexual	1
	Pansexual	1

Table 3. Pseudonyms and interview length

Participant pseudonym	Role	Supporting	Length of interview (mins)
Amy	Family member	Greta	60
Beth	Support worker	Harry	37
Catherine	Support worker	Ian	33
Dereck	Support worker	Ian	43
Ethan	Support worker	Ian	34
Frances	Support worker	Jerry	90

The support workers were all currently supporting individuals with intellectual disabilities who had expressed attraction to the same-sex or identified as LGBTQ+. The individuals receiving support had varying direct support times, ranging from 24-hour care to several hours daily. The individual supported by their family member also received care from paid support staff. All support staff had received basic induction training packages. None of the participants had received training on LGBTQ+ sexualities. Three support staff supported the same individual with intellectual disability. One participant reported that the adult they supported had a comorbid diagnosis of Autism Spectrum Disorder (ASD).

In terms of the sexual identity of the adults being supported, the participants used labels that included ‘gay’, ‘lesbian’, ‘bisexual’, or stated that the person they supported did not ascribe a label but had shown sexual attraction to people of the same gender. Table 4 summarises the demographics of the individuals with an intellectual disability whom the participants supported.

Table 4. Additional information regarding adults supported

Characteristics	Description	N=4
Gender	Male Female	3 1
Age	18-25 25-35 35-45	0 3 1
Severity of Intellectual Disability	Mild Intellectual Disability Moderate Intellectual Disability	2 2
Residential placement	Living at the family home Living in residential care	1 3
Current relationship status	Single In a relationship	4 0
Historical relationship status	Previously been in a romantic/sexual relationship Not previously been in a romantic/sexual relationship	0 4

4.3.4 Interview Schedule Development

The researcher developed a semi-structured interview schedule (Appendix 10) following a review of the current literature, in addition to discussions within the research team and a pilot interview with a parent of an adult who identified as LGBTQ+. This ensured congruence with Interpretative Phenomenological Analysis. The pilot study was not recorded, and the data was not included in the main study. Amendments to the original interview schedule were changed before interviews with participants. Questions within the semi-structured interview schedule were largely open-ended. They explored the areas of support for adults who identify as LGBTQ+, barriers to developing and maintaining a romantic or sexual life, the journey of coming out, and how the views of the paid and unpaid caregivers had evolved.

4.3.5 Data collection

Interviews were conducted using videoconferencing (Zoom version 5.0) software that enabled privacy and followed social distancing guidelines following the COVID-19 pandemic. The use of videoconferencing software was stated within the Participant Information Sheet and consent form. After completing the consent form and agreement to participate in the study, participants were provided with a convenient date and time to complete the semi-structured interview. Participants were interviewed once and were advised to sit in a familiar and confidential space. Before the interview commenced, the researcher asked participants whether they had read the Participant Information Sheet and were happy to continue. Participants were reminded that their participation was voluntary, and they could withdraw from the study at any time. The interviews were digitally recorded using a recording device.

The interviews lasted between 33 and 90 minutes. Debrief was provided to the participants verbally at the end of the interview, and a debrief form was also sent via email. No participants verbally expressed their need for further support following the end of the interview. All participant identifiable information was removed during the transcription process, and pseudonyms were used in place of names. The recordings were transcribed verbatim.

4.4 Data Analysis

Interpretative Phenomenological Analysis was utilised to analyse the transcribed data. Interpretative Phenomenological Analysis is an approach to qualitative research which has an idiographic focus, offering insight into how a person, in a particular context, makes sense of a given experience or phenomenon and is underpinned by phenomenology and hermeneutics (Smith, 1996). The researcher’s perceptions and interpretations are acknowledged and valued in the analysis of participant accounts, a process described as a ‘two-stage interpretation’ or ‘double hermeneutic’ (Smith & Osborn, 2008). As suggested within the steps described by Smith and colleagues (Smith et al., 2009), each transcript was initially analysed as an individual case study. The researcher read the data several times, created initial notes and annotations, and developed these into exploratory descriptive, linguistic, and interpretative comments. These were further developed into clusters of emergent themes. The researcher continually reflected on their interpretations compared to the participant’s accounts. The above steps were repeated for all the transcripts, and following this, connections across the emergent themes were explored. This allowed for superordinate and subordinate themes to be identified.

The researcher ensured an appropriate level of competence and knowledge of Interpretative Phenomenological Analysis to promote the rigour and coherence of data analysis. A second researcher viewed samples of transcripts, which included emerging themes. Emerging themes were also discussed with participants following analysis.

The researcher made the decision to include the one account of the family member within analysis. This decision was based on the homogeneity of the experiences of both family members and support staff in supporting an adult with intellectual disabilities who identifies as LGBTQ+. Further to this, the researcher remained aware of the limited research including the voice of lesbian women. Removing the account of the family member may have further silence the experiences of this group (Elderton et al., 2014).

4.4.1 Researcher Reflexivity

Throughout the research process, the researcher continually reflected on the influences of their own beliefs, experiences, and attitudes on the interpreting the data, as personal contexts can influence research processes (Smith & Osborn, 2008). Researcher reflexivity enables the researcher's development and understanding of interpretations of the data to be more explicit (Stevenson & Cooper, 1997). Personal experiences and prior expectations are provided to contextualise the data analysis. The researcher was a non-disabled, cis-gendered woman identifying as queer, studying for a Doctorate in Clinical Psychology. The research interest developed following reflections on personal experience of identity about sexuality and epistemological stance, and awareness of lack of support and service provision for individuals with intellectual disability who identify as LGBTQ+. The researcher expected that family members might hold more conservative or protective views of adults with intellectual disabilities who identified as LGBTQ+, with support staff expressing a liberal stance on support around sexuality and intimacy. The researcher continued to work with individuals with intellectual disabilities in a clinical capacity throughout the research process. They remained aware of the impact this may have had on interpreting the participant's experiences and accounts. Reflexivity was enabled through discussion in supervision and using a reflective diary to allow for expectations, personal views and experiences, and emerging ideas to be reflected on during the analysis of the transcripts and data. Utilising supervision also enabled the researcher to manage potential biases when interpreting the participants' accounts.

The researcher remained aware of the discourse often viewed within the literature about individuals' sexual and romantic lives who identify as LGBTQ+ and sexuality and intellectual disability. This was reflected on particularly regarding the narrative of adults with intellectual disabilities being perceived as more vulnerable or at risk of sexual exploitation. Due to this, the researcher noted that a more positive account of sexuality and intellectual disability was being sought in participant accounts and was mindful of the impact of this on the interpretation of the findings and produced themes. The researcher managed this by re-engaging with the transcripts and data and comparing the themes and analysis against participant accounts. Participants were also provided with an opportunity to discuss themes produced to ascertain whether these accurately reflected their experience.

4.4.2 Quality Assurance

Quality assurance guidance for qualitative research (Elliot et al., 1999) guided the conduct of the research study. Table 5 demonstrates how quality was ensured within the present analysis (Elliot et al., 1999; Smith, 2011; Smith et al., 2009; Yin, 1989).

Table 5. Quality assurance demonstrated in current research

Quality assurance process	Demonstrated in the current research
Owning one's perspective	Researcher provided reflective account of position in the research
Situating the sample	Participant demographic and contextual information detailed, and information provided on recruitment
Grounding in examples	A minimum of three participants were represented within each theme, and themes were evidenced with participant quotes
Credibility checks	Theme development was discussed with research supervisors
Participant validation	Follow up questions were used in the interview process to clarify accounts. Participant validation of analyzed accounts were sought following completion of data analysis.
Audit trail	Findings can be traced to original data via annotated transcripts and coding

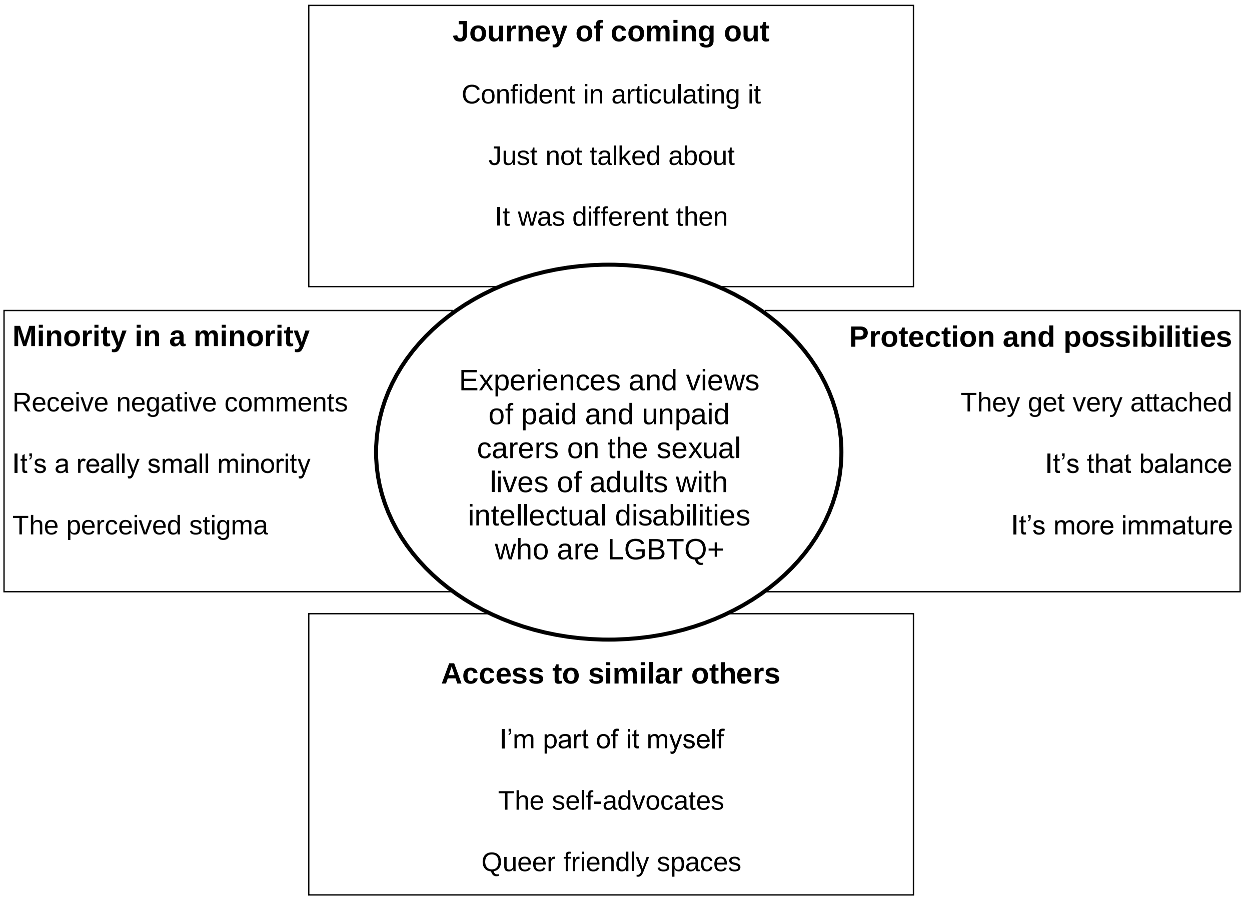
5. Findings

Data analysis resulted in four superordinate themes, each with three subordinate themes: ‘Journey of coming out’, ‘Minority in a minority’, ‘Protection and possibilities’ and ‘Access to similar others’. A minimum of three participants were represented in each theme, in line with recommendations by Smith and colleagues (2009). Table 6 details the four superordinate and twelve subordinate themes that emerged from the data, with Figure 1 illustrating the themes.

Table 6. Summary of superordinate and subordinate themes

Superordinate themes	**Journey of coming out**	**Minority in a minority**	**Protection and possibilities**	**Access to similar others**
Subordinate themes	“Confident in articulating it”	“Receive negative comments”	“They get very attached”	“I’m part of it myself”
	“Just not talked about”	“It’s a really small minority”	“It’s that balance”	“The self-advocates”
	“It was different then”	“The perceived stigma”	“It’s more immature”	“Queer friendly spaces”

Figure 1. Illustration of the superordinate and subordinate themes



5.1 Journey of coming out

Most participants described that the adult they supported had expressed sexual and romantic attraction to others of the same sex. Although none of the adults with intellectual disabilities had previously been in any romantic relationships, they all expressed their desire to be in a relationship with a member of the same sex in the future. The participants described the journey of coming out to others regarding their sexuality. The age at which the adults with intellectual disabilities came out ranged from teenage years to adulthood.

5.1.1 "Confident in articulating it"

All participants described the use of language and labels about sexuality and how this influenced the sexual and romantic expression of the adults they supported. One participant explained that their family member did not identify or discuss their sexual identity until they learned the word ‘lesbian’ during a sex and relationship group: *“We took her to a class on sexuality and sexual health…that was probably about five years ago, and I think from there she probably was a bit more confident in articulating it” (Amy).* The narrative of language and knowledge around sexuality was prominent throughout the participants’ experiences, ranging from sexual identity never being discussed to family members expressing negative views on non-heteronormative sexualities. There was an identified gap in the understanding of sexuality of the adults being supported, with one support worker describing that the adult they supported did not ascribe specific labels or identifies: *“I don’t think he would entirely understand what the word gay means, but he’s exclusively attracted to men” (Beth).* The importance of language and open discussion around sexuality for adults with intellectual disabilities highlights the need for sex education and information about non-heteronormative identities.

Although there were differences in the language used to describe sexual identity and the experiences of coming out across the adults with intellectual disabilities, the participants explained that the adults they supported expressed the desire for a partner of the same sex and hoped to enter a relationship in future. The view of what makes a relationship varied among the adults with intellectual disabilities, with some focusing on the sexual aspect of a relationship and others describing activities they would like to engage with a partner. Only one supported adult expressed the desire for marriage in future, with others focusing on finding a partner in the short term. The participants detailed discussions with the adults they supported about other aspects of relationships or a partner that are important, such as an emotional connection and shared interests: *“The romance, the sexuality, the best friend, the intimate relationship should probably tick all those boxes” (Frances).* Participants felt comfortable speaking about relationships and discussing the aspects of romance or partnership. However, some expressed some discomfort around the discussion of sex or intimate relationships. Some reflected on the understanding of the adults they supported in terms of the social rules of relationships, such as reciprocity and monogamy.

5.1.2 “Just not talked about”

The predominant theme discussed in terms of relationships and sexuality was that others in the lives of adults with an intellectual disability did not discuss or attempt to shut down conversations about sex, romance, or identity. The participants reflected on their role in supporting relationships and identified barriers that the adults with intellectual disabilities had encountered throughout their life that may have prevented them from expressing their sexual identity or developing a relationship. All the participants described that the adults they supported had family members who actively avoided or ended discussions regarding sexuality, with one participant describing that the mother of the adult they supported felt discomfort regarding her son’s sexual identity: *“I don’t think it’s something as a family they talk about. They wouldn’t talk about it” (Catherine).*

Due to their sexual expression and conversations regarding sexuality being rebuffed and discouraged by others, the adults with intellectual disabilities developed discomfort regarding these discussions with family members. One participant described that the brothers and parents of the adult she supported declined to discuss her desires to enter a relationship with a woman, so they had stopped discussing this openly within the family unit: *“I think it’s taken a long time to become comfortable talking about her emotions without somebody saying “oh you don’t want to do that” or “let’s forget about that”, type of thing” (Amy).* The participants expressed a narrative that the adults with intellectual disabilities often had to navigate acceptance from others and engaged in an ongoing process of self-monitoring and censorship in relation to their sexual identity or expression of a desire for a relationship with a member of the same sex. One participant described the adult they supported only discussed their sexuality openly with specific individuals whom they knew would be accepting: *"He discriminates who and how and when, and he knows the appropriateness, which is quite handy" (Frances).*

5.1.3 "It was different then"

A theme arising from the participants' reflections regarding the journey of the adult they supported in accepting and expressing their sexuality was the role of society and change in views in terms of social inclusion. Alongside the adults they supported going through the experience of self-acceptance, coming out, and gaining acceptance from others, the participants reflected on the journey of their views and attitudes towards LGBTQ+ identifying individuals and how this had changed over the course of their life. The participants reflected on what shaped their views on homosexuality and non-heteronormative identities, with religion, views of their own family, and generational attitudes impacting their beliefs. One participant reflected on the influence of the opinions of her parents, who were intolerant of homosexuality during her childhood, but had developed more liberal views during her adulthood: *"I think that shapes it, but I think when you go out and about in the world and you're working with people…you just learn to navigate that…you've just got to be tolerant and things like that" (Amy).* Several participants expressed that societal views had changed, *"My views have changed definitely, but I think society as a whole has changed, and it's been put into the mainstream that it's more acceptable" (Ethan).*

Participants reflected on the impact on societal and social-cultural influences and the differences between the views of younger generations compared to those who were older in age. The narrative that emerged appeared to indicate that individuals who are younger hold views and attitudes that are more tolerant, open, and liberal, with one participant explaining: *"The younger generation are more accepting, I think they have more friends that are gay you know, whereas before there was a gay crowd and a heterosexual crowd, and you crossed paths on the periphery, whereas now you all merge together and that's who you are" (Amy).* Some participants expressed a personal belief that if they identified as LGBTQ+ during their teenage years or early adulthood, they might have struggled to be open regarding their identity due to the societal norms at that time: *"If I had been attracted to women I would have never have acted on it, or spoke about it, because that would have been, you know, shock horror" (Amy).*

The impact of societal norms and changing social expectations regarding sexuality also infiltrated into the participants' attitudes when supporting adults with intellectual disabilities who identified as LGBTQ+. All participants expressed liberal and accepting views of the sexual identity of the adult they supported and described their desire for the individual to achieve a relationship and other romantic goals. One participant reflected on how her attitudes towards the rights of adults with intellectual disabilities to have access to romantic and sexual relationships had changed through supporting an LGBTQ+ identifying individual: *"I started to look at them differently and my goodness, what sort of blinkers and filters I had on for so many years, and how I had been organisationally conditioned" (Frances).* The participant reflected on the impact of the societal view of adults with intellectual disability in terms of sexuality and romantic relationships, and the advocacy involved in ensuring his rights and access to the same opportunities as others: *"In our journey, and in my own journey, with dealing with stigma and being able to support him quite fully, but it was a journey" (Frances).*

5.2 Minority in a minority

Participants acknowledged and described unique experiences and difficulties when supporting an adult with an intellectual disability who identifies as a sexual minority. This included being aware of discrimination, ableist and homophobic remarks from others, and the difficulties that may present when the adult they were supporting expressed their desire to enter a relationship. The participants described the emotional consequences of the adult they supported facing two-fold discrimination, associated stigma, and the experiences of being a minority within a minority.

5.2.1 "Receive negative comments"

Five of the participants described that the adult they supported had experienced varying degrees of abuse or discrimination from members of the local community or from family and friends. One participant expressed that this was linked to her family member's disability: *"Young boys you know, they all just laugh, she is aware of that, she really doesn't want to go anywhere unless it's in a car" (Amy)*, but also expressed that she worried about her family receiving negative comments or reactions in the community due to her sexuality: *"I can imagine if she was walking down the street arm in arm with a girlfriend, she would, not from everyone but from some people, she would receive negative comments about that" (Amy).* One participant described that the adult they supported struggled to accept his sexuality and expressed worry regarding threats of violence if he went out in public with a member of the same sex: *"He expressed a worry, you know, they would have a fight with him, he was worried about this" (Dereck).* Participants highlighted their continued vigilance against harassment or discrimination from others regarding the adult they supported when out in the community.

Participants acknowledged and expressed that people in the lives of the adults they supported problematised their intellectual disability, sexuality, or both. Some participants described that the adults they supported experienced discrimination or received derogatory or homophobic comments from family members or friends. One participant explained that the adult they supported had experienced a family member disowning them due to their sexuality and intellectual disability, and the support they provided regarding this: *"We discussed that it was because he's gay…and possibly the learning disability, Jerry being a gay man with a learning disability…the father lives away and is not so keen on his son having access to his half brother who is a gay man with a learning disability" (Frances).* This resulted in emotional distress for the adult due to the sense of powerlessness of the actions of their family member due to attributes outside of their control.

5.2.2 "It's a really small minority"

Participants reflected additional barriers to the adults they supported accessing intimate or sexual relationships due to their sexuality and disability. The narrative from the participants suggested that they believed the adults they supported could only access relationships with others who also had an intellectual disability, with one participant explaining how they may support an adult in accessing opportunities to develop a relationship: *"Groups, with other people with learning disabilities who identify as that, and they can interact with other people with learning disabilities who are gay, I just think it would be much easier" (Ethan).* This view of adults with an intellectual disability appears to place them into 'the othered'. However, participants attributed this to the adult being supported in entering a relationship with someone who has had similar experiences and therefore would have a shared understanding. Some participants expressed concern that if the adult they supported entered a relationship with someone without an intellectual disability, there would be an imbalance and they may be taken advantage of. One participant described that the adult they supported desired a partner who also had an intellectual disability, as they would be able to understand their difficulties within a relationship.

A theme that emerged from the participant's accounts was the difficulty of locating groups or clubs for LGBTQ+ identifying adults with an intellectual disability. One support worker reflected on the problem of accessing the LGBTQ+ community or resources when residing in an area outside of major metropolitan cities within the United Kingdom: *"I think all members of the LGBT community struggle in suburbia. You're not so much of a minority in a more developed city location" (Frances).* The support worker described that they had used the internet to find specialist groups, however this was with difficulty: *"I think it's hard enough for the LGBT community anyway but when you also identify as having a learning disability, it's a hyper specialism, it's really small minority" (Frances).* The internet did provide participants with the opportunity to attend online groups for adults with intellectual disability who identified as LGBTQ+ without the barrier of geographical location.

5.2.3 "The perceived stigma"

Participants expressed a prominent theme of stigma and difficulty with self-acceptance about the adult they supported. Self-stigma due to their sexuality had a negative emotional consequence on some supported adults, which resulted in them selecting whom they expressed their sexual identity and concealed their sexualities. One participant described the result of self-stigma on the self-acceptance and openness of the supported adult: *"[they] didn't come out to the family because of the stigma, the perceived stigma" (Amy).* Some participants attributed the stigma or difficulty with self-acceptance to embarrassment or the desire to fit in socially with staff and others: *"I think with me he's more open than with the men and the male staff, most of the staff workers are men. I think it depends on how he sees that male, if he sees them as "one of the guys" sort of thing, and how he views them, that really influences what he discusses with them" (Catherine).* This embarrassment and self-stigma resulted in some adults with intellectual disabilities denying their homosexuality and applying an effortful process of sexuality concealment, with one supported adult explaining to a support worker that they could not feel comfortable being openly homosexual: *"He told us as well the story that some of his ex-support members from a different company, he openly considered himself as gay and Ian said…I can't imagine living my life as gay…his brother, his other brother and friends from the past…what if they found out" (Dereck).* Support staff described that the supported adult internalised homophobic or discriminatory attitudes from others and would verbalise these attitudes towards staff, possibly to deflect from his own sexuality: *"He's said a lot of derogatory things about gay people before when I've been with him" (Ethan).* Adopting a 'straight role' enabled the adult with intellectual disabilities to reduce their sense of threat, although it created a sense of conflict and confusion.

5.3 Protection and possibilities

All participants expressed their desire to support the adult with an intellectual disability they supported in developing relationships and expressing their sexuality; however, they described reservations in terms of their perceived vulnerability, particularly about being taken advantage of sexually, emotionally, and physically. Participants explained that they felt the adult they supported was at more risk of harm due to their intellectual disability and perceived level of understanding of relationships and sex.

5.3.1 "They get very attached"

Five of the participants described that the adult they supported was more vulnerable to experiencing emotional distress when attempting to develop a relationship, particularly regarding feelings of rejection. It was acknowledged by the participants that the adult they supported may struggle with the emotional risks involved in developing and exploring romantic and sexual relationships. The narrative suggested that adults with an intellectual disability experienced emotions and feelings more intensely than adults without intellectual disability and therefore were at greater risk of getting hurt: *"They get very attached and feel very deeply and feel rejected very deeply, they feel they are rejected rather than it just didn't work out. It's the worry about that side of thing rather than anything else" (Amy).*

Participants acknowledged that being involved in romantic or intimate relationship presented with emotional risks regardless of whether an individual had an intellectual disability, and that the fear of the emotional consequences of the adults they supported being rejected should not be a barrier or reasoning for the opportunity to enter a romantic or sexual relationship: *"I suppose, it's not very fair on her because you worry too much that she'll get hurt, which potentially does a disservice that she would get more hurt than anybody else" (Amy).* The narrative suggested that some adults with intellectual disabilities may not have developed coping skills to manage difficult situations in relationships due to the overprotection of those who support them and the inexperience of being in a romantic or sexual relationship. Some participants expressed that the adult they supported identified the fear of rejection as a self-imposed barrier to entering a relationship, as they held a belief that they would receive an adverse reaction if they expressed their desire for another man: *"He was saying that if he was in a relationship he doesn't know when someone is taking the piss out of him…I said you just need to make sure you meet someone really nice who's not going to do that to you" (Ethan).*

5.3.2 "It's that balance"

All the participants talked about the perceived vulnerability of the adult they supported due to their intellectual disability, and how this may impact the development of sexual, intimate, or romantic relationships. Although the participants acknowledged the importance of romantic relationships, they expressed a fear of the adult they supported being at risk of exploitation or abuse: *"It's that balance between protecting her from getting hurt, and actually opening her up to the possibility of a nice romantic relationship with somebody" (Amy).* The participants described behaviours the adults they supported engaged in, such as taking their clothes off in front of others, touching or making sexual comments to strangers, or leaving support staff when in the community, which could place them at risk. Participants described that the adult they supported found difficulty in social situations which may impact on their vulnerability: *"She won't pick up on those social cues, she won't pick up if somebody is asking her to do something which most of us would think why is he asking me to do that, or why is she asking me to do that" (Amy)*.

Some participants reflected that the vulnerability of the adult they supported was more about being a negative influence on their lives and taking advantage of them within a relationship. In contrast, some participants expressed more concern about the adult they supported being taken advantage of sexually. One participant said the perceived vulnerability of the adult they supported was a barrier to dating and entering a relationship: *"He's dabbled with online dating…but it endangered him having a learning disability, he got too vulnerable" (Frances).*

The narrative suggested that the adults with intellectual disabilities were unable to protect themselves from harm from others, which prevented them from experiencing situations where they may be able to develop a romantic or sexual relationship. The narrative also suggests that engaging in casual sexual relationships is inaccessible for adults with intellectual disabilities. However, one participant acknowledged that this might be the desire of the adult they support: *"Other men could be looking to take advantage of him sexually, and just use him for his body and not be interested in his mind or personality. Which is his prerogative if he wants to go down that road, but even that is difficult as you can be taken advantage of, it's really difficult to engage without support with anything like that" (Frances).*

Some participants reflected on the ability of the adult they supported to safeguard themselves, and they were capable of deciding what was inappropriate and alerting others to support them: *"There was texting or something like that, and a man had gotten quite sexual asking about his underwear or something, and he did share that with me, that's a bit inappropriate he said, getting so sexual so quickly, so he's mature enough to know the appropriateness" (Frances).* Some participants acknowledged that safeguarding and protecting the adult they supported increased the risk of negative emotions and experiences, particularly feelings of loneliness: *"I suppose that's something that can make him feel quite lonely, feeling sheltered" (Catherine).* The narrative suggested that this view of adults with intellectual disability being more vulnerable created a barrier to developing romantic and sexual relationships: *"lots of them should be having girlfriends and boyfriends, and they're so friendly and able…and we're doubting…so why haven't they had a girlfriend, because no one's tried" (Frances).*

As only one participant supported a woman with an intellectual disability, gender differences and sexual relationships were not a predominant theme. However, one participant who supported a female adult with an intellectual disability highlighted the concerns of supporting her to stay safe in a sexual relationship, and described that her sexuality made her feel more comfortable in regards to pregnancy and sexual intimacy: *“It would bother me more if she was in a relationship with a guy and wanted a guy to stay over, because then I’d be thinking about the pill, so it does feel safer” (Amy)*. The participant reflected that if her family member became pregnant and had a baby, the responsibility of care would fall onto her, highlighting stereotypical views on parenthood and the duty of the mother or female family members to care for children. There was a general absence of the issue of safe sex practices from the participants’ accounts, suggesting that unless the adults they supported were in a relationship barrier devices or related sexual prophylaxis were not discussed.

5.3.3 “It’s more immature”

Some participants expressed an infantilisation of the sexual or romantic expression of the adults they supported, questioning the nature of the interactions with members of the same gender, and indicating that it was more puerile than interactions between adults without an intellectual disability: *“He had a relationship with another person with a learning disability, which I think was more friendship that was a little flirty, more immature” (Frances).*

Some participants questioned the intent behind the expression of sexuality of the adult they supported and whether this translated into the desire to be in a relationship with a member of the same gender. One participant described that her family member’s sexual orientation might be a result of the negative impact of the actions of the men in her family, rather than a genuine attraction for women: *“Whether her feelings are real or whether it’s actually a case of…one of my brothers that she was close to had a drink problem so men let her down so I don’t know if it’s that side of things or whether it’s she actually has genuine feelings for girls” (Amy).*

There was a general absence of the discussion of adults being supported in accessing sexual relationships for pleasure or enjoyment, possibly responding to the narrative of the infantilisation or immaturity of individuals with intellectual disabilities. Only one participant reported discussing sexual intimacy or pleasure with the adult they supported: *"The public don't even talk about it, it's so stigmatised, like where you can get information to get pleasure for your body" (Frances)*. The narrative appeared to be more focused on sex education, vulnerability to sexual exploitation, and protection, with less space for discussing pleasure and sensuality. This raises concern about how adults with an intellectual disability seek relationships or engage in situations that are sexually pleasurable if they are dependent on those who support them to access these, when the focus is often on inappropriate sexual behaviour and how this should be eliminated.

5.4 Access to similar others

The participants identified and described the importance of the adult they supported being in contact with others that identified as LGBTQ+ and having access to the LGBTQ+ community. The themes concerning to the superordinate theme of 'similar others' pertained to the relationship between LGBTQ+ identifying staff and service users, LGBTQ+ role models and advocates in the broader community, and queer-friendly spaces where adults with intellectual disabilities could access to contact other LGBTQ+ individuals.

5.4.1 "I'm part of it myself"

Two of the support workers were LGBTQ+-identified, with all the participants expressing accepting and liberal views on non-heterosexual identities. Two of the support workers described the desire to communicate and discuss their own experiences of sexual identity, coming out, and self-acceptance with the adult they supported, to provide a safe space and the opportunity to have contact with a similar other. One support worker described the positive emotional impact of working with LGBTQ+ individuals, *"Well I am very queer myself…I quite like working with LGBT individuals because they start to talk about stuff like that and realise I'm LGBT, you can start to see the relief and excitement in them, which I find really nice. It's something I'm always going to be supportive of because I'm part of it myself" (Beth).* Meeting similar others in terms of sexuality provided the adults with intellectual disabilities offered the opportunity to express their own identity and encourage their self-acceptance. When exploring what may be helpful in terms of future support for adults with intellectual disabilities who identify as LGBTQ+, one support worker described that sharing and providing their own experiences may enable empowerment and instill hope for the adult they support: *“telling stories, like in our own experiences, or our friends, or people who we know, how they live and how their life looks like…and that everything is alright, everything is in place” (Dereck).*

One support worker highlighted that although disclosure of sexuality may provide a space for the individual with intellectual disability to feel comfortable and accepted, there remained concerns regarding boundaries and the power and position within the role. The support worker described the uncertainty of what was appropriate to share and what may harm to the individual with an intellectual disability: *“I need to know what information I can share, and what information I can’t share…I need to watch the risk assessment…if it’s not a problem to share this information about myself then it would be fine…I am always supportive in explaining that it’s okay to be who you are” (Dereck).* This highlights support workers’ expectations of their role and where this it comes from, such as personal beliefs and experiences and organisational expectations. There appeared to be a conflict between moral positioning and policy when supporting adults with intellectual disabilities.

All participants expressed the acceptance of the adult they supported in terms of their sexuality, and some participants highlighted the importance of creating an open environment for others to feel comfortable and accepted: *“I wish he would open up about wanting a boyfriend because then we’d be able to make him feel more comfortable” (Ethan).* The theme highlights the varied approach to role of a support worker and how moral positioning influenced the view on their support and the support provided by others. This suggests that support workers view their role in supporting romantic and sexual relationships for LGBTQ+ identifying adults with intellectual disability falls on a continuum from direct support to a more open form of care. One support worker expressed their moral positioning on the inclusivity and acceptance of support staff when working with LGBTQ+ identifying adults: *"The thought of someone in care working with someone who is closeted LGBT and might not know they're working with someone and express views, that could really hurt an already vulnerable person, who you're supposed to be there to help, it would very much bother me" (Beth).*

5.4.2 "The self-advocates"

A theme that emerged from participants' accounts was that of the importance of the role of self-advocates and LGBTQ+ role models. Having access to similar others who have lived experience of intellectual disability and sexual minority empowered supported adults and positively impacted their self-acceptance: *"Just being able to meet them over Zoom, the self-advocates, that identify as gay with a learning disability that run the group, so me and Jerry are thinking, wow, this is great…It's a paid job for some of them, as a self-advocate, and meeting these role models for the both of us" (Frances).*

5.4.3 "Queer friendly spaces"

A predominant theme discussed in the context of opportunities for adults with intellectual disabilities to access similar others was the use of LGBTQ+ spaces, where they were free from discrimination and could reduce their feelings of loneliness or isolation. Participant accounts revealed that some support workers and family members had attempted to locate LGBTQ+ groups and clubs and had sought advice and guidance from individuals within the LGBTQ+ community in terms of spaces that would be suitable to access. One support worker described that they attended gay clubs and drag shows with the adult they supported and reflected on the inclusive space: *"So actively welcomed…you're so often ostracised and feel quite different. The LGBT community are experts in inclusivity, the disabled access…I feel I had almost got used to the ostracism…so I can feel my defense mechanisms going on but that was wonderful to experience that inclusivity" (Frances).* It was highlighted within the narrative that adults with intellectual disabilities often attend events or activities that may be viewed as immature or not age appropriate. The spaces allowed individuals with intellectual disabilities to engage in more ‘adult’ activities and feel like others of the same age.

One support worker described that they created an LGBTQ+ social club for individuals with intellectual disabilities to access. Having this inclusive space enabled supported adults to access similar others who also identified as LGBTQ+, impacting their isolation or feelings of loneliness. The support worker described that there were individuals who identified as LGBTQ+ but did not access the group; however, they expressed that knowing the group existed provided them with comfort knowing that those offering support were inclusive and accepting of their sexuality: *“I actually started a LGBTQ social club…to improve the support so people were able to interact with each other…a few people have shared feedback just saying it’s nice to have that sort of space, one person said they don’t get much from it, but knowing it’s there means that they know that the people they work with are queer-friendly…knowing that the group is there means that there are LGBTQ supported people…which they found very reassuring” (Beth).*

6. Discussion

The research aimed to explore the views and experiences of unpaid (family members) and paid (support staff) carers who support adults labelled with intellectual disabilities who identify as LGBTQ+. An Interpretative Phenomenological Analysis resulted in four superordinate themes, each with three subordinate themes. These themes represented: the journey of coming out and how views have changed over time, the experience of being a minority in a minority and the difficulties and barriers this may present with, the conflict experienced by support staff and family members in both protecting the adults they support whilst also recognising the importance of developing romantic and sexual relationships, and the resources available in the LGBTQ+ community and having access to others who share similar experiences.

The analysis revealed that the supported adults with intellectual disabilities expressed desire for a relationship, as similarly found within the current literature (Brown & McCann, 2018; Rushbrooke et al., 2014). The participants within the current study described that the adults they supported thought of relationships as a means to provide company and sharing experiences, although few adults described planning for the future or desiring marriage or children. Similar experiences have been reflected within previous research (Rushrbooke et al., 2014), particularly the gap between the desire for a relationship and the barriers in place, such as the opportunity to meet others and difficulty in understanding social rules and reciprocity (Neuman, 2020). Support staff and family members described their journey and experiences of changing views over time, highlighting the influence of society on the perceptions of non-heterosexual sexualities (Oloidi et al., 2020). All participants expressed a positive attitude and progressive views on homosexuality. However, with some notable exceptions, there appeared to be few proactive practices utilised by staff members to support adults with intellectual disabilities to develop or maintain a sexual, romantic, or intimate relationship. This has been reflected in previous research regarding the experiences of staff supporting LGBTQ+ identifying adults with intellectual disabilities (Abbott & Howarth, 2007). Only one participant described current guidelines and policies in relation to supporting adults in expressing their sexuality and right to relationships, highlighting the potential need for support staff to receive training or education around legislation to support adults with intellectual disabilities regarding their sexuality.

The analysis highlighted the importance of education around sexuality, sexual health and practices, and the formation and maintenance of relationships for people with intellectual disabilities, as this may lead to self-acceptance or acknowledgment of the existence of non-heterosexual labels and identities. Previous research exploring the attitudes of people with intellectual disabilities regarding LGBTQ+ status found that many adults with intellectual disabilities lacked knowledge around LGBTQ+ issues and some hold negative attitudes towards those who do not identify as heterosexual (Burns & Davies, 2011). Education may empower adults with intellectual disabilities and develop skills in articulation around their thoughts and feelings around sexuality and intimacy, which has been demonstrated in previous research (Abbott & Burns, 2007). Training around inclusive and LGBTQ+ affirmative practices for both staff members and family members may further enable a positive space for supported adults to confidently express their identity.

Analysis suggested that adults with intellectual disability experienced discrimination in relation to their sexuality or intellectual disability, both within their local communities and by family members and friends. This aligns with previous research which highlights individuals who identify as LGBTQ+ are more likely to experience discrimination and prejudice (Jones & Magowan, 2010; Wilson, 2006). This discrimination included experiencing negative or derogatory comments, threats of violence, or experiences of being disowned by family. Previous research has found similar experiences of adults with intellectual disabilities in terms of high incidences of verbal or physical abuse or bullying due to their disability (Bennett & Coyle, 2007) or sexuality (Abbott & Howarth, 2005; Smith et al., 2022; Stoffelen et al., 2013). The current study found that adults with intellectual disabilities used several coping strategies to manage this, such as choosing who to express their sexuality to or concealing their sexuality in the community.

Discrimination from others may lead adults with intellectual disabilities to develop an awareness of ‘differences’, which can reinforce the minority status. Several participants described that the adult they supported had an awareness of stigma associated with disability and sexuality, which in turn can affect personal identity and self-acceptance. Adults with intellectual disabilities who identify as LGBTQ+, and as such a ‘minority in a minority’, are exposed to several oppressions and threats to self-identity. This is reflected both in participant accounts within the present study, and also in previous research exploring the experiences of adults with intellectual disability who identify as LGBTQ+ (Bennett & Coyle, 2007; Davidson-Paine & Corbett, 1995).

Some participants described that the adult they supported expressed difficulty in accepting their sexuality or unhappiness regarding their identity, reflected in previous research exploring the experiences of adults with intellectual disabilities who identify as LGBTQ+ (Löfgren-Mårtenson, 2009). Some of the supported adults described by participants labelled their identities as ‘lesbian’ or ‘gay’, with some of the participants using the label ‘bisexual’. The self-labelling by adults with intellectual disabilities is consistent with some studies (Abbott & Howarth, 2005; Davidson-Paine & Corbett, 1995; Stoffelen et al., 2013). However, one adult with intellectual disability within the study demonstrated reluctance to use a label or identity as gay despite expressing sexual attraction to the same sex. This may be due to self-stigma or the fear of the reaction of others, as demonstrated in some previous research (Withers, 1997).

The analysis also suggested the participants held the view that the adults they supported were more vulnerable and at higher risk of exploitation from others, which caused concern around the desire for a relationship. This is often reflected within previous research regarding sexuality and intellectual disabilities (Abbott & Howarth, 2007; Pryde & Jahoda, 2018; Rushbrooke et al., 2014) which represents a common difficulty in that both family members and support staff can hold views around safety and vulnerability which can impact on the development of sexual or intimate relationships for adults with intellectual disabilities (Löfgren-Mårtenson, 2009). The accounts of the participants likely reflect the perceived issues around consent to sexual contact regarding adults with intellectual disabilities (McGuire & Bayley, 2011; Murphy & O’Callaghan, 2004), and the impact this may have regarding the balance between adult protection and the right to a sexual or romantic relationship (Cambridge et al., 2011). In both the present study and within previous research, sex is often only recognised in the context of a relationship (Hamilton, 2019). This highlights the need for both staff training and resources for families that would address knowledge, attitudes, and skills regarding the sexual lives of the adults they support.

In contrast to the historical view of adults with intellectual disability being perceived as asexual (Arias et al., 2009; English et al., 2018; Fulford & Cobigo, 2018), the participants within the present study acknowledged the sexuality and expression of the adults they supported and described them as sexual beings, experiencing sexual arousal and the desire to engage in sexual intercourse. However, some participants described gaps in the knowledge of the adult they supported regarding sex and safe sex practices, which is consistent with previous research (Jahoda & Pownall, 2014; Healy et al., 2009). The general narrative within the accounts of the participants was that no previous in-depth discussion regarding sex and sexuality had occurred and was not usually talked about. As previous research indicates that adults with intellectual disabilities may deny their own sexuality or believe the topic should not be discussed (Fitzgerald & Withers, 2013), it may be imperative that family members and support staff initiate conversations regarding sex and sexuality.

Discussions regarding the use of contraceptives or barrier methods for safe sexual practices were rarely discussed by participants. This may be due to the perceived risk of pregnancy being eliminated in same-sex relationships, with one participant expressing that she felt more comfortable with her family member engaging in a same-sex relationship as pregnancy could not occur. This also highlights the narrative within literature regarding the sexuality of adults with intellectual disabilities and specific gender concerns (Gilmore & Chambers, 2010), and the view of women as potential victims and males as more sexually impulsive. Furthermore, it may be that participants did not view discussions around the use of barrier methods or safe sex practices important or necessary unless the individual was engaging in a sexual relationship. However, this poses the risk that adults with intellectual disabilities may enter sexual relationships without the knowledge of safe sex practices (Turner & Crane, 2016). The narrative highlights the need for sex education which consciously focuses away from gendered roles and norms.

Some participants identified the importance of disclosure of their own sexuality identity and becoming a positive role model for the adults they support. Previous research has shown the negative impact on adults with intellectual disabilities if support staff express homophobic attitudes and beliefs or overlook their sexuality (McCabe & Schreck, 1992). This can lead to supported adults feeling unsafe in expressing their sexuality or internalising negative attitudes which can lead to shame and self-stigma. Previous research has shown that staff may lack confidence in discussing sexuality issues and need further education and training regarding the sexual and romantic needs of adults with intellectual disabilities (Abbott & Howarth, 2007).

Participants expressed that the adults they supported valued social contact with other adults with intellectual disabilities who identified as LGBTQ+, similar to previous research within LGBTQ+ groups for people with intellectual disabilities (Dinwoodie et al., 2016; Elderton & Jones, 2011; Withers et al., 2001). The participant accounts highlighted the need for more LGBTQ+ groups and queer friendly spaces for adults with intellectual disabilities, to increase access to positive LGBTQ+ role models (Abbott & Howarth, 2005; Dinwoodie et al., 2016) in addition to improving avenues to meet others to develop a romantic or intimate relationship.

Due to the small sample size of the study, no formal comparisons based on participant characteristics were explored and how these could possibly interact with the findings of the study. However, certain trends within the dataset were observed, particularly regarding the identified sexuality of the participants and this influence on care and support. Participants who identified as LGBTQ+ tended to discuss improving access for adults with intellectual disabilities to meet others who also identify as non-heterosexual. There appeared to be no influence of age or gender on views, contradictory to previous research (Evans et al., 2009; Cuskelly & Bryde, 2004).

6.1 Study Strengths

Participants within the study tended to provide detailed accounts of their attitudes and experiences, allowing for in-depth and rich data for analysis. Analysis and findings represented a diverse range of perspectives within the homogenous group, with quality assurance processes being applied to ensure credibility of the conclusions drawn from the participant accounts. The conduct of the research was informed by quality assurance guidance (Elliot et al., 1999). From the findings, recommendations for service improvement and research developments are suggested.

6.2 Study Limitations

The research study focused on a homogenous sample in terms of individuals who support an adult with an intellectual disability who identifies as LGBTQ+, which is the desired sample within Interpretative Phenomenological Analysis to ensure relevance and personal significance to participants. However, employing a homogenous sample means that findings and conclusions are not representative of whole populations, and there may be key differences between the experiences of those who participant within the study and those who did not. Furthermore, there is a degree of self-selection bias within the study which may impact on findings. Although the researcher recruited from various organisations and services in an attempt to mitigate the risk of systematic bias, participants who volunteered to take part in the study may hold more liberal views on sex and sexuality, in addition to recognising and valuing the rights of adults with intellectual disabilities to engage in intimate and romantic relationships. Although the recruitment process targeted services and organisations across the United Kingdom, most of the participants were from central Scotland, again limiting the generalisability of the findings to the population.

There were challenges within recruitment for the current study. One barrier identified was recruiting from private organisations, with the majority of the identified not responding to the researcher or declining to share the recruitment materials. Several organisations stated that they were unaware of any adults with intellectual disabilities who used the service and identified as LGBTQ+. Another said that they did not feel it was appropriate to share recruitment information. Further to this, some adults with intellectual disabilities who identified as LGBTQ+ expressed that they did not wish their family member to take part, as their family member was not aware of their sexuality or held negative views regarding this. One LGBTQ+ identifying adult with an intellectual disability expressed interest in her mother taking part, however, her mother stated she did not believe her daughter was sexually or romantically interested in woman so declined to participate. The recruitment challenges reflect the current literature regarding intellectual disabilities and sexuality, particularly regarding the views of adults with intellectual disability as asexual or presumed heterosexual, with LGBTQ+ identities often perceived as confusion (Arias et al., 2009; English et al., 2018; Fulford & Cobigo, 2018). The challenges for recruitment therefore impacted on the sample size of the study, particularly regarding the accounts of family members. Three of the participants worked as support staff for the same individual, which further limits generalisability of the findings. Furthermore, this individual was supported within a forensic setting, which may have impacted on the views and attitudes of the support staff, in addition to providing a unique experience and perspective which was not consistent to that of the other participants. The forensic aspect of their experiences could not be adequately considered due to the small-scale aspect of the study.

The researcher did not confirm or explore IQ scores and social functioning of the adults being supported by participants within the study, and although unlikely, it is possible some participants may not have met diagnostic criteria for intellectual disabilities within the International Classification of Diseases-10 (ICD-10; World Health Organisation, 1992). Themes were evidenced using quotes from all participants; however, it was not possible to include the full range within the findings due to issues with practicality, potentially impacting or limiting the reader’s understanding and sense of the participant’s experiences and stories.

6.3 Reflections

The analysis of the participant's accounts required immersion and concurrent reflection of the researcher's past and current personal experiences regarding sexuality and identity, in addition to working directly with individuals with intellectual disabilities. A reflective diary was utilised to explore and consider the potential for bias when developing themes, and ensure interpretations were grounded in the accounts of the participant's and not a projection of the researcher's feelings or experiences. The researcher was aware of the impact of the participant's accounts on their own feelings and sense of injustice when participant's described barriers to the development of identity or romantic relationships regarding the adults they supported, in addition to the experiences of discrimination. Initial analysis of the themes tended to have a more positive focus on participant's accounts, particularly regarding risk and vulnerability, however continued reflections enabled the themes to shift away from this emphasis.

6.4 Implications for Research and Practice

The present study provides evidence in relation to how paid and unpaid carers who support an LGBTQ+ identifying adult with intellectual disabilities perceive and experience their romantic, intimate, and sexual lives. Some of the themes raised within the analysis, such as the experiences of LGBTQ+ identifying support staff and the ethical consideration of self-disclosure verses the positive aspects of being a role model for adults with intellectual disabilities has not been previously explored. Furthermore, the impact of society on the views of support staff and family members, and how they have changed over time, has not been previously explored in terms of supporting an LGBTQ+ identifying adult. Considering the potential impact of the views of support staff and family members for adults with intellectual disabilities in terms of sexuality regarding support provision and sexual education, these issues are worth further exploration within future research.

An important finding of the present study was the general absence of sexual education for adults with intellectual disability, in addition to a lack of specific training for support staff regarding LGBTQ+ identities and sexual relationships. This is reflected within previous research which highlights the lack of implementation of policies within organisations and services for adults with intellectual disabilities (Evans et al., 2009; Blanchett & Wolfe, 2002; McCarthy, 2014; Wilson et al., 2018). Some participants expressed that they did not hold the skill or confidence to adequately acknowledge or promote the sexual identity of the adult they supported or impart this knowledge to them. The study highlights the importance of sexual education and training that not only focuses on potential risk, but also positive sexual behaviours and positive risk taking. Sexual education for adults with intellectual disabilities should be tailored to the individual in order to take in account any limitations in adaptive skills. It would also be of value to proactively focus on the positive aspects of sex and sexual relationships (Anderson, 2015; Schaafsma et al., 2014).

The study highlighted that LGBTQ+ groups for adults with intellectual disabilities are uncommon, therefore limiting access for support. Future research should explore the impact of these groups on the identity experiences and psychological well-being of adults with intellectual disabilities, in addition to the role of family members and support staff in promoting and engaging with these groups. Further research should also explore the impact of LGBTQ+ identifying staff on the identity experiences of the adults they support. There is a diverse range of sexual identities within the population of adults with intellectual disabilities, and effort should be made within services and organisations to raise awareness of this diversity and improve the self-awareness and confidence in expression for adults with intellectual disability in terms of their sexual identity.

As identified in previous research, the experiences of lesbian and bisexual women with intellectual disabilities are largely unexplored and underrepresented (Abbott & Howarth, 2007; Stoffelen et al., 2018). Within the current study, only one participant supported a woman who identified as a lesbian. Further research focusing on the lived experience of bisexual and lesbian women with intellectual disabilities is needed, particularly around support needs and sex education. There is currently limited information available for non-heterosexual identifying women with intellectual disabilities that provides adequate information on their experiences or the pleasurable aspect of sexual intercourse (Duke, 2011; Noonan & Gomez, 2011).

In terms of the implications of this research on clinical psychology services, it is important for interventions around sexuality to promote independence and expression of diversity in identity. The research findings may be useful in the development of individual intervention or groups to support the wellbeing of adults with intellectual disabilities who identify as LGBTQ+, particularly regarding the use of inclusive language and creating a safe and open space for the exploration and discussion of identity. Consultation or delivery training or support staff by psychology staff may be useful to target pejorative attitudes and increase awareness and knowledge of sexuality in both family members and support staff.

7. Conclusion

Six participants who had experience supporting an LGBTQ+ identifying adult with intellectual disabilities provided rich data regarding their attitudes and perspectives. These experiences were analysed using Interpretative Phenomenological Analysis, and the findings explored the journey of coming out and changing views, the experiences of discrimination, the perceived risk and vulnerability of adults with intellectual disabilities, and the importance of LGBTQ+ role models and queer friendly spaces. Improving existing service provision, sexual education, and training for both staff members and family members using psychologically informed practice would be useful to improve the sexual and romantic lives of LGBTQ+ identifying adults with intellectual disabilities. It is important to continue research within the area of sexuality and intellectual disabilities, to add to the evidence base and explore issues highlighted within the present study.

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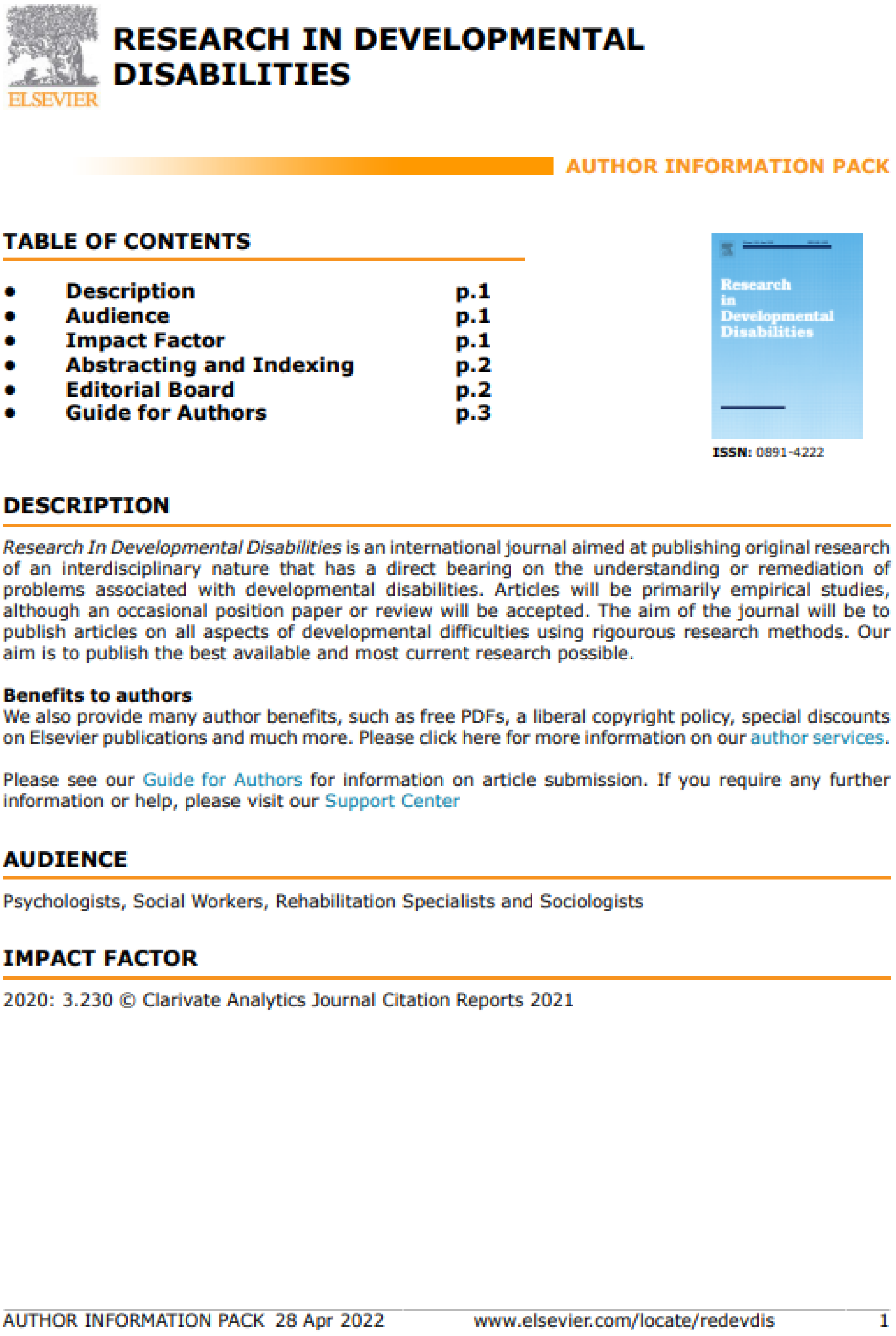
Appendices

Appendix 1: Author Guidelines for Research in Developmental Disabilities



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Research In Developmental Disabilities is an international journal aimed at publishing original research of an interdisciplinary nature that has a direct bearing on the understanding or remediation of problems associated with developmental disabilities. Articles will be primarily empirical studies, although an occasional position paper or review will be accepted. The aim of the journal will be to publish articles on all aspects of developmental difficulties using rigourous research methods. Our aim is to publish the best available and most current research possible.

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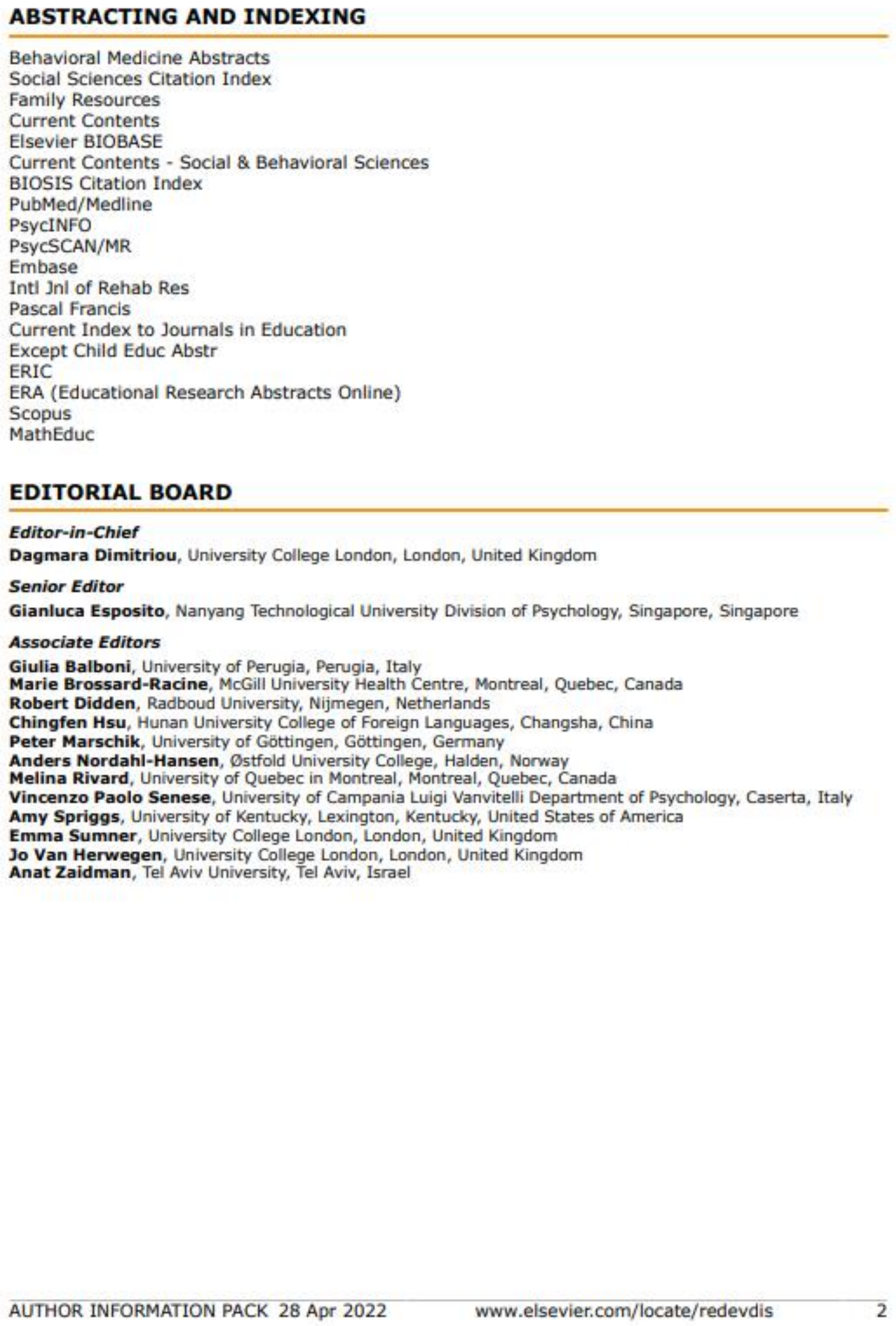

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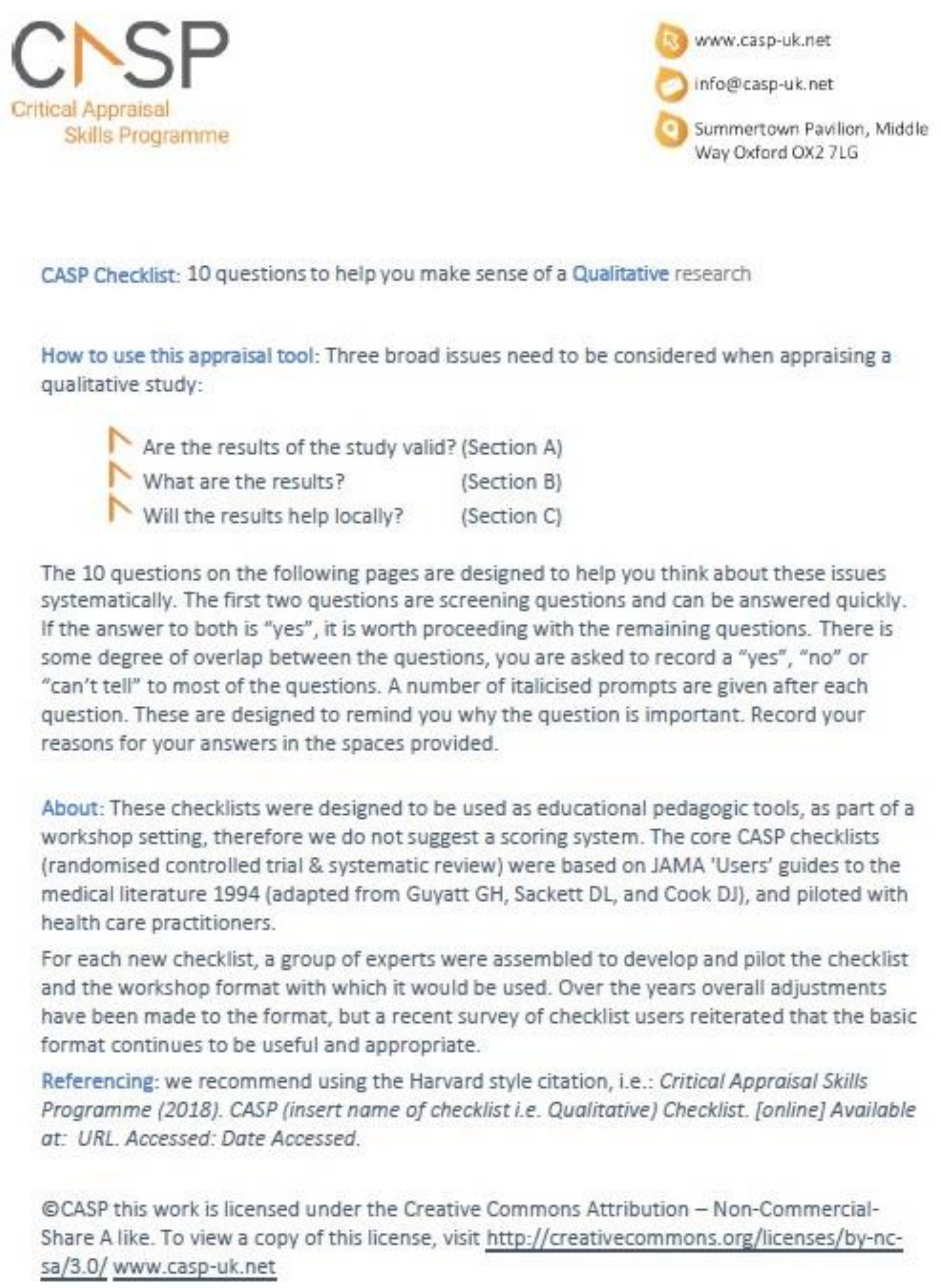
Appendix 2: CASP Quality Criteria Checklist



CASP
Critical Appraisal
Skills Programme

www.casp-uk.net
info@casp-uk.net
Summertown Pavilion, Middle
Way Oxford OX2 7LG

CASP Checklist: 10 questions to help you make sense of a **Qualitative** research

How to use this appraisal tool: Three broad issues need to be considered when appraising a qualitative study:

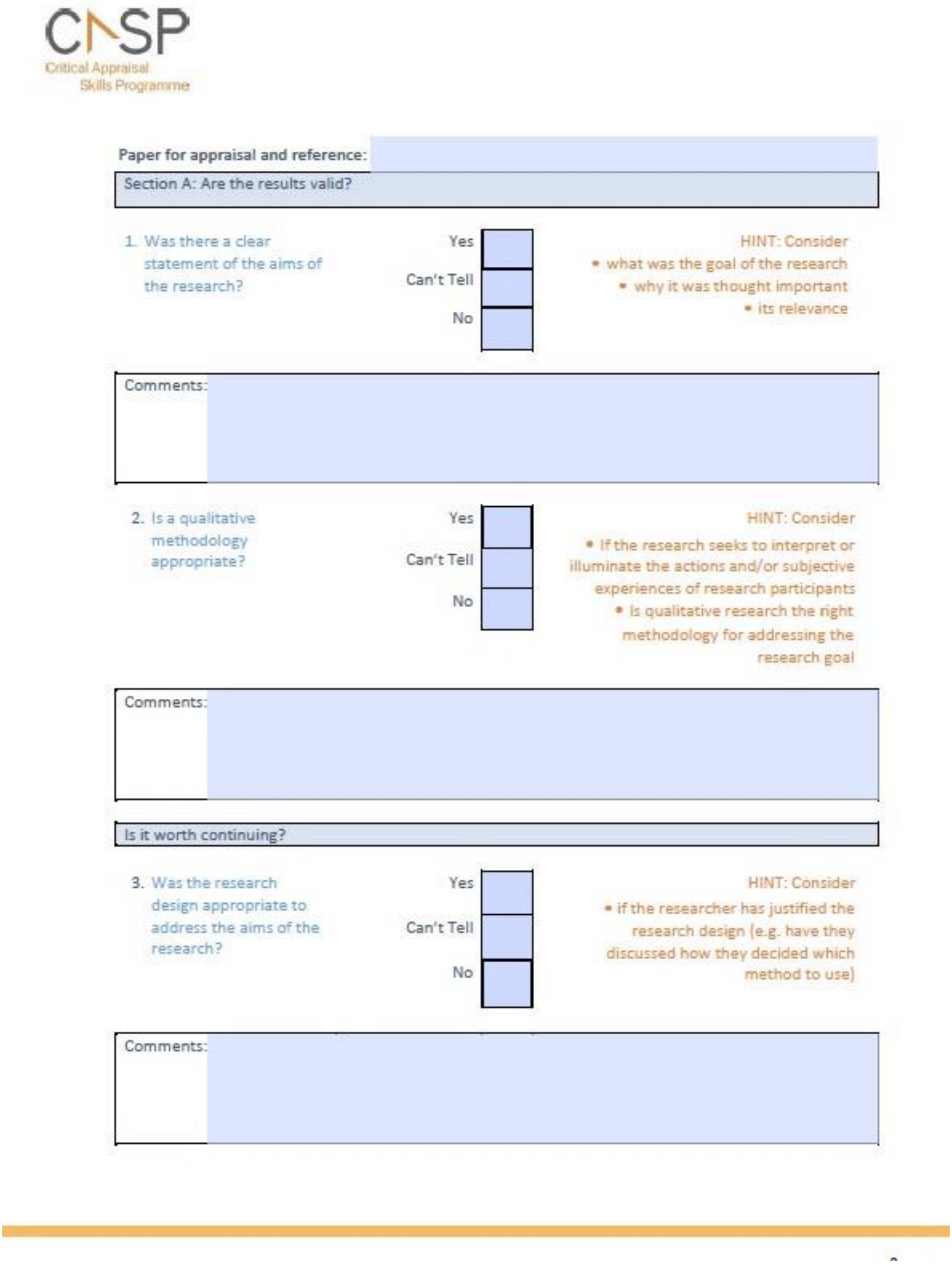
- Are the results of the study valid? (Section A)
- What are the results? (Section B)
- Will the results help locally? (Section C)

The 10 questions on the following pages are designed to help you think about these issues systematically. The first two questions are screening questions and can be answered quickly. If the answer to both is "yes", it is worth proceeding with the remaining questions. There is some degree of overlap between the questions, you are asked to record a "yes", "no" or "can't tell" to most of the questions. A number of italicised prompts are given after each question. These are designed to remind you why the question is important. Record your reasons for your answers in the spaces provided.

About: These checklists were designed to be used as educational pedagogic tools, as part of a workshop setting, therefore we do not suggest a scoring system. The core CASP checklists (randomised controlled trial & systematic review) were based on JAMA 'Users' guides to the medical literature 1994 (adapted from Guyatt GH, Sackett DL, and Cook DJ), and piloted with health care practitioners.

For each new checklist, a group of experts were assembled to develop and pilot the checklist and the workshop format with which it would be used. Over the years overall adjustments have been made to the format, but a recent survey of checklist users reiterated that the basic format continues to be useful and appropriate.

Referencing: we recommend using the Harvard style citation, i.e.: *Critical Appraisal Skills Programme (2018). CASP (insert name of checklist i.e. Qualitative) Checklist. [online] Available at: URL. Accessed: Date Accessed.*



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Paper for appraisal and reference:

Section A: Are the results valid?

1. Was there a clear statement of the aims of the research?

Yes ☐
Can't Tell ☐
No ☐

HINT: Consider
- what was the goal of the research
- why it was thought important
- its relevance

Comments:

2. Is a qualitative methodology appropriate?

Yes ☐
Can't Tell ☐
No ☐

HINT: Consider
- If the research seeks to interpret or illuminate the actions and/or subjective experiences of research participants
- Is qualitative research the right methodology for addressing the research goal

Comments:

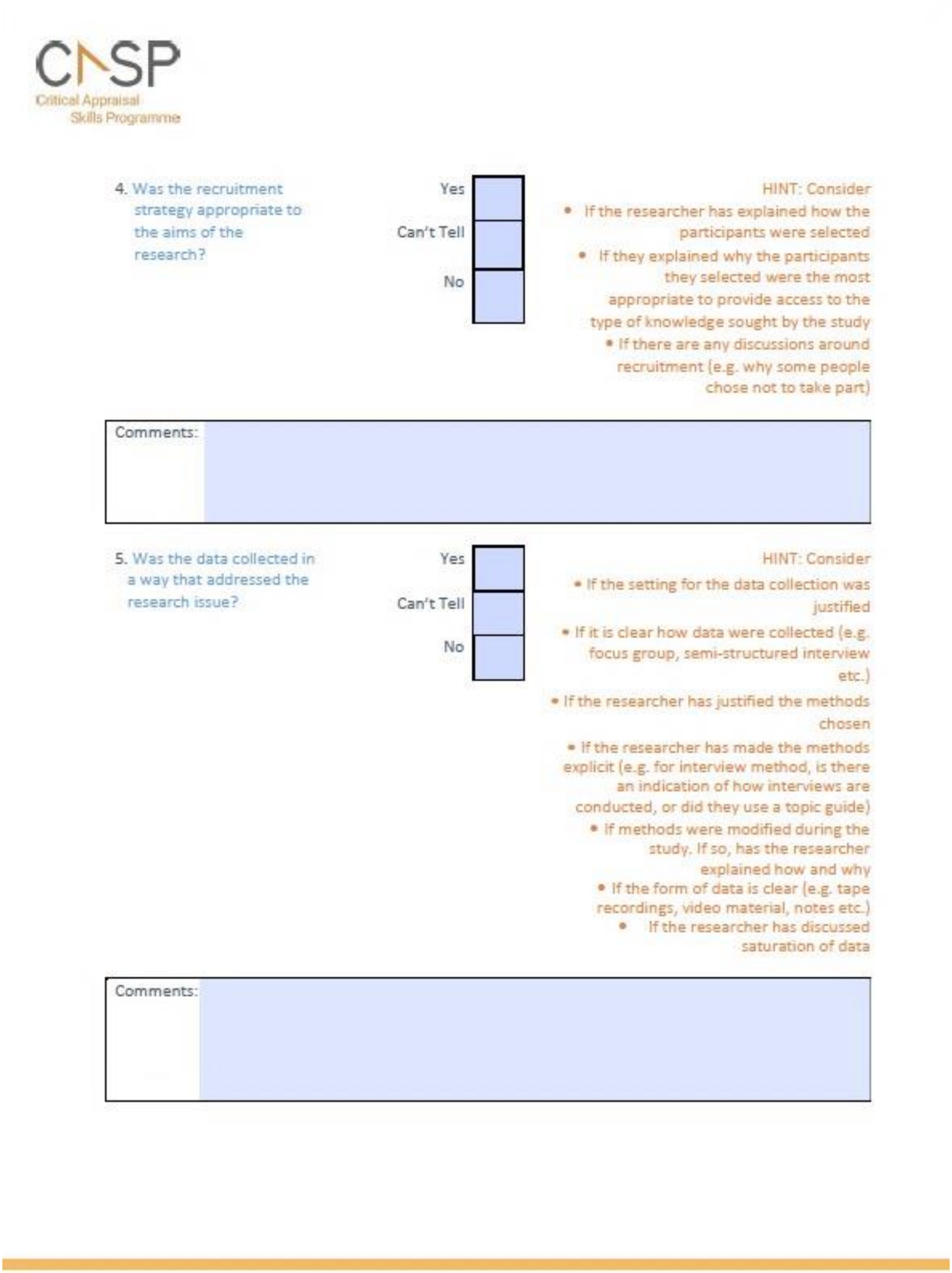
Is it worth continuing?

3. Was the research design appropriate to address the aims of the research?

Yes ☐
Can't Tell ☐
No ☐

HINT: Consider
- if the researcher has justified the research design (e.g. have they discussed how they decided which method to use)

Comments:



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4. Was the recruitment strategy appropriate to the aims of the research?

Yes ☐
Can't Tell ☐
No ☐

HINT: Consider

- If the researcher has explained how the participants were selected
- If they explained why the participants they selected were the most appropriate to provide access to the type of knowledge sought by the study
- If there are any discussions around recruitment (e.g. why some people chose not to take part)

Comments:

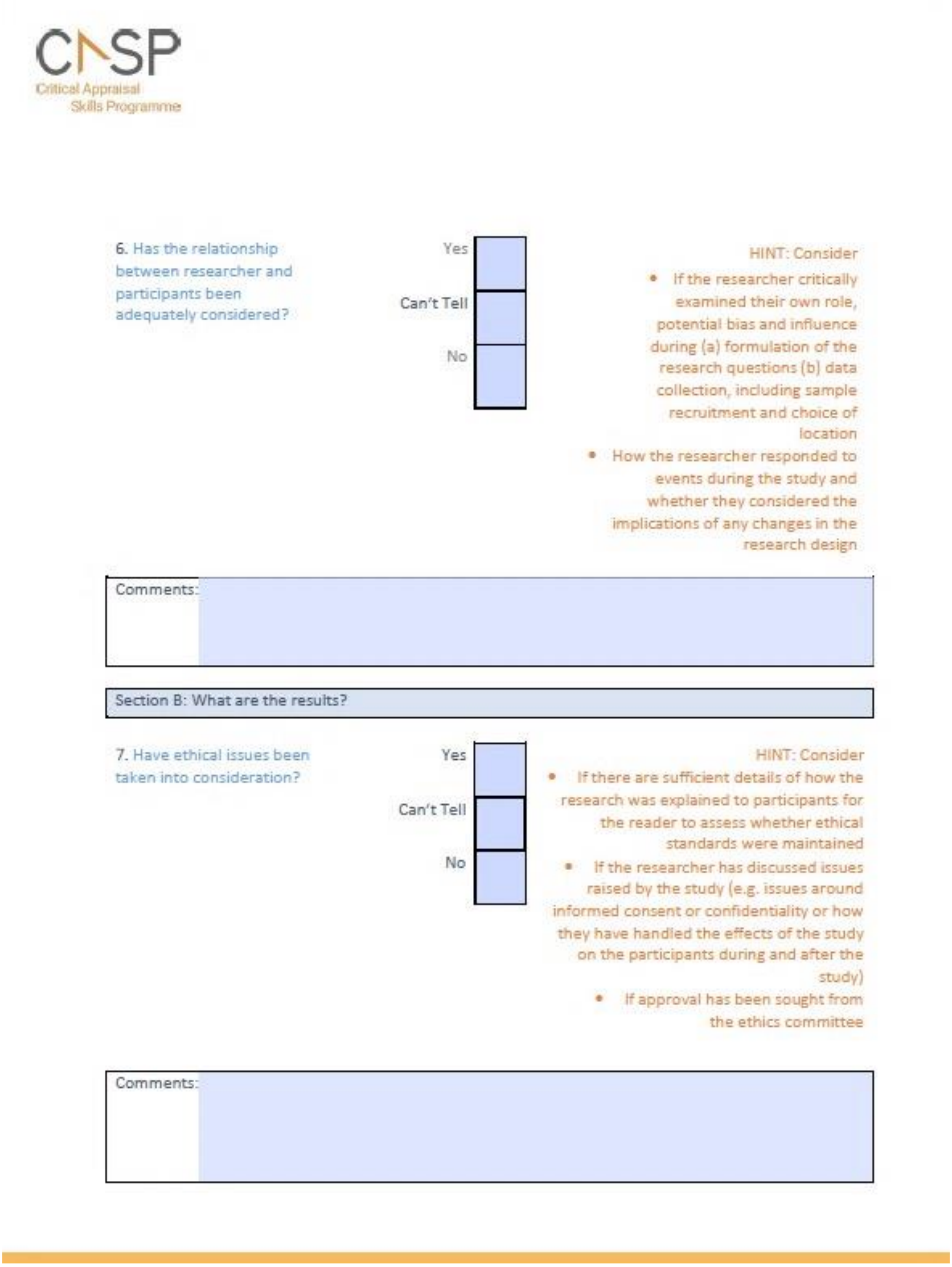
5. Was the data collected in a way that addressed the research issue?

Yes ☐
Can't Tell ☐
No ☐

HINT: Consider

- If the setting for the data collection was justified
- If it is clear how data were collected (e.g. focus group, semi-structured interview etc.)
- If the researcher has justified the methods chosen
- If the researcher has made the methods explicit (e.g. for interview method, is there an indication of how interviews are conducted, or did they use a topic guide)
- If methods were modified during the study. If so, has the researcher explained how and why
- If the form of data is clear (e.g. tape recordings, video material, notes etc.)
- If the researcher has discussed saturation of data

Comments:



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6. Has the relationship between researcher and participants been adequately considered?

Yes ☐
Can't Tell ☐
No ☐

HINT: Consider
- If the researcher critically examined their own role, potential bias and influence during (a) formulation of the research questions (b) data collection, including sample recruitment and choice of location
- How the researcher responded to events during the study and whether they considered the implications of any changes in the research design

Comments:

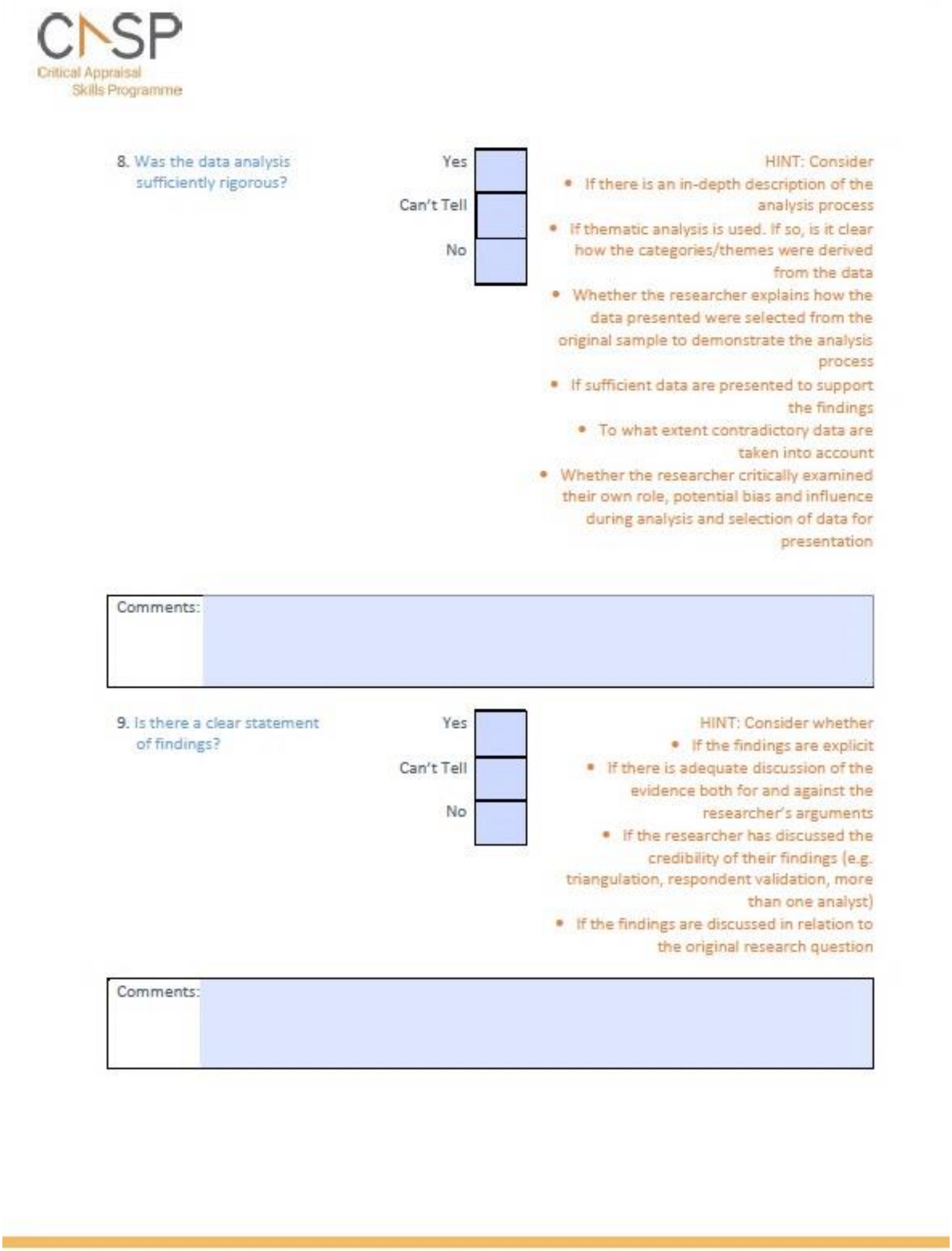
Section B: What are the results?

7. Have ethical issues been taken into consideration?

Yes ☐
Can't Tell ☐
No ☐

HINT: Consider
- If there are sufficient details of how the research was explained to participants for the reader to assess whether ethical standards were maintained
- If the researcher has discussed issues raised by the study (e.g. issues around informed consent or confidentiality or how they have handled the effects of the study on the participants during and after the study)
- If approval has been sought from the ethics committee

Comments:



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8. Was the data analysis sufficiently rigorous?

Yes ☐
Can't Tell ☐
No ☐

HINT: Consider

- If there is an in-depth description of the analysis process
- If thematic analysis is used. If so, is it clear how the categories/themes were derived from the data
- Whether the researcher explains how the data presented were selected from the original sample to demonstrate the analysis process
- If sufficient data are presented to support the findings
- To what extent contradictory data are taken into account
- Whether the researcher critically examined their own role, potential bias and influence during analysis and selection of data for presentation

Comments:

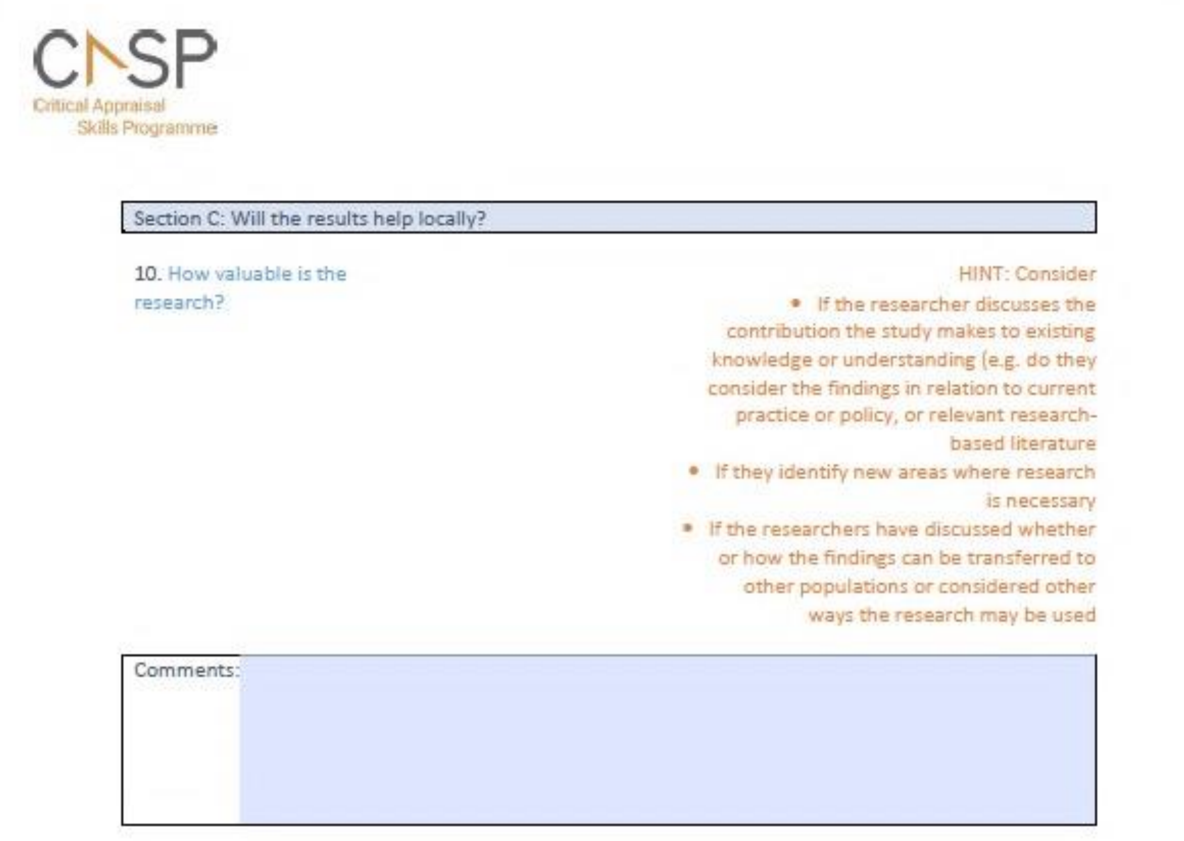
9. Is there a clear statement of findings?

Yes ☐
Can't Tell ☐
No ☐

HINT: Consider whether

- If the findings are explicit
- If there is adequate discussion of the evidence both for and against the researcher's arguments
- If the researcher has discussed the credibility of their findings (e.g. triangulation, respondent validation, more than one analyst)
- If the findings are discussed in relation to the original research question

Comments:



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Section C: Will the results help locally?

10. How valuable is the research?	HINT: Consider • If the researcher discusses the contribution the study makes to existing knowledge or understanding (e.g. do they consider the findings in relation to current practice or policy, or relevant research-based literature • If they identify new areas where research is necessary • If the researchers have discussed whether or how the findings can be transferred to other populations or considered other ways the research may be used

Comments:

Appendix 3: Systematic Review Excluded Articles with Reasons

Study	**Reason for Exclusion**
1. Stein, S. & Kohut, T. (2016). Attitudes of parents related to the sexuality of adolescents with developmental disabilities compared to typically developing peers and siblings. *Journal of Sexual Medicine, 12*(4), 283.	Focus on different population
2. Ramsten, C., Lene, M., Dag, M. & Hammar, L. M. (2020). Information and communication technology use in daily life among young adults with mild-to-moderate intellectual disability. *Journal of Intellectual Disabilities, 24*(3), 289-308.	Focus on general ICT use
3. Caton, S. & Chapman, M. (2016). The use of social media and people with intellectual disability: A systematic review and thematic analysis. *Journal of Intellectual and Developmental Disability, 41*(2), 125-139.	Focus on general ICT use
4. Shpigelman, C. & Gill, C. (2014). How do adults with intellectual disabilities use Facebook? *Disability & Society, 29*(10), 1601-1616.	Previous systematic review
5. Mitchell, K., Becker-Blease, K. & Finkelhor, D. (2005). Inventory of problematic internet experiences encountered in clinical practice. *Professional Psychology: Research and Practice, 36*(5), 498-509.	Focus on general ICT use
6. Bale, C. (2001). Befriending in cyberspace – Challenges and opportunities: A column from befrienders international. *Crisis: The Journal of Crisis Intervention and Suicide Prevention, 22*(1), 10.	Focus on friendships only
7. Thompson, D. (2019). Commentary: The internet, social media, relationships and sex. *Tizard Learning Disability Review, 24*(1), 20-23.	Reflective piece
8. Roth, M. & Gillis, J. M. (2015). “Convenience with the click of a mouse”: A survey of adults with Autism Spectrum Disorder on online dating. *Sexuality and Disability, 33*(1), 133-150.	Focus on different population
9. Seale, J. K. & Pockney, R. (2002). The use of the personal home page of adults with Down’s syndrome as a tool for managing identity and friendship. *British Journal of Learning Disabilities, 30*(4), 142-148.	Focus on friendships only
10. Löfgren-Mårtenson, L., Sorbring, L. & Molin, M. (2015). “Tangled up in the blue”: Views of parents and professionals on internet use of sexual purposes among young people with intellectual disabilities. *Sexuality & Disability, 33*(4), 533-544.	Duplicate
11. Löfgren-Mårtenson, L., Sorbring, L. & Molin, M. (2015). “Tangled up in the blue”: Views of parents and professionals on internet use of sexual purposes among young people with intellectual disabilities. *Sexuality & Disability, 33*(4), 533-544.	Duplicate
12. Lines, J., Combes, H. & Richards, R. (2021). Exploring how support workers understand their role in supporting adults with intellectual disabilities to access the internet for intimate relationships. *Journal of Applied Research In Intellectual Disabilities, 34*(2), 556-566.	Duplicate
13. Lines, J., Combes, H. & Richards, R. (2021). Exploring how support workers understand their role in supporting adults with intellectual disabilities to access the internet for intimate relationships. *Journal of Applied Research In Intellectual Disabilities, 34*(2), 556-566.	Duplicate

Appendix 4: Excerpt from Thematic Synthesis Coding

Exert from Löfgren-Mårtenson (2008)	
‘The Biggest Risk Is That Nothing Will Ever Happen To Me!’’ Experiences of Using the Net	
A majority of the interviewed young people consider the Internet to be an arena that has given them many positive experiences and adventures, especially because it provides them with the possibility of one day meeting a partner. Nevertheless, it is difficult to realize those possibilities, and only a few of the informants have met a partner through the Internet. Likewise, most of the informants declare that they in fact only have contacts with people on the Net that they already know from their special schools, jobs or other parts of their ‘‘real life’’. But a few of the young informants describe that they have created and developed relationships with people outside the sphere of those already known, and that these interactions only exist in cyberspace. Discussing his Net-contacts Mattias says:	Internet is positive Exploring and expressing sexuality, romance on the web Barriers preventing relationship Maintaining friendships Cyber relationships
“I have my best friends on the Net .. . and a girlfriend. But I have never met them.”	Romance over the web Cyber relationships
Another positive aspect about the Internet that is mentioned by informants is the possibility for the young adults to decide for themselves when, where and how to meet others. Jacob, 22, says:	Internet is positive Empowering
“They don’t know who you are ... what school you are attending. They don’t really know you at all.”	Identity on the internet
The Internet is not only merely another way to meet people. It is considered to be a unique way to meet other people, both friends and potential	Cyber relationships

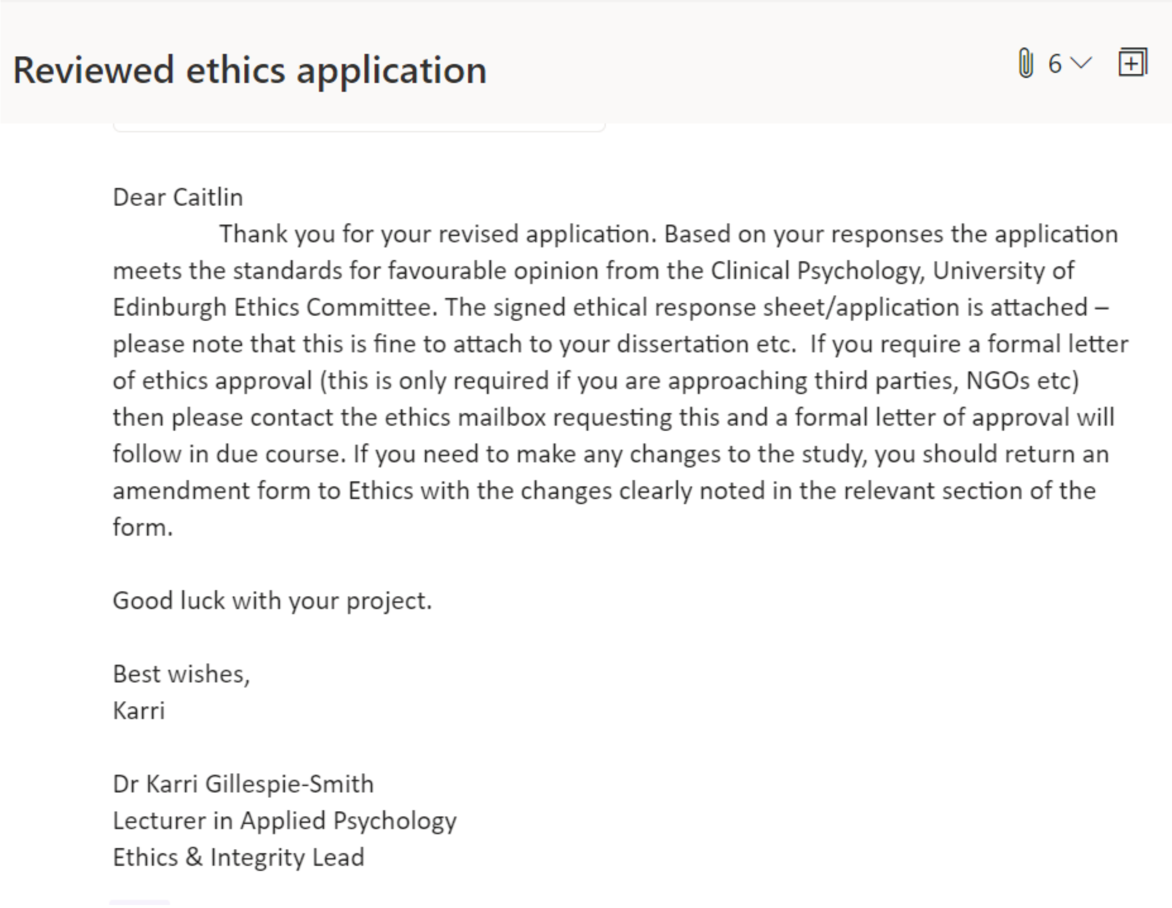
partners, for the informants. On the Internet, a young person can socialize with others beyond the control of staff and family members and they can also organize, plan and decide by themselves how to arrange these meetings.	Empowering Limitations and restrictions from others Feeling like everyone else
Also, through the Internet, possibilities are created for a secret parallel world where the informants can have a private life, something all the young people I spoke to very much appreciated.	Feeling like everyone else
They feel that through the Net they escape the control of the surrounding world. Without having to ask permission, they are, all by themselves, capable of deciding which sites they want to visit and with whom they want to communicate. Anders says:	Feeling like everyone else
“That is what is so nice with the Internet .. . I have my own time and I can do whatever I want to, whenever I want”	Empowering Feeling like everyone else

Appendix 5: Codes Produced from Thematic Synthesis Coding

Cognitive limitations of service users
Needing straightforward guidance
Feelings guiding internet behaviour
Carer confidence or expertise to manage internet use
Understanding social nuances over the web
Providing easier interaction
Internet is positive
The othered, us vs them
Identity on the internet
Feeling like everyone else
Socialising using the web
Internet role models
Internet is negative
Conflicted views of carers
Romance on the web
Exploring and expressing sexuality
Being viewed as vulnerable
Internet etiquette
Viewing and engaging with pornography
Infantile view of service users
Limitations and restrictions from others
Giving space to explore
Influences on views
Changing views and attitudes
Support to access the internet
Power imbalance between support and supported
Communicating over the internet
Managing risks
Surveillance behaviours
Anonymity
Cyber relationships
Fear of getting into trouble
Dangers of the internet
Gatekeeping access to the internet
Internet as a social arena
Flirting with others
Lack of staff training
Managing illicit content on the internet
Engaging in sexual behaviours
Looking and sending sexual pictures
Literacy and the internet
Maintaining friendships
Meeting new people
Managing contact from internet strangers
From internet to IRL
Online dating
Viewing unwanted sexual content
Shame of accessing sexual material
Carer desire to protect from harm
Empowering
Carer view of role in supporting internet use for relationships or sexual purposes

Appendix 6: University of Edinburgh REC Approval

Email from Dr Karri Gillespie-Smith, dated 29/01/21



Reviewed ethics application

Dear Caitlin

Thank you for your revised application. Based on your responses the application meets the standards for favourable opinion from the Clinical Psychology, University of Edinburgh Ethics Committee. The signed ethical response sheet/application is attached – please note that this is fine to attach to your dissertation etc. If you require a formal letter of ethics approval (this is only required if you are approaching third parties, NGOs etc) then please contact the ethics mailbox requesting this and a formal letter of approval will follow in due course. If you need to make any changes to the study, you should return an amendment form to Ethics with the changes clearly noted in the relevant section of the form.

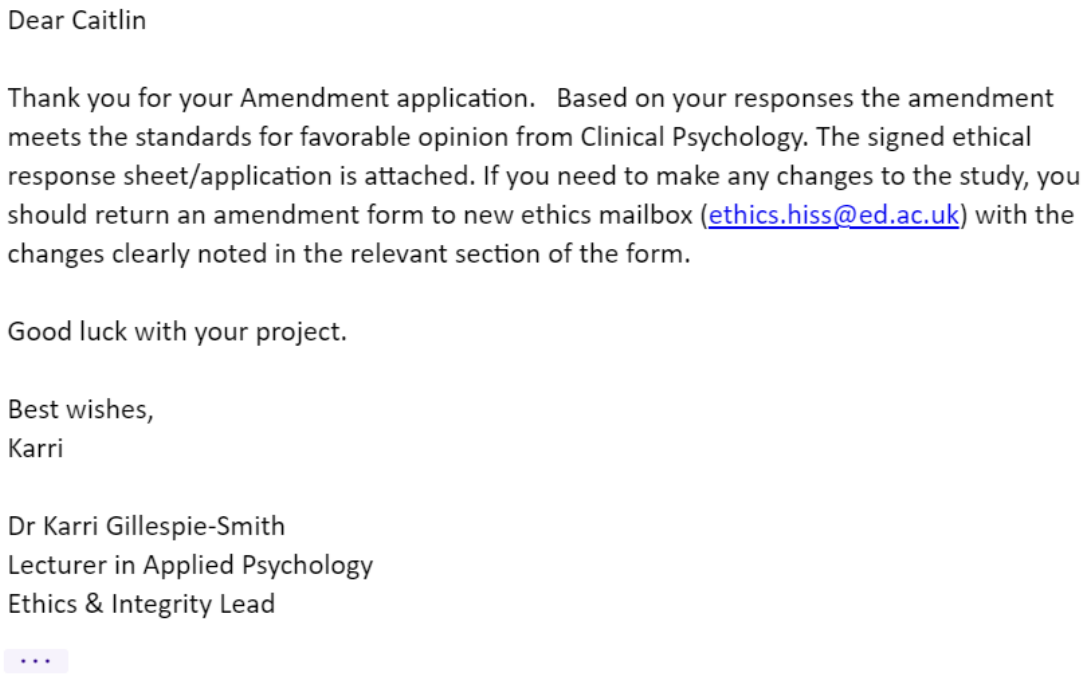
Good luck with your project.

Best wishes,
Karri

Dr Karri Gillespie-Smith
Lecturer in Applied Psychology
Ethics & Integrity Lead

Appendix 7: University of Edinburgh REC Approval Amendment

Amendment request sent August 2021
Email from Dr Karri Gillespie-Smith dated 02/09/2021



Dear Caitlin

Thank you for your Amendment application. Based on your responses the amendment meets the standards for favorable opinion from Clinical Psychology. The signed ethical response sheet/application is attached. If you need to make any changes to the study, you should return an amendment form to new ethics mailbox (ethics.hiss@ed.ac.uk) with the changes clearly noted in the relevant section of the form.

Good luck with your project.

Best wishes,
Karri

Dr Karri Gillespie-Smith
Lecturer in Applied Psychology
Ethics & Integrity Lead

Appendix 8: University of Edinburgh Ethics Application Form

University of Edinburgh, School of Health in Social Science
Research Ethics, Integrity and Governance

The forms required when seeking ethical approval in the School of Health and Social Sciences have now been merged into this single electronic document. The sections you are required to complete will depend on the nature of your application. Please start to complete the form from the beginning and proceed as guided. On completion the *entire* document should be submitted electronically to your section's ethics administrator using the email addresses detailed on the final page.

Applications submitted without appropriate documentation will be returned.

Please work your way through this form, reading the questions and accompanying information carefully. Sections highlighted in yellow are mandatory, so you must answer all the questions in these sections.

Aside from the mandatory questions you won't always need to answer all of the questions in the form. Section 1 "your project details" includes a set of filter questions that determine the rest of the questions you need to answer. Please read the notes carefully to make sure you answer the right questions. The notes contain hyperlinks so you can jump directly to the relevant section.

Sections highlighted in yellow are **mandatory**. These must be completed for every application.

SECTION 1: Introduction

This is a:

New application for ethical approval – first submission ☒
A resubmission following reviewer comments ☐
A resubmission with requested amendments ☐

Please select your School:

☒ School of Health in Social Science

Please select your subject area

☐ CPASS
☒ Clinical Psychology
☐ Nursing Studies

It is each researcher's responsibility to check whether their project requires Sponsorship, Caldicott Approval, R&D approval, and/or IRAS.
https://www.ed.ac.uk/health/research/ethics/sponsorship-and-governance

If the project requires any of these, these need to be secured prior to submitting this application.

Please tick the relevant box before proceeding:

I have checked and this project does not require Sponsorship, Caldicott, R&D and/or IRAS approval ☒

My project requires Sponsorship x	Sponsorship letter attached ☐
My project requires Caldicott approval ☐	Caldicott approval letter/email attached ☐
My project requires R&D approval ☐	R&D approval letter/email attached ☐
My project requires IRAS approval x	IRAS approval letter/email attached ☐

External Research Ethics Approval

Does your research project require the approval of any other institution and/or ethics committee, nationally or internationally?

Please state the name of the review body and the current status of your application (for example, submitted, approved, deferred, or rejected)? Please include any known submission / approval timelines.

No.

SECTION 2: Your project details

2.1 Project details

Your name: Caitlin Turner

Please enter your project title: **The sexual and romantic lives of adults with intellectual disabilities who are LGBQ+: Experiences, attitudes, and influences of formal and informal carers**

Proposed Project Start Date: August 2020

Proposed Project End Date: May 2022

Q1. Are you a member of staff or a student?

☐ Staff member

Supplementary questions for staff members only:

List the names and institutions of any Co-Investigators working with you on the project.

N/A

☒ Student

Supplementary questions for students only:

What type of student are you?

Postgraduate doctoral student

Please provide your course title or programme name

Doctorate in Clinical Psychology

Who is your supervisor?

Dr Doug McConachie

Q2. Please indicate any external ethical guidance your project has to adhere to. For example, the British Psychological Society (BPS), the British Academy, the British Association of Sport and Exercise Sciences (BASES)

BPS

2.2 Participants

Q3. Will you be collecting or generating any new data (including autoethnographic writings)?

☒ Yes

☐ No

Q4. Will you be extracting, re-coding or using existing data that contains sensitive information (i.e., identifiable information)?

☐ Yes
☒ No

If the answers to both Q3 and Q4 are 'no' you are not required to complete:

Section 4: Potential risks to participants and researchers
Section 5: Participants and data subjects
Section 6: Participant or data subject information and consent

2.3 Security-Sensitive Material

Q5. Does your research project fit into any of the following security-sensitive categories?

☐ Your research project is commissioned by the military.

☐ Your research project is commissioned under an EU security cell.

☐ Your research project involves the acquisition of security clearances.

☐ Your research project concerns groups which may be construed as terrorist or extremist

If you answer 'yes' to any of the questions above you must complete Section 8 Security Sensitive Material. You must answer all questions in the section.

2.4 Good Conduct in Collaborative Research

Q6. Will your research project involve collaborative work?

☐ Yes

☒ No

Selecting "Yes" to this question means you must complete Section 10 "Good conduct in collaborative research" later in the form. You must answer all questions in the section.

2.5 Project Funding

Q7. Is funding required for your research project? (To be completed by staff only)

Please indicate how the project will be financially supported.

N/A

2.6 Knowledge Exchange and Impact

Q8. Will there be any knowledge exchange and impact activities associated with this project? (To be completed by staff only)

N/A

2.7 Consultancy Potential

Q9. Could your research project lead to potential consultancy activities in the future? (To be completed by staff only)

N/A

SECTION 3: Description of the research

Q10: Please use the box below to describe your research; including a background summary, rationale, research questions and hypotheses, methodology, procedures. If you have identified ethical considerations that are not addressed in other parts of the form, please outline and discuss them here.

Background

The World Health Organisation (WHO, 2013) defines sexuality as a central aspect of being human, incorporating several aspects, including intimacy, gender identity, and sexual orientation (Krebs, 2007). Despite intimate and romantic relationships having several psychosocial benefits (Braithwaite, Delevi & Fincham, 2010), adults with intellectual disabilities have historically been viewed as being asexual, often having their right to develop and maintain intimate relationships denied (Arias et al., 2009).

Changes in policy within the United Kingdom, such as "Valuing People Now" (Department of Health, 2009), and shifts in societal expectations have influenced the emergence of increased independence and social inclusion of people with intellectual disabilities (Culham & Nind, 2003). Normalisation principles have emphasised the rights of people with disabilities to express their sexual needs according to social norms, as well as having access to opportunities to experience intimacy and romantic relationships (Aunos & Feldman, 2002). However, although services are becoming increasingly aware of issues related to sexuality and relationships, there continues to be a lack of policy implementation and barriers to the fulfilment of sexual expression (Evans et al., 2009; Blanchett & Wolfe, 2002; McCarthy, 2014; Wilson & Plummer, 2014). Issues surrounding sexuality are often overlooked, with an increased focus on sexual abuse and exploitation (Thompson & Brown, 1997), and sexual behaviours that challenge (Cuskelly, Bryde & Centre, 2004; Evans et al., 2009; Haynes, 2016).

Although there has been a recent emergence of literature amongst adults with intellectual disability and sexuality (Rushbrooke et al., 2014), the available research often focuses on heterosexual perspectives, with the experiences and support needs of people who identify as lesbian, gay, bisexual, and queer (LGBQ+) often underrepresented (Abbott, 2015). Due to stigma, prejudice and discrimination concerning disability and sexual orientation, opportunities to develop romantic relationships may be met with further barriers due to social exclusion and marginalisation (Jones & Magowan, 2010; Wilson, 2006). Further to this, existing research has shown that individuals who identify as

LGBQ+ are more likely to experience psychological distress in comparison to people who identify as heterosexual (Meyer, 2010). Within a recent systematic review exploring the lives of individuals with intellectual disabilities who identify as LGBQ+, it was highlighted that often individuals feel unrepresented within healthcare services and are more likely to experience negative sexual health outcomes (McCann, Lee & Brown, 2016). Within this systematic review, the authors recognised the concept of diverse sexuality and the broader spectrum of identities; however, these were not explored and remain underrepresented within the literature.

Despite a value for intimacy and desire to be in romantic relationships in individuals with intellectual disabilities (Whittle & Butler, 2018; English & Tickle, 2018), barriers remain in the place in terms of social opportunities to meet others, and lack of sexual knowledge regarding safe sex practices (Eastgate et al., 2012; Whittle & Butler, 2018). Due to fewer opportunities in gaining sexual knowledge through peer interaction (Jahoda & Pownall, 2014), views and attitudes regarding sex can be shaped by parental influence, which can also determine access to socio-sexual information (Johnson et al., 2002; Szollos & McCabe, 1995). Individuals with intellectual disabilities may remain in the family home throughout their life, receiving continued support and involvement from their parents, which may impact on their social and sexual autonomy (Kelly, Crowley & Hamilton, 2009).

Although family carers have expressed their want for their children with intellectual disabilities to have the same rights and opportunities to develop romantic and intimate relationships, they are often concerned for their safety and perceived vulnerability (Lafferty, McConkey, & Simpson, 2012). These perceptions may lead to restrictions in freedom, preventing individuals from meeting potential partners or developing a sexual relationship (Haynes, 2016). Further to this, parents may support the right for their adult child to develop a romantic relationship,

however, may have reservations if this relationship was with a member of the same sex (Blyth, 2010; Blyth & Carson, 2007; Carson & Docherty, 2002). A study conducted by Cuskelly and Bryde (2004) found that family caregivers hold more conservative views in comparison to support staff. However, this may be confounded by the relatively younger age of staff members. However, caregiver perspectives used in the study may be unrepresentative, as participants partaking in sexuality research may be more comfortable regarding this topic and may hold more liberal views.

A limited body of qualitative research has explored the experiences and views of family caregivers regarding the sexual and romantic lives of their adult children with intellectual disabilities. A recent qualitative meta-synthesis (Rushbrooke et al., 2014) explored the difficulties and challenges experienced by caregivers concerning individuals they supported, comparing the views of both paid support staff and family caregivers. It was highlighted that caregivers often feel uncertainty and lack of confidence regarding issues surrounding sexuality. Although the presumption of asexuality of those with intellectual disabilities was not a pervasive view, some caregivers presumed the sexual identity of individuals as heterosexual, often interpreting homosexual acts as experimentation (Abbott & Howarth, 2003). This perceived asexuality or heteronormative view creates a further barrier to those who identify as LGBQ+ who wish to pursue romantic or sexual relationships. Despite family caregivers expressing positive regard towards their adult children's sexual expression, this was perceived as conditional with limitations.

Although the meta-synthesis provides insight into the sexual lives of individuals with intellectual disabilities, individuals who identify as heterosexual were disproportionately represented within the studies, which may detract from the experiences of those who identify as LGBQ+. The sexual orientation and identity of both formal and informal caregivers were often not reported or explored. As this may influence their attitudes, beliefs and values surrounding LGBQ+ issues, this may be an important demographic characteristic to include in future analyses. Paid caregivers' views were also disproportionately represented in comparison to family caregivers within the selected studies; however, the review provides insight into the opinions and support needs of parents and their adult children.

Although there have been no studies exploring the experiences of family caregivers and their adult children who have intellectual disabilities and identify as LGBQ+, perspectives of the individuals themselves have been explored. A systematic review (McCann, Lee & Brown, 2016) highlighted that adults with intellectual disabilities perceived their sexuality as an integral part of their identity; however, some found difficulty in accepting their sexual orientation. It was reported that some individuals felt they were unsupported and unrepresented in intellectual disability services, highlighting the need for inclusive, responsive, and appropriate education and training for staff and family caregivers. Studies often focused on the experiences of homosexual males, with the experiences of lesbians and queer women with intellectual disabilities underrepresented. There were no multi-centre, nationwide, or international studies, which may not adequately represent the experiences of adults with intellectual disabilities within the general population, or across different cultures. Furthermore, limitations in the robustness of the studies were highlighted, particularly the presence of small sample sizes, caveats in methodology and lack of transparency in the analysis.

Rationale and overview of proposed work

To date, there are no qualitative research studies that explore the values, attitudes, and experiences of family caregivers with adult children with intellectual disabilities who identify as LGBQ+. Given the importance of sexuality to mental and physical wellbeing (Hull, 2008), and the spectrum of non-heteronormative sexual orientations, the proposed study would enable further insight and understanding of the experiences of sexual minorities within the disability populace. The proposed research study aims to address these gaps in the literature, enabling a further understanding of the potential impact of views, attitudes and values surrounding LGBQ+ individuals with intellectual disabilities and their sexual lives. This may offer insight into barriers to support or highlight factors that are important in enabling those who identify as LGBQ+ to gain fulfilment in romantic and sexual relationships.

The proposed study would adopt a qualitative design to explore ~~parents~~' family caregivers' and paid caregivers experiences, attitudes and values regarding their adult ~~children~~ family member or adult they support with intellectual disabilities who identify as LGBQ+. Semi-structured, one-to-one interviews will be used to explore ~~parents’~~ family caregivers’ and paid caregivers’ perceptions of sexual expression, intimate and romantic relationships, bodily autonomy in terms of sexual health and parenthood, and sex education.

The use of parental figures was selected due to their prominent role in enabling their adult children that they support to having access to sex education and social opportunities to meet others, as well as the influence they have on views and attitudes towards non-heteronormative sexual orientations. The additional use of family caregivers was selected due to their role in supporting adults with learning disabilities in community settings, particularly if parents are no longer alive or have lost contact.

The findings from the proposed research study may highlight further gaps in the current literature and offer perspectives for further research. This would result in more positive outcomes for individuals with intellectual disabilities who identify as LGBQ+.

Research aims and objectives

The aim of the research is to explore and examine the experiences, values, and attitudes of ~~parents~~ family caregivers and paid caregivers regarding their adult ~~child~~ family member or adult they support with intellectual disabilities who identify as LGBQ+, in terms of the expression of their sexuality and their support needs. The key areas of exploration and questioning will concern sexual expression, intimate and romantic relationships, contraception, parenthood, and sex education. From this, the principal research question is:

1. What are the attitudes, values, and experiences of ~~parents family~~ caregivers in relation to the sexuality of ~~their~~ adults ~~children~~ ~~family member~~ with intellectual disabilities who identify as LGBQ+?

In order to understand how the attitudes, values, and experiences of ~~parents~~ family caregivers and paid caregivers who support ~~their~~ an adult ~~children~~ ~~family members~~ with intellectual disabilities influence support, further research questions have been identified.

1. What are the sexual needs and experiences of adults with intellectual disabilities that identify as LGBQ+, from the perspectives of ~~their parents family members?~~ Caregivers?
2. Do the attitudes, values and experiences of ~~parents family~~ caregivers act as barriers to support, education, and the development of interpersonal relationships?

Research design

An exploratory, qualitative design will be utilised to explore the experiences of parents and ~~and family~~ caregivers in regard to ~~their~~ the adult they support’s ~~children’s family member’s~~ sexual expression. A qualitative design was selected so that the information that is contributed by participants is less likely to be constrained by the preconceived ideas of the researcher. Furthermore, the methodology allows for the subjective experience of the participant to be explored, including how meaning is attached to events. Data will be collected through semi-structured, one-to-one interviews, which will be developed based on the research questions and objectives and will be informed by themes from existing literature.

Study population

The inclusion criteria are:

- Parents, family caregivers and paid caregivers of adults (>18 years old) who have a formal diagnosis of intellectual disability under the DSM-5, who identify as LGBT

The exclusion criteria are:

- Parents, family caregivers and paid caregivers are unable to speak or read English
- Parents, family caregivers and paid caregivers of children (<18 years old) who have intellectual disabilities

- Parents, family caregivers and paid caregivers of an adult child with a disclosure of intellectual disability who identifies as heterosexual
- Unwillingness or inability to provide informed consent

Due to the ethical implications of individuals with intellectual disability providing informed consent to partake in the research, participants of the study will be parents, family caregivers and paid caregivers of LGBQ+ adults. Recruitment will utilise a convenience sample. Participants will be recruited through third sector organisations during the period of the project. Social media platforms (e.g. Twitter) will also be used to advertise the project in order to facilitate recruitment, as well as creating posts on online forums for people with intellectual disabilities (e.g. Choice Forum) as well as parents who have adult children who identify as LGBQ+. The researcher will complete first- and third-year specialist placements within Learning Disability Services in the NHS as part of their doctoral training, and will therefore have access to colleagues who can provide insight or information on relevant third sector organisations or local support providers.

Procedure

Identification of participants within third sector organisations

Department managers within relevant third sector organisations (e.g. ENABLE) will be contacted directly by the researcher, who will provide the rationale and focus of the study and recruitment aims, in addition to the exclusion and inclusion criteria. Information regarding participation will then be cascaded to staff within these services via service managers. Furthermore, the researcher will attend team meetings in order to speak to staff and encourage staff to identify potential participants. These staff members will then ascertain whether participants would be willing to receive information regarding the study and be contacted by the researcher.

Identification of participants within local authorities

Staff within local authorities North and South Lanarkshire will be contacted by the researcher or field supervisor, who will provide the rational and focus of the study and recruitment aims in addition to any relevant recruitment material. Prior to contacting the local authorities for recruitment, contact will be made to complete any additional local ethics applications.

Identification of participants within NHS organisations and services

Staff within NHS Learning Disability services will be contacted by the researcher or field supervisor, who will provide the rationale and focus of the study and recruitment aims in addition to any relevant recruitment material. Prior to this, NHS IRAS approval will be sought.

Recruitment via social media and the internet

Further to this, social media platforms (e.g. Twitter) will be used to advertise the project, as well as online forums for people with intellectual disabilities (e.g. Choice Forum) as well as parents who have adult children who identify as LGBQ+. In these instances, participants would be able to self-identify whether they are eligible to take part and are interested in providing their experiences.

Materials used to recruit participants

The researcher will provide recruitment materials, information leaflets and flyers regarding the research to staff members within third sector organisations, with contact information of the researcher. Further to this, the contact information of the researcher will be available when advertising via social media and the internet for participants to make contact. (Please see appendix for recruitment material).

Providing information to potential participants and gaining consent

A participant information sheet (PIS) will be available online for potential participants to access. Once contact details have been provided to the researcher, either through recruitment through third sector organisations or social media, the researcher will contact the potential participant to go over the PIS in detail and provide further information on the project. At least twenty-four hours will be left between providing the PIS and taking consent. The researcher will also be available for further discussion, clarifications, and to answer any further questions.

The researcher will contact potential participants at least twenty-four hours after providing them with the PIS to see if they would like to take part. A consent form will be sent via internet link for participants to complete. Following this, a time slot will be provided for the interview to take place.

Assessing whether the potential participant is well enough to provide informed consent

If the researcher feels that any potential participant’s ability to provide informed consent is compromised by mental or physical ill-health, a second opinion will be sought from the researcher’s clinical supervisor. If it is decided that the individual cannot provide informed consent, consent will not be sought at that time.

Clinical interview

Due to the effects of COVID-19, interviews will take place over Microsoft Teams videoconferencing software. University of Edinburgh policy advises that Microsoft Teams or Zoom is used for one-to-one interviews.

Microsoft Teams is part of the Microsoft Office 365 software. Office 365 meets the compliance needs for the University of Edinburgh. Using Microsoft teams would allow the researcher to send a private link to the participant via email. The meeting would be marked "private" in the researcher's Outlook, so others would be unable to join the meeting. Participants would wait in a lobby and would be invited in by the researcher, so the researcher would be able to reject the entry of others who are not the participant. The researcher would enable the option "Who can present?" to only them, enabling the participant to be an attendee. Therefore, only the researcher would have the ability to record and share content. This would protect the privacy of the participant, whilst almost remaining compliant with the University of Edinburgh's policies regarding security.

Zoom would be offered to participants as an alternative video and audio-conferencing tool. Zoom may be an easier alternative for participants to use, as it offers easy access, as users can click a button and launch a Zoom meeting without the need for excess support. The researcher would follow similar guidelines for using Zoom in terms of sending a direct link to participants, and only allowing participants access to the Zoom conference.

The researcher would connect to the University of Edinburgh's secure network before using Microsoft Teams or Zoom. The researcher would ensure that the most recent version of Teams has been downloaded, or if Zoom is being used, the researcher will use the University of Edinburgh's Enterprise account. This would ensure that the most up-to-date security features are available. The interviews would be recorded using a secure Dictaphone supplied by NHS Lanarkshire, which has a pin number for extra security.

The use of videoconferencing allows for recruitment to be extended beyond the normal geographical limitations of the researcher, enabling interviews to be conducted with participants throughout Scotland the United Kingdom, in addition to other countries outside of the United Kingdom. Interviews will be audio recorded on a password protected mobile recording device to aid with interview transcription and data analysis. This recording device would be password protected. Following the recording of the interviews, these will be pseudo-anonymised and uploaded at the earliest possible moment to the University of Edinburgh's password-protected shared drive. Audio-recordings will be transcribed, and in order to protect the anonymity of the participants, identifiable information within the transcripts will be removed. The duration of the interview will take approximately 30 minutes to 90 minutes.

The original recordings will be deleted off the recording device immediately once they are uploaded and stored on the shared drive. The recordings on the shared drive will be deleted after transcription is completed. Transcriptions of the audio-recordings will be deleted off the shared drive five years following publication of the research project. Upon the completion of the researcher's doctoral programme, the recordings will remain on the University of Edinburgh's secure drive.

Following data collection, a debrief form will be provided to participants online which they can read and print if they wish to keep it in their own possession. The debrief form will contain signposting information for relevant services and resources if the participant felt distressed, such as Samaritans and NHS 24. The debrief form will also contact information and signposting to LGBQ+ support groups.

Analysis

Interpretative Phenomenological Analysis (IPA) will be used to analyse the collected data. As the proposed study aims to explore how parents make sense of their own personal and social experiences, it was deemed a qualitative approach was the most appropriate to address the research question. IPA was chosen due to the exploration of personal experience and perception of particular events.

When developing the research protocol, the researcher considered alternative qualitative methodology, particularly grounded theory. However, IPA was selected due to the focus of exploring personal experiences and understanding perceptions of particular events, rather than the construction of theories that may drive this. Further to this, the researcher acknowledged that the participant's experiences are subjective, and participants may interpret and view the same objective experience in different ways to others. Lastly, the analysis would involve the researchers own interpretations of the experiences of the participants, whereas grounded theory would not allow for importation or reflection of preconceptions into the process of analysis.

The researcher will utilise a research diary to reflect on their own perceptions, experiences, and interpretations in regard to the study and the interpretation of the data collected. Supervision will be sought in addition to this.

The analysis will follow the six steps of IPA, as proposed by Smet al.t al (2009):

- Reading and re-reading the data
- Creating initial notes and annotations
- Identifying emergent themes
- Searching for connections across emergent themes
- Continuing analyses with other cases
- Searching for patterns across cases

Quality control

Specific criteria will be used for judging the quality of qualitative research when utilising IPA (Yardley, 2000; 2008).

Sensitivity to Context

The researcher will develop and maintain an awareness of the relevant literature regarding individuals with intellectual disabilities who identify as LGBQ+, as well as the methodology used. The researcher will reflect and consider the influences of their own age, gender, and perceived role in the interaction with participants and how this may impact on the interpretation of the data and emergent themes.

Further to this, the researcher will reflect on the social and cultural contexts of the research process. The researcher will reflect and acknowledge the influence of power dynamics in the interview process and will practice interview styles and techniques prior to commencing data collection to aid in the facilitation of rapport.

Commitment, Rigour, Transparency and Coherence

The researcher will develop skill and competence in using IPA methodology through the use of supervision and independent study. The desired sample size based on previous research studies has been determined (see Section 4.1), which will allow for sufficient analysis of the subjective experience of the participants. Rigorous processes will be utilised in the reading, analysis, and interpretation of the accounts of the participants.

The potential impact of the sampling methods selected within the research will be reflected upon and discussed within supervision. Due to the nature of the interview questions, there may be potential for bias in the representation of the experiences of the parents. Those who may hold more positive or less conservative views on sexual relationships may be more willing to discuss this or be chosen for participation by staff within services.

The sharing of coding procedures, emergent themes and quotes from participants will be shared and discussed with both clinical and academic supervisors. This will allow for further insight for the researcher and enable them to acknowledge their own motivations and assumptions and how these interact with the interpretation of the data.

Thorough documentation of the research process, including data collection and analysis, will be provided in the write up of the project. The transparency of the method will be evidenced through an audit trail of the process, including all materials used, including the research proposal, annotated transcripts, and coding.

Impact and Importance

The findings of the study will be disseminated in relevant journals. In terms of impact, the research project allows a novel insight into parent's, family caregivers and paid caregivers perspectives of the sexual lives of ~~their~~ adults ~~children family caregivers~~ who have intellectual disabilities and identify as LGBQ+.

Ethical arrangements

The research project will be conducted in accordance with the Declaration of Helsinki, and the principles of good clinical practice (GCP). The researcher will ensure all materials used in the research project, such as the PIS, consent form, and recruitment material, will have been approved by the research ethics committee prior to commencing recruitment.

SECTION 4: Potential risks to participants and researchers

Q11. Is your research project likely or possible to induce any psychological stress or discomfort in the participants or others, indirectly associated with the research?

☒ Yes
☐ No

If "yes" state the types of risk and what measures will be taken to deal with such problems

The interview questions do not focus on a topic that is likely to cause distress or adverse reactions to the participants. However, due to the nature of the research project exploring sex, sexual identity, and sexual orientation, this may cause discomfort in some participants. Participants will be informed to discuss topics that they are comfortable with and will have the option to pause the interview or withdraw if they no longer wish to continue.

The risks regarding this are low and manageable.

Q12. Does your research project require any physically-invasive or potentially physically harmful procedures?

☐ Yes
☒ No

If "yes" give details and outline procedures to be put in place to deal with potential problems.

N/A

Q13. Does your research project require the use of privacy-invasive technology, such as CCTV, biometrics, facial recognition, vehicle tracking software?

☐ Yes
☒ No

If "yes" - Give details and outline procedures to be put in place to deal with potential problems.

N/A

Q14. Does your research project involve the investigation of any illegal behaviour or activities?

☐ Yes
☒ No

If "yes" - Give details of any illegalbehaviourror activitiess you may investigate

N/A

Q15. Is it possible that your research project will lead to awareness or the disclosure of information about child abuse or neglect?

☒ Yes

☐ No

If "yes" - Indicate the likelihood of a disclosure and the procedures to be followed if you become aware that a child has been or may be at risk of harm

Risk information may be disclosed to the researcher during the semi-structured interview, including issues surrounding risk of harm to the participant or harm to others, both presently and historically. In order to mitigate this risk, participants will be informed of the researcher's duty to disclose any risk information before consent is taken.

If participants disclose risk information, this will be discussed with the researcher's field or academic supervisor. Both supervisors are qualified Clinical Psychologists employed within NHS Learning Disabilities services within Scotland. The researcher would follow guidelines within the Protection of Children and Protected Adults Policy.

If the participant is within the United Kingdom, local safeguarding procedures would be followed. Within the demographic information, postcode or zip code would be collected. Using the participant's name and postcode, this information would be supplied to the local authority as part of the duty of care of the researcher.

If the researcher feels the participant or another individual is at immediate risk of harm, this will be managed using clinical judgement. Depending on the nature of the risk information disclosed, the police may be contacted.

If the participant is outside of the United Kingdom, the researcher would go to local child protection services or authorities to gain advice. Depending on the nature of the concern, police may be notified in the participant's country.

In order to facilitate the effective handover of disclosed risk, interviews will take place during working hours (Monday to Friday, 9am to 5 pm).

The risk of this is low and manageable.

Q16. Is it likely that dissemination of research findings or data could adversely affect participants or others indirectly associated with the research?

☐ Yes
☒ No

If "yes" - Describe the potential risk for participants/data subjects of this use of the data. Outline any steps that will be taken to protect participants.

N/A

Q17. Could participation in this research adversely affect participants and others associated with the research in any other way?

☐ Yes
☒ No

If "yes" - Describe the possible adverse effects and the procedures to be put in place to protect against them.

N/A

Q18. Is this research expected to benefit the participants, directly or indirectly?

x☐ Yes
☐ No

If "yes" - Give details of how this research is expected to benefit the participants.

Research in the area of sexuality and people with intellectual disabilities is limited, particularly in the exploration of the experiences of individuals who identify as LGBQ+. The research study would highlight any potential barriers when supporting adults with intellectual disabilities in expressing their sexuality and having autonomy over their body. Furthermore, the study would provide further information for policy development and implementation, sex education for both family caregivers and individuals with intellectual disabilities, and information for services to ensure they are meeting the needs of the people they support.

Q19. Will the true purpose of the research be concealed from the participants/data subjects?

☐ Yes
☒ No

If "yes" - Explain what information will be concealed and why.

N/A

Q20. Will participants/data subjects be debriefed at the conclusion of the study?

☒ Yes
☐ No

If "no" – Why will participants/data subjects not be debriefed?

N/A

Q21. At any stage in this research could researchers' safety be compromised, or could the research induce emotional distress in the researchers?

☐ Yes
☒ No

If "yes" - Give details and outline procedures to be put in place to deal with potential problems.

N/A

Please tick to confirm you agree with the following:

I will adhere to School guidance on risk assessment and health and safety and will seek advice on project and travel insurance prior to project commencement.

☒ I agree

☐ I do not agree

☐ Not applicable

SECTION 5: Participants and data subjects. For autoethnographic research also include those who may feature in your writings.

Q22. How many participants or data subjects are expected to be included in your research project?

The sample size is influenced by several factors. When using IPA, there is often an emphasis for smaller sample sizes (Brocki & Wearden, 2006; Smith et al., 2009), with size determined by practical restrictions and richness of individual interviews. An initial sample size of 6-8 participants will be aimed for in order to achieve phenomenological insight. However, if data richness and saturation has not been reached by 8 participants, further interviews will be conducted until this is achieved. A sample size of 6-8 would be able to retain individual focus as well as adequately exploring the experiences of the group.

Q23. What criteria will be used in deciding on the inclusion and exclusion of participants/data subjects in your research project?

The inclusion criteria are:

- Parents, family caregivers and paid caregivers of adults (>18 years old) who have a formal diagnosis of intellectual disability under the DSM-5, who identify as LGBT

The exclusion criteria are:

- Parents, family caregivers and paid caregivers are unable to speak or read English
- Parents, family caregivers and paid caregivers of children (<18 years old) who have intellectual disabilities
- Parents, family caregivers and paid caregivers of an adult child with a disclosure of intellectual disability who identifies as heterosexual
- Unwillingness or inability to provide informed consent

Q24. Are any of the participants or data subjects likely to be under 16 years of age?

☐ Yes
☒ No

If "yes" - Explain and describe the measures that will be used to protect and/or inform participants/data subjects.

N/A

Q25. Are any of the participants or data subjects likely to be children in the care of a Local Authority?

☐ Yes
☒ No

If "yes" - Explain and describe the measures that will be used to protect and/or inform participants/data subjects.

N/A

Q26. Are any of the participants or data subjects likely to be known to have additional support needs?

☐ Yes
☒ No

If "yes" - Explain and describe the measures that will be used to protect and/or inform participants/data subjects.

N/A

Q27. In the case of participants with additional support needs, will arrangements be made to ensure informed consent?

☐ **Yes**

☐ **No**

If "yes" – What arrangements will be made?

N/A

If "no" – Please explain why not

N/A

Q28. Are any of the participants or data subjects likely to be physically or mentally ill?

☐ Yes
☒ No

If "yes" - Explain and describe the measures that will be used to protect and/or inform participants/data subjects.

N/A

Q29. Are any of the participants or data subjects likely to be vulnerable or likely exposed to harm in other ways?

☐ Yes
☒ No

If "yes" - Explain and describe the nature of the vulnerability and the *measures that will be used to protect and/or inform participants/data subjects.*

N/A

Q30. Are any of the participants or data subjects likely to be unable to communicate in the language in which the research is conducted

☐ Yes
☒ No

If "yes" - Explain and describe the measures that will be used to protect and/or inform participants/data subjects.

N/A

Q31. Are any of the participants or data subjects likely to be in a relationship (i.e., professional, student-teacher, other dependent relationship) with the researchers?

☐ Yes
☒ No

If "yes" - Explain and describe the measures that will be used to protect and/or inform participants/data subjects.

N/A

Q32. Are any of the participants or data subjects likely to have difficulty in reading and/or comprehending any printed material distributed as part of the study?

☐ Yes
☒ No

If "yes" - Explain and describe the measures that will be used to protect and/or inform participants/data subjects.

As the potential participants are parents of individuals with intellectual disabilities, it is not anticipated that they will have difficulty in reading or comprehending any printed material. However, if this arises within the recruitment process, easy read versions of the PIS and consent form can be developed.

Easy read versions will be developed using guidance provided within Learning Disability Services within the UK. Firstly, the researcher will identify key information that needs to be provided within the easy read versions of information. Bold text will be used to highlight information points, with an explanation provided for certain terms. In terms of layout, pictures will be used and will be on the left side of the page, with text on the right. A sans serif font will be used at a size 16 point or higher for text. Feedback from easy read versions will be sought from the researcher's clinical supervisor, who is a qualified psychologist within a Learning Disability service.

An email containing easy read versions of information will be sent to Speech and Language Therapists within NHS Lothian and/or NHS Lanarkshire, who can provide feedback and input.

Q33. Describe how the sample will be recruited.

Recruitment will utilise a convenience sample, in addition to snowball sampling. Participants will be recruited through third sector organisations during the period of the project, in addition to recruiting via social media.

Identification of participants within third sector organisations
Department managers within relevant third sector organisations (e.g. ENABLE) will be contacted directly by the researcher, who will provide the rationale and focus of the study and recruitment aims, in addition to the exclusion and inclusion criteria. Information regarding participation will then be cascaded to staff within these services via service managers. Furthermore, the researcher will attend team meetings in order to speak to staff and encourage staff to identify potential participants. These staff members will then ascertain whether participants would be willing to receive information regarding the study and be contacted by the researcher.

There is a potential bias in recruitment in terms of participants who are likely to take part may hold more liberal views on sex, sexuality, and same sex relationships. In order to try and reach participants with ranging views, third sector organisations within varying socioeconomic, religious, and cultural backgrounds. Language used within the participant information sheet and adverts have been selected to increase inclusivity and applicability to wider range of participants.

Identification of participants within local authorities
Staff within local authorities North and South Lanarkshire will be contacted by the researcher or field supervisor, who will provide the rational and focus of the study and recruitment aims in addition to any relevant recruitment material. Prior to contacting the local authorities for recruitment, contact will be made to complete any additional local ethics applications.

Identification of participants within NHS organisations and services
Staff within NHS Learning Disability services will be contacted by the researcher or field supervisor, who will provide the rationale and focus of the study and recruitment aims in addition to any relevant recruitment material. Staff will then approach service users or their parents directly to provide recruitment material. Prior to this, NHS IRAS approval will be sought.

Recruitment via social media and the internet
Further to this, social media platforms (e.g. Twitter) will be used to advertise the project, as well as online forums for people with intellectual disabilities (e.g. Choice Forum) as well as parents who have adult children who identify as LGBQ+. In these instances, participants would be able to self-identify whether they are eligible to take part and are interested in providing their experiences.

If participants identify other potential participants, then snowball sampling will be utilised to potentially recruit the participants into the research project.

Materials used to recruit participants
The researcher will provide recruitment materials, information leaflets and flyers regarding the research to staff members within third sector organisations, with contact information of the researcher. Further to this, contact information of the researcher will be available when advertising via social media and the internet for participants to make contact. (Please see appendix for recruitment material).

Providing information to potential participants and gaining consent
A webpage will be created using Qualtrics, an online survey platform. Qualtrics is recommended by the University of Edinburgh and is licenced and ready for use by all staff, researchers and students within the College of Arts, Humanities and Sciences. Qualtrics is a secure site and is protected by firewall systems, therefore offers security for inputted information. An account will be created on Qualtrics through the University of Edinburgh's portal. The researcher will create the webpage on Qualtrics, and regularly check and maintain the webpage. Qualtrics generates a URL, which can be provided to participants.

The webpage which will contain information on the study, and the participant information sheet (PIS). The information page will contain contact details for the researcher. This webpage can be accessed by participants online or can be provided by staff within third sector organisations.

Participants will be made aware of the webpage through social media (i.e Twitter), where a link will be provided. The webpage will also be sent by email to third sector organisations, which can be forwarded to potential participants.

Participants will decide whether they would like to take part in the study once they have accessed the webpage, which contains the project information and the PIS. They can then contact the researcher using the information on the webpage.

Once contact has been made by the participant, the researcher will reply to the participant with a date for interview and a link to the online consent form. At least twenty-four hours will be left between providing the PIS and taking consent. The researcher will also be available for further discussion, clarifications, and to answer any further questions.

The consent form will be available via web link, using Qualtrics software. The participant will be presented with two buttons. These buttons will give them the option to either:

1. Consent to the project, which will take them to a page thanking them for providing their consent to take part.
2. Decline to give consent to the project, which will take them to a page thanking them for taking the time to show interest in the project.

If the participant is providing their consent to take part in the project, a box will be available to input their name. This allows the researcher to know who has provided consent. The researcher will ascertain whether the participant has provided consent using the Qualtrics link prior to the interview taking place. If they have not completed the consent form at the time of the interview, the researcher will ask them to do so within the conference call.

~~The researcher will contact potential participants at least twenty-four hours after providing them with the PIS to see if they would like to take part. A consent form will be sent via internet link for participants to complete. Following this, a time slot will be provided for the interview to take place.~~

Assessing whether the potential participant is well enough to provide informed consent
If the researcher feels that any potential participant's ability to provide informed consent is compromised by mental or physical ill health, a second opinion will be sought from the researcher's clinical supervisor. If it is decided that the individual cannot provide informed consent, consent will not be sought at that time.

Q34. Will participants receive any financial or other material benefits as a result of participation?

x Yes
No

If "yes" - What benefits will be offered to participants and why?

Participants will be offered a £10 Amazon gift voucher following the completion of the interview. This is due to participants taking time out of caring duties to provide data.

Section 6: Participant or data subject information and consent

Q35. Will written consent be obtained from all participants or data subjects?

☒ Yes
☐ No

If "yes" – attach participant information sheet and consent form
If "no" – explain why not and how consent is obtained (e.g. orally), and/or if consent cannot or should not be sought for some reason, please provide a clear case and rationale for this

Please find PIS and consent form in the appendix.

Q36. Have you made arrangements to tell participants what information you will hold about them and for how long?

☒ Yes
☐ No

If "yes" - what arrangements have been made?

Within the consent form, it informs participants that their transcripts and information will be kept securely until five years after the publication of the research project. At this point in time, all information will be destroyed. ~~that their information and transcripts will be kept until the completion of the research. Following completion of the research, this information and data will be destroyed.~~

Q37. Have you made arrangements to tell participants whether you will disclose the information to other organisations?

☐ Yes
☒ No

If "yes" - What arrangements have been made?

N/A

Q38. Have you made arrangements to tell participants whether you will combine that information with other data?

☐ Yes
☒ No

If "yes" - What arrangements have been made?

N/A

Q39. In the case of children participating in the research, will the consent or assent of parents be obtained?

☐ Yes
☐ No

If "yes" - Explain how this consent or assent will be obtained

N/A

If "no" – Please explain why you won't be obtaining consent

N/A

Q40. Will the consent or assent of children participating in the research be obtained?

☐ Yes
☐ No

If "yes" - Explain how this consent or assent will be obtained

N/A

If "no" – Please explain why not

N/A

Q41. In the case of participants who are not proficient in the language in which the research is conducted, will arrangements be made to ensure informed consent?

☐ Yes
☐ No

If "yes" – What arrangements will be made?

N/A

If "no" – Please explain why not

N/A

Q42. Does the activity involve using cookies or tracking individual's activity on a website or the internet in general?

☐ Yes
☒ No

If "yes" – Describe the arrangements, you have put in place to obtain informed consent for the use of these tools?

N/A

SECTION 7: Confidentiality and handling of data

Q43. What information about participants/data subjects will you collect and/or use?

Within the interview schedule, participants would be asked to provide a general overview of ~~their adult child family member~~ the adult they support in order to give context. Near the beginning of the interview, demographic information of the participant will be obtained, including their age, gender, sexual orientation, and highest level of education. Demographic information of ~~their adult child family member~~ the adult they support will also be discussed, which will include their age, gender, sexual orientation, and relationship status. This will aid the interpretation of the data collected and provide context to the interviews. Further questions regarding sexuality, relationships, and their experiences would then be explored.

Participants will also be asked where they found out about the study (e.g. through third sector, Twitter)

X would be the name of the ~~family member.~~ Adult. Suggested items and structure for the interview:

1. *Is ~~your son/daughter~~ x currently in a same-sex romantic or sexual relationship, or have they been in the past?*

How do you feel about supporting ~~your son/daughter's~~ x's romantic relationships? Are they open to others about their sexual orientation?

2. *Can you tell me more about your ~~son/daughter's~~ x's sexual orientation or identity?* When did they first express their sexual orientation or sexual identity? How did you feel when ~~your child~~ x came out? How did your views change on same sex relationships and sexuality when ~~your son/daughter~~ x first came out? Are there any barriers or facilitators to expressing their sexuality / developing romantic relationships?

3. *What do you think has influenced your views or beliefs around sexual relationships?* What are your views on sex outside of or before marriage? What are your views on same sex relationships? How openly do you discuss sexual issues as a family? How do you think your views on sexuality have changed over time?

4. *What are the views within the wider family?* Parents, grandparents, siblings, aunties and uncles etc

5. *What are your hopes for ~~your son/daughter's~~ x's romantic life?* Do they want to live with their partner? Do they wish to get married or have a civil partnership? Do they want children?

6. *What are your fears or worries about ~~your son/daughter's~~ x's romantic life?* Do you feel ~~your son/daughter~~ x has been discriminated against due to their sexual orientation? Do you have any worries about ~~your child~~ x entering a relationship? Concerns about safety (Homophobic attacks? Concerns about sexual safety?)

7. *What have been your main sources of support in terms of ~~your son/daughter's~~ x's romantic or sexual life?* What have been your main sources of support practically / emotionally? Is there anything you've found challenging? Is there anything that's been helpful? Where have you received advice or guidance on sexual development? Where has ~~your son/daughter~~ x received sex education? Does ~~your child~~ x receive support on contraception choices?

8. *Is there anything else that you think is important that you want to talk about that we haven't already covered?*

Q44. Will you collect or use NHS data?

☐ Yes
☒ No

If "yes" – what NHS data will you collect or use?

N/A

Q45. What training will staff who have access to the data receive on their responsibilities for its safe handling? Have all staff who have access completed the mandatory data protection training on the self-enrolment page of Learn?

Only individuals involved in the research, including the researcher and supervising staff, will have access to the data. The researcher, in addition to their supervisors, has completed relevant General Data Protection Regulation (GDPR) and research data management training (e.g. MANTRA) through the University of Edinburgh, in addition to the NIHR GCP training.

Q46. Will the information include special categories of personal data (health data, data relating to race or ethnicity, to political opinions or religious beliefs, trade union membership, criminal convictions, sexual orientations, genetic data and biometric data)

☒ Yes
☐ No

If "yes" – Explain what safeguards e.g. technical or organisational you have in place; including any detailed protocols if this requires special and/or external processing, storage, and analysis.

The information collected will include the sexual orientation of the participant, and of ~~their son or daughter~~ ~~family member.~~ adult they support. In order to protect the privacy and anonymity of the participants, identifiable information will be removed at all stages of data transcription, analysis, and write up. Only individuals involved in the research, including the researcher and supervising staff, will have access to the data. ~~Information that may hold sensitive information, such as consent forms, will be stored securely in a locked filing cabinet at the University of Edinburgh or at the researcher's NHS Health Board.~~ As consent will be obtained online, this information will be stored online via the Qualtrics software available on the web. Only the researcher will have password access to this information. Audio recordings will be stored on the University of Edinburgh's secure shared drive, which will be accessed using the University of Edinburgh's VPN. Transcriptions of recordings will also be stored in the same manner. There will be no physical copies of any data.

If you answered "no" to this question, please skip Q56 and continue answering the rest of the questions..

Q47. Please indicate how your research is in the public interest:

☒ Your research is proportionate
☐ Your research is subject to a governance framework
☐ Research Ethics Committee (REC) review (does not have to be a European REC)

☐ Peer review from a funder
☐ Confidentiality Advisory Group (CAG) recommendation for support in England and Wales or support by the Public Benefit and Privacy Panel (PBPP) for Health and Social Care in Scotland

Q48. It is essential that you identify, and list all risks to the privacy of research participants. You will then need to consider the likelihood of the risks actually manifesting and the severity of harm if the risks actually manifest.

Risk	**Likelihood of risk manifesting**			**Severity of harm**		
	Remote	**Possible**	**Probable**	**Minimal**	**Significant**	**Severe**
Identifiable due to data linkage	x			x		
Identifiable due to low participant numbers		x			x	
Identifiable due to geographical location	x				x	
Identifiable due to transfer of data	x				x	
Identifiable due to access of data	x				x	

Please use this text box to record any other risks and the likelihood of them occurring, along with the severity of harm.

<u>Disclosure of risk information</u>
Likelihood: Possible
Severity of harm: Significant

<u>Privacy during interviews</u>
Likelihood: Possible
Severity of harm: Minimal

<u>Anonymity and data protection</u>
Likelihood: Remote
Severity of harm: Significant

Please identify measures you could take to reduce or eliminate risks identified as possible/significant or probable/severe.

<u>Disclosure of risk information</u>

- The proposed research study will not use a participant sample that includes vulnerable adults. However, due to the sample including parents, family caregivers and paid caregivers of adults with intellectual disabilities, risk information may be disclosed to the researcher during the semi-structured interview, including issues surrounding risk of harm to the participant or harm to others. In order to mitigate this risk, participants will be informed of the researcher's duty to disclose any risk information before consent is taken. If participants do disclose risk information, this will be discussed with supervisors and actions will be taken that align with NHS Health Board policy to safeguard vulnerable adults. If the researcher feels the participant or another individual is at immediate risk of harm, this will be managed using clinical judgement and Social Work services will be contacted. In order to facilitate the effective handover of disclosed risk, interviews will take place during working hours (Monday to Friday, 9am to 5pm).

Privacy during interviews

- The participant will be advised by the researcher to conduct the interview in a place where they have privacy. Similarly, in order to respect the confidentiality of the participant, the researcher will also conduct the interview in a private setting. If the researcher believes that the privacy of the participant may be compromised, the interview will be paused or terminated.

Anonymity and data protection

- In order to protect the privacy and anonymity of the participants, identifiable information will be removed at all stages of data transcription, analysis, and write up. Only individuals involved in the research, including the researcher and supervising staff, will have access to the data. Information that may hold sensitive information, such as consent forms, will be stored securely in a locked filing cabinet at the University of Edinburgh or at the researcher's NHS Health Board. Following the completion of the study, all consent forms will be permanently destroyed. The researcher will also complete relevant General Data Protection Regulation (GDPR) and research data management training (e.g. MANTRA) through the University of Edinburgh, in addition to the NIHR GCP training.

Q49. Will information containing personal, identifiable data be transferred to, shared with, supported by, or otherwise available to third parties outside the University?

☐ Yes
☒ No

If "yes" - Please explain why this necessary and how the transfer of the information will be made secure. If the third party is based outside the European Economic Area please obtain guidance from the Data Protection Officer.

N/A

Q50. Other than the use by third parties, will the data be used, accessed or stored away from University premises?

☐ Yes
☒ No

If "yes" - Describe the arrangements you have put in place to safeguard the data from accidental or deliberate access, amendment or deletion when it is not on University premises, including when it is in transit, and (where applicable) it is transferred outside the EEA.

All information will be saved securely on the University of Edinburgh shared drive, using password protection.

Q51. Will feedback of findings be given to your research project participants or data subjects?

☒ Yes
☐ No

If "yes" - How and when will this feedback be provided?

The results of the research project will be compiled into an easy read summary, which can be provided to participants at their request.

Participants will also be given the opportunity to meet with the researcher to discuss the interpretation of the interview transcriptions to ensure an accurate representation has been developed. This is detailed within the PIS. The participants are informed this is optional and will not affect participation within the study.

If "no" - Please provide rationale for this.

N/A

Q52. How do you intend to use/disseminate the results of your research project?

The study will be reported in appropriate format of a doctoral thesis as stipulated for submission to the Doctorate of Clinical Psychology at the University of Edinburgh. This will comprise of a systematic review and journal article, following the relevant guidelines for submission for publication. *Sexuality and Disability* has been identified as an academic journal for potential publication.

To allow for open access to the study, the researcher's completed thesis will be uploaded to the Department of Clinical Psychology Thesis Database. The findings will be prepared into a presentation following its completion and will be disseminated to the Learning Disability Service within the researcher's employing health board, with the researcher offering to present the findings.

SECTION 8: Security-sensitive material

The Terrorism Act (2006) outlaws the dissemination of records, statements and other documents that can be interpreted as promoting or endorsing terrorist acts.

Q53. Does your research involve the storage on a computer of any such records, statements or other documents?

☐ Yes
☒ No

If "yes" - Please tick 'Yes' to indicate that you agree to store all documents on that file store

N/A

Q54. Might your research involve the electronic transmission (for example, as an email attachment) of such records or statements?

☐ Yes
☒ No

If "yes" - Please tick 'Yes' to indicate that you agree not to transmit electronically to any third party documents stored in the file store

N/A

Q55. Will your research involve visits to websites that might be associated with extreme, or terrorist, organisations?

☐ Yes
☒ No

If "yes" - You are advised that such sites may be subject to surveillance by the police. Accessing those sites from University IP addresses might lead to police enquiries. Please acknowledge that you understand this risk by ticking 'Yes'

☒ Yes
☐ No

By submitting to the ethics process, you accept that your School Research Ethics Officer and the convenor of the University's Compliance Group will have access to a list of titles of documents (but not the contents of documents) in your document store. Please acknowledge that you accept this by ticking 'Yes'

Please confirm that you have contacted your School Research Ethics Officer to discuss security-sensitive material by ticking 'Yes'

☐ Yes, I have contacted my School's Research Ethics Officer
X No, I have not contacted my School's Research Ethics Officer

Section 9: Copyright

Q56. Does your project require use of copyrighted material?

☐ Yes
☒ No

If "yes" please give further details

N/A

Section 10: Good conduct in collaborative research

Q57. Does your project involve working collaboratively with other academic partners?

☐ Yes
☒ No

If "yes" - Is there a formal agreement in place regarding a collaborative relationship with the academic partner(s)?

N/A

If "no" - Please explain why there is no formal agreement in place?

The project will involve supervision from staff at the University of Edinburgh and NHS Lanarkshire. No other academic partners will be involved.

Q58. Does your project involve working collaboratively with other non-academic partners?

☐ Yes
☒ No

If "yes" - Is there a formal agreement in place regarding a collaborative relationship with the non-academic partner(s)?

N/A

If "no" - Please explain why there is no formal agreement in place.

N/A

Q59. Does your project involve employing local field assistants (including guides/translators)?

☐ Yes
☒ No

If “yes” - Is there a formal agreement in place regarding the employment of local field assistants (including guides and translators)?

N/A

If “no” - Please explain why there is no formal agreement in place

Inclusion criteria requires participants to speak and read in English, therefore no translators will be needed. All data collection, analysis, and write up will be completed by the researcher.

Q60. Will care be taken to ensure that all individuals involved in implementing the research adhere to the ethical and research integrity standards set by the University of Edinburgh?

☒ Yes
☐ No

If “no” - Please explain why care will not be taken

N/A

Q61. Have you reached agreement relating to intellectual property?

☒ Yes
☐ No

If “no” - Please explain why you have not reached agreement

N/A

Section 11: Good conduct in publication practice

In publication and authorship, as in all other aspects of research, researchers are expected to follow the University’s guidance on integrity.

By ticking yes, you confirm that full consideration of the items described in this section will be addressed as applicable

☒ Yes
☐ No

Subsequent to submission of this form, **both the applicant and their supervisor should review any alterations in the proposed methodology of the project.** If the change to methodology results in a change to any answer on the form, then a resubmission to the Ethics subgroup is **required.**

The principal investigator is responsible for ensuring compliance with any additional ethical requirements that might apply, and/or for compliance with any additional requirements for review by external bodies.

ALL forms should be submitted in electronic format. Digital signatures or scanned in originals are acceptable. The applicant should keep a copy of all forms for inclusion in their thesis.

Caitlin Turner	Caitlin Turner	18.09.2020
Applicant's Name	Applicant's Signature	Date signed

Doug McConachie

________________________ ________________________ ____20/10/20__________

*Supervisor Signature[1] Supervisor Name Date

*NOTE to Supervisor: Ethical review will be based only on the information contained in this form. If countersigning this check-list as truly warranting all 'No' answers, you are taking responsibility, on behalf of the HSS and UoE, that the research proposed truly poses no ethical risks.

ISSUES ARISING FROM THE PROPOSAL

Attachments -Missing information leaflets or fliers etc – is this the same as the social media advert?

Missing standard email template if approaching third sector parties

Need proof that sponsorship is not needed i.e. email from Charlotte Clarke.

Overview - Some of the questions haven't been answered. If they are N/A then please put this in the box so ethics committee know the applicant has had sight of these questions.

Project Summary

"…interviews will take place over video conferencing platforms (e.g. Skype)…" – double check university policy on secure videoconferencing platforms. This point is not discussed further at any other point of the application. Could we have a statement about which platform will be used, and how this meets security requirements?

"Interviews will be audio recorded on a password protected … these will be pseudo-anonymised and uploaded immediately to the University of Edinburgh's password-

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[1] Not required for staff applications

protected shared drive." – at what point will the original recordings be deleted? This needs to be communicated on the participant info screen too.

"The debrief form will contain signposting information for relevant services and resources if the participant felt distressed, such as Samaritans and NHS 24." – might also want to include LGBQ+ groups.

You seem to be relying on ENABLE for a lot of recruitment – will you obtain permission from ENABLE managers and supervisors before approaching their clients?

How will consent be obtained? Will you email the participants? Will participants be emailed and then asked to consent. Same with debrief how will you provide participants with summary of findings? You say this will be sent to them on request. How will this be sent or made available? Need a bit more clarification on recruitment and debriefing.

Q15. Is it possible that your research project will lead to awareness or the disclosure of information about child abuse or neglect? – You mention in the project summary that the recruitment will be global. The answer to this question indicates you will respond to disclosure with NHS policies and will contact Social Services. Please note that you may need to reconsider your approach if participant is outside of UK.

Q15. Is it possible that your research project will lead to awareness or the disclosure of information about child abuse or neglect? – You mention in the project summary that the recruitment will be global. The answer to this question indicates you will respond to disclosure with NHS policies and will contact Social Services. Please note that you may need to reconsider your approach if participant is outside of UK.

Q32 How will easy read versions be developed?

Q36. Have you made arrangements to tell participants what information you will hold about them and for how long? – You mention information will be destroyed once the research is completed. At what point is the research considered to be completed? For example, is this tied to doctoral thesis submission or journal publication?

Q48 - *Please identify measures you could take to reduce or eliminate risks identified as possible/significant or probable/severe.* - Again related to point above you mention here that consent will be stored in filing cabinets in NHS healthboard. This seems confused because in other points of the application you say that the participants will be filling in consent via online platform (no paper copies) and also if you are using NHS premises for data storage then you will need NHS approval?

PIS- Would have a statement here inviting participants to take screen shot of the PIS screen for their records.
"If you wish to make a complaint about the study, please contact:
Dr Charlotte Clarke, Head of School, School of Health in Social Science, University of Edinburgh, at headofschool.health@ed.ac.uk or 0131 650 4327." n.b. this is not the head of school

Consent - Need a specific statement in there saying that audio recordings of the participants voice will be recorded only and also state how and when this will be deleted.

Debrief
As above with PIS Would have a statement here inviting participants to take screen shot/ photograph of the debrief screen with the signposting for their records. You may also want

to consider links to LGBQ+ networks or groups. Again, the contact details for HoS are incorrect.

The applicant should respond to these comments in section below.

Signature:

Date: 30.11.2020

APPLICANT'S RESPONSE (If required)

Attachments -Missing information leaflets or fliers etc – is this the same as the social media advert?

Information leaflet added in appendix.

Missing standard email template if approaching third sector parties

Email template now attached in appendix.

Need proof that sponsorship is not needed i.e. email from Charlotte Clarke.

Sponsorship email included.

Overview - Some of the questions haven't been answered. If they are N/A then please put this in the box so ethics committee know the applicant has had sight of these questions.

N/A added to boxes.

Project Summary

"…interviews will take place over video conferencing platforms (e.g. Skype)…" – double check university policy on secure videoconferencing platforms. This point is not discussed further at any other point of the application. Could we have a statement about which platform will be used, and how this meets security requirements?

University of Edinburgh policy advises that Microsoft Teams or Zoom is used for one-to-one interviews.

Microsoft Teams is part of the Microsoft Office 365 software. Office 365 meets the compliance needs for the University of Edinburgh. Using Microsoft teams would allow the researcher to send a private link to the participant via email. The meeting would be marked "private" in the researcher's Outlook, so others would be unable to join the meeting. Participants would wait in a lobby and would be invited in by the researcher, so the researcher would be able to reject the entry of others who are not the participant. The researcher would enable the option "Who can present?" to only them, enabling the participant to be an attendee. Therefore, only the researcher would have the ability to record and share content. This would protect the privacy of the participant, whilst almost remaining compliant with the University of Edinburgh's policies regarding security.

Zoom would be offered to participants as an alternative video and audio-conferencing tool. Zoom may be an easier alternative for participants to use, as it offers easy access, as users can click a button and launch a Zoom meeting without the need for excess support. The researcher would follow similar guidelines for using Zoom in terms of sending a direct link to participants, and only allowing participants access to the Zoom conference.

The researcher would connect to the University of Edinburgh's secure network before using Microsoft Teams or Zoom. The researcher would ensure that the most recent version of Teams has been downloaded, or if Zoom is being used, the researcher will use the University of Edinburgh's Enterprise account. This would ensure that the most up-to-date security features are available. The interviews would be recorded using a secure Dictaphone supplied by NHS Lanarkshire, which has a pin number for extra security.

"Interviews will be audio recorded on a password protected … these will be pseudo-anonymised and uploaded immediately to the University of Edinburgh's password-protected shared drive." – at what point will the original recordings be deleted? This needs to be communicated on the participant info screen too.

Following completion of the interview, recordings will be uploaded at the earliest possible moment. The original recordings will be deleted after five years following publication of the research project. These recordings will be stored securely on The University of Edinburgh's secure drive. Upon the completion of the researcher's doctoral programme, the recordings will remain on the University of Edinburgh's secure drive.

"The debrief form will contain signposting information for relevant services and resources if the participant felt distressed, such as Samaritans and NHS 24." – might also want to include LGBQ+ groups.

The debrief form has been edited to include signposting to relevant LBGQ+ support groups.

You seem to be relying on ENABLE for a lot of recruitment – will you obtain permission from ENABLE managers and supervisors before approaching their clients?

Contact will be made with third sector organizations, such as ENABLE, to gain permission before approaching clients regarding the research study. Further to this, third sector organizations will be contacted to promote the research project on their website, in addition to send information about the project via email lists.

How will consent be obtained? Will you email the participants? Will participants be emailed and then asked to consent. Same with debrief how will you provide participants with summary of findings? You say this will be sent to them on request. How will this be sent or made available? Need a bit more clarification on recruitment and debriefing.

A webpage will be created, which will contain information on the study, and the participant information sheet (PIS). The information page will contain contact details for the researcher. This webpage can be accessed by participants online or can be provided by staff within third sector organisations.

Participants will decide whether they would like to take part in the study once they have accessed the webpage, which contains the project information and the PIS. They can then contact the researcher using the information on the webpage.

Once contact has been made by the participant, the researcher will reply to the participant with a date for interview and a link to the online consent form. At least twenty-four hours will be left between providing the PIS and taking consent. The researcher will also be available for further discussion, clarifications, and to answer any further questions.

The consent form will be available via web link, using Qualtrics software. The participant will be presented with two buttons. These buttons will give them the option to either:

1. Consent to the project, which will take them to a page thanking them for providing their consent to take part.
2. Decline to give consent to the project, which will take them to a page thanking them for taking the time to show interest in the project.

If the participant is providing their consent to take part in the project, a box will be available to input their name. This allows the researcher to know who has provided consent. The researcher will ascertain whether the participant has provided consent using the Qualtrics link prior to the interview taking place. If they have not completed the consent form at the time of the interview, the researcher will ask them to do so within the conference call.

Q15. Is it possible that your research project will lead to awareness or the disclosure of information about child abuse or neglect? – You mention in the project summary that the recruitment will be global. The answer to this question indicates you will respond to disclosure with NHS policies and will contact Social Services. Please note that you may need to reconsider your approach if participant is outside of UK.

If participants disclose risk information, this will be discussed with the researcher’s field or academic supervisor. Both supervisors are qualified Clinical Psychologists employed within NHS Learning Disabilities services within Scotland. The researcher would follow guidelines within the Protection of Children and Protected Adults Policy.

If the participant is within the United Kingdom, local safeguarding procedures would be followed. Within the demographic information, postcode or zip code would be collected. Using the participant’s name and postcode, this information would be supplied to the local authority as part of the duty of care of the researcher.

If the researcher feels the participant or another individual is at immediate risk of harm, this will be managed using clinical judgement. Depending on the nature of the risk information disclosed, the police may be contacted.

If the participant is outside of the United Kingdom, the researcher would go to local child protection services or authorities to gain advice. Depending on the nature of the concern, police may be notified in the participant's country.

In order to facilitate the effective handover of disclosed risk, interviews will take place during working hours (Monday to Friday, 9am to 5 pm).

Q32 How will easy read versions be developed?

Easy read versions will be developed using guidance provided within Learning Disability Services within the UK. Firstly, the researcher will identify key information that needs to be provided within the easy read versions of information. Bold text will be used to highlight information points, with an explanation provided for certain terms. In terms of layout, pictures will be used and will be on the left side of the page, with text on the right. A sans serif font will be used at a size 16 point or higher for text. Feedback from easy read versions will be sought from the researcher's clinical supervisor, who is a qualified psychologist within a Learning Disability service.

An email containing easy read versions of information will be sent to Speech and Language Therapists within NHS Lothian and/or NHS Lanarkshire, who can provide feedback and input.

Q36. Have you made arrangements to tell participants what information you will hold about them and for how long? – You mention information will be destroyed once the research is completed. At what point is the research considered to be completed? For example, is this tied to doctoral thesis submission or journal publication?

This has been altered to inform participants that information will be destroyed following five years of publication of the research project.

Q48 - *Please identify measures you could take to reduce or eliminate risks identified as possible/significant or probable/severe.* - Again related to point above you mention here that consent will be stored in filing cabinets in NHS healthboard. This seems confused because in other points of the application you say that the participants will be filling in consent via online platform (no paper copies) and also if you are using NHS premises for data storage then you will need NHS approval?

This has been changed. As consent will be obtained online, this information will be stored online via the Qualtrics software available on the web. Only the researcher will have password access to this information. NHS premises will no longer be used for storage as there will no be physical data.

PIS- Would have a statement here inviting participants to take screen shot of the PIS screen for their records.

This has been added in PIS.

"If you wish to make a complaint about the study, please contact:

Dr Charlotte Clarke, Head of School, School of Health in Social Science, University of Edinburgh, at headofschool.health@ed.ac.uk or 0131 650 4327." n.b. this is not the head of school

The above has been added and edited to provide the correct head of school.

Consent - Need a specific statement in there saying that audio recordings of the participants voice will be recorded only and also state how and when this will be deleted.

This has been added.

Debrief

As above with PIS Would have a statement here inviting participants to take screen shot/ photograph of the debrief screen with the signposting for their records. You may also want to consider links to LGBQ+ networks or groups. Again, the contact details for HoS are incorrect.

This has been added, and HoS information changed.

Signature: Caitlin Turner (verified by email)

08/12/2020

Changes made January 2021.

13/01/21 - Recordings are identifiable information, therefore they can not be held in a similar way to anonymous data. Why would you need to keep these recordings if you have the transcripts? Why not delete recordings as soon as you have the transcriptions?

This recording device would be password protected. Following the recording of the interviews, these will be pseudo-anonymised and uploaded at the earliest possible moment to the University of Edinburgh's password-protected shared drive. Audio-recordings will be transcribed, and in order to protect the anonymity of the participants, identifiable information within the transcripts will be removed. The duration of the interview will take approximately 30 minutes to 90 minutes.

The original recordings will be deleted off the recording device immediately once they are uploaded and stored on the shared drive. The recordings on the shared drive will be deleted after transcription is completed. Transcriptions of the audio-recordings will be deleted off the shared drive five years following publication of the research project. Upon the completion of the researcher's doctoral programme, the recordings will remain on the University of Edinburgh's secure drive.

13/01/21 – Where will the webpage be hosted? Who will create and maintain it? How will these groups find out about the webpage and access it? Will you be advertising this on social media?

A webpage will be created using Qualtrics, an online survey platform. Qualtrics is recommended by the University of Edinburgh and is licenced and ready for use by all staff, researchers and students within the College of Arts, Humanities and Sciences. Qualtrics is a secure site and is protected by firewall systems, therefore offers security for inputted information. An account will be created on Qualtrics through the University of Edinburgh's portal. The researcher will create the webpage on Qualtrics, and regularly check and maintain the webpage. Qualtrics generates a URL, which can be provided to participants.

The webpage which will contain information on the study, and the participant information sheet (PIS). The information page will contain contact details for the researcher. This webpage can be accessed by participants online or can be provided by staff within third sector organisations.

Participants will be made aware of the webpage through social media (i.e Twitter), where a link will be provided. The webpage will also be sent by email to third sector organisations, which can be forwarded to potential participants.

Consent

1. Need a specific statement in there saying that audio recordings of the participants voice will be recorded only and also state how and when this will be deleted. 13/01/21 – I can't see this added on the consent form.

This has been added.

Signature: Signature: Caitlin Turner
(authorized by email)

Date: 13.01.2021 **Date: 22.01.21**

CONCLUSION TO ETHICAL REVIEW (if required)

The applicant's response to our request for further clarification or amendments and now meets the standards for favourable opinion from the Clinical Psychology Ethics Committee.

Signature:

Position: Ethics and Integrity Lead

Date: 29.1.21

AMENDMENT/S: REQUEST FOR APPROVAL

There has been an amendment to the PIS (now V2 05/03/2021) regarding ways to contact the researcher. This is highlighted in yellow in the PIS in the appendix, and detailed below.

WHAT WILL HAPPEN IF I DECIDE TO TAKE PART?

If you decide that you want to take part in the study, there are three ways that you can get in contact.

1. Ask for your details (email address or phone number) to be passed on by the service you got this information sheet from. Once the researcher has these details, they will contact you.
2. Contact the researcher directly using the details at the end of this leaflet.
3. Provide your contact details on the online form and the researcher will contact you.

~~You will have an opportunity to ask any questions, and if you are happy to continue to take part in the study the researcher will send you a link via email to an online consent form. Once this has been completed, a~~ A date and time will be arranged to meet virtually (by video) to complete an interview which will last between 30 and 60 minutes. This interview will ask questions about your son or daughter's romantic and sexual life, including your views now and how they have changed, your experiences of supporting your child, and your hopes and needs.

Signature: Caitlin Turner (verified by email)

Date: 05/03/21

I would like to apply for the following amendments to this previously processed project which had generated a favourable opinion:

Recruitment to also include local authorities, specifically North and South Lanarkshire. In terms of who will be contacted within the local authorities, this will be staff members who are employed by the local authority (i.e. social workers) who also work with individuals with learning disabilities. In addition to this, contact will be made with staff who work in authority run services, such as day services. This method of recruitment will

be similar to that regarding third sector, in terms of contacting via email and attaching relevant recruitment material (PIS, advert).
Recruitment through local authorities would boost recruitment and enable a wider reach of potential participants.

Identification of participants within local authorities
Staff within local authorities North and South Lanarkshire will be contacted by the researcher or field supervisor, who will provide the rational and focus of the study and recruitment aims in addition to any relevant recruitment material. Prior to contacting the local authorities for recruitment, contact will be made to complete any additional local ethics applications.

A funding application has been submitted to request that participants receive compensation for their participation in the form of one £10 Amazon voucher. Contact has been made with Learning Disability and LGBTQ organisations who have strongly advised to offer monetary incentive to take part in the research and thank them for their time, due to the time taken away from parents if they have caring responsibilities. Some organisations and third sector organisations will also not advertise the research project to potential participants due to competing research that offers financial incentive taking priority. Due to the nature of the project, there are limited individuals who meet the criteria to take part in the project, therefore the financial incentive would boost recruitment and enable the minimum number of participants needed to reach saturation for IPA. £10 Amazon vouchers would be offered. This would be sent to participants following completion of the interview via email. Email addresses would have been collected when participants completed the consent form using Qualtrics, and therefore would be stored securely. Only the main researcher would have access to the email addresses. The Participant Information Sheet will be amended to include information on the payment and how information will be stored. If the funding application is unsuccessful, then payment will be funded by the main researcher.

The PIS has been amended to reflect the above.

For the above requests for amendments, changes to the original application have been highlighted in blue in the below ethics application.

Signature: Caitlin Turner (verified by email)

Date: 27/05/2021

I would like to apply for the following amendment to this previously processed project which had generated a favorable option.

Within my Research 1 proposal for the Doctorate in Clinical Psychology course, I had factored into the project that I would conduct a pilot interview before beginning interviews with participants. This was left from the ethics application in error.

A pilot interview with a parent of an adult who identifies as LGBQ+, or a parent of an adult who has a diagnosis of a learning disability will be conducted to gain feedback on questions asked. The parent would be recruited from a third sector organisation, through social media or snowball sampling, and would be informed of the purpose of the interview. The interview with the pilot interview participant would be conducted via telephone or through the same videoconferencing software as mentioned within the ethics application. Feedback would be taken from the pilot interview and brought to supervision, where appropriate changes will be made to the schedule to ensure rich data collection.

A parent of an adult who has a diagnosis of a learning disability and LGBQ+ will not be recruited for the pilot due to the availability of potential participants who meet the inclusion and exclusion criteria.

Signature: Caitlin Turner (verified by email)

Date: 16/07/2021

I would like to apply for the following amendment to this previously processed project which had generated a favorable option.

I have applied for NHS IRAS ethical approval in order to recruitment through NHS organizations and services. NHS staff who work in Adult Learning Disability services will be contacted through similar strategies employed through third sector and local authority services.

NHS staff will be sent an email with relevant recruitment material and the email will contain the rationale for the study. Changes within the ethics form have been highlighted in purple.

Signature: Caitlin Turner (verified by email)

Date: 06/08/2021

I would like to apply for the following amendments to this previously processed project which had generated a favourable opinion:

Alter recruitment to include all family caregivers (siblings, grandparents, cousins, aunts, uncles etc) in addition to parents. This would improve recruitment uptake and provide a further insight into the views of family caregivers in addition to parents. From speaking to professionals in third sector organisations, it has been highlighted that some adults with learning disabilities no longer have contact with their parents, for example, due to their parents passing away. Expanding the recruitment to include family members would provide a wider insight into the sexual and romantic lives of adults with learning disabilities regarding family caregivers who support them.

Changes have also been made to the interview schedule following feedback from the pilot interview.

Changes within the ethics application, in addition to the interview schedule and recruitment material has been highlighted in green. Changes within the ethics application have included adding the term “family caregiver” alongside “parent”, removing “parent”, and removing “child/son/daughter” to “family member”. Changes have been made within the PIS and recruitment material to reflect these changes.

Changes have been made to the interview schedule highlighted in green, regarding additional questions regarding the family. Changes have also been highlighted following feedback from the pilot interview, as below:

1. *What do you think has influenced your views or beliefs around sexual relationships?*
   What are your views on sex outside of or before marriage? What are your views on same sex relationships? How openly do you discuss sexual issues as a family? How do you think your views on sexuality have changed over time?

2. *What are the views within the wider family?*
   Parents, grandparents, siblings, aunties and uncles etc

Signature: Caitlin Turner (verified by email)

Date: 16/08/2021

I would like to apply for the following amendments to this previously processed project which had generated a favourable opinion:

Alter recruitment to include paid caregivers (i.e. support workers), alongside parents and family members. This would increase recruitment and provide further insight into the views of adults who support adults with intellectual disabilities who identify as LGBQ+.

Changes within the ethics application, in addition to the interview schedule and recruitment material has been highlighted in blue. Changes within the ethics application have included adding the term “paid caregiver”.

CONCLUSION TO ETHICAL AMENDMENT

The applicant’s response to our request for further clarification or amendments has now satisfied the requirements for ethical practice and the application has therefore been approved.

Signature:

Position:
Date:

Acronyms / Terms Used
NHS: National Health Service
SHSS: School of Health in Social Science
IRAS: Integrated Research Applications System
Section: The SHSS is divided into Sections or subject areas, these are; Nursing Studies, Clinical Psychology, C-PASS.
Ethics Administrators

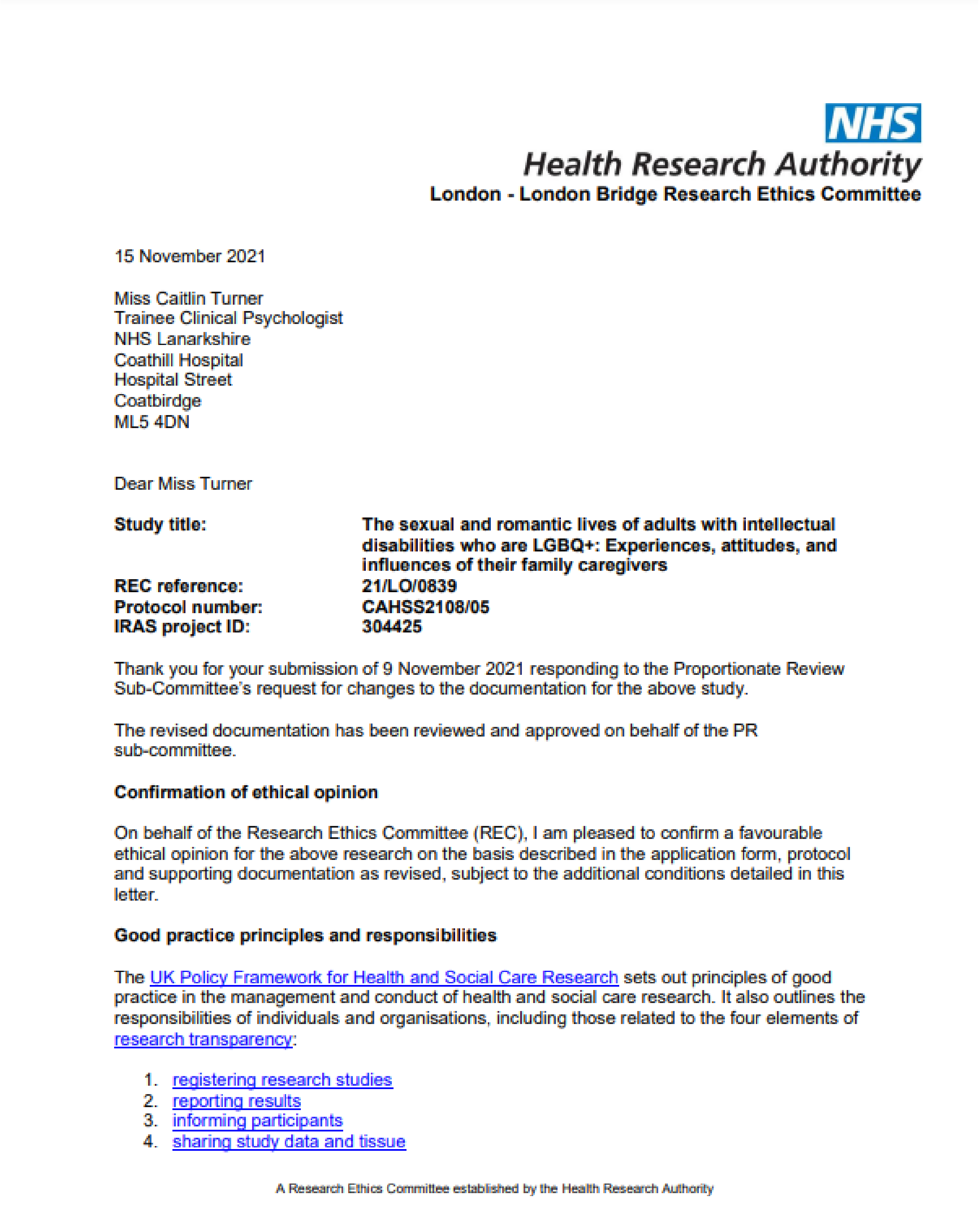
Nursing Studies: nursing@ed.ac.uk

Counselling, Psychotherapy and Applied Social Science: CPASS.ethics@ed.ac.uk

Clinical Psychology: Submitting.Ethics@ed.ac.uk

MA in Health, Science and Society:

Appendix 9: REC HRA Letter of Confirmation of Ethical Opinion Pages 1, 2, 5



NHS
Health Research Authority
London - London Bridge Research Ethics Committee

15 November 2021

Miss Caitlin Turner
Trainee Clinical Psychologist
NHS Lanarkshire
Coathill Hospital
Hospital Street
Coatbirdge
ML5 4DN

Dear Miss Turner

Study title: **The sexual and romantic lives of adults with intellectual disabilities who are LGBQ+: Experiences, attitudes, and influences of their family caregivers**
REC reference: **21/LO/0839**
Protocol number: **CAHSS2108/05**
IRAS project ID: **304425**

Thank you for your submission of 9 November 2021 responding to the Proportionate Review Sub-Committee's request for changes to the documentation for the above study.

The revised documentation has been reviewed and approved on behalf of the PR sub-committee.

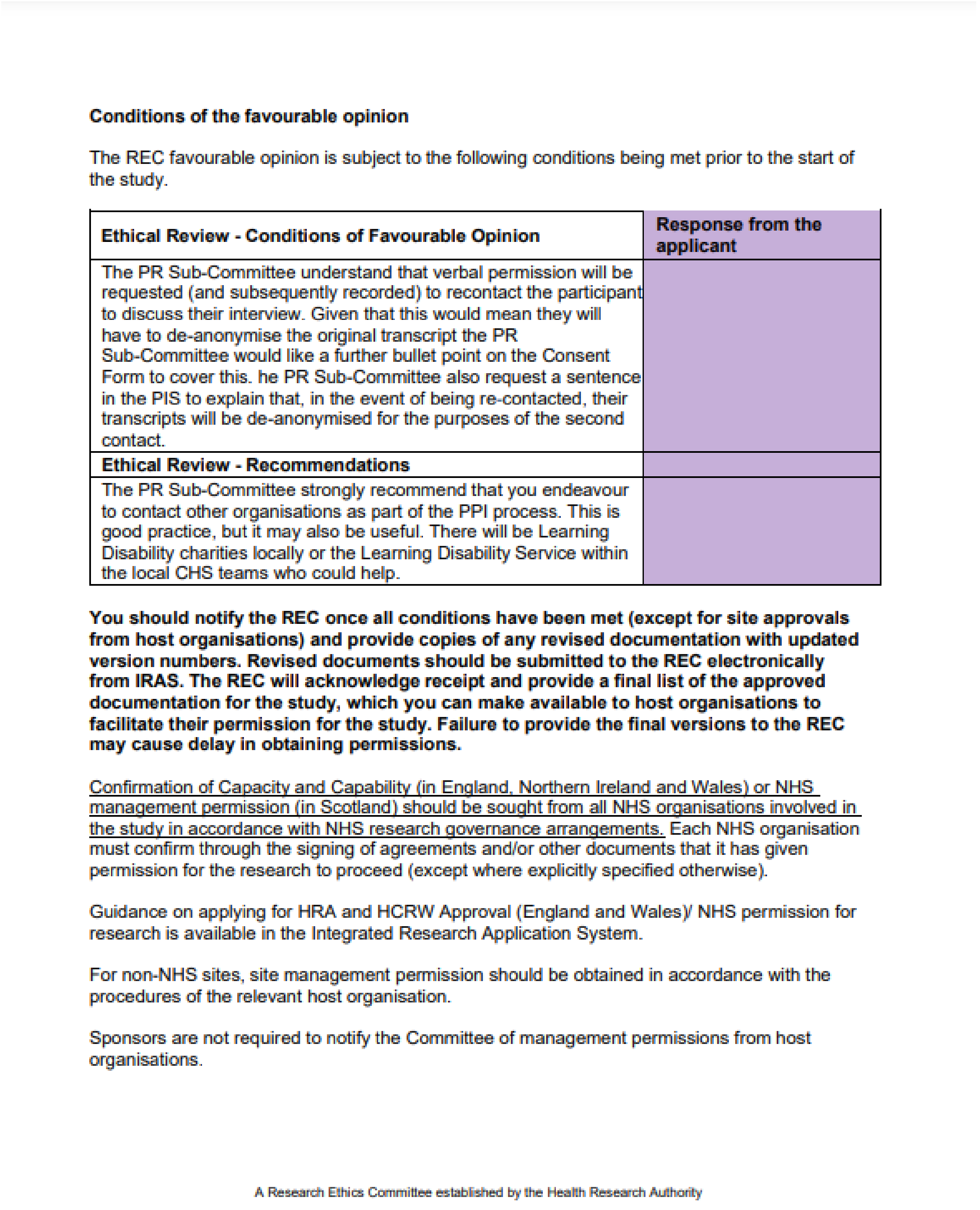
Confirmation of ethical opinion

On behalf of the Research Ethics Committee (REC), 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 additional conditions detailed in this letter.

Good practice principles and responsibilities

The UK Policy Framework for Health and Social Care Research sets out principles of good practice in the management and conduct of health and social care research. It also outlines the responsibilities of individuals and organisations, including those related to the four elements of research transparency:

1. registering research studies
2. reporting results
3. informing participants
4. sharing study data and tissue



Conditions of the favourable opinion

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

Ethical Review - Conditions of Favourable Opinion	**Response from the applicant**
The PR Sub-Committee understand that verbal permission will be requested (and subsequently recorded) to recontact the participant to discuss their interview. Given that this would mean they will have to de-anonymise the original transcript the PR Sub-Committee would like a further bullet point on the Consent Form to cover this. he PR Sub-Committee also request a sentence in the PIS to explain that, in the event of being re-contacted, their transcripts will be de-anonymised for the purposes of the second contact.	
Ethical Review - Recommendations	
The PR Sub-Committee strongly recommend that you endeavour to contact other organisations as part of the PPI process. This is good practice, but it may also be useful. There will be Learning Disability charities locally or the Learning Disability Service within the local CHS teams who could help.	

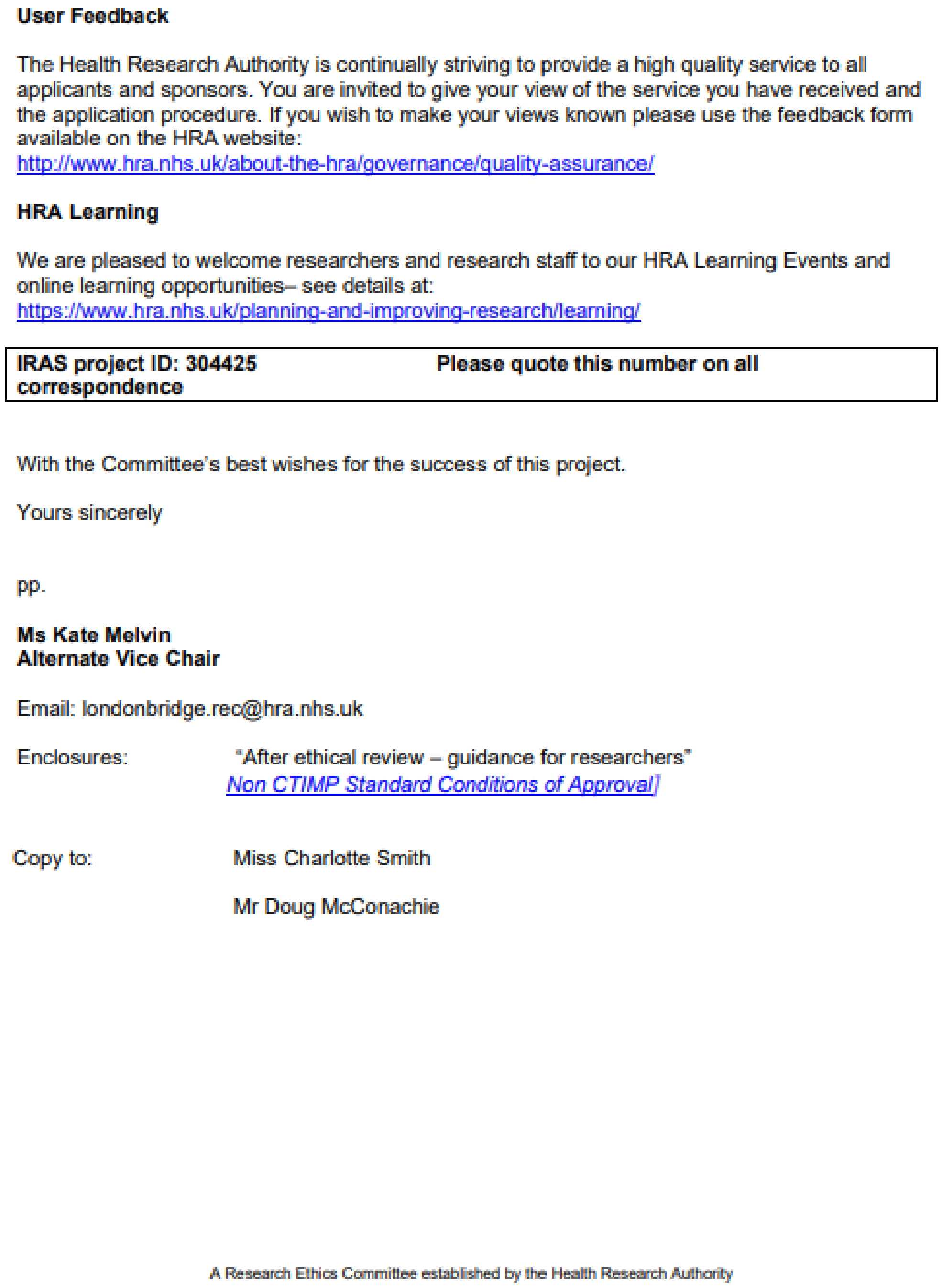
You should notify the REC once all conditions have been met (except for site approvals from host organisations) and provide copies of any revised documentation with updated version numbers. Revised documents should be submitted to the REC electronically from IRAS. The REC will acknowledge receipt and provide a final list of the approved documentation for the study, which you can make available to host organisations to facilitate their permission for the study. Failure to provide the final versions to the REC may cause delay in obtaining permissions.

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.



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: 304425 Please quote this number on all correspondence

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

Yours sincerely

pp.

Ms Kate Melvin
Alternate Vice Chair

Email: londonbridge.rec@hra.nhs.uk

Enclosures: "After ethical review – guidance for researchers"
Non CTIMP Standard Conditions of Approval

Copy to: Miss Charlotte Smith

Mr Doug McConachie

Appendix 10: Interview Schedule

- Introduction and answering any questions
- Collecting demographics of the family member being interviewed (age, gender, sexual orientation, level of education, postcode)
- Collecting demographics of adult being supported (age, gender, sexual orientation, relationship status)
- How they found out about the study

1. *Is your family member/adult you support currently in a same-sex romantic or sexual relationship, or have they been in the past?*
   How do you feel about supporting your family member/adult you support's romantic relationships? Are they open to others about their sexual orientation?

2. *Can you tell me more about your family member's/adult you support's sexual orientation or identity?*
   When did they first express their sexual orientation or sexual identity? How did you feel when your they came out? How did your views change on same sex relationships and sexuality when your they first came out? Are there any barriers or facilitators to expressing their sexuality / developing romantic relationships?

3. *What do you think has influenced your views or beliefs around sexual relationships?*
   E.g. What are your views on sex outside of or before marriage? What are your views on same sex relationships? How openly do you discuss sexual issues as a family? How do you think your views on sexuality have changed over time?

4. *What are the views within the wider family?*
   Parents, grandparents, siblings, aunties and uncles etc

5. *What are your hopes for your family member's/adult you support's romantic life?*
   Do they want to live with their partner? Do they wish to get married or have a civil partnership? Do they want children?

6. *What are your fears or worries about your family member's/adult you support's romantic life?*
   Do you feel they has been discriminated against due to their sexual orientation? Do you have any worries about your child entering a relationship? Concerns about safety (Homophobic attacks?]Concerns about sexual safety?

7. *What have been your main sources of support in terms of your family member's/adult you support's romantic or sexual life?*
   What have been your main sources of support practically / emotionally? Is there anything you've found challenging? Is there anything that's been helpful? Where have you received advice or guidance on sexual development? Where has your family member/adult you support received sex education? Does your family member/adult you support receive support on contraception choices? Have you received training on supporting sexuality?

8. *Is there anything else that you think is important that you want to talk about that we haven't already covered?*

Debrief and amazon voucher

Appendix 11: Participant Information Sheet

The sexual and romantic lives of adults with intellectual disabilities who are LGBQ+: Experiences, attitudes, and influences of their family caregivers

PARTICIPANT INFORMATION

You are being invited to take part in research study looking at the experiences and perceptions of family members of adults with intellectual disabilities who identify as LGBQ+. This is in relation to their sexual and romantic lives.

Before you decide whether you wish to take part, it is important you understand why the research is being conducted and what it will involve. This leaflet is designed to give you information on the research study. If you would like any further information, you can contact me using the details at the end of this leaflet.

WHAT IS THE PURPOSE OF THE STUDY?

We know from previous research that parents and family members play an important role in supporting their family member with developing adult relationships. We would like to find out more about the experiences, attitudes, and perceptions of parents and family members in relation to their family member’s sexual and romantic lives.

The purpose of the study is to explore the experiences and perceptions of parents or family members who have a family member with intellectual disabilities who identifies as LGBQ+. This includes how these views have changed over time, fears, and hopes, and any challenges that the family have found supporting their family member. As part of the study, parents and family members of adults with intellectual disabilities will be approached through third sector organisations.

RELATIONSHIPS, SEXUALITY AND ATTRACTION

The study is looking to explore the experiences of men and women with intellectual disabilities who experience same sex attraction or may have come out as having romantic or sexual feelings towards a person who is of the same gender.

LGBQ+ stands for lesbian, gay, bisexual, and queer. The study welcomes parents or family members of adults who identify as LGBQ+, as well as adults who have same sex attraction, or a desire to pursue a sexual or romantic relationship with another person of the same gender. It also includes adults who may have thoughts about not being heterosexual (straight).

The researchers aim to explore these experiences sensitively and in an open, non-judgemental way.

WHY HAVE I BEEN INVITED TO TAKE PART?

You are invited to participate in this study because you are a parent or family member of an adult with a diagnosis of mild/moderate intellectual disabilities who identifies as LGBQ+.

DO I HAVE TO TAKE PART?

Participation is voluntary, so it is entirely up to you. If you do decide to take part, please keep this Information Sheet and complete the Informed Consent Screen to show that you are happy to take part, and that you understand you can choose to withdraw at any time.

If you do not wish to take part, it will not affect services that you or your son/daughter receives.

WHAT WILL HAPPEN IF I DECIDE TO TAKE PART?

If you decide that you want to take part in the study, there are three ways that you can get in contact.

1. Ask for your details (email address or phone number) to be passed on by the service you got this information sheet from. Once the researcher has these details, they will contact you.
2. Contact the researcher directly using the details at the end of this leaflet.
3. Provide your contact details on the online form and the researcher will contact you.

A date and time will be arranged to meet virtually (by video) to complete an interview which will last between 30 and 60 minutes. This interview will ask questions about your family member's romantic and sexual life, including your views now and how they have changed, your experiences of supporting your child, and your hopes and needs.

Following completion of the interview, you will receive a £10 Amazon gift voucher to thank you for your time.

HOW MANY TIMES WILL WE MEET?

If you decide to take part, we will meet once virtually to complete the interview.

At a later time, there will be an opportunity to meet with the researcher again to discuss what they have found. They will also ask for your opinions on the results. This is optional, and if you decide you do not wish to meet again then this will not effect taking part in the study.

WHAT ARE THE POSSIBLE BENEFITS OF TAKING PART?

You may not get a direct benefit from taking part in the study. However, by sharing your experiences with us, this will help develop a better understanding of the experiences of parents and family members and may allow services to better support them and their family member.

ARE THERE ANY RISKS ASSOCIATED WITH TAKING PART?

There are no significant risks associated with participation although you may feel uncomfortable or upsetting to speak about your family member’s sexual or romantic lives. The interview can be stopped at any time, and you will be offered some time after the interview for debriefing if this is helpful. Support information will be provided following the interview.

WHAT IF I WANT TO WITHDRAW FROM THE STUDY?

You have the right to withdraw from the study at any time. If you wish to withdraw from the study following the interview, your information and interview recording will be destroyed.

DATA PROTECTION AND CONFIDENTIALITY

Your information will be processed in accordance with the General Data Protection Regulation 2016 (GDPR). All information collected about you will be kept strictly confidential. The interviews will be voice recorded and transcribed. During the transcription of the interview recordings, any identifying data or information will be removed, and any names will be replaced with a pseudonym. Your data will only be viewed by the researcher/research team. Interview transcripts will be safely stored during the study and will be destroyed after the end of this study. Some quotes from your responses will be used as examples of patterns of themes across all responses, however, these quotes will not include any identifiable information.

Although the researcher aims to keep all information confidential, if any information is shared within the interview in which the researcher feels that you or someone else is at risk of harm, the researcher will have a duty of care to breach confidentiality. At this time, the researcher will report their concerns to their supervisor, and take appropriate steps to safeguard any individuals involved.

WHAT WILL HAPPEN WITH THE RESULTS OF THIS STUDY?

After the end of the study, a summary of the findings will be provided to parents or family members who took part in the study, if they wish to receive this. The results will also be written into posters and leaflets that will be given to services that have been involved in the study. The study may also be published in an academic journal.

HOW WILL I FIND OUT THE RESULTS OF THE STUDY?

Following the completion of the interview, the researcher will ask if you would like to receive a summary of the findings. If you do, you will be asked to complete an online consent form and provide your email address.

WHO CAN I CONTACT IF I HAVE ANY QUESTIONS?

If you have any further questions about the study, please contact Caitlin Turner at s2007873@ed.ac.uk or Dr Doug McConachie at or Dr Alan Sutherland at

If you want to ask any questions or advice from someone external from the study then please contact an independent researcher, Dr Angus MacBeth, Lecturer in Clinical Psychology, School of Health in Social Science, University of Edinburgh at or 0131 650 3893.

If you wish to make a complaint about the study, please contact:
Dr Mattias Schwannauer, Head of School, School of Health in Social Science, University of Edinburgh, at headofschool.health@ed.ac.uk or 0131 6513954.

In your communication, please provide the study title and detail the nature of your complaint.

If you wish to raise a complaint on how we handled your personal data, you can contact our Data Protection Officer who will investigate the matter.

University of Edinburgh
Data Protection Officer
Governance and Strategic Planning
University of Edinburgh
Old College
Edinburgh
EH8 9YL
Tel: 0131 651 4114
dpo@ed.ac.uk

<u>Thank you for your time.</u>

Please screenshot or copy this information sheet for your records.
If you would like to find out more about the study, then you can contact me directly at s2007873@ed.ac.uk.
Yours sincerely,
Caitlin Turner
Trainee Clinical Psychologist
Supervised by:

Dr Alan Sutherland
Clinical Psychologist
Learning Disability
Service
Longdales
Administration Building
Kirklands Site
Bothwell

Dr Doug McConachie
Senior Research Fellow
Clinical & Health Psychology
School of Health in Social Science
University of Edinburgh
Teviot Place
Edinburgh
EH8 9AG

Appendix 12: Consent Form

CONSENT

The sexual and romantic lives of adults with intellectual disabilities who are LGBT+: Experiences, attitudes, and influences of paid and unpaid carers

1. I confirm that I have read and understood the Participant Information Sheet (V4 16/08/21) for the above study.

2. I have had the opportunity to consider the information that has been provided, ask questions, and have had these questions answered by the researcher.

3. I understand that taking part in the research study is voluntary.

4. I understand I have the right to withdraw at any time.

5. I understand that my anonymised data will be kept for the duration of the study, and will be destroyed following the completion of the study.

6. I understand that the researcher may have to breach confidentiality if information was provided within the interview that suggested yourself or another person was at risk of harm. The information would be discussed with the researcher’s supervisor.

7. I agree to take part in the above study.

Appendix 13: Author Guidelines for Journal of Applied Research in Intellectual Disabilities

1. SUBMISSION

Authors should kindly note that submission implies that the content has not been published or submitted for publication elsewhere except as a brief abstract in the proceedings of a scientific meeting or symposium.

Once the submission materials have been prepared in accordance with the Author Guidelines, new submissions should be made via the Research Exchange submission portal: **https://wiley.atyponrex.com/journal/JAR**. Should your manuscript proceed to the revision stage, you will be directed to make your revisions via the same submission portal. You may check the status of your submission at anytime by logging in to submission.wiley.com and clicking the "My Submissions" button. For technical help with the submission system, please review our **FAQs** or contact **submissionhelp@wiley.com**.

Wiley Publishing Networks

This journal participates in the Wiley Special Education publishing network and the **Wiley Developmental Science Publishing Network**. This exciting collaboration amongst our Special Education and Developmental journals simplifies and speeds up the publication process, helping authors find the right home for their research. At the Editors' judgement, suitable papers not accepted by one journal may be recommended for referral to another journal(s) in the network. Authors decide whether to accept the referral, with the option to transfer their paper with or without revisions. Once the referral is accepted, submission happens automatically, along with any previous reviewer reports, thereby relieving pressure on the peer review process. While a transfer does not guarantee acceptance, it is more likely to lead to a successful outcome for authors by helping them to find a route to publication quickly and easily.

2. AIMS AND SCOPE

JARID is an international, peer-reviewed journal which draws together findings derived from original applied research in intellectual disabilities. The journal is an important forum for the dissemination of ideas to promote valued lifestyles for people with intellectual disabilities. It reports on research from the UK and overseas by authors from all relevant professional disciplines. It is aimed at an international, multi-disciplinary readership.

In order for a paper to be considered for publication, it must be about people with intellectual disabilities. Manuscripts which focus upon autism will be considered only when the focus is also upon intellectual disabilities. Papers which focus upon autism and exclude people with intellectual disabilities will not be considered.

The topics it covers include community living, quality of life, challenging behaviour, communication, sexuality, medication, ageing, supported employment, family issues, mental health, physical health, autism, economic issues, social networks, staff stress, staff training, epidemiology and service provision.

Theoretical papers are also considered provided the implications for therapeutic action or enhancing quality of life are clear. Both quantitative and qualitative methodologies are welcomed. All original and review articles continue to undergo a rigorous, peer-refereeing process.

3. MANUSCRIPT CATEGORIES AND REQUIREMENTS

Original Articles*,* including Clinical Trials (see guidance within section 5), ***Review Articles*** and ***Brief Reports*** are accepted by the Journal. ***Theoretical Papers*** are also considered, provided the implications for therapeutic action or enhancing quality of life are clear. Both quantitative and qualitative methodologies are welcomed. Articles are accepted for publication only at the discretion of the Editor. Authors who are submitting original articles where qualitative methods have been used must ensure that their choice of method is well justified and issues relating to methodological rigor are effectively addressed.

Articles and ***Theoretical Papers*** should not exceed 6000 words;

Review Articles should not exceed 7000 words;

Brief Reports should not exceed 2000 words.

All word limits are inclusive of the abstract. References, Words in Tables, Captions/Legends, Figure and Figure captions/legends are excluded from the word limits.

Please note that papers submitted for Special Issue volumes should also not exceed 6000 words.

As of December 2019, *JARID* no longer accepts Book Reviews.

4. PREPARING THE SUBMISSION

Use of Language

The language used to describe disability differs across countries, cultures and disciplinary fields, and continues to evolve. All manuscripts submitted to JARID must use language that promotes the value of all people as full members of our shared society. Pejorative language inclusive of euphemisms must not be used. For JARID this includes the use of older language that has been used to describe people with intellectual disabilities such as “retarded”, “handicapped”, or “mentally handicapped”. Using any terms which are offensive, or patronising may lead to rejection of your submitted manuscript.

JARID recommends using person-first and/or identity-first language thoughtfully and appropriately. For example, the language used to describe both people with intellectual disabilities and autistic people has evolved based on recent advocacy efforts. When referring to people with autism, it is acceptable to use either identity-first language (e.g., “autistic people”) or person-first language (e.g., people with autism”), while identity-first language is not used to describe people with intellectual disabilities, where person-first language is preferred. Thus, people with intellectual disabilities should be referred to as people with intellectual disabilities.

We have consulted with over 40 self-advocates through Learning Disability England which included the North West Self-Advocacy Group, as well as Self-Advocacy Together and asked them what language we should use when writing about people with intellectual disabilities.

People with intellectual disabilities said that they do not like to be referred to by acronyms or abbreviations. Authors must therefore not use an abbreviation to describe intellectual disabilities such as “ID” or “LD”. Instead, use person-first

language such as children, teenagers, adults, or people with intellectual disabilities, avoiding acronyms or abbreviations.

The terms “learning disabilities” and “learning difficulties”, though used in some countries to refer to people with intellectual disabilities, can cause confusion among readers. These terms are not used by the journal to refer to people with intellectual disabilities. Authors must only use the term “learning disabilities or difficulties” where this refers to a specific learning disability/disorder– such as a specific learning difficulty in reading, written expression or mathematics. **If “learning disabilities” or “learning difficulties” are used, authors must not use an abbreviation.**

Free Format Submission

Journal of Applied Research in Intellectual Disabilities now offers Free Format submission for a simplified and streamlined submission process. Before you submit, you will need:

- Your manuscript: this should be an editable file including text, figures, and tables, or separate files – whichever you prefer. All required sections should be contained in your manuscript, including abstract, introduction, methods, results, and conclusions. Figures and tables should have legends. Figures should be uploaded in the highest resolution possible. References may be submitted in any style or format, as long as it is consistent throughout the manuscript. Supporting information should be submitted in separate files. If the manuscript, figures or tables are difficult for you to read, they will also be difficult for the editors and reviewers, and the editorial office will send it back to you for revision. Your manuscript may also be sent back to you for revision if the quality of English language is poor.
- An ORCID ID, freely available at https://orcid.org. (Why is this important? Your article, if accepted and published, will be attached to your ORCID profile. Institutions and funders are increasingly requiring authors to have ORCID IDs.)
- The title page of the manuscript, including:
    - Your co-author details, including affiliation and email address. (Why is this important? We need to keep all co-authors informed of the outcome of the peer review process.)
    - Statements relating to our ethics and integrity policies, which may include any of the following (Why are these important? We need to uphold rigorous ethical standards for the research we consider for publication):
        - data availability statement
        - funding statement
        - conflict of interest disclosure
        - ethics approval statement
        - patient consent statement
        - permission to reproduce material from other sources
        - clinical trial registration

Parts of the Manuscript

Submissions via the new Research Exchange portal can be uploaded either as a single document (containing the main text, tables and figures), or with figures and tables provided as separate files. Should your manuscript reach revision stage, figures and tables must be provided as separate files. The main manuscript file can be submitted in Microsoft Word

(.doc or .docx) or LaTex (.tex) formats.

If submitting your manuscript file in LaTex format via Research Exchange, select the file designation "Main Document - LaTeX .tex File" on upload. When submitting a LaTeX Main Document, you must also provide a PDF version of the manuscript for Peer Review. Please upload this file as "Main Document - LaTeX PDF." All supporting files that are referred to in the LaTeX Main Document should be uploaded as a "LaTeX Supplementary File."

Cover Letters and Conflict of Interest statements may be provided as separate files, including in the manuscript, or provided as free text in the submission system. A statement of funding (inlcuding grant numbers, if applicable) should be inlcuded in the "Acknowledgements" section of your manuscript.

Title page

The title page should contain:
i. A short informative title that contains the major key words. The title should not contain abbreviations (see Wiley's **best practice SEO tips**);
ii. A short running title of less than 50 characters;
iii. The full names of the authors;
iv. The author's institutional affiliations where the work was conducted, with a footnote for the author's present address if different from where the work was conducted;
v. Acknowledgments.

Authorship

On initial submission, the submitting author will be prompted to provide the email address and country for all contributing authors.

The Research Exchange submission system will extract listed affiliations from the manuscript and then ask the submitting author to verify each author's affiliation institution(s). Authors are encouraged to include the complete affiliation addresses in the manuscript (Institution Name, Country, Department Name, Institution City, and Post Code). When verifying their institution, authors will also be asked to locate their base institution only (not necessarily the department or school).

Please refer to the journal's authorship policy in the Editorial Policies and Ethical Considerations section for details on eligibility for author listing.

Acknowledgments

Contributions from anyone who does not meet the criteria for authorship should be listed, with permission from the contributor, in an Acknowledgments section. Financial and material support should also be mentioned. Thanks to anonymous reviewers are not appropriate.

Conflict of Interest Statement

Authors will be asked to provide a conflict of interest statement during the submission process. For details on what to include in this section, see the section 'Conflict of Interest' in the Editorial Policies and Ethical Considerations section below. Submitting authors should ensure they liaise with all co-authors to confirm agreement with the final statement.

Main Text File

As papers are double-blind peer reviewed the main text file should not include any

information that might identify the authors.
The main text file should be presented in the following order:

i. Title, abstract and key words;
ii. Main text;
iii. References;
iv. Tables (each table complete with title and footnotes);
v. Figure legends;
vi. Appendices (if relevant).

Figures and supporting/supplemental information should be supplied as separate files. For more information on prearing supporting/supplemental information, **click here**.

Abstract
All papers should have a structured abstract (maximum 150 words) as follows: Background, Method, Results, and Conclusions. The abstract should provide an outline of the research questions, the design, essential findings and main conclusions of the study. We kindly request that authors place the abstract and title at the beginning of the main manuscript document.

Keywords
Please provide up to six Keywords to aid indexing.

References
References should be prepared according to the *Publication Manual of the American Psychological Association* (6th edition). This means in text citations should follow the author-date method whereby the author's last name and the year of publication for the source should appear in the text, for example, (Jones, 1998). The complete reference list should appear alphabetically by name at the end of the paper.

A sample of the most common entries in reference lists appears below. For more information about APA referencing style, please refer to the **APA FAQ**. Note that for journal articles, issue numbers are not included unless each issue in the volume begins with page one, and a DOI should be provided for all references where available.

Journal article

Beers, S. R. , & De Bellis, M. D. (2002). Neuropsychological function in children with maltreatment-related posttraumatic stress disorder. *The American Journal of Psychiatry*, *159*, 483–486. doi:10.1176/appi.ajp.159.3.483

Book

Bradley-Johnson, S. (1994). *Psychoeducational assessment of students who are visually impaired or blind: Infancy through high school* (2nd ed.). Austin, TX: Pro-ed.

Internet Document

Norton, R. (2006, November 4). How to train a cat to operate a light switch [Video file]. Retrieved from **http://www.youtube.com/watch?v=Vja83KLQXZs**

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Author Guidelines Updated December 2019

Appendix 14: Excerpt of Transcript and IPA Coding

Emergent Themes	Transcript	Exploratory Comments
Managing boundaries in relationships Caregiver feeling awkward	No, they know, you know, she's the likes of she's, she finds one of the carers really quite attractive um and we've had to kind of deal with that in the sense of um she's got a husband and she's got kids and you know	Awkward feelings from caregiver around managing attraction that is unrequited Sexual attraction shown from support adult to carer
Managing boundaries in relationships	we started it off jokingly being like you know oh [husband] would kill me etc and that kind of stuff but	Using different strategies to manage feelings and attraction
Open discussion about sexuality Managing boundaries in relationships	eventually we had to be a wee bit firmer with her and kind of say I don't you know I don't fancy women you know its fine that you do but I like men, you know, if I was leaving [husband] it wouldn't be for a women type of thing you know and she accepted that	Providing message that it's okay to have same sex attraction, but managing unrequited or inappropriate expression of sexuality towards carer
	Yeah…and I'm hearing before she was about 30, had she mentioned anything about any attraction to women or was there not much chat about that kind of attraction	
	No, when she was younger she tried to kiss	Expressing sexuality when younger

Family views on sexuality shaping your own Influence on views Caregivers being overprotective Influence on views Adults with intellectual disability more vulnerable Expression being shut down by others Just not talked about	a boy a couple of times, but up until…my mum and dad brought her up, I’ve been involved in her care since 2008 and I’ve only been living with her the past couple of years, before that she was living with my mum and dad. My dad, they were both very protective of her, my mum is an old fashioned Catholic etc, so you know, anything beyond heterosexual was never really talked about, and also when Julie was much much younger and she was in school a boy kissed her, and my dad had gone bad, do you know what I mean, because he was worried she was going to get pregnant and stuff, total over-reaction, um, so I don’t think she’s comfortable with any of that, I think it’s taken a long time to become comfortable talking about her emotions without somebody saying “oh you don’t want to do that” or “let’s forget about that” type of thing, you know	Being supported by family members, the views of family members influencing the view of sexuality by the adult being supported Caregiver being overprotective Influence of religion on views, sexuality not being spoken about in the family home Father reaction was anger which portrays view that expressing sexuality or having romantic contact is wrong Fear of person with intellectual disability being pregnant – view of women as more vulnerable due to risk of pregnancy Participant expressing parent view didn’t align with her own views Family views have had impact on expression due to possible shame or embarrassment, internalising that sexual expression is wrong, or being shut down by others if expressing sexuality or attraction to another