

**Establishing a co-operative inquiry group
for people with intellectual disabilities to
explore relationships and sexuality in their
lives.**

**A thesis submitted to Trinity College Dublin, the University of
Dublin,**

in fulfilment of the degree of

Doctor of Philosophy in Nursing and Midwifery.

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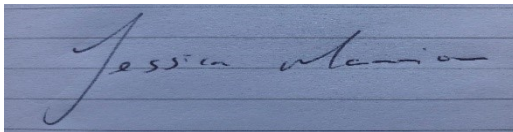
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Jessica Mannion

Date: 31st October 2023.

Dedication:

Peterlee.

You are in my heart, which has spilt into this work and onto these pages. I hope I have started to make the change I promised.

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Abstract

Previous research has shown that people with intellectual disabilities face many barriers concerning their sexual citizenship. This is due to others perceiving them as vulnerable and wanting to protect them, rooted in ingrained societal attitudes. As a result, people with intellectual disabilities cannot live the life they want. However, there is a gap in the literature from an Irish context that explores the perspectives and lived experiences of people with intellectual disabilities. We set up a cooperative-inquiry group, a form of action research, where the researchers with intellectual disabilities in this study were involved in every decision and stage, from design, to data generation, to analysis, to sharing the findings. The theoretical lens used in this study was the concept of sexual citizenship (also known as intimate citizenship), which uncovered that the researchers were denied their sexual citizenship. We were engaged in cycles of learning, reflection, and action. After many shared barriers were identified with the research team, we carried out several actions including educating ourselves on sexual health education and educating the public on the sexual citizenship rights of people with intellectual disabilities. This study was transformative to the researchers, and we propose other researchers consider this way of working on disability research, where participants can instead be researchers and lead studies and actions that are important to them. We hope this study will lead the way and move society forward in changing societal attitudes towards people with intellectual disabilities, so they have their rights to sexual citizenship fulfilled.

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Chapter One: Introduction:

1.1: Introduction:

This chapter will introduce this study on relationships and sexuality for adults with intellectual disabilities. I will begin by explaining the motivation behind my initiating this research. I will then set out the aim and objectives of the study. In Chapter Two (Positionality Revealed Through First-person Inquiry), I will explore my epistemological and ontological positions. However, I will briefly introduce these here, which are constructivism and social constructivism. What has influenced my understanding of disability will be explored. I will explain the theoretical lens taken for this thesis, sexual citizenship, also known as intimate citizenship. To end this chapter, I will briefly overview the chapters to follow in this thesis.

1.2: Background to the problem:

Firstly, I will delve into what motivated me to initiate a participatory study on relationships and sexuality for people with intellectual disabilities. Between 2008 and 2010, I completed a master's research study on the recreational needs of young disabled people in Ireland. This research was a participatory action research study with 22 young people aged between 12-25 years, with a range of disabilities, including intellectual, physical, sensory, and mental health; two young people did not have a disability. During a data collection meeting with co-researchers who were 18+, issues regarding relationships and sexuality were voiced. This topic was outside the scope of the recreational needs project but seemed relevant given that relationships and sexuality are integral to recreation, and they wanted to discuss it. The co-researchers stated they had never had the opportunity to discuss relationships and sexuality, particularly LGBTQ+ issues. They said they did not receive sexual health education in their specialised schools for disabled students and wanted to discuss these topics as they were interested in forming relationships; indeed, some already had.

I presented the study's findings at a national conference. Naively, when a national newspaper contacted me to interview before the conference, I put too much trust in the

journalist. As I spoke about the findings concerning recreation and leisure, they honed in on the relationships and sexuality aspects. When the newspaper came to print, there was an adverse reaction from an organisation supporting the study. I received a small amount of funding from this organisation to cover the meetings' costs and to pay a mentor to co-facilitate them. They also facilitated access to an advisory group and a parents' group to recruit young people. The organisation was upset at the media report, considered it inappropriate to discuss this topic with disabled people, and was concerned about their parents' reactions. The organisation stopped the group from continuing, despite no parents voicing issues and against the requests of the young people. The organisation met with the university I was studying at and tried to stop the research, but our contract did not allow for this, and the university stood behind me. A senior academic in my department contacted me. They advised that if I continued with this study, there would be a chance I would never get a job in disability practice again. He also stated that this reaction meant something and that if I continued this study, it could be excellent research and make a change. I felt that I had to stay true to the voice of the co-researchers and not hide it for the sake of my career; this topic was important to the young people, and when I tried to enable their voices, I felt silenced. It was interesting that our project was called 'Silent Voices.' So that was it. I decided to pursue a PhD on the topic of relationships and sexuality. When I contacted my principal supervisor to see if he was interested in the project, he told me he was not taking PhD students but kindly agreed to meet. When we did, he told me that others stopped him when he tried to do his PhD on this topic. He agreed to supervise me. During the first few years of the study, people offered unsolicited advice to do the study on something else. I knew that establishing the project would be challenging. Nevertheless, this reaction, the voice of the disabled young people, and the literature I had read after this (explored in Chapter Three: Literature Review) all pointed to the fact that research should be done on the perceptions and experiences of people with intellectual disabilities, relationships, and sexuality in Ireland.

1.3: Research aim and objectives:

This study aimed to generate knowledge about human experience from a group of adult researchers with intellectual disabilities on a topic(s) important to them related to the

broader topic of relationships and sexuality. In seeking to address this aim, several objectives were identified. These were:

- To establish a co-operative inquiry group comprising adults with mild and/ or moderate intellectual disabilities.
- To explore the topic of relationships and sexuality.
- For the group to refine the research focus by choosing a specific topic(s) of importance within the broad area of relationships and sexuality.
- To use the co-operative inquiry approach to explore this topic(s) in their lives.

1.4: Introduction to the study:

The method of co-operative inquiry was undertaken (discussed in detail in Chapter Four: Methodology) so that a team of researchers (who were co-subjects/ co-researchers and who co-created findings on the topic from their own lives), who were adult self-advocates with intellectual disabilities, would be meaningfully involved in all stages of the research. The inquiry included deciding which topics were relevant to research while focusing on relationships and sexuality; participating in research team meetings to discuss experiences; being involved in all study decisions; co-creating the data analysis method; co-analysing the data; applying for and obtaining funding to support the dissemination activities (all discussed in Chapter Four: Methodology); and disseminating these findings (explored in Chapter Nine: Discussions, Recommendations, and contributions). These activities took place during 20 research team meetings over 12 months, using creative methods to explore the topics (explored in Chapter Five: Visual and Creative Research Methods for the Data Construction, Analysis and Dissemination).

1.5: Epistemological and ontological positions that underpinned this way of working:

In the next chapter (Chapter Two: Positionality Revealed Through First-person Inquiry), I will explore my position concerning this study. However, I felt it would be helpful to briefly set out my epistemological and ontological positions from the outset of this work.

The decision to work collaboratively in research was born from my epistemological and ontological positions. My epistemological stance is constructivism, a paradigm that emphasises that knowledge is constructed through an individual's experiences (Coghlan and Brydon-Miller, 2014). Constructivism was implemented in this study by striving to facilitate a space to work out our version of reality (Bryman, 2004). In writing this thesis, I am providing my version of reality. I reflected on the paradigms underpinning this research by undertaking a first-person inquiry (Marshall, 2016), displaying who I was (Bosher, 2002), and writing myself into the study (Coghlan and Brydon-Miller, 2014) (see Chapter Two: Positionality Revealed Through First-person Inquiry). According to Marshall (2016), first-person inquiry is paying attention to life and participation in research and learning through self-reflective practice. I wanted to know how I impacted the study's construction, participation, and outcomes (Coghlan and Brydon-Miller, 2014). Through this, I identified past experiences lacking voice and agency due to my disability and class-based intersectional identities. I was also aware that despite these inequalities, I, as a doctoral researcher, had the privilege of being able to change my situation. These past experiences were the driving force that led me to approach research in a manner that would create opportunities for others to speak and to be heard, where together, we could act and make positive changes. Through this exploration, I became aware that the study was influenced by my values of social justice, equity, rights, access, and participation that arose from my lived experiences. Consequently, the most authentic approach to take in this study was co-operative inquiry. It was hoped that researching collaboratively would enable us to collectively construct an understanding of our experiences while breaking down power barriers and creating a space to use our voices and be heard.

My ontological position extended the constructivist paradigm and is concerned with social constructivism. Social constructivism suggests that perceptions of the world are jointly constructed through social interactions, resulting in shared assumptions (Vygotsky, 1978). Social constructivism is a beneficial concept when analysing disability as it helps the researcher to look at influences that shape the meaning of disability, such as culture, socio-political factors, societal attitudes, language, and power relationships (Zolkowska, 2016). Understanding how disability is constructed, interpreted, and experienced helps us to increase social awareness and to understand the reality of labelling and classification

for people with intellectual disabilities to increase social awareness and to understand the reality of such labelling and classification (Zolkowska, 2016). This way of thinking may offer a mechanism to articulate and make sense of the research team's experiences. Identifying the impact of labelling and perceptions on disability will bring social justice and social constructivism together (explored in Chapter Nine: Discussions, Recommendations, and Contributions).

1.6: Defining disability:

Although the research team discussed and constructed their meaning and language around disability, I came to this study with my pre-conceived perceptions, influenced from when I started studying disability studies 19 years ago, and which I will explain here as this thinking has influenced this work. During my undergraduate degree in Social Care Practice in the early 2000s, when writing for my disability studies module assessment and dissertation, I came across the work of disabled academics such as Oliver (1981; 1990; 1992; 1994; 1996a; 1996b; 1997; 1999), Barnes (1990; 1991a; 1991b; 2008a; 2008b) and Shakespeare (1999; 2000; 2006), who were pioneers of the social model of disability. Instead of focusing on the limitations of an individual's impairment, the social model focuses on the limitations in the social and physical environment to overcome barriers faced by disabled people (Oliver, 1981).

Historically, disability had primarily been viewed in society as an individual medical issue (Barnes, 2019), whereas definitions of disability saw impairment as the cause of disability (Harris et al., 1971). Academics (such as Barnes, Oliver, and Shakespeare) prescribing to the social model drew from a socio-political definition of disability created by the UPIAS (Union of Physically Impaired Against Segregation) in 1976, an organisation made solely of disabled members. UPIAS's (1976) definition of disability distinguished biological impairment and social disability. Impairment is viewed as the defect of the body, and disability is viewed as the experience caused by the disadvantages a person with an impairment faces due to how society is organised, with a focus on the inaccessible societal environment and disabling societal attitudes. 'Disability is imposed on top of our impairments by how we are unnecessarily isolated and excluded from society' (UPIAS,

1976: p.4). UPIAS further described disabled people as oppressed in many areas, such as mobility, housing, education, and work.

This understanding and definitions of impairment and disability that the social model of disability underpinned resonated with me. Like the social model, I had always viewed disability as attitudinal and physical barriers in an unjust society. I believed it was not helpful to focus on an individual's limitations but instead on why they could not live equally in society as they were, which I believed was more accessible to non-disabled people. Then, looking at why society was disabling, I felt this way of thinking helped to identify disabling barriers and work towards removing them so disabled people may live more equally with others.

This understanding and definition of impairment and disability is something that I relate to as an individual with ADHD and sensory processing disorder. I have impairments, for example, in my executive functioning skills. However, because the world (and I have found in education in particular) is designed for neurotypical people, the inaccessible environment and disabling attitudes towards me work against me, leaving me disabled. Living with my impairments would not be as challenging if the world was designed for people like me.

These definitions are used worldwide by disabled-led organisations (Barnes, 2019). However, there are limitations when applying the social model of disability to this study, where it has been argued that it has ignored those with intellectual disabilities (Aspis, 2000). Although the UPIAS definition was initially created to explain physical disability, it was expanded to include intellectual disability. As Stalker (2020) highlighted, Oliver's (1990) main text describing the social model of disability barely mentioned people with intellectual disabilities. Oliver later defended this by stating that people should not be divided into impairment groups. However, Stalker (2000) suggested that although the experiences of people with intellectual disabilities are very much like those of other disabled people, there are ways that their position may be distinctive.

An example is when the Disabled People's Movement celebrated Disability Pride. However, people with intellectual disabilities have rejected the disabled label, advocating that 'labels are for jars and not people' (Stalker, 2000: p.252). Stalker (2000) argued that people with intellectual disabilities do not always relate to or are included in the positive collective identity of disability as part of the Disabled Peoples Movement, where there has been a hierarchy of disability, where those 'more able' have wanted to differentiate themselves from those with more severe intellectual disabilities. As well as this, social model thinking sees impairment as not socially constructed, unlike disability. However, Stalker (2000) argued that intellectual disability could be seen as socially constructed, where people have been stigmatised in many ways, such as 'asexual,' 'sexually promiscuous,' 'vulnerable,' and 'an angel' (Stalker, 2000). I agree with this social construction point, and I discussed this above in exploring my ontological position of social constructivism.

When applying social model definitions of impairment and disability to this study in the lives of people with intellectual disabilities, I am aware of the possible limitations of such. It will be up to the researchers how they define and understand disability and something we may explore. However, from my stance as a PhD researcher, I have been influenced by this way of thinking. Drawing from the social model perspective and making a distinction between impairment and disability may help to identify any external barriers to create a better understanding of what is happening in the researcher's lives and possibly help us to work towards action and change.

1.7 Theoretical lens - Sexual/ intimate citizenship:

The theoretical lens used in this study is the concept of sexual citizenship (also known as intimate citizenship), which is briefly explained here and then will be used as a lens to explore the findings through discussion (in Chapter Nine: Discussions, Recommendations, and contributions). *Sexual citizenship* is a concept that uses a social justice framework (Bahner, 2021) that was born out of activism during the LGBTQ+ movement (Weeks, 1998). This concept was brought about to challenge heteronormativity and how society has structured relationships (Bahner, 2021). There are fewer opportunities for sexuality

and intimacy for those who are seen as outside of the norm (Bahner, 2021). Plummer (2003) described intimate citizenship as recognising an individual's rights and responsibilities regarding their decision-making about their intimate relationships. Sexual citizenship aims to advocate for several rights, including homosexual acts, expressing oneself without fear of violence, harassment, and discrimination, and marriage (Bahner, 2021).

Plummer (2003) discussed the concept of intimate citizenship. The words 'intimate' and 'citizenship' seem like they should be separate due to the perceived private and public spheres of each. He defined *intimacy* as a close bond between two people, which includes our close relationships and our experiences with ourselves, and through these, we consider our identity, body, and emotions. Intimacy is expressed in sex, love, and other types of relationships. He defined *citizenship* as participation and belonging in a group or community that brings rights to the fore (Plummer, 2003). Plummer (2003) argued that there is a link between the public and private spheres in intimacy, where socio-cultural transformations erode intimacy in the private sphere and create possible public, plural, and democratic forms of intimate lives.

Not everyone is considered a citizen, as some people are excluded. Regarding intimate citizenship rights, for example, reproductive rights, not all groups of people in society are treated equally. As a result, some groups cannot exist and participate in society equally to others (Plummer, 2003). These inequalities result in marginalisation, exclusion, and powerlessness (Plummer, 2003). Plummer (1995) articulated these rights in terms of control and whether individuals have control or not. This control is about one's decisions about their body, relationships, emotions, identity, representation, gender, erotic experiences, and public spaces (Plummer, 1995). Sexual minorities often become victims of abuse, harassment, coercion, violence, exploitation, hate crime, and exclusion (Plummer, 2003). Plummer (2003) suggested that the experiences of love, emotions, sexuality, the body, and childbearing must be considered for minority groups to be viewed differently and that their intimacies should be equal to those of others. He discussed how we should not be denied the right to marry, divorce, have children, have an abortion, experience our sexuality, or modify our bodies (Plummer, 2003). However, in many

traditional societies (such as those where the nuclear heterosexual family dominates), these rights are denied to those perceived as outside of the norm. Traditional intimacies are embedded in hierarchy, authority, and religious and patriarchal beliefs; they are still in existence and are less likely to embrace new forms of intimacies and sexualities (Plummer, 2003).

Although sexual citizenship has provided a framework for claiming rights (Richardson, 2000), the concept needs to be further developed to include the perspectives of disabled people (Ignani et al., 2016; Bahner, 2021). Limited research has been carried out that explores the sexual citizenship of disabled people (Ignani et al., 2016; Bahner, 2021) except for a limited number of studies such as Liddiard (2018), Iarskaia-Smirnova and Verbilovich (2020), Bahner (2021), and Evans et al., (2022). However, most of these existing studies focused on the experiences of disabled people and not people with intellectual disabilities specifically.

The narratives present in public discourse are influenced by the spiritual and moral values of what the public believes is permissible sexual behaviour for disabled people, which is usually desexualising them, coupled with ignoring and denying their sexual needs (Mladenov, 2014; Iarskai-Smirnova and Verbilovich, 2020; Evans et al., 2022). Disabled people are invisible citizens, and sex is a taboo subject silenced within public discourse (Iarskai-Smirnova and Verbilovich, 2020). Disabled people can even struggle to be recognised as sexual beings (Bahner, 2021). According to Liddiard (2018), due to the segregation, institutionalisation, and exclusion of disabled people, they have been on the margins of human sexuality and denied rights and access to sexual citizenship. Some barriers faced by disabled people include increased violence and abuse, reliance on social care and private resources, child welfare involvement, and trans-institutionalisation (moved from one institution to another) (Ignani et al., 2016). Disabled people often depend on disability services for support in their sexual lives (Bahner, 2021). Limits and constraints are imposed on disabled peoples' intimacy and sexuality by family, professionals, and broader society, underpinned by societal attitudes, religious beliefs, and mass culture (Iarskai-Smirnova and Verbilovich, 2020). This denial of intimate citizenship is contrary to the UN Convention on the Rights of Persons with Disabilities

(2006), which aims to protect disabled people's rights in the spheres of intimate life, such as their sexual identity and expression, in marriage and in starting a family (Ignagni et al., 2016; larskaia-Smirnova and Verbilovich, 2020).

Plummer (2003) argued that the experiences of love, emotions, sexuality, the body, and childbearing must be considered for minority groups whose sexuality and intimacy are being denied. Such minority groups need to be viewed differently from how they are, where their sexuality and intimacies should be equal to those of others in society (Plummer, 2003). Political participation has pushed through some of the inequalities in society for certain groups, such as those who identify as LGBTQ+. Social movements such as the LGBTQ+ movement have resulted in the transformation of people's intimate lives. Social movements can generate solidarity and recognition, redefine our understanding of justice, and propose new visions to transform society for sexual minorities (Lara, 1998).

Plummer (2003) focused on the ethics of how we can minimise harm while recognising justice, equality, recognition, and care for sexual minorities. He recommended that we could listen to the intimate stories of those affected negatively. Intimate stories can be told by disabled people through storytelling, which is crucial for political and social change and the claim for intimate citizenship (Plummer, 2003; larskaia-Smirnova and Verbilovich, 2020; Evans et al., 2022). When people share their narratives, it can help shape their lives (MacIntire, 1981). People coming together to tell their stories can create relationships and enable repressed truths to be heard (Lara, 1998). When people tell their stories, they begin to make sense of them, and empowerment can follow (Langellier, 2001). Rorty (1979) suggested that people make identities and communities and that a new description is generated through storytelling. More people can, therefore, have access to hearing how sexual minorities experience their intimate lives, what challenges they face, and how they deal with such issues (Plummer, 2003). If people listen with a will to act, they can see the world differently (Plummer, 2003) through what Nussbaum (1990) described as a moral form of learning. Lara (1998) explored the power of shifting the boundaries of the public sphere, which comes from people in a group telling their stories, and how this can transform the lives of others after that. Telling stories bridges these different worlds (Lara, 1998) and helps us to see the world differently (Plummer, 2003). People can collectively

redefine themselves, resulting in emancipation and liberation from how they were previously viewed (Iarskai-Smirnova and Verbilovich, 2020). This experience can lead to understanding and respect, resulting in a movement towards sexual citizenship (Plummer, 2003).

Studies on the sexual citizenship of disabled people (Ignani et al., 2016; Liddiard, 2018; Iarskaia-Smirnova and Verbilovich, 2020; Evans et al., 2022) have also found it beneficial to focus on sexual citizenship through the stories' disabled people have shared. Iarskai-Smirnova and Verbilovich (2020) claimed that sexual storytelling can be a tool for disabled people to fight for their right to identity. They further maintained that telling and analysing sexual stories can help to reveal the stereotypical attitudes that people experience, and this can then be used to challenge and dismantle such dominant repressive discourse which is present in the public domain (Iarskai-Smirnova and Verbilovich, 2020). Also, when a group of disabled people form and share similar experiences, it can result in solidarity and help them resist any disabling discourse together, increase representation, and help them gain the right to recognition (Iarskai-Smirnova and Verbilovich, 2020). Liddiard (2018) argued that there is political value in considering how disabled people's desires are shaped by dis/ableism. To theorise about disabled people's sexual and intimate lives, listening to their lived experiences needs to be central (Liddiard, 2018). Disabled people have framed this as a disability justice issue, noting that they have a right to an intimate life (Ignagni et al., (2016). Ignagni et al. (2016) suggested that relationships and parenting should be reimagined in the context of disabled people.

Bahner (2021) highlighted some helpful guidance when applying sexual citizenship to practice, including determining whether the right to sexual expression is recognised in policy and if organisational structures are in place to make such policy happen in practice. Concerning sexual support, it is also helpful to consider whether the rights of the disabled person have been met and not just the rights of the support staff (Bahner, 2021). These considerations provided some guidance in how I would analyse the narratives in this study to gain an understanding of the sexual citizenship experiences of the researchers and why this is the case. This study will provide a space for people with intellectual disabilities to

come together and share their sexual citizenship experiences. In Chapter Nine (Discussions, Recommendations, and Contributions), I will delve into the concept of sexual citizenship concerning this study and link it to what was found through the stories told by the researchers.

1.8 Organisation of the thesis:

In Chapter Two, I will frame and position this work ontologically by taking a first-person inquiry, using the concepts of identity (Bauman, 2004), human development (Jacobs, 1986), dramaturgical theory (Goffman, 1959; 1963), and disability passing (Brune and Wilson, 2013). Using the auto-biographical approach (Usher, 1995; 1998; Coghlan and Brydon-Miller, 2014), I will tell my story by authentically displaying my biases and assumptions. During this process, I uncovered unexpected information about myself and my beliefs, which I will share.

In Chapter Three, I will analyse the literature to seek to understand relationships and sexuality in the lives of adults with intellectual disabilities from their perspectives and based on their experiences. I will explore the historical context, the influence of the Global Disability Movement, the social model of disability, and international and national legislation and policy. I will then focus on the present-day experiences of people with intellectual disabilities through the current literature.

Chapter Four, will focus on the methodological orientation and methods used for the design and data collection. I will discuss action research and the type used for this study, co-operative inquiry. I will then explain how we experienced the cycles of learning, reflection, and action on the project.

In Chapter five, I will explain the visual and creative research methods used for the data construction, analysis, and dissemination. These included art and drawing, participant poetry and rap, creative performance and practice, joint sandboxing, *LEGO*® *SERIOUS PLAY*®, and third objects. There will be a focus on the data analysis method we co-created as a research team and used to co-analyse our data together.

The findings are separated into Chapter Six: Sexual Health Education, Chapter Seven: Lack of Opportunities to Create and Maintain Relationships, and Chapter Eight: Perceptions.

This thesis ends in Chapter Nine, where I will discuss the findings through the lens of sexual citizenship (Plummer, 2003). I will then provide the recommendations we identified throughout this study. To end this thesis, I will put forward the contributions this work adds to the area of intellectual disability and sexual citizenship.

1.9: Conclusion:

The negative reaction from my MA study, the voice of the disabled co-researchers, and the literature on relationships and sexuality for people with intellectual disabilities all pointed to the fact that a study exploring the perceptions and experiences of people with intellectual disabilities needs to be undertaken in an Irish context. To generate such knowledge, I aimed to set up a co-operative inquiry group of people with intellectual disabilities to explore the topic of relationships and sexuality in their lives. My epistemological stance is constructivism, which led me to take a first-person inquiry. Self-reflective practice and paying attention to one's participation in the study is significant for action research. It was important to highlight my social justice, equity, rights, access, and participation values, as they have influenced how I approached and carried out this study. My ontological position of social constructivism may help us articulate and make sense of our experiences as a group. We may also be able to bring social justice and social constructivism together to work through the actions in the research to challenge any issues we identify. My understanding of disability has been influenced by my own experiences of disability and by the work of disabled academics who pioneered the social model of disability. I have explained how I distinguish between impairment and disability, focusing on the barriers experienced by disabled people and, where possible, working towards removing them. There are limitations in applying the social model of disability to people with intellectual disabilities lives, which I am aware of. However, I needed to be transparent about my understanding of disability. It was hoped that identifying external barriers in the researchers' lives would give us a better picture of why their experiences

happened. When these were barriers, we could work towards action and change. The theoretical lens of sexual citizenship that was chosen fits well with my ontological position and in action research, as the theory uses a social justice framework to analyse and challenge negative dominant discourse on relationships and sexuality that have been socially constructed as outside of the norm. Limited research has explored the sexual citizenship of disabled people, and even less has researched the experiences of people with intellectual disabilities specifically. Listening to the intimate stories of people with intellectual disabilities can help push political and social change and the claim for sexual citizenship in people with intellectual disabilities. This study will provide the space for people with intellectual disabilities to come together and share their experiences on this topic. The theoretical lens of sexual citizenship will work as a social justice tool to help us examine policy, organisational structure, practice, and societal attitudes that may influence the researcher's lives.

Chapter Two: Positionality Revealed Through First-person Inquiry.

2.1: Introduction:

This chapter sets out my positionality for this study. Researchers must frame and position their work ontologically as it adds richness and depth to the writing (Marshall, 2016). Thus, Herr and Anderson (2015) recommend that the researcher ask themselves who they are concerning their setting and participants. As Marshall (2001) describes it, deconstructing one's narrative with a critical eye. I decided to do this by undertaking a first-person inquiry, where I, as a researcher, took a reflexive approach to my participation in the research and learning (Marshall, 2016). I wrote myself into the study's account (Coghlan and Brydon-Miller, 2014) by displaying myself as a person behind the writing (Bosher, 2002). I will now present this reflexive writing. I will begin by exploring why I undertook a first-person inquiry and how I did it. Then, focusing on the concepts of identity (Bauman, 2004), human development (Jacobs, 1986), dramaturgical theory (Goffman, 1959), and disability passing (Brune and Wilson (2013), I will tell my story.

2.2 Why I undertook a first-person inquiry:

I undertook a first-person inquiry for several reasons. Firstly, researchers pursuing collaborative inquiry must engage in self-reflective practice where they self-question, as it opens opportunities to learn about themselves (Marshall, 2001). Marshall (2001) describes this self-reflective practice as engaging in and moving between the inner and outer arcs of attention. She explains that by paying attention to the inner arcs, the individual looks inward and pays attention to framing issues, meaning, and deciding to speak out. It is essential to be aware of key phrases, repetitions, patterns, and themes to be aware of one's assumptions. Paying attention to the outer arcs means reaching outside oneself and looking outwards, questioning or testing one's ideas, assumptions, and sense-making (Marshall, 2001). Secondly, first-person inquiry works well with my type of person: curious, continuously trying to make connections, and making sense of how things are created (Marshall, 1999).

Although who I am is not the reason to undertake a first-person inquiry, who I am influenced the inquiry. This research and my life are interconnected and inform each other (Marshall, 2016). For example, the reason I do disability research is due to my own experiences with disability, which will be delved into further in this chapter. Thirdly, the self is a key fieldwork tool, and the type of person the researcher allows themselves to be in the study can either shape or prohibit relationships with research participants (in this case, researchers), impacting how the study is conducted and what knowledge is generated (Reinharz, 1997). By bringing the most authentic self to the research, the researcher can be fully present and immerse themselves in the experience (Coughlan and Brydon-Miller, 2014). I am aware of potential power issues, so I am reflecting on my part and how this may affect my interactions, actions, and inactions with the researchers in the study (Marshall, 1999). The first-person approach is a form of moral inquiry, where the researcher decides to delve deep into what their identity is 'not just for me, but for us' (Coughlan and Brydon-Miller, 2014: p. 352). I wanted to do this for the benefit of the research team so I could collaborate in the best possible ways and produce good-quality research. Fourthly, a driving force in doing this research is my commitment to social change for people with intellectual disabilities. When researchers want to change a situation, they must engage with the values that are entangled and attached to them so they can consider their assumptions and be open to review and develop them through the inquiry (Marshall, 2016). As a result, it is the responsibility of a researcher involved in change-making to engage in self-reflection, where they engage in questioning assumptions, theories, and ways of knowing (Marshall, 2016). Doing first-person inquiry added to the quality (Marshall, 2016) and validity of this study, as it brought to the work my experiences and identity as a researcher and as a key player, showing what impact I had on the study's construction, participation, and outcomes (Coughlan and Brydon-Miller, 2014). I will discuss power dynamics and quality in Chapter Four (Methodology). This process enabled me to be more consciously aware of how my knowledge influenced how I approached the study, which, in turn, helped to improve my research practice (Parker, 1998; Boshier, 2002; Coughlan and Brydon-Miller, 2014). Awareness is important because action research aims to elicit knowledge to inform practice, which goes beyond its

epistemological purpose and points to a moral purpose (Coughlan and Brydon-Miller, 2014).

2.3 How I undertook a first-person inquiry:

Writing this chapter facilitated my self-discovery (Marshall, 2016) and enabled me to ascertain my relationship with the research topic (Richardson, 2000). This process took place by allowing my writing to unfold, at times uncensored, at other times aware of such censoring, but by telling my story with a purpose (Marshall, 2016). This emotional recollection and reflection resulted in more profound writing and brought me, as the researcher, into the experience as a subject (Coughlan and Brydon-Miller, 2014). I was a subject as I studied myself and my impact on this study (Coughlan and Brydon-Miller, 2014).

I did this by using an autobiographical approach (Usher, 1995; 1998; Coughlan and Brydon-Miller, 2014), in which I told 'the story of the self' (Usher, 1995: p. 178), for just as the present can influence the future, so can the past affect the present (Jacobs, 1986). To make connections between my different life experiences and to make sense of them, it seemed important to understand this past knowledge and to have the ability to apply it to my position as a researcher in this study (Jacobs, 1986). I reflected on past experiences that shaped my identity. Then I articulated this learning, critiquing my awareness, understanding, and judgment based on these experiences (Coughlin and Brydon-Miller, 2014), exploring what this meant to me and how this impacted the values that I held, and which informed my research practice (Parker, 1998).

The specific method I used to tell my story is called critical autobiography - where I self-narrated to reveal my identity, exploring how my reconstructions of the past have shaped the present (Jackson, 1990). Usher (1998) recommended doing this in a deconstructive form, which meant breaking the story down into smaller parts to understand how a story was created. Here, I provide my narrative with interwoven theoretical concepts of identity, contributing to my sense-making. These are set out below as human development theory, dramaturgical theory, and the concept of disability passing. These

concepts naturally evolved as the story unfolded because they were essential to my story and are the reason they were included here.

The reflection tool I used to guide me through this process was the '5 R Framework', a model of reflection created by Bain et al. (2002). I was drawn to this method as it allowed me to report past experiences and delve deeper, reflect on how I felt at the time, and then examine it again with a new lens, sometimes many years after these experiences had happened. This process also enabled me to use a theoretical lens to sense make, and then reconstruct by reflecting on how these experiences may impact this study. These five steps included,

Reporting – of the experience.

Responding – to feelings and thoughts after that experience.

Relating – this experience to the knowledge I now have.

Reasoning – about theory and factors to explain this experience.

Reconstructing – practice by making plans on how to act in future situations.

(Bain et al., 2022).

Bruner (1985) stated that this writing process is more than just a narrative; it is transformative. Through the demands of writing - through recalling and reinventing the past, I 'reconstructed the self by writing the self' (Usher, 1995: p. 178), 'which is unveiled in the telling of the story... a progressively unfolding journey of discovery' (Usher, 1998: p. 19). Usher (1995; 1998) argued that the knowledge and self-realisation that emerge from this process of reflection could become a valuable pedagogical resource that can benefit a project. For me, I developed a better understanding of disability identity and of sharing such personal stories, which the researchers will also engage in.

This study is a political, epistemological project where I challenged the notion of an objective, detached researcher (Marshall, 2016). The validity of autobiographical approaches is often questioned due to their authenticity as they come from one person's perspective (Usher, 1998; Coghlan and Brydon-Miller, 2014). I am clear that this is subjective and from my experience. As Marshall (2016) points out, descriptions of life narratives are provisional constructions of an individual's truth created through that person's interpretation impacted by many facets, such as cultural, interpersonal, and social influences. While most people develop with shared experiences, everyone grows

uniquely (Jacobs, 1986). As well as this, societal influences can shape an individual's understanding of themselves and others (Rosenwald and Ochberg, 1992). I was aware of these intersects between social influences and the personal (Marshall, 2016). Although this writing was based on memory and self-reflection, I ensured that I took on a dual role – telling my story but reviewing it by reflecting on alternative perspectives as to my actions while questioning these memories and interpretations (Marshall, 2016).

However, I felt unsettled about the place of such personal writing in academic work. I grappled with decisions on what I felt that I could share publicly, what was appropriate to the study, how I would write it, and how the account I wrote of myself would be perceived (DeVault, 1997), especially by other academics who do not include personal accounts in their work. As a result, I wrote my whole story, reflected on sharing it, re-drafted the writing, and then cut words that I felt were inappropriate for this purpose. As Marshall (2001) explains, making judgements about what needs to be focused on is part of the inquiry. If I told all my story, it would not make it more authentic (Marshall, 2016), and, as Marshall argued, researchers have the right to keep their boundaries, and sense-making can be more important than what happened. Marshall (2016) recommended not having to say it all but using the inquiry journey material to help write this story. The deleted words of earlier drafts served their purpose as they were reflections that taught me aspects about myself that I was unaware of prior to this. Reinharz (1997: p. 5) identified twenty different selves in the research field, grouping them into three categories: 'research-based self, the brought-self, and the situationally created self.' However, I did not know in advance which of these attributes would be meaningful to the researchers and the study because, at this point, I could not foresee how I would be perceived and understood and how this would impact the process until I was in it (Reinharz, 1997). Therefore, I needed to understand my different attributes, as Reinharz illustrated before this research process began.

In the final draft of this writing, I gave a brief overview of what I felt was the driving force behind my motivation to do this study and honed in on this. I will give a brief overview of what happened after this to bring my story to the present day to give a fuller picture because as my story changed and developed over time, so did I. The next step was to focus on the identities that I felt were the most influential in my life, and therefore to this study:

my identity as a mother; my social class identity, which involved a transition from disadvantaged to working to middle class; and my disability identity, which came to consciousness during this writing. An important finding emerged during this writing when I discovered that I had conflicting views about disability. To make sense of this, I studied the literature on identity, human development, dramaturgical theory, and disability passing because these were some driving forces that caused the ambivalence in my perspectives. Here, I focused on philosophical, sociological, and psychological literature, including the classical and contemporary work of well-known thinkers such as Bauman (2001; 2004), Bruner (1985), Goffman (1959; 1963), Jacobs (1986) and Rousseau (1964), which all helped me to think and work out where I stood critically.

Before I delve into the narrative of my search for identity, I first define what identity is and set out where intersectionality fits into this while providing a rationale as to why the benefits of searching for an identity outweighed the perceived risks of such exposure, such as judgement, that may evolve for me a consequence of my searching.

2.4: Defining identity:

Identity is 'the interaction between how an individual experiences the world subjectively and the cultural and historical framework, both of which influence the subjective experience' (Dencik, 2001: p. 193). This definition means that interactions in our social world can influence our identity. True social identity encompasses structural traits, such as occupational roles, and personal characteristics, such as kind-heartedness (Goffman, 1963). It has been suggested that identity should be seen as continuously changing, transforming, and redefining ourselves (Hall, 1996; Bauman, 2004). People tend to impose normative assumptions of identity on others and are usually unaware they are doing so (Goffman, 1963). These assumptions may lead to stigma. Goffman (1963) describes stigma as when an individual's status has been exposed as different and wrong, and as a result, they are unaccepted by others.

Various intersectional elements make up my identity; some have led to privileged outcomes, and others have been experienced as oppressive. My experiences and identity

have shaped who I am and my value system, which has influenced my ontological views of social constructivism (as explored in Chapter One: Introduction) and my contribution to this research. Therefore, I have discussed these intersectional identities in the following sections while explaining how they may have influenced the research. Intersectionality is a political commitment to viewing how gender, race (Crenshaw, 1989), and other intersecting inequalities interact and shape life experiences (Kabeer, 2016); these include class, age, sexuality, and disability (Collins and Bilge, 2016). These socially constructed identities can provide for or hinder opportunities in people's lives (Collins and Bilge, 2016). Our intersectional social groupings determine a particular cultural understanding of what is seen as an appropriate way to conduct ourselves (Goffman, 1959). My prominent intersectional identities are disability and social class, as these are the areas where I experience being treated most differently.

2.5: Searching for my identity:

Soul-searching is usually only prompted when our identity is questioned (Bauman, 2004). I have questioned my own identity for many years, but, more impactfully, others have questioned my identity – mainly at times when they identified me to be different from them, not adhering to their socially constructed ideals of the role that they think that I should play, and my location in a place where they felt I probably do not belong. As Goffman (1959) proposed, people assume a specific type of individual will be in a particular social setting. For example, someone from a council estate like me would not be assumed to be a university lecturer compared to a middle-class individual.

Bauman (2004) refers to identity in terms of belonging. Identity-seeking is more appealing to those who do not feel they belong. However, individuals can be desperate to find a 'we' group of individuals with a similar identity to which they belong (Bauman, 2004). Belonging is something that, on the one hand, I have dreamt of and, on the other, rebelled against; I will delve into this later in the chapter. Bauman (2004) also suggests that identity and belonging are not a lifelong guarantee but are 'negotiable and revocable,' which I am aware of given my experiences of changing who I was, moving from a disadvantaged background to academia. Although I have changed, fitting into either place has been

difficult. For example, I no longer fit into the council estate life, but I have sometimes felt like an imposter in academia.

Seeking answers to identity problems can be risky and may end up as a curse (Bauman, 2004) because trying to understand the past can result in painful insights (Jacobs, 1986). Painful insights are something I can relate to, as this level of digging has been psychologically and emotionally demanding; I have started to question almost everything! The more I questioned, the more I soul-searched, and the more realisation I had that inequality and issues of social justice wrongly dominated many of my life experiences. I have also discovered my flaws and wrongdoings, which are difficult to own up to. Despite this risk, it was still necessary to pursue. Due to the nature of the research, the researchers would be sharing personal stories that may uncover personal experiences of inequality, social injustice, feelings of a lack of belonging, and what they may identify as personal flaws. They may decide to deconstruct and reconstruct their own identity. Experiencing this myself through this process may help me better understand and support the researchers in this study.

Despite these concerns, identity-seeking carries an essential risk that must be faced if one is to uncover and reconstruct one's identity (Bauman, 2004). Jacobs (1986) advocated renegotiating the past by re-living it in the present, suggesting it might provide a better future. For this to happen, discussing our identities and how they are moulded, even ready-made (Bauman, 2004) is necessary. Dencik (2001) argues that we can only see others in one way at a time, which depends on the context. How we view others and ourselves depends on who is deciding how the individual is being perceived, whether the person has the same or a differing opinion, and based on the comparisons we make to judge our identity against others. These perceptions are all based on how we experience the world and how history and culture have shaped those experiences (Dencik, 2001).

2.6: My building blocks:

When exploring human development, life stages, and experiences in a person's development, Jacobs (1986) gives the analogy of wooden building blocks. If each block is

placed securely on the one before it, there is a strong foundation and stable growth. If the blocks are not placed securely, the structure grows weak; if there are stressors further along, the structure collapses, leaving only the initial blocks. This results in a small structure, where the initial stable blocks stand but is a place to begin re-building. I decided to break up my story to show each block and how it impacted my present identity, giving an insight into how I see the world. This telling showed my thoughts and emotions (Jacobs, 1986), which will be set out as my story unfolds. I also set out to look at my story objectively so I could begin re-building, which I found helped to make better sense of my identity. I need to be clear that, even though I have had experiences of uncertainty, insecurity, social and economic deprivation, and lacked agency and voice (having self-pitied for far too long, which may not be evident here on the other side), I am now focussing on my strengths and using my experiences to drive change (Standing, 2016) and this is why I am drawn to action research. My partner told me that if my life were a movie, he would be unable to watch it as it would be too sad. My story has many traumas (not all discussed in this chapter), but I believe that although my life is not perfect, it does have a happy ending. These traumatic bumps along the way have been the ingredients that have moulded me to be who I am today.

2.7: This is me:

To get to the core of my identity, I needed to answer the question, 'Who am I?' (Bauman, 2004). An individual's identity depends on past and present social positions (Wetherell, 1997). As a result, I will begin with the start of my journey and work through it to the present day, highlighting the main influences.

I came from a disadvantaged background (what some may call working class, but my parents did not work). In my primary school years, I grew up in a disadvantaged council estate in Leeds, England, where my parents were long-term unemployed and survived on benefits; I had a childhood of social, economic, and cultural disadvantage. Despite this, I have happy memories of the estate, school, dance school, friends, family, and extended family.

In the early 1990s (when I was 11), my family moved to a rural village in Galway, Ireland, for a better life. The village was a predominantly white Catholic community where, at the time, English people were not readily accepted by many, and my parents remained unemployed. My teenage life was constrained by issues arising from my disadvantaged background, such as parental alcoholism (both parents). Added to these challenges were negative educational experiences, general unhappiness, and not feeling that I fit into the village, leading me to leave home and school at 15. I gained employment in a chicken factory, moving into my apartment.

A few years later, during a spell of unemployment, I decided to return to education but was told that I would lose my benefits if I went back to school, meaning that I would not have any income to survive. Luckily, I found out about Youthreach (a centre for early school leavers), which provided financial support to attend. However, when I was studying, I became pregnant as a teenager, only months into a new relationship. My baby was born with Rhesus Disease, resulting in severe intellectual disability, oxygen dependency, blindness, and epilepsy. I was told he would live to his late teens, but after spending his time in and out of hospital, he died almost a year later.

This experience was the driving force behind my motivation and passion for disability studies. During his short life, I got to see, from a mother's perspective, how difficult it was to live with a disability, particularly concerning access issues, lack of resources, negative societal attitudes, and barriers. One day, before my son died and knowing that our experiences were wrong, I promised him that I would somehow make a change for people with disabilities, and when he died, I decided I would stick to this promise. I believed this change had to be led by people with intellectual disabilities as these were their lives. However, I wanted to change peoples' negative attitudes towards disability and to remove barriers so that people with intellectual disabilities would be treated equally.

As a young woman, I had a lot to cope with, so I pursued the quest to fulfil my promise, working around the clock to keep my mind occupied. I thought a good way to start my journey in fulfilling this promise to my son would be to contact a disability organisation to ask how I could gain employment in the area. The organisation offered me two weeks'

voluntary work on a summer camp for young disabled people, which soon led to employment. I worked there for two years and took on various roles simultaneously: Special Needs preschool Assistant, In-home Support Worker for families with disabled child/ren, Speech and Language Therapy Assistant in a school for disabled children, and a Residential Care Worker in a community home for disabled adults.

Even though I loved this work and learned a lot from it, I knew that as an early school leaver without formal qualifications, I could not move up the career ladder and have the power to make a change. The best next step would be to go to university and gain qualifications. For most of my early to mid-20s, I lived off benefits and in council housing, but luckily managed to get back into the education system, first in evening classes where I studied childcare, and community development and leadership.

I was lucky that, in the early 2000s, Ireland was going through an economic boom, the Celtic Tiger, and there was much financial support for those seeking higher education. Amidst the chaos, I entered full-time higher education to study Social Care Practice, which changed my life. When I was in the second year of my degree, completing a teaching placement in a training centre, I decided that I would become a lecturer; here, I could teach hundreds of students best practices in the disability studies field and, even if only one student each semester went out and made a change within the disability sector, they could do a lot more than I alone. To make this happen, I studied training and education part-time at another university while finishing my social care practice degree. Furthermore, during this time, I gained my first part-time teaching job (teaching special needs assistants) at a private college.

During my university experience, I realised that 'changing the world' may be too optimistic, although I did not completely lose faith. I knew I could make a change, but returning to the sector would not be enough. I sought a supervisor as passionate as me, and I completed the research master's degree, which I discussed in Chapter One (Introduction). I worked with 23 young people aged between 12-25 years with various disabilities in which we undertook research together on their recreation and leisure experiences and perspectives using participatory action research. We did experience

some minor changes for individuals in the group. For example, in one research session, we had, in small groups, they made collages about what it was like to be a young person, and when they were discussing these in the larger group, they began to talk about higher education. I asked the group who would like to go to university, and the room went silent. I asked again, and there was still no movement. So, I probed the group to ask why no one was responding. One by one, the group started to agree that no one had ever asked them this before and did not know it was a choice for them. I repeated the question and told them I was asking them, and three young people raised their hands. I gave the three individuals some information about how they could start this journey. A few years passed, two of the young people completed further education courses, and one graduated with a university degree. This action and similar experiences in this study made me believe that knowledge and research can be powerful and facilitate change. As Karl Marx famously stated (and it was engraved on his headstone): 'The philosophers have only interpreted the world in various ways – The point, however, is to change it' (cited in Taiwo, 2021).

This education developed me personally as well as academically. By the time I was in my late 20s, I had gained a full-time Social Care Practice lecturing position at the university where I had studied my degrees in social care practice, where I eventually got to teach Disability Studies, my dream job. I began this PhD at Trinity College Dublin part-time and later gained casual employment there, lecturing students with intellectual disabilities about disability rights, relationships, and sexuality and teaching undergraduate nurses about relationships and sexuality for people with intellectual disabilities. During this time, I also completed a Postgraduate Certificate in Teaching, Learning, and Assessment and a Postgraduate module in Sexual Consent Promotion.

All these intersectional parts of my identity led to negative attitudes towards me, sometimes from myself but, more often, from others, which resulted in a lack of equity. These became barriers to me being able to change my status. However, I did manage to enact change in my life. I worked for years as a Social Care Practitioner, studied in four universities, obtained eight qualifications up to the master's level, and later became a lecturer in three universities. When I was in my late 30s, I had another son with my current partner, and luckily, after a worrying pregnancy and a rocky start in life, he is doing well

five years later. I have a fantastic partner and son. I have a lovely home. After 31 years living in Ireland and 14 years in academia, I have moved back to England and gained a Health, Social Care, and Social Work lecturing position, where I am researching in a learning disability research cluster at Manchester Metropolitan University. I actively research through publications and conference presentations, and I am a peer reviewer for academic journals. This life is a dream come true and a very different path from the one I started on. I am very aware of my current privileged position.

I began by saying that it may be risky to share my personal story. However, it is central to who I am and why I pursued this inquiry, so I needed to tell it. It is essential to highlight that I could not be where I am today in my life without the experiences I have had. It is also vital to point out that these experiences have impacted how I see and be in the world. I have learned that those from privileged backgrounds often negatively judge people who are different and from minority groups. I realise that often, the only way to get over this barrier is by being incredibly resilient and having the ability to fight against it, which should not be the case. I have learned that life can be very unfair on some more than others, with minority groups hit the hardest regarding discrimination, trauma, and disadvantage. I understand that people with intellectual disabilities do not usually have agency and voice, but they should. I have realised that many people with intellectual disabilities live with barriers and inequality; not enough has been done to change this. However, I have learned of the power of education in achieving change and transformation, both at an individual level and in broader society. I have experienced injustice but have learned how to access the resources I need to tackle disadvantage. Because of my experiences, I want to be able to help others who experience similar or worse injustices in their lives. I set out to make a change for people with intellectual disabilities, and I may not ever do that, but somehow, despite all the challenges, I have changed my life in the process, going to places I never imagined. I have gone from living with disadvantage, addiction, and early school leaving, with lots of loss and trauma along the way, to being a highly educated woman with a respected profession and a loving family - who just wants to change some of the injustices in the world.

2.8: The show must go on:

A perspective I have always taken was that no matter what happens, ‘the show must go on’, so when I read the work of Goffman (1959) and his dramaturgical theory, I found looking at the world as a stage relatable. I had grown up in dance and theatre school, spending most of my younger years on a stage; in my adult years, I won a scholarship for a drama school, acted in a monologue play, and had a small part in a movie, later becoming a lecturer, which comes with its audience and performance. Goffman asserts that we wear masks depending on the social context and, where I do rebel against the pretence of pretending to be somebody I am not to fit in, on reflection, I sometimes do this unknowingly. I also wear a mask to hide the many traumas I have faced and hidden parts of who I am to avoid stigma and shame. Goffman’s dramaturgical theory concludes that society shapes who we are, as we can never truly be ourselves around others. As Shakespeare wrote in his play *As You Like It*:

All the world’s a stage,
And all the men and women merely players;
They have their exits and their entrances,
And one man in his time plays many parts.

(Shakespeare, 2.7., 139-142).

If we always wear masks, we may never find our identity. Maybe the only way to truly get to know ourselves is by isolating ourselves from others for some time. While writing this chapter, I spent most of the ten months isolated from others due to Covid restrictions. During that time, I read different theoretical perspectives on identity, reflecting on my life story, re-reading and re-writing drafts while questioning everything and trying to read between the lines.

For years, I considered maybe I had ADHD but brushed it off. However, when I re-read earlier drafts of this writing, certain aspects of explaining myself jumped out, and I began to question it seriously. I also struggled much more as I worked from home with the pandemic regulations. First, I could block everything out and hyper-focus (an ADHD symptom unbeknown to me then) on reading and writing for this chapter, which I felt was incredible. I was not distracted by the outside world, but then I looked up and realised

that I was behind on all my work and home deadlines, so I had to leave working on this chapter, falling behind in everything and becoming overwhelmed. It became difficult to listen and concentrate during online lectures and meetings. I noticed I was often interrupting others when they tried to speak and spoke very loudly. Concentrating was a real challenge; I could not sit still at the desk, and I began to zone out much more than usual when people spoke to me.

While all this was happening, while reflecting on my identity, I came across an article about women over 30 who had undiagnosed ADHD. This article brought me to a self-test where I scored extremely high. I booked an assessment with a clinical educational psychologist (which I cancelled as I believed I was reading too much into it). However, after one cancelled appointment and finally going through with it - I was diagnosed with combined (inattentive and hyperactive) ADHD and, later, sensory processing disorder. A range of emotions came with the ADHD diagnosis. First, I was happy; I found the missing jigsaw piece: everything made sense. I was not stupid (something I often thought due to my struggles and how everything seemed more challenging for me to accomplish in comparison to others); it was out of my control, and maybe I could now get support so that I could work on an equal footing to those who are not faced with these challenges and make my life easier. Many positive personality traits are attached to people with ADHD; maybe this is where my quirky, passionate, and creative side originated. Then I felt disappointed and annoyed that it took 40 years for this to be recognised. I have struggled in education for many years, possibly contributing to my early school leaving. I have always found learning challenging, struggling with passive didactic teaching and learning methods, repeatedly re-reading to process information when trying to learn alone, and facing many challenges with writing. Everything seems more complex; it takes longer, with much more effort. I also struggled with everyday activities that everyone else seemed to be able to do easily. Nevertheless, I felt proud that I had this vast challenge I was unaware of; on top of all my other challenges, I still got to where I am today.

Then I was faced with whether I would come out of the ADHD closet and tell people, but I remembered the stigma attached to ADHD. Many people believe it is either something boys get and grow out of, or it is not even real, and it is down to bad parenting. When I

disclosed the diagnosis to people close to me, the general reaction was either of them discounting it as untrue, making a joke, or doing both. It made me question who I was, as many of my personality traits could be attached to my ADHD. This questioning also pushed me to reflect on my belief set about disability identity, which I will delve into below.

2.9: Disability passing:

In the past, I have hidden parts of my identity that I felt were flaws, and now I am grappling with my new ADHD diagnosis. To avoid stigma, people often conceal parts of their identity that others may see as a shortcoming (Goffman, 1963). There was a risk that this label could afford me rights and privileges from those more powerful - those who define the parameters of normality (Brune and Wilson, 2013). Disability is usually associated with helplessness and dependency (Brune and Wilson, 2013).

Reflecting, I did not want to be defined by my impairments, particularly after winning a battle of identities and changing my social status. As Jacobs (1986: p. 22) points out, '... some people can become metaphorically, if not literally, imprisoned by a label...'. According to Brune and Wilson (2013), hiding impairment to avoid stigma to fit in with the mainstream is known as disability passing. Identifying as a disabled or non-disabled person will have different meanings for different people, depending on the intersectional context (Brune and Wilson, 2013). Nevertheless, I felt like a fake, a fraudster, a cheat – on one hand, I was advocating for disability rights and associating disability with pride. However, I was concealing my impairments with shame of difference and fear of stigma. Brune and Wilson (2013) are against blaming others for passing due to the psychological toll of re-writing one's identity and the stigma one may experience.

Despite this, I still battled with guilt. While knowing that I would never view a disabled person negatively, I did not want more labels added to my already existing numerous stigmatised identities. I was concerned about the risk of losing my new identity (academic middle-class woman) and the fear of not being able to reach the future identity (where I would excel in my career further) that I worked so hard for and dreamt so longingly about, as others may view me negatively and as incompetent. Most disabled people must decide

whether to conceal or draw attention to their impairment. They may also need to decide what to do when others ignore it. Decisions on disability identity are based on pride or stigma, rooted in society's social, political, and cultural spheres (Brune and Wilson, 2013). Individuals can be ashamed to show their entire self if they believe others will perceive them negatively (Goffman, 1959). However, here I was, a disability researcher and activist, going through my journey and experiencing conflicting feelings towards what I thought were my beliefs. As much as I always try to stand out and be different, deep down, I wanted to belong. However, this conflicted with how I defined disability (as discussed in Chapter One: Introduction). I reflected on this and understood that I do define disability and impairment the same as I always did. However, things are not always as simple as that when living it, and social constructivism was critical here, as I was not ashamed of having a disability. However, I was concerned that others would treat me negatively. It made me realise that I would need to consider how the researchers experienced and felt towards their disability as it may impact their situation. It is important to note that although I will be an outsider (Herr and Anderson, 2015) in the co-operative inquiry group (I do not have an intellectual disability), having a neurodevelopmental disability, I feel that may bring the group and I somewhat closer, as I have some small understanding of experiencing disability and have something in common with the group.

Here is where I reflected on ADHD. The name itself includes the word deficits, deficits in attention, and hyperactivity - a disorder of the mind. However, I did not have a deficit in attention when I was interested (this is called situation variability); in fact, I can hyperfocus for extreme lengths of time, which results in being extremely productive (which is where my hyperactivity positively shone). Unfortunately, the label ADHD is riddled with misconceptions. The challenges of ADHD relate to executive functioning; in initiating tasks and sustaining attention, self-regulation can be difficult; for example, regulating emotions, behaviours, alertness, processing speed, and working memory can be challenging (Brown, 2013). The name ADHD does not include all the positive traits. Weiss (2005) devised a list of 29 positive traits attributed to people with ADHD, but the generalised perception of the disorder is negative, something I began to relate to. Orange (2016: p. 207) argued against the medical model, focusing on the illness, and instead viewing ADHD as something that makes a person who they are:

‘It’s what you are. It goes right to the core of how you think and how you perceive the world. If you are an adult, this is how you have always thought and perceived the world. All of your values, all of your ideas, all of your interests, everything about you’.

Unfortunately, not everyone views ADHD in this way. At the time, I believed that it was more likely that if I defined myself as disabled, I would be defined by my deficits and not by all the fantastic traits that I have as a result. Such difference often leads to exclusion, and the threat of this makes belonging so appealing (Bauman, 2004).

2.10: Masking:

Every individual is always playing a role, wearing a mask (Dale, 1941) – this mask is the role we strive for and our idea of ourselves (Park, 1950). When I started working in academia, I uncomfortably wore smart clothes (my lecturer prop – Goffman, 1959), I attended dinner parties (for the first time where I was not the waitress), ate food, and drank drinks that I had never tasted before or even heard of (and I could not pronounce their names). I had conversations I did not understand (from their content and vocabulary). I travelled to foreign countries for the first time. I presented at conferences. This life was a new world, and I concealed parts of myself, trying to be someone I was not. People tend to downplay or hide parts of who they are that conflict with the ideal version of themselves (Goffman, 1959). However, then I realised that some of my colleagues were faking accents to fit in, which, to my surprise, brought me to the realisation that maybe many of us were faking it. As Goffman (1959) claims, individuals play a part they put on a show, and the reason for such a performance is to be taken seriously by others, believing that they are that person. It seemed that we were performing to fit into something that did not exist, as we were faking it to be like each other’s fake selves. Then, during a conference dinner party to which I had invited my partner, it just felt so pretentious; all conversations were based on status, so when my unemployed partner was asked during a round table conversation what he did for a living, he lied. He felt awkward and said he would never attend these dinner parties again. These situations made me realise that I would rather not have this life if I had to fake it; being insincere felt so wrong, so I decided to be myself.

We may not believe in certain behaviours but play them to please others (Goffman, 1959). On the other hand, we may also despise conformity because we have our own set of beliefs and our way of living (Bauman, 2004). This ambivalence leaves us with an internal conflict (Connell, 1987). When we do not conform, we may be excluded from the community we wish to be part of (Dencik, 2001). When I deviated from the expected norm, this resulted in unacceptance from others and sometimes not being taken seriously in my professional role. I am indiscreet and often refuse to act a fake version of myself as it feels inauthentic and goes against my values and who I am.

However, I play what Goffman (1959) calls a front stage – an act for others to see that I am playing my part. Yes, at times, there are inadvertent clips of the backstage where contradictions show themselves (Goffman, 1959). My costume, which should be front stage (professional), is usually backstage (alternative), as is my backstage (authentic) accent instead of my front stage (fake) voice. When you are different, it can be seen as a violation (Goffman, 1956). Academia can be referred to as what Goffman (1959) called a backstage controlled profession (Goffman, 1959). Moving between the class, different audiences, moving from one stage to the next, front, and back, with the staging of props. However, this does not feel right to me, so I speak in my dialect and insist on being called by my nickname, and there is much less formality than expected. Those from working-class backgrounds are more used to spending their days backstage, whereas higher classes are the opposite (Goffman, 1959).

I lack this acting experience. Most working-class individuals perform their working roles backstage (Goffman, 1959). I used to spend most of my life in the backstage, but now the front stage dominates. When these two worlds come together, which character to play can be unknown, resulting in a diminished dramaturgical effect (Goffman, 1959: p. 137).

Sometimes, individuals do not have a choice to truly develop a new identity, as their old and new worlds may be so far apart that there may be too many contradictions (Wetherell, 1997). If they try to change, they need the past narrative to engage in dialogue to hold this position (Wetherell, 1997). Having a disability or coming from a working-class background may mean being constrained by the material and social situation (Wetherell,

1997). There may be a conflict between our home and social lives, which, in my case, are two different social classes. Social identity is not homogenous as is often implied, and we may have a mix of positions that do not fit together (Wetherell, 1997), such as my working- and middle-class identities or my academic position and ADHD.

So, with all this experience of masking or resisting masking and experiencing exclusion, I now needed to decide whether I would discard another mask and show the real me - the ADHD me. For far too long, I have worn a mask to hide the imposter, the working-class unintelligent woman who somehow accidentally got in and no one has noticed yet, but recently, that mask has been discarded, and what I see behind that mask is an intelligent newly middle-class academic woman who had just been struggling with un-diagnosed ADHD.

2.11: Growing and changing over time:

Rousseau (1964) argues that self-transformation is our only common feature. Self-identification needs to be repeatedly performed, yet because it is ever-changing, this is only partially accomplished (Bauman, 2004). Bauman (2001) argued that it may be more relevant to talk about identification – whereby through obligation or luxury, we are engaged in a never-ending process of constructing our identities.

I naturally changed as I became educated and had more opportunities to do things that a person from a disadvantaged or working-class background ordinarily could not do. I became cultured, my vocabulary widened, and the conversations I had were more educated and more profound; I grew, and although my mask changed, I did not lose sight of where I came from and who I was. This change rippled into my personal life, where I moved to a middle-class area (at least until the cost-of-living crisis hit) and lived so much more comfortably. More importantly, this rippled into my role in the research team; I wanted to be authentic, which I felt would help the development of the group so the researchers would feel relaxed to speak out, make decisions, and be who they wanted to be and to take ownership of the research team.

2.12: Conclusion:

I used the critical auto-biographical approach (Usher, 1995; 1998; Coghlan and Brydon-Miller, 2014) to tell my life story. Through telling this story, I tried to make meaning of it by breaking it into its main parts and studying identity literature. From this, I found that my experiences and identity were not solely because of growing up disadvantaged and in a dysfunctional alcoholic home, as I previously believed, but undiagnosed ADHD also played its part. The writing of this chapter was hugely powerful and transformative as it helped me to understand myself better. Also, through this process, I could see my personal agenda and biases (from my experiences) and how, because of this, I may influence the study's construction, development, participation, and outcomes (it will be collaborative, but I will play a role in this). Cultivating self-awareness is critical for action researchers, and one of the reasons for me is that I am honest about my bias and am aware of my actions, so this bias does not influence the study. Being aware at this level brought many benefits to this study (which are explored in Chapter Nine: Discussions, Recommendations, and Contributions).

The most surprising aspect that unfolded from this writing was my ADHD diagnosis, my disability passing, and my conflicting attitudes toward disability. As a result, I needed to explore why this was the case, and when considering the concept of belonging, I found that this was more important to me than I let myself believe it was and that I was concerned about further exclusion. Because I experienced a class transition and entered a whole new world while holding tight to my old one, I lived in an ambivalent state with conflicting views of my world. I realised that I wore masks, where I previously believed that I resisted this, and it made me more aware of how I have grown and changed over time. I needed to decide whether to come out of the ADHD closet and what impact this would have on the study. I spoke to one of the two critical friends' groups for advice on this topic (a group of experts in action research who advise the researcher, in this case, disabled disability studies academics, which is explored in greater depth in Chapter four: Methodology. They asked me to reflect on why I would or would not disclose my disability to the group and what impact either decision may have on the researchers. I delved deep and knew I had to be authentic; as a disabled disability activist and disability studies

researcher and lecturer, I could not hide my disability identity in shame. I had an onus to come out to the world and be proud. I decided to do this in true 'Jess style' and be creative. I wrote a poem that reflected my true feelings and submitted it to a poetry event that was creating awareness of neurodivergence, and to which it was accepted (Figure 1).

The Finale

By Jessica Mannion Twitter: @jess_mannion

Ladies and gentlemen, boys and girls, the show is about to start,
for your pleasure on front stage, let me check the chart,

Playing the expected socially constructed role, at your mercy,
Our leading actress, please, take a curtsy.

Wearing her mask, she will abandon her desires,

This fake, fraudster, cheat is a woman who conspires.
So over to you, the stage is all yours to reclaim,
don't slip, keep your audience entertained.

Thank you for such a warm introduction,
I am ready to mould, negotiate; undergo reconstruction.
This mask, I use to cover up each and every flaw,
it's my magic prop to prevent me drawing the short straw.
It hides all of my traumas and my true identity,
to avoid shame and stigma, and keep some integrity.
Even though this mask is emotionally demanding,
the show must go on, to avoid any misunderstanding.

She is hiding her deficits, her disorder of the mind,
restlessness, inattentiveness and distracted combined.
She struggles with learning, immature, impatient and impulsive,
zones out, too loud, too fast, interrupts and compulsive.
Can't sit still, hyperactive, with a racing brain,
A peculiar character, that's hard to explain.
Seeking recognition from others, to belong,
yet defiantly resisting, despising conformity... ITS WRONG!

But...

I have the ability to hyper-focus with non-linear thinking,
that's the tip of the iceberg, my ship is not sinking.
Not constrained by conformity, outside of the box thinker,
driven for self-fulfillment, a positive risk taker.
Brave, inspiring, resilient, inclusive, authentic,
Intelligent, fun, empathetic, a real romantic.
Quirky, entertaining, humorous, creative,
with passionate vision, truly innovative.

She wants to bring all of 'me' to the surface,
but then risks losing her life's purpose.
Do you really think you will win the identity battle?
Inequality, suffering, never fitting in, all of this - dismantle?
Is a menu for loneliness, rejection, abandonment and exclusion,
Is telling people this prosecution, really a solution?

The power of a label can literally imprison,
people focus on the misconceptions of your condition.

I am so desperate to fit in and find a 'we',
NO! I'm not, I despise it! I rebel, I disagree.
You've given me two voices, one with low self-esteem,
but I'm pushing that off stage, I just want to be me.

I'm closing the curtain, it's the finale, taking a bow – I AM FREE!
I am a Mother, a partner, a student, an educator, working class,
I am removing this final mask,
And I am showing all of you,
that I have A-D-H-D.

Figure 1: Coming out poem: The Finale, by Jess Mannion.

Then, I was invited to contribute to an editorial on neurodivergent identities about my experiences of being neurodivergent in an academic world from the perspectives of an established and early-career academic and the impact of such disclosure (Sheerin and Mannion, 2021). These steps played an essential part in this journey.

I learned more about ADHD by studying ADHD coaching at the ADD Coaching Academy in New York, doing neurodiversity training at work and changing how I teach as a result, seeing an ADHD coach and publishing a book chapter on my experiences of ADHD and writing (Mannion, 2024). When I got my diagnosis and was looking to see if I had sensory processing disorder, the psychiatrist and occupational therapist asked if I wanted more labels. They did not understand my perspective that it would be beneficial to understand myself better and how I did not see disability as bad but as different. At this point, I started to see neurodivergence more positively as I could do so many amazing things, things that neurotypical people cannot do. However, because we are in the minority, we are seen as the issue, and the world is not made for us, leaving us with barriers and making us disabled.

What I do know is that, due to my disability and class intersectional identities, I have lacked voice and agency in the past, but this has now changed, and I have been privileged to be able to change my situation. Now, I want to open a platform where others can have

this opportunity to speak and to be heard; then, together, we can act and possibly make a change.

Some of the concepts addressed in this chapter were relevant to the stories of the researchers and are explored in Chapter Nine: Discussions, Recommendations and Contributions. However, next, I will focus on the literature on relationships and sexuality for people with intellectual disabilities, which informed this study.

Chapter Three: Literature Review.

3.1: Introduction:

This literature review sought to understand relationships and sexuality in the lives of adults with intellectual disabilities from their perspectives and based on their experiences. As such, this review mainly drew on the work of Irish and international qualitative studies on relationships and sexuality topics, undertaken with adult participants with mild or moderate intellectual disabilities and, where available, collaborative studies with co-researchers with intellectual disabilities. This is because this PhD study focused on the perspectives and experiences of people with mild and moderate intellectual disabilities regarding relationships and sexuality using collaborative methods. I was concerned with the voice of the experts (people with intellectual disabilities) who had lived experience of relationships and sexuality and not of the opinions of other stakeholders who too often control the intimate and sexual lives of people with intellectual disabilities, such as professionals and families, and as explored later in this chapter. In Ireland, there is a lack of collaborative research on relationships and sexuality in people with intellectual disabilities from their perspectives.

Although this literature review is not a systematic review, I did employ a systematic search strategy (see Appendix 1). The concepts used were 'Intellectual Disability', 'Relationships/sexuality', and 'Qualitative and Co-produced research methodologies'. (See Appendix 1 for the search terms used for each database). The databases searched included 'Medline', 'EMBASE', 'CINAHL', 'PsycINFO', 'Web of Science', 'ASSIA+', 'EBSCO' and 'ProQuest'. The references were extracted to the systematic review tool Covidence for screening, first through a title and abstract screening and then a full-text review. The inclusion/ exclusion criteria ensured that only the studies with the following criteria were included.

Research:

- On relationships and sexuality topics.
- With people with mild or moderate intellectual disabilities.
- From people with intellectual disabilities perspectives.

- Published between 2013-2023.
- That used a qualitative method.

This inclusion/ exclusion criteria resulted in 59 studies for inclusion in this literature review.

When it was essential to gain statistics to create a bigger picture of how common something was, for example, comparing a topic on the lives of people with intellectual disabilities to non-disabled people, then quantitative studies were drawn upon, but this was minimal.

To provide an understanding of the relationships and sexuality status of people with intellectual disabilities, this chapter begins with a brief historical context, drawing on older literature. This context includes the influence of societal attitudes, the global disability movement, and the impact of legislation and policy on relationships and sexuality in people with intellectual disabilities' lives. There is also a discussion on the tension between caregivers empowering people with intellectual disabilities and sexuality while safeguarding them from abuse and exploitation.

After this brief history, the remaining themes will focus on the current status of relationships and sexuality for people with intellectual disabilities and from their perspective. This discussion will begin with people with intellectual disabilities' perspectives on love and sex. The discussion will then move on to the types of support from caregivers that people with intellectual disabilities find beneficial to have relationships and the benefits of these relationships. Next, there will be a focus on the lack of support from caregivers to have relationships, why this may happen, and the impact of this. The barriers to creating and maintaining relationships will be examined. Another theme will focus on sexual health education for people with intellectual disabilities, including the benefits, barriers, and effects of a lack of sexual health education, a comparison of sexual health knowledge between people with intellectual disabilities and non-disabled people, formal and informal types of learning, and the content and teaching methods of these programmes. The theme of sexual diversity will focus on the experiences of people with intellectual disabilities who are LGBTQ+. The

range of experiences of sexual health promotion for people with intellectual disabilities will be set out, focusing on pregnancy and parenting and the impact of these experiences.

3.2: Historical context of relationships and sexuality for people with intellectual disabilities:

Sexuality is culturally and socially determined and dependent on influences such as societal attitudes, religion, culture, policy, and legislation, which can all impact the individuals' experiences of sexuality (Bahner, 2013). This theme will explore how some of these factors have influenced the sexual status of people with intellectual disabilities historically to the present day.

The literature suggests societal attitudes have impacted people with intellectual disabilities' relationships and sexual experiences. Historically, stereotypes attached to disabled people regarding relationships and sexuality stripped away their sexual agency (Liddiard, 2018). Stereotypes included them being viewed by many as passive, innocent, exploited, abused (Liddiard, 2018), overly dependent (Rogers, 2010), an eternal child (Goyal, 2017), in need of protection (Yau et al., 2009), vulnerable, a sexual risk to themselves (Rushbrooke et al., 2014), asexual, and sexually inactive (Kulick and Rydstrom, 2015). Furthermore, they were also viewed by many as a risk to others (Lumley and Scotti, 2001), engaged in sexual behaviours that were abnormal and maladjusted (Rojas et al., 2016), being objects of fetishism (Liddiard, 2018), sexually deviant (Kulick and Rydstrom, 2015), sexually aggressive, promiscuous (Szollos and McCabe, 1995), hypersexual and in need of restraint (Liddiard, 2018). Further, people with intellectual disabilities were perceived by many as unable to consent to sexual relationships (Peckham, 2007). As Liddiard (2018) argued, people cast disabled people in binaries of protected/ unprotected, abused/ abuser, and vulnerable/ dangerous. Pleasure is considered secondary to protection; others view people with intellectual disabilities as asexual and childlike. As a result, many of their sexual desires are considered deviant by many (Liddiard, 2018).

Views on people with intellectual disabilities impact on how they live. Historically, in Ireland and internationally, through the late 19th to the early 20th century, many people

with intellectual disabilities were subject to eugenic policies and practices, where their sexuality and parenting were controlled (Monk, 2015) through institutionalisation with same-sex segregation (Howard and Handy, 2004) and compulsory sterilisation (Roy, 2010). To prevent people with intellectual disabilities from abuse and procreating as they may have disabled children, they were often institutionalised (Edgerton, 1979). Disability was primarily seen as hereditary (Bates et al., 2017a). For people with intellectual disabilities, sexual contact was usually prohibited (Howard and Handy, 2004), and any sexual interest was either repressed or ignored (McCarthy, 1999).

Since the 1960s, several factors, including improved attitudes toward people with intellectual disabilities, have contributed to positive change, albeit slow, in this regard. The change began through the activism of the global disability rights movement in the late 1960s, where disabled activists came together to advocate and protest for disability rights (all types of disabilities, not just intellectual). The movement began in America following the civil rights movement and spread internationally. The aim of this movement was for disabled people to be able to exercise their rights, gain legal protections, and end discrimination and stigma (D'Alessio, 2011). The protests led to changes in policy and legislation that led to more equal access to education, employment, housing, services, transport, and the environment. During this movement, the medical model of disability that was prominent at this time, which focused on seeing the individual as a problem that needed to be fixed (Shakespeare, 2006), was identified as having limitations (D'Alessio, 2011), and not all disabled people related to it (Llewellyn et al., 2008). As a result, the social model was born, which defined disability and impairment separately, seeing disability as being caused by societal and attitudinal barriers that needed to be addressed (Shakespeare, 2006).

After decades of work from the United Nations to change approaches and attitudes towards disabled people, the United Nations (2006) launched the 'Convention on the Rights of Persons with Disabilities' (UNCPRD), which provided a basis for change. Article 23 states that measures to eliminate discrimination in relationships, marriage, family, and parenthood should be addressed so disabled people live equally to others (United Nations, 2006). To meet its obligations under the UNCPRD, the Government of Ireland

was obliged to make legislative changes about disabled people in the country. The legislative changes included the Criminal Law (Sexual Offences) Act, part 2 (2017), which replaced the Criminal Law (Sexual Offences) Act, part 5 (1993). The earlier Act had deemed all people labelled with intellectual disabilities unable to consent to sexual relations unless they were married or living independently (Law Reform, 1993). This blanket law was discriminatory and not in line with the UNCRPD. The 2017 Act changed the status of people with intellectual disabilities in this regard. This law protected the rights of people with intellectual disabilities so that it would not assume they could not consent based on disability alone, decriminalising sexual relationships for those who can consent (Law Reform, 2017). If a person with an intellectual disability's consent comes into question, they must undergo a capacity test. Further legislation that has supported the rights of people with intellectual disabilities in Ireland is the enactment of the Assisted Decision-Making (Capacity) Act (2015), which supports decision-making for people with intellectual disabilities. Although this Act does not include relationships and sexuality, it does show that people with intellectual disabilities have a right to be supported to make their own decisions and lead autonomous lives (Law Reform, 2015).

Irish policy has influenced where and how people with intellectual disabilities live in Ireland with the move from institutional to community-based living (H.S.E., 2011). In 2011, the Health Service Executive (H.S.E.) published 'Time to Move on from Congregated Settings – A Strategy for Community Inclusion' (H.S.E., 2011). This strategy recommended that all institutions for people with intellectual disabilities close by 2018 and people move to community-based homes. De-institutionalisation (replacing institutions with community homes) changed how people were supported and lived. This support and change resulted in people being more integrated into the community and doing mainstream activities with the non-disabled population, as they are viewed as living in their homes rather than patients in an institution. As well as this, 2012 saw the publication of the New Directions policy by the H.S.E., which provides 12 individualised outcome-focused supports for people with intellectual disabilities who use day services to promote choice in their lives and to support them to be integrated into the community and use mainstream services (H.S.E., 2012).

With all this change came more of an acceptance of the rights and recognition of people with intellectual disabilities in Ireland and internationally. This acceptance resulted in more open-minded attitudes towards sexual expression. However, despite so much improvement, a protective stance still prevails, where attitudes continue to be paternalistic (Kramers-Olen, 2016), and sexuality and parenting for people with intellectual disabilities remain taboo in Ireland and internationally (Bates et al., 2017a). Some caregivers act as gatekeepers of experiences, knowledge, and fundamental rights (McCarthy et al., 2022), overprotecting people rather than enabling choice (Fish, 2016; Schaafsma et al., 2017).

There is a tension between empowering sexuality and safeguarding from abuse and exploitation (Wilkinson et al., 2015; Kramers-Olen, 2016). One of the reasons caregivers try to protect people with intellectual disabilities is because they view them as vulnerable to sexual abuse. A literature review undertaken by Fisher et al. (2016) concluded that relationships and sexuality support from professionals are meaningful because people with intellectual disabilities are at an increased risk of sexual abuse compared to non-disabled people. Tomsa et al. (2021) undertook a systematic review of the prevalence of sexual abuse experiences in adulthood of people with intellectual disabilities. The researchers evaluated 25 studies from Canada, the Netherlands, Norway, the Republic of Ireland, Taiwan, South Africa, Spain, Sri Lanka, Sweden, the U.K., and the U.S.A. Sexual abuse happened to one in three adults with intellectual disabilities, according to the analysis. The prevalence of sexual abuse was slightly higher in males (39.9%) compared to females (31.3%). Those who lived in institutions were at a higher risk of abuse, and the primary type of abuser was a peer with an intellectual disability. Prevalence of abuse was more common in those with moderate intellectual disabilities; after that came mild intellectual disabilities and a minor occurrence of sexual abuse was found in people with profound intellectual disabilities (Tomsa et al., 2016). However, these findings are from the disclosures people gave, and not everyone can or will disclose sexual abuse so these figures could be much higher. Understandably, caregivers want to protect people with intellectual disabilities to safeguard them from harm due to this high prevalence of sexual abuse. However, as a result, it has been suggested that disabled people's rights regarding control over their feelings, bodies, and relationships are not always being upheld (Ignagni

et al., 2016). Appropriate support, information, and education should be provided for disabled people, as Article 16 of the UNCRPD (2016) states that proper measures to prevent exploitation, violence, and abuse should occur. The overprotection of people with intellectual disabilities is reported to be particularly evident in group homes, which, if it is the case, could be impacting their human rights (Rushbrooke et al., 2014; Puyaltó et al., 2022). The prevalence of sexual abuse in group homes is significant to highlight because Casey et al. (2020) found that in Ireland, the most frequent place a person with an intellectual disability lives is in a group home. The effect of people with intellectual disabilities experiences in group homes will be explored in further depth later in this chapter.

The eradication of eugenics has seen the move to newgenics (or liberal eugenics), coined by Nicholas Agar (2004) which are the social, political, and medical practices to 'improve' humanity and erase disability, such as genetic testing and abortion (University of Lethbridge, 2014). The view of Newgenics remains to control the reproductive and sexual freedoms of people with intellectual disabilities, except in different ways to eugenics (Tilley et al., 2012; Walmsley et al., 2016). The modern equivalent to sterilisation and incarceration are care proceedings, adoptions, and contraceptives (often enforced upon people with intellectual disabilities) (Walmsey et al., 2016). Although enforced or coerced sterilisation is uncommon, it is not unheard of (Li et al., 2018). How this plays out, and the impact of this on people with intellectual disabilities lives will be discussed later in this chapter.

According to Alexander and Taylor Gomez (2017), sexual expression and relationships are not a priority. Everyone has a right to love and be loved (Hole et al., 2022). Participants with intellectual disabilities in studies have voiced that being in a romantic relationship is a right (Garcia Iriarte et al., 2014; Bates et al., 2017b). Sexual feelings, drives, and needs are part of being human and are not optional extras or based on I.Q. levels (Carr, 1995). Although people with intellectual disabilities do not need to be sexual, suggestions that they are asexual, as previously mentioned, are incorrect. For example, in one Spanish study, 84% of the 360 participants with intellectual disabilities who participated in the questionnaire stated they had been in a sexual relationship (Gil-Llario et al., 2018). Turner

and Crane (2016) interviewed five adults with mild intellectual disabilities to explore their social-sexual lives, and participants shared that they had experiences or desires of dating, marriage, and love and a range of sexual experiences they enjoyed (Turner and Crane, 2016).

When the sexuality of people with intellectual disabilities is accepted, heteronormative and gendered stereotypes usually dominate (Azzopardi-Lane et al., 2019), which will be explored in depth in the theme of sexual diversity later in this chapter and which demonstrates that change has been slow throughout history.

According to McCarthy et al. (2022), although people with intellectual disabilities, like anyone, should be protected from abuse, there are no ethical, moral, or logical reasons to safeguard them from relationships. Like everyone, people with intellectual disabilities should be free to make relationship choices and get their hearts broken, which is part of the human experience. The infantilisation and overprotection that have dominated societal views about relationships and sexuality for people with intellectual disabilities have led to a lack of knowledge, poor social skills, isolation (Callus and Bornello, 2017; Callus et al., 2019), rejection, loneliness (Reiter and Bryen, 2012; Bates et al., 2017b), marginalised social positions, exclusion, and a poor quality of life (Goyal, 2017). The effects of infantilisation and overprotection can result in people with intellectual disabilities feeling powerlessness and lacking agency in their relationships (Sullivan et al., 2016). These findings highlight that more needs to happen to support people with intellectual disabilities concerning the high prevalence of sexual abuse and people with intellectual disabilities' rights to relationships. It is essential to begin with understanding what the perspectives of relationships and sexuality are from people with intellectual disabilities themselves.

3.3: People with intellectual disabilities perspectives on relationships and sexuality:

The studies showed varying perspectives of people with intellectual disabilities regarding relationships and sexuality, both positive and negative. This theme will begin by exploring

the positive attitudes found in the studies and then move to the opposing perspectives. The influences individuals face when developing their sexual identity will then be addressed. This theme will end by exploring the role of self-determination when negative consequences impact an individual's sexual identity.

It has been indicated by people with intellectual disabilities that they place a high value on love and having a romantic relationship (Rushbrooke et al., 2014; McCarthy et al., 2022). Most people participating in these studies desired long-term relationships and marriage (Lafferty et al., 2013; Bates et al., 2017a; Azzopardi-Lane et al., 2019; Neuman, 2020) or to move in with their partner (Rojas et al., 2016), have children (Azzopardi-Lane et al., 2019), and they desire sex (Rojas et al., 2016). One study found positive perceptions associated with love and its importance for people with intellectual disabilities (Mattilia et al., 2017). Mattilia et al. (2017) interviewed seven people with intellectual disabilities to find out how they described love and the meaning of love in their lives. The participants focused on romantic love. They all had a concrete understanding of love and saw it as crucial for well-being. Five of the participants spoke about the emotions of love; such feelings were described as positive, natural, unconditional and could influence other emotions. All seven participants could define and recognise acts of love based on their experiences. They all identified the importance of shared experiences, time, effort, and doing things together in relationships. They also identified essential skills attached to a loving relationship, such as interaction, attention, presence, listening, problem-solving, handling conflict and adversity, tenderness, and being romantic. The participants associated love with a good life and stated it was a human right, and they longed for love and spoke about it enthusiastically (Mattilia et al., 2017).

Although the above study favoured love, other studies found that people with intellectual disabilities were negative regarding sex. Negative perceptions of sex, regardless of whether they had sex or not, were reported in an American study that explored how 14 women with intellectual disabilities perceived sexuality and how it functioned in their lives. For example, participants described sex as sickening, disgusting, displeasing, ugly, and dirty (Bernett and Ogletree, 2013). Traditional gendered stereotypes were evident in people with intellectual disabilities in the studies. For example, the women in the

American research demonstrated standard female sexual scripts. Some women believed sex was only for procreation, and a few thought that sex should not take place outside of marriage but understood why abstinence might be difficult and felt that they should at least love the person (Bernett and Ogletree, 2013). In another study, 56 men and 44 women with intellectual disabilities in Taiwan participated in interviews and focus groups to see if there was a difference in male and female attitudes toward sexuality in people with intellectual disabilities (Chou et al., 2015). Their perspectives and experiences were different and depended on other people's expectations of them, many of which were gendered. According to Chou et al. (2015), many women had negative views towards sexual activity and parenting, which their families had instilled. Women had more negative attitudes than men regarding non-reproductive sexual behaviour and parenting. The male participants shared their sexual desires, whereas the female participants shared their negative prior experiences, which they all had, and which included sexual assault, rape, and non-consensual sterilisation (Chou et al., 2015). It is worth noting that another influence here would be the societal norms, which may have facilitated a more frequent occurrence of the negative experiences identified compared to other countries. However, participants in these studies were more optimistic about love than sex, and it could be that others (such as caregivers) encouraged love but discouraged sex. It could also be because they have had past negative experiences. Next, there will be an exploration of these negative attitudes.

People with intellectual disabilities rarely view sex as pleasurable. For example, in the American study, 12 women had heterosexual sex in the past, and only two of them voiced enjoying it (Bernett and Ogletree, 2013). Fear was one of the reported reasons people with intellectual disabilities were negative about sex, particularly women, in the research. For example, many of the women in the American study were scared that sex may hurt, feared pregnancy, or contracting A.I.D.s, which they believed would kill them. Nine of the women currently chose abstinence from sex due to their fears (Bernett and Ogletree, 2013). Also, four women had experienced domestic abuse or sexual assault, most likely contributing to these fears (Bernett and Ogletree, 2013). It seems that the information they received on sex was fear-based or focused on the adverse outcomes of sex. These women may have learned sexual scripts that encouraged marriage instead of mutual

exchange, procreation rather than pleasure, and sexual suppression over sexual expression (Bernett and Ogletree, 2013).

Participants across the studies struggled to develop a positive sexual identity. For example, in the Taiwan study, for the most part, they all had limited opportunities to develop a sexual identity or to have relationships (Chou et al., 2015). Nayak (2016) believed other people's perceptions of people with intellectual disabilities and sexual identity impacted how the individual developed their identity. They undertook 48 interviews with people with intellectual disabilities in France and Switzerland on the sexual scripts they used. They found four categories of perspectives: 1. rejecting one's sexuality due to fear of pregnancy or past sexual abuse, 2. the desire for normality and seeing a lack of sex as a problem, 3. rejecting any restrictions and deciding themselves how they would experience their sex lives, and 4. when sex is forbidden to create an alternative method of sex (Nayak, 2016). This study shows that even when people are forbidden to have sexual relationships, they often find ways around it themselves. However, people can then be at further risk.

The studies demonstrated different findings about self-determination. Some participants tried to speak up for themselves regarding their sexual autonomy, some got angry, and others struggled to even talk about sex (Chou et al., 2015; Turner and Crane, 2016). For example, participants in the Taiwan study on male and female attitudes to sexuality were shy to discuss sexual intercourse, masturbation, sterilisation, and having children. One participant's father threatened to beat him if he spoke about masturbation. All the participants wanted a relationship, but most were told by their parents that they were not allowed to have sexual relationships and that they would not be capable parents, and they stated they internalised this. The male participants felt angry about the denial of their sexual rights. They also disagreed with forced sterilisation. Although the participants knew their sexual rights, they never expected to have children (Chou et al., 2015). An American study explored the meaning of five adults with intellectual disabilities attached to their sexual lives through observations and interviews by examining their social-sexual voice through their discourse (Turner and Crane, 2016). When something was essential to the participants, they expressed self-determination, such as speaking up to a parent trying

to stop marriage or speaking out to their partner about how they wanted their sexual life. They all wanted to share their life with someone and felt it would improve their quality of life. According to Turner and Crane (2016), if the individual sees the benefits of sex and marriage, their sexual self-advocacy can be strengthened.

As can be seen from these studies, the perceptions of others have often impacted the perceptions of people with intellectual disabilities. Nayak (2016) argued that in institutions, sexuality is socially constructed and labelled as deviant. The participants with negative views of sex most likely experienced negative societal attitudes toward them and sex (Nayak, 2016). Callus et al. (2019) argued that overprotection, although often well-intentioned, is a disabling barrier that affects many aspects of people with intellectual disabilities' lives, including intimate relationships. Overprotection results in structured lives, where people cannot develop to their potential and realise their abilities; they fail to learn new skills and do not live life the way they want, which results in dependence on others (Callus et al., 2019). Callus et al. (2019) argued that there needs to be a balance between protection and autonomy.

This theme found positive and negative perceptions of intimacy from people with intellectual disabilities in the studies. When it was negative, it was usually due to past negative experiences or from possibly internalising negative messages from others. Caregivers often forbid relationships and sex due to the high incidences of sexual abuse. However, when people with intellectual disabilities want relationships or sex, they often find ways around it, which could put them at further risk. Therefore, the argument of denying people to protect them may not be working. As well as this, many people with intellectual disabilities' sexual rights are being denied. Following the UNCPRD (2006), Article 16 states that disabled people must be supported to prevent abuse, and Article 23 states that disabled people have a right to personal relationships. Although achieving these two rights is not easy, one must not take precedence over the other, and denying people relationships is not a method to protect a person from abuse. Next, exploring how people with intellectual disabilities are supported to have relationships and the reported benefits of such will be set out.

3.4: Support to have relationships and the benefits this provides:

According to Rushbrooke et al. (2014), caregivers (family and professionals) have a responsibility to support people with intellectual disabilities in their relationships (Rushbrooke et al., 2014). This theme will explore what kind of support works well from caregivers supporting people with intellectual disabilities in their relationships and sexuality. Also examined next are the benefits this support provides when people with intellectual disabilities can have relationships.

Participants with intellectual disabilities have stated that professionals are essential in supporting them to achieve their romantic needs (Bates et al., 2017b; Neuman, 2020). Professionals can either be a facilitator or a barrier to people with intellectual disabilities having relationships (Sullivan et al., 2016). Several examples in the literature show how relationships and sexuality support from professionals have worked well. Most participants in the cited studies reported receiving support from staff (White and Barnitt, 2000; Bates et al., 2017b; McCarthy et al., 2020; Neuman, 2020; McCarthy et al., 2022). Participants in a U.K. study on love and relationships concluded that the opportunities they experienced enabled the development of their romantic relationships; this included learning about relationships, accessing specialised dating agencies, and the support they received from professionals (McCarthy et al., 2022). In Neuman's (2020) study exploring people with intellectual disabilities' perspectives on establishing and maintaining their relationships, participants acknowledged that the support they received from staff included information on choosing partners and assistance with matchmaking, which they found beneficial. Three participants in Bates et al. (2017b) study on the importance of romantic love for people with intellectual disabilities stated that they would not have been able to have their relationships without the support they received from staff. They found it helpful when staff helped them organise and supervise dates, have supportive conversations about their evolving relationships, enable family planning access, and allow them to share a bed with their partner. They further said that staff protected them from relationship abuse by offering them safety advice, reducing pregnancy risks, and empowering them to make their own choices (Bates et al., 2017b). Also, the staff have been supportive of LGBTQ+ relationships (Stoffelen et al., 2013; Bates, 2020), and there

are good practices where professionals have provided sexual health education (Walmsey et al., 2016; Hole et al., 2022; McCarthy et al., 2022). The exploration of support in LGBTQ+ relationships and sexual health education will be in two later themes, which participants stated are beneficial.

Relationships and sexuality support from families are also meaningful. For some people, families are the most significant support for relationships (Rojas et al., 2016). Examples of good family support are evident in studies (Neuman, 2020; McCarthy et al., 2022). In McCarthy et al.'s (2022) U.K. study on love and relationships, participants received strong emotional and practical support from their families to find a partner and maintain a long-term relationship. In an Iranian study, a participant shared how their mother suggested they bring home the girl they liked, which allowed for the development of the relationship (Neuman, 2020).

As a result of this support from caregivers, people with intellectual disabilities could have relationships. The studies drawing on people with intellectual disabilities' perspectives of their relationships show that they are a meaningful aspect of their lives (Neuman and Reiter, 2017; Bates et al., 2017b; Mattila et al., 2017; McCarthy et al., 2022). Research studies undertaken with people with intellectual disabilities found many benefits to them engaging in intimate relationships (Sullivan et al., 2013; Rushbrook et al., 2014; Bates et al., 2017b; Mattila et al., 2017; Neuman and Reiter, 2017; Neuman, 2020; McCarthy et al., 2022). For example, when interviewed on their perspectives of romantic love, findings from studies in Finland (Mattila et al., 2017) and the U.K. (Bates et al., 2017b) identified that love was essential to them all and a positive part of their well-being. The participants said it was vital for them to have a partner who loved and supported them and valued and loved their partner (Mattila et al., 2017; Bates et al., 2017b). Bates et al. (2017b) suggested that when people with intellectual disabilities are in relationships, this often negates the need for them to be cared for by staff. People with intellectual disabilities reported that relationships have a positive influence on physical and mental well-being and result in companionship (Rushbrooke et al., 2014; Bates et al., 2017b), physical intimacy, and the expression of love (Rushbrooke et al., 2014; Bates et al., 2017b; Mattila et al., 2017), peace, balance, safety, happiness, (Mattila et al., 2017), the opportunity to share

experiences, and to have someone who makes them feel special, to make plans with, and if they so wish, get married and have children (Bates et al., 2017b; Neuman and Reiter, 2017), pride, normality (Bates et al., 2017b), and social status (Rushbrooke et al., 2014; Bates et al., 2017b). Furthermore, the ten interviewed participants in U.K. research on touch in close relationships found their romantic relationships acted as a barrier against social stigma, thus reducing mental and physical health problems associated with stigma (Sullivan et al., 2013). Neuman and Reiter (2017) studied romantic relationship experiences with 80 participants with intellectual disabilities from Israel. They reported that those who experienced intimate relationships had a better quality of life, a higher sense of independence, and a more positive self-image than those who did not (Neuman and Reiter, 2017). Neuman (2020) interviewed 20 couples with intellectual disabilities from Israel, exploring their perspectives on establishing and maintaining relationships. They ascertained that romantic relationships for people with intellectual disabilities helped couples cope with life challenges, as they were a source of strength. Relationships also built their communication skills. Forty participants with intellectual disabilities interviewed as part of a U.K. study on love and relationships stated that romantic relationships provided pleasure (McCarthy et al., 2022). However, the literature rarely identified pleasure. This absence of pleasure could be due to a lack of experience discussing pleasure (Alexander and Gomez, 2017). Participants voiced fear, shame, and guilt when discussing pleasure in a study (Alexander and Gomez, 2017). According to Alexander and Gomez (2017), there is room for more discussion about feeling good, sensuality, and pleasure.

All these benefits are consistent with the needs and desires of most relationships of non-disabled people (Neuman and Reiter, 2017). Studies have identified that people with intellectual disabilities have similar needs and experiences in relationships to non-disabled people (Rushbrooke et al., 2014; Wos et al., 2021). Considering this, people with intellectual disabilities should have the same human rights regarding relationships and sexuality (Sullivan et al., 2016).

To summarise, good support from professional and family carers in the literature includes emotional and practical support. This support included education, opportunities to create

and maintain relationships, family planning, accommodating people's relationships in their homes, including group homes, and empowering people to make decisions. When people with intellectual disabilities receive the support they need, it is of enormous benefit. Discussed next is an exploration of what it is like when they do not receive this support.

3.5: Lack of support from caregivers for intimate relationships:

People with intellectual disabilities experiences of a lack of support from professionals, and family will be explored next, along with an examination of why this may happen and the effects of such.

Several studies have shown examples of staff who were not supportive (Stoffelen et al., 2013; Garcia Iriarte et al., 2014; Rushbrooke et al., 2014; Bates et al., 2017a; Rojas et al., 2016; Sullivan et al., 2016; Neuman and Reiter, 2017; Schaffsma et al., 2017; Grace et al., 2020; Neuman, 2020; Puyalto et al., 2022). Professionals are sometimes ambivalent between autonomy and risk; and some hold conservative attitudes (Schaffsma et al., 2017). The literature shows that professionals often control people with intellectual disabilities, relationships, and sexuality (Rojas et al., 2016). One study even found that staff acted inappropriately (Rushbrooke et al., 2014). Nine participants with intellectual disabilities when interviewed in a U.K. study on experiences of intimate relationships shared that their professional caregivers refused to support and, in one case, teased and embarrassed them about their relationship (Rushbrooke et al., 2014).

Schaafsma et al. (2017) argued that institutional regulations are restrictive. Sullivan et al. (2016) suggested that having a blanket policy, regulations, and rules regarding relationships and sexuality for all people with intellectual disabilities can increase vulnerability and exploitation. Sometimes, professionals exerted control and created house rules that restricted relationships, which was found most restrictive by staff in group homes (Garcia Iriarte et al., 2014; Puyalto et al., 2022). Many restrictions in group homes were discovered in the studies to include banning physical contact, masturbation, sex, and intimate relationships (McClelland et al., 2012; Bates et al., 2017b; Puyalto et al.,

2022), same-sex housing, restricting fertility through enforced contraception (Puyalto et al., 2022), not being allowed to have visitors in their home (Garcia Iriarte et al., 2014; Puyalto et al., 2022), not being allowed to live with their partner (Neuman and Reiter, 2017), and not allowed to become parents (Neuman, 2020). Many of these restrictions deny people with intellectual disabilities their human rights and are not following the UNCPRD (2016); for example, Article 19 states that disabled people are not obliged to live in a particular living arrangement, and Article 23 states that disabled people have a right to personal relationships and have the right to reproductive and family planning.

Neuman (2020) contended that people with intellectual disabilities live in constant uncertainty as they depend on their caregivers. Participants expressed anxiety and spoke about their fear of caregivers separating them from their partners (Neuman, 2020). There were different reactions across studies to how participants with intellectual disabilities reacted to such resistance from others. Their caregiver's resistance influenced some participants (Sullivan et al., 2013), whereas others had relationships regardless but kept them hidden (Stoffelen et al., 2013; Puyalto et al., 2022). Such resistance may increase the likelihood of people engaging in covert sexual activity (Grace et al., 2020). Covert sexual activity was evident in Rushbrooke et al. (2014) study that identified some participants hiding that they were having sex.

According to Sullivan et al. (2013), one of the most significant barriers to people with intellectual disabilities forming relationships is opposition from their families, who perceive them as a child whom they want to protect. This parental overprotection was found in two studies, one in Malta and another in America because their parents saw them as childlike (Azzopardi-Lane et al., 2019; Schmidt et al., 2021). Sullivan et al. (2013) further argued that making decisions, exercising autonomy, and taking risks in relationships are not usually afforded to those with intellectual disabilities. An example of a lack of autonomy in relationships is that families have restricted women more than men with relationships, which was found in a Spanish study on romantic relationships (Puyalto et al., 2022). It was rare for a person with intellectual disabilities to seek parental support in their relationships (Neuman, 2020); the literature provided many examples. For example, in a U.K. study on touch in close relationships, one participant did not disclose

her experience of rape to her family as she feared an adverse reaction (Sullivan et al., 2013).

Puyalto et al. (2022), in their Spanish study on challenges in romantic relationships, identified several barriers for people with intellectual disabilities when moving in with a partner, including a shocked response from family members who had not envisaged this as part of the individual's future. Another barrier was the participant's fear of failure that they would prove their parents right and would not be able to live with their partner. They would also need to find a job to afford to live together (Puyalto et al., 2022).

Parents can interfere (Schaafsma et al., 2017). Families often seek professional support to prevent relationships (Pulyato et al., 2022). Staff then must decide if they support the family or the couple's decision. It is dependent on the professional in how they respond to this. However, it was stated in a Spanish study that it was common for the professional to give in to the demands of the family and inhibit intimate relationships (Pulyato et al., 2022). Participants gave different examples: one where the staff supported the couple, another where the staff threatened to exclude the individual if they dated, and another who said that they would need to get permission from their mother to sleep with their partner. As a result, some participants had to resist this control (Puyalto et al., 2022).

Caregivers face the challenge and ambivalence between autonomy and risk. Disability services, such as group homes, can often have restrictive regulations, rules, and policies, and family caregivers can be overprotective. However, the research focused on the barriers and lack of support people with intellectual disabilities face rather than the support they benefit from, which was an unbalanced focus. Unbalanced findings focusing on the barriers were evident not only in these previous two themes but were common throughout the results of this chapter. The focus on the barriers may be because there are more lived experiences of barriers than support. However, to gain evidence for best practice and to move forward, more research is needed to explore what support works well. The next theme will dig deeper into the barriers people with intellectual disabilities face when creating and maintaining intimate relationships.

3.6: Barriers to creating and maintaining intimate relationships:

This theme will explore the types of barriers that people with intellectual disabilities have experienced regarding creating and maintaining relationships and the impact these barriers have on their lives.

The literature has found several barriers to creating and maintaining relationships. Firstly, it is a challenge for people with intellectual disabilities to meet people to form relationships. Participants in a U.K. study on love and relationships stated they did not know where to find a partner (McCarthy et al., 2022). A range of studies with people with intellectual disabilities discovered that the participants' social networks to find and build relationships were restricted (Lafferty et al., 2013; Small et al., 2013; Rushbrooke et al., 2014; Sheldon and Storey, 2014; Callus and Bonello, 2017; Azzopardi-Lane et al., 2019; McCarthy et al., 2022; Puyalto et al., 2022). Many restrictions are enforced upon people with intellectual disabilities, negatively impacting their relationships (Rushbrooke et al., 2014; Sullivan et al., 2016). Several studies found that the environment was controlled when people with intellectual disabilities socialise; they are rarely unaccompanied by caregivers, experience high levels of staff surveillance, and are restricted in forming intimate relationships (Azzopardi-Lane et al., 2019; Chou et al., 2020; Neuman, 2020; McCarthy et al., 2022; Puyalto et al., 2022). Chou et al. (2020) described this as institutionalising their lives and blocking their sexual rights.

Three of these studies, two from the U.K. and one from Israel, found that the participants often only meet people within their day centre (Rushbrooke et al., 2014; McCarthy et al., 2022; Puyalto et al., 2022). Furthermore, three studies, one Irish and two Maltese, detected that the participant's social networks usually comprise of family and professionals (Lafferty et al., 2013; Callus and Bonello, 2017; Azzopardi-Lane et al., 2019). There is a restriction of free time and leisure activities in comparison to non-disabled people, and carers usually organise activities where they are present (Callus and Bonello, 2017; Azzopardi-Lane et al., 2019) and spend time with other disabled people (Azzopardi-Lane et al., 2019). Participants interviewed in two U.K. studies on intimate relationships found that due to such poor integration, when people with intellectual disabilities have

maintained relationships, these have usually developed in disability-segregated settings (Rushbrooke et al., 2014; Bates et al., 2017a). Bates et al. (2017a) Irish study on partner selection suggested that participants may have only chosen their partner due to availability rather than compatibility. As a result, this may mean not sharing common interests, values, and life goals (Bates et al., 2017a). These barriers to creating and maintaining relationships are all despite the UNCPRD (2006) setting out in Article 19 that the community includes disabled people, that they have choices that are equal to others, and they enjoy full inclusion and participation; Article 23 provides that disabled people have a right to personal relationships, and Article 30 states that disabled people have access to leisure activities.

Participants in McCarthy et al. (2022) study stated that staff numbers and staff shift patterns are barriers to socialising and dating. A lack of transport and finances are barriers to accessing social opportunities to meet potential partners (McCarthy et al., 2022), as well as inaccessible transport and buildings to people with physical impairments, which act as a barrier to accessing social activities (Azzopardi-Lane et al., 2019). This results in people with intellectual disabilities being overly dependent on carers, which impacts upon their independence (Azzopardi-Lane et al., 2019).

Participants in an Irish study said they valued privacy where they lived (Garcia Iriarte et al., 2014). Rushbrooke et al. (2014) stated that the participants in their U.K. study on intimate relationships knew that privacy is a right. However, a lack of privacy has been discovered in several studies (Rojas et al., 2016; McCarthy et al., 2022). This results in not having enough time with partners (Rushbrooke et al., 2014) and limited opportunities to engage in sexual relations (Sullivan et al., 2013), particularly in group homes (McCarthy et al., 2022). Article 22 of the UNCPRD (2016) states that privacy should be respected. However, it is essential to note that it is a potential safeguarding concern if an individual invites someone to sleep over in their group home, and the privacy and rights of the co-residents need to be considered, which would not be usual in a regular house share (McCarthy et al., 2022). Participants in a study from Malta said they wished to live independently (Azzopardi Lane et al., 2019). However, there needs to be more personal assistants and community living to do so (Azzopardi-Lane et al., 2019).

One of the main barriers in the research is the over-protection (although mainly well intended) from family and professionals. Most of the concerns point to caregivers' worries about capacity and safeguarding, and one way that helps increase capacity and knowledge is by ensuring that people with intellectual disabilities have appropriate sexual health education, explored in the next section.

3.7: Sexual health education:

This theme will explore the topic of sexual health education for people with intellectual disabilities. This section includes the benefits of such education, followed by the barriers to access and the effects experienced when a person lacks sexual health education. There will be a comparison between people with intellectual disabilities and non-disabled people in their levels of sexual health knowledge. Finally, there will be a discussion on the formal and informal methods of learning sexual health and these programmes' content and teaching methods.

Several benefits of sexual health education for people with intellectual disabilities are evident in the literature. For example, a U.K. study on contraceptive decision-making provided evidence of participants who spoke positively about the value of the sexual health education they received (Walmsey et al., 2016). In another U.K. study, participants stated that they received support to access specialised dating agencies, which included support groups, workshops, and events about relationships, where they found this to be a good experience (McCarthy et al., 2022). Nineteen participants said they learned about consent and safety and felt this was valuable during interviews for a study in Canada on their experiences of sexual health education (Hole et al., 2022).

Sexual health education is a human right (Hole et al., 2022), but Frawley and Bigley (2014) argued that sexual health education rarely addresses the rights to decision-making on relationships and sexuality. Despite it being a right and the benefits of such education, people with intellectual disabilities face barriers, stigma, and discrimination regarding sexual health education (Abbott, 2013; 2015; Wilkinson et al., 2015).

Firstly, and as several studies have identified, people with intellectual disabilities lack access to sexual health education (Fitzgerald and Withers, 2013; Rojas et al., 2016; Schaafsma et al., 2017; Graff et al., 2018; Chou et al., 2020; Wos et al., 2021). The main reason sexual health education is absent is that others often control it. For example, a Canadian study on experiences of sexual health education found that caregivers (family and professionals) are uncomfortable and gatekeep the information (Hole et al., 2022). Parents who resist sexual health education do so as they do not want their adult children to discuss it (Callus and Bornello, 2017; Schmidt et al., 2021; Hole et al., 2022). Two studies from Malta and America found that this resistance also comes from professionals who lack training in this area (Chou et al., 2020; Schmidt et al., 2021). Schmidt et al. (2021) further found that disability services lack resources, standards, and policies and prevent such programs on cultural grounds or as a protective measure (Schmidt et al., 2021).

According to Schmidt et al. (2021), the result of the denial of sexual health education is that people with intellectual disabilities are being unintentionally oppressed. The chances of inappropriate socio-sexual behaviour (Bornman and Rathbone, 2016), sexual abuse, and S.T.I.s for people with intellectual disabilities may increase with a lack of knowledge of sexual health (Bornman and Rathbone, 2016). As Wos et al. (2021) found in their Polish study on parenting, several of the 24 participants with intellectual disabilities stated that they did not know what to do if they were ever sexually abused (Wos et al., 2021). Articles 16, 23, and 25 of the UNCPRD (2006) set out that disabled people should have access to information and education relating to their sexual health. These rights and lack of knowledge and education demonstrate the need for comprehensive sexual health education (Finlay et al., 2015), which may empower people with intellectual disabilities to protect themselves while benefiting from sexual fulfilment (Duguay, 2013).

Like everyone, people with intellectual disabilities have different levels of sexual health knowledge; however, it was found in two studies that knowledge is generally surface level (Jahoda and Pownall, 2014; Schaafsma et al., 2017). These studies were a Dutch study that interviewed 20 people with intellectual disabilities, assessing their perspectives on sexuality-related topics (Schaafsma et al., 2017) and a U.K. study that included interviews

with 30 non-disabled participants and 30 participants with intellectual disabilities on their sexual understanding (Jahoda and Pownall, 2014). The latter research uncovered that the participants with intellectual disabilities had less knowledge than the non-disabled participants (Jahoda and Pownall, 2014). Schaafsma et al. (2017) further identified that the information was largely superficial. A Polish study on participants' knowledge of sexuality found their knowledge incomplete (Wos et al., 2021). Despite this lack of sexual-related knowledge, participants in an Australian study on peer-led sexual health education voiced that they would like to learn more about sexual health education (Frawley and Wilson, 2016). Knowledge is low in the areas perceived as risk but focused on in most sexual health education programs. Knowledge is generally high on the topic of the body and low regarding the topics of contraception and S.T.I.s (Jahoda and Pownall, 2014; Schaafsma et al., 2017), pregnancy and birth (Wos et al., 2021; Jahoda and Pownall, 2014), and the law (Jahoda and Pownall, 2014). An example is from participants in the Polish study on knowledge of sexuality who demonstrated an excellent understanding of personal hygiene and identifying emotions. However, regarding S.T.I.s and pregnancy, they held only surface-level knowledge, did not know how these things happened or how to protect themselves, and held some incorrect information (Wos et al., 2021). The participants could also not explain when intercourse would be deemed to be rape (Wos et al., 2021). The reason people with intellectual disabilities lack sexual health knowledge could be a mix between their capacity to learn and the lack of sexual health information and education they have received.

Most people with intellectual disabilities did not receive sexual health education in school (McDaniels and Fleming, 2016). Participants with intellectual disabilities in an Australian study on experiences of the effectiveness of sexual health education found that the participants believed that those in mainstream schools received better sexual health education than those who went to schools specialised for those who were disabled (Frawley and Wilson, 2016). Mainstream sexual health education provides a more holistic approach to its content (Frawley and Wilson, 2016). The participants with intellectual disabilities in a Canadian study on their experiences of sexual health education voiced that they would like formal, accessible sexual health education (Hole et al., 2022).

Even conversations regarding relationships and sexuality are restrictive. People with intellectual disabilities usually initiated conversations regarding sexual health in the American study on the context, barriers, and recommendations of sexual health education for people with intellectual disabilities (Schmidt et al., 2021). Caregivers' (family and professionals) views can often influence people with intellectual disabilities, often focusing on the risk (Hole et al., 2022). One U.K. study included interviews with eight people with intellectual disabilities who use disability services about their accounts of how sexuality is conveyed through conversations with staff (Grace et al., 2020). The study's findings revealed that the staff focused on how discussions on these topics were inappropriate in the institution. They took an authoritative stance where they controlled the individual, such as telling them what they could or could not do (Grace et al., 2020). As a result of these types of responses from staff, people with intellectual disabilities have voiced they then feel scared or worried, such as a parent told a participant that they would die a painful death if they had unprotected sex in an Australian study on peer-led sexual health education (Frawley and Wilson, 2016).

Self-taught sexual health education comes from other sources. Participants in two studies on sexual health education, one from Poland (Wos et al., 2021) and one from Australia (Frawley and Wilson, 2016), stated that most of their knowledge came from the internet, books, T.V., and friends. An Australian study further found that because the men had limited social networks to talk to other men their age about these topics, they stated they had predominantly learned their sexual knowledge from pornography magazines (Frawley and Wilson, 2016).

When sexual health education is available, a biological discourse dominates (Chivers and Mathieson, 2000). According to Hole et al. (2022), positive sexuality is not usually encouraged in programs. Frawley and Bigby (2014) argued that sexual health education for people with intellectual disabilities has a narrow focus. Education rarely frames sex in terms of pleasure (Sullivan et al., 2013; Kulick and Rydstrom, 2015) instead of abuse and protection (Kulick and Rydstrom, 2015). Focusing on risk leaves internalised messages of danger (Hole et al., 2022). Despite this risk-focused education, it has been found not to translate into safe behaviour (Schaafsma et al., 2017). Others are telling people with

intellectual disabilities what behaviour they are not allowed to do to others, but what others cannot do to them is not being discussed (Wos et al., 2020). Frawley and Bigby (2014) interviewed 16 peer educators on their experiences of co-facilitating a sexual health education program in Australia. They found that the focus is on teaching the rules of what people are not allowed to do. In another Australian study, the researchers facilitated focus groups with 25 people with intellectual disabilities on their experiences of the effectiveness of their sexual health education (Frawley and Wilson, 2016). This study found that the focus is often gender-specific, with men's sexuality pathologized and women's education focused on hygiene, pregnancy, and self-protection (Frawley and Wilson, 2016). Others tell men the rules about sex: not to abuse a woman or get them pregnant and not to spread S.T.I.s (Frawley and Wilson, 2016). Women are educated about safety, contraception, menstruation, and hygiene, have been told to stay safe and be clean, and are put on contraception (Frawley and Wilson, 2016). The prejudiced view that sex should only occur in the context of marriage and procreation is evident in programs; this is most likely due to religious understandings of sexual behaviour or to prevent sexual behaviour (Sullivan et al., 2013). Heteronormative perspectives lacking sexual diversity primarily underpin sexual health education (Hole et al., 2022). A Canadian study on contraceptive choices for women with intellectual disabilities found that none of the participants had learned about LGBTQ+ in their previous sexual health education; they lacked knowledge on the topic, and most wanted to know more (Hole et al., 2022).

The content of sexual health education or information focuses on biology, human anatomy, reproduction (Sullivan et al., 2013; Rojas et al., 2016; Garcia Iriarte et al., 2014; Hole et al., 2022) sexual hygiene, menstruation, contraception (Frawley and Bigby, 2014), and risk avoidance (avoiding pregnancy and S.T.I.s) (Rojas et al., 2016; Schaafsma et al., 2016; Schaafsma et al., 2017; Hole et al., 2022). Content instead should focus on puberty, body image, masturbation, sexual behaviours, sexual relationships, safe sex, sexuality rights (Eastgate, 2008), communication, pleasure, intimacy, self-efficacy (Hole et al., 2022), the female body, pregnancy, foetus development, boundaries, and human trafficking (Schaafsma et al., 2017).

According to McCabe (1993), inaccessible teaching methods can impact how people with intellectual disabilities can learn about relationships and sexuality. People with intellectual disabilities should be involved in planning programs so the content is appropriate for their needs (McCabe, 1993). Most commonly, facilitators favour didactic teaching methods (where the teacher directly instructs the student) (Gougen, 2009). The researchers undertook focus groups with 10 participants in a South African study on sexual health education for women with intellectual disabilities. They found they lacked knowledge because the teaching methods were not appropriate or accessible (Bornman and Rathbone, 2016). People with intellectual disabilities can have difficulty understanding long and abstract concepts and complex terminology and have issues with memory recall or when information is given out of context (Finlay et al., 2014). Participants in a Canadian study on sexual health education spoke about their experiences with this education, where they found it lacked representation of disability in the content and materials and was inaccessible (Hole et al., 2022).

Despite sexual health education being a massive barrier to people with intellectual disabilities, there are several good examples of effective teaching methods in the literature. People with intellectual disabilities found teaching methods such as practicing skills, modelling, rehearsing, and role-playing beneficial (Sinclair et al., 2015). In a South African study on sexual health education, the participants identified essential questions about sexual health, and the researchers made social stories to teach these topics (Bornman and Rathbone, 2016). Social stories are custom-made short stories that effectively teach appropriate social behaviour, as they teach concrete skills through the visuals of easy-to-read language with accompanying pictures (Bornman and Rathbone, 2016). Creative teaching methods are helpful, including a board game on relationships and sexuality (Terras et al., 2018), anatomically correct adult dolls to teach about the human body, hygiene, and social interactions (Bodysense, 2021), the Circle Social Skills Utility™ app, an app about relationships and sexuality (Circles App, 2016), the film Sanctuary made by Irish actors with intellectual disabilities on the topic of relationships and sexuality (Blue Teapot Theatre Company, 2023), and accessible books on sexuality and masturbation (Reynolds 2014; 2015). For further resources, please see (Mannion and

Sheerin, 2023), where we provide a toolbox of resources to teach sexual health education to adults with intellectual disabilities.

Peer education benefits both the students and peer educators (Frawley and Bigbey, 2014). Peer sexual health educators with intellectual disabilities voiced that it enabled them to learn new knowledge and skills, where they now know where to find support and information, it empowered them, it allowed them to help others, and it gave them a position of credibility (Frawley and Bigbey, 2014). Because of their experiences, they were more approachable and relatable than professionals. The authors of this Australian study on peer-led education hoped it would help transform attitudes from vulnerability to seeing their capacity in sexual health education (Frawley and Bigbey, 2014).

When holistic and accessible sexual health education takes place, it is of benefit. However, others often deny access to sexual health education to people with intellectual disabilities, or when it does happen, the content and teaching methods are not appropriate or adequate, placing people with intellectual disabilities in a more vulnerable position and further at risk. Sexual health education is an area for transformation. Another area for change is explored next and is about the attitudes towards sexual diversity.

3.8: Sexual diversity:

There is a lack of research on people with intellectual disabilities and sexual orientation (Dinwoodie et al., 2016; Stoffelen et al., 2018). However, what is available will be explored here, focusing on support, perspectives, and barriers.

According to Abbot (2015), people with intellectual disabilities who are LGBTQ+ face considerable discrimination, lack of support, and barriers to relationships. A limited number of people with intellectual disabilities self-identify as LGBTQ+ (F.R.A., 2013; SSCR, 2017), and many conceal their sexual identity (Rushbrooke et al., 2014; Stoffelen et al., 2018). Commonly, they internalise the negative attitudes of others (Dinwoodie et al., 2016), which may develop into discriminatory views and negative self-perception (Meyer, 2013; Tallentire et al., 2016).

The participants in a Polish study on sexual health education stated they wanted to learn about homosexuality, transsexuality, gender reassignment, and asexuality, as they knew very little about these topics (Wos et al., 2021).

People with intellectual disabilities who are LGBTQ+ often experience double stigma (Bates, 2020; Cambridge and Mellan, 2000) and face prejudice and harassment (Stoffelen et al., 2018). Although homophobia is not unique to people with intellectual disabilities, they experience further challenges due to their disabled status, such as being told they are not LGBTQ+, which two U.K. studies detected (Dinwoodie et al., 2016; Bates, 2020). In one study, interviews took place with eight people with intellectual disabilities on their experiences of bisexuality (Bates, 2020). In another study, discussions took place with five people with intellectual disabilities who were LGBTQ+ on how they experienced their sexual identity (Dinwoodie et al., 2016). Dinwoodie et al. (2016) further suggested that others frequently problematise sexual diversity in people with intellectual disabilities. Stoffelen et al. (2013) argued that homosexual people with intellectual disabilities depend on others for care, and often, these caregivers hold negative views towards LGBTQ+, so they become further oppressed.

There is a link between challenges in identity formation and psychological distress (Hardy et al., 2013; Wiley and Bermen, 2013). People with intellectual disabilities who are also LGBTQ+ have an increased risk for psychological distress in comparison to non-disabled people, which includes mental health issues such as anxiety, O.C.D., depression, phobic disorders, psychosis, and substance misuse (Stoffelen et al., 2018). They have an increased risk of addiction, sexual problems, sexual violence, and loneliness (Clarke et al., 2010). This psychological distress has led to self-harm, suicidal thoughts, and attempted suicide (Chakraborty et al., 2011).

How others treat LGBTQ+ people with intellectual disabilities contributes to their mental health. Although not unique to disabled people, research findings report that sexually diverse people with intellectual disabilities endure bullying, discrimination, and abuse from friends, family, professionals, and the community (Dinwoodie, 2016; SSCR, 2017;

Bates, 2020). For example, participants in a U.K. study on understanding the sexual identity of people with intellectual disabilities found that all participants had experienced physical and verbal abuse, threats of violence, and discrimination due to their sexuality, gender expression, or disability (Dinwoodie et al., 2016). This abuse, violence, and discrimination happened in the community, with family and caregivers, at school, and in college (Dinwoodie et al., 2016). Many participants in a U.K. study on experiences of intimate relationships expressed embarrassment and fear relating to expressing their sexual identity and, as a result, hid it from others (Rushbrooke et al., 2014). All eight participants feared others would mock or reject them if they were open about their sexual identity in a U.K. study on bisexuality (Bates, 2020).

Professionals often lack knowledge and, in some cases, have been known to allow heterosexism (prejudice or discrimination based on a person's sexual identity), biphobia (prejudice or discrimination towards those who are bisexual), bi-erasure (the legitimacy of a person's sexual identity questioned or denied), and monosexism (others incorrectly believing that the person must only be attracted to one gender) (Flanders et al., 2015; Bates, 2020). A Dutch study on the lived experiences of homosexuality in people with intellectual disabilities identified through their 21 interviews that it was easier for the participants to discuss sexuality with sexually diverse staff (Stoffelen et al., 2013).

The reports of discrimination and abuse in these studies contradict the UNCPRD (2016), where Article 5 states that there is legal protection to prohibit all discrimination based on disability, and Article 16 states that to prevent exploitation, violence, and abuse, appropriate measures should be taken.

Studies have reported some positive forms of support. Staff attitudes may impact the support a sexually diverse person with intellectual disabilities will receive (Bates, 2020). Some participants in a U.K. study on experiences of homosexuality gave examples of the positive support they received, such as when they were supported to attend LGBTQ+ community support. One participant was supported to participate in Gay Pride, and the staff introduced them to a gay person with an intellectual disability and helped him to find a support group. Another staff member helped them to set up a bisexual dating profile.

Another participant felt comfortable coming out after seeing how well the staff supported others with their sexual identity (Bates, 2020). The LGBTQ+ support received by participants in a Dutch study on lived experiences of homosexuality varied; some got helpful support, especially when their caregiver was heterosexual. Those who received sexual health education or saw a sexologist found this helpful, too (Stoffelen et al., 2013).

LGBTQ+ support groups for people with intellectual disabilities are essential as they help to keep people safe, increase positive well-being, and enable opportunities for those attending them to develop relationships (Tallentire et al., 2016; Bates, 2020). For example, participants in a U.K. study on bisexuality voiced that the benefits of their support groups were acceptance, a sense of community, and safety. They were able to be part of the LGBTQ+ scene where they made friends, felt supported, surrounded by others with comparable difficulties, had fun, and grew in confidence (Bates, 2020).

Although there are several examples of how support has worked well, there were many more examples of how it failed to support people. Unfortunately, this has led to discrimination and abuse, negatively impacting people with intellectual disabilities. Sexual diversity is not the only area where needs go unmet. The next theme will explore sexual health for people with intellectual disabilities, another place that does not adequately address people's needs.

3.9: Sexual health promotion:

The critical areas of sexual health promotion for people with intellectual disabilities include relationships, sexual and reproductive health screening, menstruation management, contraception, sterilisation, sexual and relationship abuse, pregnancy, and parenting (Eastgate and Moyle, 2014). Eastgate and Moyle (2014) argued that people with intellectual disabilities do not have access to the same levels of health promotion, screening, and intervention as non-disabled people. This theme will explore the different experiences reported in the literature on sexual health promotion and the impact of this on people with intellectual disabilities.

Sexual health promotion research for people with intellectual disabilities has a gendered difference in its focus. Limited research exists on health promotion for men with intellectual disabilities (Bollard, 2015). Wilson et al. (2010) suggested that others problematise men's sexual behaviour and promote women's sexual health in disability research. Wilson et al. (2010) thematic analysis of prominent journals found that research paid less attention to men's sexual health than women's. There was a strong focus on problematising men's sexual behaviour. This study is 13 years old; however, through this literature search, equivalent findings were discovered with recent studies on men's sexual health focusing on sexual offending (Heaton and Murphy, 2013; Hollomotz, 2014; 2020; 2022; Hollomotz and Schmitz, 2018; Hollomotz et al., 2018; Hockley et al., 2015; Hollomotz and Greenhalgh, 2020; Melvin et al., 2020; Heppell and Rose, 2021; Hollomotz and Talbot, 2021) and very few studies focused on the promotion of their sexual health. In comparison, there was a plethora of literature promoting women with intellectual disabilities and sexual health (Lezzoni et al., 2015; Frawley and Wilson, 2016; Walmsley et al., 2016; Bollard et al., 2018; Li et al., 2018; Cytowska and Zierkiewicz, 2020; Namkung et al., 2021; Horner-Johnson et al., 2022). According to Bollard (2015), no studies exist on men's perspective of their health, yet many exist on women's perspectives. Such studies have highlighted issues in women with intellectual disabilities sexual health, such as a lack of awareness of their sexual and reproductive health and contraception (Bollard, 2015; Walmsley et al., 2016; Namkung et al., 2021; Horner-Johnson et al., 2022). Women with intellectual disabilities face health inequalities (Bollard et al., 2018). These health inequalities are widely reported in the literature and include violated reproductive rights (Frawley and Wilson, 2016). Without research on men with intellectual disabilities' perspectives on their experiences of their sexual health, there is a gap of knowledge in this area.

Research has discovered issues with sexual health screening for people with intellectual disabilities (Eastgate and Moyle, 2014; Afshar et al., 2020; Wiseman and Ferrie, 2020). Twenty-one women with intellectual disabilities participated in questionnaires and focus group interviews for a study in Scotland (Wiseman and Ferrie, 2020). Findings revealed they lacked knowledge of breast health and cervical smears, resulting in some women never having such screening and undergoing a coloscopy to remove affected cervical

tissue (Wiseman and Ferrie, 2020). There is little research on screening for testicular and prostate cancer for men with intellectual disabilities (Eastgate and Moyle, 2014). According to Afshar et al. (2020), there is a lack of screening for testicular cancer in men with intellectual disabilities, even though they are less likely to have the ability to perform a self-evaluation. This lack of screening is despite the prevalence of testicular cancer in men with intellectual disabilities being higher than non-disabled men (Hogg and Tuffrey-Wijne, 2008).

A lack of autonomy in sexual health decision-making from people with intellectual disabilities has been reported in studies (Fitzgerald and Withers, 2013; Eastgate and Moyle, 2014; Walmsley et al., 2016; Cytowska and Zierkiewicz, 2020; Horner-Johnson et al., 2022). Frawley and Withers (2013) suggested that carers primarily make decisions. For example, four of the 17 women with disabilities interviewed for an American study on contraceptive decision-making had intellectual disabilities. Three out of the four women with intellectual disabilities had limited decision-making opportunities where the clinicians did not give a choice and told them what to do regarding contraception; one even felt pressured into a contraceptive choice (Horner-Johnson et al., 2022). Interviews with 19 women with intellectual disabilities on their experiences of choosing contraception in a U.K. study found that contraception was primarily chosen and managed by others, where they were sometimes forced or persuaded by others to take the contraception without being given information to make an informed decision (Walmsey et al., 2016). The doctors prescribed contraception to manage the women's menstruation pain, even though the efficacy of this intervention was rarely followed up (Walmsey et al., 2016). Women with intellectual disabilities experience many other barriers regarding contraceptive decision-making. A lack of accessible information on contraception and side effects and a lack of clinicians' knowledge of disability and negative attitudes towards women were found in an American study on barriers to contraceptive decision-making for women with disabilities (Horner-Johnson et al., 2022). Men also experience a lack of autonomy. Eastgate and Moyle (2014) argued that men are sometimes prescribed androgen suppressant medication, such as Cyproterone, in response to inappropriate sexual behaviour, which can have multiple adverse side effects. People with intellectual disabilities are often not given the autonomy to make their own sexual health decisions

as they are infantilised (Cytowska and Zierkiewicz, 2020). A Polish study incorporating focus groups and interviews with 20 women with intellectual disabilities on their experiences and perspectives of their health found that some physicians infantilised them, asking where their mother was at appointments and refusing to examine them alone (Cytowska and Zierkiewicz, 2020).

Women with intellectual disabilities are more likely to be sterilised than women without disabilities (Li et al., 2018). Li et al. (2018) did a secondary analysis of the nationally representative survey of 'Family Growth' between 2011-2015 in America to compare sterilisation rates among three sets of women, women without disabilities, with intellectual disabilities, and with sensory or physical disabilities. They found that women with disabilities were more likely to be sterilised in comparison to women without disabilities, with rates in those with intellectual disabilities (22.1%), sensory and physical disabilities (24.7%), and no disability (14.8%). As well as this, women with intellectual disabilities were sterilised at a younger age (27.3 years) compared to sensory or physical disability (28.3 years) and no disability (29.8 years) (Li et al., 2018). In a U.K. study on intimate relationships, a participant voiced how a parent forced her to get sterilised (Rushbrooke et al., 2014). All these examples of lack of information and choice and coerced medical treatment violate people's human rights. The UNCRPD (2016) sets out in Article 23 that disabled people have a right to reproductive and family planning and the right to retain their fertility on an equal basis to others. As well as this, so others do not discriminate against disabled people based on disability, Article 5 provides for their legal protection.

Despite the control of contraceptives for women with intellectual disabilities, there are increased levels of unplanned pregnancy (Horner-Johnson et al., 2020). For example, a U.K. study that undertook a secondary analysis of the nationally-representative longitude 'Next Steps' study found that young women with intellectual disabilities were more likely to become pregnant (50%) than non-disabled young women (23%) (Baines et al., 2018). One cited reason may be that women with intellectual disabilities are given little to no information on contraception, pregnancy, and sexual health (Namkung et al., 2021). As was evidenced in the sexual health theme above, many people with intellectual

disabilities lack sexual health knowledge. People with intellectual disabilities have violated human rights concerning their sexual health. The following section will explore a specific example of sexual health, pregnancy, and parenting among people with intellectual disabilities.

3.10: Pregnancy and parenting as a person with an intellectual disability:

More studies on the experiences of mothers with intellectual disabilities, in comparison to fathers with intellectual disabilities, were found. Fathers with intellectual disabilities are underrepresented in research studies (Symonds et al., 2021; Cwirynkało et al., 2022; McConnell et al., 2022;). As a result, there is a gap in knowledge on the perspectives and experiences of fathers with intellectual disabilities. There is also a gap in studies focusing on parenting and support that works well; it has instead focused on the barriers. This gap could be due to the lack of literature in this area, but it could also be due to the negative experiences and lack of support that parents with intellectual disabilities face. This theme will explore the supports and barriers to pregnancy and parenting and the effects of such on people with intellectual disabilities.

According to Azzopardi-Lane and Callus (2015), despite the shift in rights for people with intellectual disabilities, parenthood has not been on the agenda. Dorfman (2015) argued that when people with intellectual disabilities announce they want to be or are becoming parents, they usually receive a negative response from others. Many studies have reported that people with intellectual disabilities can parent successfully (Wos and Baczak, 2021). An example of effective parenting was found through the interviews with 20 fathers with intellectual disabilities in a Polish study on the lived experience of fathers and the meaning they ascribed to fatherhood because of these experiences (Cwirynkało et al., 2022). Despite many of the fathers experiencing childhood adversity, growing up with parental alcoholism, abuse, and neglect, they wanted to become better fathers than their own and therefore tried hard (Cwirynkało et al., 2022). Several studies have found that parenting successfully is particularly evident when parents with intellectual disabilities receive parenting support (Strnadová et al., 2019; Tarleton and Heslop, 2021; More and Tarleton, 2022).

However, support is lacking. Most of the fathers with intellectual disabilities stated that they felt excluded from parenting support by professionals, who instead focused on the mothers when they were interviewed in two studies on the perspectives of fathers from the U.K. and Poland (Symonds et al., 2021; Ćwirynkało and Parchomiuk, 2023). Ćwirynkało and Parchomiuk (2023) interviewed twenty men with intellectual disabilities in Poland on their experiences of social support in parenting. The men lacked support for fathering and said they would like economic support in the form of employment, housing, finances, social and emotional support, advocacy for their parental rights, and practical support in helping them to care for their children. This lack of support resulted in them struggling financially, having poor living conditions, and experiencing loneliness from strained family relationships. The fathers stated they felt underestimated, shared negative attitudes, and lacked autonomy in decision-making from their families. However, several men rejected professional support and viewed it as professionals interfering. Participants in a Dutch study on sexuality and sexual health voiced what they would need to help them have a child: material items such as money, a house, baby things, a job, and a good partner (Schaafsma et al., 2017).

Despite the findings that parents with intellectual disabilities can parent successfully with support, there are high rates of child protection interventions and removal of children into care in comparison to non-disabled parents (McConnell et al., 2017; Tøssebro et al., 2017; Strnadová et al., 2019; More and Tarleton, 2022) and when child protection services have taken children into care, contact after that is minimal (Granqvist et al., 2014; Wos and Baczata, 2021). Various reasons have been suggested as to why this is the case, such as others viewing parents with intellectual disabilities as irresponsible due to their intellectual disability (More and Tarleton, 2022). Two mothers in one Austrian study stated that they lost custody of their children due to a combination of factors, such as a lack of confidence in their mothering abilities and because they failed to receive adequate parenting support (More and Tarleton, 2022). Two of the fathers in this study stated they had to fight for years to gain visitation rights for their children (More and Tarleton, 2022). These high rates of child protection interventions are despite the UNCPRD (2006), where Article 23 states the rights of disabled parents to receive support to give them equal access to parenthood. Also, Article 5 of the UNCPRD (2006) provides legal protection to

prohibit all discrimination based on disability and ensure equal treatment. Parents who have not had their children removed have reported high levels of surveillance from child welfare professionals (Wilson et al., 2013; More and Tarleton, 2022). However, participants with intellectual disabilities across different studies also felt they may be unable to be parents.

For example, three of the 20 participants with intellectual disabilities expressed concerns about their ability to raise a child due to having a disability during interviews for a Dutch study on sexuality and sexual health education (Schaafsma et al., 2017). This concern about effective parenting could have been for several reasons, such as lack of capacity, education, support, or resources, or they may have internalised these messages from others.

One issue for women with intellectual disabilities was how they and others reacted to their pregnancy. Wos and Baczata (2021) stated that it can be a shock when the mother has not received sexual health education and lacks knowledge in the area, and they can be scared to tell their families due to the fear they react negatively. None of the seven mothers with intellectual disabilities in a Polish study planned their pregnancies, and it took for the women to be heavily pregnant and family members to notice before the women knew they were pregnant (Wos and Baczata, 2021). This unawareness could be due to a lack of sexual health education. A common finding in the studies was an adverse reaction from family members when a woman with an intellectual disability disclosed her pregnancy. For example, interviews with ten mothers with intellectual disabilities who had given birth within the previous seven years took place for a Swedish study on experiences of motherhood. The mothers were all generally happy about their pregnancy, although many were unplanned (Hoglund et al., 2013). However, many of the women knew their families would not be satisfied, and some family members had previously threatened to overrule their autonomy and make decisions about their pregnancy on their behalf, resulting in some of the women hiding their pregnancies (Hoglund et al., 2013). Family and professional caregivers can pressure mothers to terminate their pregnancy; for example, this happened with six of the 19 mothers in a Czech Republic study

(Strnadová et al., 2019) and two of the six mothers in Austrian research (More and Tarleton, 2022).

Another finding was the concern parents with intellectual disabilities had about losing custody of their children. According to Jamieson et al. (2016), when a woman with an intellectual disability becomes pregnant, her focus is often on her concerns about losing custody; three mothers who interviewed for a U.K. study on supportive decision-making expressed this. One of the mothers terminated her pregnancy even though she did not want to, as she knew Children Services had already decided she would lose custody, as they had taken her previous child. Another mother used contraception against her religious beliefs as professionals made threats that she would lose custody if she became pregnant again. Another participant's parents would not allow her to have contact with her child, which made her feel hopeless. These mothers felt powerless and without a voice, as their family and social services ignored their wishes. All the women experienced fear, anger, and stress, which impacted their decision to seek support, disclose their pregnancy, and engage with services, as they feared their baby would be taken from them (Jamieson et al., 2016). According to Jamieson et al. (2016), this worry can become the central concern instead of the woman focusing on her baby. Mothers with intellectual disabilities shared during interviews for a Czech Republic study on mothering identity that they wanted to be more active in their children's lives but feared losing custody (Strnadova et al., 2019).

When parents with intellectual disabilities lose custody of their children, it negatively impacts them and contravenes their human rights. An example of this is from the mothers with intellectual disabilities losing custody of their children in a Swedish study on women with intellectual disabilities' experiences of motherhood (Hoglund et al., 2013). The mothers said they felt intense love and worry for their babies. However, the threats of losing custody did not impact how these women cared for their babies. They enjoyed breastfeeding, which caused distress when their babies were taken from them (Hoglund et al., 2013). In Polish research with fathers, eight out of 20 fathers with intellectual disabilities interviewed had their child removed or were involved in child protection services (Ćwirynkało and Parchomiuk, 2023). In another study, 7 of the 19 mothers with

intellectual disabilities had their children involuntarily removed from them, which caused them pain, that they shared in interviews for research on mothering identity in the Czech Republic (Strnadová et al., 2019). Family caregivers felt their first pregnancy was a mistake and permitted four women to be sterilised against their will (Strnadová et al., 2019). These are all examples of the denial of human rights, where under Article 23 of the UNCPRD (2006), there are rights to reproductive and family planning, to retain fertility, and to parenthood.

The social support the parents in these studies received had an impact. For example, four interviews with mothers were undertaken in Canada that explored the social support received by women with intellectual disabilities in pregnancy and childbirth (Potvin et al., 2016). This study found that the women lacked support, resulting in social isolation (Potvin et al., 2016). Another example is from interviews with six mothers with intellectual disabilities on their experiences of postnatal support needs (Wilson et al., 2013). Four participants received intensive professional support after the birth and perceived this as intrusive, judgemental, and harmful. Professionals told the mothers what to do authoritatively; the mothers felt their wishes were not respected. This negative support lowered their self-perceptions and capabilities as mothers, and they avoided future support (Wilson et al., 2013). However, those who experienced positive attitudes from others in a Canadian study on social support welcomed more support (Potvin et al., 2016). Some participants in a U.K. study on postnatal support needs received positive feedback from professionals visiting their homes, reassuring them. When the communication was accessible to the mother's needs, they could understand it better (Wilson et al., 2013). These findings provide recommendations for practice on how professionals can best support parents with intellectual disabilities.

How others treat a mother with an intellectual disability can impact her identity as a mother (Strnadová et al., 2019). Interviews took place with nineteen women with intellectual disabilities from the Czech Republic about their experiences in becoming a mother and how their experiences shaped their mothering. Factors that affected the mother's identity included her internal awareness, feelings, and values; attitudes of others, including her social worker and medical professionals; the child's health, the

support from her partner, available resources, and if the child was removed from her (Strnadová et al., 2019).

Mothers with intellectual disabilities experience numerous other challenges when mothering their children. For example, the mothers in a Polish study on parenting (Wos and Baczata, 2021) and a Czech Republic study on mothering identity (Strnadová et al., 2019) discussed some of the challenges they encountered with mothering. Many mothers struggle with raising a child with a disability (Strnadová et al., 2019; Wos and Baczata, 2021). In the Czech Republic study, some mothers lost custody when their children grew older as they found it particularly demanding to care for them (Strnadova et al., 2019). The mothers in both studies had financial issues as they were either on benefits or could only get low-paying jobs due to a lack of education (Strnadova et al., 2019; Wos and Baczata, 2021). In the Czech Republic study, this resulted in the mothers struggling with housing, and as such, nine of the mothers lived in sheltered accommodation and two with their parents. Also, eight of the mothers in this study had been in relationships with domestic abuse, which impacted how they could mother (Strnadova et al., 2019). Other challenges in the Polish research included doing household tasks, learning new skills to care for their babies, and concerns about losing family support in the future (Wos and Baczata, 2021).

A common opinion is that parents with intellectual disabilities are incapable; many mothers and fathers in these studies were good parents but had many barriers. The high proportion of parents who lose custody of their children or are under increased surveillance from child protection shows that more support is needed to keep these families together. Like most themes of this literature review, others deny people with intellectual disabilities their human rights.

3.11: Conclusion:

The literature review findings demonstrated that historically, people with intellectual disabilities were stereotyped as either at risk to themselves or others regarding relationships and sexuality. As a result, their sexual needs went unmet. Although attitudes

have greatly improved with the advocacy of the Global Disability movement, the move from the medical to the social model of disability, and the changes in policy and legislation, people with intellectual disabilities still face considerable challenges in this regard. Caregivers (family and professionals) face a strong tension between empowering people to have autonomy in sexual relationships and safeguarding them from abuse. This is understandable when the prevalence of sexual abuse is much higher for people with intellectual disabilities than non-disabled people. However, the literature demonstrates that denying relationships to people with intellectual disabilities does not decrease this abuse. Also, many people with intellectual disabilities have covert sexual relationships, which may put them at risk. Denying relationships is also denying human rights under the UNCPRD (2006). The research highlights numerous examples of how people with intellectual disabilities' human rights are denied and violated. These violations of human rights include the denial of relationships, a lack of appropriate and accessible sexual health information and education, coerced, and forced medical practices such as sterilisation and abortion, high prevalence of sexual abuse, high levels of child protection surveillance and interventions, and removal of children, homophobic abuse and discrimination, and the denial for people with intellectual disabilities to live how they want.

It was evident that there were many benefits to having relationships, benefits to receiving relationships and sexuality support and education when it is adequate, and parents with intellectual disabilities can parent effectively with support. However, the findings were unbalanced, and there were gaps in the literature, resulting in gaps in knowledge in these areas. The research focused on the barriers for people with intellectual disabilities, which may be because more barriers are experienced than support. However, to improve and inform best practices, more research is needed on supporting relationships, sexuality, parenting and sexual health education. There is also a lack of information on sexual pleasure in the studies, and why this is the case is unknown. There is a considerable lack of research on people with intellectual disabilities who are LGBTQ+. Some participants with intellectual disabilities felt they could not parent effectively. Although it could be assumed that this may be due to a lack of support, education, and negative views towards them, the literature did not highlight why. Another gap identified is why people with intellectual disabilities have positive perceptions of love and negative perceptions of sex.

Although it could be assumed this is due to the influence of others' perspectives and past negative experiences, there is no firm evidence.

The research findings were unbalanced regarding gender. There was a plethora of research on women's sexual health promotion, pregnancy, and parenting, but this research was lacking for men with intellectual disabilities. The reason for this was also not found, although it was assumed that this was due to negative attitudes toward the sexuality and parenting of men.

Overall, on the topic of relationships and sexuality of people with intellectual disabilities, there was a lack of literature in the Irish context from the perspectives and experiences of people with intellectual disabilities. This highlights the need for this study.

Chapter 4: Methodology.

4.1 Introduction:

This chapter focuses on the methodological orientation and the methods used for the design and data collection. I will discuss action research in the context of this study and why it was chosen. The type of action research chosen was co-operative inquiry; why this was chosen and how it was used will be set out. There will be an exploration of the four different types of knowing called an extended epistemology (Heron and Reason, 2001; 2008). The practical steps that took place to prepare before the research team began working together will be explored, including the procedures created and adapted and the sampling and recruitment. I will then describe the concept of the action research cycle and how we, as a research team, experienced this. To end this chapter, the ethical considerations, dilemmas, and concerns will be explored.

The 'participants' in this study stated they wanted to be called researchers. I have called them researchers throughout this thesis except when explaining concepts around co-operative inquiry and planning the study.

4.2: Research framework method:

4.2.1: Action Research:

Kurt Lewin (1946-1948) is known as the originator of action research. His own experiences of inequality due to his status made him understand the types of issues for people belonging to minority groups (Adelman, 1993; Bargal, 2006). Lewin wanted to find solutions to social issues and to develop a theory; this led to the initial formulation of action research when he began publishing on the topic (Bargal, 2006). He was interested in inter-group relationships (Lewin, 1946) and was the first to publish about group dynamics (Burnes, 2004). Lewin worked with practitioners to assess the outcomes of interventions undertaken with minority groups (Bargal, 2006). He realised that understanding group dynamics was not enough (Bargal, 2006). Lewin (1946) believed that social discrimination could only be addressed if we act and include those whom it affects.

He advised that if we genuinely want to understand something, then we need to try and change it (Lewin, 1946). There needed to be a method where people could engage in the process and, in doing so, to bring about change, thus, action research was developed (Bargal, 2006). Lewin (1946) argued that action research would produce more than just books and instead also improve inter-group relations, leading to social action. A group would come together to engage in thinking, identifying barriers, and action by asking themselves:

1. What is the present situation?
2. What are the dangers?
3. What shall we do?

(Lewin, 1946: p. 34).

To prevent continuing to make the same mistakes, we need to learn in the process and evaluate it (Lewin, 1946). Lewin (1946) said that this process should begin with planning by examining the idea and then deciding upon a decision for the first step of action. Next, the first step of the plan should be executed. Afterwards, the action should be evaluated, where the group can determine whether the plan worked and identify their learning. Here they will gain new insights, which will help them to plan for the next stage and to modify the overall plan. This becomes a cycle of planning, action, and fact-finding (Lewin, 1946).

I will now explain what brought me to this practice. Action research is rooted in philosophical viewpoints such as phenomenology, critical theory, hermeneutics, Aristotelian praxis, pragmatism, essentialism, process philosophies, constructivism, and social constructivism (Brydon-Miller and Coghlan, 2014). The ontological viewpoint I came from in this study was social constructivism, which I discussed in Chapter One (Introduction). As a brief reminder, my ontological position is concerned with social constructivism, where jointly constructed perceptions of the world are created, which result in shared assumptions that can impact the concept of identity (Vygotsky, 1978). It is a beneficial concept when analysing disability as it helps the researcher look at influences that shape the meaning of disability (Zolkowska, 2016). Understanding how disability is constructed, interpreted, and experienced helps us to increase social awareness and to understand the reality of labelling and classification for people with intellectual disabilities (Zolkowska, 2016).

To define action research, I drew upon the definition of Kemmis and McTaggart (1988), as this definition fits closest to how I view and do action research and why I chose this approach.

Action research is a form of collective, self-reflective inquiry that participants in social situations undertake to improve: (1) the rationality and justice of their own social or educational practices; (2) the participant's understanding of these practices and the situations in which they carry out these practices. Groups of participants can be ... any group with a shared concern and the motivation and will to address their shared concern. The approach is action research only when it is collaborative and achieved through the critically examined action of individual group members.

(Kemmis and McTaggart, 1988: p.5).

The key elements that stood out to me in this definition that was in line with my research values were that action research is centred on the participants and working collaboratively, focuses on the learning that takes place through the process rather than the end-product, and addresses social justice concerns by aiming for change. As Coghlan and Brannick (2010) discussed, the desired outcomes of an action research project are more than the solutions to the issues that arise but also the learning that takes place in this process and the contribution of this to scientific knowledge.

I will break this definition further by focusing on collaboration, learning, and change. To begin with, the collaboration is a shared experience. Action research is grounded in collaboration and lived experience (Bradbury and Reason, 2003). Participants gather data based on the questions they want answered, with the help of the researcher, and are engaged in decision-making (Altrichter et al., 2002). As Altrichter et al., (2002) outlined, all members contribute equally to the inquiry, where the researcher is a partner working with people experiencing a problem, concern, or interest rather than the researcher being viewed as an expert. This was important for me to achieve because I was aware from the literature and past experiences of working with people with intellectual disabilities that they often do not have power and autonomy in their own lives. If they are to research their experiences so they can have a voice, then addressing these issues in the study is critical. I spoke about the power of this and how it transformed our research team briefly later in this chapter and in Chapter Nine (Discussions, Recommendations and Contributions), and as will be seen, the researchers voiced themselves how important this equality and autonomy in the group was.

The next element is the learning that takes place through the self-reflective inquiry, where Dick (1991) explained that two things happen here, where the participants are researching to understand their problem and they are pursuing action or change at the same time. This is done by the group through the concept of an action research cycle (Coughlan and Brannick, 2014) by first identifying a problem and then interactively and methodologically engaging in action planning, implementing such actions, and reflecting on them (Zuber-Skerritt, 1992). Through this process, the participants are learning by doing and by the challenges, learning, and overcoming obstacles along the way (Altrichter et al., 2002). What they learn from one cycle feeds into the planning of the following cycle, where the action plan is modified and the process is repeated (Zuber-Skerritt, 1992). It is more likely that the outcomes generated are meaningful and accessible to the participants when working in this manner (Barrett and Taylor, 2002). Their conceptual knowledge emerges from engaging in this action research cycle collaboratively (Coughlan, 2016). Conceptual knowledge is knowledge people hold that is expressed through theories and statements (Heron, 1981; Coughlan, 2011). In this study, the group identified a range of topics to explore, explained later in this chapter. In the findings chapters (Chapters Six, Seven and Eight), you will see that we identified five separate issues and aimed to address them all through actions. We were not successful in achieving all our actions immediately, but we continued to work on them together post-PhD as we (all bar one) continued to work together as a research team (see the epilogue for our story beyond the PhD). Zuber-Skerritt and Perry (2002) recommended that to generate substantial knowledge to contribute to a PhD, this means going through two to three major cycles. I identified four cycles that we went through that are documented later in this chapter, although we went through mini cycles within these, where we reflected and acted on the same topic till, we worked it out and moved on.

The next element is about change. As Brydon-miller and Coughlan (2014) have advocated, when change and trying to make a difference are important, collaborative inquiry and action can support this (explored in more depth in the findings Chapters Six, Seven and Eight and Chapter Nine: Discussions, Recommendations, and Contributions). This is where the group take on multifaceted problems, commits to the knowledge and experiences of others, and works together to bring about change (Brydon-Miller and Coughlan, 2014). In

this process, the participants are critical change agents of themselves and the constraints they have identified (Altrichter et al., 2002). This was made evident throughout the process (and which is explained in Chapter Nine: Discussions, recommendations, and Contributions), where most of the researchers voiced that they changed how they viewed themselves and their disability because of their belonging to the research team, where we developed a positive collective disability identity. As well as this, they were highly critical of their issues and worked towards change in these areas with the aim to help themselves and other people with intellectual disabilities through our actions (discussed in the Findings Chapters Six, Seven and Eight).

Altrichter et al. (2002) noted that after participants reflect and act on a situation to improve it, they may make it public. We did this in several ways, by disseminating our findings to the public as part of our actions, (which are explored in the finding's chapters: Six, Seven and Eight and the epilogue).

4.2.2: Principles of action research:

Unfortunately, due to Lewin's death, he failed to methodologically frame the principles of action research (Bargal, 2006). However, he greatly influenced not only this paradigm but also the works of other psychologists succeeding him (Bargal, 2006). I will discuss some of the core principles of action research as set out by Stringer and Ortiz Aragón (2021) which include learning through (and for) action, the importance of reflection, and collaborating in participative research processes.

According to Stringer and Ortiz Aragón (2021) learning through (and for) action is when a group collaboratively construct an understanding of issues and examines actions to enhance these insights. The group can discover a better understanding by repeating the cycles of looking, thinking, and acting. The actions provide the primary source of knowledge. The principle is that if we try to change something in the real world, the response from this will help us learn more (Stringer and Ortiz Aragón, 2021). A good example of this happening in this study is that the researchers repeatedly voiced that others labelled them as 'vulnerable', and as a result, they were denied information to keep themselves safe, making them vulnerable. When we tried to seek this information, a

professional labelled the group as vulnerable, and we were left with no choice but to reject this information as we feared negative consequences. What the researchers previously vocalised was now happening in real-time and provided more learning as it gave us the opportunity to discuss it and work through it together (explained further in Chapter Seven: Lack of Opportunities to Create and Maintain Relationships). Another example is when we tried to seek three sexual health education programmes as part of our actions, and we experienced how difficult they were to access. For the one we gained access to and participated in, we could see how inaccessible it was. Through reflecting and evaluating on this experience, it helped us to work out what we needed going forward.

A second core principle of action research focuses on the importance of reflection to develop insights to inform actions (Stringer and Ortiz Aragón, 2021). This helps the group to develop a better understanding, to learn as they go and to pay attention to why things are the way they are. They can, therefore, make more informed decisions with the aim of improving their situation (Stringer and Ortiz Aragón, 2021). An example of this happening in this study is when the research team became heated when they realised their rights to marriage and children were being denied. Through reflecting on this and realising it was due to other people's perceptions, we acted on this together by creating awareness with different dissemination activities (explored further in Chapter Eight: Perceptions). Another example is where most of the researchers were negative about their disability at the start of the study, but when we reflected on this together throughout the project, we developed a positive collective disability identity (explored further in Chapter Nine: Discussions, Recommendations and Contributions).

A third core principle of action research outlined by Stringer and Ortiz Aragón (2021) is the importance of collaborating in participative research processes. The group are seen as experts on their situation and, therefore should be directly involved in addressing challenges that arise for them. This includes groups that are sometimes overlooked, such as people with intellectual disabilities. The group are engaged in a rigorous inquiry of collecting data, analysing, theorising, action, and evaluation (Stringer and Ortiz Aragón, 2021). This is exactly how we worked, where the research team were involved in every study decision, from design to data generation to analysis, to sharing the findings, and every step in between. People come together who share a problem, and the group aims

to transform their understanding of the issue and work towards resolving it (Stringer and Ortiz Aragón, 2021). We developed five actions arising from the problems we identified. Action research is a collaborative approach to investigation which is democratic, liberating, equitable, and life-enhancing (Stringer and Ortiz Aragón, 2021). The powerful impact this had on the researchers' lives is explained in Chapter Nine (Discussions, Recommendations, and Contributions). The benefits of being involved at this level include developing a deep understanding, building a constructive analysis of their situation, rejecting misconceptions, and creating solutions to their problems to improve their life (Stringer and Ortiz Aragón, 2021). This can help people to feel in control of their own lives (Stringer and Ortiz Aragón, 2021). The group will have a support network and an ongoing resource. This is exactly what the research team have, as we (all bar one) continued our work together as a research team post-Ph.D.

4.2.3: Co-operative inquiry:

I will now explore the method of action research chosen for this study, which is co-operative inquiry, also known as collaborative inquiry. I began by looking at both co-operative inquiry and participatory action research, and they were very similar, sharing many principles and practices. However, co-operative inquiry met the needs of this project closely because of the emphasis on the initiating researcher taking on the role of both co-researcher and co-subject, which I felt may help build a stronger collaboration as power dynamics could be broken down in this way. It later transpired that the researchers said they did not know I was disabled and could see we were all the same, and because we were involved in decisions, it was our group. This atmosphere helped our group dynamics and made for a stronger inquiry group. This was another reason I was drawn to co-operative inquiry; in its full form, the researchers would fully engage in every part of the study: planning, organising, facilitating, recording, analysing, and disseminating, which is not always the case for participatory action research.

The co-operative inquiry method was created by John Heron (1971) and later developed by Reason (1996) who believed that orthodox social science methods excluded participants from the decision-making that helps to draw conclusions but felt that such

participants are self-determining and could be involved (Reason, 1994). Researching in a way that worked towards self-determination is precisely how I wanted to work if the researchers wanted this. It is difficult to talk about issues and not act on them, and many minority groups have low self-esteem, so I believe that working together and building on this may help improve their situation. This did lead to self-determination (and is explored in Chapter Nine: Discussions, Recommendations, and Contributions).

Although the researchers requested to be called researchers, for the purpose of explaining the dual role of co-researcher and co-subject, I will use this terminology here. Co-operative inquiry involves two or more people coming together to inquire on a topic important to them where they are a co-inquirer. This is when they act as both co-researchers and co-subjects, researching their own lives. In this dual role, they work through the cycles of experience, reflection, and action (Reason, 1999; Heron, 1996). In this study, it meant exploring the topic of relationships and sexuality and working towards improving any issues raised by acting on them together. When the researchers acted as co-researchers, they designed and managed the project, made decisions, and reached conclusions (Reason, 1999). When they were co-subjects, they participated in the activity that was being studied (Reason, 1999). In this study, how they were co-researchers is that the researchers decided the topics to explore, chose what methods to use to explore these topics, were involved in all group decision-making, co-created the data analysis method, co-analysed the data, applied for, and were successful with two funding applications to support the dissemination activities and disseminated some of the study's findings. How the researchers were co-subjects in this study is that they attended fortnightly research team meetings for a year to discuss their experiences of the topics, where they researched their own lives, and their individual experiences were the subject of the inquiry. Here, and like all action research projects, there were two primary goals. Firstly, to solve a practical problem, address an issue or interest within the group and second, to generate new knowledge (Zuber-Skerritt and Perry, 2002).

4.2.4: Extended Epistemology:

In co-operative inquiry, during research cycles of reflection and action, the group develop their understanding by engaging in what is called an extended epistemology (Heron and Reason, 2001; 2008). An extended epistemology means there are four different types of knowing: experiential, presentational, propositional, and practical knowing (Heron and Reason, 2001; 2008) (and are discussed below).

'Experiential knowing' happens when a person has an empathetic resonance through direct contact with a person, place, or thing (Heron and Reason, 2001; 2008). Such resonance is vital for the researchers to understand and articulate their experience. In this stage, we brainstormed through discussion to refine a topic of shared importance to explore. However, experiential knowing happened continuously through all research cycles of this study.

What transpired from this experiential knowing was *'presentational knowing'*. We tried to make sense of our experiences by using visual and creative methods to work through our thoughts (Yorks et al., 2007) (which is explored in Chapter Five: Visual and Creative Research Methods for the Data Construction, Analysis and Dissemination). We then shared our creations and engaged in dialogue to try to make sense of this.

Knowing something through theories, ideas, and opinions is called *'propositional knowing'*, which is generally conveyed through informative accounts (Heron and Reason, 2001; 2008). It is the knowing that is grounded through experience and presentational forms (Heron and Reason, 2001; 2008). Through this sharing of the creative work and dialogue, we formed our propositional knowing.

Lastly, knowing how to do something is called *'practical knowing'* and is shown through a skill or capability (Heron and Reason, 2001; 2008). Practical knowing happens in co-operative inquiry when the group apply the methodology to their world (Heron and Reason, 1997). Through the dialogue, we became aware of shared issues; then we discussed why this may be the case and how we may address this through actions.

In co-operative inquiry, knowing is more legitimate if these different ways of knowing are harmonious (Heron and Reason, 2001; 2008).

Knowing will be more valid, richer, deeper, more true to life and more useful-if these four ways of knowing are congruent with each other: if our knowing is grounded in our experience, expressed

through our stories and images, understood through theories which make sense to us, and expressed in worthwhile action in our lives.

(Heron and Reason, 2008: p. 367).

Engaging in ways of knowing helped us to understand our experiences better. We engaged in inquiry cycles, and from this process, we revised the next way that we wanted to explore the experience (Heron and Reason, 1997).

4.3: Power, participation, and agency:

As this was a collaborative project coming from a social justice perspective, the focus on unequal power relationships was important (Yorks et al., 2007). I was hoping that this way of working together would shift the power relations that are usually very strong between the researcher and its 'participants'. I hoped that the research team meetings would be a space for the researchers to foster this power for themselves. I wanted to minimise ways in which the researchers may see me as 'in charge' and ways in which I may unintentionally exert power. I did this by explaining this was the case, by not taking over and ensuring everyone was involved in decision making, by asking lots of questions, by ensuring everyone got to speak and be heard, by sharing roles within the group, by ensuring everything was accessible to everyone, and by being approachable. My role would be as a resource person doing research with the group, less directive than other methods (Stringer and Aragón, 2021). I felt that if I became engaged with the research through active participation with the group, I would learn much more from them, and this would break down power imbalances, which it did (explored further in Chapter Five: Visual and Creative Research Methods for the Data Construction, Analysis and Dissemination).

This meant we would need to challenge existing perceptions of who was seen as the 'expert' and the role of the researcher-researched (Stringer and Aragón, 2021). At the start of the project, the researchers viewed the group as a class and me as a teacher. I corrected them and voiced it was our research team, and I was not in charge, but some researchers still used the terminology. This is probably due to their past experiences in groups where they did not have control and choices, where a person other than them was in charge. After research meeting seven, two researchers approached me and threatened

to leave the group if I did not move the study to in-person because they found it boring talking online and found it challenging to engage with the creative activities fully. They had requests where they would like to have the meetings held and the length and structure of these meetings. I was so pleased that they felt confident to speak out to change the group to how they wanted it to be, which I felt was because of how the group dynamics were. We had to bring it to the other researchers, but they agreed they would also like to move the research meetings to in-person. This was a breakthrough for our group; it transformed us, I was no longer seen as the teacher of a class; we were an equal research team where everyone spoke out and initiated and made decisions. I could soon see this developed everyone's trust and confidence in the group, in each other, and themselves. It also transformed me as an initiating researcher, as to this point, I was so concerned with keeping the group together as I was conscious it was already a small group. It was at this point I decided to let go, whatever was meant to happen would happen and I think this also positively impacted the atmosphere and group dynamics because I was more relaxed.

Reason (1994) advocated for the group to have full reciprocity, where their agency is respected in their ideas and actions. This happened in the study through discussing every decision as a research team and by listening to all ideas. The group members take on different roles and responsibilities depending on their skills and interests (Reason, 1994). When we began, I was facilitating most of the tasks until other researchers felt confident enough to take on roles. As Reason (1999) recommended, it is best to agree on roles early on, but the researchers did not feel comfortable at the start as needed to become comfortable in the research team. As a result, I repeatedly voiced that others could take on the role of facilitation and other roles if they wanted.

After meeting seven of 20, when we moved the study from online to in-person, the researchers became more comfortable. After this day, no one ever called me a teacher again, and no one called the research meetings a class. The researchers spoke out and began to take on roles such as facilitation, asking other researchers questions, providing feedback to other researchers, applying for funding, and putting together written documents. Each researcher's contribution was equally appreciated (Bigby et al., 2014). We as a research team drew on the knowledge and skills within the group, to produce knowledge that we could not produce without the other (Bigby et al., 2014). By

recognising the different roles within the group and by restructuring the level of control, it ensured valuing the contributions of the researchers (Bigby et al., 2014). Very quickly, different skills began to show; for example, one researcher was good at coming up with research questions, another was skilled at listening to other researchers and probing with good questions, two researchers brought humour when we needed a break from the frustrations of difficult conversations, another researcher was creative and came up with new ways to do things, one researcher offered practical solutions to problems that arose, and another researcher asked lots of important questions when we were trying to work through things. The researchers stated this was because they felt listened to and equal, especially after how I had reacted to their requests to change the group, but also because of how the group was and their experience of it. Heron (1999) spoke about such 'chaos', moving from ordered inquiry to a more chaotic form, that if there is a rich connection between the group and if they understand that there can be different meanings and outcomes, then the group can survive this, even in its early days, which can facilitate a new creative order, and this is precisely what happened, and all because of our rich connections and equality.

However, there were times when people needed guidance. For example, they needed questions to be answered if they were unsure of something and had questions. An example of this is when one of the researchers was struggling with how they would make a metaphor to represent their thoughts, and I sat with them and spoke them through it. During these times, I stepped in and supported the researchers with this. I used a light touch approach, offering enough structure to maintain the dynamic while encouraging the freedom for innovation (Yorks and Nicolaides, 2006). However, rather than always stepping in, I tried to get the group involved. This was about empowering the researchers to embrace their sense of agency (Theoharis and Causton-Theoharis, 2008). This was done; for example, when a researcher asked me what to do in a situation; instead of giving them the answer, I asked them to work through it as a group, posing specific questions to help them examine it. This shifted the power and facilitated the acquisition of their sense of agency and participation in the research team.

A voluntary social care practitioner who worked on the project as an assistant moderator and undertook the role of a critical friend. The critical friend's function was to gently

nudge me with the question ‘but why?’ on my actions and who asked me to take a step back when I over-exerted my power in the group.

I used reflective journaling and took field notes at the end of each meeting and in between where relevant, where I critically examined my thoughts and actions throughout the process. This took place to prevent falling into a position that could affect the study, designed to increase awareness of positionality and to minimise potential bias. Reflection also helped me develop my sense of agency and empower the researchers to embrace theirs (Theoharis & Causton-Theoharis, 2008). I was able to track what I was learning on the way, to highlight what was going on and why to continue doing it, as well as tracking what was not going so well and why to avoid it going forward.

4.4: Practical steps before working together:

4.4.1 The ethical process:

As this research topic was considered sensitive in Ireland, the research participants were considered ‘vulnerable’, with the concerns of possible sexual abuse disclosures and due to the nature of collaboration in the research, I spent a significant amount of time working on the ethics application. This resulted in a year’s work and the final document was 91 pages long to include the ethics application and supporting documents. This in-depth work was worth it, I was prepared and confident for almost all eventualities that could happen in the research, the research team were better protected from harm, I was prepared when concerns did arise and acted appropriately, and I passed the ethics application which allowed for this study to go ahead. Later in the study, I applied for an ethics amendment so I could facilitate the actions of the study that were unknown at the initial planning stages. This included a confidentiality agreement for those holding workshops for the research team to sign. Researchers doing similar studies need to factor in this extra time and workload.

This work begun with training. I wanted to feel comfortable to initiate a study on sexual health and to discuss such topics comfortably and appropriately, and in the event of a disclosure of abuse, I wanted to react to this in the most supportive way possible. I attended a 10-day training programme with the HSE (Health Service Executive) that

included one assessment and where I trained as a sexual health facilitator. The main learning I took from this training was how to talk about sexual health topics in an appropriate and relaxed manner. I then undertook a semester-long postgraduate module with the National University of Ireland Galway on Sexual Consent Promotion, Skills, and Practice. The two-hour lecture was every fortnight of the semester, with self-directed learning to do online in between and two assessments to complete. The main learning I took from this training was how to deal with disclosures of abuse, particularly when we practised this through role play, which became very beneficial when supporting the research team. I also became aware of the sexual consent training they offered students which I later set up with the research team at their request. Both courses provided me with the knowledge, skills, and confidence I needed to work to initiate a study on sexual health. I then completed the mandatory GDPR training with the university.

To create and adapt the supporting documents for the study, I did an extensive amount of research. The documents and materials that were devised (and are discussed in detail below) included a letter to prospective participants, a participant information letter, a consent form, a letter to the gatekeepers, a PowerPoint presentation for recruiting for the study, a case of ethics and accompanying cue cards, an informed consent procedure, a stop sign, a confidentiality agreement, a procedure if participants become uncomfortable, embarrassed, upset, or distressed as a result of participating in the research, a procedure for disclosures and retrospective disclosures, and a contingency plan for moving the study online due to Covid-19 regulations.

I developed and adapted procedures to support the research, to prevent potential harm to the researchers. These included the following:

- A procedure if researchers became uncomfortable, embarrassed, upset, or distressed because of participating in the research (Appendix 2).
- A procedure for self-disclosures and retrospective disclosures (Appendix 3).

I asked a colleague who is a social worker to review the latter procedure for feedback. We had a meeting to discuss this after her review. She believed that the steps were in line with HSE procedures but advised I should add retrospective disclosures, which I had previously omitted.

I also recruited several volunteers to support these procedures. A qualified and registered counsellor volunteered to provide counselling for the researchers if they needed it and requested it. I also recruited a volunteer qualified social care practitioner to attend the research meetings to support us where we needed it as a research assistant, and she signed a confidentiality disclosure agreement (Appendix 4). When the study moved to in-person this volunteer left and I recruited another. However, this volunteer instead became a co-inquirer as she did not want to sit in a corner and take notes; it felt natural for her to join the research team; she noted we had welcomed her in this way, so then filled out a consent form (Appendix 5). This work involved advertising and meeting volunteers in the planning stages, and them agreeing to write a letter outlining their role in the study and their qualifications for the ethics application, as well as signing the confidentiality agreement I had devised.

With the help of a critical friend's group (discussed below), I drafted accessible documents for recruitment, such as the participant information letter (Appendix 6) and consent form, as I wanted this study to be accessible to people with intellectual disabilities. This meant using easy-to-read language with large and accessible fonts and accompanying pictures. I sourced funding to recruit a sign language interpreter (which we later did not need to use until disseminating the research as the researchers did not use sign language). However, sourcing this interpreter and obtaining funding took time with online communication and filling out applications.

I then adapted existing methods to explain the proposed research to the potential participants and to ascertain whether they could give informed consent. Firstly, I devised an accessible PowerPoint and found videos made by people with intellectual disabilities explaining collaborative research. I would use both at the initial information recruitment session. People interested in the study were invited to a second information session to learn more. I adapted what is called a 'case of ethics' (Figure 2: case of ethics) with permission from Edwards (2019), who designed the case, to help deliver the information in the second session to potential participants about the study and their involvement in it if they decided to participate. The briefcase holds physical items such as an audio recorder, consent form, magnifying glass, microphone, emoticons, and a key, along with cue cards (Appendix 7) to facilitate discussion on research and research ethics. Those attending

would be asked to choose an item from the case; the cue cards attached to each item facilitate questions, answers and discussion in a non-threatening, creative and accessible way. Using a range of methods helps people with intellectual disabilities remember the information (Dunn et al., 2006) and can facilitate them being involved from the start. This approach (verbal, written, pictures, video, objects) has been identified as helpful for people with intellectual disabilities to recall information (Dunn et al., 2006). The researchers expressed afterwards that they enjoyed the case of ethics session, which helped them learn about the research and what would be involved in a creative and fun manner. They said that they understood the information better than they had when they had gotten the verbal-only information previously.



Figure 2: Case of ethics.

I then adapted an informed consent procedure (by Arscott et al., 1998), which is a procedure to ascertain whether a participant can understand the information they are given and demonstrate that they are competent to and are voluntarily taking part. This

takes the form of a brief questionnaire and a scoring protocol (Appendix 8) where potential participants were asked to attend a one-to-one session and asked specific questions to determine their capacity to consent. If they demonstrated adequate understanding and wanted to participate, they would be recruited for the study. This approach is wholly consistent with an assisted decision-making approach.

Although informed consent is required for every study, participants do not usually need to go to such lengths to demonstrate they can consent. I introduced such measures to this study because there is often a blanket view that people with intellectual disabilities cannot give legally informed consent due to their capacity (Dewing, 2008). I also foresaw that others would see the topic of relationships and sexuality as sensitive. However, capacity legislation (Assisted Decision-making (Capacity) Act 2015) reinforces that people with intellectual disabilities should be actively supported to make decisions.

On the first draft of the participant information letter, consent form, and the documents in audio/ video format, a 'critical friends' group', that is, a group of people who advise the researcher in action research (Herr and Anderson, 2015), were engaged. This group of three individuals with intellectual disabilities (one who was blind, which was good because we did not know what other impairments the potential participants may have) and their support worker were invited to provide advice from a disabled person's perspective. Over several meetings with me they reviewed the accessible documents for the study and advised how these documents could be made more inclusive. These changes included changing the way some of the documents were written to make them easier to understand, changing pictures to make them more relatable so people could understand them, and they gave me advice on how to include video/ audio in a format that would be accessible. This contributed to the final version. They then reviewed the first draft of the questionnaire and protocol of the informed consent procedure. After a thorough discussion, three extra questions were added to the questionnaire to fulfil the inclusion/ exclusion criteria. Thus, the document was developed in consultation with disabled people, and they could assess its suitability.

I then formed a second critical friends' group with two disabled academics and activists in disability studies. We spoke online throughout the study, particularly during this planning phase. They agreed to be a sounding board when I felt challenged or for advice when I was

unsure about something. They also asked me critical questions; for example, they asked if I would disclose my disability or not, asked me to think about the implications of both options and asked why I would choose to disclose or not. They were also a support as had recently completed PhDs, and we discussed our experiences of ableism in academia.

I was now ready to recruit for the study.

4.4.2: Sampling and recruitment:

Self-selection convenience sampling was used to recruit participants from the Northwest region of Ireland, as previous research that has been undertaken on this topic was from other regions of Ireland. I lived in this region, so it was convenient for me to spend regular and prolonged contact with the participants. Initially, it was hoped that 10-20 potential participants would be invited from established self-advocacy groups by contacting two national organisations to help with recruitment. Just as I was about to recruit, one of these organisations closed due to a lack of funding, leaving only one organisation to recruit from. A self-advocate is an adult with an intellectual disability who understands their rights, speaks up for themselves and makes their own decisions to be heard, to have power and control in their life, and to improve their situation (Inclusion Ireland, 2020). It may be seen as a limitation of the study that self-advocates were recruited to participate, as opposed to people not experienced at speaking out. However, because this topic was generally considered in Irish society as 'sensitive', and the group were perceived as 'vulnerable' (they were labelled as such in the university ethics application), and because there is limited research on the area, it was appropriate to initiate research with those who could advocate for themselves. It was important that the participants possessed first-hand experience or perspective on the topic and were willing to problematise in the research group. As a result, there was an inclusion/ exclusion criteria.

Inclusion criteria:

- Be 18 or more years of age.
- Identified as having a mild or moderate intellectual disability when asked during the informed consent procedure.

- Lived in the North-West region of Ireland.
- Be capable and willing to give informed consent by participating in an informed consent procedure and by signing a consent form.
- Be able to communicate verbally and give positive and negative feedback.
- Be interested in discussing the topic of relationships and sexuality.
- Understand the ramifications of the commitment and be willing to commit to the study (time, work, input, responsibility).
- Be comfortable exploring disability and sexuality in discussion and be willing to express their views.

Exclusion criteria:

Prospective participants were excluded from participating if they did not meet any of the above and:

- They cannot consent to take part after undergoing an informed consent procedure.

I also wanted to recruit participants individually rather than through a disability service as the service may be a potential barrier to the study as they may have their agenda. The overall organisation only acted as a gatekeeper, passing information on to people they thought may be interested.

Unfortunately, I was recruiting when national restrictions were enforced due to COVID-19; I had no option but to move the study online because in-person meetings were not permitted. I had already held off the study for months, and there was no way of knowing how long this would last. This restricted the number of potential participants available for me to access as according, to the gatekeeper in the organisation I was recruiting from, many people with intellectual disabilities did not have access to technology or Wi-Fi, were not proficient to attend online meetings and lacked in-person support due to COVID regulations.

I held an online information session using the accessible PowerPoint (Appendix 9) and videos for those interested. For those who requested it, I posted welcome packs (Figure 3).



Figure 3: Welcome packs.

I then held one more session online which was the creative and interactive information session using the 'case of ethics' designed by Edwards (2019), to help deliver the information to potential participants about the study and their involvement in it if they decide to participate. Potential participants were then asked to take at least 7 days to think about whether they would like to participate (the recommended timeframe in the university's ethical guidance).

Those that were interested to take part were invited back for the one-to-one online informed consent procedure (adapted from Arscott et al., 1998) to ascertain whether they could understand the information they were given and demonstrate that they had the competency to, and were voluntarily, taking part.

Four researchers signed up to the study at this point. Before meeting seven of 20, the researchers requested we move the research meetings to in-person and at this time restrictions due to COVID regulations had eased. When we made this move to in-person for meeting eight, two more researchers joined, who had wanted to join now we had moved to in-person, who went through the same protocol as above, but it was in-person instead of online. This is also where the research assistant joined and who also decided they wanted to be in the research team. One of the initial researchers left after meeting eight (which is explored in Chapter Eight: Findings)

We were ready to begin the study.

4.5: Our journey of generating knowledge, reflection, and action together:

4.5.1: The research team:

From April 2021 to April 2022, we had 20 research meetings to collect the data for our study. These meetings ranged from one to three hours, which totalled 28 hours of research meetings; nine of them were online, 11 were in-person, and they were held fortnightly. There were eight researchers in total in the research team. Although the research assistant and I did not have an intellectual disability, we both were neurodivergent with ADHD and sensory processing disorder, so we could relate to having a disability. It worked better that we were involved in the research meetings as co-subjects as well as co-researchers, as this way, we were all equal and all working together rather than me leading the team and the research assistant watching from a distance and taking notes. We called our group the R&S (Relationships and Sexuality) research Team and were all equal members of this team. For a full study breakdown, see Appendix 10 (Research meetings outline, incorporating the research cycles).

It was difficult to break down our work into specific cycles because, firstly, working in this way is not as clear cut; for example, I believe there are cycles within cycles - mini-cycles, where we are always moving forward, learning, reflecting, and acting. Secondly, we followed what Heron (1996) coined as a 'Dionysian inquiry'. Instead of taking a systematic, sequenced, and explicit approach to the research cycles (an Apollonian inquiry), we took

a more impromptu, spiralling, diffused approach, where we creatively responded to the situation as we experienced it (Heron, 1996), this is just how it happened, it worked best for us to have this flexibility as we were new to this and working it out as we experienced it. However, I identified four main cycles to share our journey.

4.5.2: The four phases of action research:

Four phases of action research have been identified by Reason (1994) and Heron (1996). Phase one is where the research team agree on the area of inquiry and puts forward some initial ideas for research. The second phase is where the research team apply these ideas. In phase three, the researchers are fully immersed in their work. Finally, in phase four, the research team returns to their initial ideas and, considering their experience, modify and adopt new ideas (Reason, 1994; Heron, 1996).

I have argued above that this does not happen as neatly as described, but I sought to demonstrate the four research cycles we experienced in the research team.

4.5.3: Action research cycles:

Action research cycle one:

This cycle consisted of the first seven research meetings online. This time was spent getting to know each other, setting ground rules together, and deciding how we would do the research. We had discussions to define what relationships and sexuality meant to us. After some researchers voiced that talking alone was boring and asked if we could use creative methods, we tried art and poetry here to explore the topics (explored in Chapter Five: Visual and Creative Research Methods for the Data Construction, Analysis and Dissemination). When we discussed the general topic of relationships and sexuality, the researchers started to identify the important topics to them. We identified which topics were most important to everyone through these discussions and began exploring them.

These topics included:

- Sexual health education experiences and barriers.
- Supports and barriers to creating and maintaining intimate relationships.
- Barriers to socialising (nightclubs) to meet friends and intimate partners.

We concluded that there was a lack of sexual health information and opportunities to meet people. We identified that this was because others (such as disability professionals and families) wanted to protect the researchers and prevent them from having relationships. We wanted to research why people stopped the researchers from having intimate relationships. Also evolving from our previous discussions, we wanted to explore the following topics more:

1. What is the most popular dating app to find a boyfriend or girlfriend for people with intellectual disabilities?
2. Is it easier or harder to find a boyfriend or girlfriend if you have an intellectual disability, in comparison to non-disabled people?
3. Where is the easiest place to get sexual health education that you can understand if you have an intellectual disability?
4. Why can't we (people with intellectual disabilities) have relationships?

We began researching these topics. However, there were attendance issues for two researchers. This is where they requested the move from online to in-person meetings and requested a new structure, which we did.

During this research cycle, we had discussions on sexual health education, and we identified barriers which were mainly other people restricting this due to their perceptions of vulnerability and wanting to protect the researchers. We decided that we would like some action on this. We wanted to seek accessible sexual health education to include a workshop on LGBTQ+ relationships and a sexual consent workshop. I volunteered to try and source these for later in the study.

Action research cycle two:

This cycle consisted of five research meetings in-person, in a private room we booked in a community centre. At the request of the group, we had a social meet-up in town before we began the in-person meetings to get to know each other better. Now that the group were happy with the structure of the meetings and we got to know each other well, the group began to commit and work together well.

We analysed the data from the action research cycle one and planned for what we wanted to research next (explored in Chapter Five: Visual and Creative Research Methods for the Data Construction, Analysis and Dissemination).

Two new researchers joined in this cycle, and I was worried about how it would impact the group dynamics. However, there were no issues, it brought the group forward as the initial researchers displayed more confidence introducing the new researchers to the team, and the new researchers brought new ideas, insights, and experiences, which gave us a new lease of energy.

We re-visited the ground rules which was good for the new researchers, but it also helped us to re-visit where we were at since we moved the meetings to in-person. This also gave us the space to change the rules to make them more appropriate for in-person research meetings.

As Heron (1990) stated, the ground rules help to establish equality of contribution and preserve confidence. I could see this when the established researchers were explaining the ground rules to the new researchers. Before this meeting I had asked the group how they wanted to introduce the new researchers and one researcher suggested that we bring in our creative materials to help him explain what we have been working on and he facilitated this part of the meeting.

Everyone had different personalities and we all had different skills, and this worked well for our research team. There was a new energy within the group, everyone seemed so excited, happy, positive, and confident. There was some repetition of discussions in these meetings such as repeating topics we previously spoke about, but they provided a good recap, enabled the researchers to get up to date with discussions and activities and then they shared their own perceptions and experiences on the topics they missed. Throughout this time, we built friendships.

The group decided on several topics to discuss which took place in two data analysis meetings and two data collection meetings (topics explored in the Findings Chapters, Six, Seven and Eight.) We used a range of visual and creative methods to do this (explored in Chapter Five: Visual and Creative Research Methods for the Data Construction, Analysis and Dissemination).

We also spoke about how the group was going, where each researcher shared that they felt there was equality in the group, and that they were listened to. The researchers compared it to other situations in their past where they experienced negative language around disability and experiences of bullying and discrimination. This was off track from the topic of relationships and sexuality, but the group felt it essential to voice it given they were comparing them to their experiences of this group.

We then planned what to focus on next to research and how we may do this.

Action research cycle three:

This cycle consisted of two in-person and two online research meetings (the online on request from the researchers due to poor weather conditions and less attendance from some). One new researcher joined in this cycle; he was supposed to start earlier but had been unwell. He brought new energy to the group and brightened our break times with singing and jokes when we experienced an ableist incident and felt heated with one of the topics we discussed (discussed below), so we needed this. He also brought a whole new perspective and experience as he was engaged to be married and was planning a family. In this action research cycle, we concentrated on fewer topics and looked at them more deeply. These were topics that were touched upon in the previous cycle. Again, we used visual and creative methods to explore the topics (explored in Chapter Five: Visual and Creative Research Methods for the Data Construction, Analysis and Dissemination).

When we were discussing online safety, we identified a lack of knowledge in this area that impacted many of the researcher's lives negatively. One researcher suggested we do an online safety course, and everyone agreed, she sourced this for the team in action research cycle four (see Chapter Seven: Findings – Lack of Opportunities to Create and Maintain Relationships).

When we discussed the topic of marriage and children, all the researchers showed heated emotions about this topic, and every one of them spoke passionately about their rights. These two things had not happened before. We decided to spend another week exploring this topic but to focus on rights. In this research meeting, we decided that we wanted to try and change societal attitudes on this topic. We came up with a range of ideas and decided to think about them and revisit them in cycle four.

Action research cycle four:

This cycle consisted of five in-person research meetings. I also met one of the researchers outside of our meeting time so we could apply for two funding applications to support our dissemination activities. This stage consisted of several activities. Firstly, we did our data analysis from the data of the previous cycle, which consisted of discussions on the topics we had covered (see Chapter Seven: Findings – Lack of Opportunities to Create and Maintain Relationships).

We planned for how we wanted to complete the research. This consisted of two of our actions in receiving training, one on sexual consent and another on online safety. We decided what topics to learn about in the online safety training. Unfortunately, we had an issue with the online safety training (discussed in Chapter Seven: Findings – Lack of Opportunities to Create and Maintain Relationships). However, this spurred the group on more with their action from action research cycle three, on creating societal awareness on how people view people with intellectual disabilities. Here, we agreed upon new actions; we decided to present at an international action research conference, make a short film from research transcripts, hold a research seminar at Trinity College Dublin and then follow this with a publication to reach a wider audience.

We spent time planning our dissemination activities. We decided to do these activities after the final research meeting and continue to meet fortnightly until these activities were complete. However, we did discuss topics such as the pros and cons of attaching our faces or names to events and publications to give everyone time to think about their decision.

During this cycle, we discovered we won the two research applications of €7,673.00 that would support our dissemination activities. We also got the news that our abstract also

got accepted at the International Action Research Colloquium 2022. It was fantastic to get this excellent news at the end of the study.

We decided to put the actions about our sexual health education and LGBTQ+ information on hold till after our dissemination activities were complete.

We also decided to spend two weeks reflecting on the project to evaluate it and bring it to an end. To do so, we used visual and creative methods (explored in Chapter Five: Visual and Creative Research Methods for the Data Construction, Analysis and Dissemination).

We prepared for the project's ending and spoke about the possibility that we could continue to be a research team. Everyone but one person wanted to continue with the research team after the dissemination activities. We spoke about what this may look like and planned for it.

To bring all the data together from the previous analysis sessions and to analyse it, we co-created a data analysis method and used this to devise the study's themes and sub-themes that were important to the group (how we did the data analysis is discussed in the next chapter).

We enjoyed reflecting on the last year together, and we were excited talking about the future. One thing that stood out about the research team was the benefit of working in this peer group, where we developed a positive collective disability identity. As Heron (1999) stated, in the inquiry process, participants need the support and challenge of engaging with their peers. He gave an example of how one co-inquiry group he worked with felt the group held the inquiry together; it gave them a space where their experiences mattered to others. This is precisely what happened here, and Chapter Nine discusses this (Discussions, Recommendations and Contributions).

We all voiced we were delighted the group was such a success. Everyone said they had enjoyed being researchers, had learnt a lot from the experience, increased their own self-confidence, built friendships, and were listened to. We had worked hard and were happy with the project. We celebrated this with a meal together. It was the end of this project, but it was not the end.

4.6: Ethical considerations, dilemmas, and concerns:

4.6.1: Disclosures of abuse:

The first ethical dilemma was about the two disclosures of sexual abuse and two disclosures of image-based sexual harassment. Due to my experience with disability studies and practice, I was aware there may be many disclosures due to the nature of the topic. This is why I had previously written the procedure for self-disclosures and retrospective disclosures (Appendix 3) and got it checked with a HSE registered social worker, as well as recruiting a volunteer registered counsellor. I followed this procedure each time and had recently completed disclosure training. All the researchers said they had dealt with these experiences legally and psychologically in the past and did not want to go through this again, bar one who said she would like to avail of the counsellor, which I organised. Because these disclosures were said in a group context, I checked in with the rest of the researchers and offered counselling to them, but they did not want this.

4.6.2: Breaking anonymity through dissemination activities:

As part of our actions, we wanted to disseminate some of the research findings by producing a short film, presenting at conferences, and publishing academically. We had lengthy discussions about whether we wanted our names and faces attached to these and the possible consequences of such. After we discussed it, we thought about it for several weeks before deciding. Everyone wanted their names and faces attached to their work. However, to provide some level of anonymity, when quotes were used, we used pseudonyms and different pseudonyms in the film than we did in the thesis to strengthen this further. We did not act out our own words in the film to provide another layer of anonymity.

4.6.3: The effect on those we included in our discussions:

In our discussions, the researchers spoke about other people in their lives, such as families and disability professionals. Sometimes, these discussions were negative towards these people. These people did not have the opportunity to give their version of events. I have discussed this further in Chapter Nine (Discussions, Recommendations, and Contributions). This study was concerned with the perspectives and experiences of the

researchers with intellectual disabilities and not of others, and their version of reality is valid. However, I would like to acknowledge that others may have other versions of reality.

4.6.4: What happens to the researchers next:

This study made the researchers aware of their rights and how they are sometimes treated wrongly and are more aware of the barriers they face. They are now more confident to speak out. The concern here is what happens when they go out to the real world with these new insights and are more aware of these barriers and denial of rights and cannot do anything about this, and the impact this may have on them. One benefit is that we have continued to be a research team, and we still have each other to talk to. However, one researcher has left the team but we stay in touch with regular social events and discussions in a WhatsApp group, so hopefully, this provides the space for people to continue conversations when we need them. The group are now aware of the support available to them if they need it outside of the research team.

4.7: Conclusion:

Action research enabled us to work collaboratively, ensure the researchers were at the centre, and focus on the learning concerning social justice issues. By forming a co-operative inquiry group, the researchers were authentically involved in all decisions and stages of this study, from design, to data generation, to analysis, to sharing the findings, and every step in between. The elements, such as listening, inclusion, equality, accessibility, and collaboration, broke down power imbalances and resulted in a successful co-operative inquiry group. The research cycles of learning, reflection, and action helped us to work together to identify our issues, discuss them and then address them. The next chapter will explain the visual and creative methods we used to help us with the learning, reflection, and action, to construct, analyse, and disseminate this research.

Chapter Five: Visual and Creative Research Methods for the Data Construction, Analysis, and Dissemination:

5.1: Introduction:

In research meeting five of this study, Chloe and Louise (researchers) said they found talking online boring and asked if we could address this. After a discussion, we concluded that we could use creative data collection methods. Some of the researchers had experience in art and poetry, which they enjoyed and liked the idea of incorporating this with research. We discussed how we may do this. The other researchers agreed that they would like to use creative methods. This chapter will examine what methods we employed, why we chose them, how we used them, and the benefits and limitations we experienced.

Visual and creative methods in research use artistic mediums to produce and represent data. We used visual and creative methods for the study's data construction, analysis, and dissemination. During data collection, creative methods can facilitate the elicitation (Bagnoli, 2009) and understanding of a social experience (Gauntlett, 2007). Instead of answering a researcher's question verbally, the participant is asked to make something in response to a prompt to help explore a topic (Mannay and Turney, 2020). Here, the participant slows down, thinks about it, and then produces something as a representation (Mannay and Turney, 2020). This results in a conversation being constructed between the researcher and participant rather than the researcher drawing information from them in a less structured, and a more relaxed and informal way (Rainford, 2020).

Creative methods and participatory research are commonly undertaken together (Brown, 2022). They are both similar and complement each other, in that they both work towards radical, politically grounded social justice and aim to minimise hierarchies and break down power differentials between researchers and participants (Brown, 2022). However, as Brown (2022) argued, employing creative methods does not always transform into participatory research. In this study, the researchers requested we use creative methods and chose which methods they wanted to use. However, they mainly looked to me to

facilitate these methods. I was also concerned about how effective these methods may be with people with intellectual disabilities and how appropriate they would be to use on this sensitive topic of relationships and sexuality. For example, people with intellectual disabilities have reduced IQ and sometimes have challenges with communication and abstract thinking, so I was concerned if they would understand the concept of creating a representation or metaphor to signify their thinking. I will discuss this more in a later section below, where I critique how the methods went when we used them. I was also concerned about what may come up for the researchers when discussing sensitive topics and if the creative methods would work. I wanted to stay true to the principles of co-operative inquiry. This meant I would be conscious of my role, responsibility and impact when facilitating the creative methods (Brown, 2022), positioning myself critically, reflexively, and transparently (Brown, 2019).

Kearns et al. (2021) suggested that creative methods were brought about to include participants in the co-production of knowledge in an accessible way. However, when reading academic texts on creative methods, they were generally not explained as being used with people with intellectual disabilities specifically or the topic of relationships and sexuality. Through a literature search, I discovered two recent studies that had employed creative methods with participants with intellectual disabilities in inclusive studies on relationships and sexuality. For example, Sitter et al. (2019) study explored sexual health experiences and perspectives of nine self-advocates with intellectual disabilities over a 12-month project. They began planning this participatory action research study together through research meetings and then made 14 short films about sexual health, love, intimacy, and sexual rights for people with intellectual disabilities. The group began by creating collages using photographs, magazines, drawings, and pictures to explore sexual health topics they wanted to research. Themes then evolved from the discussion of these collages. They then made a storyboard on a poster to represent their themes. This aided them to decide the film topics, who to interview, and the types of questions they would ask. The group also co-analysed all their data at the end of the project by looking at the data, discussion, and reflection, and they decided on the study's overall themes and sub-themes. They then used these films as an advocacy tool in the community (Sitter et al., 2019). Also, Rojas-Pernia and Haya-Salmon's (2022) Spanish study explored the

importance of social relationships and loneliness among people with intellectual disabilities over an 18-month project. They used audio-visual material, visual representation, murals, third objects, image theatre, photographs, and body mapping. Their article explored how they used the latter four creative methods. Third objects is when the participant brings a made or found object to represent a question prompt. Image theatre is where people use non-verbal language through their bodies to express their perspectives or experiences on a topic (Rojas-Pernia and Haya-Salmon, 2022). This method is common in inclusive research studies with people with intellectual disabilities to explore socially unjust experiences (Ignagani et al., 2016). After a scene is made on a chosen topic, the group discuss it. They took photographs of these scenes to represent their ideas. They used the photographs to help them discuss topics and view how they communicated and occupied space using facial expressions and the body. In body mapping, an outline of a life-size body is drawn on paper to represent their own body, and in response to questions, participants add images, words, and symbols to the drawing of the body. In (Rojas-Pernia and Haya-Salmon, 2022) study, it was used to help participants express what they felt and where they felt loneliness. According to the researchers (Rojas-Pernia and Haya-Salmon, 2022), these methods facilitated inclusive and collaborative inquiry rather than data collection tools. We however were hoping they would do both, help us collect data and to facilitate research that was collaborative and accessible. I could see from these studies that the creative methods helped elicit the data and increase collaboration and inclusion. However, I did not want to choose the methods and had to be conscious that some methods would not work due to COVID restrictions, such as image theatre, where people may touch or stand too close. However, it was good to see that creative methods were used in similar studies, in co-produced research with people with intellectual disabilities and on the topic of relationships and sexuality.

5.2: Aim and objectives of using visual and creative research methods:

After the researchers requested creative methods, we discussed why we would use them to ensure they would facilitate our research. The aim and objectives of using the visual and creative methods in this study were the following:

Aim:

Visual and creative research methods were used in this study to help us as a co-operative inquiry group to explore, reflect, and communicate our perceptions and experiences on the chosen topics, to aid the elicitation and analysis of the data, and dissemination of the findings.

Objectives:

- To facilitate the exploration of the topics and the elicitation and analysis of the data.
- To keep the research meetings interesting, fun, and engaging.
- To make the research more accessible to facilitate an inclusive and collaborative inquiry.
- To keep the research meetings more relaxed so the researchers felt comfortable talking.
- To distribute power in the group and ensure the research was led by the researchers.
- To support us with disseminating our findings to meet our actions.

5.3 How we employed the visual and creative methods:

When we began trying creative methods, we were working online due to COVID restrictions. Because our online research meetings were only one hour long and the researchers wanted to keep this time the same, they chose a creative activity and topic to explore and create in their own time and bring it to the following research meeting for discussion. For example, the first suggestion came from Chloe and Hermione (researchers), who wanted to write a poem or create an art piece to represent our sexual health education experiences. However, most researchers had yet to work on their piece when we met in the following meeting. Most said they forgot or did not have time, and Hermione said she found it difficult to represent her almost absent sexual health education in an art metaphor. After trying this process for a few research meetings and it not working, in meeting seven, Chloe and Louise requested we move the meeting to in-person and increase them to two hours so we could engage with the creative activities

more efficiently. They said they would leave the research team if it did not happen, as it was not working for them in the online format. The other researchers said they were happy with online or in-person but would prefer in-person, and COVID restrictions were eased at this point, so we changed. When we met in person we started with art, and it worked well but after that the researchers could not think of other creative activities and asked for suggestions. I spoke to them about various alternatives, and they decided which ones they wanted to try. For example, we discussed photovoice (taking a photograph to represent a response to a prompt), walking research (an interview while walking outside), and making up a song on a topic. The group were not interested in these creative activities but tried others (which are described below). Also, the researchers were initially not interested in rap, but later, Bruce and Ellen (researchers) suggested we try it, and the other researchers agreed. Near the end of the study, through discussion, Alice, Ellen, and Louise (researchers on the team) suggested a method that I had not heard of before. After some research, I realised this was a method called third objects, where a made or found object is brought in to represent a research question; they also devised a research question to reflect on relating to the third objects.

We chose one different topic to research for each research meeting, along with one creative activity to explore that topic (explained below). Sometimes, we needed more time, so did this over two research meetings, and with the nature of action research and reflection, we often revisited themes. We met for 20 research meetings fortnightly for a year. Research meetings 1-7 were online, and then we moved to in-person research meetings for the remainder of the study, except for two other meetings we held online due to poor weather conditions (please see Appendix 10 for a full breakdown of this study).

During the first hour of our research meetings, we engaged in art and drawing, participant poetry and rap, creative performance and practice, joint sandboxing, *LEGO® SERIOUS PLAY®* and third objects. Art and drawing helped us make images during each data analysis phase and when we explored the topic of marriage and children. In poetic form, we wrote short poems individually on our experiences of sexual health education and together as a group reflection at the end of the study. We wrote and performed raps in groups to consider our thoughts on online safety and how the video game *Grand Theft Auto*

influenced our perceptions of sex work. We used a drama activity to examine the topic of marriage and children for people with intellectual disabilities. We made a short film to disseminate some of our research findings on this topic. The final three creative methods were used to facilitate our final reflection on the project to evaluate it: what we had learnt, what we had taken away and what our hopes were. We were aware that we reflected throughout the project. As Bray et al. (2000) stated, the process of co-operative inquiry is not linear, mean-making happens over an extended period of engaging in the cycles of planning, action, and reflection. Learning, discovering, and mean-making were all intertwined (Bray et al., 2000). However, we decided as a group that we would like to spend a few research meetings reflecting and evaluating the project before it finished and to bring it to an end. We decided to use three creative methods to do this. For joint sandboxing (Mannay, 2019), we created scenes with sand, water, figures, and objects in response to reflective prompts. Through *LEGO® SERIOUS PLAY®* (Gauntlett, 2007), we built metaphors based on reflective prompts. Third objects are where an individual uses an object as a point of reference to focus on (Winnicott, 1968), which can help frame the topic and lead the conversation (Kara et al., 2021). We each brought a made or found object to the research meeting as a point of reference to a discussion prompt. After creating each of these visuals, we shared them with the group and engaged in a discussion to help draw out a shared understanding of these topics. Each of these methods is described in detail later in this chapter.

We sat around a large table to work individually on our creations, except when we wrote raps, a news story, and a poem in groups. Rainford (2020) recommended building rapport with participants and removing the researcher's gaze, so they do not feel watched while creating. During each activity, Alice (a research assistant and researcher on the team) and I worked on our creative pieces, which removed this gaze. We helped address some of these potential barriers, along with helping to dismantle perceived hierarchies as we all worked together. As the act and content of some of these creative methods may have exposed the researchers, we ensured that we were spread out enough to work without others seeing (Kearns et al., 2021). I explained to the researchers that they should only share their final piece if they felt happy.

In the initial stages, I facilitated the research meetings and creative activities until the research team felt comfortable either facilitating individually or contributing to the facilitation when they wanted. An example of facilitation is when Bruce (researcher) suggested he facilitate a session to introduce two new researchers to the team. Bruce decided to bring all the creative activities we had created and use them to help facilitate a discussion with the research team so the previous researchers could explain what we had discussed and prompt the new researchers to add their thoughts. This session worked well. Not everyone wanted to facilitate; for example, Ellen (researcher) said she would like facilitation training in the future as she did not feel confident to facilitate now. However, Ellen was the researcher who probed other researchers with the most questions as they spoke. She also took the lead on how we should do one aspect of the data analysis (discussed below), and along with two other researchers devised a creative method and question to research, also leading out on applying for two funding applications and organising room bookings to work on them. All these activities could be considered as methods of facilitation. I did agree to meet some of the researchers individually between team meetings to help support them plan for their facilitation, but something came up each time where they had to cancel.

The visuals did not speak for themselves (Lomax et al., 2011) but complemented the discussion (Rojas-Pernia and Haya-Salmon, 2022). As this was a collaborative project, I did not want to give this data my interpretations, so we needed space to discuss what we had created. Some researchers liked to talk while creating, which gave us the opportunity to ask questions and engage in discussion on the topic (Hickman Dunne and Pimlott-Wilson, 2021). The second hour of the research meeting was dedicated to sitting together, sharing, and discussing our creations and interpretations to explore their meaning, followed by a shared discussion from us all. Creative inquiry assists experiential learning and group discussion, and such methods can help uncover mutual understandings in the group (Rojas-Pernia and Haya-Salmón, 2022). They can aid in seeing the participant's way of seeing, through developing shared meaning (Kearns et al., 2021). Whincup (2004) draws on the work of the philosopher Dilthey (1833-1911), who asserted that people understand themselves and the world through interactions and expressions. This means that people learn through making their symbolic items, but also when they consider them

with other symbolic items (Gauntlett, 2007). We found all of these to be an advantage. Because we felt relaxed and enjoyed creating and discussing, we quickly built relationships that resulted in more in-depth findings as we were comfortable sharing. We found that when we discussed the visual, the account was much more detailed than when we did not have a visual (Kearns et al., 2021). All these discussions were recorded digitally to create a transcript.

We also photographed the visuals for reference. These were later used during the data analysis phase to help remind us of the discussions and for dissemination which brought our verbal presentations to life and helped us demonstrate what we did. Wahl (2014) noted that photographs are a powerful tool to show what has happened. However, the primary focus of the findings was the dialogue and reflection, not the photographs. What worked well was using creative methods to access personal experience (Gauntlett and Holzwarth, 2006) to take away from direct questioning and tap into unspoken narratives (Rainsford, 201). I asked permission to photograph the creative pieces on every occasion and explained that they could be used in the thesis publications and presentations about the research. Ongoing consent was sought to disseminate the work (Kearns et al., 2021).

5.4: Methods used for data collection:

5.4.1: Art/ drawing:

Art or drawing involves the participant creating a visual using various materials. We used art-based methods in two data collection meetings and each data analysis meeting. In these research meetings, I provided a range of art materials (which can be seen in Figure 4), such as paint, paint brushes, Biro[®], blackboard markers, colouring pencils, crayons, felt tip pens, glue, glitter, scissors, Blu Tack[®], Sellotape[®], different sizes of coloured paper, people cut-outs, magazines, and newspapers. One participant brought in her box of art materials. Researchers could draw, write, collage, stick things on, cut things up and paint.



Figure 4: Art materials.

I will provide an example of a study that used art to collect data that helped me to consider the possible benefits and limitations of such an approach and explain how we used arts-based methods in practice. Kearney and Hyle's (2004) study aimed to explore the emotional impacts of leadership change on school staff through drawings and one-to-one interviews. Participants in their study drew a picture to represent what the change was like for them. Afterwards, they participated in an interview to verbally explain the drawing interpretation and then had a later interview to discuss their experiences using drawing as a research tool. Kearney and Hyle (2004) found consistency between the verbal interpretations and the drawings, but in most of the drawings, the meaning would not have been understood without this verbal account. In our study, we found the same; the researchers gave their interpretation, as the art was only being used to help elicit the information and not being used as a finding. However, we discussed our interpretations as a group rather than one-to-one, which Kearney and Hyle (2004) suggested is an area for further research. Kearney and Hyle (2004) also found that the drawings gave a succinct presentation of the participant's experiences and an honest and meaningful verbal report.

However, most of the participants in their study displayed resistance to drawing (Kearney and Hyle, 2004). Reasons for such resistance include that drawing is not as typical as other creative methods in research with adults (Kara, 2015) and is not suitable for all groups, mainly when participants may be concerned about artistic ability (Rainford, 2020). This did not seem an issue for the researchers in this study, although a few commented about their artistic ability; they requested to do art as it was a method, they do in disability services. However, I provided a range of art materials where the researchers could engage in a method of art that they felt comfortable doing; for example, they could cut pictures from magazines and stick them onto a page rather than drawing. Rainsford (2020) suggested spending more time to support participants in addressing their fears, reassuring them it is not about what the art looks like but as an aid for exploration and discussion. This is something that was discussed before each art session.

We used arts-based methods in several ways in our study. The first time we used them, we drew a logo to represent our research team; however, we were working online at this point, and only Bruce and I did this creative activity. However, the two art pieces were used as a prompt for the whole group discussion. It did result in an interesting discussion of our perceptions of belonging and equality in the group. For example, the researchers stated that they felt that it was their group, that they felt listened to and had a voice, which they did not feel in other groups. They felt everyone was the same; no one was in charge, and everyone was friendly. They also noted that the group was fun. Interestingly, Bruce's logo (Figure 5) was shaped like a circle to represent our group and how he visualised us as together and equal. When he brought in his third object at the end of the study, he made a similar representation, stating that he thought it was fun to meet up because he enjoyed the conversations and felt it was our group and we had gotten to know each other very well (Figure 6).

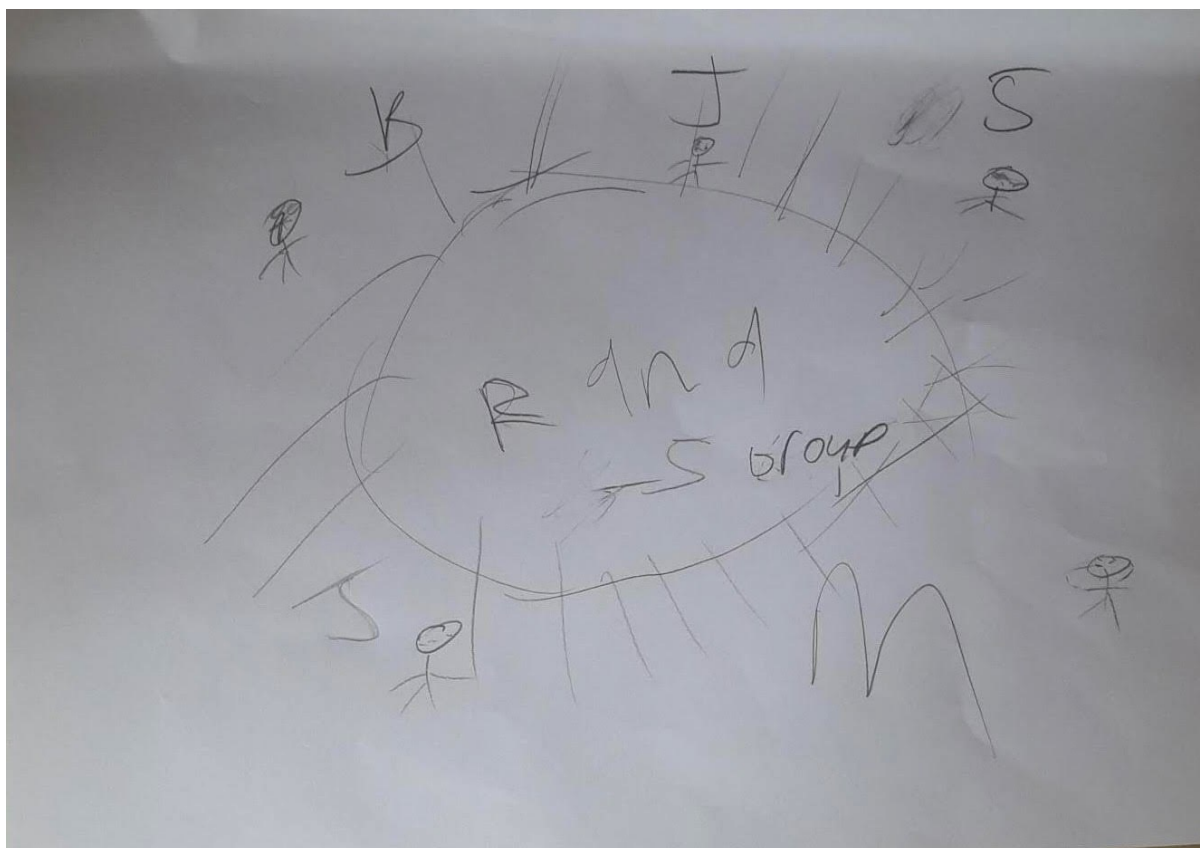


Figure 5: Bruce's logo to represent our research team.



Figure 6: Bruce's third object to represent the biggest thing he was taking away from the study.

The research team were more engaged when we used art in person. The arts-based method was used in all the data analysis sessions and is explained in the data analysis section later in this chapter. In one research meeting, we explored the topic of marriage and children through drama at the research team's request. The researchers wanted to focus on this more in the following research meeting but to hone in on disability rights on this topic. This was the one time we had not planned a creative activity because the group's discussion in the previous research meeting developed into them talking about their rights being violated, and they got upset and heated about the topic. There was no time at the end to plan for the next meeting; it was more important to discuss what was going on at that point, as I did not want anyone to leave the research meeting upset. As a result, I chose the creative activity. In the previous research meeting, the researchers debated doing drama and art, and we had just done drama, so I decided to create an art activity and linked it to the topic they wanted to discuss. The researchers had been talking about their rights concerning marriage and children and how they wanted to live but how their rights were being denied and violated. I found a worksheet to write or draw on, representing how an individual wants to live, what stands in their way, and what support they need. After each researcher completed the worksheet, they shared it and verbally expressed their views, followed by a group discussion. I found in this creative activity that the researchers did not engage with the range of art materials and mainly wrote on the sheet instead of making a visual. They did not seem to have as much interest in art in this research meeting as when we used it in the data analysis research meetings. However, this was near the end of the study, and we had used art a lot at this point. The worksheet's instructions were to write or draw the answer, which may have influenced the researchers to take the writing option. The topic was also very important and emotional. I think the researchers just needed to talk about it as they had used a creative activity the previous week to consider their thoughts on the topic. Also, they had not chosen the activity, I had, so this is probably another reason why it did not work as well. In hindsight, I could have contacted the researchers before the meeting to gauge ideas for the creative activities. However, even though they did not draw much, the worksheet questions did help us to have a discussion and helped us finish this topic and work through our feelings around it,

so it was a success. It also helped us to work out a significant action (Discussed in Chapter Seven: Findings: Lack of Opportunities to Form and Create Relationships).

5.4.2: Participant poetry:

Participant poetry can be used as a research method to develop a small story that shows the bigger picture; in a few words, poetry can help participants understand their world better by focusing on a lived experience theme (Eshun and Madge, 2021). The poetry does not need to be perfectly crafted; it is used for the research tool and not the end product (Madge, 2014). Poetic practices can help express identity, relationality, and inequality (Eshun and Madge, 2021). Madge (2014) explained that poetry can be a portal into the inner world of the person writing it, resulting in an emotive analysis of life, from a particular perspective. It can then show the authentic voice in research (Eshun and Madge, 2021). According to Eshun and Madge (2021), researchers who have used poetic forms as a research tool have found benefits in doing so. Poetry can be emotive and embodied, resulting in deeper understanding, empathy, and diverse perspectives (Eshun and Madge, 2021). It can provoke imagination, leading to unanticipated directions (Eshun and Madge, 2021). The process supports broader critical reflection, as it can be about more than the self; it is about life's social, political, and economic components (Eshun and Madge, 2021). When Chloe (researcher) suggested to the research team that we try poetry, I was concerned about how it would go. I knew she was experienced in poetry but envisaged it would be difficult for anyone inexperienced, who may not grasp this task when working alone from home. I suggested we should have an option of two activities to make it more accessible. Hermione (researcher) suggested the option between art and poetry, and the other researchers agreed.

The first time we used poetry, we agreed that we would either write a poem or do some art to represent 'our experiences of sexual health education', at home and then bring it back to the group to share and discuss. We hoped that doing the poetry or art would help us to think about our experiences of past sexual health education. Poetic practices are not just used to represent individual subjective experiences, but as a tool to engage critical discussion when sharing with the group (Madge, 2014). Poetry can help show another

person how it feels to experience something from another perspective (Madge, 2014). It can also be beneficial to the person writing it as it helps them to reflect on their experience and helps them to discuss this with the group. For example, Bruce shared that writing his poem helped him to realise that safety regarding sex was an important topic to him. According to Eshun and Madge (2021), the poems themselves are not data to analyse, but instead used as a tool to evoke imagination and to bring the experience to life. Only I and Bruce wrote poems, and no one brought art. However, we shared our poems, and it led to an in-depth discussion on all our experiences and perspectives about sexual health education. What led to this were the actions to seek sexual health education, consent training and information on LGBTQ+.

At the end of the study, we decided to write a poem together to reflect on the experience. Ellen (researcher) suggested it as had said she had never written a poem before and did not know how to do it, but she wanted to try it. We made up the method of doing it as we went along. We decided to write a few lines each on how we felt at the end of the study and see if we could put it together. After we had finished writing, we put our scraps of paper on the table and moved them around till we found an order for them. Then, we edited them to fit together and played with a title until we agreed. We were all so pleased and proud of the poem that we made together, and that represented our work on this research team together (see epilogue).

There are many other poetic forms, such as limericks, free verse, and rap (Eshun and Madge, 2021), and when the group were in person, they decided to try rap.

5.4.3: Rap:

Rap is a creative and original method for participants to have their voices heard (Byrne et al., 2020). From the literature searching, I could see it was rare for it to be documented as a research tool; more commonly, it was used in social/ youth work, and when it was used in research, rap was used with children or young people. The method can facilitate the expression of views that may be difficult when using conventional data collection methods (Byrne et al., 2020). Rap needs fewer skills than other musical forms, such as singing and

playing musical instruments (Ringsager, 2015). If participants resonate with lyrics and music, it can result in more accessible, inclusive, and participatory research (Dickens and Lonie, 2012). Rap can enable participants to learn how to articulate themselves (Ringsager, 2015) and help them be heard and understood (Ringsager, 2017). Rap has been found to address the lack of individual social agency by giving participants the opportunity to reflect upon themselves and their position in society (Ringsager, 2015). Using lyrics to express representation, the participant's narrative accounts lead to greater reflexivity and insight into their experiences (Dickens and Lonie, 2012). Sometimes, it takes the reflection process and performance to notice something in plain view, what O'Neill (2012) calls 'transformative music engagement'.

We decided to try out rap and chose to research two topics for this method. The previous week, the broad topic of online safety came up, and as part of that topic, the influence of Grand Theft Auto on our perceptions of sex workers was discussed. We wanted to delve into these two topics more. On the day, we decided to split into two and devise a rap based on the topic of most interest to us. We first listened to a few backing tracks we searched on YouTube till we found one we were happy with. We were then ready to sit with our groups and write lyrics on our chosen topic. I joined one of the groups but helped both groups. When this was done, each group took turns performing their rap to the other group. After each rap, we had a whole group discussion on the topics.

Byrne et al. (2020) used rap as a creative method to stimulate and understand perspectives and experiences in their research study. They found that it was an effective data collection method that produced valuable data. We found the same in our research; for example, in the previous research meeting, the topics of online safety and the influence of Grand Theft Auto on our perceptions of sex work came up, but the discussions were very brief. Creating raps and later discussing them helped us to unpick them more. Dickens and Lonie (2012) also used rap as a research method and found it can be a fundamental means of self-expression for those with low esteem or confidence or who lack cultural validation. However, rap does come with its challenges. Rap is associated with violence and sexism and may exclude marginalised groups further due to its label as music for low-status groups. However, it has been used as a tool for oppressed groups in

political communication, known as ‘raptivism’, and as a social movement (Ringsager, 2015; 2017). The research team did not voice any negative experiences of rap, although I could see Hermione was shy, as she often was in the research meetings. When it was their group's time to perform, she asked if they could perform it without the music as she felt more comfortable, so that is what they did. The method can also help participants voice how identified issues can be addressed (Byrne et al., 2020). Through the raps we wrote and performed and the discussions after, the research team decided that their online safety was neglected but important to them. As one of the actions of the study, we decided to seek online safety training. Rap was a very useful method to help us to uncover this.

The researchers said that they enjoyed the method, and it helped them to discuss it more in a fun way. One issue we encountered was that the room was noisy, with two separate groups talking and rapping simultaneously, so these discussions when the raps were being created were lost in the recordings. It would have been better to work together or in two different rooms. However, we had the opportunity to discuss everything as we came together as a whole group, and as explained later in this chapter, after each research meeting, the researchers had the opportunity to be involved in the data analysis and could add any important absent data.

5.4.4: Creative performance and practice:

Creative practice is an embodied form of creativity and interpretation (Gwyther and Possamai-Inesedy, 2009), which enables participants to act on the world (Denzin, 2003), by exploring a social issue (Narbed, 2021) with the aim to change it (Denzin, 2003). As another layer, there is the choice to act it out as a live performance with an audience. This method is drawn from the work of Augusto Boal's (1993) Theatre of the Oppressed (Gwyther and Possamai-Inesedy, 2009). For this method, the participants use drama to elicit and represent their experiences on a topic. Together, they form a dialogue on a common theme. They then act this situation out and ask the audience to join in on the stage with the acting out and dialogue in the problem-solving of the issue. Researchers using creative performance and practice as a research tool have found benefits. Working

in this way can help build relationships, open ways of knowing and enable working towards change (Narbed, 2021). This can challenge unequal power dynamics (Narbed, 2021). Research becomes imaginative and playful (Narbed, 2021). Performance can help express new insights and conversations (Angeles and Pratt, 2017). It is about the process rather than the end product, emphasising the co-production of knowledge (Narbed, 2021). We found that the drama helped us to tap into an emotive topic; it turned out to be the topic that the whole research team was most passionate about. We also used drama to try and change the issue through one of the study's actions.

We decided to use a similar method to Theatre of the Oppressed for this research, where we used drama as a tool to collaboratively research the topic of marriage and children for the researchers. One of the researchers initially suggested we do art, but others in the group voiced we did art so much already and wanted to try something new. Louise (researcher) suggested drama. Louise agreed to meet me before our next research meeting to prepare what drama activity we would do so she could facilitate it, but it later transpired she could not make the meeting. I was left to come up with an idea myself. Due to COVID regulations, I decided to avoid using drama with non-verbal scenes (something I had experience in) as it is more challenging to navigate when social distancing. I had to be creative and devise a drama activity; I made a TV from a cardboard box (Figure 7). Unfortunately, due to a storm, the researchers requested this meeting be online instead of in person. It was a little harder to navigate online as I could not share the box, so we agreed I could use it to perform their script. As a group, we developed two news story scripts, one on marriage and the other on having children. I put the box over my head and played the Irish news introduction music when this was done. I then read their transcribed verbatim script in a news reporter's voice. Through this method, the researchers could hear their words through my performance and further reflect, respond, and discuss their thoughts.



Figure 7: TV for creative performance and practice.

This experiential process of creative practice can lead to unpredictability (Narbed, 2021), which it did in this case and led to actions for the study. What is important to mention here is that in this research meeting, everyone became heated and passionate. I had never heard the researchers swear or use the word 'rights' before (which they repeatedly did in this research meeting). I wondered if this had to do with the topic or because of the activity as a news report. In the following research meeting, I asked the research team why this had happened, and they said it was because of the topic and the emotions it evoked due to their rights being denied and violated in something so important to them. This is discussed in further depth in Chapter Eight: Findings: Perceptions and Chapter Nine: Discussions, Recommendations, and contributions.

At this point, we made no plans to further perform the piece as, unlike the theatre of the oppressed method, we were using drama as a creative method to collect data like the other methods. Focusing on change can create risk (Rayner, 2017); as stated earlier, it is about the process, not the end product. As a result, we did not discuss going any further with our performance piece.

However, when we were planning one of the study's actions, an awareness event on the right to marriage and children for people with intellectual disabilities, we decided that we would use drama as a creative method to disseminate our research findings to reach a wider audience. Creative dissemination means that the research may reach others it would not usually reach outside of academia, which helps to bring the research or issue to life (Narbed, 2021). This becomes a powerful platform to represent and hear the participant's voices (Narbed, 2021). It can become an output, where the process develops into an innovative method of disseminating and debating the research findings (Narbed, 2021). We decided we wanted to act out a talk show interview where there would be two hosts, and the remaining cast would be the research team. We decided that the script should be devised from the transcripts of our research meetings on the topic. I read the transcripts and wrote a draft script in my own time and brought it to the next research meeting. The research team went through the script and made changes to it. We decided who wanted to act in which parts, making sure that the dialogue we spoke came from another researcher and not ourselves to provide some level of anonymity. We then rehearsed the script and got a filmmaker to record us. We now had a short film on people with intellectual disabilities' rights to get married and have children based on our research findings. We organised a research seminar at Trinity College Dublin, 'we have the right to get married and have children', for one of our study's actions to create awareness on the topic, and we played the short film for the audience. Then, we invited the audience to engage in critical dialogue about the topic. The audience included people with intellectual disabilities, parents, social care practitioners, nurses, students, and academics. The audience engaged in a lengthy critical discussion. Performance creates space for dialogue, reflection, critical questioning, new ways of thinking and knowing, and transformation (Narbed, 2021). This brings together all voices and provides a broader narrative (Narbed, 2021). We all enjoyed making the film; it was one of our favourite creative parts of the study, and we were proud to watch it back at the event. We felt it had a low budget and a tight timeframe. We decided we would like to do more research in the future and next time to make a film based on the findings but to spend more time and seek more funding to do this.

5.4.5: Third objects:

Third objects are where a participant uses an object as a point of reference to focus on (Winnicott, 1968). Knowledge, memories, and experiences are connected to the object, which may go unspoken in a traditional interview (Mannay, 2020), especially if the topic is personal or sensitive (Dumangane, 2020). Using an object in this way can help with participants understanding (Mannay, 2020). The combination of interviews with visual and physical props can contribute to the depth when exploring personal and/ or emotional topics (Dumangane, 2020). This form of show and tell can help frame the topic and lead the conversation (Kara et al., 2021). Researchers who have used third objects as a research tool have found benefits to its use. Third objects have been found to engage participants more (Dumangane, 2020) and to make for more participatory relationships, by breaking down power imbalances (Gwyther and Possamai-Inesedy, 2009). There is joint attention on the object between the researcher and participant (Isserow, 2008). Participants are often more comfortable communicating in this way (Mannay, 2020), which has been found to reduce anxiety and stress when talking about personal topics (Winnicott, 1968). This can help develop a level of rapport between the participant and the researcher (Dumangane, 2020). It is also easier to reflect and discuss when there is something to hold and look at (Mannay, 2020). Using third objects can allow the researcher to become more embedded in the topic (Mannay, 2020). This is because it enables researchers to see which objects are selected by participants when they share and discuss them, which can give a deeper insight into their world as it helps them to consider other perspectives (Mannay, 2020).

After a discussion, Alice, Ellen, and Hermione suggested that we should make something at home or find something to bring in that represents 'the biggest thing we are taking away from the group.' After some research, I found out this was called third objects and told the group. All bar one researcher made an object, that researcher brought in a found object of headphones (pictures of each object are in the findings chapters). This researcher brought something that meant a lot to her, but when discussing it, she struggled to link it to the research question, so I thought she did not fully understand what

we were doing. We did ask her, but she stated they were important to her as she liked music but still went in-depth with the discussion on the biggest things she was taking away from the research. Usually, she was late, and I would assume she forgot about the third object till the last minute and grabbed the headphones to bring something when leaving the house. We showed our objects and gave our interpretation concerning the biggest thing we were taking away from the group. This was followed by a discussion on what we learned about research. This activity led to a profoundly personal discussion, which I believe happened as people put much thought into it and made something personal. It was interesting that everyone engaged with this when they had not at the start when making things at home. It was most likely because we were at a different stage in our group development. Further details of the third objects and our discussions can be found in Chapter Eight: Findings: Perceptions).

5.4.6: Joint sandboxing:

As mentioned above, for the three final reflective and evaluation sessions, the researchers developed one method and one question to explore, but they needed more ideas for the other methods. I listed out some that I was aware of that we had not tried yet, and they chose joint sandboxing described here, and *LEGO® SERIOUS PLAY®* explained in the next section. In sandboxing, participants are each provided with a tray of sand and water and have a choice of figures and objects to create three-dimensional scenes, abstract designs, and pictures (Kara et al., 2021). Participants are asked to create a scene in response to a research question or to represent a scene on an aspect of their lives (Mannay, 2020). Participants do this by representing their perspectives and experiences metaphorically (Kara et al., 2021). As in all creative activities, we were all engaged, so we all sat together creating our metaphors, discussing while we worked and sharing our final pieces and thoughts at the end, leading to a whole group discussion. There are different methods of sandboxing. Lowenfield's 'world technique', which centralises the participant's meaning-making, is the method that fits this co-operative inquiry approach the most. This means that 'auteur theory' is applied (Kara et al., 2021); this is where the researcher must not try and interpret the scenes; the meaning should be identified by the participant and recorded by the researcher (Lowenfield, 1939). Lowenfield (1950) recommended using a three-inch deep metal tray painted blue inside, with sand (preferably two colours) and

water, and the participant should work from a table, waist height. The objects available should be of relevance to culture and include ordinary, military, and special people (special includes other cultures, circus, witches, and gnomes), tame and wild animals, houses, transport, trees, street signs and fences, as well as miscellaneous objects such as broken parts of people and objects, blocks, sticks, stones, plasticine, and planks (Lowenfield, 1950). I adapted this method, using small plastic trays and just one colour of sand for easy transport. I created a sandboxing kit (Figures 8 and 9), with disabled and non-disabled figures from babies to older people, of different cultures, occupation figures such as policemen and builders, tame and wild animals, transport, trees, street signs, fences, bits of a wooden railway track, a bridge, blocks, sticks, and stones. I could not get any houses for the research meeting, and coincidentally, one of the researchers asked if there was a house she could use when making her scene. I suggested she could use something as a metaphor for a house instead. I understand it is more challenging to represent intellectual disability, and these figures had physical disabilities, but it was the closest I could get. I explained this to the group and explained that I got these to represent disability. As metaphors, the figures can hold unrestricted and plentiful meanings (Mannay, 2020).

Researchers who use the joint sandboxing technique have found benefits to its use. As the familiar can become stale (Gurevitch, 1998), the visual and verbal metaphors can heighten the participants self-understanding (Mannay et al., 2017), as it can enable the participant to slow down and notice (Gurevitch, 1998). The method can give rise to unknown discourses and value differences (Mannay et al., 2017). Many researchers voiced scenes representing experiences and feelings of accepting their disability and themselves because of being in the group. Sandboxing has been found to progress participatory relationships in research (Mannay et al., 2017). This method was voiced among the group as one of their favourite research methods out of all the creative activities.



Figure 9: Sandboxing kit.

The full details of what is discussed next are explored in Chapter Seven: Findings: Lack of Opportunities to Form and Create Relationships and Chapter Nine: Discussions, Recommendations, and Contributions. However, I want to be able to provide some brief context here as it is relevant to the creative activity. We experienced a disabling barrier at this research meeting before we began the sandboxing when working towards one of our actions. The group expressed many feelings about this before the sandboxing activity. We took a coffee break to de-brief and then returned to the room for the sandboxing. Some of the researchers included this barrier in their scenes. It seemed that the group were much more relaxed addressing the problem during the sandboxing activity than before this activity, probably due to the therapeutic nature of the activity, which many of us voiced afterwards in our session closing reflection.

After each scene was created, each researcher shared what they had made and the meaning of each element (Kara et al., 2021). It was important that they spoke to the interpretation of the visual data to ensure it remained participant-focused (Mannay et al., 2017) and in line with the 'world technique' method of sandboxing (Lowenfield, 1939;

1950), which centralises the participants mean making and therefore applying ‘auteur theory’ (Kara et al., 2021). After each researcher shared their scenes and interpretations, others joined the group discussion, sharing their thoughts and experiences. Some researchers had not understood the concept of metaphors fully but did verbally express their views to the discussion prompts and later expressed how much they enjoyed working on the scenes with the sand. The challenge of grasping metaphors had been one of my concerns before we started using creative methods. It may be seen as a limitation in this study, but on reflection and evaluation of these methods with the research team, they enjoyed this creative method. They believed it still helped them to explore the topics better and that it was accessible to them.

All scenes were photographed with the researcher’s permission (photos in the findings chapter), where I asked each researcher to stand out of the frame briefly. However, it is worth noting, and as outlined by Lowenfield (1939), that a photograph can distort the objects; as it is taken from a particular angle, nearer objects may look larger, and smaller objects may be hidden. She recommended drawing the image instead, which I did not adapt for the study as the images were only used to show the reader the creative work and the creative work was used to help elicit the data and not as part of the analysis, and due to restricted time and artistic ability. Despite this possible distortion, the verbal descriptions can clarify much of this, and the images add an extra layer of meaning.

5.4.7: LEGO® SERIOUS (FUN) PLAY®:

LEGO® SERIOUS PLAY® was the second chosen method for the end-of-study reflection and evaluation. *LEGO® SERIOUS PLAY®* is a structured method where, through a series of steps, the individual thinks, reflects, refines, and tells a story to create a shared understanding of a topic (Blair and Rillo, 2016). They do this by building a metaphor based on a theme and then sharing it with the group for further discussion (Hickman Dunne and Pimlott-Wilson, 2021). Researchers who use *LEGO® SERIOUS PLAY®* as a research tool have found benefits to its use. It can result in a deeper reflection and a more meaningful understanding, enabling participants to better communicate this to others in the group (Blair and Rillo, 2016,) and see their experiences in a new way (Kara et al., 2021). The researchers voiced this back in our reflections and evaluations of the creative methods.

Purcell (2019) used *LEGO® SERIOUS PLAY®* in a study with students in higher education and then evaluated its effectiveness in deepening their understanding afterwards. Purcell found many benefits, where most participants engaged and enjoyed the session. Modelling and discussion transformed participants' understanding and ability to articulate this compared to discussion alone. It allowed them to reflect purposively and resulted in more fully formed views. Even those who struggled to make metaphors from models used *LEGO®* pieces to stimulate discussion. Participants articulated their ideas more effectively with modelling and discussion rather than discussion alone. As previously mentioned, one researcher initially struggled with her metaphor, but after taking some time to think about it, she created a fantastic metaphor that stimulated an in-depth discussion. Purcell (2019) further found that modelling transformed the participants' understanding. Gauntlett (2007), who also used *LEGO® SERIOUS PLAY®* in his study, followed up the research session with an evaluation and found that participants experienced revelation and self-discovery through the learning process. As well as finding so many benefits, Purcell (2019) identified challenges in the method, where they found *LEGO® SERIOUS PLAY®* not suitable for everyone, where a minority found it boring or uncomfortable. Purcell advised that alternatives should be available. Although these issues did not arise for us, probably because the researchers chose to use *LEGO® SERIOUS PLAY®*. This creative method was voiced as the most fun, along with the joint sandboxing.

We selected pieces of *LEGO®*, attached meaning to them, arranged them in a certain way, made connections till we made a whole, and then told a story of what we made, coming to new insights as we did (Gauntlett, 2007). The method can be done in an individual, shared or system model (Blair and Rillo, 2016), but we did not build a model together due to COVID regulations and social distancing. However, we worked individually but then shared our creations through discussion, creating a common meaning. The method was adapted to suit the group where we worked over a shorter time frame, as it is usually recommended to spend time playing with the *LEGO®* to get warmed up and to do exercises to learn about metaphors (Gautlett, 2007). We had been working with metaphors for the past year; this was our final session. We used this method for our final

closing reflection research meeting. One box of *LEGO*® (Figure 10) was supplied to each pair of researchers.



Figure 10: *LEGO*® kits.

We began with a discussion on metaphors, and then each researcher made a model based on a final reflection. As previously stated, we all discussed what we wanted to get from these reflective sessions, and I devised some questions based on this.

I asked the group to create something to represent:

- Your hopes for the future about relationships and sexuality.

I was hoping we could create two more metaphors representing our dissatisfactions and satisfactions in this group, but we were running out of time, so ended with a discussion on these two aspects. However, the discussion here was brief. It was our last research meeting, and we were waiting for takeout food to be delivered as part of our celebration; people were focused on the food arriving. We should have had the reflective session and the celebration on two different days. Each researcher shared their model and its meaning to the group, and then we had a whole group discussion. In our session's closing reflection, the group voiced how much they enjoyed working with *LEGO*®. When we were preparing one of our conference presentations, Bruce (researcher) said that he did not want to use the words *LEGO*® *SERIOUS PLAY*® because this did not reflect how he felt about it. He changed the name to *LEGO*® *FUN PLAY*®, and we all agreed.

5.5: Creative collaborative data analysis:

Creative data analysis 'can refer to the analysis of data gathered using creative methods... or it can refer to creative methods of analysing data gathered using creative or conventional methods (or a combination of the two)' (Kara et al, 2021, p.83). This study creatively analysed the multi-modal data using an embodied and collaborative approach. If a study is fully inclusive, there should be the option to collaborate in the data analysis. If participants have been fully involved and feel the project is theirs and the method is accessible, they may want to engage in this stage (Kara, 2015). All the researchers wanted to engage in the data analysis stage of the research.

The method needed to be systematic to yield findings embedded in the data and help with the following stages of writing, dissemination, and application (Kara, 2015). Mixed methods analysis was used in this study, which uses two or more different methods of analysis and allows for the creation of a richer understanding of the phenomena (Kara et al, 2021). I brought existing ideas and methods from the literature together to devise a systematic method of creative, collaborative data analysis that would be accessible and interesting, where we could work through the analysis together. These ideas came from

visual analysis (Kara et al., 2021), member checking (Call-Cummins et al., 2019), content analysis (Grbich, 2013), and embodied data analysis (Thanem and Knights, 2019). All these ideas and methods are described in detail below, where I will outline the devised systematic method we used.

Initially, I did not consider co-creating this method, as data analysis was new to the research team, and I was concerned with over-burdening or daunting them. Barriers to participation in collaborative data analysis may be that it is time-consuming, tedious, and repetitive (Kara, 2015). These factors needed to be considered to ensure it was accessible and engaging to the researchers. As a result, most of the analytic work took place collaboratively in the research team meetings and different accessible methods were used to support the analysis. Examples of accessible methods included making video summaries of each research meeting instead of written summaries, undertaking member checking of the data, and using arts-based methods to analyse the data.

However, as the process transpired, it resulted in a co-creation of the method in several ways. During the final process of data analysis, one of the researchers contributed to the development of the method, which is explained below. Also, after the main themes were decided and I had brought the left-over data to the research team, they came up with the idea to use some of these for sub-themes. The researchers also devised one of the reflective sessions as part of this process by designing a method and developing a research question. This co-creation made the method truly collaborative.

5.5.1: Creative, collaborative data analysis method:

Visual analysis:

This is described in the sections above but briefly summarised here as a reminder. The researchers chose one topic at each research meeting and one creative activity to explore that topic. We engaged in art and drawing, participant poetry and rap, creative performance and practice, joint sandboxing, *LEGO® SERIOUS PLAY®* or third objects. We then had space to share and discuss our creations to explore their meanings, which developed into group discussions. All these discussions were recorded to create a transcript.

Member checking:

Member checking helps to ensure that the interpretations of the perspectives are accurate. However, as Sandelowski (2002) points out, member checking should be viewed as an additional opportunity to discuss the findings instead of validating them, as perspectives can change over time. Having the space to discuss these topics again helped us to do this. I borrowed ideas from Call-Cummings et al. (2019), who sent copies of transcripts to participants for feedback to help the analysis reflect and incorporate perspectives they had previously understood. However, I wanted to find a more accessible method to do this. I listened to the research meeting recording, and with agreement from the research team, I made a 10-minute video summarising the main interpretations of each research meeting after they took place. This video was emailed to each researcher with five questions to respond to. The individuals could email back or discuss the video and questions at the following research team meeting. The latter was the most common response.

Questions:

1. Did I misinterpret any information? If I said anything wrong, please let me know what it was.
2. Did I miss any important information in the video? If I did, please let me know what it is.
3. What did you find most interesting?
4. What did you find least interesting?
5. What would you like to do or talk about next?

Content analysis:

When there is a large amount of textual data, it can be systematically categorised or coded by finding trends or patterns in the words used (Grbich, 2013). In content analysis, the repetition of words is presumed to signify their importance (Grbich, 2013). Instead of waiting till the end of the study, when we would have an overwhelming amount of data after 20 research meetings, I undertook content analysis twice during the research. The first time we decided to do this was after seven research meetings, as at this point, we moved the study from online to in-person due to the easing of COVID restrictions and

requests from the researchers. We wanted to look at where we were in the study and where we wanted to go next and felt this would guide us. We were going to do the content analysis again after meeting 15 before we broke up for a month's summer break, but instead, we decided to do it on our return to refresh us on where we were and to help us decide where we wanted to go for the remainder of the study. Here, I undertook content analysis from the next seven research meetings data. The approach was used where word frequency was identified by counting the main words used by the group and selecting the most common words from the transcripts (Grbich, 2013). After omitting words such as 'a', 'in' and 'the', the remaining keywords were written on cards. This approach enabled us to work with data that was now manageable but still meaningful. However, this was a preliminary activity as we wanted to work on the data together, dig deeper, include all our interpretations, and provide a more complete picture.

Arts-based analysis:

Arts-based analysis is when arts-based methods are used to analyse the data. The word cards from the content analysis were placed on a large table at two research meetings (after the first seven meetings and after the next seven meetings). For example, in the first data analysis session, the words were 'sex', 'girlfriend', 'boyfriend', 'sex education', and 'nightclubs'. The research team looked at the words, deciding whether to remove or add words or to bring words together. Each researcher then chose the most important word to them and made a visual with drawings and words to express its meaning. Each researcher then shared their visual and its interpretation.

For example, in the first data analysis session, Chloe chose the word 'nightclubs' and drew an image of ladies on a dance floor (see Figure 11).

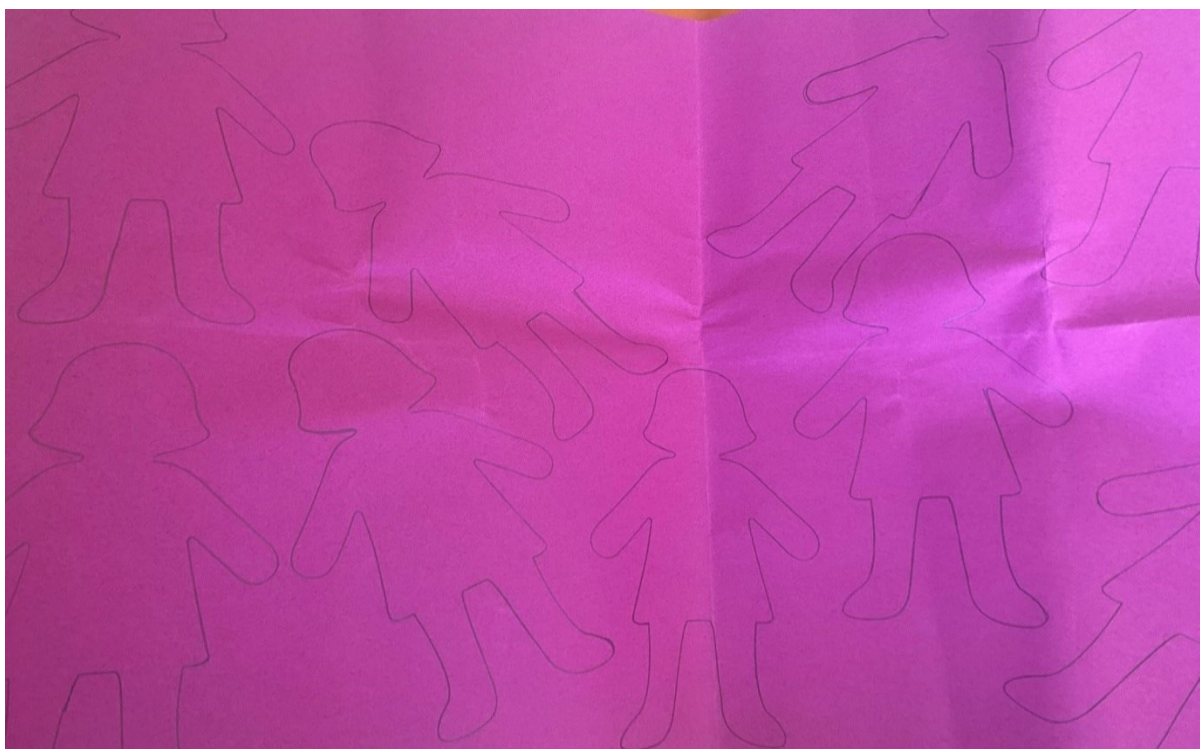


Figure 11: Chloe's artwork on 'nightclubs' in the first data analysis session.

Chloe explained that she picked the word 'nightclubs' and drew people dancing on the dance floor because she would love to go out with friends, meet new friends and possibly have a boyfriend. She expressed that she did not get the opportunity to do this and spent much time alone. The group agreed they would like more opportunities to meet potential partners and felt this was an important topic. The sharing of our art and interpretations led to further discussions, and through this process, we decided on the main themes at that point based on what was important to us and what we would like to do next.

Embodied data analysis:

Embodied data analysis helps to conceptualise the work and realise new perspectives of the data during the process (Kara et al, 2021). I was inspired by the work of Thanem and Knights (2019), as I was seeking a data analysis method that was creative, inclusive and accessible. Thanem and Knights (2019) used hard copies of the data, printed field notes and recordings of data to cut out key quotes or observations and, along with their creative artefacts from the study, spread them out on the floor and walked, crawled, and played with the data. The key quotes and observations can then be arranged into themes and sub-themes. While moving the data, photographs or images of the data can be taken to

keep track of it. Thanem and Knight (2019) recommended to keep doing this till new learning takes place and the data is seen differently. This was important because we wanted to do the final analysis of the data and bring it all together.

However, Thanem and Knight's (2019) work was not as accessible as I would have liked. Ellingson (2017) highlighted that embodiment can be done in accessible ways, such as online. I adapted Thanem and Knight's approach to making it accessible to the group by having two sessions instead of one, so we were not working for more than two hours at a time, and nobody was rushed. Also, we placed the material on the table instead of the floor, making it more easily accessible. Our artefacts included our artwork, poems, and news reports, which were displayed on a large boardroom table (see Figure 12) along with the word cards, and the raps we wrote and performed played on a speaker, like an art installation. I asked the researchers to walk around the room, play with the data, and do what felt right. I hoped that by the researchers seeing and hearing all their data in one place and by moving around it, they would then decide how we could do our final analysis.



Figure 12: Data analysis table.

Ellen (researcher) began lifting artefacts and themes from the table and suggested others do the same, advising them to choose what was important or stood out. When everyone sat down, we shared what we had and why and had a group discussion. We removed everything left from the table, and the researchers placed their data in the middle. They stood around and discussed the data, moving one item when they felt it was irrelevant and could join another theme. In this process, they decided on their study's four most relevant themes and sub-themes. The four main themes they selected were disability, sexual health education, online safety, and rights. I took photos as we developed themes. The exciting part was that a researcher suggested that we should choose artefacts and themes of importance, which made it genuinely collaborative, and it worked well.

In the following research meeting, I placed the themes in the centre of the table but brought the removed data and put it back on the table so the research team could see it in front of them if they wanted to add any items they may have omitted. We went through each piece of removed data one at a time. The researchers decided to develop sub-themes, debated what main theme each sub-theme should go under, and removed any repeated or irrelevant sub-themes. The group were happy with the four themes they had agreed upon in the previous meeting and added important sub-themes to the relevant themes. The themes and sub-themes we had now were first, sexual health education, to include LGBTQ+; secondly, online safety, to include dating apps and social media platforms; the impact of Grand Theft Auto on our perceptions of sex work; sex workers and the Gardaí as support; thirdly rights, to include relationships, LGBTQ+, love, sex, marriage and children, parents and professionals perceptions, sexual health education, group homes and the law on disability rights and consent. Fourthly, the theme of disability ran throughout, including the individual and the research team.

Creative collaborative reflection:

We ended the study with three creative, reflective and evaluation sessions. As previously mentioned, three of the researchers devised one of these sessions. These three creative methods were discussed previously but as a reminder, these were:

Third objects – To bring in a made or found object which represented ‘the biggest thing we were taking away from the research’. We followed this with a discussion on personal transformation, skills developed and acquired and what we learned about research.

Joint sandboxing - We explored the learning that took place concerning ourselves, others, disability, and relationships and sexuality during the research project.

LEGO® SERIOUS (FUN) PLAY® - We explored successes, dissatisfactions and hopes for the future from the study.

5.5.2: The end of the data analysis:

When we finished analysing the data, we stood over the table, looking at our main themes. There was a sense of pride and achievement that we had reached the end of the year of the study. We could see all our hard work in front of us, and we had brought it together and highlighted what was the most important to us.

Ellen: It felt good. It’s our work, and we did it, and I’m proud of that. I am glad I did it.

Jess: Ellen, you said let’s pick what’s important to us and that made us come to this point, so thank you. Your contribution has helped us develop a new method of data analysis.

Ellen: That makes me feel good.

Bruce: I am happy that the work is done.

Hermione: It was good looking at all the stuff we have done.

Alice: I felt overwhelmed at the amount of work. It’s amazing when you see it all out. The amount of work that’s gone into this, in just a year.

Jess: Well done to you all. You have worked for a year on this PhD project, that’s not easy. It’s amazing the work that you have put in and I could not have done this without you. It was important to work together as a team. So, thank you so much. It’s not the end but we have finished analysing our data. I’m really excited. I will take this away and have lots of fun writing it up. So that’s us done, five minutes early as well!

Everyone clapped with huge smiles on their faces.

I then took the list of themes and sub-themes we agreed upon to my desk and printed all 20 research meeting transcripts. I colour-coded each theme and sub-theme, then went through each data transcript and highlighted these themes with different colour highlighter pens. I was then ready to write our findings. Although I would need to add my interpretations to this in my role as a doctoral researcher, I would ensure that I would include the themes and sub-themes that were important to the research team.

5.6: Strengths and limitations of the visual and creative research methods:

At the end of the study, we presented 'The R&S (Relationships and Sexuality) Research Team: A Collaborative Inquiry Group. Sharing our Journey and Learning of Inclusive and Accessible Research', at the International Action Research Colloquium 2022 as part of one of our study's actions (Mannion et al., 2022a). As part of this presentation, we discussed how it felt to be involved in co-creating the data and data analysis using visual and creative research methods.

We felt that moving from online to in-person research meetings and increasing our meeting times from 1 to 2 hours helped us to do more creative activities. One of the decisions we were all involved in was to choose what creative methods we wanted to use, and the researchers liked this. One aspect that made the research inclusive and accessible was the creative methods such as sandboxing, rap, and *LEGO® SERIOUS (FUN) PLAY®*. The researchers said this is because they were inclusive and very beneficial, as most of us found it hard to express ourselves through verbal methods alone and have challenges with paying attention and writing (Mannion et al., 2022a). According to Bagnoli (2009), using creative methods in research leads to the exploration of multi-dimensional experiences, visual, sensory, and things that are not easily expressed verbally. Creative methods can be of benefit when it is difficult for participants to voice ideas as they help to deconstruct underpinning thoughts (Rainford, 2020). Through our evaluation, we identified that the visuals were effective in helping us to communicate our thoughts and kept us engaged, interested, and fun. Scherer (2016) stated that asking a question and giving time to the participant to reflect through the creative activity gives the participant more power in the process's depth and speed as they do not need to respond immediately, which can make the process more inclusive. We found this a benefit of this project; having time to think about answers made it more accessible. For example, before we used the creative methods, the discussion answers were brief and not in-depth. Another example is where Hermione (researcher) initially struggled with her *LEGO®* metaphor. After some time to think it through, she made a very strong metaphor and added a lengthy and interesting discussion. Without this time, she may not have been able to add her thoughts so effectively. Weber (2008) argued that creating metaphors can heighten understanding,

portray the indescribable, and help look at things differently. Metaphors can help participants capture complex ideas (Hickman Dune and Pimlott-Wilson, 2021) and can help them express their thoughts in a way that may have been difficult to put into words (Gauntlett, 2007). Creative methods help facilitate reflexivity, which is more than solely reflecting. Here, the participant actively reflects on the topic, truly engaging with metaphors and representations (Kara et al., 2021). These creative methods give space and time for this reflexivity (Gauntlett, 2007).

We chose our favourite methods to be *LEGO® SERIOUS (FUN) PLAY®*, sandboxing, drama, rap, and third objects because we enjoyed engaging with these the most. However, the top two favourites were sandboxing and *LEGO® SERIOUS (FUN) PLAY®* (Mannion et al., 2022a). I was not surprised these came up as favourites as everyone was excited to try something new and they were very playful in comparison to other creative methods such as art and poetry. Creative methods allow for the co-construction of data collection playfully (Literat, 2013). Play opens different ways of thinking (Gauntlett, 2007), which can result in more holistic discussions (Bagnoli, 2009). We all voiced that we found the sandboxing activity relaxing and enjoyed the sensory aspect of it. This was because of the feel of the sand in our hands, reminding some of us of the beach (Mannion et al., 2022a). This came at the perfect time, as prior to this activity, everyone was upset and angry at what had happened with one of our study's actions (explained in Chapter Seven: Findings: Lack of Opportunities to Create and Maintain Relationships). Focusing on objects can help participants feel more comfortable communicating (Winnicott, 1968), it can help reduce anxiety when discussing personal topics and provides the group with something to give joint attention to (Kara et al., 2021) rather than gazing at the initiating researcher (Ross et al., 2009). This can enable everyone to relax, generating discussion and bringing meaning through sharing stories or emotional connections (Kara et al., 2021). It also made serious topics less tense; for example, we had previously spoken about a denial of rights to relationships in group homes, which made people feel upset and angry. Also, as I mentioned previously, we had been upset due to one of our actions not being met prior to the sandboxing activity. When these topics were revisited in the sandboxing (researchers were not asked to do this, it naturally evolved from the reflection prompts), they were addressed in a much more relaxed manner and gave us the opportunity to

discuss it calmly and work through it. Hortsman et al. (2008) recommended that creative methods work well for sensitive topics, which is the case for this project and the topic of relationships and sexuality.

We found it of benefit that I and the research assistant joined in all the creative methods and discussions (Mannion et al., 2022a). Working in this way can result in a less hierarchical and more participatory experience (Kara et al., 2021), and this is precisely what it did, it made our group more equal.

We identified that another thing we learnt about research was data analysis and we were interested in doing so. Although we identified that it can be hard to think or talk sometimes, and one of the researchers felt tired doing the final data analysis. However, we felt it facilitated our voices being heard and it was fun talking about these topics. We felt it was nice to see what was important to each other and it was exciting to see the research come together. We felt excited and confident going over the data, it went smoothly and seemed to fly. This is because it was interesting to do, accessible and fun (Mannion et al., 2022a).

Outside of the researchers' feedback, I found some limitations in the creative methods. They were ineffective when working from home outside of our online research meetings, as only a few of us engaged. Also, not many engaged with meeting me outside the research team meetings to plan for their facilitation and to respond to the 'member checking' aspect of the data analysis. As a result, we did nearly all the work in the research meetings. Mannay (2016) noted this challenge in research due to impinging on participants' time outside of meetings, stating we cannot expect participants to engage with pre-tasks. Instead, Mannay (2016) recommends building the data production into the field work. When we did move to in-person and built it into the research meetings we were restricted in what we did due to COVID regulations and social distancing. Also, the meetings were two hours long, we spent the first half creating and the second hour discussing them with a break halfway. Sometimes we ran out of time and the second half felt rushed, I think three hours would be a better timeframe but that is a huge commitment for the group, and I think they would need to establish as a group before

they would do this. I did realise that it was difficult for researchers to create something to represent something they had never experienced. For example, one of the researchers struggled to create an art metaphor to represent her sexual health education because she did not experience much sexual health education. Although she was the only one to voice this, this may have been the case for others as why they did not work on their creative pieces at home. I also think it is of benefit to do different activities as we used art the most and this was the activity the group lost interest in. However, this could be that I chose the topic that week and it was not their own decision. Mannay (2016) explained how contemporary research in the social sciences often focuses on using one type of method of data production that was popular at that time, and instead, she recommends aiming for a more holistic inquiry, using a range of methods. Mixing creative methods can enable 'outside the box' thinking and create new ways of understanding (Mason, 2006). The researchers voiced that it kept the research meetings interesting for them which helped to keep them engaged. Providing a range of creative choices can make the study truly participatory (Mannay, 2016). Finally, three different researchers did not understand metaphors on three different occasions, but with extra support we overcame this. This was a concern I had at the start as it can be a difficult task to do. However, overall, the creative methods were well received and helped us to collect an enormous amount of in-depth data which I have explored in the finding's chapters next.

5.7: Conclusion:

We found the benefits of visual and creative research methods reflected that of the literature in that they were accessible, helped us to elicit and express our thoughts, helped us see other people's experiences and perspectives to create a mutual understanding, and facilitated in-depth discussions. These benefits outweighed the very few challenges we encountered. These creative methods also helped us to move from one stage of the research to the next; they acted as a reminder of what we had done before and helped us to plan to move forward, which was also particularly helpful when new people joined the research team. Using creative methods made the data analysis accessible and interesting for the research team so everyone could be involved in all stages of the study. By being involved in the data analysis, we could see all our work come together at the end; this made us proud, excited, and confident, as research was new to most of the research team,

and we had worked hard. The data analysis also helped us to see what was important to others and voice what was important to ourselves. As well as this, we loved making the film, and it was nice to have it as an output and as an advocacy tool for change. We later showed this film at a research seminar we held at Trinity College Dublin 'We Have the Right to Get Married and Have Children' (Mannion et al., 2022c), two research seminars we presented about our study at the Atlantic Technological University Sligo, and as part of our presentation 'Using visual and Creative Methods for the data construction, data analysis and dissemination in a collaborative Disability Study' at the International Creative Research Methods Conference 2023 in Manchester (Mannion et al., 2023). The research team are very much advocates for creative methods. Post PhD, we are collaborating with the ATS (Advancement and Transition Services) research network, which are housed in the College of Education, Criminal Justice, Human Services, and Information Technology at the University of Cincinnati. With relevance to this chapter, part of this project is to advise the research team on using creative methods in research. We have also co-authored and published an academic blog with Sage Methodspace (Appendix 12), sharing our thoughts and experiences on these methods (Mannion et al., 2022b). The findings that evolved from our discussions with these creative methods are in the following chapter.

Chapter Six: Findings Part One - Sexual Health Education.

6.1: Introduction:

The findings are broken up into three chapters and are based on the data collected in 20 research meetings with six researchers with intellectual disabilities and two who are neurodivergent (myself and the research assistant), between April 2021 and April 2022. I had originally begun this chapter with a biography of each researcher on the team, but later decided to omit these as I was concerned, they gave too much away and would identify the researchers and break anonymity. Pseudonyms are used throughout the findings. The findings are presented thematically not chronologically. The first chapter focuses on sexual health education and the actions of seeking such education. The second chapter focuses on the lack of opportunities in creating and maintaining relationships, focusing on the barriers of overprotection, control, and segregation from others and the risks experienced as a result. Here, our action of online safety training is explored. The final findings chapter focuses on perceptions concerning relationships and sexuality, the perceptions of the researchers, their families and disability professionals, especially concerning getting married and having children. Here there are discussions on our actions to create awareness on the topic of the right to get married and have children.

This chapter highlights the findings that emerged from our discussions on sexual health education. The researchers shared their past sexual health education experiences, their knowledge gaps, and what kind of sexual health education programme they would like to see. We examined why some of us lacked sexual health education and the impact this has had. We developed three of the study's actions concerning this theme. This led to recommendations that arose from our findings on sexual health education.

6.2: Sexual health education:

Before the research meetings started, all the researchers voiced that sexual health education was a topic they wanted to explore as it was something they lacked and was important to them. When we all came together as a group, everyone agreed that this was

the first topic we wanted to explore. The topic of sexual health education came up repeatedly throughout the year of the study. As it was so important, it became a main theme and we focused on it for actions for the study.

6.2.1: Lack of access to sexual health education:

All researchers reported and/ or demonstrated that they had received limited to no sexual health education. Bruce and Hermione were the only researchers who had participated in a past sexual health education programme. Bruce received his in his mainstream secondary school and disability training centre. Hermione had received hers in her disability training centre. Two researchers received no sexual health education; the remainder only received some basic information, such as a short video at school. This lack of access to sexual health education for people with intellectual disabilities is consistent with the literature (Fitzgerald and Withers, 2013; Rojas et al., 2016; Schaafsma et al., 2017; Graff et al., 2018; Chou et al., 2020; Wos et al., 2021).

6.2.2: Biological discourse and protection:

For those researchers who received sexual health education, it came from a biological discourse. The researchers identified that their sexual health education was focused on biology and protection as opposed to positive relationships and pleasure, which was consistent with findings from the literature (Sullivan et al., 2013; Garcia Iriarte et al., 2014; Kulick and Rydstrom, 2015; Rojas et al., 2016; Chivers and Mathieson, 2000; Hole et al., 2022). The researchers felt this happened as others wanted to protect them (discussed in more detail below).

Hermione: Like the thing I learned about relationships and sexuality was like what's in a woman and what's in a man, that sort of thing. Learning about body parts, and how to keep them safe.

The other researchers who had received basic information stated what they had received was also focused on biology and protection. The researchers voiced there was an onus on themselves to keep safe and protect themselves by being appropriate and respectful. There are similarities between this and reports from the participants in Frawley and Wilson (2016) study, where they stated there was an onus on men not to break the rules

and women to keep themselves safe. As Liddiard (2018) argued, people cast disabled people in binaries of protected/ unprotected, abused/ abuser, and vulnerable/ dangerous. Others are telling people with intellectual disabilities what behaviour they are not allowed to do to others, but not what others cannot do to them (Wos et al., 2020). These gendered stereotypes are ingrained into societal perceptions, but people with intellectual disabilities must also endure further stereotypes of being either vulnerable to abuse or a risk to others. Despite the view that they should be protected, the researchers in this study did not learn how to keep safe or what to do after an unsafe situation.

From further discussion on the content of Bruce and Hermione's sexual health education, the content included anatomy, appropriate touch, and learning how to keep their body parts private. They also learnt about respecting themselves and others, as well as pregnancy, contraception, and periods. This type of content was found in sexual health education programmes in previous studies (Frawley and Bigby, 2014; Rojas et al., 2016; Schaafsma et al., 2016; Schaafma et al., 2017). Hermione learnt about masturbation but noted several gaps in her sexual health knowledge, including not knowing what sex, sex work, or porn were.

These were the only times the topic of pleasure briefly came up in the study. When Hermione brought up masturbation and pleasure, she was then too shy to discuss it further, and the other researchers did not add to this discussion. The studies in the literature rarely identified pleasure for people with intellectual disabilities. Pleasure is considered secondary to protection (Liddiard, 2018), sexual health education for people with intellectual disabilities rarely frames sex in terms of pleasure (Sullivan et al., 2013; Kulick and Rhydstrom, 2015), and people with intellectual disabilities rarely view sex as pleasurable (Bernet and Ogletree, 2013). Not viewing sex as pleasurable comes from a fear of negative outcomes, the influence of others' sexual scripts, and risk-focused sexual health education (Bernet and Ogletree, 2013). Alexander and Gomez (2017) identified this absence may be due to a lack of experience discussing pleasure. In their study, the participants spoke of fear, shame, and guilt instead. However, the researchers in this study did not vocalise why there was little emphasis on pleasure. Some of the researchers did have negative views towards sex, which others may have influenced, and some had

been sexually abused, which may have impacted their views. This is explored further in Chapter Seven (Lack of Opportunities to Create and Maintain Relationships).

Two of us wrote poems on our sexual health education experiences and used these to aid group discussion, but as one researcher noted, she had nothing to write or draw as her sexual health education was absent. This absence of creative work was a powerful representation of her inadequate sexual health education. As can be seen from Bruce's poem on his sexual health education (Figure 13), it focused on the content of his sexual health education. He noted that it was his first ever poem to write, and it helped him to think about being safe about sex. Thinking about being safe was an interesting concept to bring up here, as his sexual health education focused on protection.

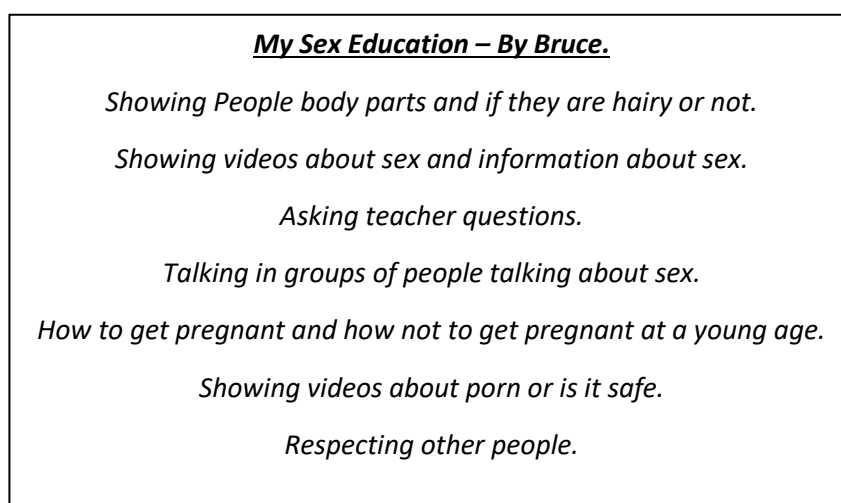


Figure 13: Bruce's poem on his sexual health education.

Bruce was the only researcher who believed his sexual health education was sufficient. However, from further discussions, he did not know about LGBTQ+, the language around sexual consent, had incorrect knowledge of contraception, and limited knowledge of abortion, and his knowledge did seem to be functional. For example, when he was explaining what sex was to Hermione, who had asked the question of what sex was, he explained:

Bruce: Putting your yolk (Irish slang meaning an object) in.
When asked to elaborate.

Bruce: The man's penis into a woman's vagina or pussy.

Bruce also believed he was shown porn in his sexual health education, which I would assume would be unlikely. He may have been shown a video about sex, which he thought was porn. Everyone else voiced that their sexual health education was insufficient for their need to have relationships. Ellen explained the education she received.

Ellen: I was in primary school, and I was in this class, and they showed me a video for about half an hour and that's all I got, nothing else. It showed how children are made, and sex, and that's all I got, I got nothing else.

Ellen never sought sexual health education after this (25 years ago). She knew she lacked knowledge and wanted this information but accepted that she could not have it. The other researchers who received little to no sexual health education were the same; they had no option as they were told they could not have sexual health education due to their intellectual disability.

6.2.3: The control of sexual health education:

The researchers argued that the reason they lacked access to sexual health education was because others controlled it. They stated that one reason was they went to a specialised school for disabled people, where people viewed them differently due to their disability and thought they should not receive this information to protect them. They felt these attitudes came from teachers in schools, parents/ families, and professionals in disability services. Similar attitudes were expressed in Frawley and Wilson's (2016) study, where participants felt they did not receive sexual health education because they attended specialised schools for disabled students and believed it would be different if they had attended a mainstream school.

Chloe believed that the reason she did not receive sexual health education was because the teachers in her specialised school would not want to teach people with intellectual disabilities sexual health education.

Chloe: It's just Jess, we went to a special school. We have never done anything like this before. We never talked about anything like that. A special school wouldn't do things like that, as they may do somewhere else, like in other secondary schools. But where we went is a special school for people with disabilities who need more help. That would have been difficult because the staff wouldn't want to do that with anybody in classes.

Chloe believed her experience would be different from that of someone who attended a mainstream school. All the researchers agreed. Bruce also noted that he felt he had a better sexual health education than the other researchers as he attended a mainstream school. Nathan believed the topic of LGBTQ+ was addressed more in his mainstream school than in his specialised school for disabled students. Research from the U.K. that compared levels of sexual health knowledge found that people with intellectual disabilities had less knowledge than non-disabled people (Jahoda and Pownall, 2014). Some reasons people lack knowledge are when education is absent, inaccessible, or inadequate.

The researchers further identified that this lack of access to sexual health education was because people with intellectual disabilities get treated differently than non-disabled people. They acknowledged that this barrier often came from parents' perspectives who did not want their adult child to participate in sexual health education as they wanted to protect them and believed this education may give them ideas to engage in sex.

Louise: They (parents) didn't want me to know about it (sexual health education). They didn't want me to get the idea of having sex education. I suppose they just didn't want me to have a relationship. Because of my disability. How other people treat me. Like they say, oh Louise, you shouldn't do that because of your disability. Say if I was raped, or assaulted, or something like that.

Hermione: My mum would be worried if I had sex education (laughing). Because going out with boys and all that. I need to be careful who I'm hanging around with. I don't be allowed to talk to some of the boys out there.

The researchers wanted sexual health education to protect themselves. Still, most of the families of the researchers with intellectual disabilities (all bar Bruce's) did not want them to have sexual health education as wanted to protect them, believing that this knowledge would enable relationships and put them at risk. As Kramers-Olen (2016) argued, attitudes towards people with intellectual disabilities tend to be paternalistic. These were adults in their 20s, 30s and 40s who were been told by their families what they were and were not allowed to do and were told this was because they had a disability. These findings are consistent with the literature that also found families resist sexual health education (Callus and Bornello, 2017; Schmidt et al., 2021; Hole et al., 2022) and forbid people with intellectual disabilities to have relationships (Chou et al., 2015). As researchers have argued (Goyal, 2017; Liddiard, 2018; Azzopardi-Lane et al., 2019; Schmidt et al., 2021), people with intellectual disabilities are viewed as external children.

As McCarthy et al. (2022) argued, some caregivers act as gatekeepers of experiences, knowledge, and fundamental rights. People with intellectual disabilities are overprotected rather than enabled to make choices (Fish, 2016; Schaafsma et al., 2017). Caregivers can also be uncomfortable, so gatekeep the information (Hole et al., 2022). Despite most of the researchers' families discouraging relationships in this study, some of the researchers had experiences of intimate relationships. People with intellectual disabilities having relationships regardless of such resistance was found in other studies (Stoffelen et al., 2013; Puyalto et al., 2022). Because the researchers in this study lacked sexual health knowledge, they were likelier to be at risk than someone with this knowledge. As Schaafsma et al. (2017) pointed out, risk-focused sexual health education has not been found to translate into safe behaviour. This is explored further in Chapter Seven (Lack of Opportunities to Create and Maintain Relationships). Infantilisation and overprotection have led to a lack of knowledge (Callus and Bornello, 2017; Callus et al., 2019). Such resistance may increase the likelihood of covert sexual activity (Rushbrooke et al., 2014; Grace et al., 2020) and, therefore risk.

6.2.4: The right to sexual health education:

Many emotions were expressed when the researchers shared how they felt because of being denied sexual health education and their rights. These feelings included being upset, annoyed, and angry.

Louise: I feel annoyed, I don't know, I just feel angry. I mean why shouldn't I be allowed. I should be allowed (sexual health education).

Ellen: Something that I didn't like, the fact that people with intellectual disabilities don't get sex education in their past. That really got to me. Why weren't we told that? We should be told, because we are humans like everybody else. I am anyway. But we should have got it and we didn't. We were shown a video and that was it, and sent off again, nothing.

This reaction of anger due to a denial of sexual autonomy was also found in studies in the literature (Chou et al., 2015; Turner and Crane, 2016). These insights from the researchers were not something they had explored before and emerged from the study. Even though they knew it was wrong that they had not received sexual health education and were aware they lacked knowledge and wanted this information, they had not addressed it till now as felt they did not have the opportunity to do so. They voiced that this process of

having the space to discuss these issues, finding their voice, and being heard was empowering for them.

Sexual health education is a right (Hole et al., 2022). Despite this, people with intellectual disabilities face barriers, stigma and discrimination concerning their sexual health education (Abbot, 2013; Wilkinson et al., 2015). Articles 16, 23 and 25 of the United Nations Convention on the Rights of Persons with Disabilities (UNCPRD) (2016) sets out that disabled people should have access to information and education relating to their sexual health. The researchers' rights were being denied. However, there is a tension between empowering sexuality and safeguarding from abuse and exploitation (Wilkinson et al., 2015; Kramers-Olen, 2016). Caregivers are often concerned because the prevalence of sexual abuse is higher in people with intellectual disabilities than non-disabled people (Fisher et al., 2016; Tomsa et al., 2021). However, Callus et al. (2019) argued that overprotection, although often well-intentioned, is a disabling barrier that negatively affects people with intellectual disabilities lives, including their intimate relationships. Callus et al. (2019) argued that there needs to be a balance between protection and autonomy. These issues are explored further in Chapter Seven (Findings: Lack of Opportunities to Create and Maintain Relationships).

6.2.5: Incomplete sexual health knowledge:

Although the information the researchers received was centred around protection, the researchers identified and demonstrated a lack of knowledge regarding protecting themselves and keeping themselves safe, demonstrating that this information was insufficient for its aim of protection. For example, when we discussed the topic of contraception, only partial knowledge about contraception was demonstrated, where the researchers incorrectly believed that condoms and the pill completely protected against STIs and pregnancy.

Ellen: And just to say, if you are in a relationship, not to catch anything like AID's or any sexually transmitted diseases. Use the condom or use the pill, that's all I know (about contraception). If you got a sexually transmitted disease, your doctor might refer you to the hospital.

Louise: I know about the pill. You get it for heavy periods, or you don't want to get pregnant. Basically, if you have the pill, it can stop you from being pregnant. Use condoms and that, you know the way. So, you don't get pregnant.

Bruce: You don't get pregnant with a condom.

There was also a lack of knowledge on how to use contraception. This lack of knowledge is consistent with the data obtained in the literature, which found that the sexual health knowledge of people with intellectual disabilities is usually surface level, superficial and incomplete, where the participants lacked knowledge on contraception, STIs, and pregnancy (Namkung et al., 2021; Wos et al., 2021; Schaafsma et al., 2017; Jahoda and Pownall, 2014). The researchers in this study's lack of knowledge were most likely attributed to their lack of adequate sexual health education.

Another topic where the researchers' lacked information was LGBTQ+. These results support previous research, which found that people with intellectual disabilities lack education and knowledge of sexual diversity (Dinwoodie et al., 2016; Stoffelen et al., 2018; Hole et al., 2022). None of the researchers in this study had been given any information on diverse relationships, and all but one researcher wanted knowledge on LGBTQ+. The researchers identified a range of terms they did not understand, such as queer, bi-sexual, intersex, and non-binary, and wanted to know more. Similar findings were voiced by participants in Wos et al. (2021) study who wanted to learn about homosexuality, transsexuality, gender reassignment and asexuality. Many questions arose from the researchers in this study, such as what it was like to be in a homosexual relationship for a person with an intellectual disability, what the differences were between hetero and homosexual people, why people were homosexual, why they want to get married and how they had children.

During one of the data analysis sessions (where we each picked a word that was most important to us to draw and then discuss with the team), Hermione explored sexual health education and focused on LGBTQ+ (Figure 14).



Figure 14: Hermione artwork on sexual health education during data analysis.

Hermione: Lesbians. I don't really know much about it like. How does it work out like?

Nathan: And how do they know?

Hermione: See the way I'm on about the gay people, right? Yeah, you know how they're a boy and a boy like together. And how do they have children? Because I often heard about that like.

Nathan: Well, I always wonder how the two women has kids?

Hermione: That's what I want to find out about, that's what I'd like to know more about, yeah.

What was different in our study, in comparison to the literature, is that none of the researchers with intellectual disabilities identified as LGBTQ+, but as some studies have found, there are a limited number of people with intellectual disabilities who identify as LGBTQ+ (FRA, 2013; SSCR, 2017). One of the researchers brought the topic up of LGBTQ+ continuously through the study; she asked a lot of questions and made a comment about her friends' perceptions.

Hermione: Some of my friends don't think I'd be able for a relationship, never mind a gay one. It may have been she was questioning her sexuality but did not have the knowledge or options to express this. A lack of identification may be because people with intellectual

disabilities have limited knowledge of sexually diverse options. It may also be because others view them as heterosexual (Azzopardi-Lane et al., 2019).

People in most of the researchers with intellectual disabilities lives, such as parents, teachers, friends, and care staff, either wanted the researchers to avoid relationships seeing them as asexual, or if they had a relationship, it was presumed heterosexual. Nathan and Hermione stated that it would be harder for a person with an intellectual disability to come out as LGBTQ+ to their families.

Hermione: I think it would be difficult.

Nathan: Because they mightn't know how to put it out, or they may think that their parents mightn't talk to them. I think it's just easier for someone that wouldn't have a disability because they'd get the words.

Nathan went on to explain why some families may respond in this way.

Nathan: Well, some of my aunts are still in the older times where it was just a man and a woman. There was a lack of literature on the topic of family's attitudes to sexual diversity and the impact of such on people with intellectual disabilities' perceptions. Studies highlighted that the participants experienced bullying, abuse, and discrimination from their families due to their sexual identity (Dinwoodie, 2016; SSCR, 2017; Bates, 2020). This is an important area for future research.

Unlike studies in the literature (Meyer, 2013; Dinwoodie et al., 2016; Tallentire et al., 2016), the researchers in this study did not hold negative views towards sexual diversity. However, these available studies on people with intellectual disabilities views of LGBTQ+ are 7+ years old, and society has come a long way with sexual diversity since then.

The researchers believed it was difficult to talk about the topic of LGBTQ+ because they lacked knowledge on this topic, and they would like more information. One researcher shared they did not know that same-sex couples could get married.

Ellen: I can't talk about it to be honest. I don't know how. I know some people, but I don't know anything. I want to learn more about it. I know about lesbians and gays, but I don't know anything else. I'd like to hear more about people that are lesbian and gay and stuff.

As well as not knowing about LGBTQ+, three researchers voiced that they could not speak much about it because they lacked experience due to being heterosexual. Bruce said he was unsure if he had learnt about it before; he did not seem to know much about it. He

expressed that he was not that interested in learning about it as it did not apply to him as he was heterosexual.

Hermione: I know one thing, a boy and a boy, or a girl and a girl can have a child anyway.

Bruce: Man and man, or woman and woman. There's pride about it.

Ellen: What's it called, gay pride?

Jess: Yeah, gay pride, so you know a bit about it, would you be interested in learning more?

Bruce: Maybe a tiny bit.

Hermione: It's important to learn about these things.

The lack of research on people with intellectual disabilities and sexual diversity and the researchers in this study voicing that it is an important and absent issue highlight that this topic is essential for future research. The researchers in this study recommended that the topic of LGBTQ+ needs to be available as a separate programme or incorporated into sexual health education programmes for people with intellectual disabilities.

Other topics the researchers voiced they lacked knowledge in were sperm donation, surrogacy, abortion, and sexual consent, where one researcher had never heard of abortion before. Five researchers had not heard of sperm donation and surrogacy before. No one had ever taught them about these topics.

6.2.6: Informal sexual health information:

One of the reasons the researchers most likely had incorrect knowledge was not just that they lacked sexual health education, but they sought information themselves in the wrong places. This lack of access to sexual health education resulted in several researchers seeking information themselves on Google searches, YouTube video searches, social media, video games such as Grand Theft Auto, porn, and TV shows such as Love Island. Throughout the study, one researcher often recommended we go online and find the information we were unsure about by searching Google. These findings were in accordance with previous studies that found when people with intellectual disabilities are denied sexual health information, they will often search for it themselves (Frawley and Wilson, 2016; Wos et al., 2021). Seeking sexual health information through such media may have contributed to the researchers in this study's incorrect and partial knowledge. An example of this can be seen in an excerpt of a conversation below when some

researchers were discussing what sex work was after the topic was brought up in discussions on how the video game Grand Theft Auto impacted our perceptions of sex work. Hermione noted she had seen sex in the game when she played it but did not understand the concept of sex work.

Hermione: I don't understand paying for sex, I don't understand it, like why do you have to pay for sex? I never heard of things like that before.

Ellen: I think it's a form of prostitution as well. I could be wrong now, but I think you have sex and then pay for it afterwards or before it. That's all I know about it really.

Hermione: Why do they have to pay somebody to do that?

Bruce: You pay them for sex and all that.

Ellen: And they pay you for having sex.

Bruce: No, you pay them.

Ellen: Oh!

Bruce: With your money, for how many hours.

Ellen: Half an hour is €50.00, years ago that's what they used to pay.

Bruce: Because sometimes they drug them and have sex with them. Because then you have to give money to the pimp or whatever you call it.

As seen from the excerpt above, the information was only partially correct; the researchers focused on having sex for money. However, one researcher did not understand why, and another did not understand who got paid. The ethical issues were not highlighted, such as drugging a sex worker or paying a pimp, and the safety issue did not come up. This was concerning as a few researchers shared that they may see a sex worker in the future as it is challenging to find a partner when a person has an intellectual disability. None of us had previously known it was illegal for us to see a sex worker; we initially only believed it was illegal for the sex worker. People with intellectual disabilities have access to the real world, which was demonstrated through their past use of this video game, but if they do not have the correct knowledge, they could be at risk if they seek a sex worker or in other areas relating to having intimate relationships. Additional research is needed to better understand some of these areas that are lacking in research, such as the impact of the video game Grand Theft Auto on perceptions of sex work (research that is common with non-disabled youth but not with people with intellectual disabilities), the impact of media on people with intellectual disabilities understanding and experiences of intimate relationships, and people with intellectual disabilities and sex work.

When the researchers received sexual health education, it was often only received when they overheard it indirectly, and this was the only way they got information about LGBTQ+. For example, when discussing LGBTQ+ and gender.

Hermione: Well, I heard someone talk about gay relationships before alright, but I wasn't talking with them. It was someone in my class. They were on about lesbians (laughs) in a bad way.

Nathan: I have heard of it (non-binary). I don't know what it means. I've heard people saying it like. Ellen linked homosexuality to STIs. She might have overheard this somewhere, as it is a common myth.

Ellen: Be careful because you might get sexually transmitted diseases if you do it without protection. Not saying you will but it depends who you are dealing with. It could be who they were with before or homosexuality.

Some of the researchers also discussed they had indirectly heard of gay pride.

6.2.7: Summary of findings relating to sexual health education:

The main findings on this topic were that the researchers had limited to no sexual health education, and their sexual health knowledge was either limited, functional, superficial, or incomplete. When their sexual health education was present, it took a biological discourse, which is how most of the researchers viewed relationships and sexuality. Pleasure was a topic that rarely came up, and the researchers did not show an interest in this for discussion. Despite resistance from others, most of the researchers still had intimate relationships, although these were heterosexual. Topics lacking in research include pleasure, LGBTQ+, the impact of the media, including video games, on people with intellectual disabilities views, and sex work.

From analysing the stories, the researchers shared the reasons behind this lack of sexual health education came from their caregivers controlling it - families, teachers, and disability professionals. The caregivers most likely viewed the researchers in a paternalistic way, wanted to protect them from abuse and exploitation, and possibly stereotyped them due to their disability and gender. There is a tension between empowering sexuality and safeguarding from abuse and exploitation due to the high prevalence of sexual abuse and society's ingrained historical views of people with intellectual disabilities sexuality; stereotyped as vulnerable. However, this protection is not working and violates people with intellectual disabilities rights. There needs to be a

balance between protection and autonomy. The law has changed internationally and in Ireland, but caregivers still do not know how to support people with intellectual disabilities sexuality. There needs to be guidance and training for professionals, education for families, and evidenced-based sexual health education programmes for people with intellectual disabilities that are accessible and focus on supporting sexuality and protecting people. Without this, the researchers sought information in the wrong places such as through media, which led to partial and incorrect knowledge. Many of the researchers had intimate relationships despite the resistance they faced and coupled with inadequate sexual health information, they could be at risk. Others should view people with intellectual disabilities more holistically and not assume they are asexual or heterosexual.

It was disappointing to hear that the researchers knew they lacked sexual health education and knowledge and wanted this information but just accepted they had no option and could never have it due to their intellectual disability. For some people, they have been feeling this for up to 25 years. To spend all these years worrying that something may go wrong because they did not have the information they needed but took the risk and had intimate relationships was hard on the researchers. When the researchers had the space to discuss sexual health education, the first topic they chose of importance, they got upset and angry. They identified that their rights were being denied and violated. They further identified that they had a right to sexual health education and were discriminated against because they had an intellectual disability. They voiced they were at risk without this information and wanted it. This was powerful. They wanted to seek accessible sexual health education and an LGBTQ+ and sexual consent workshop for the first three actions of this study.

6.3 Actions on sexual health education:

During our discussions on sexual health education, we decided this was an important topic that needed action. We decided to seek sexual health education as part of this study. Two specific areas came up of importance: LGBTQ+ and sexual consent. LGBTQ+ came about as this is the area the researchers highlighted where they lacked the most knowledge.

How sexual consent came up (and explored in Chapter Seven: Lack of Opportunities to Create and Maintain Relationships) is that two researchers were sent sexually explicit photographs online and had not realised this was a form of image-based sexual harassment. When they realised this, they decided they needed more information. Because other researchers had negative experiences of online safety and concerns about safety in relationships and sex, they also wanted to learn more about consent. We decided to seek workshops on these two areas as part of our actions.

6.3.1 Action 1: Sexual health education:

The first action was to source accessible sexual health education. As in the study by Hole et al. (2022) the researchers requested formal, accessible sexual health education. When people with intellectual disabilities have received adequate sexual health education, they have said it is of benefit (Walmsey et al., 2016; Bates et al., 2017b; Neuman, 2020; Hole et al., 2022; McCarthy et al., 2022). This knowledge may empower people with intellectual disabilities to protect themselves while benefiting from sexual fulfilment (Duguay, 2013). I agreed that I would try to find a programme. I did a lot of research and had two meetings with different disability professionals who did this training. Unfortunately, no in-person programme was available outside of Dublin, which was too far away for us to travel. I could only source a few online sessions that would not cover much information within the limited timeframe and would be costly. The trainer offered to either do this or to link in with us in the future when she had more availability to do an in-person programme over a more extended period, which would be tailored to our needs. I spoke to the group, and we decided to leave the programme until after our study was complete, hoping we could do a longer in-person programme.

However, the relationships and sexuality coordinator of a disability service in Dublin liked that we were researchers in the area and said she had an idea she wanted to bring to us and her manager. If we were interested and if she could get funding, they could train us as relationships and sexuality trainers who could facilitate sexual health education to other people with intellectual disabilities and would be paid. I brought this back to the research team, and everyone except for Hermione said they were interested in teaching,

and we all said we were interested in the training but also wanted to do more research. I suggested that if we went down this route, and we wanted to stay together as a research team after the PhD study, we could look at evaluating the programme. Everyone was happy with this. Ellen did, however, express her concerns about doing training if it was not accessible and was also worried about how a wage may impact her benefits. We decided to wait to see what opportunities arose, and then we could investigate how much earnings could be made without affecting any benefits and voice our concerns around accessibility.

As we undertook another action (discussed in Chapter Eight: Findings: Perceptions), where we presented our research at the International Action Research Colloquium 2022 (Mannion et al., 2022a), an opportunity came our way. The keynote speaker from the University of Cincinnati approached us and said that he liked our work and asked if we could meet with his faculty to explore working together. We would then be able to access accessible sexual health education for people with intellectual disabilities that included the topic of LGBTQ+ (see epilogue for further information).

6.3.2 Action 2: Sexual consent training:

We had a specific interest in sexual consent, which came about through our discussions of how important consent is after two researchers disclosed being victims of image-based sexual harassment (explained in Chapter Seven: Lack of Opportunities to Create and Maintain relationships). We identified that one of the reasons others stop people with intellectual disabilities from receiving sexual health education is they are worried that it is giving them ideas to have sex, as they cannot consent. One way of reducing this issue may be for people with intellectual disabilities to undertake sexual consent training. We wanted to learn more about this area. I took the task of sourcing sexual consent training. One Canadian study found that people with intellectual disabilities found learning about consent and safety valuable (Hole et al., 2022). I had done sexual consent training in the past and was aware of a programme. I initially spoke to the programme co-ordinator at my university, but they could only offer this training to students. I then approached the lead of this programme at another university, explaining we were not students and would

need an accessible programme for people with intellectual disabilities. They kindly agreed to hold an online live workshop. There was an evaluation at the end that would not be accessible to us all, as it was to be completed on a mobile phone. We agreed to do a verbal evaluation that would be shared with the lead from that university and in the PhD study. I brought this information back to the research team, and everyone wanted to do the sexual consent training; however, on the day, only four of us attended as different personal issues got in the way of attendance.

Alice, Bruce, Hermione, and I attended the live online one-hour sexual consent workshop. We all thought it was good.

Hermione: It was interesting.

Bruce: What was good was talking about being safe in sex and all.

Together, we discussed some learning that took place.

Bruce: You could be raped if the person did not wear a condom but pretended that they did.

This brought us to discuss the scene in the video where a woman fell asleep, and a man raped her.

Hermione: Yeah, because if you're sleeping and there's somebody trying to have sex with you, it's raping them. She didn't give the consent that she wanted to (have sex).

We spoke about being unable to consent when under the influence of alcohol or drugs.

Hermione: I kind of knew that would be wrong, having sex with somebody when they're asleep or without even asking them.

Bruce: Probably wait until they wake up.

Bruce voiced some of this was new information. The workshop gave examples of how someone could give consent, such as saying, 'Keep going, I like that,' or examples of how to say no, I do not give consent, such as 'Stop, I do not want you to do this'. Bruce and Hermione said this was new learning for them. They both said that these examples have now given them the language that they need to feel comfortable speaking out if a similar situation arises. They were aware of what consent was before this workshop but were not sure what to say to give and decline consent. They both stated they would feel comfortable articulating themselves now.

We enjoyed the workshop; it was informative free, and new learning took place, and we did appreciate that they ran it for us when we were not the target audience of students. However, we critiqued the workshop concerning accessibility to people with intellectual

disabilities and neurodivergence. There was a noise we did not like, interference with the video, and the sound lagged, so it did not go in sync with the lips moving in the video and was too loud for one researcher. This was most likely due to the workshop being held online over Zoom and at no fault of the workshop providers. Alice said she would have liked subtitles as listening and paying attention was challenging, and Bruce and I agreed. We all thought that the training went very fast, it was a lot of information to take in, and we would have preferred getting it at a slower pace in a short time. I did get confused between two of the video scenes as they were fast, but I had got distracted, so maybe this was why. We suggested the writing on the screen could have been made more accessible by having bigger writing, easy-to-read language, and colours that were not bold as they are hard on the eyes. If images were added, it would have been more accessible to us. Bruce said he would have liked to have seen actors with intellectual disabilities.

Bruce: More representation anyway, to represent us.

We all agreed. We also identified that the workshop covered the topic of the capacity to consent concerning those under the influence of drugs and alcohol but did not bring up the capacity to consent for people with intellectual disabilities. One of the barriers to sexual health education and the opportunity for relationships that we identified (explored above and will be explored in Chapter Eight: Findings: Perceptions), was other people's perceptions of people with intellectual disabilities' capacity to consent. As a result, we would have liked to have seen the capacity to consent concerning people with intellectual disabilities covered in the sexual consent workshop.

We all said we would like further information on sexual consent, and there was online training available for us at home, but we did not know whether this would be accessible. These workshops were aimed at students without intellectual disabilities. However, two of the researchers were current students and were neurodivergent, and this workshop was not fully accessible to them either. We shared this feedback with the university. The information on what did and did not work will be helpful when we are doing future sexual health education training as we can voice from the start what our needs are. Without this experience, it was hard to know. We now have some experience evaluating sexual health education, which will help our future work in this area, as evaluating a sexual health

education programme is an area of research that the researchers want to study in the future.

6.3.3: Action 3: LGBTQ+ workshop:

We also wanted information on LGBTQ+, including how to have a relationship, marriage, and children, as actions arising from the research. Participants with intellectual disabilities in Stoffelen et al. (2013) study stated they found LGBTQ+ sexual health education helpful. I tried to seek a workshop on this. I contacted numerous agencies in Ireland that support LGBTQ+ people, but only one specialised in disability, and is based in Dublin, which is too far away. All the rest were aimed at young people (under 18 years old and we were adults), and none of them could offer a workshop. The most one could offer was to train me so I could do a workshop with the group, which was beyond my role as a researcher. We decided to leave this training until after the research was complete and have the training incorporated into the sexual health education programme. We wanted the information but also understood it was not available right now. The trainer, who could later facilitate a tailored sexual health education programme for us, agreed to include LGBTQ+ in this training, and we were happy with that. However, it later transpired that we would do the programme with the University of Cincinnati instead; however, this also included LGBTQ+ education (see epilogue for further information).

6.4: Recommendations:

Together, we agreed on recommendations that free, in-person, local, accessible sexual health education tailored to the needs of people with intellectual disabilities should be made available to all people with intellectual disabilities. This should include support in finding a partner, boundaries, sexual consent, parenting, sexual abuse, and harassment, keeping safe if seeing a sex worker, online safety, and LGBTQ+ relationships. Other studies recommended sexual health content (Hole et al., 2022; Schaafsma et al., 2017; Eastgate, 2008), but we identified very different topics. This difference in sexual health content could be due to different experiences or the cultural context, as those studies were not undertaken in Ireland. We further recommended that there should be further education

and information on LGBTQ+ aimed at people with intellectual disabilities. The topic of the capacity to consent for people with intellectual disabilities should be included in any sexual consent workshop.

Training aimed at the mainstream population should still be accessible to people with intellectual disabilities as they may be in attendance. The delivery and resources of such sexual health programmes should be accessible and inclusive. This includes facilitating at a slower pace and holding workshops over a more extended period with less content. The writing should be large, using easy-to-read language, without bold coloured fonts, and with accompanying pictures. Resources such as videos should ensure representation using actors/ models with intellectual disabilities.

Chapter Seven: Finding's Part Two -

Lack of Opportunities to Create and Maintain Relationships.

7.1 Introduction:

While exploring our sexual health education, the researchers realised they lacked opportunities to meet people and form relationships. We wanted to investigate this further. The researchers said that others stopped them from having relationships and suggested that we explore why people stopped them. This fed into a later action on creating awareness of negative societal attitudes (explored in Chapter Eight: Perceptions). As part of this exploration of opportunities to meet people, we identified that we wanted to look at dating apps, as this was one common place to find a partner, as well as social media, as this was a platform where communication with others would happen. We further identified that we would look at online safety as we were concerned about safety on both dating apps and social media, and this later became one of our actions.

7.2: Over-protection, control, and segregation:

The researchers identified that one of the reasons they lacked opportunities to meet people, other than their lack of education and knowledge, was because families, teachers and disability professionals wanted to protect them from harm due to their disability. This over-protection led to paternalism, surveillance, control, and segregation, all described below. This matches what was observed in previous studies where caregivers wanted to shield and protect people with intellectual disabilities (Callus and Bornello, 2017; Chou et al., 2020; Schmidt et al., 2021; Hole et al., 2022). The researchers in this study further believed that non-disabled people stereotyped them as vulnerable.

Ellen: Well, they think we're vulnerable because we have disabilities.

Hermione: What does vulnerable mean?

Ellen: It means people will take advantage of us easy because we have disabilities.

Nathan: Because sometimes I think people are harder on someone with disabilities.

Hermione: I agree, yeah.

Chloe: The staff said they cannot help us to find a boyfriend or girlfriend.

The lack of opportunities to form and maintain relationships was a common finding in the studies in the literature (Lafferty et al., 2013; Small et al., 2013; Rushbrooke et al., 2014; Sheldon and Storey, 2014; Callus and Bonello, 2017; Azzopardi-Lane et al., 2019; McCarthy et al., 2022; Puyalto et al., 2022). The researchers in this study identified a lack of face-to-face social opportunities to meet people and form relationships and even friendships. Two of the researchers were best friends but could not arrange a coffee together.

Chloe: Staff are working with her in the house (group home), they won't let her out on her own anywhere. I was saying to the staff I could meet her in town for a coffee but the staff in the house won't let her out much.

Louise explained that the staff in the group home insisted they must go with her, and they would not have enough staff to bring her alone, and it would be up to the other three male residents if they wanted to go also. This was also found in recent studies where staff numbers and shift patterns have been found as barriers to socialising (McCarthy et al., 2022), where people with intellectual disabilities' environment are controlled, are rarely unaccompanied by caregivers, and experience high levels of staff surveillance (Azzopardi-Lane et al., 2019; Chou et al., 2020; Neuman, 2020; McCarthy et al., 2022; Puyalto et al., 2022). Also, people with intellectual disabilities rarely get to socialise with people from outside of their disability services (Rushbrooke et al., 2014; McCarthy et al., 2022; Puyalto et al., 2022). Their free time and leisure activities are restricted, and caregivers are usually present and spent with other people with intellectual disabilities (Azzopardi-Lane et al., 2019; Callus and Bornello, 2017). The implications for the researchers not being able to spend time together will not only impact their friendships but also their future relationships, as it will be challenging to meet a partner if they do not go out or are always accompanied by the staff and other people who live in the group home. Bruce, Chloe, and Louise repeatedly voiced how difficult it was to find a relationship, and Bruce and Chloe were never in a relationship before as a result. This is unsurprising given their lack of opportunities to do so. These findings are not only barriers to creating and maintaining relationships but conflict with the United Nations Convention on the Rights of Persons with Disabilities (UNCPRD) (2016), which sets out in Article 19 that the community includes disabled people, they have choices that are equal to others, and enjoy full inclusion and participation; and Article 30 states that disabled people have access to

leisure activities. These two friends should be able to meet for coffee, and it should not depend on staff availability and where their housemates want to go.

One researcher spoke about a disco in the day service she attended. She stated she was not happy with how some of the disability professionals spoke to her there as if she was a child and that she would prefer a proper club where she could stay out as long as she wanted, later at night and not only three hours earlier in the evening like this one. Chloe further stated that she would rather go to a club for people with and without disabilities.

Chloe: It's not really good because it's the same few people with disabilities they allow in that can't go anywhere else. But if we were somewhere else, they would allow anybody in. They don't have alcohol drinks there, they just give out treats like fizzy drinks, crisps, and bars. But they wouldn't be allowed (people with intellectual disabilities) to get out to a nightclub on their own. It's a pity that no one else (non-disabled people) can join if they wanted to.

Chloe was highlighting segregation and being treated like a child, as well as being told what she was allowed or not allowed to do, which was limiting her opportunities for relationships and friendships. This barrier of being treated like a child was also reported in a study in the literature (Wilton and Shormans, 2020).

Chloe and Louise suggested why they thought the disability services staff may be over-protective.

Chloe: Probably they (day services staff) wouldn't want them (people with intellectual disabilities) out on their own. Because you know the way most of them that live with their parents, they might think they might get lost somewhere or mightn't find their way back.

Louise said that the staff in her group home would not want someone (boyfriend) to like her, as they would be worried for her wellbeing.

Louise: Basically, I can't, they won't let me find a boyfriend or a girlfriend because I have a disability and probably something might happen to me.

However, Louise still noted that she wanted a boyfriend, and if she found the right person, she would also like to get engaged. Chloe suggested that Louise could not get married because she lived in a group home, and Louise agreed. Louise tried to move out of the shared group home to an apartment, but the disability service could not accommodate her as the available apartment was on the first floor, and she has a mobility impairment. Support can be dependent on funding.

Bruce noted the vastly different situations that he and Louise were in. He highlighted this difference may be due to their different life situations. Bruce noted Louise went to a specialised school for people with intellectual disabilities, and he went to a mainstream

school. Louise lived in a group home, and he lived with his mum, who was very supportive of him having a relationship. He believed he had more independence and a better life than her. Louise did share that her independence was dependent on staff resources, and they were protective of her. Further research with a focus on the different experiences between people with intellectual disabilities who are in group homes and specialised schools in comparison to those in independent or family living, and mainstream schools would shed further knowledge on this area and is a recommendation arising from these findings.

Ellen shared experiences of when she lived in a group home prior to moving to independent living in her apartment with the support of a social worker, and later, her fiancé moved in with her. Unfortunately, she had to keep her past relationship a secret in her group home, which could have led to risky situations, and she feared homelessness if she was caught out. Previous studies have also demonstrated that people with intellectual disabilities have had to keep their relationships a secret, which has put them at further risk (Stoffelen et al., 2015; Rushbrooke et al., 2014; Puyalto et al., 2022). Neuman (2020) found that people dependant on caregivers who were unsupportive of relationships lived in this constant state of uncertainty, anxiety, and fear from being separated from their partner. Ultimately, Ellen had to leave her group home to pursue her relationship, as it was the only way.

Ellen: You can't have relationships in HSE houses (group homes), why I don't know, we are not allowed a relationship. I was in a HSE house (group home). They (the staff) wouldn't let me have a boyfriend and I had one. They (the staff) said you can't have a boyfriend if you're living here, they're the rules. I kept it a secret and they never found out. I walked out of it (the group home) in the end.

Ellen went on further to share her experiences in this group home.

Ellen: That's why I'm not in a HSE house (group home). Like in my experience you have no privacy at all, you've no freedom in the house. You couldn't do it (kissing/ sex) in the house. You've to go to the other house (partners). Your money is taken off you, you have to pay 110 euro a week social welfare for the house. You had to go out in the morning and come back at 5 O'clock in the evening. You'd be around the town, there were day centres and stuff, I went to one but was told to leave it and don't come back unless I had problems. They (group home staff) write everything down in a diary about you, every single thing you do. What mood you're in, everything they write down. I said why are you doing that, they said we have to in case anything happens, we're responsible for you.

Ellen said she was not allowed to read this diary. This control from staff in group homes was also identified in a study from the literature where the participants felt constrained

and controlled by the strict house rules, staff attitudes and limited control they had (Wilton and Schormans, 2020). Studies in the literature highlighted that sometimes, professionals exerted control and created house rules that restricted relationships, which was found most restrictive by staff in group homes (Garcia Iriarte et al., 2014; Puyalto et al., 2022). Many restrictions in group homes were discovered in the studies to include banning physical contact, masturbation, sex, and intimate relationships (McClelland et al., 2012; Bates et al., 2017b; Puyalto et al., 2022), same-sex housing, restricting fertility through enforced contraception (Puyalto et al., 2022), not being allowed to have visitors in their home (Garcia Iriarte et al., 2014; Puyalto et al., 2022), not being allowed to live with their partner (Neuman and Reiter, 2017), and not allowed to become parents (Neuman, 2020). Ellen further explained the privacy issues in the group home as having no locks on her bedroom door, her bed was single, and she could not even bring friends in. This was found in the literature where participants in one study expressed a lack of privacy in their group homes (McCarthy et al., 2022). However, none of the studies identified the issue of people with intellectual disabilities who live in group homes having single beds and if this is linked to service perceptions or rules. Nor has the issue of having to leave a group home to pursue a relationship has come up. The recommendation is for additional research to understand this better.

Ellen: I was told that I couldn't have a boyfriend. I wasn't capable of minding myself, that was the exact words said by the HSE (staff). I was able to do it, but I couldn't say it because they were over all the hostels (group homes), I was afraid to say it, in case I got told I'd be homeless.

The rest of us did not have experience of living in a group home.

Hermione: I was asked if I'd like to live in a group home like that. I said no because I'd rather live with my mother and father. People living in the house as well, It's not good.

Ellen: You are not allowed a relationship.

Hermione: They have no comfort at all. They should have a right to relationships.

Jess: Why should they?

Hermione: Because they are like everybody else. I'm not interested in a sexual relationship, but people have the right to do whatever they want.

Ellen: I just do my own thing. I had to fight hard to get independence.

Hermione said the topic of group homes and rights was important to her; even though this did not impact her directly, she felt it was very unfair that people with intellectual disabilities rights were being denied in their own homes. She drew an image of this

during one of the data analysis sessions (choosing a word of importance and doing art to explore it in more detail) (Figure 15).

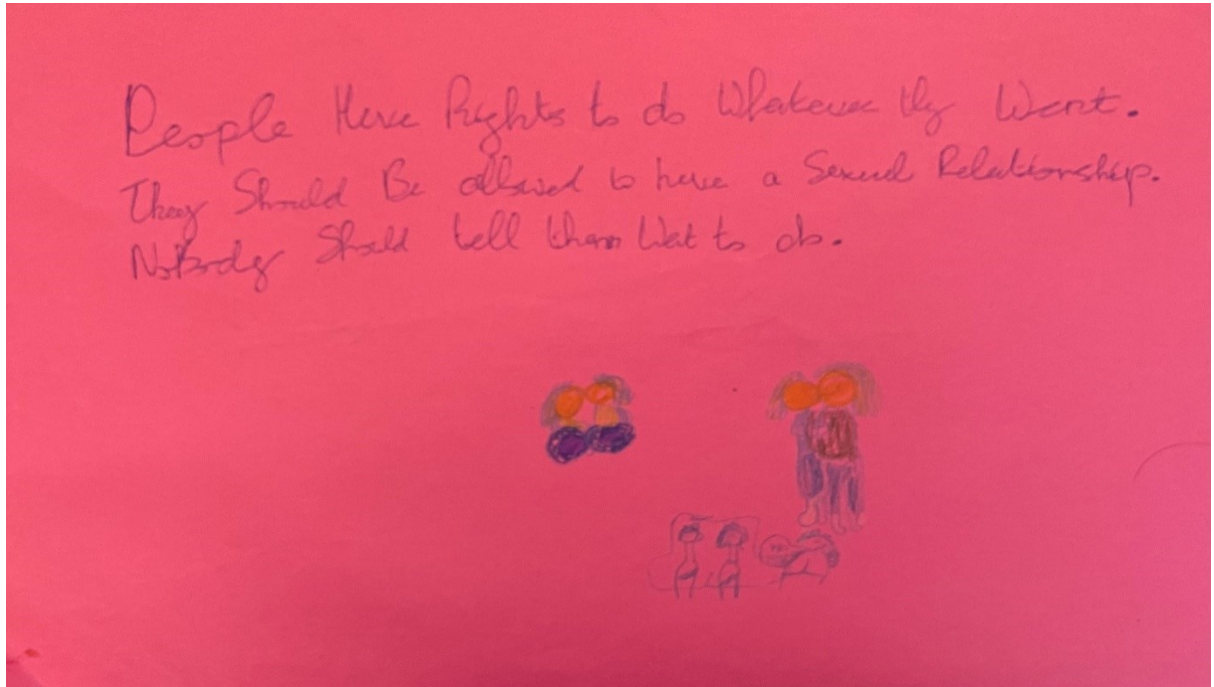


Figure 15: Hermione's data analysis art on group homes and rights.

Hermione: I wrote people have rights to do whatever they want. They should be allowed to have sexual relationships. Nobody should tell them what to do. That's about the HSE houses.

Ellen: I agree.

Bruce: I agree. Everyone can have relationships, sex, whatever they want. It's a free country anyway.

Hermione: I don't think it's fair on people who want to get on with their lives. I know people that want a boyfriend or a girlfriend and then they can't do it in the houses, it's awful.

Hermione also brought this topic into her sand scene (Figure 16) when we were exploring what we learned in the study. Hermione made a scene of a couple with intellectual disabilities trying to kiss or have sex privately, but the staff intervened.



Figure 16: *Hermione's sand scene on what she learnt about relationships and sexuality during the research.*

Hermione: There's two people kissing, or having sex, or whatever it is, and then there's another person giving out to them for having sex, like a HSE house staff. They don't want them to have sex in the house. I learnt that people can't have sex when their living in a HSE house. They are trying to have a bit of privacy too behind the thing (laughing).

Ellen: People with intellectual disabilities are equal to everyone else in the world. Do not put them in institutions.

These conversations demonstrated the huge barriers the researchers faced when they lived in group homes. Professionals were controlling how they lived their lives despite the researchers expressing what they wanted. As Rushbrooke et al., (2014) argued, the overprotection of people with intellectual disabilities is particularly evident in group homes and could impact their human rights (Rushbrooke et al., 2014; Puyaltó et al., 2022). Many articles of the UNCPRD (2006) were being contravened. Article 19 states that disabled people are not obliged to live in a particular living arrangement. It is assumed that some practical issues are at play, such as a lack of funding and staff. Despite the law changing, professionals often fear negative consequences if they support relationships. People with intellectual disabilities have been viewed as vulnerable for so long it is difficult to change this mindset. Professionals are often concerned that those they support may be abused or exploited. Article 16 does state that disabled people must be supported to

prevent abuse, but as well as this, Article 23 states that disabled people have a right to personal relationships. Although achieving these two rights is not easy, one must not take precedence over the other, and denying people relationships is not a method to protect a person from abuse. Many of these restrictions deny the researchers other human rights under the UNCPRD (2006); for example, Article 5 states that there is legal protection to prohibit all discrimination based on disability, and Article 22 states that privacy should be respected. Professionals need to be supported in how they achieve protection and rights together. This support could come through funding, guidance, training, procedures, and policy. In the next chapter, after these discussions became more in-depth and the researcher's emotions grew, we decided to work on an action to tackle these attitudes and create awareness (Chapter Eight: Perceptions).

Protective views from professionals were not the only barrier to relationships; most of the researchers experienced protective family perceptions as a barrier, too. Sullivan et al., (2013) argued that opposition from families is one of the most significant barriers to people with intellectual disabilities forming relationships, which was found in many studies (Sullivan et al., 2013; Azzopardi-Lane et al., 2019; Schmidt et al., 2021). Four researchers with intellectual disabilities in this study shared negative experiences of overprotection from their families towards them having relationships. Bruce's mother, however, was very supportive. Such support was found in studies in the literature to be beneficial because participants had received emotional and practical support to find a partner and maintain a long-term relationship (Neuman, 2020; McCarthy et al., 2022). According to Puyalto et al. (2022) families have been found to restrict women more than men. This is most likely due to the discourse around men and women, where women are seen as more vulnerable, and then the risk of pregnancy is added to this. Most of the existing research focused on the barriers to relationships and sexuality but research evidencing what is going well is lacking, future studies on this topic are therefore recommended to inform how best to support people with intellectual disabilities.

Louise shared that she had a boyfriend before, and he did not have a disability, she was happy, but they were not perfect, and it did not work out.

Louise: Well, I told my mam and dad about it, and they were not happy. They (parents) said they (boyfriends) are only trouble. They only want your money. I think mam was scared. Say something would happen to me in the middle of the night.

Jess: What did you think about that?

Louise: Like they would take advantage, exactly.

There are similar attitudes expressed by Louise's parents and participants in studies from the literature where parental overprotection was evident (Azzopardi-Lane et al., 2019; Schmidt et al., 2021). Many participants across the studies in the literature feared sex (Bernett and Ogletree, 2013; Nayak, 2016), and it was found that their attitudes and experiences were dependent on the expectations of others (Chou et al., 2015; Nayak, 2016). Louise had conflicting views; at times, she advocated for her rights and desires to intimate relationships and at other times, when talking about her parents' concerns, she also voiced she was concerned for her safety. Louise voiced repeatedly that she wanted to be in a relationship and someday get married, but these fears her parents voiced repeatedly made her too fearful to act on what she wanted. She believed that sexual health education would be needed to help her address these concerns as she had never had any before. It is important to note here that although Louise described her parents and care staff in her group home as over-protective at times, her parents, sibling, and key worker from her group home, were hugely supportive of her engaging in this study and actively went out of their way to support her to ensure she could fully participate no matter what. They wanted the best for Louise.

7.3: Avoiding risks online

The researchers in this study believed that nightclubs and online platforms such as dating apps and social media were avenues for them to form relationships. However, they lacked knowledge in this area, which created further risk, which is explored in this section. There was no research identified in the literature on experiences of nightclubs and intellectual disabilities. Dating apps were not a common theme in the literature; only one of the studies covered the topic of dating apps and agencies and was from the U.K. (McCarthy et al., 2022). This highlights knowledge gaps in these areas and a need for future research. Regarding dating apps in this study, through further investigation, the researchers identified that there were no dating apps in Ireland for people with intellectual disabilities,

which they said added to their lack of opportunity to find a partner. Two researchers used mainstream dating apps, but they both expressed or demonstrated a lack of information on dating apps and how to use them safely, as well as the other researchers who did not use dating apps. However, this did not prevent the researchers from using dating apps, which led to possible risky situations. For example, one researcher almost met a man she knew little about in an unsafe situation.

Ellen: I was to meet a guy in a car park in his van near my house. I didn't meet him, I was going to, but I didn't. I blocked him.

She also said she did not always understand the words men used and often had to block them. However, Ellen thought dating apps were good as they allowed her to talk to someone for months and get to know them before meeting them. In fact, she met her now fiancé (a man with an intellectual disability) on a dating app, which was a positive experience for her.

Another researcher used dating apps regularly and was currently talking to a man on Tinder.

Louise: I think it's good (Tinder). He sounds very good, and I would like to see him.

She felt Tinder was good because she could find information about the man she was talking to. However, on further discussion, she actually knew very little about this man.

The researchers believed social media was another suitable format for meeting new people and talking to existing friends. However, this was an area not highlighted in the literature; additional research is needed to understand this topic better, but this study shed some light on the area. In one of the research meetings, Hermione and Louise made a rap about social media and online safety (Figure 17).

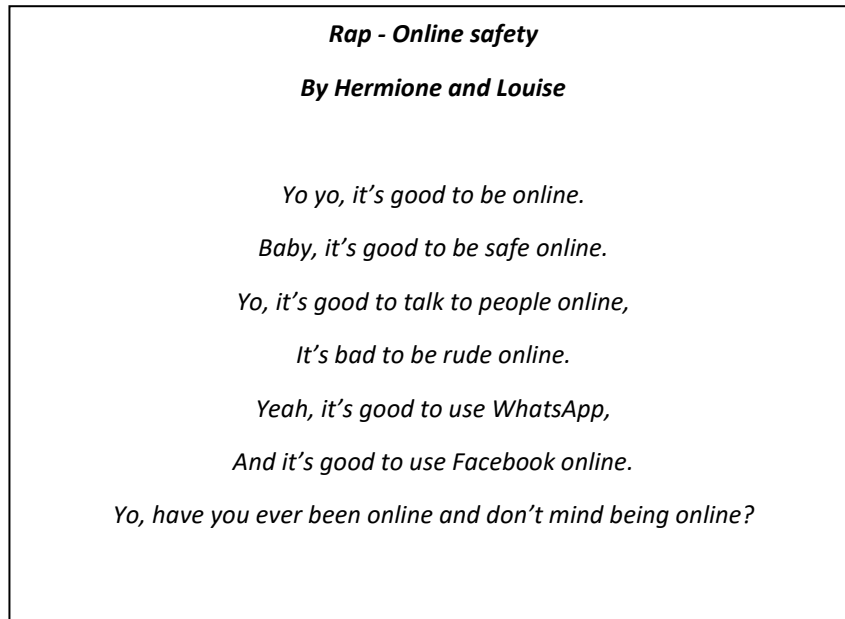


Figure 17: Hermione and Louise's rap on online safety in relation to social media.

After they wrote and performed the rap, they discussed it with the other researchers. The researchers highlighted that one significant benefit of social media apps was that they were an excellent way to meet new people and talk to existing friends, primarily through video chat.

Louise: It could help me to talk to people. Like meeting people face-to-face online.

They found this a particular advantage during the COVID-19 restrictions.

Hermione: We are not allowed to go out so online is good.

The researchers found that social media helped them to communicate with others while they were in lockdown. Everyone used Facebook and WhatsApp, some used Instagram, Twitter and TikTok. WhatsApp was a very popular method to communicate with friends because it was free and perceived as safer than other apps. However, the researchers believed that due to their lack of knowledge of online safety, they were at a disadvantage in using social media in this way. The researchers identified and demonstrated a lack of information on online safety for dating apps and social media to keep themselves safe. For example, one researcher incorrectly believed that strangers would not message them on their social media app, and other researchers found themselves in potentially dangerous situations such as getting scammed online (examples discussed below). It was highlighted that some researchers had to avoid engaging in social media or dating apps due to their safety concerns because of this lack of information, which they were aware

of. Some researchers identified that it took unsafe situations to happen to them for them to learn about online safety because they did not know before this. Initially, these researchers expressed that they felt they were more aware of online safety and were not concerned about being taken advantage of again in the future due to these unsafe experiences. However, this was not the case later, as they demonstrated they still lacked knowledge; for example, these researchers did not know it was illegal for someone to send them sexually explicit photographs or videos without their consent. At this point, the research team said they would like to learn more about online safety and sexual consent as they did not know how to keep themselves safe online through social media and dating apps. A benefit of our reflective conversations is that they helped people learn new insights about their experiences and act on them.

Some of the risks the researchers identified are explained here. Two researchers shared that they regularly spoke to strangers on social media apps, some of whom wanted to meet them in person, but the researchers did not go through with it in the end. Two researchers shared that they received unsolicited nude photographs and videos on Facebook Messenger. One of these researchers was then blackmailed but got support from their family and put some safety measures in place, such as setting up a new account with more robust privacy settings. The other researcher immediately blocked the person who sent the image. These two researchers did not know that someone sending them sexually explicit photographs or videos without their consent was illegal and a form of image-based sexual harassment. However, they knew it was wrong and did not like it, so immediately blocked these messages. Through our discussions, they stated they would like to learn more about sexual consent and online safety. This is how the sexual consent training came about, as explained in the previous chapter. One researcher shared that they spoke to someone they did not know on Facebook Messenger who offered to meet them for sex for €150.00. The researcher transferred this money through PayPal and then decided they did not want to do this. It turned out to be a scammer. However, after going to a family member for support, they retrieved their money back. Other online safety risks identified by the researchers were getting social media accounts hacked, receiving messages from strangers, and receiving messages and calls from scammers. The researchers said they did not know how to keep themselves safe when talking to people

they did not know online through social media and dating apps. When Louise advised us, she put the onus on us to avoid harm and not the other person.

Louise: Being safe online, not to go onto things you shouldn't and not to say things online that would be dangerous.

This probably stemmed from Louise's experiences of the views of others who seemed to put the onus on people with intellectual disabilities to keep safe and protect themselves by being appropriate and respectful.

New insights and actions to address the issues we identified emerged from these discussions. We identified that others wanted to protect the researchers but did not give them the information to do so because they wanted to shield and protect them. However, the researchers still accessed intimate relationships, dating apps, and social media, so were more at risk without this information. From these discussions, we as a group realised that we were not alone in these experiences and that we all needed to learn how to protect ourselves best. This is where our actions arose: we wanted consent and online safety training. We all wanted to learn more about online safety, particularly Ellen, who often voiced this during our research meetings. We agreed we would like to learn about keeping safe on websites, social media apps, dating apps, and phones and how to keep safe if meeting someone from a dating app.

Despite caregivers wanting to shield the researchers from abuse by protecting them, throughout the study, three of the researchers disclosed past forms of abuse and harassment; this included two disclosures of sexual abuse and as discussed above, two disclosures of image-based sexual harassment. These figures of sexual abuse prevalence in people with intellectual disabilities corroborate with the analysis from Thomas et al. (2021), who suggested one in three adults with intellectual disabilities have been sexually abused. The researchers who disclosed in this study had previously been supported with this through the criminal justice system, counselling, and family support. However, the researchers were supported in this study, where I followed the procedure for disclosures of abuse and retrospective abuse (Appendix 3). This meant I checked if everyone was okay as they shared it in a group context. Everyone was offered counselling, not just those who disclosed, but only one who disclosed went for counselling. Each time, I reminded the group of confidentiality and asked them not to share this information outside the group.

Everyone was happy to continue the discussions; the researchers who disclosed said they had worked through it and wanted to share it and felt okay. They had not gone into detail and had just stated their disclosure. However, I asked if they wanted to talk privately, and one did, and she shared detailed information, which I felt was upsetting to hear. I felt better when I rang and set up the counselling as I felt I could do something positive. I had the experience of many past disclosures through my social care work, so I had a lot of experience, but I think this was harder as it was for research I was doing for a PhD. I was also glad I had done disclosure training a few weeks before, so I felt I had handled it well. In ethics applications, we consider the effects on 'participants' but rarely the effects on the researcher. This area should be considered and developed for ethics committees that review applications. Disclosure training should be mandatory for any researchers undertaking similar studies.

7.4: Action Four: Online safety training.

In this stage of the study, we decided to create an action around online safety after the researchers identified that dating apps and social media were possible avenues to meet people and form relationships, but that knowledge of online safety was low. It was putting the researchers at further risk. After we had our research meeting on online safety, Ellen suggested that we could do an online safety workshop with the Gardai (Irish police) and if we liked, she could get information on it. We all wanted to do the workshop as we had reported various online safety concerns, so on request of the research team, and after Ellen passed on the information, I organised this workshop with the secretary of the local Gardai station. The afternoon before the session, the sergeant phoned me to discuss the workshop. However, in that discussion, she noted that if somebody disclosed a crime, she would need to follow it up, for example, if someone disclosed being a victim of sexual abuse. I told her that due to the nature of the research, this could happen. I asked her if someone had already gone through the criminal justice system, had got counselling and/or other supports, would find it traumatic to go through it again and would not want to do so, could it be left alone with their consent? The sergeant said that she would need to decide if the person had the capacity to make this decision as they were 'vulnerable'. I asked her how she would determine capacity, and she said she would invite a carer of a

person who disclosed to have a meeting with her and the individual, and then she would decide on capacity based on that meeting. I responded that they were not vulnerable and had the capacity to make decisions on their own without carers and that this view may be damaging to the group. The sergeant said that she would still do what she suggested. I did not want to decide on behalf of the research team, but I did not have time to talk to everyone, so I asked to postpone the workshop till I heard from the researchers.

When I met the research team, I asked them their thoughts on it. Alice, Bruce, Ellen, Hermione, Louise, and I attended this research meeting. Everyone said I made the right decision not to proceed with the training. One researcher said it could have gotten very serious if they got called in to discuss something they did not want to discuss. Another researcher said that they would have to watch every word.

Hermione: It's not fair.

Ellen: It's discrimination.

I explained that the sergeant would be right to follow up and that she was doing her job. But what was worrying is that she viewed the group as 'vulnerable' and unable to make their own decisions, and she would make this decision on their behalf, even if it was against their will. Bruce stated he was not vulnerable and could make his own decisions.

Ellen: That's not fair for her to say. How is she supposed to know?

Ellen seemed to have a firm grasp of capacity laws and explained to the group that a person would be deemed vulnerable and unable to make decisions themselves if they were a ward of court, which none of us were.

I further explained that if we did not want the Gardai to do the workshop, the sergeant offered to share materials with us on online safety and if we wanted her to come in at any time, she would.

Ellen: I don't want her in.

Hermione: No.

Bruce: Probably not, no. They should learn something about people with disabilities, do some course.

Jess: I don't either, I just didn't want to make the decision.

Ellen: The Gardai should do training about disability.

We all agreed it was a good decision, and we did not want the Garda to come to our research group with that attitude. However, the researchers were annoyed because of

the attitudes of the sergeant because they were being discriminated against due to their disability, and they were being labelled as vulnerable which they did not think they were. However, they felt this lack of training was putting them in a vulnerable position. The researchers voiced that others often think about them and treat them in this way (which is explored in Chapter Eight: Perceptions). I felt really frustrated. We were coming near the end of the year-long project, and we had come such a long way. The researcher's confidence grew, they were speaking out more and were voicing the benefits of the research on their lives. I was concerned that this could set everyone back. It would have been nice if we could have got this training as the research team really wanted it. It was disappointing to face this near the study's end. It was one thing hearing past stories, but it was very unpleasant to see the researchers being treated like this in real-time and seeing how it impacted them when this action was meant to help them. During our reflections on this experience, we decided to act on it by deciding what we would do next.

Bruce and Ellen suggested a recommendation coming from the study should be that the Gardai should have mandatory training in disability, so they have a better understanding of such issues and we all agreed. I could not source any studies on Gardai's perceptions of people with intellectual disabilities but there were several studies that suggested non-disabled people view disabled people as vulnerable (Rushbrooke et al., 2014; Liddiard, 2018). Being labelled as vulnerable and the negative impact of this was being voiced from the researchers throughout the study and now, we had experienced it. Further investigation is needed to determine if this is a wider issue as this was just one Garda perspective.

I asked the group if we could try and put it aside, that we had done a great project and that I did not want something like this to ruin it so close to the end (research meeting 19 of 20).

Jess: I think its findings for the research, I think it's telling us what we have been saying already. What do you think it's telling us?

Ellen: That we are not capable. It's wrong the Garda doesn't get it. People with disabilities should be treated like everybody else. I think that some people think that people with disabilities are not capable of nothing, that they are backward or handicapped.

Jess: I think it tells us that all we want is information on how to keep ourselves safe. And then people come along with their perceptions who don't know about disability and it's stopping us from getting that information.

Ellen: It's disappointing but what can you do?

It was disheartening hearing Ellen explain how she felt others viewed people with intellectual disabilities, but hopefully, this experience could enhance what the group had been sharing prior to this (explained in Chapter Eight: Perceptions) relating to how people perceive those with intellectual disabilities and the negative impact this has, which would strengthen the study's recommendations, with the hope for future change.

I explained I did some research to try and find other online safety training and/ or materials suitable for people with intellectual disabilities and could only find one programme but after contacting the organisation I got no response, and I was unable to access the programme from their website. I did however find an easy-to-read guide on keeping safe online made by people with intellectual disabilities, for people with intellectual disabilities, from a charity organisation in the UK called CHANGE and CMG (Care Management Group). I also found a video about online safety, made by people with intellectual disabilities, for people with intellectual disabilities, on YouTube (Northamptonshire Healthcare NHS Foundation Trust, 2019) . We decided (Alice, Ellen, Hermione, and I were present for this part of the research meeting) because we could not have the workshop as planned, instead, we would go through the guide together and watch the video. Alice put the leaflet on a large TV in the room, and we went through it together. The guide included what people like to do online, types of online abuse, firewalls, online safety tips, keeping safe on dating websites, keeping your location safe, what to do if you have a problem, organisations to contact, and a word bank defining words relating to online safety that had been used in the guide (CMG & CHANGE, 2017).

Together, as we read the leaflet, we went through it, discussing our experiences, thoughts, and things we did not understand. Alice was the most knowledgeable on online safety so when we had questions, she answered them for us. Alice explained terms that came up that we did not fully understand such as sexting, grooming, mate crime, and trolling. Ellen had some knowledge of online safety, explaining what discrimination, exploitation, hacking, financial abuse, and harassment were, as they came up in the leaflet. I also had some knowledge and explained psychological abuse and cyberbullying when they arose. Hermione understood what Firewall was but did not understand most of the other terms. Through discussion we were able to clarify things we did not understand, for example, Hermione noted that she did not know what discrimination was.

Ellen: Putting somebody down.

Ellen again said the Garda discriminated against us and explained this was on disability grounds. Another example is when Ellen did not understand what a firewall was.

Ellen: Like birth control something?

Hermione explained it was a computer package to prevent viruses. I did not understand what mate crime was and Alice explained it.

Alice: Kind of between friends. So, it's exploiting your friends for money, or food, or other things.

When we discussed the dangers of sending naked photographs in case the other person broke our trust, Hermione felt it would be funny to send one.

Hermione: It would be funny. I know, it would be funny in some ways but no, (laughing).

Ellen came in and suggested the dangers of such.

We also discussed the Gardai as a support, and I did suggest that we should not be put off asking for help from the Gardai after what happened in the group. Prior to this meeting we often expressed that the Gardai were a support to us in situations where we would need help, particularly from Ellen and Hermione.

Hermione: The Gardai are supportive if anything is wrong. Health and safety things.

However, Ellen recommended talking to a social worker instead. There was a concern after this incident that we changed our attitudes towards the Gardai, where previously we saw them as a big support but now there was mistrust. I emphasised that we should go to someone we trusted, such as a staff member in a disability service, or a family member, it was important to share if we were in trouble and needed help.

We all found the online safety resource to be good, this is because it was accessible to people with intellectual disabilities, with large easy-to-read font and accompanying images. We also found the content to be informative. We found it useful to sit together and discuss it in more detail, the resource allowed for a more thorough discussion and helped us to work out what we did not understand together (such as the discussion above where we did not understand the terminology). However, the support page was a list of UK supports, and we felt we would need to know what Irish supports were available. Also, this leaflet would not have been as effective if it was read alone as we did not understand it all.

Bruce then joined us, and we watched a YouTube video on online safety made by people with intellectual disabilities, for people with intellectual disabilities (Northamptonshire Healthcare NHS Foundation Trust, 2019). After we watched it, we shared what we thought. We enjoyed watching the video and learned from it. We liked how it was accessible and made by people with intellectual disabilities. It was informative and showed how easy catfishing can happen, and how easily someone can break trust and share a naked photo without consent. Our only criticism is that we would like to see these resources with Irish actors to relate to more as there were very few resources made in Ireland, and with Irish supports as they are all UK-based and not available to us. We agreed that this study would recommend accessible online safety training for people with intellectual disabilities should be available in Ireland and Irish resources should be used for this training. Another recommendation from this study is that further research is warranted on online experiences and online safety training for people with intellectual disabilities, and this is an area we as a research team would like to explore in a future study.

As can be seen from the dialogue above, we worked together to solve this issue. This is how we worked in almost every research meeting (after the first few when we had built relationships). This links back to the principles of co-operative inquiry, where everyone communicates as both 'co-researchers' and 'co-inquirers' where we do research on ourselves. We identified issues, reflected on them, shared our thoughts, and worked together to overcome them.

In one of the reflection sessions, Ellen brought this experience into her sand scene when we explored what we learned about ourselves, others, and disability in the study (Figure 18). It was a general prompt on what we had learnt, and Ellen identified this experience as an important learning experience.



Figure 18: *Ellen's sand scene on what she learnt about herself, others, and disability during the study.*

Ellen: I put the Garda and the stop sign, and woman staying stop in to represent the Garda and what she said, it was discrimination, so I thought it was fair to put that in, to stop the Gardai, to get more training. I learned I have a disability and I have to accept myself for who I am, I know my limits and I love myself for who I am. I learnt that people with disabilities should be treated like everybody else. I think that some people think people with disabilities are not capable of nothing, that they are backward or handicapped.

7.5: Recommendations:

There should be more support and opportunities to create and maintain relationships for people with intellectual disabilities. We would like to see inclusive nightclubs in Ireland that are for anyone to attend, are on late at night, serve alcohol, and that is accessible to disabled people. Chloe was most interested in this topic, and the whole research team did not want to do an action on it, so we instead discussed how this problem could be solved. Chloe agreed to talk to the staff in her drop-in centre about it. A few months later, the drop-in centre set up an inclusive nightclub. We do not know whether Chloe influenced this or not, as Chloe later left the study, but it was great to hear either way. Some of the researchers attended this monthly nightclub.

We think there should be an Irish dating app for people with intellectual disabilities that has information on how to find a boyfriend or girlfriend and how to keep safe on it. We

would also like to see an online safety programme available for people with intellectual disabilities in Ireland that is accessible, using Irish resources/ supports and any actors used in training videos should ensure representation of people with intellectual disabilities. Online safety training should include how to keep safe on websites, social media apps, dating apps and phones, as well as how to keep safe when meeting a person from a dating app in real life. Our experience with the Sergeant viewing people with intellectual disabilities as vulnerable led to us missing out on online safety training. The researchers identified they needed this training as lacked information, which was highlighted in the risky situations experienced and in the online abuse. As a result, we recommend that Gardai receive disability awareness training as part of their overall training to understand people with intellectual disabilities better. Finally, further research is needed to explore online experiences and online safety training for people with intellectual disabilities.

Chapter Eight: Findings Part Three - Perceptions.

8.1: Introduction:

The researchers had previously identified the differential treatment they received from families, disability professionals, and the garda. However, when we were exploring the topic of marriage and children, the area of the impact of other people's perceptions came up again.

In one of the earlier research meetings, Louise posed a question to the group for us to explore,

Louise: Why are people stopping us (people with intellectual disabilities) from having a relationship?

We decided this was an important question to seek an answer to. This section explores the researcher's views, which often were influenced by others, and the perceptions of families and disability professionals such as social workers, staff in disability day services and staff in disability group homes (also called HSE houses and hostels by the researchers), and the impact of all of this.

8.1.1: Researcher's views.

The researchers seemed to hold functional and heteronormative views on sex. Participants with intellectual disabilities in studies in the literature held traditional gendered stereotypes, which often came from their caregivers' expectations of them (Bernert and Ogletree, 2013; Chou et al., 2015). Two researchers who tried to explain sex spoke about a man putting his penis inside a woman.

Ellen: People are in a relationship, or maybe not in a relationship, but it's a man basically putting his penis inside the woman.

Some researchers did view sex and related topics as wrong. Bruce and Hermione described sex and related topics as 'dirty' on different occasions. When Bruce was referring to sex,

Bruce: The dirty business (laughing).

Hermione: There's dirty stuff involved in this but look (laughing). It's the stuff you're not supposed to bring up in front of the boys.

I asked them why they were describing sex as dirty; Bruce laughed and said it just was, and Hermione gave the impression she was uncomfortable with discussing it further. Hermione often became shy when we spoke about topics like this, and we agreed we would not go into detail at these times. This finding was also reported by Bernett and Ogletree (2013), where participants viewed sex as negative and dirty. At one point, Hermione noted that 'sex could be pleasurable sometimes.' Noting it was only pleasurable sometimes may mean it is unpleasant most of the time. Participants were rarely found to view sex as pleasurable in one study from the literature (Bernert and Ogletree, 2013). This study was based in America; no Irish studies on this topic could be found. Pleasure rarely came up in this study. When talking about pleasure, Hermione brought up masturbation. The others noted they did not know what it was, but when it was described, they did know but did not know what it was called. This could be because they have experienced it, but no one has spoken to them about self-pleasure before.

Hermione and Louise seemed to be significantly influenced by their parent's views. Hermione did not want to get married or have children.

Hermione: Well, I don't want to live on my own that's for certain anyways. I don't want to get married or have children. I just want to live with my dad. I'm living with my dad at the moment.

However, Hermione seemed influenced by whether her parents would allow her to get married or have children. They would not allow her to move into supported independent living, even though she is employed full-time.

Hermione: If I spoke to my mum and dad in the first place. I'd have to make sure it's ok with them. If they want it (get married).

She went on to discuss this further.

Hermione: See if I was living on my own, I wouldn't be able to look after myself.

Ellen: Do you think if you had support, you could do it? If you had home help coming in, or you had someone teaching you what to do.

Hermione: No.

Ellen: Because I got taught to do everything. I was living on my own when I was 18. And I had a woman coming in to help me to go through money, to budget and pay bills, and a nurse, and how to wash clothes and all that. I couldn't do anything either.

Hermione: There was something like that offered one time, but mum and dad said no. I wasn't able to wash myself, but now I'm able to do it because it's easier.

This is an excellent example of how the conversations flowed in our research meetings and where others were questioning rather than just me, which is what it was like at the

start till the researchers became comfortable. Hermione's parents made decisions on her behalf by simply saying no, and she listened to them. Despite a service offering the support she may need, her parents told her she could not do this because she could not wash herself, yet Hermione said she could do this now. This restricted Hermione's independence, and someday, she may outlive her parents.

Louise seemed to be influenced by her parent's views, who were concerned if she had a relationship and got raped or assaulted.

Jess: Are you worried about that?

Louise: Yeah, I'm quite worried about that (getting raped or assaulted). It's kind of hard for me (the concern of abuse whilst also wanting a relationship).

Louise voiced that she was in two minds; she wanted a relationship but was concerned about her welfare and that she may get assaulted or raped. Hermione also stated she was concerned about her welfare, and so were her parents. These women may have been influenced by their parent's views, who were protective of them.

Chloe seemed to be more interested in relationships in the context of friendships,

Chloe: It'll be nice to find a boyfriend maybe, and more friends. It'll be great like that. I'm always on my own all the time and not getting to hear from and meet up with people. It would be hard I guess Jess because some people with disabilities wouldn't be allowed to get out on their own. A lot of people live with others in houses (group homes) and the staff won't let them out on their own. It would be a lovely idea for nightclubs. I would like to meet new friends as well as I'm always on my own and nobody ever comes out with me for nights out where there's music on in pubs at the weekends. I would like to meet new friends to be out and about instead of being on my own all the time, it's not fair. My friends are never around to go out with me.

Chloe was voicing how isolated and lonely she was. She lived independently with support from a social worker, but all her friends lived in group homes, and their social time was restricted, which impacted Chloe. She stated that if she met friends, they could exchange numbers and meet each other outside of clubbing. However, Chloe did seem to be influenced by her key worker in her disability day service. At one point, Chloe said she told her key worker what topics we discussed in the research. Her key worker asked Chloe to request if we could change the topic to companionships instead of relationships and sexuality. We discussed this as a group and agreed that the research was on relationships and sexuality. Unfortunately, after meeting 8 of 20 of the study (the following meeting), Chloe decided to leave. She expressed her concern about talking about these topics.

Chloe: People with disabilities should not be talking about these kinds of things, it's not right.

Chloe had not expressed these views till after her key worker had voiced their view on it, and she had been pleased to discuss these topics up until this point. Although I had envisaged that a parent or professional might stop a researcher from being in the study due to the topic of relationships and sexuality, it was very disappointing to hear. Chloe seemed to be getting a lot out of the research team, so it was a shame if she was leaving only because her key worker was persuading her. This view that people with intellectual disabilities are asexual and not sexually active is common (Kullick and Rydstrom, 2015; Liddiard, 2018), so I am not surprised her keyworker suggested we research companionship instead. One study in the literature has found that caregivers can influence people with intellectual disabilities' perceptions of sexuality (Nayak, 2016). I told Chloe she was welcome back any time, but unfortunately, she never returned.

Every researcher was either in a relationship or previously was in one or desired one; three of us were engaged, and two others desired to get engaged. This desire for relationships and marriage was found in studies in the literature (Lafferty et al., 2013; Bates et al., 2017a; Azzopardi-Lane et al., 2019; Neuman, 2020). Bruce often discussed his hopes for getting a girlfriend, marriage, and children. He said it was important for him to find a girlfriend, but something he struggled with.

Bruce: I hope that I get myself a girlfriend someday.

Bruce shared that he wanted to have an open relationship with five or six casual girlfriends at one time, one for each day of the week, with a day off. In 3-5 years, he would choose the one he liked the best, who was most like him, and then he would marry that one. He said he wished to have three children and would share the raising of them. He also wanted to get a part-time job and car. He voiced that the type of girl he would like would have similar personality, interests, and clothes to him.

Bruce: A female version of me! (laughing).

Bruce identified that some of his knowledge and views came from video games such as 'Grand Theft Auto'. Grand Theft Auto is an action-adventure video game with three main characters, a gangster, a bank robber, and a gun runner, that involves driving, drugs, shooting, sex, sexually explicit language, and violence against women. It is known as controversial due to such violence.

Bruce: A woman with not much clothes on and she would pop a car open (smiling).

Jess: You are smiling, do you like that?

Bruce: Some ladies, yeah.

Bruce went on to further explain the game.

Bruce: You can play it online. Sex and ... other things.

Jess: So, you pay somebody, pay a sex worker, and have sex online?

Bruce: Yeah, and shoot them afterwards.

He further explained that she could be pushed out of the car after sex, where he could retrieve his money and run her over in his car. Grand Theft Auto is an extremely violent video game. The game is well-known and often played by young people, even though it has an 18-year and above rating. Bruce is a gamer and understands the difference between the game and reality. However, this game, the internet and porn seemed to be his only access to the sexual world. There was a chance this influenced his attitudes toward sex, relationships, and women. The rest of the research team requested to explore this topic more, as some had played the game and were also interested in the topic of sex work. They thought these would be interesting topics to explore as they were new.

We delved into this topic more in the following research meetings, where Bruce, Ellen and I made a rap about it, and Hermione and Louise discussed it with us after we wrote and performed it. We narrowed the topic to 'The influence of Grand Theft Auto on our perception of sex work (Figure 19).

Rap - The influence of Grand Theft Auto on our perceptions of sex work.

Bruce, Ellen and Jess.

Bruce:

*Yo yo, what's up!
Have you played Grand Theft Auto?
It's a video game about prostitutes and you can pay them for sex.
The car moves up and down.
You shoot them and run over them; they die.
You take your money back.*

Ellen:

*Some of us have heard of it, some if us haven't heard of it.
There is blood all over the place.*

Bruce:

*I enjoy playing, I don't mind sex workers.
I don't care about the violence, it's only a video game.*

Ellen:

*I think its demoralising,
No respect,
No good,
No dignity.
But if someone wants to do sex work, it's up to the individual.*

Jess:

*I have no problem with sex work,
If the person wants to do their job.
But I disagree with violence, murder, and theft,
It's all gone too far.
Video gaming,
Grand Theft Auto,
Prostitutes,
Sex work,
Violence,
Opinions.*

Figure 19: Bruce, Ellen, and Jess's rap about the influence of Grand Theft Auto on our perceptions of sex work.

The following is some of the discussion we had after the rap performance. Bruce, Hermione, and I shared that we played Grand Theft Auto in the past. Louise had heard of the game before, and Ellen noted she never heard of it. We shared our opinions on sex work. Hermione felt that it was okay. Then Louise gave her thoughts.

Louise: Well, I think it's a good thing because if you want to pay somebody for sex then go ahead, but if you don't want to pay somebody for sex well that's alright you know. It's up to the person basically.

Bruce explained that he played the game and learned about sex work from it. Bruce said it would probably be more challenging for people with intellectual disabilities to have sex as it is hard for them to get a boyfriend or a girlfriend, so they may need to see a sex worker and pay for sex. Two researchers voiced that they find it hard to get a partner, so would consider seeing a sex worker in the future, but feared telling anyone else this in case they would stop them. Another noted they had not considered it before, and it seemed like a good idea, but did not know if they would personally do it. Ellen expressed that she was against engaging in sex work personally.

Ellen: I know there's sex workers in (name of town she lives). I have respect for myself. If they want to, but I wouldn't personally.

We discussed the violence in the game. Bruce explained that he did not have a bad attitude to sex workers and that the violence was ok as it was just a video game.

Bruce: It's the philosophy of the video game anyway.

Ellen: I don't like the violence at all, I don't like that.

Jess: I had very similar opinions to Ellen, because I said if a sex worker wants to do their job it must be safe, but I disagree with the violence, it's gone too far.

Hermione had played this video game before but did not understand what sex was.

Hermione: Yeah, there's a lot of violence in it. And a lot of bad language in it as well. A lot of stealing involved with cars and everything. There's sex on Grand Theft Auto. I play bits of it, but I saw the sex.

From these discussions, we could see that the media and other people's perceptions either impacted the researcher's perspectives or restricted them from living their lives the way they wanted. Through further discussion, it became evident that this was also preventing the researchers from getting married.

8.2: Rights to marriage:

When we decided to explore the topic of marriage and children through creative performance and practice, we created two news reports on these topics., and the researchers brought in the barrier of other people's perceptions. The first news report we made was on marriage and people with intellectual disabilities (Figure 20). The researchers became very passionate when speaking about this subject. They explained that they had received different opinions from others regarding their views on getting married, but they were mainly negative and that it was nobody's business. They felt it was their right to get married and it was good to get married. Studies in the literature also demonstrated that people with intellectual disabilities understood their rights, including the right to love (Bates et al., 2017b; Mattillia et al., 2017; García Iriarte et al., 2015). The UNCPRD (2006) sets out in Article 23 that people with disabilities have the right to marriage.

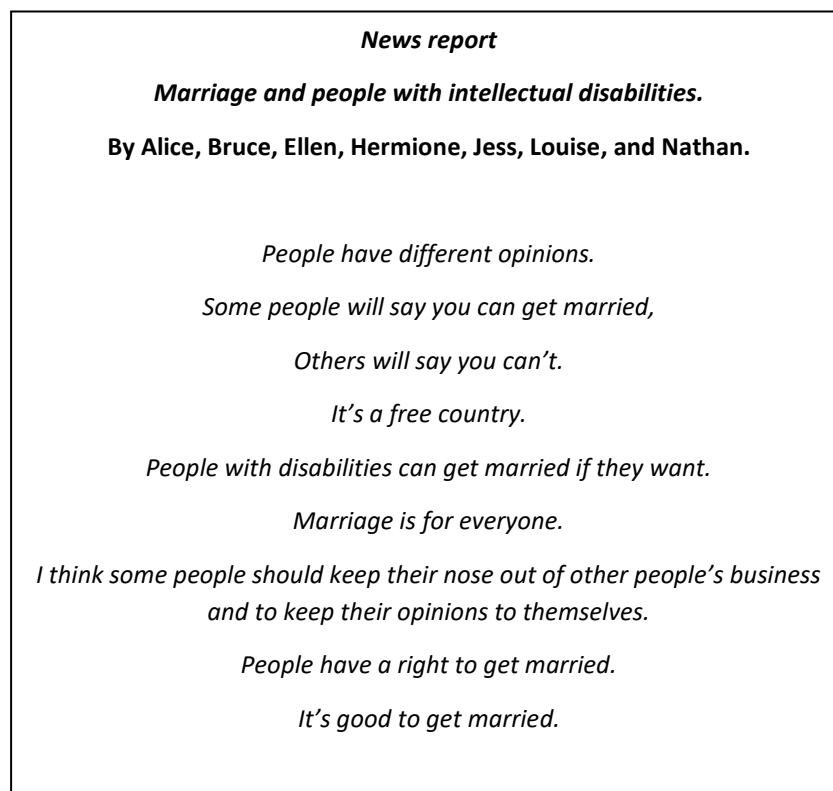


Figure 20: News report on marriage and people with intellectual disabilities by Alice, Bruce, Ellen, Hermione, Jess, Louise, and Nathan.

Although rights were discussed in the previous chapters, these findings are not written chronologically but thematically. This was the first time in the research meetings (research meeting 14 of 20) that the topic of rights came up, and a lot of strong emotions came with it.

Ellen: People have a right to do whatever they want. They should be allowed to have a sexual relationship. Nobody should tell them what to do.

Hermione: I have the same rights as you, same rights as everybody else. That's what I thought about first.

Ellen: People with disabilities are just like everybody else. It doesn't make sense.

Hermione: Yeah, at the end of the day, were just like everybody else. It's not much. I don't have much disabilities. I might have been born with a condition like that. I wasn't brain dead, I just had lack of oxygen, that's all. It means that I'm a slow learner, that's all, it's not for all of me.

Bruce: I have a disability and everyone else here has a disability. Nobody's perfect anyway and a person with a disability has a right to marriage and do sex and all that, like a person who doesn't have a disability. Do whatever you want.

Hermione: It's a free country, yeah. You can do anything you want.

Ellen: I just keep doing it, I just go ahead and do it.

It was difficult to hear these words; people were upset and passionate about this topic, and it was very unfair. Especially statements such as 'I'm a slow learner, that's all, it's not for all of me' and 'nobody's perfect' when they spoke about their impairments. I asked why rights were coming into the discussion now.

Ellen: Well, because I was told in the past that I couldn't have relationships, because I have a disability, and I thought that wasn't fair. It's discrimination.

Hermione: Everybody has a right if they want to get married.

Bruce: You've a right to do whatever you want to do anyway.

However, no one was aware of their legal rights, such as the United Nations Convention on the Rights of Persons with Disabilities (UNCPRD, 2006) or the Decision-Making Capacity Act (Irish Statute Book, 2015). Only Alice, Ellen and I had heard of the Sexual Offences Act, and Ellen shared what she knew of the old Sexual Offences Act before it changed.

Ellen: It's against the law. People with disabilities were not allowed to have sex, because they were seen to have a disability, so they were not able to have sex.

Despite this, she stated this law did not stop her, but it probably stopped others as they may have been afraid to break the law.

Nathan went on to share his experiences around marriage.

Nathan: Well, I've already proposed, I'm the only one in my friend's group that has actually proposed.

Nathan explained his friend's group were a mix of people with and without intellectual disabilities. He shared he would like to get married within four years. Hermione asked how he knew he wanted to get married.

Nathan: I just knew that this was the one. Me and her clicked from day one.

He said that love came into it. This was coming near the end of the study; at this point, the researchers had spoken about relationships and sex, but it was the first-time love was mentioned. Hermione initially said love was only important to her with her family and friends.

Hermione: It's not important for me at the moment.

Jess: Ok, do you think it would be in the future?

Hermione: Maybe someone will like me.

Jess: Do you think you would like to fall in love?

Hermione: Yeah, maybe.

Hermione seemed to be depending on someone to like her, and otherwise, she was stating love was not important. This could have been a confidence issue also.

Ellen: Love is important to me because if you love him or care about him, if you respect them and they love you and they accept your disability, then I think that's the way it should be.

Bruce also stated love was important to him. This is in accord with studies from the literature that found love was important to people with intellectual disabilities (Mattila et al., 2017; McCarthy et al., 2022). From comparing the literature, participants had more positive perceptions of love than sex (Bernert and Ogletree, 2013; Chou et al., 2015; Mattilia et al., 2017; McCarthy et al., 2022). I asked if love was important, why it had only come up now. Ellen stated that she was afraid to say it as she is in love with her fiancé and is afraid her aunts will find out and try to stop the relationship. I reassured Ellen about confidentiality in the research team and reminded the researchers that we should keep our discussions confidential, Ellen had been so worried that her relationship would be ended, which is unsurprising given her past negative experiences of this with the staff in her group home and with her family. It was possible that the lack of experience of love of some of the researchers who had not experienced relationships made this a difficult topic to discuss. Hermione changed her views later in the study when she brought in her third object that she made, which was a cross stitch with a love heart and the words love is in the air (Figure 21).



Figure 21: *Hermione's third object on' the biggest learning she is taking away from the research'.*

Hermione: The biggest thing I'm taking away from the group is love, about the topic of relationships. People with intellectual disabilities have rights to fall in love with people.

It was interesting that at the end of the study, Hermione told us the most meaningful thing to her was love. Before, she said it was not important concerning intimate relationships, but when she went away and thought about it and brought in the cross stitch she made, love was the most important element to her. Maybe she did not know it was an option for her until we explored it, and she did express here that she did learn in the study that it was a right. More research on the importance of love for people with intellectual disabilities would be of benefit. Alice highlighted the need for love and belonging as universal when creating a Lego serious play (Figure 22).

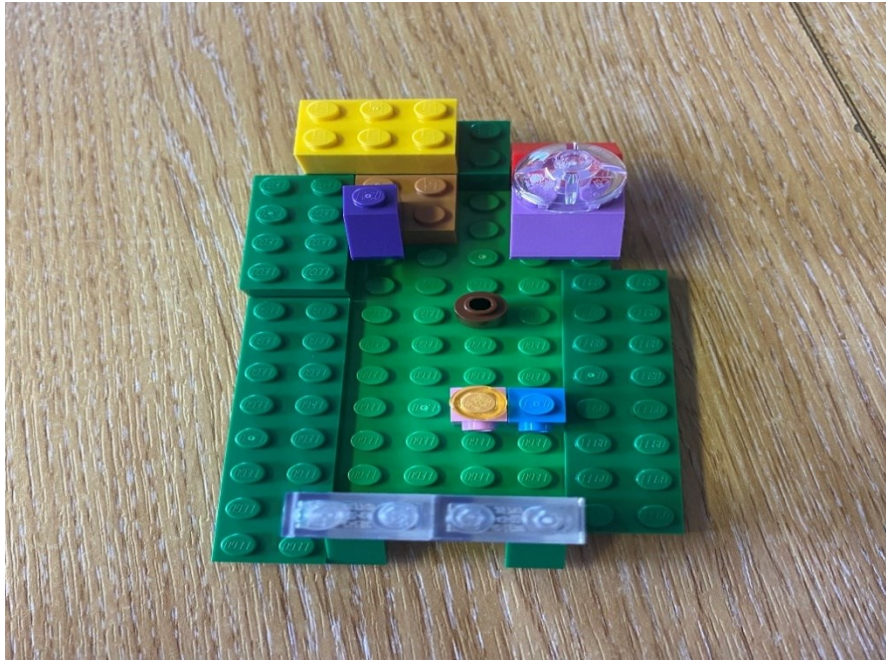


Figure 22: *Alice's Lego metaphor on' her hopes for the future on relationships and sexuality for people with intellectual disabilities'.*

Alice: So, for mine that's the entrance, like that I have a gateway, I feel like we have opened a gate for people who have any type of disability, for relationships and sexuality. I have two people here, a man and woman, a woman and woman, who knows. To show that everyone is entitled to relationships, to feel love, and stuff like that. A lovely house, a little dog, and that you're protected. Because in relationships, its important I think, to feel protected and to feel safe.

We asked Alice to tell us more about the gate as a metaphor. She said that for her, the gate was both a welcome and an exclusion. She said she has seen how people with intellectual disabilities are denied relationships through safeguarding policies and regulations and how staff treat people with intellectual disabilities in disability services. Many of the researchers had voiced this throughout the study. The gate shows how people with intellectual disabilities need to pass more obstacles to have a loving relationship, which so many non-disabled people take for granted. The gate also acts as a protective barrier for people with intellectual disabilities in expressing themselves as they are protected. But the gate also means a welcoming entrance, as with time and lobbying, relationships, and sexuality for people with intellectual disabilities are becoming more accepted by society. She said if the gate was broken down, people would be treated the same. Alice went on to tell us the two blocks represented two people, whatever gender they identify with, showing that she hopes LGBTQ+ become more accepted by society for people with intellectual disabilities. The home is what we all dream of: a nice safe, loving

place where we get to be with someone we love, which is normal for non-disabled people, and she hoped this is the future for people with intellectual disabilities. The researchers agreed; most of the researchers had articulated that this was what they wanted but there were barriers in the way, which was mainly other people stopping them due to their negative perceptions. We all agreed that this work together had opened a gate and we had walked through it, and this was just the start.

Nathan shared that in the future, he would like to live in a mansion with his wife and four children. He thinks that this will happen, but there may be barriers.

Nathan: Well people will try and stand in the way, but it won't stop me.

Nathan shared the resistance he received from his family when he told them he was in a relationship.

Nathan: I'm in a relationship and I told everyone, and they (family) started treating me differently. They told me that I wouldn't be able for one (a relationship).

Jess: What do you think they were worried about?

Nathan: I don't know, they never told me, like I've asked them, but they won't tell me.

Jess: Do you think they're worried that you might be taken advantage of?

Nathan: Well, it could be that too.

Jess: Or are they worried that your partner might get pregnant?

Nathan: Well, I'm not too worried about that one (laughs).

It was after this that Nathan told us he and his fiancé were planning a family. Nathan explained that he was still in the relationship two years later, and he was happy in it. Such opposition from families was also found in studies in the literature, where families did not feel that the participants with intellectual disabilities should be in relationships due to their disability (Schaafsma et al., 2017; Puyaltó et al., 2022). Hermione expressed that she did not know if she would get married in the future. She would need to speak to her parents first to get their advice because she lives with them. Ellen shared experiences with her family.

Ellen: Like my family. My aunt. I was engaged and she broke us up. She rang up the HSE (health board) and said to them about my welfare and we broke up then. He didn't treat me right, so she was right to do it. They were concerned about me.

This collusion between families and professionals was also reported in a study from the literature (Puyalto et al., 2022). Although Ellen felt it was the right thing to do on this

occasion, she believed her aunt did this because she had an intellectual disability. She went on to explain other negative experiences.

Ellen: She's (aunt) done it several times, not just once, loads of times. I can't have a relationship because I have a disability.

Jess: What do you think, can you have a relationship?

Ellen: I think I can yeah, I had loads of them. They (aunts) don't want me to have a relationship. My Aunts still do it, they've been up to the HSE (health board) about my welfare.

Ellen explained how her two aunts followed her and shouted at her in the street.

Ellen: They were shouting I was disobeying them; I can't have a boyfriend, they were trying to stop me.

Ellen said she had to get the Gardai to help after an advice centre advised her to do so.

Ellen: I think the Gardai are important because for myself, my family doesn't think that I can get married and have children. I just don't want them (children), it's my choice. But marriage, they stop me, my family will get involved. They (Gardai) helped me because I went to the Gardai and I spoke to them about my family and what was happening and I said they are trying to stop me having a relationship with people, with boyfriends, and I told the Gardai and my family left me alone. I said to the Gardai please talk to them to stay away from me.

As seen here, Ellen was very optimistic about the Gardai as a support. Hermione had often made similar comments. It was unfortunate that the experience with the sergeant (explored in the previous chapter) happened after they had said this, and now they had lost trust in the Gardai. The researchers voiced that when they did not get support and received opposition without explanation, it made them feel annoyed. Nathan voiced the type of support he would need to make his relationship work.

Nathan: Just for people to be understanding.

Jess: Do you think they will be?

Nathan: Not at first, but they'll get to it.

The benefits of family support were expressed in studies from the literature (Newman, 2020; McCarthy et al., 2022). McCarthy et al., (2022) also found in their U.K. study that emotional support was important, as Nathan expressed. As well as this, practical support was beneficial (Newman, 2020; McCarthy et al., 2022).

8.3: Rights to have children:

In one research meeting, the topics of contraception and sterilisation came up. The researchers voiced that others seemed to want to protect them from abuse and

pregnancy, so they either withheld the information they needed in case it would enable them or told them to keep safe by being appropriate and respectful, putting them on the pill without their consent or trying to coerce them to get sterilised to prevent pregnancy.

Ellen: And she (aunt) said to me she told the social worker to get me sterilised. She doesn't want me having kids. I don't know why, and I've asked her.

The reproductive rights of women with intellectual disabilities been violated was also found in studies from the literature, where they lacked autonomy in decision-making on their sexual health (Frawley and Withers, 2013; Eastgate and Moyle, 2014; Walmsley et al., 2016; Cytowska and Zierkiewicz, 2020; Horner-Johnson et al., 2022). Previous studies have found that caregivers primarily made contraception decisions, the participants had not been given any information and contraception was mainly used to manage menstruation and to prevent pregnancy and abuse (Fitzgerald and Withers, 2013; Walmsey et al., 2016; Horner-Johnson et al., 2022). It was also found that women with intellectual disabilities are more likely to be sterilised than non-disabled women (Li et al., 2018). Women were often forced or persuaded by others to use contraception without being given the correct information to make an informed decision (Walmsey et al., 2016). Two of the researchers in this study were unsure if they were on the pill; they took a pill and guessed it might be a contraceptive but did not know for sure. As adult women with bodily autonomy, they should have been told this. They believed they may have been put on it to regulate their periods; however, it may have been to prevent pregnancy. Although people with intellectual disabilities are often put on contraceptives to protect themselves, none of this prevents abuse. Although the existing literature highlighted a lack of autonomy and knowledge on contraceptive decision-making for women with intellectual disabilities, none of these studies highlighted that the women did not know if they were on the pill. For those who were not sure if it was the contraceptive pill or not, it was a relatively high occurrence in a small sample. As a recommendation, further investigations are required to assess if this is a wider problem for women with intellectual disabilities. The researchers voiced that it was wrong that they did not know if they were on contraception and would ask the staff/ parent concerned. They said this also highlighted the need for them to have sexual health education (which was explored in Chapter Six: Sexual Health Education). This lack of information and choice and possible coerced medical treatment violates their human rights. The UNCPRD (2016) sets out in Article 23

that disabled people have a right to reproductive and family planning and the right to retain their fertility on an equal basis to others. As well as this, so others do not discriminate against disabled people based on disability, Article 5 provides for their legal protection.

Then in another research meeting, we were exploring people with intellectual disabilities having children and others' perceptions and people restricting the researcher's rights came up again. This is when we were using creative performance and practice to explore the topic, where we made a second news report and this one was about having children (Figure 23). As can be seen from the report, there was swearing, people came across as very passionate with lots of emotions on this topic and rights were again brought into this.

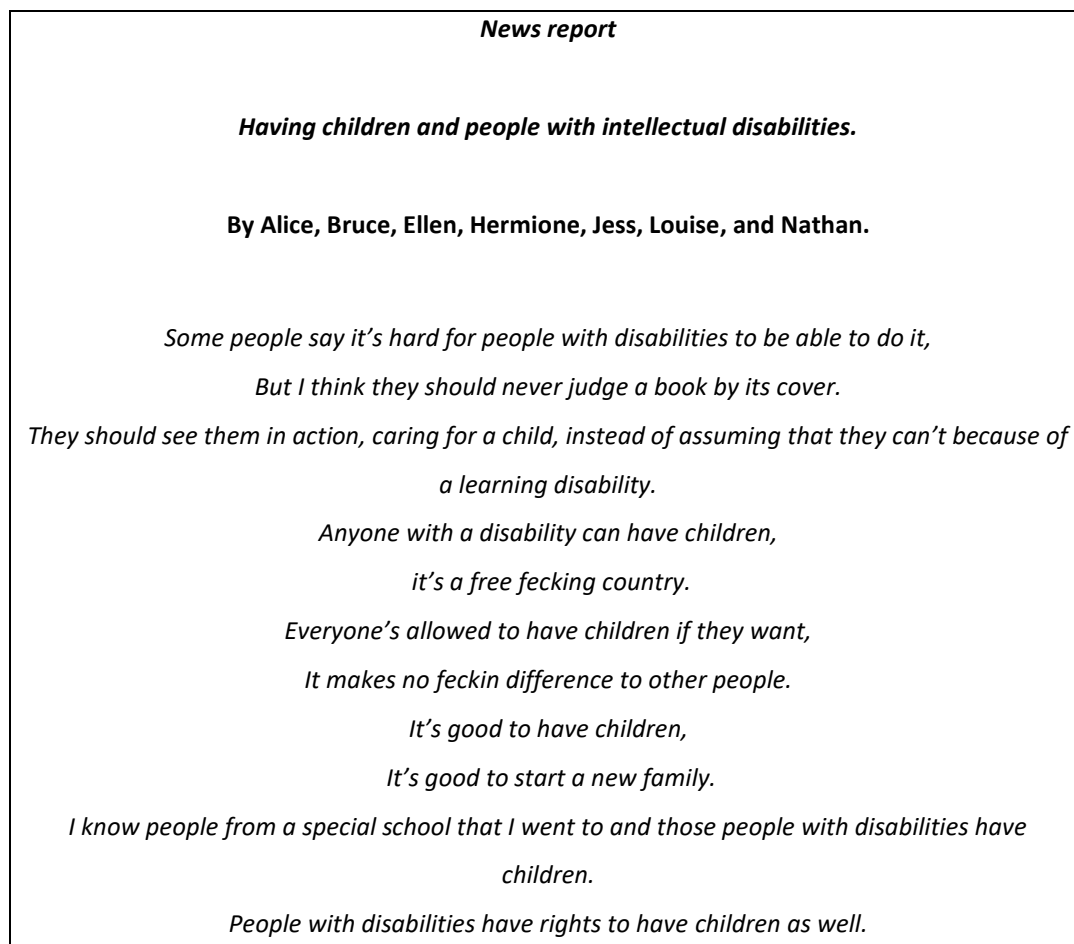


Figure 23: News report on having children and people with intellectual disabilities by Alice, Bruce, Ellen, Hermione, Jess, Louise, and Nathan.

Bruce: People with disabilities have a right to have children, like people who don't have disabilities. Everyone believed that they should not be judged or stereotyped as being incapable of having a child based solely on disability. The researchers voiced that it would be good to start a family and that they knew others with intellectual disabilities who had children. They believed it was their right to have children and it should not make a difference to other people. It was evidenced in the literature that with the proper support, people with intellectual disabilities can parent successfully (Wilson et al., 2013; Strnadova et al., 2019). Bruce made a sand scene where he brought in rights to marriage and children (Figure 24).



Figure 24: Bruce's sand scene on his learning about relationships and sexuality in the research.

Bruce: I have a Mum, Dad, and three children. I learnt that people with disabilities have a right to have a family and children and do what they want.

He said this is what he wanted in the future. He also had two cars in the scene, one for his wife and one for him.

Jess: I remember you saying before you wanted to get married and have three children, that's exactly what you have put here, that's your future, that's what you want. Its lovely to put your future into one whole sand scene. I really hope that you get that someday.

As the previous studies have found, people with intellectual disabilities desire the same relationship needs as non-disabled people (Wos et al., 2021; Rushbrooke et al., 2014). The

researchers often compared having a relationship to non-disabled people, voicing they were the same.

Louise: You know I want the same as others.

Nathan shared his experience of family planning.

Nathan: We have decided that we are going to have a child. I want to be a father.

Nathan explained he told his family. He wants to be a young Father and have his first child by next year.

Nathan: They're (parents) happy with it; they said they'd support us and that.

Jess: Ok, brilliant. Well, that's a big change. Because in the beginning they said they didn't think you could have a relationship. Why do you think they've changed their attitude?

Nathan: Because I've proved to them that I can do it. By showing them, by being nice to the woman. I think it took like the first couple of months. When I talk to them now, they're excited to know that they're going to be grandparents.

He said his fiancé's parents were also okay with it, now they had met him, although it took a little longer than his parents, which he believed was probably because they did not know him.

Jess: Do you think you'll be treated differently as a father?

Nathan: I don't think so, because I've been told by everyone now that I'd make a great father.

When Nathan expressed, he would be a great father, it was because people had told him this; he had to prove himself and get permission from others and he valued this acknowledgement. Even though he said he would do what he wanted regardless, deep down, others' support seemed to be important to him. It is not easy to be constantly fighting for things that non-disabled people have and that are human rights, especially when it's the people closest to him who are putting up these barriers.

Hermione said it would probably be more difficult for a couple with intellectual disabilities to have a child, but she did not know why. Nathan felt financially it could be more challenging. Hermione said she did not think she would have children.

Hermione: Oh, I don't know, I'd say that'd be hard now for me I'd say, because, ah, there's a lot of hard stuff going into it, I'd say (laughs). I'd have to learn how to change nappies and everything like that. And learn how to clean the babies and all. I'd need a lot of help.

Nathan said he understood what was involved with looking after children as he had experience caring for his cousin when she was a baby.

Hermione: Yeah, a lot of things involved with children as well. Like bringing the child up and all that like. Yeah, it's very hard, it's hard for me because I'd need to get help.

Ellen: Yeah, you have to, yeah.

Hermione believed she had these needs due to her disability and was not sure she would feel the same if she had help.

Hermione: If my mum would help me yeah. But I won't be interested in having a child. My mum asked me that one time, but no, because I said no, no, no I said (laughs).

Hermione shared her mother's response to this.

Hermione: She said yeah because there's a lot of work involved in it like.

Ellen: There is yeah, babysitting is very tough.

Hermione: You have to be able to look after them and make sure they go to sleep alright. You know some people, I suppose, are more able for having children and all that. Some people may be more able to handle children.

Ellen voiced that she did not think she would have children either.

Ellen: I don't know if I'd mentally cope with children because I have depression you see. I looked after kids before and it was very tough if I'm being honest.

Jess: Kids aren't for everyone, but its good you can make the decision yourself.

Ellen: I found out it was very tough. I worked in a creche, and I couldn't cope with the pressure, it was getting to me. I was going home in the evening, I had to sit down for half an hour and calm my head down.

Ellen shared two separate conversations with her social worker and the past staff in the group home she lived in about having children.

Ellen: Do you know what I don't like? If you have a disability and you have a social worker. They said they would take the child off you.

Ellen said her social worker threatened to take her child if she became pregnant. This was also found in studies from the literature that stated there are high rates of child protection interventions and removal of children into care in comparison to non-disabled parents (McConnell et al., 2017; Tøssebro et al., 2017; Strnadová et al., 2019; More and Tarleton, 2022). Ellen felt it was unfair that a social worker would take a child off someone based solely on having an intellectual disability and perceiving the person as unable to cope with parenting.

Ellen: I said in the HSE house (group home) before, what if I had a child and got married. Well, we would look into it because we don't know if you would be capable of looking after a child. They said I wouldn't cope with a child. I wouldn't mind, but I looked after kids for years in a creche and not one thing happened a child, nothing. I don't want children myself, but nothing bad happened. I didn't want to say anything, I said nothing. They said to me that some people with disabilities wouldn't be able to look after a child and have them taken off them. I felt, could you not give them a chance, if they actually do take care of the child. If they abuse the child or something happens, then take the child off them. But they should give them a chance in the first place.

One study from the literature stated that group homes forbid people with intellectual disabilities from becoming parents (Neuman, 2020). Many of Ellen's human rights were being denied and violated according to the UNCPRD (2006), where Article 5 provides legal protection to prohibit all discrimination based on disability to ensure equal treatment, Article 19 states that disabled people are not obliged to live in a particular living arrangement, Article 23 states that disabled people have a right to personal relationships, and they are entitled to support to give them equal access to parenthood.

Both Hermione and Ellen repeatedly voiced throughout the study that they would not be capable of being mothers. What became evident through the discussions was that the males wanted children and held no concerns about it. The women also repeatedly voiced that their families and professionals told them they would not be capable mothers. That is a lot of people telling an individual they are not capable. This message was most likely internalised, which was found in one study where the participants had internalised messages that they would be incapable parents (Schaafsma et al., 2017). Many people stereotype people with intellectual disabilities as incapable of being parents. People with intellectual disabilities are viewed as irresponsible due to their intellectual disability (More and Tarleton, 2022). Historically, their parenting was controlled (Monk, 2015) to prevent them from procreating as they may have disabled children (Edgerton, 1979). Despite the shift in rights for people with intellectual disabilities, parenthood has not been on the agenda (Azzopardi-Lane and Callus, 2015). In Ellen's case, I did wonder if deep down she wanted a child from some of her comments, and she stated several times she would like to learn how to look after a child. Ellen could have feared that if she had a baby, it would be taken from her, and she would lose custody, as different professionals repeatedly threatened her. Or maybe she felt she would be incapable as the professionals kept telling her this. These same fears of professional threats also prevented women from having children or disclosing their pregnancy in one study from the literature (Jamieson et al., 2016). Additional research is required to understand the impact of these messages more closely on women with intellectual disabilities and their choices in having children. Although it took some time for Nathan's family to come around, the males in this study were supported to have relationships and start families, but the females were not. Parents are often more over-protective of their daughters than their sons because they are the

ones who get pregnant, and because of the societal discourse on gender, women are seen as the more vulnerable gender and in need of protection. The existing literature focused on women and parenting, but there was a lack of research on men's experiences to compare this to. To develop a complete picture, a recommendation is that additional studies should focus on parenting and men with intellectual disabilities.

Ellen and Hermione shared that they knew people with intellectual disabilities who had children and lived independently.

Hermione: Yeah, I know a few people that used to be in the same class as me in the school for people with disabilities, who have children. But I think they know a lot more about what they are doing. The girls that I'm talking about now were more able for doing things in the school than I was able to do.

Again, Hermione was showing a lack of confidence in her abilities here. Ellen also brought the topic of rights to where people can live, get married and have children into her sand scene (Figure 25).



Figure 25: *Ellen's sand scene on 'what she learnt about relationships and sexuality during the research'.*

Ellen: People with disabilities can decide themselves what children they want, or marriage. And where I put this (pointing to a fence to represent a house), a house for a person with disabilities,

they can decide where they want to live themselves, in the community, or in a HSE hostel (group home), or in a B&B, wherever they want to live, or in a caravan, wherever. I learnt that in research and in life as well. I was put down a lot because of my disability and I was locked up before in an institution and a lot happened to me with my disability. I was treated very badly in the past because of my disability. I've learnt that people with disabilities have a right to a relationship, it doesn't matter who they are. It can be a girlfriend, or a boyfriend, or a friend, it depends on what they want, it's up to them.

Ellen had many negative experiences in a group home where her rights were violated. Although it was a community-based house, she repeatedly articulated it as an institution because of how she was treated by staff with strict rules. At this time, she was afraid to speak out if they threw her out and she would then become homeless. She managed to leave the group home, get her own apartment, later moved in with her partner and eventually got engaged. However, when Ellen joined the research team just before meeting her fiancé, even though she had gotten out of this situation herself, she did not have confidence in her abilities. She was ashamed of her disability and had negative views about herself, and although she knew it was wrong how she was treated, she was not fully aware of her rights or how far she had come to leave this situation on her own. Talking with the research team, allowed her to process this; she could see others shared these experiences and that the violation of her rights was wrong, and it was not due to her disability or the person she was. It was so powerful when Ellen voiced this in the group. She did contribute to the discussion more in these conversations. However, she had the most experience with these topics and had a lot of stories on the violation of her rights to share, as well as showing she came out at the other end and her story ended positively. She needed to tell her story and be heard, to work through it. Further research is warranted to discover if people with intellectual disabilities who have moved out of institutions to community homes are experiencing the same way of living but in a different setting.

We discussed support in relation to people with intellectual disabilities having children.

Ellen: And I think people with disabilities, if they need support to have children, they should get the support. And not just rush in and take the child off them and say this can't work and that can't work.

Hermione: Yeah, they should get more support.

We discussed what kinds of support.

Ellen: Just helping them with the children and all like that. Help to look after the children. And give emotional support, and support if you can't sleep at night with the child being up all night, if you're tired. Advice on the child's health as well.

Ellen expressed that with her health issues and not sleeping at night, she would find it difficult to function in that scenario, and having a child would make her life extra hard. Ellen said a home support worker could offer the kind of support that would be needed in this instance.

Hermione: I suppose getting sleep at night-time and if they're (baby) crying that's the hard thing about it. Because a lot of people have to be up during the night and feed the baby during the night. And that's awful. That's annoying about kids, they're awake at night.

Hermione suggested a live-in Nanny may solve this issue.

Bruce: Probably support for the parents, and some carer, help you out with the child and help you to mind the child.

Ellen: Yeah, how to mind and look after it properly, change nappies.

Several studies have found that parenting successfully is particularly evident when parents with intellectual disabilities receive parenting support, which includes families and parents being there emotionally and practically, while not interfering, and financial support. (Strnadová et al., 2019; Tarleton and Heslop, 2021; More and Tarleton, 2022). Parenting support is a right under Article 23 of the UNCPRD (2006).

Hermione then brought up a question.

Hermione: I was thinking of something there now you know. If a person with a disability has a child, would they be born with the same disability? Now there's something we've never thought about (laughing). Would they be born with the same disability? Like someone with down syndrome, would they be born with down syndrome as well?

This was an interesting topic to come up with. It may have been that Hermione heard this from someone. She did not seem to see it as a positive thing to have a disabled child.

Bruce: It depends on your genetics, of your DNA probably.

Ellen shared that her mother had the same disability as her, and she was concerned that she would pass it on to her child if she had one. Ellen and Hermione believed it would be harder to look after a child with a disability, but Ellen said she would accept the child.

The studies in the literature highlighted how challenging it can be for mothers who are raising a disabled child, particularly when they get older and display behaviours that challenge (Strnadova et al., 2019; Wos and Baczata, 2021). However, the women in these studies also lacked support.

Alice shared her third object creation, which really showed what we had voiced throughout our discussions on rights; it took some untangling of it before she could show us (Figure 26).



Figure 26: *Alices third object on ‘the biggest thing she is taking from the group’.*

Alice: As you can see there’s some shells on a string. The shells are going through the string, they’re all in a line. The string represents life, how where everyone expects you to be on this one linear path. But it never works like that, the same way a string is never going to stay straight. As you can see from me trying to take it apart. The shells represent us, because we all might look different, but to me we’re all on the same path. We’re all living our lives. We’re all looking for the same thing out of life in a sense. Just, yeah, we’re all together.

We were intrigued by Alice’s creative metaphor of life and asked her to discuss it more. She said the shells represent experiences and areas in our life that we meet at, and the string represents life. We are expected to follow life in a linear path, go to school, find a partner, and get married. The researchers shared that their path is seen differently to this and that they are not expected to do these things but that they are expected as people with intellectual disabilities to follow a different path.

Alice said the string is only straight if we hang it up, but it is still never perfectly straight. She explained that if we lie the shells down in any way, each time, we will get a different line from the strings, maybe with some overlap in parts, sharper turns, or circles. Alice

said that's what life is. There is no one path for everyone. We all agreed. She further went on to say that from her experience in this group she learnt that not one person's life is the same, and we all experience our shells and strings differently, from whether we want to get married to having children. She said was not as aware of other people's strings and shells before, and especially in her own life, she feels she's been expected to be on the straight string path, but through her own experiences, that is impossible to achieve.

The shells also represent us as a group, a community, and a society. We are all interconnected through life, and sometimes it takes crashing into each other, like if we were to put an object on a table, two shells might be beside each other, to recognise how alike we all are and how we all want to be loved in some way or form, that is significant to us in our version of love. We agreed that we all wanted similar things in life despite our disabilities. Like strings, we all get jumbled up at times and have knots in us, but if we help each other out, like the shells that keep the string in place, we can make the world a better place for everyone.

8.4 Impact of the judgements of others:

We spoke about the impact of the judgements of others regarding people's opinions on the researchers getting married and having children. Nathan and Hermione both voiced they felt annoyed when people told them they could not do something but refused to tell them why. It is hard enough being told you cannot do something, but for the person not even to have the respect to explain their reasoning behind it makes it very difficult to understand and accept. Bruce initially said he did not care, although he later said it sometimes made him angry, fed up, and annoyed. He noted if he felt that way he read comic books, played video games, or listened to music to try and take his mind off it. Nathan shared that at the time of his family's resistance, it made him feel angry, but he was going to do what he wanted to do despite their resistance. Nathan said it also made him upset, and he is still a little upset. This seemed to be the general feeling.

Ellen: I felt hurt inside, sad, and depressed. But I get up and do what I do every day, I do it anyway.

Nathan: Maybe were fed up people don't agree with it (relationships).

Ellen: Well, I felt bad I can't have children. I don't want children, but that I can't get married, and she (Aunt) wanted to get me sterilised, that really upset me.

Bruce swore a lot when he spoke about his rights, I asked him why and he said he did not know but he did feel emotion towards his rights.

Ellen: How do you feel about it? (Getting treated differently, addressing Bruce).

Bruce: Tell your parents.

Ellen: Well, you've got support in your parents, like I don't. I just write down how much I'm feeling. I have my social worker, but I don't really talk to her much. I don't tell her much because I don't trust her. Because she'd go behind my back and talk to the psychiatrist or someone about me.

Ellen said it made her feel bad and it was hard when people were judging her. I asked Ellen how she felt talking about this and she said it had been hard and she had felt bad, but she turned it around to a positive.

Ellen: I feel good because I have overcome it (being judged). I have moved on from it. I got on with my life.

The researchers wanted more information on their rights so at the following research meeting I brought in an accessible copy of the UNCRPD (2006) for each researcher. We decided to go through the section on the right to family together. Afterwards, I posed a question to the group.

Jess: So, the next time somebody says to you, no you can't do that, you can't get married, you have an intellectual disability. What do you think you might say to them based on this law?

Bruce: Feck off!

Ellen: It's my human right to get married.

The researchers shared that it felt good to be listened to on this topic as they had not been listened to before.

Ellen: I feel empowered. I can get up and I can actually know that I can get married. I thought that I couldn't get married, because my aunt kept saying it to me, and I thought that was true. That was the reality.

These feelings of a mix of anger and self-determination when it came to rights regarding relationships and sexuality were also evident in studies from the literature (Chou et al., 2015; Jamieson et al., 2016; Turner and Crane, 2016).

8.5: Action five: Challenging the perspectives of others:

From the very first research meeting, some of the researchers voiced that they would eventually like to present at a conference and publish our findings. As part of our actions, we decided we wanted to get our work out there, mainly to challenge other people's

attitudes about people with intellectual disabilities capabilities. As a result, we presented at the International Action Research Colloquium 2022 about our research team. Our presentation was called 'The R&S (Relationships and Sexuality) Research Team: A collaborative inquiry group - Sharing our journey and learning, of inclusive and accessible research' (Mannion et al., 2022a). We received a very positive response from the audience, and it was here the keynote speaker from the University of Cincinnati approached us. He stated he was doing similar work but not to this level of collaboration and was really impressed with how we were working together. This is when he asked if we were interested in exploring a possible collaboration with his faculty. (This is explored further in the epilogue). We were then approached by Sage Methodspace to write a blog on our work for Disability Awareness Month. Together we co-authored our first academic blog called 'We are proud to be researchers with disabilities' (Mannion et al., 2022b). We hoped that instead of being labelled as 'vulnerable' and 'lacking capacity' that people could now see us as researchers, public speakers, and authors, who were engaged in group facilitation, data analysis, applying for funding, presentation skills, academic publishing and in educating others. We hoped that this would help our action of wanting to contribute towards changing other people's attitudes about people with intellectual disabilities capabilities. Maybe then others would see people with intellectual disabilities as sexual beings.

We decided that the topic of rights to marriage and children was also very important to us, and we wanted to act on this, so we took some time to discuss an action around it.

Ellen: Well, I've done all I can to be independent. I've come as far as I can been independent. I don't know how to change it (other's perceptions). Just narrow-minded people and that's it, just fed up of it. There should be a law. The law would stop people from judging people with disabilities. They should support people with disabilities to live on their own and be independent. Not just to judge and say you can't cope.

Bruce: They (whoever is judging) should talk to them (person with an intellectual disability).

Ellen: Why are people with disabilities treated differently, when they're not. They're the same as everybody else. I'm the same as you or anybody else around this table. It doesn't matter. So why should we be judged?

Alice: Do you think it will ever change?

Ellen: I don't know. Well, were not really the same as everybody else. Look put it this way, if I go out and break the law tomorrow, I'd be in jail, or get a warning, or told off by the gardai or whatever. But if you have a disability, you're told something else. There's nothing wrong with people with disabilities. They're the same as everybody else. I talk to everyone exactly the same, everybody's equal.

What Ellen was explaining is that people with intellectual disabilities get treated differently if they need something (such as relationships). Yet if they break the law, for example, they get treated the same as non-disabled people and would face a prison sentence. We all wanted to do an action on the topic of rights to marriage and children for people with intellectual disabilities, as it was very important to everyone.

Ellen: Well, I think they should stop judging us and let us get on with our lives.

Alice: How would you get it out there, that people know to stop judging you?

Ellen: Well, I was told that I couldn't look after myself and I always put it into a positive light, and I push myself further and further. And I feel like I've to keep pushing myself the whole time, further and further to prove a point.

Ellen then suggested education around it for people with intellectual disabilities as they may not realise, they are capable.

Jess: So, what's more important, for you to learn about your rights so you can speak up for yourself, or to try to change people's attitudes who judge you?

After some discussion, we all said we would like to try to change people's attitudes.

Ellen: Well people with disabilities should not be judged in any way.

Hermione: They shouldn't be, no, no.

Ellen: Well, I don't let anything stop me, I just get on with my life. If they talk about me, I walk away. I'm comfortable going out and looking after myself, and cooking, and cleaning, and doing everything myself. I do that. I live independently.

Ellen suggested a topic for our action would be to aim to change peoples' judgements about people with intellectual disabilities regarding marriage and children.

Ellen: Why do people with intellectual disabilities get judged?

We looked at ways we could get this answered. We expressed an interest in awareness raising and a conference so I asked the research team if they would like to bring these two things together and hold a public lecture at Trinity College Dublin where we could share our research findings on the topic and aim to create awareness. The whole group loved this idea. One of the barriers was funding as Dublin is so far away and it would be too far to travel there and back in one day, as well as hold an event. It would be expensive for us all and some carers to stay overnight in a hotel. Ellen volunteered to apply for two funding applications with me. Once we knew we were successful in both applications at €7,673, we planned the event. We decided to extend the creative performance and practice activity we had used to explore the topic of marriage and children in our research meeting and make a short film using our own words derived from the data transcripts. After some

exploration, we decided to make a short talk show where the hosts would interview the research team about the topics of marriage and children. I went through the transcripts of all the research meetings and made a script on the topic of marriage and children. I ensured that no one would have their own words to act to provide some sense of anonymity. Then the pseudonyms used in this thesis are different to the film to add another layer of anonymity. The group broke their anonymity when they decided to disseminate their data and use their real name, but this way people would not know who said exactly what. The group went through the script and made any edits they saw fit. We rehearsed this and with a very short turn around we hired a filmmaker and made the short film. We called our event 'We have the right to get married and have children' (Mannion et al., 2022c) (Appendix 11). In this public lecture, we provided an overview of the study, with a focus on the research findings concerning rights, barriers, and needs regarding getting married and having children. The event was aimed at people with intellectual disabilities, and their families, friends and carers, disability studies students, academics, and disability professionals. We used presentation, showcasing the film, and audience engagement to share the research findings.

The event was a huge success, we had excellent attendance, mainly from academics from universities in Dublin, but also from people with intellectual disabilities, parents, and disability professionals. When it came to the discussion part, the whole room got involved, and we ran out of time due to so much engagement in the discussion. It was fantastic to start these conversations so people could leave with some ideas.

We were all very proud to attend Trinity College as researchers and present our findings to a room of academics and others, where we were seen as the experts. When we arrived at Trinity College and stood under its famous front gates, Louise threw her arms in the air and shouted,

Louise: I want to tell the world, I am a researcher at Trinity College, I want to shout it from the rooftops!

We all stood together and felt very emotional in this moment. We had come so far together. We got the camera out to take some photos of this special moment together. It felt good to be seen in a different light and to be listened to. A few people approached us

for future collaborations. It was a lovely way to end the study. But we decided to continue to be a research team, so this was not the end.

Chapter Nine: Discussions, Recommendations and Contributions.

9.1 Introduction:

This final chapter will begin by putting forward the study's main limitations. I will then use the theoretical lens of sexual citizenship (Plummer, 2003) to discuss the findings of this research. Here, there will be a focus on the denial of sexual citizenship for the researchers. I will then explain the impacts we experienced from being a co-operative inquiry group and participating in intimate storytelling. Here, I will highlight some unexpected findings. There will then be a focus on our recommendations for practice and research. To end, I will explain this study's contributions to the field of intellectual disability, relationships, and sexuality.

9.2 Discussions:

9.2.1 Limitations:

Lewin (1946), the founder of action research, argued that both groups need to be studied to improve intergroup relations. As the findings unearthed, many of the researcher's issues were due to other people's perceptions and treatment. Lewin (1946) argued that minority problems are majority problems. This means that the problems of people with intellectual disabilities are the problems of non-disabled people. However, it was challenging to work through these barriers when we did not include non-disabled people outside of our chosen actions.

As I come from a constructivist epistemological position, I believe everyone has their version of reality. The researchers gave their version of reality. However, we were missing other versions of reality of the people the researchers spoke about. Each person's version of reality is valid as this is how they experience the world, and this study was concerned with the perspectives and lived experiences of people with intellectual disabilities only. However, this study did not provide a complete picture of all the actors discussed in these stories. For example, Louise spoke a lot about her parents over-protecting her, not allowing her to have sexual health education in case it gave her ideas to have sex, as they were concerned, she would be abused or exploited. They tried to discourage her from relationships, telling her that men may use her for her money. She also spoke a lot about

the staff in her group home who did not accommodate how she wanted to live or in her social life. With just this perspective, it is difficult to know why exactly her parents and care staff are reacting in a way that is not helpful to Louise. However, because of the nature of the study and our actions, Louise's parents and care staff were involved, such as making every effort to support her to ensure she could travel to conferences by rescheduling medical appointments, working extra shifts to bring her away, contacting me outside of work hours to arrange our plans, and attending events in the audience to support Louise. They made every effort to ensure that she could be as engaged as much as she wanted in this study of relationships and sexuality. Without this context, they are seen as over-protective and deny Louise her rights. But with this context, we can see that they were over-protective as they cared about her but still did their best to support her wishes. This could have been due to their lack of support and knowledge. Without this context, it is difficult to break down the barriers the researchers voiced fully. If we had other people's perspectives, working together to resolve the identified issues may be easier. There is also the ethical element where another person's perspective of a person is being shared without the chance for that person to tell their story. However, this study did enable people with intellectual disabilities to share their stories, perspectives, and experiences that were all valid and important as it was their version of reality.

9.2.2: Denied sexual citizenship:

Plummer (2003) said intimate citizenship rights should be viewed in terms of whether an individual has control. The researchers repeatedly voiced examples of how other people in their lives had control and not them. The researchers shared numerous examples of how others denied their sexual citizenship (Plummer, 2003), where their rights to choose within their sexual lives were restricted (De Graeve, 2010). Limits and constraints are imposed on disabled people's intimacy and sexuality by family, professionals, and broader society, underpinned by societal attitudes (Iarskai-Smirnova and Verbilovich, 2020).

Most of the researcher's sexual health education was controlled by disability professionals, teachers, and families who were concerned that this education would give them ideas about having sex and that they could not consent. They wanted to protect the researchers from abuse and exploitation. As a result, the researchers were either denied

access to sexual health education, or it came from a biological discourse about respecting themselves, keeping their body parts private and appropriate touch. They were told to keep safe and protect themselves by being appropriate and respectful, but not told what to do if someone abused them. However, in this small sample alone, there were two disclosures of sexual abuse and two disclosures of image-based sexual harassment. These protective views and measures were not working in the lives of the researchers. Sexual minorities often become victims of abuse, harassment, coercion, violence, exploitation, hate crime, and exclusion (Plummer, 2003).

It was unsurprising that the researcher's sexual health knowledge was either limited, functional, superficial, or incomplete when they got their information from Google and YouTube searches, social media, video games, porn and T.V. The only times they heard about LGBTQ+ was from overhearing others and they wanted this information. They were probably not told this information, as others may have viewed them as either asexual or heterosexual.

Four of the researcher's families discouraged intimate relationships. The main reason that families discouraged relationships is that they viewed the researchers as at-risk and in need of protection, as they were concerned, they would get raped or assaulted. There is a tension between empowering sexuality and safeguarding from abuse and exploitation due to the high prevalence of sexual abuse of people with intellectual disabilities and society's ingrained historical views of people with intellectual disabilities sexuality, stereotyped as vulnerable. However, this protection is not working and denies and violates people with intellectual disabilities rights. There needs to be a balance between protection and autonomy. The law has changed internationally and in Ireland, but most caregivers still do not know how to support people with intellectual disabilities' sexuality best.

One of these families told the researcher they could not move out of the family home and go into supported living because they could not care for themselves effectively, even after the researcher learned to do this and was in full-time paid employment. This family were over-protective of the researcher.

Disabled people often depend on disability services for support in their sexual lives (Bahner, 2021). A key worker of one of the researchers thought that we should be researching companionship instead of relationships and sexuality, which is unsurprising given the dominant discourse of people with intellectual disabilities being paternalised and seen as asexual. A social worker and disability professionals from group homes imposed the strictest restrictions by not allowing people to live how they wanted, not providing privacy, denying relationships, and threatening a researcher that if she got pregnant, they would take her child from her. It was unsurprising that one of the researchers described this community group home as an institution because it sounded just like one. Also, a parent and disability professionals possibly coerced two of the researchers into taking the contraceptive pill without telling them. These are all violations of the researcher's human rights under the United Nations Convention on the Rights of Persons with Disabilities (UNCPRD) (2006).

It was even difficult to have friendships where two of the researchers could not even meet for coffee together as one lived in a group home and there was a lack of staff, so she would need to get agreement from the other three male residents to go. These researchers' social life was restricted; they experienced surveillance and were rarely unaccompanied. This was further expressed in Chloe's experiences of attending a disco run by her day service, where staff spoke to her and treated her like a child.

The male researchers were supported to start families, but the female researchers were not. Parents are often more over-protective of their daughters than their sons because they are the ones who get pregnant. Because of the societal discourse on gender, women are seen as the more vulnerable gender and in need of protection.

The sergeant who was going to provide the online safety training saw the researchers as vulnerable and as not having the capacity to consent and make their own decisions without ever meeting them and labelling them based on their disability status alone. The researchers said that this was a common view others held about them. This is because of society's ingrained historical views of people with intellectual disabilities and sexuality.

Another issue identified that there was a lack of representation of people with intellectual disabilities, which the researchers highlighted. This lack of representation was evident in resources to help their situation, particularly from an Irish context.

Other people's perceptions impacted how most of the researchers viewed themselves. They were infantilised and denied autonomy and sexual citizenship (Ignagni et al., 2016; Liddiard, 2018). This happens because traditional intimacies are embedded in hierarchy, authority, and religious and patriarchal beliefs (Plummer, 2003). Also, the narratives present in public discourse are influenced by the values of what the public believes is permissible sexual behaviour for disabled people, which is usually desexualising them, coupled with ignoring and denying their sexual needs (Mladenov, 2014; Iarskai-Smirnova and Verbilovich, 2020; Evans et al., 2022).

The researcher's general perspective of sex came from a functional, gendered, and heteronormative perspective. This is unsurprising given that their sexual health education and messages from others were focused on biology and protection as opposed to positive relationships and pleasure. Other people's messages may have also been internalised. For the two researchers who did receive sexual health education, they viewed sex as dirty and wrong. This most likely resulted from others' opinions or negative past experiences. Two of the researchers were repeatedly told by professionals and families that they were not capable of looking after themselves or having children. This seemed to influence the researcher's beliefs in themselves, where they also felt they were incapable. Many of the researchers lacked confidence, were ashamed of their disability, saw it as bad, and viewed themselves negatively.

Despite the researchers knowing the way they were treated was wrong, they accepted it as had no other choice; they believed that because of their intellectual disability, they could not have their needs and rights met. Disabled people are invisible citizens, and sex is a taboo subject silenced within public discourse (Iarskai-Smirnova and Verbilovich, 2020). Disabled people can struggle to be recognised as sexual beings (Bahner, 2021). The researchers' experiences negatively impacted their integration and resulted in exclusion and loneliness. According to Liddiard (2018), due to the segregation, institutionalisation, and exclusion of disabled people, they have been on the margins of human sexuality and denied rights and access to sexual citizenship. When the researchers got the opportunity

to discuss their experiences and identify the denial and violation of their human rights together, the researchers felt upset, frustrated and angry. It was hard for them to be told they were not allowed to do things but were not explained as to why and were not listened to.

These ableist attitudes resulted in the researchers not being able to live the life they wanted. The medical model prevailed, whereas others in most of the researcher's lives focused on their impairment and what they could not or should not do. However, the barriers others put up were causing more issues for the researchers than their impairments. From listening to the researcher's narratives throughout the study, it was clear that their sexual citizenship (Plummer, 2003) was being denied.

This denial of intimate citizenship is contrary to the UN Convention on the Rights of Persons with Disabilities (2006), which aims to protect disabled people's rights in the spheres of intimate life, such as their sexual identity and expression, in marriage and in starting a family (Ignagni et al., 2016; Iarskaia-Smirnova and Verbilovich, 2020). The Acts of the UNCPRD (2003) that were identified to be denied or violated for the researchers included:

- Article 5 – Legal protection to prohibit all discrimination on disability.
- Article 16 – Measures should be taken to prevent abuse.
- Articles 16, 23 and 25 – Should have access to information and education relating to their sexual health.
- Article 19 – Not obliged to live in a particular living arrangement, that the community includes disabled people, the right to have choices equal to others, and the right to full inclusion and participation.
- Article 22 – Privacy should be protected.
- Article 23 – The right to personal relationships, the right to reproductive and family planning, the right to retain fertility, the right to parenthood, the right to support to give equal access to parenthood and the right to marriage.
- Article 30 – Access to leisure activities.

UNCPRD (2006)

Plummer (2003) described intimate citizenship as recognising rights and responsibilities regarding decision-making about intimate relationships. Despite the researchers having negative self-perceptions and experiences in the past of being afraid to speak out, they could identify that they were being discriminated against, that their rights and decision-

making were being denied and violated, and that they wanted to be listened to and make a change for themselves and other people with intellectual disabilities. Sexual citizenship aims to advocate for many rights (Bahner, 2021), and the most important one for the researchers was about getting married and having children. Plummer (2003), when explaining intimate citizenship, stated that people should not be denied the right to experience sexuality, get married, or have children. The researcher's sexual citizenship was denied.

9.2.3: Impact of the co-operative inquiry group and storytelling:

The co-operative inquiry group enabled citizenship, as Plummer (2003) defined as participation and belonging to a group or community that brings rights to the fore. It enabled us to share our experiences, find common ground, and work through some important issues, where we highlighted where rights were being denied or violated. The researchers used the research team meetings as a place to make claims about their intimate and sexual selves (Evans et al., 2022). Here, the researchers shared their past experiences and perceptions of relationships and sexuality and the barriers they faced in accessing these fundamental human rights, particularly from those closest to them.

We were then able to act on some of the issues that were important to us. Our main aim was to share our research findings in the hope we would change societal attitudes about people with intellectual disabilities regarding their sexual citizenship. Rorty (1979) suggested that people make identities and communities and that a new description is generated through storytelling. Iarskai-Smirnova and Verbilovich (2020) claimed that sexual storytelling can be a tool for disabled people to fight for their right to identity. They further maintained that telling and analysing sexual stories can help to reveal the stereotypical attitudes that people experience, and this can then be used to challenge and dismantle such dominant repressive discourse which is present in the public domain (Iarskai-Smirnova and Verbilovich, 2020). This is crucial for political and social change and the claim for intimate citizenship (Plummer, 2003; Iarskaia-Smirnova and Verbilovich, 2020; Evans et al., 2022).

When people tell their stories, they begin to make sense of them, and empowerment can follow (Langellier, 2001). This happened with the researchers because they knew their situation was wrong, but they needed to discuss it with others who would listen and relate and then process this. Lewin (1946) described this acceptance of judgement as causing low confidence and self-esteem. When a group of disabled people form and share similar experiences, it can result in solidarity and help them resist any disabling discourse together, increase representation, and help them gain the right to recognition (Iarskai-Smirnova and Verbilovich, 2020). People can collectively redefine themselves, resulting in emancipation and liberation from how they were previously viewed (Iarskai-Smirnova and Verbilovich, 2020). Lewin (1946) described one of the biggest challenges in action research with minority groups as a lack of confidence and self-esteem among the group. The discrimination from others is targeted towards the group (in this case, people with intellectual disabilities), and not the individual, so by raising the group's esteem, it can help to work towards remedying the problem (Lewin, 1946). Most of the researcher's views changed towards disability throughout the year of the study. They did not have a positive disability identity at the start; it was something most were ashamed of, as others viewed and treated them differently, and it held them back. By the end of the study, most of the researchers said they viewed disability differently. They had not realised I was disabled and could see we were all the same, and it was not a bad thing. I believe disclosing my neurodevelopmental and sensory impairments helped. It united us as a group, having a similar shared experience and understanding. The research team believed that although other peoples' perceptions needed to change, this study helped them to change their views on themselves and their disability. This was hugely powerful and something I had not expected to come out of the study. Ellen said that this study helped her to love herself and accept her disability for the first time in her life.

Ellen: I accepted it. And I love myself more because I didn't love myself before, I had very low self-esteem. I learnt I have a disability and I have to accept myself for who I am, I know my limits and I love myself for who I am.

Louise: I learnt that we don't have to be perfect, if you have a disability, accept it.

Alice: I'd always put myself down, for hidden disabilities I would have myself. And I feel that since being in this group, I've learnt to accept them a lot better, I've learnt to face what I have, and like Louise you've just said to accept it and that nobody is perfect.

Louise: It's hard you know, when I first came to the group, I didn't know who I was, but now I know who I am.

Alice: For myself it's a mixture of seeing that so many people do have a disability, I am not alone, there's other people that have the same feelings and the same worries and the same joys as myself. And just being in this group made me feel a lot more accepted about what it is, and it doesn't hold me back in the sense of what I want to do in the world.

Ellen: I've more confidence in myself since doing this group. Because I wasn't the only one who had a disability and health issues. People with disabilities are equal to everyone else in the world.

We were on a journey there; we had changed our attitudes about ourselves and had developed a positive collective disability identity. Now, hopefully, we can change other people's negative perceptions. However, if we did not, we were stronger together. We had not only met the aim and objectives of the study, but we had experienced transformation. This experience of coming together and sharing experiences can lead to understanding and respect, resulting in a movement towards sexual citizenship (Plummer, 2003).

9.3 Recommendations:

9.3.1 Practice:

We identified several practice recommendations. There needs to be guidance, training and support for disability professionals, school teachers, and families so they can better understand how to support people with intellectual disabilities. This includes the Gardai, who should receive training about people with intellectual disabilities to understand them better. We recommend that social workers should support parents with intellectual disabilities and give them a chance before removing their children from them; they would also benefit from further training. As well as this, people with intellectual disabilities should be supported if they become parents. Others should view people with intellectual disabilities more holistically and not assume they are asexual or heterosexual. No one should deny their rights to relationships, marriage, or having children. There should be funding to enable people with intellectual disabilities to live the way they want.

We identified a range of education-based recommendations. There needs to be free, in-person, evidence-based, accessible, and tailored sexual health education that focuses on supporting sexuality and protecting people with intellectual disabilities. The content should include support in finding a partner, boundaries, sexual consent, parenting, sexual

abuse and harassment, keeping safe if seeing a sex worker, online safety, and LGBTQ+ relationships. We further recommended that there should be further information on LGBTQ+ aimed at people with intellectual disabilities. Online safety training should include how to keep safe on websites, social media apps, dating apps and phones, and how to keep safe when meeting a person from a dating app in real life. The topic of the capacity to consent for people with intellectual disabilities should be included in any sexual consent workshop. Training aimed at the mainstream population should still be accessible to people with intellectual disabilities as they may be in attendance. The delivery and resources of such sexual health programmes should be accessible and inclusive. This includes facilitating at a slower pace and holding workshops over a more extended period with less content. The writing should be large, using easy-to-read language, without bold coloured fonts, and with accompanying pictures. Resources such as videos should ensure representation using actors/ models with intellectual disabilities.

The researchers further recommended that there should be dating apps for people with intellectual disabilities in Ireland that also provide information on how to find a boyfriend or girlfriend and how to keep safe on it.

Overall, we would like to see social perceptions change towards people with intellectual disabilities, relationships, and sexuality. For this to be achieved, there must be much more disability awareness.

For all these recommendations to happen, policy needs to support it. Legislation is in place, but despite this, people with intellectual disabilities' human rights are being grossly denied and violated, so this needs to be addressed.

9.3.2 Research:

Many gaps in the literature were identified throughout this study. Some of the main areas included pleasure, LGBTQ+, the impact of the media, including video games, on people with intellectual disabilities views, and sex work.

Ethics committees should consider the harm to researchers when abuse is disclosed in studies, and disclosure training should be mandatory for researchers engaged in this type of research.

Although I identified many gaps, the research team identified they would like to train as sexual health educators, train their peers, and do research on this, using collaborative and creative research methods. We are doing this with a joint collaborative project with the University of Cincinnati and Manchester Metropolitan University. We also think research is lacking on online safety programmes and online safety for people with intellectual disabilities in an Irish context, which includes social media and dating apps, and we would like to research this in the future.

9.4: Contributions:

This study brings many contributions to knowledge. I faced many barriers when initiating the study, and others tried to stop it, but with determination, I kept going, and it paid off. This study is original, unique, adds value and advances knowledge in research on intellectual disability, relationships, and sexuality in Ireland. No studies that have included the perspectives and experiences of people with intellectual disabilities on this topic have been undertaken in Ireland since 2012. Between 2009 and 2012, there was a surge of research in this area due to the legislation changes. However, these small-scale studies were not this collaborative and in-depth, and those studies are now over 11 years old. These findings will now add new, up-to-date knowledge on this neglected and taboo research field in Ireland.

This study represents best practices in participatory approaches where everyone was involved, from design, to data generation, to analysis, to sharing the findings. Studies where participants are engaged at this level of collaboration are rare, particularly in intellectual disability research. The researchers were authentically involved in every single stage and decision of this accessible and inclusive study, from deciding what topics to research, deciding what creative methods to use, deciding the structure and venue of the meetings, co-creating, and co-analysing the data analysis method, co-analysing the data, applying for funding, and disseminating the findings. Due to complicated methods of data analysis, this is usually an area that is too complex for inexperienced researchers, and as a result, they are often excluded from this critical stage of research. If we want people to be involved in every stage and we want their contribution at this crucial point, then data

analysis needs to be made accessible. Our co-creation of a new creative, collaborative, and accessible data analysis method is a contribution to research and will provide future opportunities for researchers with intellectual disabilities to be involved in all stages of the research. The level of participation from the researchers in this study paves the way for future research where participants can instead be researchers and lead studies and actions that are important to them. We propose other researchers consider this way of working on disability research.

There are limited studies that have used sexual citizenship as a lens for research about people with intellectual disabilities. Using this method provides a social justice framework, which is important when researching topics where there are issues of social justice and people's rights are being denied or violated. It was shocking to learn how much the researcher's sexual citizenship rights were being denied and violated and to what level so many Articles of the UNCPRD (2006) were being contravened.

The benefits of these findings are that they will help others to understand this neglected area of research better and, hopefully, in turn, will improve the lives of people with intellectual disabilities regarding their sexual citizenship.

This research was transformative for the researchers in this study; therefore, it could also be transformative for other people with intellectual disabilities doing similar research. The researchers transformed from not accepting themselves and their disabilities and being denied their rights regarding sexual citizenship – to developing a positive collective disability identity and having a range of research skills by being public speakers, authors, and researchers – and being aware of their sexual citizenship rights. We hope that we, as a research team, are contributing to changing societal attitudes about people with intellectual disabilities and that this project will lead the way to move society forward regarding relationships and sexuality for people with intellectual disabilities.

Epilogue:

After this project ended and we presented at the International Action Research Colloquium, ran a research seminar at Trinity College Dublin showing the short film we made, and wrote and published an academic blog, we decided to come together and reflect on it all. Ellen suggested we write a poem together as she had missed this at the start of the study, and she stated she never wrote poetry before and wanted to try something new (see Figure 27).

A year for change

By Alice, Bruce, Ellen, Hermione, Jess, and Louise.

In the beginning, I felt a mix of being happy and nervous.

The experience was good craic.

I was excited to see my publication framed,
to tell people in the world that people with disabilities are equal to everyone else.

I felt excited to join the group,

And thankful for the opportunity.

I feel like I belong in this group,

I do not know where I would be without it.

In the beginning, I felt unsure of what was coming next.

As time had gone on,

I saw the amount of work that had been completed,
and a sense of disbelief of the amount of change that can be made in such a short time.

I felt nervous at first,

I did not fully know what I was getting into.

As time went on, I felt more confident speaking out.

By the end, I learned to love myself and my disability for the first time.

In the beginning, I was so excited,

but also worried in case it did not work out.

In the end, I was emotional, almost crying, because I could see the impact it had made on the group,
and I could burst with excitement, over the possible wider change.

I want to tell the world,

I am a researcher in Trinity College,

I want to shout it from the roof tops.

Figure 27: Poem we wrote together at the end of the study.

We were so proud and happy in this moment. All bar Hermione decided to stay in the research team, but she does meet us for social events. Shortly afterwards, two new people joined our research team, one with an intellectual disability and one who is neurodivergent. We wanted to travel internationally to a conference, so we applied to present about the creative methods we used, at the International Creative Research Methods Conference 2023 in Manchester. Our abstract was accepted (Mannion et al., 2023). During this time, I moved to the U.K. to take up an academic position in Manchester. We decided we would continue to work together through online meetings. We gained funding to support this dissemination. Seeing the research team travel from Ireland to abroad and present our work was a huge step. We enjoyed and celebrated this.

We were not only sharing our research internationally but are now working on further research internationally with two universities in two different countries. The keynote speaker of the International Action Research Conference 2022 approached us after our presentation, about the prospect of working collaboratively with the Intellectual and Developmental Disability Education Centre (IDD Education Centre), housed in the College of Education, Criminal Justice, Human Services, and Information Technology, in the University of Cincinnati. Four of us were interested; at this point, two new researchers joined our team and wanted to work on this, too. We are now working as a collaborative international research team evaluating their sexual health education programme for students with intellectual disabilities and advising the faculty on using visual and creative research methods. We have also brought the Learning Disability Cluster to this project, which is housed in the Department of Social Care and Social Work at Manchester Metropolitan University, as this is where I currently do research in my work. In the long term, the researchers plan to participate in this sexual health programme and then train to be peer educators to teach it to others with intellectual disabilities, all whilst researching it. Our research goal is to travel to America to present our research, and the American research team would like to travel to Ireland. We are currently seeking funding to support this work.

To be eligible to apply for community funding in Ireland, we applied to a Public Participation Network to become a social inclusion organisation. Our application was

successful. Ellen and Louise have volunteered to attend the network meetings to advocate on our behalf and bring information back to the research team.

We have spoken to an academic publisher regarding co-authoring a book; we are very excited to pursue this together as many of the research team dreamt of writing a book one day on creative accessible disability research.

We worked on one research project alone when we formed our research team. Now, we are a social inclusion organisation, are an international research team and are actively engaged in presenting our work at conferences and in publications worldwide, creating awareness and educating others. We are the R&S research team, and we are proud to be researchers with disabilities.

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Appendices:

Appendix 1: Systematic search strategy:

Establishing a co-operative inquiry group for people with intellectual disabilities to explore relationships and sexuality.

Concept 1? Intellectual Disability:

Medline: (MH "Intellectual Disability+") OR (MH "Persons with Mental Disabilities") OR (MH "Education of Intellectually Disabled")

EMBASE: 'intellectual impairment'/de OR 'mental deficiency'/exp

CINAHL: (MH "Intellectual Disability+") OR (MH "Mental Retardation, X-Linked+") OR (MH "Down Syndrome")

PsycINFO: DE "Intellectual Development Disorder" OR DE "Anencephaly" OR DE "Crying Cat Syndrome" OR DE "Down's Syndrome" OR DE "Tay Sachs Disease" OR DE "Learning Disabilities"

Web of Science: Keywords by topic only

ASSIA (Proquest): MAINSUBJECT.EXACT("Nonverbal learning disabilities") OR MAINSUBJECT.EXACT("Cri du Chat syndrome") OR MAINSUBJECT.EXACT("Down's syndrome") OR MAINSUBJECT.EXACT("Fragile X syndrome") OR MAINSUBJECT.EXACT("Intellectual functioning") OR MAINSUBJECT.EXACT("De Lange syndrome") OR MAINSUBJECT.EXACT("Prader-Willi syndrome") OR MAINSUBJECT.EXACT.EXPLODE("Learning disabilities") OR MAINSUBJECT.EXACT("Aicardi syndrome")

EBSCO and Proquest Keywords in title and abstract:: "Impaired intellectual function*" OR "Intellectual developmental disorder*" OR "Intelligence quotient IQ" OR "intellectual impair*" OR "Generalised neurodevelopmental disorder*" OR "Mental Handicap*" OR "intellectually handicap*" OR "mentally handicap*" OR "mental retard*" OR "Intellectual function* disorder*" OR "Cognitive disabil*" OR "cognitive retard*" OR "mental deficit*" OR "mental deficiency*" OR "mental incapacity" OR "intellectually challeng*"

EMBASE Keywords in title and abstract: 'Impaired intellectual function*' OR 'Intellectual developmental disorder*' OR 'Intelligence quotient IQ' OR 'intellectual impair*' OR 'Generalised neurodevelopmental disorder*' OR 'Mental Handicap*' OR 'intellectually handicap*' OR 'mentally handicap*' OR 'mental retard*' OR 'Intellectual function* disorder*' OR 'Cognitive disabil*' OR 'cognitive retard*' OR 'mental deficit*' OR 'mental deficiency*' OR 'mental incapacity' OR 'intellectually challeng*'

Concept 2: Relationships/ sexuality

Medline: : (MH "Sexuality+") OR (MH "Love") OR (MH "Erotica") OR (MH "Libido") OR (MH "Sex") OR (MH "Unsafe Sex") OR (MH "Safe Sex") OR (MH "Sex Workers") OR (MH "Sex Education") OR (MH "Sexual Behavior") OR (MH "Sexual Partners")

EMBASE: 'intimacy'/exp OR 'love'/exp OR 'sexuality'/exp

CINAHL: (MH "Sexuality+") OR (MH "Sex Education") OR (MH "Homosexuality+") OR (MH "Coitus+") OR (MH "Sexual Behavior+") OR (MH "Sexual Partners") OR (MH "Sexual Identity+") OR (MH "Sexual Arousal") OR (MH "Sexual and Gender Minorities+") OR (MH "Sexual Trauma") OR (MH "Intimacy") OR (MH "Love")

PsycINFO: DE "Sexual Partners" OR DE "Sex" OR DE "Sexology" OR DE "Same Sex Intercourse" OR DE "Sex Linked Developmental Differences" OR DE "Sex Roles" OR DE "Same Sex Couples" OR DE "Sexuality" OR DE "Sexual Aids" OR DE "Psychosexual Behavior" OR DE "Asexuality" OR DE "Paraphilias" OR DE "Sexual Identity" OR DE "Sexual Arousal" OR DE "Eroticism" OR DE "Sexual Intercourse (Human)" OR DE "Premarital Intercourse" OR DE "Rape" OR DE "Same Sex Intercourse" OR DE "Cisgender" OR DE "Pornography" OR DE "Sex Drive" OR DE "Sex Recognition" OR DE "Sex Role Attitudes" OR DE "Sexual Attitudes" OR DE "Sexuality"

Web of Science: KEYWORDS RUN ON TOPIC

ASSIA: MAINSUBJECT.EXACT("Sexual networking") OR MAINSUBJECT.EXACT("Sex shops") OR MAINSUBJECT.EXACT("Sexual orientation") OR MAINSUBJECT.EXACT("Sexual partners") OR MAINSUBJECT.EXACT("Bisexuals") OR MAINSUBJECT.EXACT("Presleep sexual arousal") OR MAINSUBJECT.EXACT("Sexual fantasies") OR MAINSUBJECT.EXACT("Consensual sex") OR MAINSUBJECT.EXACT.EXPLODE("Sexuality") OR MAINSUBJECT.EXACT("Psychosexual responses") OR MAINSUBJECT.EXACT("Hypoactive sexual desire") OR MAINSUBJECT.EXACT("Hypersexuality") OR MAINSUBJECT.EXACT("Sexual problems") OR MAINSUBJECT.EXACT.EXPLODE("Heterosexual relationships") OR MAINSUBJECT.EXACT("Sexual health services") OR MAINSUBJECT.EXACT("Sex role orientation") OR MAINSUBJECT.EXACT("Bisexuality") OR MAINSUBJECT.EXACT("Sexual identity") OR MAINSUBJECT.EXACT("Oral sex") OR MAINSUBJECT.EXACT.EXPLODE("Sexology") OR MAINSUBJECT.EXACT("Safe sexual practices") OR MAINSUBJECT.EXACT.EXPLODE("Sexual deviance") OR MAINSUBJECT.EXACT("Sexual permissiveness") OR MAINSUBJECT.EXACT("Sexual motivation") OR MAINSUBJECT.EXACT.EXPLODE("Homosexuality") OR MAINSUBJECT.EXACT("Sexual relationships") OR MAINSUBJECT.EXACT("Heterosexuality") OR MAINSUBJECT.EXACT("Psychosexual development") OR MAINSUBJECT.EXACT.EXPLODE("Homosexuals") OR MAINSUBJECT.EXACT("Sexual touch") OR MAINSUBJECT.EXACT("Sexual knowledge") OR MAINSUBJECT.EXACT("Sexual health education") OR MAINSUBJECT.EXACT("Heterosexuals") OR MAINSUBJECT.EXACT("Sex") OR MAINSUBJECT.EXACT("Sexual grooming") OR MAINSUBJECT.EXACT.EXPLODE("Sexual intercourse") OR MAINSUBJECT.EXACT("Sexual satisfaction") OR MAINSUBJECT.EXACT("Sexual practices") OR MAINSUBJECT.EXACT("Sexual violence") OR MAINSUBJECT.EXACT("Sex education") OR MAINSUBJECT.EXACT("Sexual gratification")

Keywords on title and abstract (ALL databases): sex* OR intimac* OR intimate* OR relationship* OR Lesbian* OR Gay* OR Straight OR Heterosexual* OR Homosexual* OR Asexual* OR Bisexual* OR Queer* OR pansexual* OR Sensual* OR Love* OR fantas* OR desire* OR longing OR fetish* OR polysexual* OR Attract* OR gender* OR friendship* OR romance* OR romantic* OR dating OR porn* OR erotica* OR psychosexual* OR masturbat* OR friendship* OR consent*

Concept 3: Qualitative and Coproduced research methodologies:

Medline: (MH "Qualitative Research") OR (MH "Hermeneutics") OR (MH "Grounded Theory")

CINAHL (MH "Thematic Analysis") OR (MH "Meta Synthesis") OR (MH "Content Analysis") OR (MH "Qualitative Studies+") OR (MH "Phenomenology") OR (MH "Grounded Theory") OR (MH "Focus Groups") OR (MH "Interviews+") OR (MH "Narratives") OR (MH "Observational Methods") OR (MH "Naturalistic Inquiry")

PsycINFO: DE "Qualitative Research" OR DE "Grounded Theory" OR DE "Content Analysis" OR DE "Interviews" OR DE "Phenomenology" OR DE "Case Report" OR DE "Narratives" OR DE "Cohort Analysis"

Embase: 'action research'/exp OR 'comparative study'/exp OR 'observational study'/exp OR 'grounded theory'/exp OR 'narratives'/exp OR 'phenomenology'/exp OR 'focus group'/exp OR 'interview'/exp OR 'descriptive research'/exp

Web of Science : keyword only search on topic

ASSIA: MAINSUBJECT.EXACT.EXPLODE("Qualitative methods") OR
MAINSUBJECT.EXACT.EXPLODE("Qualitative research") OR
MAINSUBJECT.EXACT.EXPLODE("Qualitative analysis")

Keywords EBSCO databases: phenomenolog* OR "grounded theor*" OR ethnograph* OR qualitativ* OR "action research*" OR "feminist research*" OR "narrative research*" OR descriptive OR "qualitative descriptive" OR hermeneutic* OR "mixed method*" OR "narrative analys*" OR "descriptive stud*" OR "exploratory stud*" OR "qualitative stud*" OR "qualitative research design*" OR "qualitative descriptive design*" OR "qualitative research*" OR "interpretative analys*" OR "case stud*" OR "focus group*" OR interview* OR "content analys*" OR "thematic analys*" OR "thematic coding" OR naturalistic* OR "Ethnonursing Research*" OR participatory OR observation* OR "naturalistic inquir*" OR "cooperative inquir*" OR "collaborative inquir*"

OR

(produc* OR deliver* OR implement* OR design* OR evaluat* OR facilitat* OR participat* OR writ* OR led OR lead OR input OR involve* OR collabor* OR consult) N3 (famil* OR carer* OR spous* OR parent* OR joint* OR dual*) OR co-produc* OR co-deliver* OR co-implement* OR co-design* OR co-evaluat* OR co-facilitat* OR co-participat* OR co-writ* OR co-led OR co-lead OR co-collabor* OR family-led OR dual-deliver* OR (work* AND together*)

EMBASE: phenomenolog* OR 'grounded theor*' OR ethnograph* OR qualitativ* OR 'action research*' OR 'feminist research*' OR 'narrative research*' OR descriptive OR 'qualitative descriptive' OR hermeneutic* OR 'mixed method*' OR 'narrative analys*' OR 'descriptive stud*'

OR 'exploratory stud*' OR 'qualitative stud*' OR 'qualitative research design*' OR 'qualitative descriptive design*' OR 'qualitative research*' OR 'interpretative analys*' OR 'case stud*' OR 'focus group*' OR interview* OR 'content analys*' OR 'thematic analys*' OR 'thematic coding' OR naturalistic* OR 'Ethnonursing Research*' OR participatory OR observation* OR 'naturalistic inquir*' OR 'cooperative inquir*' OR 'collaborative inquir*'

OR

(produc* OR deliver* OR implement* OR design* OR evaluat* OR facilitat* OR participat* OR writ* OR led OR lead OR input OR involve* OR collabor* OR consult*) NEAR/3 (famil* OR carer* OR spous* OR parent* OR joint* OR dual*) OR co-produc* OR co-deliver* OR co-implement* OR co-design* OR co-evaluat* OR co-facilitat* OR co-participat OR co-writ* OR co-led OR co-lead OR co-collabor* OR family-led OR dual-deliver* OR (work* AND together*)

Embase search results

The screenshot displays the Embase search results interface. At the top, the search bar shows the query: `#9 AND #12`. Below the search bar, there are tabs for 'Mapping', 'Data', 'Sources', 'Fields', 'Quick limits', 'EBM', 'Pub types', 'Languages', 'Gender', 'Age', and 'Animal'. The 'Results' tab is active, showing a list of search results with filters on the left and a results list on the right.

Results Filters:

- Expand** **Collapse all** **Apply**
- Sources** **Drugs** **Diseases** **Devices** **Floating Subheadings** **Age** **Gender** **Study types** **Publication types** **Journal titles** **Publication years** **Authors** **Conference Abstracts** **Drug Trade Names** **Drug Manufacturers** **Device Trade Names** **Device Manufacturers**

Results List:

Search ID	Search Query	Count
#13	#9 AND #12	4,622
#12	#9 OR #10 OR #11	4,228,269
#11	((produc* OR deliver* OR implement* OR design* OR evaluat* OR facilitat* OR participat OR writ* OR led OR lead OR input OR involve* OR collabor* OR consult) NEAR/3 (famil* OR carer* OR spous* OR parent* OR joint* OR dual*)) ab.1 OR 'co-produc*' ab.1 OR 'co-deliver*' ab.1 OR 'co-implement*' ab.1 OR 'co-design*' ab.1 OR 'co-evaluat*' ab.1 OR 'co-facilitat*' ab.1 OR 'co-participat*' ab.1 OR 'co-writ*' ab.1 OR 'co-led' ab.1 OR 'co-lead' ab.1 OR 'co-collabor*' ab.1 OR 'family-led' ab.1 OR 'dual-deliver*' ab.1 OR (work* AND together*) ab.1	185,636
#10	phenomenology* ab.1 OR 'grounded theor*' ab.1 OR ethnograph* ab.1 OR 'qualitative*' ab.1 OR 'action research*' ab.1 OR 'feminist research*' ab.1 OR 'narrative research*' ab.1 OR 'descriptive*' ab.1 OR 'qualitative descriptive*' ab.1 OR 'hermeneutic*' ab.1 OR 'mixed method*' ab.1 OR 'narrative analys*' ab.1 OR 'descriptive stud*' ab.1 OR 'exploratory stud*' ab.1 OR 'qualitative stud*' ab.1 OR 'qualitative research design*' ab.1 OR 'qualitative descriptive design*' ab.1 OR 'qualitative research*' ab.1 OR 'interpretative analys*' ab.1 OR 'case stud*' ab.1 OR 'focus group*' ab.1 OR 'interview*' ab.1 OR 'content analys*' ab.1 OR 'thematic analys*' ab.1 OR 'thematic coding*' ab.1 OR 'ethnonursing research*' ab.1 OR 'participatory*' ab.1 OR 'observation*' ab.1 OR 'naturalistic inquir*' ab.1 OR 'cooperative inquir*' ab.1 OR 'collaborative inquir*' ab.1	2,466,678
#9	'action research' OR 'comparative study' OR 'observational study' OR 'grounded theory' OR 'narratives' OR 'phenomenology' OR 'focus group' OR 'interview' OR 'descriptive research'	2,290,328
#8	#4 AND #7	80,357
#7	#5 OR #6	3,890,682
#6	sex* ab.1 OR 'intimac*' ab.1 OR 'intimate*' ab.1 OR 'relationship*' ab.1 OR 'lesbian*' ab.1 OR 'gay*' ab.1 OR 'straight*' ab.1 OR 'heterosexual*' ab.1 OR 'homosexual*' ab.1 OR 'asexual*' ab.1 OR 'bisexual*' ab.1 OR 'queer*' ab.1 OR 'pansexual*' ab.1 OR 'sexual*' ab.1 OR 'love*' ab.1 OR 'tender*' ab.1 OR 'desire*' ab.1 OR 'longing*' ab.1 OR 'fetish*' ab.1 OR 'polysexual*' ab.1 OR 'attraction*' ab.1 OR 'gender*' ab.1 OR 'romance*' ab.1 OR 'romantic*' ab.1 OR 'dating*' ab.1 OR 'porn*' ab.1 OR 'erotic*' ab.1 OR 'psychosexual*' ab.1 OR 'masculin*' ab.1 OR 'feminin*' ab.1 OR 'consent*' ab.1	3,797,236
#5	'intimacy' OR 'love' OR 'sexuality'	316,667
#4	#2 OR #3	606,196
#3	'impaired intellectual function*' ab.1 OR 'intellectual developmental disorder*' ab.1 OR 'intelligence quotient iq*' ab.1 OR 'intellectual impair*' ab.1 OR 'generalised neurodevelopmental disorder*' ab.1 OR 'mental handicap*' ab.1 OR 'intellectually handicap*' ab.1 OR 'mentally retard*' ab.1 OR 'intellectual function' disorder*' ab.1 OR 'cognitive disabl*' ab.1 OR 'cognitive retard*' ab.1 OR 'mental deficit*' ab.1 OR 'mental deficiency*' ab.1 OR 'mental incapacity*' ab.1 OR 'intellectually challeng*' ab.1	43,858
#2	'intellectual impairment' OR 'mental deficiency'	190,391
#1	'intellectual impairment' OR 'mentally disabled person'	592,481

4,622 results for search #13 [Set email alert](#) [Set RSS feed](#) [Search details](#) [Index miner](#)

Results **View** **Export** **Email** **Add to Clipboard** **1** — **25**

1 **Sex Education Practices for People With Intellectual and Developmental Disabilities: A Qualitative Study**
Schmidt E.K., Hand B.N., Havercamp S., Sommerich C., Weaver L., Darragh A.
The American journal of occupational therapy : official publication of the American Occupational Therapy Association 2021 75:3

MEDLINE **Abstract** **Index Terms** **View Full Text**

Medline 14/6/2022

Medline 14/6/2022

#	Query	Limiters/Expanders	Last Run Via	Results
S13	S3 AND S8 AND S12	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - MEDLINE	1,709
S12	S9 OR S10 OR S11	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - MEDLINE	2,047,500
S11	AB ((produc* OR deliver* OR implement* OR design* OR evaluat* OR facilitat* OR participat* OR writ* OR led OR lead OR input OR involve* OR collabor* OR consult) N3 (famil* OR carer* OR spous* OR parent* OR joint* OR dual*) OR co-produc* OR co-deliver* OR co-implement* OR co-design* OR co-evaluat* OR co-facilitat* OR co-participat* OR co-writ* OR co-led OR co-lead OR co-collabor* OR family-led OR dual-deliver* OR (work* AND together*)) OR TI ((produc* OR deliver* OR implement* OR design* OR evaluat* OR facilitat* OR participat* OR writ* OR led OR lead OR input OR involve* OR collabor* OR consult) N3 (famil* OR carer* OR spous* OR parent* OR joint* OR dual*) OR co-produc* OR co-deliver* OR co-implement* OR co-design* OR co-evaluat* OR co-facilitat* OR co-participat* OR co-writ* OR co-led OR co-	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - MEDLINE	196,015

	lead OR co-collabor* OR family-led OR dual-deliver* OR (work* AND together*))			
S10	AB (phenomenolog* OR "grounded theor*" OR ethnograph* OR qualitativ* OR "action research*" OR "feminist research*" OR "narrative research*" OR descriptive OR "qualitative descriptive" OR hermeneutic* OR "mixed method*" OR "narrative analys*" OR "descriptive stud*" OR "exploratory stud*" OR "qualitative stud*" OR "qualitative research design*" OR "qualitative descriptive design*" OR "qualitative research*" OR "interpretative analys*" OR "case stud*" OR "focus group*" OR interview* OR "content analys*" OR "thematic analys*" OR "thematic coding" OR naturalistic* OR "Ethnonursing Research*" OR participatory OR observation* OR "naturalistic inquir*" OR "cooperative inquir*") OR TI (phenomenolog* OR "grounded theor*" OR ethnograph* OR qualitativ* OR "action research*" OR "feminist research*" OR "narrative research*" OR descriptive OR "qualitative descriptive" OR hermeneutic* OR "mixed method*" OR "narrative analys*" OR "descriptive stud*" OR "exploratory stud*" OR "qualitative stud*" OR "qualitative research design*" OR "qualitative descriptive design*" OR "qualitative research*" OR "interpretative analys*" OR "case stud*" OR "focus group*" OR interview* OR "content analys*" OR "thematic analys*" OR "thematic coding" OR naturalistic* OR "Ethnonursing Research*" OR participatory OR observation* OR "naturalistic inquir*" OR "cooperative inquir*")	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - MEDLINE	1,877,608
S9	(MH "Qualitative Research") OR (MH "Hermeneutics") OR (MH "Grounded Theory")	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases	75,570

			Search Screen - Advanced Search Database - MEDLINE	
S8	S4 OR S5 OR S6 OR S7	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - MEDLINE	3,157,470
S7	AB: sex* OR intimac* OR intimate* OR relationship* OR Lesbian* OR Gay* OR Straight OR Heterosexual* OR Homosexual* OR Asexual* OR Bisexual* OR Queer* OR pansexual* OR Sensual* OR Love* OR fantas* OR desire* OR longing OR fetish* OR polysexual* OR Attract* OR gender* OR friendship* OR romance* OR romantic* OR dating OR porn* OR erotica* OR psychosexual* OR masturbat* OR friendship* OR consent*) OR TI (): sex* OR intimac* OR intimate* OR relationship* OR Lesbian* OR Gay* OR Straight OR Heterosexual* OR Homosexual* OR Asexual* OR Bisexual* OR Queer* OR pansexual* OR Sensual* OR Love* OR fantas* OR desire* OR longing OR fetish* OR polysexual* OR Attract* OR gender* OR friendship* OR romance* OR romantic* OR dating OR porn* OR erotica* OR psychosexual* OR masturbat* OR friendship* OR consent*)	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - MEDLINE	3,104,206
S6	(MH "Sexuality+")	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen -	46,785

			Advanced Search Database - MEDLINE	
S5	(MH "Love") OR (MH "Erotica") OR (MH "Libido")	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - MEDLINE	10,466
S4	(MH "Sex") OR (MH "Unsafe Sex") OR (MH "Safe Sex") OR (MH "Sex Workers") OR (MH "Sex Education") OR (MH "Sexual Behavior") OR (MH "Sexual Partners")	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - MEDLINE	93,026
S3	S1 OR S2	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - MEDLINE	122,968
S2	(MH "Mental Retardation, X-Linked+") OR (MH "Intellectual Disability+") OR (MH "Education of Intellectually Disabled")	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search	105,718

			Database - MEDLINE	
S1	AB ("Impaired intellectual function*" OR "Intellectual developmental disorder*" OR "Intelligence quotient IQ" OR "intellectual impair*" OR "Generalised neurodevelopmental disorder*" OR "Mental Handicap*" OR "intellectually handicap*" OR "mentally handicap*" OR "mental retard*" OR "Intellectual function* disorder*" OR "Cognitive disabil*" OR "cognitive retard*" OR "mental deficit*" OR "mental deficiency*" OR "mental incapacity" OR "intellectually challeng*") OR TI ("Impaired intellectual function*" OR "Intellectual developmental disorder*" OR "Intelligence quotient IQ" OR "intellectual impair*" OR "Generalised neurodevelopmental disorder*" OR "Mental Handicap*" OR "intellectually handicap*" OR "mentally handicap*" OR "mental retard*" OR "Intellectual function* disorder*" OR "Cognitive disabil*" OR "cognitive retard*" OR "mental deficit*" OR "mental deficiency*" OR "mental incapacity" OR "intellectually challeng*")	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - MEDLINE	35,868

PsycINFO:

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EBSCOhost

Tuesday, June 14, 2022 1:57:07 PM

#	Query	Limiters/Expanders	Last Run Via	Results
S12	S3 AND S9 AND S11	Expanders - Apply equivalent subjects	Interface - EBSCOhost Research Databases	2,971

		Search modes - Boolean/Phrase	Search Screen - Advanced Search Database - APA PsycInfo	
S11	S4 OR S5 OR S10	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - APA PsycInfo	958,289
S10	AB ((produc* OR deliver* OR implement* OR design* OR evaluat* OR facilitat* OR participat* OR writ* OR led OR lead OR input OR involve* OR collabor* OR consult) N3 (famil* OR carer* OR spous* OR parent* OR joint* OR dual*) OR co- produc* OR co-deliver* OR co- implement* OR co-design* OR co- evaluat* OR co-facilitat* OR co- participat* OR co-writ* OR co-led OR co- lead OR co-collabor* OR family-led OR dual-deliver* OR (work* AND together*)) OR TI ((produc* OR deliver* OR implement* OR design* OR evaluat* OR facilitat* OR participat* OR writ* OR led OR lead OR input OR involve* OR collabor* OR consult) N3 (famil* OR carer* OR spous* OR parent* OR joint* OR dual*) OR co-produc* OR co-deliver* OR co-implement* OR co-design* OR co- evaluat* OR co-facilitat* OR co- participat* OR co-writ* OR co-led OR co- lead OR co-collabor* OR family-led OR dual-deliver* OR (work* AND together*))	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - APA PsycInfo	111,822
S9	S7 OR S8	Expanders - Apply equivalent subjects	Interface - EBSCOhost	77,694

		Search modes - Boolean/Phrase	Research Databases Search Screen - Advanced Search Database - APA PsycInfo	
S8	TI ("Impaired intellectual function*" OR "Intellectual developmental disorder*" OR "Intelligence quotient IQ" OR "intellectual impair*" OR "Generalised neurodevelopmental disorder*" OR "Mental Handicap*" OR "intellectually handicap*" OR "mentally handicap*" OR "mental retard*" OR "Intellectual function* disorder*" OR "Cognitive disabil*" OR "cognitive retard*" OR "mental deficit*" OR "mental deficiency*" OR "mental incapacity" OR "intellectually challeng*") OR AB ("Impaired intellectual function*" OR "Intellectual developmental disorder*" OR "Intelligence quotient IQ" OR "intellectual impair*" OR "Generalised neurodevelopmental disorder*" OR "Mental Handicap*" OR "intellectually handicap*" OR "mentally handicap*" OR "mental retard*" OR "Intellectual function* disorder*" OR "Cognitive disabil*" OR "cognitive retard*" OR "mental deficit*" OR "mental deficiency*" OR "mental incapacity" OR "intellectually challeng*")	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - APA PsycInfo	22,862
S7	DE "Intellectual Development Disorder" OR DE "Anencephaly" OR DE "Crying Cat Syndrome" OR DE "Down's Syndrome" OR DE "Tay Sachs Disease" OR DE "Learning Disabilities"	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database -	67,739

			APA PsycInfo	
S6	S4 OR S5	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - APA PsycInfo	879,127
S5	TI (phenomenolog* OR "grounded theor*" OR ethnograph* OR qualitativ* OR "action research*" OR "feminist research*" OR "narrative research*" OR descriptive OR "qualitative descriptive" OR hermeneutic* OR "mixed method*" OR "narrative analys*" OR "descriptive stud*" OR "exploratory stud*" OR "qualitative stud*" OR "qualitative research design*" OR "qualitative descriptive design*" OR "qualitative research*" OR "interpretative analys*" OR "case stud*" OR "focus group*" OR interview* OR "content analys*" OR "thematic analys*" OR "thematic coding" OR naturalistic* OR "Ethnonursing Research*" OR participatory OR observation* OR "naturalistic inquir*" OR "cooperative inquir*" OR "collaborative inquir*") OR AB (phenomenolog* OR "grounded theor*" OR ethnograph* OR qualitativ* OR "action research*" OR "feminist research*" OR "narrative research*" OR descriptive OR "qualitative descriptive" OR hermeneutic* OR "mixed method*" OR "narrative analys*" OR "descriptive stud*" OR "exploratory stud*" OR "qualitative stud*" OR "qualitative research design*" OR "qualitative descriptive design*" OR "qualitative research*" OR "interpretative analys*" OR "case stud*" OR "focus	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - APA PsycInfo	840,337

	group*" OR interview* OR "content analys*" OR "thematic analys*" OR "thematic coding" OR naturalistic* OR "Ethnonursing Research*" OR participatory OR observation* OR "naturalistic inquir*" OR "cooperative inquir*" OR "collaborative inquir*")			
S4	DE "Qualitative Research" OR DE "Grounded Theory" OR DE "Content Analysis" OR DE "Interviews" OR DE "Phenomenology" OR DE "Case Report" OR DE "Narratives" OR DE "Cohort Analysis"	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - APA PsycInfo	104,083
S3	S2 OR S1	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - APA PsycInfo	1,357,822
S2	TI (sex* OR intimac* OR intimate* OR relationship* OR Lesbian* OR Gay* OR Straight OR Heterosexual* OR Homosexual* OR Asexual* OR Bisexual* OR Queer* OR pansexual* OR Sensual* OR Love* OR fantas* OR desire* OR longing OR fetish* OR polysexual* OR Attract* OR gender* OR friendship* OR romance* OR romantic* OR dating OR porn* OR erotica* OR psychosexual* OR masturbat* OR friendship* OR consent*) OR AB (sex* OR intimac* OR intimate* OR relationship* OR Lesbian* OR Gay* OR Straight OR Heterosexual* OR Homosexual* OR Asexual* OR Bisexual*	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - APA PsycInfo	1,350,023

	OR Queer* OR pansexual* OR Sensual* OR Love* OR fantas* OR desire* OR longing OR fetish* OR polysexual* OR Attract* OR gender* OR friendship* OR romance* OR romantic* OR dating OR porn* OR erotica* OR psychosexual* OR masturbat* OR friendship* OR consent*)			
S1	DE "Sexual Partners" OR DE "Sex" OR DE "Sexology" OR DE "Same Sex Intercourse" OR DE "Sex Linked Developmental Differences" OR DE "Sex Roles" OR DE "Same Sex Couples" OR DE "Sexuality" OR DE "Sexual Aids" OR DE "Psychosexual Behavior" OR DE "Asexuality" OR DE "Paraphilias" OR DE "Sexual Identity" OR DE "Sexual Arousal" OR DE "Eroticism" OR DE "Sexual Intercourse (Human)" OR DE "Premarital Intercourse" OR DE "Rape" OR DE "Same Sex Intercourse" OR DE "Cisgender" OR DE "Pornography" OR DE "Sex Drive" OR DE "Sex Recognition" OR DE "Sex Role Attitudes" OR DE "Sexual Attitudes" OR DE "Sexuality"	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - APA PsycInfo	101,757

CINAHL 14/6/22

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Tuesday, June 14, 2022 2:03:22 PM

EBSCOhost

#	Query	Limiters/Expanders	Last Run Via	Results
S12	S3 AND S9 AND S11	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database -	1,620

			CINAHL Complete	
S11	S4 OR S5 OR S10	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Complete	828,382
S10	AB ((produc* OR deliver* OR implement* OR design* OR evaluat* OR facilitat* OR participat* OR writ* OR led OR lead OR input OR involve* OR collabor* OR consult) N3 (famil* OR carer* OR spous* OR parent* OR joint* OR dual*) OR co-produc* OR co-deliver* OR co-implement* OR co-design* OR co-evaluat* OR co-facilitat* OR co-participat* OR co-writ* OR co-led OR co-lead OR co-collabor* OR family-led OR dual-deliver* OR (work* AND together*)) OR TI ((produc* OR deliver* OR implement* OR design* OR evaluat* OR facilitat* OR participat* OR writ* OR led OR lead OR input OR involve* OR collabor* OR consult) N3 (famil* OR carer* OR spous* OR parent* OR joint* OR dual*) OR co-produc* OR co-deliver* OR co-implement* OR co-design* OR co-evaluat* OR co-facilitat* OR co-participat* OR co-writ* OR co-led OR co-lead OR co-collabor* OR family-led OR dual-deliver* OR (work* AND together*))	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Complete	66,508
S9	S7 OR S8	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database -	40,123

			CINAHL Complete	
S8	TI ("Impaired intellectual function*" OR "Intellectual developmental disorder*" OR "Intelligence quotient IQ" OR "intellectual impair*" OR "Generalised neurodevelopmental disorder*" OR "Mental Handicap*" OR "intellectually handicap*" OR "mentally handicap*" OR "mental retard*" OR "Intellectual function* disorder*" OR "Cognitive disabil*" OR "cognitive retard*" OR "mental deficit*" OR "mental deficiency*" OR "mental incapacity" OR "intellectually challeng*") OR AB ("Impaired intellectual function*" OR "Intellectual developmental disorder*" OR "Intelligence quotient IQ" OR "intellectual impair*" OR "Generalised neurodevelopmental disorder*" OR "Mental Handicap*" OR "intellectually handicap*" OR "mentally handicap*" OR "mental retard*" OR "Intellectual function* disorder*" OR "Cognitive disabil*" OR "cognitive retard*" OR "mental deficit*" OR "mental deficiency*" OR "mental incapacity" OR "intellectually challeng*")	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Complete	6,435
S7	(MH "Intellectual Disability+") OR (MH "Mental Retardation, X-Linked+") OR (MH "Down Syndrome")	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Complete	36,529
S6	S4 OR S5	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced	785,069

			Search Database - CINAHL Complete	
S5	TI (phenomenolog* OR "grounded theor*" OR ethnograph* OR qualitativ* OR "action research*" OR "feminist research*" OR "narrative research*" OR descriptive OR "qualitative descriptive" OR hermeneutic* OR "mixed method*" OR "narrative analys*" OR "descriptive stud*" OR "exploratory stud*" OR "qualitative stud*" OR "qualitative research design*" OR "qualitative descriptive design*" OR "qualitative research*" OR "interpretative analys*" OR "case stud*" OR "focus group*" OR interview* OR "content analys*" OR "thematic analys*" OR "thematic coding" OR naturalistic* OR "Ethnonursing Research*" OR participatory OR observation* OR "naturalistic inquir*" OR "cooperative inquir*" OR "collaborative inquir*") OR AB (phenomenolog* OR "grounded theor*" OR ethnograph* OR qualitativ* OR "action research*" OR "feminist research*" OR "narrative research*" OR descriptive OR "qualitative descriptive" OR hermeneutic* OR "mixed method*" OR "narrative analys*" OR "descriptive stud*" OR "exploratory stud*" OR "qualitative stud*" OR "qualitative research design*" OR "qualitative descriptive design*" OR "qualitative research*" OR "interpretative analys*" OR "case stud*" OR "focus group*" OR interview* OR "content analys*" OR "thematic analys*" OR "thematic coding" OR naturalistic* OR "Ethnonursing Research*" OR participatory OR observation* OR "naturalistic inquir*" OR "cooperative inquir*" OR "collaborative inquir*")	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Complete	661,579
S4	CINAHL (MH "Thematic Analysis") OR (MH "Meta Synthesis") OR (MH "Content Analysis") OR (MH "Qualitative Studies+")	Expanders - Apply equivalent subjects	Interface - EBSCOhost Research	357,682

	OR (MH "Phenomenology") OR (MH "Grounded Theory") OR (MH "Focus Groups") OR (MH "Interviews+") OR (MH "Narratives") OR (MH "Observational Methods") OR (MH "Naturalistic Inquiry")	Search modes - Boolean/Phrase	Databases Search Screen - Advanced Search Database - CINAHL Complete	
S3	S2 OR S1	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Complete	818,842
S2	TI (sex* OR intimac* OR intimate* OR relationship* OR Lesbian* OR Gay* OR Straight OR Heterosexual* OR Homosexual* OR Asexual* OR Bisexual* OR Queer* OR pansexual* OR Sensual* OR Love* OR fantas* OR desire* OR longing OR fetish* OR polysexual* OR Attract* OR gender* OR friendship* OR romance* OR romantic* OR dating OR porn* OR erotica* OR psychosexual* OR masturbat* OR friendship* OR consent*) OR AB (sex* OR intimac* OR intimate* OR relationship* OR Lesbian* OR Gay* OR Straight OR Heterosexual* OR Homosexual* OR Asexual* OR Bisexual* OR Queer* OR pansexual* OR Sensual* OR Love* OR fantas* OR desire* OR longing OR fetish* OR polysexual* OR Attract* OR gender* OR friendship* OR romance* OR romantic* OR dating OR porn* OR erotica* OR psychosexual* OR masturbat* OR friendship* OR consent*)	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Complete	801,558
S1	(MH "Sexuality+") OR (MH "Sex Education") OR (MH "Homosexuality+") OR (MH "Coitus+") OR (MH "Sexual Behavior+") OR	Expanders - Apply equivalent subjects	Interface - EBSCOhost Research	77,947

	(MH "Sexual Partners") OR (MH "Sexual Identity+") OR (MH "Sexual Arousal") OR (MH "Sexual and Gender Minorities+") OR (MH "Sexual Trauma") OR (MH "Intimacy") OR (MH "Love")	Search modes - Boolean/Phrase	Databases Search Screen - Advanced Search Database - CINAHL Complete	

ca

☐ 5 #3 or #4 4,471,813 [Add to query](#)

☐ 4 (produc* OR deliver* OR implement* OR design* OR evaluat* OR facilitat* OR participat* OR writ* OR led OR lead OR input OR involve* OR collabor* OR consult*) NEAR/3 (famil* OR carer* OR spous* OR parent* OR joint* OR dual*) OR co-produc* OR co-deliver* OR co-implement* OR co-design* OR co-evaluat* OR co-facilitat* OR co-participat* OR co-writ* OR co-led OR co-lead OR co-collabor* OR 420,060 [Add to query](#)

☐ 3 phenomenolog* OR "grounded theor*" OR ethnograph* OR qualitativ* OR "action research*" OR "feminist research*" OR "narrative research*" OR descriptive OR "qualitative descriptive" OR hermeneutic* OR "mixed method*" OR "narrative analys*" OR "descriptive stud*" OR "exploratory stud*" OR "qualitative stud*" OR "qualitative research design*" OR "qualitative descriptive design*" OR 4,116,637 [Add to query](#)

☐ 2 sex* OR intimac* OR intimate* OR relationship* OR Lesbian* OR Gay* OR Straight OR Heterosexual* OR Homosexual* OR Asexual* OR Bisexual* OR Queer* OR pansexual* OR Sensual* OR Love* OR fantas* OR desire* OR longing OR fetish* OR polysexual* OR Attract* OR gender* OR friendship* OR romance* OR romantic* OR dating OR porn* OR erotica* OR psychosexual* OR masturbat* OR friendship* OR 6,281,386 [Add to query](#)

☐ 1 "impaired intellectual function*" OR "intellectual developmental disorder*" OR "intelligence quotient IQ" OR "intellectual impair*" OR "Generalised neurodevelopmental disorder*" OR "Mental Handicap*" OR "intellectually handicap*" OR "mentally handicap*" OR "mental retard*" OR "intellectual function* disorder*" OR "Cognitive disabil*" OR "cognitive retard*" OR "mental 48,193 [Add to query](#)

Appendix 2 – Procedure if a participant becomes uncomfortable, embarrassed, upset or distressed as a result of participating in the research.

There is a possibility that the discussion of the research topic may cause a participant to become uncomfortable, embarrassed, upset or distressed. Sensitive topics may arise such as a bad break up of a relationship that may really upset a participant. The participants will be asked at the first meeting to come up with group rules, which will be written up and put on the wall at the research team meetings. I will add the following rules if they are not considered:

1. Participants must not share other member's personal information that was shared in the research team meetings.
2. Participants should only share lived experiences if they feel comfortable to do so and they are advised not to share anything that they do not want to share.
3. Everyone will be given the opportunity to talk, and no one should dominate the meetings.
4. Everyone should listen and respond respectfully to each other.

The following steps will take place to support participants in the event that they feel uncomfortable, embarrassed, upset or distressed during discussion of these topics. To note, a qualified and registered Counsellor (Name of counsellor redacted) has volunteered to work on this project. He currently works as a Counsellor at (name of service redacted). He has agreed to be available during and after group meetings if the need arises.

He can be called on and arrive at the building in a short period of time if the need arises.

Procedure if a participant becomes uncomfortable, embarrassed, upset or distressed:

1. Each participant will be given a stop sign in their information packs.
2. The participants will be reminded at the beginning of each research team meeting that if they are uncomfortable, embarrassed, upset or distressed about anything we are talking about they can let me know or opt out at any stage. They can hold up their stop sign or say stop at any stage and the research team meeting will be stopped. This may be only temporarily (see below).
3. The participants will also be reminded at the start of each session of their group rules.
4. If the person is uncomfortable or embarrassed, they will be asked if they are comfortable to explore this with the group but if they are not we will change the direction of the discussion.
5. If the participant is upset or distressed, the rest of the group will be asked to take an early/ late break with the volunteer social care practitioner. If needed and

they need to finish the meeting early, she will wait with the remaining participants until their transport arrives.

6. I will wait with the participant who stopped the discussion and ask them if they would like to talk about this.
7. I will ask the participant if they would like to see the Counsellor. If they do, I will phone the Counsellor and then wait in the building till after they speak with them and are happy to leave.
8. Whether the participant sees the Counsellor or not, they will be asked if they would like to go home.
9. The participant will be reminded that they have the option to withdraw participation from the study either temporarily or permanently if they so wish.
10. If there are any substantial effects as a result of participation in this study, the Faculty of Health Sciences ethics committee chair and my supervisors' will be contacted. The participants name will not be given, only the details of how the effects came about, what the effects were and how it was handled.
11. As soon as possible after the incident I will write a factual report of what happened. This will be stored in a locked filing cabinet in my work office.

Appendix 3: Procedure for self-disclosures and retrospective disclosures.

Discussing relationships and sexuality may highlight safeguarding concerns that may lead to a participant to disclose.

1. An allegation of abuse
2. An allegation of retrospective abuse

1. A participant may disclose an allegation of abuse:

If a participant discloses an allegation of abuse, the following that has been adapted with the use of the HSE national policy – Safeguarding vulnerable persons at risk of abuse (2004) and the TULSA guide for the reporting of child protection and welfare concerns (2017). A Social Worker who is qualified and worked in the area has also looked at this procedure, made a recommendation which was added, and she then felt that the procedure was acceptable. The recommendation was to include retrospective abuse which I had previously omitted.

A self-disclosure of abuse is recognized when either the participant states this or they say something that alerts me to the possibility that they may have been abused. I worked as a Social Care Practitioner in the past where I have experience of disclosures and concerns of abuse. Anytime I was unsure I rang the social work team for advice (not giving the individuals name) and they were very helpful. I would do the same in this situation if I had any concerns. A concern or allegation of abuse is the only time that I would breach confidentiality, and this is stated in the PIL.

It will be explained to the participants at the start of the study that their information will be kept private and this will only be breached if they are at risk of abuse or disclose abuse. They will be reminded at the start of each meeting that if I have a concern about their wellbeing or safety that it will be passed onto the relevant persons. The relevant person can include a member of the safeguarding and protection team who will be a Social Worker, the Gardai, medical staff that would be a Doctor or Nurse and a Counsellor.

A qualified and registered Counsellor has volunteered to work on this project. He currently works as a Counsellor at (name of service redacted). He has agreed to be available during and after group meetings if the need arises. If a participant is upset in any way, they will be asked if they would like to see the Counsellor. The Counsellor will be nearby so they can arrive shortly after the call, and I will wait till after the session to ensure the participant is not upset leaving the building.

The volunteer Social Care Practitioner will wait with the remaining participants until their transport arrives.

I will always carry a charged and credited mobile phone in the case of an emergency or if I need to contact anyone on behalf of a participant.

In the event of a self-disclosure of abuse or a concern of abuse the following steps will take place:

1. A break will be called, and the remaining participants will be asked to take an early/ late tea break with the Social Care Practitioner. If needed it will be arranged that they will be picked up/ leave early.
2. I will listen, reassure, and support the person. I will remain calm and not press for details.
3. Whether I believe the disclosure constitutes abuse or needs action, or if I am unsure, the Safeguarding and Protection team will be phoned for advice, giving details about the disclosure but not naming the person. This persons contact details are:

Ms Donna Carroll

HSE Office, Community Health Care Organisation Area 1, Ballyshannon Health Campus, An Clochar, Co. Donegal.

Tel: 071 98 34660

Email: Safeguarding.cho1@hse.ie

If I cannot get in touch with the team as they are out of office, I can contact the HSE information helpline at these contact details who are also listed under the Safeguarding and Protection team contact details:

HSE Information Line

Monday-Saturday, 8am-8pm

Call Save: 1850 24 1850

Email: info@hse.ie

4. If the participant is in immediate risk, for example the alleged perpetrator is a family or staff member, it will be vital to put protective measures in place, that the participant does not leave and go into their care. In this case, the Safeguarding and Protection team and any relevant professionals such as the Gardai Siochana will be contacted for assistance. The local Gardai contact details are:

Sligo branch:

Tel: 071 91 57000

5. If the person needs medical assistance, this will be sought by phoning a GP, nurse or brining the person to A&E. These professionals can be contacted on the following:

GP out of hours service, NowDoc

Tel: 1850 400 911

Sligo University Hospital

Main switchboard: 071 91 71111

Emergency Department reception: 071 91 74504

6. After the disclosure I will stay with the participant.

7. The Counsellor attached to the study will be called so the participant can talk to them if the participant requests so. The Counsellor can be contacted on:

Counsellor:

Office: 071 98 56070

Mobile: 086 7772009

8. Where relevant the next of kin and/ or service the participant is registered will be contacted.

9. As soon as possible on that day, I will write a detailed factual report of the disclosure to include the following:

- When the disclosure was made.
- Who else was present.
- Exactly what I was told using the participants own words.
- Any other relevant information.
- Details of any professionals/ guardians that were consulted about the disclosure.
- My name, signature and date.

10. This document will be stored in a locked filing cabinet that only I have access to. A copy of this report will be sent to the Safeguarding and Protection team and the Gardai Siochana if requested.

11. As the disclosure would have happened when the participant was part of the study, the Faculty of Health Sciences ethics committee chair and my supervisors' will be contacted. The participants name will not be given, only the details of the disclosure and how it was handled.

12. The participant will be reminded that they have the option to withdraw participation from the study either temporarily or permanently if they so wish.

2. Retrospective abuse:

If a participant discloses retrospective abuse – abuse that took place during their childhood, this will be reported to TULSA. This is because the alleged perpetrator may pose a current risk to children. The 'retrospective abuse' form will be filled out and sent to TULSA

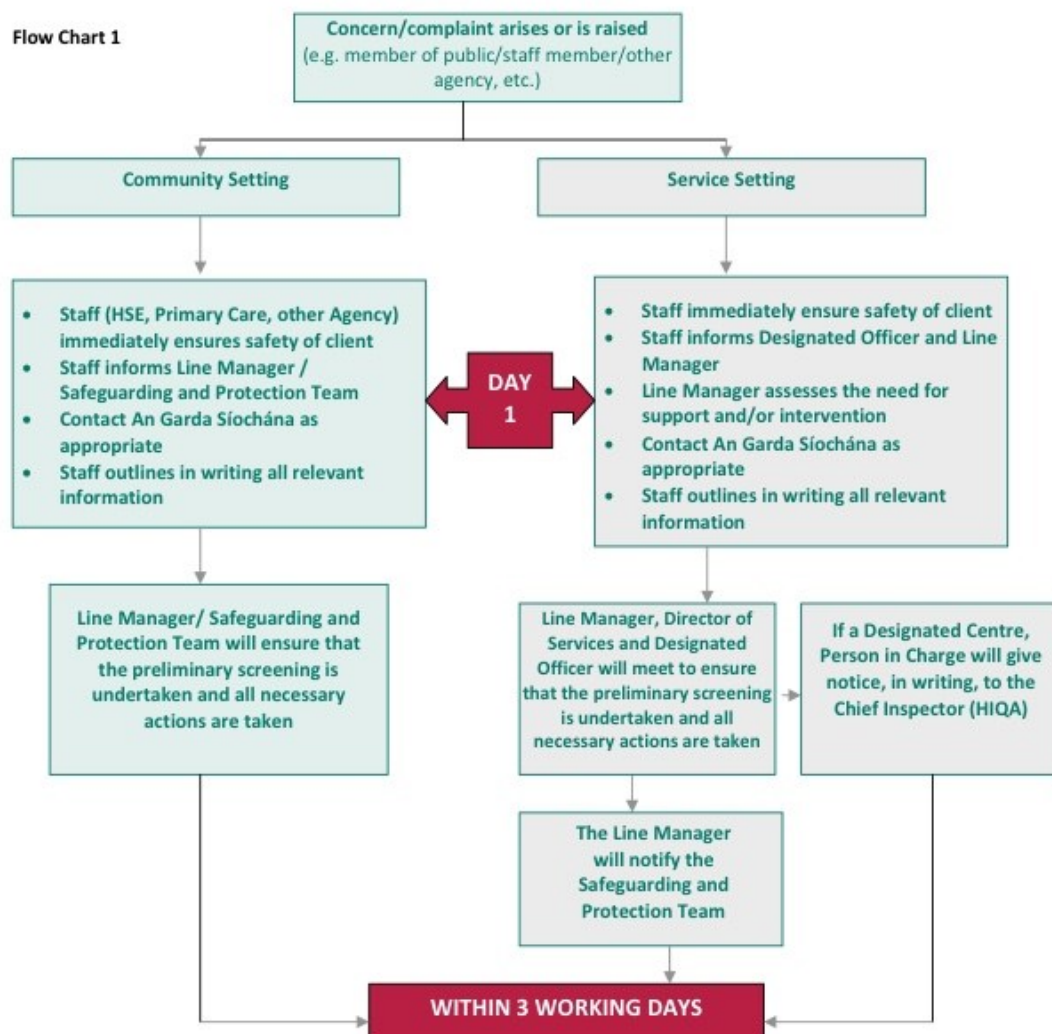
https://www.tusla.ie/uploads/content/Retrospective_Abuse_Report_Form_FINAL.pdf

and the above steps where relevant will also take place.

10.0 Stage 1: Responding to Concerns or Allegations of Abuse.

Stage 1- Concern Arises.

Flow Chart 1



Appendix 4: Confidential disclosure agreement

Title of research project: Establishing a co-operative inquiry group for people with intellectual disabilities to explore relationships and sexuality.

As a volunteer focus group moderator, I understand that I may have access to confidential information about the participants. By signing this document, I am agreeing to maintain confidentiality and the following:

1. I understand that the names and any other identifying information are confidential.
2. I agree not to disclose, publish, or make known to any person outside of the research team the information obtained from this study that could identify a participant, unless authorised to do so by Jessica Mannion and in line with the disclosure of abuse or retrospective abuse procedure (attached).
3. I understand that I am not permitted to read information about the participants or any other confidential documents unless I am doing so to support the participant. I also understand that I will not ask questions about the participants for my own personal information and only for the purpose of supporting a participant.
4. I agree to notify Jessica Mannion immediately should I become aware that a breach of confidentiality or a situation which could potentially result in a breach, whether it be on my part or on the part of another person.

Printed name: _____ Signature: _____ Date: _____

Researchers Printed name: _____ Signature: _____

Date: _____

Appendix 5: Consent Form

Please tick each box that you agree with.

	☐	I know what this study is about.
	☐	I understand that we will discuss the topics of disability, relationships and sexuality.
	☐	I understand that I will be asked to attend a research meeting for two hours every fortnight for a year. This may be up to 20 meetings in the year.
	☐	I know that I will not be named in any reports or talks about this study unless I want this to happen.
	☐	I agree that the research team meetings can be recorded.
	☐	I know that I can stop talking any time I want. I don't have to answer any questions or discuss anything that I don't want to.
	☐	I understand that if I tell Jess something that puts my safety or wellbeing at risk then she will need to tell professionals who can help support me. This may be reported to TULSA.

	☐	I agree that Jess can include things I say when she writes or talks about this study once my name and details are taken out.
	☐	I understand that the information I give will be stored for 7 years after the study has ended and then it will be destroyed.
	☐	I was given a copy of the information leaflet, and this signed consent form.
	☐	I have read, or had read to me, the information leaflet for this project and I understand the contents.
	☐	I have had the opportunity to ask questions and all my questions have been answered.
	☐	I freely and voluntarily agree to be part of this research study.
	☐	I understand that I may withdraw from the study at any time and I have received a copy of this agreement.
	☐	I will agree to not sharing other member's personal information that was shared in the research team meetings.

If you would like to consent to take part in this study, please sign below and add your contact details and the date.

Participants name:

Contact details:

You will only be contacted for research related reasons.

Phone:.....

Email:.....

Signature:

Date:

Researcher's responsibility:

I have explained the nature and purpose of this research study, the procedures to be undertaken and any risks that may be involved.

I have offered to answer any questions and fully answered such questions.

I believe that the co-researcher understands my explanation and has freely given informed consent.

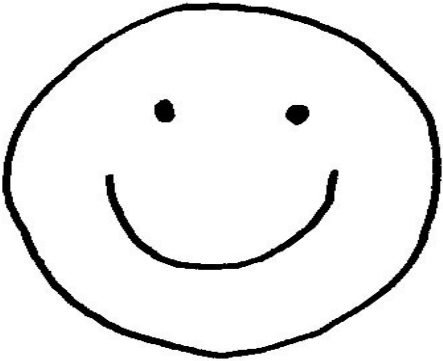
Researchers signature:

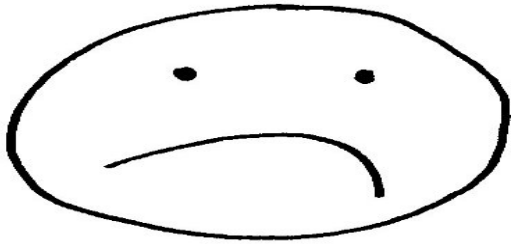
Date:

Appendix 6: Participant Information Leaflet.

Title of study: Establishing a co-operative inquiry group for people with intellectual disabilities to explore relationships and sexuality.	
Purpose of the study: The purpose of this study is to 1. Establish a group. 2. Explore the topic of relationships and sexuality. This study may also help you to develop research skills.	
Timeframe of the study: The study will run for one year, September 2020 – September 2021. There will be a one month break in August for the summer. There will also be a break at Christmas. You may be required to attend up to 20 meetings in 12 months.	

Details of research team meetings: The group will meet at 5pm- every second Thursday where possible for up to two hours. During this time, we will have research team meetings to plan and do the study. I will record these meetings by audio recording and taking notes. You can have a copy of the parts of the recordings that you contributed to if you wish.											
Can you take part in this study: If you can tick all of these boxes and can consent to take part, then you will be considered to take part in this study.	Please tick the box: <table border="1"> <tr> <td data-bbox="758 990 1070 1117">Are you 18 years old or over?</td> <td data-bbox="1070 990 1385 1117"></td> </tr> <tr> <td data-bbox="758 1117 1070 1292">Do you have an intellectual disability?</td> <td data-bbox="1070 1117 1385 1292"></td> </tr> <tr> <td data-bbox="758 1292 1070 1467">Do you live in the Northwest of Ireland?</td> <td data-bbox="1070 1292 1385 1467"></td> </tr> <tr> <td data-bbox="758 1467 1070 1641">Do you attend an advocacy group?</td> <td data-bbox="1070 1467 1385 1641"></td> </tr> <tr> <td data-bbox="758 1641 1070 1919">Are you interested in talking about relationships and sexuality?</td> <td data-bbox="1070 1641 1385 1919"></td> </tr> </table>	Are you 18 years old or over?		Do you have an intellectual disability?		Do you live in the Northwest of Ireland?		Do you attend an advocacy group?		Are you interested in talking about relationships and sexuality?	
Are you 18 years old or over?											
Do you have an intellectual disability?											
Do you live in the Northwest of Ireland?											
Do you attend an advocacy group?											
Are you interested in talking about relationships and sexuality?											

	Are you happy to talk about disability?	
Informed consent procedure: In order to be part of this study you will need to give consent. I will ask you some questions to find out if you understand the study. If you understand I will ask you to sign a consent form if you are happy to take part in the study.	 The illustration shows a person with curly hair reading a book. Above their head are two thought bubbles. The left bubble contains a form titled 'Yes's' with a smiley face and several checkboxes, some of which are marked with checkmarks. The right bubble contains a form titled 'No's' with a sad face and several checkboxes, some of which are marked with 'X's'.	
Benefits: Here is a list of possible benefits from taking part: 1. Learn about research. 2. Voice your opinions. 3. Use self-advocacy skills. 4. Have peer support and confidence building.	 The illustration is a large, simple smiley face with a circular outline, two dots for eyes, and a wide, curved line for a mouth.	

Risks: The topics we speak about may make you feel uncomfortable, upset, or embarrassed.	
Voluntary Participation: If you decide to volunteer to participate in this study, you may stop taking part at any time.	
Confidentiality: Your name will not be published in the study. I will collect some personal information, your name and contact details, but this will be used for contacting you about this study only. This information will be stored separately from the information collected in the research team meetings and will be stored by research supervisor. If you tell me anything that puts your safety or wellbeing at risk, it will need to be shared with relevant people. Relevant	

people will include TULSA, the HSE Safeguarding and Protection Scheme. They may also include where relevant, the Garda Síochána, counsellor and medical staff.

The results of this study may be published in research reports, conferences, and other media. Your identity will remain private unless you do not want it to be, for example you present at a conference, or you publish a research report with me.

This information will not be used for any future study without your consent.

All information will be stored securely and will be destroyed 7 years after the study has ended.

You will be asked to agree to not sharing other member's personal information that was shared in the research team meetings.

Permission:

This study has Research Ethics Committee approval from Trinity College Dublin.

Reference Number: (redacted), with the standard conditions that we need to abide by relevant regulations including data protection and health and safety.

This means that the researcher is doing her study in Trinity College, and they have agreed that this research can go ahead.

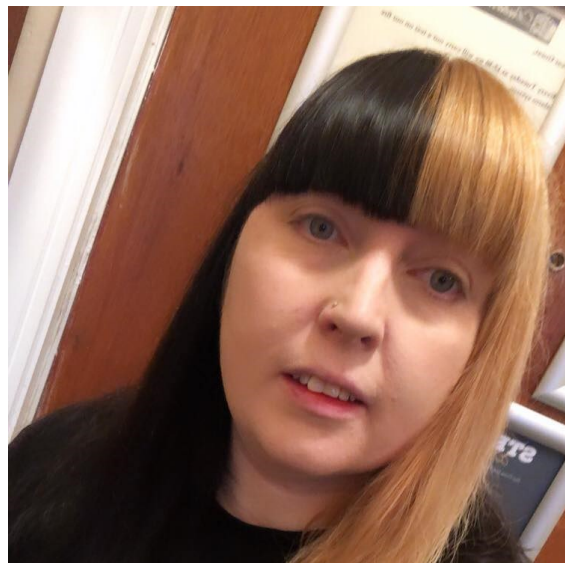
**Further information:**

Jess Mannion, the researcher on this study, is a PhD student in Trinity College Dublin.

You can get more information or answers to your questions about the study, your participation in the study, and your rights, from:

Jess Mannion who can be telephoned at (number redacted) or emailed on [\(email redacted\)](#)

I expect the findings of the study to be widely published and publicised. If you want a copy of the information you



gave during the study, please contact Jess to get this.

If you are interested in taking part:

Please attend a meeting where you can get more information about the study.

This meeting will be held at 5pm on Thursday 9th July 2020 in a community centre in Sligo town.



Complaint:

If you have a complaint about the way your personal information was handled you are free to lodge a complaint with the Data Protection Officer of Trinity College: Evelyn Fox at dataprotection@tcd.ie.



Appendix 7: Cue cards for the case of ethics.

Do you enjoy talking?

Who will hear your recorded voice?

Will your voice be transcribed and what does that mean?

How can a voice be obscured?

Why might researchers alter voices?



What is anonymity?

Do you mind hearing your own voice?

Can things that have been said be taken back?

What is confidentiality?

When might it be necessary to break the confidentiality rule?

VOICE CHANGER



MAGNIFYING GLASS

What is a research project?

What is a researcher looking for?

What is the researcher interested in?



AUDIO RECORDER

WHY IS YOUR VOICE BEING
RECORDED?

WHAT IS BEING RECORDED?

WHAT HAPPENS TO THE
RECORDING AFTERWARDS?

WHO IS ALLOWED TO STOP
THE AUDIO RECORDING?

CAN THE AUDIO RECORDING
BE DELETED?

HOW CAN YOU TELL IF THE
AUDIO RECORDER IS ON?

HOW DO YOU FEEL ABOUT
BEING RECORDED?

WHAT IS CONFIDENTIALITY?

FELT FEELINGS

How easy
is it to talk
about our
feelings?

How can
we express
our feelings
in different
ways?

Do feelings
have
colour?



Are some
feelings
more than
one colour?

How do you
feel about
participating
in the
research?

MASKS

**WHY DO RESEARCHERS
PROTECT YOUR IDENTITY?**

WHAT IS ANONYMITY?

**HOW IS YOUR IDENTITY
PROTECTED WHEN YOU ARE
PART OF A RESEARCH PROJECT?**

**WHY WON'T THE RESEARCHER
IDENTIFY YOU?**

**IN WHAT OTHER WAYS IS YOUR
IDENTITY PROTECTED?**

**WHO ELSE WILL KNOW THAT IT
IS YOU ?**

**WHAT HAPPENS TO THE
INFORMATION AND OBJECTS
THAT IS PRODUCED WITH YOU?**



FEELINGS CLOUD EVALUATION

FEELINGS CLOUD

FEELING USE WORDS
OR EMOJIS

.....

.....

.....

.....

.....

.....

.....

How do you feel about all the things we are discussing?

Is it always easy to say how you feel?

Who should you tell if I am worried about someone else who is taking part in the project?

What if we don't know how we feel?

What if you don't like talking?

Are you looking forward to taking part in the project?

Are there things you would like more information about ?

Who should you tell if you are worried about something to do with the project?

Is it ok if you don't want to say how you feel?

RELATIONSHIPS AND SEXUALITY

This project is about
experiences of relationships
and sexuality

What do you think is
important for a researcher
to know about relationships
and sexuality?

What does holding this felt
heart make you think about
relationships and sexuality?



What is a
research
project?

What is a
university?

What happens
at a university?

What is a PhD?

Who reads
University
publications?



Trinity College Dublin

Coláiste na Tríonóide, Baile Átha Cliath

The University of Dublin

**TRINITY COLLEGE DUBLIN
LOGO**



CONSENT FORM

Do you know what consent means?

Why do researchers ask you to sign a consent form?

Are there others ways of showing consent?

What are ethics?

Would you read a long consent form?

Do you know what confidentiality means?

Do you know what anonymity means?

When might your confidentiality be broken?

Is consent an ongoing process between you and the researcher?

Can you change your mind at anytime without giving a reason?

Appendix 8: Informed consent procedure.

Research title: _____

Name of individual who consent is sought: _____

Name of individual conducting assessment: _____

Date: _____

Question	Scoring criteria for the correct response	Score
(1) What will we be talking about?	Score 1: Individual gives a partial description of the research (e.g. 'it's about our experiences of relationships and sexuality', 'we will doing research on relationships and sexuality').	
	Score 0: Individual gives an irrelevant answer or one that is too vague (e.g. you will be asking me about things)	
(2) How long will you be taking part in the research?	Score 1: Individual states the correct number of months (year/ 12 months). Individual states 'September 2020 to September 2021'. They may state they are aware of the summer break and other holiday breaks.	
	Score 0: Individual does not state the correct duration/months	

(3) How often will you have to meet up with the other researchers?	Score 1: Individual states 'once every two weeks' 'every fortnight' 'person should also be aware how long meetings will last (2 hours)	
	Score 0: Individual does not state the correct frequency/ length of research meetings	
(4) Are there any good things about taking part in the research?	Score 1: Individual gives an answer with some face validity (e.g. 'gaining new experience in researching', 'meeting new people' 'I will enjoy it' 'I will be able to change people's minds', 'I will get to learn new things')	
	Score 0: Individual answers 'Yes', 'No', 'Don't know', without any explanation or irrelevant answer	
(5) Are there any bad things about taking part in the research?	Score 1: Individual gives an answer with some face validity (E.g. 'Yes it will take up a lot of my time', 'No I will enjoy it')	
	Score 0: Individual answers 'Yes', 'No', 'Don't know', without any explanation or irrelevant answer	
(6)	Score 1:	

Are there any good things about talking about disability?	Individual gives answer with some face validity (e.g. 'we are the experts' 'make some good changes' 'help the study/researcher', 'shows abilities of people' 'removes fear/nervousness'	
	Score 0: Individual answers 'Yes', 'No', 'Don't know', without any explanation or irrelevant answer. Individual states 'I don't know anything about disability', 'I don't like talking about disability'	
(7) Are there any bad things about talking about disability?	Score 1: Individual gives an answer with some face validity (E.g. 'If it's done in a mean/abusive way', 'if people with disabilities are not included in the talk')	
	Score 0: Individual answers 'Yes', 'No', 'Don't know', without any explanation or irrelevant answer. Individual states 'I don't know anything about disability', 'I don't like talking about disability'	
(8) What can you do if you decide that you do not want to take part in the research anymore?	Score 1: Individual gives an answer that suggests that they understand that they can withdraw from the research(e.g. I	

	can ask to stop', 'I can say no', 'I would tell (Support person's name) that I no longer want to be part of the research', 'I know that I don't have to take part in the research')	
	Score 0: Individual gives an answer that suggests that they do not understand that they can withdraw from the research (e.g. 'I do want to take part in the research', 'I don't want to stop' 'I don't know')	
(9) Are you aware that the research conversations will be recorded and do you know what happens to this information?	Score 1: Individual gives an answer that suggests that they understand that the research conversations will be recorded, transcribed, and written in the thesis. (eg. Yes, they are recorded on the Dictaphone and typed out, then you will write this up for your PhD work.	
	Score 0: Individual gives an answer that suggests that they do not understand (eg. I am not sure, I don't know, I don't understand or an incorrect procedure).	

(10) Do you know what will happen to the results of this study?	Score 1: Individual gives an answer that suggests that they understand that the research will be disseminated in the thesis, publications, and presentations (eg. You will write this in your thesis, we may publish papers on this, we could do presentations at conferences etc).	
	Score 0: Individual gives an answer that suggests that they do not understand (eg. I am not sure, I don't know, I don't understand or an incomplete understanding).	
(11) How do we ensure there is confidentiality in the group?	Score 1: Individual gives an answer that suggests that they understand how confidentiality will be ensured (eg. We will not tell other people what is discussed in the group outside of the meetings, I will only tell group members things about me that I feel comfortable to do so etc).	
	Score 0: Individual gives an answer that suggests that they do not understand	

	confidentiality (eg I do not know or they give incomplete information etc).	
(12) Do you want to take part in this research?	Score 1: Individual answers 'Yes'	
	Score 0: Individual answers 'No'	
Total score		/12

Scoring Guidelines

For consent to be ascertained, a score of 12/12 should be achieved by the individual with whom consent is sought.

Where an individual receives a score of less than 12/12, additional information/instruction should be given to the individual with whom consent is sought in order to overcome any gaps in their understanding of the research. It may be necessary to adopt a range of information formats (PECS (Picture Exchange Communication System – communicating with the aid of pictures)/Audio/Easy Read/Role-play) to assist the individual in meeting the requirements outlined above to give informed consent. Where a subsequent test is carried out, and where an individual's score remains outside of the optimal scoring range (12/12), the individual cannot be deemed to be able to give consent to take part in the research.

Appendix 9: Recruitment power point presentation.



Research and research ethics

What is research?



<https://www.youtube.com/watch?v=slAkSlOyJtc>

What do we want to find out?



How do we find out?



What do we do with the information we find?



<https://www.youtube.com/watch?v=E1KDGfYec-A>

What do we do with the information we find?



What you will be asked to do if
you want to take part



Steps needed 1. Informed consent



Steps needed 2. Doing the
research



Steps needed 3. Analysing the data



Step 4 presenting the findings



Time

- Time
- Dates
- commitment



Do you want to take part?



Thank-you



Appendix 10: Research meetings outline, incorporating the research cycles:

Meeting number	Topic and method	Reflection/action	Present	Online or in-person
Research cycle 1				
1	Icebreaker, getting to know each other, setting ground rules, introducing the study.	Think about topics we are interested in. If anything came up afterwards that people wanted to know about the group to jot them down.	Bruce, Chloe, Hermione, Jess, Linda, Louise.	1 hour online
2	We discussed how we defined relationships and sexuality. We shared topics we were interested in – sexual health education, the barriers to sexual health education, what supports could a person with an intellectual disability get to help them find a partner, and LGBTQ+ relationships. We discussed the barriers to socialise in nightclubs for people with intellectual disabilities and the impact this has on building friendships and creating relationships. Through discussion we concluded that this information and these opportunities were missing, and they we to look into why this was the case further and why people stopped people with intellectual disabilities from having relationships. We discussed	We decided we think further about what exactly we wanted to research. We decided to think further about a name for the research team. I agreed to send on the documents in the accessible format agreed.	Bruce, Chloe, Hermione, Jess, Louise.	1 hour online.

	possible names for our research team. We discussed how to make documents accessible for the group.			
3	We devised draft questions we were interested in researching. 1. What's the most popular dating App to find a boyfriend or girlfriend for people with disabilities? 2. Is it easier or harder to find a boyfriend or girlfriend if you have a disability? 3. Where is the easiest place to get sex education that you can understand if you have a disability.? 4. What is it like to be in a gay relationship if you have a disability? 5. Why can't we (people with intellectual disabilities) have relationships? We found images to go with our questions to put them in a document.	Bruce volunteered to make an accessible document with the questions.	Bruce, Jess, and Hermione.	1 hour online
4	We discussed the structure of the group due to some attendance issues, but most wanted to keep the meetings to fortnightly and felt one hour was enough online, so we decided to keep as we were. We agreed on a name 'the R&S (relationships and sexuality) Research Team.	We decided to draw a logo for the group at home. We decided to research if we could find any Irish dating apps for people with intellectual disabilities.	Bruce, Jess, Hermione, and Louise.	1 hour online

	We discussed our experiences and perceptions of dating apps for people with intellectual disabilities.			
5	The group voiced that they found talking boring and asked if we could add creative activities like poetry or art into the meetings. The group spoke about the possibility of moving to in-person in the future when covid restrictions allowed it. We decided to start talking about our experiences of sexual health education.	Each person decided to either draw an image or write a poem on their experiences of sexual health education.	Bruce, Chloe, Jess, Hermione, and Louise.	1 hour online
6	Those had drawn the logo shared those and spoke about them. We spoke about nightclubs and the barriers to accessing them to create friendships and relationships.	After speaking about nightclubs one member agreed to ask their day service if they were interested in setting up an inclusive nightclub in our town.	Bruce, Chloe, and Jess.	1 hour online
7	The group voiced that they are finding the meetings boring online and want to meet in-person in a local community centre where they could be more sociable and engage in more activities easier. The group wanted to do creative activities as a group and not at home. They wanted a 2-hour meeting not 1 and they wanted to have a break in the middle. Those that wrote poems on their sexual health education shared them and we had a group discussion following this.	We agreed to move the group to in-person and structure the meetings in the way the group wanted going forward. We decided to have a social meet up to get to know each other in their drop-in centre before this happened for a coffee and a chat.	Bruce (Wi-Fi was poor to engage), Chloe, Hermione, and Jess.	1 hour online
Research cycle 2				

8	Data analysis using art. Discussed the topics of nightclubs, sex, finding a partner, others stopping people with intellectual disabilities from engaging in relationships or getting married, (parents and staff in group homes).		Chloe, Jess, and Louise.	2 hours in-person.
9	Data analysis through art. We discussed sexual health education, LGBTQ+ relationships, finding a partner, social media and dating apps, what people want in a relationship, and consent. We discussed how we would work together after the summer break.	I agreed to make a video summarising our meeting and the main themes we had chosen to analyse from my perspective. The group agreed to feedback on it from their perspective.	Bruce, Hermione, Jess, and Louise.	2 hours in-person.
10	Alice joined the group. We watched the video I made summarising the data analysis session from before the summer to refresh us. We decided to discuss social media regarding relationships and online safety. We discussed video gaming in relation to its impact on perceptions of sex work.	Bruce decided that to introduce the 2 new members starting the group that we would share the past creative work and that he would facilitate the session to bring them up to date. We decided we would bring these 2 topics to the group to see if they would like to explore them further.	Alice, Bruce, and Jess.	2 hour sin-person.
11	Re-visited the group rules for our new groups members and changed them to suit in-person. Bruce facilitated the session sharing all our creative work to date and filling in the new people in what we did. This was a good refresher and heled us to see how much we have done so far.	We planned out the next few sessions. In the next meeting we decided to look at online safety and social media through the medium of rap. Then we would look at LGBTQ+. Then we would look at marriage and children.	Alice, Bruce, Ellen, Hermione, Jess, and Louise.	2 hours in-person.

	We spoke about the equality in the group and how we all feel listened to. We share opposite experiences in the past, negative language around disability and negative experiences of bullying in our school years, and experiences of discrimination in work and in the community due to intellectual disability. We had gone a little off track, but it was good to compare the difference experiences and see how the group was working well. We spoke about being treated differently and not allowed relationships due to intellectual disability, having a lack of sexual health education. There was some repetition as people were sharing what we did to date, but it allowed the new members to add their views and experiences. The group compared their different family and sexual health education experiences and could see they were all different but put this down to where they lived eg group home v's parents o independently and the attitudes of their families. We discussed contraception, pregnancy and STI's. We spoke about how our gender impacted our experiences. We spoke about past relationship experiences.			
Research cycle 3				

12	We split into 2 groups. One group made a rap about online safety and the other group made a rap about the impact of the video game grand theft auto on our perceptions of sex work. We performed these raps and had whole group discussions on these topics.	We decided that we would like to look at drama for one of the next two sessions. We decided we wanted to look at doing an online safety course and Ellen agreed to get the information on it for us.	Bruce, Ellen, Hermione, Jess, and Louise.	2 hours in-person.
13	We introduced Nathan to the group. There were many absent for different reasons, but it worked out nice that Nathan could be introduced to the group at this late stage after he could not join when planned due to illness. We discussed LGBTQ+ relationships. We discussed our own experiences of relationships including the barrier to get engaged and have children from family attitudes.	We decided to do drama in the next meeting for marriage and children. We decided to increase the meetings from 1 to 2 hours so we would have more time to work and to take a break that was not rushed too.	Hermione, Jess, and Nathan.	We moved the meeting to online due to a lack of attendance. 1 hour meeting.
14	We used drama to make two news scripts on our perceptions an experience of marriage and children. We ran out of time and the group were very passionate.	We decided to continue this topic in the next meeting and to look more at human rights for people with intellectual disabilities as people were interested in this. We were supposed to do data analysis for our last meeting before Christmas but the group showed a lot of heated emotions about this, so I wanted to work through it with them. We also thought that by doing the data analysis after the break it would give us a chance to refresh after the break and plan for the final stage of the research.	Alice, Bruce, Hermione, Jess, and Nathan.	We moved the meeting online due to poor weather. 1 hour meeting online.

15	We looked through some of an accessible version of the UNCPRD (2006), we did a small art activity to explore our thoughts and spoke more about rights in relation to marriage and children. We spoke more on our own experiences and the barriers we faced.	We identified that we wanted to create awareness on rights regarding marriage and children for people with intellectual disabilities. We came up with some initial ideas of how we may do this. We decided we would focus more on this after some thought after the Christmas break.	Alice, Bruce, Ellen, Hermione, Jess, and Nathan.	2 hours in-person.
Research cycle 4				
16	We discussed that the group will be finishing soon. We spoke about disseminating our findings and our options with a conference. We did the data analysis through art. I brought in the main words that came up in each topic we covered between September and December. We looked at the words one topic at a time, decided what words were missing or what words needed to come out. We put them into themes. The words/ topics we now had were: I, me, disability, being safe online, impact of Grand Theft Auto on the perceptions of sex work, prostitutes, sex workers, sex, contraception, the law, things like it being illegal or consent, safety online, social media, explicit message without consent, exploiting people for money, LGBTQI+ and not knowing enough about it, rights, marriage and children, the HSE house or disability	After discussing that the group would be finishing soon most of the group members said they would like to keep it going so we agreed to take some time out to think about it more.	Alice, Bruce, Ellen, Hermione, Jess, and Louise.	2 hours in-person.

	services, people judging you, it's a free country and the guards as a support. Then everyone chose a word that was important to them and made an image about it. This included the right to have children, the right to sexual relationships and barriers in group homes, and grand theft auto and sex work. We ran out of time so decided we would continue it in the following meeting.			
17	We decided that we would plan for the remaining weeks and our actions. We planned for the remaining sessions which would be an online safety training programme and consent programme as part of our actions and to reflect on the yearlong project to bring it to a close. We would then end with a celebration. We discussed how we would meet our final actions. We discussed the pros and cons of putting our name on a publication or when attending a conference to present and giving away our anonymity. We discussed how we would like to celebrate. We discussed the practical planning for the conference and research seminar.	The members present decided they wanted to continue to be a research team but to reduce the meetings till monthly. We agreed that we would need to devise a procedure on how new members joined and that the other group members would need facilitation training so they could be more confident and active in this role. We decided what information we would like to learn at our online safety training. We decided that we did not want to do a short sexual health/ LGBTQ+ programme online and that we would wait to source one after the meeting. We decided for our action on creating awareness we would hold a research seminar in Trinity College and follow up with a publication to reach a wider audience. We also agreed to apply for the action research conference for a presentation. Ellen and I agreed to meet outside of the meeting to apply for two funding applications to cover our conference tickets,	Alice, Ellen, Hermione, Jess, and Louise.	2 hours in-person.

		transport, and accommodation costs. We decided how we would like to celebrate the end of the research. We decided to go away and think about if we wanted our faces or real names attached to the research or not. We decided that we would do third objects in one of our reflections and that everyone would bring in a made or found object.		
18	We did some more planning for our research seminar and publication. We also spoke more about putting our names and faces to the study and the potential impact of such. We had forgot to look at our last data analysis so we shared our images and spoke about the topics of the right to have children, having the same rights as non-disabled people, the support people with intellectual disabilities need to have children, the challenges they may face and their concerns of having a disabled child. We also spoke about Grand Theft Auto and sex work, and group homes regarding the right to sexual relationships and the barriers. We did the final data analysis session through the embodied movement with the data. We came up with the main themes that were important to the group through our discussions.	We decided we would continue to meet fortnightly after the study till our actions were complete. We agreed to attend the online safety workshop before the next meeting.	Alice, Bruce, Ellen, Hermione, and Jess.	2 hour in-person meeting.

	The main themes were – I/me, online safety to include social media, LGBTQ+, disability, the law/ consent, rights, the impact of grand theft auto on our perceptions of sex work, the right to marriage and children, free country, sex, group homes, other people's attitudes. We spoke about how we felt completing the study and seeing all our work come together.			
19	We could not have the online safety workshop as planned so had some discussions about this and then I facilitated a session to share information on the topic to make up for this lack of workshop. We finished the data analysis where we went over the themes and made sub-themes. I shared that we were successful in our funding application. We shared our third objects and what the biggest thing we were taking away from the group was. We then did sandboxing to explore what we learnt about ourselves and others in the research, disability, and relationships and sexuality.	We decided we would try Lego serious play to do our final reflection.	Alice, Bruce, Ellen, Hermione, Jess, and Louise.	2-hour research meeting.
20	We participated in a one-hour sexual consent workshop online and evaluated it afterwards.	We organised what we would do next to plan for our research seminar, conference, and publication.	Alice, Bruce, Ellen, Hermione,	1 hour consent

	We then used Lego Serious Play to help us reflect on our learning in the research, and our hopes for the future regarding relationships and sexuality. We had our celebration.		Jess, and Louise.	workshop. 1 hour research meeting. 1 hour celebration.

Appendix 11: Research seminar

Trinity College Dublin, The University of Dublin

'We have the right to get married and have children'

Research findings from a collaborative study on relationships and sexuality from a research team of adults with intellectual disabilities

Friday 23 September 2022, 13.00-14.00

Trinity College Dublin
Coláiste na Tríonóide, Baile Átha Cliath
The University of Dublin

'We have the right to get married and have children'
Free public lecture: Friday 23 September 2022 at 1pm

#Inclusive_Research
#marriage
#Intellectual_Disability
#children
#relationships

Relationship and Sexuality
Names blocked out
RESEARCH TEAM
collaborative inquiry
Trinity
SHARING THE JOURNEY AND LEARNING
Image drawn by Dr Stephen D. Kroeger, University of Cincinnati

#Action_Research
#rights
#disability
#Creative_Methods
#sexuality

Supported by the Trinity Equality Fund

We are the relationships and sexuality research team. Our research was about exploring relationships and sexuality perceptions and experiences of adults with intellectual disabilities. This study stemmed from a research idea from Jess Mannion's Ph.D. in the School of Nursing and Midwifery, Trinity College Dublin, supervised by Dr Fintan Sheerin and Dr Vivienne Brady.

The research team consists of co-inquirers with intellectual disabilities, (names blocked out). Jess and the research assistant (name blocked out), also have experiences of disability as they are neurodivergent.

Using creative methods to help us explore topics important to us regarding relationships and sexuality, we co-created the findings based on our own experiences. We were involved in all the decisions in this study. This included deciding what topics to research and what

methods to use to explore these topics. We co-constructed the data analysis method and analysed the data together. Some of us co-wrote funding applications and were successful in receiving funding. We decided and worked on the study's actions as a team. Together we presented at an international action research conference and co-authored an academic publication.

This public lecture will be presented by the research team and will provide an overview of the study, with a focus on the research findings of one of the topics that was important to the research team. This topic is about people with intellectual disabilities rights, barriers and needs regarding getting married and having children. This lecture will be of specific interest to those with intellectual disabilities, and their families, partners, friends, and carers. It will also be of interest to disability studies students, academics, and disability professionals who would like to know more on this topic. We will use presentation, creative methods, and audience engagement to share our research findings.

We would like to thank the Trinity Equality Fund for supporting our project.

[CLICK HERE TO REGISTER TO ATTEND](#)

We are proud to be researchers with disabilities.

By (The R&S Research Team - Authors name blocked out) The writers are members of the Relationships and Sexuality Research Team, School of Nursing and Midwifery, Trinity College Dublin. With special thanks to: Jess's PhD supervisors, Dr. Fintan Sheerin and Dr. Vivienne Brady, School of Nursing and Midwifery, Trinity College Dublin.

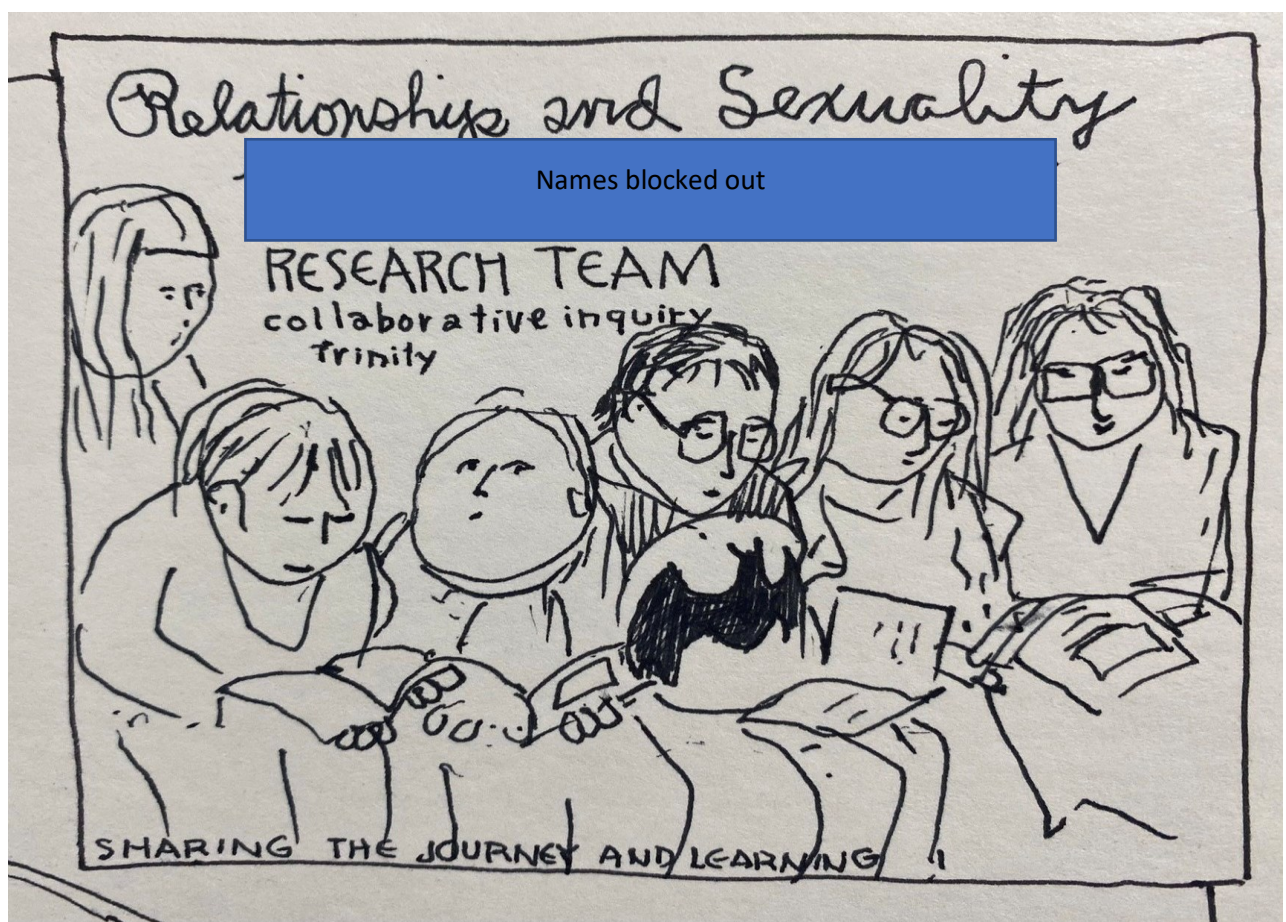


Image drawn by Dr. Stephen D. Kroeger, University of Cincinnati, that captured us during our presentation.

Introduction:

We are a relationships and sexuality research team. Our research is about exploring relationships and sexuality experiences of adults with intellectual disabilities. This study stemmed from a research idea for Jessica Mannion's PhD,

in the School of Nursing and Midwifery in Trinity College Dublin, supervised by Dr. Fintan Sheerin and Dr. Vivienne Brady.

The focus of this post is our journey of working together as a co-operative inquiry research team. We will highlight ways in which research can be inclusive and accessible to co-inquirers with intellectual disabilities who are new to research. It is disability pride month. We are all proud of ourselves and accept our disabilities, but we are even more proud to be researchers with disabilities. We hope that by sharing our journey, we will change societal perceptions of researchers with intellectual disabilities.

We formed a co-operative inquiry group, of six co-inquirers with intellectual disabilities, along with the initiating researcher and research assistant, both who are neuro-divergent, and are also co-inquirers. A co-inquirer is a co-researcher and a co-subject, who co-creates the findings of a research topic based on their own lives. We initially joined the research team to learn more about collaborative research and relationships and sexuality, and to create more awareness on the topic. The research team meetings were held fortnightly, for a year, each lasting between 1-3 hours. We all had the opportunity to be involved in all decisions in the study. As a group we decided what topics to research, what methods to use to explore these topics, we co-created the findings, and we also co-constructed the data analysis method and co-analysed our data together.

What we did:

Our holistic inquiry adopted a range of participant led, visual and creative methods for the data construction and analysis. This consisted of art, drawing, participant poetry, rap, creative performance and practice, joint sandboxing, LEGO® SERIOUS PLAY® and third objects. Through these creative methods we explored topics important to us about our experiences and perceptions of relationships and sexuality. Art and drawing enabled us to make visuals on a topic using a range of art materials (Gauntlett, 2007). Through using participant poetry we wrote short poems representing our thoughts on a theme (Eshun and Madge, 2021). We also used another poetic form, rap, where we worked together to create and perform raps on topics based on our lived experiences (Byrne et al., 2020). Creative performance and practice involved using drama to elicit and represent our experiences on a theme (Narbel, 2021). For joint sandboxing we created scenes with sand, water, figures and objects in response to a research question based on an aspect of our lives (Mannay, 2020). Through LEGO® SERIOUS PLAY® we built metaphors based on a theme (Hickman Dunne and Pimlott-Wilson, 2021). The final method, third objects is where we brought a made or found object to the research meeting to use as a point of reference to a discussion topic

(Winnicott, 1968). After creating these visuals we shared them with the group and had a discussion to help elicit a shared understanding on the topics.

We found many factors contributed to making the research accessible and inclusive. The study was made accessible from the start with easy-to-read documents and creative methods were used to explore research and research ethics. We started the study with online meetings due to Covid regulations, however, moving the study to in-person helped us to do more creative activities. We discovered the creative methods made the research accessible and inclusive. We sometimes found it challenging to express ourselves solely with verbal methods. The imagery was effective, it kept us engaged and interested, and it made the research fun. Our top two favourite creative methods were joint sandboxing and LEGO® SERIOUS PLAY®. Other ways that we felt made the research inclusive and accessible was by being involved in every decision and the group itself who included each other. This study gave us a voice.

What now?

We are now working together on different methods to share our findings with the community. This forms part of our actions, to voice what is important to us and to create awareness on our research, with the aim for change. Two members of the group wrote two funding applications together, and were successful in gaining funding to support our dissemination activities. Our first dissemination was a collaborative presentation about our co-operative inquiry group, at the 10th International Action Research Colloquium in Dublin. We wrote and presented this together. Above you will see a picture of us drawn by the keynote speaker Dr. Stephen D. Kroeger that captured us during our presentation. All members (with the exception of Jess) had never presented at a conference before, in fact, it was our first time to even attend a conference. We felt so proud in this moment. One outcome of this presentation is a possible collaboration with the University of Cincinnati. This current article is our first collaborative publication which we have written together. In September 2022 we are holding a research seminar in Trinity College Dublin and will write another publication based on that event. We hope that we will have many future opportunities to share our research collaboratively.

Final thoughts:

As we are coming to the end of the study and working on our actions together, we are reflecting on the whole experience. After the conference presentation and as we sat down together to write this article, we experienced a range of emotions; happy, proud, emotional, excited and empowered. There is a sense of disbelief that this is happening. Growing up with a disability we were told we could not do things. Now we know we can achieve ambitious goals and our research is out

there, which gives us such a sense of accomplishment. This shows how important it is to be authentically involved in all stages of research, especially dissemination, where we had the opportunity to experience this. Co-operative inquiry research can be so powerful. In this instance, many of us shared that it helped us to love ourselves and accept our disabilities for the first time in our lives. We are proud to be persons with a disability and proud to be researchers.

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