Relationships in cyberspace:

experiences of adults living with intellectual disability, accessing internet-based social media to explore sexuality and develop relationships.

by

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Candidate's Declaration

I certify that this thesis does not incorporate without acknowledgment any material previously submitted for a degree or diploma in any university; and that to the best of my knowledge and belief it does not contain any material previously published or written by another person except where due reference is made in the text.

Candidate's Name: Judith Anne Darragh

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This is to certify that the research carried out in the doctoral thesis, "*Relationships in cyberspace, experiences of adults living with intellectual disability accessing internet-based social media for exploring sexuality and developing relationships*", Disability and Community Inclusion Unit, College of Nursing and Health Sciences, Flinders University, Adelaide, Australia is the original work of the candidate, except as indicated by appropriate attribution in the text and/or in the acknowledgements; that the text excluding appendices/annexes, does not exceed 100,000 words; all ethical requirements applicable to the study have been complied with as required by Flinders University of South Australia, other organisations and/or committees which had a particular association with this study, and relevant legislation.

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Supervisor’s Name: Associate Professor Caroline Ellison

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Abstract

Introduction: The sexual activities of individuals living with intellectual disability are often more restricted than those of the general population. There has been a paucity of research that has explored the experiences of individuals living with intellectual disability direct from their own voices, about their social and sexual relationships accessing internet-based social media. The purpose of this study was to explore if individuals living with intellectual disability were accessing internet-based social media to facilitate and participate in meaningful intimate relationships and sexual activities online.

Method: Data were gathered from 30 individuals living with intellectual disability in South Australia, using one-on-one, in-depth, semi-guided interviews. Interviews were recorded, transcribed entirely by the researcher, and analysed using thematic analysis.

Findings: Individuals were accessing internet-based social media to make friends, communicate with people and plan to meet, engage in groups, research hobbies and interests, and play music and games, not to engage in sexual activities. Seven main themes were identified: ‘Making new friends and maintaining existing friendships’, ‘Engaging in hobbies/interests and pastimes’, ‘Exploring and expressing intimacy’, ‘Engaging in sexual behaviours’, ‘Opinions about other people who access internet-based social media to look at sexy pictures’, ‘Assessing and managing risks’, and ‘Barriers to accessing internet-based social media’. Systems theory provided the theoretical framework for this study.

Conclusions: The study provides an insight into the lived experience of individuals living with intellectual disability accessing internet-based social media and the influence that systems had on what they could or could not do. This study found that systems still play a significant role in the lives of people living with intellectual disability. Future research is required to explore the impact that gatekeepers and systems have on choices and decisions that individuals living with intellectual disability have the right to make.

Chapter One
Introduction

1.1 Introduction

Individuals living with intellectual disability are often excluded and marginalised in mainstream society and have been restricted and denied the right to express their sexuality (McGuire & Bayley, 2011; Winges-Yanez, 2014). This marginalisation, combined with limited opportunities to form intimate relationships and restricted private use of internet-based social media, could result in reduced access to the contemporary technologies enjoyed by the broader community to seek and form social connections.

Robbins and Jack (2006, p. 61) report that “Humans are deeply social creatures” who need to “feel they belong” (Swango-Wilson 2010, p. 164). As a consequence, most human beings have the fundamental desire to connect to others and are motivated to initiate social contact predominantly out of an inherent need to form personal relationships that satisfy their desire to belong (Mahfouz, Mahfouz, Philaretou & Theocharous, 2008; Bumgarner, 2007; Galdinsky, Ku & Wang, 2005).

Given that “communication is the keystone of social life” (Seymour & Lupton, 2004, p. 291), internet-based social media has changed the way humans communicate, interact, initiate, grow, and develop and maintain relationships (Chen & Wellman, 2005; Correa, Hinsley & de Zúñiga, 2009; Gutiérrez & Martorell, 2011; Raacke & Bonds-Raacke, 2008; Reid & Boyer, 2013). For some of society’s most marginalised people such as individuals living with disability, internet-based social media tools are rapidly evolving technological advances that could open a world of involvement and inclusion in everything that the internet has to offer. What would facilitate this choice is to have access to the opportunity. However, historically individuals living with intellectual disability have been socially excluded and devalued persistently across the world (Batey & Waine, 2015; Shakespeare, 2008). It then follows that, being denied access to new technologies, individuals living with intellectual disability will continue to be excluded from technological advances that members of mainstream society take for granted (Batey & Waine, 2015; Wehmeyer, Tassé & Stock, 2012).

Prior research in studies by Palmer, Wehmeyer, Davies and Stock, (2012); Tanis et al. (2012), and Hoppestad (2013) document the low rates of technology usage by individuals living with intellectual disability. It is also known that individuals accessing internet-based social media experience the means of escaping feelings of isolation and stigma, as well as facilitating an individual’s development of a social and/or sexual identity (Batey & Waine, 2015; D'Aubin, 2007; Dobransky & Hargittai, 2006; Jaeger, 2012). Yet, it is not clear whether individuals living with intellectual disability have experienced this. Given the opportunity, access, and availability, individuals living with intellectual disability may access internet-based social media as a communication tool with potential to open up a world of socially inclusive experiences for them (Batey & Waine, 2015)**.**

Sexuality is a part of what makes us who we are and it is unique and individual to each person, no matter their abilities (Gomez, 2012). A person's sexual activity can be expressed in various forms, such as: kissing, cuddling, holding hands, masturbation, or any category of erotic stimulation, not just from engaging in sexual intercourse (López-Sosa & Tévar, 2015; PAHO WHO, 2000)**.** For individuals living with intellectual disability, the common ways in which they express their sexuality are by hugging, kissing and attempts to make body contact with each other (Löfgren-Mårtenson, 2004).

For individuals living with intellectual disability, there are often a number of factors that may hinder them from developing their sexuality. Major influences affecting their sexual development come from beliefs and myths held by society that have led to stereotypical portrayals in media that have placed restrictions and control on their sexual development (Goggin, 2009). Stereotyping can be a barrier for individuals identified as living with intellectual disability to engage with other members of society (Swango-Wilson, 2010).

McGuire and Bayley (2011) report that while there has been an ideological shift within the services provided for individuals living with intellectual disability towards a practice of person-centredness and inclusion, it does not seem to have made an observable difference to areas concerning relationships and an individual's opportunity to express themselves sexually. Research has shown that many family members and support workers have acknowledged that, while they are aware that sexual expression is central to human existence, they still engage in restrictive and prohibitive approaches and tend to behave as 'gatekeepers' for individuals living with intellectual disability (McGuire & Bayley, 2011).

Family members, support workers, and carers have a responsibility and are often empowered to protect individuals living with intellectual disability (McGuire & Bayley, 2011). It is reported that they are the ones who provide the main sources of information and support to individuals living with intellectual disability (Robertson et al., 2001). However, they are often faced with a confronting dilemma when supporting individuals living with intellectual disability to have sexual autonomy; having legal and ethical uncertainty about their rights as support workers and/or family members (McGuire & Bayley, 2011). Consequently individuals living with intellectual disability can often be constrained from participating in relationships and sexual activities (Lafferty, McConkey & Simpson, 2012) because they are often seen as incapable and are denied control over their own lives; needing constant surveillance from caregivers and professionals (Swango-Wilson, 2010).

Access to internet-based social media has the potential to expand and enhance the opportunities for individuals living with intellectual disability to make contact with other people; to start relationships in a world which offers an opportunity for sexual intimacy "through the potential it may offer for social inclusion and greater participation in mainstream life" (Parsons, Daniels, Porter & Robertson, 2008, p. 20). Social inclusion for individuals living with intellectual disability is seen as taking part in society and controlling their own resources (Marino-Francis & Worrall-Davies, 2010). However individuals living with intellectual disability are often isolated from mainstream society and cared for by family or care providers in institutional settings (Swango-Wilson, 2010). Moreover, individuals living with intellectual disability are likely to be disadvantaged if they are denied access to the same communication channels common to other members of society (Swango-Wilson, 2010; Batey & Waine, 2015).

By accessing internet-based social media, individuals living with intellectual disability are free to reveal only information about themselves that they want others to know (Dobransky & Hargittai, 2006). The opportunity exists for individuals living with intellectual disability to be accepted as a person and not be subjected to rejection on the grounds that they have a disability. This means that there is the potential to experiment with and explore other relationships and sexuality by participating in an environment free from stigmatisation and feelings of being judged.

Additionally, since internet-based social media has become the norm in an expanding number of areas of an individual's social life (Parsons et al., 2008), being excluded from this technology means not being included in the usual activities of mainstream society (Dobransky & Hargittai, 2006; Selwyn, 2002). Having appropriate technology available is fundamental to the 'social model' of disability (Adam & Kreps, 2006).

Jaeger (2012) warned that failing to deal with issues of accessibility for individuals living with physical, sensory or intellectual disabilities has potential that "ultimately threatens to segregate people with disabilities as the permanent second-class citizens of the information age" (p. 34). Therefore having access to internet-based social media could be a key opportunity for individuals living with intellectual disability to contact other people with a view to developing relationships and exploring their sexuality.

However, individuals living with intellectual disability could face barriers accessing internet-based social media that affect their opportunities to develop and maintain intimate relationships (Lazar & Jaeger, 2011). In discourse around the existence of a 'digital divide', Chadwick, Wesson and Fullwood (2013) point out that it is not known how many individuals living with intellectual disability are actually accessing internet-based social media. Given the advent and widespread use of internet-based social media across mainstream society, the question then is, are there real or perceived barriers that could be impacting on whether individuals living with intellectual disability are accessing, participating and benefiting from the potential that this communication medium might be able to offer?

An integral part of adult development is enjoying having a freedom of sexual expression (Peterson, 2013). Regardless of a person being labelled as having an intellectual disability or not they are no different from other human beings, having the same needs, desires to express themselves sexually through relationships and sexuality being a vital part of what it is to be human (Chapman, Townsend & Ledger, 2015; Eastgate, 2008; Kramers-Olen, 2106; López-Sosa & Tévar, 2005; Craft, 1987). Without the freedom of sexual expression, individuals living with intellectual disability are being denied a natural human function.

1.2 Focus of the study

This study focuses on describing and analysing the lived experience of adults living with intellectual disability and their access to internet-based social media. The intent is to achieve this by:

- describing the lived experience of individuals living with intellectual disability to accessing, participating and benefitting from internet-based social media of their choice
- identifying any enablers and barriers to accessing internet-based social media for individuals living with intellectual disability
- identifying any challenges to actively participate in internet-based social media by individuals living with intellectual disability
- identifying any benefits of using internet-based social media for individuals living with intellectual disability in developing intimate relationships and exploring their sexuality

1.3 Overview of methodology

A qualitative approach based on elements of phenomenology will be used to explore this topic, as it enables a process to describe the lived experiences of individuals living with intellectual disability (Collingridge & Gantt, 2008). In-depth, semi-guided, one-to-one interviews were used to collect data and identify participants' experiences of using internet-based social media in relation to social media participation and the development of their sexuality and intimate relationships.

1.4 Significance of study

Previous studies have explored the use of computers, the internet and social media tools for the general public and individuals with physical disabilities. However few studies have focused on the lived experiences of individuals living with intellectual disability (Welsby & Horsfall, 2011) especially research about their use of internet-based social media.

In addition there is a lack of research about what adults without a disability do when they access internet-based social media (Rimington & Gast, 2007). There is less known about individuals living with intellectual disability and their patterns of use of internet-based social media (Löfgren-Mårtenson, 2008). The internet is now engrained in mainstream society as a communication medium; however in terms of access to this tool inequities seem to exist for some groups, including individuals living with intellectual disability (Stendal, 2012). One explanation relates to established and acknowledged gatekeepers. Gatekeepers restrict access to family members of individuals living with intellectual disability. This could be due to concerns/fears about private spheres of access to internet-based social media that relate to intimacy, romance and sexuality (Löfgren-Mårtenson, 2004). Therefore, this study will bring new knowledge about individuals living with intellectual disability and their use of internet-based social media, and highlight any restrictions preventing individuals living with intellectual disability from gaining access to develop relationships and explore their sexuality.

The outcomes of this current study will provide valuable insight into the perceptions and lived experiences of individuals living with intellectual disability about access and use of internet-based social media. Such understanding is fundamental for the development of:

- Key policy initiatives, services and support
- Understanding and recognition of the rights of individuals living with intellectual disability living in the community
- Recommendations of support practices required to assist individuals living with intellectual disability to obtain satisfactory access to and use of internet-based social media.
- Changes to education—for staff, society, service providers, and families
- Broader community attitudes about the social media activities that individuals living with intellectual disability wish to pursue.

1.5 Study purpose

The purpose of this study is to explore if individuals living with intellectual disability are engaging in social relationships online and/or using the internet to facilitate and participate in meaningful intimate relationships and sexual activities. There is a need to explore and understand what internet-based social media participants are using, their level of satisfaction with their online access and activities, the outcomes of their engagement, and the enablers or barriers impacting on and influencing their access and satisfaction. This could assist us to understand the experience of individuals living with intellectual disability around being enabled or restricted in their access to online activities of choice. What, if anything, can be recommended to bridge the gap between the concerns of significant others and the desired experiences of individuals living with intellectual disability? What considerations are needed by web and software designers to ensure individuals living with intellectual disability have the knowledge and tools to access internet-based social media? What protections can be established so they can achieve some of their goals and aspirations around relationships and sexual activity?

1.6 Nomenclature

Internet, social media, and information and communication technology (ICT) will be referred to as internet-based social media.

The terms ‘smartphones’ and ‘mobile phones’ have been used interchangeably in this study, unless stated otherwise. Smartphones are any mobile phones that are similar to a mini computer because they: allow access to the internet; download applications; take pictures; and enable the user to do more than simply make phone calls and send text messages.

1.7 Structure of the thesis

This thesis has been written in five chapters. Following this introductory chapter the study’s literature review is presented in Chapter Two. This review presents an overview of the history of disability and models of disability. Description and prevalence of intellectual disability is presented, as is literature about sexuality; internet-based social media; risks and benefits of accessing internet-based social media; participating online to engage in sexual activities; who participates; and who is prevented from doing so, controlled by gatekeepers. Finally three research questions are presented.

Chapter Three outlines the research design, and describes the methods and procedures used to collect and analyse the data as well as the theoretical perspective used to apply to the research questions outlined at the end of the literature review.

Chapter Four reports findings of the thesis through an exploration of data collected from one-on-one, semi-structured interviews, and field notes. In particular, the chapter outlines themes emerging from data from interviews with 30 individuals living with intellectual disability, participating in this study.

Chapter Five presents discussion of key findings of this current study. It also presents strengths and limitations of the study, followed by proposals for future research and policy, and a concluding summary.

Chapter Two
Literature Review

2.1 Introduction

This chapter provides an overview of the history of disability, followed by a discussion about defining disability and exploring the known body of knowledge around individuals living with intellectual disability and their use of internet-based social media as well as their approaches, strategies and opportunities to form friendships and intimate relationships.

2.2 Disability—a brief historical perspective

Societies throughout history have endeavoured to explain where disability fits into the 'social order' (Mackelprang & Salsgiver, 2016, p. 3). Neolithic tribes believed spirits were the cause of disability and operated on individuals' skulls to release evil spirits (Albrecht, 1992). The Spartans left individuals with disability to die in the countryside. Likewise Ancient Greeks believed that individuals with a disability should be left to die (DePoy & Gibson, 2004). Plato, (trans. 1991 cited in Mackelprang and Salsgiver (2016)) wrote that "the offspring of the inferior, or of the better when they chance to be deformed, will be put away in some mysterious, unknown place, as they should be" (p.183). Plato, (trans. 1991), perceived that individuals with disabilities stood in the way of a 'perfect world' (Mackelprang & Salsgiver, 2016, p. 3).

The Romans, like the Greeks, were known at times to abandon young children who were 'disabled' or deformed to die, with the justification that they were less than human (Mackelprang & Salsgiver, 2016; Rimmerman, 2013). However, not all disabilities were perceived as problematic by the Romans, especially ones that did not appear with physical differences; an example being Julius Caesar, known to have had epilepsy and purported to have visions while experiencing seizures (Mackelprang & Salsgiver, 2016).

During the Middle Ages, disability was described in moral and spiritual terms, with individuals with intellectual disability perceived as not being in harmony with God (Mackelprang & Salsgiver, 2016). When the cause of disability was believed to come from demons and/or evil experiences, society rejected individuals with disability. Attempts were made to cure individuals with disability in medieval times by magic and religious ceremonies. Individuals with intellectual disabilities and mental illness were considered witches and put to death (Mackelprang & Salsgiver, 2016; Rimmerman, 2013).

From earliest recorded history, documentation regarding the treatment and life experiences of individuals living with impairments is limited. The Old Testament allows for some insight into the attitudes of the time, but the messages conveyed have competing statements. Individuals had their attention drawn to their treatment of others: “There will always be poor people in the land. Therefore, I command you to be open-handed toward your brothers and toward the poor and needy in your land” (Deuteronomy, 15:11). However this contrasted with the warning from the Old Testament that said:

> “If you do not carefully follow His commands and decrees…all these curses will come upon you and overtake you: the Lord will afflict you with madness, blindness and confusion” (Deuteronomy 28:15, 28).

Paradoxically, while members of society were told to be charitable, disability was perceived to be a punishment from God. Records dating as far back as 2000 BCE showed that children born with congenital impairments were observed to predict the community’s future events and were viewed as a sign that the parents were responsible and had done something that had displeased the gods (Braddock & Parish, 2001).

From these ancient times to the later stages of the 20th century, people with disability shared a history of oppression, mistreatment, neglect, sterilisation, segregation, and institutionalisation (Jarrett, 2015). In the later stages of the 20th century there was a gradual shift towards recognising social influences on disability. During the 19th and 20th centuries individuals living with intellectual disability were segregated, leading them to live in isolation and exclusion (Dempsey & Nankervis, 2006; Löfgren-Mårtenson, 2004). Dempsey and Nankervis (2006) described institutions as being large residential centres where individuals living with intellectual disability were congregated and kept away from the rest of society. Although at the time, they were seen as cutting edge social developments, providing asylum (Dempsey & Nankervis, 2006), individuals living with intellectual disability were often denied their basic human rights and subjected to abuse, neglect and poor treatment (Conway, Bergin & Thornton, 1996; Furey, Niesen & Strauch, 1994).

In the three decades immediately preceding this current study, important changes occurred in the way in which disability was viewed and understood (United Nations Rights, 2010). Once, the focus was through the ‘medical model’, where the attention was on what was ‘wrong’ with the person and how to ‘fix’ them. Following on from the medical model, disability was recognised as a result of the interaction of a person with their physical environment that did not allow them to participate fully in society (United Nations Rights, 2010) and shifted attention away from the medical description of a person with a disability (Jewell, 2010). Through the social model, the focus was then on removing environmental barriers rather than ‘fixing’ the individual (Haegele & Hodge, 2016). This is discussed in more detail in relation to implications further into this current chapter.

Historically, individuals living with intellectual disability have been institutionalised and marginalised by the broad spectrum of beliefs and actions of society. The views society has had on individuals living with disability have ranged from the Eugenics Movement of the early 20th century, expressing support for the sterilisation and euthanasia of individuals living with intellectual disability (Goggin & Newell, 2005) to more recent times, where the rights for individuals living with intellectual disability have been realised through the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) (UN, 2006)

The UNCRPD (2006) endorsed the social model and recognised that disability was a human rights matter (United Nations Rights, 2010). Individuals should no longer be perceived as charity cases by some members of society, but as persons with the same human rights as those given to people living in mainstream society (United Nations Rights, 2010).

Institutions would come to be perceived as a mistake (Jarrett, 2015) and dehumanising places for individuals living with intellectual disability (Wiesel & Bigby, 2015). In Australia the call for deinstitutionalisation of people living with disability gathered momentum in the 1970s (Goggin & Newell, 2005). According to Drake (2014) deinstitutionalisation was one of the most significant social policies introduced into Australia. Bostock and Gleeson (2004) explain that disability movements across the Western world advocated for institutional care to be replaced by a variety of care networks in the community. Deinstitutionalisation would represent a major step toward the social inclusion of people with disability who were to go from living in segregated large institutions to living in community-based housing (Bostock & Gleeson, 2004; Braddock & Parish, 2001; Drake, 2014; Gooding, Anderson & McVilly, 2017; Jarrett, 2015).

According to Wiesel and Bigby (2015) the deinstitutionalisation movement found much of its motivation in the concept of ‘normalisation’, defined by Nirje (1969, p. 181) as “making available to the mentally retarded patterns and conditions of everyday life which are as close as possible to the norms and patterns of the mainstream of society”. Deinstitutionalisation meant that people living with disabilities, under the principle of normalisation (Nirje, 1969)—later known as ‘social role valorisation’ (Wolfensberger, 1972; 1983)—could live a ‘normal’, home-like, lifestyle with services superior to those experienced in the institutions being replaced (Bostock & Gleeson, 2004; Hall & Kearns, 2001; Mansell, 2006). To have as normal a life as possible, which included sexuality, there was transfer of previously institutionalised individuals from larger institutions to smaller institutions such as group homes; cooperative housing; residing with family; and some independent housing (Hall & Kearns, 2001).

The lives of individuals living with disability have slowly been improving from the middle of the last century (Kendrick, 2012), where the family support system of individuals living with intellectual disability were forced to place their relative in an institution or provide care themselves (Kendrick, Ward & Chenoweth, 2017). In recent times in Australia, with the introduction of the National Disability Insurance Scheme (NDIS), established by the *National Disability Scheme Act 2013* (NDIS Act) (Commonwealth of Australia, 2013), a new policy framework has been developed for funding services for individuals living with disability (Wiesel & Bigby, 2015). The chief principle of the NDIS is to shift from block funding to person-centred funding to supply services for individuals living with disability (Wiesel & Bigby, 2015). Funding packages are expected to be provided in Australia via the NDIS by 2019, to individuals under the age of 65 who have long-term disability (NDIA, 2016). Since the NDIS provides support to people living with intellectual disability individually, the opportunity exists to move from institutions to housing options of the individual's and/or family's choice (Wiesel & Bigby, 2015).

2.3 Defining disability

Disability is a fluid, ever-changing, complex socially constructed concept that is a characteristic of being human and includes "medical, functional, and social perspectives" (Martin, 2012; McDermott & Turk, 2011, p. 1). The construct of disability focuses on the limitations of an individual's functioning within the social context and represents considerable detriment to the person (Schalock et al., 2007). Disability has its beginning in a health condition that gives rise to bodily functioning and impairments, limitations on activities, and restricted participation within personal and environmental aspects of living (Altman, 2014; Schalock et al., 2007).

According to Shakespeare (2008) disability is "a complex, scalar, multi-dimensional phenomenon" (p. 11). The term, 'people with a disability', when viewed from a disability support service, often means "people who are experiencing a participation outcome which requires intervention either in terms of personal assistance or environmental modification" (Madden & Hogan, 1997, p. 66). According to the World Health Organization (2012) disability is:

> "an umbrella term, covering impairments, activity limitations, and participation restrictions. An impairment is a problem in body function or structure; an activity limitation is a difficulty encountered by an individual in executing a task or action; while a participation restriction is a problem experienced by an individual in involvement in life situations."

2.3.1 Intellectual disability

Historically, individuals living with intellectual disability have been long regarded as charity cases and often had their human rights discounted by mainstream society (Quinn, 2009). Prior to the promulgation of the UNCRPD (2006), individuals living with intellectual disability were protected by various general human rights conventions. Yet, despite this acknowledgement, their human rights are generally denied (Harpur, 2012). The UNCRPD of 2006 did not just re-state the rights from previous conventions but went further and created a new rights discourse that rendered human rights more obtainable for individuals living with intellectual disability (Harpur, 2012). As a result, the first human rights convention was created that expressly protected the human rights of individuals living with disability, where organisations concerned for individuals living with disability were included in implementing the 2006 UNCRPD (Harpur, 2012).

It is evident that the feelings of social exclusion by individuals living with intellectual disability are entirely justified (Frawley, Bigby & Slattery, 2015), based on active exclusion, and in some domains a need for people living with disability to fight for their life (Frawley et al., 2015; Harpur, 2012). The UNCRPD (2006) was created to endeavour to redress the historical non-compliance with human rights, but in doing so it did not merely re-state the existing human rights, it went further by creating incidental rights that were to ensure the existing rights had more clarity and as a result able to be realised by individuals living with disability (Harpur, 2012).

Moreover, the disability rights discourse created by the UNCRPD (2006) empowered individuals living with disability to have a formal involvement in the UNCRPD process. As Harpur (2012) stated: “The Convention on the Rights of Persons with Disabilities enshrines the notion that there should be ‘nothing about us without us’” (p. 2). This has been particularly significant for individuals living with disability because traditionally they have been seen as a group needing to be looked after, who require care and protection provided by other people; not individuals capable of acting on their own behalf (Bhanushali, 2007; Albert & Hurst, 2005). As Goggin (2009) stated: “People with disability have long been regarded as objects of pity, solitude, and special care and treatment” (p. 2). Kayess and French (2008) add that historically people with disability have been viewed as a “personal tragedy” and burdens on their families and society (p. 5).

Once commonly referred to as ‘mental retardation’ the term ‘intellectual disability’ has increasingly been adopted (Schalock et al., 2007). The way individuals living with intellectual disability have been named and categorised has changed over time (Parmenter, 2011). They have been viewed as monstrous and evil; of low intelligence; as tragic figures who require charity; as worthless, and as dependent (Basser & Jones, 2002). Historically, the terminology for what is now known as intellectual disability has been varied. The terms given over the past 200 years have included but been not limited to: idiocy, mental deficiency, mental handicap, mental retardation, feeblemindedness, morons, and mental sub-normality (Berkson, 2006; Brown, Radford & Wehmeyer, 2017; Goodey, 2005; Keith & Keith, 2013; Parmenter, 2011).

In the literal sense, intellectual disability "refers to some restriction or lack of ability having to do with human intellect" (Brown, 2007, p. 3). The construct of intellectual disability belongs in the expression of limitations in individual functioning that is characterised by a considerable disadvantage to the person within society (Luckasson & Shalock, 2013). Intellectual disability is not curable (Katz & Lazcano-Ponce, 2008).

According to the American Psychiatric Association (APA) (2013) intellectual disability involves impairments of general cognitive abilities that impact adaptive functioning in three domains, or areas. These domains determine how well an individual copes with everyday tasks:

- The conceptual domain includes skills in language, reading, writing, maths, reasoning, knowledge, and memory.
- The social domain refers to empathy, social judgment, interpersonal communication skills, the ability to make and retain friendships, and similar capacities.
- The practical domain centres on self-management in areas such as personal care, job responsibilities, money management, recreation, and organising school and work tasks.

While intellectual disability does not have a specific age requirement, an individual's symptoms must begin during the developmental period and are diagnosed based on the severity of deficits in adaptive functioning. The disorder is considered chronic and often co-occurs with other mental conditions like depression, attention-deficit/hyperactivity disorder, and autism spectrum disorder (p. 1).

Traditionally, intellectual functioning is subdivided into various levels (see Table 2.1) as outlined in ICD-10 (International Classification of Diseases 10th Revision) (WHO, 1992). A person with an Intelligence Quotient (IQ) of 70 or less is referred to as having an Intellectual disability.

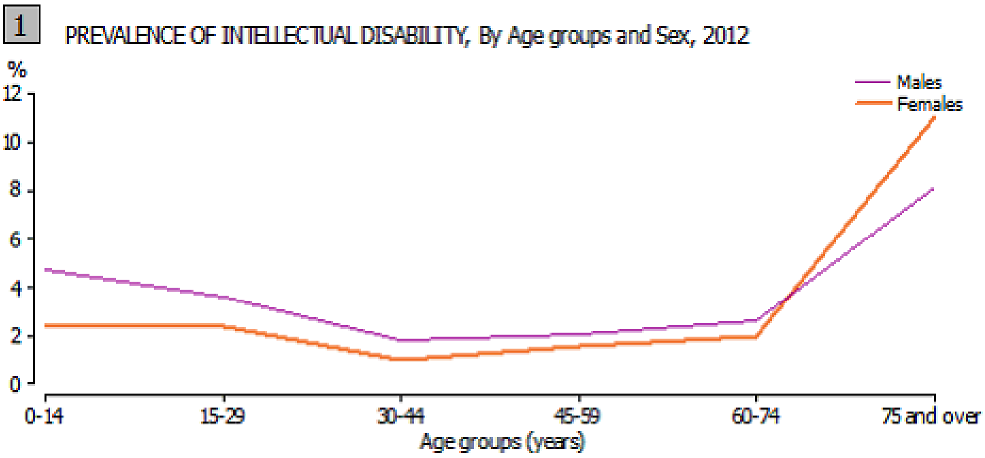
Table 2.1: Severity of intellectual disability and related issues

Classification	IQ	Typical abilities
Mild Intellectual Disability	IQ 50/55-70	Able to hold a conversation. Has independent self-care. Has practical domestic skills. Basic reading/writing.
Moderate Intellectual Disability	IQ 35/40-50/55	Limited language. Requires help with self-care. Simple practical work.
Severe Intellectual Disability	IQ 20/25-35/40	Communicates basic needs using words/gestures. Needs to be supervised doing activities. Work only in very structured settings. Common to have impaired movements.
Profound Intellectual Disability	IQ below 20/25	Not able to understand requests. Communication is very limited. No self-care skills. Usually incontinent.

2.3.2 Prevalence of intellectual disability in Australia

There were approximately 668,100 Australians (2.9% of the general population) living with intellectual disability in 2012 (Australian Bureau of Statistics [ABS], 2012). This was a statistically significant increase from the estimated 565,000 people (2.6 % of the general population) living with intellectual disability in 2009 (ABS, 2012). In 2012, intellectual disability was most prevalent in the very young and very old cohorts, with prevalence rates of 4% for children 0-14 years old and 10% for people 75 years old and over. The rates of intellectual disability were higher for men (3.3%) than for women (2.6%). As shown in Figure 2.1, women had a higher rate of intellectual disability than men in only one age group, those 75 years of age and older (ABS, 2012). The difference was particularly noticeable for boys 0-14 years old who were twice as likely to have intellectual disability as girls in the same age group.

Figure 2.1: Prevalence of Intellectual Disability in Australia, 2012



Source: ABS Survey of Disability, Ageing, and Carers 2012

2.4 Models of disability

Several models of disability have been generated in an effort to improve society's understanding of disability (Carling-Jenkins, 2014). Different terminology and different understandings are provided by each model (Carling-Jenkins, 2014). Carling-Jenkins (2014) reports each model defines the role of society, has a focus on policy and practice, and practical implications for individuals living with disability.

2.4.1 Medical model of disability

Historically, disability has been defined according to the medical model (Carlson, 2010). While there are aspects of the medical model that are important, the overall approach and narrow focus of the medical model means that many issues pertaining to individuals living with intellectual disability can often be overlooked (Harpur, 2012).

The medical model is based on the assumption that the difficulties and issues individuals living with intellectual disability experience are directly linked to their physical, sensory or intellectual impairments, thereby reducing disability to impairment and a mere biological product (Bhanushali, 2007; Brittain, 2004; Parchomiuk, 2012a). The medical model looks at what is ‘wrong’ with the person (Quinlivan, 2012) and has been geared to ‘fixing’ or eradicating the impairment (Bingham, Clarke, Michielsens & Van de Meer, 2013; Forhan, 2009).

Harpur (2012) has noted that often policies guided by the medical model can be problematic. Policy-makers tend to place importance on medical definitions in order to provide treatments, benefits and services. The policies are more about placing unnecessary attention on ‘fixing persons with disabilities’ and are written to ‘improve’ an individual’s physical or intellectual state (Harpur, 2012). Using this approach fails to concentrate on removing the environmental barriers or the delivery of support to enable individuals living with intellectual disability to ‘exercise other rights’ (Harpur, 2012, p. 2).

The medical model categorises individuals living with intellectual disability by their impairment or deficiencies, which supports the notion of ‘ableism’, which in turn rejects the ‘variance of being’ and the biodiversity view of the social model (Wolbring, 2008, p. 253). Ableism values certain abilities that lead to ‘disableism’ and discriminates against individuals who are considered to be ‘less able’ (Wolbring, 2008, p. 263). The medical model depicts an abelist view, where individuals living with disability are seen as being deficient and inferior to people without disabilities (Berger, 2013). According to Wolbring (2008), ableism has been used as a way of justifying hierarchies of rights and discrimination present in other social groups. Whereas Berger (2013) reports that ableism takes for granted that individuals living with intellectual disability are not ‘normal’ and cannot be equal to the normal people of the society. Consequently, it is society that disables people by designing everything so that it meets the needs of a perceived normal person living without disability (Quinlivan, 2012). Furthermore, ableism closes off possibilities for individuals living with intellectual disability who can be made to feel socially discriminated against and excluded from society (Campbell, 2017).

2.4.2 Social model of disability

The perception of disability as ‘cure or forget’ from the medical model, raised ire from the disability community (Jewell, 2010, p. 164). With increasing advocacy towards human rights, alternative views to the medical model emerged. The social model of disability was introduced by individuals living with a disability, and civil/human rights activists, social theorists, and the advocacy movement of the late 1960s and early 1970s (Albert & Hurst, 2004; Darcy, Taylor & Green, 2016). This model emerged from Britain’s disabled people’s movement, which formed the Union of the Physically Impaired Against Segregation (UPIAS). The movement was organised around the social model of disability and redefined ‘disability’ as something that was imposed on the lives of individuals with impairment as an additional burden imposed by a society who could not tolerate any form of biological imperfection (Cameron, 2009; UPIAS, 1976).

Unlike the traditional concept of disability originating from the medical perspective, where having a disability was viewed in terms of impairments requiring management by doctors and health service professionals (Albert & Hurst, 2005; Burchardt, 2004; Quinn & Degener, 2002), the social model of disability made a clear distinction between impairment and disability and focused on the disabling, socially imposed, environment, and attitudinal barriers (Berger, 2013; Brittain, 2004; Darcy et al., 2016; Walmsley. 2001). It was a paradigm shift in theorising disability away from the dominant view of the medical model where people with a disability were seen as a ‘problem’ to be cured or needing ‘fixing’ (Hewitt & Bogenschutz, 2015; Lordan, 2000).

The social model makes a distinction between ‘impairment’ and ‘disability’; impairment being the bodily element and disability being what society makes of an individual’s impairment (Loja, Costa, Hughes & Menezes, 2013). “Disability is not ‘natural’ or ‘given’; rather, it is the social processing, relations and meanings attached to the impaired body and mind” (Goggin & Newell, 2005, p. 28). Consequently, an individual is not disabled by their impairment, but by society’s barriers, which can be attitudinal, structural or physical (Brown & Boardman, 2011; Hughes, 2010; Quinlivan, 2012).

The social model meant that the cause of disability shifted away from individual impairment to focus on the way in which the physical environment and societal norms exclude or disadvantage those individuals labelled by society as ‘disabled’ (Burchardt, 2004; Quinlivan, 2012). According to Oliver (1996) disablement has nothing to do with the physicality of the ‘impaired’ body but rather the failure of society to adequately provide for the different needs individuals with disabilities have, as well as society’s failure to remove any barriers that the ‘disabled’ might encounter.

In contrast to the medical model, the social model locates disability not in a body that was impaired or malfunctioning, but in society where an environment excluded and oppressed individuals (Lordan, 2000). Consequently, the social model was more popular with advocates and scholars interested in the human rights of individuals living with intellectual disability (Harpur, 2012). The social model of disability provided a different perspective from the traditionalist view that saw disability as a physical or intellectual deficit or defect (Albert & Hurst, 2005; Kayess & French, 2008). The social model contrasts to the medical model by virtue of impairment which is seen as being ‘normal’ for any member of society within the social model paradigm (Albert & Hurst, 2005).

The focus of the social model was to move society's thinking away from individuals living with intellectual disability as being 'defective' and to encourage society to become more inclusive (Albert & Hurst, 2005; Quinlivan, 2012) and decrease environmental barriers (Haegele & Hodge, 2016). This was to highlight the distinction between impairment and disability by establishing that an individual's impairment does not make them 'disabled', rather it is the way in which society is structured that achieves this (Albert & Hurst, 2005; Haegele & Hodge, 2016).

However, from its inception, critics of the social model were from major disability charities and professional organisations (Oliver, 2003). Thinking that their dominance over the lives of individuals living with intellectual disability would come to an end, they directed their attention to two main areas. The first concern regards there being no place for impairment within the social model of disability (Oliver, 2013). The second area concerned allegations that the social model failed to make allowances for differences and presented individuals living with intellectual disability as one group, not taking into account the diversity and complexity of an individual's needs and life (Oliver, 2013). The overall criticism of the social model is that it gives a limited and partial explanation of what is happening to individuals living with intellectual disability in society today (Oliver, 2013).

Additionally, the social model of disability directed activists to consider the sexuality of individuals living with intellectual disability in relation to their civil rights. These related to the right to marry, the right to have children, and the right to be protected against enforced sterilisation. The activists representing the social model turned their attention to the external restraints on the sexuality of individuals living with intellectual disability that were outside of the personal dimension of impairments and deficiencies. Albert and Hurst (2005) proposed that the disabling and discriminatory behaviours of negative social attitudes towards individuals with impairments could lead to this cohort being marginalised and socially excluded. The social model calls for equality and a focus on resolving the disadvantage that many individuals living with disability encounter (Hughes, 2010).

2.4.3 Human rights approach to disability

People living with disability have the same rights as any other human being living in the world (Pinto, Rioux & Lindqvist, 2017). According to Kayess and French (2008) disability has been slowly recognised as a human rights issue from the early 1970s. The UNCRPD (2006) endorsed the social model of disability and recognised that disability was a human rights issue (United Nations Human Rights, 2010). To view disability from the human rights perspective involves a radical change in thinking and acting by all members of society. Some members of society need to recognise that individuals living with disability should no longer be perceived as charity recipients or objects that can be manipulated by other people's decisions, but rather as individuals with equal human rights (United Nations Human Rights, 2010).

The strength of the UNCRPD (2006) is that its construction of disability extends the "functional and medical orientation of traditional disability models which remain fixed and predictive" (Campbell, 2017, p. 3). According to the present UNCRPD (2006), Article 1, its purpose is to "promote, protect and ensure the full and equal enjoyment of all human rights by all persons with disabilities, and to promote respect for their inherent dignity" (p. 4).

The human rights approach includes disability from a paradigm of rights emerging from the introduction of the United Nations Universal Declaration of Human Rights of 1948 (Rioux & Carbert, 2003) where individuals who live with disability are entitled to enjoy all human rights by following a human rights framework (Rioux & Carbert, 2003).

According to Albert and Hurst (2005) 'Human rights are the fundamental, universal and indivisible principles by which every human being can claim justice and equality' (p. 3) and it is the entitlement of every individual to be able to claim their human rights and be protected and respected. Human rights are principles designed to ensure that people are able to live with dignity, free from fear, being harassed, and/or discrimination (Pinto et al., 2017).

Basser and Jones (2002) have reported that human rights principles are intended to be an assurance that being a human being is "sufficient grounds for equity and freedom" (p. 256). It is the right of every human being to be involved in shaping the decisions made that affect their lives (Hammell, 2015). This includes individuals living with intellectual disability, since they are human beings with the same inherent rights as the rest of society (Albert & Hurst, 2005; Lord, Guernsey, Balfe, Karr & Flowers, 2007; United Nations Human Rights, 2010).

According to Pan American Health Organization/World Health Organization (PAHO WHO) (2000), while "Human rights are inherent to human beings; however, recognition of inherent rights does not create rights per se." (p. 10). As reported by Verdugo, Navas, Gómez and Schalock (2012) rights are not sufficient if they are not accompanied by opportunities for individuals to exercise those rights. One of the most fundamental human rights of individuals living with a disability is 'accessibility' because no human right can be enjoyed if a person is unable to gain access, for instance, to technology, internet-based social media, sexual pleasure, and friendships.

2.4.4 Sexual rights

Sexuality is a crucial aspect of what it means to be a human being (Higgins, 2010). Higgins (2010) reports that having moved away from the medical model of disability to a human rights standpoint the focus turns to issues pertaining to sexuality and sexual expression. “Sexual rights are human rights” (Kismödi et al., 2017, p.6). However, with the emphasis being on the rights for individuals living with disability, the advancement of sexual rights had lagged behind and remains relatively neglected (Esmail, Darry, Walter & Knupp, 2010; McKenzie, 2013).

Individuals living with disability have the human right to the same sexual freedoms enjoyed by the rest of society (Dupras, 2015), which includes, but is not limited to, the right to be educated about sexuality, the right to have enjoyable sexual experiences, the right to form sexual relationships and marry, and the right to have children (Swango-Wilson, 2010). WHO (1946) states that “the sexual rights of all persons must be respected, protected and fulfilled”, with sexual expression being seen by many as a human right (WHO, 1946). WHO defines sexual rights to include the right to “pursue a satisfying, safe and pleasurable sexual life” (2005, p. 3).

Article 23 of the UNCRPD (2006) comments on the importance that State Parties “shall take effective and appropriate measures to eliminate discrimination against persons with disabilities in all matters relating to marriage, family, parenthood and relationships, on an equal basis with others, so as to ensure that:

- The right of all persons with disabilities who are of marriageable age to marry and to found a family on the basis of free and full consent of the intending spouses is recognised;
- The rights of persons with disabilities to decide freely and responsibly on the number and spacing of their children and to have access to age-appropriate information, reproductive and family planning education are recognised, and the means necessary to enable them to exercise these rights are provided” (p. 15).

Finally, as highlighted by McKenzie (2013) the purpose of the UNCRPD (2006), outlined in Article 1, is to “to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities” (p. 4), and this includes sexual rights.

2.5 Sexuality

> “To be a human being is to be a sexual being. Although there may be a range of intensity, varying over time, we all have sexual needs, feelings and drives….Although we can shape (and mis-shape) sexual expression, sexuality is not an optional extra which we in our wisdom

> can choose to bestow or withhold according to whether or not some kind of intelligence test is passed." (Craft 1987, p. 19)

The academic literature on sexuality for individuals living with intellectual disability has revealed there is no difference between them and their peers who live without disability (McCarthy, 2014; UNCRPD, 2006) and sexuality is an important characteristic of being human (Parchomiuk, 2012a; López-Sosa & Tévar, 2005; Craft, 1987). In principle this is a rarely contested view for those living without a disability, yet in reality sexuality remains problematic for those individuals living with intellectual disability (McCarthy, 2014).

This view is no different in Australia, where individuals living with intellectual disability are often seen as outsiders when matters are debated pertaining to sexuality and relationships and do not feel as though they belong (Frawley et al., 2015). Furthermore, even while there had been an acknowledgement of the human rights of individuals living with physical and other disabilities to be allowed freedom of sexual expression, in the main, individuals living with intellectual disability are seen as requiring protection and experience restrictions (Frawley et al., 2015; Winges-Yanez, 2014). Where choices have existed between facilitating the sexuality of individuals living with intellectual disability and protecting them from unwanted sexual encounters, typically protection is prioritised over empowerment (Keywood, 2003).

Individuals living with intellectual disability have sexual needs and desires (Craft, 1997; Doughty, Race, Emery & Salt, 2017), unique to each person (Borawska-Charko, Poul Rohleder & Finlay, 2017; Gomez, 2012).

According to PAHO WHO (2000, p. 8) sexuality:

> "refers to a core dimension of being human which includes sex, gender, sexual and gender identity, sexual orientation, eroticism, emotional attachment/love, and reproduction. It is experienced or expressed in thoughts, fantasies, desires, beliefs, attitudes, values, activities, practices, roles, relationships…in sum, our sexuality is experienced and expressed in all that we are, what we feel, think, and do."

Although sexuality can include all these aspects, it is not necessary that all are experienced or expressed. Nevertheless, in summary, sexuality is expressed in all that we feel, think and do. The author now introduces background information about the historical and societal perspectives of sexuality in relation to individuals living with intellectual disability.

2.5.1 Historical and societal perspectives of sexuality – intellectual disability

> "In contemporary Western societies sexuality is often understood as a private, universal, and natural aspect of social life. ... Historically, sexual conduct has been associated with polar extremes of good and evil, normality and abnormality, purity and danger, and order and disorder." (Hawkes & Scott, 2005, p. xvii).

Historically, for individuals living with intellectual disability, unlike 'ordinary' human beings, they have not been allowed the right to express their sexuality or engage in sexual relationships due to mistaken beliefs and/or negative attitudes (Richards, Miodrag & Watson, 2006; Foley & Kelly, 2009). Long disregarded, avoided, neglected, denied and not talked about, the sexual lives and sexuality of individuals living with intellectual disability has been considered 'taboo' (Cambridge, 2006; Doughty et al., 2017; Esmail et al., 2010; Isler, Beytut, Tas & Conk, 2009; Milligan & Neufeldt, 2001;Winges-Yanez, 2014).

Sexuality has been influenced by various social control methods over individuals living with intellectual disability (Löfgren-Mårtenson, 2004). The control methods used by society have been fear-based, stereotyping and punishment. Fears and myths have been projected onto individuals living with intellectual disability; they have been seen as asexual, childlike and naive or potential sexual deviants who are unable to control their sexual urges (Brown, 1994; Di Giulio, 2003; Franco, Cardoso, & Neto, 2012; Griffiths, Ionna & Hoath, 2017; McDonagh, 2007; Murphy, 2003; Sweeney, 2007).

The impact of stereotyping individuals living with intellectual disability as non-sexual or hyper-sexual has exaggerated false impressions about their sexual functioning (Bernert, 2011; Wilkenfeld & Ballan, 2011). As a consequence, individuals living with intellectual disability can be seen by other members of mainstream society as dysfunctional and unable to manage their sexuality (Bernert, 2011). Additionally, Bernert (2011) has reported society has been known to perpetuate these stereotypes by forming unfavourable opinions of individuals living with intellectual disability without having knowledge about what their life experiences have been.

Historically, the sexuality of individuals living with intellectual disability has been controlled by denial and suppression (Kempton & Kahn, 1991). The Eugenics Movement of 1880-1940 led to forced mass sterilisation and segregation of individuals living with intellectual disability from mainstream society (Kempton & Kahn, 1991) and informed past policy and practice in the area of sexuality of an individual living with intellectual disability (Johnson, Hillier, Harrison & Frawley, 2001). The policies of the early 20th century, demonstrated by the sterilisation of individuals living with intellectual disability, were developed through the flawed assumptions that people with disability lacked the capability to have sexual relationships (Friedman, Arnold, Owen & Sandman, 2014).

The fears concerning women with intellectual disability's capacity to reproduce were reasons behind the eugenic practices of enforced sterilisation and institutionalisation (Tilley, Walmsley, Earle & Atkinson, 2012). This was evidenced by the sterilisation policies occurring in the absence of consideration for the individual's need for sexuality and love (Friedman et al., 2014; Löfgren-Mårtenson, 2004). Late in the 20th century this practice began to be challenged and is rarely practised today. Tilley et al. (2012) suggest that while involuntary sterilisation might not be widely practiced in many Western countries any longer, historically it highlights "contemporary practices that can be regarded as constituting a continuation of eugenic practices by other means", (p. 414). McDonagh (2007) reported that there was anecdotal evidence that many women with disability, especially women living with intellectual disability, still had sterilisation forced upon them.

By the late 1960s and 1970s society became more tolerant about sexuality and individuals living with intellectual disability (Dempsey & Nankervis, 2006). Despite the previously held assumptions of sexuality now being challenged along with de-institutionalisation, the role of the support workers comes to the fore. Acting as gatekeepers, they are viewed as frequently generating barriers to sexuality for individuals living with intellectual disability who they directly support (Sullivan, Bowden, McKenzie & Quayle, 2013). Consequently, individuals living with intellectual disability who already faced difficulties now had to contend with obstacles, with support workers acting as regulator or controller making it difficult for individuals to experience life as fully human, including their sexual identity (Di Giulio, 2003).

However, differing opinions still remain with those 1970s medical ethics issues of capacity and issues of consent (Murphy, 2003). Individuals living with intellectual disability are still considered as having poor social judgement, rendering them incapable of engaging in responsible sexual relationships (Winges-Yanez, 2014; Milligan & Neufeldt, 2001).

Appel (2009) argues that, while there has been progress in recognising the sexuality of individuals who live with physical disability, there has been far less attention devoted to the desire for intimacy of individuals living with intellectual disability (Appel, 2009). Medical ethics during the 1970s focused on the dominant principles of competence and consent (Appel, 2009). Considering the sexual desires of individuals who were thought to have limited, or who were perceived as being ill-equipped, in their capacity to be either competent or give consent raised vexing conundrums (Appel, 2009; Keywood, 2003). The easy solution was to view sex as being off-limits for individuals living with intellectual disability (Appel, 2009).

2.5.2 Sexuality for individuals living with intellectual disability

The World Health Organization mandates: "Sexuality is an integral part of the personality of everyone: man, woman and child; it is a basic need and aspect of being human that cannot be separated from other aspects of life." (2006, p. 5). It has been established that living with an intellectual disability does not impair an individual's sexual feelings (Craft, 1997). Relationships and sexuality are a vital part of what it is to be human, regardless of a person being labelled as having an intellectual disability (Chapman et al., 2015). An integral part of adult development (Erikson, 1968) is the enjoyment and freedom of sexual expression (Peterson, 2014). Individuals living with intellectual disability are entitled to this choice and are no different from other human beings with the same needs and desires to express themselves sexually (Eastgate, 2008; Craft, 1987).

Most individuals who live with a mild or moderate intellectual disability are capable of, and show, that they have a desire for sex and sexual contact (Craft, 1997). However there are often a number of factors that may hinder individuals living with intellectual disability from developing their sexuality, as they often have limited opportunities to form, develop, and maintain intimate relationships (Lafferty, McConkey & Taggart, 2013). Societal beliefs and myths are the major influences that have affected individuals living with intellectual disability and sexual development. This has resulted in restrictive stereotypical portrayals in the media and further control being placed on their sexual development (Goggin, 2009).

Despite the professional human service practice ideology of person-centeredness and inclusion, little has changed for individuals living with intellectual disability when concerning relationships and individuals' opportunity to express themselves sexually (McGuire & Bayley, 2011). Many family members and support workers have acknowledged that, while they are aware that sexual expression is central to human existence, they still engage in restrictive and prohibitive approaches and tend to actively behave as gatekeepers for individuals living with intellectual disability (McGuire & Bayley, 2011).

A strength of the review by McGuire and Bayley (2011) that summarised the current knowledge of sexuality for people with intellectual disability was the highlighting of studies that reported the restrictive sexuality experiences of individuals living with intellectual disability compared to their wish for desire for intimacy and sexual relationships. This led McGuire and Bayley (2011) to recommend that future research was needed to look at developing mechanisms to promote a more inclusive, collaborating decision-making process between people with disability and those who provide services to them.

Another strength of the review by McGuire and Bayley (2011) was exploring the importance for individuals living with intellectual disability to self-advocate so that they can have greater autonomy in all aspects of their life and recommending the further development of sexuality and education programs so that the understanding of the fundamentals and issues relating to sexual expression and relationships for this cohort could be improved within society.

McGuire and Bayley (2011) did not provide any details of the individuals living with intellectual disability in the studies they reviewed, for example the sample size and age, type and severity of the intellectual disability. However, the reporting of the continued experiences of prohibitive and restrictive practices relating to opportunities for sexual expression by individuals living with intellectual disability was insightful and exposed that work was still required to inform society of restrictive practices. From the review, McGuire and Bayley (2011) drew attention to the importance of society understanding the norms that influence opportunities for individuals living with intellectual disability to develop a sexual identity, given that this cohort live their lives within many interacting social systems.

What we know about support for the sexual autonomy of individuals living with intellectual disability is that, while family members and support workers have a responsibility to empower and protect individuals living with intellectual disability, they often face confronting dilemmas for this to occur (McGuire & Bayley, 2011). The academic literature has revealed that individuals living with intellectual disability who engage in sexual relationships have been considered problematic by many families and/or care providers, rather than being a ‘normal’ developmental stage of being a human being (DeLamater & Friedrich 2002; Eastgate, van Driel, Lennox & Scheermeyer, 2011; Erikson, 1968; Johnson et al., 2001).

Consequently, the attitudes of parents, support workers and professional staff often constrain individuals living with intellectual disability from participating in friendships, meaningful intimate relationships, and sexual activities (Lafferty et al., 2012). Contrary to this approach, Zigler (2002) advises that individuals living with intellectual disability go through the same developmental stages and have similar social needs to individuals without disability. The difference Zigler (2002) suggests between the two groups is that individuals living with a disability proceed at a slower pace compared with individuals who do not have a disability.

In the study of Lafferty et al. (2012), conducted in Ireland, 96 stakeholders were asked questions either in focus groups and/or one-to-one interviews about their attitudes to providing relationships and sexuality education to individuals living with intellectual disability. A strength in this study lies in the sample, because a selection of stakeholders were recruited from three different groups: 48 family carers; 24 professionals from various disciplines; and 24 frontline staff. The aim of the study was to identify areas of agreement among the perspectives of the participants to guide policy improvement and practice to allow individuals living with intellectual disability access to relationships and sexuality education. However, a limitation of the study, recognised by the authors, was that the majority of participants were self-selected. This might have meant that the people who responded to participate could have been more disposed to being supportive to individuals living with intellectual disability and more open about sharing their attitudes to providing relationships and sexuality education.

Swango-Wilson (2010) reported that individuals living with intellectual disability are often seen as incapable and denied having control over their own lives, needing constant surveillance from caregivers and other specialists. One explanation for this restriction and control is the legacy of the 1970s medical ethics, which remains and continues to be exercised over individuals living with intellectual disability.

What we know about being human, is that individuals living with intellectual disability—who are human—are naturally sexual beings (Craft, 1987; Rojas, Haya & Lázaro-Visa, 2016). Discussing sexuality and relationships can be a sensitive area for anyone (Johnson et al., 2001). Rogers (2009) agrees with Johnson et al. (2001) and suggests that often the everyday intimate lives of individuals living with intellectual disability are not talked about with their families due to the sensitivity of the topic. Pownall, Jahoda and Hastings (2012) report that while sexuality is inextricably connected to an individual’s wellbeing, the reality is that sexuality continues to be extremely sensitive and an often avoided issue. This means that human and sexual rights are still being denied to many individuals living with intellectual disability despite the recognition of the benefits of sexual intimacy to wellbeing.

While there has been increased support for individuals living with intellectual disability over the past decades to be included in ‘normal’ life experiences regarding housing, employment and recreation, the area of sexuality has become a secondary issue and not supported to the same degree (Esmail et al, 2010; Gilmore & Chambers, 2010). Despite the recognition that sexual expression can contribute to a person’s positive self-image and sense of wellbeing, matters regarding sexuality have been invisible for individuals living with intellectual disability (Cambridge, 2006).

Drury, Hutchinson and Wright (2000, p. 3) write that:

> “Sex and sexuality are both a public yet intensely personal part of life where, on the one hand, there can be strict codes about what’s right and wrong, and yet, on the other, it seems that anything goes. Having a clear sense of what sexuality means for us as individuals, and being content with that, contributes to our enjoyment of happy and fulfilled lives. If the reality for most of us falls a little short of that ideal, then consider the situation for people with

> [intellectual] disabilities. For them sexuality is only mentioned as an ‘issue’, a ‘problem’ where a need to know is discouraged and basic rights can be subtly denied.”

Sexuality and disability discourse has largely focused on protecting individuals living with intellectual disability from abuse, based on the assumption that they are a ‘vulnerable’ population (Hough, 2012; Lafferty, McConkey & Simpson, 2012; Pownall et al., 2012; Appel, 2009). By taking a protectionist approach, due to individuals living with intellectual disability being presumed to be a vulnerable population (Parley, 2010), not all sexual contact/attention should be assumed to be unwanted (Appel 2009). An individual’s right to freely experience their sexuality, like all other forms of freedom, should be restricted, as Appel (2009) suggested, only to the point that is necessary to protect the individual’s own health and safety. To be too cautious and therefore prevent all sexual pleasure and intimacy in the name of protecting those who are considered to be vulnerable is in itself a violation of an individual’s basic human rights (Goldsmith & Skirton 2015; Winges-Hanez, 2014; Parley, 2010; Appel, 2009).

Individuals living with intellectual disability have consistently expressed their desire to make friends and have opportunities to spend time with them, yet meaningful relationships remain elusive (Knox & Hickson, 2001). They have fewer existing social networks (Davies et al., 2015; McCarthy, 2014; Sallafranque-St-Louis & Normand, 2017; Sullivan et al., 2013). Individuals living with intellectual disability and the few friends they have, and the ones who they do talk about, are mostly paid support workers, family and/or other individuals living with intellectual disability (Amado, Stancliffe, McCarron & McCallion, 2013; Friedman & Rizzolo, 2018; Shpigelman & Gill, 2014). Restricted opportunities to meet new people result in limited prospects for individuals living with intellectual disability to meet potential partners to express themselves with as sexual beings (Lafferty et al., 2012).

Additionally, individuals living with intellectual disability are almost always dependent on other people for their daily living arrangements along with quantity and type of information that they are given about sexuality (Bazzo, Nota, Soresi, & Minnes, 2007). Saxe and Flanagan (2014) add that individuals living with intellectual disability being denied sexual information/education is often as a result of their “gatekeepers’ fears and insecurities” (p. 48). The beliefs and values of service providers/support workers, due to their gatekeeping, are transferred directly onto individuals living with intellectual disability. This results in individuals living with intellectual disability not always having the support and information that they need about sexuality (Bazzo et al., 2007).

Research into the intimate relationships of individuals living with intellectual disability have been conducted in the United Kingdom and used qualitative methods. Data were collected from day option centres (Hollomotz, 2011). The qualitative study (Hollomotz, 2011) included 29 participants (12 men and 17 women) aged between 22 and 68 years, with a label of ‘mild’ to ‘moderate’ intellectual disability.

Participants reported difficulty meeting up with their peers outside of the day care service they attended (Hollomotz, 2011). Of the 29 participants who took part in the study, eight of 14 participants who met their partner at the day care centre reported never having seen them outside of the centre (Hollomotz, 2011).

A result of being socially constrained meant that intimate relations were often rushed, not very private or, in some cases, participants reported that they were forced to keep their relationships a secret; "individuals are thus kept in a permanent state of adolescence" (Hollomotz, 2011, p. 68). From results of her data, Hollomotz (2011) recommends further research is needed on ways to assist individuals to explore their sexuality, declaring that adults living with intellectual disability should be able to access merchandise and services from the sex industry. Hollomotz (2011) draws attention to the fact that little is known about this sensitive topic and further research investigating how to obtain sexual products and services would benefit individuals living with intellectual disability.

Likewise, a study by Wheeler (2007), conducting interviews with 12 males aged between 16 and 42 years (mean age of 25 years), living with intellectual disability, found that the participants did not feel as though they were treated as adults, despite asserting that they were sexual beings. While 50% of the males mentioned having relationships with women who they referred to as their 'girlfriend', they only spent limited time with them. A number of the males had commented that they had had the experience of support workers and the general public being unpleasant to them because they had girlfriends. A recommendation for practice from the Wheeler (2007) study was for services to provide greater support to carers on better ways to respond to the sexuality of individuals with intellectual disability they cared for.

According to Hollomotz and the Speakup Committee (2008) individuals living with intellectual disability who have restricted choice of venues to conduct sexual encounters could be at risk should they "escape to isolated or semi-private spaces to be sexually active" (p. 91). The absence of privacy can result in the normal private sexual experience for individuals living with intellectual disability becoming public (Löfgren-Mårtenson, 2004). Consequently, the vigilance of the support worker means that individuals living with intellectual disability lack privacy, which could lead them to look to less desirable settings to engage in sexual activities (Di Giulio, 2003).

Previous research has established that those individuals who live in group homes and/or supported accommodation are often deprived of the privacy and/or the opportunity for sexual expression, engaging in activities such as masturbation or sexual acts with a partner (Di Giulio, 2003; Hollomotz, 2011; Löfgren-Mårtenson, 2004). Wheeler (2007) suggests that for individuals living with intellectual disability, their opportunity to express themselves sexually is often controlled by others. For example, one woman's masturbation experience (owns a vibrator) related to how staff always took the vibrator away from her to lock it in a medicine cabinet after she had finished using it. When she wanted to use the vibrator again she was made to sign to take it away with her and again sign when she returned it to a staff member. According to Bernert (2011) placing restrictions on individuals living with intellectual disability threatens their identity as adults who are entitled to sexual autonomy. Also support staff tend to watch individuals living with intellectual disability more vigilantly as they look for 'inappropriate' behaviours (Di Giulio, 2003); becoming the 'new institutional walls' for individuals living with intellectual disability (Löfgren-Mårtenson, 2004, p. 197).

Current discourse suggests that an individual's sexual autonomy and a satisfying sexual life should be possible. Yet this remains an unresolved dilemma for individuals living with intellectual disability and their support staff (Wilson, Parmenter, Stancliffe & Shuttleworth, 2011). Individuals living with intellectual disability share commonalities with their non-disabled peers; they too are sexual beings who experience many of the same desires and aspirations. It appeared that a fear of the risks of trauma and/or abuse by having a relationship seemed to be the cause of the restrictions. Furthermore Rushbrooke et al. (2014) noted that enforcing restrictions could infringe on individuals' human rights.

2.5.3 Sex and intimacy for the general population

Sex is intensely personal and experienced universally from different cultures; between different age groups; and genders (Mackay, 2001). Vance (1984) reported that: "sexuality may be thought about, experienced, and acted upon differently according to age, class, ethnicity, physical ability, sexual orientation and preference, religion, and region" (p. 17).

Where sex research exists, it is more likely to be fertility-related, rather than sex-orientated (Mackay, 2001). Intimacy has been determined to be a fundamental human need and sexual relationships are the context in which individuals experience intimacy (Birnie-Porter & Lydon, 2013). It has been recognised that for most people who have a satisfying intimate relationship, that relationship is their most important source of happiness (Birnie-Porter & Lydon, 2013).

2.5.4 Relationships and intimacy for individuals with intellectual disability

Prior research has reported that parents want their offspring to experience the positive aspects of relationships and sexuality but view them as being particularly exposed, vulnerable to sexual abuse and/or at risk of unplanned pregnancies (Löfgren-Mårtenson, Sorbring & Molin, 2015; Löfgren-Mårtenson, 2008; Wheatley, 2005). Sweeney (2007) advises that there can be tension between healthy sexuality and personal safety so that the desire to keep 'vulnerable' individuals safe can inadvertently keep them "in the dark" (p. 36). Individuals living with intellectual disability are often taught to comply with authority, which in turn can make them more susceptible to the risk of sexual abuse (Sweeney, 2007).

The relationship and intimacy aspects of the lives of individuals living with intellectual disability have long been disregarded and avoided because of the taboo nature of ‘talking’ sexuality and the perceived difficulty in dealing with this issue (Campbell, 2017; Esmail et al., 2010; Mall & Swartz, 2012). It is envisaged that often the everyday intimate lives of individuals living with intellectual disability and their families are not talked about due to the sensitivity of the issues and the emotions such discussions evoke (Rogers, 2010). Talking about sexual matters has been considered problematic by many families and/or service providers of individuals living with intellectual disability rather than it being considered a normal part of the human condition (Eastgate et al., 2011; Foley & Kelly, 2009; Johnson et al., 2001).

As Isler et al. (2009) and Gil-Llario, Morell-Mengual, Ballester-Arnal and Díaz-Rodríguez (2018) report, individuals living with intellectual disability have the same sexual feelings, needs and desires as individuals without a disability. However Pownall et al. (2012) state that the reality is that “sexuality remains a highly sensitive and frequently neglected issue” (p. 140) for individuals living with intellectual disability. Individuals living with intellectual disability have parental or significant other input into their lives and decision-making, beyond that generally experienced by their non-disabled peers (Foley & Kelly, 2009).

2.6 Internet-based social media

> “The impact of social media has been highly significant in the evolution of online participation.” (Hollier, 2008, p.11)

Social media is a rapidly evolving field (Kaplan & Haenlein, 2010) that Correa et al. (2009) define as “a mechanism for the audience to connect, communicate, and interact with each other and their mutual friends through instant messaging or social networking sites” (p. 248). It is a generic term that describes any internet-based site that supports an interactive community (Shinton, 2012) and is the online equivalent of “engaging others in open and active conversation” (Kaplan & Haenlein, 2010), or more technically, “social media is a group of internet-based applications that build on the ideological and technological foundations of Web 2.0 that allow the creation and exchange of User Generated Content” (p. 61).

The rapid growth of social media occurred as the internet moved from being primarily an information source to an interactive, conversational type resource (Kaplan & Haenlein, 2010). The impact of internet-based social media on the evolution of online engagement has been highly significant (Hollier, 2012). Internet-based social media facilitates opportunities for individuals from diverse backgrounds and localities to come together to interact and share their common interests and aspirations (Lee & Lee, 2010) and has become firmly embedded as part of everyday life (Bargh & McKenna, 2004; Chadwick, Quinn & Fullwood, 2016; Lough & Fisher, 2016; Pernia, 2006; Vicente & López, 2010).

Internet-based social media has been recognised as the latest technological breakthrough in interpersonal communication, preceded by the telegraph, telephone, radio and television (Bargh & McKenna, 2004). The internet has changed from being primarily a venue for leisure and entertainment to fast becoming predominantly a place for interpersonal and professional communication (Gross, 2004; Valkenburg & Peter, 2011) where adults of any age have the opportunity to form and maintain relationships (Fox & Warber, 2013).

2.6.1 What internet-based social media is accessed for

A worldwide, generational, technological social, relationship and sexual practice transformation has been undertaken since the introduction of the internet (World Internet Project (WIP), 2013). Furthermore, this transformation has been far reaching into “entertainment, communication, information-gathering, and education across the globe” (WIP, 2013, p. 9). The internet has fast become an indispensable and powerful information and communication tool for society in general that has been incorporated into almost every aspect of modern human experience, used for work, business, pleasure and leisure (Kanuga & Rosenfeld, 2004).

The development of computer and internet-related technologies that evolved during the 1980s, and the World Wide Web in the mid-1990s, has dramatically changed the way in which individuals live and communicate with one another (Gutiérrez & Martorell, 2011; Kaplan & Haenlein, 2010). Initially developed for use by the military, the internet began as an enormous Bulletin Board System, where users could exchange software, data, messages, and information with other users (Kaplan & Haenlein, 2010), it has now been embraced by people of all ages and status throughout the world.

La Ferle, Edwards and Lee (2000) state that “the internet is like no other communication medium because of its ability to combine several of the unique qualities of each medium (that is, print, sound, and visual) into one” (p. 2).

Greenfield and Yan (2006, p. 393) described the internet as:

> “a complex virtual social and physical world that children and adolescents participate in and co-construct, rather than something that is merely watched (TV) or merely used (PC). The internet becomes a complex virtual universe behind a small screen on which developmental

> issues play out in old and new ways, offering new views into the thoughts, feelings, and behaviors of people of all ages."

Internet-based social media is regularly used by the average young adult for social networking (Fox & Warber, 2013; Löfgren-Mårtenson, 2008; Raghavendra, Grace, Newman, Wood & Connell, 2013). Young adults in mainstream society spend a considerable amount of time socialising on the internet (Yager & O'Keefe, 2012), and view communicating via internet-based social media as a natural medium in which to conduct their social lives (Valkenburg & Peter, 2011). Today's young people 'born into' the digital, virtual, technological world have indicated that they regard the online environment as a place that they prefer to face-to-face communications (Barak & Sadovsky, 2008). As Kanuga and Rosenfeld (2004) report, young people have grown up in a world where these technologies have been readily available for them to use. The number of adolescents who access internet-based social media far exceeds that of adults (Valkenburg & Peter, 2011) and they spend more time online and access the internet for social interaction more often than adults do (Valkenburg & Peter, 2009).

Changing the way social interactions occur has meant that, increasingly, new technology has been used and perceived as an important form of interpersonal communication (Christopherson, 2007; Shpigelman & Gill, 2014). Cummings, Butler and Kraut (2002) go as far as reporting that interpersonal communication is one of the most important uses of internet-based social media. Furthermore, Bargh and McKenna (2004) report that it is easier for some individuals to reveal their true feelings when communicating online than they can face-to-face. This could mean that online interactions are appropriate for some individuals to maintain and/or develop closeness, both to people who they know and people they do not (Bargh & McKenna, 2004).

Internet-based social media sites not only facilitate the development of virtual friendships but can see these connections extend to actual real life relationships (Döring, 2009). The abundance of internet-based social media sites has facilitated individuals to have acquaintances online as well as friendships offline (Schwab & Greitemeyer, 2015; Valkenburg & Peter, 2007). Research conducted by Valkenburg and Peter (2007) found that young adults regularly communicated online with their existing friends and established offline relationships with individuals who they first met online.

2.6.2 Individuals living with intellectual disability and internet-based social media

A number of studies have explored the experiences of individuals living with intellectual disability accessing internet-based social media (refer Table 2.2).

One well-known study that is often cited in research on the use of internet-based social media and individuals living with intellectual disability is that of Löfgren-Mårtenson (2008). The study, conducted in Sweden, using interviews to collect data, explored the experiences of a sample of 10 participants, made up of six males and four females aged between 18 and 31, who had very mild intellectual disability, using the internet. The research established that young adults living with intellectual disability used internet-based social media to socialise with people away from the control of their parents and/or care givers (Löfgren-Mårtenson, 2008). An advantage of using internet-based social media was voiced by individuals living with intellectual disability as having ability to create a space where they could experience, “a private life beyond the surrounding world’s control”, (Löfgren-Mårtenson, 2008, p. 135). Here individuals living with intellectual disability accessing internet-based social media were able to discuss and articulate their thoughts and experiences in an environment where they felt that they had more control (Holmes & O’Loughlin, 2014).

As identified by Löfgren-Mårtenson (2008) a limitation of the sample was that it did not represent different degrees of intellectual disability as the participants who were interested in participating in the research had a mild form of disability. Recommendations from the study (Löfgren-Mårtenson, 2008) were to find out more about the advantages and disadvantages of accessing the internet, since using it was part of living in today’s society.

While another study, outlined in Table 2.2 by Holmes and O’Loughlin (2014) exploring the experiences of individuals living with intellectual disability on social networking sites was interesting; it was difficult to assess the full value of the study because specific details were absent in the published article. For example, the method used included construction of case studies or vignettes, and recruitment processes were not explicit in the article. As pointed out by Caton and Chapman (2016), the processes of the development of the case studies/vignettes had not been explained.

The study by Holmes and O’Loughlin (2014), conducted in the UK, included three vignettes discussing the online experiences of three service users living with intellectual disability. The three participants were females, aged between 25 and 30, and were described as having mild intellectual disability. In the vignettes, participants described positive and negative experiences they encountered accessing Facebook (Holmes & O’Loughlin, 2014). Difficulties and issues highlighted in the study included cyber bullying, financial exploitation and sexual exploitation. One participant (25 years old) experienced difficulties with using Facebook because of her misunderstanding of what ‘friend’ meant in that context, and would make herself available for potentially risky events by accepting invitations to parties. Another participant (28 years old) was able to keep in touch with people she had been to school with on Facebook and mostly enjoyed using Facebook, but had become a target for sexual exploitation. The third participant (30 years old) explained that using Facebook meant she could extend her circle of ‘friends’ without having to physically meet any of them. As a result, this participant would accept anyone who sent her a Facebook ‘friend’ request. Consequently, she had been targeted by some male ‘friends’ on Facebook for sexual exploitation and, financial exploitation, being conned into sending money to one male ‘friend’ every week. This participant did not like the behaviour of some males and did not want to block them from her Facebook ‘friends’ list but eventually blocked those who had been exploiting her.

A limitation of the 2014 Holmes and O’Loughlin study was the small sample size, and all participants were already accessing the internet and Facebook. Since methods were only partially described, it was difficult to have a full understanding of participants recruited for the study and the development of the vignettes. Caton and Chapman (2016) had explained that they had included the study by Holmes and O’Loughlin (2014) in their systematic review because existing research on social media use by individuals living with intellectual disability was sparse. Caton and Chapman (2016) admitted being lenient in including the 2014 Holmes and O’Loughlin study in their review, but felt it important to include such a study because it added to the discussion about the experiences of individuals living with intellectual disability. A strength of the Holmes and O’Loughlin (2014) study could be posited that it included the perceptions of three individuals living with intellectual disability who were able to describe their experiences accessing Facebook.

The study by Shpigelman and Gill (2014) was targeted towards exploring the experience of adults living with intellectual disability accessing Facebook. Participants were recruited through disability groups’ walls on Facebook, targeting the USA, to complete an online survey. The sample comprised 57 adults—33 females and 24 males—who were over 30 years of age. Most participants reported using Facebook without requiring any assistance. An explanation for this (Shpigelman & Gill, 2014) was considered may have been because the targeted population recruited online were already using the internet and Facebook and had working knowledge of the technology at the time of completing the survey. Shpigelman and Gill (2014) pointed out that this could also imply that individuals living with intellectual disability who have basic cognitive abilities are capable of accessing internet-based social media.

The data Shpigelman and Gill (2014) collected were used to develop the knowledge about the use of online social networks by individuals living with intellectual disability. Summarising what the participants enjoyed about using Facebook, Shpigelman and Gill (2014) found it was being able to communicate with family and their off-line friends as well as being able to play games online. Shpigelman and Gill (2014) reported that there was a lack of data about how individuals living with intellectual disability used Facebook and no data was collected that found out if Facebook and social media sites were used for developing relationships and exploring intimacy.

A limitation of the study by Shpigelman and Gill (2014) was that there was no guarantee that the data from the responses on the online survey were solely from the person living with intellectual disability. Shpigelman and Gill (2014) conceded that, while the information received from surveys was valuable, it was important to personally hear from the participants via their own voice and suggested that further research include coercion to directly obtain more information, knowing it was coming from the source.

A recent study by Chadwick and Fullwood (2018) involved interviews with 11 adults living with intellectual disability from the UK to ascertain personal experiences of being online and using social media. Six males and five females who participated in the study, in the age range of 22 to 43, were cognitively competent and had good levels of receptive and expressive communication skills (Chadwick & Fullwood, 2018). The participants selected for the study used the internet and Facebook but primarily discussed their experiences using Facebook. A significant analysis (using semantic and latent thematic network analysis), and discussion on the subject was presented by Chadwick and Fullwood (2018).

Chadwick and Fullwood (2018) found that participants reported most of their online friends had been known to them offline before becoming friends on Facebook. This was their way to avoid adding someone who was not known to them because of concerns about safety. The participants reported they had opportunity to maintain contact with their family and friends, including friends they had met previously in school and reconnected with in a later phase in their lives. Online interactions prompted participants to connect and interact with other people about their leisure activities, games, and ‘hanging out’ (Chadwick & Fullwood, 2018. p. 59).

In the study by Chadwick and Fullwood (2018) there were some participant accounts of being monitored and ‘gatekept’ by family members and support staff. This was similar to other studies with similar findings, mostly around issues of avoiding risks and staying safe (Searle, 2014; Seale & Chadwick, 2017). Most participants mentioned they had in the past been supported from family and friends to use internet-based social media and others still required assistance in some areas, for example: staying safe online, accessing social media, and how to keep their information private (Chadwick & Fullwood, 2018). There were participants who were identified as being very competent engaging with internet-based social media.

Nine participants, who indicated they were single, did not express any interest in accessing the internet to develop new romantic relationships (Chadwick & Fullwood, 2018). Chadwick and Wessen (2016) had previously advised that more research was needed to look into the online relationships of individuals living with intellectual disability.

A preliminary Canadian study by Sallafranque-St-Louis and Normand (2017) explored the experiences of young adults living with intellectual disability or autism spectrum disorder using the internet. Eight participants, five living with intellectual disability and three with autism spectrum disorder, agreed to participate in the study. There were five participants (three males and two females) who had mild intellectual disability, with the other three participants (two males and one female) with autism spectrum disorder. The ages of participants ranged from 19 to 40.

To collect data, Sallafranque-St-Louis and Normand (2017) chose a mixed method where quantitative data were collected via a questionnaire, and qualitative data from an interview, covering the same subjects.

Results from the study by Sallafranque-St-Louis and Normand (2017) showed that all of the participants enjoyed communicating via the internet, for example using Facebook, chat rooms, dating sites and/or for entertainment, watching videos, and playing games. As Sallafranque-St-Louis and Normand (2017) pointed out, adults living with intellectual disability who have been interviewed in limited published studies, also reported enjoying accessing social networking sites to keep contact with their family and friends, and the opportunity for their social circle to expand by making new friends.

A limitation of the study was the small sample size of eight participants, of whom five were living with intellectual disability. However as the article by Sallafranque-St-Louis and Normand (2017) was reporting on preliminary data, it will be interesting to learn of any similarities or differences when reporting findings from an increased sample size. Participants who agreed to be interviewed, all did so with their support person present. This could be seen as a limitation as participants might not be as inclined to voice their true feelings and experiences while someone else was in the interview with them. A strength of the study, Sallafranque-St-Louis and Normand (2017), was that they recruited individuals living with intellectual disability to obtain their personal experiences of using the internet and did not seek the information from a third party, for example, service providers and/or family.

Sallafranque-St-Louis and Normand (2017) pointed out that accessing the internet had provided opportunities for individuals living with intellectual disability, however more education and support was required so that this cohort could stay safe and use internet applications positively.

A recent Spanish study by Chiner, Gómez-Puerta and Cardona-Moltó (2017) explored the internet use of individuals living with intellectual disability. More specifically Chiner et al. (2017) wanted to describe the use of electronic technology and the internet by individuals living with intellectual disability, to investigate risks of using the internet, and to examine behaviour that was considered undesirable on the internet. The participants, from a convenience sample, comprised 77 adults living with intellectual disability and 68 service providers from a not for profit organisation in Spain that provided support to individuals living with intellectual disabilities. The individuals living with disability in the study were drawn from an area in the organisation orientated to adults with mild to moderate disability (Chiner et al., 2017). Forty-nine of the participants living with intellectual disability were males, and 28 were females. The age range was between 18 and 51 years.

To collect data from the individuals living with intellectual disability a questionnaire was developed and personally distributed by a research team member. From the data collected it was found that the smartphone was used most to gain online access by individuals living with intellectual disability (Chiner, et al., 2017). Participants in the study reported using the internet to listen to music, watch videos, communicate with friends, and play games. All participants living with intellectual disability had experienced some type of issue when they went on the internet. Common, was being blocked from a group on the internet, being told unkind things, being threatened, or being sent sexual photographs and/or videos they had not wanted to receive. Also the individuals living with intellectual disability seldom reported engaging in undesirable behaviours when they went online. However as pointed out by Chiner et al. (2017) individuals living with intellectual disability may not have reflected honestly on their online behaviours and may have provided socially desirable answers.

A limitation of the study by Chiner et al. (2017) was recruiting participants from only one organisation as their responses are not necessarily representative of other organisations. As recognised by Chiner et al. (2017) extending their research questionnaires to other organisations would have been worthwhile. A strength of the study by Chiner et al. (2017) was that they obtained their data directly from individuals living with intellectual disability who participated in their study. The data collected will contribute to a better knowledge and understanding of what individuals living with intellectual disability do when going online.

Together, the studies in Table 2.2 provide important insights into the experiences and requirements of individuals living with intellectual disability going on the internet, and in most cases using Facebook. Even though the studies in Table 2.2 had data collected from various countries (Sweden, USA, UK, Canada, and Spain), many of the results were similar regardless of the geographical location where the internet-based social media was accessed from. In common with all of the studies in Table 2.2, participants were described as having mild to moderate intellectual disability. It would have been interesting to learn about experiences and needs of people with intellectual disability who do not come under the umbrella of mild to moderate intellectual disability.

2.6.3 Popularity of internet-based social media

With the emergence of popular internet-based social media such as Facebook®, MySpace™, Twitter, and LinkedIn (Vallor, 2011) has come an increase in the use of internet-based social media by billions of people worldwide (Bargh & McKenna, 2004) Refer Figure 2.2 for 2018 figures. Communication and information technologies have generally been accepted as omnipresent and valuable tools (Lough & Fisher, 2016) used and embraced by many members of society. Access to internet-based social media sites has provided opportunities for people to maintain social relationships and engage in sexual behaviours (Bargh & McKenna, 2004).

Internet-based social media has transitioned into a medium no longer reliant on desktop computers in homes, offices and libraries to becoming a portable ‘anywhere’ usable technology accessed via laptops, tablets, and ever-evolving ‘smart’ mobile phones, so that individuals can be online when and where they choose (Beneito-Montagut, 2011). Tremendous benefits can be derived from internet-based social media for all users because of the opportunities it offers for them to access information and communicate with other people (Chadwick & Fullwood, 2018; Shpigelman & Gill, 2014).

2.6.4 Risks of accessing internet-based social media

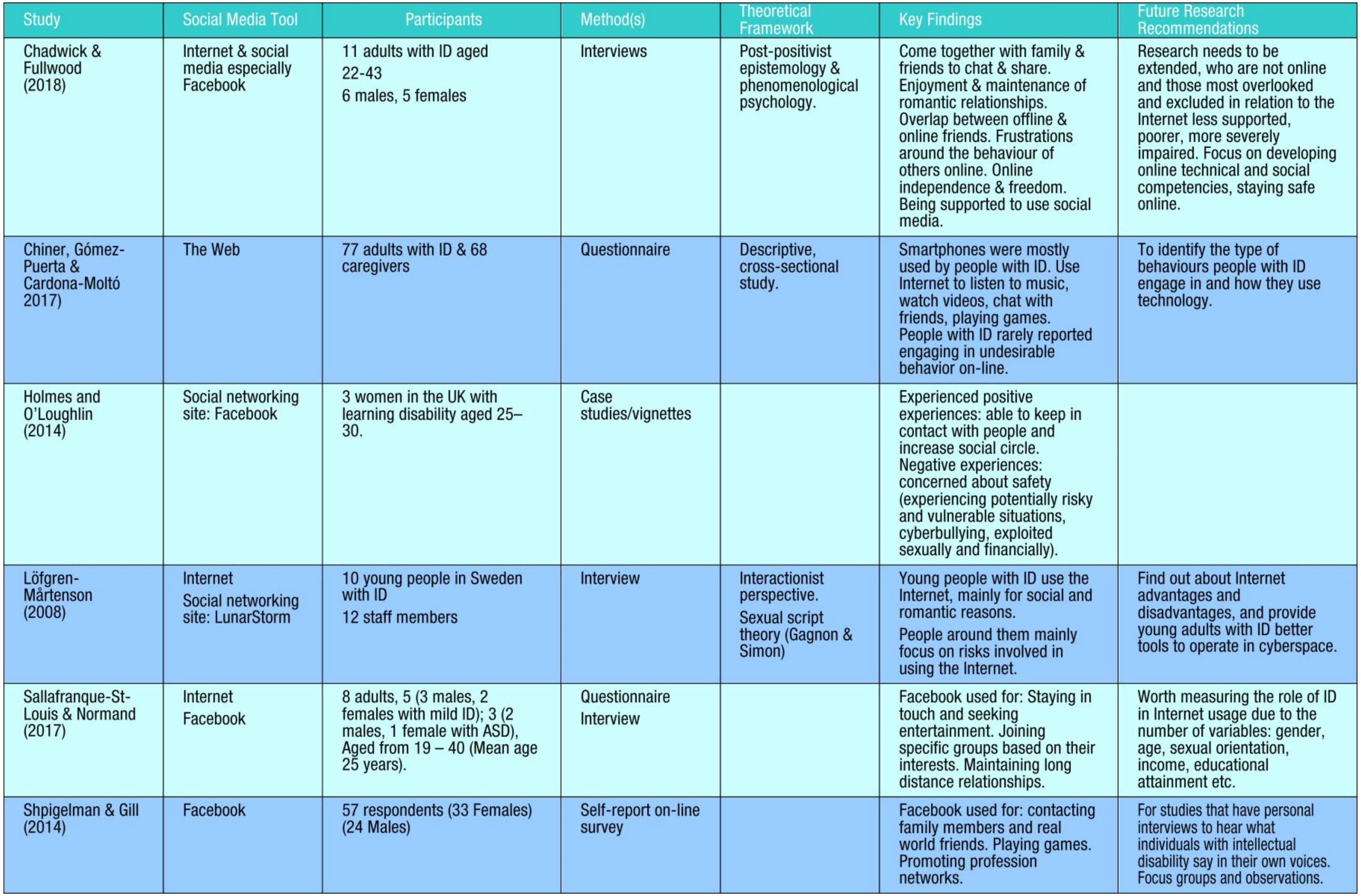
The rapid development of new opportunities presented by internet-based social media has given rise to concerns regarding the negative aspects of accessing the technology (Löfgren-Mårtenson, 2008). Much attention has focused on the negative aspects of online engagement such as: risk of being deceived, net dependency, sex addiction, and easy access to pornography and the impact this has on relationship expectations (Löfgren-Mårtenson, 2008; Braun-Courville & Rojas, 2009). Few studies have concentrated on the positive aspects of accessing new technologies, particularly around social relationships for sexual purposes (Ahn, 2011; Döring, 2009).

2.6.4.1 Assessing and managing risks

Research has reported that young adults living with intellectual disability are very interested to learn about the norms and codes when using internet-based social media (Löfgren-Mårtenson, 2008). Individuals living with intellectual disability have reported that they are conscious about the risks involved with going online, and mentioned in a study (Löfgren-Mårtenson, 2008) that they knew about dangers of being defrauded of money, and the risk of becoming addicted to accessing internet-based social media. Löfgren-Mårtenson (2008) reported that the majority of the young adults living with intellectual disability in her study focused on the risks involved in dating strangers and were able to describe different strategies that they were aware they should follow to avoid getting into trouble. Furthermore the young adults had worked out a sort of ‘internet smartness’ and knew how to handle risks (Löfgren-Mårtenson, 2008, p.133).

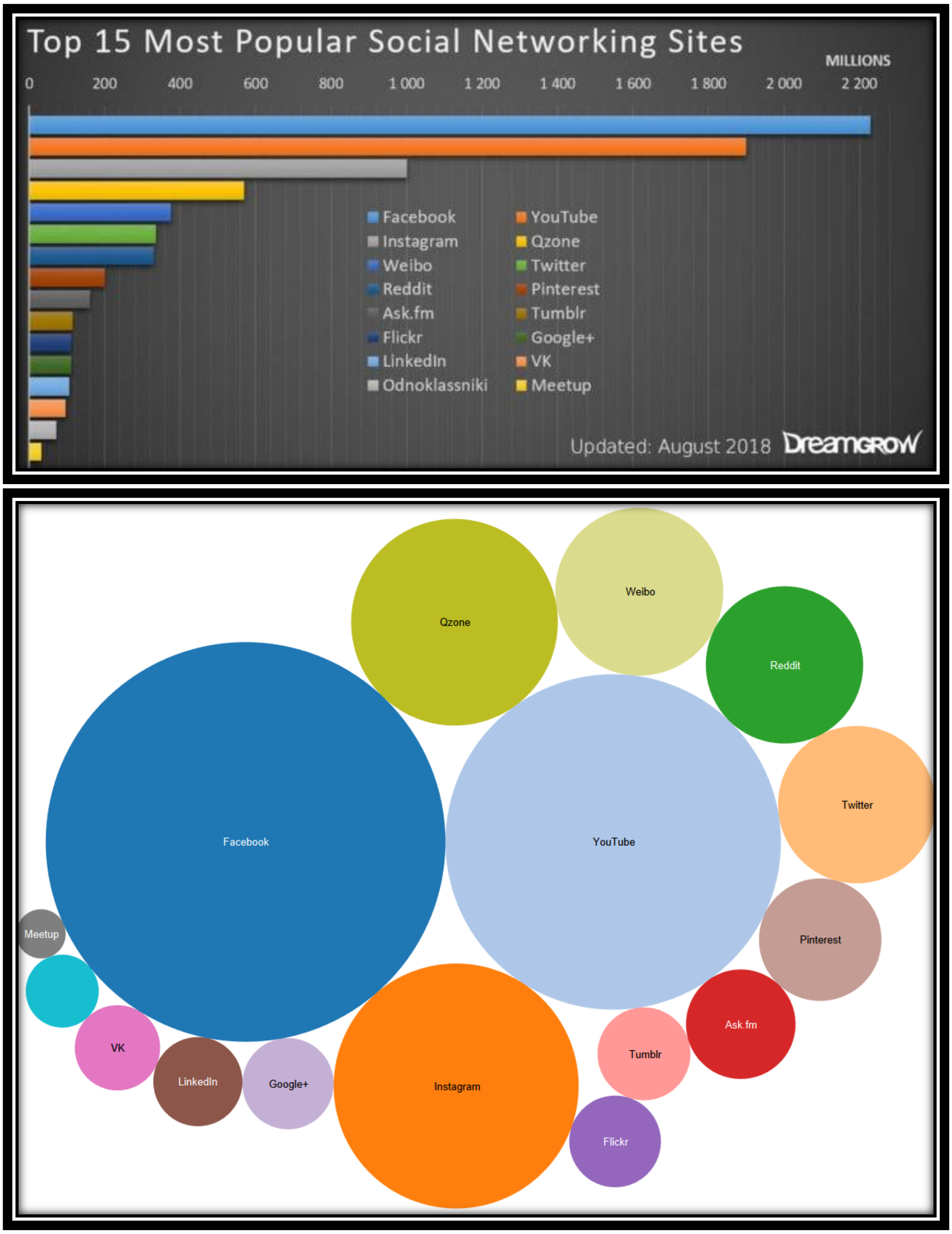
However, despite some young adults living with intellectual disability being able to articulate their knowledge of how to minimise risk, some acted in actual real life situations exactly opposite to what they had been able to communicate (Löfgren-Mårtenson, 2008). This was demonstrated by several young adults living with intellectual disability advising that they had arranged meetings with strangers, meeting them in their own home. On other occasions participants had disclosed very personal information about themselves via internet-based social media. Löfgren-Mårtenson (2008) offered that a reason for acting this way in part was because of the individuals’ longing for a partner/relationship so they inadvertently had forgotten about their security strategies.

Table 2.2: Experiences of individuals with intellectual disability accessing internet-based social media



Study	Social Media Tool	Participants	Method(s)	Theoretical Framework	Key Findings	Future Research Recommendations
Chadwick & Fullwood (2018)	Internet & social media especially Facebook	11 adults with ID aged 22-43 6 males, 5 females	Interviews	Post-positivist epistemology & phenomenological psychology.	Come together with family & friends to chat & share. Enjoyment & maintenance of romantic relationships. Overlap between offline & online friends. Frustrations around the behaviour of others online. Online independence & freedom. Being supported to use social media.	Research needs to be extended, who are not online and those most overlooked and excluded in relation to the Internet less supported, poorer, more severely impaired. Focus on developing online technical and social competencies, staying safe online.
Chiner, Gómez-Puerta & Cardona-Moltó 2017)	The Web	77 adults with ID & 68 caregivers	Questionnaire	Descriptive, cross-sectional study.	Smartphones were mostly used by people with ID. Use Internet to listen to music, watch videos, chat with friends, playing games. People with ID rarely reported engaging in undesirable behavior on-line.	To identify the type of behaviours people with ID engage in and how they use technology.
Holmes and O'Loughlin (2014)	Social networking site: Facebook	3 women in the UK with learning disability aged 25–30.	Case studies/vignettes		Experienced positive experiences: able to keep in contact with people and increase social circle. Negative experiences: concerned about safety (experiencing potentially risky and vulnerable situations, cyberbullying, exploited sexually and financially).	
Löfgren-Mårtenson (2008)	Internet Social networking site: LunarStorm	10 young people in Sweden with ID 12 staff members	Interview	Interactionist perspective. Sexual script theory (Gagnon & Simon)	Young people with ID use the Internet, mainly for social and romantic reasons. People around them mainly focus on risks involved in using the Internet.	Find out about Internet advantages and disadvantages, and provide young adults with ID better tools to operate in cyberspace.
Sallafranque-St-Louis & Normand (2017)	Internet Facebook	8 adults, 5 (3 males, 2 females with mild ID); 3 (2 males, 1 female with ASD), Aged from 19 – 40 (Mean age 25 years).	Questionnaire Interview		Facebook used for: Staying in touch and seeking entertainment. Joining specific groups based on their interests. Maintaining long distance relationships.	Worth measuring the role of ID in Internet usage due to the number of variables: gender, age, sexual orientation, income, educational attainment etc.
Shpigelman & Gill (2014)	Facebook	57 respondents (33 Females) (24 Males)	Self-report on-line survey		Facebook used for: contacting family members and real world friends. Playing games. Promoting profession networks.	For studies that have personal interviews to hear what individuals with intellectual disability say in their own voices. Focus groups and observations.

Figure 2.2: The most popular social networking sites and applications as at August 2018



Source: https://www.dreamgrow.com/top-15-most-popular-social-networking-sites/

2.6.5 Benefits and opportunities from accessing internet-based social media

Despite there being potential risks associated with accessing internet-based social media, this does not negate the many benefits access could have for individuals living with intellectual disability (Chiner et al., 2017; Holmes & O’Loughlin, 2014). Users of internet-based social media have the opportunity to expand their ‘circle of friends’, not limited to geographical locations, and connection to other people more regularly (Chayko, 2014; Holmes & O’Loughlin, 2014; Juszczyk, 2015). They can do this by creating their own virtual community where they have privacy that allows them the opportunity to follow their aspirations, and foster social networks that help to strengthen their existing ties (Peattie, 2007). According to Chayko (2014) online communities, with members with the same interests, can be less judgemental and more open than some that exist in the offline world.

Internet-based social media can open up opportunities for communication and exchange among diverse communities, which provides young adults living with intellectual disability with access to different networks, perspectives and experiences (Chadwick & Wesson, 2016; Lombardo, Zakus & Skinner, 2002). Research has shown that these ‘communities’ are where individuals living with intellectual disability can engage with other people, expand their interactions, and discuss issues ranging from medical to leisure, socialising and forming relationships (Chadwick & Wesson, 2016; Dobransky & Hargittai, 2006).

Having access to internet-based social media allows individuals living with intellectual disability the opportunity to organise their own meetings with the people they prefer rather than relying on get-togethers being arranged for them by someone else (Löfgren-Mårtenson, 2008). Kanunga and Rosenfeld (2004) report that it is the ease with which individuals are able to communicate through internet-based social media that has increased the prospect of people with similar interests finding one another and meeting anonymously to engage in sexual activities.

The evolution of the understanding of intellectual disability has emphasised an ecological standpoint whereby focus is on the person-environment relationship (Buntinx & Schalock, 2010) and identifies that the systematic application of individualised supports provides enhancement to human functioning (Schalock et al., 2007). Intellectual disability is a social construct resulting from the social and physical environment where the individual lives rather than impairment (Altman, 2014; Kayess & French, 2008).

2.7 Access to internet-based social media

Developing knowledge capital and personal life experiences can improve an individual’s potential to access meaningful and relevant information (Williams, 2013). This is because “information is critical in our lives” and helps us to “test ideas and assess risk” (Williams, 2013, p. 26). Williams (2013) adds that building knowledge capital is about an individual’s capacity to access, understand and apply information that can assist them to advance into a good life of active citizenhood. Moreover, since access to the internet is part of the public domain and knowledge capital in the 21st century, internet-based social media could contribute to a good life and promote meaningful inclusion into society (Davies et al., 2015).

Access and usage of internet-based social media, however, varies according to various social determinants such as: social gradient, work, unemployment, social support and social exclusion (World Health Organization (WHO), 2000). For example, in the Australian context, the Australian Bureau of Statistics (ABS) (2007) reports that internet access in the home is higher amongst high income earners, the tertiary educated, and non-Indigenous Australians. For individuals with limited resources whose main income is linked to social security payments, as is the case for the majority of individuals living with intellectual disability, the relative cost of accessing the internet can be a major barrier (Bardasi, Jenkins & Rigg, 2002; Williams, 2013). This view is supported by research that reports the cause of inequalities participating in internet-based social media is generally related to the cost of technology, lack of technical knowledge, and/or an individual's skills or operational ability to use computer-based technology (Sallafranque-St-Louis & Normand, 2017; Van Dijk & Hacker, 2003).

Poor access and the lack of effective use of the emerging technologies also prevents individuals living with intellectual disability from taking full advantage of what is on offer to most other members of society (Dobransky & Hargittai, 2006; Goggin & Newell, 2003). Reasons for poor access have been identified by Chen and Wellman (2005) who reported that the high costs of purchasing equipment, internet access, and a lack of contact with technical support providers impeded disadvantaged groups, such as marginalised individuals living with intellectual disability, from being able to access internet-based social media to use to their advantage.

Beyond income and access as a point of difference to accessing the internet, usability and interface becomes a potential barrier that other community users may not experience (Jaeger, 2012). Those living without disability use the internet at approximately twice the level of individuals who live with disability (Lazar & Jaeger, 2011; Simpson, 2009). Lazar and Jaeger (2011) report that individuals living with intellectual disability are not users of internet-based social media at a rate less than the rest of the population because of their lack of interest or ability to do so, but because internet-based social media is generally not user-friendly for users living with many of the types of impairments. Moreover, Goggin and Newell (2007, p.160) state that "the introduction of new technologies sees people living with disability overlooked, omitted, neglected, and not considered". Jaeger (2012) agrees, reporting that many of the people responsible for developing new technologies simply omit to consider individuals living with intellectual disability when they produce or update their products. Therefore, it is apparent that this group is under-represented and their needs generally not well considered when designing new and mainstream computer, internet, and related technologies.

Web software and hardware designers overlooked the needs of individuals living with intellectual disability (Lazar & Jaeger, 2011). In the US, where the policy for internet accessibility is the most comprehensive internationally, and clearly directs the requirements for accessible technologies, designers of web software and hardware still overlook the needs of individuals living with intellectual disability (Lazar & Jaeger, 2011). This has meant that many users who live with intellectual and other disability find that most internet-related technologies are inaccessible because of the lack of interface and usability for them (Lazar & Jaeger, 2011).

There are ways to develop and implement technologies that would make it possible for individuals living with intellectual disability to participate and engage more with online opportunities (Jaeger, 2012). However Jaeger (2012) says that developers of websites do not always appear to consider individuals living with intellectual disability when they design new products or update technologies. Jaeger (2012) suggests that a reason for website developers not considering individuals living with intellectual disability might be because designers have little or no understanding of the barriers, challenges, and issues of living with impairment and/or an indifference to the needs of individuals living with intellectual disability. Easton (2013) reports that disability appears to be "deemed a design afterthought" (p. 105) and that "the internet was not created in a vacuum" (p. 105) but developed within a society that had existing discriminatory structure.

Yet, the rights of individuals living with intellectual disability have been promoted and championed in various settings. The UNCRPD, adopted in late 2006, Article 9, asserts the right of people living with disability to "participate fully and independently in all aspects of society", which includes the internet and having access to "communication technology and systems" (p. 9). Furthermore the UNCRPD (2006) asserts that individuals living with intellectual disability have the opportunity to experience identical rights and opportunities as the rest of society (Simpson, 2009). Lack of access to technology, understood as discrimination by individuals living with intellectual disability, created a perception of there being a digital divide (Simpson, 2009) which can put individuals living with intellectual disability at further risk of social exclusion if they are not part of modern technology, designed for cognitive access, and the 'information society' (Batey & Waine, 2015; Davies et al., 2015; Goggin, 2015; McClimens & Gordon, 2009; Macdonald & Clayton, 2013).

In addition, individuals living with intellectual disability have the right to autonomy and independence, and the freedom to make their own choices as outlined in the UNCRPD (2006). Regarding accessibility, UNCRPD (2006) Article 9 – Accessibility stated:

"To enable persons with disabilities to live independently and participate fully in all aspects of life, States Parties shall take appropriate measures to ensure to persons with disabilities access, on an equal basis with others…to information and communications, including information and communications technologies and systems, and to other facilities and services open or provided to the public.…These measures, which shall include the identification and elimination of obstacles and barriers to accessibility, shall apply to, inter alia:

- “Information, communications and other services, including electronic services and emergency services.

“States Parties shall also take appropriate measures to:

- “Ensure that private entities that offer facilities and services which are open or provided to the public take into account all aspects of accessibility for persons with disabilities;
- “Provide training for stakeholders on accessibility issues facing persons with disabilities;
- “Promote other appropriate forms of assistance and support to persons with disabilities to ensure their access to information;
- “Promote access for persons with disabilities to new information and communications technologies and systems, including the internet;
- “Promote the design, development, production and distribution of accessible information and communications technologies and systems at an early stage, so that these technologies and systems become accessible at minimum cost.”

UNCRPD (2006) Article 21 – Freedom of expression and opinion, and access to information stated:

> “States Parties shall take all appropriate measures to ensure that persons with disabilities can exercise the right to freedom of expression and opinion, including the freedom to seek, receive and impart information and ideas on an equal basis with others and through all forms of communication of their choice, including:

- “Providing information intended for the general public to persons with disabilities in accessible formats and technologies appropriate to different kinds of disabilities in a timely manner and without additional cost;
- “Urging private entities that provide services to the general public, including through the internet, to provide information and services in accessible and usable formats for persons with disabilities.”

Furthermore individuals living with intellectual disability have the right to be able to access multimedia and communication technology at an affordable cost and to have “full and effective participation and inclusion in society” (UNCRPD, 2006).

The UNCRPD (2006) calls on parties to take all necessary measures to ensure that these rights are upheld and promoted. Australia ratified the UNCRPD in 2008, and so has obligations to implement policies and practices that are consistent with the UNCRPD (2006). The translation of this agenda into policy and social change has been evident in some areas of society, yet, individuals living with intellectual disability remain some of the most marginalised, poorest, least educated, and socially isolated members of society (Lang, Kett, Groce & Trani, 2011; Lordan, 2000; WHO, 2011).

The internet offers an abundance of information and interaction opportunities for individuals living with disability that might assist them to improve their physical and intellectual attainments. However opportunities to improve and gain physical and cognitive benefit from activities are not always obtainable by many individuals living with intellectual disability (Dobransky & Hargittai, 2006). Limited accessibility to technology mirrors the inequalities in society often experienced by individuals living with intellectual disability (Chadwick et al., 2013; Goggin & Newell, 2003). This is further emphasised by Jaeger (2012) who reported that the obstacles experienced by individuals living with disability to access and participate in internet-based social media replicated the barriers that have been omnipresent for individuals living with disability over decades.

When exploring the benefits of internet-based social media for individuals living with intellectual disability, previous research has focused on the access and engagement of individuals without the social and financial disadvantage often associated with intellectual disability. Consequently there is a lack of depth in our understanding of internet-based social media use for individuals living with intellectual disability, their aspirations and preferred activities to participate in, have access to, and whether or not they wish to form relationships and engage in sexual behaviours linked to accessing internet-based social media.

However access to internet-based social media and the opportunities it offers are not equally available to everyone in society (Jaeger, 2012); this occurring in the face of information and communication technologies being transferred online, and having become an essential part of daily life (Caton & Chapman; Davies et al., 2015; Goggin, 2015; Macdonald & Clayton, 2013). There are factors external to internet-based social media technologies, relating to geography, socio-economic status, and literacy, which can affect access and participation in internet-based social media (Jaeger, 2012). Jaeger (2012) reports that internet-based social media access and disability create barriers more extensive than just geography, socio-economic status and literacy. Inaccessible technologies and content built directly into internet-based social media could create vast barriers for individuals living with intellectual disability. Jaeger (2012) suggests that these obstacles reflect the long-existing barriers to mainstream society that individuals living with intellectual disability have experienced during their lifetime. Jaeger (2012) proposes that should free access be made available, training provided, and content written for local language, then barriers to using internet-based social media technologies could be minimised. For individuals living with intellectual disability, this resonates with the social model (Caldwell, 2007).

2.7.1 Participation online accessing internet-based social media

Once access to the internet has been gained, individuals have the opportunity to participate in internet-based social media which has many benefits that have infiltrated daily living (Kanuga & Rosenfeld, 2004). To benefit from the internet as much as mainstream society, individuals living with intellectual disability require access and support to technology (Batey & Waine, 2015). There are many activities that it is now assumed individuals have access to online (Ji & Fu, 2013) such as, but not limited to: paying accounts; banking; applying for Government benefits; and shopping. Furthermore it is becoming more prevalent that for some services there is only an online option, necessitating that a person be able to access the internet. As more services move primarily and exclusively to online access, the potential is for individuals living with intellectual disability to become increasingly disadvantaged and the digital divide more pronounced if they are unable to access and use the technology (Batey & Waine, 2015; Jaeger, 2012 Sallafranque-St-Louis, & Normand, 2017).

For individuals living with intellectual disability to benefit from participating on line as much as mainstream society, they need to have access to technology and support (Batey & Waine, 2015; Weymeyer et al., 2012). Having established that this access is limited by virtue of social determinants such as having limited employment, and insufficient income, for individuals living with intellectual disability access to technologies has become increasingly limited (Braddock, Hoehl, Tanis, Ablowitz & Haffer, 2013; Williams, 2013).

Individuals living with intellectual disability gave their reasons for participating in online activities so that they could be “like everybody else”, participating for “social and romance purposes” (Löfgren-Mårtenson, 2008, p. 130). A benefit of their participation was having a place where they were able to present as being disability free and escape the control of their surrounding world and professional supports.

Löfgren-Mårtenson (2008) proposed that because internet-based social media was unlikely to cease to exist, it was important to discover more about the advantages and disadvantages of gaining access, and assist individuals living with intellectual disability with ways to better handle its complexities. In fact with the advent of the ‘cloud’ it is expected that excluding individuals living with intellectual disability from cloud computing design and structure could put them at risk of becoming even more marginalised in mainstream society (Caldwell, 2011). According to Braddock et al. (2013) areas where there are potential for cloud-based initiatives to have a positive impact is in “improved personal communications” (p. 95) and “enhanced social interaction” (p. 96) (Chiner et al., 2017).

Many of the activities that individuals are able to participate in online can substitute for equivalent pursuits in the physical, face-to-face world (Barak & Sadovsky 2008). Park (2012) observed that many of the online activities that people engaged in could be considered replicas of existing real life activities. Cyberspace had become a most important place where people could meet, have discussions, conversations, learn, shop, play, build relationships, and make love (Barak & Sadovsky, 2008; Cummings et al., 2002; Juszczyk, 2015). Moreover, Haythornthwaite and Wellman (2002) observed that cyberspace was not a place that was isolated and separated from real life but an integral part of it. This meant that it would be inappropriate to treat being offline and online as separate domains when in general they have become mutually inclusive domains (Haythornthwaite & Wellman, 2002; Juszczyk, 2015). Briggle (2008) reported that the availability of new technologies has meant everyday life has become a mixture of “reality of online and offline worlds” (p. 216).

Once being able to access the internet, individuals living with intellectual disability are able to create opportunities for social interaction due to the special communication-related features of internet-based social media (Barak & Sadovsky 2008). These features are characterised by ‘textuality, availability, and multimodality’ (Barak & Sadovsky, 2008, p. 1803) and allow individuals who come from various areas of disability an opportunity to take advantage of a medium where they are not identified as being ‘disabled’, where they can avoid stigma and have a chance to feel how they perceive ‘normal’, non-disabled people would feel (Barak & Sadovsky, 2008; Shpigelman & Gill, 2014). In fact Brignall and Valey (2007) reported that individuals could experience a type of freedom should they decide to misrepresent their identity while communicating online. Individuals living with intellectual disability who are able to access internet-based social media can project an identity to their online world that may differ from their offline ‘real’ world should they desire to do so (Holmes & O’Loughlin, 2014; Shpigelman & Gill, 2014).

Research shows that young adults use a variety of the tools available on internet-based social media as a way to connect with their peers (Subrahmanyam & Lin, 2007). These include but not limited to: messaging, bulletin boards, chat rooms, and blogs, where young adults explore issues relevant to their development such as their sexuality, identity and ways of finding a partner (Subrahmanyam & Lin, 2007). However, there is a scarcity of research about what tools on internet-based social media individuals living with intellectual disability use.

2.7.1.1 Sex online

Individuals have engaged in online sexual activities since the inception of the World Wide Web (Delmonico & Griffin, 2011). Daneback, Cooper and Månsson (2005) reported that many individuals used the internet for online sexual activities. According to Brickell (2012) the internet had become an important enabler of sexual relationships in society (Bergdall, Kraft, Andes, Carter, Hatfield-Timajchy & Hock-Long, 2012). Delmonico and Griffin (2011) reported that almost every online technology could be used for sexual purposes. These activities have included, but are not limited to: cybersex; sexy chatting; finding other people to have sex with offline; locating information or advice about sexual health; romance and relationships; viewing and downloading pornography; and purchasing erotic material and sexual aids (Whitty & Fisher, 2008). With the proliferation of internet-enabled technology, the way in which young adults encountered and consumed sexually explicit material had significantly changed (Danebak & Löfberg, 2011).

2.7.1.2 Who participates in sexy internet-based social media, what and why?

Internet-based social media has been accessed by individuals as an outlet for engaging in sexual activities (Rimmington & Gast, 2007). Young adults have been known to participate in a diversity of sexual activities (Weinstein & Rosen, 1991) addressing a variety of their needs (La Ferle et al., 2000). Most of a young person's sexual knowledge is gained from their peers (Gagnon & Simon, 2005; Isler et al., 2009) and internet-based social media is a medium where individuals can be in constant communication with each other any time night or day (Amichai-Hamburger, Kingsbury & Schneider, 2013; Chayko, 2014; Davis, 2012).

Individuals can feel safe and protected because they are engaging with others that they are able to keep at a safe distance while still being intimate (Kanunga & Rosenfeld, 2004). They are also able to engage in a virtual environment where they can participate in activities that they might find difficult to engage in in real life. The unique characteristic of participating in internet-based social media is that it allows individuals to engage with others and explore their sexual curiosity and expand their sexual knowledge and repertoires as they exchange ideas and experiences. Kanunga and Rosenfeld (2004) proposed that the 'private' setting allows individuals a virtual environment where they can experience a decreased sense of inhibition because the contact can be anonymous. For individuals living with intellectual disability who participate in internet-based social media, they can be provided with an opportunity to seek relationships in a relatively non-threatening environment with the world they live in but might find difficult to be physically be a part of (Peattie, 2007).

2.8 Consequences

2.8.1 Socialising and communicating

Having accessed and participated in internet activities, it is important to understand the outcome of engagement for individuals living with and without disability. According to Parsons et al. (2008) there is a potential for individuals for social inclusion and greater participation in mainstream society.

Once face-to-face communication was regarded as the ‘norm’, however with the ever-evolving technological opportunities available, face-to-face communication and social interactions are routinely being conducted online (Dwyer, 2007). The internet has become a socially acceptable, virtual environment and an alternative place for any individual to engage in a diverse range of activities and interactions (Dwyer, 2007).

With the rapidly expanding scope of the internet becoming a tool where young adults are known to converge to communicate, has come conflicting views about the possible social consequences (Gross, 2004). Van den Eijnden, Meerkerk, Vermulst, Spijkerman and Engels (2008) found that adolescents not only regularly communicated online with their existing friends but frequently progressed to developing friendships offline that they had first established with individuals online. This is consistent with research that found many internet users stated that they met and made friends online with individuals who they later went on to meet in person (Reich, Subrahmanyam & Espinoza, 2012). There have been mixed reports in literature about the consequences of accessing internet-based social media among typically developing adolescents and adults (Mazurek, 2013). According to prior studies, the internet could reduce the social involvement and quality of an individual’s existing personal relationships (Kraut et al., 1998; Nie & Erbring, 2000). However Valkenburg and Peter (2007) pointed out that the findings were from studies carried out when internet use was still in its infancy and access was not yet essentially universal.

According to Gross et al. (2002) internet-based social media often met the needs for engaging socially and companionship. Lee (2009) reported that using online communication tools enhanced the quality of existing relationships while not appearing to influence the amount of face-to-face interactions. Online communication could be a way in which friends supplemented their face-to-face contact with each other and that also assisted them to maintain and strengthen their existing ties (Raghavendra et al., 2013; Reich et al., 2012; Wellman, Haase, Wilte & Hampton, 2001). Furthermore young adults are able to maintain their sense of connection to each other through internet-based social media regardless of the time of day from any location (Chayko, 2014; Davis, 2012).

2.8.2 Online relationships

Online relationships can be empowering for many individuals (Shpigelman & Gill, 2014; Whitty 2008). The internet is a 'place' with a unique environment where individuals are able to experience and learn about developing relationships and sexuality (Whitty, 2008). Kanuga and Rosenfeld (2004, p. 121) state that, "the internet has created a new vehicle for sexual exploration". However, for one such community, individuals living with intellectual disability, came the promise of enhancing opportunities for access, participation, benefits of developing relationships and exploring sexuality with the increased availability of internet-based social media (Dobransky & Hargittai, 2006).

Debate has concentrated on whether online relationships can be "liberating or deliberating" (Whitty, 2008, p. 1837). People who had negative perceptions about participating in internet-based social media argued that online relationships, often referred to as 'weak' ties, are not psychologically beneficial as they take time away from healthier offline relationships (Whitty, 2008). Conversely, those with a more positive stance see internet-based social media as 'places' where individuals are free to express themselves while not feeling they are being judged as they might in settings where they have to communicate with others face-to-face (Whitty, 2008). The view that Whitty (2008) aligns most with is that cyberspace has produced new opportunities for individuals to feel empowered and has unlocked new prospects for them to develop relationships with other people. As Delmonico and Miller (2003) have advised, regardless of how the internet is perceived, whether a positive or negative influence, the nature of interpersonal relationships has completely transformed.

Individuals are able to contact each other and start relationships using internet-based social media. Social network sites such as MySpace™ and Facebook® have permeated society to such an extent that it is now mandatory participation for many young people for inclusion in peer groups (Robards, 2012). For many young adults, these sites had been where they freely engaged in a social life, with friends who were considered to be a motivating force behind adolescents' use of internet-based social media (Davis, 2013).

The internet has become a 'place' that can create a sense of community for marginalised individuals, such as individuals living with disability (and young adults living with intellectual disability), providing an opportunity to engage with other people who, without access, might not have the opportunity to connect and engage with others (Barnes, 2001). As Williams and Merten (2008, p. 254) stated: "The internet provides an unrestricted laboratory setting for adolescent identity experimentation as they seek to understand how they fit into the world around them". Those individuals who access internet-based social media have been reported to form closer relationships and experience an increase in their social engagements (Valkenburg & Peter, 2007; Kraut et al., 1998).

Internet-based social media has the potential to provide individuals living with intellectual disability an important link to the community in which they live (Blanchard, Metcalf, Herman & Burns, 2008), and access to public and knowledge capital (Williams, 2013). Not only can individuals connect with people they are already acquainted with but they can form relationships with other people they meet online who they would not have had the opportunity to communicate with in the typical course of their physical life (Dutton 1999, 2005; Rice, Sheperd, Dutton & Katz, 2007). Beneito-Montagut (2011) pointed out that socialising in today's world occurred not only in the face-to-face environment but via internet-based social media.

The importance of individuals making a social connection had been enhanced by the popularity of internet-based social media such as Facebook® where people maintain personal connections (Caton & Chapman, 2016; Williams, 2013). However, technology can often be beyond the grasp of individuals who live on very low incomes (Williams, 2013). Subsequently, according to Williams (2013) individuals have a reduced opportunity to build their knowledge capital, which in turn impacts on "decision-making and action-taking" (p. 28).

Furthermore, the extent to which individuals can interact with strangers using internet-based social media and the relationships that they could form with them can be of concern for parents and/or caregivers. In the study by Subrahmanyam and Lin (2007) most of the participants had not met their online acquaintances in person and only a small minority had made contact by telephone and met face-to-face. Findings from this research suggest that most online relationships remain online.

The internet has had a direct impact upon how sexuality has been expressed, including on: "pornography, sex shops, sex work, sex education, sex contacts, and sexual subcultures" (Döring, 2009, p. 1089). Döring (2009) clarified the way in which the internet could offer new possibilities of engaging in these types of behaviours:

1. **Pornography on the internet**: individuals are able to access pornography on the internet that has been commercially produced as well as non-commercially produced; material which they are able to distribute and talk about with others online. In addition, individuals can reuse conventionally produced pornography by scanning pictures from magazines and distributing the pictures via the internet (Döring, 2009).
2. **Sex shops on the internet**: internet users are able to acquire information about adult 'toys' and sexual aids that they are then able to purchase discreetly online (Döring, 2009). Online sex shops market products such as vibrators, sexy clothing, condoms, aphrodisiacs and erotic printed media.

3. **Sex work on the internet**: The internet provided a place to market conventional ‘offline sex work’ by advertising the services of brothels and/or escort agencies as well as new ‘online sex work’ where live shows are broadcast via webcams (Döring, 2009). As Döring (2009) stated, this meant that the internet had expanded the opportunities for participants to acquire sexual services as well as being able to offer them. Sex work contrasted with pornography (previously created pictures or texts) as it comprised interpersonal contact in real time, taking place between the participant and the sex worker (Döring, 2009). The performers and participants are able to communicate with one another by chatting in real time via a webcam where participants can explain what they would like the performer to do.
4. **Sexual education on the internet**: Participants can locate information and advice discreetly about matters concerning sexual awareness, attitudes and behaviours that they find helpful and reliable from an abundance of sources (Braun-Courville & Rojas, 2009; Döring, 2009). There are conventional materials available online such as brochures and new content such as multi-media learning modules, online forums and sexual reports in online diaries and/or blogs (Döring, 2009).
5. **Sex contacts on the internet**: On the internet there are two forms of sexual contact: one where contact had been specifically initiated for online-mediated sexual exchanges such as ‘online sex’, cybersex and other contact that directed participants to real world sexual liaisons such as engaging in ‘offline sex’ (Döring, 2009). The sexual contact available on the internet can vary with participants having “fleeting engagements” (Döring, 2009, p. 1091), to long-term relationships, in contrast with commercial sexual exchanges, since these encounters are free.
6. **Sexual subcultures on the internet**: Individuals who have difficulty finding people with non-mainstream sexual preferences are able to access the internet to locate like-minded people cheaply and easily (Döring, 2009, p. 1091). The internet is used by sexual subcultures both for networking and for self-expression.

Furthermore, the research data established that sexually related activities had become routine for segments of society in the Western world (Döring, 2009). Sexuality can be found anywhere on the internet in the forms of: pornography, films, music clips with sexual content, and advertisements for sexual merchandise (Brickell, 2012). The internet is a place to browse, learn, and build relationships and make friends (Brickell, 2012).

There have been concerns about the effects and consequences of young people’s experiences and consumption of pornography (Braun-Courville & Rojas, 2009; Knox, Mok & Parmenter, 2000). The internet had provided young adults access to a substantial amount of sexual content to view in private (Braun-Courville & Rojas, 2009). In a study with 433 participants conducted in New York City, Braun-

Courville and Rojas (2009) reported that young adults exposed to sexually explicit websites, had more permissive attitudes toward sexual activities than individuals who had never been exposed to such forums. According to Braun-Courville and Rojas (2009) being exposed to pornography online had implications for young people’s sexual relationships and how many partners they had and that they were more likely to engage in casual sex. Exposure to internet pornography was found to be related to high-risk sexual behaviours that could have the potential to adversely affect an individual’s reproductive wellbeing (Braun-Courville & Rojas, 2009). Examples of high-risk behaviours that young adults who went to websites that contained sexually explicit material, were more likely to engage in were: having many partners; taking drugs during sex; and participating in anal sex (Braun-Courville & Rojas, 2009).

After an extensive review of literature by the present researcher, it was found that there was a paucity of research about whether individuals living with intellectual disability access internet-based social media for the purposes of developing social relationships or facilitating their engagement in sexual behaviours. Moreover, should they be accessing internet-based social media, how were they doing so and what were they doing? There was also a lack of research conducted directly with individuals living with intellectual disability in order to acquire their perspectives (Welsby & Horsfall, 2011) and explore their views and experiences of social and sexual relationships (Sullivan et al., 2013). Coupled with evidence from other aspects of the lives of individuals living with intellectual disability, opportunities to express their sexuality are often gatekept by family, paid support staff, and/or significant others (Greydandus, Rimsza & Newhouse, 2002; McGuire & Bayley, 2011).

2.8.3 Social media facilitator of sexual relationships in society

Internet-based social media has become an increasingly important facilitator and mediator of sexual relationships in society (Brickell, 2012). Moreover internet-based social media includes specific characteristics that make it easier for some individuals to communicate about sexuality in ways sometimes not possible offline (Danebak & Löfberg, 2011). According to Danebak and Löfberg (2011), the fact that individuals are able to type while being physically remote from others who use the internet, appeared to make it a particularly beneficial source for finding knowledge about sexuality compared to other forms of communication. Internet-based social media has transformed the manner in which people communicated with one another and has the potential to bring people closer together.

2.8.4 Individuals living with intellectual disability and internet-based social media

Internet-based social media has provided new ways for individuals to meet for romantic and sexual purposes through the emergence of places for virtual contact and meetings (Löfgren-Mårtenson, 2008). Young adults living with intellectual disability considered internet-based social media to be places that gave them positive experiences and explorations, especially because it could possibility be a 'place' where they might one day meet a partner (Löfgren-Mårtenson, 2008).

Internet-based social media allows individuals to "experiment with a sexual behaviour not just by thinking about it, but by engaging in it online and with another person without actually 'doing' it" (Ross, 2005, p. 344). Ross (2005) argued that internet-based social media had added a new dimension to intimacy as it not only allowed intimate contact online over any distance, but permitted participants the opportunity to engage in intimate discussions devoid of many of the social cues that are present when individuals meet each other face-to-face.

2.8.4.1 Anonymity

The anonymity of being able to go online was undoubtedly a major contributing factor to the popularity of this venue for developing friendships and engaging in sexual activities (Kanuga & Rosenfeld, 2004). Delmonico and Griffin (2011) reported that individuals, being anonymous, were able to explore and experiment with their sexuality in the online world beyond what they would have been comfortable doing in the real world. This was because individuals were likely to feel less shy or accountable for what they did when they separated their actions from their identity (Delmonico & Griffin, 2011).

The virtual anonymity of participating in internet-based social media could assist individuals to form close relationships by reducing the risks characteristic in disclosing personal information (Barrgh & McKenny, 2004), since disclosing personal information contributed to an individual's sense of intimacy, making the sharing of personal information easier and could assist individuals to form relationships (Bargh & McKenny, 2004).

2.8.4.2 Benefits

According to Döring (2009), a paucity of research has been conducted on the potential benefits of online sexuality compared to the main focus placed on the possible negative effects. The sexual-related content and activities that are observable on the internet are referred to as 'internet sexuality' or online sexual activities (Döring, 2009). The internet is not merely a new medium to distribute the customary forms of pornographic material. For amateur photographers, the internet has facilitated the creation of new ways to produce, distribute and receive images (Döring, 2009). The notion of interpersonal sexual encounters has been developed online and such encounters are known as 'cybersex' or 'online sex' (Döring, 2009). The activities conducted online and offline are often closely interlinked, as demonstrated by individuals who use online dating services and go on to meet real world sexual partners (Döring, 2009).

2.8.4.3 Risks and harms

In addition to the benefits, Chadwick et al., (2016) report that in general, going online can include numerous risks, for example: being involved in antisocial behaviour such as: downloading illegal information, bullying, uploading sexually inappropriate pictures; engaging in negative contact online, and: having personal information stolen, being groomed; and exposure to harmful content, such as: violent material, harmful sexual material, inappropriate advertising. However limited research has investigated potential risks and dangers for individuals living with intellectual disability who access social media (Holmes & O'Loughlin, 2012). Chadwick et al., (2016) concur with Holmes and O'Loughlin (2012), that while there are inherent risks involved in accessing social media, these risks have not been adequately studied with regards to individuals living with intellectual disability.

Lough, Flynn and Riby (2015) agree that most people face risks posed by social media, and individuals living with intellectual disability may be particularly vulnerable to bullying and being victimised online. Individuals living with intellectual disability might have difficulty interpreting social nuances and understanding social communication, elevated levels of trust, and experience feelings of isolation and loneliness (Lough et al., 2015). A study by Buijs et al., (2016) reported cases where individuals living with intellectual disability were victims of sexual harassment and financial exploitation online.

Chadwick et al., (2016) noted that the nature of the perceived risks validate an understanding of the increased restriction and gatekeeping that may occur preventing individuals living with intellectual disability from accessing internet-based social media. Having identified that tension that exists in protecting individuals living with intellectual disability from risks and conversely affording people freedom to access the online world (Chadwick et al., 2016).

Individuals living with intellectual disability can experience difficulties forming sexual relationships and may seek access to internet-based social media to fulfil personal desires (Jones, 2013). They may access online pornography, which can become problematic if they are unaware of the relevant laws, and risks could include promises of casual sexual encounters in return for high subscription fees, and receiving a false impression of what constitutes healthy sexual relationships (Jones, 2013).

2.8.4.4 Wellbeing

Prior research has shown that engaging in internet-based social media can contribute to an individual's sense of wellbeing and can lead to satisfying their psychological needs (Barak & Sadovsky, 2008; Caton & Chapman, 2016). In a study conducted by Barak and Sadovsky (2008), results highlighted that accessing internet-based social media had the potential to foster empowerment in the individuals who engaged in these activities. The study reported that the personal empowerment process that internet-based social media participants undergo is promoted by several features portrayed in the cyberspace environment that include: invisibility, anonymity, continuous availability, access to substantial amounts of information and the considerable availability of group and individual support. According to Barak and Sadovsky (2008) these features, used either individually or in combination, can produce unique psychological effects on individuals that initiate and promote the empowerment process. Consequently, access to internet-based social media has been perceived not merely as a technology, but an efficient medium to support a better life for many individuals (Barak & Sadovsky, 2008; Caton & Chapman, 2016).

2.8.4.5 Empowerment versus protection

Individuals who are dependent on others find that their opportunities to develop independence and self-determination can often be restricted because their activities are planned for them (Löfgren-Mårtenson, 2004). Murphy and O'Callaghan (2004) acknowledge that it is often difficult for service providers to balance the task of encouraging individuals to assert their sexual rights while at the same time protecting them from possible abuse. While care staff can generally have positive views towards the sexual rights of individual living with intellectual disability, these can be curtailed by an insufficient policy framework to guide active support to provide strategies around allowing for sexual expression and provide effective protection (Hollowotz, 2011).

Underlying empowerment is the basic assumption that individuals are unable to fully achieve their potential or become equal citizens when they do not have a voice in, and/or have a lack of control over, matters that effect their life (van Houten & Jacobs, 2005). To become an equal citizen requires an individual to be able to participate in their community and society; known as 'active citizenship' (van Houten & Jacobs, 2005). However, individuals living with intellectual disability have typically had limited access to many forms of effective participation within the community/society in which they live (van Houten & Jacobs, 2005). Real barriers that prevent individuals living with intellectual disability from becoming active citizens are derived from low expectations (both practical and intellectual) and lack of encouragement and support from other people (van Houten & Jacobs, 2005).

2.8.4.6 Gatekeepers

Generally thought of as being less able, individuals living with intellectual disability are often denied in their own lives and are perceived as needing constant societal protection and support by service providers, professionals, and gatekeepers to compensate for their inabilities (Altermark, 2016; Hendriks, 2007; Methven, 2009).

Individuals living with intellectual disability have parental or significant other input into their lives and decision-making, beyond that generally experienced by their non-disabled peers (Foley & Kelly, 2009). They view one of their roles as being that of a protector and someone who manages risks for individuals living with intellectual disability (Rushbrooke et al., 2014).

Parents and service providers have made it known that they feel that it is their responsibility to protect the 'vulnerable' individuals they care for, which often manifests as them 'gatekeeping' with their controlling behaviours (Löfgren-Mårtenson, 2008; Rushbrooke et al., 2014). The review by Rushbrooke et al. (2014) found that service providers felt they should assist individuals living with intellectual disability in their sexuality but also felt that they should place themselves in control of the individual living with a disability if they thought they were at risk and unable to manage their sexuality. Wheeler (2007) found that opportunities for individuals living with intellectual disability to express their sexuality was often limited and controlled by gatekeepers, despite seeing themselves as sexual beings.

Acting as gatekeepers, parents and service providers are unaware that restricting appropriate social and sexual interactions can actually leave individuals living with intellectual disability more vulnerable to being exploited, and to sexual relationships that are not appropriate (Bruder & Kroese, 2005; Holland-Hall & Quint, 2014; Sweeney, 2007).

A consequence of participating in internet-based social media, means that individuals living with intellectual disability have the opportunity to become less reliant on arrangements made for them by parents/service providers as it offers them the freedom to socialise on the internet where and when it pleases them (Löfgren-Mårtenson, 2008). Individuals living with intellectual disability reported being able to decide for themselves which sites they visited and with whom they communicated (Löfgren-Mårtenson, 2008). However, this may be challenging for people supporting individuals living with intellectual disability, who may become gatekeepers and prevent access to internet-based social media, claiming issues of protection (Chadwick & Wesson, 2016).

2.8.4.7 Service provider concerns and attitudes

Löfgren-Mårtenson (2008) found that many staff members' concerns about the perceived risks associated with accessing internet-based social media were based on their existing views that individuals living with intellectual disability were gullible and vulnerable. With this in mind, staff members were convinced that they were required to have an attitude of control and protection towards the young adults living with intellectual disability (Löfgren-Mårtenson, 2008). This was apparent in the way that they fixed times for participants to use the internet, banned pornographic and/or violent sites, and controlled which sites individuals were permitted to visit. The service providers did not perceive that internet-based social media was a suitable way for young adults living with intellectual disability to find a partner

(Löfgren-Mårtenson, 2008). In addition, the service providers (staff) had a negative view about the advantages of individuals living with intellectual disability accessing internet-based social media (Löfgren-Mårtenson, 2008). However, in contrast this was not necessarily the view held by the younger members of staff who were themselves users of the internet and thought that individuals living with intellectual disability should be permitted to chat and socialise on this medium.

Concerns have been raised about how young adults use the internet. Moreover less is known about the way in which individuals living with intellectual disability use the internet. However it is known that staff/service providers and/or family members of individuals living with intellectual disability have concerns about private activities regarding romance and sexuality (Löfgren-Mårtenson, 2004). Therefore, what remains unresolved is a comprehensive understanding as to whether individuals living with intellectual disability are using internet-based social media to develop and maintain social relationships or are accessing material, sexually explicit or otherwise, to engage in sexual behaviours.

Literature about individuals living with intellectual disability and their use of internet-based social media has presented both positive and negative perspectives (Döring, 2009). Moreover, research exploring the use of internet-based social media for sexual intentions has primarily focused not on the positive but the negative, problematic aspects, predominantly about vulnerability, abuse and/or addiction (Döring, 2009).

It has been observed that the communication possibilities of the internet enable individuals living with intellectual disability the opportunity to strengthen their existing relationships with their family and friends as well as establishing new relationships (Dobransky & Hargittai, 2006). Internet-based social media has the potential to provide individuals living with intellectual disability, who are often socially isolated and have limited ability to venture outside of their home, with a “far greater world of interaction” (Jaeger, 2012, p. 6; Löfgren-Mårtenson, Molin & Sorbring, 2018).

This current study explores the potential of internet-based social media to be positioned in the lives of individuals living with intellectual disability, in order that they can experience a social inclusion tool widely afforded to the general population. This exploration will contribute to, what is currently, scarce research specifically related to intellectual disability and individuals’ access of internet-based social media. The aim of this current study was to describe the lived experiences of individuals with intellectual disability in regard to access to internet-based social media, in relation to potential engagement, participation, and the development of sexual activities and relationships.

The research questions for this current study were:

- Are individuals living with intellectual disability accessing internet-based social media and if so what are the applications, sites and activities they are engaging with?
- What are the experiences of individuals living with intellectual disability accessing internet-based social media to develop social relationships and potentially engage in sexual activities?
- What (if any) barriers do individuals living with intellectual disability experience in accessing internet-based social media to develop social relationships and engage in sexual behaviours?

Chapter Three
Methodology and Method

3.1 Introduction

This chapter describes the research design and procedures for managing data collection, analysis and interpretation that underpin this current study. The conceptual framework for this study is aligned to phenomenological approaches, a qualitative approach with a foundation philosophy concerned with understanding and illuminating the meaning of an individual's lived experience (Bynum & Varpio, 2018; Denscombe, 2013; Murray & Holmes, 2014; Newman & Clare, 2016; Sloan & Bowe, 2014).

The chapter commences with the theoretical perspective of systems theory that provides a framework for interpreting the issues relating to relationships within families and communities, followed by the research design, a qualitative approach to gather knowledge to explore lived experiences of individuals living with intellectual disability. Procedures for participant selection criteria, recruitment, data collection, and data analysis are presented, together with ethical considerations inherent in this study.

3.2 Theoretical perspective

3.2.1 Systems theory

Systems theory is relevant to almost every facet of human experience (Swango-Wilson, 2010). As a theoretical perspective, systems theory provides a framework for facilitating interpretation of issues relating to the reciprocal relationships within families and communities including the natural environments of individuals living with intellectual disability (Overmars-Marx, Thomése, Verdonschot, & Meininger, 2014; Swango-Wilson, 2010). Unlike individual theories that see a person as the whole, systems theory sees the individual as being one part of a total system or group (López-Sosa & Tévar, 2005; Porter, 2000). A system arises from a setting and can be any ongoing group, such as a family or work group that has distinctive communication patterns, responsibilities and rules where individuals can engage with each other face-to-face (Bronfenbrenner, 1979; McGuire & Bayley, 2011; Porter, 2000; Neal & Neal, 2013).

Swango-Wilson (2010) states that 'Affiliation with a system provides identity and validation' (p. 161). However, there are individuals who may not be able to sustain the expected performance to begin and continue their affiliation within a social system (Swango-Wilson, 2010).

Individuals living with intellectual disability often experience high rates of isolation. They have fewer personal and social networks and can be excluded from mainstream society (Bigby, 2008; Friedman, & Rizzolo, 2018; Gilmore & Cuskelly, 2014; Sallafranque-St-Louis & Normand, 2017; Overmars-Marx et al., 2014; Van Asselt, Buchanan & Peterson, 2015). Individuals living with intellectual disability can be supported within a defined and succinct family unit or live in supported accommodation (Bigby, 2008; Swango-Wilson, 2010). Regardless of the situation in which individuals with intellectual disability live, they could be disadvantaged further if denied access to information and communication that mainstream society can access within the broader social system (Altermark, 2016; Swango-Wilson, 2010).

Individuals living with intellectual disability generally live within several interacting social systems (McGuire & Bayley, 2011). These systems could include, but are not limited to, family systems, peer systems, legal systems, work systems, professional systems, educational systems, and community systems (McGuire & Bayley, 2011; Shogren & Turnbill, 2010). It is important to understand and consider the culture of the systems and/or norms (Goode, Jones & Christopher, 2017) that may be influencing opportunities for individuals living with intellectual disability in the development of sexual relationships linked to accessing internet-based social media. Each system, with its own culture and norms and decision-making processes, provides a framework for analysis and understanding of the results of this current study (Goode et al., 2017).

3.2.2 Ontology

The word ‘ontology’ is derived from the Greek words *ontos,* meaning ‘being’ and *logos* which means ‘word’ (Turk, 2006). Ontology is the science of what is; it is the study of the nature of being, and processes, and relationships in every area of reality (Creswell & Poth, 2018; Kafle, 2011; Smith, 2003). Smith (1995) describes ontology as, “The study of being insofar as this is shared in common by all entities, both material and immaterial. Ontology deals with the most general properties of beings in all their different varieties” (p. 463).

The present researcher’s ontological perspective resembles that of Medina-Rico, López-Ramos and Quiñonez (2000); viewing individuals living with intellectual disability as human beings who cannot be alienated from their human rights to explore their sexuality, and enjoy the same life experiences and activities that others take for granted. Sexuality is a natural aspect of what gives meaning to being human.

This present researcher’s concepts of human rights, sexuality and disability have been constructed as a result of anecdotal evidence, personal experiences, observations, and academic studies. These concepts may vary from those held by other people who view human rights regarding sexual expression and intimacy as being ‘off limits’ for individuals living with intellectual disability, perceiving them as ‘vulnerable’ and needing ‘protection’ and placing restrictions upon them (Parley, 2010).

The researcher’s ontological position was shaped by the study design and data analysis, being sensitive to the collection of data, and considering biases in analysing data in order to make appropriate coding decisions. Direct, one-to-one interviews with participants was undertaken to gain knowledge of their personal experiences and relationships as human beings within the systems in which they were involved. As Rubin and Rubin (2005) report the purpose of qualitative interviewing is to hear and understand what in the individuals living with intellectual disability think, and allow for their voice to be heard.

A researcher needs to recognise their personal beliefs, and prejudices are part of the research process (Neuman, 2003). A key component of achieving confirmability for the researcher in this study is to disclose personal biases (Miles, Huberman, & Saldaña, 2014). Consequently, the researcher declares that she has been actively involved in managing biases by being self-aware of personally held values and assumptions. This was addressed by recording reflexive diary entries that reflected and noted researcher thoughts and feelings to identify perceptions and preconceived bias. (Mantzoukas, 2005; Polit & Beck, 2012).

The researcher’s bias was recognised personally, and another researcher/supervisor from a different field checked coding with the intention of eliminating any bias. Additionally the researcher engaged in frequent debriefing sessions with supervisors to manage the analysis of the data (Shenton, 2004). Having a fresh perspective involving diverse individuals allowed for assumptions made by the researcher to be challenged, a way to develop ideas and interpretations, and to acknowledge biases (Shenton, 2004).The assumption was that input from supervisors would contribute to having varied perspectives, reflections and analyses shaping the study (Abdalla, Oliveira, Azevedo & Gonzalez, 2018). Also the researcher provided rich, vivid quotes from all participants derived directly from the data, to enable readers the opportunity to personally critique the credibility of the study and support the interpretations.

3.2.3 Epistemology

Epistemology is the study of knowledge (Steup, 2018),”that addresses the questions of what can be known and who can know it” (Converse, 2012, p.30; Creswell & Poth, 2018; Green & Thorogood, 2014; Kafle, 2011).

The present researcher's epistemological position is a belief that all knowing is interpretative and a person's reality is shaped by the meanings that they ascribe to their personal experience; believing that participants in this study are the 'experts' in their knowing (Coons & Watson, 2013; Knox et al., 2000; Larkin, Watts & Clifton, 2006; Shaw & DeForge; 2014). Willig (2008) stated: "While experience is always the product of interpretation and, therefore, constructed (and flexible) rather than determined (and fixed), it is nevertheless 'real' to the person who is having the experience" (p. 13).

This researcher recognises the expertise of individuals living with intellectual disability and the knowledge that they are able to bring to the research project (Irvine, 2010; Kitchen, 2000; Liddiard, 2014; Warren & Karner, 2010). Therefore, the present researcher has sought the perspectives of individuals living with intellectual disability in order to elucidate information to know and understand their meaning from systems of events with which they construct their reality (Sarantakos, 2013).

3.3 Research design

3.3.1 Overview of qualitative approaches to gathering knowledge

There are broadly two approaches used to gather knowledge for research purposes: quantitative (positivist) and qualitative (interpretative) (Mackey, 2005; Sarantakos, 2013). Knowledge gained using quantitative methods seeks to discover one 'truth' that does not require subjective input in the research process (Alam & Lawrence, 2009; Sarantakos, 2013). This approach has a tendency to view the researcher as an independent 'expert' on their own experience (Alam & Lawrence, 2009, p. 277; Correia, Seabra-Santos, Pinto, & Brown, 2017). Quantitative research is positivist from its epistemological standpoint; the focus being on elements and processes that can be observed and measured (such as depression, happiness, anxiety) and on causal relationships described in verification and prediction (Porter, 1996; Sarantakos, 2013). The quantitative description can be considered limited when wanting to discover meanings that participants assign to events and experiences in their everyday lives (Green & Thorogood, 2014; Sandelowski, 2000).

Qualitative research takes an epistemological stance, where the participants are the experts and the researcher someone who learns from the expertise of the participants; by adopting this stance, participants are not just viewed as passive research subjects (Knox et al., 2000). Hence, adopting a qualitative approach in this current study not only provided answers to the present researcher's questions but also allowed for insight into the participants' feelings, their perceptions, experiences, and thoughts from their personal accounts (Cresswell & Poth, 2018; Green & Thorogood, 2014; Ivey, 2012).

Qualitative research "draws on philosophical ideas in phenomenology…to support the attention on 'quality' rather than 'quantity'" (Brewer, 2003, p. 3). This form of research does not endeavour to obtain generalised findings, but to gain in-depth insight into the lived experiences of individuals and how they understand the world they live in (Denscombe, 2013; Liamputtong, 2013; Murray & Holmes, 2014).

3.3.2 Justification for qualitative approach

A qualitative approach is considered particularly suited and useful in situations where scant research has been undertaken on a phenomenon that needs to be explored and more fully understood (Carey & Griffiths, 2017; Creswell, 2014; Green & Thorogood, 2014). Qualitative research methods are effective when researching hard-to-reach and/or vulnerable target groups such as individuals living with intellectual disability (Hartley & Muhit, 2003; Waller, Farquharson & Dempsey, 2016). Liamputtong (2013) describes vulnerable individuals as being: difficult to reach, hidden, deviant, tabooed, silent, invisible and marginalised. Many individuals living with intellectual disability could fit such a description.

A positivist approach views individuals from a non-involved position claiming ‘objectivity’ allowing the researcher to explore disability from a ‘value free’ perspective (Alam & Lawrence, 2009; Waller et al., 2016). A qualitative approach was selected in this current study because it was the best way to address the aim of this study, and research questions intended to explore the perceptions, views, intentions and logic of thinking of individuals living with intellectual disability, as described in their own words. To, in essence, act as a voice for their perceptions and lived experience. As far as individual perceptions are concerned, “there is no one single truth”, (Hartley & Muhit, 2003, p. 103; Waller et al., 2016), meaning that individuals in different environments at different times, will not interpret things the same (Darling, 2007; Denscombe, 2013; Hartley & Muhit, 2003; Liamputtong, 2013; Warren & Karner, 2010).

A quantitative approach to this current study would have been problematic, since the search for generality does not take into account the complexity of the historical and social context that has influenced the lives of individuals living with intellectual disability. According to Creswell (2003), and Waller et al. (2016) the concern of quantitative research methods is with theory testing, measurements, and numbers, while the aim of qualitative research is to “understand and represent the experiences and actions of people as they encounter, engage, and live through situations” (Elliot, Fischer & Rennie, 1999, p. 216; Hesse-Biber, 2016).

Furthermore, with a focus on statistical data and quantifiable variables, quantitative research processes may not be sensitive enough to provide an understanding of and sufficiently accurate picture about feelings and experiences from a participant’s perspective (Fossey, Harvey, McDermott & Davidson, 2002). Unlike quantitative research, where the notion of external validity concerns being able to make generalisations from the sample to the general public (Payton, 1979), the purpose of qualitative research approaches is to produce hypotheses that present the need for further investigation where partial or inadequate theories exist for a particular cohort (Creswell & Poth, 2018; Denscombe, 2013; Sandelowski, 1986; Waller et al., 2016). Therefore, qualitative research was deemed the more appropriate research method to address the aim and research questions of the current study.

A goal of the current study was to use qualitative research methods as a way to develop an understanding of social phenomena in a natural, rather than experimental, setting to assist to reveal the knowledge of the person embedded in their experience (Green & Thorogood, 2014; Sousa, 2014). This was achieved by giving appropriate emphasis to the meanings, personal views and experiences of all the participants interviewed for this study (Liamputtong, 2013). It was a critical characteristic of this current study to focus on acquiring participant's expertise and experience, thereby allowing their voices to be heard and valued. Individuals living with intellectual disability without a voice are often defined by others and "treated as voiceless objects" (Turner & Crane, 2016a, p. 2300), and have been largely silent or invisible (Dowse, 2009; Welsby & Horsfall, 2011). The researcher in the current study was determined not to treat the participants as objects of research but give them the opportunity to speak for themselves (Thill, 2015). Therefore, seeking to understand the experiences of individuals living with intellectual disability and their views was an essential aspect of this study rather than seeking the views of care givers and/or service providers (Corby, Taggart & Cousins, 2015).

3.3.2.1 Phenomenology

There are a number of schools of phenomenology (Dowling & Cooney, 2012; Sloan & Bowe, 2014); while some have commonalities, they also share distinct characteristics. The philosophies of Edmund Husserl (1859-1938), who was known as being the 'founding father' of the phenomenological movement, are different from those of his follower, Martin Heidegger (1889-1976) in relation to: ways in which the interview process is influenced; the data generated; and the role of the researcher (Lowes & Prowse, 2001; Sloan & Bowe, 2014).

The goal of using a phenomenological approach in this current research was to better understand the 'lived experience' through the lens of the individual (Converse, 2012; Flood, 2010; Heshusius, 1987; Kafle, 2011; Murray & Holmes, 2014; Tuohy, Cooney, Dowling, Murphy, Sixmith, 2013; Wertz et al., 2011). Phenomenology is a qualitative research method particularly effective in highlighting the perceptions and experiences of individuals from their own viewpoint (Denscombe, 2013; Delaney, 2003; Kettunen & Tynjälä, 2018).

In this current study the goal was to accurately describe the experiences/perceptions of individuals living with intellectual disability from an account of their life from their 'voice'. By taking a phenomenological approach, the present researcher did not adopt a position on the truth or the non-truth of the descriptions the participants shared about their experiences. Hence, aspects of phenomenological research were used as this study was dependent upon being able to extract rich data from the descriptions of each participant's experiences (Denscombe, 2013; Larkin, Watts & Clifton, 2006). This was in line with the approaches of Heidegger (Heidegger 1962; Larkinet al., 2006; Mackey, 2005; Pratt, 2012; Sloan & Bowe, 2014).

3.3.3 Exploring lived experiences

According to Creswell (2000) and Willis, Sullivan-Bolyai, Knafl and Cohen (2016), there are two distinct methods of exploring lived experiences: descriptive (eidetic) and interpretive (hermeneutic) phenomenology.

3.3.3.1 Descriptive (eidetic) phenomenology

The descriptive approach to phenomenological enquiry came from Husserl's philosophical ideas (Flood, 2010) being the study of "things as they appear" so that an unbiased and rigorous understanding of human thought and experience can be reached (Liamputtong, 2010). Husserl's fundamental concern was epistemological, to provide a "foundation for knowledge" (Todres & Wheeler, 2001, p. 3) where contact to the physical world was through consciousness and that experience was how all knowledge was gained (Matua, 2015; Priest, 2002; Sloan & Bowe, 2014; Willis et al., 2016). Individuals are seen as the vehicle through which the 'essence' or essential structure of the phenomenon being studied may be understood and explained (Bryman, 2012; Green & Thorogood, 2014; Jackson & Mazzei, 2012; Matua & Van Der Wal, 2015; Priest, 2002; Silverman, 2013).

Phenomenologists attempt to provide an understanding of the essences or internal meanings of an individual's experience in their lived world by carefully directly describing that experience to understand its essential composition (Bynum & Varpio, 2018; Green & Thorogood, 2014; Priest, 2002; Sloan & Bowe, 2014; Starks & Trinidad, 2007; Taylor & Francis, 2013; Van der Zalm & Bergum, 2000; Wertz, 2005). Eidetic phenomenology specifically aims to establish the form and nature of the reality through an individual's life experience of the phenomenon (Priest, 2002; Willis et al., 2016). In its purest form, Husserlian phenomenology requires a researcher to exclude their preconceptions and shed all their prior knowledge (bracketing) from being influential in the research process (Denzin & Lincoln, 2011; Dowling, 2007; Flood, 2010; Lowes & Prowse, 2001; Silverman, 2013; Willis et al., 2016).

3.3.3.2 Phenomenological bracketing

Heidegger (1962), Husserl's protégé, thought that Husserl's opinion that a phenomenon could be perceived by a phenomenologist without having any prior knowledge was flawed. According to Heidegger (1962) all human knowledge is acquired from living in the world (Dowling, 2013; Pratt, 2012). Therefore it would be difficult for the researcher to bracket all of their knowledge of the phenomenon and see it as if it was something new to them (Corby et al., 2015; Creswell & Poth, 2018; Sloan & Bowe, 2014). Heidegger suggested that only partial bracketing could possibly be achieved, as opposed to complete bracketing, as proposed by Husserl (Denzin &Lincoln, 2011; Mulhall, 2005). Thus Heidegger claimed as follows:

> "Understanding is never without presuppositions. We do not, and cannot, understand anything from a purely objective position. We always understand from within the context of our description and involvement in the world." (Johnson cited in McConnell-Henry, Chapman, & Francis, 2009, p. 9)

3.3.3.3 Interpretative (hermeneutic) phenomenology

In contrast to a descriptive approach, the interpretative, Heideggerian phenomenology (hermeneutics) focus was on exploring the lived experience or "Dasein" ("the situated meaning of a human in the world") rather than focusing on people or phenomena (Derico, 2017; Larkin et al., 2006; Lopez & Willis, 2004; Smythe, 2012; Thompson, 1990; Wilson, 2014). Hermeneutics looks for meanings in common practices of what individuals experience rather than what they know (Flood, 2010; Henriksson & Friesen, 2012; Sloan & Bowe, 2014; Smythe, 2012; Willis et al., 2016).

The term "life-world" was used by Heidegger (1962) to convey the view that an individual's reality is always going to be influenced by the world in which that person lives (Flood, 2010; Green & Thorogood, 2014; Sloan & Bowe, 2014; Tuohy et al., 2013). While individuals were free to choose, this freedom was not unconditional, it was limited by conditions in the person's daily life (Flood, 2010; Sloan & Bowe, 2014).

The focus of the hermeneutic phenomenologist was to describe a participant's Dasein and the influence that these meanings had on the choices that they made rather than a pure description of their perceptions of the world in which they lived (Flood, 2010; Sloan & Bowe, 2014; Symthe, 2012; Tuohy et al., 2013). An interpretative phenomenological approach was used in this current research because the study was focused on exploring and giving meaning to the experiences of individuals living with intellectual disability.

3.3.3.4 Doing, justification, challenges

Larkin et al. (2011) explained that for an individual to 'bracket' their preconceptions was to suspend them, not eradicate them but allow the person to examine them (Dowling, 2013; Sloan & Bowe, 2014). As Van Manen (1990) explained, when coming from an interpretative phenomenological researcher perspective, an individual cannot suspend or bracket pre-existing ideas already accumulated (Corby, et al., 2015).

Heidegger (1962) proposed that, since a researcher is already in the world, an interpretation of that world already exists, which it is impossible for the researcher to ignore (Corby et al., 2015; Sloan & Bowe, 2014). Hence any presuppositions that evolved from the present researcher's experiences with individuals living with intellectual disability were not set aside but were clearly articulated (Corby, et al., 2015; van Manen, 1990). However, when the present researcher began this current project, the researcher had absolutely no idea what might be found from the participants, and was curious to discover the thoughts and perceptions of individuals living with intellectual disability from their personal experiences and descriptions.

The selecting of a Heideggerian philosophy, was undertaken to best answer the aim and research questions of this current study so that meaning of experiences were interpreted according to beliefs, preconceptions and experiences agreeing that 'all knowledge originates from people who are already in the world and seeking to understand other people who are already in the world' (Lowes & Prowse, 2001, p. 474; Corby et al., 2015).

Understanding is established from the prior knowledge of the researcher, and needs to be acknowledged, because it cannot be fully bracketed out (Bynum & Varpio, 2018; Corby et al., 2015; Denscombe, 2013; Finlay, 2008, 2014; Heidegger, 1962). However, the present researcher was aware of the importance of understanding the concept of 'bracketing' and approached this current study acknowledging preconceived ideas held by the researcher (Starks & Trinidad, 2007). This was in line with Finlay (2009, 2014) and Bynum and Varpio (2018), who reported that, instead of bracketing, a researcher needs to become aware of their pre-existing beliefs (Corby et al., 2015) and attempt to suspend any existing ideas (Corby et al., 2015). In view of this, the present researcher, during and after data collection, reflected on the experience, and made journal notes accordingly, to record/ acknowledge perceived biases (Bynum & Varpio, 2018; Chan, Fung & Chien, 2013).

The Heideggerian phenomenology approach focused on the person and the context of their existence (Corby et al., 2015; Mackey, 2005; Pratt, 2012; Smythe, 2012). In phenomenology, the views of participants were collected and the researcher described their common experience of a phenomenon from the participants' detailed personal accounts (Bynum & Varpio, 2018; Creswell, Hanson, Clark & Morales, 2007; Smythe, 2012). This approach was congruent with the aim of this current study as it sought to give individuals living with intellectual disability a 'voice' to describe the experiences of their everyday life (Denscombe, 2013). This gave the present researcher an understanding from the participants' perspectives to report their personal thoughts and experiences (Corby et al., 2015; Denscombe, 2013; Lowes & Prowse, 2001; Smythe, 2012).

3.4 Procedures

3.4.1 Recruitment

3.4.1.1 Purposive sampling

Individuals living with intellectual disability involved in the present study were chosen by purposive sampling; that is, research participants were sought based on their being from a particular group or having a particular characteristic (in this case, living with intellectual disability), and could best inform the researcher about the phenomena being studied (Beail & Williams, 2014; Creswell & Poth, 2018; Denscombe, 2013; Green & Thorogood, 2014; Holloway & Wheeler, 2010; Liamputtong, 2013; Punch, 2005; Sarantakos, 2013 Smith & Shinebourne, 2012; Taylor & Francis, 2013; Waller et al., 2016).

Patton (1990, p. 169) stated that the "logic and power of purposeful sampling lies in selecting information-rich cases for study in depth" and are intentionally selected in accordance with their suitability and the purpose of the study (Coyne, 1997; Denscombe, 2013; Denzin & Lincoln, 2011; Sarantakos, 2013; Smith & Osborn, 2009; Waller, Farquharson & Dempsey, 2016). A similar approach was used by Chadwick and Fullwood (2018) in their study gathering accounts of the online personal experiences of adults living with intellectual disability using the internet and social media. In the current study, disability organisations where asked to recruit participants who met the selection criteria. Intermediaries from each disability organisation were asked to select people who they felt could best inform the research, and invite them to participate after explaining the details of the study.

The rigour of purposive sampling involved the choice of information-rich cases for in-depth examination to answer research questions (Patton, 1990; Sandelowski, 2000; Sarantakos, 2013). These cases informed the present researcher of the issues most relevant and important to the study (Beail & Williams, 2014; Denscombe, 2013; Liamputtong, 2013; Patton, 1990; Sarantakos, 2013).

3.4.1.2 Criteria for participation in the study

Individuals living with intellectual disability were invited to participate in this study based on the following criteria. Participants needed to be:

- 18 years of age and over
- eligible to receive the Australian Government Disability Support Pension and/or have been assessed as having an intellectual disability and/or were eligible to receive services from government and non-government agencies in South Australia
- interested and willing to be involved in the study
- able to provide answers verbally
- geographically available to the researcher
- able to provide informed consent.

Since the research focus was on the perceptions of individuals living with intellectual disability, no other information was sought from the views of care providers and/or family members (Bates, Terry & Popple, 2017).

3.4.1.3 Access to potential participants

Once ethics was approved, the researcher contacted various South Australian disability organisations and requested that they identify, contact, and disseminate information about the study to individuals living with intellectual disability. A *Letter of Introduction* (see Appendix 1) and details of the study were sent to key people within the organisations.

Participants were sought by approaching a variety of disability services organisations and worksites in South Australia, rather than from a single source. As explained by Creswell and Poth (2018), recruiting from multiple sources is the hallmark of all good qualitative research, as it enables the ability to report on many perspectives. It was anticipated that the findings of the present research would be richer if data collection was not confined to one location or service provider organisation but dispersed in order to broaden the range of participants and vary the experiences reported in the study (Creswell & Poth, 2018).

Disability service organisations known to the present researcher, the supervision team, and recommended by colleagues and peers, were contacted to recruit potential participants that the organisations thought could best inform the research. The researcher needed to ensure that there were no coercive elements in the selection of study participants.

The present researcher sought the assistance of professional staff from 13 disability-focused organisations in South Australia, known to provide supports to individuals living with intellectual disability. These organisations were considered because they provided a broad contact base from which information about the study could be disseminated to as many as possible individuals living with intellectual disability who were aged over 18 years and living in South Australia.

Meetings were arranged with a key representative from each organisation for the present researcher to introduce herself, and answer any questions about the study and any proposed participant's involvement. The researcher provided both verbal and written information, including brochures and posters (refer Appendix 2 and 3), outlining consent and contact details required for participation in the study.

In addition, the researcher was invited to advocacy group meetings arranged by two of the targeted organisations, so as to explain the study and answer questions. The researcher took the posters already mentioned (refer Appendix 2 and 3) to the meetings, as an aid to give a better explanation about the study in written and pictorial form, in a plain-English language format. In addition, *Information and*

Consent Brochures (See Appendix 2) were made available for anyone interested in taking part in the study.

At initial contact, staff from all 13 organisations appeared keen to assist the researcher in the recruitment process. However, only seven organisations continued contact following the initial stage. While all organisations agreed to distribute information and explain the study proposal to interested individuals living with intellectual disability, one of the seven organisations withdrew the offer, claiming that they had thought about it and decided it would be too stressful for their clients. Another of the seven organisations, that had initially expressed full support for the research proposal, reported that they were then unable to refer any interested potential participants as parents/guardians had expressed concern about their family member's involvement and were unwilling to give their adult child permission to participate.

One of the organisations that agreed to distribute information invited the researcher to an advocacy meeting to talk face-to-face with their members. For this organisation, anyone who expressed an interest to participate in the study was able to meet with the group's facilitator, who would read through the pamphlet with the interested person and answer any questions or concerns they might have about the study. If an individual wanted to participate in the study, the facilitator of the advocacy group would make a time to meet with them in private and provide assistance filling out the Consent Form if asked to. The assistance of the group's facilitator was enlisted, because individuals living with intellectual disability are thought to be vulnerable when they do not have the appropriate support to help make decisions whether to participate or not (Goldsmith & Skirton, 2015). Once the form had been completed, the facilitator contacted the researcher and acted as an intermediary to make arrangements for making a time to conduct an interview.

Time and resource constraints for the present study meant that the researcher decided to proceed with the seven organisations who identified interested potential participants and not to contact any further disability-focussed organisations.

3.4.1.4 Sample size

Sampling procedures in qualitative studies are not as rigidly set down as they are in quantitative research (Coyne, 1997; Liamputtong, 2013; Sarantakos, 2013), with no set formula strictly applied to determine the sample size required (Liamputtong, 2013). Creswell (2014) took the position that sample size was dependent upon the qualitative design being adopted, and suggested, having reviewed many qualitative studies, that a sample size ranging between three to ten participants was typical for a qualitative study that used elements of phenomenology. Starks and Trinidad (2007) reported that the exact number of participants required depended upon the goals and purpose of the study.

The sample size in qualitative research has a major effect on the quality of the research and can vary depending on the research question/s and the quality of the data obtained (Denzin & Lincoln, 2011; Sarantakos, 2013; Smith & Shinebourne, 2012; Waller, Farquharson & Dempsey, 2016). Patton (1990) averred that “qualitative inquiry typically focuses in depth on relatively small samples, even single cases, selected purposefully” (p. 169). Whereas Sarantakos (2013) stated that the sample size must be “as large as necessary, and as small as possible” (p. 183).

In the current study the researcher interviewed all participants who gave informed consent, which amounted to a total of 30 people.

3.4.2 Data collection

3.4.2.1 Semi-guided interviews

Semi-guided interviews were used in this current study to collect data from the participants. Since any researcher is unable to observe feelings, thoughts, dreams and aspirations of individuals participating in any study, it was important in this study to extract individuals’ thoughts from the interview process. Using semi-guided interviews meant the researcher could delve into the social and personal issues of the participants and place their stories in the foreground of this study (DiCicco-Bloom & Crabtree, 2006; Moriarty, 2011; Newman & Clare, 2016). The processes of this study to prepare to conduct and collect and record data are depicted in Figure 3.1.

Figure 3.1 Preparation to conduct interviews and collect, and record data

3.4.2.2 Developing appropriate questions

Questions for the interview were developed in consultation with Ralph Brew, then employed at ShineSA (Sexual Health Information Networking & Education, South Australia). This specialist was selected as he was a prominent expert in the field in South Australia, having developed a specialisation in the area of sexuality and disability through ShineSA. ShineSA was a peak agency involved providing education and assessment of sexual knowledge services to people living with disabilities in addition to consultancy services to families and disability workers. At the time of the present researcher consulting with Brew, he had been working as the Coordinator of Disability Worker Education with ShineSA for nearly 10 years, and had worked in the area of sexual health as a health worker and educator since 1987.

3.4.2.3 Constructing the interview schedule

Interview questions for the current study were developed following consideration of literature that described conducting interviews/research with vulnerable populations (including individuals living with intellectual disability) (Booth & Booth, 1994; Coons & Watson, 2013; D'Eath et al., 2005; Hartley & Muhit, 2003; Irvine, 2010; McDonald, 2012; Nind, 2008; Rodgers, 1999).

The interview questions were designed to stimulate detailed responses from the participants and provide participants with an opportunity to freely express in their own 'voices' their views and experiences (Bryman, 2012; Jackson & Mazzei, 2012; Leavy, 2014; Rubin & Rubin, 2012; Silverman, 2013) of accessing (or not accessing) internet-based social media to explore sexual relationships. As argued by Molin, Sorbring and Löfgren-Mårtenson (2017), these voices were vitally important in understanding the complexities of living with intellectual disability, and internet access.

3.4.2.4 Refining interview processes through pilot testing

A pilot interview was conducted with an individual living with intellectual disability, who satisfied the criteria to participate in this study, and who was willing to participate in the pilot. This was done to assess the appropriateness and validity of the semi-structured interview questions, process, and interview style of the researcher in this current study (Waller et al., 2016). The intention of the pilot interview was to refine the interview questions and identify any problems or issues that might arise during the collection of data (Creswell & Poth, 2018; Kallio, Pietilä, Johnson & Kangasniemi, 2016; Sarantakos, 2013). For example, the pilot study established whether the interview schedule was well constructed; if the method of data collection generated enough rich data; and if any changes or adjustments were identified that required changing (Rowley, 2012; Sarantakos, 2013). The pilot was also an opportunity for the researcher to practice the techniques of interviewing, and to work on developing a relaxed and confident interviewing style (Holloway & Wheeler, 2010; Rowley, 2012; Whiting, 2008)

The researcher in this current study referred to a prepared interview guide (see Appendix 4) and, during the pilot interview, practiced the wording of some of the more sensitive questions about sexuality, and considered how to handle any difficulties should they occur (Smith, Flower & Larkin, 2009; Smith & Osborn, 2009). The pilot interview took 42 minutes and was analysed to establish if the questions had been framed in such a way that the participant had understood and been able to respond and provide the rich data that the study sought.

At the end of the interview, feedback was sought from the participant about their perceptions of the interview process. The interview transcript was also reviewed and discussed with the three academic supervisors of this current study. The feedback from both the participant and the researcher's supervisors did not indicate that the interview questions or interview style of the researcher required significant modification and, for this reason, the pilot interview was able to be included within the final data set for analysis.

3.4.2.5 Location chosen by participants for interview

Participants were interviewed at a location of their choosing. Thirty interviews were conducted: 23 at the place of employment of the individual participant, in a quiet, private room; three participants opted to be interviewed in their own home; two in a private room at the university where the researcher worked; one in a café of the participant's choosing; and one was interviewed before attending an advocacy group meeting. Only one participant asked for someone to be with them during the interview and chose for the participant's 'mentor' to be present; the mentor was with the participant for support but did not participate in the interview. A married couple who participated in this study wanted to be interviewed together in their own home.

3.4.2.6 Confirming informed consent and advising privacy and anonymity protected

At the commencement of each interview in this current study, the researcher reaffirmed on the audio recording that participation was voluntary; participants could withdraw at any time; and could refuse to answer any question without negative repercussions. Participants were asked to complete a consent form and/or provide verbal consent on the electronic recording as evidence of their provision of informed consent to participate in this study.

At the beginning of each interview in this current study, the researcher invited participants to assign themselves a pseudonym that would only be known to themselves and the researcher; this was done to protect the anonymity of the participants and the confidentiality of the data (Creswell & Poth, 2018; Green & Thorogood, 2014; Liamputtong, 2013). It was also to help participants feel empowered that that they had some control over the process (Coons & Watson, 2013; Irvine, 2010). The researcher also assigned pseudonyms to any additional actual names mentioned in the interviews, and used general terms in place of the name of any service provider and other specific organisations.

Along with written consent, all participants gave verbal permission for their interview to be audio recorded. The researcher pre-warned each participant before asking questions that might, for some individuals, be considered to be sensitive. The importance of the participant's opinions was emphasised at the beginning and end of each interview, while reminding participants that anything they told the researcher would remain confidential. The researcher spent time emphasising to the participants that they did not have to answer any question(s) they did not want to and could withdraw at any time (Moriarty, 2011).

3.4.2.7 Data collected in interviews

Interviews for this current study were conducted over an average of 22 minutes (10-46 minutes). The interviews were designed not to go for too long, in order to maximise participant's engagement; acknowledging some participants may have difficultly elaborating on answers. The researcher made reflective notes during and immediately after each interview and analysis (Liamputtong, 2013; Smith et al., 2009) on the behaviours and activities of the participants, noting any non-verbal communications and facial expressions linked to question responses. Noting these observations provided insight into participants' possible level of comfort with the research processes and reaction to sensitive subjects not normally talked about with participants. The researcher needed to move on from a question that appeared had made the participant feel uneasy and/or had difficulty answering on only a few occasions.

According to Scerri, Abela and Vetere (2012) debriefing is an essential component of interviewing where potentially sensitive issues had been discussed, regardless of whether the participant had appeared upset or not. In consideration of this, the researcher invited participants to comment on the interview (Noble & Smith, 2015) and raise any concerns they may have had from taking part (Waller et al., 2016).

The interview process was reflected upon after each meeting and a brief analysis carried out to refine interview processes for subsequent interviews if required (Warren & Karner, 2010). Recordings of each interview were saved as an electronic audio file on a secure and private computer as soon as possible after each interview.

On completion of the interview, to compensate and thank participants for their time and expertise, the researcher gave each participant a $25.00 gift voucher to spend at their choice of any one of several department stores.

3.4.2.8 Process of transcribing the interview

Transcription is regarded as a 'pivotal aspect of qualitative enquiry' (Oliver, Serovich & Mason, 2005, p. 1273) and an integral part of the continuous nature of the data analysis process. Producing and annotating accurate transcripts is a fundamental first step in data analysis (Denscombe, 2013; Dickerson-Swift, James, Kippen & Liamputtong, 2007). For this current study, each interview was transcribed verbatim, solely by the researcher as soon as possible after the meeting with each participant. This was an effective way to get very familiar with and close to the data (Denscombe, 2013; Walleret al., 2016). In addition, confidentiality was maintained as the researcher was the only one to hear the recordings (Callus, 2017).

Since an objective of this current research was for the voices of individuals living with intellectual disability to be heard, the researcher endeavoured to capture every utterance recorded in as much detail as possible. Doing this meant that the researcher used a naturalism approach to transcription (Oliver et al., 2005). This approach captured every utterance; subtle pause; and intonation made by participants in as much detail as possible and would be used to assist the researcher make sense of the data during analysis (Azevedo et al., 2017; Finlay, 2014; Liamputtong, 2013; Oliver et al., 2005).

During transcription, any identifying information about the participant's real identity was removed to ensure confidentiality was maintained (Liamputtong, 2013). The current study's academic supervisors were given access only to participant pseudonyms. The researcher kept a list of participant's names and pseudonyms in a separate file in a locked filing cabinet, so that there could be no direct connection made between data and participants (Creswell & Poth, 2018; Liamputtong, 2013; Waller et al., 2016). All original recordings, copies of transcripts, coding information, contact lists, letters and signed consent forms were stored in a locked filing cabinet (Dempsey et al., 2016; Liamputtong, 2013).

3.4.2.9 Additional information recorded in field notes and memos

The researcher in this current study made field notes, known as 'memos', throughout the process, and immediately after, to document thoughts and observations (Denscombe, 2013; Francis, 2013; Green & Thorogood, 2014; Liamputtong, 2013; Starks & Trinidad, 2007). As experienced by Turner and Crane (2016b), the field notes recorded the researcher's initial thoughts and impressions directly after each participant interview/contact (Frawley & Bigby, 2014; Snowden, 2015; Waller et al., 2016). See Figure 3.2 as an example of a field note recorded immediately after one of the present researcher's interviews:

Figure 3.2 Memo after data collection

> *James appeared to be high functioning and was able to give more articulated answers than some of previous participants. James was even reading the next question upside down and working on his answer to that one while talking.*
>
> *While at times I found myself asking closed questions James was not just giving yes/no answers.*
>
> *We were able to build a rapport very early in the interview.*
>
> *So far it has been mothers who have been gatekeepers…for sons and/or daughters.*
>
> *I have found that by personally transcribing the interviews, I have the opportunity of reliving the emotional and non-verbal messages by participants that I might not experience reading transcripts done by a third person.*

The field notes (memos), provided a permanent and tangible record of ideas and decisions made by the researcher (Creswell, Poth, 2018; Denscombe, 2013; Green & Thorogood, 2014; Maz, 2013; Newman & Clare, 2016; Smythe, 2012). As informed by Clarke (2009) reflective entries provided a "vehicle for discovery and learning in [the] roles of researcher and analyst" (p. 76). These included a record of ideas the researcher had about elements of the data being collected, and encouraged the sorting and reworking of ideas; observations made during data collection; and descriptive and theoretical ideas (Denscombe, 2013; Engward, 2013; Green & Thorogood, 2014; Harris, 2014; Maz, 2013; Willis et al., 2016). The memos were used by the researcher to refine and make meaning of the data (Creswell & Poth, 2018; Waller et al., 2016; Liamputtong, 2013; Vaismoradi, Jones, Turunen & Snelgrove, 2016).

3.4.3 Role of the researcher

It is important to consider what the researcher brought to this project (Smith et al., 2009) through the history and assumptions held at the commencement of this study. The present researcher was positioned in this study as an active listener (Dowling et al., 2016) in the role of an absorbed collaborator whose interest lay in discovering the richness and depth of the lived world of the study's participants.

An epistemological stance was adopted by the researcher, where participants were seen as the experts, and the researcher the person who learned from the experts (Carey & Griffiths, 2017; Coons & Watson, 2013; Knox et al., 2000). This was also in keeping with empowerment, where the researcher saw the role of researcher to be a facilitator, rather than controller, who encouraged the participants to play an active, rather than passive, role in the interview process. The researcher did this by checking with participants if they had any more to add, during and at the conclusion of the interview.

Many times the 'voices' of individuals living with intellectual disability have not been included in research, resulting in their perspective being lost. The researcher in this current study wanted to avoid this happening (Irvine, 2010). The role of the researcher in this study was to provide a forum wherein the voices of the participants could be heard (Smythe, 2012) and valued, and not lost, but brought out in the open by acknowledging and documenting the participants' experiences and perceptions. During contact with the participants in this study the researcher made a deliberate effort to act as a peer who was interested in the thoughts and experiences of the participants and not as a person of 'power' who the participants had to please. This was deemed to be a crucial stance by the researcher for elucidating trustworthy responses.

Additionally, the researcher avoided using professional jargon and dressed neatly and casually, in the hope that participants perceived the researcher as a peer rather than a 'professional or researcher' or someone of 'power'. In the early 'breaking the ice' stage of meeting with the participants, before commencing the interview, the researcher explained that the interest was only in the participant's 'voice' and the desire was to discuss the participant's ideas and thoughts, and learn about their experiences and desires. The researcher explained there was no idea what the participant was likely to say and there were no 'right' or 'wrong' answers (Corby et al., 2015; Warren & Karner, 2010).

3.4.4 Ethics considerations

Ethical considerations are paramount in qualitative research (Liamputtong, 2013) and, according to Denscombe (2013), attaining ethics approval is fundamental to all good research. Therefore ethics approval was sought from and granted by the Flinders University Social and Behavioural Science Ethics Committee: Project Number 6377, in 2013.

In addition, one of the disability service organisations would not allow the researcher to conduct interviews unless they too gave ethics approval for the study to go ahead. The researcher met with members of an ethics committee from the disability service organisation to elaborate on details of the study and discuss benefits to participants. Once the committee discussed the researcher's credentials and perceived benefit to participants, the committee granted approval to conduct the study at their organisation.

The current study employed a range of measures to ensure that ethical behaviour was maintained and that the rights of every participant was protected at all times.
An important measure was the development of an information and consent brochure (see Appendix 2). The information in the brochure included:

- an outline of the purpose and aims of the research
- assertion that participation was voluntary and included the right to withdraw at any time without disadvantage
- consent forms

- information on support from
    - In-house counselling
    - Lifeline (24 hour counselling service) 13 11 14
    - Shine SA (Sexual Health Information Networking & Education) 1300 883 793
- contact details of the researcher, the principal supervisor and the Flinders University Social and Behavioural Research Ethics Committee.

Research should not cause harm to participants (Dempsey, Dowling, Larkin & Murphy, 2016; Denscombe, 2013; Liamputtong, 2013; Ruane, 2015; Waller et al., 2016; Warren & Karner, 2010). However, it was not, in the case of this current study, possible to predict or know in advance the likelihood of any negative consequences resulting from participation in the research by respondents (Dowling et al., 2016; Ruane, 2015), so it was required to have a plan that addressed any issues should they emerge (Creswell & Poth, 2018; Liamputtong, 2013). It was anticipated that participation in this current study could bring out emotional reactions or anxieties in participants after discussing sensitive issues not previously considered (Liamputtong, 2013).

For this reason, a measure used to promote ethical behaviour was for the researcher to ensure participants had access to post interview debriefing and support (Liamputtong, 2013; Ruane, 2015). To aid participants, the researcher ensured a range of appropriate supports; natural, and in-house case counselling were available to participants if involvement in this study raised concerns for any participant.

3.4.5 Criteria for participation in the study

Individuals with intellectual disability were invited to participate in this study based on the following criteria. Participants needed to be:

- 18 years of age and over
- eligible to receive the Australian Government Disability Support Pension and/or assessed as having an intellectual disability and/or eligible to receive services from government and non-government agencies in South Australia
- interested and willing to be involved in the study
- able to understand questions and provide answers verbally
- geographically available to the researcher
- able to provide informed consent.

Since the research focus of this current study was on the perceptions of individuals living with intellectual disability, no other information was sought on the views of service providers or family members (Bates et al., 2017).

See Appendix 5 for an outline of demographic information regarding participants interviewed. Details include their age, employment status, accommodation type and marital status.

3.5 Data analysis

A thematic analysis approach was used to analyse the findings. Qualitative analysis is a methodical, continuous process of observing, recording, reviewing and interpreting data to explain the phenomenon being studied (Creswell & Poth, 2018; Fossey et al., 2002; Liamputtong, 2013). The interpretive approach underlying qualitative methodologies holds that "individual thinking, as well as collective action, has intelligible meaning that can be identified, described, explored, analysed, and synthesised into coherent themes" (Minichiello & Kottler, 2010, p. 13; Green & Thorogood, 2014). This approach delivers an audit trail that adds to dependability of data analysis where in-depth descriptions of the research methods followed are provided.

The researcher in this current study began the process of analysis, engaging with data at the commencement of collection (Denzin & Lincoln, 2011; Engward, 2013; Harris, 2014; Liamputtong, 2013; Sandelowski, 2000; Smythe, 2012; Waller et al, 2016). Data were collected and analysed to allow concepts and theory to emerge through a process of continuously comparing the data (Creswell & Poth, 2018; Engward, 2013; Green & Thorogood, 2014; Harris, 2014; Markey, Tilki & Taylor, 2014; Merriam, 2009; Starks & Trinidad, 2007), using Glaser and Strauss's (1967) 'constant comparative method' (Glaser, 1965, p. 438).

Data were continuously compared as acquired over the life of the research (Green & Thorogood, 2014; Maz, 2013; Merriam, 2009; Nicholls, 2009; Waller, et al., 2016). In line with the research descriptions of Green and Thorogood (2014) data analysis and data collection continued simultaneously as the researcher made memos and documented their thoughts and observations. Memos were made during data collection and data analysis because it helped prompt analysis of "data and codes early in the research process" (Charmaz, 2014, p. 162).

The present researcher spent considerable time listening repeatedly to interview recordings, reading and rereading transcripts, and making annotations of initial comments and preliminary interpretations as a way to fully immerse in and connect to the data (Denscombe, 2013; Finlay, 2014; Smith & Shinebourne, 2012; Vaismoradi et al., 2016; Warren & Karner, 2010). Doing this allowed the researcher to gain a better sense of what the participant was trying to convey and represent participants' valid views (Denzin & Lincoln, 2011; Kuckartz, 2014; Rubin & Rubin, 2012; Silverman, 2013; Vaismoradi et al., 2016).

With each interview review, new insights were generated (Liamputtong, 2013). From the noted observations and reflections the researcher recognised points of potential significance and made initial interpretative comments. The initial notes were converted into brief phrases or emerging themes with the aim of succinctly capturing the essential meaning of what the participants had said during the interview.

After each interview, transcripts were examined, compared and contrasted by one of the researcher's university supervisors experienced in qualitative research methods. The first readings of transcripts, combined with supervisor discussions, assisted to link the initial data to the research questions and establish coding categories and themes.

Coding was central to this research study because it involved making sense of the data recorded in the transcripts (Creswell & Poth, 2018; Denscombe, 2013). The option to code manually over the use of computer software programs for analysis and interpretation was adopted as it allowed for "rudimentary analysis" to occur (Merriam, 2009, p. 174). The researcher preferred to work with 'hard' copies printed from word processor files so that different themes and meanings that emerged could be physically cut up and manually sorted and rearranged to identify patterns and connections (Green & Thorogood, 2014). This enabled naturally emerging themes and categories to be identified (Denscombe, 2013).

The researcher in this current study (inspired by Love, 1995) did this by photocopying the transcripts and colour coding emerging themes using different colour highlighter pens. Next, a manual exercise involving all the data and scissors was enlisted. Each colour was cut individually, placed in coloured piles, and then adhered to a large board in each category (see Appendix 6). This allowed for the researcher to look for any connections between the emerging themes, place them into groups guided by conceptual similarities, and label each cluster (Fade, 2004; Green & Thorogood, 2014). The aim was to arrive at a group of themes and categories and start to discuss the meaning of the data (Biggerstaff & Thompson, 2008; Green & Thorogood, 2014). The allocation and development of thematic categories were refined as the research progressed (Green & Thorogood, 2014; Waller et al., 2016; Warren & Karner, 2010).

Since analysis was a continuous process, as the data analysis progressed, any additional themes that emerged were put into new categories or existing themes (de Laine, 1997; Green & Thorogood, 2014; Sarantakos, 2013). This process was carried out for every interview transcript. Emerging themes were then listed and clustered into groups of connected themes for each participant.

Next, the research team engaged in a series of discussions to identify and shape the themes and categories. All of the academic supervisors were involved in this stage of analysis and agreed on the main themes that emerged inductively and the sub themes discussed and shaped into 18 sub themes (Goodrick & Rogers, 2015; Lincoln & Guba, 1985; Robinson, Clare & Evans, 2005). Once thematic categories were refined, the researcher developed a 'master' list, or table, of themes. According to Biggerstaff and Thompson (2008), an important process was locating these themes and arranging them in an ordered system that identified the main areas acknowledged by the participant. A table was produced with main and minor thematic categories identified for this current study (see 4.1).

3.6 Ensuring quality

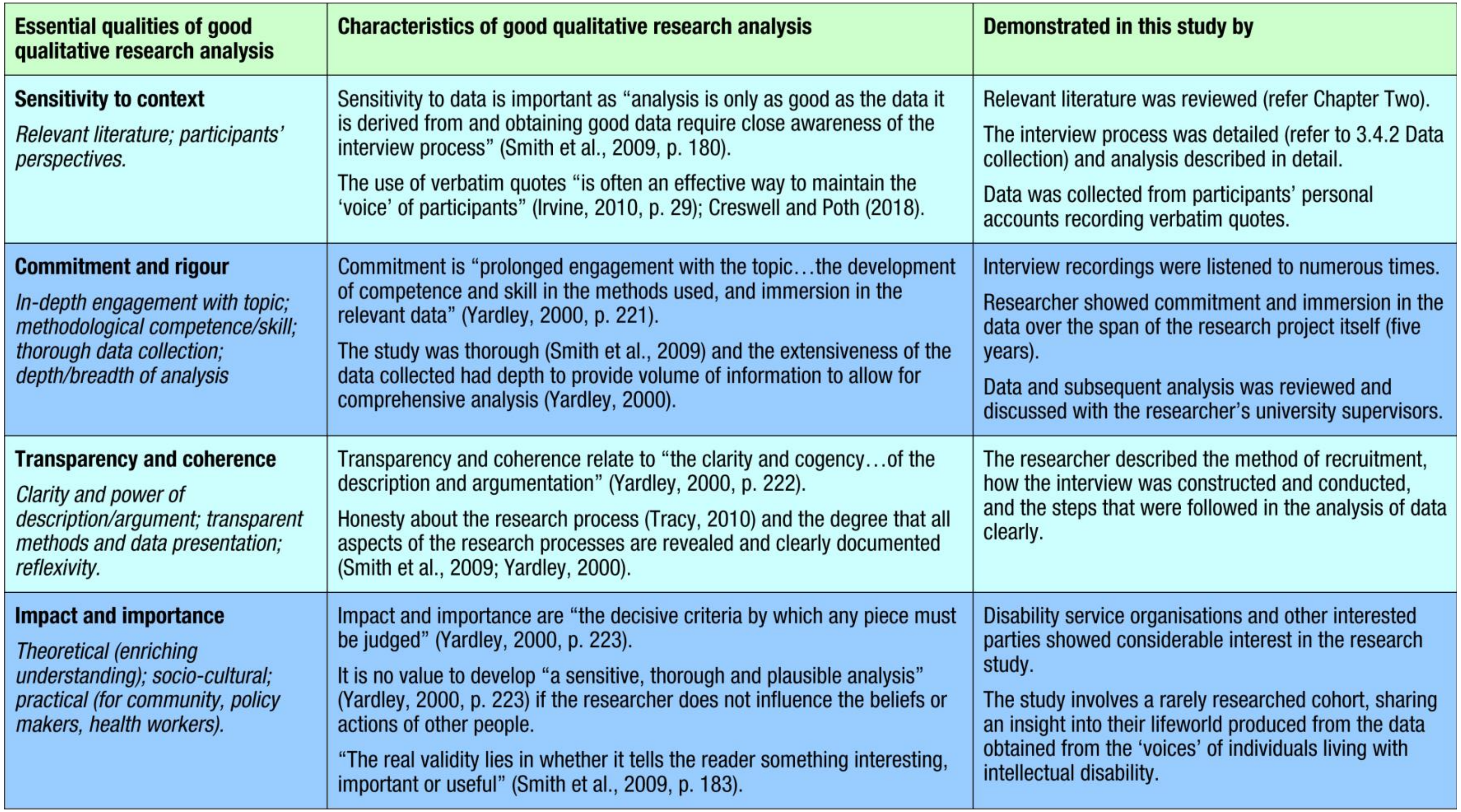
The evaluation of qualitative research is an important element of the research if the findings are to be applied in future policy or practice (Noble & Smith, 2015). Lincoln and Guba (1985) asked "How can an inquirer persuade his or her audiences that the research findings of an inquiry are worth paying attention to?" (p. 90). It can often be a challenge to assess whether research is any good (Seers & Toye, 2012). For research findings to "change how we think and how we practice" we need to have confidence in what is reported (Seers & Toye, 2012, p. 1). According to Yardley (2017) qualitative analysis must be able to: show sensitivity to context; commitment and rigour; transparency and coherence; and impact and its importance (Goldbatt, Karnieli-Miller & Neumann, 2011). Each of these characteristics and how they have been met in this present study are presented in Table 3.1.

3.6.1 Study rigour

Qualitative research offers insights into social or personal experiences which are subjective, but no less real (Giacomini & Cook, 2000; Sarantakos, 2013). Although qualitative researchers prefer to use the terms 'credible', 'trustworthy' or 'dependable' rather than 'valid' or 'reliable' (Sarantakos, 2013), it is important that researcher insights emerge from systematic observations and that competent interpretation corresponds to the actual life experiences of the participants.

The traditional positivist meanings of validity have little relevance for qualitative studies (Kvale, 1995), unlike quantitative research, where the notion of external validity concerns being able to make generalisations from the sample to the general public (Payton, 1979), the purpose of qualitative research approaches is to produce hypotheses that present the need for further investigation rather than testing them (Lopez & Willis, 2004; Sandelowski, 1986).

Table 3.1 Demonstrating good (qualitative) research



Essential qualities of good qualitative research analysis	Characteristics of good qualitative research analysis	Demonstrated in this study by
Sensitivity to context *Relevant literature; participants' perspectives.*	Sensitivity to data is important as "analysis is only as good as the data it is derived from and obtaining good data require close awareness of the interview process" (Smith et al., 2009, p. 180). The use of verbatim quotes "is often an effective way to maintain the 'voice' of participants" (Irvine, 2010, p. 29); Creswell and Poth (2018).	Relevant literature was reviewed (refer Chapter Two). The interview process was detailed (refer to 3.4.2 Data collection) and analysis described in detail. Data was collected from participants' personal accounts recording verbatim quotes.
Commitment and rigour *In-depth engagement with topic; methodological competence/skill; thorough data collection; depth/breadth of analysis*	Commitment is "prolonged engagement with the topic…the development of competence and skill in the methods used, and immersion in the relevant data" (Yardley, 2000, p. 221). The study was thorough (Smith et al., 2009) and the extensiveness of the data collected had depth to provide volume of information to allow for comprehensive analysis (Yardley, 2000).	Interview recordings were listened to numerous times. Researcher showed commitment and immersion in the data over the span of the research project itself (five years). Data and subsequent analysis was reviewed and discussed with the researcher's university supervisors.
Transparency and coherence *Clarity and power of description/argument; transparent methods and data presentation; reflexivity.*	Transparency and coherence relate to "the clarity and cogency…of the description and argumentation" (Yardley, 2000, p. 222). Honesty about the research process (Tracy, 2010) and the degree that all aspects of the research processes are revealed and clearly documented (Smith et al., 2009; Yardley, 2000).	The researcher described the method of recruitment, how the interview was constructed and conducted, and the steps that were followed in the analysis of data clearly.
Impact and importance *Theoretical (enriching understanding); socio-cultural; practical (for community, policy makers, health workers).*	Impact and importance are "the decisive criteria by which any piece must be judged" (Yardley, 2000, p. 223). It is no value to develop "a sensitive, thorough and plausible analysis" (Yardley, 2000, p. 223) if the researcher does not influence the beliefs or actions of other people. "The real validity lies in whether it tells the reader something interesting, important or useful" (Smith et al., 2009, p. 183).	Disability service organisations and other interested parties showed considerable interest in the research study. The study involves a rarely researched cohort, sharing an insight into their lifeworld produced from the data obtained from the 'voices' of individuals living with intellectual disability.

Note. Adapted from Yardley, Lucy (2000). Dilemmas in qualitative health research, Psychology & Health, 15(2), p. 219.

In qualitative research, validity is related to whether the findings of a study are 'true or certain' (Denscombe, 2013; Guion, 2002, p. 1). 'True' relates to the findings accurately representing the real situation and 'certain' means that there is enough evidence to support the study's conclusions (Guion, 2002). Polkinghorne (2005) agrees, reporting that validity and trustworthiness are related to the selection of feasible sources that support the deepening of the understanding of the experience being asked about; and to assess the "accuracy" of the findings (Creswell & Poth, 2018, p. 259; Liamputtong, 2013).

Table 3.2 elements to achieve rigour

Elements of rigour	How it was addressed in this research
Credibility	➢ Past literature reviewed ➢ Consistent interview technique of researcher ➢ Peer validation from university supervisors and external expert ➢ More than one researcher identified the themes
Transferability	➢ Clear identification criteria for participants ➢ Adequate descriptions of sample and setting ➢ Nominated purposeful sample of individuals living with intellectual disability representative of a wider demographic of participants in disability service organisations ➢ In-depth description of the data collection process and data analysis
Dependability	➢ Evidence of an audit trail including an in-depth description of research methods ➢ Documentation of the steps involved in data collection and analysis ➢ Use of citations so that readers are assisted to link the categories with the original data ➢ Peer review
Confirmability	➢ Strategies were used to limit bias in the research, such as: • Researcher kept a reflective journal • Peer review by university supervision team who audited the decision points throughout the study • Checking ideas and interpretation of data with expert colleagues (university supervisors) throughout the research process • Review of the audit trail which included raw data and thematic analysis ➢ Raw data has been stored securely if it is needed for future reference

Elements to achieve rigour adopted from Morse et al., (2002) and Letts et al., (2007).

In the current study, thematic analysis and data checking was performed by the research team to enhance ‘accuracy’ of findings and facilitate the validity of data coding and analysis. The researcher engaged university supervisors to evaluate the study, comment on findings and verify coding as themes emerged. The congruence from the comparison of each evaluator’s findings and conclusions determined whether validity had been established (Creswell & Poth, 2018; Guion, 2002). Another strategy utilised in this current study in an attempt to strengthen accuracy of findings was checking back with participants during their interview to confirm interpretations were accurate (Taylor & Francis, 2013).

According to Letts et al. (2007), when considering rigour the overarching concept is trustworthiness, made up of four components: credibility, transferability, dependability, and confirmability. Morse, Barrett, Mayan, Olson and Spiers (2002) stress the importance of credibility, transferability, dependability, and confirmability in qualitative research, because “without rigour, research is worthless” (p. 14). Table 3.2 outlines how these elements were achieved to demonstrate the current study’s rigour.

Chapter summary

This chapter has described the present study’s theoretical perspective and research approaches and explained how the participants’ experiences and perceptions were collected and analysed. Data collection techniques consisted of semi-guided in-depth interviews and reflective field notes, followed by thematic analysis. Details relating to demographics of participants, ethical considerations and threats to the integrity of research design were also presented. Chapter Four will present the findings of interviews of 30 participants living with intellectual disability that sought to explore their experiences of accessing (or not accessing) internet-based social media to develop and explore social and sexual relationships.

Chapter Four
Findings

4.1 Introduction

This chapter presents the findings from interviews undertaken with 22 males and eight females living with intellectual disability about their experiences of accessing (or not accessing) internet-based social media to develop and explore social and sexual relationships. All 30 participants involved in this study resided in South Australia and details of their employment status, accommodation living arrangements, their relationship status, and support providers will be described. This chapter will then outline the data that was collected and the seven main themes and 18 subthemes that emerged from this data.

Findings from the data addressed the following research questions:

- Are individuals living with intellectual disability accessing internet-based social media, and if so, what are the applications, sites and activities they are engaging with?
- What are the experiences of individuals living with intellectual disability accessing internet-based social media to develop social relationships and potentially engage in sexual activities?
- What (if any) barriers do individuals living with intellectual disability experience in accessing internet-based social media to develop social relationships and engage in sexual behaviours?

4.2 Demographics

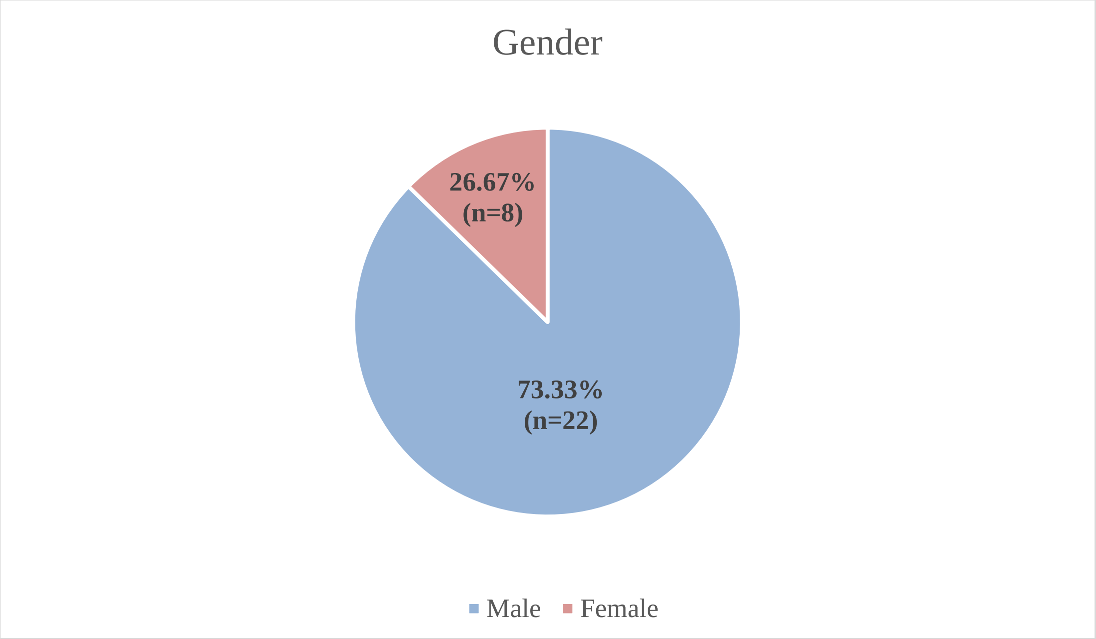
Thirty individuals with intellectual disability either living in community accommodation, private rental or with parents consented to be interviewed for the present study. Appendix 5 displays a summary of participants' demographic characteristics outlining their chosen pseudonym, gender, age, work status, living arrangements, relationship status, and providers of support. The age range was from 20 to 66 years, with an average age of 35.4 years.

While participants' level of disability was not formally assessed, interviews provided an opportunity to gather observational data indicating 27 participants' cognitive impairment appeared to have minimal impact on their communication and level of understanding of the questions they were being asked. These participants were articulate and had a functional level of receptive and expressive communication. However, three participants required prompting and rephrasing of some questions, and additional time was required to give them more time to answer. Two of the three participants who required prompting also needed redirection to the question they were answering as they were keen to relate personal stories not relevant to the interview question. The third participant struggled to answer all questions, however was able to provide relevant responses to some questions.

4.2.1 Gender of participants

Figure 4.1 shows the breakdown of gender for participants in this study: 22 males (73.4%) and eight females (26.6%).

Figure 4.1 Gender of participants



4.2.2 Age of participants

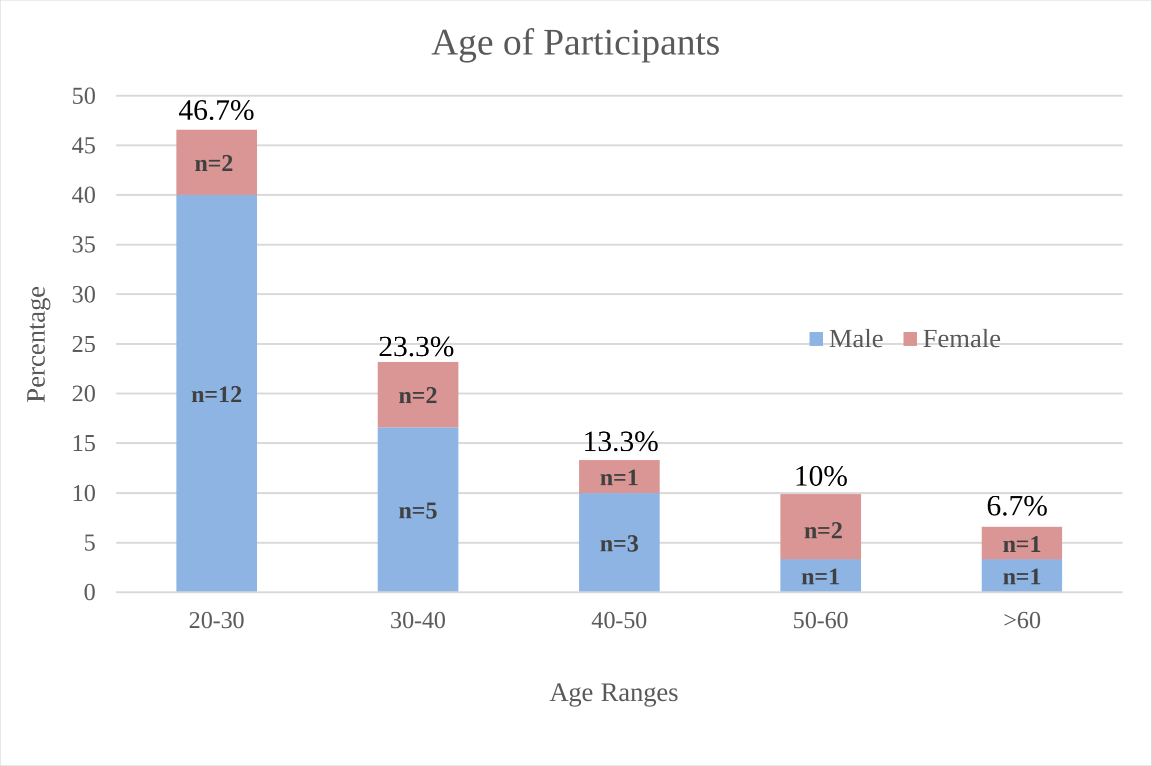
The average age of participants in this study was 35.4 (range 20-66) years old. The average age of the eight female participants was 41.6 years (range 26-63 years) and the average age of the 22 male participants was 33.1 years (range 20-66 years).

A further breakdown in Figure 4.2 shows the number of males and females in each age range.

4.2.3 Employment

The majority of participants in this study were engaged in some form of employment. Twenty-six participants (86.6%) were employed, two (6.7%) were retired and two (6.7%) were volunteers. Of those who were employed, all worked in Australian Disability Enterprises (ADEs) at the time of the interview, with 18 (60.0%) in full-time roles and eight (20.6%) in part-time roles. Figure 4.3 displays an overview of the employment status of the participants in this study.

Figure 4.2 Current age of participants at time of interview



According to the Australian Government Department of Social Services (DSS) (2017) "ADEs play an important and valuable role in providing employment opportunities to people with disability across Australia." In Australia ADEs operate within a commercial context supporting individuals living with disability to engage in many different work tasks such as production, packaging, recycling, assembly, plant nursery, maintaining gardens, laundry services, cleaning and food services (DSS, 2017). The work duties performed by participants in this current study included: garden maintenance (n = 1); administration (n = 2); laundry (n = 4); packaging (n = 5); assembly (n = 3); production (n = 3); cleaning (n = 5); and recycling packaging (n = 3).

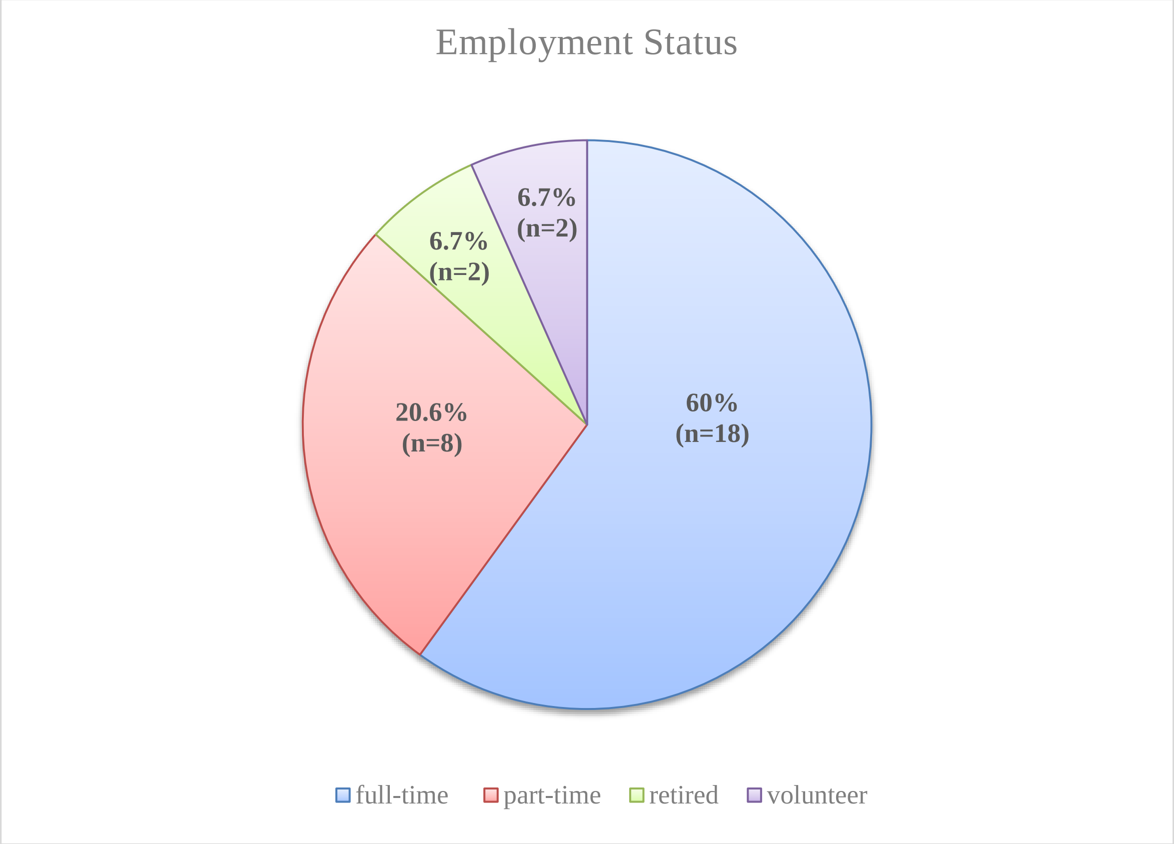
4.2.4 Geographical location

All 30 participants lived within three main geographical areas of South Australia. Twenty-four participants lived within metropolitan Adelaide (approximately 20km range from Adelaide's central business district (CBD)), five lived in outer metropolitan Adelaide (approximately 20-30km range from CBD) and one participant lived approximately 75km from the CBD, in rural South Australia.

4.2.5 Accommodation

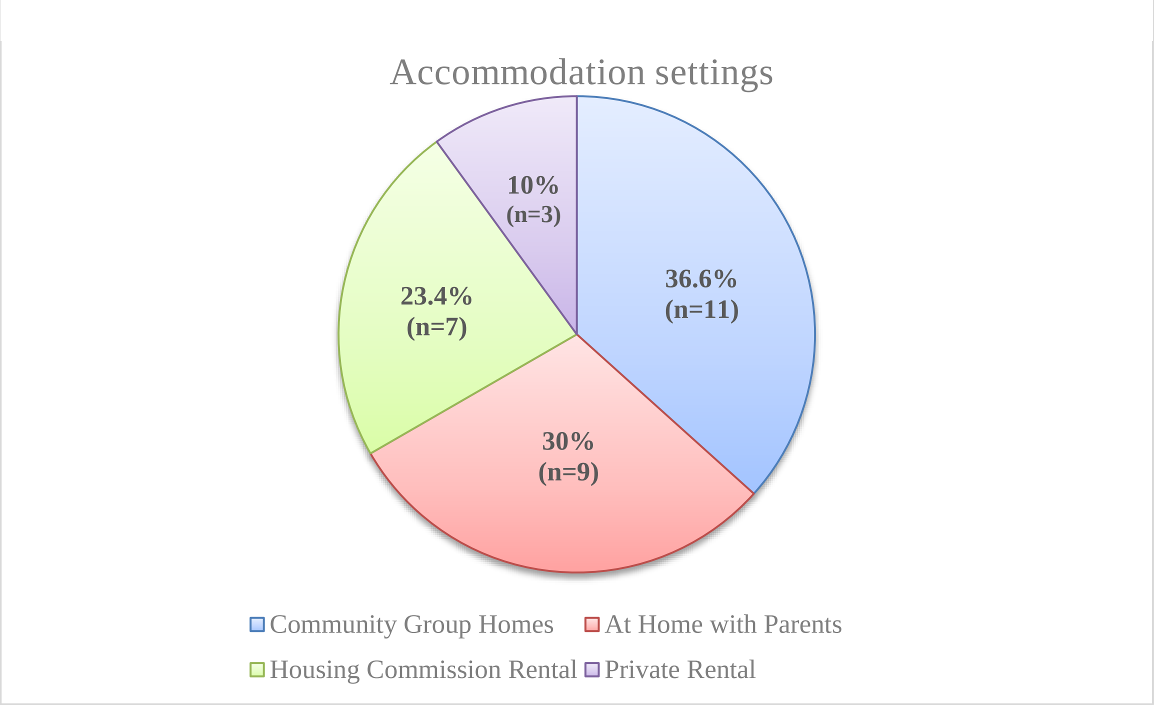
At the time of the interview 11 participants (36.6%) lived in community group homes owned by the government or a government-funded accommodation service. Ten of these participants lived in shared accommodation with two to five other people with a disability, with one other participant sharing with another person he referred to as his ‘mate’.

Figure 4.3 Employment status of participants



Nine participants (30%) lived at home with their parent(s) and/or siblings, including one participant with his parents and girlfriend. Seven participants (23.3%) rented their home from the state housing commission, with four of these participants living alone, one participant living with her husband and daughter, and a married couple who lived together. Three participants (10%) lived in private rental. Figure 4.4 displays a breakdown of the different accommodation settings the participants of this study resided in.

Figure 4.4 Accommodation settings



4.2.6 Relationship status

Of the 30 participants in this study, 50% reported being single and not in a current relationship (11 males and four females); 30% reported they were seeing someone they referred to as either their girlfriend or boyfriend (eight males and one female); 13.3% were married (two males and two females); and 6.6% (one male and pone female) had been divorced. Figure 4.5 provides the breakdown of participants' relationship status.

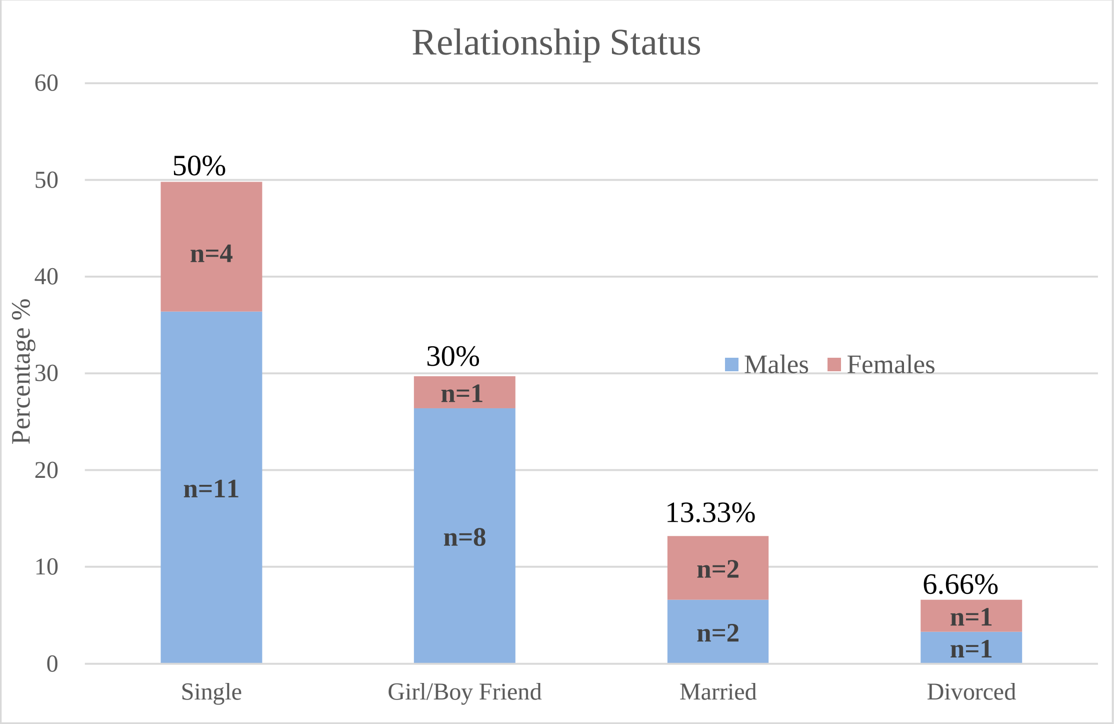
4.2.7 Providers of support

The majority of participants in this study reported family member(s) were their main providers of support. Of the 30 participants, 26 (86.6%) reported receiving support from a parent(s), two (6.7%) received support from a sibling, and two (6.7%) reported not receiving any formal support. Of the 26 (86.6%) participants who received support from a family member, three (9%) reported also having support from a key worker from a State or Commonwealth government-funded disability service provider.

4.3 Technology and internet-based social media

The next section addresses the first research question; "Are individuals living with intellectual disability accessing internet-based social media and if so what are the applications, sites and activities they are engaging with?"

Figure 4.5 Relationship status of participants



This section identifies the types of technology that participants in this current study owned/used and the internet-based social media applications they accessed and engaged in.

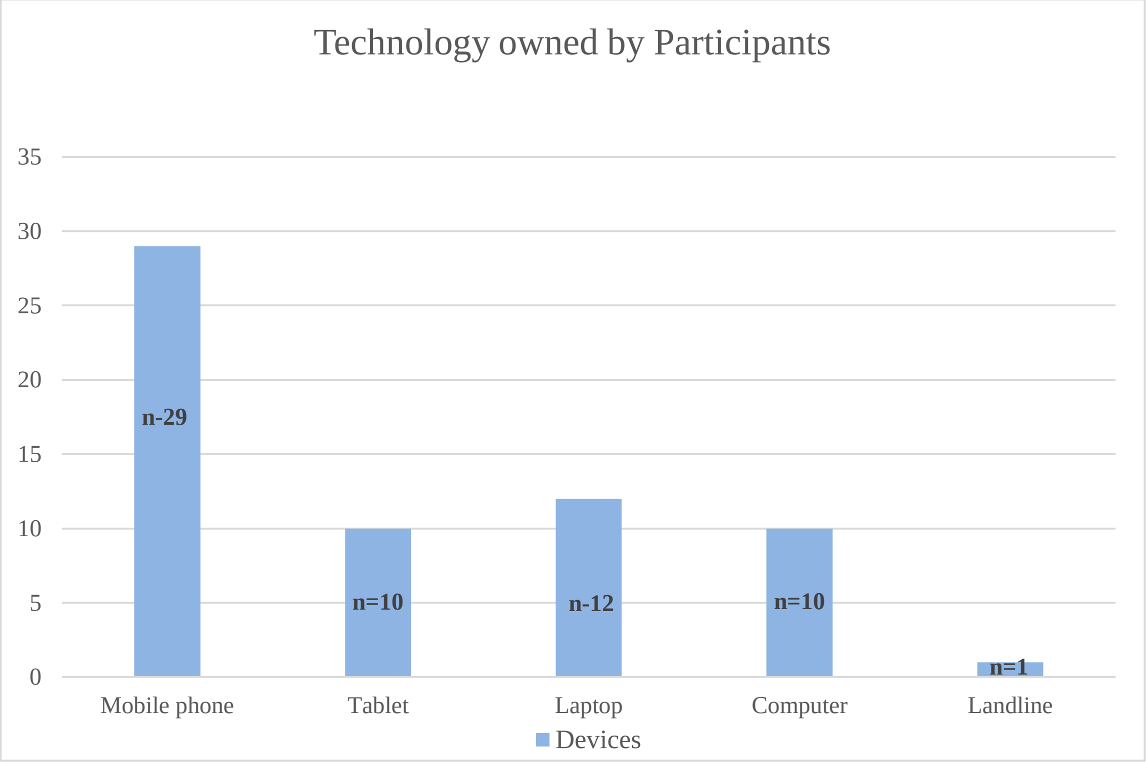
4.3.1 Technology owned by participants

As shown in Figure 4.6, the most common type of technology owned by participants in this current study was a mobile phone (n=29). Only one participant reported not having this type of technology, and used a land-line telephone for communication.

The majority of participants reported using their mobile phones not only for making telephone calls but to access internet-based social media. Looking at Figure 4.6, it is apparent that all except one participant in this study possessed at least one item of technology that could be used to access internet-based social media.

In addition, 12 participants had a laptop, 10 participants had either an iPad or a tablet, and 10 participants had a computer. Six of the 29 participants indicated they would have liked to have possessed a tablet, however four reported they had insufficient funds to purchase one and the other two were in the process of looking to purchase.

Figure 4.6 Technology owned by participants

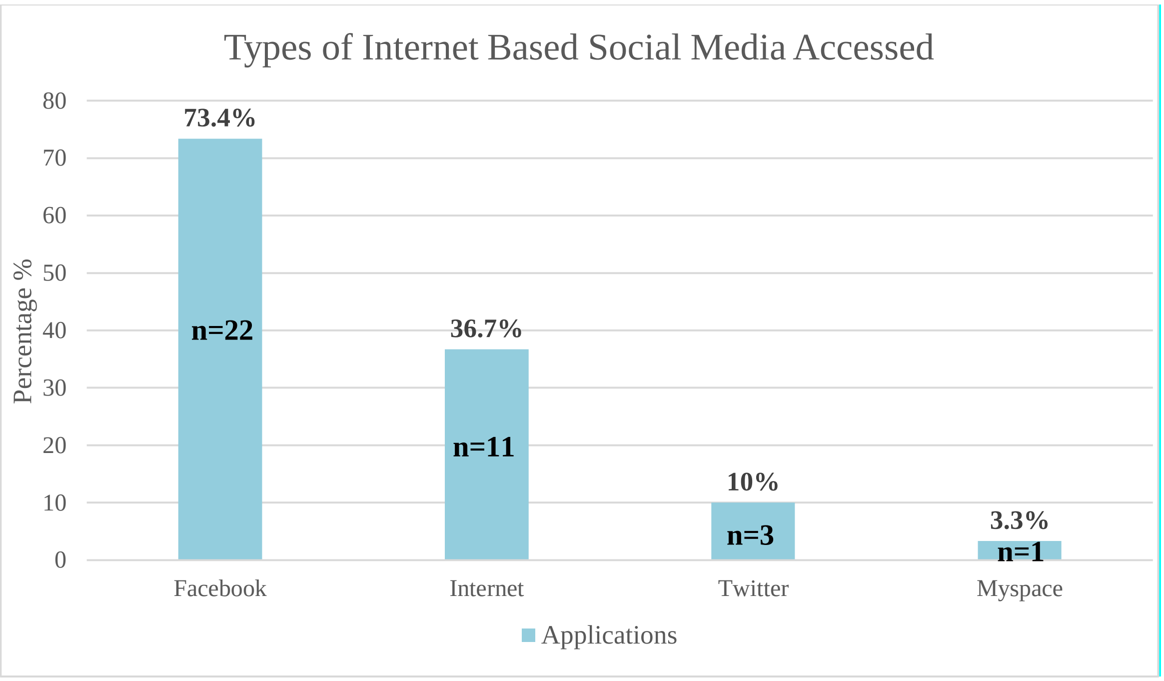


4.3.2 Access to internet-based social media

What stands out in Figure 4.7, is that the most popular internet-based social media application accessed by participants in this study was Facebook (n=22, 73.4%). One of the 22 participants who accessed Facebook also had accessed Myspace but said she preferred Facebook. Eleven participants accessed the internet and three participants accessed Twitter.

Facebook was preferred over Twitter by the majority of participants who had tried both. John (27 years old) who had used both Facebook and Twitter reported, *"[I use] Twitter…not as often as Facebook…I can't stand the word restrictions…I find Facebook easier."* Angelo (29 years old) reported, "*It's alright [Twitter] but it's a bit weirder than Facebook because…because you can actually add people easily so you don't have to send a friend request and that's a bit weird. I don't use it much though."* And Hallsy (31 years old) reported occasionally accessing Twitter but did not particularly like it, *"I do sometimes, but not all the time. I just normally check up on that [Twitter] from time to time but I'm not a big Twitter fan myself."*

Figure 4.7 Types of internet-based social media accessed



Myspace was accessed by one participant, Ellie (26 years old) who reported, *"It was okay but Facebook's better. It is easier to use. I was using…[Facebook] a lot longer than I was Myspace, so I got used to Facebook a bit more. Not many people, I didn't have many friends on Myspace, where I've got more on Facebook."*

4.3.3 Support to access and manage internet-based social media

The majority of participants reported they did not require support to access and manage internet-based social media (n=22). However one participant reported that he could go to his sister for support and another participant reported he could go to his mother for support if needed.

Hallsy (31 years old) who lived with his wife and daughter in private rental and worked full-time cleaning labels off of kegs received support from his sister to access Facebook. Hallsy reported, *"My sister normally helps me with Facebook".* Liam (24 years old) who lived with his mother and worked full-time shredding paper and emptying bins received help managing internet-based social media from his mother. Liam reported, "*My mum knows, she helps me with Facebook, she helps me."* For example Liam's mother supported him on occasions when he had seen child pornography on the internet. Talking about this issue Liam said, "*My mum said, mum shows me what to do. If something happens you don't go in it she says right if it's not good you don't do it."*

4.4 Participation in accessing internet-based social media

For participants who already accessed internet-based social media, findings related to exploring what activities they participated in and their self-reported perceptions of their experiences. For participants who did not access internet-based social media, findings outlined reasons for not having access to, or should they want to, identifying barriers they might have experienced preventing them from having access to internet-based social media. Table 4.1 provides the summary of the main and minor thematic categories for this study.

Table 4.1 Main and minor thematic categories in this study

Main thematic categories	Minor thematic categories
Making new friends and maintaining existing friendships	• Contacting friends and arranging to meet • Making new friends through Facebook • Being a member of a group
Engaging in hobbies/interests and pastimes	• Play games • Browse internet for things interested in
Exploring and expressing intimacy	• What participants did to feel sexy
Engaging in sexual behaviours	• Talking to people to feel sexy • Looking at pornography • Looking at sexy pictures • Online dating
Opinions about other people who access internet-based social media to look at sexy pictures	• Personal choice • Disgusting • Up to them/their choice
Assessing, managing and mitigating risks	• Risk assessment and managing risks
Barriers to accessing internet-based social media to engage in sexual behaviours	• External control • Technology and the internet • Personal decision • Literacy

The majority of participants reported that their engagement with internet-based social media was in the main around maintaining existing friendships, attempts at making new friends, engaging with groups and browsing online for the things that interested them. Most participants expressed a desire to make new non-sexual friendships rather than meet people on social media to develop social relationships that could result in engaging in sexual or sexually related behaviours. For example, Brendan (24 years old) said he wanted friendship: *"Just friendship just friendship that's all I'm looking for at the moment",* and John (27 years old) was adamant he wanted only friendships: *"Just as friends, not in a romantic sense."*

4.4.1 Maintaining existing friendships making new friends

One of the strongest themes that came out in the interview data was the sense that participants accessed internet-based social media for the purposes of making new friends or maintaining existing friendships without expectations of any sexual activity (see Table 4.2). This was primarily through the use of Facebook on their personal electronic devices (mobile phone). Participants in this study predominantly accessed Facebook for the purpose of contacting existing friends to make plans to catch up, plan to go out, and arrange where to meet.

Three minor themes were identified under this main theme: 'Contacting friends and arranging to meet'; 'Making new friends through Facebook', and 'Being a member of a group'.

Table 4.2 Maintaining existing friendships and making new friends

Theme	Example of participant response
Contacting friends and arranging to meet	*"Can you meet at the train station?"* (James)
Making new friends through Facebook	*"there were five of them [friend] requests…I added them because I know it's the only way to make friends"* (Jonnie)
Member of a group	*"They're [group members] on there like a pen pal kind of thing….People I never knew, I talk to on the computer."* (Garry)

4.4.1.1 Contacting friends and arranging to meet

Using smart devices and internet-based social media was an important method to contact friends for the participants in this study. Participants contacted friends to arrange to meet and engage in a range of social activities, for example: catching up; going out; meeting at the mall; going to the movies; and going bowling.

An example is Cam (36 years old) who reported what he did on Facebook to make arrangements to meet his friends, *"I just say…I do bowling every Wednesday and some of them just bowl umm bowl on a Wednesday or on a Thursday night so and I communicate with them"*. Cam accessed Facebook to get in touch with his friends on special occasions and send them messages, *"I just like to if it's someone's birthday, 'Happy Birthday' the day on it and umm 'Merry Christmas' and not just to read stuff off of, I just, I don't look at that."*

Elvis (24 years old) reported he arranged meetings via Facebook: *"I organise and say I'll meet you at Marion [large shopping mall] and this and that and I'll go meet them at Subway [sandwich bar]."* Elvis also said that he sometimes messaged friends on Facebook: *"book[s] [bowling session] and meet[s] them down the bowling alley".*

James (35 years old) reported he had quite a few friends on Facebook who he often made plans to go out with for the day. James explained how all his friends met somewhere after having made the arrangements on Facebook. James messaged friends to make arrangements to meet them, *"Can you meet at the train station?"* They replied, *"yeah, yeah"* to which James messaged back: *"I'll meet you at the deli [delicatessen, milk bar or convenience store]".*

Jonnie (20 years old) explained how he made plans to meet his friends and maintain his friendships: *"type up a few things on my Facebook, who who like to go to lunch in the city? Hang out with me for a while, and meet up for a while, see how things are going."*

John (27 years old) reported that the only way that he kept in contact with his friends and made arrangements to meet them was via Facebook, *"Occasionally I text, if they don't respond by Facebook. If they are too busy to respond by Facebook I usually send out a text."*

4.4.1.2 Making new friends accessing Facebook

There were several participants who indicated they were accessing internet-based social media chiefly to make new friends and were adamant that they did not want to engage with anyone in sexual activities.

For example, Brendan (24 years old) said he was not interested in meeting people on Facebook to engage in sexual activities but for friendships: *"just friendship, just friendship, that's all I'm looking for at the moment"*. He went on to say*, "Well I'm not, I'm not that kind of person, I'm more of a person who would rather meet up, you know, just for friendship. Umm so yeah that's, that's mainly what, what I use it for, to meet people for friendship."*

Another example was John (27 years old) who said he accessed Facebook to make friends but not to engage with them in sexual activities: *"Well for example, through the [educational institution]…I've gone there and I've been adding just random people. That's how I became good friends with [X] and [Y]."* John named another female and reported that, *"that is how I am good friends with her."* John made it clear that he only accessed internet-based social media to make new friends, not for engaging in sexual activities or romance: *"Just as friends, not in a romantic sense."*

In contrast to participants who wanted to make friends on internet-based social media, Paris (31 years old) reported that she only wanted to maintain existing friendships via Facebook, not to make friends with people she did not know: "*Umm I've used Facebook to find some of my old friends but only friends who I know"*.

Only one participant, Jacob (21 years old) had met new people and gone online to 'cam' (interact online via video-link using video cameras on a computer, tablet or smartphone) and talk to these people face-to-face on Facebook. In contrast to seeking romance, Jacob explained that he sought friendships and social communication: *"Get to meet new people on Facebook"* and said how he 'met' people face-to-face on Facebook: *"Like as in camera like in the video Messenger. [I] just talk."*

There were several participants in this current study who gave details about how they had accepted friend requests having accessed Facebook to make new friends.

For example, Jacob (21 years old) described how he accessed Facebook and accepted friend requests as a way in which he could make new friends;

> *"Well I just add them if they if there's people on there [Facebook] well I just add them as I meet I add them. I just get…just get to meet new people on Facebook when they give, if people want to be my friend I just add them on Facebook."*

Another participant, Jonnie (20 years old), accepted friend requests as he believed it was the only way to make new friends. Jonnie described one particular day when he arrived home to find, *"there were five of them [friend] requests. I didn't even know them but I added them because I know it's the only way to make friends, you get to know them well enough"*.

Helen (59 years old) reported that, *"[Facebook] really helped me; I get to meet a lot more people, a lot more friends.…Before all this happened [Facebook] it was sort of really me and that was it, nothing else, oh and my family unless someone came around to visit, that was it, or the telephone."* Helen added, *"I have met a few new people, even from here [where she worked]…I've met new people on Facebook which is really good."*

Only one participant Garry (49 years old) had accessed internet-based social media and made friends with females with the idea that their friendship could lead to sexual activities if they agreed. In contrast to all of the other participants, Garry was the only one who talked about having gone onto internet-based social media, prior to his relationship with his current girlfriend, to meet up with females: *"I've done that before. I've met people and dated them and, yeah. Before my partner, I used to live in Queensland and a couple of umm ladies there had a pretty good time."* When asked if that had led to a sexual relationship Garry responded: *"Arr sometimes. As I said I'm 49 now it's not a big thing for me. If I met somebody, you know, and something happens it happens and if it doesn't it doesn't."*

Of the nine females who engaged in this present study, Ellie (26 years old) was the only one to report any interest in seeking romance online. She reported she would consider accessing Facebook to meet someone for romance*: "If I was going to wanting a romantic thing I'd prefer it to be with somebody I already know and that I recently met up with umm I'd known for a couple of months or more umm, so yeah."*

Unlike all the other participants who accepted friends on Facebook, Christie (55 years old), reported her main motivation to access Facebook was to follow what her children had been doing. Christie discussed her main purpose for wanting access to Facebook:

> *"I have got a lot of people on my thing [Facebook] but I tend to keep myself blocked and I go on to see what's going on. They [Facebook friends] just don't know I am on, I have got myself blocked. So people don't chat to me….I don't make it look like I'm on the Facebook…but I go on there….My main thing was to be on Facebook to see what my kids are doing."*

4.4.1.3 Member of a group

Two participants shared their experiences maintaining friendships through the contact and communication they had with members of groups they had joined on Facebook and one participant described his experience having started up his own group.

One participant, Garry (49 years old), was able to meet up with members of his groups through Facebook, where arrangements were made to get together. In contrast Ellie (26 years old) made friends and maintained friendships on Facebook with members of groups she was in, however she had never met any of them face-to-face because they lived too far away from her. Ellie only ever talked to friends she made in groups via Facebook, unlike Garry who had the opportunity to meet up with members of the groups he was in through social outings.

For example, Garry (49 years old) maintained friendships by staying in contact with members from various photography groups he had joined on Facebook. Group members often made contact with Garry to make arrangements to meet, *"We are going out next weekend; blah blah blah. We can meet up."* Garry described friends he had made on Facebook: *"They're [group members] on there like a pen pal kind of thing….People I never knew, I talk to on the computer."*

Ellie (26 years old) had made new friends and maintained friendships on Facebook through groups, and explained why she chose an online social media group: *"Because they [group members] live too far* *away umm I met them in a group [on social media]. I'm in a group called [X] Social Group which is for people who attend [X] and stuff and I started taking to them in that group then he [male from the group] added me so we started talking but we have never met."* Ellie reported, *"I just talk to people, and look up stuff….I am a part of some groups where I talk to people in there sometimes but apart from that I don't do anything else."*

Interestingly, one participant, Jonnie (20 years old) made his own private Facebook group to keep in contact with friends.

> *"I made my own Facebook page…close friends only, closed group and I waited for a response last time about you know to hand my number out to every one of my friends. I haven't got a response back from that. I am hoping today I got my response."*

4.4.2 Engaging in hobbies/interests and pastimes

Many participants in the present study were interested in accessing internet-based social media to engage in activities they enjoyed doing online (see Table 4.3). Half of the participants reported browsing the internet looking for things that they were interested in. Nine participants (30%) reported that they had browsed the internet and Facebook looking for games to play. Examples of games that participants reported playing included but were not limited to: 'Candy Crush'; 'Candy Pop'; 'Bonanza'; and 'Search Word'. Six participants (20%) reported accessing internet-based social media to pursue their hobbies and interests, including: picture-taking; looking at old cars; researching events in history; looking up poems; searching for and downloading music; and playing games.

Table 4.3 Hobbies, interests and pastimes

Theme	Example of participant response
Play games	*"I've got bowling; I've got 'Candy Crush' and 'Candy Pop'….I do like playing games."* (Leigh)
Browse internet for things interested in	*"I like to go searching for history stuff, like to do with things of the past."* (Hallsy)

4.4.2.1 Play games

Finding games to play was a pastime undertaken via internet-based social media by both male and female participants. Of the nine participants who reported they accessed internet-based social media to play games, five were female (16.67%) and four were male (13.33%).

Leigh (28 years old) reported that on the internet, *"[I] play my games"*, which he named, *"I've got bowling; I've got 'Candy Crush' and 'Candy Pop'….I do like playing games."* Jonnie (20 years old) reported the games he played were, *"my Train Station game, so bloody difficult to play. I'm only on level two-forty-one."*

The games Christie (55 years old) reported playing on the internet were, *"'Double Up Slots' and 'Slot Bonanza'."* Helen (59 years old) reported that, *"I use it [internet] for games…I've got a lot of games."* When asked what Helen's favourite game was, she responded saying, *"Search Word."* Also Ellie (26 years old) played games and reported that, *"I download games off the Games Store so I can sit down and play them. I play hidden object games and stuff, so I'm usually playing them all the time."*

Unlike the other four participants, Angelo (29 years old), Andy (27 years old), Paris (31 years old), and Stella (26 years old) did not name specific games they played.

The ratio of participants who played games on internet-based social media males to females was 4:5. Of the four male participants and five female participants who played games on internet-based social media, ages ranged from the youngest, Jonnie (20 years old) to the oldest, Helen (59 years old). The male participants were aged 29 years and under, while two of the female participants were aged 55 and 59 years old. The oldest participants who played games were female with three of the five aged between 31 years and 59 years old. The older female participants in this study accessed internet-based social media to play games more than the younger male participants.

4.4.2.2 Browse internet for things interested in

Six participants (20%) reported that they accessed internet-based social media to search for things that interested them.

For example, Elvis (24 years old) explained that he browsed Facebook on his mobile, *"looking from my phone, museum of cars, old cars"* and Hallsy (31 years old) reported that, *"I like to go searching for history stuff, like to do with things of the past. I look up all the history of TV stars who I like…like Elvis."* And Brendan (24 years old) said he browsed Facebook looking for poems: *"just different poems and know just it's mainly Facebooking and looking at different poems because I sometimes like to make umm take ideas from other poems to write my own."*

Three participants (10%) browsed internet-based social media to find music they enjoyed listening to.

Justin (22 years old) reported that he downloaded music and Chris (22 years old) reported that, *"I seem to look for music all the time. I try to find other things to look at but I just don't know what to look at."* Leigh (28 years old) also reported that he searched for music on the internet and commented that he liked listening to music by girl singers, particularly Brittany: *"I like listening to them."*

One participant (3.33%) was interested in photography and taking pictures which he shared on Facebook.

Garry (49 years old) was interested in photography and had browsed Facebook to find groups to join where he could share and display photographs he had taken. Garry reported, *"I enjoy it [Facebook]. I go on there to do my photography [hobby]. I put my photos on. I've got a couple of groups I'm in with photography so I transfer my photos on my computer straight into site there and they all get 'likes' and comments and all that…makes [me] feel good".*

4.4.3 Exploring and expressing intimacy

4.4.3.1 What participants did to feel sexy

Five male participants (16.66%) reported what they did to feel sexy. Males predominantly described that personal grooming, dressing up and going out dancing was what they did to feel sexy. One male reported not being interested in doing things that made him feel sexy because he was married and no longer needed to and one other male participant cited sexual abuse against him for his reason for not being interested in doing things that made him feel sexy. One male participant described having low self-confidence and was not able to articulate what he did to feel sexy. Two participants (one male and one female) did not want to disclose what they needed to do to feel sexy. Out of the nine females participants in this study only one female gave details of what made her feel sexy.

Table 4.4 Exploring and expressing intimacy

Theme	**Example of participant response**
What participants did to feel sexy	"*Go out, go to nightclubs spend time in them and go dancing. Dancing makes you feel sexy, I like dancing."* (Liam)

Hallsy (31 years old) was not interested in doing things that made him feel sexy reporting that, "*I've got my wife, I've been with her for seven years and I'm not looking for another relationship*." Elvis (24 years old) was adamant that he was not interested in doing things that made him feel sexy, and reported:

> *"No, No…because when I was working at [a disability organisation in SA] I had sex while at [disability organisation] and I didn't like it. Some guy was really, really vile he was bad and not good and mum was involved, police was involved to sue."*

When asked what kind of things Liam (24 years old) did to feel sexy he reported, *"Go out, go to nightclubs spend time in them and go dancing. Dancing makes you feel sexy, I like dancing."* In contrast, Leigh (28 years old) said*, "I don't want to be in a strip club or anything.…That's even more embarrassing."*

Liam (24 years old) also reported wearing nice clothes and being clean made him feel sexy, *"Yeah, wear nice clothes.…Wear nice clothes, have showers so that helps, good hygiene and look after yourself."*

And Leigh (28 years old) reported, "*I do feel sexy when I'm going out somewhere. It feels sexual, it feels good.…When you are going out to a restaurant with friends and stuff. It just, just feels good dressing up."* Leigh added, *"Well feeling sexy is when you got to keep yourself clean. And you like to smell nice around people as well. You don't want to; you don't want to come to work dirty or anything."*

Similar to Liam (24 years old) and Leigh (28 years old), Chris (22 years old) reported that for him to feel sexy, *"I guess I want to be dressed neatly and stuff like that."* Angelo (29 years old) similar to Chris said, "*Probably do my hair and stuff and have a shave, umm dress nicely, that's probably about it."*

Whereas Brendan (24 years old) was not really sure the kind of things he needed to do to feel sexy and decided tht, *"well, well I'd like to be a lot fitter to make myself feel sexy obviously but otherwise well otherwise not really sure."*

Katie (30 years old) did not want to disclose what she needed to do to feel sexy saying, *"I don't know. I don't want to go down that path.…There is a reason but I don't feel like being sexy or anything like that.'* Hallsy (31 years old) when asked what kind of things he needed to do to feel sexy replied after a big sigh, "*I've got no comment for that one, sorry."* But went on to add that he was, *"Oh…God umm I just…I'm just not like everyone else what they do on Facebook umm and put pictures up of themselves. I, I don't normally do that. I just talk in general."*

Only one female, Rachael (43 years old), reported things she did to feel sexy: *"If you are trying to say attractive and things like that; I do think of me being attractive but that's all."* She went on to say, *"I don't mind my boyfriend kissing me, holding my hand, hugging me, making me feel sexy."*

In contrast, Paul (44 years old) experienced difficulty giving an answer to what things he did to feel sexy, and reported:

> *"This is a tough one. I don't have very much confidence. Yeah, it's just one of the things in, I'll go out and I'll do things and nothing really amounts. I've met some people on the way and they have been suited or when they have they have found out that I'm too, I'm too gentle.…It's either put them off or they either turn me away or end up hurting me for the wrong reasons. I've got a very 'gentle heart'. It's very easy to be hurt."*

4.4.4 Engaging in sexual behaviours

The next section addresses the second research question: "What are the experiences of individuals living with intellectual disability accessing internet-based social media to develop social relationships and potentially engage in sexual activities?"

Four themes emerged: talking to people to feel sexy; looking at pornography; looking at sexy pictures; and online dating, recorded below in Table 4.5.

Table 4.5 Engaging in sexual behaviours

Theme	Example of participant response
Talking to people to feel sexy	*"Only to my girl."* (Justin)
Looking at pornography	*"I did used to look at porn…just to get ideas, like to do things with my girlfriend."* (Hallsy)
Looking at sexy pictures	*"I don't look at things like that so, I just ignore them, ignore it, don't even look at them."* (Cam)
Online dating	*"You put your profile photo in there with all your details and they match you up with someone who might be compatible with you and start chatting"* (Garry)

4.4.4.1 Talking to people to feel sexy

Participants were asked if they talked to people to feel sexy. In general, participants did not talk to strangers to feel sexy. One participant talked to people to make friends but not to feel sexy. Two participants talked to their partner to feel sexy and not to anyone else. In contrast, one participant said that he did talk to his girlfriend but not to feel sexy. One participant felt happy talking to someone but had issues getting the confidence to talk to people. The one person who did talk to people to feel sexy did not want to answer the question in any depth.

Brendan (24 years old) said he did not talk to people to feel sexy but that he talked, *"to people to make friends and feel comfortable but not sexy."* Chris (22 years old) said, *"I feel happy when I am talking to someone. But I do have a problem; I do have a problem trying to talk to people."*

In contrast, Angelo (29 years old) said he did talk to people to feel sexy but said that, *"that's probably a question I don't want to answer."* When Angelo was asked what happened to the way he felt when he talked to people he said he had, *"I think err probably err sexy thoughts."* Whereas Justin (22 years old) said that in general he did not talk to people to feel sexy, commenting: *"Only to my girl."* Likewise Clem (63 years old) reported: *"I talk to my wife."* In contrast, Leigh (28 years old) reported he did not talk to his girlfriend to feel sexy*: "We don't talk [to feel sexy], we only talk about what we want to do in the future and stuff….That's all. Not about being sexy or anything."*

4.4.4.2 Looking at pornography

Six (20%) of the 30 participants described how they had used internet-based social media to access pornographic images and/or videos. Two participants had stopped accessing pornography because their partners did not want them to anymore. Two participants spoke of their knowledge and experience of viewing underage pornography. Only one participant reported that he actively looked for pornography; accessing internet-based social media with the blessing of his mother. One participant had viewed pornography as a way to get ideas about what to do sexually with his partner.

Andy (27 years old) looked at pornography with his girlfriend, and explained how, *"you just go to a website…scroll down and click on it and then go on a video and you see it".* When asked if he had looked for more pornography he said: *"Nah stopped looking".* When asked why, Andy reported that, *"[my girlfriend] got grumpy….She wanted me to stop watching it….She doesn't like it".* Likewise, when talking about viewing pornography on the internet, Angelo (29 years old) spoke of his partner as the person, *"who had a bit of a problem with it. She didn't like me looking up that sort of stuff, she didn't like me looking up that".* Angelo added that, "*she sort of felt a bit insecure about herself".*

Two participants, Angelo (29 years old) and Paul (44 years old), were aware that underage pornography was not legal to view. Angelo reported that he had *"got nothing pretty much against it [pornography] except for the underage. I wouldn't go anywhere near that sort of stuff".* Paul (44 years old) stated that when he browsed the internet, *"I just browse through and sometimes I stumble on the thing. I stumble on the pictures that are a way too young and it puts me right off and it makes me feel bad inside".* Paul (44 years old) described his experience having viewed underage pornography:

> *"[I] got myself into trouble looking at stuff….I got caught by my parents one time, first time I did it I got caught by my parents and they ended up getting a bill of over a thousand dollars. And I ever since I sort of like tried to stay away from it".*

Hallsy (31 years old) was the one participant who had reported he explored pornographic material on the internet to get ideas to express intimacy with his partner. Hallsy described why he had viewed pornography: *"I did used to look at porn and all that just to get ideas, like to do things with my girlfriend and all that at the time."* Garry (49 years old) who had previously viewed pornography reported that, *"I've got a missus now, I've got a missus, so I'm right".*

In contrast to the other participants, Liam (24 years old), not only viewed pornography but reported that he was encouraged to do so by a supportive family member. Liam, regularly viewed pornography. When enquiring as to whether Liam's mother (as he lived at home) knew about his activity, Liam said: *"Yes my mum does, my mum knows, she helps me with Facebook, she helps me*". Liam explained that his mother allowed him to look at pornography under strict rules: "*Only in my room in a private place. In a private place and only at night time…and not in front of people".*

Clem (63 years old) did not have the internet but was interested in getting it connected to his house. Instead he watched pornographic DVDs with his wife Josie (66 years old) saying, "*Has girls in it, and sex in it. Me and my wife [Josie] go bed and have fun, hug in bed."*

Josie (66 years old) did not have access to the internet; she was the only female who regularly viewed pornography, which she did with her husband Clem, in the form of DVDs.

4.4.4.3 Looking at sexy pictures

Sixteen (53.33%) of the 30 participants reported varying experiences and reactions to whether they had looked at sexy pictures on internet-based social media. Ten out of those 16 had not looked at sexy pictures on internet-based social media while six had. Out of the 16 participants who shared their experience and reactions about looking at sexy pictures, only two were female.

Two of the 16 participants indicated the reason they had not looked at sexy pictures on internet-based social media was because of their respect for their female family member.

For example, John (27 years old) responded to being asked if he had looked at sexy pictures:

> *"Not really. Because I've sort of been taught to [pause] I don't view women as sexual objects….I've been taught to because I live in a house [pause] I've got a mum and three sisters…they are all feminists so I have been educated by them."*

And similarly Elvis (24 years old) reported that he did not look at sexy pictures:

> *"Not for, not have I looked on my phone. I haven't, I am not that type of man who goes and looks at stuff. That it's not good my dad or my mum always tells me someone who looks like your sister or looks like a daughter not good to see. I can't see that on my phone, never seen it all ever on my phone. If I did I say no, then I say okay piss off."*

Ellie (26 years old) had seen sexy pictures on Facebook but had not actively looked for them saying: *"Oh I've had things, like I've had things pop up on my Facebook wall and I've had a look at them but apart from that no."*

James (35 years old) did not look at sexy pictures, and reported, referring to pornography sites: "*I'll get told off by mum if I do that. Mum says don't go onto any of the…those things, yeah."*

When asked if he had looked at sexy pictures Brendan (24 years old) reported: *"No I don't like. No I tend, I don't tend not to, I, I tend not to, just, just don't think it is right for me."*

Leigh (28 years old) responded to whether he looked at sexy pictures by stating that*, "I don't want to talk about that. I don't like looking at pictures on the internet. I don't use the internet just to look at girl's pictures. I don't. I, I just don't want to do it. I think it is dirty. That's why I don't want to do it."*

Greeny (50 years old) who said he had once accidentally looked at sexy pictures reported:

> *"Now I'd like to say when you look at sexy things on the internet well I try not to get involved in pornography and all that. I don't like when people want it on there, when people look it up, all that business…but what I am saying is that I don't get involved with that stuff because if I did I'd be in trouble with myself."*

Jonnie (20 years old) when asked if he had looked at sexy pictures reported:

> *"God no, I would never do such a thing. I'm not one of those people. I'm more, I'm more of those people that just want to get on with their life. That's who I am. I'm not one of, I'm not one of those people, those sickos that can do that. Because it really brings, it can really destroy your life. You can get addicted to it and it can really do something, it can really affect your life."*

Cam (36 years old) said he did not look at sexy things on social media: *"I don't look at things like that so, I just ignore them, ignore it, don't even look at them, don't umm communicate with those things. So I just blank it out and then that's all. It's silly, it's just revolting and all that."* Christie (55 years old) said she did not look at sexy pictures: *"I don't need to [laugh]. I'm old fashioned. Put down as just old fashioned."*

Hallsy (31 years old) reported he had looked at sexy pictures:

> *"Yes [said as laughing]…embarrassing. I guess I'm not that kind of guy that does that sort of stuff. But I will look at them but to try to get ideas but yeah other than that...I don't know if that, I could be wrong but umm stuff that do look sexy I don't know if they are actually doing a modelling shoot or anything like that….I don't get offended by it, but it's just okay if they put them up, yeah I could probably look but it's like yep yep but I just don't go through their profiles and find things like that."*

Andy (27 years old) said that he had looked at sexy pictures*, "Yeah I do look at pictures. Umm there's go on my phone, look at pictures, me and my girlfriend."* Angelo (29 years old) said he had looked at sexy pictures*, "Well I kind of look at that sort of stuff. I don't think there is probably nothing wrong with that but it can be if you look at urr like maybe underage or something like that."* Martin (32 years old) reported how he had looked at sexy pictures reporting: *"Ah well sometimes things on Facebook,* *they just come up…and if you had seen and just being inquisitive you find out what it's all about, you might click on that picture and it might come up with this site or whatever."*

Only one out of 16 participants who had looked at sexy pictures said that he had kept copies of them on his phone for future personal viewing.

Paul (44 years old) said he had looked at sexy pictures on the internet:

> *"I have had a look at a few things. I've carried a few things on my…I've got a few things on my phone at the moment so, yeah and I've had a look at them, they are just there just for my own personal use. I don't give them out to anyone because I don't I don't do anything I just keep it for myself. And if I'm done with it, it gets deleted. I just browse through and sometimes I stumble on the thing I stumble on the pictures that are a way too young and it puts me right off and it makes me feel bad inside. It just puts me off and I say no, it's not worth it and I then pull myself out of it."*

One out of 16 participants indicated she did not look at sexy pictures on internet-based social media because they made her feel self-conscious about her own body image and she did not feel pretty enough.

Paris (31 years old) when asked if she looked at sexy pictures said: *"Umm its aww, it's hard to explain. If I wanted to I could but I don't feel comfortable in myself looking at stuff like that."* Asked why she did not feel comfortable Paris reported:

> *"Umm because it kind of puts me, it feels like it puts me down because of the way I look. Umm but anyone's got their own sizes and what not but I don't. I feel this insecurity thing for me. Umm I don't feel pretty enough yet."*

4.4.4.4 Online dating

Only one of the 30 participants said he had accessed internet-based social media to go on dating sites. Garry (49 years old) described how he had done this many times:

> *"Well going…on a site you put your profile photo in there with all your details and they match you up with someone who might be compatible with you and start chatting and say oh well that you like that person and you wait for half an hour or at night they might be working or something, I leave a message….I'd like to get to meet you. I'd like to get to know you. So you start chatting away for maybe a week or so then a message comes and we go meet for a coffee and if there is another date…yeah, you've met that person and started chatting."*

When asked if that had led to sexual activities Garry (49 years old) responded: *"Err sometimes."*

4.4.5 Participant's opinions about other people looking at sexy pictures

Data were collected to ascertain the opinions participants in this current study had about other people looking at sexy pictures on internet-based social media. The three themes to emerge: personal choice; disgusting; and uncalled for/inappropriate, are presented in Table 4.6.

Table 4.6 Opinions about other people looking at sexy pictures

Theme	Example of participant response
Personal choice	*"It's their choice really, whether they do or not."* (Brendan)
Disgusting	*"I think it's disgusting."* (Helen)
Uncalled for/Inappropriate	*"I think it's just…you know uncalled for like people out there like to look at pornographic stuff."* (Justin)

4.4.5.1 Personal choice

Ellie's (26 years old) opinion about other people looking at sexy pictures reported: *"If people want to do it they can do it, I don't do it so I don't care really."* Similarly Brendan's (24 years old) opinion about people looking at sexy pictures: *"Well that's just their choice I reckon. I, I tend not to do that as such but every person is different. It's their choice really, whether they do or not."* Paris's (31 years old) opinion about people looking at sexy pictures: *"Umm, as long as they do it in private, I mean I'm not really fussed if they do but if someone did it in front of me I wouldn't feel comfortable, being in the same room."* Garry's (49 years old) thoughts about people looking at sexy pictures expressed the opinion that, *"[it's] each to their own I suppose; as long as you are not hurting anyone."*

4.4.5.2 Disgusting

Helen's (59 years old) opinion about people who looked at sexy pictures:

> *"I think it's disgusting. I mean there was one thing or something there, I don't know how to delete these things where they had you know bondage on it….They had women who liked being bondage and they got their photo taken while the other half were watching. You know it's not good. Things like that and some of the language, they aren't allowed to put that on TV why are they allowed to put it on Facebook?"*

Martin (32 years old) expressed his opinion about people who looked at sexy pictures: *"I think that's disgusting. People, if people want to put pictures of themselves on Facebook then that's ridiculous, that's violating yourself basically. That's my opinion; I mean everything I am telling you is what I would do."*

While John (27 years old) did not use the word ‘disgusting’, his thoughts about people who looked at sexy pictures on the internet were: *“sort of if it like seeing sexy women I see that as being disgraceful.”* John explained why he felt this way: *“Because I think it just creates this whole image that women are to viewed as sexual objects and for the women themselves it creates this whole false image and then you need to be skinny to be perfect, when they don’t.”*

4.4.5.3 Uncalled for/inappropriate

Justin (22 years old), when asked what he thought of other people looking at sexy things on the internet commented: *“I think it’s just just you know uncalled for like people out there like to look at pornographic stuff and I just don’t do that stuff, I’m not like that person. I’m a good boy.”* James’s (35 years old) thoughts about people who looked at sexy things on internet-based social media: *“I think it might be a bit umm, like umm dirty people. Dirty people doing it yeah.”* Ian’s (27 years old) thoughts about other people looking at sexy pictures on internet-based social media: “*Bad. It’s inappropriate. You can get arrested for it.”*

Christie’s (55 years old) opinion about other people looking at sexy pictures reported, *“Well some people do look at some stuff, that’s a bit inappropriate….I think it’s just a bad idea. I mean it’s just really bad for them to look at.”* Very similar to Christie, Jacob (21 years old) opined: “*Well some people do look at some stuff that’s a bit inappropriate but I don’t really do that, look at that stuff. I think it’s just a bad idea. I mean it’s just really bad for them to look at.”*

Stella (26 years old): *It’s inappropriate sometimes, some of the pictures that they put up. I wouldn’t put them on social media then everyone can see them. Not very good.”*

4.4.6 Assessing, managing and mitigating risks

The following demonstrates how participants exercised considerable judgement in assessing, managing, and mitigating risks should they meet someone face-to-face who they made friends with online, see Table 4.7.

Table 4.7 Assessing, managing and mitigating risks

Theme	Example of participant response
Risk assessment and managing risks	*“I probably would meet in an open area…not in like a secluded place.”* (Angelo)

4.4.6.1 Risk assessment and managing risks

The data collected showed that nine participants could articulate how to keep themselves safe if they went to meet someone face-to-face, they had first made friends with on Facebook. Even though few participants had actually gone/or would go to meet people they did not know, they could explain strategies they would use to keep themselves safe.

Stella (26 years old) described how she would manage perceived risks when meeting someone for the first time: *"I'd get someone to come with me. And I would take my phone as well. I take my phone everywhere so that I can contact the police if something happened".* Likewise, Ellie (26 years old) would take her phone: *"Make sure I carry my mobile on me because then I'll have someone to ring in case something does go bad"*. Ellie was also able to show her knowledge of the risk involved meeting a stranger, stating that, "*Well you don't know the person you are meeting up with, so something bad could happen like you could get raped or something like that. Umm yeah anything could happen if you meet someone that you don't know".*

Christie (55 years old) reported what she would do: *"Going to a crowded place, like a restaurant or a café, you know what I mean? If you want to have a coffee and catch up then a crowded place".* Christie identified a further precaution she could take and added that, *"I'd probably let one of my kids know so that if anything happens at least they know".* Paris (31 years old) explained how she would keep herself safe: *"Would most probably meet them in a public area where there are other people around me umm so then if anything does happen I can ask for help through people like that".*

Angelo (29 years old), explaining what he would do to keep safe, stated that, *"I probably would meet in an open area….I wouldn't meet in like maybe a park. I wouldn't meet at a park I'd meet probably somewhere like a shopping centre or umm a pub or something like that, not in like a secluded place".* Likewise, Garry (49 years old) explained how he would keep himself safe: *"Be in somewhere public; a pub or a shopping centre, have a coffee or something, where people are around".* Similarly, Jacob (21 years old) said he would keep safe by meeting, *"in the city or [named an Adelaide inner suburb]; meet them somewhere that's a bit secure. If you know what I mean?"* James (35 years old) who was not quite sure said that he would, "*just meet in a public place somewhere, I don't know where, not somewhere not dark"*.

Brendan (24 years old) described what he would do going to meet someone for the first time to keep himself safe:

> *"I tend not to be take weapons or anything with me because I'm not a violent type of person. Umm but I always keep my phone on me if I get into a bit of trouble…and if something doesn't quite work out I normally ring someone for help or if there is a local shop or something open I'll go and ask for some help".*

4.4.7 Barriers to accessing internet-based social media

The next section addresses the third research question: "What (if any) barriers do individuals living with intellectual disability experience in accessing internet-based social media to develop social relationships and engage in sexual behaviours?"

Four themes emerged: external control; technology and the internet; personal decision; and literacy (see Table 4.8.).

4.4.7.1 External control

Participants described elements of control from others who limited their ability to access internet-based social media. The participants in this study who reported not being able to access internet-based social media were mostly denied access by their parents, predominantly their mothers, or their partners from doing so. There were two participants, Andy (27 years old) and Angelo (29 years old), who ceased accessing internet-based social media to look at pornography at the request of their partners.

Table 4.8 Barriers to accessing internet-based social media

Interview Theme	Example of participant response
External control	*"My mum won't let me use um Facebook."* (Rachael)
Technology and the internet	*"Too, too complicated for me."* (Ian)
Personal decision	*"No, don't use Facebook. There's a lot of trouble on Facebook so just don't use it."* (Justin)
Literacy	*"I can't read."* (Robert)

Rachael (43 years old) reported: *"My mum won't let me use um Facebook for safety reasons"*. Rachael explained her mother's safety reasons concerns: "*Like um I can't remember the girl's name [South Australian incident reported in the media] but she used Facebook before and by meeting, meeting someone and she ended up getting murdered. That was because of that."*

Katie (30 years old) was bound by her parent's rules, reporting that her parents had directed her to only play games: "*You can play games but that's all you can do on the internet, nothing else".* Elvis's (24 years old) parents stopped him from looking at sexy pictures on social media and reported, *"Been tough and [parents] screaming at me all the time…telling me what to do and I don't like it."*

Justin (22 years old) reported that his mother had told him that, *"you can't look at pornographic stuff".* Even though Justin had told his mother *that, "I don't do that stuff".* Justin reported that his mother checked his phone regularly, looking for pornographic images, and had told him: *"Don't go onto any of* *the, those things [pornographic sites]".* James (35 years old) had a similar situation with his mother and did not look at sexy pictures: "*Because…I'll get told off by mum if I do that. Mum says don't go onto any of the…those things, yeah [referring to pornography sites]."*

Paul (44 years old) reported the reason he had no internet connection and hence restricted access to internet-based social media to develop social relationships and engage in sexual behaviours where he lived was because of his parents: *"It comes down to my parents…my parents control a lot of my finances and talking to them is so like a major issue that it will end up turning into an actual argument."*

Andy (27 years old) had stopped looking at pornography online, reporting that, *"[my girlfriend] got grumpy…she wanted me to stop watching it…she doesn't like it".* Likewise Angelo (29 years old) stopped looking at online pornography because of his partner: "*She didn't like me looking up that".*

Interestingly, lack of finances was not given as a reason for participants not being able to access internet-based social media. All participants bar one, Robert (56 years old), had electronic devices (smart mobile telephones) that could be used to connect to the internet and social media.

4.4.7.2 Technology and the internet

Elvis (24 years old) who had Facebook on his phone said, "*I have Facebook but I haven't tried it [Facebook] yet, my phone's a bit slow for Facebook."* Daniel (48 years old) had the internet but had not learned how to use it despite having had computer lessons. Ian (27 years old) had a tablet but was unable to use it after a year and reported that it was, *"too, too complicated for me."* Robert (56 years old) did not own or have access to any electronic devices, and Paul (44 years old) had no internet connection in the unit where he lived, nor did Clem (63 years old) and Josie (66 years old) in their home.

4.4.7.3 Personal decision

Paul (44 years old) did not want to access Facebook saying, "*I'm not on Facebook at all….I avoid those sorts of things for I don't want hostility coming at me."* Likewise Ian (27 years old) made his own decision not to access Facebook. Justin (22 years old) decided to stop using Facebook explaining, that *"I used to but I don't anymore….I just, I'm just, there was trouble coming to me so I just deleted it all."* Robert (56 years old) decided he did not want to access internet-based social media, saying that, "*You don't know who you meet. You meet weirdos on the internet. I don't want to meet weirdos."* And Justin said*, "No, don't use Facebook. There's a lot of trouble on Facebook so just don't use it."* Justin added that*, "I've got a missus who uses Facebook. I used it and then I switched it off, I deleted my account because it was too much trouble."* Instead Justin reported going online to "*download music and all that*."

Clem (63 years old) once used the internet to send messages to family and friends but had taken it off of his computer because he said he had kids talk dirty to him on it, he said that they typed ‘dirty’ words and he wanted it stopped.

4.4.7.4 Literacy

Only one participant reported not being able to access internet-based social media due to literacy issues. Robert (56 years old) had not accessed Facebook or the internet, shaking his head and reporting: *“I can’t read.”*

4.4.8 Gatekeeping

The gatekeepers in this study were contacted to act as intermediaries for the researcher to gain access to potential participants. While gatekeepers provide a resourceful and practical conduit to connect the researcher with participants, in this study one organisation blocked questions from being asked to the participants from their organisation.

The researcher was not permitted to ask designated questions (refer Appendix 7) to 11 participants (36 %) by one disability organisation’s representative. These participants were: Ellie (26 years old); Stella (26 years old); Paris (31 years old); Christie (55 years old); Helen (59 years old); Jonnie (20 years old); Jacob (21 years old); Martin (32 years old); Cam (36 years old); Ian (27 years old); and Garry (49 years old). This will be discussed further in an exploration of the limitations to this current study.

Chapter Summary

Interviews revealed that participants accessed internet-based social media, predominantly Facebook, to make new friends and maintain existing friendships rather than finding someone online to engage with in sexual activities. Only one participant described accessing online dating sites where he communicated with women, which sometimes ended in meeting and engaging in sexual activities.

Participants in the current study were found to access internet-based social media for similar reasonsto each other, for example: to make arrangements to catch-up and/or meet their friends for social outings; some played games; some searched for music to listen to; some engaged in groups; and others had interests and hobbies they searched for online. None of the participants mentioned financial barriers as a restriction to accessing internet-based social media.

Facebook was the most popular social media site that most participants engaged in. Participants all had smart technology to use to go online; a smartphone in particular for all but one participant who had a conventional land line connection.

Difficulties were encountered for the researcher from gatekeepers, primarily in the recruitment of participants to take part in the current study. Participants were gatekept from undertaking numerous activities online by the control of the systems in which they lived. Further discussion about gatekeepers will be presented in Chapter Five.

Chapter Five
Discussion

5.1 Introduction

This chapter presents a discussion of the findings related to the research questions; the strengths and limitations of this study; directions for further research; and implications for policy and practice. The aim of this study was to discover whether individuals living with intellectual disability accessed internet-based social media to explore, facilitate or engage in intimate relationships and/or sexual activities. This current study adds to the collective knowledge of what individuals living with intellectual disability are doing when accessing internet-based social media.

5.2 Systems theory

Applying a framework of systems theory provides the lens through which to gain an understanding of the levels of influence that interrelated systems have on individuals living with intellectual disability to develop and function. In the current study, systems that participants were part of influenced their ability to have control over access to internet-based social media, enabling them to explore sexual relationships and intimate activities if they so desired. This was by the people in their immediate environment (e.g. parents, partners, service providers) and influenced by societal attitudes and cultural norms (see Figure 5.1). Systems theory provides context to the analysis of this current study from the insight gained from exploring and reporting on the interaction with and between interconnected systems to which the participants were exposed.

5.3 Exploring key themes

5.3.1 Access to internet-based social media

Most individuals living with intellectual disability in this current study accessed internet-based social media. They were mainly interested in making new friends, and maintaining existing ones rather than accessing internet-based social media for forming intimate relationships and engaging in sexual activities. Activities of a social and leisure nature were the main reasons given by participants in this current study for accessing internet-based social media; these included: communicating with and catching up with friends; for leisure purposes such as playing online games and listening to music; and following recreational interests.

These findings are consistent with those of Chiner et al. (2017), who explored how individuals living with intellectual disability in Spain went online and used the internet, finding that the subjects of that study undertook activities similar to the participants in the current study, such as: playing games; chatting with friends; and listening to music. These results reflect those of Jenaro et al. (2018) who found that young adults living with intellectual disability in their study primarily used smartphones to access internet-based social media more for social reasons, e.g. meeting up with people, and recreational purposes, playing games online.

Figure 5.1 Systems around individuals living with intellectual disability

Not unlike the current study, in which it was found that participants predominantly used smartphones (as well as tablets, laptops and computers) to go online and access internet-based social media, participants in the study by Chiner et al. (2017) also used: computers, laptops, smartphones, and tablets, reporting that smartphones were the most popular mode of access. A possible reason that this finding is consistent with that of Chiner et al. (2017) is that the ages of participants in both studies were similar. The ages of the participants in the current study ranged between 20 and 66 years, compared to ages in the study by Chiner et al. (2017) which ranged between 18 and 51.

Despite the difference in data collection methods, the current study exhibits similarities to the study of Shpigelman and Gill (2014). The participants in Shpigelman and Gill's (2014) study were positive about communicating with family members and friends known to them, accessing Facebook, browsing the internet looking for games to play, music to listen to, and had accessed internet-based social media to pursue hobbies and interests. For example, participants in the current study reported doing similar things: Andy (27 years old), Angelo (29 years old), Christie (55 years old), Ellie (26 years old), Helen (59 years old), Jonnie (20 years old), Paris (31 years old), and Stella (26 years old) went on internet-based social media to play games; Chris (22 years old), Justin (22 years old), and Leigh (28 years old) listened to music; Elvis (24 years old) looked at old cars; Brendan (24 years old) browsed Facebook for poems; Hallsy (31 years old) searched for historical events; and Garry (49 years old) browsed Facebook to join photography groups.

Application of the theoretical lens of systems theory highlights where this current thesis diverges from Shpigelman and Gill (2014). Participants in the current study potentially had reduced system influences during the interview process as they were interviewed by the researcher without anyone else being present, with the exception of one individual, Rachael (43 years old), who wanted her mentor with her. This was in direct contrast with the method used to gather data by Shpigelman and Gill (2014), who used online surveys. Shpigelman and Gill's (2014) approach meant that there was no guarantee that respondents living with intellectual disability were solely responsible in every case for their answers to questions or were free from coercion or other system influences, e.g. family and/or service providers.

In this current study, Facebook was the most common social media site accessed. A regular social activity that participants Cam (36 years old), Elvis (24 years old), James (35 years old), Jonnie (20 years old), John (27 years old) and Garry (49 years old) participated in on Facebook was contacting friends and making arrangements to get together, leaving instructions about where and when to meet each other. Participants in this current study predominantly used smartphones. In order of popularity, tablets, then laptops, and then computers were also used to go online and access internet-based social media.

Other research corroborates that individuals living with intellectual disability access Facebook. This was echoed in findings by Sallafranque-St-Louis and Normand (2017), Chadwick and Fullwood (2018), and Holmes and O'Loughlin (2014), where, in each case, Facebook was also the most commonly accessed social media site by participants in their studies. Several participants, Hallsy (31 years old), Ellie (26 years old) and John (27 years old) in the current study had tried other social media websites such as Twitter and Myspace but preferred Facebook. This also accords with one of the participants in the study by Sallafranque-St-Louis and Normand (2017) who had other accounts (Twitter, Instagram, Pinterest, and Snapchat) but named Facebook as being her favourite.

The current study demonstrated that Facebook allows people to interact with a wide social audience (Holmes & O'Loughlin, 2014). This was highlighted by Garry (49 years old) who had made new friends on Facebook and joined groups where he interacted and shared photographs with other likeminded photography enthusiasts. Garry maintained friendships by 'talking' to group members via Facebook, making plans to meet as a group, and going on outings where they socialised, viewed and discussed each other's photographs. Another participant, Ellie (26 years old), had also made and maintained new friendships from joining groups. Unlike Garry, she did not catch-up with members of her groups in person because they lived too far away from her but they regularly engaged in online conversations about common interests. Ellie's experience mirrored that of a 25 year old female in a study by Holmes and O'Loughlin (2014) who reported that Facebook had given her the opportunity to voice and exchange opinions about hobbies with other people she shared similar interests with without having to meet them.

Internet-based social media has many benefits for individuals living with intellectual disability (Chadwick & Fullwood, 2018). Consistent with the experience of individuals living with intellectual disability in literature, this present study found that for one participant, Helen (59 years old), accessing Facebook had made an important difference to her quality of life. Helen had become housebound since developing a phobia that made her feel anxious going out alone. This condition had excluded her from visiting friends, kept her isolated and had affected her social life. Helen decided to challenge herself by finding employment which meant that she would have to leave the house. The family system in Helen's life (her husband and adult daughter) and the disability employment and service systems supported Helen to achieve leaving home with minimal anxiety.

Helen (59 years old) joined the disability employment organisation's Facebook group where she made new friends with other employees. Without the access to internet-based social media, even though she had many people working around her, she would not have actually been connected to them. Helen made many new friends on this Facebook group who she would message and sometimes make arrangements to meet for lunch. Facebook had assisted Helen to 'meet' a lot more people than she otherwise might have. While Helen had not met many 'friends' from the Facebook work group face-to-face, she commented that having more friends was "*really good*" as she explained that before Facebook, *"[It was] sort of really me and that was it"*. A point to note is that Helen was supported by a network or system that did not appear, from the interview and the data collected, to have any negative influence on her access to internet-based social media.

In the current study there was a different reason Facebook was accessed by one participant Christie (55 years old) compared to the other participants. Christie accessed Facebook so that she could see what her adult daughters were doing; so that she could keep up with their activities. This finding was consistent with that of Chadwick and Fullwood (2018) where participants in their study were interested in what others were spending their time doing on internet-based social media.

Helen (59 years old) and Christie (55 years old) were two participants in this current study who did not report being gatekept by anyone. Christie and Helen had a support network, as a system, that actively encouraged access to internet-based social media, and they had richer, more in-depth relationships and more social interaction as a result of it. Even though they did not report engagement in sexual activities, the potential was there; but for those, where the system appeared to be limiting access to internet-based social media, the potential was greatly reduced or non-existent.

One unanticipated finding of this current study was that participants; Brendan (24 years old), John (27 years old), Paris (31 years old), Jacob (21 years old), Jonnie (20 years old), Helen (59 years old), Garry (49 years old) and Ellie (26 years old), who accessed internet-based social media, especially Facebook, had ‘friends’ who were not predominantly family members. This finding is somewhat surprising, given that research (Amado et al., 2013; Friedman & Rizzolo, 2018; Lippold & Burns, 2009) had reported that for the majority of individuals living with intellectual disability, the people who they identify as ‘friends’ are predominantly family members and/or service providers, and not usually people outside of those circles.

The relationships in the current study may partly be explained by the age of participants, none of whom were teenagers and few who lived at home with their parents, or in supported accommodation, which meant that they could access Facebook and make friends outside of their immediate circle without the permission and influence of paid supports. Another possible explanation might be that for individuals living with intellectual disability having friends is vitally important for their wellbeing (Amichai-Hamburgeret al., 2013), and just as members of mainstream society go on Facebook to make new friends, so too do individuals living with intellectual disability. As a result, having made friends on internet-based social media is the reason not all of their friends are family members or service providers.

What is curious about the findings of this current study is that participants did not move from friendships to more intimate connections. There are several possible explanations for this finding. However, the reasons for this are not clear but may have something to do with monitoring and restrictions the family and service systems placed on some participants, only allowing them to make friends for social, not sexual, reasons. Another possible explanation was because participants in this study's main interest was being socially connected and making friends on Facebook to meet up with for social outings and doing things together, not things that involved sexual relationships and intimacy. It could also be age related, with single participants ranging from 20 to 40 years old not wanting to move friendships to more intimate connections, in contrast to Garry (49 years old), who had made friendships online that progressed to sexual relationships and intimate connections. These findings echo data obtained by Chadwick and Fullwood (2018) where single participants living with intellectual disability in their study did not express an interest in developing romantic relationships on internet-based social media.

In the current study, there were participants, Helen (59 years old) and Paris (31 years old), who also kept up friendships with old school friends and/or people they worked with, not only family members or service providers. These findings are consistent with those of Sallafranque-St-Louis and Normand (2017), where their participants had online social networks made up of some friends from school and friends who they worked with. This is in accord with recent studies by Chadwick and Fullwood (2018), and Holmes and O'Loughlin (2014), which indicate that 'friends' from earlier stages in their study's participants' lives were people who participants had been to school with. These findings indicate that individuals living with intellectual disability, accessing Facebook have the opportunity of maintaining existing accrued friendships online with the potential for intimate relationships to develop. Comparison of the findings with those of other studies indicates there are individuals living with intellectual disability who are able to exercise autonomy in their everyday lives and make new friends and keep in contact with existing ones. Bear in mind that most people living with intellectual disability who the researcher had access to, were not limited in the things they wanted to do by needing service providers to facilitate their activities. Unfortunately, systems in this current study limited access to potential participants, so many questions remained not clearly answered.

5.3.1.1 The system and capacity

Raising issues of capacity typically occurs when particular groups are perceived as being incapable of making choices and decisions, or advocating for themselves. Society has tended to infantilise individuals living with intellectual disability, perceiving them as perpetual children, regardless of their age or level of disability, who have limited abilities to be included in activities that mainstream society takes for granted (Parchomiuk, 2012b).

A recent study by Redgrove, Jewell and Ellison (2016) reported that one of the problems might be that the concept of adulthood is a fluid thing; while legally one is an adult at 18, for people living with intellectual disability there is some concern that, developmentally, individuals may not be at what would be typical for an 18 year old when they are chronologically aged 18. Does the question of seeing adulthood through a different lens encourage and/or facilitate gatekeeping, or access to independent and unencumbered access to internet-based social media? Further research needs to consider this.

Individuals living with intellectual disability are possibly one of the most disadvantaged groups of people, who experience the greatest influence from the family, cultural, financial, educational, employment, and service systems that support them, along with other vulnerable people, such as: people who are institutionalised, people who are hospitalised, and people with mental health difficulties (Aguirre-Martínez, de Casas-Moreno & Paramio-Pérez, 2018).

The findings reported in this current dissertation suggest that the capacity of individuals with intellectual disability to create and enjoy their own social environments, make new friends, and keep in contact with existing ones accessing internet-based social media, should not be underestimated or ignored. The current study challenges the views that some members of society have towards the capacity of individuals living with intellectual disability and their ability to access internet-based social media. This study was able to reveal that most participants were able to work out how to access internet-based social media by themselves. They had not been formally educated in how to access internet-based social media but learned from consulting with peers and having someone to go to if they had any questions.

5.3.2 Internet-based social media to develop social relationships and engage in sexual activities

The current study found that there were participants, such as Elvis (24 years old) and James (35 years old), who did not want to have any engagement with sexual activities. Was this because of historical and cultural assumptions about people with intellectual disability and sex? Were participants told "sex is not for you"? Or was it derived from the influence of many systemic influences, concepts and values such as: parental influence; cultural beliefs; no sex before marriage; the notion of being 'dirty'; previous sexual abuse; the notion that people with intellectual disability are asexual, or they are childlike, or sex deviants; or simply just because they have no interest in sex and intimacy?

Participants in this current study, when asked why they thought sex was 'dirty', and had someone told them so, reported they had explicitly not been told sex was dirty. But this could suggest an element of influence from the family system, cultural system around them in the 'hidden curriculum', possibly from their formal or social learning. Individuals are constantly influenced by where they live and interact, and shaped by social norms (Magasi et al., 2015; Whittle & Butler, 2018). As an example, one participant, John (27 years old), who lived with his three sisters and mother as he grew up, was expected to respect the women in the house. John had not been told specific behaviours he was required to engage in, but living within this family system, and seemingly resulting from his family beliefs and attitudes, it was implied.

Talking to people ‘to feel sexy’ was not an activity engaged in by many participants in the current study. The possible interference of gatekeepers cannot be ruled out. This rather interesting finding may be related to the influence of gatekeepers and the culture of the system in which they have been brought up, although there is no definitive way of knowing from the data that was collected in this study.

Participants Clem (63 years old) and Justin (22 years old) reported that they talked to their partners to feel sexy, whereas one participant, Leigh (28 years old), did not talk to his girlfriend to feel sexy; she and he reportedly only talked about their future together. Rather than talk to people to feel sexy and engage in sexual activities, one participant Brendan (24 years old) wanted to talk to people to form friendships and, similarly, one participant, Chris (22 years old), reported that if he was able to find someone to talk to, it made him feel happy. This finding is understandable because people value having friendships, without which they can become socially isolated and feel lonely (Fulford & Cobigo, 2016). In contrast to the other participants in this current study, one participant Angelo (29 years old) was hesitant in answering and said that he would rather not answer, but acknowledged that he did talk to people to feel sexy.

One participant, Hallsy (31 years old), accessed internet-based social media to view pornography primarily to get ideas about expressing intimacy with a partner, and for sexual stimulation. This finding was reported by Löfgren-Mårtenson and Månsson (2010) who also found pornography had been used as a source of information, as a stimulus for sexual arousal, and as a form of social contact. A point of difference between this current study and that carried out by Löfgren-Mårtenson and Månsson (2010) is that the data in the study reported in 2010 was collected from young adults from the general population living in Sweden and not individuals living with intellectual disability. One of the issues that emerged from the findings of the current study that adds to what is known about individuals living with intellectual disability is that they engage in viewing pornography for the same reasons as members of mainstream society.

Other participants in this current study, Andy (27 years old), Angelo (29 years old) and Paul (44 years old) had once viewed pornography but had stopped. Andy indicated that he had stopped because his partner did not want him to do it anymore. Angelo’s partner did not like him looking at porn because she, “*sort of felt a bit insecure about herself*”. There is no possible way for the present researcher to assume why the partners of participants felt this way. However it was found in the study by Löfgren-Mårtenson and Månsson (2010) that it may have been that they thought their appearance was being compared to females in the pornographic movie, or that female partners were concerned that their male partner might expect them to undertake similar sexual behaviours (for instance, engage in anal intercourse) to those portrayed in the pornographic media they watched. If they felt this way, then this might be why they did not want their partner to continue viewing pornography. Garry (49 years old) had not been influenced by anyone to give up looking at pornography; he reported being in a relationship and no longer felt the need to look.

Participants Angelo (29 years old) and Paul (44 years old) mentioned finding underage pornography while they browsed internet-based social media. Paul said that it, "*made [me] feel bad inside*". He described how once he had got in trouble with his parents having viewed an underage pornography site where he ran up a bill of over $1000. Paul described that it was bad being 'caught' by his parents and explained that since this incident he has tried to stay away from pornographic sites. Angelo related how he found nothing wrong with pornography per se but would not intentionally go to access underage pornography. Liam (24 years old) viewed pornographic sites on internet-based social media but had restrictions placed upon him. This will be discussed later in this chapter.

In the current study, only male participants had reported accessing internet-based social media to view pornography. This finding is contrary to Löfgren-Mårtenson and Månsson (2010) where both male and female participants had reported coming in contact with pornography online, either voluntarily or involuntarily. However, in common with both studies, females were reported to be less likely to report that they viewed pornography online and/or actively sought out pornography.

This interesting finding could be attributed to females being less interested in accessing pornography, or because females have underreported their exposure to pornography. As Luder et al. (2011) hypothesised, it could also be because viewing pornography is more entrenched in societal norms as being acceptable for males, and seen as more deviant for females, so practiced less, or simply admitted to by females less than males.

A possible explanation for there being a gender difference accessing pornography online in the current study compared with the study by (Löfgren-Mårtenson & Månsson, 2010) is that their study was conducted in Sweden where mandated sex education has been in schools since 1956, and sexuality has not been hidden (Daneback , Månsson , Ross & Markham, 2012). In contrast, the current study took place in South Australia, where, despite there being positive support for sex education in schools, there has been limited activity in teacher-led sex education (Talukdar, Aspland & Datta, 2013). Unlike in Sweden, in South Australia there has been a clear lack of comprehensive sex education set out in the curriculum (Talukdar et al., 2013).

The issue of sexuality, access to sexual activity, intimate relationships and how people living with intellectual disability want to engage in sexual activity and intimacy is a current topic (Brown & McCann, 2018; Whittle & Butler, 2018). In Western society there has been a concern about the accessibility of pornographic material on internet-based social media (Löfgren-Mårtenson & Månsson, 2010). In the current study, participants Andy (27 years old), Angelo (29 years old), Garry (49 years old), Hallsy (31 years old), Liam (24 years old) and Paul (44 years old) had accessed internet-based social media to view pornography.

A similarity around the reason for viewing pornography online by participants Hallsy (31 years old) and Garry (49 years old) in the current study mirrors participants in Löfgren-Mårtenson and Månsson's (2010) study. Hallsy reported looking at pornography via internet-based social media primarily to get ideas about expressing intimacy with a partner, and for sexual stimulation. Findings of the current study reflect those of Löfgren-Mårtenson and Månsson (2010) who found viewing pornography online had been used as a source of information, as a stimulus for sexual arousal, and as a form of social contact. A point of difference is that in the study by Löfgren-Mårtenson and Månsson (2010) the data was collected from young adults in the general population living in Sweden and not individuals living with intellectual disability. One of the discoveries that emerged from the current study, and that adds to what is known about individuals living with intellectual disability, is that some of the participants view pornography for much the same reasons as individuals living in mainstream society.

While Garry (49 years old) did not actually say that he viewed pornography online for sexual arousal, the inference was there when he said now that he had a partner he did not need to view pornography any longer. This finding mirrors data used from the *Second Australian Study of Health and Relationships* (ASHR2)(2014) by Rissel et al. (2017) which indicated that males were less likely to view pornography if they were involved in a regular relationship where they had their sexual needs met.

In the current study, two participants, Andy (27 years old) and Angelo (29 years old) had female partners who had them cease viewing pornography because they did not like them doing it as it made them feel inferior. This finding might be explained by the fact that there are many types of control existing within different systems. This finding is consistent with that of Rissel et al., (2018) who reported that males were likely to stop viewing pornography if they had a partner who disapproved of the activity.

An interesting finding in the current study was that one male participant, Liam (24 years old) had the support of his mother to view pornography online. However, while the family system in which this participant lived gave him some freedom it also set strict rules Liam had to follow, such as, *"Only in [your] room in a private place…only at night…and not in front of people".* While having the family system support, which according to Willams and Merten (2011) has the potential of strengthening their mother/son bond by monitoring what online technology was used for; the rights of Liam were controlled by the family system preventing him from engaging in 'normal' activities, where and when he chose to.

Older adults in the mainstream have increasingly found online dating as something they like to engage in (Gewirtz-Meydan & Ayalon, 2018). An interesting finding in the current study was that Garry (49 years old) was the only participant who revealed he had gone online to access dating sites with the intention of making female friends and developing and/or engaging in intimate behaviour. This is not an unexpected finding, since online dating sites are widely used to find sexual partners and romantic relationships (Clemens, Atkin & Krishnan, 2015). However, for other participants the cost of going on online dating sites could be prohibitive for them should the Disability Support Pension be their only form of income.

This finding may reflect Garry's age (49 years old) given that Stephure, Boon, MacKinnon and Deveau (2009) report that older people are usually the ones who access online dating sites to establish sexual relationships. Other reasons could be because Garry appeared to have a very mild intellectual disability, and the fact that he had a full time job, lived independently with his partner, and had very little (if any) help from service providers. The intersectionality of the systems, making up Garry's identity (social, service, employment, financial) and potentially the financial resources to pay for membership, if required, did not prevent Garry from having the freedom to make choices and decisions for himself.

The internet is considered by parents and teachers as a place that provides individuals living with intellectual disabilities opportunities (Molin et al., 2015). However Buijs, Boot, Shugar, Fung and Bassett (2017) posit that the internet can also present significant risks to individuals living with intellectual disability, should they lack poor insight and judgement. Perhaps the most striking finding in the current study was that participants Angelo (29 years old), Brendan (24 years old), Christie (55 years old), Ellie (26 years old), Garry (49 years old), Jacob (21 years old), James (35 years old), Paris (31 years old) and Stella (26 years old) were able to assess and articulate how to manage risks should they go to meet someone they first met on Facebook. Without having any formal sexual health education, the participants from this study were able to describe how they would exercise cyber safe practices, for example Stella (26 years old) said *"I'd get someone to come with me…I would take my phone…so that I can contact the Police if something happened"*. No participant in this study had indicated acting in a manner that would place them at risk of being exploited. This finding reflects those of Molin, Sorbring and Löfgren-Mårtenson (2017) who found most of the participants in their study were aware of the risks of accessing the internet and were able to manage difficult situations, for example, knowing to take someone with them if they went to meet someone in person who they met online.

5.4 Systems and barriers

The expectations and values of family, education, financial, and cultural systems have influenced what individuals living with intellectual disability can achieve (Swango-Wilson, 2010). Taking control over the activities of individuals living with intellectual disability and attempting to minimise their risks could be restricting the pleasure and joy of some of life's experiences that mainstream society often take for granted (Parley, 2011; Seale, 2014). Furthermore, overprotection in an area, for example where individuals living with intellectual disability want to engage in sexual activities, can actually cause them to become more vulnerable (Turner & Crane, 2016b). Not only that, while protecting individuals against risk is very important, this needs to be balanced against the negative impact that over protection can have on the lives of people living with intellectual disability. Over protection often prevents individuals living with intellectual disability from experiencing the negatives aspects of life and relationships; experiences which actually help individuals to learn (Deeley, 2002).

The current study's findings regarding gatekeeping are consistent with Chadwick and Fullwood (2018), which identify areas where participants' online activities had been monitored by the family system members. In the current study, participants reported monitoring of their internet-based social media use was primarily by their mothers, and both parents. In contrast to the study by Chadwick and Fullwood (2018) where gatekeeping was chiefly around staying safe and avoiding risks, in the current study where safety was also mentioned, gatekeepers were monitoring participants' online pornography downloads. Mothers in the current study had told their sons not to look at pornographic material, with one checking her son's phone on a regular basis to ensure he was not downloading sexually explicit content.

When accessing the internet was in its infancy, and parents sought to control content accessed by their children, they were advised to install a filter on the computer, or have the computer in a room where they could constantly monitor its use (Manning, 2018). Moving on over the years, using smart devices has become more common, and these methods are less applicable. Now, when tackling pornography viewing, it has been determined that educating stakeholders is the only way to approach dealing with issues (Manning, 2018). The mothers of participants in the current study who were gatekeeping what their adult children were accessing on their smart devices, might like to consider education, rather than constantly monitoring the devices.

Concerns have been raised about the negative impact of recent funding cuts to organisations like not-for-profit ShineSA (Barber, 2018). Reduced funding has seen the closure of two sexual health clinics and created potential limitations to counselling and education services addressing sexual health and protective behaviours for individuals living with intellectual disability (Barber, 2018). Funding cuts are the broader systems' (political, policy) gatekeeping services for individuals living with intellectual disability. Whether intentional or unintentional, these systems affect knowledge and education of individuals in this marginalised group.

As Rissel et al. (2017) explained, while society has concerns about viewing pornography, being educated could show that looking at sexually explicit images could actually produce benefits for individuals living with intellectual disability to do with sexual activities. Collective action across all systems can provide opportunities for learning about an individual’s needs and acknowledging the benefits of education and access to internet-based social media for individuals living with disability.

Consistent with literature, this current study found that for some individuals, families were “the greatest support and for others, the greatest barrier” (Rojas et al., 2016, p. 60). For example, the mother of Rachael (43 years old) was a barrier preventing her daughter from accessing internet-based social media and/or having Facebook. Rachael’s mother claimed safety reasons, but had not explained what the safety reasons were. Rachael wanted access to Facebook to keep in contact with her brother. What was surprising was that Rachael was 43, lived independently, was employed, was demonstrably a very capable person, and yet was still being closely monitored, having choices and decisions being made for her by her mother without consultation.

Rachael’s (43 years old) mother had not divulged what the ‘safety reasons’ were in relation to her daughter. There are several possible explanations for Rachael’s mother to gatekeep her daughter; possibly she has been frightened by risks involved in going online that get presented in the media (Löfgren-Mårtenson, 2008). However this is difficult to know, because people’s beliefs relating to risks of internet use are yet to be fully investigated (Chadwick et al., 2016). Or it could possibly be the over emphasis of media reports on various matters that has informed the attitudes of Rachael’s mother (Thurlow, 2006). Is there a misconception that all people living with intellectual disability would abuse the opportunity and/or make themselves more vulnerable accessing internet-based social media? Other possibilities could be: lack of education to know ways to keep safe on internet-based social media; or believing myths and stereotypes about people with intellectual disability, including the perceived incapacity of individuals living with intellectual disability to protect themselves online. After interviewing and observing the 30 participants in the current study, the researcher found no individual displaying evidence of being ‘childlike’ and/or sexually deviant and were able to report how they could keep themselves safe if necessary.

Whatever the systems, be they family, cultural, financial, educational, employment, or service systems influencing Rachael’s (43 years old) mother’s decisions regarding her mature aged daughter, changes are required to reflect the positive side of accessing internet-based social media, rather than just the negative side.

Denying individuals living with intellectual disability choice and not allowing them to take risks denies them the right to live a full and ‘good’ life (Methven, 2009; Pernia, 2006). Positive risk-taking is about managing perceived risks to enable individuals living with intellectual disability (as well as others) to have greater control over their lives (Chadwick & Wesson, 2016; Molin et al., 2017; Seale, 2014; Seale & Chadwick, 2017; Seale, Nind & Simmons 2013.)

The findings of the current study suggest that more emphasis needs to be placed on the rights of individuals living with intellectual disability, so they have the opportunity and experience to “participate fully in all aspects of life, access…new information and communication technologies and systems, including the internet”, (UNCRPD, 2006, p. 9); and “live in the community, with choices equal to others…and their full inclusion and participation in the community” (UNCRPD, 2006, p. 19).

Quinlivan (2012) and Curryer, Stancliffe and Dew (2015) report that the UNCRPD (2006) recognises that equality, independence, accessibility, dignity, and inclusion are all essential to ensure individuals living with disability enjoy the same human rights as everyone else in society. Overmars-Marx, Thomése, Verdonschot and Meininger (2014) concur, affirming that one of the UNCRPD (2006) guiding principles is for individuals living with any disability to have opportunities to enjoy all human rights and participate freely and inclusively in society.

However, having rights is simply not enough if individuals living with intellectual disability have no opportunities to exercise those rights (Luckasson & Schalock, 2013). In order to have access to the ‘good things’ in life, individuals living with intellectual disability need encouragement and support to enable them to become involved in a diverse range of experiences, life options, opportunities, and preferences (Collings, Dew & Dowse, 2016; Curryer, Stancliffe & Dew, 2016).

Other participants, James (35 years old), Justin (22 years old) and Paul (44 years old) also experienced parental gatekeeping in relation to activities on internet-based social media. Although James and Justin indicated they did not view online pornography, their mothers regularly checked their mobile phones to see what they had been accessing. The parents of Katie (30 years old) and Elvis (24 years old) monitored all their activities on internet-based social media. Katie was told that she could only play games on the internet and nothing else, while Elvis’s parents denied him viewing sexy pictures on the internet.

Paul (44 years old) was denied the opportunity to purchase an internet connection in his home by his parents so he could access internet-based social media. This was despite Paul living independently in his own place, and having enough of his own money to pay for the connection and access. Details relating to the motivations of parental gatekeeping finances were beyond the scope of this study.

Participants Ian (27 years old), Justin (22 years old), Paul (44 years old), and Robert (56 years old) made the decision not to engage in activities with people they did not know on internet-based social media. They based their decision around safety reasons recognising a potential danger accessing internet-based social media could have to their lives; for example, Robert indicated that, "*You don't know who you meet. You meet weirdos on the internet*." These participants reported that they wanted to avoid trouble which they thought could occur from meeting/communicating with people who they perceived could potentially do them harm. This is echoed in the study by Chadwick and Fullwood (2018) where participants in that study also avoided adding people as friends they did not know for similar reasons.

These reasons showed that individuals living with intellectual disability in the current study had insight into the possible disadvantages that accessing internet-based social media could pose to them. However it is also not known if it was partly due to the systems (family, service, financial) in which the individuals functioned that might have influenced their decision not to access Facebook. In addition, it was not known if participants had been formally educated about the appropriate use and benefits of accessing internet-based social media.

Perhaps it was lack of support from the systems (family, service, educational) for them to feel comfortable and educated to have knowledge on how best to protect themselves accessing social media. Alternatively, was it contrary to literature that reports that individuals living with intellectual disability are seen as incapable of performing certain activities and making real choices (Michailakis, 2003). Were the participants in the current study capable of making choices for themselves that could affect their quality of life, and knew how to avoid trouble and keep themselves safe? According to Rogers and Tuckwell (2016), it is problematic where individuals living with intellectual disability lack having 'choice' or resources to access certain social networks. Individuals living with intellectual disability are able to become proficient in technological skills with proper training and support within the systems (family, social, educational, financial) in which they engage.

Another possible explanation for opting not to access Facebook might be that participants had been over protected and controlled by members of the systems (family, service, educational, financial) in which they engaged, forbidding and/or gatekeeping them from accessing internet-based social media. It is difficult to explain this finding, but it might be related to the fear some people have that individuals living with intellectual disability could experience harm from accessing internet-based social media. Alternatively, it may be because people who have been in control lack awareness about the potential positives of accessing internet-based social media. They are not aware how many individuals living with intellectual disability are able to work out how to keep themselves safe, as found in this current study.

Chiner et al. (2017) proposed that service providers need to be more aware of the potential benefits, not just what they believe the risks of accessing internet-based social media might be to the lives of individuals living with intellectual disability. The present study emphasises the importance of implementing education/learning strategies for both individuals living with intellectual disability and the people who have influence over their access to internet-based social media so that they can consider the opportunities that having access could provide them, not just the disadvantages.

Surprisingly, literacy was a barrier for only one participant, Robert (56 years old), in the current study. The accessibility to online sites for individuals living with intellectual disability is a growing interest in society, because computer interaction has become an everyday occurrence (Schmutz, Sonderegger & Sauer, 2018). As Jaeger (2015) points out, access to the internet and having digital literacy is necessary to be part of a technologically advanced society.

Prior studies have noted that often individuals living with intellectual disability face barriers to accessing online sites as they have not been designed specifically for their use, lacking universal design (Chadwick et al., 2016; Schmutz et al., 2018). Kennedy, Evans and Thomas (2010) suggest that this is a result of a generalised lack of understanding of intellectual disability by web designers. They advise that web design technical systems are complex, so for changes to be made, engaging with a more diverse range of stakeholders who influence web design would go towards making accessibility for individuals living with intellectual disability more of a reality. It was found that language complexity was a critical barrier related to the accessibility of online sites for individuals living with intellectual disability and this issue could be dealt with by an intervention of simplifying text to aid easy navigation (Ruth-Janneck, 2011).

The current study highlights that individuals living with intellectual disability can be independent online and have positive perceptions of accessing internet-based social media, which is corroborated in the findings of Shpigelman and Gill (2014). For example, participants who in the current study reported not requiring assistance accessing Facebook, were aware of someone they could go to if help was required. This was consistent with Shpigelman and Gill (2014) who found that most of the respondents in their study used Facebook without needing assistance from a friend and/or service provider.

Participants in the current study were not required to use a computer or access internet-based social media to be eligible to participate. However this was in direct contrast to the study by Sallafranque-St-Louis and Normand (2017) where all participants were required to use a computer and be able to navigate the internet. Because participants in the Sallafranque-St-Louis and Normand (2017) study were already able to use a computer, the results might reflect a difference to the current study because of the potential for the Sallafranque-St-Louis and Normand (2017) study's participants to have more knowledge and experience. The findings reported in 2017 therefore need to be interpreted with caution as they could be skewed because of differences in ability and experience using internet-based social media, and technology.

Another difference between the current study and the Sallafranque-St-Louis and Normand (2017) study was that almost all of the individuals living with intellectual disability participating the current study (n=29 out of a possible n=30) (aged 20 to 66) used and owned smartphones. This finding is consistent with data obtained by Chiner et al. (2017) where 90% of the participants living with intellectual disability were aged between 18 and 51, used and preferred smartphones to go online. However these findings are contrary to the study by Sallafranque-St-Louis and Normand (2017) where none of the five participants living with intellectual disability owned a smartphone.

It is possible that the findings of the current study may have been skewed by the number of employed (n=26) individuals living with intellectual disability. Statistically, unemployment rates for people with a disability are far greater than those for non-disabled people (WHO, 2011). Nationally Australia's unemployment rate in September 2015 was 6.2% (ABS, 2015), with 61% made up of individuals living with intellectual disability. In the current study 26 participants (86.6%) were employed which is above the national average for individuals living with intellectual disability in Australia.

Another possible explanation for the differences in smartphone ownership is the ages of participants, for example, in the current study participants were older, ranging between 20 and 66 compared to ages of participants in Sallafranque-St-Louis and Normand's (2017) study, 19 to 40.

In the current study, participants accessed the internet on their smartphone, tablet, and or laptop/computer, wherever they wanted to, at home or where they worked. This was in contrast to participants in the study by Sallafranque-St-Louis and Normand (2017) who only accessed the internet via personal computers when at home. In common with Sallafranque-St-Louis and Normand (2017) one participant visited his local library to use a computer to go online.

5.4.1 Financial and resource barriers

For individuals with limited resources whose main income is linked to government payments, as is the case for the many individuals living with intellectual disability, the relative cost of accessing the internet can be a major barrier (Bardasi et al., 2002; Williams, 2013). This view is supported by research reporting the cause of inequalities in an individual's access to internet-based social media participation is generally related to the cost of technology, lack of technical knowledge, and/or an individual's skills or operational ability to use computer-based technology (Sallafranque-St-Louis & Normand, 2017; Van Dijk & Hacker, 2003).

While barriers to accessing technology can often be attributed to affordability, in this current study lack of finances was not mentioned as being an issue. This is where the financial technology resource system comes into place. Here in South Australia, findings suggest that in the current study the financial system in which the majority of participants were involved gave them financial independence and choice, except for one participant, Paul (44 years old), who was not constrained by the financial system, but was by his family system. Paul had wanted the internet connected to his unit but was afraid to ask his mother, who controlled his money, to make arrangements to have it connected for him as he knew she would say it was too expensive. This outcome seems to be consistent with other research which found ‘house rules’ and cost to be obstacles to getting an internet connection in the home (Sallafranque-St-Louis & Normand, 2017). In the current study Paul had the means to pay for his internet connection. However, his finances were controlled by his mother. This is an example of how the family system impacted on Paul to deny him the freedom of choice to arrange access to the internet and social media where he lived.

While Paul (44 years old) was living independently in his own unit, it was evident that he was being denied the opportunity to make his own choices and decisions. It was the choice of another person in the system in which he engaged who denied him access to having internet connection installed. This in turn would have denied him the privacy to access internet-based social media in his own home to make new friends, communicate with existing friends, and form intimate relationships going online, had he wanted to.

Those who had independent financial means, where the support systems around them did not influence how they used their money, had greater opportunities for freedom of choice than those who had restrictions placed upon them by the financial and family systems they engaged with.

Sallafranque-St-Louisand and Normand (2017) had not measured the income of participants in their study but suggested that the lack of fulltime employment for all of their participants with intellectual disability lead them to hypothesise that cost of smartphones had been an obstacle to participants investing in smartphone technology. In the current study, no participant cited lack of income as being a barrier to owning a smartphone and accessing internet-based social media.

5.4.2 Systems intersectionality

According to the State of Victoria (2016) many factors that combine to create an individual’s experiences, within a grouping of diverse factors are sometimes described as ‘intersectionality’. Intersectionality is not simply about bringing together systems, but considering how they do or do not support one another. The concept of intersectionality has been used to describe relationships between social groups, where the emphasis is on boundaries and perceptions of diversity (Woodin, 2014).

Intersectionality provides an understanding of human beings as shaped by the interconnectedness of relationships in different social settings (e.g. gender, sexuality, geography, culture, age, disability/ability, religion) (Hankivsky, 2014). As reported by Collins and Bilge (2016), "these entities, in various combinations or in total, can be accommodated under the umbrella of intersectionality" (p. 142) and occur within a context of connected systems and structures of power (Hankivsky, 2014). Intersectionality has been used to describe areas of "oppression and marginalisation" and the "processes through which oppression happens" (Wooden, 2014, p. 88).

The current study would suggest that it is not just one system that is gatekeeping or one system facilitating, it is the intersection of multiple systems interacting together, as illustrated in Figure 5.1. The system's intersectionality includes education and the potential impact of access to, or a lack thereof, to formal educational curriculum around protective behaviours, sexual health, relationships, and friendships.

The researcher also spent a number of years on a scoping committee looking at the provision of opportunities for individuals living with intellectual disability to undertake and engage in some learning around sexual health and relationships, and dating. But after years of regular meetings it was not supported by the higher system.

An unanswered question from this current study is access to formal education. What the data does not tell us about, is the potential impact of formal education on the participants of this study. The researcher's attempt to access what may have been the sexual health, protective behaviours, sexual education, the curriculum that may have been available to these participants, has not been forthcoming.

Any attempt to gather information about what the curriculum either currently looks like or would have looked like has simply resulted in mainstream curriculum being provided. Further studies need to be undertaken into the experiences that individuals living with intellectual disability have had over the past 50 years in the South Australian education system around formal access and opportunities to learn, and even current access to learn, and current access to learn about internet safety.

The researcher got information about financial systems, family systems, about support systems but did not get information about education systems. And when the researcher went back and approached the Australian Curriculum, Assessment and Reporting Authority (n.d.) seeking information about what may have been the curriculum previously and what the current curriculum was, the researcher was sent mainstream information. There was a lack of clarity as to whether the curriculum the researcher was given access to, would be or was available to students living with intellectual disability.

For the participants in this current study, there was no single discrete system. While this study alluded that one of the systems might be the potential intersectionality between finance; family; education and the potential impact of opportunities to learn, this idea was not clearly reflected in the data.

5.4.3 Gatekeeping

In the current study, two types of gatekeeping emerged: explicit and implicit. Many of the participants who were recruited were very explicitly gatekept. One disability service organisation intermediary (gatekeeper) told the researcher not to ask a selection of questions they flagged on the Interview Guide which they did not want participants to be asked. In another instance, parents of potential participants told the intermediary of a disability organisation they were not to distribute information about the study to their adult offspring as they did not want them to participate in this study.

The researcher approached disability service organisations that implicitly gatekept. These organisations took the information about the study, with one saying that the members of their disability organisation were busy working on an upcoming event that was taking all their time. It was understood that was a way of telling the researcher that they had no more of their time to participate in research as they had important business to take care of. Another disability support organisation took the information and implied they would get back to the researcher but never did, despite follow up communications.

The reason the current study may have found slightly different results is because the individuals the study actually ended up gaining access to, were individuals who did not have a controlling system; were more independent; were older; and were living independently. Because individuals who lived in a heavily managed, protective system, be that, family, cultural, financial, or service systems, the system blocked the researcher out. Had the researcher been able to interview people who were influenced more by the systems they engaged in, the research may have found different results.

5.4.3.1 Gatekeeping – experience of recruiting

Important issues emerging from this current study were the prominence and complexities of gatekeeping and the many challenges faced in gaining access to potential participants who were eligible to participate and join in the research, and this has possibly influenced the outcome.

The participants in the current study lived with supports, either informal, family/carers or within formalised supported accommodation; making up the demographic of individuals living with intellectual disability that the researcher predominantly obtained access to, to join in the study. Despite the researcher’s efforts to provide information about the opportunity to participate, recruitment of individuals living with intellectual disability was challenging because gaining access was governed by the interaction of the social systems in which they lived, overseen by third parties. This meant that more members of the cohort, eligible to take part in this study, may not have been given the opportunity to choose to participate and be involved in research that sought their experiences.

Studies have used metaphors to conceptualise what the experience of recruiting participants was similar to (Ahern, 2014; Feldman, Bell & Berger, 2003; Peticca-Harris, deGama & Elias, 2016). Peticca-Harris et al. (2016) used a metaphor of playing a game of hopscotch *"that requires flexibility and balance"* (p. 379) to conceptualise how to gain access to participants. Ahern (2014) talked about an *"endless maze of blind alleys"* (p. 10) and the metaphor used by Feldman et al., (2003) described having to *"walk down a hallway with many doors: Some of the doors are open; some are closed.…Some of the doors may open but lead to spaces behind the doors that do not provide further access.…Doors that open sometimes close.…Not all doors are completely open or shut."* (p. ix).

Consistent with the literature, metaphorically gaining access to participants in the current study was akin to running a hurdle race. Once the researcher was over one hurdle, another one popped up, some formed barriers too high for the researcher to jump over, and this continued until the researcher gained access through various gatekeepers to participants willing to be interviewed for this study.

There are many explanations for why stakeholders did not exercise their choice to promote, facilitate, or participate in the research. It is not possible for this researcher to know how many potential participants were given information about the study as direct recruitment was not allowed in terms of ethics approval. In this study organisations agreed to recruit potential participants following the initial approaches from the researcher. From organisations the approximate number of potential participants who qualified for this study may have been in excess of 250. One organisation, who had agreed to recruit for the study withdrew their support for recruitment entirely with no explanation provided. The researcher was notified in a particular instance that parents, by email, denied access to any information or knowledge about the study given to potential participants.

Looking towards the broader literature we see examples of similar gate keeping. For an example while gatekeeping was not specifically mentioned in Siebelink, de Jong, Taal and Roelvink (2006), it could be inferred that intermediaries were responsible for individual participation. Three hundred and twenty-five people considered as fitting the criteria for the study to examine sexuality and romantic relationships for people living with intellectual disability, of whom 190 were randomly chosen, staff withdrew 17 potential participants; 73 potential participants declined participation; family members withdrew permission for 17 potential participants, 17 potential participants withdrew for practical reasons. Thus from 325 potential participants, 76 potential participants (46% of the original sample) became the research participants.

And Snowden and Young (2017) report on a recent systematic review on gatekeeping in Kars et al., (2016) which identified that while gatekeeping was not the focus of the research, discussed gatekeeping as "attitudes to research and barriers to recruitment", (p. 188). Snowden and Young (2016) report on the frustration of recruitment failure and the difficulty of accessing the voice of the potential participants.

Social research is not conducted in a vacuum and gatekeepers can take control and have the potential to be paternalistic and tokenistic (Walker & Read, 2011) and prevent participants from speaking for themselves. Not every gatekeeper will be receptive to research requests and there will be some who will block access to the research and potential participants (Clark, 2010). For example, in the current study there was a disability support organisation whose hierarchy were sympathetic to the research study because it resonated with issues encountered in the organisation and were receptive to the request. They believed the idea of talking about sexuality and social media access was important and a benefit for adults living with intellectual disability. However there were unsupportive gatekeepers, for example parents and/or service providers, who held differing values and assumptions about these areas in the social world, and denied access to potential participants.

A particular instance that the researcher was not prepared for was when a key person in one organisation, minutes before the first participant interview, insisted that the researcher exclude a series of the planned questions from the interview guide, in particular the ones around sexuality (refer Appendix 7). The key person in this organisation prevented the researcher from asking these questions, commenting that they were too personal and that they would not even ask their clients such questions, despite the Flinders University ethics committee approving the questions prior to data collection.

On reflection, the present researcher questions what right the key person (a middle manager) had to repress the questions that were planned, considering that the proposed interview questions had been through a rigorous ethics review before approval was given for the researcher to ask them. It appeared, in the opinion of the present researcher, that this manager may have overstepped their professional boundaries. Not only were individuals living with intellectual disability seemingly 'controlled' by the systems in which they live, so too were others.

The present researcher met with two executives of a not-for-profit disability organisation. Discussions about the study gained support from the two executives who were very impressed with the 'sexuality' element of the research and wanted to help find potential participants from their organisation. As a result, this organisation sent out information packages to parents of adults living with intellectual disability involved in the organisation, informing them that they would be distributing the *Information and Consent Brochure* (refer Appendix 2) to potential participants.

Parents who received the information packages denied their adult offspring the opportunity to receive the information about the study without mentioning it to them. Response from parents, after learning about the proposed research, was to exercise the opportunity to gatekeep, variously communicating: *"I feel that it would be a good idea if [name of potential participant] did not receive one of [the researcher's] leaflets thanks*"; "*I do not wish [name of potential participant] to take part in this research thank you*"; *Hi [Company Manager], since [name of potential participant] doesn't use the internet there is no point in her being interviewed so my consent is not given for her to receive any forms, Regards ...*"; (after asking to see the questions), *Hi [Company Manager], I do not want [name of potential participant] to participate in this survey. Kind regards ...*".

A paradox exists in research involving individuals living with intellectual disability: the view that it is vital to protect 'vulnerable' individuals versus the need to include individuals living with intellectual disability in research to collect the best possible data to share their experiences and needs. The above examples demonstrate that individuals living with intellectual disability can be denied the opportunity to make choices because of the external control of the systems in which they live. Rather than deny individuals with intellectual disability the opportunity to make choices, systems need to be in place to support the choices that they make to allow individuals living with intellectual disability to have some control over their own lives (Agran, Soorey & Knupp, 2010).

5.4.3.2 Gatekeeping – influence on individuals living with intellectual disability

The researcher could not get access to people in the current study when they were in a situation of being heavily managed (by gatekeepers) and supported by the disability service. A possible explanation for this is that the researcher found it difficult to access people living or working within a family, employment, education, financial, cultural system, as outlined in section 5.8.

The biggest influence on the findings of this current study was the gatekeeping, because it severely restricted access to a diverse range of participants. It was a limitation of this study that was not anticipated, because the researcher had developed relationships with service providers, and had discussions with all of them prior to data collection.

This and other studies, Carey and Griffiths (2017), and Walker and Read (2011) report that gatekeeping still exists. Gatekeeping as experienced in this study reduces opportunities for engagement in research and therefore limits the pure voice of individuals living with intellectual disability in research (Thomson, Roberts & Bittles, 2014).

5.4.4 Access to internet-based social media and changing systems

Making system change can be a difficult process to achieve. As pointed out by Franz (2016) systems have a strong predisposition to continue and operate the way they always have. This could be predominantly because systems are complex groups made up of many parts, where changes in one area could bring about unforeseen concerns in other places (Franz, 2016).

However, with the current study in mind, this is not a good reason to neglect making systematic changes, especially if the system appears to deny or hinder individuals living with intellectual disabilities many of the rights and opportunities under the UNCRPD (2006). According to Wehmeyer (1996): “Until people with disabilities are enabled to be self-determined, they will remain dependent upon systems and other people” (p. 32).

For example, Shpigelman and Gill (2014) report that it is important that individuals living with intellectual disability have the right to have a say using their own voice, and in this case participate in research. Individuals living with intellectual disability need be afforded their human rights, and assistance to become more independent and exercise their own choices living and working within such systems as: family, cultural, financial, education, employment, and service systems. It is the job of the system to provide the most effective way of connecting individuals living with intellectual disability to meet their needs and provide the opportunities they deserve as equal members of society fully exercising their human rights.

The researcher in this current study acknowledges that change is difficult, but despite this, challenges need to be dealt with in the systems, such as: family, cultural, financial, education, employment, service systems, in the community, and in social circles. For individuals living with intellectual disability, system changes need to be a collective action across all networks and at the individual level; seen as a learning process, where failures in any of the systems provide an opportunity for learning and adaptation, to change the system for the better (Abercrombie, Harries & Wharton, 2015). System changes are often linked to evidence-based practice (Abercrombie et al., 2015), which is, in turn, linked to research.

Changing systems is an approach to social change, and Abercrombie et al. (2015) provide questions that systems changers should be constantly asking: “What change is needed, why it is needed, and what might be unintended consequences?” (p. 9). At the core of systems change, the answers are ways of affecting change (Abercrombie et al., 2015).

5.5 Implications for policy and practice

There is a need to alter the way many people think about individuals living with an intellectual disability; acknowledge that it is their human right to engage in sexual activities, and their right to access internet-based social media to develop relationships and engage in sexual activities. Some of the participants in this study seemed to have a good understanding and appreciation of the potential dangers of accessing internet-based social media and meeting new people.

Funding cuts have the potential to leave wide gaps in the representation of the interests of individuals living with disability (Knaus, 2017). Most states in Australia are planning to withdraw funding for disability advocacy with the introduction of the NDIS. According to Knaus (2017) the NDIS will not properly cover advocacy funding which will affect many individuals living with disability. The potential is for individuals living with intellectual disability, who have lower support needs, to miss out if they are unable to get NDIS funding to pay for sexual health and/or protective behaviour support. For individuals living with intellectual disability, will families think to put the need for this in a NDIS support plan?

The researcher in this current study recommends changing people's perceptions about having to always protect individuals living with intellectual disability from perceived harm rather than gatekeeping, and preventing or monitoring their activities. There is a need for change from being in a position of control, to working collaboratively with individuals living with intellectual disability to assist with decision-making and choices, encouraging risk-taking and enjoying activities that mainstream society takes for granted. For this to happen, it is recommended to work on finding a balance between risk and duty of care to allow opportunities for individuals living with intellectual disability where they can learn from their own decision-making.

Responding to social change requires the involvement of a diverse range of people to develop an understanding of why changes need to occur. To work towards seeing this change, it is imperative to begin consultation with all stakeholders, and work towards gaining their support. This is important so that everyone involved understands the importance of implementing changes to policies and practices, and the reason and benefits for making them. For any change to work successfully, stakeholders need to understand the purpose of implementing policies and practices, and be provided with the advantages and rationale behind considering making changes to policy and practices.

5.6 Strengths

This current study has a number of strengths:

- A strength lies in the focus being placed on the lived experience of the participants. There was no direct external influence placed on participants during interviews, because all but one had no one with them. The direct accounts of participants' experiences and involvement accessing (or not) internet-based social media, provided an understanding of the variety of activities individuals actively engaged in online.
- This study gave 'voice' to an under-researched cohort, directly from their own voices. While research has been conducted about people with intellectual disability, it is rare for individuals living with intellectual disability to be the focus of the research and to be directly asked questions to share their experiences. This research adds to what we know about individuals living with intellectual disability directly from members of this cohort.
- Amongst the 30 participants, there were individuals who had a variety of communication styles and communication abilities. There were individuals whose impairment appeared to have limited impact on their activities of daily living and there were others for whom their disability appeared to have a more obvious impact on their daily activities. A strength was that the researcher was able to ask questions and in return get answers.

5.7 Study challenges

There are limitations to be acknowledged when examining the findings of the current study:

- Current ethics and research practices designed to protect vulnerable individuals do discourage direct recruitment, for good reason. However, one of the challenges this presented to the researcher meant that there was a requirement to go through intermediaries. While the researcher realises going through intermediaries can be a safeguard to protect individuals living with intellectual disability from being coerced into participating by direct contact, it may also have acted to deny some individuals the right to hear about and be included in the research study.
- Interviews were only conducted once, and for a limited time to avoid participants becoming fatigued. However, had the researcher met with participants multiple times over an extended period, there would have been more opportunity to develop further rapport, and ensure the information collected was robust.
- The researcher was only able to engage one group of individuals living with intellectual disability at one point in time. The researcher was time bound and only experienced gatekeeping culture at a particular moment in time. At another moment in time, either before or after the recruitment, and perhaps with other staff, access to participants could have been different. It is becoming increasingly difficult to recruit participants living with intellectual disability for

research because some individuals are getting asked over and over again and have tended to tire of it, becoming research fatigued (Clark, 2008).

- There were groups of individuals who were heavily managed and supported by the disability service, family, social systems that the researcher could not get access to.
- The issue of replication is challenged by the fact that given different models of support exist for individuals in geographical locations a different cohort of individuals living in a different environment receiving different disability supports my bring about different results. Although the sample was selected purposely from a cohort living in South Australia there was no assurance that this population was typical of individuals living with intellectual disability as a whole.
- The researcher acknowledges that this current study, should it be repeated with 30 people in a different geographical location in Australia, or potentially with participants who had different supports and different levels of gatekeeping, the outcome might be different. Despite challenges with recruitment, the current study did start to get a consistent thematic response towards the last couple of interviews, where there was a level of reccurring themes and level of consistency.
- This study did not collect information on participants' religious and/or spiritual beliefs. An implication of this is the possibility that this may have influenced individual's online behaviours that were not taken into account.

5.8 Future research

Several areas are worth further investigation:

- The sample of 30 participants interviewed for this current study comprised cognitively able individuals living with intellectual disability, with good levels of receptive and expressive communication ability. Further research should be undertaken to explore the experiences of other individuals living with intellectual disability who are not online and excluded from internet-based social media, for example, less supported, financially poor, and having higher levels of support needs.
- Although the focus of the current study was to understand the unique experiences of individuals living with intellectual disabilities, further research would be beneficial that integrated these findings with research that also focused on the perspectives of significant others. This could provide an insight into the issues faced by family, education, financial, and support systems when supporting individuals living with intellectual disabilities. Also, collecting data that included significant others could have assisted to triangulate the findings and improve reliability of this study.

- There are still many unanswered questions about whether the issue of capacity lies within the individual living with intellectual disability, or within the system. Does the capacity and responsibility to use the internet safely to form relationships for friendships and sexuality, live solely with the individual? This current study would suggest that some of that capacity lives within the system. A further study with more focus on capacity is therefore suggested.
- Further research is required to provide a greater insight into the effects of gatekeepers and the reasons they tend to take control. What kind of processes need to happen for individuals living with intellectual disability to have access to the internet and the potential to form relationships and/or engage in sexual activities?
- The participants in this current study had mild intellectual disability and were mostly in employment. It would be interesting to explore the reasons behind why parents exercise control over their adult offspring. Findings from this research could form the basis for future investigation into the role and effect that gatekeepers (family systems) can have on the self-determination of individuals living with intellectual disability. It could be determined what are the best ways of educating persons in family systems who feel it is their duty to protect, rather than allow their offspring to engage in positive risk-taking, to share the decision-making and have some form of independence in the way they live their lives.
- Given the fact that there is a real concurrence between the findings of this study and other studies, that individuals living with intellectual disability seem to be accessing Facebook quite successfully, further research is required to explore how they are using Facebook. Are they using Facebook to its potential? How much time are they spending? Are there better applications than Facebook? What do we do with that information? Should we be including greater education about the use of Facebook? Are people with disability using Facebook as a tool to make new friends; if they are not, do they need some lessons on how to do that? Would they benefit from learning about online dating and the scope to facilitate or engage in intimate relationships and/or sexual activities online?

There is a missed opportunity for parents and/or disability organisations/service providers to actually understand what their offspring and client group are thinking. What is it parents and/or disability organisations/service providers are afraid of? Are they afraid that by bringing up a topic such as accessing internet-based social media to facilitate or engage in intimate relationships and/or sexual activities, that their adult child or the person to whom they are providing support or services will, as a result simply of the topic being raised, then want to undertake that activity? This current study reaffirms what other studies have said, and this is that individuals living with intellectual disability are accessing Facebook and using it to keep in contact with social networks. What is it that we do not understand about the use of Facebook for individuals living with intellectual disability? This is something that needs further investigation.

Then, taking a systems theory lens to this, how does the system impact on individuals' use of Facebook? Systems theory says that things work because they are systematic but, for some individuals living with intellectual disability, the system is interrupted by gatekeepers.

Previously posed in this current dissertation was the question, of whether participants had been told "sex is not for you". Or was this sense of sex being off limits for a person living with intellectual disability derived from a diverse number of circumstances and the influence of many systems, societal attitudes, parental influence, and cultural beliefs, such as the concept of no sex before marriage; a notion of sex being 'dirty'; previous sexual abuse; the notion that people with intellectual disability are asexual; that they are perpetually childlike; are sexual deviants; or simply just because people living with intellectual disability had no interest in sex and intimacy? (Brodwin & Frederick, 2010).

5.9 Conclusion

The current study set out to explore the experiences of people living with intellectual disability around accessing internet-based social media to facilitate or engage in intimate relationships and/or sexual activities. A study objective was to investigate if there were increasing opportunities for choice and control over intimate lives yet, unexpectedly, a key finding was that systemic gatekeeping was active and potentially limiting the opportunities for people living with intellectual disability. This is despite years of advocacy, training and policy changes based on Australia's 2008 ratification of the UNCRPD (2006). In this current study the researcher came across gatekeeping at several system levels. Despite the introduction of the National Disability Insurance Scheme, there have been systemic policy changes in recent decades that saw State and Commonwealth government funding cuts to advocacy, complaint and other services that were aimed at building capacity. There was also gatekeeping experiences at state and organisational levels and within natural social support systems such as family and guardians. This study found that systems still play a significant role in the lives of people living with intellectual disability and it is really time to talk about the 'elephant in the room'. What we actually need to research and understand is the impact of gatekeeping and systems on people's choices, and decision-making. Where does this gatekeeping stem from: lack of policy; poor staff training; poor organisational governance; or higher levels of leadership?

While there is an international move towards deinstitutionalisation, person-centred, and self-determined support for individuals living with intellectual disability, this current study would suggest that there is still an 'invisible cone of protection' that exists for individuals living with intellectual disability. The systems that exist, within which they operate, be they family systems, employment systems, education systems, cultural systems, financial systems, or service systems, still provide a potentially disempowering or choice-limiting level of influence over individuals. This invisibility is of concern, because it raises questions about whether individuals living with intellectual disability are being denied an ordinary life, where they can make their own decisions and choices, a condition of living that all individuals living in mainstream society take for granted. There has been significant research and evidence-based practice in the last 20-30 years that indicate that unless individuals have the opportunity to engage in positive risk-taking and making mistakes, they do not learn and grow (Searle et al., 2012).

From an international perspective, there is much conversation about deinstitutionalisation, person-centredness, self-determination, empowerment, and enablement. It is this current author's contention and speculation that if there were to be an analysis undertaken of the content of the mission and vision statements of many disability service organisations—including some of those that denied the present researcher access to provide information to potential participants about the opportunity to participate in this current study—it would be found that most, if not all, of the posed phraseology is used. Since individuals living with intellectual disability were not even given the opportunity to choose if they wanted to be involved in the current research or not, this author contends that such statements are simply and only rhetoric. It raises concern that there is still a tendency for disability service organisations to be paternalistic and also unwilling to manage any distress or concern that potentially might be raised. The current author poses the question that, if persons living with a disability are being asked to engage in research that might be perceived to be of a sensitive nature, where is the support for potential participants to make a truly informed decisions about whether they do, or do not, want to be involved in a study such as this current study?

Governments and disability service organisations need to provide services within and through the language and words that they espouse on websites, in policies, advertising, and in strategic planning and mission and vision statements. When asked by researchers if information could be distributed and whether individuals living with intellectual disability could be assisted to understand what the study information means, to make an informed choice; it is critical that censorship and gatekeeping is minimised or eliminated.

This current study shows that the opportunity to have the dignity of risk to make mistakes and be supported to learn from them around intimacy and social relationships is important. Some of the potential participants of this study were not seen as capable of being able to talk about this, of having a voice, of being able to make good choices or simply to make bad choices, and learn from them. However, in contrast, other disability service organisations, managed recruitment of potential participants to this current study differently, and facilitated informed decision-making. These organisations disseminated information, explaining the study, and were willing to provide support to individuals living with intellectual disability to understand what the research was about and, if the person living with an intellectual disability chose to be involved, and their engagement raised any sensitive concerns, support them.

There are aspects of the UNCRPD (2006), Article 9, which appear to not be universally implemented for individuals living with intellectual disability in South Australia. These oversights contribute to barriers to accessibility that individuals living with intellectual disability face that have prevented them from taking part in all aspects of an ordinary life. Individuals living with intellectual disability need to have equal access to such things as, but not limited to: electronic services like the internet; education and sexual healthcare; housing/independent living; and places to work. The UNCRPD (2006) supports the rights of individuals living with intellectual disability to independence and to be allowed to make choices and decisions to take up opportunities where they can enjoy all human rights and freely participate inclusively in society.

Some could read this current study with an element of disappointment that there was not a larger number of participants providing a broader spectrum of understanding. However, in any research it is oftentimes the unintended and unexpected findings that provide the richness and depth to research, and this current study is one of those studies where there were key unintended and unexpected findings. While the present researcher could be disappointed in not having access to more participants, and not having more depth and detail around the specifics of accessing internet-based social media for engaging in intimate relationships and/or sexual activities for people living with intellectual disability; interesting findings were revealed. Some previous research and the preconceived notions of lack of capacity to make choices around intimacy have also been challenged. These findings draw our attention to the importance of considering the appropriate level of support, in interacting with the systems—be they financial, family, cultural, social, educational, or employment—that individuals living with intellectual disability need in order to be supported (not gatekept) to widen their social networks via internet-based social media, to facilitate, or at least have the potential to engage in intimate relationships and/or sexual activities, should they desire.

For individuals living with intellectual disability, to learn about and have access to engage in internet-based social media should they choose too, in a way that provides social engagement, and the potential for the development of intimate relationships, we need to understand where the gatekeeping begins. Where does it come from, and where does the gatekeeping end? Who is leading the gatekeeping? How can we open up access to internet-based social media for social engagement and the potential for cybersex and the forming of intimate relationships for individuals living with intellectual disability? This study would suggest that the systems are still leading, not the individuals living with intellectual disability.

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APPENDICES

Appendix 1: Letter of Introduction

Assoc. Prof Caroline Ellison

Disability and Community Inclusion School of Health Sciences
Faculty of Medicine, Nursing and Health Sciences
GPO Box 2100
Adelaide SA 5001

Tel: 08 8201 3422
Fax: 08 8201 3646
Caroline.Ellison@flinders.edu.au

CRICOS Provider No 00114A

Hello

My name is Judith Darragh and I am a PhD Candidate in Disability and Community Inclusion, School of Health Sciences at Flinders University. I am undertaking research to complete my thesis. My supervisors for this study will be Caroline Ellison, Michelle Bellon and Louise Reynolds all from Flinders University.

The aim of my research is to explore the experiences of adults living with intellectual disability accessing the internet and social media for exploring sexuality and developing personal relationships and I will be addressing the following research questions:

Adults living with intellectual disability who access to internet and social media:

- How do they access the internet and social media?
- What/who facilitates support of their access to the internet and social media?
- How does internet and social media access facilitate the development of social relationships and engagement in sexual behaviours?
- What are their aspirations, if any, for making and maintaining friendships and developing sexual relationships through the use of social media?

Adults living with intellectual disability if they do not access the internet and social media:

- Would they like to?
- What, if any, barriers are experienced in accessing the internet and social media for these purposes?

I plan to interview approximately between 30 and 40 individuals who meet the criteria outlined below:

- Are between the ages over18 years
- Are eligible to receive the disability support pension and/or have been assessed as having an intellectual disability and/or are eligible to receive services from government and non-government agencies
- Are interested and willing to be involved in the study

- Are able to understand questions and provide answers either verbally or using an augmented communication system
- Have the capacity to provide informed consent
- Are geographically available to the researcher

I have attached a copy of my research proposal presentation for your information which provides further information about the study I am planning to undertake.

Participants will be provided with an Information and Consent Brochure written in plain English providing information and explaining the study and its aims. I have attached a copy of the brochure for you to see. Participation in the study will be voluntary and consent will be sought prior to participation as interviews will be audio recorded and transcribed. All information gathered will be kept strictly confidential.

Participation in the research will involve a 1 hour interview with the individual (and a family member/friend if desired) to discuss their experiences of accessing internet and social media for exploring their sexuality and developing personal relationships.

I have ethics approval from the Flinders University Social and Behavioural Research Ethics Committee.

I am writing to you to request permission for your organisation to promote a Brochure that provides information to potential participants to take part in my research. If your organisation is able to assist me in promoting my research I would appreciate if the Information and Consent Brochure could be distributed via the organisation's community notice and discussion boards or electronically.

If you have any further questions about my planned research please feel free to contact me at Judith.Darragh@flinders.edu.au. I am more than happy to meet with you to discuss details of my study further.

Kind Regards,

Judith Darragh

PhD Candidate

Disability and Community Inclusion School
of Health Sciences

Faculty of Medicine, Nursing and Health Sciences Flinders
University

Appendix 2: Information and Consent Brochure

About My Research

Why am I doing this research?
For many people the internet and social media have become part of everyday life.
I am interested in how people living with an intellectual disability use the internet and social media.
Examples of Social media are:

Facebook
Twitter
MySpace
Blogs

Who I would like to speak to…
I want to talk to people living with an intellectual disability aged between 18 and 26. I think that they are the best people to tell me what I need to know.

Where will we meet?
Wherever you like that is quiet, could be at home or in a park, somewhere private. However should you decide to meet in a public place keeping our conversation confidential may not be possible. You can bring someone with you if you like.

How much time will it take?
About 1 hour, only once. It depends on how you feel. We can stop anytime you like.
With your consent I will electronically record what you say.
You can read what I write later to check it is correct.

Are there any risks or discomforts if I am involved?
I don't think so. You can stop any time you like. Sometimes a person can feel upset talking about new things. If any questions do make you feel uncomfortable or give you concern please contact your counsellor or other support service or Lifeline (24 hour confidential counselling service) 13 11 14,
Or SHine SA (Sexual Health information networking & Education) 1300883793.

I will not be upset if you do not want to answer some questions. You can stop anytime you like.

What will the questions be about?
First I would like to know a little about you by asking:
What a typical day is like for you -
- If you work, go to school, or go to a day program
- Where you live
- Who lives with you
- What you like about where you live
- Tell me about your friends

For people who have gone on the internet or used social media
- Do you go on internet and social media often?
- Who helps you?
- Could you tell me about the sites you go to?
- Have you ever looked at sexy pictures on websites that have made you feel sexy?
- What do you think about seeing sexy pictures on websites?
- How does it make you feel?

For people who haven't gone on the Internet or used social media
- Would you like to?
- Could you tell me why?
- What would help you use the internet more?

What I want from you…
We will talk about what you do and if you go on the internet or social media often.
I will also ask you to suggest someone you think will add more information. This could be a family member, paid carer or friend. It does not matter if you can't think of anyone.

How to contact me.
Telephone: (08) 8201 5858 or (08) 8201 3745
or email: judith.darragh@flinders.edu.au

Relationships
in
Cyberspace
Consent Form Participant

Consent Form for Interview

I……………………………………………………………………………
am older than 18 years of age.
I agree to meet with Judith Darragh and talk about the internet and social media.
1. I have read or someone has read to me the Information Brochure.
2. I have read or someone has read to me details of what will happen to what I say.
3. I agree to my ideas and story being recorded electronically.
4. I know I should keep a copy of the Information Brochure and Consent Form in case I need them later.
5. I understand that:
   - I might not get anything from taking part in Judith's research.
   - I can stop being involved whenever I like and I don't have to answer questions I don't like.
   - My ideas and story might go into a book or a magazine (journal), but no one will know it is me and personal details about me will be kept private.
   - I can ask that Judith stop recording at any time, and that I can leave the interview without being in trouble.
   - I have talked to someone I trust (a member of my family, a carer or a friend) about taking part in this research.

Participant's signature……………………………………

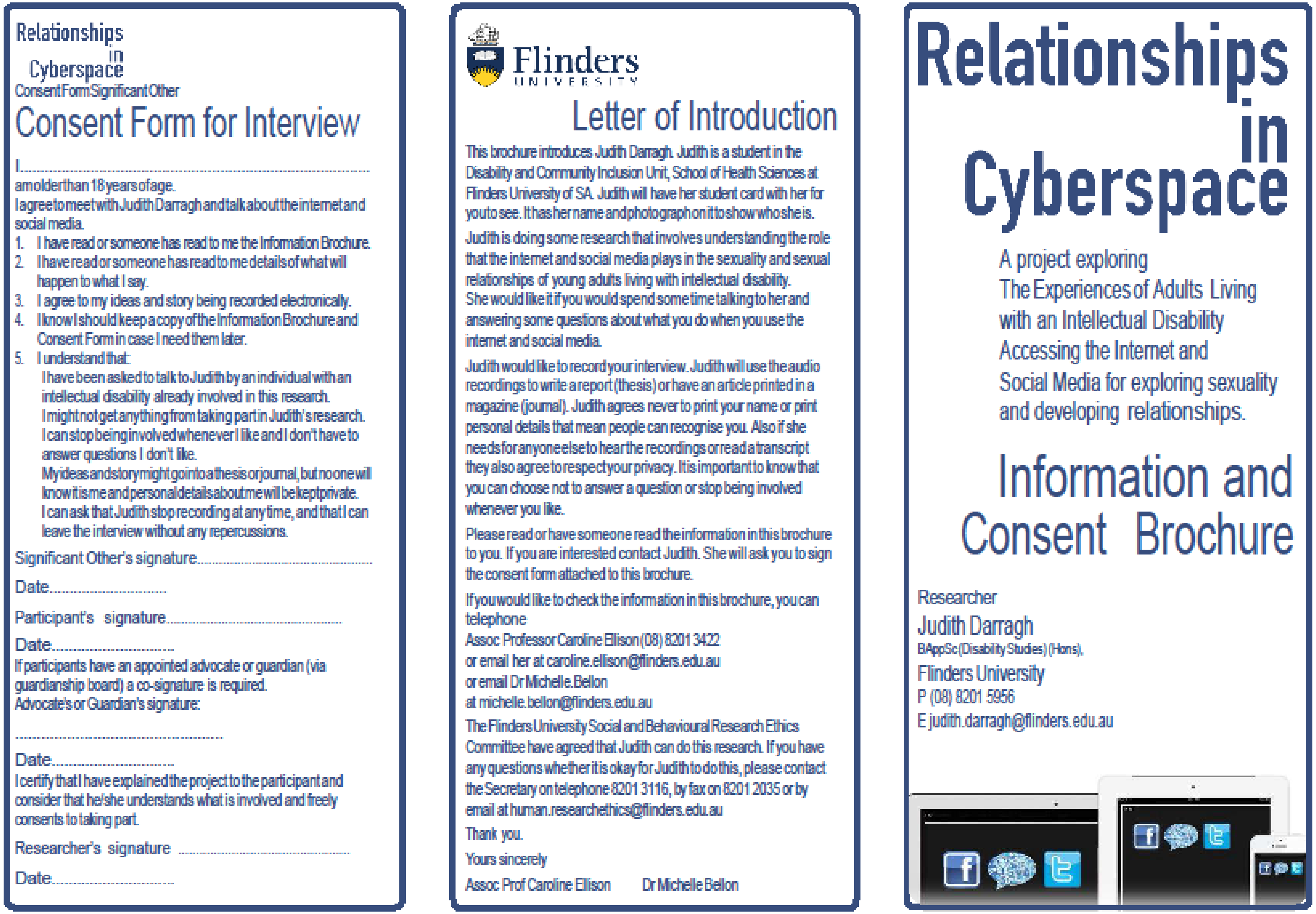
Date……………………
If participants have an appointed advocate or guardian (via guardianship board) a co-signature is required.
Advocate's or Guardian's signature:

……………………………………………………

Date…………………………
I certify that I have explained the project to the participant and consider that he/she understands what is involved and freely consents to taking part.

Researcher's signature ……………………………………

Date…………………………



Relationships in Cyberspace

Consent Form Significant Other

Consent Form for Interview

I...

am older than 18 years of age.

I agree to meet with Judith Darragh and talk about the internet and social media.

1. I have read or someone has read to me the Information Brochure.
2. I have read or someone has read to me details of what will happen to what I say.
3. I agree to my ideas and story being recorded electronically.
4. I know I should keep a copy of the Information Brochure and Consent Form in case I need them later.
5. I understand that:
   I have been asked to talk to Judith by an individual with an intellectual disability already involved in this research.
   I might not get anything from taking part in Judith's research.
   I can stop being involved whenever I like and I don't have to answer questions I don't like.
   My ideas and story might go into a thesis or journal, but no one will know it is me and personal details about me will be kept private.
   I can ask that Judith stop recording at any time, and that I can leave the interview without any repercussions.

Significant Other's signature...

Date.................................

Participant's signature...

Date.................................

If participants have an appointed advocate or guardian (via guardianship board) a co-signature is required.

Advocate's or Guardian's signature:

....

Date.................................

I certify that I have explained the project to the participant and consider that he/she understands what is involved and freely consents to taking part.

Researcher's signature ....

Date.................................

Flinders UNIVERSITY

Letter of Introduction

This brochure introduces Judith Darragh. Judith is a student in the Disability and Community Inclusion Unit, School of Health Sciences at Flinders University of SA. Judith will have her student card with her for you to see. It has her name and photograph on it to show who she is.

Judith is doing some research that involves understanding the role that the internet and social media plays in the sexuality and sexual relationships of young adults living with intellectual disability. She would like it if you would spend some time talking to her and answering some questions about what you do when you use the internet and social media.

Judith would like to record your interview. Judith will use the audio recordings to write a report (thesis) or have an article printed in a magazine (journal). Judith agrees never to print your name or print personal details that mean people can recognise you. Also if she needs for anyone else to hear the recordings or read a transcript they also agree to respect your privacy. It is important to know that you can choose not to answer a question or stop being involved whenever you like.

Please read or have someone read the information in this brochure to you. If you are interested contact Judith. She will ask you to sign the consent form attached to this brochure.

If you would like to check the information in this brochure, you can telephone
Assoc Professor Caroline Ellison (08) 8201 3422
or email her at caroline.ellison@flinders.edu.au
or email Dr Michelle Bellon
at michelle.bellon@flinders.edu.au

The Flinders University Social and Behavioural Research Ethics Committee have agreed that Judith can do this research. If you have any questions whether it is okay for Judith to do this, please contact the Secretary on telephone 8201 3116, by fax on 8201 2035 or by email at human.researchethics@flinders.edu.au

Thank you.

Yours sincerely

Assoc Prof Caroline Ellison Dr Michelle Bellon

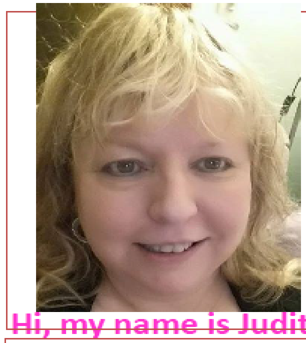
Relationships in Cyberspace

A project exploring
The Experiences of Adults Living
with an Intellectual Disability
Accessing the Internet and
Social Media for exploring sexuality
and developing relationships.

Information and Consent Brochure

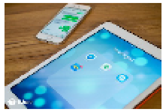
Researcher
Judith Darragh
BAppSc(Disability Studies) (Hons),
Flinders University
P (08) 8201 5956
E judith.darragh@flinders.edu.au

Appendix 3: Poster



Hi, my name is Judith

Relationships in Cyberspace: *A Project exploring the Experiences of Adults Living with Intellectual Disability Accessing the Internet and Social Media for Exploring Sexuality and Developing Relationships*

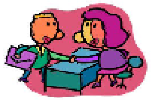


How you can take part

You can take part in some interviews.

I will come and ask you questions for about an hour

The type of questions I will ask



What a typical day is like for you.

Whether you have gone on the Internet and Social Media sites?

Could you talk about the sites you have been to?

If you haven't been on the Internet would you like to?

Whether you have ever looked at sexy pictures on websites that have made you feel sexy?

What is this study about

This study is about how people living with intellectual disability use the internet and social media.

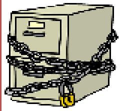
©Prawny - IllustrationsOf.com/215631

How to contact me

☎ 8201 5956 or 8201 3745

Or email:

Judith.darragh@flinders.edu.au

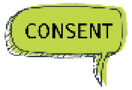


Your Privacy

Your privacy is important.

If you give me any personal information, like your name and address, I must keep this information safe.

I will not give your information to anyone else or use it for anything else.



To talk to me you will have to give me permission. This means that you agree to talk to me. I have an *Information and Consent Brochure* that gives more details about my study I will give to you.

Research Ethics Committee A special committee called the Social and Behavioural Research Ethics Committee (SBREC) at Flinders University has looked at how this project will be done. The committee wants to make sure that everyone's rights will be protected. The committee has said that this project can begin. If you are worried or have any questions about how your rights are being protected in this research, you can phone the Secretary on 8201 3116 or email:human.researchethics@flinders.edu.au

Appendix 4: Interview Guide

Individual Living with Intellectual Disability	**Alternate questions when response is NO**
Some of the questions I am going to ask you may be sensitive – I do not want to embarrass or upset you. ***If any questions make you feel uncomfortable you can stop any time you like, just let me know.*** ***You do not have to answer any question you do not want to.*** ***I am not going to be upset with you.*** ***I am going to keep what you tell me private.***	
Pseudonym	
Number	
Date	
Age	
Gender	
Interview	
Tell me about yourself?	
What do you do in a day?	
Do you go to work? ...to school? Day program?	
Where do you live?	
Who lives with you?	
What other care support do you need?	
Tell me about your ongoing care you think you need.	
What do you like about where you live?	
Tell me about your friends?	

How do you keep in contact with everyone? If Social Media ask: Who provided you with the tools? Who pays for the mobile, internet etc.?	
How do you make plans to see each other?	
Where do you see them? - At work? - In your street? - Other places?	
Can you tell me more?	
Do you use the telephone?	Would you like to? Could you tell me why?
Do you use a computer/internet/tablet?	
Do you use an IPad or smartphone?	
Do you have a computer, smartphone, tablet at home? If yes: Who bought it? Where do you use it? Internet connection?	Would you like any of these? Could you tell me why?
What kind of things do you do on them? What do you use them for?	
What do they help you to do?	
Do you have any friends who use any/all of these things?	
What do you think about that?	
Have you used Facebook or twitter?	Is there a reason you haven't used Facebook or twitter?

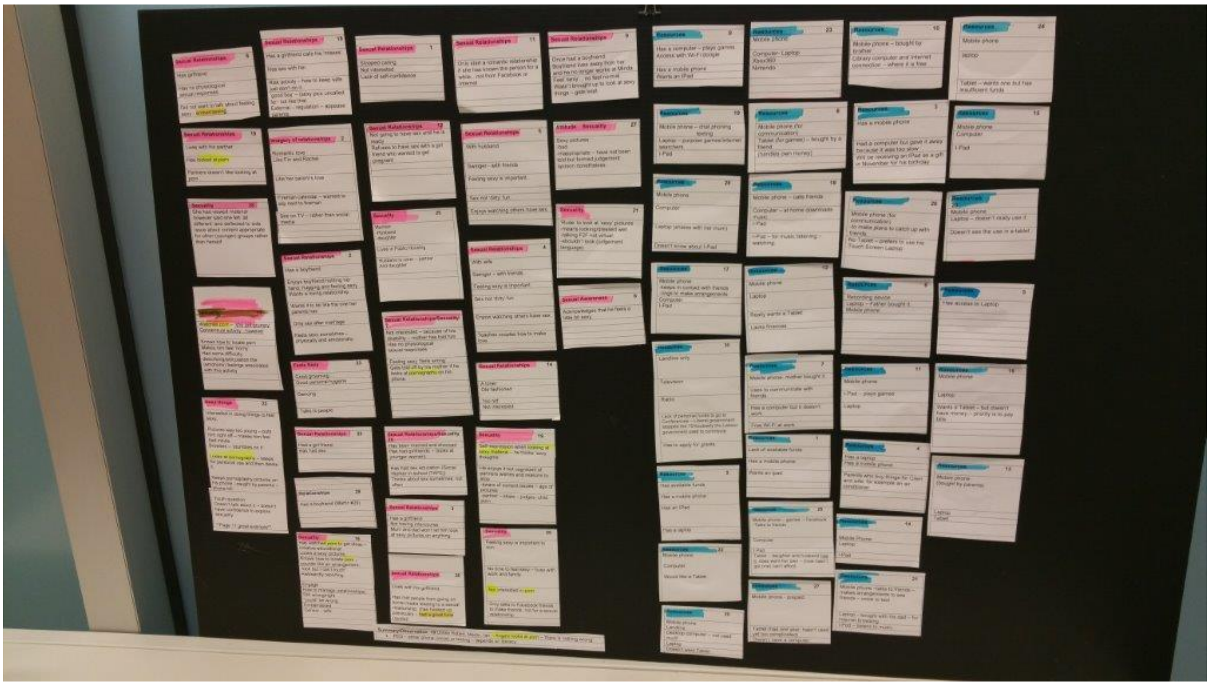
When you used Facebook or twitter to make friends how have you done this?	Is there anything stopping you now?
Did you meet face to face before you became friends on Facebook? Tell me about it.	
Do you get to meet new people? Tell me more…	
Do you have friends who you have never met face to face? Tell me how you would go about ‘unfriending someone.	
What would you do if you didn’t want to be friends with someone on Face book anymore?	
Is that alright? Tell me more…	
Tell me how you will keep yourself safe on the internet? Who taught you that?	
Have you ever arranged to meet anybody you met on the internet? Tell me more about what happened How was that experience?	
How would you keep yourself safe if you met with someone face to face you first met on the internet?	
Are you interested in doing things that make you feel sexy? Tell me more about things you like to do.	Would you like to? Can you tell me why? Why isn’t it important to you? Do you not think feeling sexy is important to you?

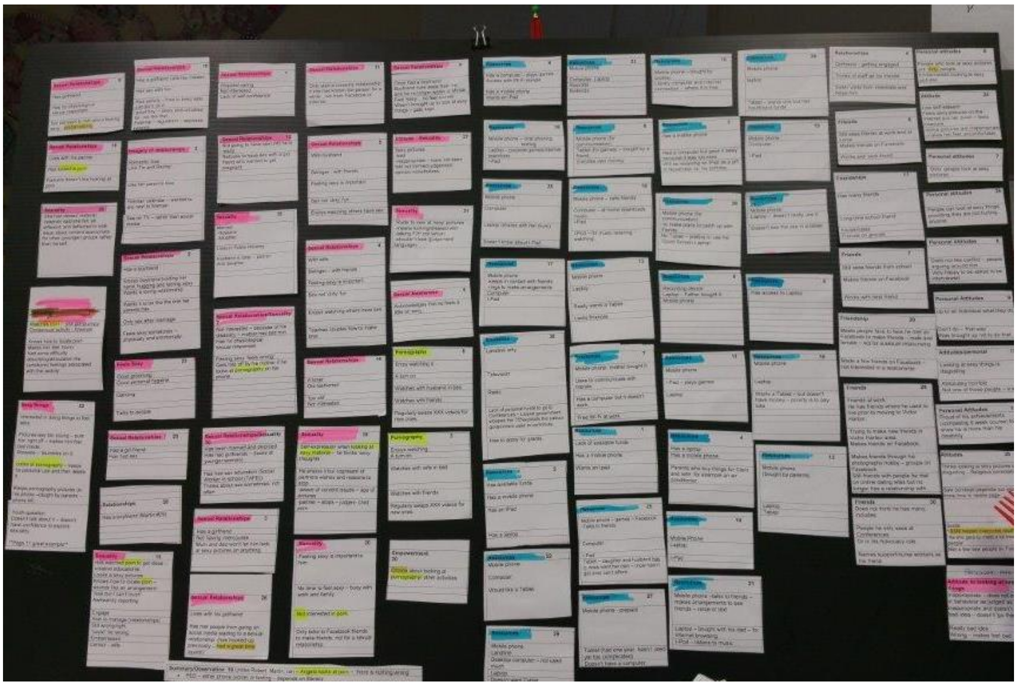
	Or has someone told you something about feeling sexy?
Can I ask what kind of things you need to feel sexy?	***Remember I told you that some of the questions I was going to ask you might be sensitive – I do not want to embarrass or upset you.*** ***If any questions make you feel uncomfortable you can stop any time you like.*** ***You do not have to answer any question you do not want to.*** ***I am not going to be upset with you.***
Tell me more.	
Do you look at pictures to feel sexy? Tell me about your experience doing this.	
Do you talk to people to feel sexy?	
What happens inside your head?	
What happens inside of your body?	
Lots of people like to look at sexy things on the internet.....What do you think about that?	
Have you ever looked at sexy pictures on websites that have made you feel sexy?	Can you tell me why you haven't? Not interested?
Would you be willing to talk about those websites?	
Tell me more.	
What do you think about seeing sexy pictures on websites?	
How does it make you feel?	

Appendix 5: Demographics

No#	Participant's Pseudonym	Gender	Age	Work Status	Style of Accommodation	Relationship Status	Support provided by	Data collected
1	John	M	27	Full time	Lives with Parents	Single	Family	Interview
2	Rachael	F	43	Part time	Community House	Single	Family	Interview
3	Elvis	M	24	Part time	Lives with Parents	girlfriend	Family	Interview
4	Clem	M	63	Retired	Own Home	Married	Key Worker	Interview
5	Josie	F	66	Retired	Own Home	Married	Key Worker	Interview
6	Daniel	M	48	Part time	Living in Group Home	girlfriend	Family	Interview
7	James	M	35	Full time	Community House	Single	Family	Interview
8	Leigh	M	28	Full time	Living in Group Home	girlfriend	Family	Interview
9	Katie	F	30	Full time	Living in a Group Home	Single	Family	Interview
10	Greeny	M	50	Full time	Supported Care Facility	Divorced	Brother/ Key Worker	Interview
11	Ellie	F	26	Full time	Private Share House	Single	Family	Interview
12	Jonnie	M	20	Part time	Lives with Parents	Single	Family	Interview
13	Jacob	M	21	Part time	Living in Group Home	Single	Family	Interview
14	Christie	F	55	Part time	Own Home	Divorced	Family	Interview
15	Cam	M	36	Full time	Lives with Parents	Single	Family	Interview
16	Hallsy	M	31	Full time	Private Rental	Married	Family	Interview
17	Andy	M	27	Full time	Lives with Parents	girlfriend	Family	Interview
18	Justin	M	22	Full Time	Lives in Care Home	girlfriend	Foster Mother	Interview
19	Angelo	M	29	Part time	Private Rental	girlfriend	None	Interview
20	Brendan	M	24	Full time	Lives with Mother	Single	Family	Interview
21	Chris	M	22	Full time	Unit in Supported Care	Single	Family	Interview
22	Paul	M	44	Full time	Private Rental	Single	Family	Interview
23	Liam	M	24	Full time	Lives with Parents	girlfriend	Family	Interview
24	Paris	F	31	Part time	Private Rental	Single	Family	Interview
25	Helen	F	59	Full time	Private Rental	Married	Husband	Interview
26	Garry	M	49	Full time	Private Rental	girlfriend	None	Interview
27	Ian	M	27	Full time	Lives with Parents	Single	Family	Interview
28	Stella	F	26	Part time	Lives with Parent	boyfriend	Family	Interview
29	Martin	M	32	Full time	Private Rental	Single	Brother	Interview
30	Robert	M	56	Advocate/ Volunteer	Private Rental	Single	Family	Interview

APPENDIX 6: Themes and Categories





Appendix 7: Disallowed Questions

Are you interested in doing things that make you feel sexy? Tell me more about things you like to do.	Would you like to? Can you tell me why? Why isn’t it important to you? Do you not think feeling sexy is important to you? Or has someone told you something about feeling sexy?
Can I ask what kind of things you need to feel sexy?	***Remember I told you that some of the questions I was going to ask you might be sensitive – I do not want to embarrass or upset you.*** ***If any questions make you feel uncomfortable you can stop any time you like.*** ***You do not have to answer any question you do not want to.*** ***I am not going to be upset with you.***
Tell me more.	
Do you look at pictures to feel sexy? Tell me about your experience doing this.	
Do you talk to people to feel sexy?	
What happens inside your head?	
What happens inside of your body?	