People with Intellectual Disability Staying Connected Online during the COVID-19 pandemic

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Declaration of Originality

I certify that this is my own work and does not incorporate any material previously submitted for any other 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 text.

Signed ______________ On: 28 / 5 /2021

Supervisor's Certification

I confirm that I have approved all aspects of the research project in this thesis, including the content of the literature review, data collection, analysis, reporting and data storage.

Signed ___ ________On: 28 / 5 /2021

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Contents

Abstract

This study sought to hear from the voices of people with intellectual disability about their experiences in online communication, particularly in relation to COVID-19 social restrictions. It recognised that people with intellectual disability have been found to have limited social networks and higher levels of loneliness than the broader community, and may therefore be more impacted by COVID-related social restrictions. The study asked rural and suburban participants with intellectual disability about their online communication experiences, the factors that assisted good communication, barriers, and strategies to work around those barriers.

An advisor with intellectual disability was employed to provide advice and critique on the study design, participant recruitment, project documentation and high level findings. Two semi-structured focus group sessions were held, one face to face, and the other held over video conference, with ten participants with intellectual disability and one support worker participant. Thematic analysis in three stages was used to analyse the data, with four themes of ‘connecting’, ‘independence’, ‘difficulties’ and ‘support’ developing. A visual representation of the themes highlighted the interactions between them, and in particular the way that support was connected with all of the other themes. Good, timely support enabled participants to have more positive communications online, and less effective or knowledgeable support meant participants were less likely to have good online communications and in some cases little online communication at all.

Participants were all able to take part in online communication during COVID-related social restrictions, but in some cases support workers and family members needed to provide assistance with devices, connecting to the Internet and working through issues that arose. When participants were connected online there were advantages for them; they sought social support, connected to activities, to family and friends, expressed themselves, enjoyed themselves and helped others to connect online. The study included older adults and some

participants with communication difficulties, who wanted to connect online, and with assistance, were able to be connected online during the social restrictions.

The four themes identified in this study, of ‘connecting’, ‘independence’, ‘difficulties’, and ‘support’ showed the benefits that can occur for people with intellectual disability through being connected online. The importance of capable, timely support to work through barriers and issues that arose was also clear, and points to the need for resourcing for support workers and family to better enable their assistance. This should include the provision of accessible information for both support people and people with intellectual disability.

Chapter 1: Introduction

1.1 Statement of issue

This study considers the social inclusion of people with intellectual disability, as typically, people with intellectual disability have been found to be more socially excluded than others (Merrells et al., 2019; Stacey & Edwards, 2013; Strnadova et al., 2018; Tilly, 2019). Increasingly, the Internet is being used to support people with intellectual disability to connect with others (Sallafranque-St-Louis & Normand, 2017; Sorbrig et al., 2017). During 2020, the coronavirus COVID-19 (an acute respiratory illness causing a pandemic that has infected millions of people (Mills et al., 2020)) caused ongoing social restrictions across the world. For this reason, this study considers how the social inclusion of people with intellectual disability might be supported through the use of online communication, particularly during times of face-to-face social restrictions due to the COVID-19 pandemic.

1.2 Statistics and significance

In Australia in 2018 17.7% of the population or 4.4 million Australians had a disability, with 5.7% of Australians having a severe or profound disability (ABS, 2019). It is estimated that 668,100 Australians have an intellectual disability (ABS, 2012). Intellectual disability has been defined by the American Association on Intellectual and Developmental Disabilities as “a disability characterized by significant limitations in both intellectual functioning and in adaptive behaviour, which covers many everyday social and practical skills. This disability originates before the age of 18” (AAIDD, 2020, p.1). Intellectual disability can impact upon conceptual, social and practical skills, causing difficulties with communication and literacy, interpersonal skills, problem solving and using devices like computers or the telephone (AAIDD, 2020). This increases the likelihood that people with intellectual disabilities will have difficulty accessing the Internet and connecting with others online.

Only 15% of Australians do not use the Internet (AIFS, 2018); however, a higher proportion of Australians with a disability (28.5%) do not use the Internet (ABS, 2020). More than half (54%) of people with an intellectual disability aged

15 years and over did not use the Internet because they had no need and/or interest, and 36% lacked the confidence or knowledge to use it (ABS, 2020). Such digital exclusion can impact upon the ability of people with intellectual disability to be socially connected and be included in the community.

1.3 Social inclusion and loneliness

Although there are differing views on the definition of social inclusion, this study will consider social inclusion in relation to the interpersonal relationships of people with intellectual disability, and the degree to which they participate in the community (Simplican et al., 2015). People with intellectual disability have been found to have very limited social inclusion. Bigby and Wiesel (2011) identified that people with intellectual disability are “among the most disadvantaged and socially excluded in Australian society” (p. 263). Young adults with intellectual disability described their experience as: “We always feel left out: Treated like an outcast” (Merrells et al., 2019, p.16).

Living independently, being included in the community and participating in cultural life, recreation, leisure and sport are outlined as human rights by the United Nations Convention on the Rights of Persons with Disabilities (2006) in articles 19 and 30. Tilly (2019) described social inclusion as being essential for people with intellectual disability to be able to make friends; however, people with intellectual disability have been found to have limited social networks and to describe high levels of loneliness (Gilmore & Cuskelly, 2014; Molin et al., 2015; Sharabi & Margalit, 2011). Being “chronically lonely” (Gilmore & Cuskelly, 2014, p.192) has the potential to have negative physical, mental and emotional impacts. People with intellectual disability often experience cognitive, physical and mental health problems associated with their disability, and chronic loneliness is likely to compound these problems (Courtenay, 2020; Gilmore & Cuskelly, 2014; Stacey & Edwards, 2013).

1.4 Information and communication technologies and social inclusion

Information and communication technologies (ICTs) have the potential to increase social connectedness and therefore decrease loneliness and support health and wellbeing (Owuor et al., 2018). Barlott et al. (2019) defined ICTs as “any electronic technology that provides the means to access information or facilitate communication . . . [including] mobile phone and computers . . . the Internet and online social networks” (p.2).

Barlott et al. (2019) found that ICTs “opened the door to possibilities” (p.1) in the lives of people with intellectual disability, by increasing choices, enabling greater independence, and increasing communication with friends, family and service providers. Caton and Chapman (2016) explored the use of social media by people with intellectual disability and found that it had positive effects on friendships, the development of social identity, enjoyment, and development of self-esteem. Both studies also highlighted factors that constrained use of ICTs, including family who were “gate-keeper[s]” (Barlott et al., 2019, p.9), and skill difficulties as well as understanding of cyber-language and cyber-etiquette (Caton & Chapman, 2016). The potential benefits of ICTs for people with intellectual disability suggest a need for increased access to ICTs and training, in order to better enable its use (Barlott et al., 2019; Caton & Chapman, 2016; Owuor et al., 2017). Training is important to assist people with intellectual disability to be able to use ICTs effectively. Similarly, training is important for their supporting family and/or support workers who can then better provide information and assistance to people with intellectual disability (Raghavendra, Hutchinson, Grace, Wood & Newman, 2018). With such ICT training and support, increased social inclusion for people with intellectual disability can therefore become more likely. However, first it is important to investigate the experiences of adults with intellectual disability connecting with others online.

1.5 Impacts of Coronavirus COVID-19

In 2020, impacts of restrictions associated with the coronavirus COVID-19, have further highlighted the importance for people with intellectual disability to be better socially included and connected (Rose et al., 2020). During COVID-19 people have been heavily reliant on ICTs to stay connected, for work, health, family and social interactions (Goldschmidt, 2020; Marston et al., 2020; Torous et al., 2020) due to the need to physically isolate, quarantine and/or to limit the number of people in certain locations at the same time. During this global pandemic, there has been the potential for greater isolation for people with intellectual disability, as many are dependent on structured activities like social clubs for social and community interactions (Mooney et al., 2019), which may have been cancelled or postponed during COVID-19. For those who are unable to use or have limited access to ICTs, the restrictions may have significantly reduced their social engagement and connectedness – Mooney et al. (2019) reported the loss of organised group settings as causing pain and upset to participants, "as [they had] lost a friend" (p.242). It is likely to have been a very challenging period, even for the people with intellectual disability who are more used to interacting with ICTs. The more common means of communicating during this period, for example Microsoft Teams, Zoom, Google Hangouts or Facetime may have complexities in accessing or configuring which can be confusing, and these communication platforms may not be compatible with the assistive technology (Owuor et al., 2017). The periods of lockdown and social isolation have been challenging for many people with mainstream technology, let alone for those with intellectual disability who may have skill difficulties or communication and literacy challenges. This makes it important to understand the experiences of people with intellectual disability in relation to staying connected online, particularly during social restrictions associated with COVID-19.

1.6 Purpose of this study

This study seeks to hear from the voices of people with intellectual disability about their experiences in communicating using ICTs during the periods of social isolation brought about by COVID-19 restrictions. It also specifically includes participants in a rural location, as there are likely to be additional barriers to accessing the Internet in regional or rural Australia, including lower quality Internet connection and increased cost (Park, 2017; Raghavendra et al., 2018). Park (2017) outlined that these ICT disadvantages can further exacerbate social isolation for rural areas.

This study, particularly in the context of COVID-19 restrictions, seeks to:

- identify understandings and experiences of people with intellectual disability in online communication
- identify what factors contribute to good online communicative experiences that assist people with an intellectual disability to express themselves and speak up online

- identify barriers to online communication and strategies used by people with an intellectual disability to work around barriers
- investigate online communication experiences of rural/regional people with intellectual disability and those in metropolitan Adelaide

Chapter 2: Literature Review

2.1 Introduction

This chapter discusses the literature on how people with intellectual disability stay connected online. An outline of how the literature review was conducted follows, along with the processes for selecting the most appropriate literature to inform the research topic. The chapter considers the literature in relation to people with intellectual disability and connection, communication, social inclusion, technology, and the Internet. The benefits for people with intellectual disability using technology and the Internet, as well as issues encountered are examined. These include issues of access, risks and gatekeeping. The awareness of risk and positive risk-taking is also considered. Finally, the current global impacts of the coronavirus COVID-19 and the consequent increase in online communication is discussed in relation to people with intellectual disability. The ways in which the literature has informed the approaches taken in this study are described, and in particular the emphasis on hearing the voices and experiences of people with intellectual disability themselves.

2.2 Methods for literature searching

The literature review for this study consisted of a search across the databases Psycinfo, Proquest Social Science Premium Collection and Scopus. Searching was across the three concepts of intellectual disability, Information Technology and Communication, and alternate search terms (see Table 1 below). Only articles in English were reviewed, and only articles specific to people with intellectual disability, not articles that included people with other disabilities.

Table 1:

Search terms used for Literature Review

Key Search Terms	**Intellectual Disabilit***	**Information Technology**	**Communication**
Alternate search terms	Learning Disabilit*	Online	Friend*
	Developmental Disabilit*	Social Media	Communit*
	Cognitive Disabilit*	Internet	Companion*
		Instagram	Engage*
		Facebook	Company
		Snapchat	Social
		Facetime	Society
		Zoom	Attach*
		Teams	Network*
		Video Conferencing	Inclu*
		IT	Interact*
		Email	Interlink*
			Interconnect*

The initial search in Scopus sourced 548 articles, which were reviewed by title, then abstract, resulting in 38 relevant papers. Articles focusing on education, schooling or experiences of teachers were not included. A similar process through Proquest Social Science Premium Collection resulted in an additional ten articles, once duplicates were removed, with a further 26 added after the process was applied to Psycinfo. Full text reading resulted in the rejection of 33 articles and the review of reference lists from short-listed articles resulted in the identification of a further 7 articles. In total, 48 articles are included in this review.

Articles were categorised into broad themes: social inclusion, technology/Internet and associated challenges and benefits, risks, and gatekeeping by carers/family. The sensitivities associated with balancing the need for digital inclusion for people with intellectual disability with those risks was another theme identified in the review. Finally, the impacts of COVID-19 and of the need to be connected were considered. A search of all articles related to COVID-19 was conducted at a later stage than the original search, due to so few articles existing initially. Some months after the original search, all articles related to COVID-19 were searched for whether they discussed people with intellectual disability, with 3 articles located.

2.3 People with intellectual disability and social inclusion

Social inclusion is often an issue for people with intellectual disability (Chadwick et al., 2013; Löfgren-Mårtenson, 2004; McVilly et al., 2006; Molin et al., 2015). Chadwick et al. (2013) identified that social exclusion occurs through being disadvantaged in society and experiencing inequality and prejudice. Lower incomes, unemployment, and fewer educational and social opportunities (Emerson et al., 2005) can be underlying reasons for this. People with intellectual disability are often restricted in what they can do and where they can go (Molin et al., 2015), with access to transport, fear and anxiety and risks being some of the reasons behind this (Mooney et al., 2019). Additionally, restrictions can also occur through parents, carers or support workers being with them (Löfgren-Mårtenson, 2008) or determining their activities (Mooney et al., 2019).

McVilly et al. (2006) identified that loneliness has been highlighted as an issue for people with intellectual disability for many years, citing Katz and Yekutiel's (1974) study reporting 61% of participants had no friends. More recently, Emerson and McVilly (2004) also found low levels of friendship.

In today's society, there is increasing reliance on computers, smartphones and other electronic devices for social connection and communication; the use of which is believed to improve social inclusion (Hynan et al., 2014). The sections below outline studies that have considered technology and Internet use for people with intellectual disability, particularly in relation to improving social inclusion.

2.4 Technology, the Internet and people with Intellectual disability

Molin et al.’s (2015) study sought views of parents and teachers of young people with intellectual disabilities, in relation to their use of the Internet and social media. Along with other results, they found that parents of people with intellectual disabilities rated their children’s risk of loneliness as being greater than that of other negative events. In a later study, Molin et al. (2017) conducted research with people with intellectual disability themselves in relation to their use of the Internet and found that there is increased risk of loneliness in opting out of Internet relations (Molin et al., 2017). However, Sallafranque-St-Louis and Norman’s (2017) study found that “[t]he loneliness and social isolation that participants with [intellectual disability] experience in real life is reflected in their online experience” (Sallafranque-St-Louis & Normand, 2017, p.7).

This is an example of the growing gap between those accessing technology and the Internet and those that do not or are unable to. This has been described as a “digital divide”. The OECD (Organisation for Economic Co-operation and Development) describes the digital divide as “the gap between individuals, households, businesses and geographic areas at different socio-economic levels with regard to both their opportunities to access information and communication technologies (ICTs) and to their use of the Internet for a wide variety of activities” (OECD, 2006, p. 1). People with intellectual disability are often unable to access devices or the Internet or both (Buchholz et al., 2020; Caton & Chapman, 2016; Davies et al., 2015; Hynan et al., 2014; Lussier-Desrochers et al., 2017; Patrick et al., 2020; Sorbrig et al., 2017; Tilly, 2019). Therefore, people with intellectual disability are less able to realise the possible benefits of using the Internet and less able to reduce their social isolation or loneliness. This makes it important for research to listen to people with intellectual disability and to find out the best ways for them to be connected online.

2.5 Benefits for people with Intellectual disability using the Internet

Where people with intellectual disability are able to access the Internet, a number of benefits in using it to communicate and/or socialise have been found. Parsons et al. (2006) found that social bonds were formed, and more recently, Chadwick and Fullwood (2018) found the same. Other studies have described friendships as being formed or maintained (Caton & Chapman, 2016; Chadwick et al., 2013; Hynan et al., 2014; Jenaro et al., 2018; Löfgren-Mårtenson, 2008; Sallafranque-St-Louis & Normand, 2017; Sharabi & Margalit, 2011; Shpigelman, 2018; Sorbrig et al., 2017). Using the Internet was also found to combat loneliness (Sallafranque-St-Louis & Normand, 2017; Sharabi & Margalit, 2011; Shpigelman & Gill, 2014) and reduce social isolation (Hynan et al., 2014). In the words of a parent of a child with intellectual disability in Sorbrig et al.'s (2017) study, "the Internet is a kind of door that can always be opened when you feel like it" (Sorbrig et al., 2017, p. 10).

Other studies found the Internet helped to extend social networks (Cihak et al., 2015), enabled social inclusion (McClimens & Gordon, 2009; Parsons et al., 2006) and increased social connectedness (Raghavendra et al., 2015; Raghavendra et al., 2018). Similarly, social inclusion engendered a sense of belonging to the community (Shpigelman & Gill, 2014; Shpigelman, 2018) and helped people with intellectual disability to feel they were visible (Molin et al., 2015; Shpigelman, 2018).

People with intellectual disability have been found to be able to create online identities that were not necessarily focused on their disability (Chadwick et al., 2013; Chadwick & Fullwood, 2018; Holmes & O'Loughlin, 2014; Salmerón et al., 2016). They felt they could have equal opportunity that way (Shpigelman, 2018), could be like "everybody else . . .[and] get away from the stigmatization" (Löfgren-Mårtenson, 2008, p.129).

Higher self-esteem has been associated with Internet use (Caton & Chapman, 2016; Holmes & O'Loughlin, 2014; Molin et al., 2017), as has enhanced self-worth (Chadwick & Fullwood, 2018).

Access to technology and the Internet has also been associated with increases in self-determination (Buchholz et al., 2018; Buchholz et al., 2020; Chadwick et al., 2013; Chalghoumi et al., 2019; Hynan et al., 2014; Löfgren-

Mårtenson, 2008; Patrick et al., 2020; Salmerón et al., 2016), autonomy (Chadwick & Fullwood, 2018), a sense of control (Sallafranque-St-Louis & Normand, 2017) and independence (Cihak et al., 2017; Löfgren-Mårtenson, 2008; Patrick et al., 2020; Raghavendra et al., 2018).

People with intellectual disability find enjoyment in using the Internet (Caton & Chapman, 2016; Chadwick & Fullwood, 2018; McClimens & Gordon, 2009; Sallafranque-St-Louise & Normand, 2017; Sorbrig et al., 2017). It also provides an outlet for self-expression (Buchholz et al., 2018; Chadwick et al., 2013), and for sharing thoughts and feelings online (McClimens & Gordon 2009; Salmerón et al., 2016). Some studies even noted that using the Internet provided impetus to overcome verbal communication barriers (Raghavendra et al., 2015; Vereenooghe et al., 2017). The use of social media sites was found to be supportive because they do not emphasise literacy skills and short messages are common. This helped communication to be more equal than if people were face-to-face or using a telephone (Buchholz et al., 2018). Furthermore, the time available to work on a communication or response in a way that is not possible in face to face communication reduced time pressure and stress (Löfgren-Mårtenson, 2008; Raghavendra et al., 2018).

Other benefits found were in self-advocacy (Chadwick et al., 2013), self-representation (Hynan et al., 2014), greater access to employment and healthcare (Cihak et al., 2017; Patrick et al., 2020), improved literacy skills (Cihak et al., 2017; Löfgren-Mårtenson, 2008; Parsons et al., 2006; Raghavendra et al., 2015; Raghavendra et al., 2018), access to educational opportunities (Chadwick et al., 2013; Cihak et al., 2017) and access to support groups (Molin et al., 2015).

2.6 Issues for people with intellectual disability accessing technology

However, studies have also found that there can be problems for people with intellectual disability in accessing technology.

2.6.1 Computer or device access

Chadwick et al.'s (2013) review found that most people with intellectual disability were not accessing the Internet as much as the general public, and that this was often due to not having access to a computer. Limited economic means were a key reason for lack of access to computers and other devices (Chadwick et al., 2013), as was also found in later studies (Lussier-Desrochers et al., 2017; Sallafranque-St-Louis & Normand, 2017).

2.6.2 Complexity of devices

For many people with intellectual disability, actually being able to use the devices is difficult or even impossible (Barlott et al., 2019; Caton & Chapman, 2016; Chadwick et al., 2013; Lussier-Desrochers et al., 2017; Shpigelman, 2018; Sorbrig et al., 2017; Tilly, 2019). For some, the devices are too complex for them to operate without assistance and ongoing support (Chadwick et al., 2013; Davies et al., 2015; Hynan et al., 2014; Lussier-Desrochers et al., 2017; Raghavendra et al., 2018).

Participants with intellectual disability in Shpigelman and Gill's (2014) study recommended that an accessible version of Facebook be developed. Following this recommendation, Davies et al. (2015) tested a cognitively accessible interface for Facebook that showed people with intellectual disability were able to complete more tasks independently, with less prompting and fewer errors, and with more enjoyment. Other studies give recommendations of possible improvements to computer programs and/or devices to better enable access. For example, Sorbrig et al. (2017) suggested provision of more verbal instructions instead of written, and for the development of assistive tools and interface. Wasserman (2019) suggested that inclusive design of information technology hardware and software, that has involved input in its development by people with intellectual disability, should be incentivised.

2.6.3 Support and training

There can be problems in enabling online activity; for example, Seale (2007) found that parents and support workers have assisted online publishing by people with intellectual disability, but that the strategies used have risked placing the people with intellectual disability in a "passive role" where they are not actively able to self-advocate.

Training is identified as an issue in numerous studies, as being needed both for people with intellectual disability (Hynan et al., 2014; Molin et al., 2017), and for staff, or family who support them to use IT (Chadwick et al., 2013; Chiner et al., 2017a; Gómez-Puerta & Chiner, 2019; Parsons et al., 2008;

Raghavendra et al., 2018; Sorbrig et al., 2017). Salmeron et al. (2019) found that support was particularly necessary for people with intellectual disability when they were searching for information on less familiar topics. In a study supporting people with intellectual disability to blog, McClimens and Gordon (2009) stated that people with intellectual disability "would not be able to increase their social capital as an independent process" (p. 20), and that the support worker was almost a "chaperone working with them" (p. 20). Other studies found that support could vary, depending upon the views of the supporter (Chadwick et al., 2013; Molin et al., 2015; Palmer et al., 2012; Parsons et al., 2008; Seale, 2007). The support of family and/or support workers is dependent upon their available time, skills, expertise and resources. Their support may vary according to whether they consider there are more problems than benefits in enabling Internet use, and their perceptions of possible risks. Views based on media stories and/or preconceptions of people with intellectual disability as being vulnerable and exposed may impact on support provided, as well as perceptions that the Internet is educational and literacy-based and therefore not suitable (Chadwick et al., 2013; Löfgren-Mårtenson, 2008).

Several studies provided specific ICT training for people with intellectual disability. Cihak et al. (2015) found that their training was generalised across different devices. Raghavendra et al. (2018) trained rural youth with disabilities to increase their performance and satisfaction with using social media via individualised goals. Delgado et al. (2019) provided instruction on selecting trustworthy web pages, and found training was effective in increasing such selection, and that this effect remained for some weeks after the training. A barrier in all these studies is the intensive nature of training, and resourcing required.

2.6.4 Age, literacy and communication

Another barrier to accessing technology and the Internet can be age, as older people may receive fewer opportunities compared to younger people, whose education is more supportive of ICT use (Chadwick & Fullwood, 2018; Parsons et al., 2008). Low literacy skills is also a barrier in many cases (Bayor et al., 2018; Caton & Chapman, 2016; Shpigelman & Gill, 2014; Shpigelman, 2018; Sorbrig et al., 2017), as are difficulties with communication skills (Caton & Chapman, 2016) and social skills (Molin et al., 2015; Sorbrig et al., 2017). Assistive technology may be a means of overcoming some of these barriers, but costs and training required can create barriers (Raghavendra et al., 2015).

In addition to having difficulty with face-to-face communication and social skills, the added complexities associated with online behaviour, such as cyber-etiquette/netiquette (e.g. the social norms, boundaries, the nature of "friends" online and inappropriate postings/pictures) have also been found to cause problems for people with intellectual disability (Baylor et al., 2018; Caton & Chapman, 2016; Löfgren-Mårtenson, 2008; Lussier-Desrochers et al., 2017; Shpigelman, 2018; Sorbrig et al., 2017). Problems included that communication was difficult where multiple meanings of words confused a person with intellectual disability (McClimens & Gordon, 2009), or the subtleties of Internet chat or quick turnaround demands of "live" chat confuse or stress the person with intellectual disability (Löfgren-Mårtenson, 2008).

At the other end of the spectrum, overuse of the Internet can also be a problem for people with intellectual disability. Jenaro et al. (2018) found that some young people with intellectual disability used the Internet excessively, particularly instant messaging, and support was required to break addiction and promote healthy use.

Therefore, it is important to further understand these issues from the perspectives of people with intellectual disability, in order to better support and enable their participation and connection online.

2.7 Risks

Many studies have outlined the possible risks for people with intellectual disability using the Internet and indicate that the usual risks may be heightened for them. This may be due to characteristics such as poor judgement or insight (Buijs et al., 2017) and lower ability to judge the trustworthiness of a source or information (Salmerón et al., 2016). People with intellectual disability may be more socially isolated (Löfgren-Mårtenson, 2008) and therefore more accepting of approaches of unknown Internet contacts.

2.7.1 Personal risks to people with intellectual disability

These risks include divulging personal information (Buijs et al., 2017; Chiner et al., 2017b; Löfgren-Mårtenson, 2008); making requests for personal information (Gómez-Puerta & Chiner, 2019); online fraud/financial exploitation (Buijs et al., 2017; Holmes & O'Loughlin, 2014); online bullying and harassment (Buijs et al., 2017; Chiner et al., 2017b; Gómez-Puerta & Chiner, 2019; Holmes & O'Loughlin, 2014; Molin et al., 2017; Sallafranque-St-Louis & Normand, 2017); and receiving or making threats (Gómez-Puerta & Chiner, 2019; Molin et al. 2017). People with intellectual disability may also be exposed to sexual material (Buijs et al., 2017; Gómez-Puerta & Chiner, 2019), sexual solicitation (Buijs et al., 2017; Sallafranque-St-Louis & Normand, 2017; Sorbring et al., 2017), or sexual harassment (Gómez-Puerta & Chiner, 2019).

Some people with intellectual disability have been subjected to identity theft, where password and login details were inappropriately shared and used (Holmes & O'Loughlin, 2014) or where personal data has been misused (Gómez-Puerta & Chiner, 2019). Believing inadequate advice or misinformation has also occurred (Salmerón et al., 2016).

2.7.2 Inappropriate behaviour by people with intellectual disability

People with intellectual disability have also been found to behave inappropriately themselves, by bullying, insulting, threatening or flirting when not desired by the other person, by making illegal downloads, misuse of personal data, or sending pornographic content to others (Chiner et al., 2017b; Gómez-Puerta & Chiner, 2019; Molin et al., 2015).

2.8 Gatekeeping

As a result of the possible risks, parents/carers and support workers often work to minimise these risks as best they can. The support provided by parents and support workers is often critical, in enabling people with intellectual disability to access technology and the Internet, and views of supporters in relation to risks, abilities and opportunities often determine degree of access (Chadwick et al., 2013; Löfgren-Mårtenson, 2008; Parsons et al., 2008). Many studies have found that supporters become gate-keepers (e.g. Barlott et al., 2019; Gómez-Puerta & Chiner, 2019; Löfgren-Mårtenson 2008; Raghavendra et al., 2018; Sallafranque-St-Louis & Normand 2017; Salmerón et al., 2019; Seale, 2007; Seale & Chadwick, 2017) and it may be "staff members' view on risk that is predominant and controlling" (Löfgren-Mårtenson, 2008, p. 136). This gate-keeping can impact both on access to technology, and on time permitted on the Internet.

There can be a tension between protecting a person with intellectual disability from these risks, and respecting and encouraging their self-determination (Chadwick et al., 2013; Chiner et al., 2017a), as well as between possible risks and their privacy (Chalghoumi et al., 2019). Davies et al., (2015) suggested further work needs to be done in balancing risks, although McClimens and Gordon (2009) highlighted that "the boundaries between care and control can be difficult to draw" (p. 23).

There then becomes a possible problem, in that risk aversion may compound the already existing difficulties by increasing digital exclusion for people with intellectual disability (Chadwick, 2019).

2.9 Balancing risk against digital inclusion and awareness of risk

Seale and Chadwick (2017) and Salmeron et al. (2019) suggested a positive risk-taking framework of shared decision-making and risk management with people with intellectual disability. Similarly, Seale et al. (2013) found that there are benefits in well-being and independence when people with intellectual disability are enabled in this way.

A number of studies have commented that people with intellectual disability were aware of cyber-safe practices and were interacting respectfully (Darragh et al., 2017; Löfgren-Mårtenson, 2008; Molin et al., 2015; Molin et al., 2017; Shpigelman, 2018; Sorbrig et al., 2017). They indicate that people with intellectual disability can participate online with awareness and reduced possibility of risk. Löfgren-Mårtenson (2008) found that some participants with intellectual disability felt that possible risk was worthwhile when balanced against the positive experiences of making friends online.

2.10 People with intellectual disability staying connected online during COVID-19 social restrictions

In the light of the study findings outlined above, this study seeks to understand how people with intellectual disability are staying connected online, particularly in the light of the current global impacts of the virus COVID-19; an acute respiratory illness causing a pandemic that has infected millions of people (Mills et al., 2020). Reliance on technology to “learn, live and stay connected” is now commonplace (Goldschmidt, 2020, p. 1) due to the pandemic.

Rose et al. (2020) outlined the many ways that COVID-19 may be impacting people with intellectual disability, and drew attention to the changes in social distancing that saw many services and social support move to electronic communication, such as video conferencing or via telephones. While Rose et al.’s study will focus on the families of people with intellectual disability, this study will consider the people with intellectual disability themselves and focus on how they are managing technology and the Internet to stay connected during COVID-19.

The possible use of video conferencing by people with intellectual disability is one way for them to stay connected online during face-to-face social restrictions. Ptomey et al. (2017) studied people with intellectual disability using video conferencing to participate in physical education sessions and found that participants not only enjoyed and took part in sessions, but also connected with other participants. Minimal parental/support worker assistance was needed, and participant feedback was very positive, with 90% saying they would participate again if the opportunity arose. This suggests that video conferencing technology may provide a way for people with intellectual disability to stay connected when social distancing measures limit face-to-face opportunities.

This study will ask people with intellectual disabilities in suburban Adelaide and in rural South Australia (Yorke Peninsula) about their experiences of staying connected online during the social distancing ‘lockdowns’ associated with COVID-19. Rural South Australians with intellectual disability have been included in recognition that many rural families may have greater disadvantage and experience greater issues around Internet connectivity (Park, 2017; Raghavendra et al., 2018). On the other hand, perhaps the Internet, if able to be accessed, may mitigate against being geographically isolated (Raghavendra et al., 2018).

Another reason for including participants from rural South Australia is to make the study more inclusive. Raghavendra et al. (2015) noted how unusual it was for a study such as theirs to be provided in a rural area and that there was a “double disadvantage of disability and rural location” (Raghavendra et al., 2015, p. 1587).

2.11 Listening to the voices of people with intellectual disability

As outlined in many instances in the studies reviewed in this chapter, much valuable information has been obtained from participants who are parents, carers and support workers for people with intellectual disability. However, there are other studies, such as that of Shpigelman and Gill (2014), which “hear what people with intellectual disabilities have to say in their own voices” (p. 1613). Similarly, Molin et al. (2017) noted that few studies reported on what the people with intellectual disability themselves said: “We will argue that these voices are of vital importance in order to understand the complexity of Internet use and intellectual disabilities” (p. 649). “Enhanced listening and understanding” (Molin et al., 2017, p. 658) is needed to hear what people with intellectual disability have to say, and hence this study endeavoured to give voice to people with intellectual disability by enabling people with intellectual disability to express their views and experiences.

2.12 Summary

This chapter has reviewed the literature on the experiences of people with intellectual disability communicating online, particularly in the light of social restrictions due to COVID-19. It considered the social exclusion and loneliness experienced by many people with intellectual disability, and how this may or may not be reflected in their online experiences. The gap described as a “digital divide” was seen as relevant to people with intellectual disability. The benefits and issues in using the Internet, and possible risks for people with intellectual disability were considered, as well as gatekeeping and the balancing of this risk. The recent literature in relation to COVID-19 and its impacts for people with disability was reviewed. Finally, literature was considered that supports the specific approach of this study to hear directly from people with intellectual disability in both rural and suburban Adelaide.

Chapter 3: Method

3.1 Introduction

This chapter outlines the processes associated with the research design, the participant recruitment, ethics approval, amendments that became necessary, data collection and analysis.

3.2 Theoretical perspective

This study has been guided by a self-determination perspective, with a view towards supporting the voices, choices, and autonomy of people with intellectual disability. Wehmeyer (1997) outlines that self-determined behaviour has characteristics of autonomy, self-regulation, psychological empowerment, and self-realisation. This is in line with the principles of Article 3 of the United Nations Convention on the Rights of Persons with Disabilities (UNCPRD) which outlines the principle of “respect for inherent dignity, individual autonomy including the freedom to make one’s own choices, and independence of persons” (United Nations General Assembly, 2006, p.1). It is also in line with current National Disability Insurance Scheme (NDIS) approaches that focus on enhancing independence and choice for people with disability (NDIS, 2021). The Australian Government’s National Disability Strategy 2010-2020 also links to Article 3 of the UNCRPD and principles of self-determination and includes an Easy English version of the document (Australian Government, 2021).

This study supported the voices, autonomy and choices of participants by providing Easy English documents that had been developed with the assistance of an advisor with intellectual disability, employed to support the study. The researcher went through the Easy English Participant Information Sheet and Consent Form with each participant and checked their understanding to be reassured of their fully informed consent. A flexible, semi-structured approach to focus groups also supported participants to take their time in responding or to ask questions where they needed. Amending the approach to the collection of data, from the initially proposed individual interviews to several focus groups where participants knew each other, was in response to the preferences of the participants. This was another way participant self-determination was supported.

3.3 Research design

An inclusive qualitative approach was chosen, using interpretative phenomenological analysis. This approach is well suited to qualitative research with people with intellectual disability (Rose et al., 2019), with the analysis grounded in the context through “case-level detail” (Rose et al., 2019, p.1008) and participant claims about their experiences. It also provides a means of hearing and highlighting the voices of people with intellectual disability (Rose et al., 2019). Interpretative phenomenological analysis is useful in analysing focus group data, being able to reflect the richer data of participants interacting with each other as well as the researchers (Phillips et al., 2016).

Semi-structured interviews with individuals were initially planned, due to the flexibility provided by this approach – for example, it may enable rephrasing of questions, flexibility to provide reassurance, reframing and more time for participants to express themselves (McDonald et al., 2013). However, as recruiting commenced it became apparent that participants preferred a group discussion approach. The chosen method of semi-structured focus groups assisted the researcher to mitigate against the biases that may occur when participants answer in a way they believe will please the researcher (Doody & Noonan, 2013). Researchers were able to follow up or enquire more deeply on answers that were of particular interest to the research aims.

Semi-structured focus groups also provide a flexible method of collecting data that provides information about participant capabilities, strengths, difficulties and facilitating factors (Biggeri et al., 2020; Hamilton et al., 2015). Further, they can enable insight into what issues need to be targeted and what types of interventions may be helpful (Hamilton et al., 2015). Focus groups can also be effective in the case of populations who are often excluded from other types of data collection (Kroll et al., 2007).

A focus group topic guide, with a series of possible questions, was developed to facilitate focus group discussions (see Appendix C).

3.4 Research procedure

Four participants with intellectual disability took part in the Adelaide focus group, with three meeting face-to-face with the researcher in a private meeting room at the organisation, and the fourth taking part through Microsoft Teams, online video conferencing technology (a communication platform that is part of the Microsoft 365 family of products (Microsoft Corporation, 2021)).

Six participants with intellectual disability and one support worker participant took part in the rural focus group, held with the rural participants all in a room together in person at the rural support service location, and the researcher, supervisor and advisor in their homes using video conferencing technology (Zoom). This was appropriate, given the location and geographical distance between the researcher and the participants, as well as the fact that the research is about connecting online. In addition, it was beneficial that the focus group took place online because in early December 2020, when this focus group occurred, South Australians were experiencing further social restrictions due to a second wave of COVID-19.

This focus group required extensive support from the service's support worker, to set up the technology and the participants in the room, so that they could see the researcher. The preliminary discussion with this group had drawn attention to the central role that support workers had played during the initial COVID-19 social restrictions, in enabling the participants to stay connected through video conferencing technology. The support workers were therefore central to the participants' experience, and able to prompt their memories (of the experiences in April 2020, during earlier COVID-19 restrictions). They also had extensive knowledge of the supports that had been required and put in place at private residences or group homes to enable the communications during the social restrictions. This is in line with other studies which have recognised the important roles of support workers (Chadwick et al., 2013; McClimens & Gordon, 2009; Molin et al., 2015; Sorbring et al., 2017). The support worker was therefore central to enabling the study focus group to occur and was also recruited as a participant due to their knowledge and experience of the online group communications.

Both focus groups took around 45 minutes, and were audio recorded in the case of the suburban Adelaide session, and video recorded in the case of the Zoom session with rural participants. The sessions enabled participants to share their experiences, including any issues and how they were able to work around the issues. Participants were able to describe the needs that were met through their online communications, and suggestions for others to be able to communicate more effectively online.

3.5 Advisor with intellectual disability

An advisor with intellectual disability was employed to provide feedback, critique and guidance throughout the project. Beail and Williams (2014) state that involving people with intellectual disability in developing research/interview questions enables more understanding about people with intellectual disability, and such inclusion is becoming a more common requirement of research funding (Bigby et al., 2014). The advisor was remunerated for the time he spent working on the project, in line with recommended practice for inclusive research (Bigby et al., 2014a; Schwartz et al., 2020).

The advisor was an adult male working in mainstream employment who had expressed an interest to the university to be considered for research, guest lecturing and advocacy opportunities. This project was well suited for the advisor, due to his understanding and use of ICT to communicate, as well as his previous experience in research with a not-for-profit association.

An early suggestion from the advisor led to the expansion of the project to include participants from a rural South Australian area, which enabled considerations of whether the experiences of those participants differed due to their geographical isolation from those residing in suburban Adelaide. Recruitment for the rural location was opportunistic through connections of the advisor. At the special request of the rural group, the advisor was present at the beginning of the focus group session, to introduce the session. Since he originally resided in that location and may have known some of the participants, to avoid conflicts of interest, he was not present for any of the focus group discussion and data collection. Similarly, being a member of the Adelaide organisation that supported participant recruitment, he did not take part in the metropolitan based focus group. However, once the deidentified transcribed data was developed into areas of broad themes and categories, the advisor was included once again to provide further input on the analysis and findings. His insights regarding the analysis, and suggestions around recommendations provided assurance that this final report was reflective of the views of the participants with intellectual disability, and that the Easy English Summary was accessible for people with intellectual disability to understand.

3.6 Ethics, risks and confidentiality

Ethics approval was obtained from the Flinders University Social and Behavioural Research Ethics Committee (SBREC)(project ID #2221) and the study aligned with the ethical guidelines of the National Health and Medical Research Council (NHMRC, 2007, updated 2018).

As per ethical requirements, all participants were provided with the Participant Information Sheet and Consent Form (see Appendix A) prior to focus group sessions taking place. Immediately prior to each focus group occurring, the researcher went through the Participant Information Sheet, and each participant reflected back to the researcher something about what they understood from the information sheet. Through this, the researcher was assured of all participants volunteering to take part in the research and understanding that they could withdraw at any time.

All participants were over 18 years of age and able to provide informed consent as legal adults. The consent form was signed in front of the researcher prior to focus groups. In the rural focus group participants signed the consent form in the view of the researcher on Zoom. The signed consent forms were then mailed to the researcher by the support worker. For practicality, the support worker responded to questions about the participant information sheet and consent form for the rural focus group. Participants were able to withdraw from the project at any time, but it was explained to them that the researchers would not be able to delete any answers or comments they had made up to that point, due to the participation of others at the same time in the focus groups.

Risk analysis was undertaken, with consideration given to any possible anxiety or worry that might be provoked by questions. Support organisation details were provided in the Participant Information Sheet and verbally reinforced by the researcher when going through the information. The sheet also outlined that the researcher might need to tell someone if they thought there was a risk to a participant’s safety or to the safety of other people, and that this might include if the researchers were told about illegal situations.

Again, these considerations were verbally reinforced before participants signed consent forms and were acknowledged by participants.

All participants were provided with a $20 gift voucher as a thank you and as recognition of their time and effort provided to attend the focus group.

3.7 Participants and recruitment

Participants met the following criteria:

- Be identified by their support service as a person with intellectual disability
- Be over 18 years of age
- Use online technology to talk to other people

The initial approach to the two organisations was through the researcher’s supervisor, and both organisations indicated a willingness to support the project. The organisations assisted with the recruitment of participants they knew who had communicated using online technology, by making personal approaches either face-to-face, by email or by telephone.

An information session took place at the rural South Australian support service, where the researcher met with potential participants and described the research and handed out participant information (see Appendix A). Potential participants were able to take the information home to talk through with family and/or support workers and were also able to discuss the proposed focus group with support workers at the support service. Contact details of the researcher and supervisors were included in the information, although no potential participants made contact prior to the focus groups.

Follow up discussions were held between the researcher and the organisations, when details were organised in relation to when, where and how focus groups or individual interviews would be held. At this point both organisations indicated that their potential participants would prefer to meet together as focus groups.

3.8 Conflicts of interest

Both organisations were known to the advisor with intellectual disability, and the suburban Adelaide organisation was known to the researcher’s supervisor. There was a possibility that the supervisor might know some of the potential participants, having worked in the disability field for over 20 years, and having undertaken her own research with people with intellectual disability. Therefore, the supervisor limited her engagement only to the initial approaches to the organisations, and did not take part in the Adelaide-based focus group where she was likely to know participants. The researcher alone carried out the Adelaide-based focus group session. The supervisor supported the researcher in the rural focus group session, where she did not know participants.

All data were transcribed by the researcher, with the supervisor reviewing the data once it had been deidentified. It was also possible the advisor with intellectual disability might know some participants, as he had worked with people with intellectual disability and also been involved in research with people with intellectual disability. Therefore, he was not involved in the data collection, transcription or initial analysis of the data and only saw higher level, summarised and deidentified results.

3.9 Data collection and transcription

Data were collected from the two focus group sessions, which included a focus group topic guide (see Appendix C) as well as demographic information about participants.

Following the topic guide, initial questions focused on the type of devices and programs used; the types of activities undertaken by participants on these devices; how participants were able to talk to others, whether they used audio and/or video; and how it felt to be talking online with others. Questions were then related to any problems or issues that had arisen while they were connecting online, either for the participants themselves, or for the people they were communicating with. Methods of resolving issues and suggestions that might assist other people with intellectual disability to stay connected online were then considered.

3.10 Data Analysis

The thematic analysis used an interpretative phenomenological approach (Moustakas, 2011) with three stages described below. Initially data was separated into units of meaning, described as segments of the data that contain understandable information, even if taken out of context (Elliott &

Timulak, 2005). These meaning units were then organised under broad headings that were tested during the next stages of analysis. Via these stages broader themes were refined into the key themes that best expressed the lived experiences of participants with intellectual disability using technology.

3.10.1 NVivo 12 descriptive content analysis

All data was entered into NVivo 12Pro. The first stage of analysis took place using NVivo 12 Pro, with broad themes being developed as units of meaning were separated and grouped in areas of communality. This first stage was reflective of the questions covered in the focus groups, for example one question directly asked "Do you have any suggestions that might help other people to talk to each other on the [device]?". For this reason, it is not surprising that a high proportion of units of meaning related to tips/suggestions. This was similarly the case for issues and activities.

On the other hand, some themes emerged that were not directly referred to in questions asked by the researcher. This was the case for a theme of help/support, for example, which emerged through participants responding to the question "What do you do when things don't work how you need them to?", when they often referred to the assistance of support workers, staff or family.

3.10.2 Excel spreadsheet - charting

The second stage of the analysis began by sorting the responses of each individual participant within the two focus groups. This process made it very clear which participants contributed the most.

After sorting responses by individual participants, each unit of meaning was reviewed. For example, a theme around bullying or online risks had only one or two items coded into it. On closer consideration of those units of meaning, it was apparent that the participants spoke with pride and satisfaction of how they had been able to manage the negative online behaviour of others. This was the case even when assistance of a family member or support worker had been utilised to respond to negative online behaviour. These participants had felt empowered and confident in managing the behaviour, so researchers recognised the statements as more appropriately coding into a theme of independence. This process of reviewing codes continued until codes had been consolidated into broader themes .

3.10.3 Mud-map – the ‘butcher’s’ paper visual exercise

At the third stage of the analysis, coding of units of meaning was facilitated by transferring the thematic content of the units onto paper – each focus group had a separate A3 page, and then the two A3 pages were transferred onto one large piece of ‘butcher’s’ paper.

The A3 pages seemed initially a collection of ideas without format or direction, but in transferring the two sheets of results of the two focus groups onto one larger sheet, interconnections between themes started to become apparent. For example, whenever ‘Difficulties’ were discussed by participants, there was often a clear relationship with ‘Support’ that had been provided to overcome or resolve difficulties.

3.10.4 Final refinement of themes

A final addition to the ‘butcher’s’ paper exercise was to highlight quotes indicative of the themes to expand and explain the meaning being created in the analysis. Particularly salient, startling, or thought-provoking quotes from participants were transferred onto post-it notes, which could then be stuck on the ‘butcher’s’ paper in alignment to a theme or where themes interconnected. This refined the themes to reflect some common experiences of participants and used participants’ own words to provide emphasis.

3.11 Validating data

A fourth reading of transcripts occurred, with a critical view towards the biases of the researcher and possible influences that may have inadvertently directed participants’ responses. Sousa (2014) emphasises the importance of following trusted processes and providing adequate descriptions and interpretations, in order to control such biases. This fourth reading checked the processes that had already occurred as well as testing the descriptions and interpretations of the data.

Both supervisors read through the transcript for the suburban Adelaide focus group, supporting the validity of the process. Additionally, the supervisor was present for the rural focus group, and the other supervisor read through that transcript as well. These actions also supported validity.

3.12 Summary

This chapter outlined the methods used in the research design, the changes made to the initial design, and the approaches to recruitment of participants. A key feature of the research design was to employ an advisor with intellectual disability to be involved in most critical parts of the research, including the development of the project and who the participants may be, feedback on easy English documents, helping to design the focus group questions, supporting analysis and writing up of the summary.

Methods of analysing the data and drawing out themes and categories from the focus groups were also described, as well as considerations regarding ethics, risks and confidentiality.

Chapter 4: Results

4.1 Introduction

This chapter describes the participants, then outlines the findings from the focus groups and analyses. Four themes developed out of the analyses, with each theme having sub-themes. Interconnections between themes are considered, along with a diagram that visually represents the themes and their interconnections.

4.2 Participants

Table 2 outlines socio-demographic and IT background data of the ten participants with intellectual disability (pseudonyms have been used to facilitate anonymity of participants). The support worker participant has not been included in the table. All participants were over the age of 18 years.

All participants had a phone, although for Tom and Stevie, access to the Internet was not available on their phones. Assistance and Internet access was provided to them when Zoom meetings occurred with the support organisation.

Table 2:

Participants with intellectual disability: Social Demographic and IT background information

Participant	**Gender**	**Age bracket**	**Living situation**	**Devices used**	**Internet access**
First focus group					
Mai	Female	30-50 yo	Family	Laptop, phone, ipad	Yes
Sharon	Female	30-50 yo	Family	Computer, ipad, laptop, phone	Yes
Connie	Female	18-30 yo	Family	Ipad, phone	Yes
Pete	Male	30-50 yo	Family	Computer, phone	Yes
Second focus group					
Tom	Male	50+ yo	Supported accommodation	Phone	No (Only if staff allow or at father's house)
Stevie	Male	50+ yo	Family	Phone	No
Andy	Male	30-50 yo	Supported accommodation	Phone, ipad, smart TV	Yes
Phil	Male	30-50 yo	Independent	Laptop, ipad, phone,	Yes
Bob	Male	50+ yo	Supported accommodation	Laptop, phone	At family member's house
Katy	Female	30-50 yo	Supported accommodation	Ipad, phone	Yes

4.3 Themes

Four major themes were developed from the analyses:

- **Connecting**: the importance of interactions with people through online communication, with sub-themes:
    - Social
    - Health
    - Employment
- **Independence**: independence being facilitated through online communication, with sub-theme:
    - Helping others
- **Difficulties**: issues, barriers or difficulties that arose in online communicating, with sub-themes:
    - Complexities with setting up devices and Internet access
    - Changes associated with software and hardware updating
    - Gate-keeping (control over Internet access by staff or family)
- **Support**: help or support provided to enable online communication, with sub-themes:
    - Support that enhances, enables and assists
    - Support that restricts, hampers or otherwise negatively impacts on independence

4.3.1 Connecting

Connecting through their online activities was very important to participants, with family and friends being particularly important, including as a source of social support. Connecting with services and with work and work colleagues was also discussed by participants in relation to their online activities.

Participants often referred to how they felt when using technology to interact with people. Sharon said that it was important to her to be able to "see what other people get up to" (Sharon, female, 30-50 years), and that being able to see people was important: "it helps me more, because I can get to talk to them" (Sharon, female, 30-50 years). Mai referred to her friendship with Sharon, and that talking together was an important way for her to manage being upset. During the social restrictions associated with COVID-19, Mai was able to use technology to do this – she would “talk it out . . . I talk to Sharon online” (Mai, female, 30-50 years).

Statements coded into this theme went far beyond low-key socialising, as the example above shows – the online connecting occurring between Sharon and Mai was a way for them to continue their relationship while they couldn’t be together otherwise, and was an important way for them to support their mental health. Mai in particular found the social restrictions very difficult – “hard one for me was I couldn’t see my friends” (Mai, female, 30-50 years) – so the online communications were very important to her.

Another development to come out of the analyses was the bringing together of statements around preferences for methods of communication, with a hierarchy of communication preference of:

- First preference: face-to-face communication
- Second preference: video communication (where faces as well as voice are accessed)
- Third preference: phone without video

This was emphasised by Andy: “see if you’re talking to someone like that, you communicate and you can see what they’re doing” (Andy, male, 30-50 years). Being able to see someone at the same time as hearing and speaking with them was very important to all participants. Tom’s words “ah – seeing faces” (Tom, male, 50+ years) and his excitement at being able to show Renee his house is a good example: “were you racing through your house showing me all through the rooms – in the bathroom and the kitchen?” (Renee, support worker).

Another example of how important being able to see someone is to the participants with intellectual disability, is the way that Bob connected with his wife who is in a nursing home, during the COVID-related social restrictions: “we each (holding mobile phone) – she borrowed one of the nurse’s – going to the window – we called it the Window of Love” (Bob, male, 50+ years). It was not without problems – “she was holding the phone – it was a bit loud sometimes” (Bob, male, 50+ years) – but was much better than not being able to see each other. As Renee said, “I believe that [Bob’s wife] talks a bit more if she can see you” (Renee, support worker). Renee thought that if the nursing home was able to set up video conferencing on a phone or ipad, that during future social restrictions Bob could talk to his wife from home, and his wife could move around and perhaps show him things or the “other ladies in the nursing home that are quite fond of [him] as well” (Renee, support worker).

Another indication of how important visual cues are to people with intellectual disability is the commentary around being able to send pictures to other people. Phil commented that he did not know how to send a picture, and Andy talked about seeing his mother on the screen, and wondered how to put his own picture onto Facebook. Andy also described how happy he was when Renee’s photo of his craft group’s project went up onto their Facebook page: “that makes it so happy that everybody’s saying what a good job you did” (Andy, male, 30-50 years). Mai talked about the importance of showing things to people with intellectual disability, when she is teaching them to use technology, and about visual cues alongside Easy English instructions.

These examples of the importance of seeing faces, and of seeing other visual cues, underline how important it is for these participants with intellectual disability to receive the necessary support to be able to connect online – especially in times of social restrictions.

Some participants also took part in physical activity online during social restrictions: “I had Zoom for sport like dancing and stuff” (Mai, female, 30-50 years). Mai also talked about staying connected with work via Teams meetings during social restrictions.

Renee, the support worker participant, talked about the difficulties for the members of her organisation (the people with intellectual disability), and the role that the organisation played in trying to check that members were coping and healthy: “it was very hard for people on the phone . . . it was just a total different world where they could see your face and we could see them” (Renee, support worker). There were many challenges for the organisation in setting up their members to be able to communicate this way, but they had found that people with intellectual disability were communicating much better when they could see each other.

4.3.1.1 Social

Family members were often who participants were connecting with; sometimes family members were the only people participants had online communication with. Andy said he had family as contacts, in response to a question on whether he talked to friends online: “no, just family ... I ring family and mum on facetime” (Andy, male, 30-50 years). Sharon found online communication a very helpful way to stay in touch with family: “ . . . I’ve got family who’re like in [country town] . . . and it kinda like helps me cos I don’t see them as much, like other family members” (Sharon, female, 30-50 years).

Friends were also important for participants to connect with. Sharon used technology for a group catch up: “I’ve got a friend who lives in America and one lives in California. So what I did is to have like a group session, so that I could see like the whole three of them” (Sharon, female, 30-50 years). As far as meeting new friends online, all participants preferred to meet people face-to-face before having online communication with them. Connie’s relationship with her boyfriend has developed online, although she said they initially met face-to-face before starting online communication the next day.

4.3.1.2 Health

Although many services during COVID-related social restrictions were available online rather than face-to-face, most participants who saw doctors during these times had telephone (audio only) consultations, with the exception of Pete, who was still able to see a doctor face-to-face. Connie advised that she accessed online mental health support and had used a webchat function to do this – “I rang Beyond Blue online, webchat them” (Connie, female, 18-30 years).

4.3.1.3 Employment

Some participants had employment that continued during COVID-related social restrictions, and their meetings for work had mostly taken place using Microsoft Teams. Pete sometimes used Microsoft Teams to attend meetings even when face-to-face meetings were not restricted, as he lived in a rural city and could not always be in Adelaide for meetings. Connecting online for work meetings was a means of being connected to each other during social restrictions – “it’s just like a bit of a catch up” (Sharon, female, 30-50 years).

4.3.2 Independence

Being independent, in particular, being able to use technology, was a strong theme. Connie commented: “I’m tech savvy…I know public transport” (Connie, female, 18-30 years), and then Mai followed this with “I know technology and transport as well" (Mai, female, 30-50 years). The researcher then followed up with a question on whether being able to talk online helps with being independent, and although Connie thought "a little" (Connie, female, 18-30 years), Sharon felt more strongly that being able to stay in contact with other family members enabled her to be more independent. This contact helped Sharon, she said, through increasing her learning and through knowing what others were doing.

Being able to use technology to pay bills was mentioned by Phil, and it was also something that Mai mentioned she would soon be able to do. Sharon countered criticism of her length of time online from some of her contacts with the statement that "you guys don't pay my bills for me. I do it" (Sharon, female, 30-50 years), and chose to block them.

When asked how it felt to be able to talk to people online, Bob described it as "very liberating" (Bob, male, 50+ years). Bob was another participant who was very capable with technology, using a number of different devices; sometimes at the same time: "I'm just sitting there and using it, playing solitaire, talking to someone – ah great, talk to you" (Bob, male, 50+ years).

Another aspect of independence was the way some participants had learned how to manage their own responses to negative behaviours of others online. Both Sharon and Mai talked about blocking people who had judged them, teased or bullied them, and Sharon nicely captured her response: "so's like – you are – like, delete, delete, delete" (Sharon, female, 30-50 years). Sharon also explained that she blocked online contacts who were a problem for her: "you should see my blocked list" (Sharon, female, 30-50 years).

4.3.2.1 Helping Others

Participants enjoyed being able to help others overcome difficulties in using technology to communicate. Mai talked about the way she had been helping other people with intellectual disability to self-advocate online, and that she "like[d] to teach people" (Mai, female, 30-50 years). Both Sharon and Mai talked of stepping others through how to connect both video and audio functions of technology to communicate with others. Sharon was amused to be able to help a friend's mum (who did not have intellectual disability) to connect online: “actually it was quite funny…she goes ‘how do we do it online’…So I had to show her how to do it” (Sharon, female, 30-50 years).

Other times this was done through text messaging, or where there were still problems Sharon phoned the person and explained how to do it. Mai described that when she helped people with intellectual disability with technology “[she] let them do it for themselves” (Mai, female, 30-50 years). In addition, Mai suggested that it would be useful for people with intellectual disability to have simple instructions with pictures: “. . . like Easy Read . . . like step one – step two” (Mai, female, 30-50 years). Connie thought that having these sort of instructions and pictures would make it easy to take a picture of them and text or message to the person having difficulties.

4.3.3 Difficulties

Participants described issues with technology like software crashing or Internet connectivity problems: “it kept cutting out, in and out” (Sharon, female, 30-50 years). Participants mentioned issues associated with Wifi, Broadband, Hotspot and shared data. Mai described having trouble with videoconference software and the Internet: “sometimes we have an Internet problem – can’t get in” (Mai, female, 30-50 years).

The support worker, Renee, talked about the difficulties participants with intellectual disability had when they tried to work between different devices: “there’s a lot of issues…about having your [devices] with the same buttons, same sort of programming, whereas these two are completely different” (Renee, support worker).

4.3.3.1 Complexities with setting up devices and Internet access

Several participants mentioned having difficulties in setting up their devices. For Bob, with his multiple devices, the connecting and operating of each of the devices was challenging. This was also experienced by Andy: “and there’s all those set ups steps of how to set it all up, but I can’t do that” (Andy, male, 30-50 years).

Support worker, Renee, described the impact of not knowing how to set up their devices for people with intellectual disability: “they don’t know how to set it up – they're losing their ability to connect with their family and friends" (Renee, support worker).

When Bob was asked how it felt to be able to connect with others online, it was the aspect of struggling to work through issues with technology and connecting the different devices that came to his mind: "very tired a lot . . . makes me tired if on it too long" (Bob, male, 50+ years). Bob also talked about not being able to use all the functions on his phone: "I can take a photo on this, but I wouldn't have a clue how to send it to someone" (Bob, male, 50+ years).

Phil was another participant who indicated the difficulties of making technology work: "trying to (hand circling by ear) – in my mind…it takes me time to work things out" (Phil, male, 30-50 years). Phil also described how different devices worked differently: "and sometimes it doesn't work on mine and it works on someone else's" (Phil, male, 30-50 years).

4.3.3.2 Changes associated with software and hardware updating

Support worker Renee talked about the difficulties for people with intellectual disability in keeping up with changes associated with technology: "they don't know about things – they get left out" (Renee, support worker). Renee described how people with intellectual disability had to rely on hearing about changes from other people, and that when buying new technology "they don't get shown how to use it or any sort of training" (Renee, support worker).

Phil gave an example of how changes can impact when asked about having used video-telephoning on his mobile phone: "I tried to do that to my sister and I can't do that anymore" (Phil, male, 30-50 years). "[Technology] keeps changing", Phil said.

4.3.3.3 Gate-keeping (control over Internet access by staff or family)

Several participants mentioned their access being monitored, for example, not being able to access the Internet used by staff in supported accommodation. Another control was described by Mai: "If I don't get off, then I get told off" (Mai, female, 30-50 years) – Mai explained that her sister monitored how long she was on the Internet. The other example was explained by Andy, that he was only allowed family as "friends" on Facebook.

4.3.4 Support

As mentioned earlier, support has been critically important in enabling participants with intellectual disability to connect online. The support worker participant was closely involved in this process for the participants in the second focus group: “Because of COVID, I think we had a lot more to do with families, because they had to assist with technology” (Renee, support worker). One person had a brother to assist, another had a sister, another his father, and yet another a nephew or sometimes his mother. Several others, who lived in supported accommodation, had staff assisting them to connect online.

Participants noted that family members were also able to provide support. Even when participants were competent IT users, family members and/or support workers were accessed to assist, if not with the IT set-up or operation, then with dealing with things like cyber-bullying or “hacking” (Connie, female, 18-30 years). When asked about how he dealt with IT issues, Bob responded with: “Oh yeah – found the off switch. Next time I saw my brother I say – hey, how do you do this?” (Bob, male, 50+ years). Bob had a good idea of how to halt the issue in the moment, but nevertheless had to wait until he saw his brother to resolve the issue.

On the other hand, support was not always a person-to-person situation, with support worker Renee describing how the organisation had put instructions into a newsletter “. . . on how to do it with the Zoom meeting – the meeting code and the password” (Renee, support worker). Other participants, who had not had access to instructions like this, discussed the possibility of putting together step-by-step instructions with diagrams and Easy Read descriptions.

4.3.4.1 Support that enhances, enables and assists

Participants mentioned people who had assisted them to set up their technology, who had problem-solved with them and who had communicated with them through their online technology. Only Sharon said she did not have current support at home: “I have to fend for myself, which I can manage quite well”(Sharon, female, 30-50 years). She did, however, mention having assistance from a disability support agency to “help [her] try and find jobs online” (Sharon, female, 30-50 years). Mai stated that she appreciated having help, particularly from her sister in relation to online harassment and bullying;

“to keep the negative kind out”(Mai, female, 30-50 years). She also made sure that she looked after herself by “hang[ing] out with the positive kind of people” (Mai, female, 30-50 years).

The support worker at the rural organisation talked about the support the organisation had provided to enable their members to connect online, which required significant contact with other family members and staff, and sometimes working closely to problem-solve technology issues: “we have been working through lots of technical stuff” (Renee, support worker). The organisation also included instructions in their newsletter on how to join the Zoom meetings, and in some cases written and pictorial instructions were developed and provided to a particular member on how to connect online with specific devices.

4.3.4.2 Support that restricts, hampers or otherwise negatively impacts on independence

Other support has not been so positively experienced by participants. Both Mai and Sharon talked of contacts who criticised their time online. For Mai it was her family member, while Sharon talked of online criticism: “so I end up blocking them, because you know, you guys don’t pay my bills for me” (Sharon, female, 30-50 years).

The support worker participant, Renee, talked about the problems for participants with intellectual disability who lived in supported accommodation. She reported that it was difficult for them to get assistance from staff to use the Internet for online meetings during the COVID-related social restrictions: “[the staff] didn’t want to share [the Internet] with the members, because you know it’s a house and they have to pay for everything” (Renee, support worker). Once negotiations had enabled those living in the house to use the Internet to connect, staff were not able to assist with any problems with the technology due to lack of IT knowledge. Time pressures also caused problems with assistance, as pointed out by Andy in relation to his mother’s assistance: “when she’s got time – cos she can’t do much at the moment” (Andy, male, 30-50 years). Similarly, Phil mentioned that his sister, although she had helped in the past “hasn’t done it for me for a while” (Phil, male, 30-50 years). Phil’s mother also was not able to assist due to her lack of technology knowledge: “no, she doesn’t touch technology” (Phil, male, 30-50 years).

4.4 Theme Interconnections and a diagram of interconnections of themes

The final stage of the analyses highlighted the way in which the different themes were interconnected. Figure 1 provides a pictorial diagram of the results of the analysis, through the development of the four themes and interconnections between them. The interconnections show in the intersections of the circles: between Difficulties and Independence (for example IT bridging gaps/barriers); between Independence and Connecting (for example sport, work, online meetings, teaching, self-advocacy); and between Connecting and Difficulties (for example IT being able to reduce the problems associated with physical distance). The other interconnection is the intersection of all three smaller circles: the intersection of the three areas of Independence, Connecting and Difficulties, exemplified by bullying and hacking. The theme of Support is linked to each of the other three themes and is depicted in the diagram as surrounding the other themes.

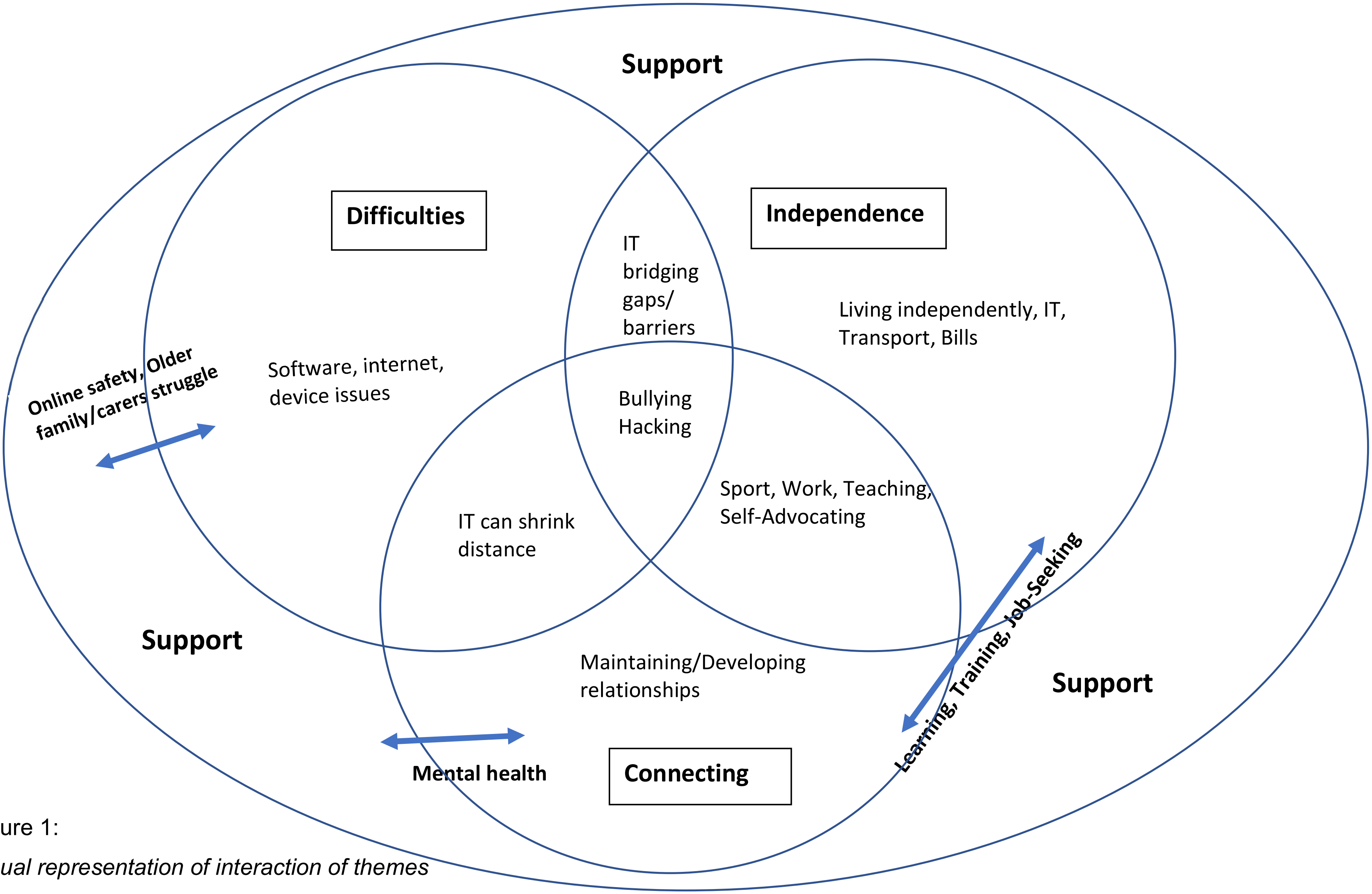

Figure 1:

Visual representation of interaction of themes

4.4.1 Difficulties and Independence

There were a number of comments that focused on the interaction between 'Difficulties' and 'Independence', but perhaps the most salient was the issue experienced by the participants in the rural focus group. Their distance from urban resources and services meant that it was not as easy for them to be connected, either socially or to support services or health supports. The difficulties experienced by participants in accessing the Internet and operating devices meant that they often struggled to connect, putting them at a disadvantage, or as Renee described it, "they get left out" (Renee, support worker). When he was able to use his technology successfully, Bob described it as "very liberating" (Bob, male, 50+ years), reflecting how technology has the capacity to foster independence, when all goes well.

4.4.2 Independence and Connecting

Other interconnections were across 'Independence' and 'Connecting', in statements made around sport, work, online (work) meetings, teaching others and self-advocating. Each of these activities were able to take place online, and participants described the pleasure and fulfilment that came from them, as they connected with others in these different aspects of their lives. In particular, during the COVID-related social restrictions, participants were able to continue these activities in a way that supported their independence.

4.4.3 Connecting and Difficulties

There was an interconnectedness between the themes of 'Difficulties' and 'Connecting', with the ability of online connections to 'shrink' the distance between people, both in the case of rural participants, and for suburban participants with family or friends interstate or overseas. Participants found the distance of loved ones or work colleagues to be difficult but stated that online communication could help them to feel included and connected.

4.4.4 Difficulties, Independence and Connecting

Whenever online bullying or hacking were mentioned, participants talked about how they had overcome the issue, each time with the assistance of a support person, usually a family member or support worker. There was self-insight shown by Mai, who recognised that she felt things deeply: “people get it to heart...I’m one of those people” (Mai, female, 30-50 years), and also took action through assistance with a counsellor and by “do[ing] something to look after [her]self” (Mai, female, 30-50 years). Both Mai and Connie had sought the assistance of a family member to resolve issues with online bullying and hacking. With this support, both were confident to continue using technology to connect with friends and family – enabling and supporting their independence.

4.4.5 Interconnections with Support

The final theme of Support required greater consideration, as it was apparent that support was common to each of the other themes. Support not only interconnected with the other themes but was integral to all of them. Where participants had good, reliable and understanding support, they experienced fewer difficulties. However, where less capable or reliable support was all that was available to a participant, difficulties were much more salient. Examples of good connections and sense of independence were much more likely where participants had good support networks.

Without support, technology was less likely (in some cases impossible) to facilitate independence. As Renee said, “on their own, no-one would be able to do it” (Renee, support worker). Support workers like Renee were critical to assisting set up technology, and problem solve issues, as were family members – a brother, father, sister, mother and nephew were all mentioned in this respect. The problems when support people were less able or unable to assist were also discussed, particularly when support people were older and wary of technology or lacking knowledge.

Assistance in relation to online bullying or scams or hacking was also critical, with most participants being very aware of the risks of these occurring and relying on support people to help them know how to reduce risks or what to do if bullying occurred.

4.5 Summary

This chapter has outlined the findings of the analyses of focus groups transcripts, with the development of four overarching themes of Connecting, Independence, Difficulties, and Support. Each of these themes had sub-themes within it. The themes, their sub-themes, and the interconnections between the themes were outlined.

Figure 1 displayed a visual representation of these themes and the interactions between the themes, showing areas of overlap between Difficulties, Independence and Connecting. The theme of Support developed to be integral to all the other themes, and in Figure 1 is seen as enveloping the other themes. Support is critical to manage the difficulties of being connected online, to enable connections to occur and to facilitate independence of people with intellectual disability through their online connections.

Chapter 5: Discussion

5.1 Introduction

This chapter discusses the findings from the analysis and considers them in the light of existing published literature, as well as in terms of a self-determination perspective (Wehmeyer, 1997). The social isolation experienced by people with intellectual disability and the potential for them to reduce this isolation by connecting on the Internet is considered, particularly in the light of COVID-19 social restrictions. Advantages and issues relating to people with intellectual disability connecting online are also discussed, along with the importance of effective and knowledgeable support. This includes the tensions between the risks of Internet use and the autonomy of people with intellectual disability, as well as the importance of ensuring the UNCRPD's (2006) principles of inclusion (Article 3) and access (Article 9) are enabled. Strengths and limitations of the study are considered, including the importance of the researcher listening to the voices of people with intellectual disability and the benefits of having the advisor with intellectual disability involved throughout the study. The pros and cons of including the support worker as a participant are also discussed. The inclusion of participants of diverse ages in this study is considered in comparison to other studies with younger cohorts of people with intellectual disability. Implications for policy and practice are outlined, as well as recommendations for future research.

5.2 Social isolation, COVID-19 and the Internet

Social isolation is an issue for people with intellectual disability (Bigby & Wiesel, 2011; Gilmore & Cuskelly, 2014; Merrells et al., 2019; Molin et al., 2015; Sharabi & Margalit, 2011), and during social restrictions associated with COVID-19, face-to-face social interactions have been limited (Goldschmidt, 2020; Marston et al., 2020; Torous et al., 2020). For the general population this has had implications in relation to mental health (Biddle et al., 2020; Newby et al., 2020; Torales et al., 2020; Xiong et al., 2020.) Given that people with intellectual disability may already be feeling lonely or isolated (Gilmore & Cuskelly, 2014; Molin et al., 2015; Sharabi & Margalit, 2011), they are at greater risk of mental health issues when the social contacts they have are disrupted (Gilmore & Cuskelly, 2014).

Participants in the current study explained how important their social interactions were through the organisations that they were members of and provided examples of the difficulties they experienced due to COVID-related social restrictions. One participant was unable to see his wife, who lived in a nursing home, and was on his own during restrictions that required people to stay at home. Another participant became depressed during the time he was required to stay at home, and the support worker liaised with his family to provide extra home-based activities for him. Mai also explained that she didn’t really like being at home, and that her preference was to be in the workplace rather than working from home: “it was a bit boring…working from home” (Mai, female, 30-50 years).

The Internet offers promise in supporting people with intellectual disability to stay connected. However, in the same way that they can experience face-to-face exclusion (Gilmore & Cuskelly, 2014; Molin et al., 2015; Sharabi & Margalit, 2011), they are often digitally excluded (Buchholz et al., 2020; Caton & Chapman, 2016; Davies et al., 2015; Hynan et al., 2014; Lussier-Desrochers et al., 2017; Patrick et al., 2020; Sorbrig et al., 2017; Tilly, 2019). This is particularly an issue with many services, including health services, education and employment seeking, going online due to COVID-19 (Gallacher & Hossain, 2020; Hodder, 2020; Majeed et al., 2020; Ohannessian et al., 2020; Qazi et al., 2020; Vlachopoulos, 2020). These difficulties being experienced by people with intellectual disability are out of line with the requirements of Article 3 in the UNCRPD (2006), which states the principle of “full and effective participation and inclusion in society” (p.1) and Article 9 which requires measures to enable participation and independence, including in relation to ICT. Similarly, the Australian National Disability Strategy 2010-2020 (Australian Government, 2011) outlines the need for “better communication and information for people with disability, their families and carers” (p.7, Easy English version).

Fewer people with intellectual disability use the Internet than the general population (Buchholz et al., 2020; Caton & Chapman, 2016; Davies et al., 2015; Hynan et al., 2014; Lussier-Desrochers et al., 2017; Patrick et al., 2020; Sallafranque-St-Louise & Normand, 2017; Sorbrig et al., 2017; Tilly, 2019), and when they do they may have restrictions placed upon the way they engage with the Internet, who they engage with online and/or the time they are able to spend on the Internet (Barlott et al., 2019; Gómez-Puerta & Chiner, 2019; Löfgren-Mårtenson, 2008; Raghavendra et al., 2018; Sallafranque-St-Louis & Normand, 2017; Salmerón et al., 2019; Seale, 2007; Seale & Chadwick, 2017).

These experiences were reflected by participants in the current study, with most being unable to connect through technology and the Internet without assistance from family or a support person: "they're losing their ability to connect with their family and friends – they don't know how" (Renee, support worker). Some participants had restrictions placed upon their access to the Internet, the length of time they were connected on the Internet, and/or the people that they were able to connect with online. These things are impacting on participants' ability to be independent, to participate in society, and to stay connected and healthy.

5.3 People with intellectual disability on the Internet: Advantages and issues

This study found that people with intellectual disability are able to access the Internet, but they need support with technology set up, Internet connecting and resolving any issues that occur. This was occasionally the case even for people with intellectual disability who were more competent with the Internet and their devices. The importance of good support for participants to connect on the Internet was depicted in Figure 1 in the way that it surrounded and encompassed the other themes from the data. The importance of such support is in line with the results of other studies, which found that support can reduce barriers to enable online access (Chadwick et al., 2013; McClimens & Gordon, 2009; Molin et al., 2015; Seale, 2007) and that support people need information and training to best provide that (Parsons et al., 2008; Raghavendra et al., 2018).

When they are online, however, people with intellectual disability can experience advantages. Participants in this study were able to seek social support, to connect to activities, to stay connected to family and friends, to express themselves, to enjoy themselves and to help other people to connect online (both people with and without intellectual disability). This interaction between ‘connecting’ and ‘independence’ was depicted in Figure 1 in the intersection of the two circles representing those themes, where activities of sport, work, teaching others and self-advocating linked the two themes. Other studies have made similar findings in relation to social connections (Caton & Chapman, 2016; Chadwick et al., 2013; Chadwick & Fullwood, 2018; Hynan et al., 2014; Jenaro et al., 2018; Löfgren-Mårtenson, 2008; Sallafranque-St-Louis & Normand, 2017; Sharabi & Margalit, 2011; Shpigelman & Gill, 2014). Chadwick and Fullwood’s (2018) study, like this current study, found that people with intellectual disability were supported to be online and also provided support to others. Chadwick and Fullwood (2018) described this support of others as providing these participants with the opportunity to have *“valued social support roles”* (p.63, original emphasis). Self-determination, they said, can come through being competent at something, and the results in this study are in line with that finding. The participants in this study felt that their online competency increased their feelings of independence.

Participants have also experienced problems in connecting online, with issues in Internet connection, with devices and with online interactions that have included bullying and harassment. Figure 1 depicted bullying and hacking as linking the three themes of ‘difficulties’, ‘connecting’ and ‘independence’, as participants showed pride in having been able to manage these issues. These are also issues that have been found in other studies (Barlott et al., 2019; Caton & Chapman, 2016; Chadwick et al., 2013; Lussier-Desrochers et al., 2017; Sallafranque-St-Louis & Normand, 2017; Shpigelman, 2018; Sorbrig et al., 2017; Tilly, 2019). Difficulties due to managing the complexities of devices were specifically raised by a number of participants in this study, and were also found in other studies (Chadwick et al., 2013; Davies et al., 2015; Hynan et al., 2014; Lussier-Desrochers et al., 2017; Raghavendra et al., 2018). Participants in this study recommended that step-by-step Easy English instructions that included pictures could be helpful to assist people with intellectual disability to connect online. Shpigelman and Gill’s (2014) participants recommended the development of a more accessible version of Facebook, and other studies have made recommendations of possible improvements to computer programs and/or devices to support easier access for people with intellectual disability

(Sorbrig et al., 2017; Wasserman, 2019). This means that provision of further training and/or resources could better support digital inclusion.

A number of studies found that support workers and family were monitoring and/or gatekeeping the Internet activities of people with intellectual disability, in order to try to minimise possible risks associated with the Internet (Barlott et al., 2019; Chadwick et al., 2013; Chadwick and Fullwood, 2018; Gómez-Puerta & Chiner, 2019; Löfgren-Mårtenson, 2008; Parsons et al., 2008; Raghavendra et al., 2018; Sallafranque-St-Louis & Normand, 2017). This study also found gatekeeping behaviours. For example, staff in supported accommodation did not allow Internet access (due to who pays for the access), and family monitored who a participant could be friends with online or they did not provide Internet access on participants' phones. Other participants described people commenting on their length of time online (Sharon, female, 30-50 years) or determining when it was time to get off (Mai, female, 30-50 years). Sharon responded to such comments by unfriending those people and continued to spend the amount of time she wished online. This example underlines the potential of support for Internet access to enable or reduce the opportunity for self-determination; where a family member has curtailed or set limits on Internet access, the opportunity for individual growth and self-determination has been reduced. Sharon's ability to determine who she is friends with online, and how long she spends connected online is a good example of how the general principle of individual autonomy outlined in the UNCRPD (2006) should work, and is also in line with the Australian National Disability Strategy 2010-2020 (Australian Government, 2011) aims for people "to have more control over their lives…[and] more choices" (p.13, Easy English version).

5.4 Support, connection, independence and overcoming difficulties

Even though challenges with gatekeeping were reported, online presence and independence were supported and enabled by the family members or staff/support workers of participants in this study. The results drew attention to the critical nature of such support, through the visual representation in Figure 1. When effective and knowledgeable support was available, difficulties were less likely to limit access for people with intellectual disability.

Such support could also assist in maintaining and developing relationships, and to support their mental health. Similarly, effective support enabled participants to increase their independence and self-determination. On the other hand, it was found that older family members or carers can struggle with the technicalities of devices or programs, and some participants had limited access for this reason. This is in line with findings of other studies (e.g. Chiner et al., 2017a; Gómez-Puerta & Chiner, 2019; Parsons et al., 2008; Raghavendra et al., 2018; Sorbrig et al., 2017) that training was needed for family members and support staff who were less confident with technology and the Internet. Again, the need for support like this is outlined in the UNCRPD (2006) and the National Disability Strategy 2010-2020 (Australian Government, 2011).

'Support' in Figure 1 is therefore seen to surround the other themes of 'difficulties', 'independence' and 'connecting'. Other studies have also found that good support is critical to enable people with intellectual disability to connect online (Chadwick et al., 2013; McClimens & Gordon, 2009; Molin et al., 2015; Palmer et al., 2012; Parsons et al., 2008; Seale, 2007). This underlines the importance for governments and services to ensure that family and support people have access to information and training, as well as ensuring that people with intellectual disability are provided with affordable access, information and training.

5.4.1 The tension between risk and protection – respecting and encouraging independence

Research in relation to people with intellectual disability has often found that support people – family, friends or support workers – may experience difficulties in knowing whether to assist or allow certain activities. In relation to IT, Chadwick et al. (2013) alluded to a "tension between protection, self-determination and lifestyle issues and gaining Internet access" (p.376). People with intellectual disability may be considered more vulnerable to risks associated with the Internet (Chiner et al., 2017a). Chiner et al. (2017a) found that people with intellectual disability were aware of risks and used different strategies to prevent risks. They also found that family members were more likely than staff to forbid the use of the Internet. McClimens and Gordon (2009) noted that it can be difficult to set "the boundaries between care and control" (p.23). There can also be a “trade-off” (Chalghoumi et al., 2017, p.201) between privacy and autonomy when people with intellectual disability use IT.

This type of tension was found in the current study, in the form of lack of Internet access for several participants (unless they were with a relative or at the support organisation), and for one participant having a parent approve friend requests. Chalghoumi et al. (2019) noted that the inclusion and autonomy of people with intellectual disability must still be enabled, if their technology and Internet access is to be the same as that of the general population. This is reflective of the principles of Article 3 of the UNCRPD (2006) in relation to respect for autonomy and the rights to choice and independence, as well as the right to access outlined in Article 9. The National Disability Strategy 2010-2020 (Australian Government, 2011) also supports these rights, and the Easy English version clearly outlines that everyone has the right to good education at all ages, including early childhood, school years and adult life and makes a commitment to improving access to information for people with disabilities. To enable these rights and therefore self-determination, a person with intellectual disability doesn’t necessarily have to have “absolute control” (Wehmeyer, 1997, p. 178), but providing education/training and enabling them to be “the causal agent” (Wehmeyer, 1997, p.178) is key.

A suggested way forward is made by Seale and Chadwick (2017), who describe a possible “positive risk-taking framework” (p.1). This framework incorporates an element of shared decision-making that the authors propose enables balancing and management of risks. “Positive risk-taking . . .stresses managing risk not ignoring it; taking positive risks because the potential benefits outweigh the potential harm” (Seale et al., 2013, p.234). They advocate that clear discussions should be held about taking positive risks and that this could change the ways that online risks are viewed for people with intellectual disability. This is relevant to the recommendations from the current study, because of the importance for people with intellectual disability to be able to connect online, especially in times of social restrictions due to COVID-19. It is important for them to be able to stay connected, and to have this means of reducing their social isolation and the possibility of being self-determined.

Referring again to Wehmeyer’s (1997) definition of self-determination, it doesn’t necessarily mean that self-determined behaviour is positive and/or successful, but can include initiating and responding to an event in a "*psychologically empowered* manner" (p. 178, original emphasis). This includes a person developing coping mechanisms and as a result, self-esteem.

5.5 Strengths and limitations

5.5.1 Inclusive Research, and Advisor with intellectual disability

Inclusive research ranges from people with intellectual disability being involved in all stages of the project (Armstrong et al., 2019; Mooney et al., 2019) to advice on certain elements relevant to the individual with intellectual disability (Davidson, 2015; Schwartz et al., 2020). The level of involvement of the advisor with intellectual disability in this study was appropriate to the resources available to the project, and the potential conflict of interest where he may have known many of the participants. The advisor therefore was not involved in data collection, analysis or the writing up of research findings, however his contribution was significant.

The involvement of the advisor with intellectual disability in this study began in the early planning stages of the project, and his input in those early stages saw the scope of the project expand to include a rural group of participants with intellectual disability. In a similar way that Armstrong et al. (2019) found with their research, the advisor in this project "opened the doors to the people we needed to reach out to" (p.1306). The inclusion of rural participants recognised that rural areas can experience greater disadvantages in terms of inclusion, and are less researched than more populated areas (Raghavendra et al., 2015).

The advisor was also important to the development of the project documentation, in particular the Information Sheet and Consent Form and the list of questions used in the focus groups. He commented on language used, pictures used to supplement the written text, and on the formatting of the documentation. This is similar to the input received from a paid research assistance with intellectual disability in Schwartz et al.'s (2020) study. The advisor's input provided assurance to the researcher that the documentation and the questions were in a format that was likely to be easily understood by the participants with intellectual disability, both in the simple English used, and in the pictures and layout of the documents.

The advisor's involvement in the rural focus group, through delivering an introduction for the session, provided encouragement to the participants of the session and enabled them to relate to what was being said. The advisor did not stay for the focus group in order to ensure confidentiality of the participants' answers, as the advisor had met the participants once before, and had a background connected with the town. Similarly, the advisor was not involved in the suburban focus group, as he is involved with the organisation that recruited those participants and he was familiar with the participants.

It was noticeable in the focus group that the advisor introduced, that one of the participants felt comfortable to ask questions about the content of his introduction. The advisor had referred to the International Day of People with Disability, and a participant asked what he meant and what the day was about. This showed a level of comfort and connection with the advisor that would likely not have occurred if the researcher had made the same introduction. No other questions for explanations or more information were asked of the researcher during that focus group.

The advisor then met with the researcher to discuss the broad findings of the project – the themes, sub-themes and the interconnections of themes – and provided input to the discussion and recommendations of this thesis.

Therefore, the involvement of the advisor added considerable value to this project, most particularly to better enabling the voices of people with intellectual disability to be heard, and therefore to the relevance of this research to the people it seeks to be assisting. This is in line with the research of others advocating the involvement of paid co-researchers or advisors with intellectual disability (Beail & Williams, 2014; Bigby et al., 2016; Schwartz et al., 2020).

5.5.2 Voices of people with intellectual disability

Other studies have drawn attention to the need to hear directly from the voices of people with intellectual disability (Abbott & McConkey, 2006; Chadwick & Fullwood, 2018; Molin et al., 2017). Following the recommendations of this previous research, this study has done that, ensuring that the experiences of people with intellectual disability have been heard.

An example of the importance of hearing responses directly from the people with intellectual disability comes with Phil's response to the researcher's question about how it feels to be able to communicate online. Phil struggled with the concept of feelings, and wasn't able to communicate emotions; instead, he explained his physical and mental tiredness when he worked with technology, which would not have been understood without hearing it directly from Phil.

A further example was Tom's response that it made him happy to see faces, when communicating with technology. He expressed this with a depth of feeling and laughed with pleasure when the support worker talked about the fun they had communicating online.

These statements from people with intellectual disability underline just how important it is to listen to their voices, as it enabled the researcher to find out about the lived experiences, feelings and what people with intellectual disability value. It is recommended future studies also seek to carry out "enhanced listening and understanding of [these] voices" (Molin et al., 2017, p.658).

5.5.3 Inclusion of participants of diverse ages

Chadwick et al. (2013) drew attention to the likelihood that younger people with intellectual disability would be more likely to have "educational and online opportunities" (p.382). The authors also stated that there is a lack of information about the needs in relation to support with IT for adults with intellectual disability, and that opportunities may reduce in the post school environment. This is also reflected in findings by Parsons et al. (2008), with some staff they interviewed considering that IT was relevant for classrooms and learning activities only, rather than for communication by people with intellectual disability.

Chadwick and Fullwood (2018) noted that adults with intellectual disability were often excluded both from the Internet and from direct research participation, as younger people were more often the focus. They recommended that research needs to be extended to include people with intellectual disability who are "less supported, poorer, older, and more severely impaired" (p.63). In relation to research of people with intellectual disability using technology to communicate, most participants in other studies were school aged or young adults (e.g. Alfredsson Ågren et al., 2020; Bayor et al., 2018; Buijs et al., 2017; Cihak et al., 2015; Delgado et al, 2019; Holmes & O'Loughlin, 2014; Hynan et al, 2014; Jenaro et al., 2018).

The participants in this project, however, were all adults and mostly aged over 30 years (only one participant was under 30). Three participants were over 50 years. A number of participants had communication difficulties and required more support; however, they were still able to use technology, and with assistance, able to use it to video-communicate during COVID-related social restrictions.

This research therefore fills a gap in the research that has not previously included participants with these abilities, in this age group, using technology to communicate. The study found that older people of varying abilities want to, and are able to, use technology to communicate when they receive the right support to enable them to mitigate barriers and resolve issues. The exploration of how people with intellectual disability were able to use technology to connect during COVID-related social restrictions is also unique to this study.

5.5.4 Focus group limitations in this study

In the same way that Clarke et al. (2015) highlighted, this current study is limited by the questions that have been used. The focus group discussion guide in the current study focused on some aspects of Internet access and use and allowed for additional prompting when topics were raised by participants. The focus groups therefore might not have covered all aspects of internet use relevant to participants or captured all aspects of their lived experience as Internet users. Participants were mostly aged 30 to 50 years and participants in or members of a specific program/organisation. Therefore, their experiences might not be generalisable beyond the group of people that took part in the study. However, if more people with intellectual disability from diverse settings are asked similar questions, more generalisable findings may begin to emerge. Nevertheless, it is hoped that the findings provide a way forward for future studies and that questions for other studies may be generated that may build upon these findings.

One of the focus groups comprised six participants with intellectual disability, as well as the support worker participant, and this meant that the time available to hear from everyone was limited. The most effective way to hear from everyone was to ask a question of each person one by one (the support worker participant carried this out). Although questions were answered by all six participants, the limitation was that it hampered the possibility of more of a conversation between participants occurring. This may have meant that the data was less fulsome than it otherwise might have been. In the other focus group, the four participants were able to talk among themselves to some degree – prompting each other, supporting each other's statements, and sometimes viewing things differently from each other. This may have been because of the absence of a support worker in the room, as well as due to the face to face nature of this focus group.

It is also possible, that the medium of video-conferencing hampered participants' communications to some degree – some participants were more confident speaking to the researcher via the camera than others, although these participants possibly had less communication difficulties than the others. In the face-to-face focus group there was also one participant taking part remotely, and this participant also spoke less often. It was difficult for the researcher to gauge if this was the result of not being in the room, or if the participant had more communication difficulties than the other participants. However, other studies have not found issues with conducting focus groups online, rather they have achieved diversity in ideas generated (Richard et al., 2021), resulted in more free discussion of sensitive topics (Woodyatt et al., 2016) and generated engagement and disclosure levels that were high (Dendle et al., 2021). There is little literature regarding online focus groups with people with intellectual disability, so it is still possible that the online nature and use of cameras made an impact. In one study on group video conferencing for adolescents with intellectual disability, Ptomey et al. (2017) found that participants were enthusiastic in taking part in the program and wished that it went for longer. The study also provided participants with opportunities to interact socially, and the authors felt that the use of video conferencing had potential to engage young people with intellectual disability.

Regardless of whether the online format was or was not a limitation, the researcher felt there was value to be gained in using the video-conference format, since this was the focus of the study. Further studies with people with intellectual disability using online focus groups may provide opportunities for researchers to undertake studies more quickly and at lower cost (Dendle et al., 2021; Richard et al., 2021).

5.5.5 The support worker participant: advantages and disadvantages

The inclusion of the support worker participant, who assisted in the second focus group, was discussed in the early stages of the project, after the researcher's introductory discussion with the rural focus group participants. Although some questions have been raised around the balance between having good support for the participants with intellectual disability and that support becoming dominating of the research (e.g. Bigby et al., 2014), the support worker in this study was necessary to enable the rural focus group to occur. In addition to setting up the technology and assisting the participants to attend the online focus group, the support worker also encouraged the participants with intellectual disability, giving them more confidence to speak up of their experiences. Additionally, as their primary experience of video communication online had been some months earlier, the support worker was able to prompt their memories, as she had been involved in their online communications during the COVID-related social restrictions.

Examples of her contributions include "and were able to do that for at least 30 minutes on our own, weren't we?" (Renee, support worker); "remember…your sister was…with Zoom meetings a couple of times, and then you did it on your own" (Renee, support worker); "Zoom, you did Zoom, didn't you – did you have to have help to do that, though?" (Renee, support worker). Renee knew what issues had arisen and the supports that had been necessary to resolve those issues and could prompt the participants with intellectual disability to remember and discuss them.

Renee was also able to provide her own experiences in supporting people with intellectual disability to communicate online, for example, in her discussion of difficulties accessing Internet in supported accommodation. Other issues raised by Renee included the way that people with intellectual disability are often left out in relation to communicating online, with technology changes, and not having support with new devices they have purchased. "But if you don't know about it . . . they don't know about things – they get left out" (Renee, support worker). Unfortunately, there appears to have been little change since

Chadwick et al.’s (2013) study, where it was reported that advances in technology have “largely bypassed individuals with [intellectual disability]” (p.390).

A difficulty associated with the second focus group was that with the six participants with intellectual disability, plus Renee, there were time pressures associated with being able to hear from everyone. Renee was able to facilitate everyone being heard, by asking questions and providing appropriate prompts to each participant. This did mean, however, that it was difficult to fit in all the planned questions, and on reflection, the researcher would provide a support worker with the list of questions ahead of the focus group. A meeting with the support worker, prior to the focus group occurring, would also enable the support worker to have a good understanding of the aims of the research project. Additionally, if an interview with the support worker was able to occur before the focus group occurred, this could reduce the time taken during the focus group for the support worker to explain her experiences and thoughts in relation to the questions.

5.6 Implications for policy and practice

The four themes of Connecting, Independence, Difficulties and Support and the interconnections between them, highlighted the benefits that people with intellectual disability can receive with the use of online communication. At the same time, the themes also showed the barriers and issues that often arose, and how critical timely, capable support is. Every participant with intellectual disability in this study, even the “tech savvy” (Connie, female 18-30 years) participants, required assistance (at least occasionally) to be successfully communicating online. For participants who were reliant on staff with limited IT experience, or aging family members with less experience, their ability to communicate online was much reduced. Consideration of resourcing IT training for both people with intellectual disability and their support workers/family members would be one way of increasing the online communication success of people with intellectual disability.

The clear preference of seeing a person’s face when communicating also highlights a need for services to prioritise video-communication over audio-only (for example telephone) during times of social restrictions. Participants said that during COVID-related social restrictions, most of their health services were using telephone (audio-only) rather than video-communication, which could put people with intellectual disability at a disadvantage. Participants said they found communication much easier when they could see the other person.

Government policy could also consider outlining requirements for IT and software companies to include people with intellectual disability when they design, advertise and sell products. This would be in line with the accessible requirements of article 9 in the United Nations Convention on the Rights of Persons with Disabilities (2006), in particular clause ‘h’ which requires governments to promote development of ICT systems to be accessible at low cost. As the support worker participant in this study outlined, people with intellectual disability are missing out on the messaging of IT and software companies; they either do not understand messages or are not aware of the message at all. Further consideration needs to be given as to how people with intellectual disability can be included.

Software companies could also consider investing in Easy-Read picture-enhanced step-by-step instructions for downloading video-communication programs, in the way that several participants in this study described. This could also have a broader uptake beyond only people with intellectual disability, for example, by older people, people not having English as a first language, or others with communication challenges.

5.7 Recommendations for future research

Future research could seek broader groups of people with intellectual disability to discuss similar questions, in a quest for greater generalisability of this study’s findings. It would also be beneficial to see further studies including older participants, as in this study, in order to broaden the knowledge of the issues for this group of people in relation to their online communication. With the likelihood of COVID-related social restrictions being in place over an extended period of time, the importance of ensuring that this group of people are not further isolated, becomes ever more critical.

This study found that participants with intellectual disability had a clear preference for face-to-face communication, and if that was not possible, for video communication rather than audio only. Given that participants stated that most health appointments during social restrictions were audio only, so research that specifically sought to listen to people with intellectual disability about the best ways for them to talk remotely with health professionals should be a priority. This is in line with Ohannessian's (2020) observations around telemedicine and that video consultations should be promoted to assist in COVID-19 health responses. A trial of health appointments by video conference for people with intellectual disability would be desirable as a way of supporting the preferences of people with intellectual disability.

Participants recommended that step-by-step Easy English guides would be of assistance for more people with intellectual disability to be able to connect online, and future research could develop and trial such guides, as well as the best ways to disseminate them for greater numbers of people with intellectual disability to access them. The prioritisation of such guides being co-designed with people with intellectual disability would also be important (Bigby et al., 2014; McDonald et al., 2013; McClimens, 2004).

5.8 Conclusion

This study set out to listen to people with intellectual disability in relation to their online communication experiences during COVID-19. That is, to hear what things had enhanced their experiences, what difficulties or barriers arose, and what ideas they had for improving their online communication experiences.

People with intellectual disability described engaging with communication online, in some cases, in quite complicated communications with multiple people on the same connection. With the right support people and assistance, all the participants with intellectual disability in this study were able to be video-connected and to communicate with others during COVID-related social restrictions. However, for some participants, the only time they were able to do this was when their support organisation put in much time and effort to liaise with their families and to set up the technology and software to enable the connection to occur. This was similar to the findings of Chadwick et al. (2013), who stated that the restriction of the use of the technology to the one setting represented "an ongoing barrier to full integration into the mainstream digital world" (p.382). People with intellectual disability have the capacity to be able to be included and less isolated during times of social restrictions, with the right support. Funding of organisations and individuals to enable this support to occur is critical, as is the dissemination of information, so that people with intellectual disability and their family and support workers know about and are able to use available technology and software.

This study is one of few to use an online focus group for data collection and has shown this can be a valuable tool for research with people with intellectual disability, particularly those in rural or remote locations. Another point of difference in this study is the exploration of how people with intellectual disability connected to others using technology during COVID-related social restrictions. It is also one of few to include older adults with intellectual disability as participants, which has provided a welcome diversity to the published literature that focused mainly on young people and the Internet. The older adults in this study all enjoyed connecting online, although a number of them had reduced opportunities to access the Internet and needed more support which was not often available to them.

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Appendix A

PARTICIPANT INFORMATION SHEET.

PROJECT: YOU CAN TELL ME ABOUT THE BEST WAYS FOR YOU TO STAY CONNECTED ONLINE.

This project is called: ‘People with intellectual disability staying connected online’.

Your family or support person can help you to read this information.

First Supervisor
Fiona Rillotta, Senior Lecturer
College of Nursing and Health Sciences
Flinders University
Tel: 8201 2108
Email: fiona.rillotta@flinders.edu.au

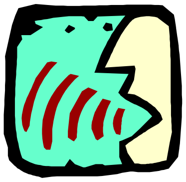
Student
Lisa O'Neill, Masters Student
College of Nursing and Health Sciences
Flinders University
Tel: 0468 526 330
Email: lisa.oneill@flinders.edu.au

Second Supervisor
Claire Hutchinson, Research Fellow
College of Nursing and Health Sciences
Flinders University
Tel: 8201 3591
Email: claire.hutchinson@flinders.edu.au

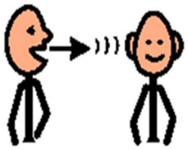
About the project

This project wants to talk with people with intellectual disability.

How do you use the internet:



- to speak up,

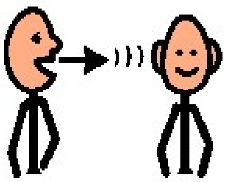


- express yourself,

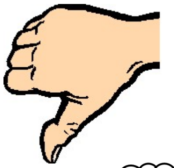
- stay connected.

This project wants to find out:

- How do people with intellectual disability communicate online?



- What things helped you to have good online talking, listening and understanding?



- What things made it difficult to do this and how could you fix the problems?

- Ideas to make online communicating easier.

What you would do

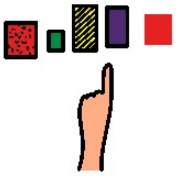
If you agree to help with this project, you will be asked to:

Have a talk with me (Lisa O'Neill) or a talk with a group of other participants and Lisa; and I would like to record our voices talking.

Tell me what you think about questions about talking, listening and understanding using online technology like Zoom or Facetime or Teams

To help in this project you need to:

- Be over 18
- Use online technology to talk to other people



The interview or group discussion will take about 45 minutes and it’s up to you if you want to do this – you don’t have to.

I don’t think the questions will hurt or worry you.

But if you are worried or upset because of helping me with this project, please tell my supervisor (Dr Fiona Rillotta) or me (Lisa O’Neill) straight away.

Other people might know that you have participated because they might see you with the researcher, or if we talk in a group you will see each other participating.

You can also contact the following services for support:

Lifeline

Lifeline – 13 11 14,
www.lifeline.org.au

Beyond Blue

Beyond Blue – 1300 224 636,
www.beyondblue.org.au

DACSSA
DISABILITY ADVOCACY

Disability Advocacy and Complaints Service of SA 08 7122 6030

You can stop

You can say no to being in this project – you can stop any time.

There will be no cost and no problem if you want to say no or stop being in this project.

Even if you start and then change your mind you can still stop any time.

You don't have to say why.

To stop contact me (Lisa O'Neill) or you can stop answering questions.

I will destroy the recording and not use any of your answers, unless you were part of group discussions. If you were part of group discussions it might not be possible to delete what you said before you withdrew.

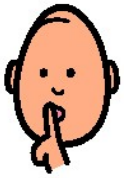
We may tell others about you if we are worried about your safety or the safety of other people while the project is happening. This might include if you tell us about illegal things.

We will not tell anyone your name or information

Only researchers listed on this form can see your information.

I will finish recording.

I will type it up.



The recording will be kept safe in my computer that has a password on it for at least five years and then deleted.

I won't use your name on my typing.

We might talk or write about what we found out.

We keep the typing safe

I will keep the typing safe in my computer that has a password on it.

Only Lisa knows the password.

The typing will be kept at Flinders University for at least five years after the study finishes.

Then the typing will be deleted.

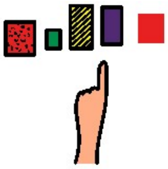
I would thank you for your time and your help

If you would like to participate, I will thank you for your time and your help.

I will give you a $20.00 voucher when we finish the talk.

I will tell you what we found out

When the project is finished, we will have a time with all the researchers, advisor, participants and other University staff and students to talk about what we found out. This would mean participants might see each other.



But you don't have to do this if you don't want to, or if you don't want anyone to know you were a participant

Or if you would like one, I will give you a short report of what we found out.

Ethics Committee Approval

The Flinders University's Human Research Ethics Committee has approved this project (project number 2221).

Questions?

If you have any questions, please ask Lisa O'Neill,

or Dr Fiona Rillotta.

If you have any complaints or worries about the way we are doing this study, you may contact the Flinders University's Research Ethics & Compliance Office team by phoning 08 8201 3116 or emailing human.researchethics@flinders.edu.au.

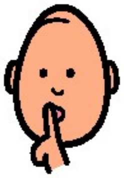
Thank you for taking the time to read this information sheet.

If you would like to be involved, please read the Consent Form that comes next.

Then if you are interested please contact the researcher, Lisa O'Neill, by calling her on:
0468 526 330
Or you can email her to let her know you are interested. Her email address is:
lisa.oneill@flinders.edu.au

CONSENT FORM

Consent Statement

☐	✓	I have read and understand the information about the project
☐	✓	I agree to help in this project.
☐		I understand that I can contact Dr Fiona Rillotta or Lisa O'Neill if I have any questions about this project.
☐	✗	I understand I can stop at any time during the project and there will be no problem.
☐		I understand that I can contact Flinders University's Research Ethics & Compliance Office if I have any complaints or problems about the project.
☐		I understand that only the researchers know that I am helping with the project, but if I choose to be part of a group discussion then other participants will know I have participated.
☐		I understand my name will not be said or written anywhere in the project information.

I also agree to:

☐	✓	participate in an interview or group discussion

☐		have my information audio recorded
☐		I understand the researchers might talk or write about what they found out and I know my name will not be in this information
☐	✓	I understand my information (but not my name) might be used for projects for up to 5 years
☐	✓	The University can contact me about other research projects

Would you like to come to a morning tea to hear what we found out:

👍 ☐ YES 👎 ☐ NO

Would you like to listen to a recording of your interview so that you can tell me if it’s all okay or if you want to add anything to it.

👍 ☐ YES 👎 ☐ NO

Signed:

Name:

Date:

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Appendix B

PARTICIPANT INFORMATION SHEET - FOR SUPPORT STAFF.

PROJECT: YOU CAN TELL ME ABOUT THE BEST WAYS FOR PEOPLE WITH INTELLECTUAL DISABILITY TO STAY CONNECTED ONLINE.

This project is called: ‘People with intellectual disability staying connected online’.

First Supervisor
Fiona Rillotta, Senior Lecturer
College of Nursing and Health Sciences
Flinders University
Tel: 8201 2108
Email: fiona.rillotta@flinders.edu.au

Student
Lisa O'Neill, Masters Student
College of Nursing and Health Sciences
Flinders University
Tel: 0468 526 330
Email: lisa.oneill@flinders.edu.au

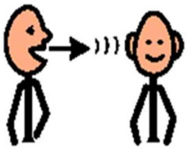
Second Supervisor
Claire Hutchinson, Research Fellow
College of Nursing and Health Sciences
Flinders University
Tel: 8201 3591
Email: claire.hutchinson@flinders.edu.au

About the project

This project wants to talk with people with intellectual disability and support staff.

About how people with intellectual disability use the internet:

- to speak up,

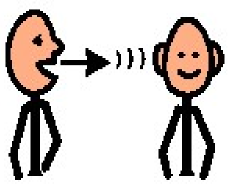


- express themselves,

- stay connected.

This project wants to find out:

- How do people with intellectual disability communicate online?



- What things helped them to have good online talking, listening and understanding?

- What things made it difficult to do this and how could the problems be fixed?

- Ideas to make online communicating easier.

What you would do

If you agree to help with this project, you will be asked to:

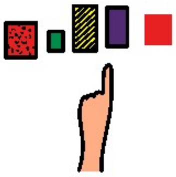
Have a talk with me (Lisa O'Neill), or with a group of other participants and Lisa; and I would like to record our voices talking. We could talk in a group if that is more comfortable.

Tell me what you think about questions about talking, listening and understanding using online technology like Zoom or Facetime or Teams

zoom

To help in this project you need to:

- Be over 18
- Be a support worker who has used online technology to talk to people with intellectual disability, or who has supported someone with intellectual disability to use online technology



The interview/ group discussion will take about 45 minutes and it’s up to you if you want to do this – you don’t have to.

I don’t think the questions will hurt or worry you.

But if you are worried or upset because of helping me with this project, please tell my supervisor (Dr Fiona Rillotta) or me (Lisa O’Neill) straight away.

Other people might know that you have participated because they might see you with the researcher, or if we talk in a group you will see each other participating.

You can also contact the following services for support:

Lifeline – 13 11 14,
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Disability Advocacy and Complaints Service of SA 08 7122 6030

You can stop

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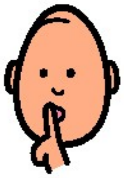

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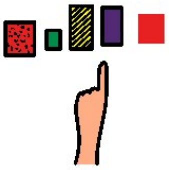

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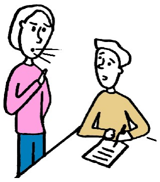
or Dr Fiona Rillotta.



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Thank you for taking the time to read this information sheet.

If you would like to be involved, please read the Consent Form that comes next.

Then if you are interested please contact the researcher, Lisa O'Neill, by calling her on:
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Or you can email her to let her know you are interested. Her email address is:
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CONSENT FORM

Consent Statement

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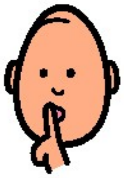
☐		I understand that only the researchers know that I am helping with the project, but if I choose to be part of a group discussion then other participants will know I have participated.
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☐		have my information audio recorded
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☐	✓	The University can contact me about other research projects

Would you like to come to a morning tea to hear what we found out:

👍 ☐ YES 👎 ☐ NO

Would you like to listen to a recording of your interview so that you can tell me if it’s all okay or if you want to add anything to it.

👍 ☐ YES 👎 ☐ NO

Signed:

Name:

Date:

Appendix C

Focus Group Discussion Guide
(Questions are semi-structured/used as a guide,
depending on how discussions go – to enable following more deeply into some questions and explanations if necessary.)

What sort of technology, or IT, or device have you used in the last few months?

(Possible prompts: That could be a mobile phone, or an iPad, or a computer or laptop.
Visual aids of possible types of technology will be used as a prompt if needed, with the
added question: Would you like to show me on these pictures?)

What sort of things can you do with that?

(Or if more than one device is mentioned, taking one device at a time, with this initial question:
Do you do different things on [naming each device]?
Let's talk about what you can do on [name particular device]
What sort of things have you been doing on it?)

Can you talk to other people on the [device]?

How do you talk to people?

(Possible prompt: is it typing or using your voice?)

How does it feel to be talking to people like this?

(Possible prompt: Is it fun, or do you get stressed, …)

OR: How is talking on the [device] different from when you talk face-to-face?

The Internet is a bit tricky sometimes, isn't it? What do you do when things don't work how you need them to?

OR: Tell me about a time when it wasn't easy to get set up and talking to someone?

(Possible prompts: What happened? Were there things that didn't happen that usually do happen? Did something not work properly? Was it the Internet that was not working the same as usual?)

Tell me about a time when the person you were talking to had a problem with their computer while you were talking or trying to talk to them….

OR:

What about when you're having trouble talking to someone – what do you do if you can't hear [or see] each other properly?

OR:

How do you fix a problem when you can't hear [or see] each other properly?

Do you have any suggestions that might help other people to talk to each other on the [device]?

Repeat questions for each device used by a participant.

Social demographic/IT background information

What age group are you in?

☐ 18 – 30
☐ 31 – 50
☐ 50 and over

What is your living situation?

☐ Live on my own
☐ Live with family
☐ Live with a support person
☐ Live with a group of people

How many people living with you?

How long have you been using IT to communicate?

How much time do you spend each day in online communication?

☐ 5 minutes or less
☐ Between 5 minutes and an hour
☐ Between 1 and 3 hours
☐ More than 3 hours

How often do you use IT to communicate?

☐ Every day
☐ Once or twice a week
☐ Once or twice a month
☐ Less than once a month

What sort of things have you done online: (as many as are relevant)

☐ Talk to and catch up with friends and family
☐ Find and meet new people
☐ Online relationships and dating
☐ Doctor appointments or other health appointments
☐ Use other services (e.g. job services)
☐ Advocating for or supporting (e.g. charity, sports team etc)
☐ Commenting on news articles
☐ Making complaints
☐ Other?

For each of the activities above, have you done these face-to-face in the past?

(Why or why not?)

Appendix D

SUMMARY REPORT

PROJECT: PEOPLE WITH INTELLECTUAL DISABILITY STAYING CONNECTED ONLINE.

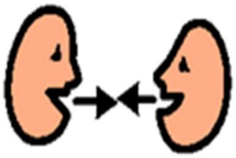
A person with intellectual disability was employed as an advisor to help with this project.

We talked to people with intellectual disability who lived in Adelaide and in the country.

We asked people with intellectual disability:

How do you use the Internet:

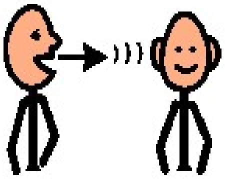
- to speak up,



- express yourself,

- stay connected.

This project found out:



- People with intellectual disability can communicate online.
- The Internet helped them to stay connected, even when COVID-19 meant they had to stay home.

- They could talk to and support each other and talk to friends and family.

- They could connect to activities and help other people to connect online.

- They feel happy to talk to their friends and family online

- Some people needed more help to connect online and did not have good support to do it.

- It would be good if the Government could pay people to have help to be connected online.

- People with intellectual disability wanted to know how to use their technology better

- People with intellectual disability had ideas to make online communicating easier.

- They said it would help to have Easy English information on how to use technology and the Internet to stay connected.