Examining Access to and Use of Internet and Risk of Social Isolation during the COVID-19 Pandemic among both Younger and Older Adults with Intellectual and Developmental Disabilities in Manitoba

by

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Abstract

Persons with intellectual and developmental disabilities (IDD) are found to be at a greater risk for social isolation during COVID-19 pandemic. While existing literature has examined the challenges faced by persons with IDD, there is a dearth of research that addresses the access and usage of digital technologies by persons with IDD as a solution to stay socially connected during the pandemic. This study therefore investigated the access to and use of digital technologies such as the internet in relation to the risk of social isolation experienced by persons with mild intellectual disabilities ID (with or without developmental disabilities) during the COVID-19 Pandemic in Manitoba. Additionally, barriers to the usage of online technology were explored.

Data for a sample of 39 adults were collected using an online survey questionnaire, and phone interviews. The key variables in this study are internet use, access to an electronic device, barriers to the internet usage, loneliness, and social isolation. Loneliness was measured using the Revised UCLA (University of California, Los Angeles) Loneliness Scale. To measure social isolation, the MSNA-ID (Maastricht Social Network Analysis – Intellectual Disabilities) tool was used.

The study was guided by the conceptual framework proposed by Castellacci and Tveito (2018), which explains how information technology affects individuals' wellbeing. The study utilized both descriptive and inferential analyses to address the research objectives. Data were analyzed using the Statistical Package for the Social Sciences (SPSS) Version 21.

We found that the majority of the study participants (89.5%), had access to the internet and possessed some form of electronic devices for online connection. The most commonly used devices were smartphones, desktop computers, and tablets. The majority of the study participants (67.6%) who had access to the internet and an electronic device used the internet for social

connection during the COVID-19 pandemic. The majority of the study participants (53.8%) perceived that their internet usage made them feel less isolated. The use of the internet was associated with a feeling of less isolation.

The results further revealed the most prevalent barriers to the usage of the internet as reported by the study participants. Results showed that the cost of internet service/equipment being too high (20.6%), having access to the internet elsewhere (17.6%), difficulty in using the internet (14.7%), and safety concerns (14.7%) were the most commonly barriers reported by the study participants.

The findings of this study can be used by persons with ID themselves, their families, members of their support networks and paid support staff for enhancing their social connectedness, and therefore reducing their risk of social isolation.

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Dedication

Dedicated to my dear family, and the persons with IDD.

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Chapter 1: Introduction

An estimated 1-3% of people around the globe live with intellectual and/or developmental disability (IDD) (Bickenbach, 2011). Intellectual Disability (ID) is a type of disability that is characterized by significant limitations in intellectual functioning and in adaptive behavior, originating before the age of 18 (American Association on Intellectual and Developmental Disabilities, 2013). Developmental Disabilities (DDs) are a diverse group of conditions resulting from impairment in individuals' physical, learning, language, or behavior, which may significantly impact their daily life activities (Centers for Diseases Control and Prevention, 2013). Since many people who have an ID may also have various types of DDs, the term persons with IDD was used to refer to those who have an intellectual and/or a developmental disability in this study.

According to data from the most recent Canadian Survey on Disability (CSD), in 2017, an estimated 22% of Canadians (6.2 million) aged 15 years and over had one or more disabilities and 1% of Canadians aged 15 years and over had developmental disabilities (Morris et al., 2018). There are about 9000 adults with IDD living in the province of Manitoba (Shooshtari et al., 2017).

Previous studies have reported that persons with disability experience loneliness, low perceived social support and social isolation at significantly higher rates compared to people without disability (Emerson et al., 2020; Krahn et al., 2015; McCausland et al., 2018; Mithen et al., 2015). The reviewed studies indicated that up to 50% of persons with intellectual disability are chronically lonely (e.g., (Stancliffe et al., 2010), compared with around 15–30% of people in the general population (Heinrich & Gullone, 2006). The cognitive, physical, and mental health

problems already associated with intellectual disability are likely to be compounded by experiences of chronic loneliness (Gilmore & Cuskelly, 2014).

The COVID-19 pandemic impacted on the world in various ways, and in a effort to decrease the spread of the virus, some strict restrictions were put in place, including social distancing. The social distancing restriction enhanced the risk of social isolation for vulnerable populations, and in particular for those with IDD (Constantino et al., 2020; Den Houting, 2020; Turk et al., 2020). To maintain good mental health and overall well-being, it is important for persons with disabilities to stay socially engaged and have meaningful social connections. The use of online social networks could have potential impacts on empowering people who might experience social isolation in their lives (Antonucci et al., 2017), including those with IDD (Shpigelman & Gill, 2014). The use of digital technology is considered a potential solution to cope with social isolation particularly during the strict restrictions of a pandemic (Government of Canada, 2020). For example, prior research has shown that the use of the internet might lower the risk of social isolation among persons with disabilities (Duplaga & Szulc, 2019; Gell et al., 2015). However, persons with IDD might face many challenges in accessing and using the internet and other information and communication technologies (ICTs) due to impairments in their physical, learning, language, or cognitive functioning and/or behavioral problems (Dobransky & Hargittai, 2006; Gell et al., 2015).

Information and communication technology (ICT) is potentially a medium that allows people with disabilities to better integrate socially and economically into their communities by supporting personal access to information and knowledge, learning and teaching situations, personal communication, and interaction and access to educational administrative procedures (Khetarpal, 2014). Information and communication technologies (ICT) are broadly defined as a

"diverse set of technological tools and resources used to transmit, store, create, share or exchange information…These technological tools and resources include computers, the Internet (websites, blogs and emails), live broadcasting technologies (radio, television and webcasting), recorded broadcasting technologies (podcasting, audio and video players and storage devices) and telephone (fixed or mobile, satellite, vision/video-conferencing, etc.)" (Peña-López, 2009). For the purposes of the present study, internet use and access were examined to understand the technology behavior patterns of persons with IDD in Manitoba.

In 2018, Statistics Canada reported that 20% of Canadians with disabilities did not use the internet (Statistics Canada, 2020). There is currently no information on the access and use of the internet for Canadians or Manitobans with IDD. Therefore, this study was conducted to examine internet usage among Manitoba adults with mild ID living in the community, and how that relates to their social connections, and the risk of social isolation.

Study Objectives

The five specific **objectives** of the study were to:

1) Determine the proportion of the study participants who had access to a) an electronic device and b) internet;
2) Examine rates of internet usage for social connection during the Covid-19 pandemic among those with IDD;
3) Explore the perception of persons with IDD with regards to internet usage and if they think the usage of the internet has made them feel less socially isolated;
4) Examine the association between internet use and risk of social isolation;
5) Explore the barriers to access and usage of online technology.

Chapter 2: Literature Review

Intellectual and Developmental Disabilities: Definitions and Prevalence

An estimated 1-3 percent of the world's population has some type of intellectual and/or developmental disability (IDD; World Health Organization, 2001). In Canada, 300,000-900,000 individuals have been diagnosed with IDD (Shooshtari et al., 2017). According to the American

Association on Intellectual and Developmental Disabilities (AAIDD), Intellectual Disability (ID) is a neurodevelopmental disorder that is characterized by "significant limitations both in intellectual functioning and in adaptive behaviour as expressed in conceptual, social, and practical adaptive skills. This disability originates before age 18." (Schalock et al., 2021). Intellectual disability affects approximately 1% to 3% of the population (Durkin, 2002; Maulik et al., 2011). Developmental disabilities can be defined as "a group of conditions due to an impairment in physical, learning, language, or behavior areas. These conditions begin during the developmental period, may impact day-to-day functioning, and usually last throughout a person's lifetime." (Rubin, 1989). According to data from Statistics Canada, in 2017, there were 315,470 people with developmental disabilities in Canada, which represents 5.1% of the total population with disabilities.

Social Isolation and Loneliness: Definitions and Measures

Social isolation is defined as a "state where an individual has minimal contact with others and/or a generally low level of involvement in community life" (Grenade & Boldy, 2008, p.469). By contrast, loneliness is "a situation experienced by the individual as one where there is an unpleasant or inadmissible lack of (quality of) certain relationships. This includes situations in which the number of existing relationships is smaller than an individual desires, as well as situations where the intimacy one wishes for is not achieved" (Gierveld & Tilburg, 2006, p.120). Social isolation is characterized by a small network and is typically measured objectively based on number of contacts (Harasemiw et al., 2017). Conversely, the concept of loneliness is more subjective, meaning that the perceived quality of the ties may be what drives the feelings of loneliness rather than the quantity of ties (Pinquart & Sorensen, 2003; Shiovitz-Ezra & Litwin, 2012). Individuals with a small number of relationships may be considered socially isolated, but

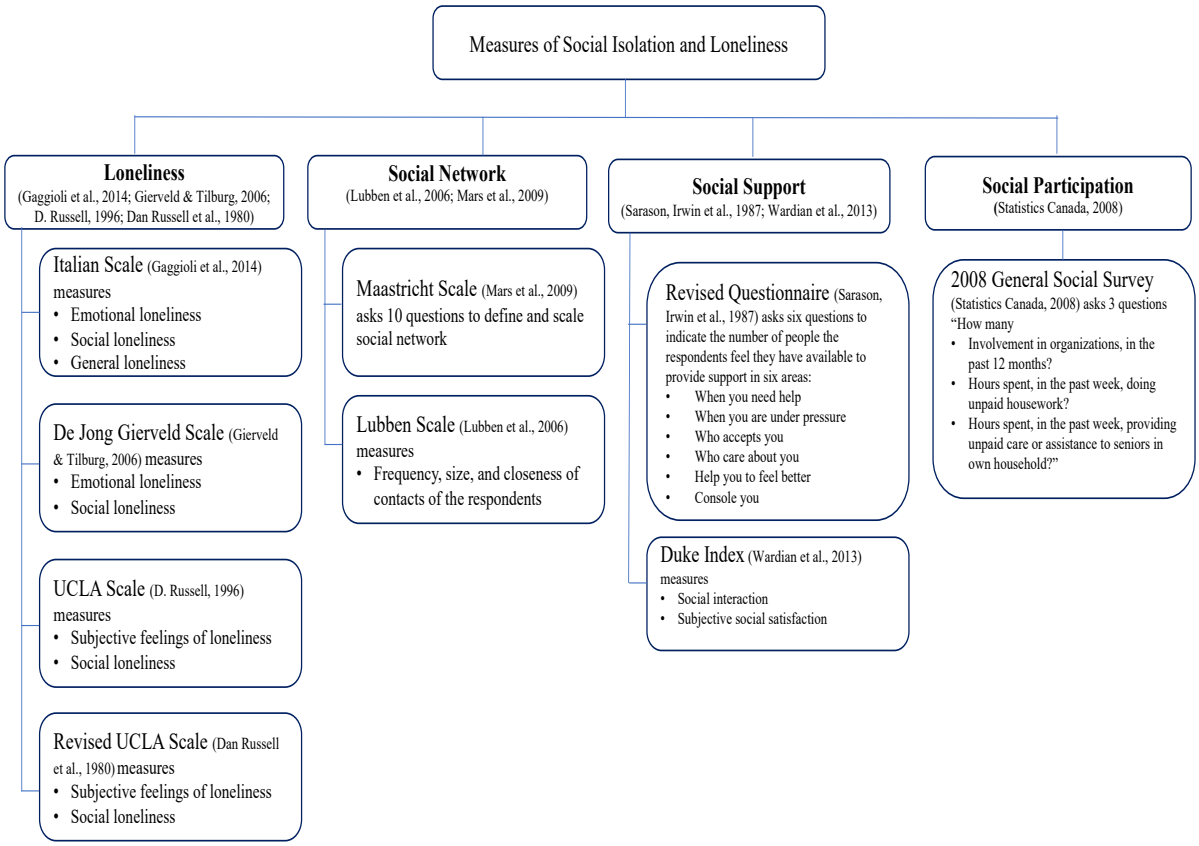
not necessarily lonely, or they might have many relationships, and still feel lonely. Therefore, with regards to loneliness, it is important to consider that being embedded in a social network that may be considered socially connected, meaning having plenty of social ties, does not necessarily mean that an individual is not lonely (Gierveld & Tilburg, 2006).

During the last three decades, several definitions and measures of social isolation have emerged. The several studies conducted on social isolation among older adults have yielded inconsistent definitions and measures leading to variable estimates (e.g. Victor et al., 2000). Apparently, there is consensus by researchers that social isolation is an 'objective' measure of relationships, and is in contrast with the 'subjective' concept of loneliness (e.g., Victor et al., 2000; Masi et al., 2010; Steptoe et al., 2013; Newall & Menec, 2019). Social isolation is a concept that enables us to examine both functional (e.g. social support) and structural (quantity of relationships) aspects of relationships. In general, there is a consensus that social isolation measurements must indicate objective 'lack' or 'absence' of social engagements (Newall, et al., 2020). However, there is no agreement on the cut-off point values to identify socially isolated individuals, which is most likely to be the main reason for the wide variation in the reported prevalence estimates of social isolation in the literature (Newall, et al., 2020).

Following a comprehensive literature review on all the different types of scales and measurements of social isolation and loneliness, available, the relevant measures can be divided into four main categories, which are Social Network, Social Participation, Social Support, and Loneliness. Figure 1 provides an overview of these main categories of social isolation and loneliness measures.

Figure 1

Measures of Social Isolation and Loneliness



Risk of Social Isolation and Loneliness among Adults with Intellectual and Developmental Disabilities

There are limited number of studies on the prevalence of loneliness, or social isolation among persons with intellectual disabilities. One study by Emerson and colleagues found that people with disability of all types experience loneliness, social isolation, and low perceived social support at significantly higher rates compared to people without disabilities (Emerson et al., 2020). The highest prevalence of loneliness was reported among young people with disabilities, who were economically inactive, lived alone, lived in rented or other living arrangements and with low levels of access to environmental assets (Emerson et al., 2020). Some

studies have confirmed that people with IDD have smaller social networks and less participation in interpersonal relationships than the general population (Amado et al., 2013; McCausland et al., 2018). Individuals' ability to communicate with others and their adaptive behaviour, in terms of being able to adjust to prevailing circumstances, are significant enabling factors for the development of personal relationships and social contacts. Hence, persons with severe disabilities are found to experience more limited interactions and involved in less social activities (Kozma, et al., 2009).

Research has shown that social integration and connectedness is significantly associated with better health (Litwin, 2001). Additionally, research has shown that individuals who are socially integrated and connected are less likely to report depression, negative self-rated health, or functional dependency (Doubova et al., 2010; Fiori et al., 2006). Social participation is also found to be associated with better health outcomes and improved quality of life (QoL) for both the general population (Ahnquist et al., 2012; McCrory et al., 2014) and for persons with IDD (Emerson, 2004; Schalock et al., 2002). On the other hand, individuals with limited social ties are found to experience poorer mental health (for example, higher levels of loneliness, anxiety, and lower levels of happiness) (Litwin & Shiovitz-Ezra, 2011), lower levels of physical activity (Litwin, 2003), and higher risk of mortality (Litwin & Shiovitz-Ezra, 2006). Fiori et al. (2006) also noted that persons with less diverse networks had worse mental health status in terms of depressive symptoms.

The Importance of Information and Communication Technology

Information and communication technology (ICT) has become a crucial aspect for community inclusion and participation (Chadwick et al., 2013). The advances in ICT can be seen in the increasing trend of using online platforms for everyday activities such as education,

banking and business, seeking of employment, seeking life partners, information searching, and maintaining friendships. This trend has magnified the importance of the access to the internet and the use of the internet for people around the world (Chadwick et al., 2013; Hoppestad, 2013).

Recent studies and surveys (Haase et al., 2021) confirm that our society has entered the digital and information age. Some studies reported that information and communication technologies (ICT) have the required potential to give people the ability to enhance their social participation. These technologies are effectively important for people with disabilities including those with IDD. The increasing trend in the adoption of ICT has allowed people with disabilities to use them as learning resources and to improve their personal autonomy (Istenic Starcic & Bagon, 2014).

Some relevant studies also found that internet use and access to the internet have an impact on autonomy, self-confidence, advocacy, developing friendship, communication, entertainment, well-being and happiness of persons with IDD (Chadwick et al., 2013; Duplaga & Szulc, 2019; Kversøy et al., 2019). However, it should be noted that the use of ICT might be challenging for persons with IDD, particularly for those with more severe disabilities.

Access To and Use of the Internet by Persons with IDD

The internet essentially drives ICT and it provides a platform to engage with online technologies (Peacock & Künemund, 2007). According to the Canadians Internet Use Survey, in 2018, an estimated 91% of Canadians aged 15 years and over, used the internet. Seventy one percent of older Canadians reported using the internet in their daily life activities (Statistics Canada, 2019). About 1% of older adults believed that disabilities related to aging were barriers for using the internet (Davidson & Schimmele, 2019). A more recent study showed that one out of five persons with disabilities (20%) reported that they do not use the internet even during the

challenging times of a pandemic (Statistics Canada, 2020). Several other studies also revealed that the use of technology is less common among persons with physical limitations and disabilities compared to general population (Gell et al., 2015; Johansson et al., 2020; Sung & Kim, 2020).

Reasons for unequal usage of internet by persons with disabilities compared to the general population include: language difficulties, lack of digital literacy, vision impairments, and memory limitations (Gell et al., 2015; Johansson et al., 2020; Sung & Kim, 2020). In particular, during COVID-19 pandemic, some studies found that older adults have been experiencing unprecedented challenges. For example, a study carried out during the COVID-19 pandemic by Haase and colleagues (2021) provides information on the facilitators of accessing technology that supports socialization and the barriers that are the most important to older adults. Among 400 participants, 91% reported that they continued to use the digital technologies that they had been using since the beginning of the pandemic. On the other hand, the remaining 9% reported that they stopped using digital technology. Various reasons were reported for stopping the use of digital technology or not using it at all. The three main reasons reported were lack of interest, lack of access, and physical limitations (Haase et al., 2021). In total, 91.5% of participants reported at least one facilitator for the use of digital technology. The reported key facilitators were prior knowledge of technology, the act of asking others for help, technological accessibility, and social motivation. Prior knowledge of and familiarity with digital technology was reported as the fundamental factor to enable them in using digital technology to make and maintain social connections with others during the pandemic. Learning how to use specific digital technologies was also reported to be helpful for the participants to stay connected with others during the pandemic (Haase et al., 2021). Many older adults believed they were not

capable of using digital technology independently and heavily relied on help from others which usually came from family members or friends to use digital technology when they need to. Having access to the latest digital technologies and devices, such as smartphones, and the availability of reliable internet connection were reported as additional facilitating factors of older adults' use of digital technology (Haase et al., 2021).

The lack of access to the latest digital technologies can be linked to the inability to afford such technologies due to the associated costs and a lack of resources. This is even more evident for people with IDD. Several studies have revealed that people with IDD are poorer, have less formal education, and have higher unemployment rates compared to their counterparts, which can hinder their access to the internet (Chadwick et al., 2013; Gell et al., 2015). Other studies showed that having access to the internet does not necessarily mean that the persons with IDD use the internet. For instance, one study found that although 50% of persons with IDD have internet connections in their homes, they had never used the internet (Recacha & Cafranga, 2011).

Some studies reported that persons with IDD as a group are more vulnerable when using online communication compared to the general population and are more likely to be the victims of online addiction, abuse, and bullying (Chadwick et al., 2013; Chiner et al., 2017). For instance, a study by Sharma et al. (2020) based on data for five persons with IDD found that all of them who used the internet were addicted to internet use, pornography, and online games. On the other hand, studies also suggest that the lack of usage of the internet is not always a choice, and demand for access to the internet by people with disabilities exist and is steadily increasing (Chadwick et al., 2013).

Chadwick et al. (2013) conducted a literature review on the internet access inequalities and opportunities for people with intellectual disabilities using forty-three studies on internet usage by people with intellectual disability found in the Web of Knowledge and PsycINFO databases. The researchers found that people with ID are accessing the internet less than other population groups and concluded that there is a need to advocate for and collaborate with people with intellectual disabilities to ensure their inclusion in the digital society given that internet use has become such an integral part of the daily lives of people around the world.

Sharma et al. (2020) investigated the use of the internet among users with mild intellectual disability using clinical interviews for a sample of 5 participants, the Internet Addiction Test, the Problematic Online Gaming Questionnaire, and the Pornography Addiction Screening Tool. The usage of the internet was investigated across three major areas: socialization, entertainment, and knowledge. The study found that all the five study participants with mild intellectual disability were addicted to the use of the internet, pornography, and gaming and concluded that there is a need to screen the addictive use of technology among mild IDD users.

Recacha and Cafranga (2011) investigated people with intellectual disability and their use of Information and Communications Technologies (ICT) by employing an exploratory study approach. The study involved 156 adults with intellectual disability who were grouped according to their IQ (IQ<=60 (below the median) and IQ>60 (above the median)) and then examined to discover their use of cell phones, the internet, and television. The researchers found that study participants generally had no difficulty using a cell phone and that a significant portion of the participants who had access to the internet, rarely used the internet. Furthermore, they found that participants generally could watch television without much hassle. They concluded that it was

necessary to further understand the drivers of the ICT behaviors of people with intellectual disability.

Social Isolation during the COVID-19 Pandemic

The COVID-19 pandemic necessitated the increased use of ICT for communication and socialization. For instance, Haase et al. (2021) investigated the experiences of older adults (aged >65 years) with using technology for socialization during the COVID-19 pandemic by conducting a cross-sectional survey. This study was conducted among 400 older adults aged an average of 72 years in the Canadian province of British Columbia. They highlighted that the use of technology had become the norm in the current digital world, evidenced by progressive technological advancements and usage made more pressing by the COVID-19 pandemic. This study buttresses the need for the access to the internet and use of the internet by people across the globe, including persons with IDD.

A study was conducted with a sample of 369 registered nurses in the countries of the United States, Canada, Ireland, the United Kingdom, New Zealand, and Australia, currently providing services to the people with IDD in their respective countries. In this study it was reported by many of participants (n = 96) that people with IDD's mental/behavioral health was adversely affected by being separated from friends, family members, and familiar paid carers as well as disruptions to daily routines and activities, including work and day programming (Desroches et al., 2022). People with IDD themselves reported that the greatest consequence of the lockdown was the interruption of social relationships with family and friends, followed by recreational and leisure activities (Navas et al., 2021).

Access to and Use of the Internet by Persons with IDD and Risk of Social Isolation

According to a study involving 30 adults with intellectual/developmental disabilities who felt socially, Spassiani et al. (2022), reported that people with intellectual/developmental disabilities were often left without access to mental health services during the pandemic. However, by connecting online, they were able to achieve meaningful participation. The researchers found that providing more online events may reduce the pressure on persons with IDD to attend in-person events, and will help fill their time and make them feel connected. Furthermore, access to online events will enable persons with intellectual or developmental disabilities to develop skills and confidence (Spassiani et al., 2022).

Billick and Veretilo (2012) reported that the use of social media as a treatment prescription was able to reduce the significant psychiatric comorbidities of a group of individuals with IDD (Veretilo & Billick, 2012). Rebola and Jones (2013) also revealed that communication technologies enrich many aspects of older adults' lives and keep their levels of social connectedness as they aged.

In Poland, a panel study was conducted among 2,259 people to assess the impact of internet use on well-being and health behaviours of persons with disabilities. After matching study participants with their socio-demographic characteristics as well as their type of disabilities, they found that the persons who were using the internet were living happier and experienced less loneliness or less suicidal thoughts. They concluded that internet users had improved well-being, better mental health and more beneficial health behaviours (Duplaga & Szulc, 2019).

Gaps in the Literature

The present study will fill several gaps in the literature. First, in general, little research has been conducted on internet use among persons with IDD in Canada. Second, although studies conducted in other countries have looked at the association between internet access and use, and risk of social isolation among persons with IDD, no study has examined access to and use of the internet specifically for social connection and if the use is associated with risk of social isolation among Canadians living with IDD during the COVID-19 pandemic. Previous studies recommended that there is a need for further studies about the nature of impairments and internet use in persons with IDD (Chadwick et al., 2013; Lussier-Desrochers et al., 2017). Understanding the extent to which persons with IDD have access to and use the internet and the factors that affect their ability to access and use the internet is important as prior research has shown that internet use by vulnerable populations such as older adults and those with physical or cognitive impairments can reduce their risk for social isolation and enhance their social connectedness (Duplaga & Szulc, 2019; Gell et al., 2015). The proposed study sought to address these gaps in the literature.

The Guiding Conceptual Framework

To address the highlighted gaps in the literature, this study will be guided by the conceptual framework in Figure 2. This conceptual framework proposed by Castellacci and Tveito (2018) explains how information technology affects individuals' wellbeing. One of the top leading and controversial features of ICTs relates to the increased possibilities that they facilitate communication patterns and social interactions, for instance using distance and online communication (Castellacci & Tveito, 2018). These new opportunities can be used in both work life and social life, potentially leading to greater well-being. Importantly, for the present study,

individuals who have higher internet skills compared to the others are more likely to benefit from these new opportunities. Whereas those with less educational backgrounds have potential risk of suffering from isolation and social exclusion (Castellacci & Tveito, 2018).

The reason why this theoretical framework was selected is that it has explicitly outlined the importance of internet use in relation to individuals' wellbeing by drawing attention to both individuals' private and working lives. In relation to personal characteristics, it emphasizes the importance of education, overall health, psychological functioning, culture and beliefs. As for the environment, it draws attention to both physical environment and socio-institutional environment. Therefore, a number of measures were included in this study to capture both social and physical environment.

This framework indicates that the positive effects and potential risks of internet use on individuals' wellbeing are mediated by individuals' characteristics including their psychological functioning, capabilities, culture, and beliefs (Castellacci & Tveito, 2018). As it is shown in Figure 2, there is an interaction between "human being activities" in terms of 'working life' (quality, type of work, and income) and 'private life' (consumption, and social life) as a result of internet use. This determines the amount of internet use and explains why the use of internet has stronger positive effects for some people and social groups than others.

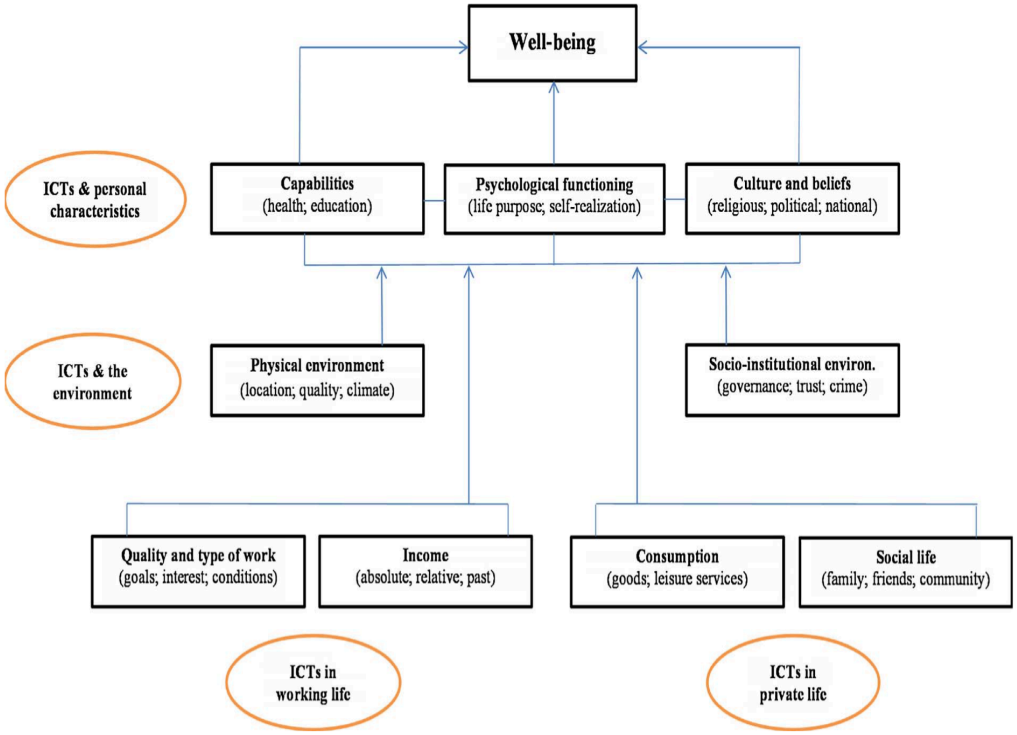
Where is social isolation located in this framework? Regarding the effect of internet use on social isolation, this framework implies that everyone's social life determines their own distinct characteristics that effect their well-being. Hence, without "social life" or in presence of social isolation; health, education, psychological functioning, religious, political, and national beliefs of targeted people would be affected and this impacts on their well-being. Digital technology can be a very effective tool in reducing social isolation and enhancing connectedness,

especially among senior citizens. The main ways in which technology help to expand social capital (any feature of a social relationship that yields reproductive benefits (Häuberer, 2011)) is by increasing communication and connectivity between friends, family, and caregivers.

Castellacci's model is important for this current study as it allows us to determine the impact of ICTs in private and working life from both the personal and environmental characteristics and how it affects the well-being of the individuals. From the personal characteristic's points of view, we included questions on the survey to examine how internet use has helped individuals enhance their heath and/or knowledge, or their religious and/or political beliefs by obtaining mostly free information available on the web. From the environmental perspective including physical and socio-institutional environments, use of internet is helping individuals with their awareness about the location, climate, governance, and crime and these are examined in this study. From the private life point of view, the extent to which internet has helped individuals to establish and maintain their social connections with family, friends and relatives is measured.

Figure 2

A Theoretical Model on the Effects of Internet Use on Well-being (Castellacci & Tveito, 2018)



Chapter 3: Methods

Study Design

This was a cross-sectional study, which involved collection and analysis of data from a survey of Manitoba adults with mild IDD in 2022. The study spanned a period of 4 months (February to May 2022) and utilized a survey questionnaire and phone interviews to elicit information from the study participants.

Study population

The study population consisted of Manitobans with mild intellectual disability, with or without other developmental disabilities, who were at least 18 years of age, living in the community in 2022. The sample for the study comprised of 39 voluntary participants who completed the survey.

According to a recent study by Shooshtari and colleagues (2017), there are about 9,000 Manitoba adults living with IDD (Shooshtari et al., 2017). The provincial government indicates that there are approximately 1,200 people with the Public Guardian and Trustee as their Substitute Decision Makers (SDM). While it is unknown how many adults with IDD have SDMs who are family member or friends, it is estimated that about 25% of them can decide for themselves (i.e., they do not need to have a SDM). This study therefore utilized adults with IDD who can decide for themselves as study participants.

Recruitment Strategy

For the purpose of this study all adults with mild IDD residing in Manitoba who were their own decision makers were invited to participate. Abilities Manitoba, St. Amant, and other organizations supporting persons with IDD in Manitoba facilitated the recruitment of study participants by connecting the principal investigator to potential study participants. Abilities

Manitoba is a network of approximately 100 agencies in Manitoba that fosters excellence in services for persons with intellectual disabilities (www.abilitiesmanitoba.org). St. Amant is the largest not-for-profit organization in Manitoba providing health and social services to persons with IDD and support for their families (www.stamant.ca). This organization offers community living options and is currently supporting 168 adults with IDD living in community group homes managed by this organization.

Members of the executive management teams (e.g., CEO or Program Directors) of the organizations sent an e-mail to all persons with IDD aged 18 years or over that they serve (potential study participants) who had no SDMs. They attached a user-friendly study information sheet describing in lay language accessible to persons with intellectual disabilities the study aims and procedures, and inviting them to take part in the study. This e-mail also included a link to the online survey and instructions on how to contact the principal investigator if potential participants had any questions about the study before they took part in the study. The online survey questionnaire (see Appendix A) included an introductory paragraph with an informed consent statement, and by starting the survey, study participants automatically consented to participating in the study.

Given that we were not looking for interviewing with proxy, those who had substitute decision makers due to the severity of their disabilities were excluded from the study and only people with mild IDD who were able to independently respond to the questions were included. It was anticipated that some of the interested individuals would not be able to complete the online survey by themselves due to the lack of access to a computer, or the internet, or due to difficulties in using digital technology. In these instances, the principal investigator contacted them, confirming their willingness to take part in the survey over the phone and obtained their

informed consent to participate in the study (see phone screening script in Appendix B). After obtaining their consent, telephone interviews were arranged in a time convenient for them. Persons with IDD were offered the opportunity to have a support person present with them if that would make them more comfortable to participate in the study. The potential participants were also given the option of completing a mailed hard copy of the survey questionnaire if they preferred. In that case a copy of the survey questionnaire along with the consent form was mailed to the study participants to complete and return.

Data Collection

The data for the study were collected through an online survey questionnaire containing thirty questions. This questionnaire was previously used in the context of persons with IDD in Canada (Sallafranque-St-Louis & Normand, 2017). The data collection process for the study participants required the participants who had access to computer and internet, to click on the link to the survey that was contained in the invitation e-mail. They thereafter answered the survey questions and submitted their responses when they had completed the survey. For those who required a telephone interview, a call was put through to them to enable them complete the survey over the phone. The phone interview required reading the survey questions to the participants and entering their responses into the online survey using my own laptop. On average each interview took approximately 15 minutes.

Study Measures

The study utilized an online survey questionnaire to elicit information from the study participants. The majority of the questions were closed-ended, with pre-defined response options. There were however a few open-ended questions where participants could provide more information about the questions. The first part of the survey questionnaire consisted of a set of

standard questions collecting socio-demographic information such as age, gender, employment status, education, living arrangement, and type of disability for the study participants. The second part contained a list of ten common online activities (i.e., search for information, read or send emails, use social networking sites, play games online, shop, make new friends, subscribe to dating sites, look at pornography, watch movie, and other). The third part of the survey asked how often they used the internet, their accessibility and barriers to internet respectively. And the fourth part consisted of questions relating to social isolation and whether/how internet has helped them to stay socially connected. The study participants were also asked if they thought that internet usage had reduced their risk of social isolation.

The key variables in this study are internet use, access to an electronic device, barriers to the internet usage, or an electronic device, and social isolation. These variables as well as other study variables were measured using different survey questions and scales. The following provide an overview of the measures used in the study.

Access to the Internet and/or Electronic Devices

The access to the internet and/or electronic devices was measured based on a single-item question on the survey. The question was "Do you have access to the Internet?" This question yielded binary responses (yes or no). Those who responded "yes" to this question were defined as those who had access to internet and coded as '1'. Those who responded "no" to this question were defined as those with no access to internet and coded as '2'.

Frequency of Internet Use

The frequency of internet use was measured based on a few rating-scale questions on the survey. The questions were "On average, how many hours per day do you spend online?" and "How often do you go online?" The responses for the first question ranged from "Less than 1

hour a day" to "More than 4 hours per day". For the second question, an ordinal variable was defined and respondents were classified into one of the following four groups based on their frequency of internet use: 1) Everyday; 2) At least once per week; 3) At least once per month; and 4) Less than once per month.

Barriers to the usage of the Internet

This was measured with the question: "What are your main barriers to the usage of the Internet?" Respondents were able to select more than one from the choices that included the following: "cost", "no need or no interest", "difficulty," "having access elsewhere", "no availability", "security or privacy concerns", "no access to unfiltered" internet" and "other reasons".

Social Isolation and Loneliness

Loneliness was measured using the Revised UCLA (University of California, Los Angeles) Loneliness Scale. This scale consisted of the following four questions: 1) In general, how would you describe your social connection? 2) How often do you feel isolated from others? 3) How often do you feel that you lack companionship? and 4) How often do you feel left out? Some of the questions were measured on a 5-point scale ranging from 1 to 5, while some were measured on a 4-point scale ranging from 1 to 4. The scores on this scale could potentially range between 4 and 19. The higher the score, the higher the level of loneliness.

To measure social isolation, we used the MSNA-ID (Maastricht Social Network Analysis – Intellectual Disabilities) tool, which comprised of three parts (i.e., the size of the social network, characteristics of the relationships and interactions with the social network, and satisfaction of the person with ID) to assess both the structural and functional characteristics of the social networks of the study participants. The tool consists of three parts: Consumptive

Participation (CP), Informal Social Participation with Acquaintances and Friends (ISP-A), and Informal Social Participation with Family (ISP-F). This study utilized a modified score range for the mean values across the different indices (CP, ISP-A, and, ISP-F). The modified score range allowed the effective use of the MSNA-ID scale for this study. The frequency of social participation in the "last four weeks" are coded according to the modified MSNA-ID social isolation scale, as follows: 0-0.49 (no social participation); 0.50-1.49 (participated 1-3 times); 1.50-2.49 (participated 4-8 times); 2.50-3.00 (participated 9+ times).

Socio-demographic Variables

The socio-demographic variables for the study were sex, education, age, marital status, and living arrangement. Study participants were asked to choose the option that best qualified them regarding the socio-demographic study variables.

Sex. The study participants had the following three options to choose from to answer the survey question, "What is your sex?" 1) Male; 2) Females; 3) Prefer not to respond.

Education. Study participants were classified into four groups based on their education level ranging from "Less than secondary education", "High school diploma", "Some post-secondary education", "College or University certificate", to "University degree".

Age. A binary variable was defined and study participants were classified into one of the following two groups based on their self-reported age at the time of the survey: 1) those who were younger than 45 years of age who were defined as "younger adults"; and 2) those who were at least 45 years of age, defined as "older adults". The classification helped to make a distinction between the two groups.

Marital Status. Study participants were classified into one of the following four groups based on their marital status at the time of the survey: 1) Married and/or living with common-law partner; 2) Widowed; 3) Divorced/Separated; and 4) Never Married.

Living Arrangement. A nominal variable was defined to classify the study participants into one of the following five groups based on their living arrangement: 1) living independently in the community; 2) living in a supported living arrangement; 3) living in a group home; 4) living with the family/foster family; and 5) other.

Data Analysis

Analytical Plan

To address the first research objective, descriptive analysis involving frequencies and percentages will be used to determine the study participants' access to electronic devices and the internet. To address the second research objective, descriptive analysis involving frequencies and percentages will be used to determine the rate of internet usage for social connection during the COVID-19 pandemic. To address the third research objective, a descriptive analysis involving frequencies and percentages will be conducted to determine the extent to which the study participants agreed that the use of the internet had made them feel less isolated (for ease of analysis, the groups "Strongly Disagree" and "Disagree" will be regarded as "Disagree"; the groups "Strongly Agree" and "Agree" will be regarded as "Agree"). A modified UCLA scale will also be used to determine the degree of loneliness for the internet users and non-users. To address the fourth research objective, the MSNA-ID scale will be used to determine if there is an association between the use of the internet and social isolation. The fifth research objective will be addressed by examining the frequency distribution of variables related to barriers to access and usage of digital technology.

Data Cleaning and Analysis

The data collected from the survey were cleaned using the Microsoft Excel package, and analyzed using the Statistical Package for Social Sciences (SPSS)® version 21 software. The data analysis centred around descriptive analysis due to the nature of the data collected. The descriptive analysis involved the use of frequencies, percentages, means and standard deviations to describe the socio-demographic characteristics of the study participants, as well as to address some of the research objectives.

Ethical Considerations

Persons with mild intellectual disability, who were able to provide consent for their participation were recruited to participate in this study. They were informed that their participation is voluntary, that they could withdraw at any time and their anonymity was assured. If they were willing to participate in the study, their informed consent was obtained as a preamble for the online survey through the Qualtrics platform and over the phone in the case of telephone interview, or by completing the hard copy received in the mail. The survey was anonymous. No names or addresses, associated with the data were collected. All the data collected were analyzed and reported at the aggregate level. The online version of the survey was created through Survey Gizmo which collects and stores all data in Canada. The only metrics captured through our operation of the survey through Survey Gizmo was the browser type, operating system, and survey completion time.

We will share what we learn from this study in scientific journals and at academic conferences. Study results will be shared (in the form of written reports, workshops, or presentations) with service providers' staff, and families of persons with IDD in Manitoba in an aggregated and anonymous fashion. This study was approved by the Health Research Ethics

Board (HREB) of the University of Manitoba. It was also approved by St. Amant Research Access Committee for recruitment of study participants.

Chapter 4: Results

This chapter provides a summary of the study results in seven sections. In the first section, the study participants' socio-demographic characteristics are described. Sections 2 – 6 provide summary results related to study objectives 1-5. The first objective of this study was to determine the proportion of the study participants who had access to electronic devices and the internet. The second objective of the study was to examine rates of internet usage for social connection during the COVID-19 pandemic among persons with IDD. The third objective of the study was to explore the subjective experience of persons with IDD with regards to internet usage and if they think the usage of this technology has reduced their risk of social isolation. The fourth

objective was to examine the association between internet use and risk of social isolation. The fifth objective of the study was to explore barriers to usage of online technology.

Description of the Study Participants

A total of 39 adults with mild IDD participated in the study. The socio-demographic characteristics of the study participants are summarized in Table 1. As shown in the table, of the 39 study participants, 31 (79.5%) were between 18 and 44 years of age, and 27 of them (69.2%) were male. The study participants had diverse ethno-cultural background: 15.4% were Indigenous; 76.9% were Canadian; and 7.8% were from other ethno-cultural backgrounds.

Participants were asked what language they speak at home. English dominated at 84.6%, followed by American Sign Language at 10.3%, and then other languages (5.2%). Ten participants (25.6%) were married and/or living with a common-law partner, while the majority of participants (74.4%) were never married. Nearly half of all participants (46.2%) were "high school graduates", individuals with "some post-secondary education" and those with "less than high school" each accounted for 20.5% of participants, and individuals with "college or university education" made up 12.8% of participants.

The employment rate of the participants was almost half split between employed and unemployed, with 43.6% working and 56.4% not working. Among those who reported being employed, the majority (76.5%) worked more than 30 hours per week, and 23.5% worked less than 30 hours per week. Less than 80% of the participants reported their yearly income, and among those who reported, 35.3% reported having an annual income of “less than $20,000”, and 47.1% reported having an annual salary of $20.000 or more.

The majority of the study participants were living with other people in either a group home, or with their families, or foster family (82%). However, about 18% of the study participants were living alone in a home in the community.

Table 1

Socio-Demographic Characteristics of the Respondents

Variables	Frequency	Percentage
Age (in years)		
18-44	31	79.5
45 and older	8	20.5
Sex		
Male	27	69.2
Female	12	30.8
Ethnicity		
Indigenous	6	15.4
Canadian	30	76.9
Other	3	7.8
Language (the most often spoken language at home)		
English	33	84.6
Other	6	15.4
Marital Status		
Married and/or living with a common-law partner	10	25.6
Never Married	29	74.4
Highest Educational Level		
Less than high school	8	20.5
High school graduate	18	46.2
Some post-secondary education	8	20.5
College or University education	5	12.8
Employment Status		
Employed	17	43.6
Unemployed	22	56.4
Weekly Average Working Hours for those Employed		
30 hours or more	13	76.5
Less than 30 hours	4	23.5
Annual Income		
Less than $20,000	6	35.3
$20,000 and over	8	47.1
Prefer not to answer	3	17.6

Living Arrangement		
Alone in a home in the community	7	17.9
With other people in a group home	16	41.0
With their family or a foster family	16	41.0

Study Participants' Internet Usage during the COVID-19 Pandemic

The first research objective of this study was to determine the proportion of the study participants who had access to electronic devices and the internet. To address this objective, a descriptive analysis was conducted. Results showed that out of 39 study participants, the majority (34, or 89.5%) reported having access to the internet, but a considerable proportion (10.3%) did not have access to internet. In terms of the age distribution of those who had access to the internet, 27(79.4%) were younger adults while 7(20.6%) were older adults. In terms of the age distribution of those who did not have access to the internet, 4(80.0%) were younger adults while 1(20.0%) was an older adult. Results further showed that all the study participants (39, or 100.0%) had access to at least one electronic device.

As for devices used**,** of the 34 study participants who had access to internet, 16 persons (47.1%) used smartphones to go online; 12 (35.3%) of them were desktop computer users; and 15 (44.1%) used tablets. Laptop and smart TV selections were each used by 9 (26.5%) respondents. Three individuals (8.82%) reported using other electronic devices for their internet needs.

As for frequency of the internet use, the majority (76%) of participants used the internet every day, while 23.5% reported using the internet less than that. 8.8% of the participants reported that they never used the internet while they had access to it. A high proportion of the study participants (41%) declared to be online for more than 4 hours a day. On the other side of

the spectrum, 23.5% reported to be online for less than an hour a day. Nearly one-third of respondents reported using the internet between one and four hours a day.

Social Isolation among the Study Population during the COVID-19 Pandemic

The second research objective of the study was to examine the rates of internet usage for social connection during the COVID-19 pandemic among those with IDD. To address the second research objective, the analyses utilized the data of respondents who had access to the internet and an electronic device. A descriptive analysis was conducted to determine the proportion of the study participants who used the internet for social connection among those who had access to internet. Results showed that a significant proportion (67.6%) of the persons with IDD who had access to the internet and an electronic device used the internet for social connection during the COVID-19 pandemic.

Perceived Effect of Internet Usage on the Risk of Social Isolation

The third objective of the study was to explore the perception of persons with IDD concerning the effect of internet usage on their degree of feeling socially isolated. To address the third research objective, a descriptive analysis involving frequencies and percentages was conducted to determine the extent to which the study participants agreed that the use of the internet had made them feel less isolated (for ease of analysis, the groups “Strongly Disagree” and “Disagree” were regarded as “Disagree”; the groups “Strongly Agree” and “Agree” were regarded as “Agree”).

Table 2 below presents the perceived feeling of social isolation due to internet usage by the study participants. Results in Table 2 revealed that the majority of the study participants (53.8%) believed that the use of the internet has made them feel less isolated. 23.1% of the study

participants disagreed that the use of the internet had made them feel less isolated, while 23.1% of the study participants were neutral (neither disagree nor agree).

The modified UCLA scale was also used to determine the loneliness scores of the study participants. The results of the modified UCLA scale on Table 3 revealed that on average, internet users (M = 8.55, SD = 3.35) had higher loneliness scores than internet non-users (M = 8.00, SD = 2.84). In general, higher scores indicate greater degrees of loneliness. This implies that internet users had slightly greater degrees of loneliness than internet non-users.

Table 2

Respondents Perception of the Effect of Internet on their Feeling of Social Isolation

Statement	**Disagree (Percentage)**	**Neutral (Percentage)**	**Agree (Percentage)**
Internet has made me feel less isolated.	9(23.1%)	9(23.1%)	21(53.8%)

Table 3

Mean Score of Respondents on the Modified UCLA

Group	**n**	**Mean**	**SD**
Internet Users	33	8.55	3.35
Non-Users	6	8.00	2.84

Internet Usage and Risk of Social Isolation

The fourth objective was to examine the association between internet use and risk of social isolation. To address the fourth research objective, we employed the MSNA-ID (Maastricht Social Network Analysis – Intellectual Disabilities) tool which comprised of three types of social participation indices: Consumptive Participation (CP), Informal Social Participation with Acquaintances and Friends (ISP-A), and Informal Social Participation with

Family (ISP-F). Table 4 presents the results of the MSNA-ID analysis regarding the usage of the internet and risk of social isolation. As reported in the measures section, the modified score range for the mean values across the different indices due to the frequency of social participation in the "last four weeks" were coded according to the modified MSNA-ID scale as: 0-0.49 (no social participation); 0.50-1.49 (participated 1-3 times); 1.50-2.49 (participated 4-8 times); 2.50-3.00 (participated 9+ times).

Results in Table 4 revealed that, on average, the study participants engaged in consumptive social participation related activities between 4-8 times in four weeks (the mean score was in the 1.50-2.49 range). Additionally, on average, the study participants engaged in informal social participation with acquaintances and friends between 4-8 times in four weeks (the mean score was in the 1.50-2.49 range). Further, the study participants, on average, engaged in informal social participation with family at least 9 times in four weeks (the mean score was in the 2.50-3.00 range).

In terms of the comparison of the association between internet usage and the risk of social isolation for internet users and non-users, the results were similar. The internet users on average, engaged in consumptive social participation related activities between 4-8 times in four weeks (the mean score was in the 1.50-2.49 range) while the internet non-users, on average, also engaged in consumptive social participation related activities between 4-8 times in four weeks (the mean score was in the 1.50-2.49 range). Similarly, on average, the internet users engaged in informal social participation with acquaintances and friends between 4-8 times in four weeks (the mean score was in the 1.50-2.49 range) while the internet non-users, on average, also engaged in informal social participation with acquaintances and friends between 4-8 times in four weeks (the mean score was in the 1.50-2.49 range). Furthermore, the internet users on

average, engaged in informal social participation with family at least 9 times in four weeks (the mean score was in the 2.50-3.00 range) while the internet non-users, on average, also engaged in informal social participation with family at least 9 times in four weeks.

Table 4

Mean Score of Respondents on the MSNA-ID

Group	CP Index		ISP-A Index		ISP-F Index	
	Mean	SD	Mean	SD	Mean	SD
Internet Users	1.77	0.48	2.33	0.81	2.55	0.82
Non-users	1.95	0.45	2.40	0.15	2.95	0.27
Overall	1.79	0.48	2.34	0.76	2.60	0.78

Barriers to the Internet Usage among the Study Population

The fifth objective of the study was to explore barriers to usage of online technology. To address the fifth research objective, a descriptive analysis was conducted. The results showed that out of the 34 individuals who had access to internet, only 17 (50%) of them actually used the internet in their place of residence. Interestingly, those who had access, but did not use the internet reported reasons (barriers) for not using the internet.

The barriers to the usage of internet reported by the respondents are summarized in Table 5. The barriers are ranked in order of the percentage of respondents who reported such barriers. Results showed that the cost of internet service/equipment being too high, and having access to the internet elsewhere ranked joint first. Then, difficulty in using the internet and safety concern ranked next. Then, other unspecified barriers ranked next. Then, not having access to the internet ranked next. Finally, not needing the internet, ranked last.

Table 5

Barriers to the Usage of the Internet

	Responses	
Barriers	**Frequency**	**Percentage**
The cost of internet service/equipment is too high	7	20.6
I have access to the internet elsewhere	6	17.6
It's difficult to use the internet	5	14.7
I'm worried about my safety on the Internet	5	14.7
Other	5	14.7
I don't need internet	2	5.9

Note: participants were able to select multiple responses as barriers to usage of the internet.

Chapter 5: Discussion

This study aimed at examining the prevalence of internet use among a sample of adults 18 years of age and over living in the community, with mild ID, with or without DDs. Issues such as accessibility to and usage of internet and electronic devices, and barriers to usage were explored. In addition, the association between usage of internet for social connection and risk of social isolation was examined. This was the first study, examining the relationship between internet usage and risk of social isolation measured both objectively and subjectively utilizing standard measures for use within the IDD population. The broad distribution of the online survey

to the agencies supporting persons with IDD across the province of Manitoba resulted in a diverse group of participants in terms of their age, sex, and other socio-demographic characteristics. However, comparing the study participants' characteristics with a population-based cohort of Manitobans with IDD (Shooshtari et al., 2017) revealed that our study sample although diverse, we cannot claim that it is representative of Manitoba adults with mild ID with or without developmental disabilities. For example, although the age and sex distribution of our study group was similar to the Manitoba cohort with IDD, all of the study participants were from Winnipeg health region. In the Manitoba cohort study, Shooshtari and colleagues (2017) found that about half of Manitoba adults with IDD (49.9%) live in Winnipeg health region. In addition, all of the participants in this study were living in community whereas Shooshtari et al. (2017) reported that about 4.4% Manitoba adults with IDD live in long-term care facilities, which were not included in our study sample.

One of the strengths of the present study is the inclusion of persons with mild IDD, who did not have substitute decision makers (SDMs) and therefore responded to the survey themselves with some help rather than by proxy. Several key findings emerged that are discussed in the section below.

Discussion of the Study Results

The **first objective** of this study was to determine the proportion of the study participants who had access to a) electronic devices & b) internet. Using the survey data, it was found that the majority of the study participants (87.2%) had access to the internet. However, a considerable proportion (12.8%) did not have access to internet. Out of 34 study participants who had access to the internet, 16 used Smartphones; 12 used desktop computers to go online; and 15 were tablet users. Each of the laptop and Smart TV selections was used by nine respondents. Three

individuals reported using other electronic devices for their internet needs. The study participants had the option of choosing more than one type of device.

It is important to note that this study was conducted during the COVID-19 pandemic, which was found to be associated with increased rates of internet usage compared to previous years. According to the International Telecommunication Union (ITU), during the COVID-19 pandemic, Internet users grew globally from 4.1 billion (54% of the world's population) in 2019 to 4.9 billion (63% of the world's population) in 2021 with an increase in remote education, remote work, remote health services, and remote communication with friends and family, However, in 2021, 37% of the world's population were not using the internet (non-users). In Canada, the internet usage rate among the general population grew during COVID-19 from 94.9% in 2019 to 97.9% in 2021 (Statista, 2022). The only study found which investigated internet usage among people with intellectual disabilities during the COVID-19 pandemic was conducted in the United Kingdom by Caton et al. (2022). The researchers interviewed a sample of 571 adults with intellectual disabilities, and found that 89.8% of their study participants used the internet during the COVID-19 pandemic, which is very similar to the findings in the current study.

The **second objective** of the study was to examine rates of internet usage for social connection during the COVID-19 pandemic among those with IDD who had access to internet and an electronic device. This study found that a significant proportion (67.6%) of the persons with IDD who had access to the internet and an electronic device used the internet for social connection during the COVID-19 pandemic. This figure was close to the figure reported by Caton et al. (2022). Caton et al. (2022) examined online social connections and internet usage among people with intellectual disabilities during the COVID-19 pandemic in the United

Kingdom using a sample of 571 adults and found that 66.4% of their study population used the internet for social connection with family and friends.

The **third objective** of the study was to explore the perception of persons with IDD concerning whether they felt their internet usage made them feel less isolated. This study found that a significant proportion (53.8%) of the study participants believed that their usage of the internet made them feel less isolated. Similarly, internet users were found to feel less socially isolated than non-users due to their internet usage.

This is similar to the findings of Caton et al. (2022) who found that persons with IDD who used the internet were likely to report not being lonely.

The **fourth objective** was to examine the association between internet use and risk of social isolation. This study found that participants who had access to the internet and used the internet engaged in some form of social participation, which reduced their risk of social isolation. Furthermore, the study revealed that participants who accessed the internet were able to be partially or fully remain connected with their families. The study participants were also socially (partially or fully) connected with their acquaintances and friends once to three times on average, in a four-week time frame. Essentially, the findings show that individuals who use the internet frequently are at a lower risk of social isolation, and vice versa. This is in line with the findings of Cotton et al. (2013) who found that people who use the internet tend to have lower risk of social isolation. In contrast, another study by Esen et al. (2013) found that an increase in internet usage leads to higher levels of loneliness (measured using a 4-item survey scale on loneliness, the Revised UCLA Loneliness Scale, (Russell et al. (1980)), which is in contrast with the findings of this study with regards to loneliness. Our findings revealed that among those with

access to internet, 14.7% reported that they never felt lonely; but all those who did not use the internet felt lonely to some degree.

The **fifth objective** of the study was to explore barriers to usage of online technology. The most frequently reported barriers to internet use for our study participants were “Cost of the internet service/equipment”, “No need the internet”, “No access to the internet”, “Difficulty of use”, “Having access somewhere else”, and “Safety concern”. For example, 20.6% of study participants indicated the cost of Internet service/equipment being too high as a barrier. This finding is similar to those of other studies conducted in other jurisdictions. For instance, Carey et al. (2005) conducted a study on the use of electronic technologies by people with intellectual disabilities in Philadelphia and Pennsylvania, in the United States of America using interview. The study involved 83 persons with intellectual disabilities. The researchers found that 10% of the study participants did not use the internet due to the high cost associated with internet service and equipment procurement.

Kim and Lee (2021) carried out a study on internet use among adults with intellectual and developmental disabilities in South Korea. The study involved 298 adult participants between ages 18 to 59 with IDD and found that 85.7% of the participants did not access the internet due to the associated cost of internet service and equipment purchase. Cresci et al. (2010) examined the differences in internet usage by urban older adults in Detroit, United States of America using a sample of 1410 participants aged 60 years and above and found that 22.8% of participants in the study did not access the internet due to the attendant expenses associated with its procurement and use.

It might be due to the cost that about 20.6% of our study participants reported that they are not using the internet in their residence as they have access to the internet elsewhere.

Interestingly, 5.9% of the respondents, indicated that they did not need online technology. This finding is similar to those of other studies. For instance, Lenhart et al. (2000) conducted a survey on the internet access intention among elderly persons in the United States of America using a sample of 12,751 respondents aged 18 years and above. The researchers found that 57% of the respondents had no intention of using the internet as they did not see a need to use the internet. Kim and Lee (2021) investigated the internet use among adults with intellectual and developmental disabilities in South Korea using a sample of 298 adults between ages 18 and 59 with IDD. The researchers found that 14.3% of the participants felt they had no need to access the internet, and as such, did not use the internet.

In our study, 14.7% of the respondents reported difficulty to use online technology as a barrier. This finding is similar to those of other studies. For instance, Cresci et al. (2010) examined the differences in internet usage by urban older adults using a sample of 1,410 participants aged 60 years and above from the city of Detroit in the United States of America with data elicited via interview method. The researchers found that non-internet user participants which accounted for 31.7% of the study participants, did not use the internet due to concerns over internet safety and difficulty in the navigation and use of the internet. Kim and Lee (2021) investigated the internet use among adults with intellectual and developmental disabilities in South Korea using a sample of 298 adults between ages 18 and 59 with IDD and found that 54% of the participants who did not use the internet attributed the non-usage to their inability to use the internet and the difficulty in using the internet.

Concerns for safety as a barrier to usage of online technology or internet was reported by 14.7% of our study participants. As noted above, Cresci et al. (2010) found that 31.7% of the participants, did not use the internet due to concerns over internet safety.

Study Limitations and Challenges

The results of this study must be considered with several limitations in mind. One limitation relates to the study sample itself. Although our study sample was diverse in terms of age, sex, and other socio-demographic factors, but we do not know if it is representative of Manitoba adults with mild intellectual disabilities with or without developmental disabilities. Therefore, the study results cannot be generalized to Manitoba population aged 18+ with mild intellectual disabilities, with or without developmental disabilities.

Another limitation of the study is the study sample size. It is important to note that this study was conducted during the COVID-19 pandemic, at a time that was very difficult to recruit the study participants. This resulted in a small sample size which prevented us from conducting any sub-population analysis, and statistical testing. The 39 study participants were recruited after extending the data collection period a few times and each time, the researcher had to submit an amendment to the University of Manitoba Health Research Ethics Committee for approval. A larger sample size would ensure that appropriate generalizations can be made, and adequate conclusions can be drawn regarding social isolation in the IDD population.

Additionally, the survey questions may have posed a limitation to the study. Although the survey questionnaire was developed based on a careful review of the literature and some of the national surveys on the use of technology, there were questions related to important factors that were missing. For example, there were no questions on area of residence as urban or rural living arrangements. If the question was asked, we would have had the opportunity to look at the effects of living arrangements on internet access and usage, and risk of social isolation for our study population.

Also, this research like any other research based on self-reported data is susceptible to recall bias. In particular, the risk of recall bias is greater in the case of questions, covering longer time periods, for example when the participants were asked questions relating to the “past 4 weeks”. As such, it is possible that participants may not provide accurate information, not deliberately, but because they cannot properly remember certain events.

Lastly, using cross-sectional data, we were unable to determine the direction of the association between internet usage and social isolation as with the cross-sectional data the temporal relationship cannot be established. Studies with prospective cohort design will be the most suitable to examine the association between internet usage and social isolation and to test if a more frequent usage for social connection is associated with reduced risk of social isolation.

Turning to challenges, the data collection period occurred during the peak of the pandemic (February to May 2022), when the care home facilities staff were dealing with a large number of COVID-19 infection cases in group homes, handling the additional workload, etc. In that situation the persons with IDD and their direct support staff and community agency managers did not consider participation in the research as a priority. This resulted in a very slow recruitment process which required extending the data collection time period a few times. In total, it took four months to collect data from the 39 individuals who participated in this study. In addition, the lead researcher had to change the data collection method from in-person interviews to online and telephone interviews to abide with the health regulations in effect during the pandemic as a precautionary measure against the spread of the COVID-19 infection, especially in working with this vulnerable population.

Chapter 6: Conclusions and Implications of the Study Findings

The majority of persons with mild ID (with, or without DD), who participated in this study had access to the internet and possessed some form of electronic devices for online connection. We learned that the internet connectivity and electronic devices were mainly used for social connection with family and friends. Those with access to the internet never felt fully isolated. The use of internet was associated with lower risk of social isolation. There were some barriers to the usage of online technology by persons with IDD including cost, and difficulty in usage.

This is invaluable knowledge gained that can be used by persons with IDD themselves, their families, members of their support networks and paid support staff for enhancing their social connectedness, and therefore reducing their risk of social isolation.

Implications for Practice/Support

Given the additional evidence provided, families, members of support network, and community staff must facilitate access to the internet and usage of electronic devices so that the persons with IDD use the technology to stay socially connected and active. According to another study that examined a sample of 30 individuals living in a grassroots disability organization located in the United Kingdom, organizations should provide online opportunities for individuals with intellectual/developmental disabilities to connect with other adults who may not be physically able to reach their communities (Spassiani, 2022). Covering the costs of purchasing equipment to connect to the internet, or offering shared electronic devices and providing training on how to use the internet and electronic devices would facilitate the access of persons with IDD to the internet and/or electronic devices .

Implications for Policy

Moreover, legislators may also be able to address the issue of safety as a major concern by implementing privacy and security measures. As highlighted in the findings section, a considerable proportion of our study participants reported that they were concerned about safety as a barrier to internet use. Policies or guidelines on online safety for persons with IDD should be developed as such policies are not currently available in Manitoba. The guidelines for online safety by The Foundation for People with Learning Disabilities, United Kingdom (2014) can be adapted for use in Manitoba.

Future Research Directions

Longitudinal studies based on a large and representative sample of Manitobans with IDD are recommended to examine how access to internet and online technology usage can enhance social connectedness and reduce risk of social isolation. A large and representative sample will enable us to explore age, sex and other sub-population differences.

Knowledge Mobilization

The findings of the study will be shared with the researchers, scholars, service providers, directors, staff, families of persons with IDD, and other stakeholders through poster display, conference presentations, and publications in scientific journals. For non-academic users such as persons with mild ID themselves, their families, friends, and caregivers, the research findings will be summarized in accessible and user-friendly language to raise awareness about the rights of the target population for safe access and use of the internet. These materials will also

emphasize the importance of usage of online technology to enhance social connectivity and lower risk of social isolation.

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