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# "You Want to Know That You're Safe": Experiences of Risk, Restriction and Resilience Online Among People With an Intellectual Disability

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## Abstract

*People with intellectual and developmental disabilities remain more digital excluded than many other groups within society. Perceived vulnerability of people with intellectual and developmental disabilities by those providing support may increase their digital exclusion and the digital divide. Few studies have considered online risk from the perspective of adults with intellectual and developmental disabilities. Online risks have previously been classified as contact, conduct and content but little is known about how adults with intellectual disabilities experience these specific risks. Underpinned by post-positivist and phenomenological epistemologies, perceptions and meanings of online risks for people with intellectual and developmental disabilities were gathered. Individual interviews were conducted with thirteen adults with intellectual and developmental disabilities who all identified themselves as self advocates. Interview discussions considered online risk experiences of being online and using social media. Data were audio recorded, transcribed verbatim and analysed using thematic analysis. Overarching themes of risk experiences, awareness and support to manage salient risks, and developing independence and resilience through online participation were identified. Accounts also identified concerns around online risks and carer gatekeeping as potential instrumental factors in digital exclusion, such exclusion was considered detrimental to wellbeing. Adults with intellectual disabilities with low support needs appeared more able to manage online risk than may be presupposed by a vulnerability-focused perspective. The importance of utilising language salient to the person when discussing risk was also highlighted. Experiential learning to better understand and manage salient online risks appears a way forward for both research and practice.*

**Keywords:** digital inclusion; intellectual disability; autism; online risk; online victimisation; cybercrime; qualitative; resilience

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## Introduction

The digital world is a central part of current human existence that can bestow both benefits and risks to those who engage with it (Chadwick, Chapman, et al., 2019). Cybercrime and online risk have seldom been explored empirically in relation to people with intellectual disabilities (Chadwick, 2019). This seems a considerable oversight as the negative consequences of cybercrime are considerable (Merritt, 2010).

Hence, there is a fundamental need for more in-depth exploration of the experiences of online victimization and perpetration of cybercrime and anti-social behaviour amongst people with intellectual disabilities themselves (Chadwick, 2019). Moreover, there is a need for greater consideration of support provision relating to online risk (Seale & Chadwick, 2017). This qualitative study adds to the small body of research investigating online life from the perspective of people with intellectual disabilities, a group of people who are often overlooked and more challenging for researchers to conduct research with due to their cognitive and communicative differences.

## **ICT Use by People With Intellectual Disabilities**

Though there has been increasing coverage in recent years, there has historically been a lack of consideration of the online lives of those with intellectual disabilities and resultant digital exclusion (Chadwick et al., 2013; Moisey & van de Keere, 2007). People with intellectual disabilities are often overlooked within society, the development of information and communication technologies (ICT) and mainstream research literature (Ali et al., 2012; Jaeger, 2015; Lee et al., 2011; McDonald et al., 2016). Digital exclusion of people with intellectual disabilities has often been reported as greater than both people with other disabilities, and the non-disabled majority (Chadwick, Chapman, et al., 2019), often with little empirical evidence supporting this assertion.

However, recent research has demonstrated that young people with intellectual disabilities use a wide range of devices and have similar patterns of use to the general population of young people in Sweden and Spain (Alfredsson Ågren et al., 2020a; Chiner et al., 2017b), but that this group do remain less digitally included than those without disabilities (Alfredsson Ågren et al., 2019). Nevertheless, people with intellectual disabilities are motivated to engage with the digital world (Alfredsson Ågren et al., 2020a; Caton & Chapman, 2016; Chadwick & Fullwood, 2018; Löfgren-Mårtenson et al., 2015) and benefit from the Internet in similar ways to those without intellectual disabilities, including maintaining and developing friendships, family and romantic relationships, gathering information, pursuing interests and leisure activities, identity and self development via social roles, education and vocation (Caton & Chapman, 2016; Chadwick & Fullwood, 2018; Chadwick & Wesson, 2016; Hoppestad, 2013; Löfgren-Mårtenson, 2008; Näslund & Gardelli, 2013; Stendal, 2012).

## **Online Risk, Vulnerability and Awareness**

Studies have found that people with intellectual disabilities are more vulnerable to risks and criminal victimisation in offline life (Fogden et al., 2016; Nixon et al., 2017). Although online risks raise concerns societally, people with intellectual disabilities are viewed as being at particular risk. Evidence has revealed that this group are viewed, both societally and by professional groups, as more vulnerable to online risks than people without intellectual disabilities (Chadwick et al., 2016; Chiner et al., 2017a, 2019; Löfgren-Mårtenson et al., 2015; Molin et al., 2015; Shpigelman & Gill, 2014). Though this finding may not hold for all family carers (Alfredsson Ågren et al., 2020b). Increased vulnerability has been linked with limited social networks and skills, desire for acceptance (Plichta, 2011), greater loneliness and depression (Normand & Sallafranque-St-Louis, 2016), and poorer insight and judgment (Buijs et al., 2016). However, young people with intellectual disabilities view themselves as at less risk than carers (Lough & Fisher, 2016b; Molin et al., 2015) and demonstrate some awareness of risk (Bannon et al., 2015; Löfgren-Mårtenson et al., 2015; Molin et al., 2017).

## **Types of Online Risk**

In addition to the benefits noted previously, potential online risks also exist, including: (i) Engagement in antisocial and criminal *conduct* (e.g., illegal downloading, bullying, uploading inappropriate material); (ii) Negative *contact* online (e.g., having personal information stolen, being bullied or groomed); and (iii) Exposure to harmful, manipulative or exploitative *content* (e.g., harmful sexual material, scams, violent, hateful or extreme material) (Livingstone & Haddon, 2010). This framework has more recently seen the addition of *contract* risks denoting the contract between people and digital providers prompted by the increasing commercialization of personal information online (Livingstone & Stoilova, 2021).

## **Extent, Experiences and Impact of Online Risks**

Research has begun to explore experiences and to a lesser degree the impact of online risk and cybercrime among people with intellectual disabilities. Survey based research has reported that only 7% of young people with intellectual disabilities were victimized online (Didden et al., 2009), failing to provide support that people with intellectual disabilities are at greater risk. Recent quasi-experimental research has linked phenotype to risk in the case of Williams syndrome (Lough & Fisher, 2016a), supporting arguments for increased support and education for people with intellectual disabilities around online risk.

A recent quantitative survey study gathered information about online risk experiences directly from 77 adults aged between 18 and 51 with intellectual disabilities in Spain (Chiner et al., 2017b). The main online risks reported by participants with intellectual disabilities were being blocked from online groups (48%), threatened (35%), insulted (46%), sent unsolicited sexual online content (35%) and having their passwords used by others without consent (36%). Though an important addition to the extant literature, this quantitative study does not elaborate on these experiences from the perspective of participants.

Buijs et al. (2016), highlighted case experiences of severe sexual and/or financial victimisation via social media, linking these with deficits in awareness and judgment. Other case study research has noted online bullying and sexual and financial exploitation experiences of three women with intellectual disabilities (Holmes & O'Loughlin, 2014).

More substantive qualitative studies gathering accounts from children and young people with intellectual disabilities and other additional support needs have revealed a variety of online risks experienced. Sallafranque-St-Louis and Normand (2017), in a qualitative study of eight people with autism, found that all five who also had intellectual disabilities experienced online risks causing them distress. These included being insulted, having false rumours spread about them, being threatened and sexual cyber-solicitation. Molin et al. (2017), from interviews with 27 young people with intellectual disabilities, found online risk experiences relating to seeking romance and friendship online and online gaming. Bannon et al. (2015) report the results of a focus group study conducted with 36 young people aged 13 to 18 years who were described as having "additional support needs". The children reported being hacked, bullied and placed at risk of sexual exploitation leading to emotional distress. This study also highlighted the lack of awareness some had of online crime they had perpetrated, in this instance, illegally downloading music.

Hence, there is a small but growing amount of literature but there remains a lack of more nuanced knowledge about the phenomenological experiences of online risk of adults with intellectual disabilities and the impact of such risks on their wellbeing and lives (Chadwick, 2019).

## **Support and Management of Online Risk**

An important aspect of experiences with online risks are the strategies people with intellectual and developmental disabilities and their support network use to manage and mitigate them. Young people with intellectual disability qualitatively report looking to peers, parents, family members and professionals (i.e., social workers) for support, advice and guidance in relation to online risk (Bannon et al., 2015; Molin et al., 2017; Sallafranque-St-Louis & Normand, 2017). Accounts have revealed independent management of online risks by young people with intellectual disabilities (Bannon et al., 2015). While seeking support can lead to positive outcomes, it was also connected to concerns that such requests could worsen the online risks (e.g., for cyberbullying) or lead to restriction in online access and subsequently to loss of the opportunities to socialize and loneliness (Bannon et al., 2015; Molin et al., 2017). Clearly then, people with intellectual and developmental disabilities face complexity when facing the challenges inherent in how to negotiate and manage online risks.

Educative strategies and monitoring strategies are the two main strategies used by those providing support to mediate online risk for adults with intellectual disabilities, with monitoring strategies appearing more prevalent, based on the existing evidence (Seale & Chadwick, 2017). Interviews with parents of children with intellectual disabilities also revealed that perceived risk can lead to more restrictive practices rather than education or information being provided (Löfgren-Mårtenson et al., 2015). In addition, levels of ICT support provided by paid staff to people with intellectual disabilities in Ireland were found to reduce as perceptions of increased risk rose (Clifford-Simplican et al., 2017). Thus, restriction, gatekeeping and monitoring of Internet use may characterize the online lives of both adults and young people with intellectual disabilities to a greater extent than those without

intellectual disabilities (Bannon et al., 2015; Chadwick, Fullwood, et al., 2019; Löfgren-Mårtenson et al., 2015). Predicated on the perception of increased vulnerability, this focus on safeguarding and protection from risk may prevent people with intellectual disabilities from living “normal” online lives (Seale & Chadwick, 2017). Hence, there is a need for further research qualitatively exploring online risk related support experiences of people with intellectual disabilities, a need this study seeks to address.

## **The Present Study**

This study presents findings from an investigation of the lived experiences of adults with intellectual disabilities, focusing specifically on online risks. With the exception of Chiner et al. (2017b), existing research has primarily focused on young people with the experiences and perspectives of adults with intellectual disabilities being largely absent in the literature thus far (Seale & Chadwick, 2017). The lines between child and adult are often more blurred for people with intellectual disabilities, with them often occupying an explicitly “non-adult” category despite chronologically being over 18 years of age. This blurring often also occurs in the existing literature around ICT use as people with intellectual disabilities with some samples including younger children, teenagers and young adults. Given the outlined need for further exploration of phenomenological experiences of online risk and associated support, this study gathers in depth qualitative accounts directly from adults with intellectual disabilities. It focusses on the experiences and impact of content and contact risks and also conduct risks, thus considering experiences of both online victimization and perpetration of anti-social and criminal behaviour. It also considers accounts of support and independence in coping with and managing digital risk experiences.

## **Research Questions (RQ)**

**RQ1:** What experiences of online risks do adults with intellectual disabilities report when using the Internet and social media?

**RQ2:** How have experiences of online risk affected people with intellectual disabilities?

**RQ3:** What support have adults with intellectual disabilities experienced relating to online risks?

**RQ4:** What supports do adults with intellectual disabilities report that they want regarding online risk?

## **Method**

### **Approach**

Post-positivist and phenomenological epistemologies underpin this qualitative study (Racher & Robinson, 2003), concerning the lived experiences, perceptions and meanings of online risks for people with intellectual disabilities. The study protocol and procedures were reviewed by The University of Wolverhampton and given ethical approval.

### **Participants**

A purposive opportunity sample of thirteen adults with mild to moderate intellectual disabilities were recruited from advocacy and social groups of people with intellectual disabilities based in the West Midlands in the UK (Table 1). Just under half (46.2%,  $N = 6$ ) were female, with the remaining seven participants (53.8%) identifying as male. Participant were aged between 20 and 50 years ( $M = 30.46$ ,  $SD = 8.45$ ) and lived in a range of accommodation including family homes ( $N = 7$ , 53.8%), independent living housing ( $N = 3$ , 23.1%) and supported living residences ( $N = 3$ , 23.1%). All participants reported having moderate to mild cognitive impairment, two reported having sensory and motor impairments and six reported having Autistic Spectrum Disorder (ASD). Twelve had regularly used the Internet and eleven currently regularly used the Internet and social media.

**Table 1.** *Participant Background Information.*

<b>No.</b>	<b>Pseudonym</b>	<b>Interview Method</b>	<b>Interview Duration (mins:secs)</b>	<b>Sex</b>	<b>Age (years)</b>	<b>Ethnicity &amp; Nationality</b>	<b>Residence</b>	<b>Self Reported Diagnoses</b>	<b>Methods of Internet Access Used</b>	<b>Frequency of Internet / Social Media Use</b>	<b>FB Friends</b>
<b>1</b>	May	Facebook Instant Messenger	80:44	Female	27	White, Irish	Family home	Down Syndrome; Mild ID	Personal Laptop	Daily / Daily	161
<b>2</b>	Ulla	Facebook Instant Messenger	51:38	Female	28	White, Irish	Family home	Down Syndrome; Mild ID	Personal Laptop	Daily / Daily	207
<b>3</b>	Sameer	Face-to-face	52:22	Male	43	Indian, British	Independent living residence	Mild ID; Hearing impairment	Personal Laptop, Mobile Phone	Daily / Daily	86
<b>4</b>	Tina	Facebook Instant Messenger	64:06	Female	36	White, British	<24 hour Supported living residence	Mild ID	Personal Laptop	Daily / Daily	10
<b>5</b>	Scott	Face-to-face	74:36	Male	32	White, British	24 hour Supported living residence	ASD / Visual Impairment / Left hemiplegia / Epilepsy	Personal Laptop, Mobile Phone	Daily / Daily	247
<b>6</b>	Don	Face-to-face	39:12	Male	22	White, British	Family home	ASD; Moderate ID	Personal Laptop Computer	Daily / Weekly	260
<b>7</b>	Gerard	Face-to-face	59:40	Male	50	White, British	Independent living residence	Mild ID	Personal desktop computer	Daily / Never	0
<b>8</b>	Ruth	Face-to-face	54:41	Female	27	White, British	<24 hour Supported Living Residence	ASD; Mild ID; Dyspraxia; ADHD	Personal Computer, Mobile Phone	Daily / Daily	262
<b>9</b>	Shaun	Face-to-face	96:38	Male	24	White, British	Independent living residence	ASD; Mild ID	Personal Laptop, Tablet, Mobile Phone	Daily / Daily	559
<b>10</b>	Jenny	Face-to-face	35:19	Female	32	White, British	Family home	ASD; Mild to Moderate ID	None	< Monthly / Never	0
<b>11</b>	Sabrina	Face-to-face	44:58	Female	20	White, British	Family home	Mild ID	Personal Laptop, Mobile Phone	Daily / Daily	397
<b>12</b>	Tony	Face-to-face	68:22	Male	30	White, British	Family home	Moderate ID	Library Computer, Mobile Phone	Weekly / Weekly	256
<b>13</b>	Sam	Face-to-face	60:33	Male	25	White, British	Family home	ASD; Mild ID; Global develop-mental delay	Tablet, Laptop, Play Station, Mobile Phone	Weekly / Weekly	10

*Note.* ID – Intellectual Disability; ASD – Autistic Spectrum Disorder; ADHD – Attention deficit hyperactivity disorder; FB – Facebook.

## Procedure

Participants received information sheets and consent forms in easy-read format before the interviews and were guided, should they wish to, to have discussions with people within their support networks and the author. To ensure full informed consent and understanding prior to the study, comprehension questions were asked. Participants were asked to explain what they understood about taking part in the study, with any parts which were not demonstrably fully understood being reiterated by the interviewer, with subsequent checking until understanding was achieved. Following this, participants were interviewed using online chat (Facebook instant messenger—used both synchronously and asynchronously) and face-to-face interview methods based on reported preference, geographical location, and support needs (e.g., if the participant required more time to compose answers asynchronous chat was used). Participants were also given the option to have someone they trust who supports them be present if they wished, none of the participants availed of this option. Instant messenger interviews were textually recorded and the face-to-face interviews were audio-recorded.

Interviews began by asking participants about the things they enjoyed online and was followed by questions about support and restriction, online risks experienced and ended by asking people about support they thought would be useful (Appendix 1). The interview schedule was piloted with one individual and language found overly complex was revised to enhance clarity, this involved a small number of minor modifications to the language used. Interviews were semi-structured to facilitate participants to direct the narrative towards their own experiences. As risks can be considered taboo topics the interviewer was vigilant during the interviews regarding observable discomfort and checked regularly whether participants were happy to continue, this formed a process of continuous consent checking. Participant wishes regarding pauses and breaks, what was discussed and what participants did not feel comfortable talking about further were honoured throughout the interview process.

Some participants found open questions and a lack of structure more challenging. In these instances, probe question used provided more structure (Finlay & Lyons, 2001). At the end of the interview, participants were debriefed and, where requested, guided to information and support to enhance their understanding of particular online risks. The researcher made himself available throughout the duration of the study to answer any questions about being online and about the study.

## Data Analysis and Trustworthiness

The interviews conducted via asynchronous chat function on social media ( $N = 3$ , see Table 1) were copied and pasted into word documents and imported into the QSR Nvivo analysis software. The remaining interviews were transcribed verbatim, following guidance from Poland (2002) to enhance the trustworthiness of the transcription approach. Each audio recording was listened through a number of times to enhance familiarity and accuracy of transcription. Draft transcriptions were checked against the audio-recordings and, once finalised, imported into QSR Nvivo where the data was analysed. Interview durations ranged between 35 and 96 minutes ( $M = 59.7$ ,  $SD = 17.0$ ).

Inductive analysis was conducted using semantic and latent thematic analysis (Braun & Clarke, 2006). This process enabled identification of general patterns in the data which were grouped into themes and sub-themes and illustrated via ideographic transcription extracts (Table 2). Stages of this analytic approach include familiarization, initial coding, searching for themes, reviewing themes, defining and naming themes, and writing the results. In extracting the inductively derived theme regarding experiences of online risk, an adapted framework (Chadwick et al., 2016) of the deductive framework utilized by Livingstone and Haddon (2010) of content, contact and conduct risks was used to support identification and organisation of the risk experiences reported in the accounts.

Data collection occurred between October 2017 and November 2019 and analysis were conducted concurrently with recruitment happening in a number of stages. The initial two online interviews conducted in autumn 2017 were analysed initially to generate initial codes. Following this seven additional interviews were gathered between autumn 2017 and autumn 2018 which were again analysed to refine and expand the original thematic structure with new themes iteratively checked for in the preceding two online interviews. This generated a more substantive final form of the thematic structure. Subsequently, an additional four interviews were conducted between winter 2018 and autumn 2019 to check saturation of themes across the participants and to confirm that the thematic structure developed held for subsequent participants. Two participants who never or, at the time of the interview,

seldom used ICT were purposively included to provide a counterpoint to the experiences of those using the Internet and to determine if, for these individuals, risk perceptions influenced their non-use. A flexible and pragmatic approach was taken regarding thematic saturation within the study, whereby sampling adequacy was judged by the extent to which the data was able to sufficiently answer the research questions and provide both depth as well as breadth of information in relation to the phenomena under study, for the target participant group (O'Reilly & Parker, 2013).

Strategies were employed to enhance the trustworthiness of the study (Lincoln & Guba, 1985; Nowell et al., 2017). The themes extracted and developed by the author and associated quotations were independently coded by a colleague for 15 per cent of the interview transcriptions to enhance the credibility of the themes derived and refined through peer debriefing discussions. This involved considering thematic overlaps and distinctions, where subthemes best fitted, merging of basic codes into grouped subthemes. It also involved confirmation of the appropriateness of the quotations in illustrating the themes. Themes identified were also member-checked with eight participants, who confirmed that the themes developed accurately reflected both the interviews conducted and their lived experiences. Background information gathered supported the transferability of the findings.

## Results

Analysis of the data revealed four overarching themes; these are detailed with associated sub-themes below and in Table 2.

### Theme 1: Experiencing and Taking Risks Online

The online risks participants had experienced are presented in Table 3. Employing the classification framework of *contact, content and conduct risks* (Livingstone & Haddon, 2010), contact risks were mentioned more frequently than content risks, which in turn were mentioned more often than conduct risks by participants. In utilising this framework to summarise risk experiences of the participants, this derived theme overlaps more often with the other themes where the meanings and affects of online risks are further elaborated upon.

For the *contact risks*, having one's social media or other account hacked and downloading viruses were most commonly reported. Online bullying seldom occurred and had been managed by participants with support when it had. One participant had been sent pornography though he and others indicated this was not something they were "into". Chatting with strangers online occurred but had not led to negative repercussions for participants.

"Well I meet him online, and it was weird for me, I thought he was all good looking, and a great body. But in person I felt he was nearly old enough to be my father. I felt very awkward, and the worst thing is he got me a present of a book." (P1, May, 27)

*Content risks* relating to violence, obscene or illegal content were least commonly reported, some participants indicated dislike or that such material was not of interest to them.

"But you do see people posting things on Facebook, and I get angry and I type 'Why the heck are you putting things like this', bloody annoying to watch I don't know why they do it, it's not even entertaining." (P8, Ruth, 27, regarding violent content)

For Sam, listening to his music, which had considerable amounts of swearing in it, was something he enjoyed and was a positive aspect of his self-identity. Advertised pay-site use was managed well from Shaun's account but had led to some financial mismanagement and subsequent online restriction for May and Sabrina. This finding links with the subtheme Digital exclusion as a risk to wellbeing discussed later in the results section.

Illegal downloading was the most commonly engaged in *conduct risk*. Having been shown how to access it by support staff and family led to normalization of this behavior with unawareness that downloading was illegal, see subtheme Awareness of online risks. Music and films were significant leisure pursuits for some participants and downloading facilitated this. Thus, more support and education is required regarding cybercrime consequences, which were not always well understood by participants. Meeting strangers offline, though risky, resulted in positive future friendships in two instances; May reported learning from the experience and felt she knew how to protect



herself in future, which illustrates the inductive subtheme Building resilience and learning through online experience discussed later. Overuse of the Internet and social media leading to reduced occupational, social and developmental opportunities was reported by six participants. Though for two this was viewed as positive, humorous and indicative of their independence. Bullying or behaving in an antisocial way towards others and sharing personal or other pornographic materials were not reported:

“No, because that’s not me, that’s not the way I’ve been brought up.” (P5, Scott, 32, when asked about bullying others online)

Younger participants reported more experience of the different types of online risk (Table 3) with a negative relationship evident between number of risks experienced and age ( $Rho = -0.577$ ,  $N = 13$ ,  $p = 0.039$ ).

## Theme 2: Awareness and Support to Manage Risk

Awareness and supports available were key factors in enabling successful online risk management but awareness was variable with the need for further supports and training evident in the accounts; it incorporated 3 subthemes.

*Awareness of online risks varied.* Awareness of hacking, grooming, and being contacted by strangers were more frequently evident in accounts. For example, Shaun, one of only two parents in the study who had a young daughter, believed grooming of young girls was common online. This may link to media representations and/or his parental role as he was the only participant who engaged in childcare for his daughter. Participant awareness of cybercrime was linked with salience to their own lives and what they had been told or warned about by carers and friends. For example, there was widespread awareness of online identity deception and misrepresentation. Participants discussed fake social media profiles, and the potential for people online not being who they say they are in pursuit of both friendship and romantic encounters. Conversely, lack of complete understanding of risks was also evident and was self-reported by some.

I: “How would you spot the fake websites?”

P3: “Different hand writings, and you have to be careful of what they put on.” (P3, Sameer, 43)

Linked with awareness were participant descriptions of needing or accessing *support to manage online risk* to enable them to stay safe. Support was sought when participants had encountered an online risk and were unsure what to do. Those who had experienced risk or uncertainty in the online world appreciated the support they had received from carers, facilitators and friends and having someone to discuss these issues with and confide in:

“...Erm think when I first started like sometimes my opinions, the way that I put them across sometimes or what I’ve said [resulted in online arguments and upset]. Erm sometimes think my mom had to warn me.” (P6, Don, 22)

Most participants reported *wanting to develop their knowledge of salient online risk* conveying the need for more information and training which they could subsequently draw on. Some participants who appeared to lack awareness of particular risks and/or spoke about understanding that they needed more support mentioned this need more:

“You want to know that you’re safe and want people to learn you to find out more about keeping myself safe while online.” (P8, Ruth, 27)

Four participants spoke about being confused by the behaviour of others online and being unsure how to interact and express themselves appropriately on social media. Some also wanted to develop better technological, ICT and Internet competence, with reports, particularly among those with less frequent or no use, of previously struggling with ICT and needing considerable support. A small number of participants did not feel that risks were salient to them and talked about finding it difficult to discuss risks that they had never experienced or did not feel they knew much about.

**Table 2.** Summarising the Thematic Analysis From the Qualitative Data Gathered Regarding the Online Risk Experiences of People With Intellectual Disabilities With Accompanying Illustrative Quotations.

Overarching themes, sub-themes and illustrative quotations.	
<b>1. Experiencing and taking risks online</b>	
1.1 Experience of online Contact risks	<p>"Well I meet him online, and it was weird for me, I thought he was all good looking, and a great body. But in person I felt he was nearly old enough to be my father. I felt very awkward, and the worst thing is he got me a present of a book." (P1, May, 27)</p> <p>"If you remember about that police officer who knocked down a 15 year old boy ... The family didn't know about it at first. They [online fraudsters] just set up a Facebook like a funding raising event which didn't even exist. ... they just set up fund raising sayings it's from the family of the person." (P3, Sameer, 43)</p> <p>"...the worst thing is trying to hack people's account." (P4, Tina, 36)</p> <p>I: "People talk people being bullied or threatened online. Has that ever happened to you?"</p> <p>P5: "Erm ... Once I was on Facebook I was called a parents kid but I just ignored it. You know but that was going to a kids, a school reunion [yeah] erm but then erm but then it was ignored ... but that was just on Facebook... I just ignored it you know." (P5, Scott, 32)</p> <p>I: "And has anyone ever made you angry or upset you on Facebook?"</p> <p>P6: [showing signs of discomfort] "Erm .... Sometimes (.) can't (.) might have been, I can't remember." (P6, Don, 22)</p> <p>I: "So did somebody try to scam you?"</p> <p>P9: "Tried to but it didn't work. I said no you're not from Virgin or whatever you're supposed to be." (P9, Shaun, 24)</p> <p>"They hacked my account, changed my password. ... and they put a picture of a big man, fat man on it and I had to go onto it and change all that...They just changed my profile picture .... Erm Facebook deleted it because they knew it was hacked...And then yeah they haven't been able to hack it since because I've been changing my password every month or every so often." (P9, Shaun, 24)</p>
1.2 Experience of online Content risks	<p>"But you do see people posting things on Facebook, and I get angry and I type 'Why the heck are you putting things like this', bloody annoying to watch I don't know why they do it, it's not even entertaining." (P8, Ruth, 27, regarding violent content)</p> <p>"Not my type ...I've never got into that... I've never talked to mum because as I've never done it." (P5, Scott, 32, when asked about pornography, extremist information and violent online content)</p> <p>"Er a lot of them are metal bands and well one of my favourites is er five finger death punch. ... Well it's a heavy metal band but it's a lot of foul language in it. So I have to have the head phones on yeah." (P13, Sam, 25)</p>
1.3 Experience of online Conduct risks	<p>"It was in a sexual nature, I thought the guy was a good looking guy. And it turns out that he didn't look the way I thought, it was weird and strange for me. There was more than one guy. One guy, said to me that he would ring the police on me because I was flirty and all that, and he was doing the same, and it turned out the whole time he was in relationship, and he did the online thing on the side ... it felt good at the start, when the flirting and all that, that was fun, and sexual talk, I think it got too much for him, and that's why he wanted to ring the police. For me it was innocent, then he came out and stop what you are saying and he was all like I am going to ring the police." (P1, May, 27)</p> <p>"No because I never have my cards on me." (P5, Scott, 32, when asked about engaging in using pay sites)</p> <p>"No, because that's not me, that's not the way I've been brought up." (P5, Scott, 32, when asked about bullying others online)</p> <p>"Nope, If someone asked me [to share naked pictures or pornography] I'd obviously tell them where to go... because I'm fairly straight forward with stuff like that if I feel uncomfortable with something I generally tell people where to go, unless I haven't picked up on it." (P8, Ruth, 27)</p> <p>"Nope, nope nope nope. No I'm not that sad. Urrr [laughing]." (P8, Ruth, 27, when asked about meeting someone from the Internet offline)</p>

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## 2. Awareness and support to manage risk

2.1 Awareness of online risks	<p>"Yeah because of fraud. So fraud, hacking and things stuff like that you see... Some people could start Facebook with your name on and stuff like that." (P3, Sameer, 43)</p> <p>I: "How would you spot the fake websites?"</p> <p>P3: "Different hand writings, and you have to be careful of what they put on." (P3, Sameer, 43)</p> <p>"It's something I do a little bit, and don't do as often as I used to, I used to go on Youtube converter and you can download free songs that way off Youtube, I buy my music now off Amazon, as and when I need it ... I used to go to the [supported social group for people with ID] in Dudley, I asked somebody there [support staff] and erm, they showed me ... because obviously I like my music and I wanted to listen to it so they just showed me how to do it and once they'd shown me once I was well away and kind of got on with it and got the music off that I wanted ... I didn't really [know it was illegal] to be fair... But at the same time, unless somebody tells you you don't know do you?" (P8, Ruth, 27, regarding illegal downloading)</p> <p>"I think they went through my things [social media account]. I don't know how they do it." (P9, Shaun, 24)</p> <p>"There's a lot of grooming on there [social media]. There's a lot you know people doing on there that are not very safe on there basically. So people go on there to look for like grooming to girls or whatever and they will put them in danger." (P9, Shaun, 24)</p> <p>"Erm you got to think about danger and stuff... people who you don't know...Don't talk to them." (P10, Jenny, 32)</p> <p>I: "So you've never really been bullied online?"</p> <p>P12: "No."</p> <p>I: "No. Erm what would you do if you were?"</p> <p>P12: "Report it ... There, there's erm an app, a site on Facebook where you can click to report this person ... and it come up the reason why you want to report this person. And it comes up with all these different answers why, and you choose the suitable one, and they deal it from there." (P12, Tony, 30)</p>
2.2 Support to manage online risks	<p>"...Erm think when I first started like sometimes my opinions, the way that I put them across sometimes or what I've said [resulted in online arguments and upset]. Erm sometimes think my mom had to warn me." (P6, Don, 22)</p> <p>"I got my account hacked, I had to go to a friend of mine to block it." (P7, Gerard, 50)</p> <p>"... with [support worker]. He does give me a lot of help [with job-hunting online]. ... But I'm really helped, because [advocacy group facilitator] does a lot for me." (P7, Gerard, 50)</p> <p>"I try to be careful about who I add [on Facebook], mainly people I already know from school, from college, but if there's somebody, someone I don't know, I'd generally ask ... I'd probably ask the staff some questions and obviously find out more info." (P8, Ruth, 27)</p> <p>"I'd say you'd probably need some [support] but some you'd try and deal with yourself. So I'd try and deal with it myself but as I said I've got [fiancé's name] support as well. If anything did happen he'd be right behind my back." (P8, Ruth, 27)</p> <p>"If you got mutual friends, you can ask your friend about your mutual friend and see who it is. That's what I do, [ask them] how do you know this person?" (P9, Shaun, 24)</p>
2.3 Wanting to develop knowledge to manage salient online risks	<p>"You want to know that you're safe and want people to learn you to find out more about keeping myself safe while online." (P8, Ruth, 27)</p> <p>"I do want to learn more technical things on the computer yes. So if I come across anything and need help to do it I know how to do it." (P8, Ruth, 27)</p> <p>I: "So have you done any kind of erm computer skills training?"</p> <p>P10: "No."</p> <p>I: "Would you like to?"</p> <p>P10: "Yes please. ...you know printing stuff out it's hard to print isn't it sometimes? It didn't work." (P10, Jenny, 32)</p> <p>"[Discussing support for online risk] ... unless you've had it happen to you it's hard to answer." (P9, Shaun, 24)</p>

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### 3. Developing independence and resilience through online participation

- 3.1 Avoiding and managing risks independently  
"I am aware off it [risks of speaking to strangers online] and I don't talk to people I don't know I only talk to friends sisters and boyfriend and cousins." (P2, Ulla, 28)  
"Erm somebody errr sent me a picture of their willy quite a while ago which I thought was rather strange, so I thought no sod off. No. Go away, I don't want to know, twat. [Laughing] but I'm hoping that never happens again because I basically told them where to go and I wasn't polite with it ... I blocked them ... I just tried to forget about it." (P8, Ruth, 27)  
"If I don't know people I don't friend them." (P9, Shaun, 24)  
"Someone threatening me ages ago and I just blocked them ... [they said] I'm going to come down and punch you and all this. I said that's nice of you, I don't know who you are. ... I ain't putting up with this so I'm blocking you. ... and then they couldn't get back in touch because they are blocked ain't they." (P9, Shaun, 24)  
"I've had these requests come through and if I don't know them I decline them straight away ... I know if I don't know their name then I'll access them through message first because you accept them you can send them messages ... put how do you know me or do you know me? If so where from? And see if they reply back." (P12, Tony, 30)
- 3.2 Building resilience and learning through online experiences  
"Just that I don't want to find myself in a situation that I can't get out off ... I mean like if someone like a guy, is saying stuff to me, that I don't think is nice ... and long time ago, I did online dating, it didn't turn out the way I actually wanted. I never did it again. And never will... it is important to me that to believe in my abilities and strengths, because that makes me the person that I am." (P1, May, 27)  
"So you have to just be careful of which ones [websites] you go one. That's why I would rather get a recommend from a friend than going straight to, if they know a place if I was to get something first than just go straight on it...That's the best thing to do." (P3, Sameer, 43)  
I: "Do you feel like you understand more things because you get to practice them on the Internet?"  
P7: "Yes because when I learning me and I just got the confidence. ... I never use, I never use the computer." (P7, Gerard, 50)  
"I said you have to put yourself in webcam to make sure it looks like you on that picture. So he did. ... And then give each other number to go to Anfield and he said you can have my number there. ... So if he said no I would have said you don't, you might not be a real person then... Because it shows he's a good person as well." (P9, Shaun, 24, regarding meeting fellow football support offline for first time)

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### 4. Online risk, restriction and digital exclusion

- 4.1 Online concerns and self imposed digital exclusion  
"I don't want to be on Facebook. It's not very safe. ... because people can get er like, like, I had a friend and he was on Facebook and he had threatened, threatened message ... and that's why I don't like about it. I don't want to be on Facebook.... No. I don't, I don't, I can't trust it. I don't like it." (P7, Gerard, 50)  
"Because that's what I mean there's a lot of people that are doing nasty things on it and there's no need to be nasty on there but that's what they do." (P9, Shaun, 24)  
I: "Is there anything else you want to ask or say about the internet?"  
P10: "Is it bad sometimes? ... I get a bit worried because it's got rude things in it, like sex on that ain't it?" (P10 Jenny, 32)  
"...but it's also a negative to me as well because it can, it has affected erm confidence before. So that's why when I said I stopped using it ... certain people were hassling me not on Facebook, in, well like work time ... so that's why I stopped using Facebook because if I didn't use it they couldn't hassle me to be on Facebook ... and it was probably, I say a year, probably about a year and half ago I went back on. Yeah, yeah, yeah I just suspended till time till I was happy with confidence to move back on and keep using it again." (P13, Sam, 25)

4.2 Digital restriction, gatekeeping and control by carers	<p>"The only thing my mum is worried about is for me staying online for long periods of the day and night, I am learning to control that now...She wants me to have a life, and live it, and to go to bed at a reasonable time. That is what she wants for me. ... I just need to control it better. It is like a addiction." (P1, May, 27)</p> <p>P1: "I don't say much about it to my mum, but sometimes she does ask me what do I do on it"</p> <p>I: "and what do you say to her?"</p> <p>P1: "Well I say that I am not doing inappropriate stuff"</p> <p>I: "what do you mean by inappropriate stuff?"</p> <p>P1: "it could be in a sexual thing, or offending, that is what I mean about inappropriate stuff" (P1, May, 27)</p> <p>I: "Would you like a computer or mobile phone?"</p> <p>P10: [Laughing] "I would if I'm allowed yeah."</p> <p>I: "So why do you think you're not allowed to have one?"</p> <p>P10: "Because I might waste too much money on it, credit on it. ... that's why, I don't have a mobile phone, because they don't let me have a mobile phone, because I waste it.... I was phoning on my friend on it. I wasted my credit didn't I. My dad stopped me using it." (P10, Jenny, 32)</p> <p>"So like, when I don't get on with work, my teacher's like 'Sabrina!', and I'm like 'what?', 'put your phone away'... So then when my teacher's not looking I get my phone out. And then my teachers ... started bringing out these phone boxes now. ... Yeah at college, so they're colored boxes yeah. And basically they put them on your desk, on each desk, and you can put your phone in and shut the lid, and at the front of the class until your lesson is finished. And then the teacher says you can have your phone back now. ... it's so annoying." (P11, Sabrina, 20)</p>
4.3 Digital exclusion can lead to societal exclusion and is a risk to wellbeing	<p>"I had an epileptic fit at one library [where he works as a volunteer] and I wouldn't cut it [hours] down but they cut it down to 1 hour I stopped working at [library name] and transferred me down to [library name] where I still do my computer training. I love it." (P5, Scott, 32)</p> <p>"I'm worried about the budget (.) the cuts (..) I'm worried about my disability, it just went on top of me (...) and my support's been cut. The people at the job centre treated me like scum. I had to apply for jobs online and I'd never used a computer at the time. It's very hard because I've got learning difficulties, why should be people suffer because they've got learning disabilities. [Name of support worker] is teaching me now but I've had a lot of viruses and Trojan horses on it (home computer)." (P7, Gerard, 50)</p>

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*Note.* I – Interviewing researcher. P – participant.

**Table 3.** *Reported Risks Experienced by Participants.*

No.	Pseudonym	Having account hacked	Being bullied online	Chatting with strangers	Downloading a virus	Seeing / sent pornography	Seeing violence online	Accessing illegal information online	Signing up for pay sites	Meeting strangers met online offline	Sharing naked pictures of self	Bullying / being antisocial online	Illegal Downloading	Spending too much time on social media	Spending less time on work / learning	Spend less time with friends / family
1	May	✓	✗	✓	✓	✗	✗	✗	✓	✓	✗	✗	✗	✓	✗	✗
2	Ulla	✓	✗	✗	✗	✗	✗	✗	✗	✗	✗	✗	✗	✓	✗	✗
3	Sameer	✗	✗	✗	✗	✗	✗	✗	✗	✗	✗	✗	✓	✗	✗	✗
4	Tina	✗	✗	✗	✗	✗	✗	✗	✗	✗	✗	✗	✗	✗	✗	✓
5	Scott	✗	✓	✓	✗	✗	✗	✗	✗	✓	✗	✗	✗	✗	✗	✗
6	Don	✓	✗	✗	✗	✗	✗	✗	✗	✗	✗	✗	✓	✓	✓	✗
7	Gerard	✓	✗	✗	✓	✓	✗	✗	✗	✗	✗	✗	✓	✗	✗	✗
8	Ruth	✓	✗	✗	✗	✓	✗	✗	✗	✗	✗	✗	✓	✗	✗	✗
9	Shaun	✓	✓	✓	✓	✗	✓	✗	✓	✓	✗	✗	✓	✓	✗	✗
10	Jenny	✗	✗	✗	✗	✗	✗	✗	✗	✗	✗	✗	✗	✗	✗	✗
11	Sabrina	✗	✗	✗	✓	✗	✗	✗	✓	✗	✗	✗	✗	✓	✓	✓
12	Tony	✗	✗	✗	✗	✗	✗	✗	✗	✗	✗	✗	✗	✗	✗	✗
13	Sam	✗	✓	✗	✓	✗	✗	✗	✗	✗	✗	✗	✓	✗	✗	✗
Total N / %		6 / 46.2	2 / 15.4	3 / 23.1	5 / 38.5	2 / 15.4	1 / 7.7	0 / 0.0	3 / 23.1	3 / 23.1	0 / 0.0	0 / 0.0	6 / 46.2	5 / 38.5	3 / 23.1	2 / 15.4

It was also evident from the discussion of these future developmental support needs, that some participants found identifying their own support needs around risk challenging. When this appeared to be the case, the interviewer used the specific risks listed in Appendix 1 to help orient the interviewee to identify their own specific support needs. For some participants this was effective, however, for others this did not help elicit identification about their support needs. When this was observed by the interviewer, experiences from their own lived experiences, reported earlier in the interview, were used as prompts. This process better facilitated support need identification for these participants. Hence, salience of online risk was an important factor in both awareness of risk and the support needs of participants.

### **Theme 3: Developing Independence and Resilience Through Online Participation**

Learning to be more independent and autonomous around risk management and developing via meaningful online experience was evident in the accounts.

For those participants who engaged more regularly with social media and the online world, accounts included stories of *avoiding risk or experiencing and then going on to manage risk independently* without support. Strategies employed included deleting people from social networking accounts, changing passwords regularly, checking authenticity through contact, blocking people from making online contact, reporting people to website and ignoring negative content and contact.

"Someone threatening me ages ago and I just blocked them ... [they said] I'm going to come down and punch you and all this. I said that's nice of you, I don't know who you are. ... I ain't putting up with this so I'm blocking you. ... and then they couldn't get back in touch because they are blocked ain't they."  
(P9, Shaun, 24)

Participants did not talk much about how the risks had affected them emotionally, or about negative impacts of online risks. Instead, they described risk experiences, and actions taken following them, with learning from these experiences and discussions with others evident. Interviews also contained stories of how people had learned new skills through both on- and off-line interactions about online risks and also by experiencing the risk first hand and learning how to manage these in future. Thus, some participants *built resilience and learning through their experiences*.

"Just that I don't want to find myself in a situation that I can't get out off ... I mean like if someone like a guy, is saying stuff to me, that I don't think is nice ... and long time ago, I did online dating, it didn't turn out the way I actually wanted. I never did it again. And never will... it is important to me that to believe in my abilities and strengths, because that makes me the person that I am." (P1, May, 27)

### **Theme 4: Online Risk, Restriction and Digital Exclusion**

A final overarching theme (comprising 3 subthemes) related to experiences of online digital exclusion and how this could serve as a risk to participation, inclusion and wellbeing.

*Self imposed digital exclusion* occurred for one participant who did not use social media, though he used his computer regularly. He opted out of social media due to worry and fears around possible risks. Other participants also described similar *online concerns*, namely having personal, social and financial information and accounts hacked or stolen, computer safety from viruses, and privacy, which led, in some accounts, to reluctance to engage with activities online.

"I don't want to be on Facebook. It's not very safe. ... because people can get er like, like, I had a friend and he was on Facebook and he had threatened, threatened message ... and that's why I don't like about it. I don't want to be on Facebook.... No. I don't, I don't, I can't trust it. I don't like it." (P7, Gerard, 50)

Though few participants signed up for pay sites, finances did play a role in access and online restriction. Prior experiences that had led to large mobile phone bills subsequently led to *gatekeeping and restrictions by family*

*carers*, whereby previous freedoms were removed to protect against further financial cost. These were also instrumental in the lack of computer, Internet and social media use by Jenny.

I: "Would you like a computer or mobile phone?"

P10: "[Laughing] I would if I'm allowed yeah."

I: "So why do you think you're not allowed to have one?"

P10: "Because I might waste too much money on it, credit on it. ... that's why, I don't have a mobile phone, because they don't let me have a mobile phone, because I waste it.... I was phoning on my friend on it. I wasted my credit didn't I. My dad stopped me using it." (P10, Jenny, 32)

Underpinning this restriction appeared to be looking after the best interests of participants, but strategies for development of financial and digital management skills were not evident. *Carers also exerted control and restriction* following risk experiences, for example, Sabrina had threats of restriction and her phone taken away so she would engage with her college work and May had, unbeknownst to her parents, met male strangers offline who she had originally met online. In these cases accounts suggested carers trusted the person supported but still exerted control over ICT use.

*Digital exclusion leading to societal exclusion* was also a risk to wellbeing. For example, Scott reported ICT work and societal support related challenges. His employing organization's inability to support him with an ongoing health issue led to an undesired contraction of his work role and working hours which negatively affected him by removing a valued social role within his life that gave him both occupation and purpose. For another participant, despite being motivated to find work, the lack of ICT skills and support had led to him almost being sanctioned and losing his disability benefits because he did not have the necessary skills and was inadequately supported to apply for work online with no training offered.

"I'm worried about the budget (.) the cuts (..) I'm worried about my disability, it just went on top of me (...) and my support's been cut. The people at the job centre treated me like scum. I had to apply for jobs online and I'd never used a computer at the time. It's very hard because I've got learning difficulties, why should be people suffer because they've got learning disabilities. [Name of Support worker] is teaching me now but I've had a lot of viruses and Trojan horses on it (Home computer)." (P7, Gerard, 50)

## Discussion

This study aimed to explore the phenomenological lived experiences of risk by people with intellectual disabilities, findings which were primarily inductively derived from the data and as such themes did not simply and conveniently map onto the original research questions. So as to honour the accounts of the participants the discussion will summarise findings that arose from the accounts which were not specifically expected based on the originally derived research questions and will also address the research questions. Contextualisation of findings, potential study limitations and future study suggestions are incorporated at appropriate junctures.

### Summary of Key Study Findings

A lot of emphasis has been placed upon the increased vulnerability to risk of people with intellectual disabilities. This study does not support the notion of the Internet as a perceived place of danger for people with intellectual disabilities. Vulnerability, though apparent, did not strongly emerge as a theme in participant accounts. Instead, findings support the idea that people with an intellectual disability are motivated to be online and have awareness of online risk but that people's digital skills need to be supported to develop further. This aligns with findings from the recent work of Alfredsson Ågren et al. (2020b) when investigating younger people with intellectual disabilities technology use and other prior research work (cf. Caton & Chapman, 2016). Participants described protecting themselves and avoiding online dangers, but also had confusions and concerns and wanted to learn and develop new understandings and skills to enable them to independently keep themselves safe online.



## **Experiences of Online Risk by People With Intellectual Disabilities**

Addressing research question 1, accounts indicated that contact risks were more commonly experienced than conduct risks which, in turn, were more commonly experienced than content risks.

### ***Experience of Contact Risks***

As found previously, people encountered risks when attempting to achieve connectedness and intimate personal relationships online (Normand & Sallafranque-St-Louis, 2016, 2016; Plichta, 2011). The propensity to engage with unknown others towards a romantic relationship online may be underpinned by a number of intrinsic and extrinsic factors in need of further exploration.

With regard to support, these could include the potential restriction on and discouragement from engaging in intimate and romantic relationships by family carers. If this is the case, then it may be that the person with intellectual disabilities may desire these relationships more and may be less cautious when entering into interactions with strangers who they view as potential romantic partners.

### ***Experience of Conduct and Content Risks***

Online antisocial behavior (e.g., online bullying), perpetration of online crime (Conduct risks), accessing illegal, violent or obscene material (Content risks) were more seldom reported. This may be because participants may not have felt comfortable disclosing taboo and less socially desirable information about themselves. Some participants demonstrated some discomfort when discussing these risks mirroring the finding from prior research that conduct risks may be less likely to be discussed or disclosed by people with intellectual disabilities (Chiner et al., 2017b). This presents a potential study limitation as it is possible that lack of existing rapport and/or discomfort with the interviewer and topic may have impeded disclosure of cybercrime and risk. Further work is needed to explore problematic online behavior in people with intellectual disabilities as little currently exists. Such work would be improved by introducing measures to develop trust and relationships with the participants with intellectual disabilities prior to broaching of such sensitive topic areas.

## **The Effects of Online Risk on People With Intellectual Disabilities**

Participants experienced a range of risk with less apparent negative impact than might be predicted based on prior research. Concerning research question 2, increased or heightened negative traumatic impact of online risk was not evident in the accounts, refuting an increased vulnerability hypothesis, with the possibility that impact may be lessened due to reduced awareness for people with intellectual disabilities or that the ability to express distress may be reduced (Berger et al., 2015). Additionally, participants may have been reluctant to revisit the traumatic feelings associated with online risk experiences, may have forgotten them as a form of coping and may not have wished to disclose them to the researcher. Emotional impact of risk experience was not prominent in the accounts, with practical support more readily discussed. Nevertheless, emotional responses to contact risk involved language connoting discomfort (i.e., weird, strange, uncomfortable, awkward) and in relation to online content and conduct discomfort, disgust and fear (i.e., strange, angry, worried, concerned) were evident. Future research into the psychological, emotional and lifestyle impacts and repercussions of online risks along with coping strategies used by people with intellectual disabilities is indicated.

## **Independence and Support in Managing Online Risks**

For research question 3, support, though accessed, was less evident in accounts than narratives recounting independent self-management.

### ***Self-Management Through Experience for Online Risk***

Accounts corroborate, for adults with intellectual disabilities, prior study findings from younger people of having awareness, self-management of risk and accessing support when needed (Bannon et al., 2015; Chiner et al., 2017b; Löfgren-Mårtenson, 2008). This highlights parallels that exist between the findings around online risk between

adults and younger people with intellectual disabilities. However, for the adults here, there appeared more focus on being able to access support when required and developing knowledge and awareness towards independent self-management of risk.

It was evident that people could manage risk (Bannon et al., 2015) and did build coping strategies and resilience from experiencing online risks with positive risk taking being evident in some accounts (Starke, 2013). This supports assertions made by Seale and Chadwick (2017) that some people with intellectual disabilities will be able to manage online risks themselves and that a better balance between autonomy versus safeguards should be enacted with individuals with intellectual disabilities who use the Internet and social media. Future work is needed to unpack the complexities of intersecting safeguarding, self-determination, positive risk taking and online participation agendas.

Learning through online experiences was a key aspect of participants' online lives and learning. Vygotsky's (1978) activity theory of social cognitive development appears a useful underpinning to this, with carer and peer interaction also serving as supportive facilitators of development in some instances (Cromby et al., 1996; Vygotsky, 1978). Participants all had some awareness of online risks but there were still areas of self-confessed difficulty where people need more support with evidence of areas where particular risks were not well understood (Buijs et al., 2016).

### ***Social Capital as a Source of Online Risk Support***

Accounts support the idea of social capital being a support for resilience in people with intellectual disabilities (Condor et al., 2015; Hamilton & Atkinson, 2009; Starke, 2013). It also provides evidence that rather than restricting people's exposure to risk, support which adopts a positive risk-taking approach, where risk is accepted as an integral part of life from which people develop skills to manage future risk, is more fruitful for participant growth, independence and well-being (Alaszewski & Alaszewski, 2002; Duerager & Livingstone, 2012; Perske, 1972; Seale, 2014).

The ways in which carer attitudes, living circumstances and restrictiveness of support around relationships and ICT use interact with engagement with, and management of, risk in people with ID is clearly in need of further study. Literature has already implicated impulsivity as a contributory factor in engagement in online risk for people with William's syndrome (Lough & Fisher, 2016a, 2016b) but this work needs extension to other groups and to incorporate support related factors more fully as these may be aspects of people's lives more amenable to positive adaptation and change.

### **Support Needs of People With Intellectual Disabilities to Manage Online Risks**

Addressing research question 4, people's ability to articulate what their support needs were around online risk appeared better executed within their everyday lives than based on labels of risks that were not part of their lived experience. Hence, to enable people with intellectual disabilities to identify their own support and developmental learning needs regarding online risk salience is a key consideration. Salience has been linked to trust in social networking sites in previous literature focusing on the risk of disclosure of personal information in social media (Lo, 2010). In contrast, salience of risk appears to be relevant to risk awareness, risk recognition and understanding of developmental support needs among people with an intellectual disability.

This finding also highlights the need to be person-centred when thinking about how to best inform and work with people with intellectual disabilities toward improving their digital literacy around the existence and management of potential online risks. Educational training programs that incorporate principles of respect, self-help, trust and rapport-building and experiential learning, tied to salient lived experience and using language familiar to the person with intellectual disabilities, are recommended based on the findings here.

### **The Risks of Digital Exclusion and Restriction**

Privacy online was a concern for some participants. Viseu et al. (2004) in their qualitative study of individuals considered to be "on the wrong side of the digital divide" in Canada revealed that interviewees felt a high degree of concern for user privacy, though an equally pronounced sense of resignation to the inevitability of diminished digital privacy. Qualitative research by Chalhouni et al. (2019) also highlights privacy breaches as a risk for people

with intellectual and developmental disabilities. These findings resonate with the lived experiences of the participants here where concerns regarding privacy was one factor underpinning self-imposed digital exclusion.

Carer awareness of risks experienced by their family members with intellectual disabilities could prompt digital restrictions, similar to findings from research investigating younger people with intellectual disabilities (Löfgren-Mårtenson et al., 2015) again demonstrating parallels in experience between both adults and young people. A further factor in digital restrictions imposed by carers was financial problems, also recorded as a concern in prior literature (Chadwick et al., 2016). Use was a negotiated process in these instances between people with intellectual disabilities and their carers with the balance of power often appearing to be held by the carers. Given the age of participants it would appear that people may be being held to different standards, compared with their contemporaries without intellectual disabilities, with prolonged infantilization (cf. Seale & Chadwick, 2017). Such restrictions may be viewed as impediments to development, confidence and freedom online for people with intellectual disabilities. How such restriction is managed and negotiated when there are potential risks online requires further study, along with consideration of how such negotiation interacts with self-determination, human rights and providing person-centered support to adults with an intellectual disability. Further study of differences in digital restriction between adults and young people with and without intellectual disabilities would further illuminate whether discrepancies in self-determination do exist.

Though fear of risks was evident as a contributory factor in self-imposed and carer mediated digital inclusion, it is important not to overlook the risks to wellbeing of being digitally excluded for those with more mild cognitive impairments for whom societal expectations may be rising. This appears particularly important given the current state of the world during the COVID-19 pandemic where many services, supports, social networks and leisure and work activities have moved online (WHO, 2020; Zaagsma et al., 2020).

## **Study Limitations and Future Directions**

A limitation of the present study is that the topic guide focused on the three Cs (Content, Contact and Conduct), which omits the more recently added fourth C of Contract (Livingstone & Stoilova, 2021). This additional set of risks refers to the individual being an online consumer and being party to or exploited by potentially harmful online contracts. Nonetheless, security risk did feature in both the reasons for digital restriction and exclusion in the empirical accounts within this study (see above for further discussion). Hence, although not explicitly requested in the topic guide, these risks arose as important to digital exclusion through the accounts of the participants. Future research should specifically and more explicitly explore these Contract risk experiences among people with intellectual disabilities.

A further limitation of this study is that it focuses purely on those with mild cognitive impairment, who often acted as self-advocates, potentially increasing self-presentations of being able to independently manage online risk. The levels of self-determination, agency and resilience displayed by the adults in this study may not hold for those people with greater support needs living in more congregate settings. Research is needed exploring the experience of risk amongst those people who may have greater levels of vulnerability to explore their experiences, meaning and support needs around digital risk and online criminal victimisation and perpetration.

Thematic saturation was approached in the data collection and generalisation was not a core goal of the paper, which instead focusses on the interpreting the meanings people with intellectual disabilities give to their risk experiences. Nonetheless, it is unlikely that full coverage of all online risks was provided in this paper, especially for those with low base rates of occurrence or that are seldom successful (e.g., phishing emails). Future research should begin to focus more on the experiences and effects of specific types of cybercrime and online risk on people with intellectual and developmental disabilities.

## **Conclusions**

The adults with intellectual and developmental disabilities with low support needs in this study appeared more able to manage online risk than may be presupposed by a vulnerability-focused perspective. However their ability to communicate their need for support around these risks appeared less well established. The importance of utilising language specific to the person when discussing and supporting people regarding online risk is recommended. Enabling people with intellectual disabilities and their carers to better understand and manage online risk appears a way forward for research and practice.

## Conflict of Interest

The author has no conflicts of interest to declare.

## Author's Contribution

This study was devised and conducted by Dr. Darren Chadwick.

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# Appendix

## Topic Guide

1. Experience of being online and using social networking sites
2. How they access the online world and support to get online
3. Activities they engage in online
4. Enjoyment and challenges they had experienced of being online
5. Online risk experiences and awareness (probes below)
6. Summing up and debrief

## Specific Questions Pertaining to Risk Experiences

Have you...

1. had your had passwords stolen or your accounts used by someone else?
2. been bullied or threatened on the Internet?
3. chatted with people who you don't know on the Internet?
4. got a virus on your computer?
5. seen (or been sent) nude pictures or sex on the Internet?
6. seen violent things on the Internet?
7. seen illegal things on the Internet? (e.g., how to get drugs, or extremist information)
8. signed up for websites that cost a lot of money? (e.g., dieting sites, online games, gambling sites etc.)
9. met up with someone offline (for a drink or a date) who you have made friends with on the Internet?
10. shared any naked pictures of yourself (or other pictures of naked people) with other people?
11. written things about other people online that they wouldn't like?
12. downloaded films and music without paying for them?
13. spent too much time on social networking sites?
14. spent less time on work and learning new things because you were on the Internet?
15. spent less time with friends and family offline because you are on the Internet?



## About Author

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