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## ORIGINAL ARTICLE

# Interactional power and support in digital inclusion of an adult with intellectual disabilities: a case study analysis

Darren D. Chadwick<sup>1</sup>  | Susan Buell<sup>2</sup> <sup>1</sup>Liverpool John Moores University,  
Liverpool, UK<sup>2</sup>University of Dundee, Dundee, Scotland,  
UK**Correspondence**Darren D. Chadwick,  
School of Psychology,  
Liverpool John Moores University,  
Tom Reilly Building,  
Byrom Street,  
Liverpool L3 3AF,  
UK.Email: [d.d.chadwick@ljmu.ac.uk](mailto:d.d.chadwick@ljmu.ac.uk)**Abstract**

Digital inclusion of people with intellectual disabilities is not commensurate with those without disabilities. Societal, political, financial, individual and interpersonal barriers help explain this disparity. Caregivers can act as both support and gatekeeper to internet access and use by adults with intellectual disabilities. This study investigated micro-level interpersonal factors influencing access and use of the internet by an adult with intellectual disabilities to explore the balance and interplay of power and support around the processes of digital inclusion and online risk taking. Taking a case study approach, perspectives of three key stakeholders were gathered via interviews: the person with intellectual disabilities, his mother and a paid support worker. Perspectives and experiences were contrasted using systemic functional linguistic analysis of discourse to explore the ways power and support were represented in the language of negotiated digital inclusion. Dynamics between the parent and person with intellectual disabilities and between the parent and paid staff clearly influenced processes of digital inclusion and were affected by varying priorities, positions and perceptions of power to allow, disallow and monitor access and use of the internet. These had the power to shape and drive internet access. Language choices by the person with intellectual disabilities showed that he was not fully aware of the risks involved in engaging with certain aspects of digital inclusion but how he spoke about the internet indicated some autonomy in technology use. Supporting the development of digital competence, confidence and resilience in people with learning disabilities should be combined with support to increase self-awareness regarding digital risk. Those supporting people with intellectual disabilities towards digital inclusion need additional guidance on how to do this effectively for the people they support.

**KEY WORDS**

intellectual disabilities, digital inclusion, power, support, online risk, self-determination, information &amp; communication technology

**Key Points**

- People with intellectual disabilities sometimes have less awareness of the risks they take online and less understanding of how to manage them.
- Family carers close to them often worry about this risk-taking and try to protect their family members from being harmed online.
- Support workers also feel concerned about risk taking and see the management of this as part of their job.

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- People with intellectual disabilities, their family carers and support workers may benefit from training and co-construction activities to learn how to manage digital risk better.

## INTRODUCTION

Developments in information and communication technologies (ICT), with the internet at the forefront, are changing the knowledge, service, employment and social interactional opportunities available to people with intellectual disabilities (Chadwick, Chapman & Caton, 2019). This change has been accelerated and exacerbated by social distancing requirements under COVID-19 (Caton et al., 2022; World Health Organization, 2020). Staying safe for many people with intellectual disabilities during the pandemic has led to a complex mixture of a loss of access to regular pre-COVID-19 services, and a reduction in supported opportunities for work, social contact and entertainment. This has necessitated greater digital inclusion to maintain well-being (Caton et al., 2022; Chadwick et al., 2022).

### Digital participation of people with intellectual disabilities

Prior to the COVID-19 pandemic in the UK, 22% of people with disabilities had never been online (ONS, 2019). Research has also shown that digital inclusion is consistently lower for people with intellectual disabilities (Alfredsson Ågren, Kjellberg & Hemmingsson, 2020a; Johansson, Gulliksen & Gustavsson, 2021). There is evidence highlighting the existence of a disability digital divide and additional pronounced digital poverty among people with intellectual disabilities (Johansson et al., 2021). Recent literature regarding the digital divide in relation to people with intellectual disabilities has moved from initial consideration of basic access to ICT and the internet, through to use of ICT and subsequently on to the study of full digital participation for people with intellectual disabilities (Alfredsson Ågren, Kjellberg & Hemmingsson, 2020b; Chadwick & Fullwood, 2018). This has aligned with increasing digital access, use and participation by people, in particular younger people with intellectual disabilities (Alfredsson Ågren et al., 2020b; Chiner, Gómez-Puerta & Cardona-Moltó, 2017; Feng et al., 2008).

Use of technology may have increased during COVID-19 (Caton et al., 2022), though there is international evidence that people with intellectual disabilities remain more excluded (Chadwick et al., 2022). Recent research has identified other groups with intellectual disabilities who are more at risk of digital exclusion; this

includes older people and those who live in housing supported by paid staff (Anrijs et al., 2022).

### Benefits of being online

Many online benefits have been identified in relation to people with intellectual disabilities, including those related to education and learning, communication, social interaction and connectedness, identity expression and development, participation, advocacy, civic engagement and empowerment, and agency and self-esteem (Alfredsson Ågren et al., 2020b; Caton & Chapman, 2016; Chadwick et al., 2019; Chadwick, Quinn & Fullwood, 2017; Glencross et al., 2021; Hoppestad, 2013; Löfgren-Mårtenson, 2008; Stendal, 2012). There is also evidence that use of technology has enhanced digital skills and online self-determination and increased motivation to be online (Caton & Chapman, 2016; Chadwick & Fullwood, 2018; Löfgren-Mårtenson, Sorbring, & Molin, 2015; Näslund & Gardelli, 2013).

### Online risk experience

There are also numerous risks to being online. Large increases in online crime have been seen over the past few years and these have escalated during COVID-19 (ONS, 2022). Exposure to harmful content (e.g., advertising, scams, violent or hateful material, harmful sexual, extremist or racist material) (Chadwick, 2019; Chiner et al., 2017) affect all users including people with intellectual disabilities who are often less aware of the risks. Negative contact online (e.g., having personal information stolen, being bullied or groomed, unwelcome persuasion/coercion) have all been reported by people with intellectual disabilities as a direct or indirect result of engaging with strangers online (Bannon et al., 2015; Buijs et al., 2016; Chiner et al., 2017; Holmes & O'Loughlin, 2014; Molin, Sorbring, & Löfgren-Mårtenson, 2017). People with intellectual disabilities are also at risk of becoming engaged in antisocial conduct (e.g., illegal downloading, bullying, uploading sexually inappropriate pictures or text) (Chadwick, 2019) due to being less aware of the illegalities of what they are doing and more open to exploitation. Levels of online crime and victimisation are still largely unknown for this population and many incidents go unreported or un-noticed (Chadwick, 2019). Unfortunately, these risks

of being online can reduce digital participation (Bannon et al., 2015; Chadwick, 2022; Molin et al., 2017).

## Vulnerability to risk

Although online risks raise concerns societally, people with intellectual disabilities are viewed as particularly at risk (Chadwick et al., 2017; Chiner et al., 2017; Löfgren-Mårtenson et al., 2015). Research has revealed a tension between benefits gained from the freedom to engage in online experiences for people with intellectual disabilities and family carer concerns regarding their family members online safety (Caton & Landman, 2022; Lough & Fisher, 2016). Recent research, however, has also indicated that an increased perception of vulnerability may not always be held by family carers (Alfredsson Ågren, Kjellberg & Hemmingsson, 2020c).

Accounts of risk experiences have linked risk with: (1) limited social networks and desire for acceptance; (2) greater loneliness and depression and lower self-esteem and (3) poorer insight and judgement (Bannon et al., 2015; Buijs et al., 2016; Molin et al., 2017). Nevertheless, there is evidence of some risk awareness in young people with intellectual disabilities (Bannon et al., 2015; Molin et al., 2017; Normand & Sallafranque-St-Louis, 2016) and that people with lower support needs are able, through experience and support, to build digital resilience and manage online risk in their lives (Chadwick, 2022).

## Support for digital inclusion of people with intellectual disabilities

Strategies used to support digital inclusion and manage online risk have also been developed although the success of these has not been adequately demonstrated (Chadwick, 2019). These have included: educational support strategies in the form of a therapeutic support group, levels of monitoring being put into place (e.g., chaperones or supervision), and gatekeeping (evidenced through family carer reports) (Bannon et al., 2015; Löfgren-Mårtenson et al., 2015; Molin et al., 2017; Seale & Chadwick, 2017).

Recent research has revealed that the knowledge, interest and values that support staff placed on interactions facilitated by technology influenced the use of digital technology (Clifford-Simplican et al., 2017). Support staff also had diverse views regarding how responsible they were for facilitating digital participation (Balasuriya, Sitbon & Brereton, 2022). These authors recommended that co-design be implemented in digital inclusion initiatives with support workers occupying the roles of co-user and where appropriate acting as proxy for the person with intellectual disabilities.

## Power in support relationships

People with intellectual disabilities are often reliant on support staff or family carers to facilitate all aspects of life, including ICT use. Hence their ability to enact independent decision making is often mediated by carers. Self-determination models can contribute to understanding of how online risk decision-making occurs and how it is mediated by support. Risk taking is a component of functional self-determination (Wehmeyer, 1999; Wehmeyer & Garner, 2003). The self-determined learning model (Mithaug, 1998) identifies equity of opportunity as central to engagement in self-determined pursuits, which may include risky behaviours. The tripartite ecological model of self-determination (Abrey & Stancliffe, 2003) considers the control people have over life areas they consider important. Usefully, in this latter model concordance of control exercised and control desired is addressed, with collaborative control in decision-making operating for those who require support. The current study focuses on this interactional decision-making and how power is shared.

In terms of power-sharing versus power through protection, a clear safeguarding agenda has been reported as used by those providing support, involving gatekeeping and monitoring of digital access (Seale & Chadwick, 2017). Carers saw greater risk in digital technology use by people with intellectual disabilities than they saw for themselves (Chiner et al., 2017). Within positive risk taking, potential harm, failure or disappointment of using technology were viewed by carers as less important than growth, self-determination and well-being (Seale & Chadwick, 2017). Increased coping and resilience may arise via opportunities for digital experience and risk taking through possibility thinking which is generated from a position of power-sharing (Seale, 2014). Recent work by Seale (2023) has found that when carers were 'possibility focussed' (i.e. creative, resilient, sharing decision-making and managing risk) digital inclusion was facilitated.

## Rationale/the present study

Carer gatekeeping and control have been highlighted as protective but also transgressive of the human rights of people with intellectual disabilities to self-determine and make their own decisions. This appears particularly true for risky online decision making.

Taking a nested ecological approach (Chadwick et al., 2019) lower considerations of digital risk seem present at the macro level. There appears to be a lack of governmental policy and support in the UK to enable reduction of risks. Furthermore, technology design does not consider the accessibility of risk reduction measures for people with intellectual disabilities. At the

micro level, support for people with intellectual disabilities from paid carers, employers and family carers appears to be variable, with a wish to balance safety and risk within people's lives. This can lead to people with intellectual disabilities being held to a different standard (Seale & Chadwick, 2017) whereby their human right to self-determine their actions is more readily violated by carers who may expect more evidence of competence in managing risk than they would from people without intellectual disabilities.

Little research has considered power dynamics regarding digital risk in the lives of people with intellectual disabilities at this micro level where balancing risk and safety sits in the domain of those in closest contact with those people who are using ICT, usually family carers and paid support workers. Often they are striving for a balance between power-sharing and power-through-protection. The playing out of these power differentials can be expressed through verbal communication. Interview data on the topic of digital risks from three different stakeholder perspectives is likely to provide useful insights to elucidate the phenomena of support relating to potential online risk.

A case study perspective considering the voice of one person with intellectual disabilities in relation to digital risk alongside the voices of his mother and key support worker was conducted. Taking this approach is both novel and provides a detailed in-depth micro-level insight into the differing interpretations of digital risk in the lives of a person with intellectual disabilities and allows us to contrast and triangulate these perspectives. Fine grained discourse analysis allowed the nuances of language choices to be investigated to reveal these distinct digital inclusion and risk perspectives.

## Aims and research questions

The aim of this study was to investigate the perspectives of a person with intellectual disabilities on their own digital inclusion and to compare this with both family carer and staff carer perspectives and to answer the following research questions:

1. To what extent did the choice of language used by each of the three participants represent distinct meanings and power positionings in terms of digital risks and digital participation:
  - a. Through analysis of how people and places were represented
  - b. Through analysis of voice and positioning of one participant in relation to the others
  - c. Through the textual coherence and cohesion of the interviews
2. How did these distinct positionings differ and integrate perceptions of digital risk across the three participant

narratives such that increased understanding of how to manage digital risk might be reached.

## METHOD

### Approach

Discourse analysis incorporates a range of different approaches to analysing spoken and written language in both oral and text formats. Methods range from critical discourse analysis (Van Dijk, 2005) and conversation analysis (Silverman, 2000) to other forms of linguistic-based discourse analysis. Systemic functional linguistics (Halliday & Matthiessen, 2013) is one such approach and has been applied to the data in this study. Previous research using this method has shown how expressive word choices affect the impact of health messages (Segal, 2008) and also shape social identities for people as either actively contributing to their care or as acted upon by experts (e.g., Vanstone & Kinsella, 2010). Grue (2011) argues that linguistic discourse analysis can be similarly applied to investigate issues of representation and social positioning in disability-related discourse although this has so far happened very rarely. Systemic functional linguistics (Halliday & Matthiessen, 2013) is typically applied to textual data. The approach looks at the underlying meaning of language through three interdependent functions that are related to semantic choices. It has previously been applied to interview text data and can show how a certain "culture unfolds in its social context" (Fernandez, 2018:4). This works by highlighting how patterns of word choices made in specific contexts give rise to particular meanings, which, in turn, may underlie specific perspectives and ideology and/or enact particular power relations within an interview transcript.

### Participants

Participants in the case study were a person with intellectual disabilities and autism (Pseudonym = 'Steve'), his mother ('Mum') and his key support-worker ('Support worker'). These were recruited using purposive sampling via existing networks. Network contacts were asked to identify a person with intellectual disabilities who was a user of ICT and lived independently and had, what they considered, a supportive and enabling carer team around him including both paid staff and a support worker.

Steve was male, White British and 32 years old. He lived in a 24-hour supported living residence in the West Midlands of England UK with a team of support staff and a keyworker there who worked closely with him. Steve self-identified as having a mild intellectual disability, autism, a visual impairment, left hemiplegia

and epilepsy. He used technology daily on his personal laptop and mobile phone and had over 200 friends on Facebook. Interview duration was 74:36 minutes. The three interviews revealed that he had experienced online contact (hacking, bullying, negative interaction and exclusion) and content (accessing explicit sexual material and pornography) risks in the past.

His mum was 64 years old, divorced and had a close relationship with Steve and was in daily to weekly contact with him. She was very involved in his life and volunteered and ran a community centre for people with autism in the local areas, which Steve attended. She had been very involved in the development of Steve's technology-related skills and had engaged in a number of discussions with him about the risks of the internet. She had herself done some computer courses and so considered herself fairly 'tech savvy'. Interview duration was 85:40 minutes.

Steve's keyworker had been working in supported living for 7 years and had been a senior member of support staff for 6 years within the residence where he worked. Prior to this he had worked in the voluntary sector. He supported five tenants with a range of care needs, with severe to mild levels of disabilities. Areas of support he identified for the tenants, including Steve, were emotional support, daily living skills, supporting people through all aspects of their lives and to find employment. He worked typically 5 days per week with a range of 4–7 days, with sleep in nights. He did not use social networking sites but did use ICT (computer and mobile phone) to access news, sport and for other aspects of his life. He would also use technology to keep up to date on the interests of the people he worked with (e.g., for Steve wrestling and bowling), though he did not always have an interest himself in these things. He did this to facilitate social interaction and to enable him to provide better person-centred support. Interview duration was 63:38 minutes.

## Procedure

Ethical approval for the project was gained from the University ethical committee. Interviews were conducted with the three participations regarding the digital inclusion, technology use and online risks experienced by Steve. Study materials (information sheet and consent form) were sent to participants via email by a gatekeeper 2 weeks prior to the interviews. Participants replied to emails and were contacted via phone to discuss the project, to answer any questions and to arrange a time and place suitable for participants to conduct the interviews. All interviews were conducted face-to-face prior to COVID-19. The first author went through the information sheet and consent form again with each participant at the start of the interviews. For Steve, understanding

of the project was checked at the beginning and end of the interviews.

During interviews the interviewer followed a pre-prepared topic guide while also being responsive to the direction the interviewee wished to take the interview. When the interview deviated far from the core topic, the interviewer respectfully allowed that part of the conversation to conclude and then reoriented the interview back to the topic under study, though this did not often occur. Due to the sensitive nature of the topic a process of continuous assent was implemented whereby the researcher remained vigilant throughout the interview to any signs of discomfort and distress and where this happened paused the interview, provided reassurance, and checked with participants how they wished to proceed. This only occurred once during the interview and the participant indicated that they very much wished to proceed.

At the end of the interview background and demographic information was collected. Finally participants were debriefed and guided to additional information and support. Steve was asked, during the debrief, if he would like an easy-read copy of the study findings.

## Linguistic discourse analysis

A detailed systemic functional linguistic-based discourse analysis was performed on three interview transcripts in order to document some of the ideological aspects of the risks and benefits of digital inclusion as perceived by three different participants, all stakeholders in Steve's care. This enabled the researchers to compare the linguistic choices of the three participants in relation to the same phenomenon of interest according to three main overlapping functional parameters: referential, interpersonal and textual (Halliday & Matthiessen, 2013).

**The referential function** of language is enacted when language is used to represent the reality of the 'story'. This refers to the main 'characters' and 'events' and how they relate to each other, where, when, why and how. In systemic functional linguistic terminology, this includes: the **participants** expressed through nouns (e.g. *policy*), noun phrases (e.g. *the most effective policy*) or pronouns (e.g. *it*), the **processes** of 'doing' or 'being', expressed through verbs or verb phrases (e.g., *We directed the group to read the policy*) and the **circumstances** (place, time, manner and reason), expressed by adverbs and prepositional phrases or subordinate clauses (e.g. *the NHS introduced this policy gradually [manner] last year [time] in the East of England [place] because teams were already trained to use it there [reason]*). In linking participants to processes, we can observe the agency role ascribed to the participants, whether actor (e.g. *people with intellectual disabilities make choices / express their views*) or acted upon (*people with intellectual disabilities are encouraged / protected*).

These choices shape the ideological content of texts in terms of the levels of agency and responsibility assigned to key participants.

**The interpersonal function** of language is implicated when speakers or writers make linguistic choices to interact with other speakers or readers, including the use of interrogatives (e.g. *why are we not implementing this policy in the UK?*) or imperatives (e.g. *Introduce this policy in the UK now!*) and expressing their views on people and events (e.g. *This policy is excellent/ineffective*). Different levels of interactivity may also be enacted by the choice of particular pronouns of address (e.g. *I, we, you, they*) and the use of modal verbs (e.g. *must, may, should, will*) to modulate expressions of certainty, desirability or willingness. Through these choices, interviewees adjust their position to the interviewer (e.g., their authority and power, if any).

**The textual function** of language is enacted by structural choices which impact on the overall meaning conveyed (i.e. its *cohesion*). A text (in this case the interview transcript) may, for example, be constructed in the form of an argument to be persuasive or as a narrative piece with the purpose of entertaining. This is supported by the use of particular connective structures (e.g. *and, moreover, however, firstly*) as well as grammatical and lexical back and forward referencing. The reception and comprehensibility of a text is additionally affected by the length and complexity of its sentences and the level of structural or vocabulary repetition. The comprehensibility of a text, its overall *coherence*, relies also on the readers' existing contextual knowledge of the topic addressed.

**Data analysis process.** Systemic functional discourse analysis looks at words chosen within a linguistic context and this has been taken into account in the analysis and interpretation of the data. Insights into the family and care context added further depth to the discussion of results and these were drawn on as relevant so as not to detract from the main findings.

Each interview was read once thoroughly for content familiarisation. With attention to each function in turn (referential, interpersonal, textual), each interview was then analysed by hand. Relevant words and constructs were systematically highlighted depending on whether they corresponded to referential (nouns/ verbs) interpersonal (modal verbs, imperatives and speaker position) or textual function (the flow of the conversation). One third of each interview was re-analysed by a second author and any disagreements were resolved through consensus discussion. Word choices were collated and judgement was made about dominant and least frequent terms used / selected in each interview for analysis. Comparisons could then be made of the linguistic choices and different linguistic functions that constructed meaning within the discourse of each interviewee.

## Findings

Findings are presented descriptively for each participant with close alignment to the three linguistic functions; referential, interpersonal and textual (Halliday & Matthiessen, 2013).

### Interview 1 with 'Steve'

**Referential function.** The nouns dominant throughout this interview were:

friend(s), Facebook, information, football, private

Less dominant were nouns:

email, phone, twitter, photo.

Most of the verbs used were high frequency and general, that is, 'got, go, send', with the exception being 'pick it up' (i.e., *learn*). This latter phrase may represent his acknowledgement and understanding of his process of development regarding technology. Steve was able to explain about his internet use to the interviewer and he had a clear understanding of specific technology-related vocabulary. The linguistic choices made by Steve reflected his main purpose for using digital social media was to establish and maintain friendships. Compared to other interviewees, despite discussing online contact risks (e.g., being hacked and experiencing negative social interactions and exclusion), he did not use any of the terms:

risk, safety or bullying.

This could reflect that he had less awareness than his family or paid carer (who did use these terms) of previous bullying episodes related to the use of social media in his life as potentially risky or dangerous. Alternatively, he could have been reluctant to engage in a discussion about specific negative episodes. This is supported by the lack of mention of online content risks (e.g., accessing sexually explicit material and pornography) which were mentioned in the family and paid carer interviews.

**Interpersonal function.** Steve described some of his interaction with online systems as:

'confusing' and 'difficult' and people as sometimes 'annoying'.

He used the word 'myself' more often than other interviewees and challenged the interviewer by using the phrase 'depends who I'm speaking to'. This demonstrated his ability to retain control over his online communication despite the 'confusing, difficult and annoying' aspects of the technology and of the people he met.

Despite not using many value-related terms or modal verbs (could, should, would), autonomy was evident (albeit marginally) in Steve's choice of pronouns in relation to himself and digital inclusion.

**Textual function.** Steve deviated from the theme of digital inclusion on eight occasions in the interview. At times, this interrupted overall coherence of the interview discourse. Some information was thus hard to follow. Indeed, some of the diversions were due to Steve misunderstanding the language used by the interviewer. However, he was supported with three verbal summaries of what the conversation was about by the interviewer. This facilitated a more cohesive discussion. Despite possible power imbalances arising in the conversation between the interviewer and Steve, he was clear about the topic, keen to have his voice heard and was agreeable about maintaining the interview through to the end.

Turns taken by the participant were relatively short and the interviewer often equalled these in length showing that efforts were being made to support a balanced conversation around knowledge of a shared topic.

#### **Interview 2 with Steve's mum**

**Referential function.** Fronting Steve's mother's representation of Steve's interaction with social media, were nouns:

“risk, balance, manage, independent, Facebook.” Less frequent nouns used were “scams, porn, critical faculties, tension, rape, trouble, safety net, life experience, repercussions, consequences, parent, friend, story.”

Incidental nouns used were:

benefits, employment, implications, freedom, street-wise, chains.

Verbs included:

approve, groomed, understand, taught, learning, exposed to, showed, led, realise, explore, involved, tortured.

The choices of vocabulary made by Steve's mother reflect an awareness of risks she perceived in his use of social media as relatively high compared to Steve. Some of the words used also show a concern about more extreme risks:

consequences, groomed, tortured, chains, porn, rape, trouble

but she also countered these with terms that moderated the risk such as,

freedom, benefits, safety net, friend, approve, explore, learning.

**Interpersonal function.** Evaluative words that described Steve's mother's own sense and her perception of Steve's online inclusion were:

safe, sceptical, concerned, appropriate, liberal, dangerous, naïve, vulnerable, dodgy, normal, heavy-handed, savvy.

Again, these were more evident than evaluative words used by Steve and negative language was balanced by terms such as:

balanced, safe, savvy, normal.

She used a number of reflexive pronouns ‘himself, themselves, myself’, unlike Steve or the staff member showing an awareness of the overall aim of autonomy for her son. She also used repeated negative imperatives and directives:

“do not, don't, never” that demonstrated her concern about online risk.

Emphatic words and qualifiers were used by Steve's mum, especially when describing how she talked to her son about social media. For example:

“lay out definite guidelines...always ask somebody, always ask first,” “absolutely ballistic,” “very very cynical and very skeptical” and “world-wearying.”

Neither the staff member nor Steve used emphatic words or qualifiers in the same way. This may reflect the level of Steve's mother's concern about his internet use which, in her account, is balanced with her wish for his independence.

**Textual function.** This interview was linguistically coherent. Both interviewer and participant took equal length turns. Both took responsibility to bring the conversation back to the topic and there was a natural flow to the conversation with humour and structure. This demonstrated an equal balance of power over the shared topic of digital inclusion where neither party was attempting to demonstrate more expertise than the other.

#### **Interview with Steve's support worker**

**Referential function.** The nouns most often used by the carer were:

supporter, job, supported living, library, shifts, families, monitoring, control, safe environment.

Less used but evident were nouns:

internet, urges, mind of a child, safeguarding, trends, options, boyfriend/girlfriend,

balance, psychologist, psychiatrist, pornography, law, scam, risk, trust.

Verbs were less used to describe the processes of digital inclusion:

“support, manage, monitor” were most common and also, “training, gambling, trusted”

Language showed a clearly defined role perceived by the staff member and this was fore-fronted throughout the interview in a way that suggested he held a protected status with his involvement in social media use by those he cared for. Similarly, the ‘*library*’ was frequently mentioned, also as a protected space for social media use that devolved responsibility from himself to another entity. Professional terms were used ‘*psychologist, psychiatrist*’, as well as reference to the ‘*law*’ which neither of the other interviewees used, further emphasising his professional stance, as did the verbs ‘support, manage, monitor’.

## Interpersonal function

Value laden terms, that is, modal expressions ‘*could, would, should*’ and expressions of mood were used more often than Steve or his mother to represent understandings of digital inclusion for Steve and others.

Huge blow, epilepsy, to his credit, so active, the next best thing, luckily, vulnerable, manipulative, dark, huge impact, obsessed, driven away, free reign, old habits, overbearing, restricted, high and mighty, in awe, clashed, big cheese, cajole, entitled, discard, desperate, drawn in, repeatedly messed about, stand back, degrading.

These terms reflected an understanding of risk but words were less related to concerns compared to some of the terms used by Steve's mother. Rather they described disability, behaviours and processes perceived in the interaction between social media and Steve. He used ‘*T*’ more frequently than any reflexive verb constructions (e.g., ‘*myself*’) and this suggested a focus on his own professional role.

## Textual function

Some follow-through of themes was evident but sporadic. The support worker spoke for turns at least three times longer than the interviewer but discourse was often fragmented and not linguistically coherent (i.e., not referring back to topics or previous mention of terms). This imbalance might be evidence of the support worker delivering his knowledge of the shared topic as a perceived expert observer in his professional role.

## Discussion

### Key findings

Awareness, responsibility, power and agency in relation to the risks and benefits of digital inclusion for a man with intellectual disabilities [‘Steve’] differed in the accounts of a support worker, parent and the person with intellectual disabilities. The linguistic choices made by the three participants showed different levels of knowledge, insight, and concern regarding the benefits and risks of digital inclusion, aligning with and extending prior research (Bannon et al., 2015; Löfgren-Mårtenson et al., 2015; Molin, Sorbring & Löfgren-Mårtenson, 2015). All participants recognised some benefits to being online, corroborating prior research findings (Caton & Chapman, 2016; Chadwick et al., 2019).

The way that online places, people and actions were represented by nouns and verbs (*representational function*) demonstrated the focus of each participant. Steve used words that were strongly related to the social aspects of having friends online and sharing sport and photos on social media (Caton & Chapman, 2016). His use of language demonstrated very little awareness of any risks that he might have taken in the past or potential risks in the future (Molin et al., 2015). These positive aspects were mirrored by Steve's mum in her recognition that friends, [digital] freedom and independence were important for her son. However, many of the nouns and verbs that she used reflected a strong concern for his safety and her worry about the possible consequences of digital participation (Löfgren-Mårtenson et al., 2015). In contrast, the support worker used fewer terms to represent positive benefits of online presence but did use words such as ‘balance’ and ‘trust’. Several terms that he used shifted these into the realm of institutional or professional life ‘supporter’, ‘job’, ‘safe environment’ (Clifford-Simplican et al., 2017). Depending on their role (Steve as the main protagonist and beneficiary of being online, Steve's mum as facilitator and protector, and the support worker as institutional representative), each participant reflected a different understanding of the benefit versus risk balance of online participation. Benefits only outweighed risk in Steve's discourse. As a result, in representations of protection, both family and institutional came to the fore.

In terms of the stance taken by each participant and how they represented themselves in relation to the others (*interpersonal function*), certain power differentials emerged. Despite the fact that Steve demonstrated more limited insight into the potential risks of being online he did use the word ‘*myself*’ often and this showed awareness of his own agency in his online engagement. The language that he used to describe risky situations or when things went wrong pointed more to bewilderment than recognition of risk: ‘confusing, difficult, annoying’. Steve's mum generally felt that she was open

and liberal in her response to risky online situations recognising herself as 'sceptical' and her guidance was peppered with emphatic advice. This emphatic use of directives when she gave advice to Steve reflected her personal worry and possibly also her perceived lack of control and loss of agency over Steve's internet use. In contrast, the support worker, who saw his role primarily as a professional in his interaction with Steve, used many value-laden terms 'so active' 'the next best thing', and 'repeatedly messed about'. While these demonstrated an understanding of the risk involved in Steve's online engagement they also showed a level of agency and control imbued by his own professional control and institutional back-up (Chadwick & Fullwood, 2018) which allowed him a certain level of detachment from the possible consequences. Comparing these three interpersonal stances, Steve's main response to difficulties online was one of confusion. Without the backup knowledge and awareness of risk, he presented himself in a vulnerable potentially risky position leading to reduced autonomy. Steve's mum had insider detailed knowledge and heightened awareness of risk, particularly the more serious and extreme risks, yet her word choice demonstrated limited agency to protect him from harm. The support worker presented as professionally confident in his power and control over Steve's online participation. He recognised the risks but displayed a more distant responsibility and felt protected from accountability by his position. This aligns with notions of autonomy and mastery within the functional self determination model. Steve felt autonomy over online choice and this was supported; however, his mastery over encountering risk online was less evident, demonstrating further developmental need.

In terms of the coherence and cohesion of the interviews and the flow of discourse between the interviewer and participant (*textual function*) distinct patterns were identified for each of the three participants. For example, in terms of word length and time, the support worker spoke nearly three times as much as the interviewer. This was not reflected in the other two interviews with the family carer nor with Steve. His patterns of response were long, he often used vague terminology and this led to a fragmented argument where tensions between on-line over-protection and online freedom could be seen (Seale & Chadwick, 2017). Steve often needed prompts to return to the topic of the interview and although the balance of turns between him and the interviewer were relatively even, his turns were usually very short and he used limited vocabulary. The need for so many prompts within this discourse pointed to a vulnerability and power differential in Steve's projected internet participation with other, more articulate, online contacts. Steve's mum's discourse was balanced with even lengths of turns between her and the interviewer moving between topics of online risk and freedom.

This paper adds to previous insights into how support staff and family carers view and support digital risk-taking by their family members with intellectual disabilities (Balasuriya et al., 2022; Chiner et al., 2017; Löfgren-Mårtenson et al., 2015). The distinct discourses highlighted different tensions at play in relation to digital participation and risk for each of the three participants. For Steve's mum the primary tension was between wishing to protect Steve from harm versus the wish for Steve to be independent and have a full life. For the support worker the primary tension was wanting to protect and enable Steve to have a full life online versus the distance of his professional role and organisational drivers and responsibility. Finally, for Steve tension existed between his wish to be an independent self-determining individual online versus the confusion that arose when interacting online with others which he could find 'annoying' and challenging.

## Limitations and strengths

The small number of participants and interviews conducted for this study mean its primary strength is in exploring discourse in depth across key players to better understand the nuances of differing tensions and motivations. Recruitment of the participant with intellectual disabilities was facilitated by an advocacy group within the lead authors networks. Steve was identified as a good fit for the study because he was particularly adept and engaged with the use of technology within his everyday life. His mother was also digitally literate, running a Facebook group for people with intellectual disabilities and autism. Hence, two of the participants within this case study could be viewed as more digitally engaged, than other carers and people with intellectual disabilities. Any developers using this case study would need to consider the high expertise of these participants when transferring the findings. Nonetheless, this study does offer a tridimensional perspective which can be used to inform the development of interventions about online risk to better support these three groups. It also highlights the importance of considering multiple perspectives and including the voice of people with intellectual disabilities regarding digital inclusion.

## Future directions

Findings from this paper also resonate with Raghavendra et al. (2013) and Newman et al. (2017), whose interlinked studies focused on home based, goal-oriented support for digital inclusion which included family members. The study found that young people with differing specific types of physical and communicative disabilities required long-term, personalised, intensive support both from outside and inside the

family, in order to get online. Further research investigating the role that the sharing of power plays within these support relationships when relating to more risky online pursuits is indicated.

The need to co-create positive risk-taking oriented interventions with people with intellectual disabilities, their families and support workers is evident. For family members and support workers interventions should focus on enabling them to enact collaborative control (Abrey & Stancliffe, 2003) and balance the need to allow their family member freedom and agency and alongside their desire to protect. This should reduce carer feelings of impotence in the face of the online risks being taken by their family member. For people with intellectual disabilities these should focus on education about types of risk and how to manage risk, request support around risk and be resilient when encountering online challenges.

### CONFLICT OF INTEREST

The authors have no conflicts of interest for this study.

### DATA AVAILABILITY STATEMENT

Open access to the data is not available for the study as it was not incorporated within the consent procedures for the study.

### ETHICS STATEMENT

Ethical approval for this project was granted by the lead author's University ethics committee.

### ORCID

Darren D. Chadwick  <https://orcid.org/0000-0002-4963-0973>

Susan Buell  <https://orcid.org/0000-0002-1496-6557>

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