Strengthening Connection for People with Intellectual Disability in Emergencies: Social Media and Access to Essential Information

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Strengthening Connection for People with Intellectual Disability in Emergencies: Social Media and Access to Essential Information

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Abstract

Climate change is increasing the rate and severity of emergency events globally which is having disproportionate impacts on the most marginalised community members, including people with intellectual disability. In an emergency many people with intellectual disability do not have access to the information they need, in formats they understand, to utilise vital services and survive. Concurrently social media has become a vital tool for sharing information and building connections for people with and without disability. This research aims to build a better understanding of how people with intellectual disability engage with social media in an emergency to identify gaps in response efforts and improve emergency messaging.

Keywords: Intellectual disability, social media, emergency management, information seeking, digital divide.

1   Introduction

During and in the aftermath of a disaster people with intellectual disability fail to receive the information they need in formats they can understand (Caton et al, 2022; Chadwick et al, 2022). It is well established that in an emergency (as defined by the Emergency Management Act 1986 (Vic, Austl)), people with intellectual disability experience higher rates of exploitation, abuse and mortality than the general population, endure significant disruption to services and have limited access to timely information in accessible formats (Doody & Keenan, 2021; Gaskin et al 2017; Roth, 2018; Stough, 2015; Villeneuve, 2021). This was particularly evident during the COVID-19 pandemic (the pandemic), which had a significant impact on the 252,000 Australians estimated to have an intellectual disability (AIHW, 2020) and remains a feature of many emergencies including floods, fires and storm events. 'Intellectual disability' is described as a permanent condition that can affect a person's comprehension, skills and behaviours (Inclusion Australia, 2022). A long history of ableism has resulted in people with intellectual disability experiencing generally poor health and mental health outcomes, high levels of unemployment, they often live in segregated housing, and can face unique barriers to accessing and enjoying the benefits of the digital world (Caton et al, 2022). There is a body of research highlighting the 'digital divide' which exists between how people with and without intellectual disability access technology (Bayor et al, 2019; Caton et al, 2022). This divide is impacted partly by discrimination which limits employment opportunities, restricting the type of technology people with disability can afford to purchase and the support they can access to learn how to use it (Heitplatz, Bühler, & Hastall 2021). Further, the digital divide is exacerbated by inaccessible hardware and software, which can be text heavy and require strong literacy skills (Williams 2020). Over time, advocates have worked to lobby for change to ensure equal rights for people with intellectual disability, including promoting forms of digital accessibility. In Australia, these changes are often instigated by peer-led activist collectives called self-advocacy groups (Kendrick, Ward, & Chenoweth, 2017). Despite the considerable and hard-won gains of these groups, people with intellectual disability continue to experience significant limitations on their rights in all areas of life, including how they are supported in a crisis and in their access to emergency information online.

In an emergency, people with intellectual disability need accessible information to ensure they can have equitable access to assistance. The Australian government has an obligation under international human rights law, particularly the Convention on the Rights of Persons with Disabilities (CRPD) to provide emergency information in accessible formats. However, this information provision has been described as inadequate and inaccessible, particularly during the pandemic (Caton et al, 2022; Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, 2021). Described as an 'information crisis' (Chadwick et al, 2022), this service deficit continues to place people with intellectual disability at serious risk of harm and results in increased stress and anxiety as they attempt to navigate changing health directives (Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, 2021). In response, non-government agencies have tried to bridge the information gap by producing their own documents in accessible formats (such as 'easy read', which is an information method that combines pictures with simplified plain language text) but this caused more confusion for many people with intellectual disability, who reportedly struggled to determine which information source was trustworthy (Chadwick et al, 2022). Further research suggests people with intellectual disability can be reliant on informal networks to interpret information and can intentionally avoid engaging with inaccessible information limiting their ability to make informed choices about their safety when separated from their natural supports (Lazrus, et al 2012; Stough, 2015). These issues highlight how important it is for people with intellectual disability to have independent access to information in formats they can understand in an emergency.

Research shows that during the pandemic many people with disability sought emergency information on social media (Dobransky & Hargittai 2021; Dai & Hu 2021). This signalled a shift away from consuming information from official government directives in an emergency to relying increasingly on their own peer networks to overcome news gaps in disaster responses (Lazrus, et al 2012; Stough, 2015; Stough and Kellman, 2018). Generally, we know social media is being used by people with intellectual disability specifically to connect socially, learn, and share information (Bayor et al 2019; Dobransky & Hargittaib, 2016; Williams 2020). Further, a reliance on technology during the pandemic encouraged many people with intellectual disability to go online to access services, information, and connect with friends (Caton et al, 2022 Chadwick et al, 2022). However, prior to this, very little research has been undertaken to explore how people with intellectual disability are using social media in an emergency. With climate change increasing the frequency and intensity of emergency events, it is vital that we build a better understanding of all possible communication tools to ensure the most marginalised community members can access vital, sometimes life-saving, information.

This article introduces research which aims to address urgent issues facing people with intellectual disabilities during emergencies. It asks:

How are people with intellectual disability using social media in an emergency?

This question will broadly explore how people with intellectual disability are using social media to access information, seek social supports and engage with emergency services. This article seeks to answer this question by providing an overview of available literature related to how people with disability broadly and also those with intellectual disability use social media in their everyday lives and in emergencies. We then suggest some propositions to guide future research, using participatory methods to interview people with intellectual disability to further understand their experiences online. The results of this research will help guide recommendations for policy makers on how to utilise social media as a tool for service and information delivery in an emergency. By doing this research, we hope to encourage governments to take a strategic approach in delivering on their obligations under the CRPD and other key international human rights instruments. We anticipate that this could in turn protect the rights of people with intellectual disability to access support on an equal basis with others and affording them greater autonomy over decisions impacting their lives in emergencies.

2　Background

2.1　How people with intellectual disability are using social media

While people with intellectual disability are using technology at lower rates than the general population, accessing social networking sites (SNS) remains their primary reason for going online (Caton et al 2022; Dobransky & Hargittaib, 2016). A review of the literature revealed individual circumstances and general access issues are impacting how often and in what ways they can access social media. Research exploring why people with intellectual disability are accessing SNS, indicates that the most common reasons are to strengthen relationships and to explore their interests (Caton, et al 2022). People with intellectual disability are using SNS generally as passive consumers of information, rather than creating their own content, and are preferencing individual platforms for different functions (Dobransky & Hargittaib, 2016). Research shows Facebook is being used to connect with family and friends, Snap Chat and Instagram are used to share interesting content, and YouTube is being used to consume media around special interests both alone and in person with friends sharing a single device (Bayor, et al 2019). One study showed users with low literacy preferred WhatsApp because they could use the platform to communicate using recorded messaging functions and emoticons (Heitplatz, Bühler, & Hastall 2021). These studies suggest that people with intellectual disability are accessing a wide range of platforms for a diverse range of reasons, using their initiative to make adaptions to how they use each platform based on their individual access needs. Researchers have suggested that the digital world, including SNS, could also offer an alternative more inclusive community, where individuals can control their online environment to fit their individual access needs (Dobransky & Hargittaib, 2016). Researchers have also proposed that the use of SNS could enable some people with intellectual disability to engage with the broader disability rights movement (Caton & Chapman, 2016).

Despite high levels of interest in SNS, there are some barriers in both the usability and accessibility for people with intellectual disability (Glencross, et al 2021). Beyond connectivity issues, hardware and software barriers include costs, platform design barriers (for example SNS are text heavy, password protected and have regular updates to functionality and layout) (Williams, 2020), sensory motor skills required for use (Caton & Chapman, 2016), and a lack of training opportunities (Heitplatz, Bühler, & Hastall 2021). Importantly this suggests that people with intellectual disability face general barriers accessing and utilising ICT which could impact how they engage online in an emergency. The literature points to a number of barriers impacting on how people with intellectual disability access SNS generally. However, how these limitations impact on their information seeking behaviour or access to vital supports in emergencies is not yet well understood.

Proposition one: People with intellectual disability face barriers when engaging with SNS, including inaccessible hardware, software and content which could impact on how they access valuable supports online in emergencies.

Proposition two: People with intellectual disability have limited opportunities to learn the skills they need to independently navigate SNS, which could prevent them from utilising these platforms in an emergency.

Beyond general service deficits, one of the reasons people with intellectual disability lack adequate training to navigate SNS is because of some supporters and families who may play the role of gatekeeper,

controlling how and what people with disability can access (Williams, 2020). This gatekeeping may be underpinned by the view that people with intellectual disability cannot learn the skills required to use these platforms (Bayor et al, 2019), and general safety fears (Williams, 2020). While some people with intellectual disability report experiencing abuse, sexual harassment, and victimisation online (Sallafranque-St-Louis & Normand, 2017), there is some evidence, as a more general comment, to suggest that these safety concerns are exaggerated (Glencross et al, 2021). As a result, evidence suggests there may be restrictions placed on what people with disability are allowed to access, when in practice they have the same information seeking interests as people without disability (Williams, 2020). This is also reflected in the research field, which remains focused on the barriers and concerns of social media use over the potential benefits (Glencross et al, 2021). This is significant because it signals how assumptions, grounded in ableism, can restrict access to social media and autonomy in information seeking for people with intellectual disability.

Proposition three: The attitudes, assumptions, and knowledge of those supporting people with intellectual disability, including formal and informal carers, can place limitations on how they engage with social media.

2.2 Literature review

A scoping review of the literature was undertaken to determine what academic research exists on the experiences of people with disability generally, and intellectual disability specifically, using social media in emergencies. This review included a search of key databases, including Google Scholar, Scopus, Web of Science and ACM digital library. The search spanned the past 12 years and included key terms related to intellectual disability and disability generally, emergencies (example bushfire, COVID-19) and social media (example, Facebook, Instagram). The search uncovered that there is limited research related specifically to the experiences of people with intellectual disability. This is consistent with academic research generally, in which people with disability are often considered a homogenous cohort (Kent & Ellis, 2015; Stough & Kellman, 2018) and that there are limited studies exploring the experiences of people with intellectual disability engaging with ICT (Sallafranque-St-Louis & Normand, 2017; Williams, 2020). This literature review, and the research gaps identified, has resulted in the following propositions which will guide future research.

2.3 How people with disability broadly, and intellectual disability specifically, are using social media as an emergency response tool

The review of the literature uncovered three main ways people with disability are using SNS in an emergency including to access information, to fill service gaps and to advocate for more inclusive responses (Dai & Hu 2021; Dobransky & Hargittai 2021; Morris, Mueller & Jones, 2014). A survey comparing information seeking behaviour between people with and without disability during the pandemic identified people with disability as engaging more with emergency information on SNS than people without disability, specifically to access, share, and create content (Dobransky & Hargittai, 2021). However, notably, only a small proportion of people with intellectual disability appear to be using SNS to access information in an emergency (Caton et al, 2022). A recent UK study highlighted that only one in five were using social media to source information (reading news articles, seeking advice about restrictions) about the pandemic (Caton et al, 2022). While this research indicates a divergence in how people with intellectual disability and people with disability generally use SNS, there are obvious gaps in the literature. Further in-depth enquiry is required to confirm these findings and determine a rationale for the difference in information seeking behaviour.

Proposition four: People with intellectual disability are not using SNS to access information at the same rates as people with disability generally, which could impact on their ability to make informed decisions in an emergency.

People with disability are using SNS to develop and share accessible content for their peers, filling an important gap left by inaccessible official government information (Dai & Hu, 2021). Information gaps are increasing the likelihood of risk of abuse and exploitation online causing distress, anxiety and hindering recovery efforts following emergencies (Alathur, Kottakkunnummal, & Chetty, 2021). These outcomes may create an increased mistrust of government consistent with the negative experiences of people with disability have navigating government service systems in general (Goggin & Ellis, 2020). Social media has been identified as a tool to support the distribution of official information to new audiences, including people with intellectual disability, supporting them to have more equitable access to communications material (Bricout & Baker, 2010). While the literature supports the claim that, theoretically, SNS could be used to strengthen and expand the reach of formal emergency responses, there are gaps in the available data and this theory requires further investigation. These gaps include an

absence of studies with an explicit focus on people with intellectual disability and which consider how individuals utilise their informal digital connections in an emergency.

Proposition five: Government information is not accessible for people with intellectual disability in an emergency and social media has potential to fill this service gap.

Research shows SNS are being used by people with disability to access advice, medicine, and essential services in an emergency (Bricout and Baker 2010, Dai & Hu 2021). Recent studies revealed people with disability were using Twitter and WeChat during the pandemic to reach out to their networks both known and unknown for financial assistance or to find products that were unavailable due to supply issues (Dai & Hu 2021, Valencia & Kirabo, 2021). Support seeking included social support, with many people with intellectual disability relying on friends and family online during the recent pandemic, which provided a welcome respite from feelings of loneliness and isolation (Caton et al, 2022).

Social media is being used as an advocacy tool to demand equal access to services and supports in an emergency. People with disability are using SNS to lobby government decision makers identifying systemic failures and highlighting the unique experiences of people with disability (Dai & Hu, 2021). Other activities involved tagging supermarkets and services urging them to do more to support people with disability to have equitable access to the supplies they needed (Valencia & Kirabo, 2021). Further, during the pandemic, online networks were also useful in building alliances and challenging stereotypes between people with different types of disability who recognised and leaned on each other's individual strengths online during the crisis (Dai & Hu, 2021). Available research suggests, however, that people with intellectual disability are not using SNS to advocate for better services in an emergency and we don't have evidence to better understand why (Caton et al, 2022). This point highlights limitations within the current research which, given the evidence pointing to SNS being used as an advocacy tool, is an important area for further enquiry to ensure we understand any barriers to people with intellectual disability in speaking up for their communities.

Proposition six: Social media is a valuable tool for people with intellectual disability, particularly in an emergency, where they can use these platforms to access information, seek support and advocate for their human rights.

3 Agenda for future research

The pandemic has increased interest in this research area but there are many gaps, including building a strong understanding of emergency-specific information-seeking behaviour in people with intellectual disability, which require further enquiry. While Caton et al (2022) completed a large-scale study exploring the social media habits of people with intellectual disability in the pandemic, this research failed to determine why only one in five participants were using SNS to access information. In addition, very few existing studies used an inclusive research methodology; for example, few used 'peer researchers', which refers to people with intellectual disability taking an active role in research about their peers. The use of peer researchers is an increasing priority in research concerning persons with intellectual disabilities, both based on claims about equity as well as improving the quality of research, as discussed below. In many of the studies, data collection tools, such as surveys, were used that tend to be inaccessible to people with intellectual disability (Dobransky & Hargittai, 2021; Morris, Mueller & Jones 2014; Stough & Kellman, 2018).

To answer the research question, a field study is proposed. In the first instance, participatory research methods will be used to speak to people with intellectual disability about their experiences using SNS in emergencies, including but not limited to the COVID-19 pandemic. This will include working with a local Melbourne-based self-advocacy group comprised of persons with intellectual disability to determine the accessibility of the research questions and identify any gaps in the areas of enquiry. We will then employ a peer researcher to help co-conduct semi structured interviews with up to 10-12 participants with intellectual disability. Participatory research approaches were chosen because, by including people with intellectual disability as co-researchers, we hope to increase the validity of the study while also utilising their lived experience to improve the process, and networks to support the recruitment of participants (Bishop, 2014; Heitplatz et al., 2021; True, Alexander, & Fisher, 2017,) Participatory research is reflective of promising practice in disability research and involved ensuring the subjects of research are actively involved in designing studies and collecting data (Johnson, & Walmsley, 2003; O'Shea et al, 2020), and is consistent with international human rights law (CRPD, art 4(3)).

The interviews will be recorded, transcribed and the data analysed to identify emerging themes about how social media is utilised by people with intellectual disabilities in an emergency. The themes from this study will inform future qualitative research to provide more detailed contextual policy and legal

perspectives, including the role of the CRPD in safeguarding the rights of people with disability in an emergency. The research participants will be informed by the themes of the previous study but may include the perspectives of caregivers, service providers and government policy makers. The data from this research will be used, in the first instance, to develop a series of recommendations for government and disability service agencies. These recommendations will improve the accessibility of emergency messaging, as well as strengthening digital preparation, response and recovery efforts. These efforts will endeavour to support people with intellectual disability to exercise autonomous information seeking in an emergency, giving them further agency to make decisions impacting on their wellbeing.

4 Conclusion

The United Nations has cautioned that our reliance on digital technology in a post pandemic world is permanent, and if we don't manage this shift, it will undermine the human rights of people with disability (United Nations, 2022). People with intellectual disability have the right to receive support and guidance in an emergency, and the failure to provide timely and accessible information puts them at serious risk in communities where the number and severity of emergencies is increasing rapidly. We know that people with intellectual disability are using SNS to access social supports, information and pursue their interests. There is, however, space for further peer-led inquiry about how we can better utilise this tool as an emergency response instrument. By providing better information in an emergency, we could ensure that people with intellectual disability can exercise agency over their own lives and access supports and safety information on an equal basis with others. This research is needed to ensure that future responses to emergencies utilise all communication channels to better ensure that some of the most marginalised community members are not left behind.

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