**Submission to the United Nations Committee**

**on the Rights of Persons with Disabilities regarding**

**the** **Day of General Discussion examining Article 11 of the Convention.**

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I, Heidi Peart, am a PhD candidate with the University of Melbourne, Australia in the School of Computing and Information Systems. My research is focusing on accessible digital support for people with intellectual disability during times of disaster and humanitarian risk. In my career I have worked for a range of disability service providers, self advocacy groups and government agencies in policy and development roles working towards full and equal community inclusion for people with disability. This submission was written with input from my academic supervisors at the University of Melbourne representing the fields of Law, Social Work, Information Systems (IS) and Information Behaviour.

1. **Recommendations**

This submission recommends the Committee emphasise the positive role digital technology - and particularly social media - can play in safeguarding the rights of persons with intellectual disability in situations of humanitarian risk and natural disaster. To secure these benefits, governments and civil society must ensure online information is accessible and caters to the specific needs of persons with intellectual disability.

In this submission, I wish to draw on my research concerning accessible online information for people with intellectual disability during disasters[[5]](#endnote-5) **(Appendix one)** to make the following recommendations:

1. That world governments listen carefully to people with intellectual disability, and work with them to identify strategies to address the unique challenges they experience in preparing for, responding to and recovering from humanitarian disasters.
2. That world governments carefully consider the role of ICT in ensuring full and equal community participation of people with intellectual disability and take steps to ensure that they are afforded equal access to devices and education.
3. That world governments, communities, and disability service providers take proactive steps to ensuring people with intellectual disability are afforded the skills and resources to exercise agency in emergencies, including recognising the role ICT can have in ensuring equitable access to information.
4. That research institutions invest in and carefully monitor research examining how people with intellectual disability use social media in emergencies to determine if these platforms could be used to aid response and recovery efforts.
5. That world governments develop evidence-based standards for information distribution online in emergencies that is co-produced with people with intellectual disability from civil society organisations, in particular self advocacy groups.
6. **Introduction**

Thank you for the opportunity to make a written submission to the committees Day of General Discussion regarding Article 11 of the Convention on the Rights of Persons with Disabilities (CRPD).

This submission highlights the challenges people with intellectual disability face in emergencies, including retrieving timely, accessible information online. We go on to introduce the opportunities and challenges offered by social media as a tool for supporting emergency management response and recovery efforts. Finally, we suggest that further research is needed to ensure equal digital inclusion and information access for people with intellectual disability in a crisis.

1. **The experiences of people with intellectual disability in emergencies**

As the committee would be aware people with intellectual disability experience unique challenges in emergencies. Describing themselves as the ‘*Left behind of the left behind’[[6]](#endnote-6)* people with intellectual disability experience higher rates of distress, are more likely to be abused and have higher mortality rates than people with disability generally[[7]](#endnote-7). There are many variables contributing to these outcomes including a history of ableism, segregation and marginalisation which exacerbate their exclusion from mainstream emergency responses[[8]](#endnote-8).

1. **Article 21: Freedom of expression and opinion, and access to information**

Article 21 of the CRPD affirms that States Parties will provide timely public information in accessible formats for people with disability, including intellectual disability[[9]](#endnote-9). However, in situations of risk and humanitarian disaster, people with intellectual disability continue to identify that access to information is challenging[[10]](#endnote-10).

The COVID-19 pandemic was described as an ‘information crisis’ which left people with intellectual disability overwhelmed concurrently by at first a deficit, and then an excess of information from multiple sources as the crisis progressed[[11]](#endnote-11).

People with intellectual disability identified several challenges finding key health and safety messaging including limited access to support workers to aid the interpretation of information, limited easy read documents, and difficulty navigating online platforms where information was held[[12]](#endnote-12). Researchers also observed that some people with intellectual disability experienced challenges in identifying which information online was trustworthy.[[13]](#endnote-13)

In Australia, there are no national emergency management standards to inform the delivery of responses, including information provision, that are disability inclusive or responsive[[14]](#endnote-14). This is a problem because it means there are also no consistent standards for the provision of accessible, targeted information for people with intellectual disability. This policy gap has the potential to leave those without appropriate support vulnerable when making decisions about what to do or where to seek help in a crisis.[[15]](#endnote-15)

1. **Access to digital technology and social media in emergencies**

As climate change increases our exposure to humanitarian disasters, concurrently so too does our engagement with digital platforms, such as social media, which many use as a mechanism for connecting locally and seeking real time information in an emergency.

There is research to suggest that many people with intellectual disability are engaging with social media, indeed studies indicate this is the primary reason they go online[[16]](#endnote-16). In everyday life they are using social media to express their identity, connect socially and explore their interests[[17]](#endnote-17)

However very little research exists to describe how people with intellectual disability are using social media in emergencies specifically[[18]](#endnote-18). Prompted by the COVID-19 pandemic a small number of studies showed during the crisis people with intellectual disability were using social media to access services[[19]](#endnote-19), leisure activities[[20]](#endnote-20), maintain connections[[21]](#endnote-21) and for a small proportion, to access essential information [[22]](#endnote-22).

These findings highlight differences in the way people with and without disability are accessing information online. Significantly it shows that people with intellectual disability are accessing information online in emergencies less than the general population[[23]](#endnote-23). Understanding this behaviour is important when we consider that using social media is the primary reason people with intellectual disability are going online.

The UN have cautioned that digital communication, including social media, is swiftly replacing other communication channels worldwide, and that communities and governments must ensure people with disability aren’t left behind in this rapid transition[[24]](#endnote-24). Indeed, failing to understand the information behaviours of people with intellectual disability in this context, potentially prevents emergency response teams from targeting key messages to the digital spaces they inhabit in ways they can easily engage with.

Further studies also identified a number of barriers to equitable digital access including gatekeeping by families and carers[[25]](#endnote-25), unsuitable hardware[[26]](#endnote-26), inaccessible software, cost[[27]](#endnote-27), a lack of digital literacy[[28]](#endnote-28) and safety, both real and perceived[[29]](#endnote-29). Indeed, without overcoming these barriers people with intellectual disability will continue to experience disadvantage in emergencies as warning, and response information is increasingly digitised. Building a strong evidence base is the first step to developing policy to begin to address these challenges in communities and services.

1. **Research exploring how people with intellectual disability use social media in Victoria, Australia**

**Appendix one: ‘***Strengthening Connection for People with Intellectual Disability in Emergencies: Social Media and Access to Essential Information’* introduces research currently in development which will examine how people with intellectual disability in Australia are using social media in emergencies.

We ask that the committee review and consider this paper along with our submission.

Through semi-structured interviews with people with intellectual disability this research will examine their experiences on social media in emergencies. Through this study we hope to build a stronger evidence base for the development and distribution of emergency communications.

1. **Concluding comments**

In conclusion, we know that there are differences in information behaviour between people with intellectual disability and the broader community. In a world where information is increasingly published online, full and equal digital inclusion is one crucial step that is needed to ensure people with intellectual disability have the same access to information and services in an emergency.

To achieve equal access, we must ensure that people with intellectual disability are included in considered research relevant to their online behaviours, including social media use. We anticipate that this could aid decision-makers to develop more responsive evidence-based policy to meet the support and information needs of people with intellectual disability in emergencies.

**Appendix:**

Peart, H., Chang, S., Gooding, P., Davidson, J. and Paterson, J (2022) Strengthening Connection for People with Intellectual Disability in Emergencies: Social Media and Access to Essential Information. ACIS 2022 Proceedings. 34.https://aisel.aisnet.org/acis2022/34

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1. Dr Piers Gooding is a Senior Research Fellow at the Melbourne Law School, His work focuses on the law and politics of disability, and particularly mental health, with an interest in algorithmic and data-driven technology. [↑](#endnote-ref-1)
2. Professor Shanton Chang is a research and teaching academic in the School of Computing and Information Systems, University of Melbourne. His work focuses on information security, and information behaviours from a social-technical perspective with a focus on health, business and educational contexts [↑](#endnote-ref-2)
3. Dr Jennifer Davidson is a research and teaching academic with the school of Social Work, University of Melbourne. Her work is focused on how individuals and families can be supported to navigate and make decisions in complex service systems, in the context of social work, health, law and disability. [↑](#endnote-ref-3)
4. Professor Jeannie Marie Paterson, is a research and teaching academic and the co-director of the Centre for AI and Digital Ethics, a collaborative research, teaching and policy centre. Her work is focused on consumer protection and consumer credit law, data privacy, and the regulation of emerging technologies, AI and robotics. [↑](#endnote-ref-4)
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