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Threats to valuing diverse voices in public debates about disability. A case study from social media: A response

In *Threats to valuing diverse voices in public debates about disability. A case study from social media*, Anderson (2022) reports on the findings of a small-scale research project exploring the social media activity of disabled activists in relation to evidence presented to the Australian Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability. The Commission has been hearing evidence in different formats since 2019 and will report its findings to the Australian government in 2023. The case study focused on Twitter activity during Public Hearing 3 where evidence was heard about living in group homes. One of three themes identified, challenging the legitimacy of the researcher, is the focus of the paper which raises critical issues and considerations around how self-advocates and researchers work together on and offline.

Anderson locates her analysis within the context of the centrality of inclusive research with people with intellectual and developmental disabilities. She draws on a large literature that underlines the importance of self-advocates and researchers working together to generate research findings “which can make a significant contribution to knowledge and improve quality of life” (p2). She further reflects on the challenges this approach brings, particularly around the imbalance of power and the representativeness of the self-advocates involved. These challenges can lead to tick box involvement rather than genuine participation, and Anderson underlines the importance of recognising that self-advocates involved in research are often those with the skills to speak out.

While concerns around digital engagement and exclusion of people with intellectual disabilities pre-date the COVID19 pandemic (Caton and Chapman 2016), this has intensified in the past two years as the gap between those who are able to access the internet and those who cannot widens. More people with intellectual disabilities can access the internet and use platforms such as Microsoft Teams and Zoom due to a fast tracking of support to ameliorate the consequences of government-imposed conditions of lockdown (McCausland, Luus, McCallion, Murphy, & McCarron, 2021, People First Dorset, 2021). There is however contradictory evidence around the online activities of people with intellectual disabilities; some research suggests that social media activity among this group is characterised by risk, vulnerability and support (Caton and Landman 2022), while other studies highlight increased social inclusion and relationships, the development of self-esteem and enjoyment, and accessing information (Chadwick, Chapman, & Caton, 2019; Shpigelman, 2018; Seale et al 2019; Martin et al 2021). Anderson’s paper alerts us to issues relating to the interaction between self-advocates and disability researchers, including how and when we work together and what we can do to facilitate collaboration online.

Anderson found considerable negativity on social media towards the involvement of disability researchers giving evidence at the Hearing. Disability advocates strongly articulated how non-disabled people should not be speaking for them and it was arrogant to try to do so. Evidence that did not resonate with people’s experiences was discounted and the study found a lack of understanding around the research methods underpinning the evidence being heard. For Anderson, some of this negativity was interpreted as threatening or inappropriate and she points to similarities with a Twitter ‘spat’ among UK based disability advocates and researchers in 2020 when researchers were challenged about how inclusive their research was in practice. I was part of this series of exchanges, and this can be an uncomfortable space with little guidance for how to respond. In part, responses are influenced by the level of comfort and engagement people have with the platform more generally.

The appeal of social media platforms, in this case, Twitter, varies. Some people embrace the medium and regularly engage in it professionally, personally, or both. It can be a stimulating and democratising space where people are able to contribute their views, knowledge, and expertise around limitless topics. Others are less enthusiastic and view social media as an add on rather than an actual space of interaction and engagement. Anderson makes the point that social media is not like 'the terrestrial world' which is governed by normative rules and expectations. These rules generate familiarity and a sense of safety. She contrasts the negative responses of the Twitter commentators with productive and fruitful partnerships which exist between advocates and researchers. These collaborations are, however, typically organised and managed by researchers, policy makers or other professionals with little space for spontaneity, creativity or even 'unruliness' in such a controlled environment. There is a risk here that, while articulating their concerns without necessarily following conventional rules of engagement, what the commentators are saying is dismissed as wrong threatening.

That self-advocates and allies have the freedom to say what they think in a public arena should be applauded. Twitter, and other social media platforms, potentially offer opportunities for developing relationships, collaborative work and engagement between people in ways unfettered by academic forms of convention. Our challenge is for researchers to work better with self-advocates on their terms, including how, when, and if combined perspectives are needed, as in the context of a formal situation like the Royal Commission. As researchers, we need to better understand how to engage with and respond to online commentary about our work, particularly when this commentary is negative. I am concerned that viewing such comments as threatening implies ownership of a space which is contrary to inclusive research and the associated challenges of power imbalances. People who are marginalised often have no choice other than to use techniques of resistance that are, by definition, outside of the way things usually work. We must take care not to interpret these interactions with a normative lens of a mainstream world in which behaviours are ordered (and controllable).

We need to learn to navigate this terrain more effectively while remaining mindful that many people with intellectual disabilities are excluded from this space. If research evidence is dismissed by disability activists, it is incumbent upon us to present our methods and our findings in a more accessible way. Anderson highlights how some research findings can be complex and difficult to understand, however there is considerable scope to try to bridge this inaccessibility gap. This could include, for example, producing and sharing short video or audio clips about our research, presenting our findings directly to self-advocacy groups and producing easy-read booklets about different research methods. The British Journal of Learning Disabilities, for example, has introduced 'Responding to...' papers where self-advocates are invited to comment on journal publications (see, for example, Hopkins et al, 2022). This process includes discussing the paper with the authors to enable a richer understanding of the research to be shared before the commentary is written. While we have typically focused on including people in research, we have much more work to do around making our research methods and approaches understandable and accessible. This could have headed off some of the frustration expressed by the Twitter commentators around the evidence presented at the Hearing. Finally, Anderson recognises that some Twitter responses are reflective of a deep and understandable anger and frustration at the slow pace of change. We should not lose sight that, as researchers in this area, we are implicated in this.

References

Anderson, S (forthcoming) Threats to valuing diverse voices in public debates about disability. A case study from social media. *Research and Practice in Intellectual and Developmental Disabilities*.

Caton, S., & Chapman, M. (2016). The use of social media and people with intellectual disability: A systematic review and thematic analysis. *Journal of intellectual and developmental disability*, *41*(2), 125-139.

Caton, S., & Landman, R. (2022). Internet safety, online radicalisation and young people with learning disabilities. *British Journal of Learning Disabilities*, *50*(1), 88-97.

Chadwick, D., Ågren, K. A., Caton, S., Chiner, E., Danker, J., Gómez-Puerta, M., ... & Wallén, E. F. (2022). Digital inclusion and participation of people with intellectual disabilities during COVID-19: A rapid review and international bricolage. *Journal of Policy and Practice in Intellectual Disabilities*.

Hopkins, R., McGrath, J., Hogan, B., Skehan, P., & Acheson, L. (2022) In response to "'Ethno… graphy?!? I can't even say it': Co-designing training for ethnographic research for people with learning disabilities and carers". *British Journal of Learning Disabilities*. 50 (1)

McCausland, D., Luus, R., McCallion, P., Murphy, E., & McCarron, M. (2021). The impact of COVID-19 on the social inclusion of older adults with an intellectual disability during the first wave of the pandemic in Ireland. *Journal of Intellectual Disability Research*, *65*(10), 879-889.

Martin, A. J., Strnadová, I., Loblinzk, J., Danker, J. C., & Cumming, T. M. (2021). The role of mobile technology in promoting social inclusion among adults with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, *34*(3), 840-851.

Seale, J., Choksi, A., & Spencer, K. (2019). 'I've been a whizz-kid since I've been at college': Giving voice to the collective memories of adults with learning disabilities about the role that technology has played in their lives. *Disability Studies Quarterly*, *39*(4).

Shpigelman, C. N. (2018). Leveraging social capital of individuals with intellectual disabilities through participation on Facebook. *Journal of Applied Research in Intellectual Disabilities*, *31*(1), e79-e91.