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

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ABSTRACT

This study aimed to highlight the threats that use of social media poses to valuing diverse voices and different kinds of expertise about disability in public debates by exploring how disability advocates responded on social media to the evidence presented by researchers to the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability. Data were collected from the social media platform Twitter during the first week of Public Hearing 3 of the Royal Commission in December 2019. Tweets by 48 individuals and 27 representatives of advocacy groups who were not described as academic researchers in their Twitter profile were collected, anonymised, and coded using template analysis techniques. Findings showed that social media commentators were critical of the presence and participation of researchers in the Commission hearings and questioned the legitimacy of their research methods and findings. These commentators stated that researchers should not speak "for" or "about" people with disabilities and rejected evidence that did not resonate with their own individual experience. For the Commission to deliver meaningful recommendations to improve the disability sector, disability policy and the lives of people with disabilities, it is important to value both stories of lived experience and rigorous research evidence. Public discourse that undermines the relationships between researchers and disability self-advocates and advocates may be unhelpful for future collaboration on the development of better policy and practice.

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In the last two decades, co-production or inclusive research has become important as a way to bring together the lived experience of people with disabilities and the work of disability researchers. While "working together" is lauded as a gold standard in policy, there are important questions to be asked about representativeness and power in research projects (Bratteteig & Wagner, 2012, Chinn & Pelletier, 2020; Walmsley et al., 2018). The advocates and self-advocacy groups who are invited to be part of research

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*Accepted under the editorship of Dr. Chris Fyffe, Associate Editor, *Research and Practice in Intellectual and Developmental Disabilities* projects (Anderson & Bigby, 2017; Chinn & Pelletier, 2020) are often people with developed skills in speaking out, already actively engaged in policy consultation, and are not necessarily "representative" of all people with disabilities (Walmsley, 2004). For people with intellectual disabilities, there are key issues to be addressed in the design and conduct of inclusive research to ensure "genuine participation" (Raman & French, 2021), which avoids tokenism or the exclusion of people with severe and profound disabilities. The goal of "equal partners" (New South Wales Council of Social Service, 2017) is a simplistic one, which risks glossing over some of the inherent tensions in the processes and activities of co-producing work (Chinn & Pelletier, 2020). A number of authors have written about the challenges of doing inclusive or participatory research with people with intellectual disabilities (Bigby et al., 2014; Dowse, 2009; Harrison et al., 2001). They raise questions about the roles of both the people with disabilities and academics in conducting and disseminating the research, and how both "fidelity" to lived experience and "feasibility and rigour" in research can co-exist (Bigby & Frawley, 2010; Chappell, 2000; Conder et al., 2011; Kiernan, 1999; Nind, 2011; Ramcharan et al., 2004). In spite of some of these challenges, people with intellectual disabilities and researchers can bring a range of complementary skills to research projects, which can make a significant contribution to knowledge and improve quality of life.

There are many voices in disability policy and practice in Australia and the roles that self-advocates, advocates, and their organisations play are significant. Disability researchers, some but not all of whom use inclusive methods, also have important roles to play in generating an evidence-base to support better practice in the disability sector and better outcomes for people with disabilities. Debates about the weight and relative importance of the contribution of these groups highlight some of the ongoing challenges of bringing together the perspectives of those with lived experience and others with research knowledge (Liddiard et al., 2019) in fora such as the Commission and in public debates about disability. Some of the most public of these debates, occurred on the social media platform Twitter during the hearings of the Commission discussed in this article.

Social media platforms and their almost ubiquitous use have altered the ways in which individuals express both approval and outrage, unconstrained by some of the factors that limit them in the terrestrial world (Crockett, 2017). Golder and Macy (2015) described Twitter as a "digital socioscope," recording human behaviour and interactions in real time, becoming an important if flawed forum for commentators and citizen journalists to initiate and direct debate about both broad and niche social issues. Twitter posts provide opportunities to observe immediate, reflexive, and unpolished responses of social media commentators to a phenomenon. Analysis of tweets can give important insights into the ways that different groups react to what they see or hear, providing in some ways a microcosm of perspectives. Issues relevant to people with disabilities, and the disability sector more broadly, are energetically commented on and debated on social media when a significant public event like the Commission provides a focal point for debates.

The establishment of the Commission in April 2019 was an important outcome of sustained advocacy by many people with disabilities, disability advocacy organisations such as People with Disabilities Australia, and prominent individuals like Greens Senator Jordan Steele-John (Hutchens, 2018). Royal Commissions are used by Australian governments to inquire into issues of "public importance" (Tjandra, 2021) and they have "prestige, independence, and coercive powers" (Tjandra, 2021, p.6), which lend weight to their findings and recommendations. The terms of reference for the Commission were developed in consultation with the state and territory governments, disability peak bodies, and advocates. They covered what should be done to:

- prevent, and better protect, people with disability from experiencing violence, abuse, neglect and exploitation
- achieve best practice in reporting and investigating of, and responding to violence, abuse, neglect and exploitation
- promote a more inclusive society that supports the independence of people with disability and their right to live free from violence, abuse, neglect and exploitation. (Royal Commission into Violence Abuse Neglect & Exploitation of People with Disability, 2021, p. 1).

Themes were developed for a series of public hearings held in different states beginning in September 2019. At the time of writing, the Commission had been running for 2 years and held 16 public hearings. It is due to report its findings to the Australian Government in September 2023.

The Commission hearings received some attention from mainstream media outlets, most prominently from ABC television, whose reporter Norman Hermant was present for most of the sessions and filed several reports. The graphic and distressing accounts of experiences of abuse presented on the first two days by several frank and courageous self-advocates with intellectual disabilities attracted most coverage. On social media, the Commission itself was active in sharing updates about the timetable of hearings and witnesses and responding to questions. During the week-long Public Hearing 3, disability advocates were highly engaged with the Commission proceedings, particularly on the Twitter social media platform. This hearing was open to the public and the Commission made available a livestream with both sound and vision.

Chair of the Commission, Ronald Sackville, commented in his opening address that the scale of the task before it was significant "We are required, among other things, to expose violence against, and abuse, neglect, and exploitation of people with disability in all settings and contexts. We are to do this by means that include the sharing of individual experiences" (Royal Commission into Violence Abuse Neglect & Exploitation of People with Disability, 2019b, p. 3). Also included in his opening remarks was an expectation that different types of evidence would be presented, and that the Commission should provide a "forum" for people with disabilities to share their experiences. While he did not explicitly use the word "research" in his commentary, Sackville also stated that the role of the Commission is to "inquire what should be done" to promote a safer and more inclusive Australian Society, and that "relevant evidence" would be heard.

This article reports on a small study that explored the ways disability advocates responded on social media to the evidence presented by disability researchers to the Commission. It aims to highlight the threat that the use of social media poses to valuing diverse voices and different kinds of expertise about disability in public debates.

Method

Qualitative methods were used to collect and analyse the "tweets" posted by disability advocates and their organisations in response to evidence presented by researchers to the Commission during one week of the hearings, which took place in Melbourne, Victoria, in December 2019. The focus of the hearings was on experiences of living in group homes. The Commission called 25 witnesses to give evidence during this week, including people with disabilities, advocates, bureaucrats, a service provider, and academic researchers from the fields of disability studies, social work, law, and criminology.

Inclusion criteria

The study utilised publicly available tweets collected from the Twitter social media platform. Tweets were included if they were authored by individuals, or individuals on behalf of groups, who were not described as academics or as researchers in their Twitter profile, who tweeted about Commission Public Hearing 3, between 2/12/2019 and 06/12/2019, using one or more of the hashtags frequently used in tweets about the hearing during this period: #disabilityRC, #DisabilityRC, #DisabilityRCRage, #DisabilityRoyalCommission #OurRoyalCommission, #thisisourdrc, #ourdrc. Tweets (486 in number), which contained one or more of these hashtags, were collected. These tweets were posted by 48 individuals, and 27 representatives of advocacy groups. Using the protocol developed by Rivers and Lewis (2014), no geo-locating data were downloaded from the Twitter platform and no tweets have been included verbatim in this article, in order to limit the ability to use phrases to search for individual authors (Rivers et al., 2013; Rivers & Lewis, 2014).

Twitter is a public platform with millions of users. While many of these users are identifiable, there are many duplicate accounts, users with aliases, and tweets can be posted through auto-generation, making it impossible to ever confirm their source with a high level of accuracy. While it was not possible to verify the authors of the tweets, attempts were made to include only those that appeared to have been posted by known users, public organisations and advocacy groups, and self-advocates. While social media platforms offer opportunities for a wide range of people to participate in public discourse, a forum like Twitter is designed for use by literate and technically-skilled individuals, who can react in "real time." There is a level of complexity in its use that makes it inaccessible to many people with intellectual disabilities without significant support. The largely unmoderated nature of the Twitter platform and the lack of an ability to verify the authors or origin of tweets makes it difficult to say, with certainty, something of substance about the authors of tweets. Most of the tweets included in the data were from paid or volunteer advocates from advocacy groups and organisations. It is not possible to know whether the tweets were actively constructed with people with disabilities or whether the authors were themselves "speaking for" or "speaking about" people with disabilities.

The tweets were harvested from the Twitter platform and labelled before being anonymised. Only tweets in English language were included. Tweets that contained only personally-abusive content were removed from the data set. Template analysis was then used utilising the following steps: preliminary codes were assigned to the data in order to describe the content, patterns were observed and reviewed, and themes were then developed and named using a coding template (Brooks et al., 2015).

The study received approval from the Human Ethics Committee of La Trobe University, Australia.

Findings

Three key themes emerged from analysis of the data. These were; (1) critiques of the disability sector, (2) shock and distress in response to harrowing evidence about abuse, and (3) challenging the legitimacy of researchers.

Critiques of the disability sector

The tweets amplified the range of problems identified in the evidence presented with the way disability support services were delivered. These included poor communication between staff and service users and their families and carers, a lack of staff training, inadequate responses to complaints from group home residents about a lack of choice in daily living, a lack of privacy, and about dealing with the survivors of abuse and violence in ways that respected their human rights. Authors posted "staff don't know what they're doing half the time," "no one asks, and no one listens," "there's not enough respect," "staff walk in and out of bedrooms," "complaints are handled really badly," "problems get covered up." Group homes were characterised in a number of posts as being a "house" but not a "home" for people with disabilities. Many called for the immediate closure of all group homes.

Shock and distress

Evidence presented to the Commission included graphic descriptions of violence and abuse experienced by people living in some of the large institutions in Victoria during the 1980s. It included a detailed commentary on living conditions at Kew Cottages, the oldest institution for people with intellectual disabilities in the state (Victoria). All of this evidence was extremely upsetting for many observers and responses on Twitter were understandably ones of shock and sadness such as; "I can't bear this," "can you believe this?," "not acceptable!," "need to take a break and splash my face with water after listening to this awful story," "so horrific." Some questioned why material that could be "triggering and upsetting" for survivors of abuse was heard in a public rather than private session. Also presented was evidence about recent abuse in group homes run by a well-known disability provider. This, too, prompted horrified reactions. For example, conduct of the CEO of service provider Yooralla, who was questioned about the way her organisation had responded to more recent criminal acts by staff and complaints of violence and abuse of people with disabilities, was described in tweets as "a series of moral and ethical failures," "a disgrace," and "totally inadequate."

Challenging the legitimacy of researchers

Many tweets challenged the presence of, participation in, and evidence provided by academic researchers at the Royal Commission. Authors of tweets on this theme reacted negatively to academics giving evidence writing; "why is a person without a disability speaking at the Royal Commission?," "this is a waste of time," "it's another person without a disability talking, we can speak for ourselves!," "it's another 'so-called professional' at the Royal Commission," "they think that they know about 'lived experience' when all they do is talk to people about it." The second day of the hearing week coincided with the International Day of People with Disability, and this generated some further commentary about the number of people without disabilities giving evidence at the Commission: "it's our day! why is this academic talking about us"; "our Royal Commission, our day, where are the people with lived experience?"; "disrespect to talk about us on this day"; "another bloody so-called expert." One account posted that an academic giving evidence wanted to see people with disabilities "disappear" from public conversations about the Royal Commission but did not identify which aspect of the researcher's submission prompted the comment. There were also some personal attacks on the manner and facial expressions of several of the academics giving evidence. Social media commentators commented negatively about their perceived demeanour posting that they "should show more humility"; "she smiled at the Commissioners, that's not respectful"; "why are they so pleased with themselves?"

Responding to the evidence

Some of the tweets endorsed the evidence presented by researchers, particularly their commentary about the lack of safe and affordable housing for people with disabilities, although other tweets questioned its veracity. It appeared that where the personal experiences of the social media commentators accorded with the research evidence presented, they offered an affirmation such as: "what he just said is true, my brother can't find a suitable rental anywhere"; "there's no choice, people with disabilities can only afford crappy places on the fringe of Melbourne"; "people live in group homes as there's no alternative"; "I believe what he says, not enough housing out there"; "I remember those bad things happening, she's telling the truth." Where evidence did not match the experience of the tweeters it was dismissed as being without value: "what is the point of this?"; "long-winded and irrelevant, I only want to hear about lived experience"; "again we hear from time wasters at our hearing." Many of the tweeters from advocacy organisations reacted angrily to research evidence about measuring quality in group homes and practices to improve the lives of people living in group homes: "why are we talking about 'good' group homes when we know they should all be closed tomorrow!"; "this is not useful, who cares about improving group homes, I hate them"; "if you haven't lived in a group home you have no business talking about it."

Research methods

Some of the tweets were critical of the methods used by researchers, even when those methods were not explicitly described or had been misunderstood: "how do they know if they haven't talked to every person in a group home, every person is different"; "she says she watched the staff working that's not the same as letting the people speak". A number used the term "inclusive research" meaning that there were co-researchers with disabilities working on research and described it as producing evidence of higher value than other methods: "if the research isn't inclusive then it's no good"; "people with disabilities are the experts they should decide what to research and do the work." One academic, who was asked directly if her work was "inclusive," responded that much of her work focused on the lives of people with severe and complex intellectual disabilities, who may not be able to contribute as co-researchers in a way that would be meaningful to them or to other researchers. Tweets in response to this were highly negative: "this is ridiculous all research must be inclusive"; "it's nothing about us without us, or we won't be part of your research"; "everyone can be a researcher."

Allies or not?

A number of tweeters used the word "allies" in their criticism of researchers presenting evidence at the Commission. They tweeted, for example: "people with disabilities need allies"; "allies let people speak for themselves"; "this person is not an ally she is talking about people's lives, it's so arrogant." One author posted that "people with disabilities carry a heavy burden, allies should step up" and that "allies should be loud," but later posted in response to a researcher speaking about her experience of supporting self-advocates; "they should show humility and not pretend to be on our side." The standpoint of people with severe and complex disabilities were not represented in the tweets, and tweets did not acknowledge the evidence presented by some of the researchers about the experiences of this particular group.

Discussion

The focus of the discussion is the third theme, "challenging the legitimacy of researchers," as it illustrates some of the challenges of respecting different perspectives confronted by stakeholders in the disability sector. A key finding was that criticism made on social media by advocates about the academic researchers was their presentation of something other than the authentic voices of people with disabilities. There seemed to be a perception that in "speaking about" they were "speaking for" individuals or groups of people with intellectual disabilities. For example, researchers who were presenting evidence about decades-long or nationwide studies were not making claims about individual experience but providing commentary on patterns and practices in the sector. There was also no acknowledgement in any of the tweets that researchers may themselves be speaking about their own lived experience.

Commentary about inclusive or co-produced research suggested that the social media commentators believed that this approach would be more likely to generate what they regarded as the authentic voice of people with intellectual disabilities. There was no acknowledgement that it would never be possible to hear the voices of all individuals, particularly those with severe and complex disabilities, or that the constraints of the hearing may not have afforded researchers the opportunity clearly explain the ways in which rigorous research attempts to uncover and describe social phenomena more broadly. The implication from some of the tweets that inclusive research might somehow have produced different evidence suggests a lack of understanding that ethical and rigorous research does not have to be a positivist exercise, but in the context of the disability sector, a reflexive approach within a human rights framework can produce valuable findings.

It seems possible that if inclusive research was presented to the Commission, it may have attracted less criticism from tweeters, but it may also have been rejected if it had been presented by academics. Goodley and Moore (2000), themselves academic researchers, suggested that the disability movement is “routinely side-lined” by academic discourse as it is “convenient” for academics to produce work that is inaccessible to people with intellectual disabilities. From my perspective, as an academic observing the evidence presented to the Commission, there are a few problems with Goodley and Moore’s claim. Some of the evidence presented to the Commission was indeed complex, drawing on years, and in some cases decades, of extensive and rigorous research. There was little indication that researchers were “conveniently” producing inaccessible outputs, but undoubtedly some of their evidence was difficult to understand, particularly for people with intellectual disabilities. Some of the evidence presented had been produced using “inclusive” methods, but for those tweeters who took the stance that researchers were “so-called professionals,” even this was regarded as a poor or unacceptable substitute for individual life stories. Personal stories are powerful and important but without research, it is hard to compare them and to “debate and discuss” their implications for practice (Funnell, 2021, p. 15–30).

Another perspective may be that “research can be exploited” to draw academics and people with disabilities together to create knowledge and challenge structures and practices that negatively impact on people with disabilities (Goodley & Moore, 2000). However, this seems unlikely if one party partially or wholly rejects the work of the other, as was suggested by these tweets. Understanding more about why the evidence presented by researchers drew such a strong negative response from Twitter authors may be important for future research collaborations and for planning dissemination of inclusive and non-inclusive work.

Criticism of the academics giving evidence was, in some instances, quite derogatory and personal, and while Commissioner Sackville had cautioned against any person “using social media to cause damage, disadvantage or loss” (Royal Commission into Violence Abuse Neglect & Exploitation of People with Disability, 2019a), the very nature of the Twitter platform seems to create a disinhibition to malign and discredit.

While it is outside the scope of this article to provide commentary on the effectiveness of the Commission itself as a vehicle for presenting a range of types of evidence, these findings mirror the conclusions of a wider body of research that suggests social media commentary would be of dubious value as a forum for considered analysis of its activities.

It is a problem for reasoned public discourse and for the making of good public policy that research, which may be complex or deal with sensitive topics, might be suppressed or over-simplified to satisfy a small number of social media users. In the same way that some disability advocates on Twitter argued that researchers should not "speak for" or "speak about" people with disabilities, they repeatedly did so themselves.

Limitations

This was a small case study based on data from a five-day period using particular hashtags. Following these tags beyond the period of the Commission hearings may have generated useful additional evidence about the perspectives of the social media commentators. The theme of the hearings in the week of this study was "group homes for people with disability"; it is not known whether evidence presented by researchers at past and future hearings that focus on other aspects of the sector (e.g., health or education) would generate similarly negative commentary and, therefore, it is not possible to generalise these findings. The protocol for using Twitter for research developed by Rivers and Lewis (2014) provided a useful tool for extracting and analysing the data. However, the issue of balancing privacy and confidentiality in the presentation of data from a source where identities cannot be verified remains a significant challenge in using data collected from this platform.

Conclusion

People with disabilities were among the most vocal proponents of a Commission (Hutchens, 2018), and they are right when they say that there is much work to be done to challenge the barriers that continue to prevent people with disabilities from living full lives of their own choosing. Some of the tweets in this study are reflective of a deep and understandable anger and frustration at the pace of change. There are an increasing number of examples of people with disabilities, individually or through advocacy and self-advocacy organisations, participating in policy review and development and research. These collaborations are important and, in my experience, fruitful. The negativity of the Twitter commentators presented here towards research and researchers contrasts starkly to the productive partnerships between researchers and people with disabilities that have led to good outcomes in practice (Salmon et al., 2018; Walmsley et al., 2018)

Social media platforms and other public forums offer advocates opportunities to be highly critical of researchers for "not being inclusive" and dismiss research findings as being less credible than lived experience. Understanding more about this response is important for researchers to enable them to more effectively communicate their findings and develop inclusive collaborations. The power of the anecdote, the life story, the evidence of people with disabilities presented at the Commission, is undeniably important. The evidence presented by researchers is also powerful. It had a strong human-rights focus and reflected many of the current challenges in understanding the considerable work that needs to be done to enhance the self-determination and well-being of people with intellectual disabilities who live in group homes. To dismiss or diminish the evidence presented by either of these groups would be a grave error. No individual can speak for all individuals and no research can capture each and every person's experiences. A number of the researchers and some parents who presented at the Commission made people with severe and profound intellectual disabilities the focus of their evidence and this is important because they were not represented by others giving evidence, nor were they participants in discourse on social media.

As a postscript, I point to similarities between the trend identified in this case study whereby advocates challenged the legitimacy of researchers using Twitter and what occurred throughout 2020, in the United Kingdom, when prominent disability advocates used Twitter as a vehicle to challenge researchers about a perceived lack of inclusivity and the limited availability of "easy read" versions of research data and reports. Advocates echoed the language used in responses to the Commission, referring to researchers as "ableist," "unprincipled," "unethical," and "not allies," and calling their work "bullshit" and "tokenistic." Some of the United Kingdom researchers responded by withdrawing from the platform, others by providing examples of where their work has sought to be inclusive, and a few with more personal rebukes; "you are bullying people"; "don't try to stir up trouble, be involved in the project if you want things to change"; "you are mean and unhelpful." Engaging in this way seems unsatisfactory for all parties and once one spat ends, another quickly begins.

In 2007, Neil Crowther attracted some criticism from both disability activists and academics with his paper entitled "Nothing without us or nothing about us." He argued that the entrenched disadvantage experienced by people with disabilities needed to be tackled through "alliances" between people with disabilities themselves and others including "collaborators." Oliver and Barnes (2008) response described Crowther as "well-intentioned" but "misguided" and not showing adequate "respect" for the achievements and history of disability movements. There are strong echoes of this dialogue in the Twitter material presented in this article, and it seems unlikely that when the findings of the Commission are published that the perspectives of the authors of those tweets will have shifted.

There will be major challenges ahead in the implementation of the reforms likely recommended by the Commission, and "isolationism" (Crowther, 2007) on the part of any of stakeholder group in the disability sector will do little to promote better lives for people with disabilities. In the Commission's hearings, while disability advocates on Twitter were strongly stating a desire to see all group homes closed, researchers were presenting a pragmatic and nuanced view about living conditions and practice in those homes. Researchers not overtly "anti" group homes were interpreted by some on Twitter as being "pro" group homes. Moving debate about such important issues as where and how people live from such polarising assumptions will be critical to rigorously making the case for improving the quality of life for people living in groups homes by changing the way they operate or perhaps closing them down.

People with intellectual disabilities are not highly visible in the Australian community. Research evidence and their stories of lived experience can co-exist to provide different lenses through which to view policy and practice and advocate for change. There is scope for more work to be done to better understand the ways in which "representativeness" (Chinn & Pelletier, 2020) is understood and communicated in research. Researchers can also work more closely with people with disabilities to "distil" (Walmsley et al., 2018) and share their findings (Chinn & Pelletier, 2020). Oliver himself in 2019 also argued for an alliance between activists and researchers (and those who are both activists and researchers) for the same end: "Disability activists and academics need to support each other to ensure that those cracks where the light gets in are blown wide open" (Oliver, 2019). More broadly, there is a danger that if research is not used to the fullest extent to inform change in the disability sector, potential benefits to the quality of life and the full exercise of the human rights of people with disabilities may be delayed or remain unrealised.

Disclosure statement

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