

Brain injury community: seeking action on Royal Commission findings

I was an anaesthetist and intensive care specialist, commissioning Western Australia's first non-tertiary intensive care unit and becoming the State Medical Director of DonateLife WA. On 16 September 2018, I broke my neck, lumbar spine, jaw, multiple ribs and both hands in a cycling accident during a charity race in Melbourne. Worst of all was the diffuse axonal brain injury that ultimately ended my medical career. That trauma paved the road to a new life for me, writing about my own experiences as a survivor and working as a researcher and advocate for vulnerable Australians, especially those who are members of the brain injury community.

The Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability¹ was established in 2019 to address the discrimination and lack of awareness that affects so many of us who are disabled and marginalised. Recognising and dealing with the day-to-day challenges associated with disability is the key to reducing the exploitation and neglect of those who are vulnerable. The *Disability Discrimination Act 1992* (Cth)² and the International Convention on the Rights of Persons with Disabilities (ratified by Australia in 2008)³ already prohibit discrimination on the grounds of disability. The Senate Community Affairs References Committee's very first recommendation in 2015⁴ was for a Royal Commission into violence, abuse and neglect of people with disability. Three and half years later, the Australian Government established the Royal Commission and engaged in extensive consultations to settle the terms of reference.¹

Five years on from my traumatic brain injury, the process of rehabilitation continues. I am learning to live outside of the career I love through advocacy, and I remain hopeful for a productive, dynamic future. My optimism, however, does not extend to meaningful action following the publication of the Royal Commission's report on 28 September 2023.¹ The Commission's four-year program of public hearings, research and harrowing individual depositions revealed the scale and extent of the violence, abuse, neglect and exploitation of people with disability.

Sustainable policies and practices are needed to translate the values and standards of our communities into the human rights of people with disabilities. Such a change will require government commitment and the collective effort of public institutions, private organisations, and society at large. There must be a shift from seeing disability as a limitation to recognising it as a different but equally valid way of experiencing the world.

As someone living with the consequences of a brain injury, I am acutely aware of the challenges we face in dismantling systemic barriers and fostering inclusivity. Nevertheless, I also witness the resilience and potential within the disability community. The richness of our contributions and the diversity of our

perspectives, not our injuries, define us. The road ahead is lined with opportunities for innovation, understanding and transformation but is also fraught with obstacles.

Traumatic brain injury in Australia is a common and difficult problem to address. Extrapolating from New Zealand data,⁵ there are 190 000–200 000 cases per year in Australia, of which about 20 000 are moderate to severe injuries. The complex nature of brain injury means that the rate and degree of patients' recovery varies greatly.⁶ Severe traumatic brain injury has a high mortality rate of 30–40%, and less than 50% of patients achieve long term independence.⁷ The lifetime costs per incident case of traumatic brain injury are estimated to be \$2.5 million for moderate injury and \$4.8 million for severe injury across Australia.⁸ From 2006 to 2015, there was no improvement in either survival rates or functional recovery for people with traumatic brain injury. This rehabilitation failure indicates a significant need for the development of more effective treatments that can decrease death rates and enhance the quality of life for brain injury patients, as well as alleviate the broader, adverse effects on families and society.⁹

The Royal Commission envisions an inclusive Australia where individuals with disabilities have equal opportunities to enjoy life, make meaningful community contributions, and experience cultural safety and belonging.¹ Its 222 recommendations outline the full extent of the disabled community's expectations, including autonomy, access, and the dignity to make choices and take risks. Key focus areas are inclusive education, employment, housing, and fair treatment within the criminal justice system. Additionally, there is an emphasis on improving experiences for First Nations people with disabilities and enhancing disability services through the National Disability Insurance Scheme Quality and Safeguards Commission. The Royal Commission also aims to strengthen governance, measure changes effectively, enhance independent oversight, and ensure effective complaint mechanisms, all while monitoring the progress and effectiveness of these implementations.

In my own experience, traumatic brain injuries are a disturbing mix of physical and psychological experiences. Walking is not just a matter of balance and coordination; it involves conquering fears of humiliating unsteadiness and falling. Speaking is not simply a means of communicating my needs; it also allows me to express my pain and anxieties. Writing about the past is not just a rehash of old yarns; recalling who you were creates a path to the future. My family inspires me to keep living and fighting for my newfound community. We are forever grateful for the support provided by acute and rehabilitation teams of doctors, nurses, physiotherapists, occupational therapists, and neuropsychologists who

Bruce Powell¹

Joshua Powell²

¹ Monash–Epworth Rehabilitation Research Centre, Monash University, Melbourne, VIC.

² School of Psychological Sciences, Monash University, Melbourne, VIC.

bruce.powell@monash.edu

doi: 10.5694/mja.252178

have helped me to this point. My wife and I have had the pleasure of meeting other members of the acquired brain injury community across Australia, and those occasions are always emotional and poignant, reminding us of how lucky I am to survive and advocate for the brain injury community and other vulnerable groups.

Implementation of the Royal Commission's recommendations is a matter of great urgency and necessity. While Australia remains divided by constitutional issues related to the recognition of our First Nations people, the future for vulnerable groups within the Indigenous community and beyond remains uncertain. The Commission's recommendations demand wide-ranging innovation and cooperation across Australia's states and territories at a time when bipartisan collaboration is low.

Rehabilitation from the devastating, life-changing impact of traumatic brain injury demands a great deal of hope and faith. We hope that all Australian jurisdictions care enough about the plight of the disabled community to act swiftly and decisively upon the Royal Commission's recommendations. Meanwhile, we will keep faith in the commitment and skills of our health care professionals and their remarkable work for the vulnerable such as those with brain injuries.

The Royal Commission's vision is to create "a more inclusive society that supports the independence of people with disability and their right to live free from violence, abuse, neglect and exploitation".¹ Will the governments tell our communities which recommendations they plan to act on, which they do not, and why? Will the needs of the brain injured, and other vulnerable communities trigger bipartisan collaboration and cooperation?

The Australian federal, state and territory governments have until 31 March 2024 to publish their written responses to the Commission's recommendations. We will hold them to that timeline. It is time to deliver.

Competing interests: No relevant disclosures.

Provenance: Not commissioned; not externally peer reviewed. ■

© 2023 AMPCo Pty Ltd.

- 1 Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability. Final report: executive summary, our vision for an inclusive Australia and Recommendations. Canberra: Commonwealth of Australia, 2023. <https://disability.royalcommission.gov.au/system/files/2023-11/Final%20report%20-%20Executive%20Summary%2C%20Our%20vision%20for%20an%20inclusive%20Australia%20and%20Recommendations.pdf> (viewed Nov 2023).
- 2 Federal Register of Legislation. *Disability Discrimination Act 1992* (Cth). <https://www.legislation.gov.au/Details/C2018C00125> (viewed Nov 2023).
- 3 United Nations. Convention on the Rights of Persons with Disabilities (CRPD). <https://social.desa.un.org/issues/disability/crpd/convention-on-the-rights-of-persons-with-disabilities-crpd> (viewed Nov 2023).
- 4 Parliament of Australia, Senate Standing Committees on Community Affairs. Violence, abuse and neglect against people with disability in institutional and residential settings, including the gender and age related dimensions, and the particular situation of Aboriginal and Torres Strait Islander people with disability, and culturally and linguistically diverse people with disability. Report, 25 Nov 2015. https://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Community_Affairs/Violence_abuse_neglect/Report (viewed Nov 2023).
- 5 Feigin VL, Theadom A, Barker-Collo S, et al. Incidence of traumatic brain injury in New Zealand: a population-based study. *Lancet Neurol* 2013; 12: 53-64.
- 6 GBD 2016 Traumatic Brain Injury and Spinal Cord Injury Collaborators. Global, regional, and national burden of traumatic brain injury and spinal cord injury, 1990-2016: a systematic analysis for the Global Burden of Disease Study 2016. *Lancet Neurol* 2019; 18: 56-87.
- 7 Myburgh JA, Cooper DJ, Finfer SR, et al. Epidemiology and 12-month outcomes from traumatic brain injury in Australia and New Zealand. *J Trauma* 2008; 64: 854-862.
- 8 Access Economics. The economic cost of spinal cord injury and traumatic brain injury in Australia. Report by Access Economics Pty Limited for The Victorian Neurotrauma Initiative. June 2009. https://scia.org.au/wp-content/uploads/2022/02/Access_Economics_Economic_Cost_of_sci_and_tbi_in_Australia_June_2009.pdf (viewed Nov 2023).
- 9 Beck B, Gantner D, Cameron PA, et al. Temporal trends in functional outcomes after severe traumatic brain injury: 2006-2015. *J Neurotrauma* 2018; 35, 1021-1029. ■