Damian Mellifont &
Jen Smith-Merry (Eds.)

LIVED EXPERIENCE OF DISABILITY

Disability Research and Australian Disability Policy

Disability Studies

Collection Editor
DAMIAN MELLIFONT

LIVED PLACES
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Abstract

This volume is informed by authors with lived experience of disability as well as genuine disability allies who hold a common passion towards making positive and practical differences in the lives of people with disability across Australia and further afield. It provides you with an opportunity to read and learn about lived experiences of disability together with their practical implications for future disability research and policy directions. Policy issue areas addressed in this book are wide-ranging and include those of codesign shortfalls, restrictive practices, linguistic and information deprivation, challenges confronting older people with dual sensory impairment, healthcare shortfalls in rural settings and the need for an increase in codesigned research in higher education and more broadly in policy design. Included in the volume are intriguing and timely research topics which hold strong potential to inform evidence-based disability policy in Australia as well as other places.

Key words

disability, policy, Australia, research, lived experience, inclusion

Contents

Content warning

Readers are cautioned that this book contains references to and descriptions of violence, restrictive practices, suicidal ideation and disability discrimination. Readers are also advised that references to disability discrimination and restrictive practices are prevalent in Chapters 1 and 3, respectively.

Learning objectives

1. To understand the complexities and challenges in defining what counts as lived experience of disability.
2. To understand and explain the negative impacts of information accessibility gaps for people with disability.
3. To be able to explain why stakeholders with lived experience of disability need to be genuinely included in the codevelopment of disability policies in Australia and elsewhere.
4. To be able to describe some of the pressing disability issues in Australia that are yet to be recognised by policymakers.
5. To be able to identify some of the key barriers to including and valuing scholars with disability in Australian universities.
6. To be able to describe the various benefits that accompany disability research and broader policy that is codesigned and codeveloped with researchers with disability.

Introduction

Welcome to this exciting addition to the Disability Studies Collection. In the following chapters, you will read about lived experiences of disability together with their practical implications for future disability research and policy directions throughout Australia. We trust that you find these lived experiences of disability and related research and policy discussions to be engaging, educational and inspiring. This book is informed by authors with lived experience of disability as well as genuine disability allies who hold a common passion towards making positive and practical differences in the lives of people with disability across Australia and further afield. Please note that the first Editor will have more to say in relation to lived experience of disability in the chapter to follow where they delve deeply into this intriguing subject.

Why is the inclusion of lived experience of disability a central theme which binds the chapters of this book together? An appreciation and centring of the lived realities of any people's experiences are now increasingly fundamental to arguments which are supportive of self-determination and human rights (Bennett et al., 2024). Historically, people with disability have had limited involvement in redressing the disability policy issues which are key to their well-being (Ndlovu & Woldegiorgis, 2023). This is still the case and this gap continues to impact the way people with disability are included in society. There is much evidence supporting the role of stigma and discrimination towards excluding people with mental disability from employment, education and healthcare opportunities (Cummings et al., 2013; Evans-Lacko et al., 2012; Langmead, 2018). Yet, regardless of harmful disability stereotypes rarely impacting on people without disability, it is these persons who are often empowered to implement policy actions and decisions on behalf of the aforementioned population (Olsen, 2020). In a progressive development, the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) embraced a core principal that people with disability hold a fundamental right to be involved in the policies and decisions which affect them (Löve et al., 2017; Stein & Lord, 2010). By embracing this principal, the UNCRPD challenged a previously unrestrained norm in terms of who is included in disability policymaking (Löve, 2023). Specifically, Article 4(3) of this Convention requires governments to actively include people with disability in the development and implementation of disability policy and legislation (Löve et al., 2017). The rights of people with disability to be actively included and respected in disability policymaking activities therefore needs to be consistently acknowledged and enacted upon within Australia and beyond.

Advocacy has played a central role in promoting the inclusion of people with disability in disability policymaking. A right to participate in disability policymaking stems from the demands of people with disability to be treated as citizens who hold capacity to inform policy decisions and directions which impact upon their lives (Gunnarsdóttir & Löve, 2024; Quinn, 2009). This has been denied to people with disability in the past. As noted above, people with disability can hold shared experience of various forms of exclusion in society and the relevance of such experience to disability policymaking should not be downplayed. It is this shared experience which holds potential to build connections among people with disability, to progress meaningful engagement through this collective voice and to impact policy (D'Cruz et al., 2020; Veitch, 2024). Shared experience can act to inform not only pressing disability policy issues in employment, education and healthcare but also the measures that are urgently needed to redress them. Potential therefore exists for disability policymaking to be improved through having more people with disability who are not only qualified as policy professionals, but also who are qualified in terms of holding various lived experiences of disability (Mellifont & Smith-Merry, 2016). People with disability therefore need greater representation in codeveloping the policies that impact upon their lives as policymakers, and also as stakeholders who are included in welcoming and accessible disability policy consultations.

We the Editors of this volume hold a strong and shared appreciation for the importance of evidence-based disability policy that is informed by researchers with lived experience of disability and their allies. In putting together this volume we were motivated to have an open platform for people to present their perspectives on the inclusion of lived experience in policy in order to redress the gaps in current scholarship and policy design. Despite people with disability experiencing worse health than those without disability, various areas of disability policy interest remain under-researched (e.g. disability services and healthcare) (Krahn et al., 2015; Slattery et al., 2023). This indicates a need for greater government investment in disability policies whose issues and measures are informed by research that is either led by people with disability or codesigned with people with disability. Where disability studies are conducted, the inclusion of researchers with disability can vary from tokenistic inclusion right through to genuine inclusion as respected members of the research team (Bowers et al., 2008; Mellifont, 2023; Simpson, 2013). Smith-Merry et al. (2024) warned that the inclusion of researchers with disability risks falling away in the critical writing up of findings stage. By including lived experience of disability throughout the research process, power inequities can be challenged while the knowledge and expertise of the cohort to be most influenced by research findings is recognised (Chapman et al., 2024; Series, 2019). Conversely, exclusion of researchers with disability in studies about disability contributes to unequal opportunities for these researchers to be a part of knowledge production (including the academic careers that this knowledge production also supports), research that is not generalisable and ultimately poor disability policy outcomes (Ouellette, 2019; Rios et al., 2016; Slattery et al., 2023). Studies conducted with researchers with disability can require adjustments and accommodations, including access to assistive devices and other technologies; these are often not supported (or included) as part of research funding applications, which means that the knowledge of people who require support is also excluded (Watharow & Wayland, 2022). Consequently, the representation of researchers with lived experience of disability remains low where such accommodations for researchers with disabilities are needed (Bennett et al., 2024;

Mellifont et al., 2019). Unaccommodating disability research environments therefore need to be recognised and addressed as a disability policy priority.

We now provide a quick introduction to each of the following chapters. As mentioned above, in the upcoming chapter, the first Editor addresses the challenging question of who has lived experience of disability. Next, Jade McEwen critically discusses what 'good' disability policymaking codesign looks like. Bethany Easton and co-authors will then examine the pressing requirement to include lived experience perspectives in discourse concerning restrictive practices which confront people with disabilities. In their chapter, Cassandra Wright-Dole then draws on their lived experience of linguistic and information deprivation as well as scholarly evidence to call for recommendations to improve social and other outcomes for people with disability impacted by informational loss. Annmaree Watharow, Georgia Fagan and Moira Dunsmore discuss the importance of including the lived and living experiences of older persons with dual sensory impairment in disability policies and practices. Next, Scott Denton raises their policy observations, concerns and evidence-based ways forward regarding the pressing issue of experiences of Charcot-Marie-Tooth Disease in rural Australia. Jayne Garrod's chapter highlights the importance of participatory, insider, and codesigned research in terms of understanding the lived experiences of neurodivergent people. Last, Paul Harpur and colleagues investigate the University of Queensland's Champions of Change: Disability Inclusion Research and Innovation Plan in terms of its capacity to foster disability-inclusive research in higher education. Included among the chapters are suggested research topics which hold strong potential to inform evidence-based disability policy in Australia as well as other places. We conclude this text by offering learning objectives as well as a set of discussion questions for readers' careful consideration and responses.

Before going any further and reflecting our shared passion for disability research and disability policymaking, we would like to take this opportunity to offer our sincere thanks to the wonderful authors for their insightful and valuable contributions to this book. It was an honour and a pleasure to work with each of you in bringing this volume together. We would also like to thank the Lived Places Publishing cofounder, Mr David Parker, for his enthusiasm and support for not only this project, but also for the Disability Studies Collection more widely which we have both been enthusiastic champions of since its launch. We sincerely hope that you enjoy your reading journey into the lived experiences of disability as shared throughout this volume together with their implications for future disability research and policy directions in Australia and beyond.

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1

Who has lived experience of disability?

Damian Mellifont

I acknowledge the Turrbal people as the traditional owners of the land upon which this chapter was written and I pay my respects to elders – past, present and emerging.

Introduction

I start with a quick introduction of myself and this chapter, including its aims, scope and structure. I also provide a few words regarding the choice of language style that is to be applied throughout my writing.

I am currently employed as a Lived Experience Postdoctoral Fellow and Lecturer with the Centre for Disability Research and Policy (CDRP) at the University of Sydney, Australia. I have been with the Centre since 2014 when I first joined in an Honorary Postdoctoral Fellow role. I am now a member of the CDRP leadership team that sets strategic direction for the Centre and very much enjoy my employment in an accommodating and inclusive environment. Such an environment does not just magically appear. This welcoming and safe workplace culture has been championed by the Centre's former Director and respected disability researcher and ally, Professor Jennifer Smith-Merry. An inclusive CDRP work environment stands in stark contrast to my prior work experiences in a policy role in the public service. It was in this inflexible government setting where my approved accommodations were inconsistently provided and where I would not openly disclose my neurodivergence for fear of discriminatory responses.

Having a formal medical diagnosis of obsessive-compulsive-disorder (OCD), I am neurodivergent. As a neurodivergent researcher, my lived experience-led and co-produced studies are designed to have positive and practical impacts on the lives of people with disability. These studies inform about redressing ableism (i.e. disability discrimination), together with practical and timely ways in which to advance the greater economic and social inclusion of people with disability. For example, a study that I led with Professor Jennifer Smith-Merry and Dr Kim Bulkeley on the policy issue of disability employment (specifically the under-representation of employees with lived experience of disability across Australian Disability Services) revealed that only half of these service organisations have at least one employee with disability and less than a quarter (24%) of organisations have a board member with disability (Mellifont et al., 2023). Highlighting the policy relevance and timeliness of our study, this research informed questioning at Public Hearing 32 of the Royal Commission into the Violence, Abuse, Neglect and Exploitation of people with disability held in Brisbane from 13 to 17 February 2023. More broadly, my research advocacy efforts support the disability inclusion mantra of 'nothing about us without us' to be widely applied across disability research and policy settings in Australia and elsewhere.

I now commence this chapter by addressing the thought-provoking question of who has lived experience of disability? My response to this question is to be informed by a critical examination of scholarly constructions of lived experience of disability, together with their complexities and practical implications. Next, I critically discuss the topic of representations of lived expertise in disability research and disability policy spaces. I then build an evidence-based case for including more people with lived experience of disability in codesigned and co-produced disability research and policymaking activities. I conclude my chapter by providing readers with a summary of avenues for future research relating to the intriguing question of 'who has lived experience'?

Before this chapter gets underway, some quick words in relation to the disability language that is to be applied. Person-first language reflects the social model of disability where people are positioned before their disability (e.g. researcher with disability) (Disabled People's Organisations Australia, 2022). The social model of disability and its support for a removal of barriers to social inclusion and the introduction of anti-discrimination law stands in contrast to the medical model and its medicalisation of people with lived experience of disability (Linton, 1998; Shakespeare, 2006). I purposefully use person-first language in the writing of this chapter. And while I choose to identify as neurodivergent rather than a person with OCD, I do not expect others to follow my personal choice. That is to say, I respect the rights and freedoms of others to choose how they prefer to identify.

Scholarly constructions of lived experience of disability, complexities and practical implications

Now, onto the question of who has lived experience of disability? Noting the complex nature of this question, I start by recognising that the language of lived experience is open to construction with no fixed meaning available (Byrne, 2013; Mellifont & Smith-Merry, 2021). In terms of lived experience of disability, it needs to be realised that everyone has lived experience but not everyone has lived experience of disability such as mental ill health (Morgan & Lawson, 2015; Smith, 2014). Disability allies are included among this latter group. Woodard et al. (2012) noted the importance of disability allies as faculty champions in the academy. Allies can thus lay claim to holding lived experience in providing valuable disability allyships, as expressed in educational settings in this instance. These experiences, however, do not extend to the personal challenges that many staff and students with disability experience on and off campus. Prominent among these challenges is ableism (i.e. disability discrimination) (Mellifont, 2023; Mellifont et al., 2019). While there exists a 'uniqueness' to an individual's lived experience (Bennet et al., 2024, p. 9), shared insights can accompany direct experiences with dismissal and discounting (Byrne, 2017; Duvnjak et al., 2022). These are deep and intimate constructions that cannot be attained from simply reading about or observing discrimination as experienced by people with disability. Understanding can at times be difficult to put into words given the hurt, trauma and emotions involved.

Gaps in understanding as well as misrepresentations of disability are readily found in the field of disability care. Carers can be said to have lived experience of caring for people with disability. However, if a carer does not have a disability, the same individual cannot justifiably or ethically lay claim to having lived experience of disability. Rieck et al. (2019) captured the complexities of a mother who provided care for a young adult with an intellectual disability. It needs to be recognised however that this particular individual's lived experiences are different to the lived experiences of the person with intellectual disability for whom they care. Acknowledging the challenging and often times uncompensated work that many carers regularly carry out, respect for lived experience of disability is nevertheless needed to avoid misrepresentation. In this light, Chapman, Dixon, Kendall, et al. (2024, p. 2) explicitly stated in their methods 'to ensure that the scoping literature review was grounded in the perspectives of lived experience of disability, the authorship team was formed to include a senior academic (EK) who is a family member of people with disability and has personal experience of a degenerative disabling health condition'. Helping to explain this intersectionality, this particular senior scholar is exposed not only to their lived experience of disability, but also to the experience of having family members with disability.

Closely aligning to queries about who has lived experience of disability is the question of who holds expertise? Lived expertise is defined as 'knowledge, insights, understanding and wisdom gathered through lived experience' (Sandhu, 2017, p. 5). So, while lived experience can be thought of as raw experiences, lived expertise is the knowledge that comes from reflecting on these experiences (Cataldo et al., 2021). Hence, accompanying lived experiences of disability such as mental ill health is a level of expertise that cannot otherwise be rightfully claimed, and this expertise along with the voices of people with disability need to be privileged, respected and valued (Byrne & Wykes, 2020; Chapman, Dixon, Ehrlich, et al., 2024; Mellifont, 2019). For instance, peer researchers' insider expertise as gained through their lived experiences of homelessness successfully informed a study on this topic (Elliott et al., 2002; Massie et al., 2018). One does not have to search too far, however, to identify instances where respect for and representations of lived expertise is deficient or missing altogether. Gibbs (2022) made the observation that while many with lived experience are often the experts (e.g. academics, professionals), they rarely are positioned with the so-called experts who maintain power. While leaders without disability and their achievements in disability research and policy spaces need to be recognised and appreciated, it is the ethical leader without disability who is prepared to have power fairly redistributed with people who have relevant lived expertise and professional qualifications (or the capacity to develop professional expertise through training). It is noteworthy however that there exists no training in the world that can successfully provide lived expertise of disability to leaders without disability.

Remaining cognisant of the above-mentioned possibilities for misrepresentation and the protection of power bases, there are no set criteria that can be neatly applied to define what counts as lived experience of disability. Strong arguments are made against any direction or efforts towards the development of this criteria. Roennfeldt and Byrne (2020) posed the puzzling question of what counts as lived experience and what level or amount of lived experience is counted as 'enough'? In addition to this questioning, any attempts to develop and rigidly apply criteria to lived experience of disability is to risk dismissing individual differences by forcing people to justify themselves (Voronka, 2016; Waddingham, 2021). Complicating matters even further, organisational recruiters have expressed biases with preferences voiced for less disordered forms of disability, with lived experience of mental illness falling outside of what is considered 'a socially acceptable disability type' in many cultures (Bakhshi et al., 2006, p. 25; Waddingham, 2021). Anderson and Bigby (2023) also questioned the transferability of lived experience on occasions where boards of organisations that support people with intellectual disabilities engage individuals with lived experiences of sensory or physical disabilities. It should therefore not be assumed that lived experience of a particular disability somehow magically transfers into the holding of expertise in another disability type.

With multiple and at times competing constructions of lived experience, disability policymakers need to apply caution when engaging in related lively discussions which can and do ensue. According to Jones et al. (2021), debates about terminology, including that of lived experience, can act as a distraction from the significant policy issues at hand and where people with disability continue to be under-represented in policy activities. Activities that are key to informing about the disability challenges to be raised in the first place and subsequently how these issues are to be addressed (or, aligning with the satisficing model and reflecting the realities of policymaking, reduced). I have witnessed occasions on social media where individuals attempt to position their constructions of lived experience of disability as correct and unquestionable, while at the same time publicly disrespecting and demeaning the constructions of others. Upon reading such negative social media commentary, I cannot help but think that this energy would be better served in collaborative efforts to expose and address the common enemy of people with disability; this enemy being ableism (i.e. disability discrimination).

So far in this chapter, I have referred to *lived experience of disability* which implies reflections on or descriptions of past experiences with disability. Studies have, however, made mention of *living experience with disability* to capture various present happenings (e.g. the masking of disability, experiences of bullying etc.) (Anika, 2021; Dillaway et al., 2022). This highlights the appropriateness of language capturing disability experiences happening in the now in addition to those experiences which have passed. This brings us to future tense and *yet to be lived experiences of disability*. With around 15% of the world's population with lived experience of disability, this percentage is rising as people age (United Nations, 2024). 'Yet to be' lived experiences of disability is thus a growing policy issue for policymakers in Australia and elsewhere.

Appreciating the aforementioned complexities surrounding who has lived experience of disability as well as the timings of these experiences, freedom of choice in expressing lived experiences (e.g. experiences associated with madness, neurodivergence, survival, disorder, disability etc) is needed. Individuals can flexibly identify with one or more terms (e.g. mad, neurodivergent, survivor, disordered, person with disability) or other descriptors and at different times. From my perspective and as noted in my introduction, I identify as neurodivergent on the proviso that my