

COMMENTARY

Starting with us: Imagining relational, co-designed policy approaches to improve healthcare access for rural people with disability

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Abstract

Context: Access to healthcare for rural Australians is a wicked problem, particularly for rural people with disability. Contemporary healthcare access frameworks in Australia tend to overlook geography, use a 'one-size-fits-all approach', and disregard the valuable relationships between key rural healthcare stakeholders, including rural people with disability, rural health services and health professionals. The United Nation's Convention on the Rights of Persons with Disabilities requires the Australian Government to engage people with disability in the design of policies that will shape their day-to-day lives, including their access to healthcare. However, the nature and extent to which rural people with disability, rural health professionals and other key rural stakeholders are involved in the design of Australian policies impacting the health of rural people with disability are unknown.

Aim: This paper examines approaches taken to engage rural people with disability and health professionals in the design of Australian disability policy impacting healthcare access, and reimagines future processes which can improve healthcare access for rural people with disability.

Approach: Co-design and ethics of care lenses are applied to policy design approaches in this paper. We approach this work as rural disability and health academics, rural health professionals, and as rural people with disability, neurodivergence and family members of people with disability.

Conclusion: We argue future co-designed policy approaches could focus on driving change towards equity in healthcare access for rural people with disability by harnessing the relational nature of rural healthcare.

KEYWORDS

co-design, disability policy, ethics of care, healthcare access, rural populations

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1 | INTRODUCTION

There are over 4.4 million people in Australia living with disability.¹ People with disability experience more challenges in meeting public health guidelines and are at increased risk of preventable, chronic disease.² People living in rural, regional and remote Australia (rural herein) are more likely to experience poorer health outcomes than their metropolitan counterparts.³ This is concerning because rural people, including those with disability, face chronically poor healthcare access made more difficult by persistent healthcare workforce shortages in rural areas.⁴

Beyond inequities in health, healthcare access and rural health policy focus,⁵ the disparate geography of rural Australia has clearly shaped the health system, and the way rural people with disability engage with it. Rural people with disability often travel significant distances to access specialist services,⁶ although not everyone requiring services can travel.⁷ For Aboriginal and Torres Strait Islander people with disability living in remote communities, culturally responsive service access is particularly difficult due to a number of reasons, including a lack of services in place.⁸ The COVID-19 pandemic has presented new challenges for rural healthcare access, including state border closures and travel limits. The shift to telehealth service delivery has produced mixed results for people with disability, by reducing travel and allowing services to be provided in a comfortable and familiar place,⁹ but also introducing barriers due to technical access requirements, the digital divide, internet bandwidth and low socio-economic position also experienced by rural people.¹⁰ Health policy is required to reflect these diverse rural healthcare access experiences.¹¹

Resultant from the Australian geography is a rural healthcare system that is generalist in nature, where rural health professionals see rural people with a broad range of clinical presentations.⁴ This generalist approach emphasises the importance of the relationships that support access to healthcare for rural people with disability. Due to social and geographical proximity in rural communities, rural people and health professionals may know each other outside of healthcare. Such actual and potential dual relationships may support rural people to navigate and access healthcare, or create access barriers, for example due to concerns about anonymity.¹² Ethics of care is a moral theory that can help to understand relational characteristics in rural healthcare.¹³ Ethics of care emphasises the interconnected, interdependent and relational nature of humankind, rather than individualistic ideals that suggest people are able to freely interact with others on their own terms.¹⁴ Of particular importance, ethics of care suggests a 'primacy of connection', where there is an assumption of existing relationships rather than separation between

What is already known on the topic:

- Rural people with disability have poorer access to healthcare in Australia than their metropolitan counterparts
- Co-designed policies can help to shape suitable solutions to issues faced by people with disability
- Approaches to engaging people with disability in policy design vary

What this paper adds:

- Recent policy design relating to rural people with disability fails to harness the relational nature of rural healthcare
- Valuable connections between rural people with disability, rural health professionals and other rural stakeholders could shape co-designed disability policy approaches in the future

people and communities.¹⁵ Despite the associated healthcare access issues for rural people with disability, healthcare access frameworks often overlook geographical characteristics and disregard the valuable and existing relationships between key rural healthcare stakeholders,¹³ including rural people with disability, rural health services and health professionals.

In this commentary paper, we (Appendix S1) explore approaches taken to engage rural people with disability and health professionals in the design of Australian disability policy impacting healthcare access, because how these policies are designed can impact the extent of their influence on the day-to-day lives of rural people with disability. Adopting an ethics of care lens to understanding rural disability policy design makes clear how relationships are central to our experiences in the world, and by extension, how rural health professionals and other rural stakeholders are intrinsically involved in the process of navigating health access with rural people with disability.

2 | CURRENT STATE OF APPROACHES TO POLICY DESIGN

Over the last few decades, the nature of engagement expected in disability policy design has shifted. The concept of co-design is now commonly cited in policy documents, although often loosely used and poorly defined. Blomkamp¹⁶ defines policy co-design as a 'design-led process, involving creative and participatory principles and tools to engage different kinds of people and knowledge

in public problem solving' (p. 731). Following Blomkamp, co-design in disability policy requires policymakers to adopt an iterative approach that actively involves people with disability in the processes that define problems and identify solutions, and to use suitable tools to engage those involved in meaningful ways. The uptake of co-design in policy design relating to people with disability has been driven by the United Nation's¹⁷ Convention on the Rights of Persons with Disabilities. Article 4[3] states people with disability must be represented in the development of relevant legislation and policies. However, opportunities for representation do not necessarily address the disparate nature, community heterogeneity and geographical vastness of rural Australia.

The remainder of this paper discusses the engagement of rural people with disability, health professionals and other key rural stakeholders in the design of two recent disability policies that in the coming years will impact access to healthcare for rural people with disability in Australia: Australia's Disability Strategy 2021–2031,¹⁸ and the National Roadmap for Improving the Health of People with Intellectual Disability.¹⁹

2.1 | Australia's disability strategy 2021–2031

Australia's Disability Strategy 2021–2031 (the Strategy) builds on the National Disability Strategy 2010–2020 by listing the health and well-being of people with disability as one of seven outcome areas.¹⁸ In 2018, an independent review of the impact of the National Disability Strategy 2010–2020²⁰ involved targeted consultations with 150 representatives from key organisations (including government bodies, peak disability organisations, human rights commissions, service provider organisations and expert bodies). These consultations involved face-to-face focus groups in each state and territory, and face-to-face individual interviews, telephone interviews and written responses.²⁰ The review suggested the future Strategy look beyond the National Disability Insurance Scheme implementation, consider policy impact in other areas including for people living in rural areas, and improve responsive action with people with disability, community organisations and advocacy groups at government levels including at grassroots level.²⁰

The federal government's two-stage consultation on the impact of the National Disability Strategy 2010–2020 and proposals for the Strategy occurred in 2019 and 2020 respectively. Both stages involved stakeholders via targeted and public consultation,²¹ and policy development overseen by a steering group comprising disability and carer sector stakeholders—of which no rural specific

stakeholder groups were reported.²² In stage 1, 3751 people were consulted including people with disability, families and carers, advocates and service providers, disability representative organisations, support workers, educators, health professionals, academics and business owners. These participants were consulted via face-to-face community workshops (76% of workshop participants in metropolitan settings, 24% in rural communities and one workshop location unclearly reported), targeted consultations with Aboriginal and Torres Strait Islander people (in various non-reported locations in Tasmania, Northern Territory, Western Australia, South Australia and Queensland), face-to-face and online forums and via an online survey.²³

In stage 2, the Strategy position paper outlining government proposals to include in the Strategy was released prior to consultation. Engagement during this stage was conducted mostly online due to COVID-19, via focus groups, telephone interviews and workshops. These engagements were targeted at groups who were not well represented in stage 1, including people with intellectual disability, psychosocial disability, people with disability from culturally and linguistically diverse backgrounds, young people with disability and people with disability living in rural areas. This process also included families and carers, peak bodies, universities, service providers and individuals relevant to education, health, safety, justice and employment for people with disability.²⁴ The workshops provided an opportunity for stakeholders to inform ideas for inclusion in the targeted action plans to impact a relevant area within a 2-year timeframe. Ideas generated for action plans relevant to community attitudes on health and well-being of people with disability included requirements for co-designed health services with people with disability.²⁴ In addition to the two-stage consultation process, the Department of Social Services also conducted an online public submissions process, workshops with academics and Disability Representative Organisations, consulted Aboriginal and Torres Strait Islander people with disability, supported relevant webinars and engaged state and territory government officials.²⁴

The Strategy's consultation process included a range of stakeholders and adopted a range of engagement processes that have clearly informed the Strategy itself. For instance feedback provided via the consultation process informed ministerial agreement to establish an advisory council to advise ministers throughout the Strategy's implementation,^{18,25} which includes 'people with lived experience of rural and remote communities'.²⁶ However, the Victorian Council of Social Services²⁷ submission to the Strategy's position paper suggested that limited attempts to include people with disability in initial conversations about the Strategy's focus impacted the capacity for its co-design.

2.2 | The National Roadmap for improving the health of people with intellectual disability

The National Roadmap for Improving the Health of People with Intellectual Disability (the Roadmap) was released in 2021.¹⁹ The Roadmap resulted from the 'Our Health Counts—End Deadly Discrimination' campaign led by New South Wales Council for Intellectual Disability and Inclusion Australia²⁸—leading self-advocacy organisation and peak body for people with intellectual disability respectively. The Roadmap will form part of the federal government's Primary Health Care 10-Year Plan, once developed, and will work towards meeting health outcomes in Australia's Disability Strategy 2021–2031.²⁹ The Roadmap aims to improve timely access to quality healthcare and thus improve the health outcomes for people with intellectual disability in Australia. It has six key objectives, including the provision of support for health professionals to ensure quality healthcare for people with intellectual disability.¹⁹

Consultations for the design of the Roadmap began with an initial roundtable in 2019 and were impacted by COVID-19. Despite this, the initial consultations resulted in a draft policy that informed further consultations between late 2020 and early 2021. These consultations included roundtables, targeted group discussions, an online questionnaire and resulted in the further development of the draft Roadmap. A final roundtable occurred where participants considered the draft Roadmap.¹⁹ The Roadmap consultations included: people with intellectual disability, family and carers, academic and clinical experts, intellectual disability advocacy organisations, peak medical, nursing, allied health, pharmacy and oral health organisations, disability service organisations, universities, Primary Health Networks, the National Disability Insurance Agency, federal government departments, the National Disability Insurance Scheme Quality and Safeguards Commission, the Australian Commission on Safety and Quality in Healthcare, and health professions regulatory bodies.¹⁹

The campaign that led to the development of the Roadmap involved people with disability and provided policy suggestions, many of which were included in the Roadmap, for instance, the primary care enhancement program.²⁸ The Roadmap's approach to engaging people with intellectual disability in the lead up to and during the policy design process is a step forward because historically, disability policy design has typically failed to include people with intellectual disability in meaningful ways.³⁰ The involvement of people with intellectual disability and other stakeholders in the Roadmap's design, and need for co-design in the Roadmap's implementation, was emphasised in the policy.

3 | REFLECTIONS AND CRITIQUES OF CURRENT APPROACHES TO DISABILITY POLICY DESIGN IMPACTING RURAL PEOPLE WITH DISABILITY

Both the Strategy and the Roadmap policy designs were influenced by a range of contextual drivers, particularly the COVID-19 pandemic and subsequent public health restrictions. Both policies could be considered to incorporate some processes, principles and tools of co-design, as defined by Blomkamp,¹⁶ although neither policy defined policy co-design or explicitly illustrated how co-design principles were followed. The Strategy's consultation engagement processes certainly involved people with disability and other stakeholders that would be impacted by the eventual policy. However, the process did not involve people with disability in the early stages of policy design where problems are typically defined.²⁷ In contrast, the Roadmap's development was driven by a disability campaign to improve the health of people with intellectual disability. This is important because it allowed people with disability to be involved in the shaping of policy problems and solutions, although it remains unclear which stakeholders were involved in the different consultation phases and methods.

The Strategy and the Roadmap policy designs were not rurally focused. It was not clear if rural health professionals were involved in the Strategy's consultation process. Face-to-face engagement appeared to favour metropolitan regions, with surveys and online approaches being considered accessible options for engagement for regional and rural and remotely-based people, except for six face-to-face community workshops in non-metropolitan settings, and consultations with Aboriginal and Torres Strait Islander communities. The Roadmap did not clarify whether rural people with disability or rural health professionals were involved in consultations, or the nature and extent of their possible involvement. Rural people and contexts were mentioned five times in the Roadmap, largely to acknowledge the need for different service models, although plans to achieve this were not specified. These oversights are somewhat expected given the policies are of national relevance. National-level policy designs often struggle to stretch beyond the rural/metropolitan binary and account for the multiplicity of places and communities because doing so is a complex undertaking.³¹ However, approximately one-third of Australia's population are rural dwellers who are more likely to experience poor health outcomes,³ and so it could be argued that national-level disability policy design ought to incorporate an explicit focus on rural contexts. Minimal focus on rural contexts in national disability policy could have significant

implications for the development of rural-focused strategies and lead to metrocentric policy implementation, further embedding health inequities for current and future rural people with disability.

Both policy designs included people with disability and their families and other stakeholders such as health professionals, although neither acknowledged the interconnections and relationships between rural people with disability and health professionals as a design consideration to reach optimal healthcare outcomes in rural contexts. Rural people with disability and rural health professionals in existing relationships may have been inadvertently involved in the Strategy's community-based workshops, although a purposeful approach to draw on rural relations in these consultations was not made explicit. COVID-19 may have prevented the adoption of rural community contextually driven engagement processes in the Roadmap policy design.

Finally, no approaches, methods, or what Blomkamp¹⁶ calls 'tools' were described in either policy to promote ongoing, relational co-design and continual contribution to policy design including people with disability, families and carers, and health professionals in rural areas. Built into the Roadmap is an approach to implementation that involves governance by people with intellectual disability, families and carers, health and disability sector representatives, representatives from universities, registration bodies and professional colleges, and federal and state/territory government representatives.¹⁹ However, there is no mention of rural community or rural stakeholder involvement in the implementation governance group.

4 | A RELATIONAL, CO-DESIGNED APPROACH TO POLICIES INFLUENCING HEALTHCARE FOR RURAL PEOPLE WITH DISABILITY

This paper examined and critiqued two recently developed Australian disability policies. While significant effort was made to engage a range of stakeholders in both disability policy design approaches, with regard to rural people with disability, the disability policy designs described fell short of Blomkamp's¹⁶ definition of policy co-design. It is evident in these policies that suitable and more evidence-based policy co-design approaches are required to capture and include the voices of rural people with disability, rural health professionals and other stakeholders, and the processes and relational practices underpinning rural healthcare. The use of occasional teleconferences and surveys may appear to support the engagement of rural people with disability and other

key rural stakeholders. However not all rural people can engage using these approaches. Furthermore, these approaches may not capture important contextually specific processes, including relationships between rural people with disability, health professionals and others, and thus fail to shape policies to consider rural healthcare characteristics.

There are a broad range of scientific approaches for co-designing policies that consider the complex nature and needs of rural communities.^{32,33} Drawing on ethics of care thinking, particularly the notions of interdependency¹⁴ and primacy of connection,¹⁵ governments looking to co-design disability policy with rural people should work to understand existing relationships and networks between people with disability, health professionals and other key stakeholders in rural communities, and acknowledge the complexity and established and multiple relations within these communities before developing rural co-design approaches.³³ Building on these existing rural relationships, governments could consider employing a community leader³⁴ to support the development and facilitation of rurally located and grounded relational dialogue networks incorporating rural people with disability, their families, rural health professionals and other stakeholders. These networks could use existing relational processes and act as a local forum for discussion on proposed policy changes impacting rural people with disability, and as a place to capture multiple perspectives and conduct relational co-design work to influence new policies and submission writing. The use of such an approach would fit within a distributed rural proofing approach to disability policy that acknowledges the diversity in regional, rural, and remote areas and promotes bottom-up, participatory, democratic processes.³¹

5 | CONCLUSION

Current Australian disability policies illustrate some co-design principles and processes, although do not appear to have adopted the design approaches necessary to ensure rural people with disability, their families, health professionals and other rural stakeholders are engaged in a way that draws on and harnesses the relational characteristics of rural healthcare. This is problematic given rural people face significant barriers to accessing healthcare. Future disability policy design could consider starting with rural people; centrally positioning rural people in policy design and adopting suitable approaches to ensure rural people with disability, rural health professionals and other key rural stakeholders are actively engaged in a more evidence-based, co-design process.

AUTHOR CONTRIBUTIONS

CQ: conceptualization; project administration; writing – original draft; writing – review and editing. AO: conceptualization; writing – review and editing. NH: conceptualization; writing – review and editing. LA: conceptualization; writing – review and editing.

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CONFLICT OF INTEREST

The authors have no conflicts of interest to disclose.

ETHICAL APPROVAL

Ethical approval was not required for this study because it did not involve human participation or personal data.

DISCLOSURE STATEMENT

This commentary paper is original and has not been published elsewhere, nor is it currently under consideration for publication elsewhere.

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SUPPORTING INFORMATION

Additional supporting information may be found in the online version of the article at the publisher's website.

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