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**Exploring the Disability Royal Commission's views on the inclusion of people with intellectual disabilities in the decision-making and governance of disability services**

Bernadette Curryer <sup>1,2</sup>

ORCID 0000-0002-1324-7817

Michelle Donnelly <sup>1,3</sup>

ORCID 0000-0001-6601-9749

Kim Roots <sup>1</sup>

ORCID 0009-0000-9709-0142

***Affiliations:***

1. Side By Side Advocacy Inc.
2. Centre for Disability Research and Policy, Sydney University
3. Southern Cross University

***Corresponding author:***

Dr Bernadette Curryer

bernadettecurryer@gmail.com

## ***Abstract***

Traditionally, people with disabilities have been excluded from the decision-making and governance of organisations that provide disability-related services. From a human rights perspective, people with disabilities should be involved in all decisions that affect their lives. This article is exploring the Disability Royal Commission's (the Commission's) findings on the inclusion of people with disabilities in the decision-making and governance of disability service providers, with a particular focus on findings that relate to people with intellectual disabilities. An analysis of the Commission's findings and recommendations was undertaken, with reference to relevant Public Hearing reports and other Commission publications. During the public hearings, the Commission was critical of disability service providers that did not include the perspective of people with lived experience in their decision-making and governance. The Commission recognised the capacity of people with intellectual disabilities to undertake governance roles, provided they receive necessary support. The Commission made several recommendations to increase the leadership of people with disabilities within disability-related organisations, including policy development and co-design roles. While the Commission supported the involvement of people with disabilities, including intellectual disabilities, in the governance of disability services, specific recommendations to guarantee, facilitate and resource such inclusion were missing.

***Keywords:*** intellectual disability, inclusive, governance, decision-making, boards

## ***Introduction***

Governance is the system by which an organisation is controlled, and the mechanisms by which it, and its people, are held to account (Governance Institute of Australia, 2022). Good governance requires board structures and processes that suit organisational needs and involve

the right people (Purpose at Work, 2023). For disability-related organisations such as disability service providers, disability peak bodies, and organisations that provide disability advocacy, the right people arguably include their key stakeholder cohort, people with disabilities. Good governance of disability-related organisations should lead to the meeting of organisational objectives that result in the provision of quality services and supports that people with disabilities need.

The Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (the Commission) was established to explore ways to prevent and respond to such violence, abuse, neglect, and exploitation. The terms of reference of the Commission include the authority to inquire about “what should be done to 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” (Commonwealth of Australia (CoA), 2019, April 4, p.2).

Within an inclusive society, people with disabilities “are respected... get an equal chance to take part...feel important...can build good relationships and make friends...get the support they need in the community” (CoA, 2020, Dec.4, Easy read version, p.12). For people with disabilities to have equal participation, the authors suggest that people with disabilities should have the opportunity to take on different roles within their community, and, for some, this may include involvement with organisational decision-making and governance.

The reference to a more inclusive society is very relevant to this article and its authors. We are part of a project exploring the experience of inclusion of people with intellectual disabilities in the decision-making and governance of community organisations, particularly within the disability sector. We acknowledge our ideological stance, believing that people with disabilities, including people with intellectual disabilities, have a right to be involved in

decisions that may affect them and their lives. These decisions may be of a personal nature, or they may be of a civic nature. Involvement in the decision-making and governance of disability services is one way that people with disabilities can influence the type and quality of services offered. We also acknowledge that there are people with other cognitive disabilities, such as acquired brain injury, who may experience similar barriers to participation in civic decision-making; however, this article will focus on people with intellectual disabilities as that is the authors' area of experience.

The current article focuses on the potential impact of the Commission's findings and recommendations on the inclusion of people with disabilities in governance roles. The involvement of people with intellectual disabilities is the particular focus of the article, as inclusion of this cohort is often absent.

### ***Background***

People with disabilities have a right to participate in, and contribute to, their society. Article 29 of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) affirms that people with disabilities should be treated as active citizens in society with the right to make decisions about their own lives and fully participate as members of that society. The Convention expects signatories to actively foster an environment in which people with disabilities can “effectively and fully participate in the conduct of public affairs, without discrimination and on an equal basis with others, and encourage their participation in public affairs.” This includes the “participation in non-governmental organisations and associations concerned with the public and political life of the country” (United Nations, 2006, Article 29b).

The right of people with disabilities to participate in public affairs, sits alongside a growing expectation that the composition of boards of community organisations should be diverse and representative of their stakeholders and community. According to the stakeholder theory of boards (Chambers et al., 2013), the role of board members is to understand and represent the different people who have some involvement with, and are impacted by, an organisation and its actions. This theory argues that “the inclusion of a range of different stakeholders drives an inclusive approach that represents a wide spectrum of societal opinions, balances competing priorities and avoids dominance by one group with particular interests” (Chambers et al., 2013, p.20). The Organisation for Economic Co-operation and Development also promotes the inclusion of a diverse representation of the community, believing diversity within boards allows different views to be heard, influences processes, and promotes social cohesion (Organisation for Economic Co-operation and Development, 2020).

### ***Findings and recommendations***

The Final Report articulates the Commission’s support for an inclusive community. The Final Report’s Executive Summary (CoA, 2023, Sept. 29) includes direct quotes from people with disabilities who express a wish for inclusive communities where they are valued, visible, and able to contribute. The importance of people with disabilities having leadership roles, being “active agents at all levels of service, agency and bureaucracy” is identified by a governmental executive (CoA, 2023, Sept. 29, Executive Summary, p.8). The Commission summarises that “all service providers should take steps to ensure the views and wishes of the people with disability using their services are at the forefront of decision-making about service delivery” (CoA, 2023, Sept. 29, Executive Summary, p.156).

Volume 10 of the Final Report (CoA, 2023, Sept. 29) focuses on disability services, with section 3.3 exploring disability service provider governance. Within this section, there is a discussion of the ‘Inclusion of people with disability in governance and management’ (pp.113-115) and ‘Participation in organisational decision-making’ (pp.115-117). These sections recognise that governance practices affect the way services function, their culture, quality, and the resulting service experience. The role of the board and organisational leaders in developing a human rights culture to safeguard clients was noted.

Promising practices identified by the Commission include:

- formation of formal committees of service users and supporters, who report to, and meet, the boards
- participation by service users in decision-making about service design and delivery
- consideration of the level of board representation by people with disabilities
- active recruitment of people with disabilities to board and leadership roles (CoA, 2023, Sept. 29, Vol.10).

Within the recommendations of the Final Report (CoA, 2023, Sept. 29, Executive Summary, pp193-312), there is a clear expectation that people with disabilities should be included in consultations about service delivery, be a part of the development of policies and procedures, and take on advisory, design and leadership roles. Some examples of recommendations about inclusive practice are summarised below:

- **Recommendation 4.21** (p.203) Strengthening awareness and understanding of disability rights - through delivery of co-designed and co-delivered training programs

- **Recommendation 5.2** (p.209) Review and update of Australia’s Disability Strategy - to be undertaken in partnership with people with disabilities and their representative organisations
- **Recommendation 5.5** (p.211) Establishment of a National Disability Commission - with the chair and majority of commissioners being people with disabilities, representing the diversity of people with disabilities
- **Recommendation 5.7** (p.213) Focal points across jurisdictions to implement the Convention on the Rights of Persons with Disabilities - with inclusion of people with disabilities in leadership positions
- **Recommendation 8.23** (p.278) An action plan to end violence against women and children with disabilities - developed by and for women with disabilities
- **Recommendation 10.1** (p.285) Embedding human rights - human rights to be embedded in the design and delivery of disability services, supported by the development of co-designed training and resources, together with opportunities for discussions about challenges and practice between service providers and people with disabilities
- **Recommendation 10.5** (p.287) Advocacy - a co-designed advocacy program, initially for people in supported accommodation funded by the National Disability Insurance Scheme (NDIS)
- **Recommendation 10.14** (p.292) Developing model policies and procedures including policies and procedures to safeguard people with disabilities and in consultation with people with disabilities.

The importance of effective, inclusive governance is well summarised in the following quote from the Final Report’s Executive Summary:

The governance and leadership of disability services dictate organisational culture and practice. They influence how providers embed a human rights culture and identify and manage risk, including the risk of violence against, and abuse, neglect and exploitation of, the people receiving their services...Good governance practices bring transparency and accountability to decision-making and decision-makers. Investment in disability leadership and meaningful engagement with people with disability also strengthens transparency and accountability. (CoA, 2023, Sept. 29, p.157).

### ***Critique and discussion of the findings and recommendations***

Throughout the Commission's work, there is clear support for the involvement of people with disabilities in the planning and provision of disability services, including at a board level. However, there are three areas that the authors suggest lack sufficient emphasis in the final recommendations and may therefore result in a missed opportunity for real change to board composition and governance practice.

#### *1. Lack of specific recommendations about inclusion of people with disabilities on the boards of organisations providing disability services and other disability related organisations*

The importance of inclusive governance was identified early in the work of the Commission. In the Issues Paper, Promoting Inclusion (CoA, 2020, Dec. 4), the Commission explains that a genuinely inclusive society values difference and respects the dignity and equality of all human beings. This paper, with reference to the Convention on the Rights of Persons with Disabilities, notes that:



Full and effective participation entails the inclusion of people with disability in a range of decision-making bodies at local through to national levels. Inclusion is the result of a process and commitment to eliminating barriers... transforming culture, policy and practice to accommodate the differing requirements and identities of individuals with disability (CoA, 2020, Dec. 4, Issues Paper, p.5).

The need for inclusion of people with disabilities in disability service governance roles was identified during the public hearings. Public Hearing 13 - Preventing and responding to violence, abuse, neglect and exploitation in disability services (a case study) was one of a number of public hearings exploring the actions, or inactions, of disability service providers. This hearing included a single case study of a large disability service provider. The significance of this case study “goes beyond the specific circumstances of the case study and extends to systemic issues” (CoA, 2022, April 5, Hearing Report 13, p.1). Review of this case study, together with Public Hearings 20 and 23, was undertaken in an effort by the Commission to understand the way in which disability services responded to allegations of violence, abuse, neglect or exploitation, and included examination of governance practices.

Reflections by the commissioners during Public Hearing 13 indicated a concern about the lack of inclusion of service consumers in the decisions being made by the boards and management of disability services. The Commission encouraged organisations to consider ways to involve consumers in organisational decision-making.

It is important, therefore, that disability support providers implement governance structures and management processes that are representative and inclusive of the people who receive their services. That ensures that people with disability are

involved in decisions about their care and support which protect and promote their interests. (CoA, 2022, April 5, Hearing Report 13, p.98).

The Commission also stated that increased inclusion of people with disabilities, not necessarily consumers, would be beneficial to board governance.

...the inclusion of people with disability as directors is likely to expand the range of experience, skills and knowledge available to the board and to improve the quality of services provided to the people with disability (CoA, 2022, April 5, Hearing Report 13, p.101).

The absence of people with disabilities on the boards of service providers was identified as contributing to ineffective board practice. It is noted that not every person with disability may want, or have the capacity for, a role on a board. However, this does not mean that they cannot have their views included in the decision-making processes of organisations. If an organisation values the perspective of people with disabilities, they will ensure that there are a variety of ways that a person can be involved, so that their views are heard and considered in the decision-making process.

While it is acknowledged that the presence of a board member with disability could not guarantee better protection for service users, it is felt that the inclusive approach would be more likely to provide a wider perspective to the decision-making process.

...the very point of involving people with lived experience of disability in the decision-making process affecting them or other people with disability is to bring

insights, understanding and perspectives that will not otherwise be available to the decision-making body. (CoA, 2022, April 5, Hearing Report 13, p.100).

While Finding 21 from Hearing 13 recognises the value of including board members with skills and expertise in financial, commercial or legal fields, it also found that

...the lack of directors with lived experience of disability significantly impeded the board's ability to discharge its responsibilities effectively. Specifically, the lack of directors with lived experience of disability contributed to the board not being fully informed about the challenges Sunnyfield faced in ensuring the safety, support and wellbeing of residents in Sunnyfield's disability residential accommodation (CoA, 2022, April 5, Hearing Report 13, p.104).

The composition of a board may have impact on the board's effectiveness. Many organisations value a board that has a spread of skills and expertise, often in areas such as business, accounting or law. The Australian Institute of Company Directors recommends, as Principle 3.3 of its not-for-profit governance principles, that "the board reflects a mix of personal attributes which enable it to fulfil its role effectively" (2019, p. 4). Experience of living with a disability, which may include the experience of using disability services, could be a valuable personal attribute for disability-related organisations. The presence of people with disabilities on boards may complement other board-related skills by providing insight and knowledge of the experience of those using disability services, potentially bringing a different perspective to discussions of service quality (Wallace et al., 2023a).

The principle of ‘*Nothing about us without us*’ comes from the belief that “policies, procedures, rules, regulations, etc., should not be created for any population without explicit input from the very population that these rules and guidelines will be impacting” (Women With Disabilities Australia, 2022). This concept recognises the knowledge that comes from lived experience and it follows that the voice and perspective of people with disabilities should be heard in all decisions that may affect them. Decisions may be at a personal level, such as where I live, what I do and who I spend time with. Decisions may also be at a community or service level, such as what services are available, how they are made accessible and other issues that benefit from the perspective of lived experience.

However, despite government policy changes towards social inclusion, Johannes et al. argue that “historical...power relations remain effectively unchanged” (2017, p. 42), resulting in people with disabilities continuing to report the experience of exclusion and marginalisation. In their submission to the Commission, the Disability Leadership Institute highlights this issue:

Until we address the lack of leadership, the lack of presence in decision-making spaces, we will remain unequal. It will continue to be assumed that we are not able to make decisions, that we are not able to assess risk, that we do not understand what might be best for us and our broader community, and we will therefore be subjected to appalling levels of violence and abuse. (CoA, 2023, Sept. 29, A Brief Guide (Final report brochures), p.16).

The Commission’s strong message of support for the inclusion of people with disabilities on the boards of disability services could have been made more explicit in the final report and

linked to existing accountability measures. Inclusion in the decision-making of disability services is incorporated into practice standards, including the NDIS Practice Standards (NDIS Commission, 2021) and the Disability Services and Inclusion Rules 2023 (Australian Government, 2023). For example, one of the indicators of Governance and Operational Management for NDIS providers states:

Opportunities are provided by the governing body for people with disability to contribute to the governance of the organisation and have input into the development of organisational policy and processes relevant to the provision of supports and the protection of participant rights. (NDIS Commission, 2021, p.7)

The lack of a clear, specific final recommendation regarding the inclusion of people with disabilities on the boards of disability services is, we believe, a missed opportunity to make a change to the current situation where the people services are supporting are largely missing from organisational decision-making processes and structures.

*2. Lack of a specific recommendation that people with intellectual disabilities (as distinct from people with disabilities more generally) should be included in governance and leadership roles within disability services*

The final recommendations of the Commission fail to explicitly identify the inclusion of people with intellectual disabilities in governance roles within disability services. People with intellectual disabilities are the largest cohort of adults receiving NDIS funding, with almost 21% of adult NDIS participants reporting intellectual disability as their primary disability (NDIS, 2023). This number does not include people with intellectual disability who have

another disability, for example autism or cerebral palsy, as their primary disability. Grouping people with intellectual disabilities as part of the broader group of people with disabilities, a process known as dedifferentiation (ASID, 2023), may result in a failure to consider the unique needs and preferences of people with intellectual disabilities. If organisations do not ensure people with intellectual disabilities are included in governance and decision-making roles, then the voices and perspective of people with intellectual disability may not be heard, and therefore not fully considered in organisational decision-making (Curryer, 2022).

Inclusion of people with intellectual disabilities as board members has been practiced for many years by a limited number of Australian organisations. Two examples, the NSW Council for Intellectual Disability and Self Advocacy Sydney have, for many years, had a number, if not a majority, of people with intellectual disabilities on their boards. However, the inclusion of people with intellectual disabilities in governance roles of disability service providers has not been widely practiced. The limited practice of inclusive governance is reflected in, and possibly a result of, the lack of research into its effectiveness. Research into the impact of inclusive governance, both on organisational effectiveness and client outcomes, is required.

The responsibility of the boards of disability service providers to ensure the quality and safety of their services, is being increasingly emphasised (Wallace et al., 2023b; Hough, 2022). The knowledge that comes from the lived experience of intellectual disability may benefit a board's understanding of the impact of disability, maintain focus on what people with intellectual disabilities want from a service, and what is perceived as quality. Qualitative research on the experience of inclusive governance supports this assertion (Curryer et al., 2023).

Any concerns that people with intellectual disabilities are automatically unable to undertake the duties of board membership due to the complexity of the role were rejected. The Commission stating during Hearing 13 that:

...we do not accept that people with disability including people with cognitive disability, are incapable of filling the role of a director...many people with cognitive disability are able to manage their own affairs and to participate in professional activities including corporate governance. The question of whether a particular person with disability can serve as a director has to be considered in the light of the supports that can and should be provided to that person (CoA, 2022, April 5, Hearing Report 13, p.102).

However, the need to provide support that meets individual needs is recognised. The Commission explained that "...there is no legal impediment to ...service providers...having people with disability on their boards and providing them with the support necessary to enable them to discharge their duties" (CoA, 2022, April 5, Hearing Report 13, p.103).

Providing support to enable a person to carry out governance-related duties is seen by the Commission as an appropriate accommodation to enable effective inclusion. This is consistent with the Australian Law Reform Commission's recommendations for changes to the Corporations Act to ensure that the capacity of a person to undertake the decision-making required for governance is assessed in the context of supported decision-making (Australian Law Reform Commission, 2014, Recommendation 11-3). This means that a person can undertake a director role, even if they require support to understand, retain and use information to make and communicate a decision. While the Australian government has

not yet implemented the Australian Law Reform Commission recommendations, the Commission specifically stated that this does not present a barrier to people with disabilities taking on a board role, with the support they need (CoA, 2022, April 5, Hearing Report 13, p.103). People with intellectual disabilities may require individualised support to review reports and prepare for board meetings, support to engage during meetings, and contact between meetings to maintain connection and undertake any other board related activities (Curryer et al, 2023; Side By Side Advocacy, 2023).

The lack of a clear, specific final recommendation regarding the inclusion of people with intellectual disabilities in decision-making and governance roles may result in the continuation of the current situation where the specific perspective of this cohort may be missing from the decision-making of disability services.

*3. There is a lack of guidance about the practical steps required for disability services to move towards inclusive governance practice*

A number of the recommendations of the Commission (CoA, 2023, Sept. 29, Executive Summary) identify the need to involve people with disabilities in consultations, co-design and co-delivery of programs, and other leadership positions including as chair and commissioners on the proposed National Disability Commission. However, there is no guidance given about the creation of pathways to these positions, where people are provided with relevant training and experiential learning opportunities. Inclusion of people with intellectual disabilities in a range of leadership and advisory roles provides important experiences and skill development. It allows people to be involved in decision-making in a way that suits their interests and abilities, and for some, may start them on the journey towards involvement at a board level. Development of pathways to civic involvement helps



to develop the skills of people with disabilities, providing a larger pool of people who are developing skills that would allow effective involvement at a governance level. To prevent unnecessary barriers to people who may have been excluded from many skill development experiences in the past, it is important to think about providing a range of role options, together with accessible training and support.

There has been some limited work undertaken on supporting the inclusion of people with disabilities in governance roles. Time limited projects, such as ‘Voice at the Table’ (Victoria), ‘On Board with Me’ (Western Australia), and ‘The Inclusive Governance Project’ (NSW) have developed training and resources for such inclusion. The Inclusive Governance Project is exploring the experiences of people with intellectual disabilities in governance roles. The findings indicate that non-tokenistic inclusion is possible as long as an organisation:

- values the voice of people with intellectual disabilities
- creates pathways to provide relevant skills and experiences
- ensures meetings and other board activities and communications are accessible
- provides individualised, independent, skilled support
- is committed to overcoming any barriers that may arise (Side By Side Advocacy, 2023).

If people with disabilities are to be meaningfully included in the decision-making and governance of disability organisations, the following questions need to be addressed.

- What expectation should be placed on disability organisations to ensure the voice of people with disabilities, including intellectual disabilities, is being heard, considered, and acted on?

- How will organisations be supported to move to an inclusive governance model?
  - change management support
  - inclusion training for governance and management teams
  - additional or revised resources (e.g., constitution review, new and accessible policies).
  
- When considering the inclusion of people with intellectual disabilities, how will effective support be provided and resourced? A commitment to inclusion of people with intellectual disabilities is likely to involve additional expenses and resources including:
  - accessible governance training
  - employment and training of board support staff, skilled in the specialised role of supported decision-making within a governance context
  - preparation of accessible documents
  - support to attend board meetings and access communication technology.

Clear directions from the Commission may have assisted organisations to support and prioritise greater inclusion of people with disabilities, including intellectual disabilities, in governance and other leadership roles. More research on the process and outcomes of inclusive governance may also assist organisations to understand how and why such a change is important.

### ***Conclusion***

The Commission has identified the lack of involvement of people with disabilities in the governance of disability-related organisations and has expressed the view that this practice not only fails to be inclusive, it also prevents lived experience of disability guiding the provision of quality services that actually meet the needs and preferences of service recipients. The recognition of the ability of people with disabilities, including intellectual disabilities, to undertake governance roles is welcomed. However, despite strong statements throughout the Commission hearings, there are gaps in the Final Report and recommendations that could facilitate greater inclusion of people with disabilities, including intellectual disabilities, in the decision-making and governance of disability-related services and organisations. Recommendations to ensure the inclusion of people with disabilities in the governance of disability services, the development of accessible training and skill development opportunities, and provision of ongoing support are required to bring about meaningful change to board composition. Based on the preliminary findings of research being undertaken by Side By Side Advocacy (Curryer et al., 2023), it is the view of the authors that when more people with intellectual disabilities have the opportunity to be involved in the decision-making and governance of disability-related organisations, the responsiveness of organisations to the needs and preferences of this key stakeholder group will be enhanced.

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