# Submission to Disability Royal Commission

**Inclusion of people with intellectual disability in organisational decision-making and governance**

## Authors of this submission

This submission was prepared by

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This submission is informed by an ILC funded qualitative research project that is exploring the experience of inclusion of people with intellectual disability on Boards and committees of community organisations, particularly those with a disability focus. It commenced in 2020 and is due to finish in February 2023.

This project is being managed by Side By Side Advocacy, Parramatta, NSW. Southern Cross University is providing ethical oversight of the research. The research team is made up of Dr Bernadette Curryer, Ass. Prof Michelle Donelly (Southern Cross University), Kim Roots (EO Side By Side Advocacy), Dr Margaret Spencer (Sydney University), Katrina Sneath (Co-researcher with lived experience of intellectual disability) and Will Harding (Co-researcher with lived experience of intellectual disability). The research team is supported by a Consultative Reference Group, made up of the research team and seven community members with backgrounds of lived experience, academic research, disability advocacy and local government.

## Background

The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) marked a shift from a charity-based model of disability, promoting people with disability as active citizens in society with the right to make decisions about their own lives and fully participate as members of society. The UNCRPD expects signatories to actively foster an environment in which persons 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). To ensure that Australia is fulfilling its obligations under international law, the introduction of the National Disability Insurance Scheme Act (2013) states "people with disability should be supported to participate in and contribute to social and economic life to the extent of their ability."

The phrase "*Nothing About Us Without Us*", popularised by disability rights activists, positions people with intellectual disability as knowledge-bearers and recognises the importance of lived experience. While there is an expectation that boards of community organisations should be diverse, representative of their stakeholders and community. However, people with intellectual disability continue to be underrepresented in governance structures. The participation of people with intellectual disability has the potential to improve the quality of service provision. The failure of community organisations to ensure people with intellectual disabilities voices are represented on their boards and management committees suggests the voice and views of people with intellectual disability are not being heard or acted upon.

## Research aims

This research project aims to promote the inclusive governance of community organisations by:

- understanding the experiences of Board members with and without intellectual disability

- recognising structures, policies and procedures that are likely to promote the inclusion of people with intellectual disability and support their recruitment, decision-making and leadership

- developing resources for community organisations that are seeking to engage with more inclusive governance approaches.

## Research methodology

The research uses qualitative methodology, with a phenomenological approach to analysis. The stages of the project include:

- Data Collection: Explore the experience of Board and Management Committee members, both with and without intellectual disability. Look at the policies and procedures of organisations, speak to staff supporting the Board and observe how meetings and decision-making is undertaken.
- Data Analysis: Identify the strengths and limitations of current models. Identify the structures and processes that support the full inclusion of people with intellectual disability in governance. Identify the skills and supports required by people with intellectual disability and how these can be best provided.

## Findings

Five themes, with several sub-themes have emerged from the research. The following table gives a brief overview of the findings

| Themes and subthemes | Key points | Implications | Examples of relevant quotes |
|---|---|---|---|
| **Pathways to Board membership**<br>• Individual level<br>• Organisational level<br>• Community and sector responsibility | While some disability organisations, particularly those involved with advocacy, have created pathways to Board membership for people with intellectual disability, this is generally not the case for disability service providers.<br><br>Individual experience and motivation for Board membership varies, often based on wanting to contribute and have a valued role.<br><br>Successful inclusion at governance level usually occurred when there was inclusive involvement | People with intellectual disability require a better understanding of Boards, options for involvement and responsibilities attached.<br><br>Organisations need to make a commitment to holistic inclusion. Board recruitment practices should reflect a commitment to inclusion of people with intellectual disability.<br><br>Community/Disability Sector to act on a vision of inclusion, developing accessible training and resources that will increase the governance skills of individuals, and guide the change to inclusion within organisations. | "I thought maybe that [becoming a Board member] will give me more chance to show I can do the job, and then that way, hopefully, people can see that I can do a whole lot more than what they think I can do" [P1]<br><br>"That group [advisory sub-committee] is more of a training group in leadership skills, and meeting skills, and advocacy, self-advocacy. So, it's a little bit of a learning ground for maybe pre-board" [P5]<br><br>"…is our company trying hard enough to find them [potential Board members with disability], is it that the pipeline doesn't exist" [P17]<br><br>"For people with intellectual disability, there's a whole lot of |

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| | throughout the organisation<br><br>Although there have been some time-limited projects, no accessible Board training is available on an ongoing basis. | | social attitudes that need to be addressed, but there's also a whole lot of confidence building and capacity building that needs to be done for people with intellectual disability to fit – to be able to hold their own at those tables of power" [P8] |
| **Experiences within a Board**<br>• Being heard<br>• Impact of Board culture<br>• Meeting processes<br>• Decision-making processes<br>• Communication practices<br>• Experience of inclusion or exclusion | Board processes, practices, and culture have an impact on the degree of inclusion and involvement people felt within meetings. | Changes to the way Boards are structured and run need to be considered. For example, size of the Board, frequency and length of meetings, and communication techniques need reassessment. The Board culture also requires examination and change to be truly inclusive. | "So one of the differences was that there was space made to ensure that the board members with intellectual disability had the opportunity to speak and that their perspectives were elicited in the course of the meeting and…that was a bit different from other boards that I've been on.  Just that decision-making process was slowed down" [P16] |
| **Support provision**<br>• Complexity of the support role<br>• Supporter attributes, skill and training<br>• Support provided<br>• Identifying support needs<br>• Board member training and skill development<br>• Result of failure to provide adequate support | Individualised support  needs to be provided.<br><br>Effective support includes pre-meeting preparation, support during the meeting as well as between meetings.<br><br>The support role is complex, yet no training is available. | Need for funding to employ skilled support staff.<br><br>Need for development of training that upskills supports – e.g., to ensure they can support decision-making without influence, understand the roles and responsibilities of Board members, explain complex issues in accessible formats. | "People totally underestimate the difficulty and the challenges of actually providing proper support to person on the board…it's way more than just helping the person to get there and making sure they get home.  It's actually a very complex skill that requires a reasonable understanding of procedural matters and the actual organisation, the purpose of the organisation. And then basically, the support person is really managing the meeting in an important way with the perspective of the opportunities for the person with an intellectual disability to contribute and be involved in a meaningful way, and so they need to speak up, maybe even interject just to make space for that person to contribute" [P11] |

| Themes and subthemes | Key points | Implications | Examples of relevant quotes |
|---|---|---|---|
| **Concerns creating barriers**<br>• Complexity of Board role<br>• Conflict of interest<br>• Current Board culture<br>• Unsure of role a person with intellectual disability holds on a Board<br>• Meeting the support needs<br>• Lack of resources<br>• Worried about liability – for individual and organisation<br>• Fear of tokenism | While many organisations expressed interest in inclusive governance, they also had concerns which created barriers to change. Open discussion of concerns, providing information, education, resources are needed.<br><br>Looking at concerns with a risk mitigation response would assist the breaking down of potential barriers. | Support for organisations undertaking a change to inclusive governance is important.<br><br>There is a need to address issues of resources and funding.<br><br>Potential benefit of a facilitated 'Community of practice' (requested by some service providers) to work through complex issues has been identified. | "…they find it incredibly hard to actually be inclusive – not against the idea, they just can't actually do it. And I think changing the pace, changing the language is difficult for organisations"[P5]<br><br>"If you believe in something, the conversation has to be, what will it take, not, this is hard so we won't do it. And once you say what will it take, it needs to then be…a coherent and consistent approach across the organisation" [P6]<br><br>"It costs money to do it well, and you need to have a really good budget to support it, and for organisations that aren't willing to spend money, it becomes tokenistic, and it just won't work"[P10] |
| **Outcomes**<br>• Individual level<br>• Organisational level<br>• Sector level | Outcomes of including people with intellectual disability on a governance level were generally positive, with reports of individual growth, organisational benefit and an increased focus on the voice of people with intellectual disability. | Reinforces benefits of inclusive governance.<br><br>Further research could be undertaken to quantify benefits. | "I felt included 'cause I could have a voice, I get to have my say for my opinions, and decisions about what I think of the ideas of what's being offered, and I felt that at least I had some value to the organisation" [P01]<br><br>"…overall, I think it was a really positive experience and I think that it did bring perspectives to decision-making that otherwise would not be there…So they…pushed us to recognise the abilities of the people that we served more than perhaps we look at" [P16]<br><br>"The nature of our business is representing people with intellectual disability. It's absolutely incumbent on us to ensure that people with disability are central to all the decisions we make…[it] completely grounds us and centres us – it's our soul" [P08] |

Overall, the findings indicate that inclusive governance is best achieved when an organisation has a holistic view of inclusion. Inclusive governance should not be viewed as an isolated practice but as part of a plan of inclusion of people with disability, including intellectual disability, at multiple levels and in varying roles, throughout the organisation. Such inclusion should be part of the strategic plan of an organisation, based on the individual structure and activities of each organisation. Examples of possible opportunities for organisational inclusion may include involvement in organisational membership, employment, co-design of programs, projects and resources, co-production, program evaluations, auditing, advisory committees, systemic advocacy and Board membership. For inclusive governance to work, there needs to a commitment to the concept of inclusion, supported by practices developed at a constitutional, policy, and procedural level.

## Implications

*Individual level*

People with intellectual disability have the right be involved in the decision-making and governance of community organisations, however, they may require the following to enable their involvement:

- Clear pathways to involvement at a governance level
- Accessible governance training
- Support to undertake the role and responsibilities of Board membership.

*Organisational level*

All community organisations, particularly disability-focussed organisations including service providers, advocacy organisations, and peer support groups, who want to include people with intellectual disability in their decision-making would benefit from:

- An organisational commitment to the concept of inclusion
- An organisational commitment to the concept of Inclusive Governance
- Development of recruitment strategies that will promote the involvement of people with intellectual disability
- Review of their Board structure, meeting processes and communication style to increase accessibility
- Planning for skilled support provision, that provides support for both preparation prior to meetings and support during meetings.

*Community and Sector level*

The broader community and disability sector needs to consider:

- Offer accessible governance training for Board members with intellectual disability
- Develop training for support people e.g., with skills relating to supported decision-making
- Facilitation of a Community of Practice for organisations wanting to develop an Inclusive governance plan.

*Government level*

The Government needs to:

- recognise the barriers to meaningful inclusion of people with intellectual disability on management committees and board
- provide appropriate funding and resources to support meaningful inclusion.

## Project outcomes

There will be a final report available early in 2023. It is expected that an academic journal article reporting on the study will also be published. These will be supported by practical resources for inclusive governance such as a set of guiding inclusive governance principles, a plan of action template for community Boards using the emerging themes as a framework, and practical templates for preparing the agenda, minutes, reports and other documents. Resources developed from the findings will be freely available on the Side By Side Advocacy website http://sidebyside.org.au/inclusive-governance-project/

## Recommendations for the Disability Royal Commission

We ask that you consider in your deliberations, the importance of including people with intellectual disability in the decision-making and governance of disability organisations. In order to achieve effective involvement, the following questions need to be asked:

1. **What expectation should be placed on disability organisations to ensure the voice of people with intellectual disability is heard, considered, and acted on?**
   Examples of practical forms of inclusion that would increase the voice and power of people with intellectual disability in the decision-making of organisations include:
   - the inclusion of people with intellectual disability on Boards
   - the setting up of advisory groups with transparent accountability reporting the results of consideration of recommendations by the Board
   - employing co-design/co-production model within organisations.

2. **How would funding to enable effective support for inclusive governance be provided?**
   A commitment to inclusion requires resources, including:
   - payment of skilled support staff
   - preparation of accessible documents
   - support for access to Board meetings (e.g., transport, IT, internet).

3. **How will organisations be supported to move to an inclusive governance model?**
   A move to an inclusive governance model may require:
   - change management support
   - resources (e.g., templates for action planning, availability of skilled support staff)
   - training for current governance and management teams.

## Further information

If you require further information, please contact:

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