



# The Inclusive Governance Project

## Project Report Executive Summary

### **Background**

The right for people with disability to be involved in the decision-making of disability services and other community organisations is clearly recognised in the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD). While there are more people with disability taking a governance role, the inclusion of people with intellectual disability remains the exception. A greater understanding of how organisations can effectively support people with intellectual disability to be involved in the decision-making and governance of community organisations is needed.

### **Research method**

A phenomenological, qualitative study was undertaken to understand the experience of inclusion of people with intellectual disability on a Board. Data was collected through individual semi-structured interviews, observation of meetings, and constitutional reviews. 27 participants were interviewed, including Board members with and without intellectual disability, Senior Managers and Board support people. Inclusive research strategies were used, with people with intellectual disability employed as co-researchers and involved in co-design groups.

## Findings

Inclusive Governance appears to work best when it is part of a **holistic, organisational-wide approach** to inclusion.

The following themes and sub-themes emerged from the data:

<b>Themes</b>	<b>Sub-themes</b>	<b>Brief explanation</b>
<b>Theme 1</b> Impact of inclusion in governance	a) A valued role b) Additional perspective and skill c) Challenging stereotypes	Board membership is valued by participants with disability as they feel respected and their views heard, organisations have the benefit of hearing those voices and the community sees the contribution that people with intellectual disability can make.
<b>Theme 2</b> Pathways to board membership	a) Individual preparation b) Embedded inclusion c) Sector responsibility	Inclusion at a governance level requires skill development with practical experience, opportunities to be involved throughout the organisation, and availability of accessible governance training.
<b>Theme 3</b> Experiences impacting inclusion within boards	a) Board culture b) Board structure c) Communication practices d) Meeting processes e) Decision-making processes f) Experience of exclusion	A positive experience of inclusion within boards is helped by a supportive and respectful board culture, clear communication, board structures and meeting processes that are accessible, and decision-making processes that encourage open discussion. Without these characteristics, people feel excluded from real involvement.

<p><b>Theme 4</b> Support provision</p>	<p>a) Providing support</p> <ul style="list-style-type: none"> <li>• Meeting preparation</li> <li>• Support during meetings</li> <li>• Contact between meetings</li> </ul> <p>b) Complexity of the support role</p> <p>c) Supporter training</p>	<p>Support is best provided before, during and between meetings. The support role is complex, requiring specialised skills.</p>
<p><b>Theme 5</b> Concerns become barriers to inclusion</p>	<p>a) Complexity of board role</p> <p>b) Legal responsibility</p> <p>c) Meeting support needs</p> <p>d) Perceived conflict of interest</p> <p>e) Current board culture</p> <p>f) Fear of tokenism</p>	<p>Concerns about inclusive governance were raised. These related to either the individual’s ability to undertake the responsibilities of a board role or the organisation’s ability to provide a supportive environment.</p> <p>Concerns included the complexity of the role, possible legal consequences, perceived conflict of interest, organisations not being culturally prepared or adequately resourced to provide the support that is needed. These meant that some people feared any involvement would be tokenistic.</p>

## Implications

The themes informed 5 Principles of Inclusive Governance. These principles can be used by organisations to guide the implementation of a more inclusive model of governance. They also assist people with intellectual disability and

the general community to understand what they should expect from organisations who claim to be inclusive.

## 5 Principles of Inclusive Governance



1. Inclusion of people with intellectual disability in the decision-making and governance of community organisations is valued.



2. There are clear pathways to Board membership for people with intellectual disability.



3. Board meetings and activities are accessible, meeting the inclusion needs of people with intellectual disability.



4. Individualised, skilled support is provided.



5. There is a commitment to making inclusive governance work.

## Resource development

Resources have been developed and are freely available on the Side By Side Advocacy website. These resources include videos that explain the project outcomes, easy read documents, resources for accessible meetings and support provision, and an Action Plan template based on the 5 Principles of Inclusive Governance. These resources are all freely available on the Side By Side website <https://sidebysideadvocacy.org.au/inclusive-governance>

## **Project outcomes**

The research findings have guided organisational strategies at Side By Side Advocacy, to increase the involvement of people with intellectual disability in the decision-making of the organisation. These include:

- a proactive membership engagement strategy to increase organisational membership. This includes the removal of any membership fee to reduce possible financial barriers to membership.
- a constitutional change with the addition of a new organisational object:

To evaluate and implement ways that people with intellectual disability can be more meaningfully included in all aspects of the work of the organisation including the governance of the organisation.

The outcomes of these changes include:

- increased organisational membership by people with intellectual disability
- inclusion of a person with disability as a board member, together with individualised support
- focus on communication accessibility throughout the organisation
- involvement of people with intellectual disability in co-design activities
- increased engagement with people with intellectual disability through capacity building activities such as the Parramatta Leadership Project.

Other organisations have begun to use the learnings from the project.

Examples being the creation of a 'Participant Reference Group' in an

accommodation service. This group is currently learning its role, and reports to the CEO. It is planned that they will report straight to the board soon. Another disability service has created a 'Disability Advisory Board'. This group discusses, and makes recommendations about issues that are concerning the Board. Their recommendations have resulted in actions being taken by the Board, including the appointment of a client inclusion officer.

### **What is still needed?**

Further work is required to develop resources and provide educational opportunities in 3 main areas:

1. create and support pathways for people with intellectual disability that increase their experience and knowledge to undertake governance-related roles. Included in this is the development of accessible governance training and proactive outreach to people with intellectual disability
2. train and mentor community and disability organisations to increase their inclusivity at a governance and workplace level
3. develop and run training programs for Board support people.