



Inclusive Governance Preliminary Project Report

July 2024

The Inclusive Governance Project was run by Side By Side Advocacy Inc., under the ethical guidance of Southern Cross University. The project has been funded by the National Disability Insurance Agency and the Commonwealth Department of Social Services.

This report has been prepared by Dr Bernadette Curryer (Research Lead) with input from Katrina Sneath and Will Harding (co-researchers), Kim Roots (Executive Officer) and Michelle Donnelly (Board member).

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Inclusive Governance Project

Easy Read Report



This report tells you about the **Inclusive Governance** Project. It tells you what the project is about, what it has done, and what it found out.



For this project, Inclusive Governance means that people with intellectual disability are included in the decision-making of community organisations. This might be by becoming a **Board** member.



A Board is a group of people who make important decisions about the way an organisation works.



The Inclusive Governance Project was run by Side By Side Advocacy.



The project was funded by the Australian Government.



We wanted to understand what it is like to be a Board member and have an intellectual disability.



We wanted to know how to support people with intellectual disability to be included on Boards.

What did we do?



We did some research.

We interviewed 27 people



- Some were Board members with intellectual or other disability
- Some were Board members without disability
- Some were senior managers
- Some were Board support people.



We asked them about their experience and what helped to include people with intellectual disability on a Board.



We thought about what they told us.

What did we learn?



5 themes came from the research.

Themes are main ideas.



We can use these themes to help organisations include people with intellectual disability on Boards.



Theme 1 – Impact of inclusion in governance

This theme is about what happens when people with intellectual disability are included on Boards.



When people with intellectual disability are on Boards

- they feel good



- organisations hear their voice



- the community sees what people with intellectual disability can do.



Theme 2 - Pathways to Board membership

This theme is about learning the skills and having experiences that help you to be a good Board member.



To be a good Board member people need to learn

- the role and responsibilities of being a Board member
- how to speak up
- how to make decisions for organisations.



You can learn skills and be involved in the decisions organisations make by

- becoming a member of an organisation
- taking part in co-designing groups
- joining advisory committees
- joining Board sub-committees.

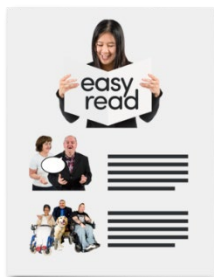




Theme 3 – Experiences impacting inclusion within boards

This theme is about things that help people with intellectual disability feel included on a Board.

Boards need to make their meetings and other activities accessible for people with intellectual disability.



This means that

- information is given in a way you understand
- meetings are held in a place and at a time that you can get to





- there is enough time during the meeting for you to speak and ask questions



- you understand how decisions are being made



- the Board is supportive, respectful, and encouraging.



Theme 4: Support provision

This theme is about how people with intellectual disability can be supported on a Board.



Support

You can have a person to help you.



They should give you the support that you need.



The person who supports you should be trained to know how to support you in a Board role.

This person should help you



- prepare before meetings by going through each report so you understand the information and any decisions that you need to make



- during meetings to keep up with the meeting, and make sure people listen to you



- keep in contact between meetings and let you know any new information.



Theme 5 - Concerns become barriers to inclusion

This theme is about the worries some people have about including people with intellectual disability as Board members.



Worries about what could go wrong can stop people being included.



Some people were worried that their organisation did not know how to include and support people with intellectual disability on their Board.



Some people were worried that people with intellectual disability did not have the skills to be good Board members.



We need to work out ways to overcome these worries so that they do not stop people with intellectual disability being included on Boards.

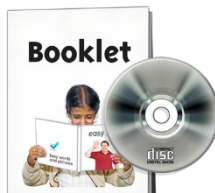
How did we share what we learnt?



We wrote about our research.



We went to **conferences** and told people about our findings. Conferences are where lots of people get together to talk about issues.



We made **resources**. Resources help people to understand the information and findings from the project. Some of these resources are videos.



The resources were made together with people with intellectual disability as co-designers.



These resources, videos, and other information are on our website
www.sidebysideadvocacy.org.au/inclusive-governance



For more information, call Side By Side Advocacy on 98085500.



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:

Themes	Sub-themes	Brief explanation
Theme 1 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.
Theme 2 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.
Theme 3 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.
Theme 4 Support provision	a) Providing support • Meeting preparation • Support during meetings • Contact between meetings	Support is best provided before, during and between meetings. The support role is complex, requiring specialised skills.

	b) Complexity of the support role c) Supporter training	
Theme 5 Concerns become barriers to inclusion	a) Complexity of Board role b) Legal responsibility c) Meeting support needs d) Perceived conflict of interest e) Current Board culture f) Fear of tokenism	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. 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.

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 made available. 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.

Project Background

The Inclusive Governance Project is a research-based project being undertaken by Side By Side Advocacy Inc. in association with Southern Cross University. It is an Information, Linkages and Capacity Building (ILC) project, now overseen by the Australian Government Department of Social Services. This project was originally planned to run until February 2023, however an extension by the funding body means that it will now run until end of June 2025.

The aim of the project

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 who are seeking to engage with more inclusive governance approaches.

What is meant by the term Inclusive Governance?

Inclusive Governance, when used in the context of this project, is specifically about people with intellectual disability having a chance to be involved in the decision-making and governance of community organisations. These organisations may be disability specific, or they may be mainstream.

Project stages

The activities completed during the project will be reported under the following headings:

- A. Planning and preparation
- B. Research method
- C. Findings
- D. Implications
- E. Development of resources
- F. Dissemination of project findings
- G. Implementation examples
- H. Considering the future

A. Planning and preparation

Staffing

The project began in March 2020, with the Research Officer, Dr Bernadette Curryer, appointed in a 0.5 FTE position commencing July 2020.

Co-researchers, with a lived experience of intellectual disability, Will Harding and Katrina Sneath, commenced as casual staff in January 2021. They usually worked 5 hours a fortnight.

Consultative Reference Group

The formation of a group of stakeholders to provide guidance. Initial terms of reference were developed in December 2020. The group met every 3 months.

The members of this group are:

- Kim Roots (EO Side By Side Advocacy)
- Ass Prof Michelle Donelly (Board member and Lead Researcher SCU)
- Prof Ian Eddie (Excelsior College)
- Penny Pedersen (Ryde City Councillor)
- Dr Margaret Spencer (Sydney University)
- Marian Onofomi (Multicultural Disability Advocacy Association)
- Nicole Lee (NSW Council for Intellectual Disability)
- Jessica Mooney (IDRS) – until March 2021
- Fiona Given (Board Member Side By Side Advocacy) – until Feb 2022
- Shu-Hua Chan (Self-advocate)

Terms of Reference - Consultative Reference Group (CRG)

The Inclusive Governance Project is managed by Side By Side Advocacy Inc., in association with Southern Cross University. It is funded by the NDIS as part of the Community Inclusion Capacity Development program.

The aim of this project is to

1. explore current community organizational governance models that support the inclusion of people with intellectual disability. This may be at a Board or Management Committee level, or possibly within Advisory Groups or Steering Committees.

2. undertake research to explore the experience of members of such Boards or Management Committees (both with and without intellectual disability)
3. develop best practice models based on analysis of strengths and weaknesses of current models
4. implement and evaluate the chosen governance model within Side by Side Advocacy Inc.
5. disseminate the models to community groups within New South Wales (in person and via website).

Purpose

The purpose of the CRG is to be an advisory group to the Inclusive Governance Project.

Membership

- Membership of the CRG is by invitation from Side By Side Advocacy. Side By Side Advocacy will identify:
 - People and/or organisations who are interested in the promotion and support of increased involvement of people with intellectual disability in the decision-making of community organisations
 - People with a variety of expertise, with an aim to include people with:
 - a lived experience of intellectual disability
 - research expertise
 - governance knowledge
 - experience supporting people with intellectual disability (particularly about decision-making)
 - understanding of the specific needs of Culturally and Linguistically Diverse (CALD) and Aboriginal and Torres Strait Islander (ATSI) communities

- Term – CRG members will be involved for the length of project (to end February 2023) or until involvement is no longer required or able to be given (additional note – project extended until June 2024).

Roles and responsibilities

The CRG will:

1. foster strategic networking connections
2. provide advice based on individual or organisational expertise and experience
3. provide project direction recommendations.

Authority:

The group may recommend actions; however, the final decision-making will be undertaken by the staff and Board of Side By Side Advocacy, in line with the funding agreement with the DSS.

Meeting arrangements

- The group will be chaired by the Research Project Officer (Bernadette Curryer) with co-chair being the Side By Side Advocacy EO (Kim Roots)
- Meeting frequency – Meeting every quarter
- Location- Zoom until after Covid-19 restrictions cease, then for discussion (a meeting room is available at West Ryde or Eastwood offices of Side By Side Advocacy if required)
- Agenda – prepared by Chair
- Minutes – prepared by Chair
- Communication between meetings- via email or telephone as required.

Reporting

- No reports are required from the CRG – although any major actions or suggestions will be included in the reports to the Side By Side Advocacy

Board (prepared by Bernadette / Research Project Officer) and to the funding body as required.

Confidentiality

While the group members are free to discuss the general aims and activities of the project with colleagues, there may at time be documents and information that is given in confidence. Documents shared amongst the group members are to be treated as confidential and not forwarded onto to others without prior permission.

Involvement of people with intellectual disability in the project

Co-researchers

Employment of co-researchers, Katrina Sneath and Will Harding – working fortnightly from Jan 2021, through to the end of June 2024.

- Katrina and Will have contributed to the project in many ways, including interviewing participants, discussing the analysis, video resource development and production, and presentation of results at conferences and meetings.
- Will and Katrina have also contributed to Side By Side Advocacy by understanding the organisation, assisting in website development and reviewing resources to advise on accessibility.
- Their involvement has not only been important because of what they have done, but also as a role model of inclusion, and maintenance of focus on the needs of people with intellectual disability.
- As they had limited previous involvement in research, training in research techniques was provided and reinforced by practice.



Will and Katrina
outside the office
in West Ryde.

Feedback from Will and Katrina

When asked what they valued most about their time working on the Inclusive Governance Project, they responded:

“The two conferences that I have presented at. To be able to tell other people about the project which I find important, getting out the information to others so that they can understand the importance of inclusive governance and spread it to their friends and other people they know.” *Will Harding*

“Open discussions – in conversation and with each other in a team. Sharing ideas and opinions throughout every activity, we have collaborated with each other...finding images on websites for Easy Read, to simplify for people with disabilities.” *Katrina Sneath*

Co-design groups

Co-design Group: During the project, a group of people with intellectual disability was included in the co-design and production of resources. They met

4 times in January/February 2023, and together with the project team and videographer Tom Greenwood, developed and produced the videos that outline the 5 Principles of Inclusive Governance. See <https://sidebysideadvocacy.org.au/inclusive-governance/> They met again in August 2023 to review and give input into other resources.



The co-design team working on resources

The co-design team included Will and Katrina, together with Sarah, Jeff, Nathan and Quang. They were supported by Nicole and Nicola, students from Sydney University on placement.



The co-design team planning the Principles videos



The co-design team showing their enthusiasm

Other involvement of people with intellectual disability in the project

- a member of the Consultative Reference Group has an intellectual disability
- some of the participants in the research have an intellectual disability.

Literature review

A literature review of articles published about inclusion of people with intellectual disability was undertaken, with the assistance of a Social Work student (Naomi Oei, Sydney University). This review identifies the limited research that has been undertaken on inclusive governance.

Search strategy

A search was undertaken of the following databases: Scopus, CINAHL, Web of Science, and PSYCInfo. The keywords for searching included the following:

“intellectual disability” or “mental retardation” or “learning disability” or “disability” or “developmental disability”

AND “boards” or “management committee” or “governance”

AND “inclusion” or “inclusive” or “diversity.”

The search using the terms listed yielded 477 results. After duplicates were removed, this search yielded 283 results.

To determine the inclusion of articles, we inspected the title and abstracts of these 283 articles. Articles were selected on the following basis:

1. Articles focussed on the involvement of people with disability on a Board
2. Articles included people with intellectual disability
2. Articles were published after 2000
3. Articles were written in English

The title and abstract review identified 21 articles based on the above criteria.

A manual search of references in these articles, identified another 6 articles.

After a full text review of these 27 articles the authors found that 4 articles were relevant to the criteria.

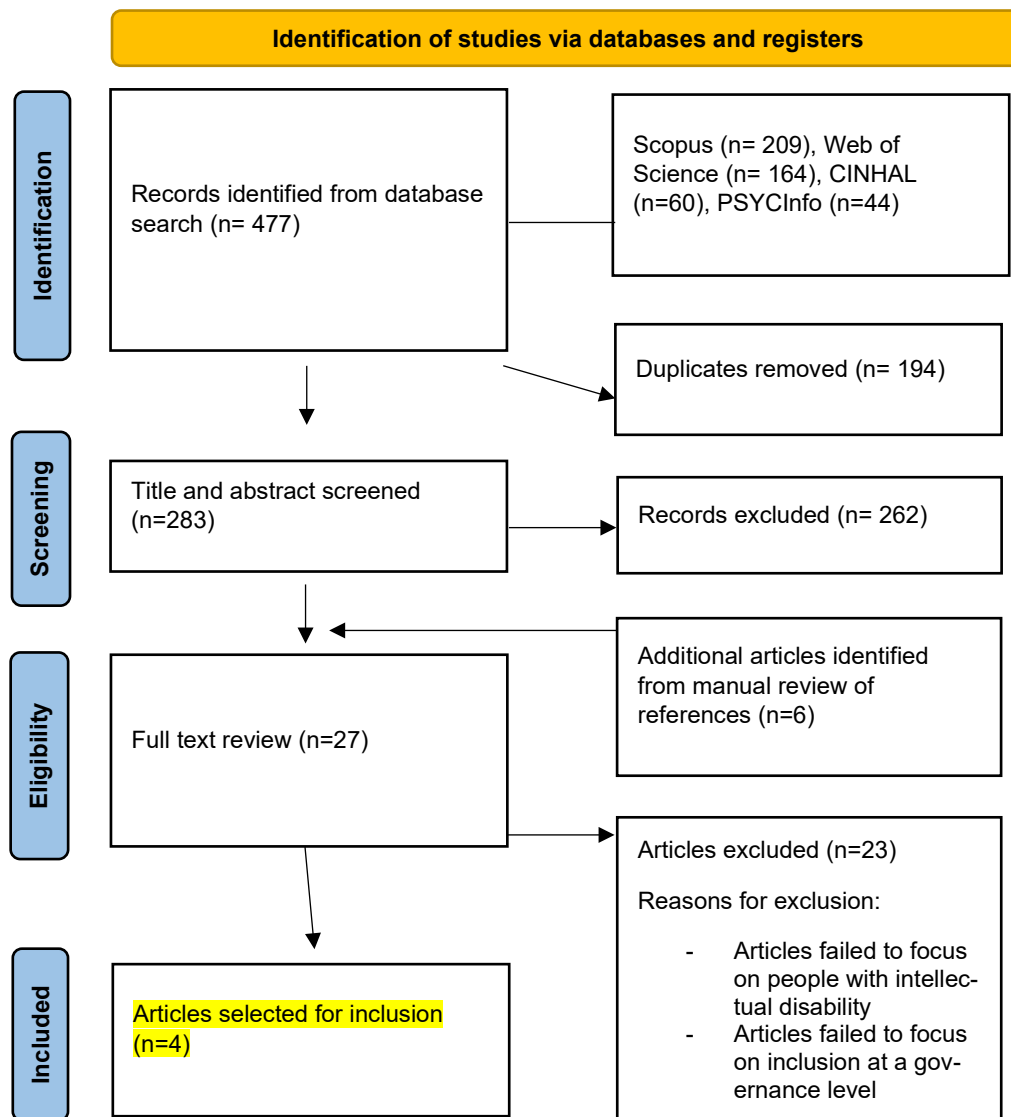


Figure 1: Literature search and screening PRISMA diagram

None of the identified articles explored the inclusion of people with intellectual disability on a Board of a community organisation. However, the articles did explore the involvement of people with intellectual disability in Learning Disability Partnership Boards or Government Disability Advisory Bodies. Learning Disability Partnership Boards are committees responsible for the design, management, and delivery of services for people with disability at a council level in the UK. They are made up of service delivery staff, adults who have an intellectual disability and family members. Disability Advisory Bodies

are committees set up to provide advice to government departments that provide services to people with disability. As these are both involved in the governance of disability service provision, they were included.

Table 1: Peer-reviewed literature on involvement of people with intellectual disability at a governance level

Article	Purpose & design	Structure & decision-making process	Supports provided	Potential barriers to inclusion
Fyson, McBride, & Myers. (2004). Progress on participation? Self-advocate involvement in learning disability partnership boards. United Kingdom.	To gather information about the experiences of self-advocates who were involved in Learning Disability Partnership Boards (LDPB). Study design - Interviews were conducted with individuals or small groups from 8 council areas Information was gathered about the meetings, their frequency, information accessibility, support provided and the self-advocates' personal experiences of attending board meetings.	There were 1-5 self-advocates at each LDPB meeting. Representatives of service providers also attended meetings Only two cases demonstrated a formal mechanism for decision-making	More frequent, shorter meetings Most Boards used accessible communication formats – big print size, jargon-free documents, pictures and symbols as well as text. One board had written information available on audio tape Social services manager met with self-advocates a short time before each meeting to discuss agenda items	Lack of practical supports inaccessibility of venues poor acoustics
Riddington, Mansell, & Beadle-Brown. (2008). Are partnership boards really valuing people? United Kingdom.	To explore the involvement of people with learning disabilities in Learning Disability	Meetings were co-chaired between a council manager and a person with learning/ intellectual disability	Easy read minutes and agenda Agenda displayed on a flip-board	Lack of practical support such as accessible venues and easy read documents.

Article	Purpose & design	Structure & decision-making process	Supports provided	Potential barriers to inclusion
	Partnership Boards (LDPB). 3 LDPBs were selected as case studies. LDPB meetings were observed Interviews were conducted with a range of partnership representatives.	Average of 36 people in each meeting. Average length of meetings- 2.5 hours Most agenda items didn't require decision-making. Run more like a forum for managers to be transparent about service decisions with an opportunity to raise issues	Microphones (to help people hear and slow down speed of discussions) Traffic light card system (for voting and to raise an issue) Assigned person ('word police') to notify speakers if they used a word, they did not understand 5 min break between each agenda item Tables were arranged informally around the room Briefing sessions before and after meetings	Contributions from people with disability were limited: less than 5% of the meeting time (average) less than a quarter of the meeting attendees (average). The involvement of people with learning/intellectual disability was generally superficial, receiving information without any decision-making or strategic role.
Frawley & Bigby. (2011). Inclusion in political and public life: The experiences of people	To explore the experience of participation in governmental advisory bodies.	Not reported	Most of the support was individualised, provided by a support worker external to the advisory bodies	Inaccessible meeting processes – long meetings, agenda and minutes not in plain English,

Article	Purpose & design	Structure & decision-making process	Supports provided	Potential barriers to inclusion
with intellectual disability on government disability advisory bodies in Australia, Victoria, Australia.	9 people with intellectual disability, all members of disability advisory bodies at a state or national government level, were interviewed. 12 other people involved in the meetings were also interviewed. Observations of meetings were also undertaken.		One site provided training on participation, meeting skills and how to communicate effectively in these forums	lack of preparation for the issues being discussed Difficulty understanding information Feelings of disempowerment and loss of confidence due to poor preparation, perception of lack of respect from staff and community
Fyson & Fox. (2014). Inclusion or outcomes? Tensions in the involvement of people with learning disabilities in strategic planning. United Kingdom.	To examine inclusive practices within Partnership Boards and the outcomes of Board processes Mixed methods used across three phases of data collection and analysis: - scoping exercise - postal survey - semi-structured interviews.	Partnership boards typically had 21-30 or more people People who had a learning disability were between 10% and 22% of participants, always the minority More men than women attended the meetings, with younger people (under 30 years) were more likely to attend than those over 60 years No formal decision-making process- 47% reported that they made decisions based on consensus agreement.	Documents, including minutes, in accessible formats (e.g. Easy Read) Banning the use of jargon Traffic light cards to enable the individual to slow the pace of the discussion ‘Break out’ groups to allow discussion to take place in smaller groups.	Location, with inadequate funding as to improve transport access Lack of formal decision-making processes. Most partnership boards were co-chaired by someone with a learning disability (82%), however, co-chair position was considered tokenistic with the co-chair without a disability having more control.

Accessible meeting practices

Accessible formats

The literature suggests that some of the advisory or partnership Boards have attempted accessible practices during meetings. The three case studies described by Riddington et al. (2008) used 'easy to read' minutes and agendas in meetings. However, Frawley & Bigby (2011) and Fyson et al. (2004) found that there was a failure to translate documents into easy English. This led to members of advisory bodies with intellectual disability feeling ill-prepared for their role and fostered feelings of inadequacy (Frawley & Bigby, 2011). Riddington (2008, p. 662) supports the use of easy-to-read documents in meetings regarding it as a “positive move” to make organisational documents more understandable. Other accessibility adjustments included ensuring documents were free from jargon, and the use of big print size and images (Fyson et al. 2004, p. 31). One of the boards observed by Fyson et al. (2004, p. 31) utilised the use of audio recordings as an alternative accessible format. The absence of easy-to-read documents and other accessibility adjustments can be considered a barrier for people with intellectual disability to fully participate in the decision-making process in an organisation.

Use of support workers

Frawley & Bigby (2011, p. 33) found that most of the support received by members of the government advisory bodies was individualised, provided by an external support worker. Support workers would assist in note-taking and translating the documents into plain English (Frawley & Bigby, 2011, p. 33). However, despite the external support, participants described the process as

being quite rushed as they were only able to meet with a support worker an hour before meetings (Frawley & Bigby, 2011, p. 33).

Change of meeting structure

Some of the partnership Boards observed by Fyson, McBride & Myers (2004) split into sub-groups during meetings, allowing for smaller group discussions and then coming back to the full meeting to make joint decisions. Additionally, the partnership Boards held meetings monthly, rather than quarterly, with a shorter agenda to assist people with intellectual disability to concentrate without feeling over-tired. The frequency was also thought to reinforce the meeting process.

Other practical supports

Microphones were utilised to allow people to be heard, with one person speaking at a time, slowing down the speed of discussions. Traffic light cards were also used to indicate a wish to raise a matter during the meeting and 'word police' notified the speaker if they used a word that they did not understand. Meeting venues were accessible for the groups observed by Riddington et al (2008), however, Fyson et al. (2004) found that other participatory Boards overlooked the accessibility needs when people had both intellectual and physical disabilities. Some meeting rooms contained poor acoustics making it difficult for self-advocates to hear other members or make themselves heard. While such practical support was seen as beneficial, it was not enough to ensure that people with intellectual disability were actively participating in decision-making processes.

Potential barriers to inclusion

Attitudes of other members

Collegial support is a contributing factor as to whether a person with an intellectual disability is fully participating in the decision-making process in the organisation. Members who believed that other members respected their capacity and potential to contribute reported a more meaningful involvement (Frawley & Bigby, 2011). Fyson & Fox (2014, p. 244) found that a physical presence at a meeting does not guarantee meaningful inclusion, with one participant reporting “There can be problems because people can jump in - they don’t listen to us.” Riddington et al., (2008) found that contributions of people with intellectual disability on participatory Boards were limited with their contributions lasting no longer than one minute each.

Lack of training

Frawley & Bigby (2011) found that there were inconsistencies regarding how advisory bodies prepared their members with intellectual disability. Of the advisory bodies investigated, only one participant received training on participation, meeting skills and effective communication in a forum setting (Frawley & Bigby, 2011). One participant in the Frawley & Bigby (2011, p. 34) study expressed their feelings of inadequacy when it came to voicing their opinions as they felt a lack of practical experience or education in comparison to other members.

Unclear decision-making process

Riddington et al., (2008) found that many items on the agenda required no decision-making at all, with only four decision-making occasions observed. Similarly, Fyson & Fox (2014, p. 245) found that the boards observed generally lacked a formal decision-making process with about half of the decisions based on “consensus agreement.” As the co-chair with intellectual disability was often sidelined in discussions, and limited input from the members with intellectual disability, this suggests that the opinions of members without disability were heard more, and therefore had a greater influence on discussions and decisions.

Other literature

Due to the limited literature found in peer reviewed journals, an extension of the search was made to grey literature, that is reports published without formal peer review. Three project reports are reported below.

Table 2: Grey Literature reporting inclusive governance

	Project / Study purpose	Pathway to involvement	What supports are recommended	Potential barriers to inclusion	Overview
Deloitte - The Inclusion Imperative for Boards (2019) USA.	Focuses on the benefits of diversity and inclusion on corporate and Non-Profit boards. Not necessarily people with intellectual disability. Interviewed 14 executives and board members and two diversity and inclusion subject matter experts Semi-structured interviews	Individual demonstration of expertise in the areas of governance, diversity, and inclusion	Inclusion should be supported by the organisation as a whole – should be included in the company’s mission statement, organisation’s objective, vision, mission, and strategy. Use of inclusive language, thinking and actions in all relevant proceedings and practices. Forming an inclusion specific committee.	Organisational culture – failure to have inclusive leadership influences organisation’s culture. Majority of boards surveyed did not consider inclusion and diversity as separate concepts – most board efforts focused specifically on diversity.	An inclusive culture allows employees to see themselves as part of a high-performing organisation in which teams collaborate and consistently meet client and customer needs. Teams perform better when they are diverse and inclusive. There is less groupthink and more innovation. High performing boards are found to have a gender balance and inclusive behaviours.

	Project / Study purpose	Pathway to involvement	What supports are recommended	Potential barriers to inclusion	Overview
Voice At The Table (VATT) 2019 Victoria, Australia.	Civic participation project that aims to address the barriers to civic, social, and political participation of people with cognitive disabilities. 21 people completed the pilot program in 2016. This was followed up by delivery to 30 participants with cognitive disabilities in 2018. Project is ongoing.	Six-day training developed and co-facilitated by people with cognitive disabilities Refresher training and skills development for Voice at the Table graduates Inclusive Meeting practice training for organisations Development of resources for participants and organisations On-going mentoring and support for consumer advocates and participating organisations	Practical support such as: -sending out information before the meeting -have someone go through the agenda and minutes -use Easy English and the agenda in big print. Ensure everyone's voice is heard.	Lack of practical supports and inaccessible information People may lack confidence or feel intimidated, reinforced by negative attitudes of others Limited organisational understanding of the challenges faced by people with cognitive disabilities Lack of effective support Limited availability of training and resources Few opportunities to practice learned skills.	People with cognitive disabilities are able to provide organisations and government with fresh ideas and ways of doing things VATT believes that meaningful inclusion of people with cognitive disabilities in civil, social and political roles will lead to increased confidence, better services, higher satisfaction scores, more inclusive practices that benefit clients and make policies more relevant.

	Project / Study purpose	Pathway to involvement	What supports are recommended	Potential barriers to inclusion	Overview
People With Disabilities Western Australia 2019 On Board With Me Project, Western Australia.	Aims to improve the representation of people with disabilities on boards in the Western Australia community services sector. The Board Disability Survey was sent online to 88 community service organisations with a 48% response rate. 75% of respondents were Board Directors, CEOs or C-Suite employees.	71% of Board directors said the trigger for them to join the Board was because someone on the Board, or the organisation asked them to apply. Candidates were required to be Board ready, previous governance training is critical in the selection criterion. Candidates must be seeking out Board roles and not wait for recruiters to approach them – they needed to drive the process to succeed.	-accessible venue -access and support with transport -accessible information (e.g. plain English, large print, Auslan interpreter) Organisational support: -pre-meeting support if required, -mentoring outside of board meetings -flexibility to attend remotely Skills and capability development: Funding for additional training, mentoring program for new board members	Merit-based selection systems may hide biases, protect the status quo, and enable the assumption that systems and processes are objective. Few boards require Directors to complete disability awareness training. Underestimation of people with disability's knowledge, with a focus on what a person can't do and an assumption that the person can only provide a lived experience of disability and not broader life.	People with lived experience bring a more profound, personal understanding to the broader discussion when placed in leadership roles and have a direct impact on framing social policy, system management, planning, education, program development and evaluation.

Conclusion

There is a very limited amount of literature regarding inclusive processes and structures implemented by organisations to support people with intellectual disabilities in governance roles. The existing literature indicates that some Boards have introduced practical support for people with intellectual disability. Practical support may include the use of 'easy to read' documents, audio recordings, accessible choice in venue or the use of external support during meetings. However, despite the practical support, there are barriers that prevent people with intellectual disability from meaningfully contributing to the decision-making process. The literature indicates colleagues may undermine the person with intellectual disability's ability to contribute to the decision-making process leading to a sense of inadequacy or being spoken over. Furthermore, the failure to provide the appropriate support, training or knowledge to encourage people with intellectual disability to actively participate in the decision-making process within organisations may be exclusionary. Failing to provide practical support in addition to other intangible barriers may lead to direct and indirect discrimination of people with intellectual disability. Thus, the roles of people with intellectual disability on the committee or Board may be tokenistic. More research is required on how to organisations can assist in improving collegial attitudes, as the development of collegial relationships correlates to increased self-confidence in a person's own abilities and skills (Frawley & Bigby, 2011). More research is required on how Board structures and meetings can accommodate the needs of people with intellectual disabilities.

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B. Research method

Research Aim

The proposed project will investigate a range of governance models, structures, policies and procedures that are used in community organisations to determine the strengths and weakness of the governance models and structures in promoting the recruitment, decision-making and leadership of people with an intellectual disability from the perspective of people with intellectual disability and other Board and management committee members.

Research questions

Following discussions with the Project team, the Consultative Reference Group and consideration of the literature search outcomes, the following research aims were identified:

To better inform efforts to promote inclusive governance an investigation was undertaken:

- to understand the experience of inclusion of people with intellectual disability from the perspective of Board members with and without intellectual disability, senior management staff and Board support people
- to recognise structures and processes that are likely to promote the effective inclusion of people with intellectual disability and support their recruitment, decision-making and leadership.

Methodological approach

A descriptive phenomenological design (Sundler, Lindberg, Nilsson and Palmer, 2019) was employed to explore the experiences of people involved in inclusive governance and to understand the meaning of those experiences.

Ethics

Ethical approval for the research was obtained from the Southern Cross University Ethics Committee (Approval Date: 03/07/2020 Approval Number: 2020/082).

Recruitment

Participants were recruited through the promotion and advertising of the study online and through networks within the disability and community sector. People expressing an interest were provided with further information and a consent form. This information was also available in plain English formats. After receiving information about the study, 27 people consented to participate.

Participants

27 people participated in at least one in-depth interview. These participants are as follows:

- 5 Board members with intellectual disability
- 6 Board/Committee members with disability (not intellectual)
- 4 Board members without reported disability
- 8 Executive Officers or other Senior Managers
- 4 Board support people

These participants have experience with Boards from 21 community organisations. Some people described experiences with more than one organisation, and some organisations had multiple (up to 4) people describing their experience of inclusion. These organisations were made up of:

- 11 disability advocacy or peak body organisations (5 specialise in intellectual disability)
- 9 disability service providers

- 1 youth peak body

Data Collection

Semi-structured, in-depth interviews were conducted with 27 participants. The project lead was involved in all interviews, except participants 07 and 11 (who were interviewed by Dr Marg Spencer). Co-researchers with lived experience of intellectual disability assisted the project lead with 11 of the interviews. Each participant was interviewed for an average of 62 minutes. Second interviews were conducted with 3 of the participants who had an intellectual disability (P01, P02, P03) to provide extra time for them to reflect and consider their responses. Two of the participants (P03 and P07) used alternative communication methods, both typing their answers to questions.

Interview guides were developed for Board members, staff, and support people, including a plain English version of the interview guide for Board members with intellectual disability. We asked each participant to describe their involvement in governance roles, the structure of the Board or committee, meeting and decision-making experiences, support provision, and their experience of inclusion.

The understanding of the experiences of the participants, and the contexts in which these experiences occurred, was supplemented by observation of three Board meetings and the review of the constitutions of nine advocacy and intellectual disability peak bodies. Over 70 discussions, outside of the formal interviews, have been held to promote the Inclusive Governance Project and to understand the current environment and general thoughts about inclusive governance by the wider community. Discussions have been held with disability service providers (n=17), disability advocacy organisations (n= 10), governance

and constitutional specialists and training bodies (n= 9), academics specialising in intellectual disability, governance or decision-making (n=8), peak bodies (n= 5) and other interested people.

Data analysis

This project undertook a thematic analysis based on a phenomenological approach. This means that the experiences of Board and Committee members was explored. Using an inductive and iterative approach, the data was read and reread, looking for patterns and recurrent themes that emerged from the data. NVivo software was used to manage the data – including the audio of interviews, the typed transcripts, field notes and a record of observations - and organise preliminary data analysis. Themes and subthemes were discussed with co-researchers, other members of the project team and the Consultative Reference Group. Member checking of participants, with and without disability, representing Board members, Executive Officers and support people, were completed. Data saturation was reached when no new ideas or themes were emerging. This resulted in the cessation of participant recruitment. Table 3 gives details of the participants, with the participant code referring to participant number, followed by the organisational code (see Table 4 for organisational code details).

Table 3: Participant characteristics

Participant number_ Organisational code/s	Main Role	Gender	Lived experience of intellectual disability	Lived experience of disability other than intellectual
P01_AB	Board member	Female	Yes	autism
P02_C	Board member	Female	Yes	
P03_BC	Board member	Male	Yes	physical, uses alternative communication methods
P04_D	Executive Officer	Female		
P05_C	Support Person	Female		
P06_EO	Executive Officer	Female		
P07_EF	Board member	Female		physical, uses alternative communication methods
P08_G	Executive Officer	Male		
P09_H	Support person	Female		
P10_I	Executive Officer	Male		
P11_E	Board member	Female		
P12_J	Board member	Female	Yes	
P13_K	Board member	Female		physical
P14_JLM	Board member	Male		
P15_B	Executive Officer	Female		
P16_J	Board member	Female		
P17_N	Board member	Female		physical
P18_K	Support Person	Male		
P19_P	Board member	Male	Yes	
P20_Q	Executive Officer	Female		
P21_R	Board member	Male		sensory
P22_C	Support person	Female		
P23_S	Board member	Male		
P24_T	Executive Officer	Female		
P25_U	Advisory Committee	Male		physical
P26_B	Board member	Female		physical
P27_R	Senior manager	Male		sensory

The participants involved in the interviews drew on experience with 21 organisations. Table 4 provides de-identified information about each organisation.

Table 4: Organisational Characteristics

Code	Type of Disability Organisation	Main client group	Board has or has had members with intellectual disability
A	Advocacy	Intellectual disability	Yes
B	Advocacy	Disability – CALD	Yes
C	Advocacy - peer led	Intellectual disability	Yes
D	Disability Service Provider	Disability - general	
E	Advocacy	Intellectual disability	Yes
F	Information	Physical disability	
G	Advocacy – peer led	Intellectual disability	Yes
H	Disability Service Provider	Disability - general	Yes
I	Disability Service Provider	Disability - general	Yes
J	Advocacy	Intellectual disability	Yes
K	Advocacy – peer led	Disability – CALD	Yes
L	Disability Service Provider	Disability - general	
M	Disability Service Provider	Disability - general	
N	Disability Service Provider	Disability - general	
O	Advocacy	Disability - general	
P	Advocacy – peer led	Disability - general	Yes
Q	Peak Body	Youth	
R	Disability Service Provider	Sensory Disability	
S	Disability Service Provider	Intellectual disability	
T	Disability Service Provider	Disability - general	
U	Disability Service Provider	Disability - general	

Review of Board structures and constitutions

- The structure and constitutions of 9 advocacy or peak bodies were examined (including SBSA)
- Details of membership, Board size, quorum, stakeholder representation, office bearers, tenure, and other points of interest were compared
- This gave an overview of how a variety of community organisations structured their governance mechanisms.
- Information found in Constitution and Annual Reports, publicly available on either the Australian Charities and Not-for-profits Commission (ACNC) website (www.acnc.gov.au) or individual organisational websites.

Observation of Board meetings

- We observed Board meetings of 3 organisations; one had several people with intellectual disability on their Board, one had several people with disability other than intellectual, and one had no identified people with intellectual disability
- This helped us to understand the practical way in which people with intellectual disability were included. It also allowed us to observe how people may be present but excluded from the decision-making.

C. Findings

Five overarching themes and 21 sub themes emerged from the analysis. An illustrative model of the relationships between each of the themes was developed and appears in Table 6 below.

Table 6: Emerging themes and sub-themes

Themes	Sub-themes
Theme 1 – Impact of inclusion in governance	a) A valued role b) Additional perspective and skill c) Challenging stereotypes
Theme 2 – Pathways to Board membership	a) Individual preparation b) Embedded inclusion c) Sector responsibility
Theme 3 – 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
Theme 4 – Support provision	a) Providing support Stage 1 - Meeting preparation Stage 2 – Support during meetings Stage 3 – Contact between meetings b) Complexity of the support role c) Supporter training
Theme 5: Concerns become barriers to inclusion	a) Complexity of Board role b) Legal responsibility c) Meeting support needs d) Perceived conflict of interest e) Current Board culture f) Fear of tokenism

The number of participants contributing to each theme and sub-theme is presented in Table 7, below:

Table 7: Participant contribution to each theme and sub-theme

Theme	Participants contributing to each theme	Sub-theme	Participants contributing to each sub-theme
Theme 1 Impact of inclusion in governance	16	a) A valued role	7
		b) Additional perspective and skill	11
		c) Challenging stereotypes	3
Theme 2 Pathways to Board membership	20	a) Individual preparation	7
		b) Embedded inclusion	14
		c) Sector responsibility	6
Theme 3 Experiences impacting inclusion within Boards	20	a) Board culture	13
		b) Board structure	2
		c) Communication practices	11
		d) Meeting processes	5
		e) Decision-making processes	7
		f) Experience of exclusion	6
Theme 4 Support provision	21	a) Providing support	14
		Stage 1 - Meeting preparation	11
		Stage 2 – Support during meetings	8
		Stage 3 – Contact between meetings	7
		b) Complexity of the support role	12
		c) Supporter training	8
Theme 5 Concerns become barriers to inclusion	17	a) Complexity of Board role	7
		b) Legal responsibility	5
		c) Meeting support needs	10
		d) Perceived conflict of interest	6
		e) Current Board culture	4
		f) Fear of tokenism	5

Each theme will now be explained, with transcript excerpts that illustrate each of the themes cited. Transcript excerpts appear in inverted commas or using indented text. After each transcript excerpt a code is provided from Table 1 indicating the various participants contributing each of the quotes. Reference to Table 1 provides details of the role of each participant and their lived experience. In addition, the contribution of each theme to the overall model is represented diagrammatically.

Theme 1 – Impact of inclusion in governance



The first theme that emerged was the positive impact of inclusion of people with intellectual disability in the decision-making of organisations. This theme is divided into 3 sub-themes, the impact on the people with intellectual disability who take on a governance role (a valued role), the impact on the organisation (additional perspective and skill) and the impact on the community (challenging stereotypes).

a) A valued role

People with disability spoke of different motivations to become a Board member. For people with disability, one reason for joining a Board was to have a valued role that was viewed as prestigious by both the organisation and the general community. Barriers to other valued roles enhanced the appeal of a Board role. Board membership became an avenue to showcase skills and highlight ability, a way to “show I can do the job, and then...people can see that I can do a whole lot more than what they think I can do” [P01_AB]

Others wished to make a difference for others. “I felt like I could help people who have greater challenges than I did.” [P07_EF]. Some felt that they could contribute to specific issues, often based on lived experience. For example “how to organise the fundraising [and improve] footpaths” [P03_BC].

A belief in the right of people with intellectual disability to be involved in organisational decision-making was another motivator. “It comes from my passion [for] human rights and advocacy” [P19_P], and “...a right to be included on Board[s], to be able to make decisions in policy development, reviewing policies, how an organisation is run, what that organisation does, programs, activities” [P01_AB].

Participants described positive experiences associated with Board membership. They reported that they enjoyed being heard, learning new skills, and having a valued and respected role. There was a sense of connection with others, they were able to show their abilities and contribute. "I feel very involved...gives me a chance to go out and reach people and not be isolated...that is very important to me" [P02_C]. Other positive aspects of involvement at a governance level include being able to express an opinion that is listened to, respected, and may result in change. This experience was observed by a Board support person who noted that as a Board member "...you feel valued...that you['re] respected...that people will look at you through different eyes" [P09_H].

Inclusive experiences resulted in observable, positive personal development. "I've watched people that...hardly said a word, and then just blossomed...they could talk for themselves...it was absolutely beautiful" [P25_U]. However, there were also reports of stress related to the expectations of the position and the election process.

However, the experience was always positive, with some reports of stress related to the expectations of the position. A participant who was recently the chair of an organisation noted that her position came with responsibilities, "It's very stress[ful]...I'm a chair. I need to be there...I can't be late" [P02_C]. Stress was also felt over the election process. The desire to have a place on a Board and viewing the election as an indication of success created a situation that at times caused distress.

It's been very upsetting where it's been so close that you might have thought you'd get onto the Board...then you're feeling so sad and you feel like you want to cry, because you haven't had that success when you might have been having that success for the last two or three years [P01_AB].

b) Additional perspective and skill

Inclusion of people with intellectual disability in governance roles also has a positive impact at an organisational level. It allows the voice, perspective and lived experience of people with intellectual disability to be considered in an organisation's decision-making. It also provides other Board members with the experience of really getting to know people with disability, and can create a cultural shift within an organisation, assisting the Board to ensure the focus is on the needs of their client group.

Lived experience heard and considered

When people with intellectual disabilities are included on a Board, their lived experience can have a direct impact on the Board's decision-making. This was particularly seen in activities such as policy development and review, and decisions about programs and activities.

Inclusion provides an opportunity for people with disability to be "the ones who give the information to the service and say, "Well, this is what we want"" [P01_AB]. It saves Boards trying to guess what people with intellectual disability think [P12_J] and provides an opportunity for people with intellectual disability to be part of the conversation. "...you got to have a person with disability on that Board so they can have their say and have their opportunity to speak up about stuff that's concerning people with disability" [P19_P]. The inclusion of a Board member with lived experience of intellectual disability is an addition to the Board's skill-mix. "...[its] not about them representing others with a disability...what they're bringing is a skill" [P04_D]. This skill is the provision of a specific perspective to the Board, as noted by a Board member with intellectual disability, they provide "experiences as a person with an intellectual disability, what that's like" [P12_J].

The involvement of people with intellectual disability in Board discussions increases the consideration of their perspective in the decision-making process. Repeated reference to experiences of abuse by a Board member with intellectual disability, led one Board to recognise the need for an increased focus on safeguarding. As one Board member noted "that was such a salutary lesson, and it completely changed the way we, at the time, approached the policy development" [P11_E].

For Board members themselves, having a person with intellectual disability on the Board created change. Their presence

...made me express my ideas more clearly in the meeting and it certainly helped to focus on the perspective of at least that person with disability...that meant that that caused me to reflect more than I perhaps would have on that perspective [P16_J].

Increased understanding of disability

The experience of working with a Board member with disability increases the understanding of disability and its impact. As one Board member with intellectual disability stated, “They should have someone there with disabilities so that they will [be] able to learn what they do...like how to talk to people with intellectual disability or multiple disabilities...how they should work” [P02_C]. An Executive Officer of a disability service provider supported this by giving an example, “...when we had a client come to the [Board] meeting with cerebral palsy...at first, I think it was very confronting for them [Board members]. They need more experience of actually speaking to somebody with an intellectual disability” [P04_D].

A support person also recognised the importance of other Board members having a working relationship with people with disability, explaining that it helps them to “...actually understanding who in heaven’s name they're working for” [P09_H].

This understanding includes awareness of the ability of people with disability. One example given was that Boards can be very cautious and risk adverse, having a person with intellectual disability on the Board “...pushed us to recognise the abilities of the people that we served” [P16_J].

A cultural shift

People spoke of the inclusion of people with intellectual disability within the activities of an organisation, including at a governance level, as creating a cultural shift within the organisation.

If everybody is thinking that way, and everybody's attuned to including people in their work and there's an expectation that the voice of people with disability will be part of that work, then it becomes part of the culture of the organisation, it's a cultural shift [P06_EO].

Organisations that actively included people with intellectual disability perceive such inclusion as integral to their organisation and its work. Inclusion “completely grounds us and centres us – it’s our soul...it astonished me to think that any advocacy group can claim to represent people without actually having representative structures in place to ensure their voice is governing” [P08_G]

Similarly, one Board member described the need for inclusion.

In order to be able to be properly informed...to be able to make sensible decisions...to do any kind of planning, you cannot do it without the full participation of people with lived experience...So, it's a matter of moral

coherence to have people involved in every level of the organisation who have lived experience. It deepens the whole endeavour [P11_E].

While inclusion may create some challenges and require some change in current practices and resource allocation, a belief in inclusion was viewed as positive for organisations. This was summarised by a Board member with disability. "...if they actually believe it, like we believe...it will grow better...it will have better outcomes...they'll just be better overall with the input and contribution of people with disability" [P21_R].

c) Challenging stereotypes

The benefit of people with intellectual disability being involved on Boards has an impact that extends out into the wider community.

One participant would offer her lived experience as a participant of the NDIS to other members of the Board as she knew this would help them pass on this knowledge to their social and family networks. Other Board members with intellectual disability took on a representative role for the organisation. This provides both a positive role model of what is possible as well as practical involvement with the activities of other organisations. One example was when working with a partnering university, the Board members were able to assist in research design, speaking at conferences and other university-led activities [P22_C].

Observing the inclusion of people with intellectual disability at a governance level also had an impact on support workers' views about what was possible for people with disability. As one senior manager described,

...their perception of the customer has changed because they have seen the person with disability come to this meeting, be treated with respect...it's this valued role. She's treated like a peer and not less than...that has changed that worker's perspective of that person [P24_T].

In this manner, organisations supporting people with disabilities are directly modelling the inclusive change they are working towards in the community. Involvement of people with intellectual disability on Boards is part of push for people with disability to take on a greater role in their communities. "I truly believe in peer power...that having peers with disability on the Board so they can have conversations and help their organisations grow...so they can go out there and do awesome stuff in the community" [P19_P].

Theme 2 – Pathways to Board membership

The second theme that emerged from the data is about the pathway to Board membership for people with disability. The experience of moving towards Board membership can be considered from an individual, organisational and community level. People with intellectual disability need an increased understanding of how they may become more active in the decision-making of community organisations, and develop the skills required. Organisations and the wider disability and community sector have a responsibility to facilitate and enhance these pathways.



a) Individual preparation

Getting onto a Board

The pathways to Board membership varied. For some participants there was a clear pathway that made Board membership a natural progression from other aspects of organisational involvement. Previous experience in the groups and committees of the organisation was a pre-requisite to Board membership.

“That’s how everyone gets on [via a members forum/committee] so they’ve had experience...so they know what the meetings are going to be a little bit like” [P12_J]. Others responded to advertisements that were promoted in organisations with which they were already associated [P25_U]. While a direct, personal approach convinced one participant to work past perceived barriers. “I just got a call from [previous EO]...I said, “I can’t come...it’s hard for me to come,” “We will give you taxi.” So I came in a taxi, then I joined the disability Board” [P26_B]. Some organisations have a lengthy nomination and election

process, and people are required to campaign on their own behalf. "People would nominate and they'd do a few lines about why they wanted the role, what they were good at, what they were experienced at...that went out on the ballot papers ... for members to know about them" [P22_C].

The varied experience of participants indicated that individuals need to find out the specific pathway[s] that an organisation uses for recruitment or to nurture Board members, if they are to become involved at a governance level. One Board member with intellectual disability advised people to become involved with an organisation prior to accepting a Board role, "...get to know your organisation a bit better...then over time, you know the organisation very well and then make a decision like to get on the Board" [P19_P].

Learning how to be a Board member

The need for training in Board skills was acknowledged by some participants, who accessed training that was provided in-house by some organisations. This training not only gave people skills about being on a Board, it also served as a way to screen the preparedness of prospective Board members.

Everybody has to attend Board training...they go through...each of the roles, what's required for each. And then, you get interviewed...They test your knowledge and then they'll make the decision...whether, yes, you can go for that position and get nominated, or no, you can't because you couldn't answer the questions, or you need more training [P01_AB].

Training addressed the practical aspects of meetings, how meetings are run, understanding reports and taking part in discussions. Involvement in training gave one of the participants, a person with intellectual disability, the confidence to assert themselves within a meeting "I feel confident enough because I have enough training...they train me how to speak up, how to be confident...when you go out to a meeting, what will you say, what sort of technique you need...how you stand, where you stand...how to do it." [P02_C]. The need for such confidence was not limited to participants with intellectual disability. One participant with a physical disability reflected that despite being a long time member of a Client Advisory Committee,

It would be the next step for clients to sit on the Board...I'll have to sharpen up all my skills and stuff ...It would be a big step if the actual national committee did take on a client to go up on the Board. I'm not saying I'd like to be the person. There's probably other people out there a lot more qualified than myself [P25_U].

The need for training about aspects of Board membership, such as an understanding and commitment to confidentiality was also acknowledged, "...they have to know not to tell anyone what is talked about in the meetings." [P12_J]

Having an opportunity to observe a Board meeting in action can give people an understanding of a Board member's responsibilities and help a person to identify what they may need to learn. "...what skills they would like to learn, what sort of things that they want to do, and then be able to come up with a path of when they're going to be able to be taught those skills. Even sitting next to someone who already does it so they can see how [it is done]" [P01_AB].

Ultimately, people felt a need to earn the respect of the rest of the Board, to prove their worth.

I've been there for the whole journey...to now where we do brainstorm and everything like that. But we had to earn our place and come up with ideas and solve problems...if they weren't going to get any information out of us, we would have been just deadwood [P25_U].

b) Embedded inclusion

Organisations need to consider several aspects about their organisation and how they can create a clear pathway to involvement by people with intellectual disability at a governance level.

Organisational culture

Board and management beliefs about the inclusion of people with disability, including intellectual disability, was a crucial aspect impacting the success of inclusion for participants.

I think this comes back to culture...to whether the Board says that diversity on the Board is important...organisations who do well at disability inclusion in the workforce, actually believe, truly believe, that having people with disability in their organisation is beneficial [P21_R].

This view was supported by another participant who identified the role of senior staff in creating a truly inclusive culture.

The barriers need to be broken down. I've heard of organisations that have so-called got these inclusions and so-called got these policies, but it's a tick-a-box, they don't actually believe in it...it's got to come from the top down. If your CEO or whoever is running the place, absolutely,

believes with a passion that if someone with disability, whatever the disability is, can actually have a role in their organisation, then it will filter right all the way down [P27_R].

Having inclusive leadership within an organisation means that the voice of people with disability remains central. "...if it did come down to something very contentious and decisions were very difficult to make, the leadership of people with intellectual disability would come first" [P22_C].

Board structure

Some organisations set the expectation of inclusion of people with intellectual disability on their Board in either their constitution or policies. The importance of this is explained by an Executive Officer of an advocacy organisation.

It's absolutely incumbent on us to ensure that people with disability are central to all the decisions we make...so the [self-advocacy group] is not only a feedback mechanism... it is a governance mechanism. That's why it's in the constitution. It's part of our governance driving [P08_G].

Without specific rules about the inclusion of people with intellectual disability within a constitution, there is a risk that such inclusion is dependent on the beliefs of a changing Board or management. This is identified by a support person,

...there was no mandate for them [people with intellectual disability] to be on there at all. So, if the culture of the Board changed, the organisation changed, there wasn't any rule to say, 'Well, you have to have people with intellectual disability' [P22_C].

A Board Charter, identifying inclusion as a key principle and focus of an organisation, is an option used by some organisations instead of including specific inclusion details within the constitution. "Put the principles, the striving, the culture, the requirements, into a Board charter, which is a more living, breathing document..."[P21_R].

Recruitment and election strategies

The way in which an organisation recruits Board members has an impact on who joins a Board. Ensuring people understood an organisation, its values and mission was seen as the first step in ensuring "they're joining the Board for the right reasons" [P06_EO].

Recruitment of people with intellectual disability onto a Board requires specific planning. Some organisations that include people with intellectual disability on their Board have quite well-planned and organised processes. One Executive Officer [P08_G] described his organisational recruitment process in which two Board members are voted onto the Board, drawn from a sub-committee made up of representatives of self-advocacy groups.

In many cases, recruitment of potential Board members was largely through personal networks, “People knowing people” [P07_EF]. The need for specific skills was another determinant of the recruitment process. Participants recognised the benefits of lived experience, viewing this as a skill. “Who should be on our Board?...I'm a strong proponent of skills based...you draw upon the people that you need, and if lived experience...is helpful then, of course, that influences your recruitment” [P21_R]. However, some Boards remain unsure about the skills that a person with lived experience of intellectual disability may bring. “Having someone with intellectual disability on the Board, I don't have a problem with that...it just really has to be around how they can contribute and you don't really know until you get them here” [P23_S].

Organisations need to consider their nomination and election processes and ensure both are understood and accessible. Providing new nominees with the support needed to become an integral member of the organisation needs careful planning and consideration.

People tended not to vote for someone who was newer to the organisation...I think that that was certainly a weakness...People seem to value people that they knew and trusted...You have to have resources and ways to involve a variety and a diversity of people regularly so that...[when] they go through a nomination process, they understand the organisation and they understand what they're getting into [P22_C].

One description of the election process preferred by a Board member with intellectual disability was “We have a piece of paper. You tick your boxes, and then you vote, and then we will announce [who was elected] at the...AGM” [P02_C]

Skill development

Organisations need to consider the skills that Board members require and support the development of these skills. An understanding of Board member's role

and responsibilities is critical, and is often achieved through a combination of training, observation and mentoring.

The need for a realistic understanding of the work involved in Board membership was described by a Board support person.

You really have to...come to all the meetings, do your prep work, and if you don't want to do that, it's not going to work. So we make sure everybody knows it is a bit boring sometimes. It's not a hilarious activity all the time. There's some serious things involved [P05_C].

Observation of the Board in action is required by one organisation before a nomination is accepted. "They've got to come along and observe the meeting before they put up their hand to volunteer to come on to the committee. They should actually know what it is and what they'll do first" [P08_G].

Formalised observership programs, that can last for up to a year, are offered by another organisation as part of their recruitment strategy to increase the number of Board members with disability.

I basically act as a fly on the wall...I get to watch the whole thing, read the papers, ask questions, and I get a fair bit of mentoring from the CEOs and the chair...I love the program...I really learnt a lot and I felt really safe and supported to have conversations and to ask questions [P17_N].

The provision of training, together with practical experience of organisational activities increases the ability to undertake Board responsibilities, "to get you from where you are to where we think you need to be in order to be as best a contributor to the Board as possible" [P21_R]. A Board support person described the growth observed in a current Board member with intellectual disability.

The change in them is very profound...He's just come such a long way from our first meeting, when he joined the Board...to now. [It] is just really an enormous improvement. So, I think it does take a few years. And I think that pre-work that people do on the subcommittee and doing other meetings and leadership, training, those things are all really important. I think if you just come into a Board meeting cold, it'd be pretty bad [P05_C].

The recognition that developing the required skills takes time, means that the length of Board terms was deliberately set at 3 years by one organisation "to give people time to grow into the role" [P22_C]. Effective induction to the

Board is another way to assist the people in learning about the role of the Board and Board Members and would include detailed explanations of both general and financial responsibilities [P24_T].

Training opportunities and resources need to be individualized, including the development of accessible resources [P05_C] which may be required for some Board members. A support person working for an organisation that has a high number of people with intellectual disability on their Board noted that Board members, current and potential, were keen to attend annual Board training sessions to maintain or develop their skills. These training opportunities were “a yearly thing...very bespoke for individuals...often around learning while you do stuff and debriefing what you’ve learned afterwards” [P22_C].

The actual training may be role specific, looking at what a Board member, chair or vice chair does [P02_C]. It may also be of a more general nature including financial training, public speaking, or media training.

The skill of being able to speak up is necessary for influencing decision-making. Organisations need to ask what training is needed in order for people with intellectual disability to be fully participating, “so their voice is really strong in the organisation...to get to a point where they really influence the Board and influence what we do” [P10_I].

Sometimes the training needs to be at a very basic level, to prepare a person and help them understand the concept of meetings and how to participate. This may need to be completed prior to attendance at an actual meeting.

We had a new young Board member for a while and he is very enthusiastic, but he needed a lot of extra support initially to be able to understand how the meeting worked. So it was easier to work [with him] on his own with that kind of information. And then eventually he started coming to the group meetings [P05_C].

The success of skill development may be impacted by the level of importance given by key members of an organisation, and the resulting engagement with the organisation. One participant described her experience, “[The new executive officer]’s been more supportive of the governance committee...their skills, helping them to grow, learn, involving them in different projects in different ways” [P01_AB].

Alternative involvement

Board membership is one way in which people with intellectual disability can be involved in the decision-making of community organisations. However, many of the participants spoke of other ways in which people could have input into decisions-making.

There was a recognition that Board membership was not a role that everyone wanted or was ready for.

Just because someone might not be ready for the Board, doesn't mean they're not ready to be engaged... committees are a great opportunity to bring others who are not directors into an advisory capacity with no decision-making powers, and no fiduciary or director's duties as a very safe environment...there's also other forums...they might have what we call a client reference group that are properly constituted through a process of application regulated through a proper process, are convened and run properly...a great opportunity for people to provide feedback, to be involved in some of the thinking, but from a particular cohort's perspective [P21_R].

Membership of committees is one way people can gain the experience to make an informed decision about Board membership.

It was important for people to be part of the group so that they weren't thrown in the deep end...they knew that sometimes it was the wrong time or perhaps not everybody is cut out for the type of work that Board work is, but they'd be cut out for lots of other important roles in the organisation...people needed time to get to know what the organisation did, to get used to working together with people, to get used to some of the conventions of meetings [P22_C].

Advisory groups were recognised as "...a training group in leadership skills, and meeting skills, and advocacy, self-advocacy...a learning ground...pre-board" [P05_C]. However, these groups can also be an effective way to be involved in organisational decision-making. An advisory group "... gives advice, it doesn't make decisions...as long as the Board listens to that advisory committee, I think that has a lot more benefit of inclusion than a full director on the Board" [P14_JLM].

Advisory groups can also keep Boards informed about the reality of life experienced by people with disability.

We've also got [an] advisory group, and that's solely made up of clients that report to the Board...they meet every quarter when the Board meets, and they give reports to the board of what's happening out there in real-time, what's happening out there in life, and what's happening out there in the community, so it's giving our Board a first-hand experience of what our clients are going through [P27_R].

c) Sector responsibility

The experiences of the participants indicate a need for the community and disability sectors to play a role in supporting the inclusion of people with intellectual disability at a governance level. The community sector needs to act on the vision of inclusion, encouraging and resourcing inclusive engagement and opening up opportunities. There is a perception by participants that community Boards are not a reflection of the diversity of the community and organisational stakeholders.

I think that the representation of people who...experience significant disadvantage, notwithstanding disability, would be low across community Boards. It would be I suspect mostly middle-class people ... they would be dominating most community Boards... so that's a big issue for all community Boards [P11_E].

The sector has a responsibility to reduce barriers to inclusion, and one such barrier is social attitudes, and for “people with intellectual disability, there’s a whole lot of social attitudes that need to be addressed” [P08_G]. The responsibility for ensuring the pathway to Board membership is developed rests not just on individual organisations, but the whole sector. As one Board member noted about the absence of people with intellectual disability on her Board observership program, “...is our company trying hard enough to find them? Is it that the pipeline doesn’t exist?” [P17_N]

A change in the power imbalance experienced by people with intellectual disability is required, with a view to more people having access to positions of power. Opportunities to develop at a personal, social and political level need to be provided.

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...We’ve got to teach people how to think politically, and before they can think politically, they have

to think socially, and before they can think socially, they have to understand their own wishes and opinions, and then act for themselves personally, otherwise they'll just get torn apart out there [P08_G].

Inclusion requires commitment, and this needs to be community wide. As outlined by one participant, "Inclusion isn't something that we have to do, inclusion is something we want to do and we want to embrace, so we want to make sure we embrace it from the prime minister all the way down to the person that is putting mail in somebody's in tray. We all need to embrace this and mean it and live it and support it." [P27_R]. Such inclusion needs to recognise the diversity of our communities and respond in an inclusive manner. "I'm quite passionate about inclusive governance...inclusion from a number of perspectives...making sure that the information that's put to a Board is accessible...your constitution uses gender neutral language, all sorts of different elements" [P21_R].

Governance training is offered in the community organisation sector. However, there is rarely training that is accessible for people with intellectual disability. It is important that accessible training is offered and meets the needs of the people taking part.

We did the training [governance] with [local] Council...this was people from the Board, and other people from the organisation. We spent time with the facilitator customising it ... because the training wasn't accessible for some people. [P09_H]

Theme 3 – Experience of inclusion within Boards

Once on a Board, participants spoke of factors that impact the experience of inclusion, including Board culture, Board structure, communication practices, meeting processes, decision-making methods, and exclusionary experiences.



a) Board culture

The culture of a Board impacts the experience of Board members. The attitude of the other members of the Board has a direct impact on whether Board members with a disability feel able to voice their views. A respectful Board encourages all members to ask questions or express opinions. When an organisation makes a deliberate choice to act inclusively, it helps to create a culture of inclusion. “We’ll recognise that we will be trying to run it inclusively, this is the purpose of it, and this is how we’re going to run it...because that’s just in place from the beginning, it’s not an issue” [P05_C].

A Board that is in tune with all Board members will have a greater understanding of what supports may be required, providing a supportive culture that helps to meet individual needs.

I think what the Board requires is collective empathy, and that to put themselves into the shoes of the person...entering this room physically, and being asked to travel...get from their house...to the Boardroom...presenters will be presenting...there'll be people dialling in, there'll be food served, there'll be coffee served, there'll be a need for toilet breaks...the whole thing, because being a director is not just rocking up to a Board meeting for two hours. It's everything else. And if the organisation culturally, or the Board culturally, has the empathy to appreciate the experience of the person with disability, then they can implement the measures that may be required to help that be a much more smooth and inclusive experience, and what better way to improve that collective empathy than to have people with disability on the Board in the first place [P21_R].

Participants with disability who were involved with organisations that practiced inclusion at a Board level reported “I always feel included...we are always being included...they are very good at making sure that you are included.” [P12_J].

There were a variety of experiences that made one participant feel particularly included. These were being given valued roles within the organisation, such as presenting a report at the Board meeting, being on staff recruitment interview panels, joining in social groups, information sessions or staff development opportunities. Being part of a culturally diverse group that included a number of people with disability was also helpful. “If you have a lot of people with disabilities, they get included a lot more. You feel good. When you’re the only person that can be a bit tricky” [P01_AB].

The number of people with intellectual disability on a Board influences the sense of inclusion and may create a culture where people feel confident to say what they think.

There’s a lot of confidence to be gained by having more and more peers together, and you’re more likely to say what you really mean instead of trying to please the rest of the Board...it really creates a particular culture amongst Board members [P22_C].

In the Boards that included people with an intellectual disability, positive relationships were fostered. “There’s a lot more effort put into relationships and...being at ease, having a fellowship amongst the Board...so people feel confident, and they feel powerful in that space” [P22_C].

A positive, supportive Board culture needs to be developed and nurtured.

When it comes down to it, you’re dealing with egos, you’re dealing with power issues, you’re dealing with all those sorts of human things, and the only way that that works is...maintaining a culture of forgiveness, of goodwill, and not allowing it to become a power struggle [P08_G].

The position of Chair is seen to have a particularly influential role in the culture within a Board. “I think it's the chairperson ... that organises and creates that level of inclusion...the chairperson is the one who makes people feel included and makes you stay on track. [P14_JLM]

The organisational mission and values may be useful as a guide to create a positive Board culture. “How do you achieve the organisation's purpose...

vision...values? You first need to know them, you need to understand them...That's the greatest thing you need to remember, "Why are we here?" [P14_JLM].

A caring and respectful culture assists with inclusion. "It works because I feel confident to talk...no one laughs at you"[P02_C]. Consideration of access is important, "They always include me as part of the group and in the conversations and they always make sure that I'm there"[P03_BC]. The need to consider the physical setting, and its impact on inclusion, was identified. "It's more about

accessibility, the rooms...we had a round table, and everybody could fit in the room nicely [P09_H]. Concern for the well-being of all Board members is also important, with a check done at the end of each meeting. "...at the end of the meeting one of the Board members is like, "I just want to know...how is everybody doing, wellbeing-wise."...We do dedicate some conversation time to just checking in with each other" [P13_K].

In contrast, Boards with critical or dominant members make it difficult for people with less confidence to speak up [P16_J]. Board members that were less friendly created a barrier to speaking up, "...some of them are incredibly serious...Some of them you have to be very careful what you say about certain things...you've got to think "Can I say that?" " [P12_J]. Respect and friendliness were viewed as important for a positive work relationship. "They accept your meaning. They really respect you" [P02_C].

Involvement in organisations that embrace diversity, including at a Board level, resulted in participants feeling accepted, a part of the group. Diversity was accepted as a normal part of the organisation "Because we are used to it, doesn't seem anything unusual to us" [P26_B]. When Board members are active within the organisation, inclusion is experienced as an organisational norm.

Our Board members...they're always there doing a project...doing videos with people...telling stories. They're doing all sorts of things...our Board members are so heavily involved that we weren't particularly having to work hard to make them feel included. I think they just were included but sometimes too much...then you have to let that person have a rest...checking in with people, make sure it's not too much...so it's probably more an issue of being over-included [P05_C].

b) Board structure

The experience of Board membership is impacted by Board and organisational structure. The size of an organization may increase the complexity of Board meetings. “I think the bigger the organisation, the more difficult it can be for the person, simply because the agenda gets so big” [P09_H]. Some people spoke about the use of sub-committees to reduce the amount of work needing to be done at each Board meeting, one example being a governance committee:

...they were delegated because they needed more attention than could be provided and what’s realistic in a board meeting every three months...They had to maintain strong communication with the rest of the Board and particularly if there were some sticky issues that really needed to go back to the Board, and occasionally, there’d be extraordinary meetings and things like that, or there’s big decisions to be made that require a whole of Board input, they’d be referred back. So, the Board meetings themselves were still pretty complex and there was always difficult to get through the agenda in the time allotted” [P22_C]

Another Board structure that may impact the experience on a Board is the length of Board terms. Developing the required skills and confidence takes time, so setting a longer Board term length was thought to allow “people time to grow into the role” [P22_C].

c) Communication practices

The communication methods used by an organisation also has an impact on the experience of inclusion. Organisations that successfully included people with intellectual disability on their Board ensured that clear, effective communication was a priority. Examples of communication practices that support inclusion included the use of plain English¹ as the usual communication method and providing key documents in Easy English². Ensuring regular contact and

¹ “Plain English is a direct style of writing for people who can read at a reasonable level. It helps people who want to read and understand information quickly. Plain English is sometimes known as plain language or Everyday English. Plain English looks and sounds like standard forms of writing” (Centre for Inclusive Design, 2023, p.4).

² “Easy English is a writing style that helps people who find it hard to read and understand English. It is simpler and has a lower reading level than Plain English. Easy English is also called easy-to-read or Easy Read...it uses short sentences with an image or picture” (Centre for Inclusive Design, 2023, p.4).

communication is maintained is important. And as with all support strategies, communication needs should be assessed on an individual basis.

Two-way, active communication

Respectful two-way communication is valued by Board members with intellectual disability. “It’s having the people listen to you and taking your ideas and opinions and hearing their views and opinions” [P01_AB]. Taking time to really listen is important. Listening to people with lived experience of disability can occur both in and out of Board meetings. One participant reported how the Board Chair sat in on every Client Advisory Committee meeting as “he just wanted to hear what was going on...with the clients...so he could take that back to the Board meeting” [P25_U].

Being actively listened to, with your ideas acknowledged, is an experience that supports a sense of inclusion. “Well, 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.” [P01_AB]. Having your meaning understood emphasised the sense of inclusion. “They include me, they accept my meaning...So when I say something, they agree. That means they got my meaning in there so I’m happy because they listen” [P02_C]. Being listened to creates a positive and enjoyable experience, “...he is just genuinely excited every meeting to be able to give his opinion on something and that everyone’s listening” [P05_C]. When this then moves to actioning ideas, there is a further sense of value and inclusion. “They help you with some of your ideas, [for example] to do with the fundraising”. [P03_BC]

A variety of methods to support communication are used to increase accessibility of communication, including “visuals and technology” [P03_BC]. The importance of listening, allowing people to have some ownership of the discussion was recognised as essential by an Executive Officer of a disability service. “We learnt we can’t overcomplicate a meeting in terms of what we ask of the meeting... otherwise it’s just what the organisation is asking and it’s not about what people are saying” [P10_I]. Really listening to each Board member is critical, and requires a deliberate focus. “So we’d need to learn, and that staff need to learn to really listen and give people a chance to say what they have to say” [P10_I].

Giving people time

Giving people the time they need to communicate is essential. When sufficient time and support is not provided, the communication experience may be negative.

The people with disabilities on the Board at that stage needed more time to actually speak...one person used assistive technology, another person spoke, but it took maybe one or two minutes for him to actually verbalise, because of his physical disability to actually get the words out. So, they were often silenced, not because the Board didn't want them to speak, but they were always looking at the watch. Once we made the meetings longer, it was a lot easier for people to contribute. The Board...were very mindful of making sure that everybody could speak [P09_H].

Communication practices that met the communication needs of the Board member assisted people to feel included. This was demonstrated by giving people extra time to respond when using alternative communication methods. "They use a communication device but everybody respects that person highly. She indicates when there's something she wants to communicate...sometimes there is a pause while she types...she is able to communicate what she wants to" [P06_EO]. The use other methods of communication, for example mind maps, also helped one participant express their thoughts [P03_BC].

Communication preferences

Accommodating the communication preferences of people is also important [P26_B]. A participant who uses alternate communication methods, communicating through typing, identified the need for a focus on communication within a Board he was on.

I would like to see some improvement on communication within this group. Because I am non-verbal, sometimes I struggle to get my opinion out...I also think that if there were some notes and dot-points recorded from the meetings, this would be helpful to remember and reflect afterwards [P03_BC – written response]

As one participant summarised, "I think it's acknowledging what people say and it could be through different formats, like chat, or written...giving them the time to actually speak as well and for the people who haven't been heard from asking them if there's anything they like to add or to comment on" [P13_K]. While one participant certainly felt included in the meeting process, he also acknowledged he needed to actively engage and let people know he had something to say. "I feel 100 percent included in all conversations, in all meetings...It's just how they do it...everyone with disability can be heard and talk about stuff...sometimes you just have to get yourself in there or by raising your hand or waving your hands to get attention. [P19_P]

Clear communication methods

Communicating in a way that is understood is another key element of inclusion that is not always practiced at all levels.

People would have the conversation and the discussion, but it would be at a level of language that might exclude people...when we did our policies, we used to say, this is parliament speak, this is plain English, and this is Easy Read, so we would actually hand out the policies three times...but we didn't do that in the Board meetings, and we should [P09_H].

The importance of reports not only being written in accessible formats, but also containing the information needed to make good decisions was acknowledged. "We've changed that format [staff report] recently to make it a bit more accessible and to hear about what's going on in the organisation, how much we're growing or what's been difficult" [P13_K].

d) Meeting processes

The way in which meetings and other Board activities are run impacts the experience of Board membership. Purposeful thinking about what actions make people feel included and ensuring these are incorporated into the meeting is required. A number of recommendations about practical steps to increase inclusion within meetings were made by participants. These included:

- Reminders about inclusive practice, "So we have an inclusive practice reminder at the beginning of every meeting...It's just a reminder of how we actually run the meeting" [P05_C]
- Suitable pace of a meeting, ensuring "the meeting goes as long as it needs to go for someone to have their say, and I think sometimes it's very easy to get impatient and move on quickly and that cuts someone's voice out and that's really bad" [P10_I].
- Ensuring everyone gets a chance to have a say, "go around the table, make sure everyone says something, don't expect them to put their hand up." [P08_G]
- Simplifying the process, "demystifying and simplifying the Board process, and the material put to a Board is going to be a benefit to everybody" [P21_R]
- Consider the agenda and restrict number of items to what the members are able to cope with as "... we [Client Advisory Committee] would rather

talk about two things well than more than two things badly...to balance people's fatigue, people's interaction styles. Two is a lot and two seems to be enough at the moment" [P24_T],

- Making the meeting agenda run in a consistent manner was thought to help as "doing things in a regimented way is helpful for everybody" [P21_R]
- Keeping to the agenda, "...one of our inclusive practice reminders is to stay on the agenda and on task" [P05_C].
- Including a social component as "...that opportunity for people to reconnect and remember names, faces, to have that interaction is super important" [P24_T].

When inclusive practices are routinely practiced, it becomes a natural part of the meeting process. As described by a person involved in an organisation for people with a sensory disability,

It's all done really just as a matter of course [adaptions for disability]. These processes I've spoken about are so embedded...this is just business as usual...this is the way it's done here...that goes relatively unnoticed...it just fades into the background of what is normal within the culture of the Board, to go through these processes" [P21_R]

e) Decision-making processes

An important role of Boards is to make decisions on behalf of the organisation. The decision-making process varied between Boards. However, the importance of making sure all Board members are active contributors to those decisions was identified.

The decision-making role of Board members, and the voting process used within their organisation was generally well understood by participants, one describing the process as

...we all have voting rights...we all vote, not with all decisions, the really serious decisions we vote. " And if there were disagreements? "Well, normally we would just keep talking about it, maybe if we can, bring it back to the next meeting. See if we can change the people's minds [P12_J].

Decision-making by consensus was a common process, with a formal voting process often only used for issues viewed as important. "I don't think in 18 or 20 years of being on Boards, and advising Boards, have I personally ever seen

an actual vote...most environments would say, "If three were against, that's three too many. Why are you against it? Let's talk about this some more."
[P21_R]

This form of decision-making carries a risk that unless people voice that they are against a motion or discussion it would be assumed they are in favour, "there's an expectation that if you're not speaking up, it's 'cause you don't want to" [P16_J]. The need for active debate of issues was identified.

It was actually quite a harmonious Board which always worried me, 'cause if people weren't disagreeing ever with such a high proportion of people with intellectual disability, I'd always be wondering, 'Oh, gosh, are people really saying when they don't agree with something or they don't quite understand all the aspects of it to be able to make a decision? Are people really telling me or not?' [P22_C]

To overcome this risk, a skilled chair is required. One who leads "a well-honed, respectful Board where people can express their views openly and be respected for those views...a good chair, ought to be able to get to a view where even if we don't have 100% wanting to say yes, there's no one in the room who's actually vehemently opposed" [P21_R].

The consensus approach to decision-making, together with a chair that invites all people to express their thoughts on a matter, was thought to be the most inclusive approach to decision-making.

I think the casual consensus approach...lends itself to a far more collegial decision-making environment and is arguably a more inclusive way of doing things...A good chair...would be noting that particular people in the room have been a bit quiet...and would actively seek to engage that person, and to encourage them...And you can see how a person with intellectual disability might feel a bit swept up in the process. It might have been moving quickly, more quickly than they're quite able to take in, they might need a little bit more time to process, they might need their support person to help them understand something...and they might need to be explicitly invited to contribute, and be given that permission almost to speak, and I think that would be really important in a genuinely inclusive governance scenario. [P21_R]

However, it is important to remember that expressing a view may be difficult for anyone who is not confident to speak up in a group, or who may need a longer time to clarify their thoughts. Allowing enough time, providing

accessible information, and giving support with the decision-making process was identified as important to encourage engagement in the decision-making. Adaptions to the process may help all Board members take an active role in the decision-making.

...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_J].

Similarly, the development of complex documents, such as the strategic plan, require a process that provides information in a way that is understood, and time given for consideration of each person's view.

I worked even more fully with them [Board members with ID] to help them understand the purpose of the strategic plan and what it would mean...We had individual sessions, and we had some group sessions with board members...it took a long time to do all this and the backwards and forwards and finally came to the board for final approval [P05_C].

At times, expert opinions were sought to support the decision-making. An example given was regarding employment and human resource advice, "...we see that we need to be mindful [about HR issues] so we call a consultant...and it helps" [P26_B]

Having some control of the decision-making process was acknowledged as important for Board members with disability. An example given by a participant was about the rewriting of policies into plain English and Easy Read:

The people with the intellectual disabilities said, "Okay, those ones can write the plain English and when they've done that, we'll do the pictures, we'll do the Easy Read." So they made those decisions themselves...that's how they were all done and they did it all [P09_H].

It was stressed that real inclusion in decision-making, particularly around complex and important issues such as strategic planning, requires early and thorough involvement. "Inclusion in things like the ethical framework and the strategic planning...very important for Board members to be involved in those decisions, but it's not just at an approval level...having people's input really early on...is very important." [P05_C]

f) Experience of exclusion

While most participants who had experience with inclusive governance practices primarily reported experiences of inclusion, there were some experiences that resulted in feeling excluded. Failure to address these issues may contribute to the risk of exclusion or tokenistic involvement. The following experiences were reported by participants.

Boards where people with disability were a minority were more likely to exclude or make involvement difficult.

There's often not many designed out there just for people with disabilities, or a majority of people being people with disabilities...You don't feel like you belong, and you feel like if you were to join, you'll not get success in gaining a position, because they're focused more on people without disabilities, and not so much people with disabilities and being inclusive [P01_AB].

Not being involved in all aspects of governance, such as policy development, was a particular experience of exclusion for one participant, "...they would go and make a decision on a policy around something, and you didn't get to say as to what else you wanted added in there" [P01_AB].

Meeting practices that failed to consider or make adjustments to cater for the support needs of people with disability were seen as exclusionary. Poor communication practices, both verbal and written, were specifically identified. "...the papers that are handed out at the Board meeting are sometimes just inaccessible. So that means people don't want to be on the Board, because it's boring, and we don't know what you're talking about" [P09_H].

Similarly, another participant reported that

...conversation[s] that happen at those meetings have a level of assumed knowledge and use a very particular terminology without explanation...if somebody was just thrown into that mix who had an intellectual disability, I think they may well not completely understand the processes or what they're being asked to do [P06_EO].

A long-time Board member of an organisation was described as not being given "...the support that he needs to be able to contribute in a significant way to many of the decisions...there are a few matters which he does have a good interest in, his opinion counts, but it's a little bit tokenistic." [P11_E]. Lack of

independent support, both before and during a meeting, are another clear inclusion barrier. “...no one goes through the meeting agenda...or the minutes with the person in advance, or facilitates their jumping in...I [another Board member] make feeble attempts to...try and link him with what's happening with the meeting, or give him the space to say something, but it's an uphill battle.” [P11_E]. This same Board member was described by another participant as being “actively excluded, told to be quiet and was given a notebook and a pen [to doodle]...it was a significant part of his life...I felt most uncomfortable...it was so tokenistic and went against our core values” [P07_EF].

A lack of time was also identified as causing some exclusionary practices.

I'm the chair...and I come up with the agenda...I feel like one hour is often not a lot of time...I feel like people haven't been able to participate as much as I want 'cause we're always trying to wrap up on time...I'm not saying I'm dismissing anyone but obviously I'm not giving it the opportunity for further discussion [P13_K].

Theme 4 – Support provision

The participants spoke of the importance of individualised support for Board members with intellectual disability. A three-stage support framework was identified, incorporating meeting preparation, support during meetings, and contact between meetings. The complexity of the support role and the need for support people to have specialised training were discussed.



1. Impact of inclusion in governance



2. Pathways to Board membership



3. Experience of inclusion within Boards



4. Support provision



5. Concerns become barriers to inclusion

a) Providing support

Objectives of the support role

The support role was recognised as important by participants that had experience of this role. One example was of an organisation that provided a support person to the person with cognitive disability to go through all of the Board documents ahead of the meeting and then to sit with that person to make sure that the person understood the discussion and was able to have input into the discussion and then understood the vote. Time was allowed within the meeting to ensure that that could happen. and the meeting was run at a pace and in a manner that ensured that the person could understand the content of the discussion and make informed decisions about what came before the Board [P16_J].

The support person was observed to be building the level of involvement of people with disability in Board meetings.

...the other members of the board without disabilities can see that the others are learning and they're engaging more...so increased participation. Like people are putting aside some time in their week to meet with [name of support person] talk with him and to actually be part of the Board, which is really good [P13_K].

Identifying individual support needs

The support provided to Board members with intellectual disability needs to be individualised to their support needs and preferences. Board members with support needs often felt the responsibility to lead the identification of support needs, "...you'd have to specify and tell them what support exactly [you needed], or what is it that you're not understanding...to say, "This is what I need help with," and then someone would arrange that" [P01_AB]. Many were proactive in asking for help "I always ask someone...get all the information you need...so I would email them and say, "Hey", with my concerns, and then they come back to me with an email reply back"[P19_P]. Support was not forced onto people, however it was usually wanted and accepted. "People decided whether they needed it [support] or not. And in my experience, everybody decided they wanted it" [P22_C].

Making an effort to get to know a person and their support needs is important. This was explained by a Board member. "I feel like I could learn a lot from them as well in how to best support them and I guess I wouldn't really know how to

do it unless I have a conversation with that person” [P13_K]. The identification of support was also an outcome of a close, supportive relationship. A close relationship meant that the support person was “...able to build up that relationship, to be able to read the person...understand the way that the person being supported needs support” [P09_H].

Providing support that suits the individual and is culturally aware is important.

The Board members have a different disability. And when it is a multicultural organisation, if they don't take care of the people with disability who had joined the Board, according to their disability, then what's the point of being a member of the Board? This is inclusive-ness...when they say, yes, they are including everyone who is deserving, who is applying for the Board, then they should also consider about their disability, about their culture [P26_B].

Support provision also needs to be planned and ready from the start of a person's involvement.

It can be quite frustrating for any person with any disability that first day you sit there...everybody's running around, scrambling, trying to make things happen...it really breaks somebody inside and that doesn't give them the confidence to continue on...they [the organisation] need to do the research, they need to make sure the very moment that person walks in the door, they feel supported [P27_R].

The engagement of the individual may be a key indicator of their level of understanding.

I can sort of gauge the person's understanding by the way they respond back to us...if the person starts talking about something else, then that means the person is not interested, is not concentrating on what you're saying, or is not understanding...I try to go back... and if still it doesn't work then...we take the person's word because sometimes you say, “Okay, do you understand what we are trying to decide here?” and then they would say, “Oh, yes”[P15_B].

While acknowledgement of the support that may be required to access training and understand responsibilities is important, this does not remove the need for each person to be effective in their role and to make a valued contribution to the organisation.

People need to understand that you don't have someone with a disability on the Board because it's a nice thing to do. It has to be a value add...so if someone is underperforming, that conversation needs to be had...is there any training or support that you can give that person to lift their skill set, and if they're still not making it, then the hard decision needs to happen...whether they had a disability or not [P10_I].

Planning support

The objective of the support provided is to ensure the person can take an active role in the meeting and decision-making. The support should be arranged in such a way that it "will help them to understand...for them to be able to do their role better without limiting what they can do" [P01_AB].

A well-thought out plan with ongoing, active support is required. One participant developed a plan of support to assist a person with intellectual disability to take a leadership role in an organisation. She noted,

He hasn't suddenly stopped having an intellectual disability, he's not suddenly fantastic at setting up the equipment and thinking through some of those processes but he is a good speaker. So, he has the scaffolding around him so that he is set up for success in the context in which he operates and that was a considered process [P06_EO].

Tools, such as easy-read documents may be an option but need to be incorporated into an individualised support plan rather than relied on in isolation from other supports.

It really is about getting people the right information and getting people information in easy-read, if they need easy-read. Not all our Board members do need it...it's just making sure that you really think what everyone's understanding, what it is they're making a decision about and why [P05_C].

Co-ordination with other supports within a person's life may be necessary.

So getting to the meetings usually wasn't a big problem, because workers had also worked out to arrange to pick people up a little bit earlier, and it stopped being a problem once we made it at ten o'clock in the morning, and because we finished in the afternoon, we didn't have a problem anymore of getting back in time for the homecare-type supports [P09_H].

Increasing the self-awareness of Board members so that they are aware of when they may need additional support to undertake their role is important. Providing flexible support arrangements that allow the person being supported to enlist extra support when needed, recognises the person as being in control of the process.

As a Board member, if I need supports, I ask for supports. Mainly I'm pretty independent, so I'm pretty good with being part of the Board meeting. But if I don't understand something, I'll email someone and say, "Hey, I don't understand this. Can you explain it a bit more?" So I do have peer supports in this organisation. We all work together and we give each other peer support, which is fantastic [P19_P].

Peer mentoring was seen as part of the support provided in some organisations. Mentors required specific skills and understanding of the context in which they were supporting a person's development. Some organisations use previous Board members as mentors. The skills of one mentor with intellectual disability was recognised.

She's there [Board mentor with intellectual disability] because she's highly skilled and understanding when people don't understand. She herself doesn't understand sometimes and she is supremely confident to ask. And we don't expect her to know everything, but we expect her to put up her hand when she doesn't, and she does [P08_G].

While support needs vary, some common ideas about how support should be provided emerged. A consistent, well planned support process, that includes preparation before each meeting, support during the meeting and contact as needed between meetings, appears to work best.

So, in terms of Board members that have intellectual disability, it's trying to find something that works for them in terms of supporting them to be part of the Board...to prepare and to reflect after meetings as well...and there's also trying to find ways that they could bring their voice forward in those meetings [P18_K].

Stage 1 - Meeting preparation

Setting aside sufficient time for a review of reports and other information is a key component of successful preparation. While all Board members need to prepare for meetings, it is particularly important for people who may need additional time and support to consider and decide on a response to issues being raised. Preparation ensures "people have had their thought process happening.

So, no surprise of what's going to come on the agenda is really important" [P10_I]. A support worker of a participant suggested that he thought it was important that the participant knew the purpose and content of any meeting to give him time to think about what he wanted to contribute. This suggestion was met with an enthusiastic 'thumbs up' by the participant [P03_BC].

Some organisations have a very structured and resourced Board support strategy. One past Board support person explained what preparation for a Board meeting was like in the organisation she previously worked in.

There's a support officer who helps to prepare people for meetings and for decision-making. So, there are hours that are paid, set aside for extra support for people who need it in the lead up to meetings. Documents and other information are provided in easy-read, and are explained to people, and time is spent making sure that people are going into meetings properly informed, with their eyes open and that they've also had the chance to talk about, dissect, deconstruct the issues with the supporter [P22_C].

This preparation was given "...at a pace and in a manner that ensured that the person could understand the content of the discussion and make informed decisions about what came before the Board" [P16_J].

A participant with lived experience of both intellectual disability and Board membership of that organisation explained that good preparation helped her to be able to speak up in meetings, and to make well thought through decisions.

Support is good...[it has]given me confidence to talk because if I don't do preparation, you can't talk...She [support person] will ask me question "Is that [what] you think is fair to everyone on the Board?"...I will think deeply and make the decision...it's my decision. And she says it's my decision because...I'm the Board director" [P02_C].

Receiving the meeting papers with enough time to go through them and be able to have questions answered prior to a meeting was important. As a Board member with intellectual disability explained,

I used to get...a big bundle of papers...to go through. If I got them on Friday, I could read them by Tuesday...if I couldn't read the words I would highlight them, and then when I go into the meeting an hour before I would say [to EO]...these are the words I can't read...are any of these words important?" [P12_J].

The timing of preparation support is important.

Most people prefer to have it [preparation] on the day before the meeting so we've just talked about all the issues and then we go about the meeting, which makes for a fairly long and tiring day, but the issues are fresh in everyone's minds that we've talked about [P05-C].

In some cases, support was given immediately prior to a meeting,

So we just got into the habit of meeting earlier before the Board meeting for a couple of hours and so we...read through the materials with the person and then made a few notes about any comments that the person made or any comment or interest that the person expressed and then perhaps discussed with them anything in particular they would be interested to say [P11_E].

However the support was provided, the need for preparation was a common belief. "So, the primary issue is making sure that [they]...are able to participate at a level even to others, right? For that to happen, there needs to be preparation...So I go along and talk about some of the issues we're going to be talking about" [P08_G].

In some organisations, the preparation sessions were opened up to other Board members, with positive experiences.

You can pop in, just join and then we'll go through it together. Even our Board members without disabilities came and they thought it was really great because they were able to build the capacity of others and really have a good discussion...often times, there isn't enough time [in the Board Meetings] to unpack what it is that we're doing, why is this important [P13_K].

The preparation of summary documents allowed a focus on the issues of importance for one Board member with disability. This process was explained by a support person.

There were 11 documents that were sent out, and she found that very overwhelming...So, she decided that what she wanted me to do was that I would receive it, I would read through everything first, and I would do a summary page...and then she would decide from the agenda, what was important to her, and then we'd go to that particular document... So there were some of those projects that she was really interested in. She'd always read those reports, and I would read them to her, and then

she would stop me, and we would highlight things that she thought was important [P09_H].

Stage 2 – Support during meetings

The second stage of support occurs during a meeting. The support provided should be as unobtrusive as possible, without drawing attention to the support person.

[Support person's name] will sit there quietly and just check in. "Did you understand what he just said?" [Or] "Could you just wait a minute, [chair's name]? I just need to check that we're all on the same page as you. Is that okay?" or, "Can you just slow down?" [P08_G].

Similarly, a support person described her subtle actions, "She'd have the notes that we'd made together with the drawings or whatever, so that she could speak to it, and so it was basically just a nudge, "Don't forget" [P09_H].

However, at times the support person may need to take a more active role, to ensure the person is given a chance to express their views within a meeting. "To make that space for them to speak up, to make sure that what they were saying was understood and the significance grasped by other Board members" [P11_E]. One Board member with an intellectual disability described the support she received to make sure her thoughts were heard.

If I need to say something...I'll tell her something, and she'll say "oh yeah, that's good". So, she'll say "[my name] has got something to say about this"...that's what they would do, they would remind you when you had something to say about a topic, to make sure that you did say it [P12_J].

Similarly, a support person described how she made sure she was aware of what the person wanted to say, and then ensured this was achieved.

I'd often find out from people what points they really wanted to raise beforehand and if the person themselves didn't find an opening to raise what they wanted, I'd create the space for them to do it by saying, "Can we can just hold on for a minute? There was something that I think so and so wanted to say about this topic." And if they found that they couldn't get it all out, they couldn't remember every part of it...I'd say, "And I remember that you also said –" blah, blah, blah – "Is that right? Is that what you wanted to say?" that kind of stuff [P22_C].

The support person needs to monitor and react to the way the meeting is being conducted. “Even though people have done lots of preparation, you do need to remind the meeting sometimes that we need to slow down or the need to summarise the main points...there’s that interplay between the preparation and actual meeting” [P22_C]. The use of plain English and then checking the concept being discussed is understood is important.

We try to, as much as possible, be plain English as we can...in making decisions we try to repeat and try to explain in different manners. If we’re having difficulty in this, we try to paraphrase it or make sure that it is delivered in a way that can be understood by the person...ask the person if the person understands and repeat it back to me [P15_B].

It can be a very physically active role if support is being given to more than one person. “She [support person] will run around the chairs. Like if anyone would need any help, hand up, and then she will go there”[P02_C]. To help in this situation of multiple people needing support, other Board members can be involved BY providing a supportive environment,

We’ve been doing a system called the buddy system where we had kind of buddied up members without intellectual disability to a Board member with an intellectual disability just for that sort of immediate – what page are we on, little bits of support, so that then I can be supporting someone who needs a little bit more support [P05_C].

This buddy system was also described by another participant,

At various times, there’s been a buddy type system as well on the Board where a person with disability buddies up with a person without intellectual disability...I think that that’s actually a good idea because it means that it’s easy for very busy Board members, who may be professionals, to mistakenly feel like they don’t have a part in supporting the rest of the Board...So the role of the supporter to the Board is not to be the only supporter. They model, if needed, how good support in that environment might look during a meeting [P22_C].

The physical set up of the meeting room is another consideration, to promote the inclusion of Board members with disability. “So if I’m setting up a room, I will consciously put the president...sitting across from the person that had the highest support needs...because then, he had to look at them” [P09_H].

Support may also be required for meetings that are being held online. In this case, the support person should be in the same location as the Board member

requiring support. "...[support person] has been coming to our place...she brings her computer and her mobile phone, and we do it on Zoom...I wouldn't know how to use a computer, otherwise I wouldn't be doing zoom" [P12_J].

Stage 3 – Contact between meetings

Another important role of the support person is to make contact between meetings. This checking in maintains contact and provides an opportunity to assess whether the support has been effective or if anything else is needed.

After every meeting, it might not necessarily be on the day, we might have a real quick chat about it, because she'd be tired, but then I'd arrange to go back and see her in a couple of days or the following week, and we'd just go through, just checking everything that we've looked at [P09_H].

This between meetings support assists the Board member to keep in touch with the organisation and allows time for thinking about what the Board or committee is focussed on.

The committee meets four times a year formally...but we do work before and after every meeting to make sure that all committee members are fully understanding to the best of their abilities...they're then supported to either reflect back on what's happened or think about what's coming in the next meeting. They might have questions, comments, concerns [P24_T].

Providing reminders of any extra tasks that the Board member is required to do is another task of the support person.

Some Board members put their hand up for that [sub-committee] and then I will remind them of that and help them to schedule in when they would meet as a group. So, quite often, a lot of my role is as a PA for Board members, sort of managing time and their commitments [P05_C].

Board meetings can be quite onerous, requiring effort and concentration for extended periods. One participant, with extensive experience of Boards advised,

Have plenty of rest before the meeting. You need rest. You come and you gotta have a good sleep the night before. You gotta have a good sleep so that way you are ready and you're alert for each meeting...And then other thing is I also recommend that you've gotta have someone with you to help you and support you. So you need someone who's been

on the Board recently. So you need someone then with you to talk about and have a chat and if you have any problems from that meeting, that's the person that you can talk to [P19_P].

In addition to preparation for specific meetings, ensuring Board members understand current issues or topics of importance is required to enable Board members to make informed and strategic decisions. The involvement of the support person may be necessary. One example provided by a support person was around the time that the NDIS was being introduced.

As the NDIS was coming in...our Board was really pressed by the staff to help decide...how did we see ourselves continuing in the time of NDIS...it was a very busy time support-wise because we would...do a lot of education about the topic as a whole in between Board meetings so that when we came even to do the prep for the Board meeting, everyone knew what the overall topic was about and the ramifications of making certain choices [P05_C].

The level and type of support between meetings is largely dependent on the support needs of the individual Board member.

We have a participation support officer who we always say, "Look, [name of participation support officer] is available to talk or to support you in doing whatever." And some individuals use him more than others, not everyone does need to use him, and he always does try to have individual check-ins with them saying, "Hey, can I do anything to support you on the Board?" [P13_K].

A key component of the support is regular and clear communication between the support and the person being supported. "So we communicate really often, she knows my schedule... I email through.... She'll look at it, think about it and we talk again to each other on the phone. I think phone is the best" [P02_C]. Ongoing checking that the support being provided is meeting needs is required, with one participant emphasising the need to "...follow-up, follow-up, follow-up, always see how the person is and what they need" [P27_R].

b) Complexity of the support role

The relational aspect of the support role, based on a trusting relationship with an in-depth understanding of the person and their support needs, is described by several participants. "To have that person in the room...who has that rapport, that relationship, that way of communicating, where the trust between

the two...for them to participate...it's so bespoke and unique to that person in those relationships" [P21_R]. These relationships are based on values. "So there's some shared values that you're working with and there's the collective values of the organisation, but then there's your personal values as well" [P22_C]. What people wanted was a person that they had a good relationship with, who they could turn to for support. "What you need is a person that can take time with you and talk about information out of that Board meeting...go over the paperwork part and then they did the writing on behalf of you" [P19_P].

One participant, a Board support person, acknowledged the reciprocity of the relationship and the knowledge held by the people she supported. She described it as a "partnership...support doesn't mean I've got the expertise and I'm going to give it to them so they can do their job. That's not how it worked" [P22_C]. The role requires a trusting relationship, with an in-depth knowledge of the person.

We've set up her [committee support person] role to be a real point of trusted connection with those committee members. So, she has developed quite a good relationship with them and can have quite tailored conversations matched to their communication style, to their literacy, and to their cognition" [P24_T].

Well understood, two-way communication is critical to the support relationship. A good support relationship was seen as "a pure conduit...[with] its own bespoke language" Understanding each individual's communication techniques was seen as important.

...sometimes they've got to interpret at the meetings...we might not understand them as well. And the way they're trying to put the point across, we're not understanding it, but the support worker can speak for them, 'cause they understand [P25_U].

[P21_R]. This was achieved through "time and willingness for things to be re-explained, and just watching...getting to know people's body language on whether they get it or don't get it and having those little tricks" [P09_H]. Failure to develop such a relationship, results in poor support provision.

They were there to support him to come to the meeting...this [support] person was completely shocked and surprised..."I had no idea about any of this. I didn't know this was a thing that he was doing or that he could do. No one told me anything about it" [P05_C].

The support person needs to be able to work with the individual, understanding their needs and help them to be active participants.

...being able to balance the conditions that were needed to make sure people were not participating in a token sense, but they were actually really participating in real discussions and real decisions...you do have to respond to the rhythms that people have around processing information and around developing what they want to say about it and then how you make decisions based on the information that's at hand [P22_C].

The difficulty of supporting without influencing was recognised. "It is really difficult [to not influence decisions]...it's something that you have to be really conscious of all the time you're doing that work and reflect really honestly with yourself" [P22_C].

The support role must integrate with the organisation. "Experience and knowledge of the organisation is really, really important" [P10_I]. This view was expanded by another participant.

So, if you're working in a vacuum, if you don't understand the context, then the value that you're adding to that volunteer's experience is not going to be as much...the person in their role had to be a knowledgeable person who had some capacity to provide guidance...who really understood the mission, the values, had the capacity to impart knowledge...had been to meetings themselves. So, it's quite a skilled role, and it does require an experienced person" [P06_EO].

Independence of support

The need for the Board support role to be filled by people independent from the Board was identified. There were several reasons given for this. One was so that they did not bring preconceived ideas about the Board business.

...it's useful to have somebody from outside...I don't mean that there is a legal, formal conflict of interest having somebody within the organisation as a support person, but I think that an independent person can help the person with intellectual disability bring an independent mind to the issues to be decided [P16_J].

There was a strong feeling that support people should not be driving their own agendas or trying to influence decisions. The support person needs to support without influence.

They should have integrity and step out of it and say, "This is the decision that you have to make in this meeting. These are the good things. These are the bad things. So, leave them alone to make a decision. Do not try to influence [P15_B].

The intensity of Board meetings mean that the Board support person must be able to focus solely on their support role, and not be caught up with the business of the Board.

Other Board members are busy with their own view, and their own comments, and their own agenda...the idea that you could be a Board member at the same time as providing the support, it's very, very tricky. I think it would be really hard for someone to do that very well. You've got to be thinking about an awful lot at the meeting [P11_E].

c) Supporter training

Development of skills

The support person's skills are critical to the success of the support provision. The complexity of the skill set required was identified by a Board member.

People totally underestimate the difficulty and the challenges of actually providing proper support to a 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 contributing to 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_E].

Many of these skills are developed through working closely with people with intellectual disability. The reciprocity of this relationship as a learning experience was explained by a Board support person, who stated:

I learnt a hell of a lot from people with intellectual disability about assumptions I didn't even know I had. They pointed those out and called me out on those very often and fearlessly and they're actually the very best teachers I've had and I know how to do my job because of them,

and they are people very experienced in organisations and in public education and community education and in policy but also in life...I feel very blessed that I had time with them and how much they taught me. And very much a partnership...support doesn't mean I've got the expertise and I'm going to give it to them so they can do their job. That's not how it worked [P22_C].

The importance of developing the right skill set as also identified.

So it was growing into the role as well. We all learnt by doing and I also learned a lot from watching various experienced people on staff and on the board as well...I don't think that we can say this is unskilled work...it's definitely very skilled. It needs time and it needs money put into it as well. It needs to be resourced properly for it to be genuine [P22_C].

Similarly,

One, to be able to build up that relationship, to be able to read the person, if that makes sense, understand the way that the person being supported needs support...that's a skill that you've got to have...be able to build up a rapport with whomever you're supporting...what he wanted or what he didn't want, all those sorts of things [P09_H].

The organisational knowledge, developed over years of practicing inclusive governance, was used to guide and develop the skills of Board support people.

I tried to really see what the other people before me had done and not necessarily just divert entirely from their processes. So over time, we've kind of moved away from some things and we've brought new things in [P05_C].

Undertaking the support role well requires time, first to learn the role and then to work with the Board member. This has not always been well done, as explained by an executive officer.

...from time to time, we've recruited people...to provide support, but we haven't really briefed people well enough and so they feel like a shag on a rock. They've never really had the time other than the actual meeting so there's no chance for the person to actually read through the minutes in advance, discussing agenda with the person, making bullet points, note a couple of points where the person has had something to say to help the person to speak up during the meeting. You know, all the layers of that have been very tricky, so we haven't done well [P10_I].

Skills of clear communication

The support staff need to learn to meet the communication needs and preferences of those people they support.

Training for the staff is around giving information and breaking the information down so someone can understand it, really understand all the ins and outs of it without influencing opinion...and that staff need to learn to really listen and give people a chance to say what they have to say [P10_I].

The presence of different communication styles must be understood and accepted.

I think you need to be able to tune into and respond to a different speed...and a different communication style or many different communication styles. Expecting people to conform exactly to what's considered "professional" – in inverted commas – practice on a Board or in a meeting is not a good recipe [22_C].

Multiple skills were needed to be "...able to re-explain things for people, and being able to re-explain verbally but then also to put things into Easy Read [P09_H].

One participant described the support worker as an "interpreter" to help him get his message across as he learns the skills of communication in a meeting situation.

My support worker might jump in and say, "No, he means it like this." 'cause it's just the way I'm talking to them...my language is slowly changing to learn to talk at meetings. I wasn't very good at the start. But now, I'm starting to feel a lot more confident talking at meetings [P25_U].

If support isn't being given well, intervention may be needed. "Sometimes I'll have a chat with [support person] on the side and say, "You tend to be talking a bit too much" [P08_G].

Understanding boundaries of the support role

While having a working knowledge of Boards and their responsibilities is useful, it is important that a support person does not take on the role of being an unofficial Board member. As described by one participant who has a legal background

I think they certainly need to be well-educated enough to know what the sorts of words are and the sorts of concepts that we're talking about.

The boards are there for, often, the strategy, or risk-management, or custodianship of the organisation, or the culture of an organisation. There are going to be certain things that come up all the time so someone would have to be really financially literate, I think. It would be helpful if they were familiar with the general process of how a board operates in order just to help know when it's time to say something, or when it's time to be quiet or whatever [P21_R].

However, this participant also highlighted the need for the support person to remember the boundaries of their role.

You also don't want the support people to be accidentally or inadvertently becoming shadow directors, or in some way themselves acquiring some form of fiduciary-related duty to the organisation because they're, in fact, the ones making the decisions, not the individual. So almost the more skilled, and knowledgeable, and professional they can be, but the more ignorant of being a director, ironically, might actually make it a safer environment for them [P21_R].

Theme 5: Concerns become barriers to inclusion

There were a number of concerns voiced during the interviews. Seven out of the eight Executive Officers or senior managers interviewed expressed concerns. Despite participants stating they were willing to consider changes that would encourage the inclusion of people with intellectual disability on their Boards, having concerns appeared to be a barrier to embracing and implementing inclusive government practices. Concerns were most strong from people who had little experienced working with a person with intellectual disability in a governance role. Concerns need to be addressed and strategies identified to ensure barriers are overcome. This is well expressed by one manager who stated:

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 [P06_EO].

Inclusive governance requires a commitment to do what it takes to make it work. "We need to put in the supports, and the culture, and build that supportive framework around it" [P20_Q].



a) Complexity of Board role

A common concern expressed by participants was the complexity of the Board members' roles and concerns whether a person with intellectual disability would be able to undertake the responsibilities required as a Board member. This challenge was explained by a Board member without disability, who also acknowledged that decision-making about complex issues can be hard for many Board members, not only those with disability.

There was a great degree of complexity and nuance in some of the decisions that had to be made...and I think that it was difficult for the Board members who had intellectual disability to be able to retain all of the options and weigh the various options and therefore contribute to the decision-making in that way. So they were certainly aware of the content of the discussion, but I think it was difficult for them just because they were really involved, complex, factually strategic and difficult decisions for all of us. I think that was particularly difficult for the Board members with a cognitive disability...I think it would've been difficult to be able to support the Board members with a cognitive disability to really participate in some of the decision-making. And really, I hate saying that 'cause I think that's not true of most of the decisions [P16_J].

This recognition of the complexity of decision-making reinforces the importance of clear, accessible information that supports the informed decision-making of all Board members.

So, in practical terms, we responded by trying plain English [reporting] and to do as many visuals [as possible]. So, our financials are presented in graphs and visually, making sure that the treasurer explains things in

plain English and gives people the opportunity [to ask questions]. But being realistic, as I said before, a lot of people, not just the self-advocates, wouldn't understand all of it [P08_G].

The business aspect of running an organisation means that decisions are not just being made in relation to the needs of people, but also the systems that support the organisation to operate. Such business-based decision-making may be particularly difficult for many Board members.

While our people with disabilities is our sole purpose for existing, we still need to run it in a business-like way...we've invested in...equipment and systems upgrade...it's the level of business decisions that you need to make that are so vital, because this is equipment that will help us stay up-to-date in the industry but...the level of financing, etcetera. It's not always easily understood [P14_JLM].

The need for Boards to be skilled managers of public funding also contributed to the level of concern. One executive officer noting,

There's a distinction between a governance board and a community Board...the expectation from funders and the government is that once you're dealing with public funds to a certain level, you're actually looking at business skills [P04_D].

It was recognised that it may not be the regular work of the Board that may be particularly challenging.

You might go six months without any major decisions...but then there might be some very significant decisions that come up and to sign off on them, you really do have to be fully across them. To ask someone to sign off on them when perhaps they're not fully across them. It can be actually quite unfair [P14_JLM].

A clear understanding of the role of Board members, as individuals, is important. Without this, there can be an unrealistic expectation that people, through their personal experience of disability, can take on a representative role.

I don't think it's fair to ask committee members who have this knowledge and experience of their home and their life and their take, to then somehow think – well, now make an assumption based on all these other people with disabilities that you've never heard of and that you don't know [P24_T].

While the responsibility to create an accessible structure with effective support is on the organisation, a commitment is also required by each Board member. Ensuring potential Board members are aware of the commitment required to be a Board member, and then supported to meet that commitment, is not always achieved.

One lady...has not attended any meetings this year...I can't actually get to why but there's always – there's a different reason each time...I'm not saying they're not real reasons...are they feeling some pressure about being on the actual Board? As much as it sounded, “Yeah, I'd like to do it,” when you get to the reality of it...[P14_JLM].

The challenge of the complexity of Board decision-making has been addressed by organisations scaffolding the practice of inclusive governance through an integrated system of skill development (see theme 2), accessible information (see Theme 3) and individualised support (see Theme 4).

b) Legal responsibilities

As noted in the previous sub-theme, there was a recognition that the decisions being considered at a Board level are complex. This raised a concern about the liability for the individual, as well as the Board as a whole.

There comes some very significant discussions and very significant decisions, and decisions we potentially take [have] legal consideration and even to budgeting. We approve budgets and [if] the place goes bankrupt because of our ineptness, well we've got a liability... Is that fair? [P14_JLM].

It was also recognised that each Board member has a responsibility, regardless of any disability. “...sometimes [there] are some challenging questions and challenging situations and if you're a director, you're a full director...and the law has quite strengthened in the last ten years around being a director, and what your role and responsibilities are” [P14_JLM].

Concern was also raised about the potential liability that may be extended to the organisation if a Board director had an intellectual disability.

An individual has to declare conflicts of interest, has to act in the best interest of the company, has to act in good faith. All of these directors' duties and principles are principles that the individual has and if they don't do it, they could individually find themselves in trouble. Whether

you could then say, “Well, the company itself is also on the hook here,” because it ought to have done better in ensuring that that person was more skilled than they were, or the company itself is at fault because it allowed a person who was unqualified onto the Board [P21_R].

The need for skill development was recognised as a mitigating action that could reduce liability. However, this did not remove the concern that people would remain vulnerable.

From a governance point of view, you need to assure that people have got the skill set so they don’t put themselves in a vulnerable position in terms of making a decision...they can’t be a passive Board member...it could put them in financial [liability] or could end up in jail” [P10_I].

From a Board member with a legal background, the following summed up both the concerns and a strategy for reduction of risk.

My two big concerns though are around liability for decisions, that we do things that sometimes with all the support and the best will in the world, people are not always understanding and able to have the legal capacity to make, and also that there are decisions that with all the support in the world, there is a limit on the person’s cognition that means that they are going to struggle to make an informed decision on. How do we address that?...Good risk management framework and compliance framework [P16_J].

Certain parts of a meeting, where discussions become complex, may be particularly challenging and it may be necessary to pause and to provide additional support on those occasions. This requires a specific support response and knowing the needs of the individual Board member. This is explained in the following comment:

Not every Board meeting is full of risk but when it does come up, I think a prompt of some sort, or a discussion, a side discussion needs to happen...not everyone needs that, but for those people that do, I don’t want to set someone up for failure [P10_I].

Another participant described the importance of good governance processes to protect all Board members.

The Board makes a decision as a collective...the Board processes should protect all members from being in a vulnerable position...I don't think it's the disability that's the issue. I just think its Board processes need to

protect members and be really thorough in those explaining bits [P20_Q].

c) Meeting support needs

Some participants identified a concern with their ability to meet the individual support needs of Board members with intellectual disability. There was a number of support issues identified as potential barriers to inclusion, such as balancing different needs within meetings, providing support without influence, and ensuring adequate support is provided.

However, concerns were raised about the balancing of support needs with meeting processes. “Certainly, everybody really needs to balance both the need to...move through the business...but move through it in a way that’s balancing the needs of people who need to go a bit slower and have more thorough conversations”[P22_C]. Managing the agenda is required to pace the meeting speed appropriately, and this can be difficult. “[It] has been quite challenging to hear everybody's thoughts and to follow because it's quite a fast meeting, a lot of things to talk about. The meeting goes quite fast and I probably speak faster than I should” [P13_K].

There was a lack of understanding about the support process and how this would be managed. One concern was that any support provided may have an influence on decision-making. One executive officer noted that “...the person might just be influenced [by] what you [support person] have just said, or we really cannot gauge whether the person understands what you are saying” [P15_B].

Knowing when support is required is another challenge faced, particularly if support is not seen as an expected accommodation. “There was an assumption that they didn’t require it [support], which was [sometimes] justified but not always” [P16_J].

Arranging supports that actually help a person can also be challenging, it takes time and organisation to achieve results.

That’s the problem about getting a support person...it’s just that little bit too hard to get someone to go through the papers before the meeting. We would go like an hour early...normally the EO would go through the papers with us [P12_J].

Ensuring confidentiality was another issue that challenged people. One Board member had been told that "...it's going to be really hard to find anybody that we think will... understand that they're not allowed to talk about what they're doing to help the person" [P12_J].

While the importance of supporting a person to develop positive interactions with other Board members was recognised, participants did not feel confident that they knew how to do this. This was clearly described by one Board member who described a difficult experience.

On one of the Boards, one of the people with intellectual disability, there were a range of issues that were directly related I suspect to behaviour that arose because of the person's disability...there was an acceptance of very unreasonable behaviour because the person had a disability...There was conduct that I suspect was a result to a degree of disinhibition but also because there was no holding to account for difficult behaviour or consideration of whether that was the appropriate person to be on that Board and that created absolute chaos...I think probably one of the reasons they didn't deal with the behaviour was because they wanted to be supportive of the Board member because of their disability [P16_J].

Other challenges that may arise could be due to a lack of prior experiences to draw on to provide an understanding of the boundaries within Board relationships.

That person [Board member with intellectual disability] has some fundamental needs for relationship which are not being met. They're very socially isolated and so then when they have access to contact details, they, of course, reach out to the person which becomes overwhelming to some Board members [P11_E].

The concerns expressed demonstrate that a commitment to making inclusive governance work by providing adequate supports is necessary. The provision of THIS support requires resources, both in terms of human resources (trained staff) and financial resources. At times it was felt that current funding did not provide the money to purchase the level of support needed. One participant with significant support needs, reported being told by an organisation that they needed more funding to provide the support that he required "more, they needed more" [P03_BC].

The sustainability of inclusion, when specific funding is not available, is also of concern.

I suppose that's unknown. I think at the time in this particular [title] funding, they specifically had something in it about supporting Board participation, decision making in organisations or something like that and I don't know if they changed the scope of this funding [P13_K].

Sufficient funding to cover resources was important, "...it's impossible to expect that it's always going to work perfectly unless it is properly resourced" [P08_G]. And organising the support takes both time and money "I think it's more work...and for an organisation...they'd need to think about the financial side of putting in those extra supports" [09_H].

Without adequate resources, inclusion was expected to fail. "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_I].

Effective support requires identification of support needs, skilled support provision, and adequate resourcing. Theme 4 provides details of how support is best addressed.

d) Perceived conflict of interest

There were concerns that it is a conflict of interest for a client, current or previous, to become a Board member. This may be because of previous relationships the person had developed as a client of the organisation.

...it was more problematic managing relationships because of the nature of the relationships that the Board members with intellectual disability had with the staff of the organisation at a time where there [were] staffing issues as well [P16_J].

Such concerns may also arise over other organisational relationships of potential Board members, such as being a family member. "I think there's a respect for having a family on the Board, but managing the single interest that can come with that, you've got to have a person that can adapt" [P04_D].

Any decision-making needs to be in the best interests of the organisation and to meet its objectives, rather than a response to an individual's personal situation and preference. This requirement of all Board members needs to be clearly explained prior to a person taking on a Board role.

One of the things we do ask family members to be really careful of is that they're there to represent the organisation and what's happening in

the organisation, not about their specific issues...and it'd be the same with the person with the disability if they were a client. So you're there to represent everyone, not just yourself [P10_I].

Any potential conflict of interest can also be reduced by setting up guidelines, as one executive officer explained. !

We had provisions in our policy..."There will be no special treatment for our governance committee when they want to use our service." So if they have any inquiries or they need support, you have to be on the waiting list just like anyone else. No special treatment [P15_B].

It is important that an organisation assesses the reasons any person may nominate for a Board position. However, it was thought that for people with a disability, a lack of other valued roles may be a primary reason. Checking that "they're joining the Board for the right reasons for them, not because perhaps they lack roles in their life and they're role famished and so they're looking for any role to bring anything" [P06_EO]. A discussion about other options for inclusion in an organisation may assist in identifying the best role. The personal needs of a Board member, if not met elsewhere, may create a situation where the needs of the organisation are not the priority of a Board member. This is not an issue that only relates to people with intellectual disability, consideration of a person's life situation may be required.

...to me, the bigger barrier is this need, this big need that's between the meeting and this person...It's this idea of the barrier of the overwhelming need...if I'm having trouble putting food on the table for my family and putting my hand up to be able to be on a community Board and to give it my full attention...I am more interested in what you are doing with the leftover food from the supper [P11_E].

The identification of unmet needs occurs best within a Board culture that cares for its members and where support people get to know the Board members well. This should be followed by relevant actions to address the issues, such as referral to advocacy, support options for taking a leave of absence, if necessary, together with a plan for a return to the Board if possible.

e) Current Board culture

Some participants were concerned that people with intellectual disability would not easily fit into the current culture of their Board.

I think it would be very challenging...the meeting structure would have to change and the language would have to change...if not properly dealt with, I think it could frustrate others... And I think that it could be a key danger for the smooth running of a Board meeting, meeting everyone's expectations, having different expectations [P04_D].

The ability of Board members without the experience of disability to act in an inclusive way was identified as a barrier. "...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" [05_C].

Many current Board meeting practices are not inclusive. There was a feeling that some Boards would not be willing to change to more inclusive procedures if this may affect their preferred or customary work practices. The pace and length of meetings was identified as one example of such practice.

I don't want them to be overlooked in a fast-moving conversation. So sometimes the board runs on an hour, an hour-and-a-half timeframe, mostly on a monthly basis or even a bi-monthly basis, and they don't want to be there longer than that [P10_I].

Recruiting people with disability who feel comfortable and included may also be difficult. As one current Board member explained, "They are finding it harder and harder to find people to get onto the Board...I think it is just the legal side of it, just the complicated language that they sometimes talk. It makes it very hard" [P12_J].

This concern highlights the need for Boards to examine their culture, identify what may be a barrier to inclusion and work towards change. Examples of effective inclusion in practice have been discussed in Theme 3.

f) Fear of tokenism

Attempts to have an involvement by people with intellectual disability at a governance level may be tokenistic, and it was clear that this was something that people wanted to avoid. "Having people on the Board can be tokenistic, that you're just sitting there, but you're not really involved" [09_H].

One suggestion to improve involvement is to ensure Board members have a good understanding of the organisation. This may best be undertaken by involvement at different levels.

One of the things that I identified probably a couple of years ago was that our Board members didn't always know what projects we did specifically...they didn't really know what kind of work [Org C] does. And I think that understanding the organisation, what kind of projects do they do, why do we do them, what work do we do, could we do fee-for-service, what kind of fee-for-service work do we do, why do we do that – I think all that stuff's really important if you want the person to be able to make good decisions and also to enjoy the process more and have a feeling that they're more connected to the organisation. I think that's really important" [05_C].

The fear of tokenism has caused some organisations to withdraw all attempts at involving people with disability. One example was provided by a disability service provider. "We had a client forum many years ago and, in the end, we closed down because it became very tokenistic, and I said, "If we can't do it properly, there's no point having it" [P10_I].

To prevent tokenism, a commitment to doing whatever it takes to make inclusion succeed is needed.

"For us, it's a rights-based motivation, so then we need to put in the supports, and the culture, and build that supportive framework around it. If it's just to tick-a-box, then it's the wrong motivation" [P20_Q].

Ensuring diversity, including a number of people with disability was suggested so "...that they're not feeling like they're that token person". Overall, while inclusion may create some challenges, require some change in current practices and resource allocation, a belief in inclusion was viewed as positive for organisations. This was summarised by a Board member with disability. "...if they actually believe it [inclusion], like we believe...it will grow better...it will have better outcomes...they'll just be better overall with the input and contribution of people with disability" [P21_R].

Overview of key results

The analysis of the data provides an insight into the experiences of Board members and others involved in organisational governance. The findings inform the following key ideas for consideration:

Holistic Inclusion

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 be a commitment to the concept of inclusion, supported by practices developed at a constitutional, policy, and procedural level.

Five Principles of Inclusive Governance

Five Principles of Inclusive Governance emerged from the research, these can be used to guide and evaluate an organisation's inclusivity at a governance level.

The following figure identifies the 5 principles and the themes that informed their development. An Easy Read version of these principles is then presented.

Figure 2: Themes to Principles

Theme	Principles of Inclusive Governance
1. Impact of inclusion in governance	1. Inclusion of people with intellectual disability in the decision-making and governance of community organisations is valued
2. Pathways to Board membership	2. There are clear pathways to Board membership for people with intellectual disability
3. Experience of inclusion within Boards	3. Board meetings and activities are accessible, meeting the inclusion needs of people with intellectual disability
4. Support provision	4. Individualised, skilled support is provided
5. Concerns become barriers to inclusion	5. There is a commitment to making Inclusive Governance work

Figure 3: Easy Read Principles of Inclusive Governance



Principles of Inclusive Governance



Inclusive Governance means that people from many different backgrounds are included in the decision-making of an organisation.



The Inclusive Governance Project has been looking at the inclusion of people with intellectual disability.



Inclusive Governance works best when people with intellectual disability are included in all parts of an organisation.



There are **5 Principles of Inclusive Governance**.
These principles guide the way organisations should work.



1. We include people with intellectual disability when we are making decisions. We value this inclusion.



2. We make it easy for people with intellectual disability to get involved in our organisation. They will learn skills and have experiences that will help them to become involved in our decision-making.



3. We make our Board meetings and activities easier for people with intellectual disability to understand and be involved.



4. We provide the support that people need.



5. We will try to do whatever is needed to make Inclusive Governance work.

D. Implications

Implications

The implications of the research findings vary at individual, organisational, community/sector and government levels.

Individual level

People with intellectual disability have the right be involved in the decision-making and governance of community organisations. However, to take up this right, they need to:

- understand the value of their involvement, the impact it may have on themselves, the organisation and the community.
- understand the pathway to involvement in decision-making of an organisation that they are interested in, and have the opportunity to develop skills and experiences that will support this involvement
- be able to access the activities of an organisation, including receiving information in a way that they can understand
- receive the support they require to undertake roles they take on
- be committed to the organisation, and do their best to carry out the responsibilities

Organisational level

Community organisations who want to include people with intellectual disability in their decision-making would benefit from:

- organisation-wide discussion of the value of inclusion, identifying current practices and gaps
- development of recruitment strategies that will promote the involvement of people with intellectual disability in as many ways as

possible, providing learning experiences and skill development to assist inclusion in a wide range of settings

- 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.
- an organisational commitment to the concept of Inclusive Governance

Community and Sector level

The broader community and disability sector needs to consider:

- provision of accessible governance training for Board members with intellectual disability
- development and provision of training for Board support people, recognising the level of skill this position requires, and the critical role played
- 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.

E. Development of resources

The research findings were used to guide the development of resources. Some resources inform people with intellectual disability about inclusive governance, what it means and what support they can expect. Other resources are for organisations, to assist their implementation of inclusive governance strategies.

Resources for people with intellectual disability

- About the Project – Easy Read http://sidebysideadvocacy.org.au/wp-content/uploads/2023/07/1-Project-outline_easy-english-1.pdf
- Project Report – Easy Read http://sidebysideadvocacy.org.au/wp-content/uploads/2024/07/Inclusive-Governance-Project_report_Easy-Read.pdf
- 5 Principles of Inclusive Governance – Easy Read <http://sidebysideadvocacy.org.au/wp-content/uploads/2023/10/Principles-Easy-Read-v1.1.pdf>
- Explaining the 5 Principles – videos <https://sidebysideadvocacy.org.au/inclusive-governance/#findings>
- Let your voice be heard – video <https://www.youtube.com/watch?v=J1CTbBO9UNs>

Articles and papers about Inclusive Governance

- Article- Response to DRC (post print) http://sidebysideadvocacy.org.au/wp-content/uploads/2024/07/Response-to-DRC_RAPIDD_postprint_version-3.pdf

- Article – Commentary on article by Hough (post print)
<http://sidebysideadvocacy.org.au/wp-content/uploads/2023/12/RPID-2022-0037-Curryer-Commentary-POST-PRINT-VERSION.pdf>
- Discussion Paper 1 – PWID in governance roles
[http://sidebysideadvocacy.org.au/wp-content/uploads/2023/12/Discussion-Paper-1 -PWID-in-governance-roles_final.pdf](http://sidebysideadvocacy.org.au/wp-content/uploads/2023/12/Discussion-Paper-1-PWID-in-governance-roles_final.pdf)
- “A Call to Action” – video challenging organisations to move towards inclusive governance https://youtu.be/EzkrEK_uZ24

Resources for Organisations

- Action Plan http://sidebysideadvocacy.org.au/wp-content/uploads/2023/12/Inclusive-Governance-Action-Plan-Template_Dec2023.pdf
- Agenda – Easy Read https://sidebysideadvocacy.org.au/wp-content/uploads/2024/07/Agenda_Easy-Read_template.pdf
- Report options
 - Easy Read http://sidebysideadvocacy.org.au/wp-content/uploads/2024/07/Report_Easy-Read_template.pdf
 - Plain English http://sidebysideadvocacy.org.au/wp-content/uploads/2024/07/Report_Plain-English_template.pdf
 - Financials- Plain English http://sidebysideadvocacy.org.au/wp-content/uploads/2024/07/All-financial-reports_Plain-English.pdf

Board Support Person related information

- Board Support Person – Role description
http://sidebysideadvocacy.org.au/wp-content/uploads/2024/07/Board-Support-Person_Position-description.pdf
- Preparation for meeting template http://sidebysideadvocacy.org.au/wp-content/uploads/2024/07/Meeting-Preparation-Form_template.pdf

F. Dissemination of project findings and outcomes

1. Discussions with stakeholders

There have also been many discussions held with a wide variety of stakeholders. These discussions were not recorded and are not formally included in the research findings. However, they do increase the researcher's understanding of governance issues and provide context to the experiences explored. Contact with these stakeholders was a way to raise the profile of the Inclusive Governance Project, help the stakeholders to understand the research, be aware of findings and resources, and start to consider the issue of Inclusive Governance.

In total, discussions have been held with 65 organisations or interested individuals (as at 20/6/24). This number does not include the 27 individuals who consented to, and participated in, formal interviews.

The organisations and individuals came from the following areas:

- o disability advocacy organisations and peak bodies (n= 15)
- o disability service providers (n=16)
- o governance and constitutional specialists and training bodies (n= 8)
- o academics specialising in intellectual disability, governance, or decision-making (n=8)
- o other interested organisations or individuals (n= 18)

2. Conference/workshop presentations:

Preliminary findings have been presented at the following conferences or workshops:

- o ASID Conference – Online November 2021
- o CEO Meeting (NDS) – Online December 2021 (invited presentation)

- ILC Grants Showcase -Online March 2022
- ASID webinar - August 2022
- NDS Governance Summit – Brisbane Oct 2022 (invited presentation)
- Possibility Conference – Melbourne Oct 2022 (invited presentation)
- ASID Conference - Online Nov 2022
- Having a Say Conference – Valid & Inclusion Australia – Geelong Feb 2023
- LaTrobe University Seminar – online August 2023 (invited presentation)
- Lumen Conference – August 2023
- Civic Leadership Conference – October 2023 (invited presentation)
- ASID Conference – November 2023
- Centre for Disability Research and Policy – Sydney University April 2024
- IASSIDD – Chicago USA, August 2024

3. Journal articles

Curryer, B. (2022). Commentary on “Governing for quality and safeguarding: What might disability service provider boards learn from others?”
Research and Practice in Intellectual and Developmental Disabilities, 42-47. <https://doi.org/10.1080/23297018.2022.2157321>

Copies of this article are available at

<https://www.tandfonline.com/eprint/J8SQA7GCSKT68TXDX89T/full?target=10.1080/23297018.2022.2157321>

Curryer, B., Donnelly, M., Roots, K. (2024). Exploring the Disability Royal Commission's views on the inclusion of people with intellectual disabilities in the decision-making and governance of disability services.
Research and Practice in Intellectual and Developmental Disabilities, 11(1), 133–144. <https://doi.org/10.1080/23297018.2024.2342417>

Curryer, B., Donnelly, M., Roots, K., Spencer, M., Harding, W. & Sneath, K. (2023). *Inclusion of people with intellectual disability in the decision-making and governance of disability and community organisations*. Manuscript accepted for peer review.

4. Disability Royal Commission submission – July 2022

A submission was made to the Disability Royal Commission in July 2022. This submission detailed the issue of Inclusive Governance, and the preliminary findings of this research project. The following questions were raised:

- 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.

- 4. 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
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5. 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).

6. 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.

G. Implementation



Side By Side Advocacy

Changes undertaken by SBSA to increase involvement of people with intellectual disability in organisational decision-making and governance

Side By Side Advocacy, as an organisation, has been interested in the concept of a more inclusive governance model since the idea of applying for funding was first considered in 2019. As the project was undertaken, the Board was kept updated via regular reports. In 2022 and 2023, two planning sessions were held with the Side By Side Advocacy Board and senior staff. The Action plan template was used to guide the discussions and assist the organisation identify actions to move towards a more inclusive governance model. Two key actions were the revising of the constitution and the development of a new membership engagement strategy.

Constitutional changes:

- **A new point was added to the Organisational Objects:**
2.1.5 '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
- **An alteration to fees and subscriptions was made:**
7.1 No joining or annual fees related to membership of the association.

SBSA's membership engagement strategy raises several considerations for attracting and maintaining increased membership by people with intellectual disability:

- A growth in membership that includes core stakeholders has the potential to add valued roles to people's lives that they may otherwise lack. It also has the potential to progress organisational inclusive practices more quickly and coherently within the organisation than would happen without such a strategy.
- This is consistent with the preliminary findings of the Inclusive Governance Project that people with disability benefit from having multiple leadership and engagement pathways.

- Members can influence organisational decisions, including:
 - input into the strategic direction of the organisation,
 - vote on Board membership,
 - become Board members,
 - vote on Constitutional changes.
- Becoming a valued member of an organisation such as SBSA has the potential to do the following for members who have an intellectual disability
 - bring a sense of belonging
 - experience a different organisational relationship other than as client or program participant
 - assist a move from self and societal perception and being only a 'taker' of services to one of 'contributor' or 'leader'
 - exposure to information
 - opportunity to provide perspective of lived experience through member consultation
- Implications for organisational behaviour:
 - Increased need to provide accessible information
 - Embrace co-design principles into activities and programs

Actions to support this strategy would include

- policy review (particularly regarding membership)
- consider all communication methods to ensure accessibility
- promotion of membership – highlighting benefits to individuals
- Ongoing engagement with members – annual survey, invitation to co-design opportunities, regular communication through accessible newsletter and social media
- Review of membership costs
 - Change to membership fees, \$0 membership fee to reduce economic barrier to membership
 - Apply this to everyone so that people with disability are not 'othered'
 - This strategy has been reviewed, pro-bono, by a reputable law firm

Outcomes of these changes

Increased engagement of people with intellectual disability throughout the organisation. This is evidenced by:

- increased organisational membership by people with intellectual disability
- attendance at AGM by people with intellectual disability
- involvement of people with intellectual disability in co-design activities
- practical engagement with people with intellectual disability through capacity building activities such as the Parramatta Leadership Project
- appointment of a person with intellectual disability as a Board member, together with individualised support

Other Organisations

Case Study

Creating a Participant Reference Group

What have we done?

- We are in the process of setting up a Participant Reference Group
- 15 residents have expressed interest in joining the group
- First meeting is planned for April 2024

What worked well?

- High interest in the group by the residents
- Organisational wide support – Board, CEO, staff and residents

Challenges

- The concept of having their thoughts put forward at a governance level is new to the group

What helped?

- Support from Board, commitment of CEO and other staff
- Access to planning support from Side By Side Advocacy and its Inclusive Governance Project
- Access to Supported Decision-Making training by CID, described as ‘empowering’

Future Plans

- Initially the group will report to the CEO, but plan is to eventually report directly to the Board



About the organisation

Disability accommodation service

Size – small (7 purpose-built homes)

Company limited by guarantee, with a Board of 9 members.

No history of inclusion of Board members with a disability.

“This is a very exciting time in the lives of the people we support. We are all on a steep learning curve and accept this is not one giant leap to perfection...rather it is incremental steps in the right direction.”

Staff member

Case Study

Creating a Disability Advisory Board

What have we done?

- set up a Disability Advisory Board – with plans to meet every 3 months
- currently consists of 3 people with intellectual disability or neurodiversity and 2 carers of people with disability
- one member is a current client, the others are interested community members

What worked well?

- each meeting has a focus on one issue that the Board would like some advice, for example 'Complaints Process' and 'Service Quality'
- outcomes so far:
 - position of Client Inclusion Officer recommended, approved and created (filled by a person with disability)
 - QR code in group homes for instant feedback by either residents or visitors

Challenges

- recruitment of people with intellectual disability
- managing expectations of group and its recommendations

What has helped?

- support from the Board, with commitment of CEO and other staff
- access to planning support from Side By Side Advocacy and its Inclusive Governance Project – including a presentation to the Board
- Board member who champions inclusion of people with intellectual disability

About the organisation

Disability Service Provider – accommodation, community day programs, social activity groups, plan management, support coordination, and 1:1 support

Size – medium to large

Company limited by guarantee, with a Board of 6 members.

No current Board members with a disability

“...the work the Disability Advisory Board is doing is opening conversations...the Disability Advisory Board's reports and recommendations have influenced the way the Board works and that has definitely brought about a positive change”

DAB member

I. What is still needed?

What is needed is a multi-faceted approach to the creation of environments and skills that support the leadership and participation of people with intellectual disabilities in civic decision-making and governance. Further work is required to develop and provide resources in 3 main areas:

- create and support pathways for people with intellectual disability that increase their experience and knowledge to undertake governance-related roles. Proactive outreach to meet people with intellectual disability should be part of the strategy.
- train and mentor community and disability organisations to increase their inclusivity at a governance and workplace level
- develop and run training programs for Board support people

A mix of increased awareness, specific training, and mentoring is required.

J. References

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