[00:00:00] Welcome to the second episode of the Inclusive Governance Podcast. I'm Dr. Bernadette Currier. I've been leading a research project exploring the inclusion of people with intellectual disability in organizational decision-making and governance. In this episode, we'll be discussing the five principles of inclusive governance that have been developed as a result of what we found out of our research.

I'm thrilled to have Katrina Snees joining me again for this discussion. Katrina has been working alongside me as a co-researcher on the project. We also have Kim Rootes with us today. Kim is the executive officer at Side By Side Advocacy. So Katrina, can you start us off with the first principle? H- hi, everyone.

The first principle is that inclusion of people with intellectual disability in the decision-making and governance of community organizations is[00:01:00]

valued. This principle was informed by the experience of people who took part in our research. They reported that being a part of an organization's governance gave them a valued role. The involvement of people with intellectual disability also allowed the organization to hear a different perspective and understand the impact of disability, and it challenged the stereotype of people with disability, showing them as contributors to services, not just the recipients of services.

Kim, can you please give some practical e- examples of how Side By Side Advocacy shows that they value and include people with intellectual disability in their decision-making? Absolutely. There are many examples of how Side By Side Advocacy shows they value and include people with intellectual disability in decision-making.

I mean, we could be here all day discussing this because people with intellectual disability are involved in decision-making [00:02:00] all the time. People with intellectual disability are on interview panels when we're recruiting new staff. They help us decide what projects we'll run. They co-design training materials and promotional materials.

People with intellectual disability co-present workshops. They're members of the organization that guide our work. They're encouraged to join our board. They're employed as members of our team. Actually, only today, Side By Side Advocacy was invited to talk about a project on local radio, and one of our peer leaders, Su Hua Chan, led the conversation.

She shared her hopes and dreams in her words. We're also striving to ensure that people with intellectual disability have the information they need in formats that suit them, like plain English, Easy Read, video, and audio. Fairly obviously, people can't be meaningfully involved in decision-making unless they understand what is being decided and have the [00:03:00] time and support to make those decisions Kim, can I ask, is it easy to find people to do those roles in your organization?

Not always. Many people with intellectual disability haven't had the opportunity to take on leadership roles or get i- involved in advocacy organizations. Some of them have never even heard the word advocacy. So one of the things that we've done is go out to places where people with intellectual disability just ordinarily are, like in a day program, or an Australian Disability Enterprise, what used to be called a sheltered workshop, and go there, same time, same place regularly, sometimes taking lamingtons and biscuits as a way of being a positive introduction to us, and just get to know the people, start to talk to them about the kind of work the organization does, invite them to participate in workshops so they start to dip their toe in to the [00:04:00] world of advocacy.

And then, if they find it interesting, enticing even, we invite them to consider getting involved more intimately with the work of the organization. But it's something that takes time. There aren't rows of people who are aware of advocacy lining up to do the work. It's a long process, and, and people need time to think about what some of those really technical words mean, like advocacy.

Well, that probably then leads us well into the second principle. The second principle that is there s- there are clear pathways to board and membership for people with intellectual disability. This principle was informed by the research participants talking about the skills and training they received that helped them in their governance roles.

However, there is currently a gap in accessible governance training. This means that people with intellectual disability do not have many opportunities for learning about governance processes. It became clear that an inclusive [00:05:00] culture where people with intellectual disability were involved in different activities within the organization supported inclusion at a governance level.

Kim, can you please tell us some ways that Side By Side Advocacy is trying to help pe- people understand and get r- ready for involvement in governance r-

roles? Absolutely. Side By Side Advocacy is giving people with intellectual disability the chance to get ready for governance roles in a few main ways.

One is that we're supporting people to understand that they have rights and responsibilities, and to speak up about issues in their own life. Starting with yourself is a good place. We're also running workshops that are co-designed and led by people with intellectual disability that are about rights, speaking up, and thinking about issues that matter.

These workshops give people practice speaking up. We've also started a leadership group for people with intellectual [00:06:00] disability. Group members are getting an understanding of how to be an effective self-advocate They're learning about decision-making roles they can take part in, both at Side By Side Advocacy and beyond.

They're learning from each other. We've employed a peer leader who's been on boards, led campaigns, met with politicians and more to share her experiences with the group. Leadership group members are developing skills, making connections, and taking actions on matters that interest them. Being part of a leadership group has helped participants think about speaking up as part of a group, not only as an individual, and that's a very different skill set.

We're also encouraging people with intellectual disability connected to the organization to become members, to come to our annual general meeting, to vote, to ask questions about how the organization operates. We've also talked about governance roles. People with intellectual disability currently on boards have spoken about what's involved.

They've [00:07:00] shared why they joined a board. All of these things help people know decision-making roles are possible, that people will listen to what they have to say, and that they can make a difference. The, the third principle is that the, the boards and the meetings and activities are accessible. Meetings the inclusion needs of people with intellectual disability.

This principle was informed by the research findings that showed inclusion is impacted by the board culture, the board structure, their communication practices, and their meeting and decision-making processes. Kim, what has Side By Side Advocacy done to make, uh, its process more accessible? We've done a range of things to make meetings more accessible.

A big aspect is a shared commitment to meaningful inclusion. We're committed to do what it takes for people [00:08:00] with intellectual disability to be valued

contributors to our board. Interestingly, what we've found is that a focus on accessibility is good for everyone. I'll share some specific strategies. One is that we have an agenda so that everyone knows what we'll be discussing in advance.

Another important strategy is that reports are prepared in a way that's easy to understand. They're in plain English, they avoid jargon, they have clear sections, they set out decisions that need to be made, and they highlight any decisions or issues for the organization, including possible risks. Another strategy is that we distribute reports well ahead of board meetings.

This gives people time to read reports and consider their position. We've also employed a person to support board members to get ready for board meetings and perform at their best. And again, that [00:09:00] leads into the fourth principle. The fourth principle is that individualized skilled support is provided.

This principle was informed by the findings that support was best provided in three stages. Firstly, pre-meeting preparation to ensure the purpose and content of a meeting was understood, all reports read, and any questions or comments identified before the meeting began. This was followed by support during the meetings to ensure the person was following the meeting process, that they had a chance to speak up, and what they wanted to say was listened to.

Contact between meetings to ensure ongoing connection with the organization and that any agreed actions were completed on time was also important. Effective support appears to work best when it is based on a trusted relationship with a skilled support person who individualizes the support they provide to [00:10:00] match the needs of the person.

Kim, how does Side By Side Advocacy provide support to board members? Well, one key way is via a paid support person. The person we've employed to provide support to the board is very skilled and experienced. She's a former executive officer who has a good understanding of governance. She understands the role of the board.

She also has lots of experience supporting people to speak up. She's great at providing scaffolding and being in the background rather than taking over. She takes the time to get to know the person she's supporting and the kind of support they need. She's led by the person she's supporting. She's available before board meetings to go through board papers.

She can assist in thinking through any questions people may have or ideas they'd like to share. She's also available at meetings to ensure people have the

chance to speak up and feel confident to [00:11:00] speak up, and have the time to speak up. Sometimes people need a little bit more time to think through what they wanna say, and she helps them hold that space.

After meetings, she's available to debrief and to give support for any kinds of follow-up actions that might have flowed from the meetings. So having a skilled person is important. The functions of a board support role are very different to those generally considered to be part of the role of a support worker We also provide training for board members.

What that training involves depends on the needs of the person on the board. The fifth and final principle is that there is a commitment to making inclusive governance work. This principle was informed by concerns raised by some participants. These concerns included the complexity and responsibility of the board role, uncertainty about how to provide support, whether the board culture was [00:12:00] open to inclusion, and a general fear of tokenism.

These concerns became barriers to inclusion for some organizations, and unless there was a commitment to do whatever it takes to overcome them, inclusion was not successful This commitment requires a number of resources, including energy, time, money, and skilled staff. Kim, how does Side By Side Advocacy show it's committed to inclusive governance practices?

Side By Side Advocacy shows its commitment to inclusive governance practices by constantly examining and considering what we do. We have created new policies and new strategies that reflect this commitment, like our stakeholder engagement strategy that has a focus on encouraging people with intellectual disability to become members.

We've updated our constitution to ensure it reflects our commitment. For example, we removed any fee for membership so that finances wouldn't be a barrier to people with [00:13:00] intellectual disability getting involved. As an executive officer, I keep the board informed of the steps the organization is taking to get more people with intellectual disability involved in our work.

Our employment of a supporter for the board is another demonstration of that commitment. So Kim, is it easy for an organization to, to make that commitment, or, and is it worthwhile, I suppose? Oh, it's, it's absolutely worthwhile. Um, Side By Side Advocacy is an organization that specializes in advocacy for people with intellectual disability.

It just simply doesn't make sense to not be including people with intellectual disability in our decision-making. Um, people with intellectual disability have the day-to-day experience of the barriers that they're experiencing. They've thought about what gets in the way. They know what will support them best.

Of course, we need to include them, [00:14:00] but what does it take? It takes a recognition of the need to include people. It takes commitment, and that's something that needs to involve everybody. A what-will-it-take attitude is really important because inclusion isn't easy. It takes time, it takes money, and it takes a one person at a time to make sure that that inclusion is meaningful.

It's not something that you decide to do, work through a checklist, and tick and forget. It's something that you need to be thinking about every day in everything that you do, and putting in the time, money, and commitment to make sure that it's really meaningful. So it sounds like a real cultural change has been experienced.

Well, it depends on the prevailing culture at the time when things are considered. Um, as an advocacy organization, we've always valued the voice of people with disability. Um, one of the challenges, though, for small organizations is resourcing. So [00:15:00] really prioritizing that voice is something that needs to be considered and thought through and committed to in the long term, um, for everyone involved, for the board, for the executive officer, and for all of the staff.

Everybody has to have an u- understanding of why it's being undertaken, why it's important, and undergo the necessary steps, processes, and training to make it work. Great. Well, thanks, Kim, for the examples you gave of an organization responding to the principles of inclusive governance. In our next episode, we will talk about some things that might help anyone with an intellectual disability who's interested in taking on governance roles.

Thank you to Katrina and Kim for joining me today. Our conversation was recorded on the land of the Burramattagal clan of the Dharug nation. We pay our respect to elders past and present. The Inclusive Governance Podcast is a project of Side By Side Advocacy. We're a non-profit [00:16:00] organization specializing in advocacy for people with intellectual disability.

You can find out more about our work, including easy-read information, on our website, sidebysideadvocacy.org.au, or call the Side By Side Advocacy office on

0298085500. And we've linked more information about our research project in the show notes. The research project was funded by the National Disability Insurance Agency and the Commonwealth Department of Social Services. The Inclusive Governance Podcast is produced by Dani Stewart. I'm Bernadette Currier.

Thanks for listening