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Commentary on “Governing for quality and safeguarding: What might disability service provider boards learn from others?” (Hough, 2022)

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“Governing for quality and safeguarding: What might disability service provider boards learn from others?” by Hough (2022) explored the current pressure being placed on Boards of disability services to take a greater role in ensuring quality and safeguarding within their organisations. The lack of research on the involvement and effectiveness of disability service Boards’ involvement in overseeing quality and safeguarding is identified. As studies from the hospital and health sectors have found a correlation between Board governance practice and patient outcomes, it is suggested that there may be a similar correlation between Board governance practice of disability service providers and the quality of their services and safeguarding of people with disabilities who use them. One strategy to increase the focus of governance practices on quality and safeguarding is increasing the diversity of Board membership to reflect the communities and key stakeholders they are serving. For disability organisations, this would mean a greater presence of people with disabilities. The recent appointment of Kurt Fearnley, a person with a physical disability, as Chair of the Australian National Disability Insurance Agency, is an example of this in practice. However, the inclusion of people with intellectual disabilities, despite their being a major user group of disability services, is generally absent. This commentary will explore the benefits of diversity and inclusion within a Board, why it is important to ensure people with intellectual disabilities are represented, and what is being done to support their inclusion in the decision-making and governance of community organisations.

Importance of diversity and inclusion

Hough (2022) has recognised that the composition, structure, and processes of a Board may have a direct influence on governance, and indirectly on service delivery, quality, and safeguarding. Diversity and inclusion are terms that are increasingly being linked to good governance, with many corporate and not-for-profit organisations attempting to increase the diversity of their organisation. Diversity refers to the involvement of people with different characteristics, such as age, gender, cultural background, sexuality, or lived experiences of disabilities. Inclusion is the practice of welcoming diversity and ensuring equal opportunities for involvement and contribution. It is noted that “diversity is a state of being... while inclusion is a set of behaviours and can be ‘governed’” (Fucci & Cooper, 2019, p.2). Inclusion strategies that increase diversity but also create inclusive cultures are required. The Board has a key role in influencing diversity and then ensuring inclusive behaviours, both within the Board and throughout the organisation.

Similarly, inclusion of people with disability throughout an organisation has benefits at both an individual and organisational level. Marginalising groups of people by not including them in organisational decision-making, maintains a power imbalance. Arnstein (2019) illustrated the power imbalance and maintenance of inequity as a ladder with the “rungs” ranging from non-participation (manipulation, therapy), tokenism (informing, consultation, placation), through to power (partnership, delegated power, citizen control). People with intellectual disabilities have been traditionally excluded from positions of power, with at best tokenistic involvement. Such lack of inclusion impacts organisations, reduces the perspectives and experiences drawn on in discussions, and may have a strong impact on the strategic directions of organisations. Inclusion of people with disability increases disability awareness, provides a wider pool of experience, and results in a re-evaluation of the contribution that people with disabilities can give at consumer, employee, and Board levels (KPMG, 2018)

The United Nations Convention on the Rights of People with a Disability (UNCRPD) commits signatories to actively promote an environment in which persons with disabilities can “effectively and fully participate in the conduct of public affairs, without discrimination and on an equal basis with others” (United Nations, 2006, Article 29). Participation in non-government organisations and involvement in public and political life is specifically included in the convention. The National Disability Insurance Scheme (NDIS), the primary funding system for people with disabilities in Australia, states “people with disability should be supported to participate in and contribute to social and economic life to the extent of their ability” (NDIS Act, 2013, Part 2.4.2). Despite such obligations, people with disability continue to be underrepresented in leadership roles and on boards. The Australian Disability Strategy 2021-2031 (Commonwealth of Australia, 2021) identifies as a policy priority the need to increase the involvement of people with disability in leadership and decision-making roles. It is believed that such inclusion will enable the perspective of people with disability to be taken into account, resulting in decisions that reflect the diversity of the community.

As noted by Hough, “nothing about us without us”, a phrase popularised by disability rights activists, positions people with disabilities, including those with intellectual disabilities, as knowledge-bearers, acknowledging the importance of lived experience. People with intellectual disabilities should have an opportunity to be involved in the decision-making of any group or organisation that they have an interest in. This is particularly important when it is an organisation that provides services to, or represents the needs of, people with intellectual disabilities. Such involvement may be at a board or governance level. Other opportunities for people with intellectual disabilities to have a say and influence service delivery could be through providing feedback, involvement in focus groups about key organisational issues, co-designing programs, and participation in client advisory groups. Hearing the voice of people with intellectual disabilities in multiple ways is important. However, without clear inclusion strategies, skill development of the individual, and ongoing support, it is unlikely that there will be anything other than tokenistic involvement. A symbolic gesture without real involvement is particularly likely when appropriate supports are not understood or provided (Beckwith et al., 2016).

Research about people with intellectual disability in governance roles

There has been very little empirical research about the inclusion of people with intellectual disabilities at a Board or governance level. However, some research has explored inclusion at an advisory level. A study of the participation of people with intellectual disabilities on government advisory bodies indicated that people with intellectual disabilities often feel

underappreciated and that other committee members fail to acknowledge their abilities (Frawley & Bigby, 2011). Collegial support, that is a sense of support and inclusion provided by other committee members, was a contributing factor as to whether a person with an intellectual disability fully participated in the discussion and decision-making process. Provision of such support requires an inclusive culture within the group.

Studies have also looked at the inclusivity of Learning Disability Partnership Boards. in the United Kingdom. These Partnership Boards, set up in response to the 2001 Valuing People white paper (Department of Health, 2001), are responsible for strategic planning of disability services for adults with learning disability in each local authority area. They were initially required by legislation to include people with intellectual disabilities, and although no longer a statutory requirement since 2011, many continue to do so. The Partnership Boards also include family members and a wide representation of health and community services. These studies found there was limited decision-making involvement by the members with learning disability. Rather, there was a sense of tokenism, with people without disabilities continuing to have more control (Fyson et al. 2004; Fyson et al, 2014; Riddington et al, 2008). While people with learning disability may have been given a voice, their involvement in strategic planning or decision-making was limited (Fyson & Fox, 2008).

Initiatives reflecting a commitment to increasing involvement of people with disabilities at a Board level

There has been some practical work done to support the inclusion of people with disabilities on Boards. “Voice at the Table”, being run by the Self Advocacy Resource Unit in Melbourne, Victoria, is specifically designed for people with cognitive disabilities. This project aims to increase the participation of people with cognitive disabilities on Boards and advisory groups within government, the disability sector and mainstream organisations. This is being undertaken through Voice at the Table consumer advocate training, and provision of support and resources to increase the inclusivity of meeting processes (Voice at the Table, 2019). A key concept of this project is the emphasis on people with cognitive disabilities leading and co-designing the program.

Similar programs have been undertaken in other countries. For example, in the United Kingdom, the Bringing Change to the Board project (Inclusion North, 2021) aimed to build the governance skills and confidence of people with intellectual disabilities or autism, believing this would strengthen organisations through increased diversity and provide inspiration for others to become inclusive. The reported results included increased confidence and participation by individuals at a governance level. For organisations, there was an increased awareness and knowledge about the benefits of inclusion, and practical ideas about how this could be implemented.

There are other initiatives that target increased inclusion of people with disability in general, without a specific focus on intellectual disability. Within Australia, this is evidenced by a number of time-limited projects. The On Board with Me Project (PWDWA, 2019), has attempted to improve the representation of people with disabilities on the Boards of the community services sector in Western Australia. Training programs included key governance competencies, and development of professional profiles and networking opportunities. Increased representation rate, improved recruitment strategies, and removal of barriers were

supported through development of policy templates and recruitment guides. Similarly, the Multicultural Disability Advocacy Association ran a project called “Future Leaders Training Program”. This project, targeting people from culturally diverse backgrounds, aimed to develop the governance and leadership skills and confidence of people with disabilities, family members, or carers. The evaluation of this project identified improved knowledge of the service system, increased understanding of meeting processes, and development of public speaking skills as key to the increased confidence reported by participants (Human Capital Alliance, 2020).

Other evidence of an increased interest in increasing the involvement of people with disabilities at a governance level is the offering of scholarships for people with disabilities to attend governance training. Training offered by the Australian Institute of Company Directors (2022) is one example. While this program does not specifically exclude people with intellectual disability, they do not have a focus on the specific learning or support needs of this group. Board observership programs are another initiative which provide Board experience to people with disabilities, without the governance responsibility. The aim of the Hireup observership program is to increase the representation of people with disabilities on Boards, to involve more people with disabilities in organisational decision-making, and to provide career development opportunities (Hireup, 2022).

Inclusive governance in action

The inclusion of people with intellectual disabilities in the governance of community organisations is not without precedent. There are a number of organisations where people with intellectual disabilities have not only held Board positions, but make up the major proportion of the Board membership. One such organisation, the New South Wales Council of Intellectual Disability, models inclusion throughout the organisation, including at a governance level with a majority of its Board members having an intellectual disability. This governance structure is planned and supported. An organisational evaluation noted that “support for inclusion is ongoing and not left to chance” (Bigby & Henderson, 2018, p.3). One key achievement identified in this report is the development of leadership capacity among the organisation’s members with intellectual disabilities, providing not only a source of Board members but also people able to take on advisory and educational roles within the sector.

In response to the lack of empirical research into the experience of Board membership by people with intellectual disabilities, an Inclusive Governance Project at Side By Side Advocacy is currently being undertaken. This research-based project is exploring inclusive governance and the experience of Board members, with and without intellectual disabilities, senior management, and support staff. While this research is still underway, preliminary results indicate that holistic inclusion, throughout the organisation, creates an environment where the voice of people with intellectual disabilities is heard and valued, and governance skills can be developed. The importance of clear pathways to Board membership, together with accessible Board structures and processes, individualised support, and a commitment to doing what it takes to make such inclusion work, has been identified (Curryer, 2022, Curryer et al. 2021).

Conclusion

Hough (2022) has raised some important questions about the role of Boards in ensuring service quality and the safeguarding of clients. The inclusion of people with intellectual disabilities at a governance level may provide the additional perspective of lived experience, helping organisations to maintain a focus on the needs and preferences of this group, who make up a large proportion of disability service clientele. How such inclusion can assist Boards to move towards a role of oversight of service quality and safeguarding is worth further exploration.

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