

Phillippa Carnemolla: BIndDes, MDes, PhD

Phillippa is a Senior Research Fellow and Industrial Designer with extensive experience in design practice, research and education. Phillippa has a Bachelor of Industrial Design and Master of Design (Research) from University of Technology, Sydney, and a PhD from UNSW, Sydney. Her PhD, completed in 2016, investigated the impact of home modifications on care giving and health-related quality of life. Phillippa's research interests are focused on human-centred and inclusive design of housing, urban infrastructure and new technologies for older people and people living with disability.

Opportunities to support social inclusion for people with intellectual disability at a local level

Dr Phillippa Carnemolla

Abstract

Local government is a tier of Australian government responsible for public administration within a geographically-localised area. The role of local government authorities (councils) is increasingly expected to extend beyond being a service provider, to showing community leadership.

Embedded within the local community, councils are well placed to lead the wider community towards social inclusion. For this reason, an inclusive research team at the University of Technology Sydney (UTS) undertook a project to explore ways of building the capacity of councils in Australia to include people with intellectual disability in all aspects of everyday life. The research team also investigated the level to which councils engage and include people with intellectual disability across community and civic life.

The research team included people with intellectual disabilities as core team members as well as co-facilitators of the research activities. Nine focus groups were conducted with forty-five people with intellectual disabilities from six different council areas across two states of Australia (New South Wales and Victoria). The World Health Organization's (WHO) Age Friendly Cities 8 domains framework (2007) was used as a framework for data analysis and identifying opportunities for change.

The study was designed to demonstrate the value of engaging with people with intellectual disabilities and found that they are able and willing to contribute. However, they are rarely asked their opinions about their experiences in the local community.

Keywords: Intellectual disability, social inclusion, research methods

Overview of the method

Recruiting, preparing for and facilitating focus groups by and with people with intellectual disabilities required attention to be given to the design of all communication materials, as well as the structure and the delivery of the focus groups. The participants came from metropolitan and rural areas of New South Wales and Victoria.

All participants had lived experience of intellectual disability and resided in the local area where the focus groups were conducted. The participants were given the option of either participating in a one-to-one interview or a focus group and all participants, except for two,

Everyone with an intellectual disability was welcome with no limitations or boundaries set on communication requirements, such as whether they needed to be verbal or non-verbal. Of the 45 participants, 43 communicated verbally and 2 participants used alternative communication methods to contribute to the discussions, accompanied by a known support person.

What the research asked

The purpose of the study was to understand the perspectives of people with intellectual disabilities on their local community, with a focus on council services, public places and personal experiences in the local community. The research was driven by the following research questions:

- What do people with intellectual disabilities know about councils and what they are responsible for?
- What types of local places or services and facilities are utilised and valued by people with intellectual disabilities in their local area?
- How do people with intellectual disabilities experience the range of services and facilities offered by their council?
- What types of improvements to local services and places do people with intellectual disabilities want to see?

The research questions were framed in everyday language with the key question "What if you do if you were boss of your local council?" This question encouraged participants to talk about themselves and what they wanted in their local community. They were also asked about what they like to do and where they like to go.

What the research found

People with intellectual disability have valuable information to share with councils. However, they are excluded from social and civic interactions and consequently, their needs and preferences are not understood or implemented. Grouping people with intellectual disability under the generic term "people with disability" risks leaving them out unless communication and engagement strategies are made more accessible. Briefly, the research revealed that people with intellectual disability want their council to:

- Provide accessible information (in a range of formats) about what is happening in the community and how to participate
- Provide someone to speak to or even better, face to face contact
- Employ people with intellectual disability
- Find ways for people with intellectual disability to feel safer and more welcome in the community
- Get to know local people with intellectual disability
- Help people with intellectual disability to access better transport
- Improve public toilets and safer pedestrian crossings
- Offer quiet spaces at noisy, busy events

Unfortunately, people with intellectual disability continue to be excluded from many aspects of community life and civic decision making. Intellectual disability is less visible than other forms of disability. By speaking with people with intellectual disability and respective councils, this research found there are many opportunities for improvement. Some require specific funding, but there are also opportunities for improvements by just taking a different approach. People with intellectual disability should be able to take their rightful place as equal citizens of all communities. Consequently, some changes are necessary.

A framework for analysis and change

The World Health Organization's (WHO) Age Friendly Cities framework is a useful tool for assessing the needs of any marginalised group at the urban scale and at local government level. It also worked well as a framework for reporting the findings of the research in this case. The eight domains of the WHO framework are: Outdoor spaces and buildings; Transportation, Housing, Social participation, Respect and social inclusion, Civic participation and employment, Communication and information, and community and health services. Councils do not have direct control of transportation, housing or health services. These are the responsibility of state governments. However, they can advocate for improvements.

Outdoor spaces and buildings were a key topic in all focus groups. Lack of accessible facilities, wayfinding and navigation were of particular concern. Street signs were in the wrong places or not making sense to participants. Availability of clean toilets prevented some from going to parks and other places.

Although transportation is not a council responsibility, accessible transport infrastructure and services were an issue for most participants. Also, participants did not feel safe using public transport.

Housing is also outside the remit of councils but once again, lack of accessible and affordable housing was discussed in the focus groups.

In terms of social participation, participants wanted to have events were friendly and where they could meet nice people. This desire highlights how excluded and poorly people with intellectual disability feel in the community.

Related to social participation, the domain of respect and social inclusion was of particular concern. Participants did not feel welcome or safe everywhere in their local community. A change in attitude towards people with intellectual disability is sorely needed. For example, shop staff needs training to help people with intellectual disability to complete a shopping task without making them feel as if they don't count or pushed away.

When it comes to communication, the message from people with intellectual disabilities is diversity and flexibility. What this means is providing a range of communication types and pathways to accommodate individual preferences (email, telephone, direct person-to-person, texting, etc.).

Councils are required to develop and update disability action plans. However, council community consultations for these plans do not include people with disability and consequently their voices are left out of civic affairs which mean nothing changes for them.

Council staff are generally trained to help people with various disabilities, but it seems less so for people with intellectual disability.

Summary

People with intellectual disabilities who participated in this research highlighted that practices that influence inclusion span not only the physical accessibility of space, but inclusive communications and social inclusion.

Participants want to know what is available and how to get around the community. The role of place and space in supporting people to feel safe, socially connected and included was a strong theme in the data. Public spaces, such as train stations, were physical places where people often did not feel safe. Conversely, the participants said they enjoyed visiting their local café and regularly seeing people they knew. They often had favourite shops and locations where there were familiar faces and people who they could chat with and stay for a while to chat and feel happy.

60 October 2021 Vol-16 No-10 Design for All Institute of India

For some participants, this was a café, for others, it was the local pool or shopping centre.

The results from the focus groups indicated that the information people valued most included knowing about community events, to know where there are safe, physically inclusive places to go, and how to get around their community. They also want respectful encounters with people in the community. Currently, they find people are impatient, unkind or unfriendly.

By adopting the 8 domains of the WHO Age Friendly Cities framework for action, councils can improve the participation of people with intellectual disability. It also provides a framework for community consultations.

This study shows that people with intellectual disabilities aspire to contribute to their local community and can add value and perspectives to the progression of inclusive practices and environments. It also shows that people with intellectual disability can build confidence through their participation in research projects and community engagement activities provided there is peer support and validation of their views.

Given our findings about safety and respect in public space, there is an opportunity to further research how the designs of built environments impact community attitudes and behaviours from a social inclusion, respect and well-being perspective.

This research study forms part of a wider project designed to enhance the capacity of councils in Australia to include people with intellectual disabilities in all aspects of citizen life. For further information on this study see "If I Was the Boss of My Local Government" and "Towards inclusive cities and social sustainability".

61 October 2021 Vol-16 No-10 Design for All Institute of India

References

Carnemolla, P., Kelly, J., Donnelley, C., Healy, A., & Taylor, M. (2021). "If I Was the Boss of My Local Government": Perspectives of People with Intellectual Disabilities on Improving Inclusion. Sustainability, 13(16), 9075. https://www.mdpi.com/2071-1050/13/16/9075

World Health Organization, Global Age-friendly Cities: A Guide (2007).

https://apps.who.int/iris/bitstream/handle/10665/43755/9789 241547307_eng.pdf?sequence=1&isAllowed=y

Carnemolla, P., Robinson, S., & Lay, K. (2021) "Towards inclusive cities and social sustainability: A scoping review of initiatives to support the inclusion of people with intellectual disability in civic and social activities". City, Culture and Society, Vol 25,

https://doi.org/10.1016/j.ccs.2021.100398