My Home My Community— improving inclusion for people with intellectual disability

1. Summary of impact

For many, local government is associated with bins and building permits, but local councils can also help create more welcoming communities for those with intellectual disabilities according to Phillippa Carnemolla, Senior Research Fellow at UTS's School of Built Environment.

As project lead on My Home My Community, Phillippa has spent the last 12 months with a team developing resources to help Australian councils become more inclusive of people with intellectual disability. And consultation has been a big part of the brief.

So far, the six-strong My Home My Community team has workshopped ideas with 15 Sydney metropolitan councils and garnered the views of 50 people with intellectual disability through focus groups.

They've also commissioned datasets to better understand the demographics of different LGAs with Professor Julian Trollor (UNSW)[1] and are currently working with Professor Sally Robertson (Flinders University)[2] to pull together examples of best practice—both within Australia and internationally.

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[1] The Dataset described was commissioned by The University of Technology Sydney for the My Home My Community Project funded by the National Disability Insurance Scheme (NDIS). This data has been extracted by Professor Julian Trollor and Dr Preeyaporn Srasuebkul from the Department of Developmental Disability Neuropsychiatry, School of Psychiatry, UNSW Sydney, using linked data funded by a National Health and Medical Research Council Australia Partnerships for Better Health grant (ID: APP1056128); Title: Improving the Mental Health Outcomes of People with an Intellectual Disability). The original dataset cohort was conceived and designed by Professor Julian Trollor.

[2] Professor Sally Robinson, Professor in Disability and Community Inclusion
College of Nursing and Health Sciences, Flinders University.

Practicing what they preach, the inclusive research team at UTS brings a diverse range of experiences together, including expertise in advocacy, design and lived experience of intellectual disability, and includes Jack Kelly, Aine Healy, Catherine Donnelley, Megan Taylor and Kiri Weller.

Ultimately, Phillippa hopes to bring this research together in one place with other useful resources in June 2020.

"We want to share this information on a platform that is open, that brings the collective knowledge around inclusion practices and intellectual disability together and that privileges the voice of people with intellectual disability."

My Home My Community is funded by the federal government through the National Disability Insurance Scheme Information Linkages and Capacity Building (ILC) Grants Program.

2. The problem

People with an intellectual disability are often excluded from social events and mainstream services in their community.[3] Local councils have a role to play in improving the situation, both within their organisation and in the community more broadly. Unfortunately, many local councils don't have a lot of contact with people living in the community with intellectual disability, or how they might like to participate more in the community. On top of this, local councils may not feel they are equipped with the skills to change this. This project is about improving access to all mainstream services, not simply delivering specialised disability services.

A contributing factor is that people with intellectual disability aren't often directly consulted when it comes to the policymaking that affects their lives, says Phillippa. "A big part of this project has been about understanding how Local Governments can

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[3] Wilson N., Jacques H., Johnson A., Brotherton M. (2016), 'From Social Exclusion to Supported Inclusion: Adults with intellectual disability discuss their lived experience', *Journal of Applied Research in Intellectual Disabilities* (JARID), 2017, 30, pp 847–858.

make decisions in a way that is inclusive of everyone who is impacted by that decision. This is what the resources are all about."

Research Associate on the project and focus group lead, Jack Kelly, agrees. Prior to coming to UTS, he worked at the Centre for Disability Studies at The University of Sydney. He currently also works with the Council for Intellectual Disability (CID) NSW. Jack also has cerebral palsy and passionately believes that the time has come to stop pigeon-holing people.

"Holding an event one day a year for International Day of People with Disability does not make your council inclusive," he explains. "Events are good, but there have to be more where the disability is not the focus. I mean having another disabled disco? Why does it have to have the word 'disabled' in it? Can't it just be a disco?"

3. Beneficiaries

There is a legislated requirement for local governments in NSW to produce Disability Inclusion Action Plans (DIAP)—but little material on how this can best be done to achieve real improvements to services and facilities is available. There is also very little information around on how to engage people with intellectual disability in this process. For these reasons, the project resources are likely to be useful tools for councils around Australia.

It's hoped that the data on the prevalance of intellectual disability in individual LGAs will also help local government better target resources, plan services and apply for federal funding for projects aimed at becoming more inclusive. Collating information on examples of good practice, both here and overseas, will also assist this.

While people with intellectual disabilities and their families will ultimately benefit from changes at councils arising out of the research, so, potentially, will the whole community.

As Phillippa puts it, "Having more accessible, easy to understand information in a range of formats about events, activities and how to participate will mean that everyone who wants to get involved, can."

"Clarifying and simplifying wayfinding signage also helps makes things easier for those who may not have mobile phones, read maps or be able to access the internet."

4. Approach to impact

The project has sought perspectives from a range of stakeholders—including council representatives and groups like CID—but it's the focus groups the team undertook with 50 people with intellectual disabilities that are at its core.

Run by Jack Kelly, their purpose was to understand how much people with intellectual disability knew about what councils could offer them; potential blocks to this understanding, lived experiences of facilities and services; and what people would change to improve things.

From this process the team identified four themes and 10 issues, among them the lack of clear communication about things like upcoming events, the desire to be heard, safety, and the need for facilities like clean public toilets.

One thing that was consistent across all the groups was that people hadn't had the opportunity to have their opinions voiced before.

"For many it was the first time anyone had ever asked them about their local community, about what they'd change. I think that's actually one of the main pieces of advice we'd give to councils—you need to go out to listen to people with intellectual disability who live in your local area," says Phillippa.

Interviews and workshops have also been undertaken with council representatives from 15 councils across NSW and VIC to assess what is required from their perspective – because any resources need to be practical and sustainable to be applied within local government. Changes in funding arrangements, lack of appropriate resourcing and a dearth of accurate datasets were all identified as potential issues.

5. What has changed as a result of this work?

5.1 The outcomes

The research team has workshopped ideas with 15 local governments in a mix of metropolitan and regional areas and garnered the views of 50 people with intellectual disabilities through focus groups.

They've also commissioned datasets to better understand the demographics of different LGAs (with Professor Julian Trollor at UNSW) and are currently working to pull together examples of best practice—both within Australia and internationally (with Professor Sally Robertson at Flinders University).

The research findings, in particular the workshops with local government representatives, have direct implications for how to support more inclusive practices in local government, particularly as not all local governments are the same.

"We know that councils are diverse organisations—not all have a dedicated inclusion role, no two budgets are the same, and all are at different stages of how they address inclusion for their communities. So finding ways of connecting local governments from different areas to share knowledge, like through our workshops, has become important too."

In turn, the project team hopes to provide resources to council in a way that is both practical and easy to use on a day-to-day basis, and that meets local governments wherever they are at.

"We've created some easy to use tips and guides for local council to refer back to about how to be more inclusive. I hope that our tools are used and not just put on a shelf, because at the end of the day we all deserve to be included in our local communities," explains Jack.

Eventually, the resources the team have created will be made available through a website that will better disseminate research and good practice, and also give people

with intellectual disabilities the chance to share their perspectives through video and blogs.

Targetted resources for council on how to better engage with people with intellectual disabilities in their community— such as FAQs, guidelines, and 'top-tips'—will be available in June 2020.

5.2 Impact

For Phillippa and the team, the process behind *My Home My Community*—engaging with people with intellectual disabilities directly, as well as involving a variety of stakeholders from councils to disability advocates and the CID—has an impact beyond the immediately obvious.

"We are often asked what is 'best practice'? We have been open to developing this through continuous discussions and reflection with the team. It is the team environment that is building my understanding of best practice. We continue to learn by doing, through projects like this and the people we are working with," she says.

It is still too early to say what the long-term impacts of *My Home My Community* will be but, according to Phillippa, the ultimate aim is a more inclusive community—for everyone.

Honorary research associate, Aine Healy, who has brought her experience in advocacy and knowledge translation to the project, explains, "Inclusion is everyone's responsibility. Being able to bring together lots of ideas, tips, stories, policies, evidence and good will has really helped people understand just how they can help make inclusion a reality."

6. **What has helped you accomplish this work?**

"The networks that have been developed as part of My Home My Community have been fundamental to its success," says Phillippa. "Particularly those with the CID and Local Government NSW."

The small but tight-knit UTS team—comprised of Phillippa, Jack Kelly, Aine Healy, Catherine Donnelley, Megan Taylor and Kiri Weller—has also been vital.

As Phillippa explains, "Everyone in this team are activists in their own way. They've all brought their own expertise and knowledge, as well as different levels of lived experience, and life experiences more generally. I think one of the big things for the university, and for me, is employing people with lived experience of intellectual disability on the team. People often ask if that's been the trickiest bit and I always say, 'No actually, that's been the best bit.'"

7. Challenges

Overcoming the worry of being a 'perfect' inclusive employer, of getting it right first off, and accepting that inclusive practice can be an evolving concept, has required ongoing effort, according to Phillippa.

"When we initially got the grant, I was talking about it using the words 'co-design' and then one of the team members rightly asked 'is this really co-design if you didn't have anyone involved with lived experience when developing the grant?'. We didn't and 'co-design' is an often mis-used term. But if you realise halfway down the track that you could have done something better, you can't go back to the beginning. What you can do instead is think about how you can do things differently hereon in – and what language you use to accurately describe your practice. This kind of work, [whether you're a council or a university], has got to be flexible and it's got to meet people where they're at," she says.

"My message to other employers and researchers is that you don't have to be perfect at this. Our team are always happy to share what we have learnt with others. There's value in the fact that we're on the road to improving inclusive practices, we are aware and we're having a go. We're doing it as well as we can and we're sharing what we've learned. That's what really matters and it has never been more important than now."