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How do self-advocates use community development to change attitudes to disability?

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Abstract

Background: Negative attitudes remain a major barrier to the equality of people with disability, especially when coupled with the lack of autonomy imposed on many people. This paper analyses how disability self-advocacy groups seek to change community attitudes and work towards systemic change by mobilising knowledge from their lived experience.

Methods: The paper applies a cycle of praxis community development approach (a cycle of experience, learning and reflection, synthesis and planning, and implementation and review) to conceptualise and analyse their activities. The methods were a desktop document search, focus groups and reflective analysis with members of two self-advocacy groups.

Findings: A synthesised data analysis found that applying the four-part community development framework was useful to understand the practice and the purpose of work by self-advocacy groups to change attitudes. The analysis also demonstrates the benefits for advocates and codesigned activities to intentionally apply the cycle of praxis model to guide their future efforts to change attitudes.

Conclusions: The research provides evidence that self-advocacy groups achieve sustained impacts on attitudes in the community, beyond the direct benefit to their members. Government investment in self-advocacy has potential to leverage wider system change in attitudes to achieve policy goals for the rights of people with disability. Methodologically, the research also has implications for the benefit of inclusive roles in reflective analysis to understand the lived experience of how practices contribute to system change. The design is an opportunity for inclusive researchers to intentionally incorporate reflective analysis into research processes.

KEYWORDS
changing attitudes, community development, cycle of praxis, disability, lived experience, self-advocacy

1 | INTRODUCTION

Negative attitudes remain a major barrier to the equality of people with intellectual disability,[1] and these negative attitudes are particularly egregious when coupled with the lack of autonomy many people experience. Increasingly, disability practice draws on codesign models and participatory approaches to enact change and improve access, inclusion and participation for people with disability in the community. The important role of self-advocacy groups in making change is well acknowledged. The ways that they mobilise this knowledge from lived experience to work towards broad systemic change, such as shifting attitudes, is less explored. Our team of academic researchers worked with self-advocates to find out more about this and wrote this paper about our work together. This paper addresses the research question: how do self-advocacy groups work to change community attitudes?

2 | BACKGROUND

We make the case for changing attitudes through a lens of human rights and self-advocacy, using a community development approach called the cycle of praxis (Peterson, 2018) to frame how self-advocacy groups facilitate and enact change in community attitudes.

2.1 | Attitudes and the case for attitude change

Attitudes impact on and shape our everyday experiences and behaviours. The understanding we adopt in this article is that attitudes are learned negative or positive responses or evaluations that determine and reflect how we interact or engage with (behave toward) others and different situations (Fazio, 1989). While attitudes are held by individual people they are also 'formed, reinforced and experienced at a community level' (Fisher & Purcal, 2017, p. 162) and, we argue, at a societal level. Many social attitudes are formed through misconceptions or a lack of awareness and are often perpetuated through negative stereotypes (Bolt, 2014, p. 1). Behaviours from negative attitudes range from indirect discrimination to outright vilification and abuse. Negative attitudes can have significant impacts on the lives of people with disability and are major barriers to their participation, equality and the fulfilment of their human rights (Fisher & Purcal, 2017).

Although legislation has progressed internationally to prevent the exclusion, abuse and oppression that people with disability face, negative and discriminatory attitudes remain pervasive and ingrained (Lawson & Beckett, 2021). Ultimately, attitudinal change corresponding with changes in policy and law is needed (Bolt, 2014). Changing attitudes towards people with disability is critical to challenging the socially created disadvantage and marginalisation they experience.

Attitude change takes place at different levels and through policy and interventions (Heijnders & Van Der Meij, 2006; Michie et al., 2021). The levels of change are the individual (personal level); relationships between people (interpersonal level); the organisation (organisational level); the community (community level); and the government or governmental structures; and the multilevel approach—where change is effected through more than one level of engagement. Implementing and sustaining change requires action and focus across all levels (Idle et al., 2022).

2.2 | Human rights model of disability

One way to understand the need to change attitudes is through a human rights model of disability. This model, which we adopt in this paper, focuses on equality and rights and makes evident the role of government, legislation and law to ensure people with disability have the same realisation of their rights as other citizens. A strength of the human rights model articulated in the United Nations (UN) Convention on the Rights of Persons with Disabilities (United Nations, 2006) is in the claim to rights for all people, 'regardless of their particular health or body status' (Fazio, 1989). The human rights model aligns with the social model of disability, which understands disability as the interaction between people living with impairments and environments filled with physical, attitudinal, communication and social barriers, which may 'hinder their full and effective participation in society on an equal basis with others' (United Nations, 2006, Preamble [e]). The social model points to the social production of inequality and injustice. Social production means that change is possible, as people are disabled by social barriers rather than by their impairments or differences (Shakespeare, 2014).

2.3 | Self-advocacy

Realising the rights of people with disability is one of the purposes of self-advocacy. The concept of self-advocacy encompasses individual and group resistance to oppression. It also describes a broader social movement led by people with disability (Petri et al., 2017). Self-advocacy is practised by organisations and groups and navigated by individuals in different forms. 'Self-advocacy is about speaking up for oneself' (Chapman & Tilley, 2013, p. 257). Self-advocacy is focused on the pursuit of social change and the attainment of rights (Chapman & Tilley, 2013). Goodley has argued that the 'emergence of a self-advocacy movement for people with disability was heavily influenced by the social model of disability', which invites the inclusion of self-advocacy and promotes self-determination and self-empowerment of people with disability (Goodley, 1997, p. 373).

Self-advocacy groups counter the everyday exclusion and oppression experienced by people with disability, who 'have lower rates of workforce participation, poorer health and wellbeing, lower levels of participation and higher rates of poverty' (Bigby & Frawley, p. 254) compared to the general population. For people with

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[1]'People with intellectual disability' is the preferred community and policy term adopted in Australia, where this research was conducted.

intellectual disability, self-advocacy encourages participation in broader society, and often involves activities, political action, skills development, research and social networks (Chapman & Tilley, 2013). Self-advocacy groups also act as important places for people with disability to gather and share their life experiences and raise awareness of common issues that they face. To promote inclusion in society, many self-advocacy groups focus on change around negative attitudes which are known barriers to fulfilling their human rights. Addressed through the social model of disability, the practice of self-advocacy acknowledges 'a shared experience of disablement through exclusionary societal structures, attitudes and practices' and unleashes 'a shared commitment to resistance and social change' (Fazio, 1989).

The trajectory through which self-advocacy developed in Australia coincides with its prominence rising in countries such as the United States and the United Kingdom in the 1980s (Buchanan & Walmsley, 2006), although with the significant limitations of receiving less financial support. Although self-advocacy groups have successfully managed to advocate for meaningful change, Australia still favours a model of advocacy that involves allies speaking up on behalf of people with disability, rather than supporting people with disability to speak up for themselves. Further issues remain prominent in the realm of self-advocacy within Australia. As self-advocates continue to work closely with their supporters, issues of power imbalance arise as support can easily veer into control (Chapman & Tilley, 2013). One way self-advocacy organisations and groups address these concerns is through the application of the model of community development, as we demonstrate in this study. The process of community development is a mechanism of social change (Lawson & Beckett, 2021), and as such has the potential to influence communities and facilitate broader systemic change in society.

2.4 | Self-advocacy and community development

While programmatic approaches to self-advocacy can be reductive due to the pressures of funding requirements and emphasis on delivery outcomes, self-advocacy organisations focused on the building of community are founded in recognition and a shared commitment to 'social justice, equality, and community responsibility' (Fisher & Purcal, 2017).

Disability self-advocacy groups enact change by sharing their personal experiences of exclusion, oppression and injustices to create solidarity and suggest action to respond to their shared experiences. They focus on shared goals (human rights), participation (Michie et al., 2021), voice and agency.

2.5 | Community

Self-advocacy can be a way of forming or challenging communities. The concept of community is much debated. Historically, scholars have proposed that community is formed with others with shared values or beliefs (Bradshaw, 2013, p. 17), or between those in close physical proximity (locality). However, shared values and beliefs can lead to problems of exclusion, lack of political voice and discrimination. In the 21st century, community is no longer bound by geographic locality, and instead might be grounded in virtual worlds (6). Community can also be defined through engagement with others in 'networks of affective laden relationships' (Etzioni, 1996, p. 127). Community is formed in encounters between and with each other, whereby positive community building is grounded in recognition and respect, mutual care and responsibility, sharing common identity (Bhattacharyya, 2004), and a sense of solidarity and belonging.

2.6 | Community development and the cycle of praxis

The concept of community development provides a way to understand how the actions of self-advocacy groups bring about change in wider communities. Community development is a broad field, and operates on the 'basis of a commitment to social justice, social equality and the principles of universal human rights' (Kenny et al., 2017, p. xxiv), underpinned, according to Bhattacharyya, by the three principles of 'self-help, felt needs, and participation', as the foundations of 'solidarity and agency' (Bhattacharyya, 2004, p. 5).

In this paper, we seek to understand community development as a method used by self-advocacy groups to facilitate and enact change in community attitudes. One method for realising community development is through the cycle of praxis, where actions are conducted by 'intentional reflection, mindful action and the willingness to learn from ongoing reflection' in a cyclical approach (Peterson et al., 2020, p. 19).

The cycle of praxis is a new framing of community development, applied in both research and practice contexts as a way to prioritise lived experience as a catalyst for change. Its authors note 'reflection on the values behind a given approach becomes *praxis* when that reflection intentionally interacts with action to create new knowledge —including a new understanding of a group or individual's capacity and self-story (2020, p. 12).' The underlying assumptions of the cycle of praxis are that change requires knowledge of lived experience, ongoing action and reflection, and that outcomes for stakeholders matter (Peterson, 2018).

The cycle of praxis for community development is centred on people's lived experience (Peterson, 2018) and is a process of making sense of and choosing our responses to our own experience (Peterson et al., 2020, p. 19). Lived experience determines the felt needs of the community and acts as the insertion point into the cycle (Figure 1).

The cycle of praxis has four areas of focus:

- Experience—lived experience and felt need, paying attention to and inviting voices of those whose experience is missing

THE CYCLE OF PRAXIS
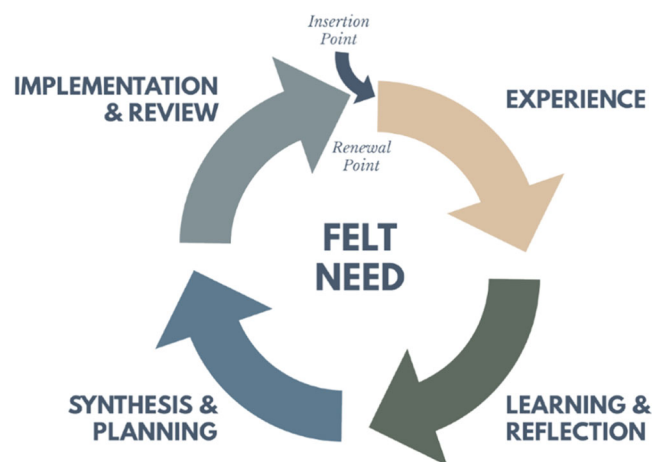### for community development

FIGURE 1 The cycle of praxis for community development (Peterson, 2018).

- Learning and Reflection—learning from others' experiences, reflecting on understanding and generating new ideas
- Synthesis and Planning—recognising insights from what we have learned and shaping strategic action based on that knowledge, and in response to the felt need
- Implementation and Review—implementation through direct action, addressing the problem in a meaningful way for the person and the community

We apply the cycle of praxis model to the research question: how do self-advocacy organisations work to change attitudes to disability? In this way, we are able to examine whether applying a community development framework contributes to understanding how self-advocacy organisations change community attitudes about disability.

2.7 | Changing community attitudes to improve inclusion for people with disability study

Data for this paper are drawn from fieldwork conducted for a study into changing community attitudes to improve inclusion for people with disability commissioned by the Australian Disability Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disabilities in 2021–2022.

The *Changing Community Attitudes* study comprised an evidence review and qualitative research (fieldwork interviews and focus groups). The evidence review adopted a scoping approach to draw together the literature on good practice in policy to change attitudes (published elsewhere). The review outlined the levels for change, the

types of policy, and interventions, synthesised across the six disability strategy areas (Department of Social Security, 2021; Idle et al., 2022)

A purposive sample of people with expertise on the topic were invited to participate in qualitative focus groups and interviews, which were conducted with participants based on their role in advocacy ($n = 21$), community ($n = 22$), business ($n = 2$), government ($n = 12$) or academic work ($n = 3$). Interviews were adjusted to be accessible for people with intellectual disability with easy read support material and interview questions. Fieldwork focused on understanding the intersections of lived experience of disability with positive practice and the conditions needed to create positive change.

Data from the study were analysed using the framework developed in the evidence review, which identified ways attitude change takes place at different levels and through policy and interventions, across the levels of intervention (personal, inter-personal, community, organisational and government). The results from the study are published elsewhere. This paper is further analysis of the self-advocacy data only.

3 | METHOD

Preliminary analysis of fieldwork findings in the broader research study highlighted how self-advocacy organisations function as producers of change. In particular, we were struck by their community development approaches. These observations led to additional analysis of the data with advocacy organisations.

In this paper, we consider two case studies of self-advocacy organisations to explore how self-advocacy groups work to change community attitudes towards people with disability and work towards systemic change by mobilising knowledge from their lived experience. The two case studies are of self-advocacy organisations the South Australian Council for Intellectual Disability (SACID) and Queenslanders with Disability Network (QDN). Ethics approval was from UNSW Sydney (HC210533) and Flinders University (ref. 4772). The organisations agreed to be named in this article. Quotes from participants in this article are anonymised with pseudonyms where people prefer.

3.1 | Analysis of existing fieldwork data using the cycle of praxis

The second round of analysis focused on the two self-advocacy organisations and considered the data against the four parts of the Cycle of Praxis, to understand how these organisations use a community development approach, and why a community development approach is useful for changing attitudes (how these organisations did or would change attitudes). Already transcribed data was recoded by author one and moderated by author two, coding deductively by using the cycle of praxis as an organising frame. Researcher discussions among the academic team drew out themes

from the coded data. These preliminary themes were then translated into easy English and discussed with the self-advocacy groups, as described below.

3.2 | Additional fieldwork to verify and deepen understanding of the analysis

Following preliminary analysis, a member of the research team returned to participants from the two case study organisations (n = 8) to conduct further fieldwork to increase our understanding of their community development approach for generating change. Easy-English summary materials of the analysis were prepared to support discussion with the group. In the second (in-person) focus group, participants were asked to consider the roles and activities of key staff and how they thought their work affected change. Consultation was conducted via email with the second self-advocacy organisation due to location and time constraints at the organisation. Members of the organisation discussed the questions among their team, using inclusive approaches. The research team transcribed, coded and reviewed the analysed data from the second set of fieldwork together with that from the previous stage, using the cycle of praxis framework as an organising frame. We then checked about the results of this analysis discussion with the groups afterwards to confirm everyone's agreement.

3.3 | Description of self-advocacy organisation participants

3.3.1 | QDN

QDN is a Queensland state-wide organisation for people with diverse disabilities, including many people with cognitive disabilities. Their work is focused on disability rights and advocacy and is a network of around 30 peer support groups, which 'inform, connect, lead, and influence change' (QDN). The focus of the work done by QDN privileges people's experiences and need. Importantly, self-help, felt need and participation are built into the QDN advocacy framework. Examples include how QDN develops peer relationships within communities that reflect the experiences of that community, is involved in 'building capacity', works with local 'felt need' and is founded on participation.

3.3.2 | South Australian Council on Intellectual Disability (SACID)

SACID was established to represent and advocate for people with intellectual disability living in South Australia. It 'works towards achieving a community in which people with intellectual disability are involved and accepted as equal participating members' (SACID). Sixteen peer educators (inclusion advisors) who are people with

intellectual disability are employed at SACID in paid roles. SACID runs workshops for people with intellectual disability around issues that are of interest and concern to their community and interested members of the public. These workshops are designed by peer educators with support and revolve around issues such as decision making, safety, and healthy minds. Workshops are conducted with inclusion advisors, who describe their role as teaching others how to talk about these issues and some administration.

3.4 | Participant codesign in analysis and writing

In the final step, the research team returned to the self-advocacy group participants to discuss the findings in this draught article, which were presented in plain English for discussion, clarification, correction and further analysis. Self-advocates were involved in draughting the plain English figures in this article, contributed to the discussion and added important depth to the team's understanding of the cycle of praxis. Both groups will be involved in developing an accessible summary for wide distribution.

Limitations of the study were that the initial parts of the research did not include the self-advocacy groups, except as participants. Their role in reflective analysis for this paper was more active in applying the cycle of praxis and helping the academic team to think more deeply and carefully about how it could apply to real-life contexts. Further research could continue the cycle of reflection with other self-advocacy groups to explore the question further.

4 | RESULTS

In this section, we detail how the work of the two organisations can be understood as focusing on community development to change community attitudes to people with disability. We use the four stages of the cycle of praxis for community development as our analytic lens: experience, learning and reflection, synthesis and planning, and implementation and review (Peterson, 2018).

All quoted findings have been reviewed by the participating organisations. The plain English text discussed with self-advocacy participants is included at the beginning of each findings section. This text has been reviewed by research participants from one of the organisations who felt that these descriptions accurately represented their work and participation. This text illustrates the key critical ideas of community development practices employed to make change (Figure 2).

4.1 | Experience

The first stage in the cycle of praxis is experience, and both self-advocacy organisations, QDN and SACID drew on the experiences of people with disability and their families and communities to inform their work. A key assumption within the Cycle of Praxis model is that
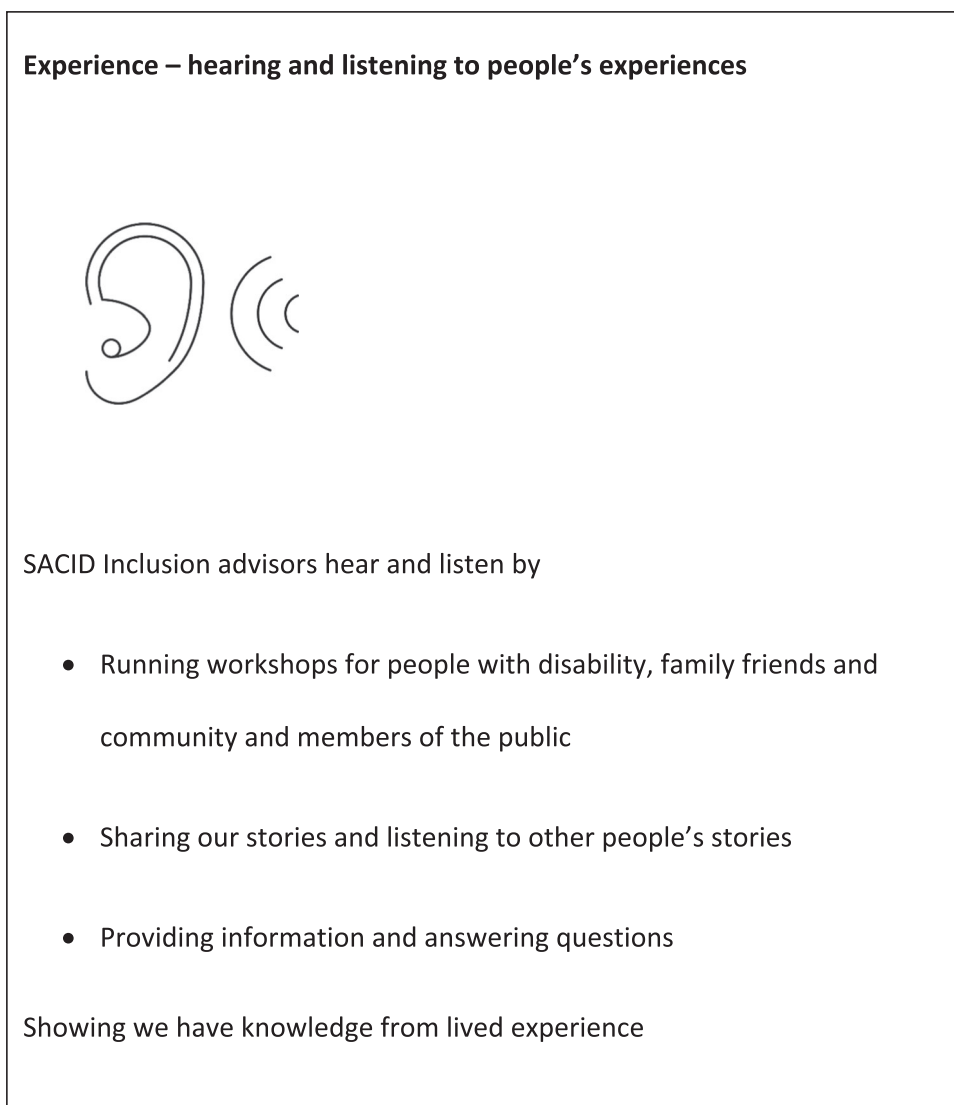
Experience – hearing and listening to people's experiences

SACID Inclusion advisors hear and listen by

- Running workshops for people with disability, family friends and community and members of the public

- Sharing our stories and listening to other people's stories

- Providing information and answering questions

Showing we have knowledge from lived experience

FIGURE 2 Experience–hearing and listening to people's experiences.

people who are experiencing challenges are best placed to articulate their felt need (Peterson et al., 2020, p. 3).

4.2 | Storytelling and lived experience

In both case studies, QDN and SACID actions to address attitudinal change were driven by people directly impacted by the issue. This approach is evident in how they conducted their work. QDN codesign principles and networks are built on lived experience as a foundation (QDN). Paige from QDN explained that:

> Whatever the attitudinal change is targeting, then 'the target group', 'the end product', 'the customer', whoever is going to be the most impacted by this needs to be front and centre and involved in designing

what the approach will look like and how they think that will work.

In their role in the development and presentation of SACID workshops, inclusion advisors also drew on lived experience to inform other people. The inclusion advisors explained that the focus of change should address their priorities and that their voices and the range of different voices of people with disability must be at the centre. Several participants described how listening to and speaking from lived experience helps them understand the diversity of people's experiences. Tim said it was valuable to:

> … hear the information from someone who has a disability, [and they] can explain how or what it is to live with a disability.

Both QDN and SACID are founded on ensuring that diverse voices from people with disability are heard, acknowledged and instrumental in the focus of, and drive for, any change. Ruby, an inclusion advisor, explained that although many people may have similar disabilities, people's experiences are different:

> Everybody's experience is different—totally different to everyone in this room—[and these differences can] open up a new conversation.

4.3 | Peer led

Peer leadership is another cornerstone in both case studies. The example from QDN illustrates how as an organisation working across a large geographic area, local peer knowledge helps to establish what needs to be changed and who needs to be part of the conversation. Local peer led action ensures that priorities of each community are the focus of change in that location. QDN staff also described their position as outsiders coming into a community to work with people and how they do that through locally based networks:

> if we're talking about say a locational community like a town in Far North Queensland, what we've done is we have made sure that we've identified and located a person with disability, and we actually connect through them and ask them who we should be speaking to in a local community.

> We would then be trying to organise what we call a community conversation, … where we will invite anyone, but we particularly target local councils, local government mainstream agencies that may be in these places and any of the other broad-brush organisations.

SACID inclusion advisors use their experience to support others to learn about issues that affect them. One inclusion advisor, Alice, talked about how their Staying Safe workshop series supported people with intellectual disability:

> [we] got about 351 people with ID to come—part of that was having my friends, I can teach them how to be safe out in community, and what is around them too.

Several participants thought that hearing information through other people's experience helped them to understand different ideas and situations.

Both organisations use a reflective and intentional approach of learning from diverse lived experiences to change the attitudes and behaviour of other community members. Storytelling used in this way is a form of community participation and community building, and a method for 'understanding sense making' and action in community development (Shakespeare, 2014) (Figure 3).

4.4 | Learning and reflection

As part of the learning and reflection stage of the community development approach, recognition of people's agency or self-help, felt need and participation were evident in both QDN and SACID's work.

4.5 | Working in a team

SACID inclusion advisors talked about what it meant to be an inclusion advisor and their working process. They explained that they learned alongside each other in their team, worked and supported each other. One advisor, Ruby, explained how relationships affected their participation:

> We work as a team, with people I know and who care about me. We are a family.

Inclusion advisors said they looked out for each other, with the coordinator's support. Several participants talked about how it was important that the work environment felt safe. Rose said:

> [it] was really important to me that when it came to a job to not feel isolated and discriminated, and I don't feel that here.

Ruby explained the team worked to build each other's success and participation:

> Having someone who helps you when you are having a hard time [helps]. How they support you. 'This happened, but how can we help you get past that?'

By contrast, one inclusion advisor described how things had been different for her in other situations, such as being bullied at school. She stated her frustration about inaction by authorities about inclusion. Ruby described what it meant to her to have effective support and rights, and the impact where these are withheld or not available:

> If you can't support me the way that I need it, then why am I even here … doesn't make sense to me.

4.6 | Listening across difference

At QDN any approach to implement or support change begins with locally based knowledge and collaboration. QDN works with a set of principles that detail how they use codesign to support people with disability in their communities and work toward positive change, centred around 'authentic voice, collaborative action, rights, respect and resilience' (QDN, p. 4). Prioritising hearing and valuing diverse voices, they 'work together to learn from the collective wisdom, values and experience', to ensure 'those with limited or no voice are heard and valued' (p. 9). A QDN participant said:

Learning and reflecting on what we heard

It is important to

- Work as a team

- Understand, trust and help each other

- Know your rights

- Have support for decision making

- Take time to think about and speak about things

- Listen to people with disability – all experiences are different

- Not take it personally

FIGURE 3 Learning and reflecting on what we heard.

... it's been really important that we involve people with disability in looking at what the solution needs to be, along with the other key stakeholders, from the beginning, that we're actually using ... the stories based on people's lived experiences to actually create a different level of understanding and awareness amongst people.

In this way, the organisation systematically drew through experience into their learning and reflection processes to amplify opportunities to influence attitude change in the community. In one example, QDN described learning and reflecting on the diversity of lived experience for people who experienced housing insecurity or homelessness. In another programme they supported people to access disability support (NDIS) and explained how they specifically sought to include multiple and varied voices.

We've specifically got people who are part of the group of peer facilitators [about access to disability support] who have been homeless, who have been part of the Criminal Justice System, who are living in community housing at the moment, who have had those issues maybe from a gay, lesbian, transgender background and be of Aboriginal and Islander background, to actually tell the story about their life.

Further, they explained QDN engaged in local knowledge and local expertise as part of the learning and reflection. They listened to define what the local issue was and how they might address local priorities (Figure 4). A manager said:

We call for local leaders in communities. They can be people with disability but we want to make sure that they are embedded and respected within their community wherever possible as a leader to start with ... and if we're trying to focus on particular cultural backgrounds, then we would make sure that ... any work with that group

Putting together all the information and planning ahead

- We collect information, have the right support, and time to make

  change

- Know your rights

- Know the steps for making change

- Make your own decisions based on the information you know

FIGURE 4 Putting together all the information and planning ahead.

would need to be totally respectful of the different cultural values. ... What are some of the cultural norms? who do you seek permission from to go into a particular community? who are you going to work with? who are your group? How are Elders or seniors defined in different communities? And again, having that conversation about what might be the best approach.

4.7 | Synthesis and planning

The third stage of the community development cycle of praxis—synthesis and planning—is illustrated through ways the organisations structured approaches to make change and influence attitudes. In this stage, self-advocacy organisations had identified an issue for intervention, listened and learned from lived experience, at the personal and interpersonal, organisational or community levels. The self-advocates have scaffolded this knowledge to both resonate at a personal level and meet strategic policy goals. The examples are from national to local and specific campaigns.

4.8 | Taking steps to make change

QDN described their participation in national campaigns where they had worked with other organisations and the community, which led

to addressing a felt need and making change. The Building Better Homes Campaign was designed to improve building accessibility through embedding it into building codes. The campaign relied on participation across the QDN network, from state-wide community connections and working with peer groups at a local level, to pressure federal and state government decision makers to change the National Construction Code. At the time of writing, five Australian states and territories including Queensland had signed on to the Code (Building Better Homes Campaign, 2022). A manager said:

> we were one of the organisations ... to actually help ... introduce a mandatory accessibility standard into the building code and to have it legislated.

Paige explained that to bring about change, QDN employed their existing peer networks and skills and lobbied:

> We were able to get members of our local groups to actually target federal politicians up here who were fence-sitting, as well as the state government ... And a number of our peer group members and leaders in marginal seats actually went and made appointments ... those conversations would not have been held had they not believed it was important to get the change because everyone knew the issue. But also having confidence and knowledge and skills to be able to feel

comfortable, to sit with a politician and say, 'Hey mate, this needs to change for these reasons'.

4.9 | Learning from experience and planning for change

At the individual and interpersonal level, many SACID workshops focus on the needs of people with intellectual disability and support them to make change. This requires resources, information and effective support. Some self-advocates changed their own attitudes and behaviour after being exposed to experience, learning and reflection. Through their work and advocacy, they focused on changing the attitudes of other people.

One inclusion advisor described his experience around planning to change jobs. Gavin had work through a disability employment service and was keen to move to a new job. He told us, 'how hard it was' and that because of 'steps you have to do, it was easier to stay there'. He was also told by the disability employment service that 'If you leave you won't get another job'. He explained that the self-advocacy organisation helped him to plan for change. The process involved gathering information, understanding his rights, accessing support, gaining knowledge around decision making and going through the steps to make the transition. Gavin now draws on his experience to support other people to make changes.

4.10 | Knowing your rights, sharing information

Providing information, training and skills to communities and to people with disability are at the centre of SACID's workshop programme. They conduct community workshops, such as the disability awareness and inclusion workshop for medical and allied health professionals (SACID), share information at expos, and offer workshops around rights, safety, relationships and NDIS planning. Inclusion advisors participate in expos by sharing information and promoting SACID workshops. Sharing individual experiences in workshops has ripple effects on people's families and the broader community. Their work has effects on others in creating change (Figure 5). Alice, an inclusion advisor, said:

> It's important that we are people with disability – people relate to our lives because they can see themselves. If we can do it, they can do it too.

5 | IMPLEMENTATION AND REVIEW

5.1 | Active participants in change making

QDN has been active across Queensland to change attitudes. They said they are able to make change because they work at multiple levels of engagement from the personal to the organisational and structural. Regarding the campaign to adopt the National Disability Insurance Scheme, a QDN manager explained:

> I suppose that our lived experience over many years has been that in order to get those kinds of attitudinal changes that we've wanted, there has had to be intervention across a range of levels... we've needed to have some kind of high-level human rights or legislative base.

The voices and presence of people with disability in the implementation and review of any change brought visibility and authority. QDN's Paige said:

> you need to make sure that you are also building that capacity and the confidence of the very people that are this so-called disempowered end product to feel confident, to have the conversations that need to be held, whether it's with the neighbour next door, whether it's with the shop owner, the local politician, whether it's with the international change maker.

5.2 | How do we know if it's working?

Inclusion advisors told us many personal stories of how self-advocacy has made positive change in their own lives. One inclusion advisor observed, when asked about how SACID workshops might effect change, 'you can just see it in people, you can see it in the outcomes and in what we do'. Rose described her experience following her diagnosis with disability: '[I] can definitely say they have helped me a lot about knowing my rights and what I am entitled to' and she developed confidence, 'we can do anything even if we have a disability'. Inclusion advisors connected implementation and review to the impact of their own work. They also reflected collectively about how their work was changing attitudes in the community, thinking about the numbers of people who were exposed to their work, and impact measures such as evaluation and peer review.

Self-advocacy is underpinned by rights in the work of both QDN and SACID. QDN explained that while some change may appear small, any positive change can have significant impact on the dignity and wellbeing of people with disability. It is possible to see the impact of these small changes. The manager said:

> Some of our groups have run campaigns just simply to make sure [people] can get their money out of a bank. Sometimes they can't get to the local pharmacy ... and it is the only one in town ... and it's not accessible.

To get those changes, you're changing community attitudes, you're changing individual businesses' attitudes, [and] what we find is, it's so important that you've got some support within the broad community to start with.

Implementing change and reviewing it to see if it worked

- Need the right support, resources, others who believe in you and believe in yourself

- A good workplace is where people support each other – people believe in each other

- Observe other people and their achievements

- Active in making change and supporting the rights of people with disability

FIGURE 5 Implementing change and reviewing it to see if it worked.

6 | DISCUSSION

The research addressed the question of how self-advocacy organisations change attitudes about disability through their work. We applied a community development approach as a conceptual and analytic lens, with the four stages of the cycle of praxis: experience, learning and reflection, synthesis and planning, and implementation and review (Peterson et al., 2020). We applied that approach because self-advocacy groups usually work from a personal experience level, which sometimes also influences other local and national levels of social interaction (Henderson & Bigby, 2016). If self-advocacy groups intentionally leverage from personal to other levels, their work has the potential to not only change the lives of the people involved, but also to change community attitudes (Chapman & Tilley, 2013, p. 4).

The synthesised analysis of data about the activities of the self-advocacy groups to change attitudes found that the work of these groups could be understood through a community development lens. The data were from an evidence review, national interviews and reflective analysis with two advocacy groups. Analysing the data with the cycle of praxis framework was a way to document the practice and the purpose of the attitude change work by the self-advocacy groups. Members of the groups drew from their own experiences, and as a group they reflected on their experiences to inform new work. These reflections came from past negative experiences and positive changes from the self-advocacy work they were involved in. They intentionally worked from these reflections to extend their cycle of work beyond their individual experiences. The extensions included building social networks with other people with shared experiences and local social leaders, as well as beyond to other

communities and national influence. These networks became platforms for personal and community change, including policy change that reinforced further attitude change (Building Better Homes Campaign, 2022).

These findings reflect the cycle of praxis framework as a way to understand how self-advocacy can be effective to change community attitudes to disability. The novelty is demonstrating how the framework informs understanding about how the work of self-advocacy contributes to strategies to change attitudes. The research has implications for policy, practice, theory and methods, as outlined below.

The findings have implications for policy about changing attitudes and the contribution of self-advocacy to that goal. The second iteration of Australia's Disability Strategy (2021–2031) to implement the UNCRPD added an additional outcome of changing attitudes across the other six outcome cares, such was the urgency of attitude change highlighted by the disability community. The evidence on effective policy to change attitudes emphasises the need to take a systems approach (Brzykcy & Boehm, 2021, p. 7) and build from the leadership and lived experience of people with disability (Fisher & Purcal, 2017; Petri et al., 2020). This research found that self-advocacy groups are adopting approaches to changing attitudes that are consistent with that evidence about effectiveness. An implication for policy is that further government investment to support self-advocacy at personal and system levels has potential to leverage wider system change in attitudes that influence the way large systems operate, such as funding personalisation (Meltzer et al., 2021).

These findings also contribute to theory about how to change attitudes through policy and practice. Current theory of attitude change emphasises the need for multilevel interventions to effect change (Kenny et al., 2017; Perloff, 2017). Our findings not only reinforce that theory, but also demonstrate how grassroots action can operationalise it. The structure of self-advocacy groups necessarily means that they work from the personal perspective. But by taking a community development approach to their work, they can target community and national impact on attitudes. This combination of advocacy types is common to recent strategies of advocacy organisations (Bigby & Frawley, 2015) as they navigate government policy and funding changes.

This research also has implications for the way that self-advocacy groups operate and prioritise their activities (Bigby & Frawley, 2015; Chapman & Tilley, 2013). Adopting the cycle of praxis to guide operations could be useful for self-advocacy groups that intend to influence changes beyond the lives of their own members. This research retrospectively interpreted the work of two self-advocacy groups through reflective practice with these groups. A more direct practice would be for self-advocacy groups to use the framework to guide their work. A direct application could build from their current practice and inform new steps and directions to achieve change for themselves and sustained impacts on attitudes in the community.

This research also contributes to community development theories (Kenny et al., 2017). The application of the cycle of praxis to understand current practice was a useful tool for the self-advocacy groups. This is a novel application because it was used as a reflective tool to understand what they have intuitively done, rather than a framework to guide practice (Peterson et al., 2020). The finding was that the four parts of the cycle reflected how they worked. The research process illustrates how such frameworks can be applied in unexpected ways for reflection, research and to guide future practice change. More generally, the analysis also demonstrated the value of the cycle of praxis model for guiding future efforts to change attitudes, not only by self-advocacy groups, but also other community and government organisations (Idle et al., 2022).

The unusual research design offers potential for inclusive researchers to plan for critical reflection by people with intellectual disability (Carnemolla et al., 2022; Milner & Frawley, 2019). The need for further reflective research emerged from a government-commissioned research project (Idle et al., 2022), where the self-advocates began as participants in that project. The preliminary results demonstrated that a more inclusive role in reflective analysis was required to understand how self-advocacy groups were contributing to attitude change. This emergent design is an opportunity for inclusive researchers to anticipate reflective moments and intentionally incorporate them into research processes earlier. It is important to our group that we use the work we have done together here to develop an accessible paper targeted to people with intellectual disability to promote these ideas widely.

7 | CONCLUSION

The findings of this analysis demonstrate how the practices of disability self-advocacy groups can help to change community attitudes towards people with disability. Applying a cycle of praxis community development approach to analyse their activities reveals that they contribute to systemic changes through mobilising their knowledge from their lived experience. The analysis found that applying the four-part community development framework was a useful way to understand the practice and the purpose of work by self-advocacy groups, and the avenues they have to change attitudes. The analysis also demonstrates the value of the cycle of praxis model for guiding future efforts to change attitudes. Government investment in self-advocacy would have potential to leverage wider system change in attitudes.

AUTHOR CONTRIBUTIONS

CONFLICT OF INTEREST STATEMENT

The authors declare no conflict of interest.

DATA AVAILABILITY STATEMENT

Data and materials are available at https://disability.royalcommission. gov.au/publications/changing-community-attitudes-improve-inclusion-people-disability.

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