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Voices of change: bridging past and present in disability self-advocacy

Linda Steele^a, Phillippa Carnemolla^b, Leonie Mclean^c, Laura Naing^c,
Jemima Macdonald^c and Jonathon Kelleher^c

^aFaculty of Law, University of Technology Sydney, Sydney, Australia; ^bFaculty of Design and Society, University of Technology Sydney, Sydney, Australia; ^cThe New South Wales Council for Intellectual Disability, Surry Hills, Australia

ABSTRACT

The disability self-advocacy movement emerged and grew through campaigns for governments to close disability institutions and support independent living and community participation for people with intellectual disability. Although there are individual and organisational histories of the self-advocacy movement, not all younger self-advocates have deep knowledge of this history. This article presents findings from a collaborative research project on opportunities for intergenerational learning on self-advocacy. We argue that intergenerational learning and public recognition of the history of the self-advocacy movement is central to acknowledging the significant contributions of self-advocates, learning from their work and stopping repetition of past injustices. Learning and recognition must be reflective and open processes informed by diverse experiences and understandings of disability institutions and self-advocacy.

POINTS OF INTEREST

- Self-advocates are people with intellectual disability who speak up for themselves about what is important.
- Self-advocates campaigned to close disability institutions which are big places where many people with disability were made to live.
- Many younger self-advocates today don't know about the work that older self-advocates did to close disability institutions.
- This collaborative research project explored opportunities for younger and newer self-advocates with disability to learn from older and more experienced self-advocates about what they did in the past to close disability institutions.
- The project also looked at ways the wider community can recognise and value what self-advocates did in the past to close disability institutions.

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CONTACT Linda Steele  linda.steele@uts.edu.au

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Introduction

Self-advocacy involves people with intellectual disability 'speak[ing] for themselves about the things that are important to them' (Inclusion International n.d.). The self-advocacy movement emerged through campaigns for governments to close disability institutions and support independent living and community participation (Traustadóttir 2006). Lived experiences of the 'first generation' of self-advocates (Frawley and Bigby 2015) are documented in self-advocate's life stories (McRae 2014; People First New Zealand 2010; Walker 2015) and histories of self-advocacy organisations (Walmsley and The Central England People First History Project Team 2014). Sharing culture and experience within a social movement's community between older and younger activists ('intergenerational learning') is an important dimension of movement building (Bhatia 2023; Cornejo et al. 2021; Edell, Mikel Brown, and Montano 2016), including in the disability context (Chandler et al. 2022; Climaco 2020; Mattlin 2022).

This article presents findings from a collaborative research project exploring opportunities for intergenerational learning in the self-advocacy movement in New South Wales (NSW) Australia. The research was a collaboration between the University Technology Sydney (UTS) and The New South Wales Council for Intellectual Disability (CID). This article is co-authored by members of the research team consisting of two people with intellectual disability (McClean, Naing) and two people without intellectual disability (Macdonald, Kelleher) from CID and two academic researchers from UTS (Carnemolla, Steele). Their roles in the project are elaborated on in the 'Background' and 'Methodology and methods' sections below. The project emerged from earlier research projects together on the significance of the history of disability institutions to contemporary intellectual disability rights (Carnemolla and Steele 2024; Kelly et al. 2024; Steele, Carnemolla, et al. 2023). Through focus groups with self-advocates of differing ages, connections to disability institutions and levels of self-advocacy experience, we explored why learning about the history of self-advocacy is important, what younger self-advocates want to learn, and how this learning might occur. The team produced a series of public-facing and accessible outputs informed by the findings from the focus groups.

We argue intergenerational learning and public recognition of the history of the self-advocacy movement is central to acknowledging the important contribution of self-advocates, learning from their work, and stopping repetition of past injustices. Learning and recognition must be reflective and open processes informed by diverse experiences and understandings of disability institutions and self-advocacy.

This article's exploration of intergenerational learning about the history of self-advocacy is timely. There is widening interest in disability social movement history, such as in the United States of America (USA) (Climaco 2020; Dias and Chadwick 2024; Lebrecht 2020) and Australian contexts

(Hallahan and Flinders University 2021; Royal Commission into Violence, Abuse, and Neglect and Exploitation of People with Disability 2021). There is renewed focus on the role of self-advocates in deinstitutionalisation by reason of the right to independent living in Article 19 of the UN Convention on the Rights of Persons with Disabilities (CRPD) (United Nations Committee on the Rights of Persons with Disabilities 2022). Documenting and making publicly available self-advocacy and deinstitutionalisation history counters erasure of this history through redevelopment of sites of former disability institutions (Carnemolla and Steele 2024). Celebrating and learning from the self-advocacy of first generation self-advocates is increasingly urgent as they are ageing.

The article makes three contributions to scholarship. To disability studies scholarship the article contributes critical reflections on the contemporary significance and application of the history of the disability self-advocacy movement (Buchanan and Walmsley 2006; Carey 2009; Goodley 2000; Traustadóttir 2006; Walmsley and The Central England People First History Project Team 2014) and the complexity of generationality and temporality in understanding the self-advocacy movement (Frawley and Bigby 2015). Second, it provides a nuanced, experientially driven conceptual understanding of 'institutions' and 'self-advocacy' building on critical disability studies scholarship on carceral control and resistance (Ben-Moshe 2020; Ben-Moshe et al. 2014). Third, the article contributes empirical insights on the self-advocacy movement to social movement scholarship, a body of scholarship in which disability occupies a marginal place (Beckett 2006).

We begin by outlining self-advocacy, its role in deinstitutionalisation, and its connection to disability history. This is followed by a broader discussion on public history and intergenerationality in social movements. Next, we present the project methods, key findings and limitations, concluding with implications for disability studies and self-advocacy practice.

Background

Self-advocacy and deinstitutionalisation

Self-advocacy consists of two dimensions: developing skills for individuals with intellectual disability to speak for themselves and campaigning on systemic issues facing people with intellectual disability (Buchanan and Walmsley 2006). Organisations engaged in self-advocacy define the practice as: 'a civil rights movement for people with intellectual disabilities', 'people speaking-up for what they think is important', 'making your case and negotiating for what you want' (SARTAC n.d.) and 'speaking up for our rights, our needs and the things that are important to us' (Advocacy for Inclusion n.d.). Self-advocacy is a mechanism for collective representation

and an individual means of expressing preferences and asserting rights (Buchanan and Walmsley 2006). Self-advocacy provides opportunities for social connection, belonging and building disability identity (Bellon et al. 2025).

Self-advocacy emerged through campaigns for closure of disability institutions and independent living for people with intellectual disability (Buchanan and Walmsley 2006; Carey 2009; Friedman et al. 2020; Goodley 2000; Traustadóttir 2006; Walmsley and The Central England People First History Project Team 2014). Scholars identify 1960s Sweden as the birthplace of the modern self-advocacy movement which soon spread to other nations including Australia (the focus of this article), USA, and the United Kingdom (UK) (Buchanan and Walmsley 2006; Traustadóttir 2006). Self-advocacy now extends to other disability groups including people living with dementia and autistic people (Bryden 2005; Waltz 2023), although this article focuses on the intellectual disability self-advocacy movement.

Self-advocacy practices and histories are diverse and internationally there are a range of different trajectories. Since the emergence of the modern self-advocacy movement, in Australia self-advocates have led efforts to close disability institutions, end disability segregation and progress opportunities for independent living and community inclusion. They have also led activism to enhance opportunities for agency and autonomy in the community – including through supported decision-making and inclusive governance – in resistance to persistent discrimination, paternalism and coercion. However, the rights of people with intellectual disability have not been a linear, progressive journey. Institutionalisation remains a significant international human rights issue despite the CRPD providing for the right to independent living and community participation (Palmisano 2017; Rimmerman 2017; United Nations Committee on the Rights of Persons with Disabilities 2022). In order to advance deinstitutionalisation, the UN Committee on the Rights of Persons with Disabilities (CRPD Committee) calls on governments to engage in truth-telling and memorialisation related to injustices of disability institutions as well as funding self-advocacy organisations (United Nations Committee on the Rights of Persons with Disabilities 2022).

The self-advocacy movement faces enduring political issues in a contemporary 'deinstitutionalised' context. Deinstitutionalisation is an 'unfinished project' (Steele and Punzi 2024) with new institutional settings (e.g. group homes) and other forms of segregation, exclusion and discrimination in the 'deinstitutionalised' community throughout the lifespan (such as segregated schooling, employment and recreation, substitute decision-making and sub-minimum wages) (Spivakovsky et al. 2020). There are enduring tensions between parent advocacy and self-advocacy, with parents both 'allies and obstacles' to the rights of people with intellectual disability (Carey, Block, and Scotch 2020).

History of the New South Wales Council for Intellectual Disability

CID is a New South Wales (Australia) advocacy organisation founded over nearly 70 years ago. One of the primary foci of CID's advocacy during the 1980s and 1990s was deinstitutionalisation (Bigby and Henderson 2018). CID's advocacy now includes aspects of independent living, community inclusion (e.g. employment, inclusive governance), accessible information and health (Bigby and Henderson 2018). CID is a membership organisation with 87% of members being people with intellectual disability. This together with CID's networks means it can work with people with intellectual disability to share their stories which might otherwise be lost. CID remains an important repository of history and lived experiences of advocacy related to deinstitutionalisation.

Our collaborative research

Carnemolla and Steele are engaged in a program of collaborative research with CID on the significance of the history of disability institutions to contemporary intellectual disability rights (Carnemolla and Steele 2024; Steele, Carnemolla, et al. 2023; Kelly et al. 2024). Carnemolla and Steele's first research project with CID (also done in collaboration with Leanne Dowse and People with Disability Australia) examined what people with intellectual disability want the public to remember and learn about disability institutions. The team found strong support for recognising and celebrating the contribution of self-advocacy to deinstitutionalisation while also finding that not all people with intellectual disability, including self-advocates, are deeply familiar with this history.

In a related project, Steele and Carnemolla analysed planning and heritage documents on the New South Wales government's application to rezone Peat Island – a former disability institution – for tourism and recreation. Their analysis formed a CID submission opposing the rezoning (Steele and Carnemolla 2021). A key finding of this project was that intellectual disability rights activism (including self-advocacy) related to Peat Island was not recognised as cultural heritage (Carnemolla and Steele 2024). Collectively, these findings highlight the continued relevance of the history of self-advocacy, and the importance of providing opportunities to learn more about this history.

Disability history and self-advocacy

The self-advocacy movement has a rich history which is underrepresented in scholarship on preserving, memorialising and communicating social movement history (Berger and Koller 2024; Ševčenko 2023). Self-advocacy history is documented in multiple ways. Self-advocates are authors and truth-tellers sharing their experiences of institutionalisation and activism in their published life stories (McRae 2014; K. Walker 2015). Self-advocacy organisations document and share histories on their websites, such as the USA-based Self Advocacy Resource and Technical Assistance Center, UK-based People First

and Aotearoa New Zealand-based People First New Zealand. Disability studies scholars discuss the history of self-advocacy in their work on deinstitutionalisation and community inclusion (Carey 2009; Frawley and Bigby 2015) and on the impact of disability activism on systemic change (Stace, 2022). The Disability History Association curates works exploring intersections between disability history and more widely recognised public histories, challenging and enriching traditional historical narratives (The Disability History Association n.d.).

Intergenerational learning in social movements

Advocacy and activism have historically benefitted from and been sustained through exchange of knowledge, strategies, and experiences across generations, creating dynamic relationships in which learning flows in both directions. This intergenerational exchange is evident in disability rights social movements (Chandler et al. 2022; Climaco 2020; Mattlin 2022) and other social movements, such as climate justice, racial justice, gender equality, and HIV/AIDS (Bhatia 2023; Cornejo et al. 2021; Edell, Mikel Brown, and Montano 2016; Rodriguez 2023; Roy and Ayalon 2022). Older activists pass down critical lessons from their lived experiences and mentor younger leaders, and younger activists can learn from those lessons and recognise and honour elder activists' struggles. This dynamic is reflected in the concept of 'passing the baton' – intentional sharing of expertise and leadership between older and younger advocates to ensure the continuity of the movement and progress on a common struggle.

Generations in social movements learn from each other in mutual ways. In climate justice movements, younger activists often call for greater action, challenging older generations to adapt to new realities, reconsider past strategies and use their political and economic power to amplify younger voices and create meaningful partnerships (Roy and Ayalon 2022). Reciprocity in intergenerational activism allows movements to draw strength from historical knowledge while embracing contemporary innovations, ensuring adaptability and resilience in the face of evolving social and political challenges.

Intergenerational learning is present in the self-advocacy movement. Self-advocates reflect on the influence of previous generations of self-advocates on their own experiences (Mattlin 2022) and their sense of responsibility as experienced advocates to share their knowledge and advocacy experience with younger people with disability (Nankivell 2024).

Methodology and methods

Methodology

The project applied disability human rights and inclusive methodologies. Disability human rights methodology aims to achieve tangible outcomes that

advance the rights of people with disability. It focuses on issues identified by people with disability, and involves people with disability in the research process to produce accessible and impactful research outputs (Arstein-Kerslake et al. 2020; Fisher and Kayess 2019).

Inclusive methodology prioritises active involvement of people with intellectual disability as co-researchers, research strategists, sense-makers and co-authors throughout all research stages. It centres lived experience as critical knowledge, ensuring people with intellectual disability have meaningful control over research questions, methods, and outcomes. It challenges traditional research hierarchies and power dynamics by creating spaces for co-production of knowledge and promoting inclusion and agency of people with intellectual disability (Carnemolla et al. 2022; Walmsley and The Central England People First History Project Team 2014).

These methodologies are reflected throughout our project. The project was prompted by an issue of concern to research participants in Carnemolla, Steele and CID's first research project discussed earlier (Steele, Carnemolla, et al. 2023). The funding application for the project was drafted by Carnemolla, Steele and CID. Focus groups were designed by Carnemolla, Steele and CID (including Mclean and MacDonald). CID staff produced all recruitment and focus group information in Easy Read. CID staff experienced in research with people with intellectual disability – MacDonald and Mclean – developed the focus group PowerPoint slides and script and then co-facilitated the focus groups. Mclean's leadership in the focus groups coupled with her sharing personal experiences of self-advocacy and disability institutions during the focus groups fostered an atmosphere of inclusion and respect. Data analysis involved a sense-making stage with CID staff with intellectual disability experienced in empirical research (Mclean and Naing). Project findings were accessibly communicated through videos and Easy Read resources (see 'Project outputs' section below).

Recruitment

The project received approval from the University of Technology Sydney Human Research Ethics Committee (ETH 24-9330). Research participants were recruited through targeting NSW self-advocacy organisations and contacting some disability service providers. Two CID staff members not involved in the research project did the recruitment to ensure no actual or perceived coercion or bias. Twenty-one people were recruited. This met the target sample of 20. There were nine female participants, eleven male participants and one non-binary participant. Three participants were First Nations people and four others were from culturally and linguistically diverse backgrounds.

Data collection

To respect the sensitivity of research conversations, participants were given the choice to share their experiences in a group setting or individually. All research participants chose to participate in a focus group. However, two of these research participants later participated in interviews due to an accidental recording failure at their earlier focus group, ensuring their insights were captured for analysis.

Focus groups explored aspects of self-advocacy and disability institutions:

1. Key experiences and lessons learned by self-advocates.
2. Advice for present-day self-advocates based on these experiences.
3. Effective ways to share the history, experiences, and lessons of self-advocacy.

Focus groups were scheduled based on participants' availability, resulting in diverse groups in terms of age, gender, self-advocacy experience, and familiarity with disability institutions. Focus groups were co-facilitated by Mclean and MacDonald, ensuring shared facilitation roles and fostering inclusivity. They designed focus group PowerPoint slides and script. Mclean shared her own perspectives on and lived experiences of disability institutions and self-advocacy. Steele and Carnemolla attended focus groups to listen. They did not participate in discussions beyond introducing themselves and participating in the icebreaker.

Personal accounts of disability institutions often include descriptions of violence, abuse, abandonment and isolation. Sharing these experiences can be an important form of truth-telling. However, this process can also be traumatic for the person recounting their story and those listening, including for people who have not themselves experienced disability institutions. To ensure safety and support, there was a counsellor from Interrelate present during and available after all focus groups. The counsellor's availability was explicitly communicated to all participants. This approach allowed the facilitators to focus on ensuring the conversations were both productive and safe for everyone involved.

There were 5 focus groups with the 21 participants. All focus groups were hybrid. Each focus group lasted two hours. We recorded ten hours of conversation.

Data analysis

Recordings were transcribed. Participants were deidentified and allocated alternative names corresponding to their focus group number. Deidentification was in compliance with the HREC approval. Participants were given the choice in the consent form whether to be publicly named (first name only or first and last name) in project outputs and those who elected accordingly are

named in the article. Some participants are also named and featured in a series of videos about self-advocacy and deinstitutionalisation which were developed on the basis of the project findings. Carnemolla and Steele conducted a preliminary round of data analysis by thematically analysing the transcripts using NVivo. The coding schema was structured by asking questions of the data structured by: who, what, when, where, why and how. This approach has been tested on earlier projects by Carnemolla and Steele directed towards practical outcomes (Steele, Carnemolla, et al. 2023; Steele, Swaffer, et al. 2023). This coding schema involved the following:

- Who: who are self-advocates, old or new self-advocates
- What: what are disability institutions, what is deinstitutionalisation, what is self-advocacy
- When: memories of self-advocacy, past impacting present, learning across generations
- Where: context of self-advocacy community v institution, range of settings where self-advocacy used
- Why: why learn about self-advocacy, why self-advocate
- How: how to self-advocate, lessons from self-advocacy, what still need to learn about self-advocacy, how to remember self-advocacy and disability institutions

Through their data analysis Carnemolla and Steele looked for practical information about self-advocacy skills and remembering and learning about self-advocacy and disability institutions. They also looked for conceptual information about disability institutions, deinstitutionalisation and self-advocacy, self-advocacy identity and remembering self-advocacy and disability-institutions.

Carnemolla and Steele produced a draft report with six findings, representative quotes from the data and sensemaking questions. They provided the report to MacDonald and Mclean for the next round of data analysis. MacDonald and Mclean met online twice over a period of two days (total of two hours). MacDonald had already familiarised herself with the document and was aware of the content and questions for sensemaking. MacDonald summarised each finding for Mclean, along with a few quotes to solidify understanding. They discussed whether the information was an accurate account. They also discussed the sensemaking questions. MacDonald had her screen shared as they went through the findings and typed notes on what was discussed. MacDonald and Mclean then read through the notes to ensure an accurate representation.

The findings report informed a third stage of data analysis involving sensemaking the findings with researchers with intellectual disability. Research team members without intellectual disability (MacDonald and Kelleher) tested the findings with team members with intellectual disability (Mclean and Naing). Mclean, having been involved throughout the project, had a deep understanding of the concepts discussed. Naing, while new to this project,

brought a fresh perspective and relevant experience from a prior collaboration with Carnemolla and Steele (Steele, Carnemolla, et al. 2023).

MacDonald and Kelleher conducted one-hour online meetings with Mclean and Naing individually. Each session began with an overview of the project, followed by an Easy Read summary of the findings report to ensure accessibility. MacDonald and Kelleher then facilitated discussions using the three identified areas for sensemaking within the findings report as conversation starters, with questions rephrased in accessible language to facilitate meaningful engagement. Outcomes of the sensemaking sessions were shared by MacDonald with Carnemolla and Steele, and Carnemolla and Steele engaged with these outcomes in finalising the findings.

Findings

There are four key findings through analysis of the focus group data. These findings are: self-advocates have diverse understandings of ‘disability institutions’ and ‘deinstitutionalisation’, self-advocates have rich and complex understandings of ‘self-advocacy’, self-advocates have nuanced understandings of age and generations in placing themselves in the trajectory of self-advocacy, and education about and remembrance of older self-advocates is important.

Diverse levels of understandings of ‘disability institutions’ and ‘deinstitutionalisation’

Self-advocates have varying levels of knowledge of disability institutions and deinstitutionalisation. A small minority had limited awareness, with G4P2 stating, ‘I didn’t even know [...] it was even such a thing’. Some self-advocates had a deep understanding, shaped by personal experiences of institutionalisation and its impacts. G2P1, who experienced various institutional settings—including childhood disability institutions, group home training centres, public housing, and boarding houses—shared extensive knowledge of NSW deinstitutionalisation policy, citing specific dates and government reports. They highlighted the violence and injustices within these settings, recalling an investigation that found the institution failed to meet disability care standards. G2P1 described ‘being made to do slave labour in the laundry’ of an institution. G2P1 noted there was ‘no psychologist, no one in the institution to talk to us’ and the government ‘didn’t actually monitor the institution at all, they just left, put us there with a file and left us to our own devices’. G2P1 also recounted their sister’s experience, where she was chained purportedly to prevent self-harm, prompting G2P1 to report it to the police as criminal behaviour.

Some self-advocates without lived experience of disability institutions identified connections to people who had been institutionalised: ‘I just want to say that I actually know someone that was in an institution’ (G1P3);

Though I may not have lived experience I've been taught experience from just sitting and chatting with people' (G2P3).

Some self-advocates expanded the definition of disability institutions beyond large residential centres to include other carceral settings such as foster care, children's homes, Aboriginal children's homes, mental health facilities, asylums, prisons, and group homes. Self-advocates without direct experience of disability institutions shared experiences of these settings, emphasising their similarly harmful impacts. One participant (Justen) described being removed from family at a young age and placed in out-of-home care, which they viewed as their first institutional experience before entering the prison system. They recounted abuse leading to homelessness and repeated escape attempts, expressing a strong desire to stay with their family despite authorities intervening to return them to out-of-home care institutional settings.

G5P1 described their experience of incarceration in prison, including sexual assault and solitary confinement for self-harm stating they were placed in a dry cell for seven days without bedding or basic necessities due to a lack of understanding about disability: 'the dogs in the pound get treated better than you'. G5P2 identified group homes as institutions, saying 'we went to a group home, so yeah, that was an institution'. G5P4 recounted their time in an orphanage in Central Europe. Self-advocates also spoke of having experienced segregation, discrimination and exploitation in other segregated settings such as segregated education and segregated employment.

Self-advocates had varying levels of understanding about the term 'deinstitutionalisation' with many finding it difficult to pronounce and not in accessible language. Some were familiar with the term through their advocacy work, such as Kylie Scott, who described it as 'getting out' of institutions. However, others had never encountered it, as reflected in a focus group exchange where G5P4, G5P2, and facilitator Mclean acknowledged they had not heard the term before the research project.

Rich and complex understandings of 'self-advocacy'

Self-advocates viewed self-advocacy as grounded in autonomy and voice describing it as 'standing up for people with disabilities and your friends' (G1P3), 'mak[ing] decisions for themselves' (G2P1), '[s]peaking up for yourself' (Emma), '[p]utting your foot down and not budging if you know something's not right' (G2P3), and '[s]omeone who stands up for their own rights' (Elizabeth Young).

They viewed self-advocacy as involving a rich set of practices including protest, human rights advocacy, storytelling, teaching and decision-making. For example, G4P1 emphasised 'provid[ing] education' within their cultural communities. Justen highlighted 'storytelling', Lex Tan referred to '[s]upported decision making' and G4P1 spoke of 'standing up for your human rights'.

Nuanced understanding of temporality in self-advocacy identity

Self-advocates took varied approaches to identifying as 'old' or 'young' self-advocates. Some based this on age. Charitha De Silva considered themselves 'old' in their late twenties. Others based this on their level of knowledge of disability institutions and/or self-advocacy. G4P2 described themselves as 'a bit of the older one', due to their awareness of institutional practices. G5P2 referred to themselves as an older self-advocate due to years of self-advocacy experiences, despite being in their early 20's. In contrast, G5P4 referred to themselves as 'younger', stating 'I'm still learning'.

Some self-advocates identified themselves as younger due to their lack of lived experience in disability institutions. For example, Alexander Elliott considered themselves younger, stating, 'I don't have any institution experience'. Some older self-advocates who had lived in disability institutions as children identified as younger because they joined the self-advocacy movement later in life.

While self-advocates were asked to identify as 'older' or 'younger', some proposed an additional category of being 'in between'. This category reflected having knowledge or connections to disability institutions without having lived in one. Rory Keyes described themselves as 'in the middle' due to their substantial knowledge of institutional history, stating, 'I didn't live through that, but I know more than the stereotypical younger advocates'. Similarly, G1P1 identified as 'in between' because, while they had family members with institutional experiences, they personally avoided it after closures and instead attended special schools and experienced foster care. Self-advocates of all ages and experience levels identified skills and strengths they can share with others.

Self-advocates identified a range of skills utilised in their practice. These include communication skills such as public speaking ('speaking up on different issues' (G1P3)), giving university presentations (G1P1), 'making sure we talk about things that matter to us' because 'when something isn't right or we need to fix something, we talk about it and try to find solutions' (G4P2)), and educating others ('having connections and educating' (G4P1)). Research skills include ways to access quality information ('finding out the right information' (G1P1); 'I'm the person that will read through every single legal political document in the universe to try and find if something's wrong or not'. (Elizabeth Young)).

Although self-advocacy is linked to the closure of institutions, G2P1—who had extensive lived experience of institutionalisation and knowledge of NSW deinstitutionalisation policy—highlighted the challenges of self-advocacy *within* institutions. They explained that threats and intimidation, such as being locked in toilets or cupboards, publicly discredited, or sent to worse institutions, deterred people from speaking up. They explained it was only after they left disability institutions they could begin to advocate: 'The

minute I left the institution I'd started with all my claims. First we went to police'. Since leaving disability institutions G2P1 has had many self-advocacy successes including lobbying politicians, speaking at rallies, making complaints, taking legal action and training their support workers.

Self-advocates shared successful self-advocacy experiences across various settings. Focus group facilitator Mclean described filing a complaint about an activity group where she spent her time supporting a friend who was deaf and had unconventional means of communication instead of enjoying the activity, stating, 'I paid to go, but the support people should have been helping her'. She also recounted 'getting out of a sheltered workshop' she had worked in 'for 19 and a half years' earning \$6 an hour and standing all day. Through a series of meetings, she asserted her desire to transition to open employment, saying, 'I had to be strong about what I wanted'. Now at CID, she conducts advocacy workshops and recently trained a major grocery chain on fair wages. G1P1 also shared their self-advocacy success in relation to segregated employment: describing it as so negative that they considered calling the police due to staff harassment, including being followed into the restroom and rushed. Eventually, they decided to leave, stating, 'I walked in one day and said, look, I've had enough. This is my last day'.

G4P1 described 'escaping' from their group home after management ignored their concerns about residents using drugs: 'it was a really unsafe environment and I felt like I wasn't being listened to'. G5P1 shared their experiences of self-advocacy in prison, including challenges related to food and medication access. They recounted contacting the ombudsman after their dietary needs were ignored, saying, 'I had to keep harassing, harassing, harassing'. They also struggled to access prescribed medications, explaining, 'I was unmedicated, and they punished me for my autism being bad. Then I finally got my meds'.

Self-advocates shared successes in addressing systemic issues. G1P1 described their pride in protesting, saying, 'standing with my placard [...] side-by-side with a good mate [and fellow self-advocate], [...] with the media all over us, and just right in the centre of town'. G5P4 spoke about the courage it took to speak at a major government inquiry, stating, 'I was worried at first, but once I did it, it felt amazing. This is what I want to do'. Elizabeth Young highlighted their experience in parliament, emphasising the importance of being heard by politicians. G2P3 identified CID campaigns they were involved in as key successes. Self-advocates also offered valuable advice to new self-advocates, emphasising perseverance ('stick at it', '[d]on't give up', '[i]t's pretty hard so just stick at it' (Elizabeth Young)), courage ('[d]on't be afraid' and '[c]ome out of your shell' (Alexander Elliott); 'face your fears' (Lex Tan)), action ('be involved' (Alexander Elliott)) and self-belief ('[f]ollow your dreams and you will be heard' (G5P4); '[b]elieve in yourself' (Rory Keyes)).

G2P1 who had extensive lived experience of institutionalisation and knowledge of NSW deinstitutionalisation policy stressed the importance of reclaiming power:

We have still got a long way to go [...] we're [...] persevering and we don't want people to be frightened of coming forward for those that have been in institutions, we want to get the message out there, they can't hurt us anymore and give back the power that was taken from them many years ago. We need people with intellectual disability to speak out what happened to them, that's the only way we can bring those perpetrators to justice.

G5P4 spoke of standing up for one's rights and not allowing others to undermine your experience:

standing up for your right and having the self-respect. You are telling your story because you want people to know and tell. [...] if anyone tried to say, it wasn't that bad living in that home, come on you're making – you've got to say no, you don't understand. You don't know the trauma that we've been through and frankly if you heard my story, you would be shocked what happened.

Importance of learning from and public remembrance of older self-advocates

Self-advocates without direct experience of advocacy related to deinstitutionalisation expressed a strong interest in learning from those involved in deinstitutionalisation. G5P4 suggested asking self-advocates about their experiences, motivations, and the impact of their stories, stating, 'We could ask them what made them become self-advoca[tes]. How it felt and how their story affects people [...] I want to talk about this because I don't want anyone to go through that again'. Self-advocates were particularly interested in the deinstitutionalisation process and the strategies used asking questions such as: 'What is the first step of getting deinstitutionalisation?' (Kylie Scott); whether there were any '[m]arches and protestors' (G2P2); and 'How did they succeed in the end?' and 'who did they talk to' (G2P3). These discussions facilitated learning within the focus groups, particularly from G2P1 who had extensive lived experience in disability institutions and NSW deinstitutionalisation policy.

Self-advocates recognised the need for broader public recognition and remembrance of older self-advocates to honour their contributions. Justen highlighted storytelling, stating, 'my storytelling is based on my generation and about people who aren't here today that died from all that'. G4P2 stressed remembering efforts in closing institutions, saying 'remember[ing] everything that they did to get them closed down would be a great thing'. G1P1 explained: 'through all the struggles and all the fighting to close it down, they got closed down' which 'teaches that if you really want to do

something, fight until the cows come home, literally, and don't give up, no matter what'. G4P1 emphasised inspiration drawn from past self-advocates, stating, 'their hard work to close institutions inspires me and the younger generation to do more'. Rory Keyes and Madison discussed teaching disability history in schools, including to students with intellectual disability.

Another reason for public remembrance is to prevent history from repeating itself. G4P2 stressed, 'it should be remembered how we closed them down and never happened again'. Similarly, Elizabeth Young emphasised remembrance is crucial to ensure history is not repeated: 'This is what happened.... we need to know about it, so it doesn't happen again'. G5P1 highlighted the need for awareness, stating: 'people need to know about these cruel places more, because not many people speak about them. [...] we also need to remember the people that did advocacy on these institutions as well, because if it wasn't for them, these places might still be running or might still be suffering'. Madison talked about the role of education in preventing recurrence and fostering inclusion: 'we need education about these things to stop them happening so students know to talk to other students with intellectual disabilities to find out that they are exactly the same as everyone else. [...] It's why Germany teaches the Holocaust [...] as soon as the student is old enough to understand'.

Self-advocates suggested various ways to remember and educate others about self-advocacy and disability institutions. G5P1 proposed creating a website featuring key historical milestones, photos and short videos. They also suggested a day of remembrance: 'a day of remembering how bad [...] institutions were'. Elizabeth Young recommended published materials, comparing them to books on LGBTQIA+ rights that document significant events and key figures. Other ideas included public talks and a published document (G2P2), a dedicated library (G2P1), and videos (G5P4). G1P1 spoke about the need for celebration of self-advocates whilst acknowledging past struggles: 'You don't want to make it so sad. But you want to [present] what the outcome was, and then where you do not want to go back to. [...] we still can take up the fight if we need to'.

Self-advocates considered site-specific recognition of former institutions. Madison discussed on-site tours but acknowledged challenges, noting 'a lot of those places probably don't really exist and were probably replaced by high rise apartments or office blocks, or God knows what else'. G1P1 proposed demolishing the buildings and creating parklands with a memorial, 'if it holds so much bad memories, put a park there. [...] Some sort of memorial or something [...]. But make it a joyous spot instead of a depressing one'. They also emphasised the importance of demolition to prevent future institutional use, explaining, 'if the buildings are still there, the Government always has that option, and that's what you do not want'. Kylie Scott advocated to 'bulldoze all the institutions'.

Some self-advocates noted the issue of trauma in relation to public remembrance of self-advocates. G5P4 explained: 'they probably have had really bad trauma. So, they kind of want to tell this story because they want people with intellectual disability or anyone in general to not go through the same thing. They tell the story, so it doesn't affect them too much'. In a similar vein, G5P1 stated: 'we need to remember the people that were there, and probably the trauma that they went through and probably still live with today'.

Limitations

As the first project of its kind in NSW, our research provided novel insights into conceptual and practical dimensions of self-advocacy and intergenerational learning. However, a key limitation was the difficulty in recruiting participants with lived experience of disability institutions. Although the target sample was met, the number of self-advocates with such experiences was limited. While one of the goals of our research was to hear the stories of those who lived in disability institutions, identifying participants with lived experiences of disability institutions proved challenging. Some individuals with intellectual disability have either moved away from the region where they were institutionalised or passed away since institutional closure. Moreover, some people with intellectual disability with lived experiences of disability institutions do not want to speak about their experiences or participate in research which cannot guarantee concrete policy outcomes. Some with lived experiences of disability institutions may have felt uncomfortable participating or re-traumatised due to their recent participation in the Australian Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability which was widely viewed in the disability community as inadequate, disappointing and harmful. Supporters and advocates offered to speak on behalf of people with intellectual disability with lived experiences of disability institutions, however this did not fit with the ethics approval nor with the objectives of the project. Further, self-advocacy is not necessarily possible in institutional settings which then orients the category of 'self-advocates' towards people with intellectual disability who have not spent a considerable amount of time in a disability institution.

Discussion

Our findings establish the importance to self-advocates of intergenerational learning and public recognition of the history of self-advocacy in the context of deinstitutionalisation. For self-advocates, learning and recognition is central to acknowledging the significant contributions of self-advocates, learning from their work and stopping repetition of past injustices. Our findings additionally establish that learning and recognition must be reflective and open

processes informed by self-advocates' diverse experiences and understandings of disability institutions and self-advocacy.

Our findings contribute self-advocates' perspectives to disability studies scholarship on the history of self-advocacy (Buchanan and Walmsley 2006; Carey 2009; Friedman et al. 2020; Goodley 2000; Traustadóttir 2006; Walmsley and The Central England People First History Project Team 2014). Self-advocates in our study emphasised the importance of understanding self-advocacy history to prevent the repetition of past injustices and to address contemporary challenges faced by people with intellectual disability. This perspective offers opportunities to bridge historical scholarship with critical disability studies, particularly in addressing and redressing present-day human rights violations (Ben-Moshe et al. 2014; Rossiter and Rinaldi 2018; Steele, Swaffer, et al. 2023) and historical disability injustice (Rosenblatt 2018; Steele 2022) and memorialising disability experience (Carnemolla and Steele 2024; Punzi 2024; Punzi and Steele 2024; Reading 2022). Given the broader relevance of self-advocacy to other disability groups – such as autistic people and people living with dementia – intergenerational learning is important in fostering reflection and practical engagement within a range of disability rights movements.

Self-advocates' emphasis on intergenerational learning and public recognition of their role in deinstitutionalisation, highlights an underexplored area within disability human rights scholarship and practice. While the CRPD Committee recognises importance of truth-telling in deinstitutionalisation (United Nations Committee on the Rights of Persons with Disabilities 2022), this focuses on people's experiences of human rights violations and does not explicitly extend to a public record of and memorialisation of activism and resistance. Disability studies and disability human rights scholarship can support this work through engaging with emerging memory studies scholarship on the right to memory (Tirosh and Reading 2023) and scholarship on intergenerational knowledge and practice transmission in social movements (Bhatia 2023; Cornejo et al. 2021; Edell, Mikel Brown, and Montano 2016). We now turn to explore some specific issues and tensions arising from our findings.

Meaning and boundaries of self-advocacy

Self-advocates have a rich understanding of the concept of self-advocacy. This reflects existing disability studies scholarship on the meaning of self-advocacy (Buchanan and Walmsley 2006). However, the repressive nature of disability institutions can restrict those living within them from becoming self-advocates (as noted by G2P1 in sharing their experiences), thus biasing the concept towards individuals already out in the community and potentially excluding those whose advocacy and activism is restricted and shaped

by their carceral circumstances. People who use unconventional ways of communicating might also be excluded from the meaning of self-advocacy. The parameters of 'self-advocacy' might undermine people's diverse experiences and practices of agency, resistance and advocacy in institutional settings which do not fit within understandings of 'self-advocacy', including practices that have been read as 'challenging behaviour'. Indeed, even survival is itself a form of resistance. The paradigm of self-advocacy might prevent an intersectional history of disability resistance, notably people with disability who advocated in non-disability-specific carceral settings and First Nations people with disability's resistance to settler colonialism (Avery 2018; Bostock 1991).

This means that framing the project around 'self-advocacy' may have limited the opportunity to explore *how* people resisted and survived in institutional settings. It might also have reduced the opportunity to contest assumptions and hierarchies within self-advocacy to enrich our understanding of what activism and advocacy mean for people with intellectual disability living in disability institutions and other carceral and oppressive contexts. Other experiences of agency, resistance, survival, activism and advocacy might be excluded from historical documentation, learning and recognition processes related to self-advocacy. Further research at the intersection of self-advocacy and critical disability studies on challenging behaviour, critical criminology on resistance in carceral settings, and settler colonial studies could help examine boundaries and hierarchies within the self-advocacy movement, uncovering new narratives and practices for public recognition and learning.

Temporality and intergenerationality

A nuanced understanding of temporality and intergenerationality is necessary. Generations cannot be defined by chronological age. This is particularly true where individuals have come to the self-advocacy movement later in life such as due to their family preventing participation in self-advocacy or because of institutional or segregated circumstances – being chronologically aged as 'old' but politically 'young'. Second, self-advocates in our study interpret generations differently, linking it to chronological age, direct experience of disability institutions, and experience of self-advocacy. Further scholarship on generations in self-advocacy is necessary and this can provide new avenues of inquiry for critical disability studies scholars engaged in disability and temporality (Kafer 2013; Rice et al. 2017). For self-advocacy practice, these insights on generations emphasise the importance of not equating age with experience and ensuring that older individuals with intellectual disability—including those in residential aged care—have opportunities to learn about and engage in self-advocacy.

Intergenerational knowledge sharing is a two-way process. Older self-advocates bring valuable lived experiences as survivors of the past, offering insights into diverse experiences and expressions of self-advocacy as discussed in social movement scholarship on intergenerationality (Nankivell 2024; Rodriguez 2023). At the same time, younger self-advocates contribute their perspectives on advocacy in areas such as community inclusion, health-care, disability services, and housing. Some self-advocates may have more experience with formal advocacy through organisations, providing opportunities for peer-to-peer knowledge exchange. They can share insights into contemporary practices of structured advocacy and activism, while older self-advocates offer a truth-telling perspective shaped by their historical experiences. This reciprocal exchange enriches understanding and strengthens the collective practice of advocacy across generations.

From learning and recognition, to redress and justice

Self-advocates' personal experiences of harm – in disability institutions and in contemporary contexts – and their recognition of the wrongfulness and injustice of these experiences was a strong thread in our empirical study. Sitting beneath the pride of the successes they discussed was often an unresolved injustice that had enduring impact. Disability studies scholarship on self-advocacy history can explore the contemporary justice dimensions of past experiences. This could draw on the rich body of scholarship on historical injustice that has developed in the racial and gender justice contexts (Nutti 2019; M. U. Walker 2006; Young 2011) and is beginning to be applied in the disability context (Steele 2025). For self-advocacy practice, the significance of largely unresolved and unredressed injustice to self-advocates' past and present experiences might require self-advocacy organisations to raise awareness of these experiences and work towards accountability and redress for these harms (J. F. Kelly et al. 2023).

Diversity of institutions and institutional experiences

Self-advocates do not understand 'institutions' as limited to intellectual disability-specific largescale residential settings and as extending to other settings such as group homes, out of home care, segregated education, and prisons. This confirms earlier research by Steele and Carnemolla (Steele, Carnemolla, et al. 2023) and the rich critical disability studies scholarship on the 'institutional archipelago' and 'carceral' control (Ben-Moshe et al. 2014).

Disability studies scholars can recognise this broader understanding of 'disability institutions' by providing opportunities for people with intellectual disability to define and share their diverse experiences of disability institutions. Disability advocacy organisations can take an expansive approach to 'disability institutions', potentially engaging with the work of Disability Justice

activists (Berne and Sins Invalid 2016) and the UN interpretation which takes a broader approach to the term (United Nations Committee on the Rights of Persons with Disabilities 2017, 2022).

Today is tomorrow's history

Our empirical study highlights how and why deinstitutionalisation and desegregation are not complete – this is an ‘unfinished project’ (Ben-Moshe et al. 2014; Benoot 2025; Steele and Punzi 2024). Self-advocates are dealing with similar struggles but in different settings and times, thus underscoring the non-linearity and circularity of political progress for people with intellectual disability. As an unfinished project, the history of the self-advocacy movement’s role in deinstitutionalisation is still unfolding such that documenting what is currently happening as *tomorrow's history* is central.

Developing methods for a challenging context

The decision of individuals with lived experience of disability institutions not to participate in research on disability institutions must be respected and the limitations of others speaking on their behalf acknowledged. This in turn highlights the limits of what we can learn from people, including people with intellectual disability, who have not themselves experienced disability institutions. For some individuals, revisiting traumatic experiences may not be something they wish to engage in for the purposes of research. People with intellectual disability should not be expected to repeatedly relive trauma for the sake of research or knowledge-sharing.

Moving forward, we will continue to prioritise non-traumatising methods for gathering accounts of lived experiences of and perspectives on disability institutions, learning from other scholars and researchers in related fields where stories of trauma form the basis of narratives (Gagnon and Novotny 2020). Self-advocacy organisations must ensure actions on intergenerational learning and public recognition of self-advocacy history prioritise trauma sensitivity and explicit acknowledgement of who is speaking.

Project outputs

The research team produced a series of public facing and accessible outputs based on the findings. CID produced three short videos – on disability institutions, the significance of self-advocacy, and the importance of remembering its history – to enhance public understanding. Each video features unscripted conversations between self-advocates inspired by the findings. While unscripted to encourage natural discussions, MacDonald

and Kelleher provided preparatory support to participants. The videos, available on CID's website and YouTube channel, include captions and a trigger warning.

CID produced three Easy Read resources for self-advocates. These were on the topics: disability institutions, remembering self-advocates, and being a self-advocate for closing disability institutions. Carnemolla and Steele provided feedback on these resources. An additional Easy Read guide produced by Carnemolla, Steele and CID provides disability advocacy organisations, researchers and governments with insights into how to approach research conversations on disability institutions based on learnings from this project and earlier projects in the program of research.

Conclusion

This study underscores the continuing significance of the self-advocacy movement in addressing enduring legacies of disability institutions and advancing the rights of people with intellectual disability. By foregrounding intergenerational learning and public recognition, this research highlights how histories, strategies, and lessons of past self-advocacy efforts can inform and sustain the present-day movement. Intergenerational learning is not simply the transmission of knowledge but a reflective and reciprocal process that enables younger self-advocates to celebrate the contributions of earlier generations, learn from their successes and challenges, and address contemporary injustices with deeper insight and resilience. Historical awareness helps ensure current and future advocacy efforts remain vigilant against the re-emergence of institutional forms and practices that undermine autonomy, independence, and community participation for people with intellectual disability. By honouring the contributions of past self-advocates, the movement can foster a deeper understanding of its roots and cultivate a sense of collective purpose and identity.

There are complexities and challenges in intergenerational learning and public recognition. Learning from the past requires sensitivity and openness, recognising that the histories of institutionalisation are deeply personal and often traumatic. By engaging in a dialogic and reflective process, the movement can build a nuanced and inclusive understanding of its history, ensuring that it informs present-day advocacy in meaningful and ethical ways.

Intergenerational learning and public recognition are tools for preserving history and strategies for ensuring the sustainability and adaptability of intellectual disability rights movements and accountability and redress of historical injustice. By embracing intergenerational learning and fostering a commitment to remembering and building on its history, the movement can remain a transformative force for social change.

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