Listening to People with Intellectual Disability about Institutions

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ABSTRACT

Despite the ongoing impacts worldwide of institutionalisation on people with intellectual disability, the public knows little about large-scale disability institutions that have been the focus during the late 20th century of deinstitutionalisation efforts (historic institutions) and the people who lived there. An interdisciplinary team of researchers (including those with intellectual disability) undertook research with people with intellectual disability to explore what and how the public should learn and remember historic institutions. The project found that people with intellectual disability support community engagement with histories and lived experiences of historic institutions, in order to repair past wrongs, end contemporary practices of institutionalisation, segregation, and exclusion, and realise transformative equality and inclusion. People with intellectual disability should lead these initiatives, with appropriate support in recognising the very live memories and traumas associated with them. This article provides a model of inclusive research for turning the harms of past institutionalisation into an educational and reparative experience.

Introduction: Historic Institutions, Deinstitutionalisation, and Social Justice

During the 20th century, millions of people with intellectual disability[1] worldwide lived in large-scale residential settings specifically for people with disability. Over the past 50 years in many nations, these settings have been gradually closed through government policies of deinstitutionalisation. In this article, we use "historic institutions" to refer to these settings. Other people with intellectual disability lived or currently live in residential settings such as group homes and forensic facilities that share many features of historic institutions in terms of being segregated from the wider community and having an absence of choice and control over living arrangements. We refer to these latter settings as "contemporary institutions". Both historic institutions and contemporary institutions contradict the human rights of people with disability, including the right to independent living and community inclusion in Article 19 of the UN Convention on the Rights of Persons with Disabilities (CRPD). Pursuant to the 2022 Guidelines on Deinstitutionalisation by the CRPD Committee, governments must abolish all forms of institutionalisation, provide opportunities for individuals to leave institutions and access housing and support within the community and have deinstitutionalisation processes that aim to end all forms of institutionalisation, segregation, and isolation. The 2022 Guidelines emphasise that moving beyond a world

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1. People first language used as the preferred language for the Council for Intellectual Disability, the collaborating research organisation.

of institutions requires governments to fully acknowledge and redress former and current experiences of historic and contemporary institutions, including through processes of truth-telling, apology, individual redress and social repair (Committee on the Rights of Persons with Disabilities, 2022).

This article provides a model of inclusive research on institutions that is highly relevant to both the reparative dimensions of the 2022 Guidelines and broader real-isation of Article 19 and other human rights of people with disability. We argue involvement of people with intellectual disability in sharing histories and lived experiences of historic institutions is important to deepen public understanding of, reckoning with and repair of ongoing negative impacts of institutionalisation, segregation and exclusion of people with intellectual disability *and* to advance positive experiences of transformative equality and inclusion.

There are five factors that make make this article particularly timely and relevant to people with intellectual disability and society more broadly.

First, the personal impacts of historic institutions are still significant and reverberate for many people in society. People with intellectual disability were placed in historic institutions without their consent. Some were subjected to violence; worked without pay; did not get enough care and education, and had little or no contact with their families. People with intellectual disability who were in historic institutions continue to live with the physical, psychological and relational impacts of historic institutions after they left (Rossiter and Rinaldi, 2019) and continue to experience social exclusion years after leaving a historic institution (Bigby, 2008). Some parents of people with intellectual disability who put their children in historic institutions are traumatised by what happened to their children when there were limited ways to resource disability support within family settings (Andrews Zucker, 2020).

Second, there has been little visibility of the histories and lived experiences of historic institutions. There have been limited official efforts to specifically reckon with, redress, and repair the injustices of historic institutions, the very existence of institutions, the coercive placement of people in historic institutions, and the myriad of harms experienced within them (Stace, 2022; Steele, 2022). This absence of official response contrasts with government apologies and redress schemes in other contexts such as Indigenous children who were removed from their families and communities pursuant to official government laws, policies and practices (e.g. members of Stolen Generations in Australia), and survivors of institutional child sexual abuse. While the experiences of some people with intellectual disability in historic institutions will intersect with these other contexts, the relevant official responses have not been inclusive and accessible to people with disability (People with Disability Australia, 2021). The absence of official response to historic institutions might be shifting with recent developments towards truth-telling through official government inquiries in several countries including the Australian Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability in Australia, the Aotearoa New Zealand Royal Commission of Inquiry into Abuse in Care, the Massachusetts (US) Commission on The History of State Institutions for People with

Developmental And Mental Health Disabilities, and the Vermont (US) Truth and Reconciliation Commission on institutional, structural, and systemic discrimination. However, it is still too early to tell whether these will result in recognition, individual redress, and social repair for the full scope of harms of historic institutions. There is growing recognition and practices of engaging the community in learning about and remembering historic institutions emerging in several countries including sites of conscience (place-based memory projects) of specific sites of historic institutions in America and England (Steele, 2022) and community education programmes (Community Living Ontario, 2022). Without proper acknowledgement in these various ways, historic institutions remain what Maria Tumarkin (2022) terms in the context of gendered violence, an "open wound" yet to be healed.

Third, the resistance of people with disability in historic institutions to their detention and living conditions provided foundations for deinstitutionalisation and community living, and the contemporary disability rights and self-advocacy movements (Ben-Moshe, 2020). For example, in her memoir, late Australian self-advocate Kim Walker (2015) documents her journey from being institutionalised in a historic institution in her childhood and early adulthood into living independently in the community. Walker became a leading Australian and international self-advocate and was particularly known for her advocacy against cluster disability housing (a form of contemporary institution) in the aftermath of the closure of historic institutions. People with intellectual disability have also contributed to the CRPD's development and operation – including on deinstitutionalisation – such as New Zealander Robert Martin who has lived experience of historic institutions and is now a member of the CRPD Committee (Stace, 2022).

Fourth, some people with intellectual disability remain housed in historic institutions that have not yet closed, while others live in contemporary institutions. In some countries, historic institutions remain a key form of housing for people with disability, whereas in some other countries historic institutions *are* closing but are being replaced with smaller-scale contemporary institutions (see, e.g. Allen, 2020; Disability Rights International, 2019; Disability Rights International, 2020). Further, even in countries such as Australia where deinstitutionalisation has considerably progressed, group homes (a form of contemporary institution) remain a dominant form of housing for people with intellectual disability (Disabled People's Organisations Australia, 2020) and when funding is available for individual support, some people with intellectual disability might find that the way disability support staff work and the culture of support have many features of institutionalisation (Summer Foundation, 2020).

Fifth, experiences of congregation, segregation, and coercion – all key features of historic institutions – continue to be prevalent for people with intellectual disability living in the community, shaping their daily lived experience. Self-advocacy organisations and representative organisations for people with intellectual disability continue to lead global and local campaigns demanding full inclusion of people with intellectual disability (Inclusion International, 2021).

Despite the ongoing relevance of historic institutions to people with intellectual disability, too often, the histories and lived experiences of these places are

erased. The public knows little about historic institutions and the people who lived in them. Historic institution sites are often redeveloped for other uses once they close. These processes do not provide the opportunity for people with intellectual disability to have input into their future uses, nor do they provide opportunities for public engagement with these places' disability histories. For example, in 2021 the state government of New South Wales (Australia) applied to rezone Peat Island, the site of a state-run historic institution for 99 years. The rezoning application and supporting documentation did not recognise the significance of the site to people with disability, nor did the community engagement consultation processes, communication, and information incorporate any level of inclusive practice or design. Without accessible or inclusive planning processes or materials, people with intellectual disability were unlikely to be aware of, and thus unable to participate in, these consultation processes and activities (Steele and Carnemolla, 2021). Similarly, a government-run sport and recreation camp for school children on Milson Island (close to Peat Island), the site of a state-run historic institution for 37 years does not deliver any education at the camp to acknowledge the island's institutional history (Steele, 2022). Lack of public knowledge about historic institutions compounds dehumanisation of the people and sends the message that their lives still do not matter. This prevents acknowledgement of the role of self-advocates in deinstitutionalisation and reforms within the community and also prevents recognition, redress, and learning from this past to ensure it is not repeated beyond the walls of historic institutions.

This article presents the findings of an Australian research project with people with intellectual disability on historic institutions. An interdisciplinary team of researchers (including researchers with intellectual disability) in partnership with the Council for Intellectual Disability and People with Disability Australia, undertook focus groups with people with intellectual disability to explore what the public should know and remember about historic institutions, why this learning and remembering is important and how it should occur. As the first Australian project of its kind, this project is a pilot study focused on developing an appropriate method for a larger-scale, national study. As such, the project did not recruit people with direct lived experience of historic institutions to participate in focus groups. Future research and any future practices based on research findings will be directed to this group.

To set the context for reporting on our study we next canvas existing literature on intersections of historic institutions, deinstitutionalisation, and social justice. Following this, we introduce methods to explore what people with intellectual disability think the public should know and learn about historic institutions. We then present key findings from focus groups, identifying important interrelated factors to consider in engaging with historic institutions to advance human rights and social justice. Last, we reflect on the findings in the context of the work of disability advocates for human rights and social justice, and implications for research and practice.

Some scholars have argued that segregation, congregation, and coercion of people with disability has continued despite deinstitutionalisation, yet is often obscured by

arbitrary binaries of institution/community that assume the community is a place of freedom and inclusion. Critical disability scholars propose the term "institutional archipelago" to refer to the network of "diverse services and spaces" – including closed and community settings – through which disability oppression occurs (Chapman, Carey, and Ben-Moshe, 2014, 14). Coercion and control of people with disability that occurs in the community, including through laws and practices framed as empowering and inclusive, has been termed "deinstitutionalised community" (Spivakovsky, Steele, and Weller, 2020). These are central concepts in developing our current understanding of the intersection of segregation, congregation and coercion of people with intellectual disability and counter the persistent orientation towards disability history in terms of the "dark past" which prevents us from seeing new or continuing forms of oppression in the community (Altermark, 2018).

The re-use of historic institutions after they have closed is understood to contribute to forgetting their histories, erasure of injustice, and marginalisation of people who lived there. Scholars have characterised the re-use of historic institutions in Australia as "painting over the oppression of people with disabilities and [. . .] failing to acknowledge the horrendous practices which occurred in these places" (Goggin and Newell, 2005, 122). The redevelopment and gentrification of sites of historic institutions in Ontario (Canada) have been seen to enable erasure of the histories, where "the process of deinstitutionalisation itself, and how these former sites of containment are being redeveloped, help illuminate a continuing legacy of exclusion" (Abbas and Veronka, 2014, 121). Focusing on psychiatric asylums in the UK, Canada, and Aotearoa New Zealand, Moon, Kearns, and Joseph (2015) propose four distinct "afterlives" of asylums as "retention" for mental health care uses, "transinstitutionalised" for other institutional uses such as a prison or university, "residential use" such as expensive housing developments, and "dereliction" involving abandonment and disrepair (Moon, Kearns, and Joseph, 2015, 25–26, 129–130). Exploitation of historic institution sites for "dark tourism" that exploits its institutional history is identified as an additional "afterlife" (Betiks, 2012). For example, the former Pennhurst State School and Hospital site in Pennsylvania (US) is used as a haunted house amusement, and the former Beechworth Asylum site in Victoria (Australia) is used for ghost tours.

Researchers have explored how people with disability and their allies are reclaiming histories, memories, and places of historic institutions. Scholarship documents the experiences of former residents of Huronia Regional Center in Ontario (Canada) in acts of reconnection, remembrance, and resistance in response to their experiences of historic institutions (Rossiter and Rinaldi, 2019). Others analyse possibilities of place-based memory projects about historic institutions such as sites of conscience (Punzi, 2022; Steele, 2022). Burch documents practices of remembrance and oral history by Indigenous families and communities with a connection to the former Canton Asylum for Insane Indians, a federal psychiatric hospital in South Dakota (US) (Burch, 2021). In the UK, the "Social History of Learning Disability" group at the Open University documents disability social history of historic institutions and

deinstitutionalisation from the perspectives of people with intellectual disability (Brownlee-Chapman et al., 2017).

For people with intellectual disability, actively shaping how their individual and collective histories are presented, recorded and remembered remains a rare experience. The value of "inclusive research" is widely recognised and recent Australian inclusive research undertaken about local government and community inclusion has highlighted that inclusive priority setting is valuable and critical in building local communities inclusive of people with intellectual disability (Robinson et al., 2022). A number of reviews have mapped the scope of literature, informing how inclusive research is conceptualised (Bigby, Frawley, and Ramcharan, 2014). They describe the value of inclusive research and the central voice of co-researchers with intellectual disabilities (Strnadová and Walmsley, 2018). There is also an established body of research dedicated to "community-based participatory research" with people with intellectual disabilities (McDonald and Stack, 2016; Nicolaidis and Raymaker, 2015) and reflections of people with intellectual disability working in diverse research teams (Carnemolla et al., 2022). While there is a wealth of research on the problematic dynamics of the histories and sites of historic institutions, there is far less research that explores the perspectives of people with intellectual disability. Developing a body of inclusive research on this topic is important for shaping disability and inclusion policy and practice that aligns with the preferences and priorities of people with intellectual disability.

Methods

The project researchers constitute an interdisciplinary team traversing law, built environment design, and disability studies disciplines, and representatives from the Australian Disabled People's Organisations Council for Intellectual Disability and People with Disabilities Australia. Our project design was guided by representatives from the Council for Intellectual Disability and People with Disabilities Australia, including a self-advocate with intellectual disability with lived experience of historic institutions. The project methodology aligns with the disability rights movement's "Nothing About Us, Without Us", drawing on inclusive research methods and on what is described as "disability human rights methodology" (Arstein-Kerslake et al., 2020). Ethics approval was obtained from The Human Research Ethics Committee of the University of Technology Sydney (ETH018-2713). All research activities were conducted in accordance with this approval.

Project Planning and Recruitment

Robert Strike, a self-advocate and person with lived experience of institutions, helped authors Steele, Carnemolla, Spencer, and Dowse with the design of the project, notably the focus group topics and accessibility of information.

We recruited a convenience sample of participants. Council for Intellectual Disability staff not otherwise associated with the project contacted members about participating in the research. Those who responded were provided with the participant

information statement and consent form in Easy Read and were required to provide written consent to participate. Following extensive recruitment efforts, our final sample, consistent with our targets, was nine participants with intellectual disability. The project was a pilot study. The sample is not representative and, due to the sensitive nature of the project, we did not want to over-sample.

People with direct lived experience of historic institutions were not invited to participate due to the topic's sensitive nature. It is anticipated that this group will be invited in a subsequent stage. However, some participants had lived in contemporary institutions such as group homes or institution-like settings such as prisons. Some participants had grown up during the time of historic institutions or had friends or colleagues who had lived in historic institutions. In being recruited through the Council for Intellectual Disability, all participants had knowledge of advocacy and some of the present-day systemic advocacy issues related to deinstitutionalisation.

Data Collection

There is evidence that focus groups can offer people with intellectual disability a supported, conversational environment where confidence can be built through participation, peer support, and validation (Cambridge and McCarthy, 2001). Some of the authors (Carnemolla, Spencer, Kelly, and Dowse) have experience using focus groups in other studies that seek the perspectives of people with intellectual disability and so focus groups were deemed the most appropriate data collection method for this study. However, in a research setting, people with intellectual disability can have a range of preferences regarding how conversations take place, including one-to-one interviews. For this reason, participants were offered the option of speaking individually to researchers, or being part of a focus group.

Three focus groups and one interview were held with nine people with intellectual disability. Focus groups were initially planned in early 2020 as face-to-face, but due to COVID-19, we gave respondents the choice of participating in a face-to-face or online session. One focus group was in-person, and two focus groups and one interview were online. The focus groups and interview were co-facilitated by author Steele (law academic and chief investigator) and author Spencer (formerly Senior Inclusion Manager at the Council for Intellectual Disability and associate investigator). Spencer has extensive experience in focus group facilitation and Easy Read communication. A trained counsellor with experience working with people with intellectual disability and their families (including in the current context of the Disability Royal Commission) was present at the focus groups and also available afterwards. The groups were run using an open semi-structured format. This enabled two-way conversations between facilitators and participants (Mason, 2017). Participants were asked questions about their awareness of historic institutions. Then three topics about historic institutions were explored: what should the public know about historic institutions, how should this information be shared, and how should historic institutions be publicly remembered?

Analysis

The focus group recordings were transcribed and de-identified. The transcript data were thematically analysed using an inductive approach to identify broad patterns of meaning (Braun and Clarke, 2012). This initial coding was undertaken manually by author Steele. Following a group discussion of emerging themes with other research team members (authors Carnemolla, Spencer and Dowse, and Fleur Beaupert), a coding schema was applied to identify aspects of what, when, why, how, and who:

- **Who** is involved in telling the public about historic institutions in the past,
- **What** should we mention when we are publicly sharing information about historic institutions in the past,
- **When** should the historic institutions have been operating that we are talking about (i.e. what about contemporary institutions),
- **Where** should the information about historic institutions be shared,
- **Why** should we tell people about historic institutions, and
- **How** should we tell people about historic institutions?

This approach enabled a more nuanced understanding of the topic by drawing out the complexities of participants' understandings of historic institutions and the practices of remembering and learning. Following the initial coding by Steele, Carnemolla, Spencer, Dowse, and Beaupert each engaged in iterative coding of one of the four transcripts. Another author then identified themes emerging from and cutting across the codes for discussion in this paper, choosing those themes that were relevant to enhancing disability advocates' and disability policymakers' engagement with historic institutions and social justice. The coded results were synthesised into a set of main findings.

These findings were further verified and validated in follow-up discussions with authors who are also advocates from the Council for Intellectual Disability. Steele and Carnemolla shared the themes they identified in the transcripts with authors Kelly and Naing, who helped interpret the information. Kelly and Naing also helped think through engagement with circumstances leading to placement in historic institutions, focusing on good and bad experiences of people with intellectual disability, the role of families in remembering, the role of younger people with intellectual disability, and how to connect findings to current issues, including contemporary institutions.

Pilot Project

The project discussed in this article is a pilot study focused on developing an appropriate method to use in a larger national study. As the project team's first empirical research on this topic and the first project of its kind in Australia and noting the traumatic nature of the research, the researchers wanted to test their methods before researching with people with direct experience of historic institutions. This was particularly important given the project had only modest funding and coincided with COVID-19, thus limiting the capacity to engage in face-to-face research with

intensive participation support. Future research as part of an ongoing collaboration with the Council for Intellectual Disability will be focused on people with direct lived experience of historic institutions.

Findings

In this section, we discuss our findings. In summary, people with intellectual disability supported the public learning about and remembering historic institutions, however, there was no agreement about how this should occur.

Varying Levels of Knowledge of Historic Institutions

People with intellectual disability have varying levels of knowledge about historic institutions. While none of the participants had lived in historic institutions, there was significant variation in understanding and knowledge of historic institutions among participants. Every individual who had a deeper knowledge of historic institutions expressed sadness and empathy about others' experiences of historic institutions and acknowledged that they, too could have been institutionalised. Their responses show how much the topic affects them even if they have not lived in a historic institution. As we return to below, this complexity is a crucial reason for taking a careful approach.

Some spoke of family members, friends, or colleagues who had lived in historic institutions. Toby, who had experience supporting people currently being moved out of a large-scale residential setting as it was being closed, observed that he had recently discovered he had an aunt who had lived at that same historic institution decades earlier. Participants who had knowledge of historic institutions spoke of the discriminatory and harmful circumstances surrounding historic institutions. Emma shared her knowledge of the stigma around disability that drove placement of children with intellectual disability in historic institutions. Toby spoke of historic institutions being like prisons: "Like once they're locked in, they had no voice whatsoever, and when they do speak up they'd get punished for it". Toby spoke of a visit to a historic institution years earlier which still impacted him: "I was in there and I'd seen what people calling out, shouting, and screaming [. . .] And, yes, it was just really frightening to see that type of stuff that's still happening. And it's still happening now".

For some participants, the focus group provided an opportunity to learn about and reflect on historic institutions for the first time. Katherine stated: "Well I heard of institutions, but I wasn't quite sure what it means". For others, it enabled them to gain a deeper understanding. Emma observed, "Well I didn't know anything about institutions, so it's a learning curve for me". Katherine referred to the focus group as "a learning experience, because we'd never heard of the word [institutions] [. . .] we didn't know what they were". Danielle found the new information about historic institutions and the discussion on rights at the focus group empowering: "I felt really empowered by it. I feel positive, you know, just get out there and do it".

These reflections demonstrate the importance of raising awareness amongst people with intellectual disability about historic institutions and a full exploration of the concept of "institution" with people with intellectual disability involved in developing any initiatives. This has value in terms of shared understanding and clarity of understanding because of the sense of empowerment that comes from having learnt this history. There is value in awareness-raising within the self-advocacy community to begin understanding the specificities of the history and lived experiences of historic institutions and their connections to current-day advocacy issues, including contemporary institutions. However, the need for awareness-raising is likely to be even greater in the broader intellectual disability community, particularly among those who have had less or no involvement in advocacy.

Multiple and Expansive Understandings of Institutions

There is no singular, shared understanding amongst people with intellectual disability of "institutions". When the concept of "institution" was introduced in the focus group, some participants identified this with settings other than historic institutions. For example, Danielle identified features of historic institutions in group homes where she had lived and spoke about her experiences of bullying in group homes as relevant to our understanding of historic institutions. Toby (who had a deep knowledge of historic institutions) saw connections between historic institutions and group homes from his experiences supporting people who leave a historic institution: "I think well people who are moving out that institution now are going into group homes. Groups homes, mini institutions. Group homes are like another institution but they are smaller ones". Katherine and Tim spoke about group homes as institutions, drawing on observations of their friends' experiences. Katherine explained the circumstances of one of her female friends:

> The staff aren't very nice to this person sometimes, the way they speak to her and that they didn't give them the right to make their own decisions [...] I wouldn't like to live in that kind of situation.

Katherine and Tim also spoke of a friend who lives in a cluster of group homes located on a rural property away from town. The property gets cut off by floods, there is no public transport into town, and the residents spend their days at a day programme located elsewhere on the farm property. Conor spoke of similarities between the difficult choices for families in the past, and the contemporary issues around people moving into group homes. Mark spoke of his experience in prison as relevant to the meaning of "institutions". He spoke of being "targeted for my [disability] in there" and being "violently abused by corrective service staff".

The expansive approach to "institutions" that emerged from the focus groups and the connections that some participants made between different living arrangements highlight three issues. The first issue is recognition that people with intellectual disability still experience institutionalisation in other settings. The second is that institutions are not simply a thing of the past. It is essential to recognise and explore the connections people with intellectual disability see between historic

institutions and their current experiences of segregated living, including in contemporary institutions like group homes. While in the Australian context the National Disability Insurance Scheme (NDIS) delivers individualised funding packages that are intended to prioritise "choice and control" by people with disability, participants made clear that there are aspects of institutionalisation that can still happen in the context of NDIS funded accommodation and supports. The third issue is that these connections between past and present provide essential information for government and disability services to understand the problem of repeating the past in designing future systems and the need to work harder to realise the human rights of people with intellectual disability.

Complexity of Experiences of Historic Institutions

The history of historic institutions is complex and nuanced. It encapsulates the experiences of both people with intellectual disability and their families, and dimensions both of harm and injustice and resistance and rights. Participants agreed that the public should be taught about the bad things that happened to people with intellectual disability in historic institutions. Katherine stated that the public should learn that people with disability had no choice in living in historic institutions. A number of participants with a deep knowledge of historic institutions also emphasised the importance of acknowledging the difficult circumstances facing families with children who went into historic institutions. Peter reflected that it: "must be very, very traumatic [. . .] especially for the parents". Emma also observed the impacts on family: "It just makes me want to scream that their parents weren't given the chance to help bring them up. They were wanting to stay. I don't think sorry goes far enough".

In contrast to these negative perceptions of historic institution experiences, other less negative aspects were identified. Toby noted that for some people, the historic institution was their home: "It's been their home for a very long time". Others emphasised the importance of recognising aspects of the histories of historic institutions that represent the strength and resistance of people with intellectual disability and how far this community has come in terms of their status in society. Some referred to Kim Walker's memoir (mentioned in the introduction above), as noted by Emma: "I got the insight from reading Kim's book, and I think we cried throughout the whole book. What she achieved, it's like, yes, we can do anything". Emma drew on Kim Walker's book (Walker, 2015) to explain the importance of learning about the positive aspects of people's experiences:

> You can form good friendships in institutions, like Kim did, because I think that's what got her through [. . .] And then when she did get out of the institution, she started to thrive, she started to grow and do amazing things. Because started to stand up for [. . .] She stood up for herself. That can be hard when you're in an institution, to stand up for yourself. That girl had guts.

Toby also noted the importance of remembering advocates, referring to Walker's book: "this is what we should remember those awesome people".

The complexity of experiences of historic institutions demonstrates the importance of a nuanced approach to how historic institutions are represented and sensitivity in understanding the circumstances of people with intellectual disability and their families.

The Necessity for the Public to Learn and Remember

It is important for the public to learn about historic institutions. There was recognition of general silence about historic institutions. Conor made the point that we have no museum acknowledging disability history: "It's amazing, we got a museum nearly everything under the sun. Why don't we have a museum for people with disabilities?"

Participants identified several reasons why it is important to learn about historic institutions. These reasons fall within four areas: acknowledgement of past harm, learning from the past, accountability for harm, and realising human rights. First is the importance of acknowledging what has happened to people with intellectual disability in the past. Central to this is honouring the lives of people with intellectual disability who lived and died in historic institutions and celebrating the work of self-advocates with intellectual disability who lived in historic institutions and fought for rights. Related to this is centring the experience and voices of people with intellectual disability, notably former residents of historic institutions. Emma explained,

> *We need to get people's stories out there. We need to let people know what was going on. Why families weren't given the option. I think it's going to be a hard conversation, but I think we need to have this conversation now.*

the past can also contribute to recovery and healing of those who lived in historic institutions, as noted by Peter: "it may be helpful in their recovery maybe".

The second set of reasons relates to ensuring that learning from the past of historic institutions contributes to improved future circumstances for people with intellectual disability, including in the provision of disability services. For example, Conor stated: "[. . .] going into the future, you learn from the mistakes, and you improve on what you've already done". Danielle noted: "we have to learn by experience and knowledge about what happened to make it better". Katherine spoke of the government not continuing institutionalisation: "it would be awful if the government lets it happen and people are very frightened to go into institutions if they still open". Katherine explained that people with disability in historic institutions should be given the choice to leave: "Because if it happened to us, we would like it to be set right. We would like to have our freedom to say that we can go".

A third set of reasons relates to accountability and redress. Emma noted the limits of apologies as a form of recognition: "I think sorry just doesn't go far enough". She recognised the challenge of a singular apology to capture the depth and complexity of people's experiences: "Everyone's situation is different. I don't think one particular word is going to fit the jigsaw puzzle in this". Some participants believed that learning about historic institutions could be more meaningful

than empty apologies. Mark said of an official apology: "For me it's not enough, because they need more". Mark also referred to an apology as being "as good as a golden handshake". Toby also considered an apology insufficient: "For me, it's not enough". Toby explained that the government "needs to put the action behind the words" and act to close historic institutions: "there's no institutions, so that every person could be out in the community doing the awesome stuff that they love doing".

A fourth set of reasons concerns public learning as a basis for deeper under-standing of and realisation of human rights for people with intellectual disability. People who were in historic institutions are humans who should be respected and have their human rights recognised. Renee explained that learning about historic institutions "would really change their attitudes. They need to change attitudes toward disability. Some people are still not [. . .] Are treating disability the wrong way". Following Renee's point, Conor noted the endurance of negative attitudes to people with disability:

> *One of the things I think is still shocking that still goes on, and I've experienced it with some of my friends, is, you still get those words like, spastic retard. I hate those words, and yet, for people with disabilities, they still hear them.*

Thus, learning about historic institutions is important for dealing with our past and making a better future for people with intellectual disability.

The Importance of Specific Groups Learning and Remembering

Participants suggested that specific groups in the community could be targeted for learning about historic institutions and highlighted five groups for whom learning about historic institutions would be particularly beneficial. First, many participants identified children as a group who should learn about historic institutions. This was primarily framed in terms of learning about historic institutions as part of Australian history in school. Emma stated that learning "needs to get into schools, in the school curriculum" and that

> *it might be a scary topic, but I think it would be good in a history lesson, or someone talks to [senior high school] students about what went on and give them a sense of what children in an institution missed out on.*

Mark, who had experience of the criminal justice system, also spoke of teaching children in juvenile detention centres: "I want to back in the Juvenile Justice and talk to the kids this time [. . .] Talk to the kids, and inmates' kids".

Some participants noted the importance of politicians and public servants learn-ing about historic institutions as a second key group to target so that learning can inform decisions about disability policy. A third group some participants spoke of were workers who support people with disability, including in group homes, learn-ing about the history of historic institutions. Danielle drew on her own experiences in a group home to explain this point:

> *Find the carers. Training carers to be what they are called. Carers. Which means, you know, care for the people. Don't just leave them. Or say, oh well. You don't deserve love. Or, I don't want to help you because you're doing this or that. Or get in your room. Or if you don't put your jumper on, you're not going out, out to ten-pin bowling or something like that.*

Tim spoke about the importance of training staff to improve how they treat people with disability: "Because the younger ones don't know what it's like [. . .] they never heard of [institutions] so you've got to train them". Agreeing with Tim, Katherine stated staff training should send the message: "Don't treat them like animals".

A fourth priority group some participants spoke of was people with intellectual disability. It was suggested that learning about historic institutions is a way to empower people with intellectual disability to become agents of change. This is relevant for younger people with intellectual disability who have not grown up with historic institutions as a dominant aspect of Australian society, as noted by Mark: "That puts people on alert that anything like this could happen". Toby suggested educating doctors and nurses as a fifth priority group:

> *Because there's a lot of discrimination there as well, with doctors and nurses. And when we are first born with a disability, the doctors will go to the mothers and say, hey, they have disability. They should be in an institution [. . .] there should be education around doctors and nurses, and how to talk to parents.*

Thus, learning needs to be targeted both in terms of the content delivered and the aims and intended outcomes of that education.

Sensitive Approach to Content

Remembering and learning about historic institutions must be done in a way that recognises the complexity of what happened in historic institutions and the circumstances leading to people (particularly children) going into historic institutions and the ongoing impacts on people with intellectual disability, their families and communities.

Participants with deep knowledge of historic institutions spoke of the importance of approaching the topic sensitively and carefully Toby said, "This is a very raw topic". He noted that talking about historic institutions: "Could traumatise some people [. . .] Some people don't like talking about it too much [. . .] It definitely brings back the past, of that traumatising event that has happened in the past". Emma stated: "It could be a really emotional period in their life [. . .] You've got to look at how it's going to affect people as well". Peter said:

> *So we need to be very, very careful and very mindful if we did that. And do it in a way, that it won't bring back that rawness inside them. And be sensitive in how we do it. And I know I'm speaking as a little outside of the square here, but whether we know it or not, those people are still around. It will bring back memories to them [. . .] But they have left that part behind. Well, we don't want to bring those memories back.*

Emma spoke of particular sensitivities for children with disability and their parents around delivering content in segregated "special" education settings:

> If they're in a special school, you've got to do it in a way that's not going to upset them, because you've got to look at their needs as well, because their parents might have been given the option to put them in an institution or not.

Thus, it is important to take a cautious and sensitive approach to engaging the disability community (notably individuals who had lived in historic institutions and their families) in developing any programmes for remembering and learning.

Leadership and Involvement of People with Intellectual Disability

People with intellectual disability should be involved in public learning about historic institutions. Participants observed the importance of people with intellectual disability being involved. One reason is that it is their history, as noted by Danielle: "The people who've gone through this, are our teachers".

Another reason is that people with intellectual disability are the experts on ensuring learning and remembering is inclusive and accessible to people with intellectual disability. To maximise engagement of people with intellectual disability, it is important to consider support, accessibility, taking time to discuss, share, and process what is being discussed, and the need for all involved to have knowledge/awareness of disability. However, some participants emphasised the importance of approaching involvement in a sensitive manner, because of the complexity of the topic, as discussed in the preceding section. Emma specified the need for support:

> There'll probably need to be counsellors around, because it's a very emotional and very tough topic to do. I think it's going to be a long process to get the information to make people know what they [. . .] You've got to have the right preparation, which can take quite some time. It could take several months to be able to get people in the right frame of mind. But also let them know that it's okay to be emotional. It's okay if you want to feel angry, scared, whatever, but emotional and physical support when people need it.

Thus, any learning and remembering of historic institutions must centre the leadership and involvement of people with intellectual disability.

Mode of Delivery

While there was consensus that public learning about historic institutions is necessary, the focus groups provided no clear agreement on how this should occur. Participants offered many different suggestions: use of the Council for Intellectual Disability website and including information in Easy Read, workshops, use of mainstream media, and a museum-style travelling exhibition. Conor and Emma suggested reflecting on historic institutions at the International Day of People with Disability. Others made population-specific suggestions such as teaching to school students through a documentary or a book, and workplace training of disability support staff.

Participants had various ideas for what should happen to the buildings and land of historic institutions. Katherine proposed a plaque. Emma also proposed a plaque, but emphasised that any statue or plaque should be focused on the human dimension. In contrast, Tim was not in favour of any recognition: "No. I would just leave it [. . .] It will bring back memories for other people, you know? Some of them bad ones, who've have been in there". Tim thought a statue would be upsetting to people with disability who had lived in historic institutions: "because they wouldn't like it, because if they see it then they would just about cry".

The lack of detail and consensus on this is not surprising. This preliminary exploration of the topic was taking place in the context of an absence of existing practices on learning and a focus on advocacy on this history. The concept of historic institutions and the connection between the past and current rights was new to many participants. The topic of remembering historic institutions is complex and nuanced, requiring careful and ongoing exploration, particularly in relation to how to balance trauma.

Regardless of the particular mode, some participants made general suggestions about delivery. These are the need to ensure teaching is safe and respectful to people with intellectual disability and others who might be affected.

The other is to ensure the content is accessible, including through Easy Read. And the importance of getting to people living in regional areas.

Discussion

In this section, we discuss some of the implications of the findings for future engagement with the histories and lived experiences of historic institutions in Australia.

The Importance of Engagement with Disability History

The research has established that learning about and remembering historic institutions is a meaningful, relevant and needed area for further exploration in research and practice. The findings discussed in this paper suggest how the work of disability activists and policymakers advocating for human rights and social justice for people with disability can be broadened and enriched through engaging with the memories, experiences and places of historic institutions. However, diverse levels of knowledge of historic institutions among participants highlight the necessity for more exploration with intellectual disability advocacy organisations around how histories and lived experiences of historic institutions can inform advocate training and rights education and might inform systemic advocacy. In particular, the history of the advocacy movement itself is crucial.

Participant reflections on group homes and other settings as contemporary institutions confirm the critical arguments made by scholars such as Chapman, Carey, Ben-Moshe, Spivakovsky, Steele, and Altermark about recalibration and endurance of segregation, congregation, and coercion irrespective of deinstitutionalisation in relation to historic institutions. This research has provided further evidence of the continued influence of our institutional past on current disability

support and housing policy, practice, and culture. In doing so this research has established the importance of learning about historic institutions for accountability and continual improvement of contemporary disability services. Many organisations re-formed and rebranded after deinstitutionalisation without any internal reckoning, redress, or repair processes. Moreover, workers in historic institutions might now work in disability services – including in contemporary institutions – with no understanding of the injustices of historic institutions nor awareness of how traces of these injustices remain in contemporary support and accommodation in which they work.

The research has established the importance of engaging governments at all levels involved in managing sites of historic institutions, planning, built environment, and heritage professionals to ensure history is acknowledged in subsequent use and development of sites, and people with intellectual disability are included in these processes. Our research confirms research by scholars such as Abbas and Voronka critiquing the re-use of historic institutions. A key part of this might be the exclusion of people with intellectual disability from the processes through which re-use occurs.

Findings from this study also reinforce the point made by researchers in deinstitutionalisation and intellectual disability (Bigby and Fyffe, 2006) that closing historic institutions has not ended the exclusion of people with intellectual disability in community and civic participation. Governments at all levels are responsible for implementing policy that supports meaningful engagement with people with intellectual disability, and builds an understanding of how to ensure people with intellectual disability can participate meaningfully in all community discussions that affect their lives. In the case of the redevelopment of Peat Island, a historic institution in NSW, Australia, Steele and Carnemolla brought the lack of inclusive planning and engagement practice by the NSW government in the redevelopment of this site to attention in their report (Council for Intellectual Disability, 2022) which highlighted that governments also display a lack of understanding of the social heritage importance of sites of historic institutions, focusing on architectural heritage. The study presented in this article provides important evidence that the social heritage of historic institutions is critical for governments to engage with and to value, not only because they are important to people with disability and their families, but also because it has intergenerational significance for people with disability more broadly, and the rightful inclusion of people with disability in our communities. Recognising and valuing the site's social history at any stage of its re-use sends an important message that social stories and history cannot be erased simply by the change in use of the building. What happened in historic institutions must be openly reckoned with through shared knowledge and clarity of knowledge. In terms of the heritage and site recognition itself, further engagement with governments and planners on the social heritage of former sites of historic institutions will form a critical part of the future dialogue about this research, as led by people with people with intellectual disability.

The methodological approach taken in this project has been designed to include people with intellectual disability at all project stages. It is an important example of centring the lived experience of people with intellectual disability within all research activities and outcomes arising from the research, and provides a model of inclusive research on institutions that is highly relevant to both the reparative dimensions of the 2022 Guidelines and broader realisation of human rights of people with disability. While this pilot study is exploratory, we have shared an example of how to meaningfully include people with intellectual disability in establishing the lines of enquiry of research into historic institutions, as well as employment of people with intellectual disability in the data analysis verification, data synthesis and strategic directions of future research. In doing so, we contribute to the growing and rich literature demonstrating inclusive research practices with people with intellectual disability (Strndova and Walmsley, 2018). Our study also builds upon earlier inclusive history work, documented by Atkinson and Walmsley (2010), which stresses the importance of "nothing about us without us" and joins institutional histories and life histories together, as told by people with intellectual disability. In addition to inclusive research methods, people with intellectual disability working on this project team continue to be central to informing how the narratives and translations of this research are shared more broadly with the community.

Focus Group Practice

Our focus group methodology was designed to support an inclusive research practice within the project. All research activities considered the very sensitive and possibly traumatising subject matter being discussed. We introduced an additional layer of analysis to test the sense-making from the focus group transcripts. We conducted discussions with authors who are also self-advocates as an additional way of validating the coding and findings with people with intellectual disability.

Throughout this project, authors together have learnt the importance of taking time to discuss key concepts and identify shared and divergent understandings. Given the subject matter, having a counsellor present for the focus group discussions was extremely important when considering the risk of distress. We were grateful to the counsellor for their guidance at the focus groups. While we were concerned about extended times between research activities, often due to COVID-19, we now consider this to be positive. We recognise the need for a slow and thoughtful process in research projects that involve diverse perspectives, with data to sensitively analyse and validate in inclusive ways.

Areas for Further Exploration

In moving forward with remembering and learning, we focus on six areas that warrant further exploration.

One is the complexity of the concept of "institution" which is well-established in scholarly research, as discussed earlier. This project has shown how people with intellectual disability themselves see and experience these connections. Discussing

historic institutions can be one way to reveal some of the complex ways control and segregation manifest in contemporary accommodation and support arrangements which are often juxtaposed to a darker past.

A second area is the value of connecting the historic institutions to good and bad aspects of present-day experience (e.g. human rights and advocacy, versus community exclusion and group homes) – what has changed, and what do we still see happen today?

A third area is how historic institutions intersect with other experiences of structural oppression, notably settler colonialism and the Stolen Generations. This could be explored through engagement with First Nations people with intellectual disabilities and First Nations disability advocacy organisations. The work of Scott Avery (a profoundly deaf and Aboriginal scholar of the Worimi people), establishes that truth-telling is central to healing and self-determination for First Nations people with disability (Avery, 2020).

A fourth area is exploring histories of institutionalisation of people with intellectual disability are intertwined with experiences of people with other disabilities, and how historic institutions impacted people with disability more broadly. In particular, many institutions referred to in this article also housed people with psychosocial disability.

A fifth is how to engage with families and the circumstances surrounding entry into historic institutions. This could be explored through engagement with family advocacy organisations.

A sixth area is the relationship between historic institutions and reparations. The 2022 Guidelines on Deinstitutionalisation make clear that truth-telling, individual redress, and social repair are integral to deinstitutionalisation and ultimately realising the right to independent living and community inclusion. The inclusive research outlined in this article provides a model for the ways that the harms of past institutionalisation can be documented, exposed, and turned into an educational and reparative experience relevant to repairing past wrongs and realising a future without institutions. Indeed, the lack of an official apology about historic institutions as a formal process for people with disability and their families to rest their grief and sorrow has been identified as an issue of importance by author Kelly. Since this project, advocating for an official apology for government policies on institutionalisation has become a priority advocacy issue for Kelly and the Council for Intellectual Disability.

Conclusion

At a time when institutionalisation often remains the norm rather than the exception across the world, it is important to recognise and reflect on the histories and lived experiences of historic institutions and what lessons can be learnt for the contemporary respect and rights of people with disability. This article has presented findings on how people with intellectual disability want this remembering and learning to occur. While highlighting their support for this, the study notes

the need for a cautious approach, mindful of the complexity of the topic while being respectful to people with intellectual disability and their families. It is also clear that people with intellectual disability can benefit from learning about historic institutions, and this research plays a part in raising this awareness. As such, this article has identified the next steps in a longer-term research programme. Central to the next steps is engaging with people who have lived experience of historic institutions, carefully considering the familial dynamics of historic institutions, and developing resources to enhance understanding within the intellectual disability community.

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