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Article

Looking Back When Moving Forward: Researching Sites of Former Disability Institutions

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Abstract: This article discusses an inclusive research program where colleagues and co-researchers (with intellectual disability) guide and inform future research practice to ensure research is targeted to areas of significance and relevance to them. The research program is about sites of former disability institutions. Many people with intellectual disability in Australia were segregated and forced to live in disability institutions until deinstitutionalisation efforts became mainstream in the late 20th Century. We are a team of four people based in New South Wales, Australia. Our team includes disability advocates and researchers who have contributed to a program of research exploring connections between sites of former disability institutions and contemporary disability rights. In this article, we reflect on conversations about our research undertaken so far and where the research goes from here. We explore five pillars of action informing how research relating to disability institutions can progress: 1. Current use: research exploring erasure of experiences of institutionalisation communicated through educational resources and maps about current use of sites of former disability institutions; 2. Reparative planning processes: research developing frameworks for alternative approaches to planning and heritage processes supporting alternative uses of former sites of disability institutions; 3. Official recognition and redress: research exploring perspectives on governments formally recognising and remedying experiences of people with disability who were institutionalised; 4. Community-led repair and remembrance: research identifying practices for both celebrating advocates with disability and reckoning with and repairing familial and social bonds broken through institutionalisation; 5. Community-inclusive practices: research exploring endurance of institutional practices in disability accommodation in community settings. These five pillars are underpinned by three foundational layers: advancing disability human rights; reckoning with intersections between disability institutions and settler colonialism, other dynamics of oppression, and eugenics; and using inclusive practices.

Keywords: disability institutions; disability activism; disability history; human rights; redress; reparative planning

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1. Plain Language Summary

- This article is about conversations between four researchers talking about a project called "Remembering Disability Institutions".
- The team includes disability advocates and researchers who have worked in inclusive research and disability rights.
- People with intellectual disability are core team members in this research, deciding what is important and how we can learn from the past.
- People with disability in Australia and throughout the world were often forced to live in large residences called "disability institutions". People with disability in institutions were separated from society and treated badly.

- Many disability institutions have closed, but the experiences of people with disability who lived in these places still matter.
- Since they have closed, many disability institutions have been redeveloped or sold. This often means their history is forgotten, and people cannot find out what happened there.
- The team talked about why these old disability institution sites matter to disability rights and inclusion today, and ways we can remember and share the stories of people with disability.
- The Five Important Areas: Our conversations together showed us there are five main ways to guide how we should think about and use these old sites. These are:
    1. Current Use: Understanding what these places are used for today, and making sure their history is not erased or forgotten.
    2. Future Planning: Making plans to use these old sites in ways that respect their history and the people who lived there.
    3. Official Apologies and Redress: Asking the government to recognise, apologise for, and repair the harm done to people with disability in disability institutions.
    4. Community-Led Repair and Remembrance: Helping families and communities remember the people who lived in disability institutions and celebrating advocates with disability.
    5. Inclusive Practices: Making sure the mistakes of the past are not repeated in today's disability accommodation and support.
- The team wants to make sure the public understands what happened in disability institutions so the same mistakes are not made again.
- The research calls on governments and communities to work together to recognise the history of these places and make things right for the people who lived there.
- In the next stage of our research, we will continue to make sure people with disability lead the way in remembering these places and shaping how we move forward with disability rights and an apology from government.

2. Introduction

This article discusses an inclusive research program incorporating activities of reflection and sensemaking, where colleagues and co-researchers (with intellectual disability) guide and inform future research practice to ensure research is targeted to areas of signifficance and relevance to them.

The research program discussed in this article is about sites of former disability institutions. Many people with intellectual disability in Australia were segregated and forced to live in large-scale residential settings ("disability institutions") until deinstitutionalisation efforts became mainstream in the late 20th Century. Many of these disability institutions have now closed. After sites close, they can be sold, redeveloped, or abandoned (Abbas and Voronka 2014; Moon et al. 2015). Researchers, advocates and activists are beginning to explore connections between afterlives of these sites and present-day disability social justice issues (Punzi and Steele 2024). We are a team of four people based in New South Wales, Australia, which includes disability advocates and researchers who have contributed to a program of research exploring connections between histories and experiences of sites of former disability institutions and contemporary disability rights. In this article, we reflect on conversations about our research undertaken so far and where the research goes from here.

Since 2020, authors Steele and Carnemolla have been working together in collaboration with the Council for Intellectual Disability (a New South Wales disability rights organisation led by people with intellectual disability) on a program of research projects taking former sites of disability institutions in New South Wales as their entry point into exploring connections between disability rights, urban planning, heritage, and redress. Research was undertaken by authors Steele, Carnemolla, and Kelly (with other colleagues), listening to people with intellectual disability about how they want disability institutions to be remembered (Steele et al. 2023). Parallel to that project, Steele and Carnemolla made submissions to government in collaboration with the Council for Intellectual Disability opposing redevelopment of a site of a former disability institution (Steele and Carnemolla 2021). The submissions were accompanied by an advocacy campaign involving an open letter and Easy Read resource (Council for Intellectual Disability n.d.a). Reflecting on this work, Carnemolla and Steele have also considered ways people with intellectual disability can play leading roles as agents of activism and change in how institutional heritage is interpreted and institutional history is communicated to wider communities (Carnemolla and Steele 2024). A central objective linking these outputs has been foregrounding the views of people with intellectual disability about what the public should know and remember about disability institutions, and exploring diverse official government and community-led pathways though which this can occur. Most recently, the four authors (Kelly, Creighton, Steele, and Carnemolla) collaborated on developing a framework for future research that builds on key findings from the earlier research.

Our collaboration has confirmed five pillars of action informing how research relating to sites of former disability institutions can progress: current use of sites of former disability institutions, reparative planning processes for sites of former disability institutions, official apologies and redress, community-led repair, and community-inclusive practices.

Whilst our research is closely focused on the Australian context of disability institutions, it has relevance internationally. Worldwide disability institutions are a common feature of disability history and—unfortunately in some nations—disability presents and futures. Deinstitutionalisation and redress for institutionalisation are increasing international human rights concerns and violence in disability institutions is a topic of government inquiries in some nations. Our article offers inclusive research approaches and critical framings and connections to understand sites of former disability institutions as integral to realising disability human rights through a diverse range of policies and practices including heritage, urban planning, access to justice, and disability supports.

The article begins with an overview of disability institutions and introduces scholarship and activism engaging with connections between afterlives of sites of former disability institutions and contemporary disability rights. We then discuss the significance of people with intellectual disability narrating their own experiences. Next, the article describes how we approached our collaboration through a series of reflective discussions. We then present results of our discussions about researching, remembering, and redressing. Finally, we discuss the implications of the results for research on former sites of disability institutions.

2.1. Disability Institutions: Closure, Erasure, Endurance. . . and Disruption

Despite ongoing impacts of institutionalisation on many people with intellectual disability and their families and communities, the Australian public knows little about disability institutions and the people who lived there. In this article, we use “disability institutions” to refer to large places and buildings where people with disability were congregated, detained, and segregated from the wider community. People with disability who lived in disability institutions were often subjected to violence, neglect, and forced labour (Goggin and Newell 2005; Hallahan 2021).

We write this paper at a time when most disability institutions in Australia have closed their doors, over fifty years since deinstitutionalisation started in Australia (Hallahan 2021). Within Australia and internationally, sites of former disability institutions are often redeveloped for other uses. Their new uses do not provide opportunities for public engagement with lived experiences, memories, and social histories of these places—too often, their past is erased (Abbas and Voronka 2014; Moon et al. 2015; Punzi and Steele 2024). This is exemplified by the New South Wales Government’s application to rezone for tourism and recreational use the site of a former disability institution it operated for 99 years (Peat Island Residential Centre). The government’s application failed to recognise the disability history of the site and people with disability were not specifically included in the rezoning application process (Carnemolla and Steele 2024).

Even though most disability institutions in Australia are now closed, their impacts on people with disability are ignored; and practices of segregation, coercion, discrimination, and neglect that shaped treatment within disability institutions endure in the community. These practices endure in laws, accommodation and service models, professional knowledge, and staff behaviour in the "deinstitutionalised" community (Spivakovsky et al. 2020). Australia's recent Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability ("Disability Royal Commission") highlighted widespread harm of people with disability in the community, including in disability accommodation settings (Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability 2020, 2022, 2023).

Continuities in harm across institutional and community accommodation settings for people with disability indicate the oppressive nature of disability accommodation is attributable to a range of dynamics, rather than simply depending on the large size of the building and high number of occupants. Indeed, Disabled People's Organisations and the United Nations Committee on the Rights of Persons with Disabilities ("CRPD Committee") have argued disability institutions are not definable by a particular size or architectural form, but rather by institution-like characteristics such as lack of control over daily routine and shared supports (People First of Canada 2010; United Nations Committee on the Rights of Persons with Disabilities 2017, 2022). People First of Canada (the national Canadian national organisation for people who have been labelled with an intellectual or developmental disability) explains what it means to experience institutional life, even beyond the closure of disability institutions themselves: "An institution is any place in which people who have been labelled as having an intellectual disability are isolated, segregated and/or congregated. An institution is any place in which people do not have, or are not allowed to exercise control over their lives and the day to." (People First of Canada 2010). Recently, self-advocates from Australia and Aotearoa New Zealand described their lived experiences of disability accommodation settings as having institution-like characteristics:

> *"Self-advocates said that they were concerned that small group homes and supported living services have replaced larger institutions, which have almost all closed.*
>
> *Self-advocates felt that many people with intellectual disabilities, including people who live in the community do not have any choice in the support that they receive or control about how they spend their time.*
>
> *Self-advocates spoke about how special schools, respite care, and sheltered workshops could also be described as institutions because people with intellectual disabilities do not have choice and control"* (Inclusion International 2021, pp. 29–30.)

Deinstitutionalisation is central to the CRPD Committee's interpretive guidance on what governments need to do to realise the human right to independent living and community inclusion (United Nations Committee on the Rights of Persons with Disabilities 2017, 2022). This guidance identifies as important governments providing access to remedies, redress, and reparations for disability institutionalisation, including apologies and truth-telling (United Nations Committee on the Rights of Persons with Disabilities 2022). These guidelines are silent, however, on the specific issue of the future of the sites of former disability institutions. This silence is significant because buildings and the natural landscapes these buildings sit within provide "a kind of testimony that goes beyond words" (Byrne 2019, p. 413) and are powerful in their capacity to be effective agents for remembering history from multiple perspectives (Byrne 2019; Lloyd and Steele 2022).

The silence on sites of former disability institutions within the CRPD Committee's interpretive guidance can be filled with emerging research and activism exploring relationships between these sites and present-day disability social justice issues. Disability rights activists have resisted subsequent uses of sites of former disability institutions that erase lived experiences and social history. For example, using the slogan "Disability Rights Not Christmas Lights", disability rights activists in Massachusetts (USA) staged protests and led an online petition against use of the site of the former Walter E. Fernald Developmental Center for Christmas lights show: "Today, in its ruins, the City of Waltham is allowing the Lions Club to host a month-long holiday light show fundraiser that will erase disability rights and replace them with Christmas lights" (Action Network 2021; see also Green 2024). The Council for Intellectual Disability in New South Wales (Australia) ran a campaign (in which authors Steele and Carnemolla were involved) consisting of an open letter and submission opposing tourist and recreational rezoning of the former site of the disability institution, the Peat Island Residential Centre (Council for Intellectual Disability n.d.b; Steele and Carnemolla 2021). People with lived experience of disability institutions have proposed re-engaging with sites of former disability institutions in various ways to re-claim space, narratives, and humanity. Specific examples related to psychiatric institutions include creative performance and history tours recognising people's labour at the Toronto Asylum Wall, Canada (Reaume 2024) and an onsite café for informal social meetings over a cup of coffee on the grounds of the former psychiatric hospital, Lillhagen hospital, in Gothenburg, Sweden (Lindbom and Punzi 2024). Scholars propose that place-based memory practices, also called "sites of conscience", can be used to connect memories and histories of disability institutions to contemporary disability rights issues (Punzi 2022; Steele 2022; Steele and Punzi 2024). These examples of activism and research suggest that strategies directed towards increasing public awareness about disability institutions and experiences of people with disability who lived in these institutions might advance the rights of people with disability, including by bringing about changes to community attitudes, policy, and service delivery, and might also be a means for redressing some of the injustices of institutionalisation.

2.2. *Personal Storytelling and Activism*

Authors Steele, Carnemolla, and Kelly found through their empirical research that people with intellectual disability want the public to learn about and remember disability institutions. Learning and remembering should include recognising harmful dimensions and celebrating resistance and activism. These authors also found people with intellectual disability must be leaders in shaping both narratives of these sites' pasts and the physical futures of these sites (Carnemolla and Steele 2024; Kelly et al. 2023; Steele et al. 2023). This research resonates with the strong focus on centring lived experiences and voices of people with disability in disability history (Rembis et al. 2018). For example, the UK Social History of Learning Disability group developed practices and methods for historical research led by people with intellectual disability (Atkinson and Walmsley 2010). The Donald Beasley Institute in Aotearoa New Zealand gathered life stories of people with intellectual disability and people who are neurodivergent who had lived in institutions. These stories were reported to a public hearing of the Abuse in Care—Royal Commission of Inquiry (Stace 2022, p. 163).

People with intellectual disability remain excluded from discussions and decisions about sites of former disability institutions. Discriminatory assumptions about incapacity associated with people with intellectual disability have meant they have not been considered capable of authoring their own histories (Green 2024). Moreover, people with intellectual disability are rarely consulted on matters relating to their local communities (Carnemolla et al. 2021; Robinson et al. 2022). Similarly, people with intellectual disability have historically not been invited to lead or even contribute to discussions on deinstitutionalisation (Steele et al. 2023).

However, people with intellectual disability have authored their own accounts of institutionalisation and post-institutional life, including their resistance and advocacy. Kim Walker narrates her life story in "*Forgotten and Found: My Life Story*" (Walker 2015), a journey from childhood institutionalisation to becoming a leading Australian disability rights advocate and reconnecting with her family. The short film "*Stockton a Time of Change*", narrated and presented by Leigh Creighton (Community Disability Alliance Hunter 2016), involves interviews with people with intellectual disability—including Rob—as they were leaving Stockton Residential Centre. "*King of my Castle: Rob's Story*" by Hunter Circles narrates Rob's experiences living in the community (Hunter Circles 2022). International examples include the late Robert Martin's memoir (McRae 2014). Robert Martin was a New

Zealand disability rights advocate and the first member with intellectual disability of the CRPD Committee.

These examples of personal accounts are extremely important to understanding both institutional legacies and enduring impacts on people's lives, and pathways from disability institutions. Authors Steele, Carnemolla, and Kelly's foundational research discussed earlier in this section provides evidence that people with intellectual disability want their stories to be told. The research also indicates young people with disability who may not have had experience of disability institutions themselves recognise the importance of hearing the stories of being in disability institutions and learning about the activism of older generations of people with intellectual disability who paved the way for institutional closures and recognition of disability rights (Steele et al. 2023).

3. Our Way of Working Together

This article documents a series of conversations we held as a team reflecting on future stages of our research program on Remembering Disability Institutions and related knowledge-sharing activities. The conversations we document are a form of collaborative reflection focusing on the perspectives of team members with intellectual disability who are co-authors, co-researchers, and self-advocates.

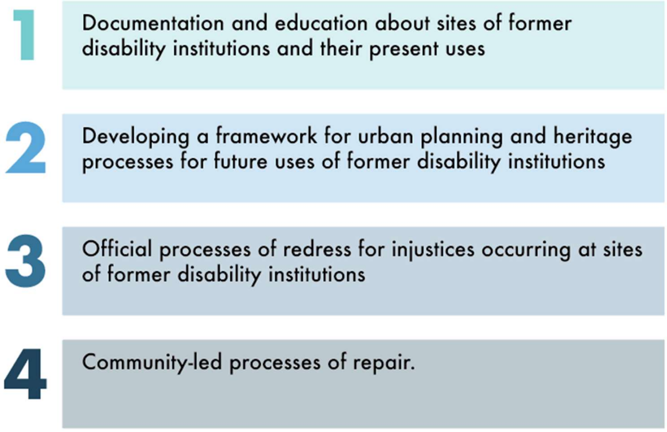
3.1. Research That Led Us to Our Conversations

The first stage of research involved authors Steele, Carnemolla, and Kelly, with a larger team of researchers, speaking to people with intellectual disability about disability institutions (Steele et al. 2023). This research project was approved by the University of Technology Sydney Human Research Ethics Committee ETH20-4755. People with intellectual disability told us the public should remember and learn about disability institutions. This was considered an important foundation for recognising what happened in disability institutions, celebrating self-advocacy, stopping further injustices against people with disability, and improving recognition of people with disability's human rights and their access to appropriate supports and participation in their local communities. Importantly, remembering the *past* of disability institutions was seen as important to *present and future* human rights recognition.

In this first stage of research, we spoke to people in New South Wales, Australia. We did not speak with people with intellectual disability who had lived in disability institutions. There are several reasons why. Some people do not want to speak about their experiences in disability institutions. Many people who lived in disability institutions may have moved away, whereas others have since died, making it very difficult to find people with lived experience in disability institutions. However, we did speak to people who identified their experiences as aligning with features of disability institutions, such as having been incarcerated in prison, studying in segregated schooling, and living in a group home. An Easy Read version of our results has been published by the Council for Intellectual Disability (n.d.a) and published in research outputs (Carnemolla and Steele 2024; Steele et al. 2023).

One finding of the research project was the importance of intergenerational learning between older and more experienced advocates, and younger people with disability. This finding provided the basis for a successful funding application by the Council for Intellectual Disability in collaboration with co-authors Carnemolla and Steele to the New South Wales Government's Disability Advocacy Futures Program. The funding is supporting a project during 2023 and 2024 identifying key lessons from disability self-advocacy in relation to deinstitutionalisation and community inclusion (University of Technology Sydney Human Research Ethics Approval ETH24-9330). The project involves focus groups with a range of self-advocates across generations, ages, and levels of experiences. Rather than focusing on experiences of disability institutions themselves, the project focuses on knowledge exchange and capacity building, and celebrating successes of self-advocacy. The project will produce two videos sharing key lessons, an Easy Read summary for self-advocates and other people with intellectual disability, and a learning resource for government and broader community to facilitate their engagement with this important history and body of knowledge.

Parallel to development of the intergenerational self-advocacy project, authors Carnemolla and Steele were interested in developing a broader program of research in collaboration with the Council for Intellectual Disability, taking forward the various threads in the findings. They had identified four areas arising from the findings of the first stage of research. These four areas take sites of former disability institutions as a lens through which to explore contemporary disability rights and inclusion. These are illustrated in the Figure 1 below:



1. Documentation and education about sites of former disability institutions and their present uses
2. Developing a framework for urban planning and heritage processes for future uses of former disability institutions
3. Official processes of redress for injustices occurring at sites of former disability institutions
4. Community-led processes of repair.

Figure 1. Four areas of interest to explore in our conversations.

We were also interested in how to situate this work in connections with First Nations people with disability, First Nations' connection to Country, and Australia's settler colonial context. These are vital dynamics of Australia's disability history, present and future (Avery 2018) we had not been able to explore in depth in our earlier work.

The program of research was timely and even urgent. Closures of remaining disability institutions in New South Wales meant the future use and processes related to sites of former disability institutions was time-sensitive. The final recommendations of the Disability Royal Commission overlooked systematic redress for people with disability who have experienced violence, abuse, neglect, and exploitation, including in the context of disability institutions. Author Kelly was particularly concerned about progressing advocacy towards a national apology (Kelly et al. 2023). Author Creighton has been a leader in the Hunter region of NSW in advocating for community inclusion for people moving out of disability institutions, including the Stockton Centre (Community Disability Alliance Hunter 2016), and our research coincides with a period of uncertainty about the future use of the site of the former Stockton Centre.

As part of continuing to develop our research program, the team (co-authors) came together in a series of reflexive and sensemaking activities. These conversations were an important step to consolidate the research undertaken to date and listen to members of the team who are also self-advocates and people with intellectual disability about how to progress activities arising from this research and guide further research projects.

From the first project, we learned people with intellectual disability agreed on the importance of sharing institutional histories more widely throughout our communities—in schools, with disability support staff and organisations, and with young people with disability. However, we did not explore in detail what content should be shared or how. We also did not explore what an apology or redress might involve. While our first project established importance of education directed towards people with intellectual disability (additional to the broader community), we did not identify principles or practices that could guide accessible and inclusive learning. Thus, we needed to further develop our future research in terms of key research questions and topics, and research outputs and outcomes. Our conversations documented in this paper are designed to inform these next steps.

3.2. Our Reflexive Approach

Underpinning this research program, and our work together in this article, is the principle that research investigating and affecting the lives of people with disability must be inclusive at all stages and shaped by input from people with disability. In line with this principle, this article contributes to the knowledgebase on inclusive research by reflecting on and documenting our processes that sit behind the substantive findings of our research project. We are reflecting on our practice together and documenting activities driving the direction of new research. Through this we are sharing how inclusive research encapsulates collectively exploring, scoping, and deciding upon what is important to remember from research already undertaken, and what research to embark upon next. Thus, we show how inclusive research is not limited to involving people with intellectual disability as research participants or co-researchers in data-collection activities such as interviews or focus groups. Reflexive approaches have been applied in many inclusive research projects to incorporate and document personal experience. For example, Carnemolla et al. (2022) reflected as a team of diverse researchers as a way of sharing what they learnt through their experiences working together. Other papers have documented or reflected on their inclusive research approaches and processes using autoethnographic writing (Milner and Frawley 2019; Schwartz et al. 2020; Schwartz and Durkin 2020). Experiences of individual researchers with intellectual disability have also been documented (White and Morgan 2012), and the process of building inclusive teams has been explored (Strnadová et al. 2014).

As a team, we could see value in finding a way to fund the conversations after the completion of the funding period for one stage of our Remembering Disability Institutions research and before the start of funding for a new stage of that research. In previous research, this “in between project” time has manifested as a funding gap (Carnemolla et al. 2022), particularly in terms of paying for labour related to developing new projects and preparing knowledge translation and research presentations of project findings of completed projects. However, for this program of research we were funded by the University of Technology Sydney Disability Access and Inclusion Fund to work in this “gap” to build the direction of the next stages of research, also providing the basis for funding applications for further specific projects. These conversations ensured all team members were recompensed for their time, and we had a process of extending and continuing the team knowledge, experience, and collaboration. These funds meant conversations could be held to support progression of our research program in ways meaningful for our experienced co-researchers, as well as people with intellectual disability more broadly. Funds also covered costs related to presenting at the 2023 Australasian Society for Intellectual Disability on the first stage of the project (by Carnemolla and Kelly) and emerging ideas related to the reflective discussions (by Steele and Creighton).

Reflections in this paper were captured between August 2023 and January 2024 as a series of group discussions in person and online between the co-authors. Jack Kelly and Leigh Creighton reflected on the four areas of further research identified above in Figure 1, drawing on their perspectives as people with intellectual disability and self-advocates, and their involvement in the first stage of the project. In the following discussion, we use initials to refer to our team members to attribute specific contributions to the discussions. First, we describe each team member and the ways each has worked on the program of research being discussed.

Jack Kelly (JK) is an Honorary Research Fellow of University of Technology Sydney and a disability advocate with lived experience of disability. JK has been involved in the program of research for 2 years. He was involved in sensemaking of empirical findings in the first stage of research, and then as a co-author on a research output related to that project (Steele et al. 2023). At the time of writing, JK is an inclusive research co-researcher, a self-advocate, and a project worker for the disability advocacy organisation, the Council for Intellectual Disability.

Leigh Creighton (LC) is a long-term advocate for the closure of disability institutions in New South Wales, Australia (Community Disability Alliance Hunter 2016). LC was involved as a research participant in the first stage of research. LC consults to the Council for Intellectual Disability and is passionate about sharing his experience as a person living with Down syndrome.

Phillippa Carnemolla (PC) is employed by University of Technology Sydney as an academic in the Faculty of Design Architecture and Building. PC has worked on inclusive research projects in partnership with the Council for Intellectual Disability since 2018 and joined with LS's initial application related to the Remembering Disability Institutions research, along with Leanne Dowse, Council for Intellectual Disability and People with Disability Australia.

Linda Steele (LS) is employed by University of Technology Sydney as an academic in the Faculty of Law. She was previously a lawyer at the Intellectual Disability Rights Service and now serves on its board. LS initially applied for funding to undertake the first stage of the Remembering Disability Institutions research following an earlier project on sites of conscience in the context of child welfare institutions in collaboration with the Parramatta Female Factory Precinct Memory Project (Steele et al. 2020).

Group discussions (between PC, LC, LS, and JK) were intended to explore JK and LC's perspectives as advocates and researchers on the four areas identified from findings of the first stage of research (see Figure 1), in order to shape future direction of the research program. Perspectives were specifically sought on research outcomes and what outputs should be focused on and who these should be for. For each discussion, PC and LS framed a list of open questions designed to explore JK and LC's perspectives on important next steps. Notes were taken at each discussion, and questions asked were framed around:

How should we progress our research and who should be involved as researchers and research participants?

In what ways should we share our research findings? What types of research outputs should we design and how?

The questions related to three themes—overarching aspects of research practice, research areas related to current and future uses of sites of former disability institution, and official and community-led redress for institutionalisation.

4. Reflections

In this section, we present the contributions of JK and LC to the conversations. Here we document responses to questions posed in Table 1.

Table 1. Semi-structured questions used to guide our conversations.

Discussion Topic	Sample Questions
Research Method, Outcomes, Outputs	What is important for us to learn more about through our disability institutions research? How should we involve people who have lived in disability institutions in our research? Who should we work with? And why? What are your thoughts on disability accommodation given our research findings linked these settings to institutional experiences?
Remembering (existing and future uses of sites)	What should we prioritise in our research on ways to remember people who lived in disability institutions who have died? Maps: Discuss the value of a map of former disability institutions, who is it for, what is included, where should it be displayed? Books/Stories/Education: Discuss thoughts on sharing more stories about disability institutions from the perspectives of people with intellectual disability.
Redress (official and community redress)	What should we prioritise in our research on what government should do for people who lived in disability institutions? Should we explore how people who lived in disability institutions can have a say in what the government does?

4.1. Researching

Ensuring people with intellectual disability are engaged in future research and decision-making related to the Remembering Disability Institutions research was of the utmost importance in the conversations.

In reflecting on what is important for us to learn more about with our disability institutions research, JK wanted to share information about what happened in institutions. This information should include stories from people with intellectual disability who lived there. JK also wanted people with disability to have a say about what happens to disability institutions that still need to close.

In reflecting on how we involve people who have lived in disability institutions in our research, JK advised we need to connect with people with intellectual disability from around Australia working towards an apology. In further research, we can talk to more people with intellectual disability who live in disability institutions. We should ask them what they want people to know about the institutions.

In our first research project, group homes and prisons were also identified by research participants as types of institutions (Steele et al. 2023). For this reason, it was important for us as a team to consider how former disability institutions may link to people with disability's current experiences of disability support, incarceration, community participation and living arrangements. JK and LC had strong and clear views on this, seeing exploration of this connection between former disability institutions and contemporary disability accommodation as vital to ensuring research on the past can shape current living conditions. Emerging from these conversations is recognition that remembering and learning about disability institutions and understanding links between historical narratives and current structures is important for repairing past wrongs and reshaping government and societal understanding of truly inclusive places and practices.

Drawing on his experiences as a leading self-advocate and peer supporter in the Hunter region who has been involved in supporting people transitioning out of the Stockton Centre into disability accommodation, LC said the government apology for disability institutions must include people living in group homes. LC referred to group homes as mini-institutions. Some group homes have security fences. Some people who live in group homes cannot get out and spend time with friends. Some people who live in group homes are being bullied and abused. LC emphatically stated people living in group homes might have a disability, but they are people first.

In contrast, JK reflected on the connection between former disability institutions and the Australian National Disability Insurance Scheme (NDIS)-funded disability support and accommodation. The NDIS is Australia's national funding scheme that provides funds for people with disability. Funds may include accommodation, supports, and services, and are allocated based on assessments of eligibility and individual need (NDIS n.d.). JK highlighted the importance of choice in living arrangements as being an ongoing issue for people with disability, even under the National Disability Insurance Scheme. JK reinforced the need for better quality and safeguard systems in place to prevent providers from making housing decisions based on financial viability of models linked to disability support type, not considering the compatibility of housemates, or not prioritising the living arrangement preferences of the people with disability to whom they provide support.

4.2. Remembering

As a team, we reflected on how we communicate the histories of disability institutions. It was agreed there were two main ways of sharing knowledge with wider communities. One way is using maps and timelines to communicate information about buildings and sites to provide place-based disability history. The second way is by sharing stories of people who lived in disability institutions.

In the conversations, we discussed how mapping former sites of disability institutions could be a useful way to give visibility to the prevalence of disability institutions in particular locations, given many are no longer physically apparent because they have been closed and reused. Mapping was proposed by PC and LS in light of other projects around the world (Cultural Heritage Online n.d.; Reparations Task Force 2023; Justice for Magdalenes Research 2017; Palomba 2020; Carnemolla et al. 2023), and broader approaches to radical cartography. PC and LS were particularly interested in how mapping could communicate lived experiences and how maps could be made accessible (Carnemolla et al. 2023).

Design and sharing of an Australian map of all former disability institutions was discussed in detail to explore what types of institutions should be included on such maps; what information could be shared on a map and why; where such a map is displayed or accessed (e.g., online or in a book); what area the map covers; how the map is designed and who contributes to it; and who the main audience is for a map (including if it is for people with intellectual disability).

JK and LC agreed any mapping process should be available to the public. The idea of the map published as a book was also discussed, with a clear position that books play an important role for specific audiences, and the map should be available to wider audiences and be able to be updated. For example, JK reflected that a public version of a map should not be in a book, because it will get stuck on a shelf somewhere. The map could be online so it can be edited and updated as more information about disability institutions is discovered. LC advised the map could have photos and images about when each disability institution opened and when it closed. He also suggested a similar map of disability segregated schools.

We considered the audience of a map of former disability institutions and how that would inform the way we communicated information. JK suggested two versions—one for researchers such as PC and LS who want detail, and one for people such as JK and LC who want something more useful and beautiful. LC agreed on two versions, including with a version in Easy Read that could be downloadable and printed at home.

We also considered thinking beyond a printed map. We explored the idea of a map as an installation. We all agreed this would be a unique opportunity to engage with the wider community in a museum or gallery. LS discussed the floor map in the District Six Museum in South Africa, where former residents of the racially segregated District Six and their families could add information to the map. LC and JK supported a similar approach with a floor map of institutions at the front door of the museum, which could be made by people with disability.

A sensitive approach to information was a key concern in our discussions. Throughout our conversations, JK and LC were very clear that each act of knowledge sharing about disability institutions comes with great sensitivity. LC acknowledged some people would not like to read this information and some people would. JK noted we would have to make sure information on a website is respectful and knowledgeable and is not too graphic and would not open old wounds for people with intellectual disability. On the other hand, JK noted knowledge sharing involved a fine line because we would not want to shy away from what has happened in disability institutions. Similarly, LC was of the view he did not want knowledge sharing to require people who lived in disability institutions to open old wounds associated with their experiences. He emphasised it is important to remember people keep on having nightmares about when they lived in disability institutions. If we talk with them about disability institutions, they could get upset and think about suicide. People who do not communicate through words might have difficulty expressing their feelings. Ultimately, LC concluded talking about disability institutions might be hard, but it is important we talk about them and hear stories of people who experienced them.

4.3. *Redressing*

We focused part of our conversations around the role and actions of governments in recognising the histories (both individual and collective) of disability institutions. This was particularly important given governments' roles in funding and operating disability institutions, and making laws and policies about disability institutions. Here, we reflect on our opinions about redress, apology, and who should be remembered.

The clear message arising from these conversations is governments should be involved in redress, including apologising and providing compensation to people with disability who lived in disability institutions. JK felt strongly about the need for a government apology. JK explained Australia cannot make the disability system better until past harms are acknowledged and accepted, and sorry is said for what happened in the past to people who were forced to live in disability institutions. JK talked about an apology being a clear and public acknowledgement that past ways of treating and institutionalising people with disability were wrong; it is an important starting point for change and is relevant today, even many years after disability institutions have closed.

LC emphasised governments should give a public apology to all people who have been in disability institutions. Apology was necessary because people were locked away and their lives destroyed. They screamed to get out, but their screaming was seen as a behavioural problem, and no one helped them. LC was also of the view governments should also give compensation to people who lived in disability institutions who are still alive. They need compensation because their lives were taken away from them. They missed out being in the community. They had their independence taken away. They missed doing things everyone else does. LC proposed we must also remember the people who lived in institutions who have died in order to acknowledge what they contributed during their lives. LC drew on his personal experiences of having a cousin who lived in the Stockton Centre and passed away.

LC reflected on whether people who lived in disability institutions have a say in what governments do with former sites. He advised they must help decide how disability institutions are remembered because they have lived experience of disability institutions.

5. Discussion

We had the opportunity to create a space for conversation about, and reflection on, our disability institutions research. Through our conversations, we considered some difficult questions about why this is a sensitive research topic, and how we progress this important body of community-led work. Our discussion confirmed the necessity of a trauma-informed approach and being careful about the content we share, the way research is conducted, and the audiences we seek to engage with and guide.

Together we shared information and exchanged ideas to shape our future work together and how we share this knowledge with the wider community, including:

- Importance of continued efforts towards a formal apology by government to people who were forced to live in disability institutions.
- Ongoing trauma-informed approaches—the sensitivity of the information and the need to carefully consider audiences of future knowledge-sharing.
- Ongoing relevance of institutional practices now, in relation to disability support and disability accommodation.
- Creation of new ways to communicate institutional histories, such as maps or books, must be engaging and meaningful for people with disability, and be available in relevant formats to researchers, government, and wider communities (of all ages, and both disabled and non-disabled).
- People with intellectual disability are end-users of research, and thus research outputs should always be designed with their needs in mind.

Our reflexive discussions provided nuance and depth to the four areas of research that emerged from the first stage of the Remembering Disability Institutions research. During our discussions, we used a visual representation of the four areas of research that emerged from our research—this was drawn by LS and used as a visual reference during our conversations. As a result of our discussions, we revised our four areas into five areas, with co-author PC drawing a new diagram. A key addition was a fifth area on community-inclusive practice to capture the significance of using disability institution experiences and histories to transform practices in current disability accommodation settings and wider communities. This addition was confirmed with JK and LC and is illustrated in Figure 2 below. This forms five action pillars, which provide our planned research path to continue our inclusive research program about looking back when moving forward from disability institutions.

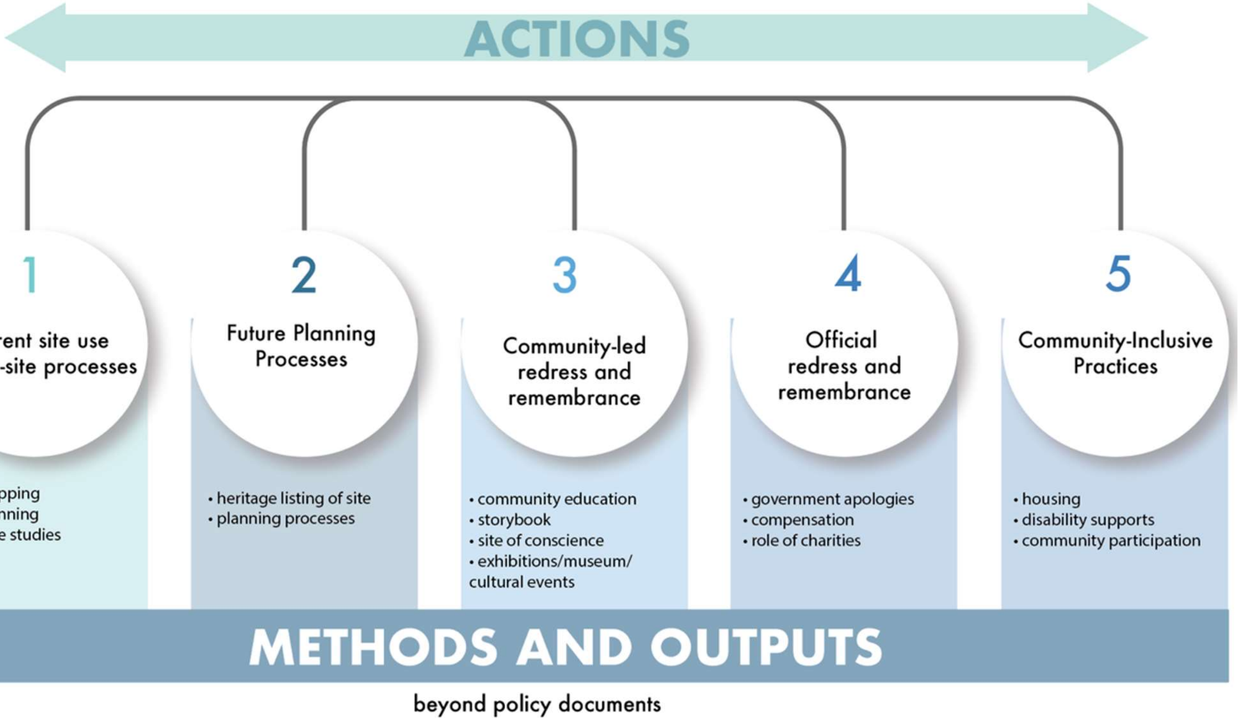


Figure 2. The five action pillars related to remembering and repairing based on reflexive discussions about disability institutions.

The five action pillars are:

1. Current use: research exploring the erasure of experiences of institutionalisation communicated through educational resources and maps about the current use of sites of former disability institutions;
2. Reparative planning processes: research developing frameworks for alternative approaches to planning and heritage processes supporting alternative uses of former sites of disability institutions;
3. Official recognition and redress: research exploring perspectives on governments formally recognising and remedying experiences of people with disability who were institutionalised;
4. Community-led repair and remembrance: research identifying practices for both celebrating advocates with disability, and reckoning with and repairing familial and social bonds broken through institutionalisation;
5. Community-inclusive practices: research exploring endurance of institutional practices in disability accommodation located in community settings.

These five pillars are underpinned by three foundational layers: advancing disability human rights; reckoning with intersections between disability institutions and settler colonialism, other dynamics of oppression, and eugenics; and using inclusive practices.

Our discussions as a team also highlighted research having concrete outcomes in the present-day lives of people with intellectual disability. For PC and LS, this underscores the importance of accountability in research to people with intellectual disability and ensuring research is always directed towards change (Veitch and Rinaldi 2024). Prioritising concrete outcomes gives rise to an additional way of structuring our program of research around three interconnected outcomes driving research—remembering, repairing, and reshaping illustrated in Figure 3 below.

Figure 3. Research outcomes based on the reflexive discussions.

6. Conclusions

This paper highlighted reflexive and sensemaking activities arising from a diverse research team working on inclusive research with people with intellectual disability. More specifically, these activities centre on team discussion to guide the future of our research program of Remembering Disability Institutions (Carnemolla and Steele 2024; Steele et al. 2023; Kelly et al. 2023). This paper discusses the perspectives of researchers (and co-authors) JK and LC, who are also disability advocates, on what are important aspects of ways forward in our research and community knowledge sharing.

Together, the co-authors reflected on the research that they had undertaken so far, and LS and PC asked JK and LC what was important to them as we discussed together the next steps and, as disability advocates, how they thought knowledge from the research we collaborated on should be shared beyond this project. Of primary importance is that conversations such as these will ensure investment in research is targeted to areas of significance and relevance to PC and LS's colleagues and co-researchers' lived experiences and extensive expertise in disability advocacy on institutionalisation. This reflection contributes to the development of ideas, as well as shapes the direction of future funding applications and research projects. It is important for us as a team to progress the research responsibly, and this approach is one way we build in accountability to the community to which our research relates.

As we work toward the next phase of our program of research, PC and LS are beginning to engage with communities connected to specific sites of former disability institutions across Australia. JK, PC and LS are building connections with researchers and self-advocates overseas. We are also, as a team, working alongside advocacy organisations to hold conversations with local government members, State government members, and government property managers. We are focused on using our research to help guide these leaders and departments on ways to ensure processes to determine the future uses of former sites of disability institutions engage with and are led by people with disability themselves. The conversations documented in this paper are significant in locating future work together in a disability-led reparative framework. This framework moves forward from disability institutions in a way that properly recognises the experiences and expertise of people with intellectual disability and positions them as best-placed to lead our communities towards a future where disability institutions and their practices are not replicated. While focused on the Australian context, our research provides inclusive research approaches and critical framings and connections to re-imagine the afterlives of disability institutions in other countries and show how research can contribute in new ways to global efforts to realise the human right to independent living and community inclusion.

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