



## **Listening to People with Intellectual Disability about Institutions.**

### **Plain English Summary**

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#### **Introduction**

Despite 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 20<sup>th</sup> century of deinstitutionalisation efforts (historic institutions) and the people who lived there. An interdisciplinary team of researchers undertook research with people with intellectual disability to explore what and how the public should learn and remember historic institutions. The research team included researchers with intellectual disability, and representatives from Australian Disabled People's Organisations Council for Intellectual Disability and People with Disabilities Australia.

#### **Methodology**

The project methodology aligns with the disability rights movement's 'Nothing About Us, Without Us', drawing on inclusive research methods and a 'disability human rights methodology'. A self-advocate and person with lived experience of institutions, helped with the design of the project. Nine people with intellectual disability participated in focus groups. A trained counsellor with experience working with people with intellectual disability and their families was present at the focus groups and also available afterwards. Participants were asked: what should the public know about historic institutions, how should this information be shared, and how should historic institutions be publicly remembered?

#### **Summary of main findings**

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 have varying levels of knowledge about historic institutions and there is no singular, shared understanding amongst people with intellectual disability of 'institutions'. 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 is important.



People with intellectual disability explained that the history of historic institutions is complex and nuanced. It encapsulates experiences of both people with intellectual disability and their families, and dimensions both of harm and injustice and resistance and rights. A nuanced approach must be taken to how historic institutions are represented, with sensitivity in understanding the circumstances of people with intellectual disability and their families.

It is important for the public to learn about historic institutions. The reasons why fall within four areas. Firstly 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. 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. A third set of reasons relate to accountability and redress. A fourth set of reasons concerns public learning as a basis for deeper understanding 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.

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. These groups are: school children, politicians and public servants in order to inform decisions about disability policy, workers who support people with disability, and people with intellectual disability (particularly younger people with intellectual disability who have not grown up with historic institutions as a dominant aspect of Australian society).

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.

People with intellectual disability should lead these initiatives, with appropriate support in recognising the very live memories and traumas associated with them.

### **Summary of main implications**

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. 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. More exploration with intellectual disability advocacy organisations around how histories and lived experiences of historic institutions can inform advocate training and rights education and systemic advocacy.

This article provides a model of inclusive research for turning harms of past institutionalisation into an educational and reparative experience. Taking time to discuss key concepts and identify shared and divergent understandings is important.

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.

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.

### **Find out more**

Council for Intellectual Disability: <https://cid.org.au/>

Council for Intellectual Disability campaign to stop redevelopment of site of former disability institution: <https://cid.org.au/our-campaigns/peat-island/#:~:text=In%202022%20the%20NSW%20Government%20made%20the%20Darkinjung,return%20of%20Peat%20Island%20to%20the%20traditional%20owners>

People with Disability Australia: <https://pwd.org.au/>

Author bio Linda Steele: <https://profiles.uts.edu.au/Linda.Steele>

Author bio Phillippa Carnemolla: <https://profiles.uts.edu.au/Phillippa.Carnemolla>

Author bio Leanne Dowse: <https://research.unsw.edu.au/people/emeritus-professor-leanne-dowse>

Journal article on disability institutions as sites of conscience: <https://journals.sagepub.com/doi/abs/10.1177/26326663221103435>

Journal article on inclusive research: <https://www.mdpi.com/2076-0760/11/5/182>

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