

# SITES OF CONSCIENCE

Place, Memory, and the Project  
of Deinstitutionalization

Edited by Elisabeth Punzi and Linda Steele



**UBC**Press · Vancouver

# Contents

---

Acknowledgments / viii

Introduction: Sites of Conscience, Social Justice, and the  
Unfinished Project of Deinstitutionalization / 3

LINDA STEELE and ELISABETH PUNZI

**Part 1: Centring Survivor Voices and Experiences in the  
“Afterlives” of Disability and Psychiatric Institutions / 27**

**1** Historical Memory, Anti-psychiatry, and Mad People’s  
History / 29

GEOFFREY REAUME

**2** Contested Memorialization: Filling the “Empty Space”  
of the T4 Murders / 46

ELENA DEMKE

**3** Names on Frosted Glass: From Fetishizing Perpetrator  
Mindsets to Disability Memorialization of the Victims / 64

DAVID T. MITCHELL and SHARON L. SNYDER

**4 Truth, Reconciliation, and Disability Institutionalization in Massachusetts / 80**

An interview with ALEX GREEN

**5 “I’m Not Really Here”: Searching for Traces of Institutional Survivors in Their Records / 91**

JEN RINALDI and KATE ROSSITER

**6 Listening to Peat Island: Planning, Press Coverage, and Deinstitutional Violence at a Potential Site of Conscience / 109**

JUSTINE LLOYD and NICOLE MATTHEWS

**7 “The Old Concept of Asylum Has a Valid Place”: Patient Experiences of Mental Hospitals as Therapeutic / 126**

VERUSCA CALABRIA and ROB ELLIS

**Part 2: Learning from Sites of Conscience Practices / 143**

**8 Benevolent Asylum: Performance Art, Memory, and Decommissioned Psychiatric Institutions / 145**

A conversation with BEC DEAN, LILY HIBBERD, and WART

**9 Constructing History in the Post-institutional Era: Disability Theatre as a Site of Critique / 166**

NIKLAS ALTERMARK and MATILDA SVENSSON CHOWDHURY

**10 The Workhouse and Infirmary Southwell: Collaboration with Learning-Disabled Neighbours and Partners / 182**

An interview with JANET OVERFIELD-SHAW

**11 Intellectual Disability in South Africa: Affirmative Stories and Photographs from the Grahamstown Lunatic Asylum, 1890–1920 / 196**

RORY DU PLESSIS

**12 Pathways to Disrupt Eugenics in Higher Education / 213**

EVADNE KELLY and CARLA RICE

- 13** “You Just Want to Do What’s Right”: Staff Collusion in Institutional Abuse of People with Learning Disabilities / 231

NIGEL INGHAM, JAN WALMSLEY, and LIZ TILLEY

**Part 3: Social Justice and Place Making in the Absence of Sites of Conscience / 249**

- 14** A Place to Have a Cup of Coffee: Remembering and Returning to a Dismantled Psychiatric Hospital / 251

HELENA LINDBOM and ELISABETH PUNZI

- 15** A Sense of Community within a Site of Amplified Stigma: The Strange Case of Spookers / 266

ROBIN KEARNS, GRAHAM MOON, and GAVIN ANDREWS

- 16** Naming Streets in a Post-asylum Landscape: Cultural Heritage Processes and the Politics of Ableism / 283

CECILIA RODÉHN

- 17** “We Bent the Motorway”: Community Action on Exminster Hospital / 298

NICOLE BAUR

List of Contributors / 315

Index / 322

## Introduction

# Sites of Conscience, Social Justice, and the Unfinished Project of Deinstitutionalization

---

LINDA STEELE and ELISABETH PUNZI

Despite the closure of many large disability and psychiatric institutions during the past four decades, deinstitutionalization remains an unfinished project. It is a project that includes open-ended failures – transinstitutionalization<sup>1</sup> and the continued operation of many disability and psychiatric institutions – that sustain oppression and undermine the popular assumption that the closure of disability and psychiatric institutions has delivered social justice to disabled people and to people experiencing mental distress. In 2020 and 2021, with the unfolding worldwide events of COVID-19 and their disproportionate and lethal impacts on disabled people and on people experiencing mental distress, we were reminded that although we might think of disability and psychiatric institutions as relics of the past, many disabled people and people experiencing mental distress still live in institutions such as long-term care homes, group homes, disability residential centres, mental health facilities, and prisons. Indeed, it is becoming increasingly apparent that long-term care homes (also known as nursing homes and aged care facilities), which house older and disabled people, are particularly lethal institutions that have largely survived the deinstitutionalization project (Dehm, Loughnan, and Steele 2021; Herron, Kelly, and Aubrecht 2021) and now sit at the margins of social justice activism and critical scholarship on disability and psychiatric institutions. COVID-19 provided an important reminder that the persistent existence of disability and psychiatric institutions presents ongoing challenges to the realization of social justice, that deinstitutionalization

is an ongoing necessity (Knapp et al. 2021; Quinn 2021), and that the disability and Mad<sup>2</sup> communities' institutional experiences of violence and death over decades and centuries demand action and justice (Page and Pandit 2020; Sheldon, Spector, and Wildeman 2020; Wong 2020). It is thus increasingly urgent that we find new ways to understand and engage with the endurance of institutionalization and with the unfinished deinstitutionalization project and its open-ended failures.

This edited collection engages with specific historical moments and sites of deinstitutionalization to consider afresh how disability and psychiatric institutions impact social justice for disabled people and for people experiencing mental distress. This collection explores how memories and places of former disability and psychiatric institutions can provide more intimate, nuanced, and materially grounded insights into the ongoing roles that institutionalization and, indeed, deinstitutionalization play in the oppression of disabled people and of people experiencing mental distress. We propose that it is the ongoing commitment to keeping alive the heritage and memories of these places, the humanity of the individuals who resided there, and the experiences of survivors, rather than the simple closure of these institutions, that holds the greatest potential for community recognition, accountability, and action on institutionalization, institutional violence, and current disability and psychiatric oppression. Ultimately, realizing social justice might in part be connected to the disability and psychiatric institutions themselves and depend on what we as communities, activists, and scholars do with these places and their memories.

Our edited collection uses "sites of conscience" as a concept, analytical framework, and set of practices through which to critically re-engage with the political possibilities of specific historical moments and sites of deinstitutionalization in a context of the endurance of institutionalization and the unfinished project of deinstitutionalization. Sites of conscience practices are activities such as walking tours, survivor-authored social histories, performances, and artistic works situated on or generated from sites of systemic harm, suffering, and injustice (Ashton and Wilson 2019; Brett et al. 2007; Ševčenko 2002). These practices are premised on the persistence of past injustices in the present and are directed toward eliciting within the community greater understanding of and commitment to addressing the continuity of injustice across time and the ongoing perpetration of further harm. These practices connect histories of place to contemporary social issues in order to move the community toward action for social change. Sites of conscience practices are already being used in relation to a number

of former disability and psychiatric institutions, such as in Canada, Australia, England, and the United States, and there is much potential for broader engagement with sites of conscience by the disability and Mad communities, by critical disability, Mad, and critical mental health scholars, and by practitioners in heritage, planning, human rights, law, and policy-making. Moreover, the collection connects sites of conscience with current experiences of eugenics logics and settler colonialism, thereby illuminating how the pressing social justice issues encountered by disabled people and by people experiencing mental distress are interrelated with the political struggles of diverse marginalized populations.

In this introduction to the collection, we first map out where deinstitutionalization and social (in)justice critically intersect with heritage, materiality, and memories of disability and psychiatric institutions. Next, we discuss sites of conscience and then introduce how each chapter engages with the thematic concerns of the book.

### **Deinstitutionalization, Transinstitutionalization, and Social (In)justice**

“Disability and psychiatric institutions” is a term used in this collection to refer specifically to “large-scale residential settings in which disabled people [and people experiencing mental distress] live in circumstances of congregation and confinement and are segregated and isolated from the community, purportedly in order to achieve goals of health, welfare and control” (Steele 2022, 3). Although often associated with a particular architectural form – large, old-fashioned brick buildings – disability and psychiatric institutions are characterized by the power dynamics of coercion, control, violence, and dehumanization (Chapman, Carey, and Ben-Moshe 2014; Rossiter and Rinaldi 2018). The United Nations Committee on the Rights of Persons with Disabilities (2022, 2–3) has offered a definition of institutions and institutionalization:

There are certain defining elements of an institution, such as obligatory sharing of assistants with others and no or limited influence as to who provides the assistance; isolation and segregation from independent life in the community; lack of control over day-to-day decisions; lack of choice for the individuals concerned over with whom they live; rigidity of routine irrespective of personal will and preferences; identical activities in the same place for a group of individuals under a certain authority; a paternalistic approach in service provision; supervision of living arrangements; and a disproportionate number of persons with disabilities in the same environment.

Institutionalization of persons with disabilities refers to any detention based on disability alone or in conjunction with other grounds such as “care” or “treatment.” Disability-specific detention typically occurs in institutions that include, but are not limited to, social care institutions, psychiatric institutions, long-stay hospitals, nursing homes, secure dementia wards, special boarding schools, rehabilitation centres other than community-based centres, half-way homes, group homes, family-type homes for children, sheltered or protected living homes, forensic psychiatric settings, transit homes, albinism hostels, leprosy colonies and other congregated settings. Mental health settings where a person can be deprived of their liberty for purposes such as observation, care or treatment and/or preventive detention are a form of institutionalization.

Since the late twentieth century and continuing through to the present day, many nations have engaged in processes of “deinstitutionalization,” which refers to the closure of disability and psychiatric institutions and the movement of former residents into community settings. Deinstitutionalization is frequently hailed as a significant milestone in disability rights during the mid- to late twentieth century, and it is seen as providing an impetus for the introduction of rights-based legislation (such as the Americans with Disabilities Act in the United States) that has impacted the lives of disabled people (Downey and Conroy 2020). However, with regard to social justice, many have questioned the negative impacts and unintended consequences of deinstitutionalization for disabled people and for people experiencing mental distress.

One of the most enduring and popular criticisms of deinstitutionalization is that the closure of disability and psychiatric institutions was not matched by sufficient community-based housing and supports, resulting in many former residents being subjected to inequality, criminalization, and even transinstitutionalization (Topor et al. 2016). Often, this criticism claims that deinstitutionalization has failed, and it calls for a return to the institution model of housing and support. Scholar of critical disability studies Liat Ben-Moshe has criticized this argument. She proposes that this framing attributes the root cause of failure to individual, untreated mental distress, thus overlooking the structural conditions that drive inequality, criminalization, and incarceration, enable state irresponsibility, and justify non-consensual psychiatric treatment and detention (Ben-Moshe 2017). Building on Ben-Moshe’s criticisms, this edited collection is not focused on simplistic and reductive approaches to deinstitutionalization.



Disability activists and critical disability and Mad studies scholars offer more complex and nuanced reflections on how the practice and rhetoric of deinstitutionalization – as an unfinished project with open-ended failures – relates to social justice. One set of criticisms focuses on understanding institutionalization, deinstitutionalization, and transinstitutionalization as parts of a broader range of practices of confinement, control, and violence. Some scholars and activists argue that former disability and psychiatric institutions are parts of a larger “institutional archipelago” of confinement and control (Ben-Moshe, Chapman, and Carey 2014, 14) or parts of a “Medical Industrial Complex” (Mingus 2015) that extends to community-based alternatives. The closure of more obvious and stereotypical brick-and-mortar disability and psychiatric institutions has the rhetorical effect of suggesting justice and progress, thus masking how control and confinement are maintained, including through the continuation of the epistemologies of disability and the models of care that shaped the treatment of disabled people and of people experiencing mental distress in disability and psychiatric institutions (Ben-Moshe 2020; LeFrançois, Menzies, and Reaume 2013). There are also connections between disability and psychiatric institutions since individuals across their life could often end up in multiple sites and systems, despite ideas about scientific and precise diagnoses and about the ability of assessments to provide absolute and singular categorizations, ideas that still prevail (Steele 2020). Moreover, disability and psychiatric institutions are interconnected with a range of welfare and penal institutions – such as child welfare homes and industrial schools, Indigenous residential schools or homes, prisons, immigration detention centres, and juvenile justice detention centres – that target a variety of marginalized populations as part of the broader logics of eugenics (Chapman 2014).

Scholars and activists have also drawn attention to the role that disability and psychiatric institutions play in settler-colonial violence by sustaining what historian Patrick Wolfe (2006, 388) refers to as the “logic of elimination” – that is, the dispossession, displacement, and elimination of First Nations and Indigenous people (Avery 2018; Burch 2016, 2021; Chapman 2014; Whitt 2021). Scholars and activists have also offered critiques of the complexities of the relationships between disability, mental distress, and reckoning with and repairing settler-colonial violence. American Indian studies scholar Dian Million (Tanana Athabascan) (2013) argues that medicalized discourses of trauma and healing that have structured reconciliation processes in Canada, including in relation to institutional violence, can fold back into, rather than disrupt, the very systems and practices of colonial control

that they are purportedly directed toward redressing. Profoundly deaf and Aboriginal scholar of the Worimi people Scott Avery (2020, 15), writing in the context of the Australian Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disabilities, states that “truth-telling is needed to expose the structural influences on the incidence and impact of violence [against First Nations and Indigenous people with disability] that otherwise remain unspoken of.”

Another set of criticisms concerns the relationship between deinstitutionalization – as an unfinished project with open-ended failures – and justice. Some argue that the disability and psychiatric institution (in its brick-and-mortar form) occupies a central position in narratives of disability rights, often positioned as the “dark past” against which a more progressive present and future are understood (Altermark 2018, 156). In this approach, deinstitutionalization – cast as a historical phenomenon – is the moment of justice. Drawing the line of (in)justice at the point of closure of the disability or psychiatric institution not only allows society to move on without reckoning with and redressing the full complexity, scope, and ongoing impacts of that institution but also obscures the continuities of violence in the “progressive” reforms and alternatives that follow closure (Steele 2022). Some critical disability and Mad studies scholars and former residents, using empirical research methods and autoethnography, have explored the ongoing harms and injustices of disability and psychiatric institutions, which have lived on well beyond deinstitutionalization and formal legal and political redress processes (Burghardt 2018; Malacrida 2015; Rinaldi and Rossiter 2021; Rinaldi, Rossiter, and Jackson 2017; Rossiter and Rinaldi 2018). In the aftermath of deinstitutionalization, some critical disability scholars and socio-legal disability scholars have reflected on activist and legal strategies for achieving legal and social justice change that is transformative, situating these objectives in a broader context of prison abolition, anti-racism, and other anti-carceral and anti-oppression struggles (e.g., see Ben-Moshe 2020; and Wildeman 2020).

### **Former Disability and Psychiatric Institutions and the Erasure of Injustice**

Activists and scholars remind us that former disability and psychiatric institutions were places where disabled people and people experiencing mental distress once lived, worked, and learned – sites not only of violence, harm, and death but also of resistance, survival, and the love and friendship of residents. They were places, too, where individuals sometimes experienced concern from compassionate staff members. Their closure is a testament to the survival, leadership, and activism of disability and Mad communities.

Yet many former disability and psychiatric institutions have been repurposed for other uses, including as hotels, spas and wellness facilities, university campuses, residential areas, business parks, community mental health centres, aged care facilities, refugee camps, and even amusement parks and haunted houses (Moon, Kearns, and Joseph 2015; Mussell, Walby, and Piché 2021). The redevelopment of these institutions forms part of the broader neoliberal trajectories of gentrification and privatization. Commonly, the heritage of former disability and psychiatric institutions becomes reduced to architectural and material features, with the oppression and resistance of former residents being sentimentalized, sensationalized, or erased rather than recognized, remembered, and redressed. In the subsequent uses of former psychiatric institutions, two strategies have been identified that reflect the typical limits of remembering the former site: strategic forgetting, achieved by co-opting institutional features such as isolation and seclusion as positive with no explicit recognition of the earlier psychiatric use of these features for repressive ends; and selective remembrance, undertaken through the heritage preservation of “architecturally-distinguished buildings” (Moon, Kearns, and Joseph 2015, 25–26, 129–30).

Planning and heritage processes do not always provide opportunities for former residents and their representative organizations to give input on decisions about the redevelopment and future uses of institutional sites (Yahm 2014). Moreover, former residents’ experiences and memories are often not even comprehensible as forming part of the heritage of a site. Here, the insights of scholars of critical heritage studies help us to understand that disability and psychiatric institutions constitute “difficult heritage” (Macdonald 2009) or do not fit within “authorized heritage discourses” (Smith 2006, 4) that present a particular view of history that conforms to nationalist ideals (McAttackney 2020). According to anthropologist and museologist Sharon Macdonald (2016), difficult heritage concerns wrongdoings perpetrated by nations. But there are always memories and counter-narratives that demand recognition. Using the example of Germany, Macdonald shows that it is possible to publicly address the horrible past and to acknowledge difficult parts of the nation’s history; it might even be a sign of moral cleanliness and strength to officially admit wrongdoings and to recognize the victims. Such transitions do not occur on their own but are the result of efforts by victims’ organizations, committed stakeholders, and pressure groups (Macdonald 2016).

In settler-colonial nations, the redevelopment of disability and psychiatric institutions on unceded lands of Indigenous and First Nations people

needs to be considered in the context of reconciliation and accountability for the institutionalization of First Nations and Indigenous peoples as one part of broader concerns with First Nations and Indigenous truth-telling and self-determination (Avery 2020). Moreover, sites of former disability and psychiatric institutions might be places of oppression and injustice for First Nations and Indigenous people, including where the construction and operation of the disability and psychiatric institutions are connected to the displacement and dispossession of First Nations and Indigenous people. If not acknowledged, these dynamics of oppression and injustice can be further entrenched through any subsequent redevelopment of such sites or through use of the site as a disability site of conscience. The sites of former disability and psychiatric institutions might be places of cultural significance to First Nations and Indigenous people, thus giving rise to questions about how any practices related to disability sites of conscience will support their custodianship of the land and their self-determination regarding the present and future use of that land. In acknowledging some of these complexities of place, scholars have identified a series of considerations at the intersection of disability, Indigeneity, and place (Larkin-Gilmore, Callow, and Burch 2021):

- Place as nourishment for our work as relatives, scholars, and activists.
- Different approaches to place: as the location where things happen; as relational with beings, identities, and systems of power; and as a cross-generational experience that impacts individuals, communities, and nations.
- The many meanings of occupation and accountability – living on other people's lands and how those lands have been used by colonial powers to disable.
- The disablement of land, water, and air, alongside living beings.

These considerations invite a nuanced and multi-layered engagement with place and land in the context of disability and psychiatric institutions and social justice.

Even though there are examples of the official remembrance of disability and psychiatric institutions (Downey and Conroy 2020; Reaume 2016), these accounts often do not recognize and reckon with wrongdoings perpetrated in disability and psychiatric institutions. On the contrary, wrongdoings might be rationalized by presenting them as innovations, or abusive interventions might be deemed necessary, or at least understandable, due to

the lack of effective treatment (Rodéhn 2020). Thereby, violent interventions and the disciplines that promoted and professions that performed them are excused rather than questioned, and oppressive practices are seen as occasional failures on the otherwise exemplary road to justice and humane treatments (Punzi 2022). Such misrecognition is not uncommon in the heritage sector, even though heritage managers and curators might have good intentions (Waterton and Smith 2010). Official acts of remembrance can focus on staff and family members' memories and agency, thus marginalizing the experiences and resistance of survivors/victims and giving rise to ongoing epistemic injustice (Fricker 2007). However, those who have been exposed to oppression in disability and psychiatric institutions are increasingly claiming their rights to remembrance and a place in history, as exemplified by the Museum der wahnsinnigen Schönheit, a "Museum of Mad Beauty," described in the chapter by Elena Demke, which a group of psychiatric survivors proposed in the 1990s to situate at the very place in Berlin where it had been decided during the Nazi era that persons classified as disabled or mentally ill should be murdered (Rotzoll et al. 2006).

Redevelopment can sever any opportunities for former residents or disability and Mad communities to have ownership or custodianship of former disability and psychiatric institutions, to influence how the history and heritage are interpreted or represented, and to access the site for purposes of healing and memorialization. The sale of property and the subsequent financial enrichment of the former owners of disability and psychiatric institutions can overlook the forced labour that contributed to the very existence and economic value of these sites (Downey and Conroy 2020; Reaume 2009).

These challenges of engaging with former disability and psychiatric institutions in ways that realize social justice, rather than erasure and oppression, provide the impetus for this edited collection.

### **Sites of Conscience, Deinstitutionalization, and Social Justice**

Sites of conscience provide opportunities for political engagement with former disability and psychiatric institutions. Sites of conscience practices are centred on "remember[ing] the past to build a better present and future," and organizers of these activities make a "specific commitment to democratic engagement through programs that stimulate dialogue on pressing social issues today and that provide opportunities for public involvement in those issues" (Brett et al. 2007, 1). Maria Tumarkin (2022, 331) defines sites of conscience as "a movement and a methodology of community-led place-making and place-tending around histories of violence, loss, dispossession,

displacement, incarceration – and so, always, in the same breath, around histories of survival, resistance and activism.”

Sites of conscience practices have been utilized in a variety of former disability and psychiatric institutions. One example is the Pennhurst Memorial and Preservation Alliance in Pennsylvania, an online museum about the former Pennhurst State School and Hospital (Beitiks 2012; Pennhurst Memorial and Preservation Alliance n.d.). Also, on Staten Island in New York, the Willowbrook Mile is a self-guided walk around former Willowbrook State School – now a campus of the College of Staten Island, City University of New York (College of Staten Island n.d.; Fritz and Iwama 2019). Moreover, the nineteenth-century brick boundary wall of the former Toronto Asylum for the Insane (now the Centre for Addiction and Mental Health), its last remaining structure, has been the epicentre of walking tours, theatre performances, and activist interventions (Reaume 2016). And in Southwell, England, the Workhouse, operated by the National Trust, is a “prototype of the 19th century” and includes the Firbeck Infirmary for poor individuals who were too sick to work in the Workhouse, an infirmary that later became a nursing home after the closure of the Workhouse (National Trust n.d.).

Sites of conscience practices are not only about remembering disability and psychiatric institutions as a historical phenomenon but also about eliciting public reckoning with the injustices of these places in terms of their continuing role in disability and psychiatric oppression, the ongoing trauma done to survivors, and the demand for collective accountability and action from the broader community. Sites of conscience practices can centre the experiences, voices, and leadership of disabled people and of people experiencing mental distress, thus serving as a form of epistemic justice (Fricker 2007). Sites of conscience practices can also involve the custodianship and control of former institutions by disabled people and by people experiencing mental distress. These practices, too, can honour the lives of former residents, can celebrate their resistance, survival, and friendships, and can sustain the ongoing and broader impact of legal or political victories associated with the closure of institutions (Steele 2022). The possibilities for disability social justice through sites of conscience intersect with the broader possibilities for disability activism through artistic practice (Kelly and Orsini 2017).

It is timely to critically engage with the political possibilities of sites of conscience both as a set of practices and as a concept and analytical framework that can enrich our understandings of the role in social justice of

the materialities, temporalities, corporealities, spatialities, and legalities of disability and psychiatric institutions, institutionalization, and deinstitutionalization. An exploration of the intersections of sites of conscience with social justice (and with narrower conceptions of legal justice and human rights) is particularly timely given the increased focus on redress, citizenship, accountability, and justice by means of the litigation and government inquiries related to disability and psychiatric institutions (and to other institutions that target a variety of marginalized populations as part of the broader logics of eugenics) that are currently underway in many jurisdictions worldwide, some of which arose in reaction to the impacts of COVID-19.

An exploration of the intersections of sites of conscience with social justice is also timely given the ongoing engagement of national governments and civil society with the United Nations Convention on the Rights of Persons with Disabilities (CRPD). Article 19 of the CRPD – which concerns the right to live independently and to be included in the community – requires signatory nations to “adopt a strategy and a concrete plan of action for de-institutionalization” (United Nations Committee on the Rights of Persons with Disabilities 2018, 12). To date, signatories have not met this obligation. However, if this obligation is to be met, the United Nations Committee on the Rights of Persons with Disabilities (2022, 7–8) has clarified that signatories must not only close institutions but also introduce legal and policy frameworks that “enable the development of inclusive community support systems and mainstream services and the creation of a reparations mechanism, and guarantee the availability, accessibility and effectiveness of remedies for survivors of institutionalization.” The committee has explained that reparations must go beyond financial compensation and extend to forms such as apologies and truth-telling (17–18).

The emerging connection in international human rights norms between deinstitutionalization and reparations suggests that the CRPD might provide openings to explore the role of the memories, geographies, and materialities of former disability and psychiatric institutions in reparations, thus helping to bring about the broader realization of disability human rights. Indeed, survivors and their allies, as well as human rights and transitional justice movements in other contexts – such as after conflict, Apartheid, slavery, and colonialism, and more recently after the closure of Indian Residential Schools and Magdalene Laundries – have engaged with sites of conscience practices as part of structural justice and in efforts aimed at eliciting state and community accountability (Cooper-Bolam 2019; McAtackney 2020; Ševčenko 2011a, 2011b; Toth and Hibberd 2021). However, political



pressures giving rise to the closure of disability and psychiatric institutions might also provide an impetus for states to cleanse these sites of their difficult histories in order to amplify the efficiency of their progress from a “dark past” (Altermark 2018, 156).

Despite their possibilities, sites of conscience practices also give rise to questions and challenges. First, there is little empirical research on how the impacts of disability and psychiatric sites of conscience are experienced by community members and on how these impacts effect social change, as well as little documentation regarding the perspectives of disabled people and of people experiencing mental distress (Steele 2022).

Second, the possibility of utilizing sites of conscience practices in relation to specific former disability and psychiatric institutions depends on the ability to gain access to sites. Access can be challenging when these sites have been sold. Indeed, the issue of access is particularly pertinent if the new use of a site depends on a history that is either cleansed (e.g., through residential gentrification) or exploited (e.g., as a haunted house) (Beitiks 2012; Punzi 2019).

Third, there might be tensions between reclaiming a former disability or psychiatric institution for the disability community and reckoning with First Nations and Indigenous justice related to dispossession of the land on which the institution is situated and with the role of such institutions in settler colonialism. It is unclear the extent to which existing sites of conscience practices related to disability and psychiatric institutions move beyond a singular set of disability injustices to grapple with multiple (intersecting) injustices and with settler colonialism (Steele 2022). Such an approach can result in missed opportunities for public recognition of a broader range of injustices on land that is itself at the core of Indigenous dispossession, displacement, and genocide; sites of conscience practices can unintentionally be implicated in settler-colonial violence (Chalmers 2019). Scholars suggest that the very notion of a “site” of conscience is a settler concept and that a shift is needed if we are to include understandings of First Nations and Indigenous worldviews and approaches to memory (Andrew and Hibberd 2022).

### **This Collection**

This edited collection aims to bring into conversation scholars working across diverse disciplines and jurisdictions to investigate how specific historical moments and sites of deinstitutionalization offer fresh insights into the role that the memories, geographies, and materialities of disability and psychiatric institutions play in realizing social justice for disabled people



and for people experiencing mental distress. In doing so, it uncovers possibilities for heritage, curating, and memorialization to be in transformative relationships with urban redevelopment, human rights, law, and activism aimed at addressing the endurance of institutionalization and the ongoing project of deinstitutionalization. The collection is thematically structured in three parts, each exploring a set of concerns.

### **Centring Survivor Voices and Experiences in the “Afterlives” of Disability and Psychiatric Institutions**

**Part 1** explores how the voices and experiences of former residents tend to become silenced when they are centred in what scholars have referred to as the “afterlives” of former institutions (Moon, Kearns, and Joseph 2015), particularly their redevelopment and reuse. The chapters are authored by disabled people and by people experiencing mental distress, and/or they draw on the lived experiences and insights of disabled people and of people experiencing mental distress, as well as the insights of their allies.

In **Chapter 1**, Geoffrey Reaume writes about historical memory and memorialization, how the histories of people deemed mentally ill or disabled have been allowed to be forgotten and how some academic historians try to marginalize critical interpretations of psychiatry articulated by those who have been in the position of the patient. These historians may marginalize the voices and memories of survivors of psychiatry by portraying them as anti-psychiatry without defining what that means, thereby lumping together critics of psychiatry as belonging to one undefinable type, who are therefore all the easier to dismiss. Another way to marginalize survivors of psychiatry is to use an either/or framework in which people are portrayed either as former patients/activists or as academic historians and to describe the two groups as having different aims. Reaume shows that people may be both activists and historians. He also shows that history is still very present for many activist-historians. Accordingly, memorialization is not just an academic pursuit. On the contrary, survivors’ important perspectives and knowledge create a more truthful presentation of history.

In **Chapter 2**, Elena Demke shares her experiences of being part of a group of activists who strove to honour the victims of the Nazis’ campaign of involuntary euthanasia, known as Aktion T4, carried out at psychiatric killing centres. This activism occurred at the very site where Aktion T4 was planned and organized: Tiergartenstraße 4 in Berlin. She describes how survivors of the campaign and survivors of psychiatry who were born after Aktion T4 spent decades struggling for thoughtful remembrance and for

the acknowledgment and termination of oppressive current practices. The efforts were unsuccessful, not least since the memories and narratives of survivors were neglected and silenced. This outcome ultimately shows the importance of a site of conscience perspective.

In [Chapter 3](#), David T. Mitchell and Sharon L. Snyder explore approaches to the memorialization of disabled people who died during the Second World War in Germany and Austria at Nazi psychiatric killing centres operated under Aktion T4. Mitchell and Snyder explore the different ways that disabled people's voices and experiences can be accessed in the context of scant direct testimony from those who died and in the context of a memorialization of killing centres that fetishizes perpetrators' perspectives. Mitchell and Snyder propose the concept of a "stretchier" form of witnessing that tells the story of Aktion T4 from the perspective of disabled people. Stretchy witnessing includes maps of the physical location of the ashes of deceased disabled people as material remnants of disabled lives and the memoirs of family members of deceased disabled people.

[Chapter 4](#) presents an interview with Alex Green. Green introduces the transitional justice framework of truth and reconciliation as one possible way to reckon with the histories of former disability institutions and to make sense of their ongoing impacts in the present. Green focuses on the Walter E. Fernald Developmental Center in Waltham, Massachusetts, a former disability institution with a significant disability history both nationally and internationally. Recognizing that people with intellectual disability have historically been excluded as legitimate knowers – including in the specific context of public history – Green proposes that the truth and reconciliation framework is particularly pertinent because it is premised on centring the voices and perspectives of former residents.

In [Chapter 5](#), Jen Rinaldi and Kate Rossiter explore disabled people's interventions in their institutional records. Rinaldi and Rossiter focus on the case study of Ontario's Huronia Regional Centre in the context of its failure to accurately and comprehensively document the lives of the disabled people who experienced extreme control and violation within its walls for years and decades. Rinaldi and Rossiter discuss their experiences of recording disabled people engaged in reviewing and reflecting on their own records, and they argue that speaking back to the archives can be both a form of resistance to violence and its ongoing impacts and ultimately a mode of restorative justice.

In [Chapter 6](#), Justine Lloyd and Nicole Matthews explore the inclusion of the voices and lived experiences of disabled people in media discourse on

deinstitutionalization. Matthews and Lloyd focus on the case study of the closure in 2010 of a disability institution on Peat Island in Australia, which was operated by the state government for ninety-nine years. They argue that the exclusion of disabled people from media discourse on Peat Island's closure, an exclusion that occurred in the context of the broader erasure of the physical evidence of the institution, reflects what they call "deinstitutional violence." They suggest that a site of conscience might be one way to centre disabled people's experiences of institutionalization and deinstitutionalization and thus a means to counter this violence.

In [Chapter 7](#), Verusca Calabria and Rob Ellis argue that our duty to remember the difficult pasts of mental hospitals needs to be balanced by the memories of victims, survivors, and citizens in the context of the failings of community care. The chapter focuses on an in-depth oral history of a former patient and service user who encountered life as an in-patient at Shenley Hospital in England. The authors highlight the ongoing challenges faced by former patients during the period following deinstitutionalization in the United Kingdom.

### **Learning from Sites of Conscience Practices**

[Part 2](#) explores how engagement with memories and places of former institutions can support social justice for disabled people and for people experiencing mental distress. The chapters present case studies of current practices of sites of conscience, as well as memorialization and artistic practices.

In [Chapter 8](#), Bec Dean, Lily Hibberd, and Wart explore the role of performance art in engaging the public in histories of psychiatric institutions while connecting these histories to a broader range of injustices. They focus on the case studies of two sites in Australia: Callan Park, which is a former psychiatric institution that operated for around 130 years; and Lavender Bay, where a prison-asylum hulk was moored in the early eighteenth century. Dean, Hibberd, and Wart propose that engaging with place provides opportunities for nuanced understandings of the central contradiction of welfare institutions as both caring and violent and for accounts of the embodied experiences of those who have lived in these institutions and who continue to be impacted by them even after they leave.

In [Chapter 9](#), Niklas Altermark and Matilda Svensson Chowdhury provide an analysis of two theatre plays co-created and performed by persons/actors with disability, one staged in Finland and the other in Sweden. Altermark and Svensson Chowdhury relate these performances to institutionalization and to the unfinished process of deinstitutionalization. Through

their analysis, they reveal that despite the dominance of the idea that current disability policies are the opposite of those that characterized the institutional era, this view does not convey the truth.

[Chapter 10](#) presents an interview with Janet Overfield-Shaw, who is chair of the Workhouse Network and of the Workhouse and Infirmary Southwell in England. The interview captures a moment in a process of change for the individual property and for the National Trust as a whole. Many of the elements discussed in the chapter have become embedded in reset programs established by the National Trust following the COVID-19 pandemic, including programs focused on the National Trust's new core activity of forming partnerships with local communities and businesses, which in turn has led to the creation of the new role of program and partnership officers. The chapter refers to an overarching project of reimagining, whose concept is heavily influenced by the memory-to-action approach of the International Coalition of Sites of Conscience. This approach is a force for change that enables inclusive, co-creative work with neurodivergent partners, artists, and participants. This work aims to produce interpretations from lived experience in the presentation of the nineteenth-century historical institution to visitors and seeks to inspire them to move from memory to action.

In [Chapter 11](#), Rory du Plessis explores the potential of photographs contained in institutional files to memorialize and humanize disabled people who lived in disability and psychiatric institutions. Du Plessis focuses on the case study of photographs of some former residents contained in the files of the Grahamstown Lunatic Asylum in South Africa. Du Plessis proposes that even though the photographs and accompanying documentation were produced in an institutional context, they are open to different interpretations that can redress the eugenics history of disability.

In [Chapter 12](#), Evadne Kelly and Carla Rice investigate the role of educators in reproducing the legacies of colonialism and in justifying the oppressive practices of disability and psychiatric institutions. They take the example of the University of Guelph to show how the eugenics and euthenics that were taught at the university's precursor now uncannily emerge in the current slogan of the university: "Improve Life." Kelly and Rice themselves work at the university and accordingly have the possibility to engage with its institutional history of human-betterment ideas and practice and to analyze how mechanisms of not knowing currently operate.

In [Chapter 13](#), Nigel Ingham, Jan Walmsley, and Liz Tilley explore the role of oral history in addressing contemporary institutional violence. Building on their earlier work on the oral history of disabled people who have

lived in disability institutions, they turn their attention to the oral histories of the nursing staff of long-stay disability institutions. They suggest that these oral histories reveal the ethical complexities of working in these contexts and the possibilities of staff members' perpetration of and complicity in violence. Engaging with these oral histories can contribute to a deeper understanding of the causes of disability oppression and violence and in turn can enable staff employed in contemporary disability social care to end these practices.

### **Social Justice and Place Making in the Absence of Sites of Conscience**

**Part 3** explores the challenges and possibilities of realizing social justice when places of former disability and psychiatric institutions are used not as sites of conscience or memorialization but for other purposes. The chapters present case studies of current practices of urban planning, heritage management, and reuse/redevelopment in relation to former institutions.

In **Chapter 14**, Helena Lindbom and Elisabeth Punzi explore the adaptive reuse of former psychiatric institutions as places for community social gathering, such as cafés. Punzi and Lindbom take as their case study the Lillhagen Hospital in Sweden, which operated in the twentieth century as a psychiatric institute for around sixty years. They focus on the concept of a cup of coffee as a little thing that holds much significance in terms of meaningful opportunities for connection, friendship, and community. Challenging our understanding of what a site of conscience can be, the authors shift our attention from the grander ambitions of museums, walking tours, and memorials to the intimate and smaller-scale opportunities of interpersonal interactions, arguing that these interactions restore something that is taken in institutionalization and that they provide a foundation for mending social relations moving forward.

In **Chapter 15**, Robin Kearns, Graham Moon, and Gavin Andrews explore the reuse of former psychiatric institutions as haunted houses. They focus on the case study of Spookers, an attraction located on the site of Kingseat Hospital in New Zealand, a former psychiatric institution. They argue that this haunted house has a complex and ambivalent relationship to its former use. The attraction provides opportunities to recognize the former hospital, yet it ultimately falls short of meaningful remembrance and critique while offering those who work at Spookers opportunities for community, identity, and belonging.

In **Chapter 16**, Cecilia Rodéhn discusses the process of giving names to streets in a post-asylum landscape during the 1990s. Focusing on the former

hospital area of Ulleråker in Uppsala, Sweden, Rodéhn investigates the role that naming plays in the production of cultural heritage. The study reveals that street naming works as a way to remember the (predominantly male) staff members at the hospital and the social elite and that, as a result, the heritages of the Mad and the working class are largely forgotten. The chapter investigates how this process is imbued with the politics of ableism and also connects the discussion to social class and gender.

In [Chapter 17](#), Nicole Baur describes how in 1987, almost 150 years after its grand opening, changes in health policy and the erosion of services and support led Exminster Hospital to close its doors. The question about what would become of its remnants had occupied the minds of local authorities, hospital staff, and the wider Exminster community for nearly two decades. Against the backdrop of recent developments in heritage preservation, which give increasing weight to the input of lay people, this chapter traces the conversion of the former psychiatric hospital near the city of Exeter in England into a luxury residential estate, focusing on how its heritage was intentionally and unwittingly preserved through intense discussions between experts and lay people. Based on interview data, oral histories, and material artifacts collated in the two-year participatory project *Remembering the Mental Hospital*, the chapter illustrates people's efforts, frustrations, successes, and failures in trying to preserve Exminster Hospital. Findings demonstrate a keen interest in preserving the hospital's heritage, rooted in the ties between the hospital and the surrounding community, but they also show that efforts were frequently hampered by the diverging agendas of the groups and actors involved in the process. At the same time, their input regarding the hospital's preservation created a legacy in itself in the form of material and immaterial heritage, including streets named after former hospital staff, hospital buildings and premises now used for community purposes, and a wealth of stories.

## **Conclusion**

In the face of the enduring presence and harmful impacts of disability and psychiatric institutions, this collection responds to the challenge of finding new ways to understand and engage with the unfinished deinstitutionalization project and its open-ended failures. Through diverse sites, lived experiences, and contexts of institutionalization, contributors to this collection offer reflections on the role of the memories, geographies, and materialities of former disability and psychiatric institutions in the realization of social justice for disabled people and for people experiencing mental

distress. The collection offers new paradigms and strategies for building hopeful and just futures that deliver accountability and repair for the harms of disability and psychiatric institutions and that honour the lives and celebrate the activism and resistance of disabled people and of people in mental distress.

## NOTES

- 1 Transinstitutionalization refers to a process in which persons who previously would have been patients or residents in large psychiatric or disability institutions are now placed in other types of institutions that are equally coercive, such as group homes or even prisons.
- 2 In this book, the terms “Mad community,” “Mad people, and “Mad scholars” are used. These terms are connected to the field of Mad studies, which integrates theory, research, activism, artistic expression, and a focus on the lived experiences of those who, currently and throughout history, have identified as Mad, including scholars and practitioners. Lived experiences are seen as forms of knowledge. Biomedical approaches are rejected, and the word “Mad” is deliberately chosen to reclaim its history and to overturn its solely negative interpretations because it has a common meaning and is disconnected from modern biomedical terminology. Mad studies is historically connected to the Mad pride movement and is, just like this movement, a form of radical and disorderly counter-narrative, counter-philosophy, and/or counter-culture – uniting those who challenge or denounce orthodox terminologies and interventions as well as reclaim expertise based on the knowledge of those who have lived these experiences in the past and present (e.g., see Beresford 2020; LeFrançois, Menzies, and Reaume 2013; and Reaume 2019).

## REFERENCES

- Altermark, Niklas. 2018. *Citizenship, Inclusion and Intellectual Disability*. London and New York: Routledge.
- Andrew, Brook, and Lily Hibberd. 2022. “The Blacktown Native Institution as a Living, Embodied Being – Overcoming Trauma through Zones of Creativity at Places of Australian First Nations’ Living Memory.” *Space and Culture* 25 (2): 168–83.
- Ashton, Paul, and Jacqueline Z. Wilson. 2019. “Remembering Dark Pasts and Horrific Places: Sites of Conscience.” In *What Is Public History Globally? Working with the Past in the Present*, ed. Paul Ashton and Alex Trapeznik, 281–94. London: Bloomsbury.
- Avery, Scott. 2018. *Culture Is Inclusion: A Narrative of Aboriginal and Torres Strait Islander People with Disability*. Sydney: First People’s Disability Network Australia.
- . 2020. *Something Stronger: Truth-Telling on Hurt and Loss, Strength and Healing, from First Nations People with Disability*. Sydney: Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability.



- Beitiks, Emily Smith. 2012. "The Ghosts of Institutionalization at Pennhurst's Haunted Asylum." *Hastings Center Report* 42 (1): 22–24.
- Ben-Moshe, Liat. 2017. "Why Prisons Are Not 'the New Asylums.'" *Punishment and Society* 19 (3): 272–89.
- . 2020. *Decarcerating Disability: Deinstitutionalization and Prison Abolition*. Minneapolis: University of Minnesota Press.
- Ben-Moshe, Liat, Chris Chapman, and Allison C. Carey, eds. 2014. *Disability Incarcerated: Imprisonment and Disability in the United States and Canada*. New York: Palgrave Macmillan.
- Beresford, Peter. 2020. "Mad; Mad Studies and Advancing Inclusive Resistance." *Disability and Society* 35 (8): 1337–42.
- Brett, Sebastian, Louis Bickford, Liz Ševčenko, and Marcela Rios. 2007. *Memorialization and Democracy: State Policy and Civic Action*. Santiago/New York: Latin American School of Social Sciences/International Center for Transitional Justice/International Coalition of Historic Site Museums of Conscience. [https://www.ictj.org/sites/default/files/ICTJ-Global-Memorialization-Democracy-2007-English\\_0.pdf](https://www.ictj.org/sites/default/files/ICTJ-Global-Memorialization-Democracy-2007-English_0.pdf).
- Burch, Susan. 2016. "Disorderly Pasts: Kinship, Diagnoses, and Remembering in American Indian–U.S. Histories." *Journal of Social History* 50 (2): 362–85.
- . 2021. *Committed: Remembering Native Kinship in and beyond Institutions*. Chapel Hill: University of North Carolina Press.
- Burghardt, Madeline C. 2018. *Broken: Institutions, Families and the Construction of Intellectual Disability*. Montreal and Kingston: McGill-Queen's University Press.
- Chalmers, Jason. 2019. "Settled Memories on Stolen Land: Settler Mythology at Canada's National Holocaust Monument." *American Indian Quarterly* 43 (4): 379–407.
- Chapman, Chris. 2014. "Five Centuries' Material Reforms and Ethical Reformulations of Social Elimination." In *Disability Incarcerated: Imprisonment and Disability in the United States and Canada*, ed. Liat Ben-Moshe, Chris Chapman, and Allison C. Carey, 25–44. New York: Palgrave Macmillan.
- Chapman, Chris, Allison C. Carey, and Liat Ben-Moshe. 2014. "Reconsidering Confinement: Interlocking Locations and Logics of Incarceration." In *Disability Incarcerated: Imprisonment and Disability in the United States and Canada*, ed. Liat Ben-Moshe, Chris Chapman, and Allison C. Carey, 3–24. New York: Palgrave Macmillan.
- College of Staten Island. n.d. "Willowbrook Mile: About Us." <https://www.csi.cuny.edu/about-csi/president-leadership/administration/office-vp-economic-development-and-community-partnerships/reporting-units-and-initiatives/willowbrook-mile/about>.
- Cooper-Bolam, Trina. 2019. "Workhouses and Residential Schools: From Institutional Models to Museums." In *Cybercartography in a Reconciliation Community: Engaging Intersecting Perspectives*, ed. Stephanie Pyne and D.R. Fraser Taylor, 143–66. Amsterdam: Elsevier.
- Dehm, Sara, Claire Loughnan, and Linda Steele. 2021. "COVID-19 and Sites of Confinement: Public Health, Disposable Lives and Legal Accountability in



- Immigration Detention and Aged Care." *University of New South Wales Law Journal* 44 (1): 60–103.
- Downey, Dennis B., and James W. Conroy, eds. 2020. *Pennhurst and the Struggle for Disability Rights*. Houston: Keystone Books.
- Fricker, Miranda. 2007. *Epistemic Injustice: Power and the Ethics of Knowing*. Oxford: Oxford University Press.
- Fritz, William, and Ken Iwama. 2019. "The Power of Place-Based Legacies in Advancing Reengagement with Community." *Metropolitan Universities* 30 (2): 63–71.
- Herron, Rachel, Christine Kelly, and Katie Aubrecht. 2021. "A Conversation about Ageism: Time to Deinstitutionalize Long-Term Care?" *University of Toronto Quarterly* 90 (2): 183–206.
- Kelly, Christine, and Michael Orsini, eds. 2017. *Mobilizing Metaphor: Art, Culture, and Disability Activism in Canada*. Vancouver: UBC Press.
- Knapp, Martin, Eva Cyhlarova, Adelina Comas-Herrera, and Klara Lorenz-Dant. 2021. *Crystallising the Case for Deinstitutionalisation: COVID-19 and the Experiences of Persons with Disabilities*. London: Care Policy and Evaluation Centre, London School of Economics and Political Science. <https://www.lse.ac.uk/cpec/assets/documents/CPEC-Covid-Desinstitutionalisation.pdf>.
- Larkin-Gilmore, Juliet, Ella Callow, and Susan Burch. 2021. "Section II Introduction: Place." *Disability Studies Quarterly* 41 (4). <https://production.ojs.dsq-sds.org/index.php/dsq/article/view/8771/6314>.
- LeFrançois, Brenda A., Robert Menzies, and Geoffrey Reaume, eds. 2013. *Mad Matters: A Critical Reader in Canadian Mad Studies*. Toronto: Canadian Scholars' Press.
- Macdonald, Sharon. 2009. *Difficult Heritage: Negotiating the Nazi Past in Nuremberg and Beyond*. Abingdon, UK: Routledge.
- . 2016. "Is 'Difficult Heritage' Still Difficult? Why Public Acknowledgement of Past Perpetration May No Longer Be So Unsettling to Collective Identities." *Museum International* 67 (1–4): 6–22.
- Malacrida, Claudia. 2015. *A Special Hell: Institutional Life in Alberta's Eugenic Years*. Toronto: University of Toronto Press.
- McAtackney, Laura. 2020. "Materials and Memory: Archaeology and Heritage as Tools of Transitional Justice at a Former Magdalene Laundry." *Éire-Ireland* 55 (1–2): 223–46.
- Million, Dian. 2013. "Trauma, Power, and the Therapeutic: Speaking Psychotherapeutic Narratives in an Era of Indigenous Human Rights." In *Reconciling Canada: Critical Perspectives on the Culture of Redress*, ed. Jennifer Henderson and Pauline Wakeham, 159–77. Toronto: University of Toronto Press.
- Mingus, Mia. 2015. "Medical Industrial Complex Visual." *Leaving Evidence*, February 6. <https://leavingevidence.wordpress.com/2015/02/>.
- Moon, Graham, Robin Kearns, and Alun Joseph. 2015. *The Afterlives of the Psychiatric Asylum: Recycling Concepts, Sites and Memories*. Farnham, UK: Ashgate.
- Mussell, Linda, Kevin Walby, and Justin Piché. 2021. "Can You Make It Out Alive? Investigating Penal Imaginaries at Forts, Sanitaria, Asylums, and Segregated

- Schools." *Journal of Qualitative Criminal Justice and Criminology* 10 (3). <https://doi.org/10.21428/88de04a1.d3d18f84>.
- National Trust. n.d. "The Workhouse and Infirmary." <https://www.nationaltrust.org.uk/visit/nottinghamshire-lincolnshire/the-workhouse-and-infirmary/index>.
- Page, Cara, and Eesha Pandit. 2020. "Intersections of Justice in the Time of Coronavirus." Funders for Justice, March 25. <https://www.nfg.org/news/intersections-justice-time-coronavirus-cara-page-eesha-pandit>.
- Pennhurst Memorial and Preservation Alliance. n.d. "The Mission of the Pennhurst Memorial and Preservation Alliance." <http://www.preservepennhurst.org/>.
- Punzi, Elisabeth. 2019. "Ghost Walks or Thoughtful Remembrance: How Should the Heritage of Psychiatry Be Approached?" *Journal of Critical Psychology, Counselling and Psychotherapy* 19 (4): 242–51.
- . 2022. "Långbro Hospital, Sweden – From Psychiatric Institution to Digital Museum: A Critical Discourse Analysis." *Space and Culture* 25 (2): 282–94.
- Quinn, Gerard. 2021. "COVID-19 and Disability: A War of Two Paradigms." In *COVID-19 and Human Rights*, ed. Morten Kjaerum, Martha F. Davis, and Amanda Lyons, 116–32. Abingdon, UK: Routledge.
- Reaume, Geoffrey. 2009. *Remembrance of Patients' Past: Patient Life at the Toronto Hospital for the Insane, 1870–1940*. Toronto: University of Toronto Press.
- . 2016. "A Wall's Heritage: Making Mad People's History Public." *Public Disability History*, November 21. <https://www.public-disabilityhistory.org/2016/11/a-walls-heritage-making-mad-peoples.html>.
- . 2019. "Creating Mad People's History as a University Credit Course since 2000." *New Horizons in Adult Education and Human Resource Development* 31 (1): 22–39.
- Rinaldi, Jen, and Kate Rossiter. 2021. "Huronion's Double Bind: How Institutionalisation Bears Out on the Body." *Somatechnics* 11 (1): 92–111.
- Rinaldi, Jen, Kate Rossiter, and Liza Kim Jackson, eds. 2017. *Canadian Journal of Disability Studies* 6 (3).
- Rodéhn, Cecilia. 2020. "Emotions in the Museum of Medicine: An Investigation of How Museum Educators Employ Emotions and What These Emotions Do." *International Journal of Heritage Studies* 26 (2): 201–13.
- Rossiter, Kate, and Jen Rinaldi. 2018. *Institutional Violence and Disability: Punishing Conditions*. Abingdon, UK: Routledge.
- Rotzoll, Maike, Paul Richter, Petra Fuchs, Annette Hinz-Wessels, Sascha Topp, and Gerrit Hohendorf. 2006. "The First National Socialist Extermination Crime: The T4 Program and Its Victims." *International Journal of Mental Health* 35 (3): 17–29.
- Ševčenko, Liz. 2002. "Activating the Past for Civic Action: The International Coalition of Historic Site Museums of Conscience." *George Wright Forum* 19 (4): 55–64.
- . 2011a. "Sites of Conscience: Heritage of and for Human Rights." In *Heritage, Memory and Identity*, ed. Helmut Anheier and Yudhishtir Raj Isar, 114–23. Los Angeles: Sage.

- . 2011b. “Sites of Conscience: Reimagining Reparations.” *Change Over Time* 1 (1): 6–33.
- Sheldon, Tess, Karen Spector, and Sheila Wildeman. 2020. “Viruses Feed on Exclusion: Psychiatric Detention and the Need for Preventative Deinstitutionalization.” *Ricochet*, April 12. <https://ricochet.media/en/3038/viruses-feed-on-exclusion-psychiatric-detention-and-the-need-for-preventative-deinstitutionalization>.
- Smith, Laurajane. 2006. *Uses of Heritage*. London and New York: Routledge.
- Steele, Linda. 2020. *Disability, Criminal Justice and Law: Reconsidering Court Diversion*. Abingdon, UK: Routledge.
- . 2022. “Sites of Conscience Redressing Disability Institutional Violence.” *Incarceration* 3 (2): 1–19.
- Topor, Alain, Gunnel Andersson, Per Bülow, Claes-Göran Stefansson, and Anne Denhov. 2016. “After the Asylum? The New Institutional Landscape.” *Community Mental Health Journal* 52 (6): 731–37.
- Toth, Naomi, and Lily Hibberd. 2021. “Parragirls Past, Present: Unlocking Memories of Institutional ‘Care’: Witnessing and Creative Reparation in the Aftermath of Parramatta Girls Home.” *Synthesis* (13): 94–114.
- Tumarkin, Maria. 2022. “Theorising Otherwise: Sites of Conscience and Gendered Violence.” *Space and Culture* 25 (2): 331–40.
- United Nations Committee on the Rights of Persons with Disabilities. 2018. “General Comment No. 5 on Article 19: Living Independently and Being Included in the Community.” CRPD/C/GC/5.
- . 2022. “Guidelines on Deinstitutionalization, Including in Emergencies.” CRPD/C/5.
- Waterton, Emma, and Laurajane Smith. 2010. “The Recognition and Misrecognition of Community Heritage.” *International Journal of Heritage Studies* 16 (1–2): 4–15.
- Whitt, Sarah. 2021. “‘Care and Maintenance’: Indigeneity, Disability and Settler Colonialism at the Canton Asylum for Insane Indians, 1902–1934.” *Disability Studies Quarterly* 41 (4). <https://production.ojs.dsqsds.org/index.php/dsq/article/view/8463/6299>.
- Wildeman, Sheila. 2020. “Disabling Solitary: An Anti-carceral Critique of Canada’s Solitary Confinement Litigation.” In *The Legacies of Institutionalisation: Disability, Law and Policy in the ‘Deinstitutionalised’ Community*, ed. Claire Spivakovsky, Linda Steele, and Penelope Weller, 87–102. Oxford: Hart-Bloomsbury.
- Wolfe, Patrick. 2006. “Settler Colonialism and the Elimination of the Indigenous.” *Journal of Genocide Research* 8 (4): 387–409.
- Wong, Alice. 2020. “Freedom for Some Is Not Freedom for All.” Disability Visibility Project, June 7. <https://disabilityvisibilityproject.com/2020/06/07/freedom-for-some-is-not-freedom-for-all/>.
- Yahm, Sarah. 2014. “Oregon State Hospital Museum of Mental Health.” *Journal of American History* 101 (1): 203–8.

© UBC Press 2024

All rights reserved. No part of this publication may be reproduced, stored in a retrieval system, or transmitted, in any form or by any means, without prior written permission of the publisher.

UBC Press is a Benetech Global Certified Accessible™ publisher. The epub version of this book meets stringent accessibility standards, ensuring it is available to people with diverse needs.

---

### Library and Archives Canada Cataloguing in Publication

Title: Sites of conscience : place, memory, and the project of deinstitutionalization / edited by Elisabeth Punzi and Linda Steele.

Names: Punzi, Elisabeth, editor. | Steele, Linda, editor.

Series: Disability culture and politics.

Description: Series statement: Disability culture and politics | Includes bibliographical references and index.

Identifiers: Canadiana (print) 20230553176 | Canadiana (ebook) 20230553338 | ISBN 9780774869324 (hardcover) | ISBN 9780774869355 (EPUB) | ISBN 9780774869348 (PDF)

Subjects: LCSH: People with disabilities – Deinstitutionalization. | LCSH: Mentally ill – Deinstitutionalization. | LCSH: Memorialization. | LCSH: Social justice. | LCSH: Psychiatric hospitals.

Classification: LCC HV1552 .S58 2024 | DDC 305.9/08 – dc23

---



BRITISH COLUMBIA  
ARTS COUNCIL



BRITISH  
COLUMBIA

UBC Press gratefully acknowledges the financial support for our publishing program of the Government of Canada and the British Columbia Arts Council.

UBC Press is situated on the traditional, ancestral, and unceded territory of the x̱m̱əθḵw̱əy̱əm (Musqueam) people. This land has always been a place of learning for the x̱m̱əθḵw̱əy̱əm, who have passed on their culture, history, and traditions for millennia, from one generation to the next.

UBC Press

The University of British Columbia

[www.ubcpres.ca](http://www.ubcpres.ca)