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Introduction: Sites and shapes of transinstitutionalization

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Introduction: Sites and shapes of transinstitutionalization

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Transinstitutionalization is, admittedly, an unwieldy and contested term. Once used primarily to describe the movement of people from almshouses to state facilities (Morrissey & Goldman, 1986), from psychiatric institutions to prisons (Thakker et al., 2007), and to insufficient networks of community support (Slovenko, 2003), the word is now mobilized to capture the numerous ways in which institutionalization and institutionalizing conditions are sustained in the era of neoliberal inclusionism. It is, when used in this way, what Bonnie Burstow calls a refusal term (2013)—in this case, a rejection of the notion that the institutionalization and institutional violences against people whose lives are marked by medical pathologization have been eradicated. It is a demand for critical interrogation of education, language, psychiatric hospitals, assessment practices, warehousing, community-based care, and incarceration, among other sites, where the authors in this collection find themselves and others. The prefix "*trans"* in *trans*institutionalization speaks directly to the ways that the institution has shifted across various cultural sites and shapes, carried from our past to the present through social policy, care work, education, and incarceration, to name a few. Transinstitutionalization pushes and pulls us in multiple directions as we consider its many forms, and the places wherein it takes root in our lives.

Knowing that the complexities of transinstitutionalization unfold over time, our starting point for this special issue is a loose explanation of four ways in which the notion of transinstitutionalization can be mobilized. First, the transfer of mad and disabled people from large state-run institutions to, and between, prisons, rooming houses, and hospitals over the last sixty years (e.g. Simmons, 1990; Ignagni, 2011; Fabris & Aubrecht, 2014). Second, the closure of many

deaf schools and the assimilative transfer of deaf students into educational facilities built for hearing students (Snoddon and Weber, this issue). Third, the making of institutional-like conditions in spaces of "community-based" care such as day centres, boarding homes, and schools (e.g. Spagnulo, 2016). The fourth use of the term is less straightforward, but equally rich, and refers to the elusive ways in which institutions linger through, and are written out on, mad, deaf, and disabled bodies outside of the existing edifices of confinement and control (e.g. Fabris, 2011; Haley, 2017a). Transinstitutionalization is at least these four things—to explain transinstitutionalization in a linear, direct way is to downplay the nuanced layering that is offered by the contributors to this special issue. Transinstitutionalization is a complex, deceptive, and deeply racialized, gendered, classed, and colonial set of processes that are part of our modern lives. Mapping the ways in which institutions and institutional violences are hidden in plain sight is crucial to understanding the contours of transinstitutionalization.

Sites and shapes of transinstitutionalization

The complexities of transinstitutionalization are difficult to observe because in the Global North, institutionalization and the institution itself have been falsely historicized. Consider, for example, that within those parts of Turtle Island now also known as Canada, the institutionalization of disability and madness is often presented as obsolete—a past "treatment" approach to body/mind difference rooted in outdated medical frameworks of normalcy and problematic desires for confinement and "cure" that were rectified through deinstitutionalization. At the same time, as Snoddon and Weber articulate in their contribution to this special issue, the deinstitutionalization and dismantling of some deaf schools in the name of "inclusion" were, and remain, an attack on sign language, deaf culture, and deaf people. They demonstrate that deaf schools were sites of

learning and belonging for many. We also know that institutions, such as asylums, hospitals, and regional centres, were places of ableist, racist, and colonial violence (Simmons, 1990, Menzies & Palys, 2006; Malacrida, 2015). These multidirectional processes of institutionalization and transinstitutionalization across mad, deaf, and disabled people's lives are being concealed (see Barron, 2020). The institutional history of this place is suppressed, sanitized, and/or incomplete (see, for example, the *History of Developmental Services*, Ministry of Community and Social Services, Ontario) and the present conditions that sustain institutional violences are being ignored. In the desire to both historicize and celebrate deinstitutionalization, two falsehoods have been constructed: first, that deaf schools were and are always or only places of institutionalization, and second, that the institutionalization of disabled, mad, and deaf people is a thing of the past. These schisms between our considerations of deaf, disabled, and mad people demonstrate that institutionalization—and thereby transinstitutionalization—is never only one story that can be neatly told.

The concept of transinstitutionalization thickens when applied to today's rehabilitation centres, some state-run group homes, sheltered workshops, long-term care facilities, youth centres, prisons, and other sites where mad, deaf, and disabled people are confined. These contemporary sites are treated as necessary and distinct from the large asylums and centres that come to mind when institutionalization is mentioned. At the same time, service provisioning within the community often embeds institutionalizing conditions, such as isolation and control over reproductive, sexual, romantic, and family life (Haley, 2017b), proving—again—that institutionalization is very much still with us. In response, some communities of survivors, activists, and researchers continue to surface hidden records and stories in the interest of preserving survivors' cultural knowledges of institutionalization (davis halifax et al., 2018; Burghardt, 2018;

Irwin, 2009; Zbitnew, 2015). And, like the authors here, they draw attention to the ways in which institutions and institutionalizing practices, including those like contemporary public schools that are enacting audist inclusionism, are drawn out, sustained, and change shape in the contemporary moment. Given that institutionalization is thought and experienced through many directions and contexts, we assert that its ongoingness is complex and that its presence—insidious as always—must have a place in contemporary critical disability studies.

Amid this broad perspectival flux over what institutionalisation was, and is, and against whom it is enacted, there is a persistent unwillingness on the part of those in power to acknowledge the multiple continuities of institutionalization that are being carried forward in law and policy. While some institutions have indeed closed, there are many, such as the Centre for Addiction and Mental Health (CAMH) in Toronto, Ontario, that remain open and are constantly redesigned and even renamed in an effort to shed the institutional history of the place while still pathologizing and confining large numbers of people involuntarily. Concurrently, mad activists keep the history of CAMH alive through work that points to past and present confinement (Voronka, 2008), such as historic tours of the original walls surrounding the facility that include stories of those who lived and worked there, many of whom carved their names into the wall they were forced to build without pay (Reaume, 2010). In many official records, the practice of institutionalizing people, such as those held in CAMH, purportedly ended with the reduction of days of care in large provincial psychiatric hospitals and the closure of some hospitals; the new era of "community integration" is celebrated. Here, again, we notice the changing shape of institutionalization amid varying physical and conceptual sites.

We offer this special issue as a reminder that there has never been an "end" to institutionalization. As the authors featured here demonstrate, there are multiple continuities of institutionalization. Rather than hitting a markable stopping point, the power of institutions continues to bear out in our lives, often changing shape and disguised as intervention for the greater good. The relentless persistence of institutionalization, and the ways in which it leaks into our lives—past, present, and future—are what we refer to here as transinstitutionalization.

Transinstitutionalization in our lives

If you are like us, experiences of transinstitutionalization may feel like they are woven into your life endlessly and without your consent. Therefore, we open this special issue by positioning ourselves in the midst of transinstitutionalization in different ways, and to different ends.

Tobin LeBlanc Haley is a white, cis, mad woman from Atlantic Canada who, thanks to COVID-19, works in Toronto but lives in New Brunswick. As a privileged mad woman, LeBlanc Haley has extensive experience attempting to conceal her madness, sometimes successfully, sometimes unsuccessfully, in an effort to avoid the long reach of the psy-disciplines and the ridicule, pathologization, and fear experienced by mad people. As a very privileged white woman, she has not experienced many of the most violent forms of contemporary institutionalization. However, she has observed it first-hand in her non-academic frontline work with people living at the nexus of poverty and disability (broadly defined). She remains frustrated by the incongruity of the "official" history of deinstitutionalization and community integration and by the everyday lives of people labelled or identifying as mad, deaf, and disabled. Therefore, LeBlanc Haley uses her role as a researcher to highlight the continuities of institutional violence across the diverse groups

that make up the disability community, but especially those people who live with deeply racialized, classed, and gendered poverty. A large part of her work involves collaborating with folx living with so-called "community-based care." In spaces of "community care," accessing necessary social services means highly medicalized state surveillance becomes woven into the fabric of everyday life—where something as simple as taking the bus to see family requires paperwork and a receipt—and where police violence, criminalization, and incarceration, especially among Indigenous, Black, and People of Colour disabled people, is a regular occurrence. LeBlanc Haley is committed to practicing, and always improving, an intersectional, anti-racist, and community-centred engagement with contemporary forms of transinstitutionalization, working alongside other mad, deaf, and disabled folx in pushing back against the myth that widespread institutionalization is a thing of the past.

Chelsea Temple Jones is white, cis, queer spoonie living in Toronto. She is newer to the concept of transinstitutionalization, having taken this special issue as a starting point to inform her critical work around intellectual disability as a cultural phenomenon. Her intergenerational research, which is often co-curated by institutional survivors and young, labelled people, is informed by familial experiences with intellectual disability. Her brother, Kevin, a labelled man who recently moved from Saskatchewan to Ontario, is leading her family in navigating social and medical systems that echo each other in often confusing ways from one place to the next. And in between these systems are pathic moments of concern, such as when the pair flew together across Canada amid the COVID-19 pandemic and airline staff insisted that Kevin answer standard, but inaccessible, questions about his health. In this moment, Temple Jones slid behind airline staff and silently fed Kevin the answers, shaking her head "no"—as in: there has been no fever, no cough, no feeling ill today. Airline staff insisted on taking their temperatures, anyway. This small cheat

foreshadows the interdependent wayfinding amid complex systems of surveillance that Temple Jones expects to move through in the future: travel through and between cities; care at home, in hospitals, and at other sites; sitting in waiting rooms of all kinds; and a flurry of flummoxing forms about anything, everything, and sometimes nothing at all. For families with intimate ties to intellectual disability, nonverbality, and other forms of difference that exist on the outskirts of institutional expectations around normality and cure, the absurdity of the notion of institutionalization as a long-gone phenomenon is felt in the daily weariness of administrative work piled on over time and concern about what will happen to loved ones in the future—all of this broken up only by small, sly moments of a collective "no."

Articles awaiting you

This historicization of the institution in Canada is a dangerous obfuscation of the ongoing realities of racialized, gendered, classed, and colonial confinement in the lives of mad, deaf, and disabled people in the era of neoliberalism. Institutionalization remains very much a part of the contemporary moment, manifesting in large-scale hospital confinement, as Lucy Costa and Jessica Evans describe in this issue, and in the state-sanctioned criminalization, surveillance, isolation, incarceration, and impoverishment of mad, deaf, and disabled people. The contributors to this special issue are researchers and activists who speak to the ways in which people's lives still intersect with institutionalization. Many continue to experience and witness institutionalization and institutional-style conditions in their daily lives.

The issue opens with a commentary by Kristin Snoddon and Joanne Weber, two deaf scholars and teachers who questioned our representation of deaf people in our original call for

papers. In that call, we attempted to invoke a history of oralism in deaf schools—as well as resistance to this practice and the ongoing struggles of the deaf community to access sign language. We wrote that deaf schools in Canada are run by d/Deaf people. Snoddon and Weber were quick to correct us, explaining that these schools are *not* run by deaf people. They also objected to the representation of deaf schools as "institutionalization," pointing out that this labelling may be harmful to deaf children who are at risk of the disabling effects of delayed language development due to barriers around learning sign language. Snoddon and Weber's warning was clear: the conflation of deaf experiences with the rhetoric of deinstitutionalization can perpetuate normative understandings of inclusion. Thanks to the generous call-in from Snoddon and Weber, we immediately understood our mistake and strove toward unlearning our misconceptions about deafness in the wider context of transinstitutionalization. We re-issued the call for papers with their guidance. And now, never wishing to bend toward rhetorics of inclusionism, and in the interest of ensuring that deaf representation comes from scholars whose work and lives are entwined in deaf education systems across the country, their commentary opens this special issue. Snoddon pairs her experiences in Ontario with Weber's experiences in Saskatchewan, offering a thoughtful, deaf-centred, and intersectional perspective on what transinstitutionalization means for deaf people today as sign languages remain under threat through institutional organization.

Next, by telling an Anishinaabe story, Nicole Ineese-Nash takes aim at the label of disability. This label, she argues, is a colonial tool that does not align with Indigenous worldviews and perspectives of difference. Scholars elsewhere have made clear that disability is an "alien" term for some Indigenous communities, and that there is a need to create dialogue between Indigenous and non-Indigenous people around disability and experiences of impairment, which are culturally varied (Connell, 2011; Rivas Velarde, 2018). For Ineese-Nash, the structures of

oppression that support disability in its many manifestations come with colonial and eugenic histories (and presents) that have pathologized Indigenous ways of being and have therefore fostered institutional dependency. She writes specifically about the seemingly relentless requirement that Indigenous children, and their families, interact with assimilatory institutions, bringing home the point that disability, race, and other social relations of power are never one-dimensional and that their contemporary complexities are rooted in the colonial happenings of our world (Fenton, 2016, p. 205).

Following Ineese-Nash's work is an article by Jessica Evans and Lucy Costa that takes the readers back to the large institution, specifically the forensic mental health care system. Concerned about the rising rates of incarceration among women and the absenting of female forensic mental health patients from the gender-based analysis (GBA+) commitments of the federal government, Evans and Costa highlight the conditions facing women living at the intersection of psychiatric institutionalization and criminalization. Taking as the starting point the limitations of a GBA+ framework, Evans and Costa trouble both the cis-male centrism of the forensic mental health care system and the forensic mental health care system itself, demanding meaningful inclusion of the knowledges of women and service-users.

Next, Sally Kimpson examines how women living with chronic physical and mental impairments are impacted by the B.C. income support program. Writing as a woman who both lives with a disabling chronic illness and who has accessed disability income support, Kimpson characterizes her accounts as interested. Drawing on rich interview data with disabled women, Kimpson mobilizes Foucault's concepts of biopower and governmentality to challenge the B.C. government's neoliberal claims of fostering "independence, community participation and citizenship [among] disabled people in the province." Kimpson demonstrates how disabled women accessing

income support are subjected to policies and practices that create significant uncertainty. This production of disabled women accessing income support as "uncertain subjects"—the title of this piece—is an example of the ways in which transinstitutionalization is constituted through neoliberal arrangements of essential social services.

Next, Michelle Hewitt takes a skeptically intergenerational turn, asking: What happens when you're chronically ill and your community supports cannot care for you at home? Grounded in her own explorations of futurity and wonderings about what her life will look like as her Multiple Sclerosis progresses, Hewitt reports from the field. She chronicles her tenure as an advocate for age-appropriate care in British Columbia and offers the stories of young people living (or "warehoused") in long-term care facilities. Embedded in an analysis of "temporal dislocation," Hewitt describes conversations with disabled folx, advocacy organizations, and politicians, noting all the while that chronic illness is "out of step" with conventional life and the moments wherein life is lived out somewhere between the personal and the political. Driven by the understanding that advocacy must manifest as more than empathy, and must be translatable to those in power, Hewitt serves up activism for age-appropriate care as an intricate dance rather than as direct action. And, even with crip time on her side, Hewitt recognizes the tensions between time spent living one's daily life and time spent curbing power relations.

This issue breaks from the traditional academic format mid-way with the third piece in this collection, a photo essay focused on constructions of disabled childhoods. The photos are a curated assemblage of the everyday work of families, who, authors Kathryn Underwood, Jessica Vorstermans, and Kathryn Church argue, are tasked with producing the "normal" child. The images in this piece are the product of a larger institutional ethnography project informed by interviews with mothers, grandmothers, fathers, and foster parents across Ontario. The photos

showcased here include that of "tender objects"—crafts and toys and other things found at home and elsewhere. The reproduction of photographs in this context is a method that challenges dominant discourses of normate childhoods, collected by authors who argue that disabled childhoods are a product of diagnostic identification rather than individual experiences of difference.

This special issue closes with a sunset photograph and text by Kim Collins and Anne Zbitnew. Shared from the interdisciplinary installation "A Stitch in Time: Mourning the Unnamed," this black and white textual installation transposes a figure in Victorian mourning dress—importantly, the period during which many of the large-scale institutions were built in Canada—into a modern urban landscape. This photograph and text capture the changing sites and shapes of institutionalization in Canada over the past 150 years; that is, this photograph and text capture transinstitutionalization.

The aims of this collection

The study of transinstitutionalization necessarily varies by context. In this issue we guard against misconceptions that institutionalization is an action that took place in the past, whose loose ends we are now trying to tie together and where contemporary institutionalizing conditions are merely legacies that will, in time, fade away. To think of institutionalization as something of the past is to gently scratch its surface. And, given the wide breadth of transinstitutionalization and the many lives and stories it encompasses, we are aware of the limitations of covering this vast topic in one special issue. Yet, following a call to include disability in developing new approaches to understanding modernity (Van Trigt, 2019), our aim with this collection is to gather the latest

research and reflections on transinstitutionalization as a topic that can take flight in our theoretical and cultural imaginations, a topic that can help us transcend the dangers of "theoretical complacency" that come with imagining the ongoing as a past, one-time thing (Bauman, 2000, p. 3).

Rooted in select slices of histories and contemporary realities located on the parts of Turtle Island now also known as Canada, the first intention of this collection is to provide an overview of transinstitutionalization as a topic of study in critical disability studies. The voices featured in this collection highlight the dynamic links between historical and contemporary thought around transinstitutionalization as it is felt through individual lives, and what these affective experiences reveal about the wider social, structural, and cultural factors that shape our individual navigation through ableist, colonial systems.

The second aim of this collection is to show how studies of transinstitutionalization contribute to methodology and theory in critical disability studies. The articles here showcase a wide array of methods, from storytelling to photography to art installation. These methods and methodologies speak to the complex issues of describing lives that are intertwined in the business of confinement and cure. Drawing on a wide range of theories from critical disability studies, deaf education, Indigenous knowledges, and more, this collection edges toward an interdisciplinarity uptake of transinstitutionalization, which we feel is necessary given its wide reach across experiences and social locations.

Ultimately this collection debunks notions that institutionalization has ended, and instead offers a launching pad for further discussion and development of transinstitutionalization as a topic area in and around the interdisciplinary landscape of critical disability studies. Leaning into the partialities and limits of knowing as transinstitutionalization reveals itself and is exposed in

multiple shapes and through various sites, this special issue sheds early light on transinstitutionalization as a concerning cultural trajectory to which we find ourselves and others all too tightly bound.

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