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Canadian Journal of Disability Studies Special Issue: Institutional Survivorship Editorial Introduction

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Histories of disability are too often inextricably linked to histories of institutionalization. This is to say that part of the historical experience of people who have been labeled as disabled includes the damaging experience of social confinement and removal to institutional spaces. As an editorial team, we come to this special issue as members of a collective invested in the critical uptake of survivor knowledge as a force for political transformation. Since 2013, a group of artist-researchers and artist-survivors, including the editors of this special issue, have collaborated on *Recounting Huronia*, a project funded by a Social Science and Humanities Research Council Insight Development Grant. Using arts-based methods, we have explored histories of institutionalization at the Huronia Regional Centre (formerly the Ontario Hospital School, Orillia), which was the largest residential facility in Canada for persons diagnosed with intellectual disabilities. Huronia opened its doors in Orillia Ontario in 1876 and remained in operation until 2009. As survivors recount, it was a place of widespread and brutal physical and sexual violence, material and psychological deprivation. Huronia was an institution that survivors repeatedly refer to as haunted, and imagined being burnt to the ground, demolished, but not forgotten.

Over the past four years, our collective has been processing and presenting traumatic memories of institutionalization, reliving intensive punishments, sexual and physical assault, deplorable living conditions, disrespect and mistreatment, estrangement from and loss of loved ones. We have told these stories through poetry and visual methods such as collage and photography, in cabaret performances, dance and song. We have, in the telling, found audiences with open minds and hearts, and we have found community in one another. We did this work together taking up Premier Kathleen Wynne's public apology to survivors on behalf of Ontario: "we will protect the memory of all those who have suffered, help tell their stories and ensure that the lessons of this time are not lost" (2013, para. 9). Wynne's apology comes under suspicion by many survivors (including in the pages of this special issue), and indeed she represents a government constrained by persistent forms of brutalizing neoliberal normativity. Survivor memories, on the other hand, reach toward the imagining of a radically different world than the ones out of which institutions such as Huronia have arisen, a world where relationalities across difference are infused with respect, dignity, and human rights.

This special issue is one forum we imagined for showcasing and preserving such histories and critical knowledge of institutionalization, one wherein we throw into relief a recurring theme in narratives of institutionalization: namely, survival. What does it take to survive conditions that work to threaten life and diminish personhood? What toll does survival take on the body? How pressing is the guilt of survival when others have not? What ethical and political demands do survival stories make on society as a whole? In the call for papers for this special issue we construct notions and experiences of survival within the context of institutionalization, construed broadly to include psychiatric facilities, hospital schools, prisons, detention centres, refugee camps, group homes, and chemical control in community settings. While the articles included

here largely deal with experiences of psychiatric facilities and institutional settings like Huronia, it is important to place these accounts and analysis within the larger context framed in the call. These histories are understood to comprise valid knowledge spoken through individual voice that offer a partial but important view of institutional survivorship and that intervene upon those conversations taking place around the recent history of the Truth and Reconciliation Commission on residential schools, racially imbalanced incarceration and policing, institutional forms of housing and shelter, and the ongoing medicalization of disability and difference.

Article Summary

Oral histories. The stories told here unfold in myriad ways: through narrative and imagery, scholarly analysis, poetry and sound. The special issue opens by centering oral histories of institutional survival. Building a Disability Oral History Toolkit for the Centre for Independent Living in Toronto and the Department of Physical Therapy at the University of Toronto, Fady Shanouda and Karen Yoshida posit that "oral history methods provide communities with the opportunity to learn from disabled people's stories of struggle, achievement, activism, and change" (2014, p. 9). They predicate their work on the principle that disabled persons are experts of their experience in opposition to the modernist institutions who have claimed expertise over us all. Acknowledging disabled persons as experts of their own experience requires of us several responsibilities. First, we offer by way of set-up that the narratives in this special issue have not been sanitized; they rather lay bare deep and embodied traumas. Histories of institutionalization entail violence, neglect, and indignity, both endured and witnessed. Their retellings can be heavy: graphic and difficult, evoking fear, loss, and pain. Second, we come to these stories on their own terms, as we challenge hegemonic normative

society to recognize that there is authenticity in those lived realities that have been silenced thus far. Oral history-making emerges and coalesces around a set of complex understandings of truth in relation to power hierarchies and subjectivity, which we understand must be engaged critically in terms of what demands are placed on how truths are represented, whose voices are gaining representation, whose remain silent, and whose purposes are being served within a context where the political agency of disabled people remains highly compromised. Thus, in this issue, we relieve these histories of the constraints of fact checking and cushion them from assertions of exaggeration. Rather, we uphold the notion that the truth of trauma may be communicated through multiple registers.

This special issue thus begins with Carrie Anne Ford and Cindy Scott, who worked respectively with Kate Rossiter and Jen Rinaldi to explore their memories of the Huronia Regional Centre, where they were institutionalized through their childhoods. In *Trauma from the Past*, Ford moves through fragmented experiences of Huronia—everyday happenings and encounters with staff marked by shaming, exploitation, and deprivation. Reflecting on the toll recounting takes, she ends her narrative wondering what would have become of her had she not left, what it would have meant for her to have been buried in one of the many unmarked graves of inmates on HRC grounds. Scott recounts her own experiences in *That's My Story & I'm Sticking To It*, both in word and through visual representation, her article showcasing collaged scrapbook pages where she layers and transforms photographs from the HRC, claiming them in the process. Scott proclaims the need for both other institutional survivors and the public to know the truth about Huronia, and that speaking out is a key dimension of her survivorship. The authors' accounts each conveys how trauma is inscribed on the body and also reflects upon the

embodied experience of sharing histories: Scott finds relief in getting "the story out," Ford finds the trauma lingers within her.

Autoethnography & advocacy. Personal narrative remains a prominent feature in the articles that follow, carrying on autoethnographic and critical life writing methodological traditions in the Disability Studies field (Jarman & Monaghan, 2017). Several of our authors embedded and organized their lived experience in and alongside scholarly analysis, reflecting upon what lessons can be yielded from experiences of institutionalization—what we can make of survivorship by heeding survivors. In *Self-Advocacy from the Ashes of the Institution*, social worker Sue Hutton collaborates with survivors Peter Park and Martin Levine, and Shay Johnson and Kosha Bramesfeld to recount survivor memories while institutionalized in residential facilities designed to hold persons with intellectual disabilities. Their work contributes to what they see as the importance of formal documentation of survivor experiences through inclusive research methods. The authors present written narrative alongside directed visual representation of experiences of institutionalization in the form of pencil drawings to provide for accessibility. Having experienced institutions in which all control was completely stripped from the survivors, the authors stress the need for obtaining control by people with disabilities over their own representation. Toward this end, self-advocacy groups that work toward ending institutionalization and that validate, respect, and support the dignity of survivors are identified as key to disabled persons' liberation.

Clementine Morrigan in *Failure to Comply: Madness and/as Testimony* also demands control over the representation of her strategies for survival. Morrigan describes how the self-harm practices to which she resorted, self-protective strategies which she understood as resistance against and testimony to violence she was experiencing, became coded as "acting out"

symptoms in the psychiatric incarceral space. Morrigan's reclaiming of the meanings of self-harm frames the problem of how experience of institutional trauma is often disbelieved because of the terms in which it is expressed. She writes from her embodied experience with the intention of eliciting a visceral response in the reader and a call to action.

And in *Unheard Voices: Sisters Share about Institutionalization* by Madeline Burghardt, Victoria Freeman, Marilyn Dolmage, and Colleen Orrick, three disability advocates reflect upon the ways in which they lost their respective siblings to institutions. Here especially, and across the three articles enclosed in this section, the authors interweave oral history, poetic prose, and photography to talk about how the social norm of handling disability with institutionalization troubled the white nuclear family ideal. Burghardt and colleagues describe how the absence and erasure of the disabled sibling becomes a fullness of grief and loss that has lasting repercussions on individual family members. The definitive lesson gained from the authors' reflections is that experiences of violence and loss motivated them to join advocacy and activist movements, movements that can only succeed when survivors' histories and needs are centered.

Ally scholarship. In our next collection of articles, academic allies reflect on the responsibilities allies have around how legacies of institutionalization are told and how survivors are honoured and supported. Madeline Burghardt's work in *Institutional Survivorship: Abandonment and the Machinery of the Establishment* concerns how institutions' custodial frameworks have engendered loss, isolation, and abandonment for survivors and their families. Burghardt locates the onset of institutionalization as an approach to difference within the emergence of the modern capitalist colonial nation state and its distinction between the productive and non-productive body relative to the demands of a market economy. The decision to institutionalize made by family members (as discussed in *Unheard Voices* and preceding

articles) is constructed as inevitable within the capitalist framework and as such, understanding capitalism plays an important role in understanding the consequences experienced by people with disabilities. That capitalism, while vastly contested from multiple directions, remains steadfast and ideologically fortified in real historical terms, forms a threat to disabled persons of continual traumatization and marginalization. The inextricable link that Burghardt identifies between capitalism and the marginalization of disabled persons means that liberation cannot occur within capitalism.

In *Writing Institutionalization and Disability in the Canadian Culture Industry: (Re)Producing (Absent) Story*, Chelsea Temple Jones focuses in on how a progressive, pro-union Canadian journal is influenced by the culture industry and the demands of consumer capitalism in its ability to probe issues of how disability rights are defended within the labour movement. Jones moves deftly between material and symbolic concerns, referencing Frankfurt school criticism as a way of revealing the contradiction between the institutionalization of disabled persons constructed as "non-productive bodies" and the labour rights of workers who rely on institutions for their jobs. Likewise, the culture industry imposes ableist terms in regards to how disability is written about, terms that reflect the ableism inherent in capitalism. Jones further complicates her discussion by taking a reflexive turn, observing her contrasting positions as a sister, an advocate, and a journalist who operates both within the culture industry and in resistance to it. Jones raises questions as to how disability is narrated, who gets billed as experts of disability narratives, and what happens to the disabled subject when their story is told within ableist culture industry paradigms. Here she identifies the tendency for the culture industry to re-inscribe notions of "fixing" disabled persons through inclusion within capitalism as opposed to

engaging with the possibilities in those challenging stories the culture industry prefers to leave behind.

In *Escaping "The Organism, Signifiance, and Subjectification" in the Recounting Huronia Project*, David Fancy picks up the discussion of symbolic representation developed by Jones by providing an example of storytelling that challenges the tropes and discourses of disability within the culture industry, and works toward greater survivor agency and a liberatory end. Engaging in an artistic collaboration with Huronia survivor, Barry Smith, Fancy applies Deleuzian theory to make sense of their meaning-making processes. Fancy considers the strength of Deleuzian understandings of art approaches as working beyond fact-based understandings of survivor experiences by taking up the persistent truth and authenticity of creative tellings. For Deleuze, art language opens up the possibilities for non-binary and non-hierarchical understandings of experience, meaning, disability, and thus subjectivity that work against the pathologization and stratifications imposed on disabled bodies through institutionalization. Fancy introduces the notion of "fabulation," where art creates an experience that is generational, insightful, and durational. He closes by echoing Jones's critique of the progressive culture industry's inability to deal with the challenging life experience stories of disability, observing that within the progressive Huronia survivor ally movement there has been resistance to working through creative modes in favour of re-inscribing ableist relations within disability activism.

Artistic expression. Taking up Fancy's argument for the importance of artistic methods, this special issue ends with two artistic responses to institutional survivorship, particularly to surviving the Huronia Regional Centre. In *apology, under erasure*, nancy viva davis halifax erases, while still leaving a legible trace, words from the public apology to Huronia survivors delivered by Ontario Premier Kathleen Wynne. halifax explains that the words erased from the

apology text reflect the inadequacy of the state's response and the troubled class action lawsuit outcome. The words that remain legible speak to the persistence of violence despite Wynne's conciliatory gesture, to the hollow promises and humble posing that constitute this forced apology. Erasure as an act is a powerful tool of the nation state (through its culture industries, through the nuclear family ideology, even within its progressive activist factions), but it can also be mobilized as an act of resistance that allows new meanings to emerge in the place of the erased text. Again, the importance of survivor words that emerge and escape from marginal spaces, of the institution and the text, is where the hope lies.

We end with Marla Hlady and Christof Migone's piece *Soundfull: A Wall Speaks, A Door Shakes, A Floor Trembles*, which describes the sound amplifying interactive installation that they set up in the rooms of the Huronia Regional Centre during a site visit in October 2014, which was attended by survivors and researchers of the *Recounting Huronia* project. As professional individualist artists, Hlady and Migone brought their sound expertise to bear on the physical architecture of Huronia, where the memories absorbed in the walls reflect and speak back. By creating an audio apparatus by which survivors could, in turn, speak back to the walls of the institution and tell their stories of pain and trauma, Hlady and Migone took on the role of creative guides. As moments unfolded of walls and survivors speaking through the sound equipment, feedback loops occurred which amplified and distorted the sound, pushing the limits and bringing the audience/participants into a crisis moment, channeling the intensity of violence that had occurred within this building and thus evoking the survivors' calls to tear the place down. Here, again, survivor testimony is inscribed into space, reverberating against and off walls that held the life stories erased from social memory.

Normative, positivist-based symbolic systems override and subalternize what we posit here as the legitimate truths and knowledge conveyed through creative, alternate, and embodied lived experience forms of expression. Much is at stake in this binary approach; for instance, in the class action lawsuit, individual stories that could be corroborated or found "factual" warranted a larger settlement than others whose stories were subject to doubt. For an institution that was structured in a way to mete out violence, it seems merely a convenient, neoliberal cost-cutting affair to base settlement on individual stories and not the systemic form of the oppression itself. Either way, denying or undercutting the monetary compensation to many survivors is a re-traumatizing violence. Every piece in this journal asserts the right of people to speak to institutional violence from their own experience and on their own terms (or those available to them). Each piece argues for preventing the erasure of lived experience expression in the culture industry. Each piece shows the reader an expanded understanding of how truths can be conveyed: how symptom can be testimony, how story can be both art and truth, how art can capture the traces, spaces, resonances, and sounds that carry story, story that can only give a more complete understanding of the kind of hierarchical society we are busy recreating as "normal" everyday life. Not the stories that society necessarily wants, but the ones we need to open up to in order to do the ethical work required to overcome the of persistence systemic institutional violence.

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