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Intragenerational Trauma: Family Stories of Institutionalization and Policies of Care

Traumatisme intragénérationnel : L'importance des histoires familiales dans l'élaboration des politiques

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Abstract

Despite the official closing of many institutions for people labelled/with intellectual disabilities in Canada, the emotional and relational effects of institutionalization continue to reverberate in the families of institutional survivors. Although often an unheard group, siblings of survivors offer insights on institutions' long-lasting effects on individuals and families, and on the ways in which their stories can contribute to more just and sound policy decisions moving forward. In this paper, five siblings share their experiences of the intragenerational trauma they have experienced as a result of their brother's or sister's institutionalization and offer critical perspectives on addressing this chapter in Canadian history as one step towards creating policy that will address the needs and concerns of people labelled/with intellectual disabilities, their families, and communities.

Plain Language Summary

- Most developed countries have closed many of their large institutions for people with disabilities. This is a good thing.
- Institutional survivors and members of their families still feel the effects of institutionalization.
- The brothers and sisters of people who lived in institutions are also sad and angry about what happened.

- It is important to share stories about institutions and about what happened in families so that it does not happen again. These stories can help decision-makers to make better decisions about how to care for people with intellectual disabilities and how to create a society where everyone can flourish.
- We need to think of better ways to care for each other.

Résumé

Malgré la fermeture officielle de nombreuses institutions pour les personnes étiquetées/ayant une déficience intellectuelle au Canada, les effets émotionnels et relationnels de l'institutionnalisation continuent de se répercuter dans les familles des survivants de l'institution. Bien qu'il s'agisse souvent d'un groupe dont on ne parle pas, les frères et sœurs des survivants nous éclairent sur les effets à long terme des institutions sur les individus et les familles, et sur la façon dont leurs histoires peuvent contribuer à des décisions politiques plus justes et plus saines pour l'avenir. Dans cet article, cinq frères et sœurs partagent leur expérience du traumatisme intragénérationnel qu'ils ont subi du fait de l'institutionnalisation de leur frère ou de leur sœur, et offrent des perspectives critiques sur la façon d'aborder ce chapitre de l'histoire canadienne comme une étape vers la création d'une politique qui répondra aux besoins et aux préoccupations des personnes étiquetées/ayant une déficience intellectuelle, de leurs familles et de leurs communautés.

Résumé en termes simples :

- La plupart des pays développés ont fermé un grand nombre de leurs grandes institutions pour personnes handicapées. C'est une bonne chose.
- Les survivants des institutions et les membres de leur famille ressentent encore les effets de l'institutionnalisation.
- Les frères et sœurs des personnes qui ont vécu en institution sont également tristes et en colère à cause de ce qui s'est passé.
- Il est important de partager des histoires sur les institutions et sur ce qui s'est passé dans les familles afin que cela ne se reproduise pas. Ces récits peuvent aider les décideurs à prendre de meilleures décisions sur la manière de s'occuper des personnes atteintes d’un handicap mental et de créer une société où chacun peut s'épanouir. Nous devons trouver de meilleures façons de prendre soin les uns des autres.

Mots-clés : institutions, les familles, traumatisme intragénérationnel, des histoires,

Introduction and Context

The emergence of the deinstitutionalization movement in the latter decades of the twentieth century in most Western countries, a time characterized by a collective international commitment to human rights and to a sense of increasing government obligation towards all people's well-being (Simmons, 1982) led to the closure of many government-run, total institutions for people with intellectual disabilities. In Canada, the 2009 closure of Huronia, the oldest of Canada's large institutions for people with intellectual disabilities, and the 2019 closure of the Valley View Centre in Moose Jaw, Saskatchewan, are two such examples.[i]

While these closures are viewed within the disability rights community as a significant step forward in the long history of disabled people's mistreatment, the transition to community-based living for people with intellectual disabilities has not been without obstacles. These include several jurisdictions' decades-long allegiance to austere neoliberal policies, resulting in inadequate funding for families and community groups who wish to design and implement alternate community living models but lack the financial means to do so, as well as the imposition of regulations that limit people's choices regarding where they can live or the extent to which they can be gainfully employed in order to receive support from the state (Carpenter, 2007). Lack of foresight in the decades leading up to institutional closure in many jurisdictions has led to thousands-long wait lists for permanent homes for disabled people (Ontario Ministry of Community and Social Services Housing Task Force (henceforth OMCSS HTF), 2018; Inclusion Canada, 2020; 2019), which some governments have paradoxically used to justify the trans-institutionalization of disabled people into long-term care facilities, as well as the re-emergence of facilities that are strikingly similar to the institutions of old, albeit on a smaller scale (LeBlanc Haley & Temple Jones, 2020; Ontario Ombudsman, 2016; Spagnuolo, 2016). Perhaps most importantly, self-advocates and allies point to the ongoing use of institutional practices that mimic total institutions' regimentation, surveillance, and lack of choice despite their community-based settings (Ben-Moshe, 2011; Hutton et al., 2017).

Beyond these generally visible threads of institutionalization that linger in current administrative and living situations, there exist other, less visible effects, including the ways in which institutionalization has affected the family members of institutionalized individuals. Like other atrocities that extend temporally and spatially beyond its immediate nucleus of impact, the institutionalization of labelled people has had profound and long-lasting effects not only on survivors, but on their surrounding circles and communities. The purpose of this paper is to explore these expansive and long-lasting effects with siblings of institutionalized individuals. Through interviews with five siblings, I investigate the ongoing emotional and relational effects of institutionalization, the extent to which they continue to reach within their families, and the often life-long emotional work that their coming-to-terms-with has necessitated. In addition, in alignment with the theme of this special issue, I consider how reflecting on family experiences such as these can inform future policy decisions regarding the needs and concerns of people labelled/with intellectual disabilities, their families, and communities.

This paper consists of four parts. First, I examine theoretical and empirical contributions to our understanding of intergenerational trauma and how these can contribute to an understanding of what I refer to here as trauma's *intra*-generational effects. Following the work of scholars of the Holocaust as well as Indigenous and other scholars who have led the way in exposing trauma's intergenerational effects, I explore its lateral or horizontal outcomes, or the ways in which it reaches across and through generations—in this case, to the siblings of institutionalized individuals—and how this continues to affect them in material, emotional and intellectual ways. In addition, I draw from the work of Karen Barad and Donna Haraway, which, although originating in fields divergent from those typically associated with the needs and concerns of disabled people, contributes to this discussion[ii]. Barad and Haraway engage theories of diffraction as a way to understand the seemingly infinite possibilities for phenomena's long-term effects. Simply put, diffraction refers to the ways in which the effects of different phenomena—in this case, the social and relational effects of institutionalization in families and society—can spread more widely and in different directions than previously anticipated and can become entangled and intersect with each other. In the second section, I draw from conversations with siblings of institutional survivors to explore the ways in which institutions' effects continue to reverberate in their personal, family and work lives. For the purposes of this paper, I spoke to five participants from an earlier research project in which I interviewed institutional survivors and members of their families to explore the effects of institutionalization on family relationships and understandings of disability (Burghardt, 2018). In the third section, I reflect on the themes that emerged from these conversations and consider them against the theories of trauma and diffraction examined earlier. Specifically, what are the implications of these reverberations on family stories, memories, and relationships? What surfaces in the wake of this historically unjust way of treating disabled people, beyond the direct experiences of survivors? And finally, I consider the ways such reflections can be used to inform future policy decisions to better meet the needs of disabled people and their families, and to prevent the re-iteration of past oppressive practices.

Inter / Intragenerational Trauma

Scholarly work on the multiple and intergenerational effects of trauma emerged in the latter decades of the twentieth century. First articulated in literary and academic writing by the children of Holocaust survivors, writers such as Epstein (1979) began to give voice to the individual and collective experience of trauma being passed from one generation to the next (Berger, 1997; Hoffman, 2004). These post–World War II endeavours have spawned significant theoretical and practical discussion on the degree and means by which traumatic histories are carried forward, often in complex ways (Berger, 2010; Kidron, 2003). Some scholars discuss the emotional and practical effects of trauma that inform personal relationships and life choices (Hirsch, 2008; Kidron, 2009), as well as the potential for long-term effects within families (Hechler, 2017). Others focus on both the potential and limits of individual and collective memory. Raczymow, for example, famously described the memories of subsequent generations of Holocaust survivors as "shot through with holes" (as cited in Berger, 2010, p. 150), encapsulating their traumatic yet incomplete nature. Hirsch, in earlier work (1997) in which she introduced the term *postmemory*, suggests that complications can arise when attempting to come to terms with previous traumatic events, when one's "connection to the object or source is mediated not through recollection but through an imaginative investment and creation" (p. 22). Other scholars have offered counter-discussions, such as Field's (2014) ambivalence towards second-generation identification, and van Alphen's (2006) challenge to current engagement with the term "survivor" in reference to subsequent generations.

This reflexive work has been undertaken by other communities that have experienced oppression and marginalization over time, including Black American and Black Canadian communities

(Nichols Fairfax, 2020; Phillips & Pon 2018), diaspora and refugee communities (Guyot, 2007; Merali, 2004), and Indigenous and First Nations communities. In Canada, Indigenous scholars, activists, and allies have done significant work on the ways in which trauma can become materialized in people's lives and passed from one generation to subsequent ones, even if later generations did not themselves directly experience harmful practices such as Indian residential schools (Assembly of First Nations, 1994; Bombay et al., 2014; Deiter, 1999; MacDonald & Hudson, 2012). These scholars have demonstrated trauma's potentially far-reaching effects, such as the disruption of traditional parenting knowledge (Ball, 2009), and negative influences on well-being (Paradies, 2016) and education (Bougie & Senécal, 2010).

While there are significant experiential differences between the groups named above— each group has been subjected to oppression and violence uniquely directed at them for various reasons, informed by varying degrees, sometimes extreme, of racism, classism, genocidal intent, and ableism, among others—reflection on the shared experience of trauma that is passed on to subsequent generations can be helpful in understanding the mechanisms of trauma and how it ends up being lived in people's lives (Bombay et al., 2014, Evans-Campbell, 2008). Scholars note that while we cannot impose a general theory of intergenerational trauma onto multiple experiences, this scholarship can be "relevant to numerous other contexts of traumatic transfer" (Hirsch, 2008, p. 108), particularly in the context of the family. Drawing from the aforementioned scholarship, and in particular from Hirsch's encouragement to consider other contexts of traumatic transfer, in this paper I am examining the horizontal, lateral, or intragenerational effects of long-term institutionalization within families as experienced by the siblings of institutionalized individuals. There are important reasons to draw from sibling accounts.

In general, scholarly work has demonstrated the importance of sibling relationships in one's identity formation due to processes of both identification and contrast and indicates a need to further this line of enquiry in order to expand the work that has thus far emphasized intergenerational relationships (Davies, 2015). In particular for our purposes here, scholarship regarding sibling relationships in families in which there is a disabled child has historically been written from the perspective that disability is the problem around which other family members must determine how best to cope, adapt, and problem-solve (see, for example, Dumas et al., 1991; Giallo et al., 2012; Macks & Reeve, 2007, Pilowsky et al., 2004; Verté et al., 2003). However, recent scholarship that engages with critical as opposed to clinical frames offers a more fulsome and nuanced account of siblinghood, including the need to take the disabled child's perspective into account (Burghardt, 2018; Jones, 2019; Meltzer & Kramer, 2016, Richardson & Jordan, 2017). These scholars challenge the predominant methodology of examining family function or dysfunction as a product of disability and point out that discussions concerning the family must turn from a focus on the disabled individual to the social and political reactions and responses that more typically influence decisions and dynamics within families. Siblings of institutionalized individuals offer critical insights owing their unique position of not being the primary object of their parents' decision to remove a child from the family, nor having agency in the decision, yet directly experiencing its implications, nonetheless.

The siblings of institutionalized individuals have thus lived a paradox: although their parents often justified the disabled child's removal as one way to ensure adequate attention and care to their non-disabled children, the institutionalized child continued to play a central role in the family narrative, their intentional absence a constant reminder of the wound that existed in the family fabric, and a source of the ambivalent mixture of confusion, guilt, remorse, anger, and sometimes relief that many siblings experienced (Burghardt, 2018). Further, siblings offer important insights regarding the constructed nature of disability. This is on account of the realization, often years later, that the explanations given to them by their parents regarding the reasons for their siblings' institutionalization were challengeable, the fluctuating social and political definitions of disability forcing a re-calibration of the degree to which their parents' decision was justified (Burghardt, 2018).

In addition to the above insights, there are further reasons to draw from sibling experiences. First, many of those labelled/with intellectual disabilities use communication methods that can take time for non-disabled people to learn (Jones, 2019), and thus possibilities for public expression and dissemination of their experiences can be more limited. Siblings are often among those who best understand, or are committed to learning how to understand, their disabled brother or sister, and often assume the role of holding their knowledge and experience as it emerges over time (Jones, 2019), particularly as parents age. Further, the public fora that have taken place with some traumatized groups have occurred to a lesser degree with survivors of institutions for people labelled/with intellectual disabilities. For example, in 2013, although litigants in the Huronia Class Action lawsuit against the Ontario government had been promised a day in court during which they would be able to publicly share their stories in front of the presiding judge, this did not come to fruition, and a settlement was reached without a public reckoning[iii]. This official silencing of survivors' accounts remains a difficult chapter in the deinstitutionalization experience for Ontario survivors, who feel that they were deprived of the opportunity to share publicly what had transpired while they were under government watch. Siblings' public accounts of familial experiences have helped to address this vacuum (Burghardt et al., 2017; Dolmage, 2011; Freeman, 2019; McKercher, 2019), including exploring alternate ways to uncover the experiences of their brothers and sisters. Further, many people labelled/with intellectual disabilities do not have children or grandchildren (although many do), and thus the diffusion of family stories and their emotional effects more typically extends outwards, horizontally and diagonally, to siblings, nieces, and nephews.

Scholars who have done work in the area of siblings' experiences extend a caution, however. Meltzer & Kramer (2016) point out that much sibling research in families in which one member has a disability has focused unilaterally on the experiences of non-disabled siblings at the expense of hearing from disabled people about their experiences of kinship. Disability and family studies would do well, they suggest, to embrace more radical, inclusive, and participatory research methods to contribute to the inversion of traditional and typically more oppressive models. Colleen, one of the participants in this study (introduced below) affirms this perspective when she notes, "we were not the obvious vectors of trauma…. what we went through was nothing compared to what my brother went through," reiterating the importance of providing opportunities for survivors to safely share their experiences. Further, despite work that has begun to fill the void regarding the experiences of institutionalized people, gaps remain. Indeed, the siblings of institutionalized people with whom I have spoken have all described a lack of knowledge when it comes to their brother's or sister's incarceration. Beyond the details of when and where he or she was institutionalized, most have no idea what their siblings' days were like, are not aware of the things that he or she liked to do, and do not know the details of their suffering. Victoria, for example (introduced below), whose sister Martha was institutionalized at the Rideau Regional Centre, remarks that, in retrospect, she is shocked at the lack of interest she and her family demonstrated about Martha's lived experiences in the institution, and how little they knew about her situation. Colleen remains troubled by a time when she was certain that her brother was being sexually abused, but she and her family were unable to obtain official answers about the situation. She explains that “he did not have the words to tell me what had happened,” and although she was later able to tell her brother, “I think I know what happened to you; I’m sorry about what happened to you,” she continues to carry a deep sense of guilt, grief, and frustration that she was unable to stop what was happening to him and to communicate with him about this traumatic period in his life.

Sample, Methods and Limitations

In 2014, I completed a research project in which I interviewed institutional survivors who had been institutionalized between the late 1940s until the 1980s, as well as members of their families, including siblings and parents (Burghardt, 2018, 2014). Ethics approval for the project was obtained from York University’s ethics review board[iv]. For the purposes of the present paper, I reached out to five of the original research participants and asked if they were willing to discuss the ongoing reverberations of institutionalization in their lives. All of the participants had provided written consent to participate at the time of the original interviews, and they provided further written consent for this phase of the project. One-on-one interviews were conducted between February and March 2021 using Zoom technology. Notes were taken and transcribed and were sent to each participant for review and clarification.

These participants were invited to contribute owing their indication at the time of the original interviews that they were open to further discussion should future work necessitate this, and each had stressed the importance of knowledge mobilization on the broader social effects of institutionalization. I am aware of the methodological limitations of reaching out to a small sample of participants, specifically, that theorizations based on our conversations cannot be generalized to all siblings or to all families in which one family member was institutionalized. This is especially the case with regard to the geographic and historic specificity of the phenomenon being explored, that is, the experiences of Canadian families with a family member who was institutionalized in the decades following World War II. However, qualitative research scholars have indicated that small, purposive samples are valuable owing their ability to provide in-depth understandings of particular phenomena and the meanings people attach to them (Hesse-Biber & Leavy, 2011, p. 45), and as openings to emergent knowledge (Reid et al., 2017, p. 191) especially, I posit, during transitional historical moments, such as the current transition towards what Carpenter (2007) calls the *neo-asylum era*. A further limitation could be that my familiarity with the participants might have foreclosed possibilities of disagreement or divergence, potentially limiting more robust conversation and outcomes. Future research in this area could include explorations of the experiences of a broader and larger cross-section of siblings, as well as other contemporary family constellations, particularly in the context of the ongoing institutional practices discussed above.

A further limitation is the gendered nature of the sample, as all of the current participants were women. This is due, in part, to the predominance of women in the original sibling sample, which consisted of nine women and two men. As I explain in earlier work (Burghardt, 2018), the sisters of institutionalized individuals were generally more forthcoming and were more likely to be interested in participating in the original project, while brothers, in general, were more reluctant to do so. While it is beyond the scope of this paper to do an in-depth interrogation of the reasons for this gender imbalance and the reluctance of some of the brothers of institutionalized individuals to participate, scholars indicate that men's hesitation to participate in interview-based qualitative research is not an unusual phenomenon (Polit & Beck, 2008). Suggested reasons include men's reluctance to engage with topics that might lead them to appear vulnerable and less in control (Affleck et al., 2013), situations that remain "taboo" for many men (Oliffe & Thorne, 2007, p. 150), especially for those of the demographic cohort involved in this project, as well as these being traits typically associated with femininity (Butera, 2006, p. 1271). Butera also suggests that traditional social constructions of maleness include an avoidance of situations that might encroach on the barriers traditionally erected around one's private life (Butera, 2006, p. 1272), an incursion that the original project was likely to include.

The central implication of this gender imbalance is that while the five participants in the current study shed light on the lived effects of institutionalization on family members who are women, particularly with regard to the emotional labour[v] performed by each of the participants both on their own behalf and on behalf of their families (discussed in more detail below), we are not able to gain the same insight with regard to male family members. This does not necessarily mean that men in this situation were not deeply affected or even traumatized by the experience of institutionalization in their families or that they did not perform emotional labour, but the gap in the record about men's experiences in this area has led to a paucity of knowledge, one which future research might look to address.

The five participants include Carmen, whose younger sister was institutionalized at the Huronia Regional Centre and now lives at a group home in the community; Colleen, whose younger brother Gerry was institutionalized at Southwest Regional Centre and went on to live in smaller community-based group settings; Victoria, whose younger sister Martha lived at the Rideau Regional Centre and later at a home in the community after being discharged; Marilyn, whose younger brother Robert lived and died at the Huronia Regional Centre; and Erin[vi], whose younger brother lived and died at a private institution. Based on my conversations with these women, three principal themes emerged—confusion, loss, and trauma; protecting the family; and vocational and life choices—each of which I explore in more detail below.

Siblings' Stories

Confusion, Loss and Trauma

The women described the shared experience of confusion and loss due to the removal of their brother or sister from the family home. Marilyn explains that her grieving began the moment her parents returned from the hospital without the baby she had been looking forward to caring for. She recalls repeatedly walking around the block with her toy baby carriage, realizing now that even as a five-year-old child she was trying to address her grief by replacing her baby brother with a doll. Victoria describes the confusion she experienced when she was four years old and her sister Martha, her closest playmate, was admitted to Rideau at the age of 21 months. Carmen describes coming home from school one day, her sister gone. She does not remember any discussion regarding the decision to send her sister away, and this remained something that was not to be brought up in family conversations. Only Colleen describes being included in some family discussion of her brother's leaving. She recalls her mother telling her that her brother Gerry would be going away to "boarding school", a depiction which Colleen initially felt jealous of. Despite the explanation, Colleen still experienced Gerry's leaving keenly, as did her other brothers, one of whom hid a tiny pair of Gerry's sneakers in his drawer for a long time.

For Marilyn, Victoria, Carmen, and Erin, the loss was compounded by the lack of explanation, leaving them to guess the reasons for their brother or sister's removal. The vacuum of information created stressful situations: siblings often assumed that the child's leaving had something to do with his or her behaviour, leading to the assumption that they, too, could be subject to such a decision if they displeased their parents. Further, the lack of explanation normalized the silence surrounding decisions made about the removed family member: siblings learned that it was reasonable to not discuss the institutionalized child nor to include them in family decisions. Victoria explained that this fostered an environment in which the rest of the family did not consider the kind of life that their brother or sister might be living within the institution, essentially reducing them to someone not worthy of attention. These situations could be described as leading to trauma by negation: the void created by the absence of discussion became a source of anxiety—an unspoken conversation, but one which took up emotional energy nonetheless. This void also established a template about the ways in which disabled people could be treated, something the siblings had to renavigate as adults as they came to know their sibling or to reflect on their experience.

The stress surrounding their brother's or sister's institutionalization was often experienced as shame. Siblings were first faced with their parents' shame, which often stemmed from more than one source—the shame of having had a disabled child, in addition to the shame of having "put the child away". As these women grew up, they then had to contend with their own shame and sadness about the decisions that were made within their family. Although parents during this era were largely pressured to institutionalize, disabled children were not, for the most part, forcibly removed from the family home. Siblings have thus had to contend with the knowledge that their parents had willingly, albeit not without reluctance in some cases, given up their child. In addition, this was not a burden that could be easily shared, owing the negative connotations ascribed to families that had a disabled family member at the time (Burghardt, 2016). Still now, siblings note that there are few social spaces in which to process this difficult aspect of their family history: despite greater knowledge of Canada's institutional history, this remains an under-addressed area in mainstream fora, and is considered a private, domestic topic for individuals and families to process (Burghardt, 2018).

When discussing their attempts to make sense of their parents' decision and the losses that accompanied them, the women expressed some appreciation for the difficulties their parents had encountered, as their decision had been made during a time when parents were under enormous external societal pressure from expert authorities and extended family members to institutionalize. The women came to appreciate that their mothers in particular had suffered from an assumed and gendered societal perception of the 1950s and 1960s that they were not capable of raising a disabled child on their own, a point made more evident when the absence of social supports and fathers' presence in the home are considered. In spite of this awareness and an increased empathy on the part of the women here, most of them also expressed anger, a wish that their parents had been willing to demonstrate more resistance to the forces at work in their lives. In addition, the women have become resigned to a state of irresolvability: there will always be some aspect of this chapter that cannot be brought to closure at an emotional level. As Erin described it, "I don't know where to put this… ."

Protection of the Family

Despite the feelings of confusion and shame described above, the siblings all described a felt sense of responsibility to protect their families and their family story while growing up. While this looked different in each family, the siblings all described denying, defending, minimizing, or keeping quiet some aspect of their home or family life in order to protect their parents from the repercussions of the decision they had made. For example, Colleen remembers one occasion when she and her father, who was a member of the local parents' group for families with disabled children, visited Huronia, Ontario's largest institution and the one considered by many parents to be the 'worst one' (her brother was living in a different institution). She was shocked by the conditions inside. The visit took place in mid-winter; snow was coming in through cracks in the windows in a large room while residents sat about wearing only undershirts. She realizes now that she did not draw connections between the conditions she was witnessing at Huronia and the possibility that her brother might be experiencing something similar. Somehow, his placement in a different institution acted as a buffer against this possibility, a perspective that allowed the family to avoid discussing the potential harm he might be experiencing. Additionally, through various jobs, professional positions, and her own role as the mother of a disabled child, Colleen grew increasingly knowledgeable about the history of and conditions within institutions. However, although she frequently acted as an advocate on Gerry's behalf, she generally chose not to discuss institutional conditions with her parents or non-institutionalized brothers. She felt she needed to protect them from the full ramifications of their decision, allowing them to continue to believe that Gerry's institutionalization had been best for him and for their family. In a starker example, when Colleen's suspicions that Gerry had been sexually abused were confirmed by the presiding coroner after his death, then, too, she decided not to discuss this with her family, fearing that this would make the situation even more difficult for her dad and brothers.

Similarly, Victoria explained that her early rejection of her sister Martha stemmed from a perceived need to remain loyal to her parents and signified an agreement with their decision to institutionalize, an agreement that also served to assuage some of her mother's guilt. Erin explained how, at the age of three, she was not allowed to tell anyone about the institutionalization of her brother nor his existence, even with her other, non-institutionalized brother, to the point that he remained unaware of his brother's existence until he was an adult. This sense of loyalty within a context of secrecy is an example of Foucault's depiction of secrecy as a "shelter of power" (1990, p. 101), wherein both the parents' power and the secrets they asked their children to keep mutually informed and enforced the other, in part as one way to hold the family together. This sense of loyalty was also complicated by fear. At-home children were very aware of what happened to siblings who did not "behave" or meet parents' expectations, and they understood from an early age that it was dangerous to transgress the secrecy that had been asked of them or to initiate discussions that dealt with the complex emotions the situation engendered.

Victoria, Carmen, Erin, and Marilyn all described investing significant emotional and physical energy into protecting a certain image of their family, something they learned to perform even though it had never been directly asked of them. They were expected to reiterate the narrative that their family presented outside of the family home, including, for example, how many children were in the family or where the "absent" child lived. Carmen described feeling responsible, from a young age, for "getting her family going," partly to maintain their public persona. This involved vigilance and watching other family members, especially her mother, for signs of depression or depletion and re-animating them so that they could continue to function. At the time, she thought this was normal, and it was only through later reflection that she understood that children are not normally expected to be the organizing and invigorating force for their families.

The role of family protector is made more complicated when juxtaposed against the feelings of disappointment and irresolvability described above. This conflict between fidelity to the family versus feelings of shame and anger due to decisions and their outcomes echoes Koegeler-Abdi's (2021) work on the contradictory nature of the emotions evoked through family secrets. Her research, similar to the experiences of the women here, points to secrets' multi-faceted nature: the burden they pose, their protective potential, and sometimes, as a source of resilience. Rather than this ambivalence leading unequivocally to inconclusiveness and frustration, Koegeler-Abdi suggests that family secrets can function as a "storage device" that "stores potentially harmful information until circumstances have changed sufficiently to safely process them" (p. 73). These findings are reflected here, as the women described engagement with the material of their lives as adults, through reflection and therapy, academic work, and vocational choices, described below.

However, this discussion is distinct from others that concern family secrecy owing to the particular situation of the family member around which the secrecy revolved. Institutionalized individuals occupied strange family roles: they *were* the secret yet were excluded from the process of its creation and function. In addition, people with intellectual disabilities are frequently dependent on the assistance of others to "right" the story, in this case, to potentially uncover its secretive aspects, and they often carry the additional burden of being neither heard nor believed.

Vocational and Life Choices

The women indicated that their career paths were influenced by their experience of having a brother or sister labelled/with an intellectual disability who spent several years in an institution. Their vocational choices are distinct—ranging, for example from academia to social work to social justice leadership—yet all of them share the common thread of searching for clarification about the issues raised due to their siblings' institutionalization through their work.

Victoria is a scholar of the history of Indigenous-settler relations in Canada. She feels that her scholarly interests are connected to her own childhood experiences, despite the fact that she does not have Indigenous heritage. She believes that her desire to understand Indigenous experiences of displacement and forced relocation, something she learned about prior to reflecting on her sister's experience of institutionalization, stems in part from witnessing, as a very young child, her sister Martha being uprooted and placed in an institution before the age of two. Her study of Indigenous-settler relations, and exposure to the stories of Indian residential school survivors, revealed to her the harm perpetrated by institutional oppression and pushed her to "get past the denial that institutionalization was necessary" for her sister. In addition, her scholarly work has paralleled questions about her own family's participation in the larger Canadian narrative of rejecting certain bodies and minds due to their perceived inability to reach normative standards of performance and achievement. Thus, her scholarly journey has been her way to approach questions of home, place, harm and belonging that emerged in her family.

Carmen also notes that her academic work—narrative self-inquiry as research methodology—stems directly from her early life experiences. She realized early in her career that there was much in her life experience that was “tucked into a corner” that she needed and wanted to reflect on, and rather than separating her self-reflection from her academic work, she chose to address it and to study the ways in which this methodology can be used to assist people to come to terms with difficult life experiences.

Interestingly, both Carmen and Victoria describe encountering phases in their academic work: initially, a deepening entanglement with the emotional effects of their family histories, and later, a gradual disentanglement due to the perspective that the passage of time and concentrated reflection allowed. For example, Victoria noted that while there are resonances between her family’s story and the experiences of Indigenous peoples in Canada, such as blatant rejection based on “difference” and perceived incapacity, she later realized she needed to disentangle the stories she was hearing in her research from her own, to avoid “over-identifying” with an experience that was mutually informative but not identical.

Erin describes how she has always had an “instinct” towards advocacy work on behalf of vulnerable people “of any kind.” Although the circumstances of her childhood—the existence of her institutionalized brother kept secret, even within the family—prevented her from feeling that she had the capacity to act as an advocate for her brother, she has enacted her advocacy in other ways, particularly with Indigenous people and people experiencing homelessness.

Colleen pursued a career as a college professor who taught developmental service workers. She notes that although the time that her brother Gerry spent in an institution was relatively brief, it has been the source of her life’s work, both as a teacher and in her work with people with intellectual disabilities in various educational and support settings. Colleen noted that only very recently did she realize the parallel between a job she held at a small institution for people with intellectual disabilities immediately after graduating from university and her own brother’s situation, who lived in an institution not far away. She never connected these two examples of institutionalization in her life, despite their similarities, and wonders now if she carried an underlying motivation to seek out work with people who were in a similar situation as her brother, but that she was unable to address that parallel at an emotional level.

Similarly, Marilyn indicates that her choice of vocation, a social worker who worked with people with intellectual disabilities, is directly connected to her brother being institutionalized, to the point that she even took a position at the institution where he had lived. She realizes now that her vocational choices have been part of a much bigger journey of searching for her brother, a journey that has not ended. Marilyn saw her brother Robert only once in her life, at his own funeral when he was eight years old. She feels that her search for him began the day her parents returned from the hospital empty-handed, and that her search for the full story of his life continues. She has also learned that the story of her brother and her relationship with him—albeit distant and im-material, their bodies never having shared the same space together—is not necessarily linear and “correct,” but rather is one that she has pieced together from fragments of stories she has heard from others over several decades. The story of her brother is thus also a reflection of her own search, her coming-to-terms with what happened.

Discussion: Understanding Diffraction in the Context of Family

The five women who participated in these follow-up interviews have offered insights on the ongoing effects of institutionalization in their lives and in their own families. As introduced earlier, diffractive models of analysis are helpful here due to their capacity to consider the multiple, non-linear, and reiterative effects of significant life events on individuals and families. The concentric effects that diffuse outward from institutions' central point of impact evoke theoretical linkages with Barad's and Haraway's work on diffraction. Barad's (2014) theory of diffraction is a useful tool in understanding the multiplicity of effects that can emerge from one phenomenon (institutionalization) which is simultaneously singular (in terms of its specificity within each family) and multiple. Haraway (1992, cited in Barad, 2014) suggests that analysis based on the principles of diffraction as opposed to the more traditional practice of reflection "invites" us away from "the illusion of essential, fixed positions" (p. 29) of both people and phenomena's effects, allowing for a more entangled interpretation (Barad, p. 36) of the ways in which the consequences of trauma travel, propagate, and collide with each other. This methodological approach is helpful when considering how the incarceration of one family member might affect several family members, in different ways, over time, as it suggests an almost-infinite number of possibilities for institutionalization's long-term implications. This opens the analysis not to predetermined themes (including those traditionally ascribed to intergenerational trauma), but to what happens outside of traditional inheritance schema, and within relationships that are not able to partake of more typical communication and social practices.

First is the matter of memory. Barad (2014) describes the process of "re-turning to the past" (misspelling intentional), to re-turn the past "over and over again," an iterative process that acknowledges a "multiplicity of processes" (p. 168) rather than one, linear recalling of what happened to oneself or within one's own family. When considered in this way, the differential recollection of events, either by two people in the same family, or even by the same person, becomes productive rather than problematic. Indeed, remembering "wrongly" can reveal a great deal about the story underlying the attempt to remember. Accounts from the women here provide evidence of this process and its potential productivity. They have come to realize that their remembering differently over time is not necessarily problematic; rather, it is indicative of different phases in their journey of coming to understand what happened to them and their brother or sister.

For example, Marilyn tells a poignant story that demonstrates the interesting role that memory has played in her coming-to-terms with what happened in her family, and how "re-turning" to bits of the story decades later has revealed her own journey in that regard. When she was a young teenager, she was having lunch in a restaurant with family friends in the town where her brother was institutionalized. She excused herself to use the washroom, but instead went to a phone booth near the door, where she looked up the institution's phone number. She said that she never intended to call; she just wanted to see that the place where her brother lived actually existed. She found the number and, without dialing, returned to the table. Only very recently did she learn that the restaurant in her memory did not open until one year after her brother's death in the institution. She was surprised when she learned this; she had been certain, in the way in which she had remembered the story for decades, that her brother had still been alive when she had searched for that phone number. Now she understands that indeed, she must have known he had died—she had, after all, been at his funeral one year earlier—but that her search for the phone number was more about where she was in her "search" for her brother at that particular moment—still looking, still confirming where he lived, one year after he had died. She realizes now that whether or not the memory was "correct' is less important than recognizing it as part of an active and ongoing search for the location of the boy she had never met, a boy who thus in some ways remained alive despite having died a year earlier.

There is also the matter of memory in families, wherein memories can be multiple, in contradiction with each other, and riddled with silences and lack. Akin to what was discussed earlier with respect to the lack of opportunity for people with intellectual disabilities to tell their own story, the sisters here emphasized how the process of "making up the story" continues. For example, Erin states that because she has no documentation of her brother's time in the institution, nor any record of his death, "I don't even know what truth I have." The absence of almost all records of her brother means that his story and that of her family remains open to interpretation; it also reveals the problem of determining who gets to tell the story. However, she acknowledges that it is less important to try and align her memories with those of her remaining family members—something that she feels is currently impossible—than to acknowledge that she does have *a* truth, one that represents her own memory of her brother and what happened to him, and that record does have meaning.

In addition to memory, a diffractive analysis helps to reveal the multiple ways effects can reverberate within families and in the broader society, often in ways unseen or unpredicted. Victoria describes this as "echoes" of people's past lives repeating themselves in current patterns. For example, she feels that her parents' decision to send her sister to an institution before the age of two has "shaped her utterly" and has had a profound and lasting effect on her relationships with herself and with her children. She feels that her family's fundamental rejection of "difference" drastically impeded her ability to accept herself and her sexuality, and that her parents' rejection of her sister conveyed the message that there are some people that we simply don't have to love. She feels that she and others in her birth family suffered greatly from the "reasonableness" of closing oneself off to a loving relationship because of perceived difference, only to realize later in life that she had missed out on the opportunity to develop a friendship with her. She feels that the lack of loyalty demonstrated by her birth family has played out in her own relationships, as she has often felt driven to never abandon anyone, even when it might be detrimental to stay. She feels that these patterns also reverberate in her relationships with her children, and that they have absorbed the practices she established in order to deal with her encounters with guilt, loyalty, and fear of abandonment.

Others explained how their childhood practice of protecting their family from the emotional repercussions of institutionalization—for example, by being careful not to discuss difficult topics—carried forward into their own parenting. Carmen notes that her mother's difficulty dealing with the situation and her own discomfort visiting her sister in the institution led her to delay facilitating a relationship between her sister and her daughters until they were adults. Similarly, Marilyn recalls that, for reasons she is still trying to understand, she delayed sharing the story of her brother with her children, perhaps in part to protect them from a piece of her family history that she found troubling.

What emerges from the foregoing stories of institutionalization's vast inter- and intragenerational effects is the extent of the emotional labour absorbed and produced by these women. In alignment with scholarly research on the emotional and mental labour typically performed by women in the context of family (Erickson, 2005; Hochschild, 2012 [1983]; Robertson et al., 2019), the participants here performed labour, as early as childhood, that involved maintaining the integrity of the family and overseeing and managing others' well-being, including that of the missing sibling, despite not being physically present to him or her, even beyond their death. This tangential finding regarding the emotional labour of siblings points towards possible future work regarding the ways in which incarcerative systems such as institutionalization, informed by patriarchal systems of logical efficiencies, also reflect and reinforce gendered divisions of labour, particularly with regard to care work.

It is striking, when one contemplates the initial intention of institutions—to sequester away a problematic and unproductive population and to alleviate pressure on families—to consider the range of its previously-unforeseen consequences. The loss of potential relationships, lost opportunities to learn about difference, understanding, and inclusion, silence in families, burdens on children—the list is extensive. And while this is a difficult chapter in the history of any jurisdiction that has embraced the use of incarcerative methods to deal with people considered different, understanding these losses and the ways in which effects have been lived across and through families can and indeed must be used to inform future decisions about how we care for each other.

Moving Forward: How Reflecting on Families' Experiences can Inform Future Policy

Trends in policy decision-making since the introduction of austerity practices in the late twentieth century have included an increased reliance on empirical, quantitative, and measurable data. The emergence of an "audit and accountability culture" has privileged an "instrumental" model of decision-making that "feeds on metrics to establish 'what works'" (St. Pierre, 2011, p. 611), resulting in decisions that can be "conventional, reductionist… and sometimes oppressive" (p. 611). Research that abides by these standards, while useful in terms of obtaining a picture of the scope of programs and services, fails to account for the ways in which policy decisions affect interconnected webs of people in deeply personal and intimate ways. The qualitative findings discussed in this paper suggest that more intentional reflection on the effects of past practices can inform future directions in the support of people labelled/with intellectual disabilities and their families.

First, the reflections above indicate that decision-makers must take history into account. A better understanding of the historical conditions that allow phenomena to develop can lead to a better understanding of its effects and of the current situation. Currently, governmental systems allow policy-makers to make decisions without a thorough understanding of how crises have emerged, and without a full reckoning of what may come from them (Bryant, 2016). For example, by the time the Ontario government opened the Rideau Regional Centre in 1951 and the Southwest Regional Centre in 1961, the parents' movement was alive and well in the province, and parents were already agitating for improved conditions and institutional closure (Burghardt, 2018). It is important to understand why the government continued to pursue total institutional models despite emerging opposition. Predominantly conservative governments in Ontario through much of the 20th century were reluctant to close large institutions due to their role as economic engines that employed hundreds of people in rural communities, traditionally part of their voting base. Taking these motivations into account can contribute to more planful (and just) policy moving forward—in this case, to acknowledge that previous policy decisions were grounded in economic and political interests and not in the interests of those most implicated—persons with intellectual disabilities who were forced to live there (Simmons, 1982).

On a larger scale, part of this historical reckoning includes recognizing the institutionalization of people labelled/with an intellectual disability as part of the broader historical narrative of Canada's treatment of difference (Chapman, 2014). Understanding institutionalization as part of Canada's nation-building project helps us to see more clearly how much of Canada's colonial history is tied to the segregation of "non-productive" people who were not considered worthy of inclusion or citizenship. For example, for the families that were part of this research, much of the decision-making regarding their children's placement in institutions concerned parents' felt need to protect the image of the strong, successful, and primarily white nuclear family (Burghardt, 2016). Victoria points out that the Ontario government, in their efforts to increase the numbers of children being institutionalized, produced a propaganda film entitled *One on Every Street* (c. 1960), which conveyed the message that intellectual disability "was a scourge," but that the government was offering a solution through public institutions. The film suggests that "the Nation" was caring, yet "care" was offered on conditions of differentiation and segregation and existed on the same continuum as violence (Chapman, 2014). This care/violence was justified by the need to create the ideal Canadian citizen or to rid the public sphere of those unable to become one, practices that governments have repeatedly used to exclude marginalized people throughout Canadian history (Thobani, 2007).

Further, Erin questions the extent to which collusion and collaboration contributed to the institutionalization of people labelled/with intellectual disabilities. She notes that the *Truth and Reconciliation Commission of Canada* (2015) undertaken by and with Indigenous people has illuminated how different disciplinary systems, primarily church and state, worked together to segregate Indigenous people, and feels that more work needs to be done to determine the colluding parties in the case of disability. While the research discussed in this paper reveals the role that parents played within families when decisions were being made, more work is needed regarding the professional expertise and systems within which the parents were embedded, including churches, health experts, and policy advisors who were preoccupied with determining the most publicly palatable and least expensive ways to support disabled children. Understanding these "interlocking" systems (Chapman et al., 2014) and positioning the incarceration of people labelled/with intellectual disabilities within the broader umbrella of Canada's foundational narrative can serve as reminders to decision-makers to draw from what we have already learned about Canada's dismal record in this regard.

Second, and following from the first, the likelihood of unanticipated effects must be taken into consideration in policy development. History has repeatedly demonstrated that repercussions from "well-intentioned" policies, including interpersonal and intragenerational ones, are more complex and have more unforeseen negative consequences than initially predicted (Boyce et al., 2001; Prince, 2009; Trent, 1994). Beginning from the position that repercussions are inevitable as opposed to exceptional might encourage decision-makers to consider possible future repercussions at individual, family, and community levels at the outset (Braybrooke & Lindblom, 1970), rather than imposing policy reactively and then justifying the emergent negative impacts as necessary, if unfortunate, side effects.

The intragenerational effects discussed in this paper are one such example. At the peak of the institutional era, authorities made decisions under the assumption that this would be best for everyone in the family. Yet the Ontario government's recent celebratory stance regarding the "successful" end of the institutional era contradicts these earlier assumptions and belies the emotional effects that continue to reverberate through families decades after their family members were institutionalized. It is telling that all five of the participants here have indicated that addressing the after-effects of the institutionalization of their brother or sister, and coming to understand the meaning this holds in their lives, has been a major life task. While hindsight of course offers a clearer perspective, the increase in retrospective reflection in Canada in recent years regarding harmful segregation policies points to the need to incorporate feedback loops and policy evaluation from the outset and from the ground up, such that harmful consequences might be anticipated.

The current placement of people labelled/with intellectual disabilities in long-term care homes in Ontario, introduced at the beginning of this paper, is a material example of this (Ontario Ombudsman, 2016; Spagnuolo, 2016). While the closure of total institutions for people with intellectual disabilities has been met with relief and a no-going-back stance from survivors (Ford & Rossiter, 2017; Hutton et al., 2017 Scott & Rinaldi, 2017), the network of institutionalized care for seniors has become a default "solution" for disabled people who need more support than their own families and support systems can provide. This can be linked directly to a lack of preparedness by the province prior to institutional closure—the impact of which, if the report by Williston in 1971 recommending closure is taken as a starting point, the government had almost 40 years to consider—has resulted in high numbers of disabled people still living in institutional settings (OMCSS HTF, 2018; Spagnuolo, 2016).

A lack of inter-ministerial communication further influences this issue. Currently, in most jurisdictions, policy decisions are made ahistorically and in ministerial isolation (McDaniel & Bernard, 2011; Myers & McDonald, 2014). It is likely that despite some increase in public awareness of the negative repercussions of institutionalization, these effects have not been integrated into decisions attempting to address the ongoing need for community-based living. As Spagnuolo (2016) notes, it is unlikely that provincial governments have seriously considered the long-term negative effects of institutionalization pointed out by people with intellectual disabilities and their allies, as plans to build identical, large facilities to warehouse older people, and others considered to need them, march on. In the same way that governments in the 1950s relied on institutional models to meet the needs of families with a disabled family member despite indications that all was not well (Berton, 1960), seventy years later, governments continue to do so[vii].

Finally, the siblings' accounts here point to the guidance that such testimonies can provide to decision-makers. Policy creation processes must mandate the inclusion of those most implicated—in this case, people labelled/with intellectual disabilities and their families—as well as those with expertise in the situation's historical development (Boyce et al., 2001). Disability activists' rallying cry, "nothing about us without us"[viii]—now in its third generation—remains as valid now as it did when first uttered in its call to the international community to include disabled people in any decision affecting them. As Prince (2009) and others have pointed out, this call remains necessary, as decision-making processes continue to exclude those with most at stake. And while siblings of institutional survivors did not themselves endure years of separation from family and community, their stories here attest to the importance of including their experiences as part of careful considerations of how we might better care for each other.

Concluding Remarks

The siblings in this paper described the institutionalization of their brother or sister as a formative feature in their lives that continues to have profound effects. Carmen notes that during times when it felt especially difficult to process her family history, her sister felt like a “spectre” to her, a haunting that would not leave her alone. Erin also describes feeling haunted by the never-to-be-finished story of her childhood. Considering that Canada continues to rely on large institutional models to care for vulnerable and marginalized people, decision-makers would do well to pay attention to these hauntings and to the inter- and intragenerational effects of the trauma of institutionalization described here, and to prioritize original models of care that allow families and disabled people to determine creative, imaginative ways to live supported and engaged lives in the community.

Key Messages From This Article

People with disabilities: It is important that we hear stories from people who were institutionalized and from their families. Their stories explain how institutionalization has hurt people over time. They remind us that it is important to create good and safe homes for everybody.

Professionals: People with disabilities and members of their families have important and sometimes painful stories of institutionalization within their family. Supporting people with disabilities and their families includes listening to these stories and advocating for inclusive and caring living arrangements.

Policy Makers: Decision-makers need to understand how and why people with disabilities were institutionalized in the past, and that these models have harmed and continue to harm disabled people and their families. They need to take the effects of institutionalization into account when making decisions about living arrangements for people with disabilities.

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[i] While I acknowledge the international nature of the trends described in this section, including deinstitutionalization and the effects of austerity measures, the research described in this paper focuses on Canadian trends and phenomena.

[ii] Karen Barad works at the intersection of feminist theory and theoretical physics; Donna Haraway works at the intersection of feminist theory, science and technology studies.

[iii] On September 16, 2013, survivors who had gathered outside of the Ontario legislature were informed that their scheduled appearances in front of the presiding judge for the Class Action, at which they had planned to share testimony of their experiences, would not be taking place that day. The next morning, when survivors and their supporters again gathered in anticipation of finally being able to provide testimony, they were informed that a settlement with the plaintiffs' lawyers had been reached, and that their testimonies would not be heard. While the government's reasoning for this silencing has never fully been made public, survivors and their allies suspect that it was likely due to concern about the damaging effects of public knowledge of the suffering people experienced while under government 'care'.

[iv] York University's Office of Research Ethics, certificate #STU-2012-103

[v] Thank you to an anonymous reviewer for pointing this out.

[vi] Pseudonym; all other names are participants' actual names, used with their permission.

[vii] It is important to note that the problem is not only that disabled people are being placed into long-term care homes, but that long-term care homes exist in the first place, another example of government preference for simplified, totalitarian models in which the needs of the institution always supersede those of its residents (Goffman, 1961).

[viii] The phrase "nothing about us without us" has its origins in early 20th-century solidarity movements in Eastern Europe. It was introduced to the Disability Rights Movement in the 1990s by South African disability rights activists Michael Masutha and William Rolands, who had heard it used by an unnamed Eastern European activist at an earlier gathering.