The Un-Making of Difference:
The Winding Road of Deinstitutionalization in Ontario, 1960-2018

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Abstract

The institutionalization of people with an intellectual impairment lives in the shadows of Canadian history. In Ontario, in the late 1800s and early 1900s, social and medical ideas about human difference emerging from the eighteenth and early nineteenth centuries resulted in the massive push toward segregation and institutionalization of all kinds of “undesirable” types of people, including those with a physical and mental impairment. Although institutionalization itself, as a “solution” for people without an intellectual impairment came under early fire by medical experts and policy makers, these arguments were not applied to children or adults with an intellectual impairment. I will argue that the appeal of institutionalization, which persists despite decades of irrefutable evidence about its extraordinary harm, continues to exist because the beliefs and attitudes of those who made the decisions to institutionalize in the first place continue to circulate, and to dominate our thinking about what is “best” for people with an intellectual impairment. These attitudes fundamentally deny that people who have an impairment are “persons” in the same sense as those who do not have an impairment are. My thesis outlines the various elements which have shaped attitudes toward people with an intellectual impairment since the late nineteenth century, and the ways these attitudes (medical, social, and political) were built into the physical landscape of the province, in the shape of congregate institutions. Using oral history interviews with many of the survivors of these institutions, I argue that these attitudes about personhood are fundamentally wrong, and detail how the agency and activism of the intellectually impaired, themselves, was a crucial element in institutional closures and the crucial (yet unfinished) shift toward community living.
Acknowledgements

Too often survivors of institutions are not the tellers of their own history so it was important to me that the experience of survivors remained front and centre throughout this project. My most sincere thank you to the survivors and family members who opened up your hearts and shared your stories with me. To the survivors, I know this thesis is a small offering of the respect you deserve and a humble platform from which your resilience, perseverance and compassion shines through. Your ability to forgive in the face of unspeakable trauma and loss is a powerful testament to the humanity that is accessible in all of us, should we choose to exercise it.

Thanks to Brock University Research Ethics Board and my supervisor Dr. Renee Lafferty- Salhany for guiding me through the application process and for their support of this research. Thank you to my second reader, Dr. Maureen Lux for offering her insight and considerations in the final phase of writing. Many of these interviews would not have been possible without the support of Community Living Welland Pelham’s Executive Director, Barb Vyrostko. Special thanks to Juli Goldhawk for assisting in setting up interviews and providing background information.
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Introduction

In 2008, a number of class-action lawsuits were levied against the Government of Ontario by former inmates of provincially operated institutions for people with an intellectual impairment\(^1\), who were seeking retribution and compensation for mistreatment and abuse suffered during their confinement. One of the first of these was put forward by Toronto law firm Koskie-Minsky with Marie Slack and Pat Seth, former inmates of Huronia Regional Centre, as the lead plaintiffs.\(^2\) When Huronia closed its doors in 2009, the certification process for the legal case was complete. It was a ground-breaking endeavour: the courts not only allowed the class action suit to proceed, but in 2013, a settlement in the amount of $35 million dollars was reached for inmates who lived there between 1945 and 2009 which, opened the door for the similar suits that followed.\(^3\) What is of specific significance to this thesis regarding the case, however, is not the amount of the settlement, or even that it succeeded; rather, it is the fact that none of the former inmates were given the opportunity to testify in court.\(^4\) The trial thus encapsulates a central tension in the experience of living with an intellectual impairment in the late twentieth century (an era of rights-talk and recognition) wherein, we see a clear and positive advancement

\(^1\) While the term intellectual impairment is predominantly used throughout this thesis when referring to individuals who have an intellectual disability, there are times when the language employed reflects the historical time period (i.e. “idiot” and “moron”) in which people lived. Without question, certain terms used to describe individuals with an intellectual impairment during those historical time periods are derogatory, divisive, and embedded with the pain, suffering and trauma for those with lived experience. This further illustrates how language (then and now) is used as a means to subjugate and strip individuals of their personhood based on perceptions of “difference.”


for the rights of a group of people who have been historically marginalized. However, these
former inmates, who by virtue of their voicelessness (even if that silence was imposed by legal
requirements of the trial procedure), were simultaneously re-marginalized in this very moment of
recognition. They were not given the opportunity to speak for themselves. The historical causes
and consequences of this tension - what it meant for the individuals and their families in Ontario,
during the late nineteenth and twentieth centuries - are what this thesis explores.

As I will show, social and medical ideas about human difference emerging from the
nineteenth century resulted in the massive push toward segregation and institutionalization of all
kinds of “undesirable types” of people in Canada in the late 1800s and early 1900s, from
paupers, orphans and delinquents, to those who were mentally ill, and those with physical and
mental impairments. Institutionalization itself, however, as a “solution” for people without an
intellectual impairment came under early fire: as the case of Canada’s orphan homes illustrates,
experts in many different fields successfully, if not evenly, managed to argue that congregate
facilities were both punitive and harmful to the health and wellbeing (physical and emotional) of
the inmates. However, these arguments were not applied to children (or adults) with a mental
impairment: tens of thousands of these people were housed in large scale congregate institutions
until almost the 21st century, and many still remain in congregate care homes. As I will
demonstrate, there has also been a recent, troubling push in Ontario to re-institutionalize people

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5 While there were significant differences in the timeline for the de-institutionalization of “normal” children in
Canada, the broad consensus in the child welfare field that congregate care was unacceptable was well established
by the post-World War Two period. See Bullen, “J.J. Kelso and the ‘New’ Child Savers: The Genesis of the
Children’s Aid Movement in Ontario,” *Ontario History* 82, no. 2 (June 1990): 107–28; Andrew Jones and Leonard
Rutman, *In the Children’s Aid: J. J. Kelso and Child Welfare in Ontario* (Toronto: University of Toronto Press,
1980); Renée Nicole Lafferty, *The Guardianship of Best Interests: Institutional Care for the Children of the Poor in
Halifax, 1850-1960* (Montreal: McGill-Queen’s University Press, 2013); Patricia T. Rooke and Rodolph Leslie
Schnell, *Discarding the Asylum: from Child Rescue to the Welfare State in English-Canada (1800-1950)* (Lanham,
MD: University Press of America, 1983); Neil Sutherland, *Children in English-Canadian Society Framing the
with a mental impairment. I will argue that the appeal of institutionalization, which persists despite decades of irrefutable evidence about its extraordinary harm, continues to exist because the beliefs and attitudes of those who made the decisions to institutionalize in the first place continue to circulate, and to dominate our thinking about what is “best” for those with an intellectual impairment. These attitudes fundamentally deny that those who have a disability are “persons” in the same sense as those who do not have an impairment are. True deinstitutionalization cannot occur until society recognizes that personhood applies to all.

Understanding what “personhood” means and why it matters — historically and in the present day — is presented here in an exploration of the lived experiences of those with an intellectual impairment and their families in Ontario, in the post-World War Two period. Methodologically speaking, the ability to speak to these experiences was a challenge. Despite some recent scholarly attention, the history of deinstitutionalization and the stories of the survivors of institutions for the intellectually impaired largely exist in the shadows of Canadian history. For this reason, I chose to centre my thesis on the voices of the survivors (primarily from the Niagara Region) and their stories - not the stories and perspectives of the administrators. While access to the internal records of provincial institutions were made available for public research as part of the settlement of the class action lawsuits, I also had to reconcile the time constraints involved in completing this degree and, as such, I focused on

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building this thesis on the foundation of the oral histories. There are other limits to the availability of archival records which made this decision clearer. In 2011, for example, Ontario’s Centre for Addiction and Mental Health (CAMH) initiated a policy to allow the destruction of archival patient records going back to 1976, for former inmates of two large provincial institutions. It is increasingly important that historians, researchers, educators, family members, and authors continue to explore the records that are available, so as to ensure that the people who were institutionalized are recognized and that the general public is exposed to, and learns about, Canada’s dark history of institutionalizing people with an intellectual impairment.

As many survivors are now well into their senior years, however, it is essential that their stories are heard and documented if we (and future generations) are to realize and understand the dangers of institutionalization. For all of these reasons, this thesis is built around multiple oral history interviews with survivors and some family members. I have also employed published memoirs, extensive comparative historical studies of other types of institutions, publications from experts (including psychiatrists, sociologists, health care professionals, policy makers, etc.) who worked with the intellectually impaired, and the contemporary records of advocacy organizations. Using these sources, my thesis will outline the various elements which went into shaping attitudes toward people with an intellectual impairment in the late nineteenth and early twentieth centuries, and the ways these attitudes (medical, social, and political) were built into

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8 While annual reports made to various provincial bodies are available for some years and do reveal the attitudes of institutional administrators, the politically charged nature of these reports made them irrelevant for understanding the historical experience of former inmates. I have employed them, therefore, when required, to understand the opinions of administrators, rather than to explicate the lived experience of inmates. For the Huronia records see Archives of Ontario, Ontario Records Government Series RG 4-154. Huronia Regional Centre class action records Dates of Creation1889-2009, Dates of Accumulation 2010-2013, Physical Description 22.3 GB of electronic records (66,282 documents).
the physical landscape of the province, in the shape of congregate institutions. I then examine the lived experience of institutionalization in the post-war period — from the former inmates’ perceptions and responses to the physical environment, the abuse and neglect suffered in the institutions, and their experience of separation from loved ones. These interviews and accounts also allow for a deep consideration of the reasons why families accepted, and even sought, institutional care for their family member who had an intellectual impairment. Very importantly, experiences in these institutions led many former inmates to actively challenge, within their communities and across the nation, their own continued incarceration. Their activism demonstrates, fundamentally, that popular notions which see deinstitutionalization as a passive experience for the institutionalized — i.e., they were “rescued” by “normal” people — is both historically inaccurate and harmful, as it perpetuates the kind of voicelessness suggested by the Slack and Seth lawsuit. The advocacy of those with an intellectual impairment (and their families) themselves, through organizations like People First, and their experience of and understanding of life outside of the institutions forces those who do not live with an intellectual impairment to reconsider what it means to be different, and what it means to be human. This reconsideration is crucial for truly dismantling the problematic, and continuing, ramifications of institutional care in Ontario (and hopefully beyond). Indeed, while some of the buildings have been demolished or repurposed, popular attitudes about their former inmates have not. At a fundamental level, then, this study will necessarily expand our understanding of deinstitutionalization as something more than an historical process of administrative change.

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9 On the methods employed, and theoretical influences upon, my oral historical work, please see Appendix A.
Defining ‘Personhood’

While this thesis is, at its core, a history of the administrative, legal, medical and social responses to people with an intellectual impairment in Ontario, as well as, a history of the experiences and activism of the survivors themselves, it is also an exercise in intellectual history. Historically, I argue that the ways society (in this case, mainly in Ontario) responds to difference, particularly that represented by intellectual impairment, has not changed much since the middle of the nineteenth century: segregation and confinement in institutions, was, and is, a persistent ‘solution’ posed by those who see the intellectually impaired as being different, threatening, and threatened, by the routines of ‘normal’ life. These beliefs, as I will demonstrate, are deeply rooted in the province’s history, in the medical, political and social desire for ‘progress’. At its core, however, these medical, political, and social responses are also rooted in beliefs about what it means to be human: decisions were (and are) made to confine, to segregate, to treat differently, those with an intellectual impairment, because they were/are ‘different’ from others — others who clearly see themselves (whether implicitly or explicitly) as superior, better-functioning versions of a human being. As my desired goal, as an historian and a community activist, is to change this understanding of intellectual impairment, to inspire others to see past “difference” into commonality and eliminate the apparent necessity for institutions, it is necessary that I begin this ‘history’ with an explication of what I mean by the term ‘personhood.’

My definition of this term is deeply influenced by the work of Canadian historian and philosopher Charles Taylor, and (discussed below) Pedro Tabensky, a philosopher at Rhodes University. Taylor presents a number of components, which he believes must be considered essential to seeing oneself, as much as anyone else, as a rational person. In his book, The
Sources of the Self, Taylor situates his theory of modern selfhood within frameworks, or “qualitative distinctions,” that “provide the background explicit or implicit, for our moral judgements, intuitions or reactions.” Taylor is resolute in his insistence that “doing without frameworks is utterly impossible for us; otherwise put, that the horizons within which we live our lives and which make sense of them have to include these strong qualitative discriminations.” Taylor’s moral framework is intrinsically connected to “ends or goods” that are beyond what we would deem “worthy or desirable” because “they command our awe, respect, or admiration.” Taylor argues that these goods “stand independent of our own desires, inclinations, or choices, and that they represent standards by which these desires and choices are judged.”

At the core of his theory is the crucial realization that the way any one person thinks, feels, and experiences life is not only different from those around her, but “[t]his is what makes me a being that can speak of itself in the first person.” First person thinking lends an individual certainty about her own existence and allows her to experience and express the other core elements of personhood, including knowing, control (of both space and expression), respect, and dignity.

Knowing, as Taylor describes, is the beginning of intelligence and the understanding of self. It encapsulates not only knowledge about one’s surroundings, but the possession of memories which allow an individual to both know and interpret her experiences in the world.

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10 Charles Taylor, Sources of the Self: The Making of the Modern Identity (Cambridge, Mass: Harvard University Press, 1989), 26, 14-15, 27, 20. Taylor [14-15] acknowledges the basic definition of morality as “respect for others.” However, he broadens this definition to include what he terms “moral thinking,” which is comprised of “three axes” of thought to include “our sense of respect for and obligations to others, and our understandings of what makes a full life.” He notes that the third axe involves ideas surrounding dignity that are particularly relevant for this thesis and will be explored more fully later on.

11 Ibid., 15,133, 131.
The fact that knowing engages a person’s ability to interpret further implies, very significantly, that that person possesses a will: with will comes the power to exert choice, and to express what an individual believes is best for her.12

This conception of personhood fundamentally sees identity13 as something that stems from knowing what is important to us and thereby, allows us to take a stand or have a firm position about an issue. One’s identity is worked out through the process of determining what is worthwhile, good, and “what ought to be done or what I endorse or oppose,” a process that is housed within what Taylor calls, as previously mentioned, a person’s moral framework, or moral “space.” This space is the place “in which questions arise about what is good or bad, what is worth doing and what not, what has meaning and importance for you and what is trivial and secondary.” In other words, Taylor states, identity, personhood, “is the horizon within which I am capable of taking a stand.”14

Also significant to the development of identity is Taylor’s discussion on selves who “are beings of the requisite depth and complexity to have an identity,” or be in the process of finding their identity. Taylor admits that our ability to articulate one’s self can never be fully explicit because language itself has its own limitations and is constantly being adapted and clarified. However, language cannot exist outside a “language community” which identifies a critical

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13 Helen Graham [139] in her article, “How the Tea is Made,” references UK philosopher, Simon Duffy who was also influenced by the notion of self-determination as set out by Nirje (discussed below Part 4). Duffy believes that the foundation of self-determination “is already resident within the individual.” In his book, Keys to Citizenship, Duffy wrote: “we each have our own unique identity, one that may be lost or hidden, but an identity which is truly our own.” For more see, Helen Graham, “How the Tea is Made; or, the Scoping and Scaling of ‘Everyday Life’ in Changing Services for ‘People with Learning Disabilities,’” British Journal of Learning Disabilities 38, no. 2 (June 2010): 133-143 and Simon Duffy, Keys to Citizenship: A Guide to Getting Good Support for People with Learning Disabilities, (England: Paradigm Consultancy & Development Agency, Ltd., 2006).

14 Taylor, 27
feature in Taylor’s making of oneself: “a self exists only within what I call ‘webs of interlocution’” or, quite simply put, “we achieve selfhood among other selves.”

Understanding and making decisions about what is good and bad, what has importance for the person, or what is trivial or harmful, can only be decided by the knowing individual herself. The loss or limit of moral space, therefore, could - and as the history of institutionalization shows us does - “spill over into a loss of grip on one’s stance in a physical space.” In other words, the ability to choose what is best, and what makes a person happy, is fundamentally stripped away when their ability to choose how and where to live is denied them. As my interviews will show, institutions represented a complex system of abuse which, though it was defined as, and believed to be, “best” for those it confined, actually stripped inmates of their identity, or made it a struggle to find it.

To be stripped of identity, of the ability to know and choose within one’s own moral and physical space, is also to be denied another crucial component of Taylor’s definition of personhood: dignity. Dignity is “the characteristics by which we think of ourselves as commanding (or failing to command) the respect of those around us.” He notes that this type of respect is “thinking well of someone, even looking up to him, which is what we imply when we say in ordinary speech that he has our respect.” Importantly, dignity is also central to the right and ability to choose a path to happiness. For the self, Taylor argues, there must be a “sense of … dignity,” an awareness of “the superiority of the good life, and the inspiration to attain it.”

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16 Ibid., 28-29.
17 Ibid., 152.
In essence, Taylor premises his work on personhood starting with a person’s “sense of his own dignity” as being a component of what constitutes a rational being.

Pedro Tabensky argues, convincingly, that there is a universal human need for happiness. “[O]ur lives, understood as wholes,” he writes, “are fundamentally lives that derive their meaning from the fact that they are ideally directed towards the achievement of the *eudaimon telos*” — or with happiness as the end goal. However, and significantly, the *eudaimon* that Tabensky is referring to is not the superficial, vacuous, knowledge-less happiness that some early advocates for institutionalization believed was a ‘natural’ condition for those with an intellectual impairment. Tabensky’s happiness, rather, is an ethical theory that is deeply embedded in justice and requires the participation of the community that surrounds us in upholding and defending it. Tabensky defines personhood, therefore, as “a concept that pertains not to the inner working of a human body but, is more a functional concept in that it pertains to the sort of complex activity that constitutes our rational nature.” While we can describe what it means to be human in biological terms, he says we need “the vocabulary of folk-psychology that we can describe persons as creatures with beliefs, thoughts, emotions, desires, expectations, intentions, intentional behavior, and so on.” He states that we are all “meaning-bearing” imperfect “creatures.” Tabensky’s *eudaimonia* can only be achieved by living an ethical life within a healthy community where the “ideal social order” is one that offers up the environment for and cultivates “the expression of difference.”

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18 See particularly Helen MacMurchy, “The Parents’ Plea,” *Canadian Journal of Mental Hygiene* vol. 1, no. 3 (1919): 211-212, which is also discussed below, in Part 1.

If happiness is “the goal of life” and as such defines us as persons, the notion of happiness is therefore a rational idea. If people with an intellectual impairment experience, express, or contribute to the happiness of others they are demonstrating rational thought and are therefore fully human. Tabensky’s application of personhood is interwoven within the concept of “communal justice,” or the idea that “individual virtue and public justice” cannot exist unless the “general good plays in the achievement of eudaimonia by the members of a given community.” If true happiness can only be fully achieved in a community where its “members express care and concern for the community at large,” then collectively the members of the society risk jeopardizing their own personhood when people are excluded based on difference. Tabensky goes on to say that “we often consider a life in which deep conflicts have been well integrated to be an exemplary life. The capacity to overcome, which is a virtue we seem to regard very highly, can be seen as the capacity to integrate deep conflict in exemplary ways.”

All of the survivors I interviewed and those written about in this paper demonstrated enormous personal power because not only did they survive, but all of them were able to “integrate deep conflict in exemplary ways.” Throughout the interviews, survivors shared and demonstrated knowledge, possessed a sense of self and identity, and persisted in making their own choices and pursuing their own sense and experience of happiness. Just as is the case with every person, the survivors I interviewed are no more imperfect or perfect than anyone else. And, as Tabensky argues “a rational creature is always and necessarily to be a creature in the process of coming to terms with the world.”

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20 Tabensky, 10, 32.

21 Ibid., 40.
institutionalization, as I hope to demonstrate, can only happen — both for those who were confined, and those who were not — by acknowledging that we are all persons.
1. The Making of Difference: The History of Institutionalization in Ontario

Defining and Confining Madness & Disability At Home & Abroad

Disability and difference were perhaps not always seen as a negative reality in society. Historian and researcher Henri Striker, for example, suggests that the silence of the Middle Ages regarding disability may indicate that those who were different “were spontaneously part of the world and of a society that was accepted as being multifaceted, diversified, disparate.”22 For complex reasons, this vision of disability did not last. By the eighteenth century, as part of what Michel Foucault called the “Great Confinement,” western society began the mass internment of people living on the fringes of society — including those who were intellectually disabled. In part, the writings of the great thinkers in this era, in particular Locke, Bacon and Newton and their emphasis on reason as the elevating feature that separated humans from animals influenced how society perceived these particular people.23 And, while historian Roy Porter has argued that, particularly in England, these “undesirables” remained the responsibility of their families and continued to move freely in society until the enactment of the New Poor Law in 1834, there was growing articulation of their fundamental difference from most other people.24 There was not,

22 Henri- Jacques Striker, A History of Disability, (Ann Arbor: University of Michigan Press, 1997), 65-66. Referring in part to the idea that physical difference was seen as an affirmation of the diversity of Creation and part of God’s plan, Striker argues that, in the Middle Ages, “Normality was a hodgepodge, and no one was concerned with segregation, for it was only natural that there should be malformations. This was more than tolerance; it was real life, with which one compromised as best one could, without wishing to change it by various techniques and various treatments, and without wishing to exclude it either. There was an acceptance, at time awkward, at times brutal, at times compassionate, a kind of indifferent, fatalistic integration, without ideology but also without confrontation.” For more on St. Augustine’s potential influence on thinking about disability, see Taylor, Sources of the Self, 131, 134-139.


however, any clear articulation of the differences between those with an intellectual impairment and those who were declared “mad.”

This blurring between madness and intellectual impairment characterizes the history of institutionalization in Canada. The earliest mention of the confinement of those having an intellectual impairment in Canada can be traced back to 1639 when Quebec became the first province to construct a hospital to provide treatment and care for the “indigent, crippled and idiots”. This provision of care in Quebec was termed “farming out” which essentially meant that the government had a contract with the Catholic Church to provide this service, a system that persisted, in that province, into the mid-1900’s. Conditions in the Hotel Dieu under both French and English governance were appalling. In a report in 1824, member of legislature John Richards said that the conditions within the “cells” were more likely to exasperate madness than “cure it”. Richards saw no evidence of “moral or medical treatment” being applied to the patients within its walls. Further criticism followed when “American social reformer,” Dorothy Dix visited the gaols in Quebec City and Montreal some twenty years later. Abhorred by the “squalor, filth and mismanagement of the inmates Dix took her complaints to Sir Charles Metcalfe, the Governor General of Canada at the time. Metcalfe responded by sanctioning the “building” of an additional asylum in Beaufort25 a little over two miles from Quebec City. Situated on two hundred acres, an “old manor house” was converted into a temporary asylum which opened its doors in 1845 to receive 120 patients from the Hotel Dieu in Quebec. To be clear, the Beaufort Asylum was not a “state institution” and continued on with the practice of the “farming out” system as it had done before with the Catholic Church, except its new proprietors

were Drs. Morrin, Frémont, and Douglas. Four years later, the doctors started construction on the permanent asylum on a “70-acre property at La Canardière, just over a mile from the city of Quebec that boasted a nice view of the harbor. The main large building had long wings on either side and like other institutions the heating and ventilation systems were not equipped for the large population of inmates and it was vulnerable to fires- such as the one that broke out in the winter of 1875 killing twenty-six inmates. Chosen to oversee the asylum was Dr. Douglas, “an activist and reformer,” who was moved by “the prevailing British ideological paradigm of the Romantic Period with its emphasis on individual integrity and deep introspection.”

Douglas was most likely influenced by the work of William Tuke in England and Phillippe Pinel in France in the late 1700s who introduced their own versions of moral treatment. Moral treatment was “a loosely defined approach” meant to help people with a mental illness to build “internal controls” so as to manage their illness. Most often it was felt that this was best achieved by getting away from the city which was seen to hold the stresses of life and find peace and solitude in a “small, quiet facility in the country.” Pinel believed that the causes of disturbances in people judged to be insane were largely produced by an overwhelming sense of depression that occurred in response to “the shocks of life,” such as poverty, thwarted love or business failure. As Pinel spent time talking to patients, he came to know them by their “virtues,” and placed less of an emphasis on biological factors as a cause of their illness, or a potential source for their cure. Upon further review of their history and response to treatments,

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27 Sussman, 170.

Pinel concluded that the medically prescribed treatments did little to help patients and often were the cause of “prejudices, hypotheses, pedantry, ignorance, and the authority of celebrated names.” Pinel advocated instead for non-violent, humane treatment of patients and under his supervision, people got better. Although Douglas was among the few psychiatrists (or alienists, as they were often called) who believed in moral therapy, instituting change proved to be difficult, likely for a number of causes – the prevailing one being Canadians’ beliefs and attitudes toward those with a mental illness and or impairment. When Dr. D.H. Tuke, “world-renowned Quaker alienist from London England,” visited the asylum in 1884 he condemned the living conditions as among if not the worst he had seen throughout his travels in Europe.

Ideas related to confinement by the late 1700’s were also shaped by notions of nationhood. According to Jason Haslam and Julia Wright in their book Captivating Subjects: Writing Confinement, Citizenship, and Nationhood in the Nineteenth Century, nationalism produced two key outcomes in a society: sovereignty and self-development for the nation which was subsequently conferred upon its citizens. However, for the state to maintain its sovereignty it had to be able to ensure the freedom of its citizens while having the ability to “forcibly contain or 'transform' improper citizens and those excluded from citizenship.” As confinement applied to those who were placed into madhouses, it was a means to control the

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29 Whitaker, 21,22,20. In 1793, Philippe Pinel was appointed by the revolutionary government to oversee the insane asylums in Paris.

30 Sussman, 170.

31 Julia M. Wright and Jason Haslam, Captivating Subjects : Writing Confinement, Citizenship, and Nationhood in the Nineteenth Century (Toronto: University of Toronto Press, 2005). Also significant to maintaining its sovereignty was the nation’s power to keep people out of the country as well. As such, legislation in 1869 contained restrictions that were applied to people who were mentally or physically disabled. For a more fulsome discussion on citizenship as it applied to immigration see Jen Rinaldi and Jay Dolmage, “‘Of Dark Type and Poor Physique’: Law, Immigration Restriction, and Disability in Canada, 1900-30,” in Disabling Barriers: Social Movements, Disability History, and the Law, eds. Ravi Malhotra and Benjamin Isitt (Vancouver: University of British Columbia Press, 2017), 104.
mad (and the impaired) and protect the rest of society from their influence or “contagion”.

However, Haslam and Wright make the argument that “domestic” confinement was also about determining the “people deemed capable of participating in the public sphere and those who (were) excluded from such participation.” To be confined was a mark of exclusion put upon those who were not considered to be citizens. Haslam and Wright argued that the state’s duality in ensuring freedom for citizens and also enforcing the “exclusion of non-citizens” was derived and perpetuated from ideas related to subjectivity that “define(d) the proper citizen,” while the state’s ability to protect “the political and economic rights of the citizen rel(ied) on the use of penal servitude and slave labour.”

I would further argue that this connection between confinement and the loss of citizenship also represents a loss of dignity (and reflects a lack of respect) for the person who is confined. Our ability to move or direct our movement within ourselves or within a physical space is a visible indicator that sends a signal out to others about our autonomy. Not only does it send out a message to others but, in the words of Charles Taylor, in essence “our dignity is so much woven into our very own comportment.” Taylor explains it like this,

“The very way we walk, move, gesture, speak is shaped from the earliest moments by our awareness that we appear before others, that we stand in public space, and that this space is potentially one of respect, or contempt, of pride or shame. Our style of movement expresses how we see ourselves as enjoying respect or lacking it, as commanding it or failing to do so.”


33 Taylor, 15.
While I address notions of shame below, I think it is apparent how one’s self esteem would be impacted from the act of confinement in a prison, a madhouse, or an institution. Often the practices, punishments and methods of treatment inflicted upon people while in confinement simultaneously denied or restricted the inmates’ ability to move or resist, further amplifying the impact that bodily confinement had on his or her self-esteem. Confinement signified a loss of citizenship thereby indicating a ‘lesser’ status that did not demand respect for the individual which, in turn, contributed to a loss of humanness that reinforced and perpetuated the authority of those in power.34

By the late 1800s, the damaging potentials of these distinctions increased as there was a hardening notion of normalcy, particularly as it applied to how society defined differences related to the physical body and race. As historian Douglas Baynton argues, stricter notions of normality began to emerge in the late 1800s to early 1900s, as a means of “measuring, categorizing, and managing populations.” The Industrial Revolution, evidence of a world experiencing dynamic change brought with it new markers for defining progress. According to Baynton, normality and what was considered to be natural, were equated with a “pervasive belief in progress.” Normality served as “an empirical and dynamic concept for a changing and progressing world, based on the premise that one could discern in human behaviour the direction

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34 James Moran in his book *Committed to the State Asylum: Insanity and Society in the Nineteenth-Century Quebec and Ontario*, detailed [81] the treatments forced on patients at the Toronto Temporary Asylum by some of its earliest physicians. Dr. William Rees, the first man in charge was known for his “depletive therapy” which included cupping, bleeding, doses of antimony and tartar emetic, as well as “the application of blisters of Spanish flies, and the use of setons to remove amounts of blood appropriate to the patient’s condition.” Rees’s treatment regime also “employed cold ‘affusion’ on the shaved head and low diet.”
of human evolution and progress and use that as a guide.” Importantly, this notion of progress was strictly limited. As Gail Bederman has demonstrated, it was employed in the United States, under the guise of the psychologically-complex sounding idea of Recapitulation, by those seeking to establish the social, legal, and physical superiority of white over Black Americans. Normality, as defined in specific ways linked to the physical body, was the now the critical marker used to determine the fate of given society and also served as a means of defining what was good and right.

Critical to influencing societal norms as to what was considered to be good or normal, were physicians. Historian of medicine Erica Charters, for example, has shown that in the mid-eighteenth century, British physicians working with the imperial Navy, recording observations about the physical capacities and health of British sailors and colonized people, laid the groundwork for modern ideas about fundamental racial difference between human beings. Essentially, by linking observations of difference to the physical attributes of white Britons and brown labourers, they rooted understandings of humanness in the appearance of bodies – and,

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Valverde [60,118, 46-47], in her discussion of nationalism identifies the period between the 1880s and WWI as a crucial time of transition in Canada whereby Canada was catapulted from a “sparsely populated,” agrarian country to an urbanized industrialized nation by the 1920s– a transition largely built on the backs of an industrialized working class. Reformers equated the social problems that arose as a result of this rapid urban transformation to issues of morality, placing a greater responsibility on white, Protestant, middle class women to reproduce and nurture Canada’s future citizens so as to perpetuate their “race” and values. Ridding the nation of dirt and disease became synonymous with eliminating moral vice and decay; symbolic of this moral decay were the feebleminded. For more see, Mariana Valverde, The Age of Light, Soap, and Water: Moral Reform in English Canada, 1885-1925 (Toronto: McClelland & Stewart, 1991).

not surprisingly, defined their own white bodies as superior. Striker similarly asserted that physicians were critical to influencing societal norms as to what was considered to be good or normal. Moreover, as physicians played a larger role in identifying causation of illness and disease, particularly by the end of the eighteenth and through the nineteenth centuries, their status increased. With growing status, their opinions were increasingly accepted as truth, and by the late eighteenth century, physical abnormality was increasingly viewed as being in opposition to progress, a visible sign threatening to drag humanity “back toward its past, toward its animal origins.”

Likewise, Striker wrote “All deviation was defined in relation to a line, every abnormality in relation to a norm, every sickness in relation to an idea of wellness.” Physicians mandated with eliminating disease and treating illness were well-positioned to make these distinctions. Striker argued the asylum emerged in tandem as “medicine and the medical profession” took their place at the forefront of society. The insane and the disabled were now under the control of the “medical establishment,” and the medical model of disability had taken root.

Madness elevated the idea of abnormality, defining it as a condition in which individuals existed in a permanent state of infantilization. Erika Dyck and Alex Deighton in their book, *Managing Madness: Weyburn Mental Hospital and the Transformation of Psychiatric Care in* 


39 Baynton, 36.

40 Striker, 158, 104-105.
Canada, proposed that individuals who fit the criteria for “madness” were seen as “subhuman and therefore could be subjected to sub- or inhuman conditions.” In such a state, individuals were perpetual children and therefore required parental and state regulation in all areas of their daily lives. Since individuals with an intellectual impairment fell under this sub-human category, institutionalization was again justified as the obvious societal solution for managing a “burdensome” segment of the population, who were seen as more equivalent to animals than their fellow humans. Worse than burdensome, however, those having an intellectual impairment were not only seen as a barrier to progress, but a threat. By the mid 1800’s, Darwin’s theory of evolution was fertile soil for the philosophical and pseudo-scientific movement of eugenics to take root – a movement which reinforced these ideas about those considered to be threats/burdens because of mental and physical difference.

Historians Ivan Brown and John Radford, among the first historians to write about disability, argued that in the 1880’s “eugenics beliefs were widely held throughout industrialized countries, with only some minor opposition.” Focused on illuminating and eliminating deviation by deliberate breeding policies for humans, eugenics further influenced policy making regarding intellectual impairment in disturbing ways. Darwin’s cousin, Sir Francis Galton, building upon Darwin’s knowledge of animal and plant evolution, developed his theory on eugenics and “applied it to society as a whole.” Galton argued that social problems such as prostitution and poverty would continue to plague society unless nature was provided with assistance in “weeding out” the “unfit.” The scientific thinking of the time asserted that individual species “that best fit their environments” were most likely to survive and reproduce thereby evolving

41 Erika Dyck and Alex Deighton, Managing Madness: Weyburn Mental Hospital and the Transformation of Psychiatric Care in Canada (Winnipeg: University of Manitoba Press, 2017), 10.
their species. In applying this theory to the area of human resources, eugenics proposed that society could be supported in its evolutionary process by “encouraging the procreation of those most fit and by discouraging procreation of those least fit.” Individuals with a disability were among the “least fit” and great efforts were taken by policy makers to try to ensure that people with an intellectual disability did not procreate. One of the key ways employed to accomplish this was the building of congregate institutions in which the so-called ‘unfit’ could be segregated and, in some cases, sterilized. In all cases, those sent to these institutions were, by the logic underlying then-scientific understanding of humanity, believed to be abnormal, leading lives which were incompatible with, and sometimes threatening to, “progress.” These ideas, which directly shaped understandings of, and approaches to, the intellectually impaired, were also pervasive in Ontario during the late nineteenth and early twentieth century period of institution building.

Asylum Building in Ontario & the Medicalization of Intellectual Difference

In his book, From Asylum to Welfare, Political Science Professor at York University, Harvey Simmons, identified 1835 as a critical year for policy making for those with an intellectual impairment in Upper Canada - what would eventually become Ontario. It was in this

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year that the House of Assembly selected three doctors to form a committee to tackle the problem of the province’s “lunatics” and “idiots.” Early on, the work of this committee suggests that it was the “lunatic” who inspired the most concern and generated the activity which shaped the province’s early institutions. One of the doctors, Committee Chair Dr. Charles Duncombe, upon his tour of institutions in the United States, returned home quite impressed by their so-called moral treatment programs for the insane — programs inspired by the work of Philippe Pinel. Duncombe argued that moral treatment cured mental illness and it was cheaper to build an asylum than house people in jails or try to provide for them through charity. Responding to this recommendation in 1839, a colonial Act sanctioned “the erection of an Asylum within this Province for the reception of Insane and Lunatic persons.” It was followed by the Lunatic Tax Levy later that same year which essentially stressed that it made more fiscal sense for municipalities to send people to the Provincial Lunatic Asylum (PLA) than pay for the maintenance of local institutions.

On January 21, 1841, the Provincial Lunatic Asylum opened up its temporary location in Toronto in what was previously known as the old jail on King Street. However, since municipalities were not required to help with accommodation costs at the PLA, nor was it now in their best interest to provide ‘housing’ locally, the asylum quickly began to fill up—particularly with people who had an intellectual impairment. From a policy standpoint, the defining line between the insane and those deemed to have an intellectual impairment was (as elsewhere) never clear, and the result was that people with an intellectual impairment were understood as

43 Harvey G. Simmons, *From Asylum to Welfare*, (Downsview: National Institute on Mental Retardation, 1982), ix. Moran [49] also states that prior to 1840, those considered to be insane were housed within “their local community or in county jails” which contributed to overcrowding and concerns about “mixing various problem groups under one roof” - see *Committed to the State Asylum*. 

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being little different from the insane, except that they were generally seen as ‘incurable,’ even under the promising aegis of moral therapy. Indeed, the legal definition of *lunatic* was broad enough to make this practice sensical to colonial officials: a lunatic was, legally speaking, “every insane person, and every person being an Idiot or Lunatic, or of unsound mind.” The housing of both groups in a single institution quickly led to crowded conditions, and increased costs. Debate soon followed over separating the insane from the incurable but safety concerns over what might happen to the incurable if they were released from the institution, initially won out.44

The temporary asylum was administrated by a board of twelve volunteers, who operated independently of government oversight. The lack of oversight was common in the nineteenth century, and signaled a general acceptance of the idea that the well-heeled members of society who ran the institutions were both intellectually and socially superior, perfectly well suited to the administration of an asylum for ‘unfortunates’.45 As a sign of the tumultuous start of the institution (and perhaps the lack of qualifications of the board members), internal strife between the board of directors and the medical superintendents resulted in a high rate of turnover, with four superintendents managing the facility through the decade beginning in 1840. Not

44 Simmons, 7, 2, 3, 22, 6, 9-10.

surprisingly, for those confined to the PLA, their existence was not much better than the conditions found in the jails at the time. Moral treatment, or whatever that might have implied with regards to day-to-day care routines, was a moot point. In 1845, during his tour of Canada, Dr. James Hack Tuke in addition to his stop in Montreal and Quebec, also visited the PLA and said it was “one of the most painfully and distressing places I ever visited.”

Under the care of Medical Superintendent Dr. Rees, Tuke described the seventy inmates inside as suffering, miserable, and starving. Despite this, the first permanent asylum in Ontario opened, unfinished, in 1850, on Queen Street West and offered few living improvements for the 211 inmates who were transferred there from the old jail.

The Lunatic Tax Levy was revised in 1853 to the Toronto Lunatic Asylum Act, marking a significant shift in government control over the asylums. Based on the Provincial Penitentiary Act of 1851, the act clarified the Crown’s responsibility for the asylum and henceforth, administration was provided through a paid board selected by the government. 1853 was also a pivotal year for the PLA with the appointment of Dr. Joseph Workman as Superintendent, a role he would perform for twenty-two years. To his credit, Workman is noted throughout academic

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46 Thomas E. Brown, “Workman, Joseph,” in Dictionary of Canadian Biography vol. 12, University of Toronto/Université Laval, (2003) http://www.biographi.ca/en/bio/workman_joseph_12E.html (accessed June 15, 2020). Conditions took a darker turn in 1850 with the appointment of the first superintendent of the permanent PLA John Scott, who soon became embroiled in a “scandal involving the dissection of patients.” The grisly discovery was made during an investigation of a coffin that revealed “only a portion of the deceased,” which lead to an inquest and subsequent admission by Scott that “dead patients’ parts were occasionally removed for ‘anatomical purposes.’” Scott, being the son-in-law of Commissioner Roaf, was reprimanded but not dismissed and three years later he was replaced by Joseph Workman. See Moran, Committed to the State Asylum, 62-64.

47 Ibid., 3.

48 CAMH, “History of Queen Street Site.” (2020), https://www.camh.ca/en/driving-change/building-the-mental-health-facility-of-the-future/history-of-queen-street-site. Over the years, the PLA has seen many name changes but most people will recognize the building on Queen Street as CAMH or the Centre for Addiction and Mental Health. Of historical significance is the wall surrounding the building (parts of which still remain) known as the Heritage Wall which, was constructed in stages using the “unpaid labour by asylum patients that was considered to be a part of their treatment.”
discourse for his diligence in attempting to improve the quality of life for those confined within the institution.\textsuperscript{49} A few years later, in 1857 the asylum and penitentiary boards were amalgamated\textsuperscript{50} followed by more legislation with the Prison and Asylum Inspection Act of 1859, which saw the appointment of five government inspectors. The inspectors were also made responsible for hospitals and prisons, which meant that asylums now fell under the government policies that covered those other institutions: they were, if only on paper, defined as places for the sick and those who required confinement and segregation from the rest of society. This new regulation also meant that regardless of the intention of the inspectors, “mental health and mental retardation policy would be primarily influenced by the interests of government, rather by the interests of the inmates of the public institutions.”\textsuperscript{51}

\textsuperscript{49} V E. Appleton, “Psychiatry in Canada a Century Ago,” in \textit{Canadian Psychiatric Association Journal} 12, no. 4 (August 1, 1967): 355-356, \url{http://search.proquest.com/docview/1970183184/}. Appleton argues that Workman did try to improve the living conditions during his tenure at the PLA, referencing [355] Workman’s investigation to determine the cause of the plethora of cases of dysentery and diarrhea during his first year of service. His investigation revealed that the basement drains were never connected into the main sewer which resulted in a huge cesspool of waste that had accumulated under the basement floor for years. Further to this, in \textit{Committed to the State Asylum}, Moran writes [85-86] that Workman also discovered that the asylum’s foul drinking water was caused by the close proximity of the discharge and intake pipe, resulting in the mixing of waste and fresh water. Additionally, Moran [65-66] discusses Workman’s discovery of a well-established system of plundering within the institution resulting in the “retirement” of the “dairy woman” and the dismissal of a cook which dramatically increased the inmates’ food portions. Workman was so intent on putting an end to the thievery that he mandated all staff to remain on the grounds for a month during which time he established a solid understanding of the food supply and consumption. Moran states that Workman then purged the institution of staff considered to be “unworthy of their posts” resulting in the dismissal of an entire ward of nurses. As Moran and other sources have consistently noted, from the beginning of his tenure Workman repeatedly articulated his concerns regarding overcrowding in the institution which unfortunately fell on deaf ears and continued to be a problem throughout his time there. On the contrary, Reaume in “ Patients at Work: Insane Asylum Inmates’ Labour in Ontario, 1841-1900,” offers a more measured account of Workman’s treatment of the inmates in his analysis of patient labour within the PLA, including the use of the inmates’ labour to clean up the cesspool under the asylum which Reaume described as “reeking filth” and “sickening work” [71-72]. As such, the unpaid labour of inmates was economically motivated and played out in ways that were far from an employer/employee relationship. See Reaume’s chapter in \textit{Mental Health and Canadian Society: Historical Perspectives}, eds. David Wright and James E. Moran (Montreal: McGill- Queen’s University Press, 2006), 71-72.

\textsuperscript{50} Thomas E. Brown, 6.

\textsuperscript{51} Simmons 18, 19, 21.
Simmons argued that this custodial model was the result of many motives, one of which was to relieve families and communities of their “financial burden,” especially poor people who could not afford to provide care for their child or loved one. Whereas, in the past the community, church or family had taken on this cost, Simmons wrote that, “[c]ustodialism was specifically intended as a social control device.”

It is possible that these institutions were seen by some families as helpful – that some may have employed them for their own purposes and taken advantage of their existence to manage temporary family stresses (like unemployment of a breadwinner, for example). It is also clear that at least some found them a necessary evil to manage the health needs of their children when other options were simply not available. As Jessa Chupik and David Wright have shown, institutionalization was a last resort for many families who had exhausted their options and resources in an attempt to access alternative services including osteopaths, massage therapists, the Toronto Hospital for Sick Children, and clinics like the Toronto General Hospital Psychiatric Clinic.

However, the social control argument has dominated current understanding of the purpose of institutions for the mentally ill and disabled in Canada. Andre Cellard and Marie-Claude Thifault, for example, in their review of the early uses of asylums in Lower Canada, referred to a government special committee report in 1824 that emphasized the sheer impossibility for families to provide adequate supervision that their loved one’s state of mental

52 Ibid., 45-46.


health required. It was therefore in the best interest of the family and society to remove the person from their home. Asylum staff did pay a degree of lip service to the idea that their facilities could help the individuals they housed yet, many families resisted being pressured into institutionalizing their loved one, and when they did, their resistance was blamed for causing additional harm to their son or daughter’s condition. However, between 1850-1880 a large number of advocates and families managed to keep their loved ones at home in the community. It wasn’t until the later part of the 1800’s when Saint-Jean-de Dieu and Verdun saw an increase in families placing loved ones in asylums which might have been due in part to an increase in urbanization that caused families to use institutions to meet their needs. The authors noted that even with an increase in institutionalization, the common trend was for families to return for their loved ones a few weeks later, in effect using the institution as a form of respite. Cellard and Thifault’s argument was similar to Simmons in their conclusion that, from the beginning, the purpose of asylums was an attempt to provide “social regulation to manage, supervise and control marginalized people.”55

Whether administrators of these particular institutions in Ontario were inspired by the desire to control, rather than to care for or cure their inmates, it was not long before their services were expanded, and calls were made to segregate the “lunatics” (those who might be cured) from the so-called “idiots,” who were deemed incurable. In 1862, administrators requested additions to the PLA and lobbied the government to build additional asylums, as indicated in a report

55 Andre Cellard and Marie-Claude Thifault, “The Uses of Asylums: Resistance, Asylum Propaganda, and Institutionalization Strategies in Turn-of-the Century Quebec,” in Mental Health and Canadian Society: Historical Perspectives, eds. David Wright, and James E. Moran (Montreal: McGill-Queen’s University Press, 2006), 111, 101, 103, 109, 110, 104. The authors note [104] that orphans and abandoned children made up for the majority of children admitted in the early 1870’s and this steady increase resulted in the construction of two more institutions in 1872 at Saint-Julien and later in 1889 at Sainte-Anne de Baie-Saint-Paul specifically for “insane children” and “idiots or imbeciles from birth.”
delivered by Inspector James Moir Ferres. According to Ferres, the problem was that too many “idiots” were taking up space in asylums, thereby diminishing the care and treatment of the insane. Ferres wrote, “There will be found in them a great number of fatuous and idiotic persons, who in my opinion, are not proper inmates of an asylum for the treatment and cure of the insane.” Providing detailed descriptions of each asylum under his watch, Ferres consistently articulated his position regarding “lunatics” and “idiots.” “Idiots,” due to their “unvarying stolidity” did not warrant the knowledge and attention of the asylum physician when all they required were treatment for common ailments that any doctor could provide. Nor did the lodgings for “idiots” need to be “of the same expensive character as is required in those for the insane…In point of fact, while an asylum is the proper place for the lunatic, there is no real necessity for the idiotic at all.” Ferres called for municipalities to chip in to help cover the costs of institutionalization for the “idiots,” but ultimately felt that these individuals were best cared for at home by their families. He wrote, “For the one the asylum is a necessity, for the other it is made available as a convenient means of riddance.” Ferres stated that for the idiot, whose “mental facilities obscured from birth, are beyond medical skills, and generally stolid, they require no other attention than a regard for cleanliness demands,” and might as well be locked up in a jail.

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56 Simmons, 12, 13, 15.


58 According to Simmons [28] the Ontario government was increasingly putting pressure on municipalities in the 1870s to take on some sort of fiscal responsibility to provide housing for those with an intellectual impairment even if it meant having separate rooms in jailhouses. See Harvey Simmons, From Asylum to Welfare.

In that same year, in an annual report of the Board of Inspectors of Asylums and Prisons, Ferrers and his cohorts further addressed the need for “the erection of a second lunatic asylum in Lower Canada,” along with the completion and enlargement of some of the existing asylums. Interestingly, this later report dropped concerns about the mingling of the insane with the incurably disabled and emphasized the kind of desire for control which Simmons argued was the central motive for institution building in the nineteenth century. With an influx of population, this report noted, it was simply ludicrous to think that the existing asylums could keep up to the growing need for confinement. Ferres quickly established the context for his argument by explaining the dangers that even “harmless” lunatics posed to society, further reminding government not to forget that “the sight of folly and idiocy is in itself a generative cause of folly,” so much so in fact that “[to] allow epileptic, unmanageable, repulsive or dangerous lunatics to wander at large in society is in itself a very serious evil.”

He was not speaking for all those in the field: a few pages later in the report, Ferres mentioned Dr. Workman’s resistance to the board’s recommendation of increasing the asylum’s maximum population by 50, so as to accommodate 400 people. He countered Dr. Workman’s concerns by posing this question,

“whether it is not better to expose the 350 patients who are already in the institution to these inconveniences, rather than expose families, and society itself, to the dangers attendant on allowing lunatics-curable or incurable - to go at large, in view of the frequent and dreadful occurrences of which they are the cause, in addition to being a subject of alarm in their neighbourhoods?”

60 Jordan Special Collections: Canadian Pamphlet Collection, Queen's University: Canada. Board of Inspectors of Asylums, Prisons, etc., Annual Report of the Board of Inspectors of Asylums, Prisons, &c., For the Year 1863 (Montreal, n.d.), 2-3 (hereafter “AR, Board of Inspectors, 1863”).

61 AR, Board of Inspectors, 1863, 7.
Ultimately, Ferres and his colleagues successfully argued that the threat lunatics and the
intellectually impaired posed to the public was far greater than the problems associated with
overcrowding or mingling of types.\textsuperscript{62} Indeed Ferres was talking out of both sides of his mouth as it is clear in the first report that he is adamant in his assertion that housing the intellectually impaired in institutions was utterly pointless and a waste of resources; yet if not in the care of their families, the intellectually impaired posed a threat so great to society that the obvious and only solution was institutionalization. Those with an intellectual impairment were incurable and therefore undesirable, so much so, that their physical and psychological needs were considered irrelevant to the protection of the “normal” and therefore the “worthy.”

In 1867, the province quickly dissolved the old board of the Provincial Lunatic Asylum and in doing so assumed control over asylums, hospitals and charitable institutions. The province selected one inspector to oversee all three and under the management of Inspector John Woodburn Langmuir, Ontario’s social service system became what one scholar has described as one of the “most efficient and cheaply run in North America.”\textsuperscript{63} Importantly, as other scholars of institutional care have argued, efficiency and frugality were often achieved at the expense of those being cared for in the institutions – a painful necessity due to the rising costs of keeping these expansive facilities open.\textsuperscript{64} Simmons noted that the Orillia asylum, in particular, received less government funding than any of the other institutions. Even though children and young

\textsuperscript{62} Ibid., 7.

\textsuperscript{63} Thomas E. Brown, 6.

\textsuperscript{64} See Lafferty, Guardianship of Best Interest; J. R. Miller, Shingwauk’s Vision: A History of Native Residential Schools (University of Toronto Press, 1996); John S. Milloy, A National Crime: The Canadian Government and the Residential School System, 1879 to 1986 (Winnipeg: University of Manitoba Press, 1999). Efficiency and frugality were also influenced by the racial “science” of the day as these institutions were clearly built to accommodate “lesser” folks.
people made up for a large part of its population, the inmates received less fish, poultry and meat than the inmates in other institutions. Not surprisingly, staff wages and salaries were also much lower than what employees were paid at the other institutions. It would take until the early 1900s for Ontario’s provincial government to address these shortfalls, by forcing municipalities to help foot the bill of institutionalizing people by charging them for “indigent patients sent to a provincial asylum.” By 1912, the province also pushed back against its early decision to assume control of all those considered insane or disabled, and legislation passed wherein municipalities were directed to provide houses of refuge.\textsuperscript{65}

In some senses, however, the cost of segregating the apparently “unfit” was a small price to pay for the protection that separation offered for a particular community. As Dyck and Deighton observed, in Canada, institutions segregated individuals away from society as a preventative measure against “the genetic threats posed by fecund but allegedly degenerate people.”\textsuperscript{66} The increasing influence of Social Darwinism on governments placed the feeble minded at the heart of the eugenic movement. Social Darwinists believed that too many “unfit” people were surviving past infancy and so an argument for controlling the birth rate of individuals with lower intelligence started to gain traction.\textsuperscript{67} Not only were the mentally deficient living longer, in many people’s eyes, they were a menace to society. Without proper controls in place they threatened the very well-being of society due to their economic

\textsuperscript{65} Simmons, 67.

\textsuperscript{66} Dyck and Deighton, 13.

dependence, social incompetence and “immoral” behaviours. In his article, “Sacred Daemons: Exploring British Columbian Society’s Perceptions of “Mentally Deficient” Children, 1870-1930,” Nic Clarke, stated that the attention surrounding mental deficiency as a danger to society was “largely due to the rise of eugenics.” Clarke argued that studies from this time period asserted that mental deficiency was linked to primitive forms of humanity and could be passed down the familial chain resulting in “anti-social behaviour and racial degeneration.”

Individuals with an intellectual impairment soon became targets for sterilization as a reaction to the fear that their condition was hereditary. In 1896, The National Council of Women increasingly began to voice their concerns about the number of “simple” girls who were allegedly reproducing at alarming rates. In a national survey, the group determined there were 1,235 women across Canada living with a disability, 900 of them in Ontario. For advocates like Helen MacMurchy, the gravity of the situation was clear; left unchecked this rapid reproduction of mental defectives combined with a “noticeable decline in the birth rates of their ‘best’ classes” could lead to “the stagnation and collapse of civilized society.”

Dr. Helen MacMurchy, a member of The National Council of Women, appointed Official Inspector of the Feeble-Minded in 1906 and a self-styled child welfare expert, was a strong

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69 Simmons, 9.

70 Clarke, 66-67.
advocate for public health reforms and a leading figure in the eugenics debate in Canada.\textsuperscript{71}

There is a general consensus among scholars that MacMurchy was a firm believer in the value of a eugenics policy, a policy that she and other supporters felt was necessary due in part to their concern that immigrants from Eastern Europe - who were increasing in number in Canada - were more likely to suffer from feeble-mindedness. MacMurchy felt that institutionalization of the feeble-minded had no real success in preventing the perpetuation of the condition and strongly advocated for sterilization as a preventative measure.\textsuperscript{72} She worried that the feeble-minded population was on the rise, largely due to feeble-minded women’s supposed ability to reproduce more quickly when compared to typical women.\textsuperscript{73} This posed a problem for middle class, “normal,” women whose prevailing identity centered around the family – and whose fertility rate was alarmingly low, according to reformers like MacMurchy.

Sterilization was another form of segregation that ensured the eventual eradication of the intellectually impaired. Dyck and Deighton, in their discussion of the sterilization of individuals with an intellectual impairment, point to Alberta as the province that was most widely involved in the practice after it instituted the Sexual Sterilization Act in 1928; the act empowered provincial medical and institutional authorities to sterilize 2,822 people. They also mentioned

\textsuperscript{71} On MacMurchy’s influence in the child welfare field, see particularly Dianne E. Dodd, “Helen MacMurchy: Popular Midwifery and Maternity Services for Canadian Pioneer Women,” in Caring and Curing Historical Perspectives on Women and Healing in Canada, eds. Gorham and Dodd (Ottawa: University of Ottawa Press, 1994); 135-161. Wheatley also confirmed that eugenics was a hot topic in Toronto which she argued stemmed from “legitimate concerns,”; concerns that were further compounded by the influx of “over three million poor immigrants” in the 1800 to early 1900’s, most of whom settled in Toronto, increasing its population “by more than a quarter million.” Wheatley detailed the poor living conditions or “hovels” with their overflowing outhouses which only added to people’s misery- “cholera, diphtheria, and scarlet fever epidemics, raging bouts of syphilis… and contaminated milk giving rise to the dreaded “summer diarrhea.” While Wheatley felt that MacMurchy had a measure of compassion for those living in poverty, she stated that MacMurchy failed to understand how poor working wages exasperated and perpetuated poverty. See And Neither Have I Wings to Fly, 371-372.


\textsuperscript{73} Simmons, 69.
Tommy Douglas, “the future architect of Canada’s system of socialized medicine,” who, in 1933, wrote his master’s thesis entitled, “The Problems of the Subnormal Family,” based on the lives of twelve women institutionalized at Weyburn Mental Hospital. Douglas determined that the women’s ability to procreate threatened future generations of “subnormals.” Douglas advocated that “subnormals” who did not have the capacity to be integrated back into the community “should be sterilized or congregated on work colonies.” While Douglas may have disavowed this belief after the Second World War (as many pre-war eugenics supporters had done), his advocacy in the 1930s speaks to the pervasiveness and power of eugenic thinking in Canada. 

Dyck and Deighton argued that by the 1930s, “the public was largely supportive of legislation that significantly expanded the government’s authority over people deemed mentally defective” and segregation, coupled with sterilization, was a powerful expression of eugenics. In Ontario, while sterilization was never legally endorsed, it was heartily supported by many prominent reformers, including MacMurchy, who served as a special inspector of the feebleminded from 1906-1919.

If sterilization wasn’t an immediate option, it was clear to MacMurchy that preventative measures needed to be put into place and she insisted that feeble-minded women, in particular, needed to be placed in custodial institutions, as did their children, for what she considered the

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74 Dyck and Deighton, 73-74, 76-77.

best interest of the “individual, the family and the nation.” In 1899, the NCW directed their provincial counsels to petition the provincial government for the “custodial care of feeble-minded women,” particularly those in their child bearing years between the ages of fifteen and forty-five. Referred to as the “mental hygiene movement,” groups like MacMurchy’s and the Canadian National Committee for Mental Hygiene, founded in 1918 by Dr. C. K. Clarke worked to promote their cause through various ways, some of which included educating the public on eugenics, lobbying the government for policies focused on controlling the reproductive capacity of defective women either through “segregation and/or sterilization,” and arguing for stricter immigration policies to reduce the number of “defectives” coming into Canada from abroad.

The province in response to the lobbying of these types of groups did amend a number of


77 Ibid., 75-76. My colleague Kimberley Gavin, Executive Director of Brockville and District Association for Community Involvement reminded me that unmarried, pregnant women who did not have an intellectual impairment were also a target for institutionalization. Previously an instructor for the Developmental Services Worker program at Centennial college, Kimberley recalled a class visit (about 15 years ago) to Huronia during which she came across a book that documented births at the institution. Kimberley remembers lines and lines of cursive handwriting that meticulously detailed the baby’s resident number, weight, description (mongoloid, etc.) and status (whether the baby was born dead or died or was ‘given away.’). Kimberley Gavan, Telephone conversation with Carolyn Fast, July 16, 2020. Pregnancies that occurred within the institutions often resulted in termination as survivor Cindy Scott recalled the rape of two young girls with an intellectual impairment by two staff members while she was at Huronia. Scott said that the girls became pregnant and were taken “down to the hospital beds in the tunnel and ha[d] the babies taken out of them. The babies were burned and put in the back in the baseball field.” See Cindy Scott and Jen Rinaldi, “That’s My Story and I’m Sticking To It,” Canadian Journal of Disability Studies 6, no. 3 (2017): 28.
previous bills that made it easier to institutionalize feeble minded women, hold people longer and forbid marriage bills for those considered to have a mental impairment.  

At the request of many of the provinces, the Canadian National Committee for Mental Hygiene was also involved in establishing a clear criterion for labelling mental deficiency, and further distinguishing its characteristics from those who were labelled insane. The commissioners determined that mental deficiency was a permanent condition of “‘arrested mental development’ whose victims’ mental capacity never progressed beyond that of a child,” unlike mental insanity which was “a curable disease” because the person’s mind was ‘normal’. The commissioners then attempted to distinguish levels of deficiency that fell under the categories of “idiot” to signify a “‘mental age’ of 3 years or less” followed by ‘imbecile’ to identify defectives having a “mental age of 3 to 7” and finally ‘moron’ and ‘feeble-minded’ to distinguish “those whose mental ages” fell within the range of 7 to 11 years of age. Essentially, their ability to convey these distinctions to the public through their campaigns relied upon physical markers and appearance, so they emphasized the facial expressions of those who fell under the categories as idiots, imbeciles, and morons; interestingly, the children featured in the promotional portraits were all female (See Figure 1, next page).

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78 Ibid., 75-76.

79 Clarke, 69-70. Simmons [79,88] argued that distinguishing between a feebleminded and mentally defective child proved to be more difficult. According to MacMurchy, mentally defective children were evidence of an evolutionary problem. Whatever mental defect existed in the children, was believed to be matched with a defective sense of morality. Sub-normal children were ruled by their “lower animal faculties.” MacMurchy and her supporters would later expand their reach, forming the Provincial Association for the Care of the Feeble-Minded. See Simmons, From Asylum to Welfare.
Although the feeble-minded (of all classes) were deserving of pity, love and kindness, they were also seen as a threat to the order of society due to their perceived natural tendency
toward prostitution, crime, and begetting illegitimate children. In a short publication entitled “The Parents’ Plea,” MacMurchy identified the need to create a “happy permanent home” for the mentally defective child who despite their parents’ dreams and prayers would forever remain a “permanent” child. Writing out of her “sympathy” for parents subjected to the “sad fate” of bearing and raising a defective child, MacMurchy was adamant that the only reasonable option for “self-respecting, self-supporting and fairly well-to-do parents of a mentally defective child” was to place their child in a “private institution-a permanent home.” While these types of institutions existed elsewhere, in the United States and Great Britain, it was time that Canada provided a place for defective children who, under constant supervision, would have all of their needs tended to. It was this belief in the perpetual childlike state of the feeble-minded (and the way in which that state led them to lives of vice, pauperism, and dangerous fertility) that many women, seen as the gatekeepers to the home and responsible for nurturing future citizens, feared was a threat to middle class values and the nation’s progress.

There was also growing focus on an individual’s intelligence, as a metric of normalcy, particularly as it applied to the strength of the nation. Intelligence testing was increasingly applied to immigrants, military recruits and school aged children. Of particular concern with regards to the intelligence of the nation was the issue of immigration. Rinaldi and Dolmage identified the school as the bellwether for signaling the dangers of defective immigrants slipping into the classrooms. A 1925 article in the *Toronto Globe*, for example, reiterated complaints from the Toronto School Board concerning 1,000 “mentally subnormal” students who were

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80 MacMurchy, 211-212.

81 Radford and Park, 5. Simmons [88] stated that the population growth in Ontario increased by 34% between 1901-1921 while the number of people living in cities between 1891-1921 increased by 108%. See *From Asylum to Welfare*. 

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unsuitable candidates to receive instruction within the public-school system. Historian Robert Menzies, as cited by Rinaldi and Dolmage, argued that in Canada between the 1920s to the beginning of WWII,

“more than five thousand people were deported from Canada based on the “feeble-minded” diagnosis, a practise “bolstered by theories of eugenics and race betterment and drawing on public fears about the unregulated influx of immigrants…nourished by the flood of nativist, fac(ial)ist, exclusionist, eugenist, and mental hygienist [sic] thinking in Canada during this period.”  

For example, consider Dr. C. K. Clarke’s, MacMurchy’s colleague and founder of the National Committee for Mental Hygiene, who produced an unpublished novel, The Amiable Morons, that was distributed to members of cabinet. In his book, Clarke played upon the anxiety that many Canadians felt toward the undetected and hidden dangers within those labelled as ‘morons.’ Clarke later spent a month teaching officials how to detect and properly inspect the arrival of four thousand immigrants at St. Johns. It is not surprising then that Michael Steele during a debate in the House of Commons in 1919 expressed his concerns about the spreading of feeble-mindedness because of their ability to rapidly reproduce. According to the authors, it was eugenic inspired discourses such as these, which contributed to the tightening of borders resulting in the rejection and denial of entry to many people in an effort to protect the nation against contagion.

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82 Jen Rinaldi and Jay Dolmage, 109-110.

83 Ibid., 108-111.
The belief that intellectual differences signaled medical conditions which were both threatening and potentially destructive to Canadian society persisted well into the inter-war period and beyond. It was a belief which made institutional care seem persistently necessary, despite the concerns raised about its effects on ‘normal’ children –those without an impairment– who, in contrast, largely due to circumstances beyond their control, found themselves housed in orphanages or children’s homes in the community. With the establishment of the Ontario Department of Health in 1923 and the appointment of a Minister of Health, difference was increasingly being referred to as a medical condition; one that required specialized treatment in “specialized facilities” preferably in a country setting here or abroad. Many asylums were renamed “hospitals,” further underlining belief in a medical model of difference. This medical model, which Katherine Ott talks about in her research on modern prosthetics, relied on diagnosis, either formal or informal, as a means of categorizing difference according to loss and inadequacy. Furthermore, she argued that “the medical model assumes dependency, whether on a health care system or the kindness of strangers and family.” Under this model, dependency required that difference be labelled as a disability for it to be “validated by the health care system” in order for individuals and families to receive any kind of supports or services. Simmons stated that by the 1930s, Ontario’s hospital system was a “close-knit, centralized and hierarchical system that was almost immune to outside change.” However, one thing continued to remain the same, the need to separate two groups of people with an intellectual impairment;

84 Radford and Park, 10-11.
those who needed permanent custodial care to protect them from society or protect society from them, and the relatively few who could be trained and could one day return to the community.\textsuperscript{86}

\textit{Stigma & the Rationalization of Segregation and Institutional Care}

The ideas and beliefs that fueled the construction of Ontario’s institutions not only emphasized difference and hinted at the threat such differences posed to the general population, they did so by mobilizing medical ‘expertise’ and rhetoric. This medicalization of difference made options other than institutionalization extremely difficult to perceive. MacMurchy, along with other reformers, believed that most children with an intellectual impairment required permanent institutionalization, and their arguments were convincing for most policy makers and the general public. Only a few deficient children could be equipped or trained with basic skills, and with regard to girls, only a select few could be taught to be sexually responsible. So MacMurchy and her supporters, who included doctors and educators, campaigned for special classes for “mentally defective children” as a tool to determine who needed to be institutionalized. MacMurchy emphasized that special classes were a means to determine the capacity or degree of deficiency of the child, while confirming the fact that “no skill, no knowledge, no training – nothing – will ever change a mentally defective child into a normal child.” MacMurchy was adamant that the feeble-minded be placed in “a permanent and happy home for their permanent childhood, for they will always be children.” In 1916, Dr. H. L. Brittain, director of the Toronto Bureau of Municipal Research, reiterated MacMurchy’s beliefs and underlined common understanding that the intellectually disabled were, in fact, different

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\textsuperscript{86} Simmons, 142, 108.
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types of beings altogether, stating that the “Mingling normal and subnormal children always results in a dead loss to both classes.” In using the word ‘classes’ to distinguish between normal and feeble-minded children, Brittain and MacMurchy were applying evolutionary language to insinuate that the children were of two different species entirely. In effect, language was employed to dehumanize those it described. Perhaps it should not be surprising, therefore, that the treatment of those who were institutionalized was frequently inhumane.

87 Simmons, 75-76,78-79,87. Similarly, Lafferty noted in that in 1920s in Halifax’s reformatories for boys the persistent problem of overcrowding meant that segregating the inmates was not an option resulting in what some concerned observers described as the mixing of “neglected, dependent, defective, and delinquent boys herded together to the mutual damage and disadvantage of all.” See Guardianship of Best Interests, 118.
2. “Everything was taken away:” The Experience of Institutional Life

The Language of Architecture

From the opening of Ontario’s first institution in 1876, to the closing of the last one in 2009, over 50,000 people in the province were confined within their walls (see Figure 2). While the medical and political decisions which surrounded their administration say much about the ways that those 50,000 people were viewed, so too does the construction and layout of the institutions themselves. Wolf Wolfensberger, disability advocate for policy reformation, argued that architecture is and of itself a language, and when applied to the architecture of institutions, it serves as a direct statement that individuals with a developmental impairment were seen, at best, as dangerous, and at worst, as sub-human.

The title of this section comes from my interview with Lily, who in describing the devastating loss she experienced upon being institutionalized said, “everything was taken away.” All names of those who granted my request for an interview have been changed to protect their privacy. See Appendix A.

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90 Simmons, 161.
Many of the earliest provincial institutions were designed to impress\textsuperscript{91} (signaling, in some ways, the benevolence and wealth of the government and/or the institutions’ benefactors), but they were also designed to house large numbers of people, and do so in a way that signaled their difference and underlined the apparent need for segregation. This is clear in the location and design for Huronia Regional Centre in Orillia. In 1870, the government closed the old hotel at Orillia that had been functioning as a branch asylum since 1861, only to open it up again in 1876. Within two years Orillia’s asylum was once again filled to capacity, and a new asylum was built on the shores of Lake Simcoe for the specific purpose of housing people with an intellectual impairment. Completed in 1887 and situated on 150 acres of land, the multi-storied red-brick building was, by 1900, home to 654 inmates – exceeding its capacity by 104 people.\textsuperscript{92} From the outside, the building is stately and imposing (see Figure 3, next page); the central building had classrooms on the main floor, and those deemed to be trainable slept in the dormitories on the upper floor.

\textsuperscript{91} Like the institutions, Lafferty [90] writes that the orphanages in Nova Scotia were “architecturally impressive” reflective of “Victorian-era’s literature, with elaborate wood trim, gabled windows, and carved lintels.”

\textsuperscript{92} Simmons, 24,29-31,34.
Those deemed unfit for education or training at Orillia were relegated to the institution’s so-called cottages, whose construction was first inspired by the efforts of Provincial Inspector John Langmuir. The cottage system, which was also considered an option by many in the child welfare field, was intended to house children in smaller, less ‘institutional’ settings, and thereby mimic, more closely, ‘normal’ home environments in order to give residents a better, more therapeutic, environment. Huronia’s first “cottages” completed in 1872, were almost as large as the main building of the institution and were employed only as a means of segregating the trainable from the untrainable. The “intimidating… stark sterile red-brick blocks with rows of often grilled grimy windows,” not remotely home-like in design, were employed to house those who lacked mobility (see Figures 4a and 4b).

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93 Lafferty, in describing the “homes” writes that although there was an attempt to “decorate and improve interior spaces with clean linens, wallcoverings, curtains and flooring,” the cottage system or, the breaking down of the “larger, congregate buildings” into smaller residences “housing fifteen to twenty children each, all of whom had similar dispositions and backgrounds,” was used to segregate children, particularly those who were considered deficient. See Guardianship of Best Interests, 90, 118-19.
Figures 4 A and B: The Cottages at Orillia

A: Cottage B (demolished in 1960); photo from the Archives of Ontario

B: Cottage K (photograph by Thelma Wheatley (http://www.thelmawheatley.com/1-the-institution-physical-appearance))
Built in 1951, Rideau Regional Centre in Smith’s Falls reflects a much more modern design, but the complex is, like the institution in Orillia, meant both to impress and assure outsiders that those within its walls could be cared for, and kept entirely separated (See Figure 5, next page). Sitting on 354 acres of land, the fortress eventually grew to contain a gym, 800 seat theatre, multiple wards, a morgue, operating room, kitchens and laundry facilities. By the time the centre closed in March of 2009, it had accumulated 800,000 square feet of buildings, the equivalent of “650 houses.” Gord Ferguson, who was just shy of his tenth birthday when he entered the Smith Falls facility in 1958, described it as “a distant place even for those who lived nearby.” At the time, more than 2,000 people were living there and Gord described it like a “big town in the 60’s but with much less freedom.” Indeed, the sprawling complex of red brick, is unmistakably built as both hospital and prison, its walls and windows made from shatterproof and soundproof materials. High ceilings were adorned with shielded, or partly shielded lights, while the windows were imbedded with wire mesh.

That provincial institutions felt, for those who lived in them, more like prisons than homes, was powerfully affirmed by my interviews of some survivors, who expressed the belief that they had been placed in them because they were “bad.” Krista was sent to Rideau Regional Centre in 1961 at the age of 9, where she stayed until the age of 21. When asked why she thought she was institutionalized she responded, “Me bad.” When questioned if she herself thought that

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95 Simmons, 161.
she was bad, she responded “No”. Lily, who was sent to Oxford Regional Centre at the age of 17, responded that she thought people were institutionalized for “mainly bad behaviour.” Other survivors, more troublingly, when asked the same question of why they were institutionalized said that they didn’t know. Reg, institutionalized at the age of 6, spent 20 years of his life in institutions without a clear understanding of why he was sent there. When I asked him if he wanted to be there, he quickly responded by saying, “No way. You crazy…not there.” Selby was sent to live at Huronia at the age of 9 and although he spent 13 years in institutions, he said

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98 Reg, Interviewed by Carolyn Fast, Welland, Ontario, August 1, 2019, 17.
he didn’t know why they put people in there. Simon, institutionalized at the age of 9, when asked by his sister if he understood why he was sent to live there, just shook his head “No.”

Peter Park’s writings about his experience at Oxford Regional Centre underline this awareness that institutions were, for inmates, not homes (or even treatment centres), but prisons, and that those confined within them were frequently confused about the reasons why. Initially, Peter agreed to go to Oxford Regional Centre, which originally opened in 1905 as an Epileptic Hospital, for treatment of his seizures. This decision was made after he, his family and a friend of the family met with two doctors who assured him that his seizures could be cured at the institution. It was 1961, and Peter, 20 years old at the time, was reassured that he could leave at any time on his own volition. Peter said that it was very clear to him upon his arrival to Oxford Regional Centre that this was not a place that he wanted to be. He wanted out, but the paper that said he could leave on his own will was suddenly “lost” and Peter was trapped in a place that had an organized system of roles and rules: rules that when challenged or broken had their own system of punishments.

As time went on, Peter’s father, a pharmacist, grew concerned over the amount and types of medications that Peter was being forced to take. His father eventually appealed to the court for the release of his son, but his attempts failed. Peter refused to take the medications which

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101 Hutton, et. al, 6-9. Simmons, [106] also notes that institutions were also a place to test out new drugs using the inmates to conduct experiments on. Regarding the institution in Orillia, he noted that in 1925 there were a number of epidemics and at one-point Connaught Laboratories conducted scarlet fever tests and immunized some of the inmates without parental consent.
landed him in the D Ward, a bare concrete cell that had a locked door, a tiny sliding window and a drain to use for toileting. Peter, stripped of his clothing, was forced to lie close to the open drain so that the staff could see him whenever they looked through the tiny window, enhancing their ability to police by restricting his movement in single room. In comparing institutionalization to a prison sentence, Peter said,

“In a jail you are treated better than you are in an institution. When you go to jail, you know when your time is served. In an institution you might have a life sentence. But you don’t know day to day. They are all lying to you and you don’t know the truth. You have no rights at all, not even privacy in the institution. You just don’t know when you are going to get out, if ever. And you didn’t even commit a crime.”

102 Hutton et. al, 7.
The cycle of abuse and dehumanization repeated itself over and over throughout his 18 years of
confinement, half of which Peter said he spent locked up in the D Ward.103

The Interior Message

The interior spaces of these institutions rarely managed to dispel the atmosphere of
confinement, or to reflect a place where inmates could feel at home. At Rideau, for example,

furnishings were sparse and the furniture chosen was heavy and large, intended to anchor in
place and make it difficult to move or throw. Long corridors of beds, barely 2 feet between each
one, were clustered tightly together in each room to maximize the space and allow for easy
policing of the inmates; Males and females were also kept separate, making it more efficient for
staff to manage the inmates with as little personal interaction as possible (and, undoubtedly, to
prevent unwanted mixing of the sexes).104 Photographs taken in the 1960s and 1970s at Rideau,
show a complete absence of any personal items or artwork in these wards.105 A similar
atmosphere existed at the Huronia Regional Centre’s wards in 1911 (see Figure 7, next page),
and as budgets for these places continued to be shoestring, there was often little effort made to
improve the setting or comforts of the inmates. What Gord Ferguson remembered the most

103 Ibid., 6. Oxford is one of the oldest institutions in Ontario, having opened in 1905 as an Epileptic Hospital.

104 Simmons, 161. Lafferty points out that analyses of children’s homes for “normal” orphans or half-orphans,
significantly reflects a very different emphasis on interior décor. While many children’s homes were, like these
institutions for the intellectually impaired, set apart from the community, reports to government inspectors
frequently took pains to underline how interior spaces were designed to be home-like and welcoming, to mimic
single-family dwellings as much as possible. Indeed, as Lafferty discovered in Halifax, institutions whose size
mitigated against such homelike settings were often the first targets of government and social-workers’ critiques.
See Lafferty, Guardianship of Best Interests, pages 115-131.

105 “Tentative Settlements Reached in Rideau Regional Centre and Southwestern Regional Centre Class Actions,”
Salam Toronto Media Inc., December 28, 2013, https://salamtoronto.net/2013/tentative-settlements-reached-in-
about Rideau, for example, was the “overpowering smell of body odours and disinfectant,” and, “As one town resident put it ‘you could smell the place for miles around.’”

The troubling atmosphere inside the homes was revealed starkly in my interviews with survivors. One of the most disquieting of these was about Rosa who, institutionalized from birth in 1956, spent her entire childhood inside the walls of the impenetrable fortress that was Rideau Regional Centre. Rosa’s sister, Lisa, vividly recalled seeing Rideau for the first time enroute home from a family outing to the Canadian Expo, in 1967. In describing the structure, she said,


Figure 7: Residential Ward at the Huronia Regional Centre, circa 1911. From https://www.mcss.gov.on.ca/en/dhistory/lifeInstitution/lifeInstitutionPhotos_lifeInst.aspx

The troubling atmosphere inside the homes was revealed starkly in my interviews with survivors. One of the most disquieting of these was about Rosa who, institutionalized from birth in 1956, spent her entire childhood inside the walls of the impenetrable fortress that was Rideau Regional Centre. Rosa’s sister, Lisa, vividly recalled seeing Rideau for the first time enroute home from a family outing to the Canadian Expo, in 1967. In describing the structure, she said,

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106 Ferguson, 26-27, 29-31.

107 Lisa, Interviewed by Carolyn Fast, Niagara on the Lake, Ontario, August 9, 2019, 2.
“I remember it as clear as a bell because they had big south facing windows. We went in, and it was a very long building, we went in and I can’t remember, actually I have a feeling, it was like V-shaped…And we went up to the second floor…pretty sure – yeah it was the second floor – and there was south facing windows. Big south facing windows and they had all the bedrooms there, it was a very wide hallway. I would say…14 feet wide, the hall. And then behind the hallway were the rooms, were the wards where they slept.”

In essence, Lisa is describing a hospital with its sterile environment void of any reference to articles that might be found in a home. She didn’t talk about bright wallpaper or children’s drawings on the walls. Instead she describes a large, multi-level space with lots of rooms and wide hallways. Even in describing the rooms, Lisa referred to them as “wards” where people slept. Parents were rarely allowed onto the wards where their children spent much of their time and Lisa’s family was not prepared for what they were about to see. Rosa, now 11 years old, was among the assembly of children sitting in highchairs. Lisa said,

“And all the kids were lined up in highchairs along the wall, looking out with the sun pouring in…It was a very sunny day…but I thought poor kids, they can’t – there were no blinds or anything. And mom asked to see where she slept. And it was a big crib with a lid on it. And…it was very hard on mom because she’d never actually seen Rosa in where she lived. I think that was the first time- mom had seen her, I think when she was in Orillia as an infant.”

108 Lisa, 4-5.
Even the sunlight “pouring in” through the big windows is oppressive and one can imagine the discomfort of sitting in sweltering heat without any means of escape. It must have been extremely troubling for Rosa’s family to see her, at 11-years-old, confined to a highchair, and equally horrifying to realize that most of her life (practically from birth) had taken place in a crib with a lid on it. It is impossible to escape the visual correlation of the crib with a lid on it to that of a coffin. It also speaks literally to the need to contain and confine those deemed to be the most undesirable or different. Rideau presented, to Rosa and her family, a visible manifestation of the level of devaluation that was a regular occurrence within the walls of the institutions.

*The Power of Segregation: Location*

![Image](image.png)

Figure 8: Artistic Interpretation of the Huronia Regional Centre found on the corner wall inside the building, *University of Ontario, Institute of Technology*. Renderings such as this one demonstrated the manner in which institutions were located at a distance, surrounded by supposedly salubrious green spaces.
What was also significant in shaping the inmates’ experiences of these institutions, were their locations. With few exceptions, institutions for the intellectually impaired were isolated from the wider community. For some, the locations were justified by their function: a bucolic, natural setting and manicured grounds were considered healthier and more salubrious than anything an urban setting had to offer – a belief which resulted in the locating of many other types of institutions in rural areas across Canada. As seen in a painting of Huronia (Figure 8, above) that hung inside the institution, the lush, green rural space is emphasized, while the institution itself is situated in the background, diminishing its formidable size. The painting further romanticizes the institutionalization of children in particular, as noted by the well-dressed girl in the red dress collecting flowers in the foreground, and the boy playing some sort of game involving a racquet. To the left of the children is a tiny little sailboat floating in a small pond further emphasizing the idyllic environment.

What is equally clear, however, is that the distance imposed between the institutions and nearby communities was also inspired by the notion that the disabled were somehow potentially contagious and shameful. Brown and Radford have also argued that, as a result of the

109 On the setting and programming of Canada’s orphanages, see especially Rooke and Schnell, Discarding the Asylum, Lafferty, The Guardianship of Best Interests, and Xiaobei Chen, Tending the Gardens of Citizenship: Child Saving in Toronto, 1880s-1920s (Toronto, ON: University of Toronto Press, 2005). The supposed moral superiority of rural spaces was part of what mobilized child savers like England’s Thomas Barnardo (among others) to send thousands of poor children from urban England into Canada. On child emigration schemes and this view of the countryside see Brian J. Els, “Creating Free and Good People: Idealization of the Countryside in the Berlin Orphan Administration, 1890-1914,” The Journal of the History of Childhood and Youth 3, no. 3 (Fall 2010): 411-426; Marjory Harper, “Cossar’s Colonists: Juvenile Migration to New Brunswick in the 1920s,” Acadiensis 28, no. 1 (Autumn 1998): 47-65; Elaine Hadley, “Natives in a Strange Land: The Philanthropic Discourse of Juvenile Emigration in Mid- Nineteenth-Century England,” Victorian Studies 33, no. 3 (Spring, 1990): 411-439. Wheatley [369-370] also talks about “children of the English Poor Laws,” wherein, 80,000 children from England and Scotland and 125,000 from Wales sent to Canada between 1868 and 1925. The Canadian government supported this by subsidizing travel costs and provided a “per capita payment” to the recruiting agencies. Wheatley described them as “gutter children” and suggested that many parents didn’t know at the time that their children had been shipped away. Upon their arrival in Canada many were sent to work on farms and lived in deplorable conditions. Some of these children ended up in institutions like the one at Orillia and it was not uncommon that once that happened institutionalization continued to plague these families for generations after. See Wheatley, And Neither Have I Wings to Fly.
geographical separation from the community, there was a “practical and corresponding conceptual lifting of family and community responsibility” for the inmates. The feeble-minded were psychologically “set apart in people’s minds as those who live[d] elsewhere, as different and as not one of us.” It was this type of physical and psychological detachment, which solidifies what Radford and Park identify as the prevailing belief that institutions were “the best place” for individuals with a disability to live because that was where they “belonged.” Accounts of those who did live in them, make it clear that these effects were felt.

Family members testified frequently to the impact that the geographical displacement had on their ability to stay connected with their loved ones. Elise recalled that trips to Orillia to visit her brother Simon were limited due to the distance. For Lina and her family, distance and the cost of making the trip to visit her brother Les impacted their ability to stay connected, especially after her parents separated. Lina, 15 years old at the time, remembered how hard it was for her mom to try to make ends meet for her and her two sisters still living at home while working a “menial job.” She said, “whenever we could afford, we would go up. And then when my husband came along, like a year and a half later, he would drive us up and…he would take us to go see Les.”

The government’s practice and preference of erecting institutions in rural locations further fractured the family’s ability to stay connected to their loved ones. For those inside the buildings, the devastating loss of familial connections simultaneously eliminated further possible connections to the outside world and, as such, inmates were not seen as belonging to – or being valued as – members of any community.

10 Brown and Radford, 19.
12 Lina, interviewed by Carolyn Fast, Welland, Ontario, August 1, 2019, 3.
This loss of familial connections was not only felt by family members who lived in “normal” homes, however, but was affirmed by some of the survivors I interviewed. Lily, for example, recalled being sent to live at Oxford Regional Centre at the age of 17. She said that upon entry into Oxford, nobody came to visit. “Everything was taken away,” she said. Her two brothers effectively ceased to exist and while she still thought about them, she was told by staff not to. It wasn’t until after she was released from the institution and reunited with her brothers that she learned of one brother’s recent marriage.113 Similarly, when I asked another survivor, Selby, if any of his family visited him while he was at the institution, he simply said, “No.”114 Gord Ferguson’s separation from family was so complete that years after his release, his Aunt had little recollection of the sixteen years he had spent at Rideau Regional Center because no one visited and no one ever spoke about it.115

Work & Training

Away from the outside world, separated from families in locations which were considered more wholesome and therapeutic, attempts were made to teach “life skills” to inmates who were deemed capable of being educated. They were given lessons in how to garden, clean, and in some cases, engage in farm work. Gord Ferguson, for example, had many jobs at Rideau which included working in the laundry room, dining room, kitchen, post office and garbage collection. Gord also worked in the potato field where his job was to weed by hand the thousands of hills of potatoes. Labour was mandatory for the able bodied and if someone refused to do their assigned

113 Lily, 9,10.
114 Selby, 7.
115 Ferguson, 27.
job, they would be transferred to another one. However, Gord remarked that consistent refusal to work resulted in the individual being “called lazy and punished by scrubbing the ward down.” Total refusal to work resulted in being locked in “the side room.” What his account reveals is that inmate’s labour was employed as a means of enforcing discipline and that the “life skills” taught were usually determined by the needs of the institution, both financial and practical: inmates did the work of janitorial staff and produced food which was either consumed by inmates, or sold. This kind of labour effectively ensured the perpetuation of a system that confined people who were different and deemed incapable of living typical lives. Simmons revealed, for example, that in the 1920s, Superintendent Downey at Orillia focused proudly on creating an institutional workforce which was so successful that the institution was soon providing other institutions with clothes and shoes. With a minimal 1-2% of the total population being discharged each year, Downey requested new teachers in 1921 so that some of the students could be taught to read and write to increase their productivity in contributing to the institutional economy, thereby sustaining their “permanent home.”

Abuse

Throughout these accounts of the setting, furnishing, putting to work, and disciplining of inmates in these institutions was the pervasive presence of abuse. In fact, abuse and witnessing the abuse of others was commonplace, affirmed by and the survivors and family members I interviewed, as well as in published survivor memoirs. Peter Park wrote that witnessing the

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116 Ferguson, 37-38.
117 Ibid., 37-38.
118 Simmons, 105.
abuse of other inmates at Oxford Regional Centre was worse than the abuse he suffered himself because of the helplessness he felt knowing that if he intervened he would be punished.119 During my interview with survivor Les, when asked about the institution said, “They beat everybody up,” which he knew wasn’t right.120 David McKillop, one of the lead plaintiffs in the legal suit against Rideau Regional Centre, was four years old when he was sent to the institution. David said, “I got beaten up by staff, sexual assault, everything ... You couldn't do [anything] about it. ... You couldn't say [anything] at that time.”121 Gord Ferguson also witnessed the abuse of others, including his friend Caesar, whom he saw die from a seizure. Gord wrote that the staff thought Caesar was pretending to have a seizure and threw a bucket of cold water in his face to make him stop ‘fooling’ around. Gord wrote, “Caesar died on the floor. His heart stopped. I witnessed my friend die.” Gord said that the staff told the other inmates about the seizure but omitted the bucket of water. Although it was rumored that the staff member who threw the bucket of water was fired, he resurfaced a few months later on a different ward.122

In his book, Never Going Back, Gord wrote extensively about the abuse he endured over the 16 years he was confined at Rideau Regional Centre. He remembered seeing his mother upset during one of his visits home when she noticed that his knees were red and raw. 11 years old at the time, he had been forced to scrub the floors with a toothbrush. He wrote that as a child he often wet the bed and many a night, staff would make him stand in a corner with the soiled sheet over his face until the day staff came in. As he grew up, Gord said that he was always one

120 Les, Interviewed by Carolyn Fast, Welland, Ontario, August 1, 2019, 11.
122 Ferguson, 37.
of the larger guys and some staff enjoyed seeing him fight other inmates. Staff would incite him by saying mean and threatening things to him making it clear to Gord that if he didn’t fight the other boy, he would get beat up. In his teenage years Gord also suffered sexual abuse by two male staff. Gord said that for many years he felt ashamed following the abuse because the men made him think it was his fault. The memories of that time turned into nightmares that plagued Gord his entire life.123

For survivors who didn’t communicate verbally, the impact of living in the institution continues to be a visible reality. Sisters Lisa and Dana spoke about Rosa’s “temper,” and how, unable to verbalize her thoughts, she will often scream to express that she is upset or does not want to do something. While the sisters have no way of knowing what actually happened to Rosa, they see how she intuitively looks out for herself by screaming if she is really upset, or by holding on to someone. Lisa referred to Rosa’s holding on to someone as her “quiet fear” and interprets that to mean Rosa is saying, “This is really making me uncomfortable.” Even offering to help move her chair in at the table is met by screams unless Rosa “is in control of the moving.” Lisa assumes that the screaming is due in part to the fact that Rosa grew up in the institution and her survival depended on learning to stick up for herself because no one was going to do it for her. In saying that, Lisa was immediately drawn back to her memory of meeting Rosa for the first time, sitting in a highchair in the glaring sunshine, unable to walk. She said that Rosa to this day will not lie down, maybe due to the years she spent in the crib with the lid on it. This makes going to the doctor or dentist out of the question, which limits her access to medical care and, if needed, potential treatment. Lisa said that there was a time when Rosa

123 Ferguson, 33, 35-36.
didn’t like men and still will not consent to any type of gynecological exam. She wonders if that is a result of sexual trauma. The implications of Rosa’s confinement are far reaching, as are the missing pieces of not knowing what actually happened to her inside the walls of Rideau Regional Centre.124

Another survivor, Lily, also experienced and witnessed traumatic events while she was confined at Oxford Regional Centre. When asked the question, “What do you think people should know about institutions?” Lily responded, “Don’t put them (people) there. Never.” She continued, “A lot of people died from there. You’re unsafe...you’re un-....you always fighting for happiness (you) don’t really see but you don’t give up hope.” I asked if any of her friends died in the institution and she replied, “I didn’t really have friends at that point…cause everything was taken – family was taken away.” She said, “No support. Every time you talked to somebody you get hit for it.”125 When asked if she thought that the threat of physical abuse by staff kept people from making connections, Lily responded “yeah.” Similarly, another survivor named Elaine said that thinking about her time spent at the institution brought back “bad memories.” She remembered two staff women, one in particular who repeatedly told the inmates to “Shut up.” Elaine said, “She kept saying that to almost everyone.”126 Violence or the threat of violence ensured that inmates remained segregated even from one another, while staff maintained absolute control over the individual.

The pervasiveness of abuse and the appalling conditions in which the inmates were confined was not a secret in the post-war period. While many family members – like Rosa’s –

124 Lisa, 4, 9,10.

125 Lily, 6, 9, 10

witnessed or became aware of these conditions themselves, there were also notable moments of exposure in the mainstream media. Perhaps one of the most notable articles was Pierre Berton’s scathing report published in the *Toronto Daily Star* in 1960. In it, Berton reflected on a recent trip to Huronia Regional Centre with his friend and his friend’s son – the boy was being dropped off following his visit home over the Christmas holiday. It was 1959 and Berton described the deplorable conditions the inmates existed in – buildings wracked with peeling paint, large holes in the walls and floors and leaky roofs. With so many people crammed into worn out spaces, Berton described the smells as “appalling, even in winter.” Berton continued,

“On one floor there is one wash basin to serve 64 persons. On another floor, where the patients sometimes must be bathed twice or three times a day, there is one bathtub for 144 persons — together with three shower outlets and eight toilets. Prisoners in reformatories have better facilities.”

What haunted Berton the most was the overcrowding – that condition which was considered something of a necessary evil in the nineteenth century— in order to protect the general population from the ‘dangers’ of the disabled or mentally ill. With a population of 2,807, 900 of those people lived in 70-year-old buildings that offered no way of escape in the case of emergencies, such as a fire. Berton’s fears were not unfounded as he recounted the death of a patient by suffocation, three years prior, due to a fire in the basement. Everywhere he looked Berton saw beds “crammed together, head to head, sometimes less than a foot apart.” There were beds “on the veranda” and in classrooms, beds in rooms previously designated for occupational therapy and “in the playrooms that can no longer be used for play.” With regards to
the ages of the numerous children that resided within those walls, most fell well under the age of six.127

One would think that the knowledge of such appalling conditions would have placed a damper on the demand for placements. However, according to Berton, there was a wait list of 4,000 names of people waiting to have a loved one or family member admitted to this particular institution – 1,500 of those were recent applications made within that year. Berton reasoned that the insatiable demand for beds was due to an increase in Ontario’s population, medical advances that caused people to live longer, and urbanization, which brought people into cities and disrupted familial supports. Berton closed his article with a warning and a chilling reference to Hitler and his death camps. He wrote, “After Hitler fell, and the horrors of the slave camps were exposed, many Germans excused themselves because they said they did not know what went on behind those walls; no one had told them. Well, you have been told about Orillia.”128

127 Pierre Berton, “What’s Wrong at Orillia; Out of Sight—Out of Mind,” *Toronto Daily Star*, January 6, 1960. Perhaps not unsurprisingly, social workers and child development specialists dealing with “normal” children were especially critical of, and concerned about, the institutionalization of younger children (ages 4 and below): homes which served this demographic were a particular target for welfare reformers and faced the most scathing reviews from child psychologists. See Lafferty, *Guardianship of Best Interest*, esp. 193-241.

128 Ibid.,
3. He “will never be normal:” Understanding Family Motives

*The Ghost of Helen MacMurchy: Medical Advice in the 1950s*

Given that conditions in these institutions were not secret, we are left with the problem of understanding why so many families were seeking placements for their children. A recurrent theme in the interviews I conducted suggests, quite powerfully, that the majority of Canadians believed fundamentally, as MacMurchy and others had insisted decades earlier, that segregation of children with an intellectual impairment was in the best interest of the child him or herself, as well as the best interests of the family unit. Certainly, many parents felt that institutions offered specialized care that their child would benefit from and in some cases, might even prove itself integral in facilitating their child’s return home. Siblings Lisa and Dana remember that institutionalization was a common response to intellectual impairment. When their sister, Rosa, was born with Down Syndrome in 1956, the doctor’s response and the immediate response among many of the family members was to seek institutional placement. This was the case for Gord Ferguson: as no school in the community would take him, his mother’s decision to send him to Rideau was an attempt to provide some form of education for her son.

Institutionalization for children like Rosa reflected a common attitude among medical professionals at this time, that *normalcy*, defined within the confines of a well-functioning,

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129 Lisa and Dana, Interviewed by Carolyn Fast, Niagara on the Lake, Ontario, August 9, 2019, 1. Yet, in comparison as Lafferty [182] has effectively argued, in the 1940s and 50s there was a “growing body of literature on personality development” and the detriments of institutionalization on ‘normal’ young children. She references American psychologist, William Goldfarb who stated that the institutionalization of infants delayed “all aspects of his development.” He argued that children who were institutionalized were “more fearful, aggressive, restless, socially ‘retarded,’” and apathetic, and they generally exhibited “lower intellectual output” and a higher degree of speech defect” than those children who were placed into foster homes. Goldfarb concluded that children who were institutionalized were “less capable of normal human relationships.” For more see Lafferty, *The Guardian of Best Interests*.

130 Ferguson, 26.
middle-class nuclear family, was to be maintained at all costs. This left families with an intellectually impaired child few viable options. An article in a 1958 edition of *Maclean’s Magazine*, entitled “A better world for retarded children” starts by describing an intellectual impairment as an “affliction as literally a fate worse than death.” In the article, intellectual impairment was defined as “all degrees of mental defect arising from arrested or imperfect mental development as a result of which a person is incapable of competing on equal terms with his normal fellows or managing himself or his affairs with normal prudence.” The article included quotes from doctors, such as the physician from Sick Children’s Hospital in Toronto who said that he would rather tell a mother that her child was going to die from leukemia than deliver the news that her child “will never be normal.” A pediatrician from Kitchener stated, “I’d rather have to tell parents, ‘Your child is dead.’” Many families looked to medical experts like the doctors in the article for direction and hope. Sadly, many physicians saw little hope for improvement or any semblance of a “normal life” for children born with an intellectual impairment.

*Shame & the Pressure to be ‘Normal’*

The emphasis on normalcy implied by physicians’ attitudes speaks to the pervasive shame which, for some, came with the presence of a child or sibling with an intellectual impairment – a shame so thick that it seeped into nearby communities. Ferguson wrote that the

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presence of Rideau Regional Centre in his hometown of Smith Falls, for example, created a sense of shame within the community itself. He said, “There was a shame in the community and within some families of knowing anyone who lived there.”

Simmons noted a similar sentiment regarding the opening of the asylum in Orillia, originally a branch insane asylum of the PLA, in 1861. In the early days it seemed that the town itself was deliberately oblivious to the asylum and preferred to ignore the presence of those who were confined inside its walls. According to Simmons in the 1890s, it was reported that the Church of England gave a concert there in the summer, but no other organization or church visited the asylum. The asylum at Orillia, like the one in Smith Falls, was regarded as a place that provided shelter for those who seemingly could not possibly survive or contribute to the community. Alternatively, this sense of shame let the community off the hook, so to speak, of having to think about the plight of those behind the institutions’ locked doors.

Sometimes the stigma surrounding the institutionalization of a loved one was so great that siblings didn’t even know they had a brother or a sister living in one. In the interview with sisters Lisa and Dana, Lisa described the day her mother came home without the baby they had been waiting for. It was 1956, and Lisa remembers waiting expectedly, excited for her mom to come home from the hospital with the new baby. Her mother came home, but there was no baby. The baby was simply gone, without explanation or discussion. It would be years before Lisa learned that her mother, upon giving birth, was denied seeing her baby. Because baby Rosa had

133 Ferguson, 27.

134 With the completion of the Rockwood Insane Asylum in Kingston and the opening of the London Asylum for the Insane, the Orillia branch asylum was closed in 1870. Orillia re-opened in 1876 as the Asylum for Idiots and Feeble-minded—exclusively for mental defectives.

135 Simmons, 20, 9, 47.
Down Syndrome, Lisa’s mother was refused access to her daughter for 24 hours so as to prepare herself to see her child. When I asked Lisa and Dana why they felt the family made the decision to send the baby away, they said that their grandmother and Aunt Beth, who was with their mother the day Rosa was born, were influential in making the decision. Lisa recalled, “Granny being a very, strong powerful woman and Aunt Beth being a pediatric nurse at Sick Kids, and in those days, everybody was institutionalized. It was very rare… that they weren’t.” The sisters can only speculate as to the conversations that went on behind closed doors that led to the decision to send Rosa away. Lisa later learned that it was her mother who dressed Rosa and got her ready to go. As her mother said her goodbyes, she told Rosa that she would see her again and one day she would come home.

Lisa’s younger sister Dana was about 9 years old when she found out about the sister she never knew existed. As Lisa described, the family had been at Expo 67 and on their return trip back home, made a stop at Rideau Regional Centre in Smith Falls. Dana remembers being in a state of shock and doesn’t think she actually even met Rosa that day because she has no recollection of entering the building. When attempting to describe how she felt upon finding out she had another sister, Dana said, “Even, you know, my childhood prior to that, I don’t have very

136 Lisa and Dana, 7, 1, 24. In her article, “‘He Was a Secret’: Family Narratives and the Institutionalization of People with Intellectual Disabilities.” Disability & Society 30, no. 7 (August 9, 2015): 1071–1086, Madeline Burghardt examines the impact of “secretive family narratives” (post WWII in Ontario) on siblings and their institutionalized family member. She writes that for some, “family narratives” provided a base from which an “assured ‘storied sense of self emerges,’” while for others, find one’s way through the family narrative required “ongoing re-calibration and negotiation.” What is interesting is Burghardt’s analysis of power within this context in which she describes the impaired sibling’s “‘storied sense of self’” as one rooted in “otherness and difference” who, by their absence maintains the family’s power to control the narrative. Similarly, some of the siblings Burghardt interviewed expressed feelings of powerlessness because they could not change the situation and in some cases, siblings had to wrestle with feeling of “‘complicity’” in keeping the silence. The impact of these narratives went beyond the family unit to the point where the institutionalized individual “were not granted a place physically, metaphorically, or narratively–within their families or communities…” See pp, 1071-72, 1078-79, 1082.
much memory of. So, clearly, I’ve shut away a lot (laughs) and…yeah so, that would’ve been my, that was the first time that I even knew that she existed.” Lisa commented that Rosa was two years older than Dana, and the age difference also played a part in Dana not knowing she had a sister. Lisa explained that she and her older sister were playmates whereas, Dana didn’t have a playmate because Rosa was missing. Their youngest brother, being the only boy and the baby in the family, also lacked a sibling to play with. Lisa said, “So it did make the family dynamic interesting and it’s because of Rosa…Rosa was missing.” Lisa described Rosa’s absence as a “hole.” She said,

“There was a hole…there was hole that could’ve changed the whole family dynamic. You know, how my mother reacted to things. How my father reacted to things. How we reacted…and how we still react.”

Lisa said that even today, friends are surprised when they find out that she has a sister who lives in Niagara and often ask why they haven’t met her. When Lisa tells them that Rosa lives in a group home, it leads to another conversation which often leaves her friends feeling “embarrassed” that they asked the question in the first place. In some ways, this feeling of embarrassment is a remnant of the community shame that kept family members from visiting loved ones or talking about them. In Gord’s case his family and extended family didn’t talk or

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137 Dana, 2. Dana’s lack of information surrounding her sister’s existence is not an isolated experience, but one that Burghardt labels as “the most tragic level of deception.” Burghardt references Erin’s story of her brother David who, having died in the institution was brought home for his burial. Erin recalled attending his funeral in the family’s living room, while her younger brother Frank was sent for a sleepover at someone’s house. Frank’s discovery of the secret years later further fractured “any trust that had existed in the family” and remains a painful “topic.” For more see “‘He was a Secret’: Family Narratives and the Institutionalization of People with Intellectual Disabilities,” 1078.

138 Ibid., 19.

139 Ibid., 20.
ask about the years he spent at the institution, even following his release. While Rosa’s sisters articulated a “hole” in the family due to Rosa’s absence, in some ways her absence continues to play out in real time still today.

From Lisa’s perspective, Rosa’s birth had a dramatic impact on her mother. Although her mother had a picture of Rosa “in a swing being pushed by a nurse” she thinks that the picture was most likely mailed to her mother because, to her knowledge, her mother never visited Rosa prior to the Expo trip. What is clear in Lisa’s memory is that the mother she knew before Rosa’s birth and the mother she knew after, had changed. Dana wondered if their mother suffered post-traumatic stress as a result of the decision to send Rosa away. Lisa agreed and added that their mother’s childhood was not great and these experiences “sort of doubled down on how she felt about herself.” Dana doesn’t remember her aunts or uncles ever mentioning Rosa either. It wasn’t until she had a family of her own that Dana remembered her uncle mentioning how “horrible it must have been for our mother.” Dana said, “[a]nd it just shows you right there,

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140 Ferguson, 27.

141 Mental health advocate and psychiatric survivor, Geoffrey Reaume, described the similar impact that stigma had on the families whose loved ones were institutionalized for mental illness. Many families failed to maintain contact with their loved ones due to the “guilt and shame” they felt because of the belief that mental illness and intellectual impairment was hereditary. Some families were even reluctant to disclose their contact information when their loved one was institutionalized so as not to be labeled themselves. Other families requested visitor restrictions in an effort to control who visited their loved one so as to nip gossip in the bud and some even went so far as to forbid the institution from using official letterhead or envelopes when corresponding with them. In his book, *Remembrance of Patients Past: Patient Life at the Toronto Hospital for the Insane, 1870-1940*, Reaume referred to a 1908 census involving eight provincial mental institutions where, out of a combined total of 5,500 inmates, there were 400 “friendless patients” deemed eligible to be released back into the community. Reaume stated that although efforts were made to secure their reintegration, “with few exceptions the local authorities would not co-operate, so most of these patients remained confined.” One can further imply that without families there to advocate for the release and re-integration of their loved one back into society, the possibility of such an opportunity was slim. See pp. 182, 195, 197, 192. Also see Madeline Burghardt’s book *Broken: Institutional Families and the Construction of Intellectual Disability*; (Montreal & Kingston: McGill-Queen’s University Press, 2018) and Victoria Freeman’s, *A World Without Martha: A Memoir of Sisters, Disability and Difference* (Vancouver: Purich Books, 2019).

142 Lisa, 6.
there’s no communication between her own siblings.” Dana went on to say, “Her family didn’t talk to her about it,” even though “there were quite a few nurses in the whole family.”

In another interview, Elise recalled that the decision to send her brother Simon away at the age of 9 was met with controversy by a couple of neighbours and one grandmother. She said that the result of that decision caused some upset in the family to the point where “people stopped seeing each other.” Simon had epilepsy and experienced seizures from infancy which caused brain damage due to oxygen depletion. An uncle, with means, arranged for Simon to be seen by Dr. Wilder Penfield in Montreal, a world-renowned brain surgeon at that time, who did perform brain surgery on her brother. Dr. Penfield determined that the brain damage was irreversible and eventually the decision was made to send Simon away. Elise reflected on the mentality of the time being: “Don’t accept the person for who they are but let’s fix them.” Elise’s reflection about “fixing” as opposed to “acceptance” warrants further consideration as it applies to distinguishing between trying to “fix someone” so that they are more like everyone else versus “accepting” someone by recognizing that difference does not negate their personhood.

Elise, 10 or 11 years old at the time, reflected on the heartbreak of learning that Simon was going to be sent away to live somewhere else. She still struggles to understand why that decision was made. She said,

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143 Dana, 7, 12.

144 Neuro, “Wilder Graves Penfield,” McGill University, 2020, https://www.mcgill.ca/neuro/about/history/notable-figures/wilder-graves-penfield. An article in the Toronto Star on May 11, 1960 announcing Penfield’s “unexpected” retirement heralded him as “one of the best-known neuro-surgeons and brain specialists in the world.” The article credited him with identifying the cause of epilepsy and mapping the brain, in addition to other significant neurological discoveries. He was the director of the Montreal Neurological Institute and served as the chair of the department of neurology and neurosurgery at McGill University. For more see, “Plans to Write: Dr. Wilder Penfield Ends Medical Career,” Toronto Star, May 11, 1960.
“…so growing up with Simon as my brother I could see how his life went and how my life went and how totally unfair that was because why – why? People would say to me, “Well it’s obvious why.” Well no it’s not obvious why. We’re brother and sister, why did our lives diverge like that? That’s just – no one will ever explain that to me properly, in a way that will make sense in my head.”145

Figure 9: Photograph of Simon. Photo courtesy of Simon and used with permission.

While it was evident from our discussion that Elise’s parents loved their children and wanted to do the best they could for both of them, the pervasive stigma attached to their son’s intellectual

145 Elise, 2, 1.
impairment weighed heavily on the family. Elise recalled a conversation with her mother who tried to explain to her why her brother had to be sent away.

“…she wasn’t telling me that to blame me and she didn’t want me to feel any blame. But she just said I want you to know that it wasn’t an easy decision and that…Like imagine parents being told to make a choice between their two children? That was basically what it was, you know. You have to sacrifice your son in order to help your daughter. And there weren’t people around saying “No, that’s false.”

Similarly, another sibling I interviewed, Lina, remembered the stigma she and her siblings felt because her brother had an intellectual impairment. She described the impact of her family’s decision to send her brother Les to Huronia Regional Centre at the age of 9.

“There were positives and negatives. The pressure was off our mom…and, growing up kids always made fun of Les, so the pressure was off of us girls. They weren’t making fun of us because Les was different. And…but then of course the negative side was he wasn’t there…we didn’t get to grow up with him…and…I mean my parents separated not long after.”

For Lina’s family, trying to find the balance between supporting and caring for Les, and having a “normal” family life was unsustainable at the time. The removal of Les from the family home relieved the “pressure” the girls felt when Les was teased. While sending Les to the institution somewhat eased their mother’s stress as a sole parent trying to keep the family afloat, whatever sense of relief his absence brought could not offset the loss of a son and a brother.

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146 Elise, 2.

147 Lina, 3.
Maintaining a Normal Family Unit

Many placements were also made because of the very real financial and physical challenges presented by children with an impairment, a reality compounded by the lack of community or government supports and the prevailing belief that institutions were “better” for these children. Indeed, parents feeling overwhelmed with the responsibility of care and having little support from extended family, was a common theme throughout many of the interviews. Previously raised by her father’s aging grandparents from birth, for example, Billie was returned to her birth family at the age of five years old. It had taken five years for Billie to learn to toilet and feed herself on her own and her grandparents were no longer able to physically provide the continual care that she required. Coco, delighted to have her sister home, assumed more responsibility in the day-to-day running of the house by making dinner, taking care of her siblings and supervising the piano lessons. Within a couple of years, however, Coco’s mother was overwhelmed with Billie’s needs and the decision was made to send her to an institution. Coco remembers begging her father not to send Billie away. Her desperate pleas were to no avail. Coco said,

“The decision was made when she was about 7, I was 9. My mother was overwhelmed honestly. There was 3 of us other children. There was myself and two younger siblings to Billie and 7 years apart. My mother was finding it too much to deal with. That’s why they made the decision to put her into Blenheim but first went to London to orientate her for a month. Then at 7 went to Blenheim till she was approximately 18.”

148 Coco, Interviewed by Carolyn Fast, St. Catharines, Ontario, August 9, 2019, 1, 2.
Coco remembered how the impact of that decision played out among her extended family. Understandably, the grandparents who had raised Billie the first five years of her life, were “very upset by it,” as were her father’s siblings who “stopped associating” with Coco’s family for decades following the decision. When asked if any of those family members were in a position to offer support to help keep Billie home, Coco responded that while her family lived in Grimsby, the closest relatives were in Toronto and “weren’t really interested in helping out.” She continued, “Sometimes you wonder, well if you have such a strong opinion, maybe you’d like to pitch in and help.” For 14 years, her father made the trek to Blenheim two to three times a year to bring Billie home for visits with her family.149

Sisters Angie, Tamara, and Rene also saw how overwhelmed their mother was in trying to provide care for their sister Vivian. Given their large family and their father’s mental illness, the decision was made in 1966 to send eight-year-old Vivian to Pine Rest Christian Hospital, a private hospital run by a church in Michigan. Again, the distance made visiting difficult and Rene remembered visiting her once while she was in Michigan. Vivian was later transferred to Palmerston, or Midwestern Regional Centre, in 1971. When asked why they thought their parents decided to send Vivian away, Angie responded, “That’s got to do with our family dynamics. My dad was mentally ill, he’s schizophrenic and that basically started when I was about 10 years old. So that was just around the time that Vivian was born.” She went on to say, “Yeah, so that just increasingly got difficult. Mom had 8 kids… and no money and it was – no transportation – it was just untenable. And a big piece of that… was the rest of us, right?” Most of their extended family lived outside of Canada so much of the responsibility of taking care of

149 Coco, 2-3.
the children and later, their father, fell on the girls’ mother who eventually could not keep up with the demands of care required to keep Vivian at home.  

For Lina’s family, it was a storm that shattered the delicate balance that many families fought to maintain in order to keep their children at home. Lina and her family lived in St. Catharines and their home, at that time, was right next to a school. It was 1959, and Lina remembers a violent storm during which the school’s chimney fell onto their house. She said, “And our mom and we four kids were in the house. Les was downstairs with our mom and I think that was very traumatic for him. So he started acting out and he wasn’t making progress at school anymore. So I think, as Les said, it was perceived to be the best thing cause our mom just couldn’t handle him anymore and our father wasn’t around very much, so all of the responsibility fell on her, with four kids. So at the time we would have been 10, 9, cause it was around his 9th birthday, 8, and then 6 ½.”

For Les, the trauma he experienced from the effects of the storm affected his behavior which was the tipping point that lead to the decision to send him to Huronia Regional Centre. As Lina mentioned, it was her mother who was already shouldering much of the responsibility for caring for Les and the rest of the family. Juggling the responsibilities that came with caring for a young family on her own and taking care of Les became more than she could manage.

For another family, the death of a mother played a role in the decision to institutionalize Hana. Amy recalled her sister Hana growing up in a loving and happy family prior to the passing of her mother. Hana was only 11 years old when her mother died and Amy noted that

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150 Angie, Tamara, Rene, Interviewed by Carolyn Fast, Welland, Ontario, July 8, 2019, 1,4, 5, 2.
151 Lina, 2.
after the loss of her mother, things “got a little dicey.” Amy, much older than Hana, was already married and lived away from home, leaving just her dad at home to care for Hana. Upon the passing of her mother, Amy and her husband moved closer to home to help her dad care for Hana. The arrangement worked until a few years later when her father announced he was getting remarried. Amy said that the woman her father married made it clear that she “wasn’t gonna raise another child,” and Hana was sent to Blenheim. Amy, now with a growing family of her own, didn’t feel she could assume full time care and responsibility of Hana. The decision to send Hana away was her made by her father and Amy said, “Nobody had a choice in the matter.” The rest of her siblings, much older than Hana, were living in the United States at the time. Still, in retrospect, Amy expressed regret that although she felt assuming full time care for Hana was not a feasible option, “I always felt guilty about it…”152

Another sibling identified the breakdown of his family as the impetus for his sister’s institutionalization. From a young age, Burt and his siblings were separated and placed into foster care. Burt felt that his sister Lily’s placement into foster care paved the way for her confinement at Oxford Regional Centre in 1971 at the age of 17 years old. Burt said that he saw his parents occasionally while he was in foster care but doesn’t remember seeing Lily very often. Looking back at his life, Burt said that he and his sister never gave up and despite the loss of contact, the siblings never lost their connection to each other which was apparent upon their reunification years later – a closeness that continues to this day.153

152 Amy, Interviewed by Carolyn Fast, Stevensville, Ontario, August 2, 2019, 1,3.
153 Burt, Interviewed by Carolyn Fast, Welland, Ontario, June 28, 2019, 5-6
Central to some interviews, clearly, was the stress that supposedly unfit loved ones placed on the family unit. One of the siblings I interviewed, Elise, remembered her mother telling her that it was in her best interest that her brother Simon be sent away. She said,

“…that for my sake, Simon should be gone. That for my sake, in order for me to get the attention I needed and in order for me to be able to have my friends over and all those things, that it would be better if Simon was in an institution.”

Similarly, for another family, sister Rene recalled her mother’s concern regarding the relationship between her younger brother and her sister Vivian who had an intellectual impairment. Vivian and her brother were playmates even though Vivian was four years older. Rene said, “my little brother was starting to act like Vivian,” which, as time went on became a “big issue” as her mother tried to raise her siblings with little outside support. Her four-year old brother’s mimicking of his older sister’s behaviours placed further strain on the family and eventually the decision was made to send Vivian away at the age of eight years old.

Throughout the stories shared by survivors and their siblings, it was clear that parents did their best to cope for as long as they could in managing the daily demands of life while trying to keep their child at home; for many, the decision to send a child away was extremely difficult and made when they were at their wit’s end. Wheatley in describing the complexity of the situation wrote that although “putting one’s child away was always voluntary in Canada, parents held a certain implicit power they might not have been fully aware of.” In most situations, in order for a child to be institutionalized, parental or guardian consent was needed which meant that the

154 Radford and Park, 10-11.
155 Elise, 2.
156 Rene, 2.
parent or guardian had to have some sort of relationship with a medical professional or
government official. For children already under the authority of the state, institutionalization
was an easier course of action, as in Lily’s case who was sent away at the age of 17 years old.
Wheatley argued that for parents to make the decision to institutionalize their child they had to
be “coerced”, or as MacMurchy said, “‘taken firmly by the hand,’” so as to accept two ideas,

“that putting their “mentally defective” child away was for the child’s “own good”- a
phrase constantly reiterated throughout the century – with the state assuming all rights of
wardship; and the notion that trained staff in an institution could provide far superior care
to home care. It was the parent’s duty to acquiesce.”¹⁵⁷

This notion of duty speaks to the tension of the time: there is a notable, powerful difference in
narrative between the official standpoint that institutionalization was the appropriate course of
action, versus the path parents struggled along before making the choice to institutionalize their
child.

¹⁵⁷ Wheatley, 369.
4. The Unmaking of Difference: Personhood, Activism, & the Push for Deinstitutionalization

The ‘Knowledge Elite’: Erving Goffman, David Vail, Bengt Nirje and Wolf Wolfensberger’s Emergent ‘Expert’ Critique of the Institutional Response to Intellectual Impairment

The battles waged by and within parents, in their struggle to find a way to navigate their circumstances and provide care for their children in the face of overwhelming social pressure to institutionalize, gained some support in the post-war period, as psychologists and academics conducted research that shed a dark light on the practice of institutionalization. Some of this research focused on the institutionalization of “normal” children that had been conducted since the early part of the twentieth century: social workers made frequent, if not always convincing arguments (for institutional staff or governments), that congregate facilities were psychologically and social damaging for children. In the wake of the Second World War, following well-circulated analyses of the problems faced by institutionalized children penned by John Bowlby and Anna Freud, the consensus that children should not be housed in congregate facilities was nearly impossible for institutional staff to ignore. Freud argued that separating children from their parents during the “preschool wartime evacuation in England” caused more “mental and emotional damage” than the impact of children experiencing the “physical destruction of their homes and neighbourhoods.” In a 1950 report for the World Health Organization, Bowlby forbid the institutionalization of infants completely, making allowances for institutionalized care on an emergency, short term basis only, for children over five. The negative impact of removing a child from her home was so detrimental to the development of a child’s personality that
institutions were no longer seen as being in the best interest of the child. This pressure also came to bear on discussions surrounding the institutionalization of the intellectually impaired, though the effort to make a case for de-institutionalization was far more difficult to make.

Sociologist Daniel Bell describes these professionals as the “knowledge elite” who were intentional in their goal of influencing society and reshaping policies. As Bell points out, their power rested in “their ability to structure the way we think and talk about social problems.” This diverse group was made up of social scientists, a few psychiatrists and sociologists, including Wolf Wolfensberger and prominent Canadian sociologist Erving Goffman, who questioned the logic behind “medical and psychiatric models as applied to mental health and mental retardation policy.” They questioned why institutions were failing to provide solutions and the more they questioned, the more it became increasingly evident that the problem rested in society’s attitude toward those with an intellectual impairment or a mental illness.

Canadian sociologist Erving Goffman was one of the first to bluntly, and critically, articulate these concerns. His research, conducted in the 1950s and early 60s, and coming on the heels of Canada’s flirtation with eugenic policies, reflected (even as it critiqued) contemporary concerns about the belief in contagion. The concern that an individual’s ‘stigma’ (their impairment) could spread to those who were close to him or her, Goffman noted, was the reason that people avoided or ended relationships with those who were stigmatized. In the context of

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158 Lafferty, 182-83. Lafferty notes that prior to Freud and Bowlby’s findings, provincial psychologist J.C Harding, upon his inspection of the infant homes in Halifax, was especially concerned about the older children living in the home who presented delays in speech and “mental advancement” from lack of stimulation. Harding concluded that children having lived in the home for more than a year were especially impaired making it “impossible” to determine if their mental impairment was “due to dullness” or a result of their environment (183). In Ontario, the concerted effort to close congregate homes and establish foster care as an alternative for “normal” children was spear-headed by John J. Kelso. See Bullen, “J.J. Kelso and the ‘New’ Child Savers;” Jones and Rutman, In the Children’s Aid.

159 Simmons, 195, 197
continued institutionalization in Canada, it also helps to explain why those with an intellectual impairment continued to be housed in congregate facilities. Institutions not only contributed to the stigmatization of the intellectually impaired, their creation was also an acknowledgment of stigma: they simultaneously reflected and reinforced the stigma associated with intellectual impairment or mental health issues. This stigma was not only crushing to the individual but, in turn, devastating for members of the individual’s family.

In his ground-breaking 1963 book, *Stigma: Notes on the Management of Spoiled Identity*, Goffman argued that stigma was society’s definition of “undesired differentness from what” was expected, upon which the dominant members build a “stigma-theory” or ideology justifying the person’s inferiority and the potential danger he or she represented. According to Goffman, this stigma-based theory was the gateway to the belief that the stigmatized person is “not quite human.” Goffman identified three types of stigma: physical, character (which included one’s cognitive ability), and tribal. A physical stigma, or an “abomination of the body” was the most obvious one and covered various physical defects or genetic deformities (including those which the Canadian National Committee for Mental Hygiene purported to detail in its promotional materials from 1924: see above, Figure 1). However, “blemishes of individual character” was a bit more all-encompassing as it related not only to undesirable character traits, such as being dishonest or having a weak will, but it was further assumed that those characteristics were derived from “a known record of, for example, mental disorder, imprisonment, addiction, alcoholism, homosexuality, unemployment, suicide attempts, and radical political behaviour.” The final stigma – tribal, had to do with nationalism, religion and race which could be passed down throughout generations infecting entire families. Goffman argued that for the person
possessing any one of the three stigmas, the result was always the same: the undesired trait turned the ‘normal’ people away from the individual. In Goffman’s words, the individual “possesses a stigma, an undesired differentness from what we had anticipated,” thereby disrupting the social exchange. For those living with an intellectual disability, the response was not only a turning away, but a physical, enforced separation.

Not surprisingly, Goffman identified the school as the first place of “stigma learning,” wherein the greater the disability, the more likely the individual would be sent to a “special school for persons of his kind and the more abruptly he will have to face the view which the public at large takes of him.” Goffman wrote, “[he] will be told that he will have an easier time of it among ‘his own’, and thus learn that the ‘own’ he thought he possessed was the wrong one, and that this lesser own is really his.” Having stripped the individual of possibility and having removed the need for any type of expectation, the individual’s sense of belonging is relegated to others who have the same stigma. Goffman believed that the persistent onus on the stigmatized person to accept or tolerate society’s failure to acknowledge his humanity ensured that the “normals” always maintained their perceived sense of superior status. Because the stigmatized individual’s experience, or story, was not believed or entertained – often because it differed from “normal” experience – the supremacy of the “normal” experience was assured. He concluded that dismissing the stigmatized person’s experience allowed “normal” people to remain secure in their privilege and status, having never been challenged to gain a greater understanding or self-awareness of their own intolerance. Of particular concern to Goffman were long term


161 Ibid., 33, 113, 117, 121.
institutional inmates who, having been confined for over ten years, were deemed “to be the most incurable or so-called psychiatric failures.”

Goffman coined the term “total institutions” in his efforts to describe how long-term institutionalization virtually made it impossible for former inmates to adapt to life outside of the institution. He defined the “total institution” as “a place of residence and work where a large number of like-situated individuals, cut off from the wider society for an appreciable period of time, together lead an enclosed, formally administered round of life.” He added that in the “total institution” the “human needs” of multiple people are managed “by the bureaucratic organization of whole blocks of people” which is usually “split between a large managed group…and a small supervisory staff.” Since there were a large number of people segregated together based on commonalities of difference and only a small number of staff, Goffman concluded that the staff had to organize their work in ways that ultimately were dehumanizing.

David Vail, Medical Director for the Minnesota Department of Public Welfare, greatly influenced by Goffman’s work, expanded on the reality of total institutions in his book, *Dehumanization and the Institutional Career*. Published in 1966, Vail built on Goffman’s observations, expanding his definition of a total institution to include:

1. An organized system of roles and rules.

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162 Dyck and Deighton, 149.

163 Goffman, 4. As Dr. Geoffrey Reaume recently brought to my attention there are many historians, including Edward Shorter, Joel Braslow and Gerald Grob, who oppose Goffman’s belief in “total institutions” as exaggerated, to which I would disagree. I would argue that one must first acknowledge that real choice involves a diverse offering of experiences, opportunities, risks, successes and failures. The removal of one’s right to choose to the extent that the “human needs” of a large, segregated group of people are managed solely by a smaller, powerful, autonomous group, is crucial in understanding the implications of institutionalization in the manner in which Goffman is attempting to describe it.

2. An organized system of punishments and rewards involving the total life experience of the person.

3. A rationale or doctrine of the organization, binding staff and inmates alike.

4. People-work, Goffman’s term connoting man as inanimate object.

5. Mortification

6. Self-perpetuation

While number one is self-explanatory, the remainder of the points perhaps warrant a bit of an explanation. Regarding point number two, Vail stated that since the person was bound to live out his or her existence in the institution, the person was never able to escape punishment. For the person that was institutionalized this meant that if he/she behaved badly outside the ward, he/she would receive punishment not only at that time but would face additional punishment upon their return to the ward. Vail argued that this “organized” and total “system of punishment and rewards,” was carried out “to extremes.” Punishment was supported by a rationale which mental hospitals defined as treatment. For those deemed untreatable, further dehumanization occurred, through what Vail called, “people-work.” According to Vail, “people-work” was “the application of industrial production techniques to human affairs,” wherein, “the record is kept not really of individual persons and what besets them, but simply of categories.”

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165 Similar to Vail’s usage of the term “people-work,” Charters, in her examination of how physical differences in British soldiers reinforced perceived notions of other differences refers to the adaptation of the term “practise of returns.” Originally used to describe the system of “controlling and checking expenditure on items such as uniforms and rations,” “returns” was applied to the soldiers as a way of tracking and inventorying the “number of men serving who were fit for active duty.” As such “categories of returns” used terms such as “‘fit for duty’, ‘sick present’, ‘sick in hospital’ and ‘dead’” to describe the soldier’s capacity to perform his duties. For more, see Charters, “Making bodies modern: race, medicine and the colonial soldier in the mid-eighteenth century,” page 225.
conducting “people-work” included “transfer,” “death,” “open and closed cases” and “discharges.”

Vail’s term mortification (point five), referred to Goffman’s term “stripping” when upon a person’s admission to the institution, he or she was “stripped of his appurtenances, his worldly possessions, his clothing, even his hair.” The cutting of a person’s hair upon entry was a common practice in institutions and discussed in one family member’s story. Amy remembered the shock of seeing her sister Hana for the first time after she was sent to the institution in Blenheim. Amy said,

“I remember going up there visiting her, and she had beautiful long hair – they got that all cropped off. And there she is running around, clutching all her possessions. They had her on Valium, because I talked to people. You know, I was so shocked to see what had happened to her in that institution. And they said, well, she wasn’t adjusting. Well no wonder she wouldn’t adjust. She came from a loving family and put in an institution where you had to fight for everything you got. It was awful.”

The cutting of a one’s hair was a direct assault on the individual’s identity and in the case of Amy’s sister, the realization of a new and brutal reality of having to fight for her survival. Hana’s story is also what Vail is referring to regarding punishments and rewards supported by a treatment rationale wherein, Amy upon questioning why Hana was running around clutching her belongings was told that it was Hana’s fault because she was not adjusting. Hana was also

166 Vail, 59, 65-67.

167 Amy, 2. In the nineteenth century, needy children who entered orphanages often had their hair cut short – ostensibly, it was argued, to eliminate filth and lice associated with their poverty. The practice was discontinued in many places by the early twentieth century as it was seen as marking the children as distinct, or abnormal, preventing them from integrating into their local neighbourhoods and schools. Yet, practices like this continued to be forced upon inmates at institutions long after WWII as seen from Amy’s retelling of Hana’s hair being cut.
medicated without consultation with her family, an example of people-work, aimed at further
dehumanizing Hana by reducing her status to that of an innate object or just another case, not a child. Another example of mortification within the context of institutionalization was the loss of “personal privacy, especially with regard to excretion and other bodily functions” as individuals had to use the bathroom while under staff surveillance and in the presence of other inmates.\textsuperscript{168}

The final characteristic, self-perpetuation, Vail argued was essentially caused by feelings of “perpetual guilt.” The institution convinced the individual that they were confined because they must be “wrong, bad or worthless,” such as in my interview with Krista, who when asked why she thought she was institutionalized said, “me bad.”\textsuperscript{169} However, there was little that inmates of the institutions could do to turn things around because the rules, punitive in nature, changed or were applied inconsistently. Vail wrote, “There is no pattern to be discerned, no way of learning how to escape punishment, how to please anyone, how to be better.” Furthermore, the rationale of the institution being treatment solidified the person’s guilt because they would never be deemed to be well. Therefore, if the individual co-operated with the treatment, nothing improved and if the individual was uncooperative, he or she would be subjected to further punishments.\textsuperscript{170} As the accounts from survivors of these institutions make clear (see above) both Goffman and Vail’s assessments were reflective of the realities of institutional life for many thousands of people in Ontario.

\textsuperscript{168} Wheatley [246] details the grisly experience of the children from the Lumsden family who were institutionalized at Huronia. In describing the lack of privacy when using the washrooms, she wrote that the boys lined up to use the crowded washroom at the back of the dorm where, upon entry, they urinated in “tin lavatories with no doors” under the supervision of an attendant.

\textsuperscript{169} Krista, 10.

\textsuperscript{170} Vail, 68, 70, 72-73.
While Goffman and Vail focused on what made institutions unfit dwelling places for all human beings, Bengt Nirje was looking at institutionalization from a very different perspective. Nirje, Executive Director of the Swedish Association for Retarded Children and (in the early 1970s) a policy consultant for the Ontario Ministry of Health, is credited with developing the theory of Normalization. Nirje references the period between 1963-1966 as the beginnings of his formalization of a theory of Normalization. He described his theory as “pedagogical device” used during his speaking engagements, to contrast a “normal day, week or vacation” of a typical person with that of a person with an intellectual impairment. Using an inductive theory, Nirje wrote that he “gradually saw an underlaying coherence in my observations and analyses, such that I started to call this coherence a ‘principle.’” Normalization according to Nirje meant “that you act right when you make available to all persons with intellectual or other impairments or disabilities those patterns of life and conditions of everyday living that are as close as possible to, or indeed the same as, the regular circumstances and ways of life of their communities and their culture.” Nirje determined the conditions of a normal life centered around eight key factors:

a) A normal rhythm of the day.

b) A normal rhythm of the week.

c) A normal rhythm of the year.

d) The normal experiences of the life cycle.

e) Normal respect for the individual and the right to self-determination.

f) The normal sexual patterns of their culture.

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g) The normal economic patterns and rights of their society.

h) The normal environment patterns and standards in their community.

His thoughts on normalization, particularly, were aimed at how residences for people with an intellectual impairment were designed and operated. Of significance to this thesis is to note that not only is his theory rooted in an appeal for rights, but it more importantly originated “from the point of view of people with intellectual disabilities themselves.”

Nirje’s theory emerged over a number of years as a result of his work with diverse, vulnerable demographics. One such experience that was critical in his understanding of the dangers of institutions was his role as social welfare officer in a refugee camp in Traiskirchen. This camp emerged in response to the decimation of the Hungarian Revolution in 1956 by Soviet forces. With almost 200,000 refugees fleeing into Austria, Sweden put together a team and Nirje agreed to go with them. His primary responsibility was to maintain the “morale of the camp.” Nirje witnessed first-hand the dislocation of hundreds of thousands of people, fractured families and the disruption of identity. He was particularly affected by the knowledge that once a person was labelled a refugee, the person was stripped of their past. He wrote, “No one cares about it, no one believes it and nobody trusts you. Your situation is bleak, uncertain and anonymous.” He observed what it was like for 100 to 160 people to share a dormitory in dismal conditions and was impacted by how difficult it is to live closely with so many people without any space for privacy, activities, rest or to keep one’s belongings.

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172 Nirje, 17, 28.

173 Nirje, 20-21. It is important to note that Nirje’s approach in the camp was based on his respect and acknowledgement of the individual’s autonomy. This was evident in his insistence on open, consistent messaging with people and encouragement of democratic processes with a focus on problem solving. As a result, the members of the camp were empowered to create and deliver programs ranging from sports, to language courses and kindergarten classes.
Nirje’s work on normalization paved the way for Wolf Wolfensberger’s Social Role Valorization theory (SRV). A psychologist by trade, Wolf Wolfensberger’s work in the 1970s, which was grounded in Nirje’s principle of normalization, has had the greatest influence on policies and practises related to disability in Canada and the United States. According to Wolfensberger, SRV, was defined as “the application of what science has to tell us about the defense or upgrading of the socially-perceived value of people’s roles.” Wolfensberger argued that the best way to implement the principle of normalization is through SRV, wherein individuals with a disability were actively engaged in roles that society values, which was a practical means of challenging societal norms and acknowledge the personhood of others.174

Wolfensberger also addressed stigma within the context of devaluation. In *A Brief Introduction to Social Role Valorization: A High Order Concept for Addressing the Plight of Societally Devalued People, and for Structuring Human Services*, Wolfensberger argued that people make instantaneous judgements when meeting for the first time, either positive or negative, on a conscious or subconscious level. He stated that, “there is no such thing as value-free or neutral perception,” so when the evaluation of someone is negative, it is referred to as devaluation. If a person is seen as devalued, they will be treated as a ‘lesser’ being and as a result, are more likely to experience a poorer quality of life. Once devaluation has occurred, it forms a rift between the individual and other people. People start to pull away from the person who is devalued.175 Goffman described a similar rift that occurs when concern related to the

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174 Wolf Wolfensberger, *A Brief Introduction to Social Role Valorization: A High-Order Concept for Addressing the Plight of Societally Devalued People, and for Structuring Human Services*, 3rd ed. (Syracuse: Syracuse University, 2004), 58. His theory aligns with that of Taylor’s in the sense that socially valued roles are determined within a web of interlocutors who, through their relationship with the individual, testify to her personhood.

stigma surrounding the individual spreads to those close to him or her, causing others to avoid or end relationships with the stigmatized individual.\textsuperscript{176}

In his chapter from the book, \textit{A Quarter- Century of Normalization and Social Role Valorization: Evolution and Impact}, Wolfensberger acknowledged Vail’s work around dehumanization and dignity.\textsuperscript{177} However, one can also see Vail’s influence on Wolf’s writing about devaluation. Wolf’s use of the term “judgement” was derived from Vail’s observations about perception. Vail, in emphasizing the significance of perception, stated that how we “perceive the other person will determine the set of our attitudes and behavior towards him.” If people are seen as non-human, they will be treated as non-humans and if the relationship is one of dependency, the person will take on the characteristics “ascribed” to him or her. Vail wrote, “We first see the other person in a particular way and then our mutual behavior increasingly and cumulatively reinforces the reciprocal perceptions of the relationship.” For Vail, people were devalued in four ways:

1. Man as trivium: Man into child.

2. Man as inanimate object. Vail noted that this can be done actively wherein the person is seen as “a machine or instrument, a thing of action” or passively wherein the person is seen as “a product or package, a unit of production.”

3. Man as animal: The beast, the brute.

4. Man as other: The unnamed and unnameable.\textsuperscript{178}

\textsuperscript{176} Goffman, 30-31.


\textsuperscript{178} Vail, 35,36.
Wolfensberger argued that the final process of devaluation for individuals with an intellectual impairment often resulted in institutionalization. He stated that people who are devalued are not afforded the “good” things in life that ‘typical’ people tend to enjoy. Not only does this cause rejection, isolation, lack of respect and an absence of authentic relationships, but people are often robbed of their autonomy. Goffman too noted that by congregating the individual with “persons of his kind,” he or she is forced to “face the view which the public at large takes of him,” affecting the person’s sense of self or autonomy. Goffman argued that the individual “will be told that he will have an easier time of it among “his own”, and thus learn that the own he thought he possessed was the wrong one, and that this lesser own is really his.”

According to Wolfensberger, the most tragic form of devaluation occurs when the individual is seen as subhuman, non-human or as a subhuman animal. The final stage of this type of devaluation is objectification at which time the individual is likely to be forced into an institutional setting. It is at this point, when the individual is segregated from society, that the risk for neglect and abuse increases exponentially.

Goffman, Vail, Nirje and Wolfensberger had proven that segregating and institutionalizing people created “total institutions” which meant that the devaluation and dehumanization of the inmates inside was an inevitable outcome. The outcomes identified in their research aligned with social reform attempts that started to spring up as veterans returned back from World War II. Many veterans, some having acquired a disability themselves, recognized the inegalitarian society they were returning to and that realization had an impact on

179 Wolfensberger, “A contribution to the history of Normalization…,” 4,12.
180 Goffman, 33.
how people thought about institutionalization. The horrors exposed in the concentration camps were not soon to be forgotten and many veterans were committed to extending the idea of citizenship to encompass “certain social, as well as political rights.” Parents, as discussed below, were starting to demand services for their children from a human rights perspective as well. After WWII, Wolfensberger referred to what he called “a very vague construct of “attitude change,” – a response to fascism that focused on examining the “development of mass prejudices.” He contended that prejudice grew out of ignorance and ignorance revealed the need for education, making education the remedy to prejudice. He further argued that it was this type of thinking that was behind public tours of institutions, a popular activity in the 50s and 60s: attempts made to “educate” the public about mental illness and mental impairment but inevitably further devalued the people confined inside. Yet, the urge to institutionalize continued as the government endeavoured to meet the insatiable demand for beds by building onto existing institutions and constructing new facilities. While the failings of institutionalization were becoming increasingly clearer, the need for a paradigm shift seemed unavoidable. However, the shift did not come as a result of government innovation or social revelation; ultimately, the push to deinstitutionalize came from within.

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182 Simmons, 158. In contrast, Burghardt points out [1077] that the “context of post -World War II normativity” also played a role in families resorting to institutionalization as a means to protect and preserve the family home and social standing. Burghardt situates [1074] Goffman’s theory of “passing” – or an individual’s effort to look and behave in ways that society deems acceptable or “normative” to that of “familial attempts to be seen as socially acceptable and “impairment free,” and as such the existence and removal of a child with an impairment is hidden by secrecy. See, “He was a secret’: family narratives and the institutionalization of people with intellectual disabilities.”

The provincial preoccupation with institutional care as a response to intellectual impairment — and the continued power of stigma and shame — was a significant barrier to the acceptance of ideas like those articulated by Goffman, Vail, Nirje and Wolfensberger. Indeed, despite research and writing in the 1950s, 60s and 70s, contributing to the broad western discussion of civil rights at the same time that child welfare experts were digging in their heels on the issue of institutional closures for ‘normal’ children, governments from the mid-1940’s onward provided financial and institutional support for the expansion of residential facilities for the intellectually impaired. In 1945, George Drew’s Conservative Ontario government authorized the construction of the hospital (Rideau) in Smith Falls in an attempt to meet the demand for beds. Completed in 1951, within a few years of its opening the new hospital experienced a shortage of beds, so Huronia Regional Centre in Orillia was granted permission to admit children under the age of 6 years old. Construction began on Huronia’s existing facilities to provide for the accommodations of an additional two to three hundred children. By 1955, Huronia experienced another bed shortage and an additional three hundred beds were added.

Significantly, however, the work of sociologists like Goffman, Vail, Nirje and Wolfensberger provided a language, grounded in professional expertise, which had the potential to counter the dominant ‘expert’ response to the presence of the intellectually impaired in the community. These scholars laid the groundwork for discussion — and potentially activism —

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184 This phrase originated from Valerie Billingham who, while listening to a panel at the Slazburg Global Summit in 1998 said, “nothing about me without me,” as her interpretation of what the session was about. Self-advocates have coined the phrase since as a mantra for self-autonomy. See Casey Quinlan, “Nothing About Me Without Me- 20 Years Later,” Science 37, April 25, 2018, https://www.science37.com/blog/nothing-about-me-without-me-progress-in-participatory-healthcare/.

185 Simmons, 160
that was rooted *not* in arguments about simply improving conditions in institutions so as to make them function more humanely, but rather in the notion that the inmates of those institutions had a claim to personhood which was as inalienable as any other ‘normal’ person might claim.

Personhood could not be exercised in confinement. For those on the outside, the closure of institutions is often seen as having been rooted in scandal and outrage in response to the grave injustices that were committed against the inmates forced to exist behind its walls. I would argue, however, that the force for change came from within the walls as inmates and former inmates pushed to gain their release and secure their freedom. Pierre Berton may have given many people *pause* with his shocking exposé of Huronia, but it was self-advocates and their families who banded together in Canada and around the world to exert political pressure that focused on the recognition of their human rights.

The first notable, unified resistance to institutionalization came in the form of grassroots organizing among parents concerned about the institutionalization of their children. Notably, this resistance appeared well before discussion of the negative effects of institutionalization for the disabled became more commonplace. In the 1930’s some parents started to gather together publicly in search of solidarity in their private struggles. Family networks popped up in Montreal, Saskatchewan and then Ontario, forming a coalition that increasingly pushed to voice their concerns in public forums. Perhaps, the most notable face in the movement in Ontario was Victoria Glover, who, in 1948, wrote a letter to the editor of the *Toronto Star* regarding the education of her intellectually impaired grandchild. Glover wanted to know why her grandchild was barred from attending regular school without access to any sort of education in the
neighbourhood where she lived.\textsuperscript{186} Glover invited other parents experiencing similar challenges to meet with her. Her letter garnered responses from thirty parents and seventy people showed up to a meeting in the basement Carlton Street United Church in Toronto.\textsuperscript{187} Access to education and services became the galvanizing issues that brought families together. Local associations soon grew to become provincial associations that advocated with the government and provided service coordination in communities. Provincial associations morphed into national ones, the most prominent one being the Canadian Association for Retarded Children in 1958 which is now known as the Canadian Association for Community Living.\textsuperscript{188}

In the 1960s and 70s, the push to deinstitutionalize people with an intellectual impairment had taken root and Ontario saw a series of legislative acts passed, including the Vocational Rehabilitative Act of 1966, and the Homes for Retarded Persons Act.\textsuperscript{189} Internationally, parents and professionals were looking to connect with each other to find new solutions and ways of caring for those with an intellectual impairment. Perhaps the first indicator of this global quest for innovation was President Kennedy’s President’s Panel on Mental Retardation, launched in 1962, which sent study groups around the world to find new practises. In 1963, the European League took on a new name and role as the International League of Societies for the Mentally Handicapped. This was followed by the formation of The International Association for the Scientific Study of Mental Deficiency in 1964.\textsuperscript{190} All of these developments occurred against the

\textsuperscript{186} Canadian Association for Community Living, “About Us,” 2017, https://cacl/who-we-are/about-us/.
\textsuperscript{187} Clare, 88.
\textsuperscript{188} Canadian Association for Community Living, “About Us.”
\textsuperscript{189} Simmons, 185.
\textsuperscript{190} Nirje, 31.
backdrop of the civil rights movement, which certainly played a role in the emergence of a “rights” movement within the disability sector.

However, at the heart of this “rights” movement was great ambiguity as to whether there ought to be an appeal for legal rights or “human rights” for the intellectually impaired, and further discussion ensued surrounding the intersectionality between the two. In some ways, advocating for legal rights presented a clearer way forward than demanding equality for people with an intellectual impairment, thereby entitling them to the rights and freedoms of people without an impairment. The legal rights movement reflected European influences wherein organizations advocated that services were a right and not a privilege. This belief was supported by two essential thoughts, the first being that by defining services as a legal right the result would be more funding. The second was that defining services as a right would help to eliminate the social stigma attached to funding. The main goal of the movement therefore, was to secure “rightful funding of schooling” for children with an intellectual impairment. Wolfensberger said that by the mid 1960’s there was a “terrible impoverishment of concepts,” so much so that parents and advocates “were so worn out battling the school system that they could hardly see around the corner of the next small step forward.” He explained it this way,

“Also, many (parents) had been brainwashed into holding extremely low expectations for retarded persons. Protection and kindness loomed much larger in their minds than anything else. And most professionals were very bankrupt in their visions, if not outright dehumanizing.”

The battle fatigue parents felt from taking on a school system that was deeply rooted in a prevailing culture that saw intellectual impairment as an incurable and futile condition, combined
with the lack of vision among professionals, further muddied the waters in the fight for human
rights for the intellectually impaired.\textsuperscript{191}

\textit{The Williston Report (1971) and After}

However, the effort to establish clear legal rights was bolstered by growing public
knowledge of the abuse and mistreatment of inmates in Ontario’s institutions. Their clear failure
to provide appropriate treatment and care for those with an intellectual impairment in Ontario
was not only exposed by the influential pen of Pierre Berton, but it was further exposed in the
Williston Report of 1971. Significantly, this report hints at powerful, individual-level resistance
and rights of the inmates themselves. Williston, a well-known Toronto lawyer, was appointed to
investigate the deaths of two former inmates, Jean Marie Martel and Frederick Elijah Sanderson,
who had recently been released from Rideau Regional Centre in Smith Falls.\textsuperscript{192} Jean-Marie
Martel was 24 years old when he was released from Rideau and placed on a farm to work. He
told the social worker that he wasn’t being treated well on the farm and tried to leave a few
times. On his final attempt to escape, Martel was found walking in the cold suffering from
frostbite on his ears, fingers, nose and toes. 19-year-old Frederick Elijah Sanderson was also
released from Rideau and placed on a work farm. He repeatedly told his social worker that he
didn’t want to stay on the farm. Although he was brought back to the institution on a few
occasions, he was always returned to the farm. On March 5, 1971 Frederick committed suicide
by hanging himself in the hayloft. Williston was charged with leading the investigation

\textsuperscript{191} Wolfensberger, “A contribution toward normalization…,” 55, 56

\textsuperscript{192} Simmons, 192-93.
particularly, from the standpoint surrounding public and government responsibility for inmates when they were no longer under “direct custodial care by the Government.”

At this time Nirje had just accepted a job at the Ontario Ministry of Health to develop training and programs intended to support inmates transitioning out of the institutions and into the community. Ironically, the same week that he began his work at the Ontario Ministry of Health was the week that Williston began his six-week investigation. Nirje, Don Zarfas and Connie Hawley “worked closely with Williston” and Nirje’s vast history and knowledge of the origins and functions of institutions was evident in Williston’s overview of the shortcomings of these facilities. Williston, extensive in his investigation, toured institutions and met with interest groups and families. His report was comprehensive, complete with an analysis and recommendations on the entire field of policy as it applied to those with a developmental disability. Williston was particularly scathing in his assessment of large institutions and detailed concerns which would have seemed eerily familiar to those who, in previous decades, had levelled their critique on congregate homes for ‘normal’ children. They included overcrowding, lack of stimulation for the inmates, the weakening of familial relationships, insufficient number of professionals to provide care, fire hazard issues within the buildings, the exploitation of the inmates’ labour, and the stigma that followed the person upon his or her release.

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194 Nirje, 42-43. Nirje also notes that his decision to accept the position was in part fueled by his belief that in Ontario there was a “desire for change” and a “positive atmosphere” toward progress. Admittedly, Nirje acknowledged the irony that he was now working in institutions, but his focus was on developing training programs to help transition individuals out of the institution and connect them to services in the community.

195 Simmons, 193-94.
importance to Nirje was that Williston showed “the lack of coordination among existing community services.” It was evident that too many ministries were involved in “financing and overseeing the numerous pieces of legislation” which contributed to a “lack of coherence and efficiency among the responsibilities” of those involved.196

Williston’s recommendations reflected normalization teachings: the belief that a person with an intellectual impairment had a right to live in the community and experience a typical life, similar to that of a person without an impairment.197 Significantly, Willison also stated that society had a part to play in ensuring that the individual had “assistance, protection, opportunity and shelter,” so that he or she could be a “contributing member of the community.” This, in turn, provided the foundation from which a person could experience a “decent standard of living so that he can walk through life with dignity.” Williston’s first recommendation called for the immediate phasing out of large institutions due to inadequate conditions, costs, overcrowding, lack of trained staff, the stigma inmates suffered due to their internment, inadequate administration of services, and its geographical isolation from communities. Perhaps most importantly, he acknowledged the “profound psychological effect on both staff and residents” and that a “century of failure and inhumanity in the large-multi-purpose residential hospitals,” should in and of itself indicate a “weakness in the system and inspire us to look for some better solution.”198

Also of great importance was Williston’s affirmation that parents had a right and responsibility to keep their child at home. Williston stated that the needs of every child were the

196 Nirje, 43.
197 Simmons, 195.
198 Williston Report, 4, 65-68.
same: “family ties, emotional warmth, understanding and acceptance.” All children benefitted from and needed to experience growth, socially, emotionally and physically in preparation for their future. Williston felt that the optimal place for such fundamentals to flourish was in the family home, unless the family was unable to provide care or the environment was too unhealthy for the child to remain in. He further proposed that adults with an intellectual impairment have access to housing options in their community that were just like everybody else’s, such as a house or an apartment. For those who needed “residential provisions,” Williston emphasized smaller facilities located within the community that were close to the individual’s familial home. He stated that those living in the residences “must be integrated with and closely associated with the educational, recreational and commercial facilities in the area.” Other residential options included boarding houses for children, foster homes for children, separate long-term residences for children and adults, chronic care facilities and residential treatment centres. Williston agreed that all people should have access to recreational, commercial, educational, and professional resources in the community the same way as the rest of the society.

In 1971, Ontario’s new health minister, Richard Potter, tabled a number of Williston’s recommendations aimed at the facilities in northeastern Ontario. Potter met his promise to reduce the number of people at Huronia Regional Centre, however, not by integrating them into their communities or supporting their families, but by transferring inmates to other institutions like the Oxford Medical Centre. Three of the survivors I interviewed were transferred from

199 Ibid., 70. In this, Williston was applying similar logic which guided decisions made by social workers about ‘normal’ children, and whether they should be allowed to live with their parents or placed in foster care. Williston also warned that it was not healthy for an individual to live at home “indefinitely” and upon adulthood, “should ordinarily be expected to leave home the same way as any other child” (71).

200 Ibid., 73.75.

201 Simmons, 195, 192, 193-4.
Huronia to Oxford in the 1970’s. Although the government promised to improve existing facilities to offer “more dignity to those patients,” they also continued to purchase empty buildings in Orillia and Cobourg to serve as residences. One such example was a former radio station in Picton that housed 375 people until 1980. The government’s obsession in scooping up deserted buildings, such as former religious institutions, army garrisons or hotels (or radio stations!) to house those with an intellectual impairment or illness had persisted for over a century, and the challenge of stopping the practice was clearly not going to be achieved by a single government report.202

In March of 1972, however, as part of the response to the Williston Report, a Task Force on Mental Retardation was formed through the Cabinet Committee on Social Development to record problems. Their interim report, titled The Welch Report or The Welch Green Paper (after the Honorable Robert Welch, Provincial Secretary for Social Development) and the others that followed, became the basis for the change in the Government of Ontario’s policy to deliver services to people with an intellectual impairment within the context of community living. The Welch Report was the gateway for the emergence of social services that aimed to provide support so people could live in the community. The paper criticized shelter workshop programs and (again) recommended the phasing out of large institutions.203 Under the existing system, the delivery of services had been shared between six ministries: “Health, Education, Community and Social Services, Colleges and Universities, Labour, and the Attorney General.”204 A tangible

202 Ibid., 199, 200.
203 Simmons., 203-205, 207.
(and significant) outcome of the report was government passed the Developmental Services Act in 1974 which shifted the oversight of services from the Ministry of Health – an association which maintained the notion that the disabled were a medical ‘problem’ – to the Ministry of Community and Social Services.205

However, like the Williston Report, the paper did not go far enough to address the real problem (both cause and effect of the institutions), stemming from society’s failure to see people with an intellectual impairment as “normal.” Instead, the report acknowledged in the introduction that,

“As a result of a number of studies published in Canada and abroad, we have come to realize that the problems faced by majority of the mentally retarded are primarily of a social rather than a medical nature, and the segregation of these persons in isolated institutions is not an adequate, let alone a suitable, form of care.”206

The focus was on care and the directive was to provide better suited services to individuals in the community “as an alternative to institutionalization.” Welch, like Williston described mentally impaired people as having extremely low intellect which caused “their subnormal functioning.” It was “their subnormal functioning” that in turn required the provision of “special training, education and social services.” However, a notable difference in the language employed by Williston was his use of the word “dignity” in his first “statement of principles and objectives:”


206 Welch Report, 1.
this is important to highlight because it is an acknowledgement that the impaired person ought to have some level of respect afforded to them. In outlining society’s responsibility toward the treatment and care of the intellectually impaired Williston wrote,

“Thereafter, society must provide each with such assistance, protection, opportunity and shelter as will enable him to take his place as a contributing member of the community and ensure to him a decent standard of living so that he can walk through life with dignity.”

There are places in Williston’s report where there appeared to be an attempt to reference personal traits and human characteristics when describing those with an impairment, especially when it came to all children having the same human needs. Welch’s language, on the contrary, was much more deficit-focused as he described how the mentally impaired person was “unable to organize his thought processes in an efficient way” to the point where “he cannot usually function successfully as an independent member of our society.” He continued to classify people according to their “level of competence” or level of impairment and their need for “special treatment.” Although Welch made the distinction that “special treatment” did not mean segregation, he stated that many people would “require an environment that is protective and highly structured.”

Welch conceded that it was important for individuals to make their own decisions, but he did not equate decision making with personal autonomy. In his words, a “necessary precondition to a life of normalcy, in both institutional and community settings” was that the impaired person “must be encouraged and allowed to make their own decisions and determine their own needs, as

207 Williston Report, 4, 6, 7, 70.
far as this is possible.” It seemed for Welch that people with an intellectual impairment had limited capacity in being able to make decisions about wants or needs, yet they should be “allowed” to try, which implied that the person essentially needed to ask permission to make personal decisions. Welch’s focus was really on outlining the steps needed to transition a person from the institution to the community while still ensuring that the individual was essentially under the authority of a guardian or a government or community agency. This was particularly evident in point one of his four areas of focus listed below:

1. Guardianship and protective services for impaired adults “must be provided in the community.”

2. Reallocation of resources from the institution to the community to provide residential care and counselling.

3. Development of employment and welfare policies that align with the general public and also apply to those with an impairment.

4. Coordinated service approach to ensure that care is provided in the community.

Although the recommendations opened up pathways for local agencies to provide services within the person’s community, guardianship by the family, agency or Guardian of the Public Trust was still seen as a prerequisite to community integration. The prerequisite of guardianship undermined personal autonomy because it was not offered as a support that could be considered as needed, instead guardianship was essentially, the individual’s “get of jail” card. If there was no guardianship order in place then the individual was not free to be released whether they required that level of support or not. Community and remote institutions would still provide

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208 Welch Report, 9.
residential and treatment options for the more severely impaired, with community institutions assisting in transitioning people from the large institutions into the community. Again, for those with a “severe” impairment little had changed as the institution would continue to exercise total control over their lives.\textsuperscript{209}

One can surmise from Welch’s brief and begrudging list of recommendations concerning the types of programs that should be offered in the community that he was not entirely convinced as to the benefit of community integration. For example, consider the disclaimer Welch wrote after he listed the categories of programming,

“The efficiency and effectiveness of delivery systems are affected by the location of these services. A closed institution provides most of them; but since a life of normalcy is our goal in caring for the mentally retarded, a full range of services will have to be provided in the community as well.”\textsuperscript{210}

In essence, what he was saying was that the intellectually impaired already had “most of” the programming they needed conveniently located all under one roof- the institution. However, since the focus was on providing care for the impaired similar to how those without an impairment received care or accessed services, then a whole bunch of services would have to be offered to them as well. Programming was not thought of within the context of how to make existing systems and structures work for everybody, instead separate provisions would need to be

\textsuperscript{209} Welch Report, 11, 12, 15, 16.

\textsuperscript{210} Ibid., 4.
made because individuals with an intellectual impairment were still seen as separate from the rest of the community.\textsuperscript{211}

Welch’s list of programs fell under the following categories, many of which undermined the individual’s autonomy:

1. Preventative services with the focus on pre-natal care and diagnosis.
2. Case finding, diagnosis and counselling.
4. Vocational training.
5. Recreational programs.
7. Medical, dental and legal services.
8. Residential and treatment facilities.\textsuperscript{212}

Certainly, there was considerable advancement in medical knowledge surrounding causes of impairment, some of which could be prevented during pregnancy or treated after birth,\textsuperscript{216} but the first two points were reflective of the continued influence of thinkers like Helen MacMurchy, and her obsession in policing women’s reproductive capacity — particularly as that applied to a woman who had an impairment. Historically, diagnosing a child with an impairment was a way to track defective children so as to categorize those who were trainable and those who would

\textsuperscript{211} As Megan Davies and others note [80-81], the 1960s ushered in Medicare which changed the way healthcare was offered throughout Canada, including how mental health services were offered – which to this day consist of fragmented pockets of programs that are “under-funded, under-resourced and overpopulated.” Since the closure of the institutions, families and individuals are forced to navigate complex paths to access medical, employment and housing services. See Megan Davies, et al., "After the Asylum: The History of Madness in Canada. Après l'asile: L'histoire de la folie au Canada by Megan Davies et al.," in Deinstitutionalisation and After Post-War Psychiatry in the Western World, eds., Despo Kritsotaki, Vicky Long, Matthew Smith, Matthew (Switzerland: Palgrave Macmillan, 2016), 80-81.

\textsuperscript{212} Welch Report, 4.
require permanent institutionalization. Reminiscent of Vail’s term “people-work”, the intellectually impaired were still being referred to as “cases” in need of finding and diagnosing which again referenced the medical model of treatment. It was unclear what Welch’s intention regarding “counselling,” with regards to who needed it and why? What was clear though, was that individuals with an intellectual impairment were still seen as needing specialized training, treatment, housing and education which continued to place them outside of mainstream community services or programs utilized by members of the society who did not have an intellectual impairment. The final category relating to residential and treatment centres once again underlined the prevailing assumption that confinement was sometimes necessary for the “good” of the individual. Karen McCauley and Duncan Matheson pointed out in their article, “Perspective: From Institution to Community Living, to Social Inclusion-Unrealized Policy Promises,” that Welch failed to recognize the role families played in taking care of their child at home and the supports needed to make that happen on a daily basis. According to the authors, this was a “significant omission” as Williston had strongly recommended extensive supports be offered to families so that they could keep their children at home and also detailed a variety of housing options so families could look forward to a day when their son or daughter could move out of the family home.213

People First

Perhaps it is not surprising, given this tension between the language of individual rights and the continued provincial emphasis on custodialism, that the mid-1970s marked the peak of

213 McCauley and Matheson, 4, 7.
institutionalization in Ontario, and saw the emergence of organized, political activism from those with an impairment themselves, which demanded recognition for their rights as citizens and their release from the institutions. By 1974, the provincial government was running sixteen large institutions housing over 8,000 people while a mere eight community homes functioned, four of them sponsored by local associations. In 1973, self-advocates from across North America gathered for a conference in British Columbia. At the forefront of members’ minds was the subject of human rights, primarily the right to choose where they wanted to live and with whom they wanted to live with. The group took on the name People First and the movement was largely focused on deinstitutionalization.

Co-founder of People First in Ontario, Peter Park, held his first People First meeting in Brantford in May of 1978 and it was a significant moment in which people came together to talk about their human rights in the province. Peter said that he knew he “was on the right track” and soon he was travelling around the world speaking to “large groups of people about their rights.” By the 1980’s People First groups were popping up across Ontario, and the provincial body was formally established in 1982. The advocacy movements were further validated by the United Nation’s “Declaration on the Rights of Disabled Persons,” issued on December 9th, 1975. It would be a global catalyst for change as countries were challenged to create and implement legislation that protected the rights of and provided opportunities for people with a

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214 It is interesting to consider Taylor’s argument on rights and legal rights here. On page 11, he states that in “higher civilizations,” humans that were awarded respect included “the whole human species.” However, Taylor writes that he finds it “peculiar that in the West “this principle of respect has come to be in terms of rights.” Taylor states that while this has become “central to our legal systems” (and elsewhere in the world) something similar has taken place in our moral thinking. He argues that now it is the law that “I must obey” whereas, universal or natural rights place the onus on the “possessor.” See Taylor, Sources of the Self.


disability. Finally, there was an effort to include people with a disability in decision making processes so they could make recommendations to government, such as the Ontario Advisory Council for the Physically Handicapped that was established in 1975. Federally, the Bureau on Rehabilitation was put in place in an attempt to “coordinate national efforts to promote the interests of disabled people.\textsuperscript{217}

As well as advocating for the recognition of rights, People First was also deeply involved in legal action directed at the province’s mishandling of the institutions, and mistreatment of those with an intellectual impairment. Peter Park, in fact, acknowledged his meeting with David Baker, a human rights lawyer at ARCH Disability Law Centre as the catalyst for his career as an activist outside of the institution,\textsuperscript{218} and People First took on significant legal battles impacting the lives of people with an intellectual impairment, almost from its first inception. In his book, \textit{Never Going Back}, self-advocate and founder of the Brockville People First chapter, Gord Ferguson, records that he first became involved in People First in the 1980’s during the so-called Eve Case.\textsuperscript{219} It was then that Gord met Peter Park, along with Barb Goode and Harold Barnes, who were national leaders of the movement at the time. The Eve case involved a woman, Eve was not her real name, who was opposed to her mother’s decision that she should be sterilized. Eve’s mother upon seeing her daughter holding hands with a young man from school, worried that Eve might become pregnant and wanted her to be sterilized. Initially, the mother’s request was denied by the Supreme Court of Prince Edward Island but the judgement was overturned in


\textsuperscript{218} Hutton, et al., 10. Peter remembered reading a magazine his father sent him while in the institution that was about self-advocacy. From that moment on, Peter said he knew that he wanted to be an advocate so that no one else would have their rights stripped from them like what had happened to him in the institution.

\textsuperscript{219} Ferguson, 92.
the Appeal Court. However, the Official Trustee of PEI supported Eve and the decision was appealed all the way to the Supreme Court of Canada. The Eve Committee was formed in 1981 consisting of Barb Goode, Harold Barnes, David Lincoln and Peter Park. Together, the committee learned how to work with lawyers to prepare for the case and in 1985 it went to court. A year later the Supreme Court of Canada decided in favour of Eve.\textsuperscript{220} It was precedent setting, as it was the first time that people with an intellectual impairment won recognition of their rights at the Supreme Court level.\textsuperscript{221} Their successful advocacy flew in the face of common arguments, made since the earliest attempts of Canadian governments to regulate the lives of the disabled, that those with an intellectual impairment were somehow incapable of making their own decisions about living and working in the ‘real’ world.

Similar suits followed, many initiated by survivors, including People First member David McKillop who served as the lead plaintiff in the case against the government for the mistreatment of former inmates at Rideau Regional Centre. A settlement was reached in this case in 2013 in the amount of $20.6M for former inmates of the Centre, and $12.1M for former inmates of Southwestern Regional Centre living in either of the institutions between 1963 and 2009.\textsuperscript{222} 2016 marked the final class-action suit that saw former inmates of twelve other institutions receive $36M, having lived in any of those institutions during the 1960s to 1990s.\textsuperscript{223}

\textsuperscript{220} Canadian Institute for Inclusion and Citizenship, “Eve Case Resources,” \textit{The University of British Columbia,} \url{https://cic.arts.ubc.ca/the-eve-decision-1986/4641-2/}.

\textsuperscript{221} Hutton, et al., 11.

\textsuperscript{222} CBC News, “Settlement Reached in Rideau Regional Class Action Lawsuit…”

People First members were also instrumental in initiating the name change of many associations and organizations dedicated to supporting people with an intellectual impairment. Previously, many of those organizations had the word “retarded” in their title, and members pushed to have the “r word” removed and replaced with the phrase Community Living. Gord remarked that this was a significant win because self-advocates were finally being heard and recognized as “competent to speak for ourselves,” whereas, before “both in the institution and in some of the associations, other people were deciding what was best for us.” Significantly, changing the language around intellectual impairment – a change initiated and executed by those so labeled – began a crucial phase of addressing the underlying conceptions of the wider national community.

It is no surprise that People First members have also been vocal in their opposition to laws related to euthanasia and assisted dying. As already mentioned in this paper, too often decisions about a person’s quality of life and right to live was, and in some cases is today, decided by others with little regard or consultation with the person themselves. Gord wrote, for example, that laws related to euthanasia and assisted dying can be “very dangerous” for people with a disability because “people are afraid of disability. They judge us and think that they would rather die than live like we do.” Individuals with an intellectual impairment can also find themselves vulnerable to the decisions that family members make. During my interview with another People First Ontario member and survivor, Lily, she remembered the group working on a case involving the death of a young girl at the hand of her father. Lily said, “Her dad was a

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224 Ferguson, 92-93.
225 Ibid., 93-94.
killer, put her in the truck. She was handicapped. She was happy. But he was gonna put her in an institution. He ended her life right there.”

*Formalizing the Rights of The Disabled - the Legal Responses*

In 1981, these provincial (and national) efforts to expand the rights of the intellectually impaired was given international attention, as the United Nations announced and celebrated the International Year for Disabled Persons. This was followed by the UN Decade of the Disabled Persons from 1983-1992, an extraordinary moment which, by its length alone, reflected the deep changes required to recognize their equality, in Canada as elsewhere. Indeed, as noted, it was in December of 1975 that the UN issued its Declaration on the Rights of Disabled Persons, a key document in detailing the rights of people with a disability — and one which clearly fell on many deaf ears.

This international recognition in the 1980s and 1990s, however, bolstered the continued quest for disability rights in Canada. In 1982, Ontario’s Human Rights Code saw the addition of the prohibition of discrimination for those with a disability. Under this Code every individual, irrespective of disability, had the right to “equal treatment” regarding housing, employment, services, facilities, and becoming a member in professional associations, unions or self-regulated occupations. The Code also banned “direct and indirect discrimination – including constructive discrimination where a requirement, qualification or other factor that is not designed to discriminate in fact restricts or excludes a protected group.” The Code, with its additions,

\[226\] Lily, 10.
exercised supremacy over all of Ontario’s legislation. In 1985, a provision was also added to
the Canadian Charter of Rights and Freedoms, “the equality guarantee,” or the right of every
person to have “equal protection and equal benefit of the law without discrimination.” The
provision ensured that this right also applied to people with an intellectual or physical
impairment. A year later, the Employment Equity Act in 1986 also included people with a
disability.

The promise of these legal advances was severely curtailed by a global recession in the
later part of the 1980’s and first part of the 1990’s, which seriously impacted financial supports
for people with a disability and the organizations that supported them. People saw their social
assistance funding dramatically reduced while disability related organizations lost any subsidies
previously received. Relationships between the disability community and government
representatives also took a hit as staff were relocated or their positions eradicated. What did
emerge from the ashes of the cutbacks, however, was the rise of interdisciplinary academic study
analyzing “the role of disability in society.” This critical analysis of how disability played out in
society looked to international studies on disability with a focus on people with lived experience
owning their history and stories. In 1987, the provincial government of Ontario committed to


229 Galer.

230 Ibid.
closing the institutions by 2012. However, due to mounting pressure and rumblings of potential lawsuits initiated by former inmates and their families, the government accelerated the process and the last institution was closed in 2009.

In Ontario, 2005 saw the unexpected and rather remarkable creation of the Accessibility for Ontarians with Disabilities Act (AODA). The AODA is a compliance and complaint-based model wherein government and organizations were mandated to submit compliance reports stating they were meeting predetermined standards for ensuring accessibility. Part of Ontario’s legal framework, the AODA aimed to guard the rights of people with a disability and promote their contribution as citizens in all parts of their society. The public was also invited to forward their complaints regarding issues of inaccessibility, all as part of a collective effort to produce a “barrier-free society in Ontario by 2025.” The Developmental Disabilities Act was replaced in 2008 with the Services and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act. McCauley and Matheson commented on the “rhetoric of social inclusion” as being “prolific in disability policy today but lacking a general agreement as to what the term really means. What was also problematic to this new Act, the authors pointed out, was that there was no definition in the Act as to what inclusion meant. Instead there was criteria that needed to be met such as “quality assurance measures” related to personal choice with the onus placed on service agencies to ensure that the individual was involved in various activities in the community, again according to their choice and “identified in their individual support plan.”

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They argued that this approach to community involvement meant that it was the community agency’s job to support the person with the intellectual impairment in fitting in to the community while exploring opportunities that were available to the person, “as opposed to proposing any kind of structural re-orientation to make the community more accepting and accessible to all people, with diverse abilities.” What was further problematic was the lack of clear enforcement regulations which meant the “developmental services sector” hadn’t had to “operate under the same rigorous standards as residential facilities for children and seniors.”

“Hope... look at me now:” Signals of Personhood

The limitations of this 2008 Act — its implicit demand that those with an intellectual impairment and their support networks take on full responsibility for ‘fitting in’ to a society which, for centuries, viewed them as an impossible fit — reflects a troubling historical consistency in the understanding of intellectual impairment as a whole. However, it is equally clear that through the activism of the impaired, their families, and burgeoning (if relatively repressed) intellectual and legal rhetoric around rights, abilities, and personhood, something was happening. By the 1980s, ostensibly responding to the economic downturn and shrinking of budgets, the provincial government had started moving people into group homes and smaller institutions. For some families, this shift not only brought their loved one physically closer to home, but also brought them into the family; ironically, it might be said that the loss of government assistance once determined to ‘fix’ families, now made it possible for some survivors to be reunited with their family members.

233 McCauley and Matheson, 5-6.
These family reunions were not always easy, but became a vital part of the broader recognition, even if only among family members, of the personhood of their once-estranged sibling. During my interview with Lisa, for example, she laughed as she spoke about the budget cuts which, ultimately, were the catalyst in bringing Rosa home. She said, “I’m not sure, but there was one weekend a month where they tried to get everybody out and home. And they basically called my mother and said, you’re taking Rosa home. Pick a weekend. And it forced mom to have Rosa home.” Lisa remembered going to her mother’s home during those visits because her mother, not really knowing Rosa, didn’t know what to expect and was uncomfortable being alone with her estranged daughter. Lisa said, “But it was a good thing ‘cause it forced mom to look more deeply into her relationship with Rosa. And it was then that she started taking her shopping for her clothes instead of taking clothes to her.” These small steps marked a significant change in mindset, as Rosa’s mother gradually got to know Rosa for the first time – and was able to accept that she had the ability and right to do something as simple as choosing her own clothing.

Wolfensberger attributed this kind of change in mindset among family members and organizations to the fact that Normalization and the ideas surrounding it were becoming more “widely known and accepted.” SRV was influencing the way practitioners taught about disability. In retrospect, people could make connections between ideologies from other movements, such as the Civil Rights movement, to the ideas presented in the teachings of Normalization and SRV, providing further validity that people with an intellectual impairment had rights too. The increased visibility of people with an impairment in the community, inspired

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234 Lisa, 24.
by this combination of budget cuts, legal pressure on institutions, and scandals about conditions therein, made it increasingly clearer that the implementation of these theories was not only possible, but could make things better for people with an impairment than the previous ways of doing things.\textsuperscript{235}

My interviews also revealed, in an unexpected way, fundamental proof of the damaging effects which the experience of large-scale congregate institutions had on people, and the ways that this slow and uneven process of de-institutionalization became part of the way that survivors’ lives improved. Elise, in speaking about her brother Simon, noted that his resolve and his ability to be happy, was strengthened after his release because each place he was moved to after the institution was better, and smaller, than the one before, resulting in a better quality of life. She explained that from Orillia, he went to live on a farm run by Bethesda, an organization that has supported people with an intellectual impairment since 1937.\textsuperscript{236} Elise described his move to Bethesda as “like getting out of jail even though there were 200 people and they were all living on the same property. It was better than 2500 people who didn’t do anything all day, right.” From there Simon was transferred to a smaller institution run by Community Living Welland Pelham where 16 or so people lived at the time.

Elise said each move was “like downsizing by 90% each time.” Simon’s last move was to a group living situation, a house owned and staffed by Community Living Welland Pelham which he shares with three other people. Elise, in describing his current living arrangement said,

\textsuperscript{235} Wolfensberger, “A contribution to the history of Normalization…,” 96.

\textsuperscript{236} For more on the history of Bethesda and their services see, https://bethesdaservices.com/pages/index/Home.
“He was among the first...he and two of them are still alive. Two have passed, four of them lived there together. So it’s been pretty stable as far as geography, not so stable as far as staff necessarily, but compared to other similar organizations, it’s been pretty good stability.”

Significantly, Elise said, “He didn’t regress in his moves. Each move was to a better place than the one before. And I think that gave him support.” Simon’s ability to adapt helped him to endure constant change and disruption to his environment until his release, wherein each move provided a brighter glimmer of hope that things were getting better. What is also powerfully evident is that each move was to a place that more closely resembled a typical home which is in and of itself a powerful contradiction to the notion that people with an intellectual impairment needed to be housed together in a special place for their own “good.

Indeed, many survivors I interviewed made it blatantly obvious, by their descriptions of their lives outside of institutions, by their sense of their own experience within their communities, that the arguments once made for the necessity of their segregation and confinement were, simply, wrong. Many became self-advocates and members of People First. Others went on to find work, get their driver’s license, own a car, purchase a home, and marry. In all cases, their lives have given proof of their personhood — the ability to know, to make decisions guided by their moral framework, and to seek happiness in ways that are not what early

237 Simon, 5-6.

238 Speaking about Simon in his home now, Elise said, “He likes order and he likes some predictability but he’s flexible. But, try and put the 3 coasters on the wrong table and you’ll get told and he’s the same with staff. Staff are always telling me if you put the book in the wrong place, he’ll tell you and not nasty but says no that’s not where that book goes, that goes there. And then everybody can find everything. Everything is in order. And if they need to find something or they need to know something they go to Simon.” Elise, 5.
advocates of congregate segregation would have believed possible (or, perhaps, even healthy for them or their families and communities). 239

This evidence of personhood was powerfully reflected in survivors’ understanding of work. Raised by her grandparents, for example, Elaine was sent to Huronia in 1955 at the age of 8 years old. It would be sixteen years before she would be released to live with an aunt in St. Catharines, and later to a boarding home, before having a home of her own that she now shares with her husband. Elaine noted that she worked and had a friend in the institution. 240 In fact, working would remain an important part of her determination to build a life for herself outside of the institution. Throughout most of the interview, Elaine spoke with great pride about her various work experiences. For her, as for many people, work was meaningful, served a purpose, and was a way for her to make some sort of sense out of her circumstances. When asked what she wanted people to know about her, she replied, “I am a person who likes doing work.” Following her release from the institution, Elaine worked with her aunt cleaning at a hotel in St. Catharines. After a couple of years of doing that, she worked at a restaurant in Welland, and later as a cleaner at a church: she also spent some time working at a sheltered workshop 241 in Welland. Elaine found purpose in the rational and autonomous structure of her work and there is nothing “different” in what she was experiencing from what other “typical” people experience who also

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239 Davies et al., speak to the shift in perspective and power dynamics some of the practitioners and nurses who were previously employed in institutions experienced as a result of transitioning to community-based positions. They write that working in the community offered some a greater understanding regarding the “nature of confinement” and provided an opportunity for them to see “ex-patients as people.” For more see Davies et al., “After the Asylum in Canada: Surviving Deinstitutionalisation and Revising History…,” 92.

240 Elaine, 12.

241 For more on sheltered workshops see Judith Fingard and John Rutherford, “Deinstitutionalization and Vocational Rehabilitation for Mental Health Consumers in Nova Scotia since the 1950s,” Histoire Sociale/Social History, 44 no. 2 (2011): 385-408.
find their work to be an important part of their life and identity. When asked what she wanted to be remembered for, she replied, “That I…let’s see…I like…all I did with my life was just try to get along and don’t fight.” Elaine’s ability to find a purpose in the midst of deprivation and confinement speaks to her own sense of dignity and rationality.

The survivors I interviewed also reflected on happiness in ways that fundamentally contradict late-19th and early 20th century ideas about the sort of perpetual and permanent “child-like happiness,” that was apparently natural for the intellectually impaired, used to justify and absolve wider society of any concern about housing these people in large scale institutions. When I asked Reg what makes him happy, he was quick to talk about his love of coffee, particularly visiting Tim Hortons and using his rewards card. At the time of our interview, Reg was also looking forward to going on vacation on a cruise ship and had already visited the library in search of books about ships. Reg also told me that he really loves train travel and has been on trips where he has taken the train. When asked if he wanted to change anything about his life, his initial response was no, but after a few minutes of conversation he piped up, “I want change…you know what. I wanna get a job.” When I asked what kind of job, he said he wanted to “work at the donut shop.” One of Reg’s support staff present during the interview, was clearly surprised upon hearing his response. She said it was the first time he had ever mentioned wanting to have a job. When she asked him if he wanted to pour the coffee he immediately responded “I wanna do the money.” Reg’s response is a great example of what

242 Elaine, 15, 1-3.
243 Reg, 12, 8, 9, 14.
Wolfensberger’s concept of Social Role Valorization, a tool that helps members of society see the potential in others who are perceived as different and thereby, acknowledge their personhood.

Selby, when posed the question of what he wants people to know about him, replied, “I’m easy goin’…I got a wife…I always buy my wife coffee from Tim Hortons. I like to treat my wife.” I turned to his wife who was sitting in on the interview and she nodded affirmatively. I pressed on, “When do you feel really happy?” He responded, “I smile every day.” “Every day? Every day is a good day? You smile every day?” I asked. Selby broke into a huge grin and we all laughed. We talked about what he loves most about his life right now and he listed off his home, new scooter, bedroom, music room and drums. Selby, an avid drummer and singer shared that he had recently quit playing the drums. When I probed further as to why the sudden retirement, Selby looked first toward his wife, then back at me, and replied that he was too loud. Selby went on to tell me about the night he was playing his drums really loud. Selby and his wife also share their home with a housemate who lives in the basement apartment below them. Selby said that as he was playing, “everything was shakin…and the light on top of the ceiling, it fell right down.” He continued,

“So I….Kevin was workin’ that night. And Kevin came into my music room and said, “Selby, you were playin’ the drums so hard and the light it fell down and it broke.” And I says to Kevin, I says, “Kevin, am I in trouble?” Kevin says, “Selby, nope. Accidents happen.” So, I quit playin’.”

After we finished laughing, I asked what he wanted people to remember about him. He simply stated, “I’m good. I’m not bad.”

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244 Selby, 1, 2, 3, 5, 10.
Les, also a music lover, is part of a local orchestra that performs in Niagara: “Gives me something to do,” he said. Anyone who knows Les also knows that he is a committed Blue Jays and Maple Leaf’s fan, so much so I was told that the color on his bedroom walls reflects his passion for these two teams. Les was also looking forward to a vacation on a cruise and told me about other cruises he had taken as well. He talked about his nieces and nephews whom he enjoys spending time with. Les is also a great-uncle and likes to hear about what his sister Lina’s grandkids are up to. When I asked him what he would like people to remember about him, Les engaged his sister for help in answering. Lina said that Les is a loving brother and uncle and although he can seem shy when he first meets someone, he is a very social guy. Likewise, Krista also has nephews and enjoys being an auntie— her face lit up when she talked about being greeted by her nephews as “auntie!” Some of the things she likes to do include shopping, spending time with her friends, seeing her brother and bowling: “I won two trophies,” she told me. While she likes her job, she especially likes being paid for the work that she does, which gives her some freedom to do what she wants to do.

Rene and Angie, reflecting similar beliefs, want people to respect their sister Vivian and understand “that she’s a human being and should be treated as an equal.” Tamara added, “And to be seen as a person like you said, not for her disability, but for her abilities.” When asked what they would like Vivian to be remembered for, Angie and Tamara responded that Vivian is a “very joyful person” and “loves people.” In describing what they feel Vivian’s purpose in life is, Angie said,

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245 Les, 2, 6, 10, 11, 16.

246 Krista, 5, 3, 4, 6.
“Well you know it’s like showing anybody that’s different they need to be accepted…she insists on it pretty much…She’s that kind of person. You know, she’s not hiding away in a corner so much. She’s coming to say, hey come on over here and interact with me. She’s very much like that.”

Rene interjected, “Even if you don’t want to.”247 This is Vivian’s horizon, on which she stands and invites others to get to know her for who she is. Similarly, when I asked Elise what she wanted Simon to be remembered for she said,

“I just want them to know he was a good person. He had a lot to contribute. He was strong in the face of adversity. He lifted me up when I was down many times. He’s such a deeply caring person and yet he’s overcome a lot of rejection and…and he forgives me. Sometimes I get cranky, eh Simon? Sometimes I get cranky and he forgives me…”248

Both Vivian and Simon in spite of their suffering and losses, continue to shine in the fullness of who they are as demonstrated by their zest for life and love for people.

Lisa and Dana admitted that they really still don’t know Rosa very well, making it difficult to answer questions relating to ‘who’ they think Rosa is. However, one thing that is helping the sisters reconnect with each other are Rosa’s tea parties. Lisa explained, “She has tea parties once a month. And it’s for the people that she wants to have, and she invites them to her tea party. And it gives her that level of control.” It is through the tea parties that the sisters gain a fuller picture of who Rosa is by meeting the people in Rosa’s life who are important to her. Each of Rosa’s guests know her in their own way and it is through these relationships that the

247 Angie, Tamara, Rene, 1, 13, 15.
248 Elise, 4-5.
sisters are getting to know Rosa. In discussing their thoughts on Rosa’s purpose in life, the sisters talked about how she has taught them about compassion and patience. Dana also said that Rosa helped her mom get in touch with her own emotions. She said, “Rosa was here to teach mom about her own emotions, as well as the rest of us.”

These interviews also demonstrated, as Taylor’s work underlines, the need to rethink how we understand communication. Speech has become the defining baseline of what communication is, and the inability to communicate in this fashion has, historically, been a marker of problematic – and even dangerous – difference. It has provided a clear justification for institutionalizing the non-speaking individual and making assumptions about their capacity and identity. Removing the assumption that only speech can be used to communicate, however, forces not only a recognition of the personhood of the non-verbal individual but, as Taylor would argue, it also brings us a clearer sense of our self: we become ourselves among others. My interviews presented not only clear evidence that non-verbal communicators were not as nineteenth century ‘experts’ declared them to be - lacking understanding, unassuming, and uncomplicated, incapable of feeling worry or distress, or other ‘normal’ human emotions in the way that ‘we’ do – but also underlined the cooperative nature of communication itself. Often, it was their family members and supporters, the people with whom the individual has a reciprocal relationship with, who understood and knew what they were trying to communicate. Dana and Lisa during their interview, as previously mentioned, talked about Rosa’s tendency to scream when something was bothering her or when things were not going the way she wanted them to. In thinking through Rosa’s responses, Lisa concluded that Rosa’s screams are one of the

249 Lisa and Dana, 21, 16, 25
outcomes of living in the institution based on the reality that she had to “stick up” for herself because “nobody else [was] gonna do it.” Dana interjected at that point and said, “That would be her soul speaking. Saying, this is what’s best for me,”250 or in Taylor’s words, it was her way of demonstrating that “the soul is better known to itself than the body.”251 Rosa, fully aware of her existence, having experienced her thoughts, experiences and activities according to her own self and according to her own ways of knowing demonstrates her agency by screaming – forcefully declaring ‘this is what is best for me.’

All of my interviewees, in different ways, expressed agency in integrating their experience of institutional life into their self-identity, as Rosa has done. Many of them also reflected frankly on the long-term effects of their confinement and revealed a determination and strength which is both familiar to many ‘normal’ people, and contradictory to any argument made that they lack personhood. I think about Simon, with his sky-blue eyes and infectious smile who, when asked if he ever felt like giving up, shook his head, “no.” I pressed further and asked him why he didn’t give up. His sister Elise looked at Simon and said, “you found people that you liked,” to which Simon immediately looked at his sister’s companion, Rick, who was also sitting in on the interview. Rick responded, “You’re making me feel good Simon.” When Elise asked if Simon had boys and girls that were friends in the institution, he nodded, “yes,” but when asked if he considered any of the staff friends, he immediately shook his head, “no.” It was easy to see that Simon is a “people person,” an attribute that helped him survive and one that Elise continues to marvel at today. She said, “…it didn’t go away...like you’d think that would

250 Lisa, 3-4.
251 Taylor, 141.
have been beaten out of him…at some point where you just give up and say you know, ‘to hell with this’.” In thinking back, she credits her mom and dad as being “that kind of person too. They both were outgoing …made friends and held friends close.”252 It was very apparent in watching Simon and Elise interact, that they hold their family history and each other very close to their heart. They are two people who know each other very well which was evident in their comfort in being with each other and in their understanding of one another. What was also apparent was that Simon and Elise were expressing personalities and characteristics similar to their parents and here too, we see that Simon is no exception to that. The fact is that there is nothing “different” about how Simon finds fulfillment in human relationships with friends and family.

I also asked Lily during our interview, “Why didn’t you give up?” to which she quickly responded, “I know someday I have a dream be free.” Lily was placed in Oxford Regional Centre at the age of 17 years old, after having been removed from her home as a child and placed in foster care. Separated from her two other brothers, who were in different foster homes, Lily said, “When I turned...13 foster care was mean. And there were people telling me, men, at that point, it was all men and they were being mean….It shouldn’t happen but it still does.” In the three years that Lily spent at Oxford no one came to visit and she didn’t make friends for fear of suffering physical abuse from the staff. In spite of her traumatic childhood and adolescence, Lily didn’t give up on her dream of being free. She knew she would be free someday, even if it involved years of struggle and took a long time to happen. When I asked Lily what her purpose is

252 Elise, 4-5.
in life was, she said it is to help others.\textsuperscript{253} She maintained this core of her identity in spite of the horrible things that happened to her (and others) while she was institutionalized. Lily’s dream and pursuit of freedom, even while experiencing great pain and overcoming many difficulties, is what Tabensky refers to as harmonizing. He states that the “task of harmonizing is typically a task of adapting to new, unpredictable, and at times disruptive circumstances.”\textsuperscript{254} For Lily, this ability to adapt was guided by her knowledge of what was right and wrong, and her knowledge of what was important to her – to be free. Having been a long standing member of People First, she has taken a stand on many issues over the years that were important to her and in doing so, she has actively been living out her purpose in life to help others.

When I asked Lily how her life is now, she responded, “Better than it was.” She explained, “More support I ever had. People care when something goes wrong and what else… trying to think…There’s always somebody to help you through rough and bad times.” I asked her if there was anything she wanted to change about her life right now to which she responded, “Nope.” Finding that hard to believe, I pressed on. “Is there anything you wish to do or any goals or dreams that you have that you would like to do or see happen?” I asked. She replied, “One dream to help others which I’m doin’ now. That was one of the dreams come true…I don’t really have another one.” Lily described being put into an institution as being “stuck,” a stark comparison to the life and freedom she enjoys now. In thinking about a time when she was really happy, she said, “When I turned 65 I had a big birthday. That was a happy memory.”

\textsuperscript{253} Lily, 5, 9.

\textsuperscript{254} Tabensky, 32.
Nearing the end of our conversation, we talked about how she never let go of her dream of being free to which Lily responded, “Hope…look at me now.”

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255 Lily, 4, 5, 10, 3.
Conclusions

On March 11, 2010, Canada ratified the 2006 UN Convention on the Rights of Persons with Disabilities, as a promise to better the economic and social circumstance of people living with a disability while enhancing their political and legal rights. The Convention, activated by the UN in May of 2008, set a record for the highest number of signatories in the history of a UN Convention in its opening day, and has been described as the first “comprehensive human rights treaty of the 21st century.” Disability Rights Attorney Megan Rusciano described the document as a “dignity approach to human rights” that “compels societies to acknowledge persons with disabilities as valuable because of their inherent human worth.” Also of importance to Rusciano was that the convention acknowledged society’s role in creating “social barriers that prevent people with disabilities from fully recognizing their civil, political, economic and social rights, and it obliges state parties to remove these barriers.”

Charles Taylor wrote that to defend “human rights is to connect respect for human life and integrity with the notion of autonomy. It is to conceive people as active cooperators in establishing and ensuring the respect which is due them.” Unfortunately, as this thesis has demonstrated, legislation cannot change deeply-rooted ideas which, for over a century, were proclaimed as true by medical experts, psychologists, educators, and policy makers, and which

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denied the human rights of people with intellectual disabilities. Laws cannot enforce respect for a human life. This reality continues to reveal itself in horrific ways. In 2012, Guy Mitchell, having been sent out to get water, drowned in the cistern at the home into which he had been placed. A police investigation revealed that the home was in utter disarray and squalor “with no heat, no functional plumbing, feces strewn everywhere and no food in the fridge; a place not fit for human habitation.” Yet, Guy’s caseworker, having visited that same residence two days prior to his drowning, “found nothing amiss.” Guy was not the only one placed at the rural dwelling either, as another “adult male and a female child, both with developmental disabilities” lived there too. As a result of the inquest, in 2015—almost a decade after Canada’s ratification of the UN Convention—the Ministry of Community and Social Services in Ontario finally indicated that they would introduce new measures to take effect in 2016 that would “increase the safety and security of adults with developmental disabilities who choose to live with a host family.”

Let me be clear: no one “chooses” to live in the type of conditions described at the ‘home’ Guy was placed at. Helen Graham in her article, “How the tea is made,” refers to the work of professor and long-time disability advocate Michael Smull who unpacks what choice really means by looking at “three aspects”: “preferences’, ‘opportunities’, and ‘control.’” Quite simply, ‘preferences’ refer to what people really want, “while opportunities reflect what is available”: control is essential in order to exercise the personal authority the individual needs in order to “make use of an opportunity to satisfy a ‘preference.’” In Foucauldian terms, Graham

259 McCauley and Matheson, 7.

states that an individual’s expression of legitimate control is dependent upon “the extent of their freedom, the range of opportunities from which they are choosing and the breadth of their sense of what is possible.”

Given that Guy’s caseworker knew of the deplorable conditions Guy was living in and didn’t seem to have a problem with it, it is highly unlikely that Guy was offered a real “choice” in determining where he wanted to live.

Consider also, Doug Ford’s comment in 2014, prior to becoming Ontario’s premier, regarding a group home for autistic teens that was ‘ruining’ an affluent Toronto neighbourhood. As if copied directly from the pages of history, Ford blamed the Liberal government for creating the problem by closing down the Thistletown Regional Centre, which he described as a “beautiful centre, had 43 acres that allowed families to have their children with challenges there. Since she has closed down they have dispersed these folks throughout the west end.” Premier Kathleen Wynne responded that “[t]he services and programs that Thistletown provided were transferred to the community and the closure is in line with government efforts to ‘build a more co-ordinated mental health system.’” What seemed to be particularly upsetting to Ford was that the youth—particularly the “violent ones”— were leaving the residence unaccompanied, which Ford implied had something to do with an increase in the number of vehicles being broken into. Ford described the impact that the presence of the group home (and its residents) was having on the neighbourhood as a “nightmare.” In challenging Ford’s comment, mayoral opponent John Tory categorized Ford’s comments as “‘deeply regrettable and from another age.’” Sadly though,

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261 Graham, 137.
Ford’s comments are evidence of an ongoing “age,” as MacCauley and Matheson pointed out, then and now: when it comes to the stigma surrounding individuals with an intellectual impairment, even the most “comprehensive human rights legislation, from the Charter of Rights and Freedoms, to provincial Human Rights Codes,” cannot seem to curtail discrimination and abuse.

Indeed, although 2009 marked the official (and extraordinarily late) closure of Ontario’s institutions, communities continue to grapple with making space for people with an intellectual disability to belong, live, work and build relationships. Many families, overwhelmed with the daily demands of caregiving, struggle to imagine, much less take pragmatic steps, toward creating rich, vibrant, and sustainable lives alongside their sons or daughters outside the confines of service. It is equally clear that the Canadian Government (to say nothing of the province) struggles to conceive of a country wherein people of differing abilities work and live together. As Jen Rinaldi and Ray Dolmage argue, “opportunistic eugenic uses of the concept or label of disability have always operated as a key or central theme within Canada’s colonial history” and, as such, have continued to shape Canada’s immigration policy until quite recently. They give as evidence the Hilewitz and De Jong families’ cases against the Government of Canada in 2005, for the government’s attempt to deny them permanent residence because their intellectually impaired children “could require social assistance in the future.” Although the government’s decision was overturned by the Supreme Court of Canada, the authors state that the cases affirm


263 MacCauley and Matheson, 7, 6.
that Canada’s immigration policy “has consistently labelled people with disabilities as non-desirable.” The authors also reference Harper’s nod to ‘old stock Canadians’ as the basis for his government’s rejection of offering health care to Syrian refugees.264

Deinstitutionalization across Canada continues to be a slow process in some of its provinces, as noted in a 2017 report from the Canadian Centre for Policy Alternatives, which made it clear that institutionalization continues to be a community response to the realities of intellectual impairment, despite an apparent agreement that institutions are harmful. Its readers would be “shocked to learn,” they wrote, “that Canada still operates large institutions for people with intellectual disabilities.” The report stated that approximately “900 people are languishing in large institutions (100 beds or more) in Manitoba, Saskatchewan and Alberta. And according to a civil society parallel report submitted to the United Nations in 2017 by a group of Canadian disability organizations, these institutions continue to receive new admissions.”265 In October, 2018 Toronto Law Firm Koskie-Minsky, on behalf of lead plaintiff David Weremy, announced a $50 million class action suit against the Province of Manitoba for its role in administering the Manitoba Development Centre in Portage La Prairie because of allegations of widespread abuse


265 Natalie Spagnuolo and Kory Earle, “Freeing our people: Updates from the long road to deinstitutionalization,” Canadian Centre for Policy Alternatives, July 4, 2017, https://www.policyalternatives.ca/publications/monitor/freeing-our-people-updates-long-road-deinstitutionalization. Davies [77-78], refers to a 2004 study by “Canadian psychiatrists Patricia Sealy and Paul Whitehead” that in assessing the impact of deinstitutionalization starting in the 1960s, found that “the process of reorganising the system also introduced new features of transinstitutionalization,” meaning that people ended up — and continue to end up, in other types of ‘institutions’ like nursing homes, prisons, mental health facilities and shelters. See Davies, et al., “After the Asylum in Canada: Surviving Deinstitutionalisation and Revising History…”. Spagnulo and Earle also speak to transinstitutionalization in their article stating that in 2017, 30,000 people with an intellectual impairment were living in “congregate care facilities and group homes, while 10,000 adults under the age of 65 were living in “hospitals, nursing homes and similarly unsuitable long term care environments” due to a shortage of appropriate supportive housing options.
against the inmates. Opened in 1890 as the “Home for Incurables” the Government of Manitoba responded to the allegations in February for 2019 stating that, “Manitoba's operations of MDC has at all times been reasonable and appropriate,”— the centre remains open today.

Similarly, the Michener Centre in Red Deer Alberta, although scheduled to close in 2015 (Premier Jim Prentice reversed this decision in 2014), continues to operate for the 120 adults with an intellectual impairment living there. Prentice decided to keep the centre open so that “all of the residents were permitted “‘to live out their remaining years in this special place.’”

In Ontario, response to the challenges of community integration has been a troubling call for a return to congregate solutions. In 2017, the Toronto Star outlined a proposal from Mark Enchin’s, founder of Angel Oak Communities, to purchase Ignatius Jesuit Centre in Guelph, Ontario, to create a “self-sufficient community” for those with intellectual disabilities. Enchin, father to a daughter with Autism, believes this is the best alternative to ensure his daughter has the care and support needed should he no longer be able to provide for her. Enchin stated that the “community” would feature day programming for adults with a disability along with an onsite bakery and a greenhouse where the residents could “work” to generate income and learn

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266 Koskie- Minsky, “Manitoba Development Centre Class Action,” https://kmlaw.ca/cases/manitoba-development-centre-class-action/


268 Elissa Carpenter, “Families of Michener Centre Residents say dental service closure puts them in a tough spot,” CBC News, July 15, 2020, https://www.cbc.ca/news/canada/calgary/michener-centre-developmental-disabilities-dental-care-alberta-province-1.5650900. In 2007, Members of People First and the Deinstitutionalization Task Force toured the prairie provinces interviewing survivors of Valleyview (SK), the Michener Centre (AB) and Manitoba Development Centre. In contrast to Prentice’s description of Michener as a “special place,” one woman interviewed during the tour said that upon her visit to the Michener Centre (the first institution she had ever visited), she was so disturbed by what she saw inside that she went outside and vomited. She said, “What kind of humanity are we that we would force people to live under those conditions?” (42:23-28). David Weremy, lead plaintiff in the 2018 suit against the Government of Manitoba, is featured in this video advocating for the closure of the Manitoba Development Centre. For more, see People First of Canada, The Freedom Tour, YouTube video, 53:02, 2008, https://www.youtube.com/watch?time_continue=3141&v=0tKw7vGo3ro&feature=emb_logo.
new skills. Enchin’s dream for his daughter is right out of the pages of the history books and reminiscent of the photographs and paintings of grand, nineteenth-century buildings situated on acres of land in the lush countryside. While advocates of the Centre would decry this comparison and argue that Angel Oak Community would be well-run, free of abuses, adequately funded, and provide a holistic and happy environment for its residents, I would say only that the same arguments were made by well-intentioned people in the nineteenth century. As Helen MacMurchy wrote in 1919, “we must make an institution with a home spirit and environment” so that the “Poor fellow” who cannot manage himself, might be managed. The outcome of segregating vulnerable people in buildings of bricks and mortar, outside of the rest of their community, is clear: almost without exception (whether one is looking at the history of intellectual disability, physical impairment, residential schools, or homes for neglected and poor children) it ends in abuse. Indeed, in the vast majority of cases in Canada, the reality of abuse begins with the act of confinement itself: confinement of people with an intellectual impairment is an affirmation of inequality. Gord Ferguson, put it this way: “…when you put that many people together that the rest of the world does not value, you know that bad things will happen.” The moment society justifies inequality, the acknowledgment of the individual’s personhood quickly begins to unravel.

270 MacMurchy, 211.
272 Ferguson, 89.
Today, there are other concerns, beyond continued institutionalization, which attend this disregard of personhood. These concerns are profoundly connected to the belief, characteristic of policy in Ontario since the nineteenth century, that others have the right and obligation to make decisions for the intellectually impaired. Policy makers rarely consult those whose lives are directly impacted by their decisions, and as a result, policies lack the necessary context and understanding to be anything more than oppressive and restrictive for those who are governed by them. As I write this thesis, the world is in the grip of a global pandemic and, once again, the lack of consultation and involvement in the political realm of people with an intellectual disability is evident. Discussion and decisions about prioritizing health care and treatment for people with an intellectual impairment is shedding further light on how we value life in our province and country. A CBC opinion piece on April 19, 2020 by Roxanne Mykitiuk, professor at Osgoode Hall Law School and Director of the Disability Law Intensive Program at York University and her colleague, Trudo Lemmens, professor at the Faculty of Law and the Dalla Lana School of Public Health at the University of Toronto, called for governments to affirm their commitment to ensure that the human and ethical rights for individuals with a disability are upheld. The professors stated that many elderly and people with a disability fear that they will be left behind should they fall ill with COVID-19. Mykitiuk and Lemmens emphasized that in some cases individuals might require accommodation in order to provide consent or understand information presented to them and that duty to accommodate goes part and parcel with “key ethical human rights obligations” that must be “affirmed in clinical triage policies.” The authors stated:
“People with disabilities must not be sacrificed based on faulty presumptions and stereotypes about living with disability. On the contrary, a duty to accommodate may require providing them with some level of extra care to ensure that they receive a fair chance of survival in critical care.”

Furthermore, they argued that any type of disability not related to survival cannot be used as grounds for prioritizing treatment under COVID-19 guidelines.273

And, as I write this paper, there is also growing controversy, concern and opposition surrounding Canada’s Bill C-7, which, if passed, would enable people wanting to die to receive medical assistance to do so, even if they are not yet deemed to be at the “end of life.” The worry for people with an intellectual impairment and their supporters, is that policies like this can make it easier for decisions to be made that could in turn lead to the death of people with a disability just because they have a disability. There is also fear that Bill C-7 will reinforce existing stereotypes and stigma in our society which suggest that it is better for people with a disability to be dead than to have to live with a disability.274 The fear surrounding the possible implications of Bill C-7 is not unfounded. In the 1990’s, renowned bioethicist Peter Singer’s views on euthanasia, abortion and pre-natal diagnosis were well known around the world. Singer argued that it was morally acceptable to determine that some lives were “less worth living,” and that


some lives were “not worth living at all.” In an 1999 interview with *The Guardian*, Kevin Toolis coined Singer as a “preference” utilitarian, who believed that “actions are not judged on their simple pain-and-pleasure outcome, but on how they affect the interests, the preferences, of anyone involved.” For Singer, this consideration of interests is rooted in the capacity of the species’ ability to suffer. This means that when a life has been deemed not worthy to live, such as in the case of an infant who has a disability, the course of action morally compels those with the power to do so, to end the infant’s suffering as “quickly as possible.”

Singer justified his stance by the fact that many doctors recommended the termination of a pregnancy in cases where the fetus is severely malformed or there has been a pre-natal diagnosis of Down’s Syndrome or spina-bifida. Singer argued that “Ninety per cent of women over 35 have pre-natal testing, and of those who are told their fetuses have Down’s Syndrome or spina bifida, 95 per cent will terminate the pregnancy.” Singer concluded that the decision to terminate the pregnancy confirmed his belief that “there is a widely shared view that it’s better not to have a child with those conditions.” He stated,

“It may still be objected that to replace either a fetus or a new-born infant is wrong because it suggests to disabled people living today their lives are less worth living than

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275 Peter Sundström, “Peter Singer and ‘Lives Not Worth Living’--Comments on a Flawed Argument from Analogy,” *Journal of Medical Ethics* 21, no. 1 (February 1, 1995): 35.

276 Kevin Toolis. “The Most Dangerous Man in the World,” *The Guardian*, November 6, 1999, 3. On utilitarianism, Toolis defined it as “the best moral good” that produces “the happiness of the greatest number,” wherein actions are “judged” according to the end result. The guiding question to determining the “best moral good,” centres on whether the action “reduce(s) suffering and/or increase(s) happiness.” Toolis noted that the second aspect of utilitarianism is that there has to be “equality of interest” so the pleasure of one party involved cannot take precedence over the suffering of another party.
the lives of people who are not disabled. Yet it is surely flying in the face of reality to deny that, on average, this is so.”

Toolis, in reflecting on Singer’s arguments, posed this question to his readers: “Is Singer just stating out loud what we all think but are too afraid to speak? Toolis referenced that in the 1980’s and 90’s in Britain, for example, it was common practice for heart surgeons to deny children with Down’s Syndrome life-saving operations. Toolis’s example further illustrates the type of decision making that continues to persist today, decision making that is done without consultation with individuals living with a disability and their supporters. In fact, what Toolis is implying is that normal people are the ones who can and should define what suffering, joy, and experience, must be.

Activist and author Jenny Morris situates these issues — around choice and the assessment of joy and suffering — into a framework which explicitly critiques our assumptions about identity, dignity, and human rights. In her book Pride Against Prejudice: A Personal Politics of Disability, she questions why suicide by non-disabled people is considered to be “disturb(ing),” yet for disabled people it is thought to be a matter of human rights or “rational behaviour?” She questions, particularly, the idea that “normal” judges and doctors can make

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277 Toolis, 6. Taylor [78-80] addresses utilitarianism as a moral philosophy that attempts to answer the question, “What should I do?” by providing “basic reasons.” Taylor explains its three-pronged response like this: “Well, work out what would produce the greatest happiness for the greatest number.” Or, “work out what I could choose when I have treated other people’s prescriptions as if they were my own.” Or, “think what norm would be agreed by all the people affected, if they could deliberate together in ideal conditions of unconstrained communication.” In rejecting qualitative distinctions Taylor writes, “[t]here is just desire, and the only standard which remains is the maximization of its fulfillment.” Taylor describes this rejection of moral distinctions as “curious blindness” and argues that it is because of “that curious blindness to the assumptions behind their own moral attitudes, utilitarians and modern naturalists in general, can just focus on the negations for the older distinctions and see themselves as freeing themselves altogether from distinction as such.” Therefore, it is relatively easy for Singer to promote his assumptions about what makes a life worth living because he only has to take into account his own point of view. See Taylor, Sources of the Self.

278 Toolis, 7.
decisions for supporting euthanasia for disabled adults, and the too-commonplace assumption that having a disability automatically makes life not worth living. Importantly, as the knowledge elite and civil rights activists of the immediate post-War years frequently did, she examines the correlations between this type of thinking with the Nazi’s program of extermination aimed at people they determined to be undesirable, which included people who had a genetic illness or an intellectual impairment. Morris also speaks to the liberty that “normal” people take in making decisions over the lives of those seen as different and writes, “Non-disabled people feel that our differentness gives them the right to invade our privacy and make judgements about our lives” and that somehow, “[o]ur physical difference makes our bodies public property.” As she poignantly argues, “Our ideas about disability and about ourselves are generally formed by those who are not disabled.”

The interviews conducted for this thesis have demonstrated both the fallacy and danger in these kinds of assumptions and ideas about those with an impairment. They not only undermine the political, medical and cultural notions about the limited capacities for pleasure, choice and identity which have guided policy in the province, but also demonstrate that disregarding those notions and seeking full inclusion and participation of all of a community’s different members, enriches our own lives, as much as it does the lives of those with an intellectual impairment. In drawing on the work of Taylor, Tabensky and Wolfensberger, I would argue that at the centre of

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279 Jenny Morris, *Pride Against Prejudice: A Personal Politics of Disability* (Philadelphia, PA: New Society Publishers, 1991), 15-37. More recently, Nancy Hanson Professor and Director of Disability Studies at the University of Manitoba in response to the 2015 Supreme Court of Canada overruling in favour of assisted suicide, echoed similar sentiments to that of Morris. She writes, “Often, disabled people are faced with the reality of having to make the case for being here. We are often perceived as taking up space that naturally belongs to the non-disabled. Our space is usually not of our choosing: marginal, tentative and subject to removal.” See Nancy Hanson, “Better dead than disabled, I don’t think so,” *University of Manitoba Today News*, February 13, 2015, [https://news.umanitoba.ca/better-dead-than-disabled-i-dont-think-so/](https://news.umanitoba.ca/better-dead-than-disabled-i-dont-think-so/).
what makes us human is the soul. One does not have to subscribe to a belief in a higher power to recognize that there is an essence or an energy that exists within all people and that we, as people, are aware of our existence and have access to our inner self in ways that are specific to each one of us. It is in that personal place of knowing that we start to sort out life according to what is important to us, and within the context of what we perceive to be good or bad. It is in the sorting out of our thoughts and feelings that we build our intelligence and demonstrate our will.

However, like Taylor I also see how part of the key to knowing who we are comes from our relationships with others. I think of Elise and Simon who hold their history and each other close in their hearts. I also think of Lisa and Dana who admit that they still don’t really know Rosa because of their limited interactions with her. True reciprocal relationships are key to knowing and being known. It is through those relationships that we can see people for who they really are. I agree with Wolfensberger that one way for society to see people with an impairment as fully human is through socially valued roles. Those roles serve only as a point of entry for interactions that hopefully over time will grow as we daily accept the invitation to get to know each other better. The roles are simply a pathway that points to personhood in action. It is also through relationships that we see that a universal desire for happiness is paramount to the human

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280 Elise and Simon’s bond reminded me of the heartbreaking stories of two mothers, Florence Repouille and Anna Greenfield’s and their relationships with their sons, Raymond and Jerome. Raymond and Jerome, both with an intellectual impairment, made newspaper headlines in the United States when they were murdered by their fathers (against the wishes and knowledge of their mothers) in the 1930’s. The murders were described as ‘mercy killings’ and the public were generally sympathetic toward the fathers because they felt that the men had little choice: the fathers could either continue to bear the ‘burden’ of caring for the boys, institutionalize them or euthanize them. The press constantly referred to Florence’s son, Raymond, as “virtually dead” and “so physically disabled that he did not qualify as a living person.” Florence, however, offered a different perspective—one in which she saw her son as fully human and severely disabled. During her husband’s trial Florence stressed “the ways in which Raymond interacted with her and his environment.” She knew the foods he liked to eat and the games he liked to play and even though Raymond could not see her, Florence knew he recognized her presence. She knew he loved her and would not survive in an institution: “For Florence, Raymond was a complete and beloved person in a way that accepted his disabilities.” For more see, Janice Brockley, “Martyred Mothers and Merciful Fathers: Exploring Disability and Motherhood in the Lives of Jerome Greenfield and Raymond Repouille,” in The New Disability History: American Perspectives, eds. Paul Longmore and Lauri Umansky (New York: New York University Press, 2001): 295, 301, 302, 304.
experience. However, Tabensky requires us to reach higher and contribute to an ethical and just form of happiness that requires the participation of a community that values and welcomes difference. Containment, control, segregation and confinement deny people’s human right to live in the abundance of who they are as people. When those who are ‘normal’ allow this to happen in thought or in action, in essence, they are not living in the fullness of their own potential by denying themselves the opportunity to lead ethical, just, and sustaining lives. This concept of what it means to be a person requires a change in mind that demands a total dismantling of ‘difference’ for only then can we fully recognize and realize the potential that exists in all of us.
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Appendix: Oral Interviews, Methods and Practice

Theoretical Influences

As noted in my introduction, Charles Taylor and Pedro Alexis Tabensky’s work on personhood was foundational to the research conducted for this paper. Tabensky, for example, insists that the quest for happiness is intrinsic to each one of us and is an integral component of what it means to be a person:281 this idea inspired many of the questions which I asked the survivors of Ontario’s institutions. Understanding what they experienced, how it shaped their lives both in and out of the facilities, fundamentally demands acknowledging that “they,” like “us” possess this desire for happiness. My decision to include family members in the interview process was also largely influenced by Taylor’s insistence that narratives must encompass the individual’s “whole life,”282 wherein the reality of being known by others becomes integral in protecting one’s humanness. Taylor’s use of moral frameworks resonated with my belief that all human beings have a moral framework that gives meaning and shape to their lives. Hearing the stories of survivors and their families reaffirmed my conviction that we all use narrative to make sense out of our lives, irrespective of any type of impairment. It is the narrative within our evolving story that provides us with meaning to our past and leads us into our future.283

281 Tabensky, 10. Tabensky, [10] argues “that happiness is the goal of life—it is the goal that defines us as persons,” and that “individual happiness cannot be separated from the overall happiness of the community which individuals dwell.”

282 Taylor, 50.

**Interview Recruitment and Process**

The recruitment of participants for this research was initiated by Barb Vyrostko, Executive Director of Community Living Welland Pelham. Those who were willing to be interviewed, survivors and family members, were each provided with consent forms in plain language summarizing the purpose of this research. Those who agreed to participate signed consent forms and were informed verbally and in writing that they were free to end their participation at any time. Interviews were audio recorded and written transcripts were provided after the interview for participants to review. When needed, family members and supporters read the transcripts to survivors to ensure that they were comfortable with their narrative being used in the writing of this paper and that they were comfortable with the way in which their thoughts and experiences were recorded. The original wording of the participants was kept intact as much as possible, even if there were grammatical errors, so that I could ensure their own voice was heard. Interviewees were also assigned a pseudonym to respect their privacy. Interviews focused on specific questions for survivors and family members which, as listed below, were intended to give voice to their experiences and unpack the ways in which those experiences challenge (as much as they are challenged by) modern conceptions of personhood.

**Questions for Survivors**

a) What would you like people to know about you?

b) Can you tell me about a time when you felt really happy?

c) What do you love the most about your life right now?

d) Is there anything you would like to change about your life?
e) Why do you think people were put into institutions?

f) When you think about the time you spent in the institution did you ever feel like giving
up? Why didn’t you give up?

g) What do you think people should know about institutions?

h) What would you like people to remember about you?

Questions for Family Members

a) What is your relationship to the family member that was institutionalized?

b) What would you like people to know about your loved one?

c) Why did your family feel that institutionalization was the best decision for your loved
one at that time?

d) What was the reaction among family members, friends and/or neighbours regarding the
decision to send your loved one to an institution?

e) Looking back, how did that decision impact the family?

f) What would you like people to remember about your loved one?

g) Knowing your loved one as you do, what would you say is his/her purpose in life?

Interviewees’ Background Information

(As noted above, the names of all interviewees have been changed to protect their privacy; those
whose recollections have been published as memoirs are referred to by their real names)

- Elaine (Survivor)- Sent to Huronia Regional Centre, 1955, 8 years old. Released in 1971.
- Reg (Survivor)- Sent to Huronia Regional Centre, 1959, 6 years old. Transferred to Oxford

• Selby (Survivor)- Sent to Huronia Regional Centre, 1959, 9 years old. Transferred to Oxford Regional Centre, 1972. Released in 1975.


• Simon (Survivor)- Sent to Huronia Regional Centre, 1957, 9 years old.

• Burt (Family Member) – brother to Lily

• Angie, Tamara, Rene (Family Members)- sisters to Vivian

• Lisa, Dana (Family Members)- sisters to Rosa

• Elise (Family Member) – sister to Simon

• Coco (Family Member)- sister to Billie

• Lina (Family Member)- sister to Les

• Amy (Family Member)- sister to Hana

Survivors Not Interviewed

I was unable to interview two of the survivors listed below due to their passing before the completion of this research. In two other cases, I only had access to interview their siblings. Some of these survivors’ life experiences were shared during the interview with their siblings and as such, they are recognized among the survivors mentioned in this paper.


• Hana- Sent to Southwestern Regional Centre, 11 years old. Released in 1970s. (Deceased)
• Billie- Sent to Southwestern Regional Centre, 1963, 9 years old. Released in 1977.

(Deceased)