

“Society seems like it doesn’t even know...”:  
Archival records regarding people labelled with intellectual disability  
who have been institutionalized in Manitoba

by

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Society seems like it doesn't even know the wrong they are doing with institutions. I don't believe it. I think they know.

— Scott Klassen, *Institution Watch*.

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## **Abstract**

This thesis examines issues surrounding access to records relating to people labelled with intellectual disability who have been institutionalized in Manitoba. It argues that the devaluation of people labelled with intellectual disabilities, together with the failures and difficulties in acquiring, preserving, describing and accessing records that describe the historical experiences of people labelled with intellectual disability who have been institutionalized, allows society to continue to seem like it does not know “the wrong they are doing with institutions.” In conclusion, this thesis advocates for means by which the experiences of people who have been institutionalized could be created, archived and more broadly available to the public.

## Acknowledgments

The views, opinions and conclusions of this thesis are only my own and no official endorsement by Manitoba Health, Seniors and Active Living, Manitoba Families, Manitoba Infrastructure, the Manitoba Civil Service Commission or other data providers is intended or should be inferred.

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And last, but never least, my heartfelt gratitude to my husband Sandy and my son Hayden for their unwavering support and love. One does not simply walk into Mordor – or a graduate degree – without companions such as these.

## **Dedication**

This thesis is dedicated to the participants of The Freedom Tour.



## **Introduction: “How can anyone say the institution is good?”**

Scott Klassen lived for twenty-one years in a Winnipeg institution. Since leaving the institution twenty-five years ago, Klassen lives and works in the city. He is a disability advocate who sits on boards and speaks at local, national and international events on the right to live in the community. Comparing his life inside the institution to the life he leads outside in the community, he asks “How can anyone say the institution is good?”<sup>1</sup>

In 1995, during the publicity surrounding Leilani Muir’s legal action against the Alberta government for her forced sterilization and institutionalization, the Canadian public began learning about the eugenic practices of our not-so-distant past.<sup>2</sup> The court awarded Muir almost \$1 million in damages, including \$250,000 specifically for the “damages connected with the detention” of Muir in Alberta’s Provincial Training School for Mental Defectives. The court said that her confinement in the institution

resulted in many travesties to her young person: loss of liberty, loss of reputation, humiliation and disgrace, pain and suffering, loss of enjoyment of life, loss of normal developmental experiences, loss of civil rights, loss of

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<sup>1</sup> Klassen, 3. See also, Community Living Winnipeg, “Board of Directors,” accessed August 1, 2016, <http://communitylivingwinnipeg.com/about-us/board-of-directors/>.

<sup>2</sup> Muir received widespread newspaper as well as television coverage during the legal trial. After her death, media attention was again prevalent. For example, see “Woman who successfully sued Alberta over sterilization dies,” *CTV News* March 16, 2016, accessed June 26, 2016, <http://www.ctvnews.ca/health/woman-who-successfully-sued-alberta-over-sterilization-dies-1.2819243>. In this article, Muir is recognized for opening “a floodgate of claims” from other sterilization victims and for bringing public attention to the historical eugenic practices of Alberta. See also Tu Thanh Ha, “Leilani Muir made history suing Alberta over forced sterilization,” *The Globe and Mail* March 16, 2016, accessed June 26, 2016, <http://www.theglobeandmail.com/news/alberta/woman-who-made-history-suing-alberta-over-forced-sterilization-dies/article29256421/>.

contact with family and friends, subjection to institutional discipline.<sup>3</sup>

Through this 1996 award, the Alberta court recognized the damages wrought to individuals through institutionalization, but thirty years later large institutions still continue to be run by provincial governments in Alberta and Manitoba. Scott Klassen argues that “society seems like it doesn’t even know the wrong they are doing with institutions. I don’t believe it. I think they know.”<sup>4</sup>

This thesis examines issues surrounding access to records relating to people labelled with intellectual disability who have been institutionalized in Manitoba.<sup>5</sup> It argues that the devaluation of people labelled with intellectual disabilities together with

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<sup>3</sup> “Summary,” *Muir v. Alberta*, 1996, accessed June 26, 2016, <http://www.canlii.org/en/ab/abqb/doc/1996/1996canlii7287/1996canlii7287.html>. Dr. J.C. Clarkson, in his commissioned report on institutions in the province of Manitoba, noted that not only were the institutions isolated and so promoted schisms within relationships, “the general population rejects institutional living for other environmental reasons—noise, regimentation, and a feeling of anonymity. These add to the disadvantages inherent in their existence.” J.C. Clarkson and M.D.T. Associates, *Mental Health and Retardation Services in Manitoba* (Province of Manitoba: Department of Health and Social Development, 1973), 88. This report is often referred to as “the Clarkson report.”

<sup>4</sup> Klassen: 4. Somewhat similarly, disability advocate and lawyer Paul Lombardo has said that the history of eugenics in the United States has “hid in plain sight.” Cited in Chloe S. Burke and Christopher J. Castaneda, “The public and private history of eugenics: An introduction,” *The Public Historian* 29/3 (2007):10.

<sup>5</sup> The advocacy organization People First of Canada uses the terms “people with an intellectual disability” and “people who have been labeled with intellectual disability.” People First of Canada, accessed January 30, 2016, <http://www.peoplefirstofcanada.ca/about-us/people-first-of-canada/>. Sarah Harms also follows the lead of People First. Sarah Harms, “A Study of Community Living Log Books as Genre,” (Master’s thesis, University of Manitoba, 2009): x. I use terminology that incorporates the word “labelled” to emphasize the social relations that determine who is labelled. As Keith and Keith state “our linguistic conceptualization of intellectual disability...shapes how we actually see and treat people.” Heather Keith and Kenneth D. Keith, *Intellectual Disability: Ethics, Dehumanization and a New Moral Community* (West Sussex, UK: Wiley-Blackwell, 2013): 124. Keith and Keith note that “many theorists and practitioners debate the very concept of ‘disability’ as either something internal to the individual (‘impairment’) or external and social, such as a person being made ‘disabled’ by lack of accessibility to buildings or to education.” (xi). The term “disability” is itself complicated and subjectively determined. Karen Hirsch says “A disabled person may and may not be under medical care and may be in excellent or poor health. The identity of a ‘person with a disability’ is something that some people choose to claim even if their disability is relatively minor and others choose to reject in spite of a visible and/or significant disability.” Karen Hirsch, “Culture and Disability: The Role of Oral History,” *The Oral History Review* 22/1 (1995):1.

the failures and difficulties in acquiring, preserving, describing and accessing records that describe the historical experiences of people labelled with intellectual disability allows society to continue to seem like it does not know “the wrong they are doing with institutions.” In conclusion, this thesis advocates for means by which the experiences of people who have been institutionalized could be created, archived and more broadly available to the public.<sup>6</sup>

In instances of other social groups that have faced past injustices, such as Indigenous people in Canada and their experience of Indian Residential Schools, archival records have played a key role in the historical, legal, and public education efforts that are recently beginning to bring about much needed social change. In Scotland and Australia, reviews of government policy toward children “in care” have been undertaken with consequent critical examination of recordkeeping practices.<sup>7</sup> Such reviews, and bodies such as Canada’s Truth and Reconciliation Commission, have brought increased public attention to both the lived experiences of hundreds of individuals and to how records relating to these experiences are created, preserved, and accessed. Indeed, the

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<sup>6</sup> Burke and Castaneda say that although we may look at the eugenic practices of sterilization and institutionalization as wrought “by the imposition of governmental authority,” it is important to remember that eugenic practices “thrived...because of the active and enthusiastic participation of large numbers of ordinary people.” They also note that “eugenicists were some of society’s ‘best’ citizens.” See Burke and Castaneda: 8-9. See also Carolyn Strange and Jennifer A. Stephen who state that “over the first half of the twentieth century, eugenics in Canada was modern, scientific, and respectable.” Carolyn Strange and Jennifer A. Stephen, “Eugenics in Canada: A Checkered History, 1850s-1990s,” Alison Bashford and Philippa Levine, eds., *The Oxford Handbook of the History of Eugenics* (New York: Oxford University Press, 2010): 524.

<sup>7</sup> For the Scottish review see The Scottish Government, *Historical Abuse Systemic Review: Residential Schools and Children’s Homes in Scotland 1950 to 1995* (Edinburgh: 2007), accessed June 24, 2016, <http://www.gov.scot/Resource/Doc/203922/0054353.pdf>. This review was led by Tom Shaw and is often referred to as “The Shaw Report.” For information on the Australian reviews, see Find & Connect, “Background,” accessed June 24, 2016, <https://www.findandconnect.gov.au/about/background/>.

review in Scotland later resulted in new legislation about recordkeeping.<sup>8</sup> In Canada, class action suits have been brought against two provincial governments on behalf of people labelled with intellectual disability who had been institutionalized and prompted official government apologies from the British Columbia and Ontario governments.<sup>9</sup> Although these actions brought public attention to these issues, as did the case brought by Leilani Muir, it does not seem that public understanding of the history of the institutionalization of people labelled with intellectual disability has become widespread. Further, although part of the Huronia class settlement included conditions for the archival preservation of, and access to, historical records relating to the trial, social justice issues relating to people labelled with intellectual disability do not yet appear to have been picked up by archivists in the same way that rights issues relating to residential schools and children in care have captured archivists' hearts and minds.<sup>10</sup>

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<sup>8</sup> For a brief description, see the abstract for the 2012 ICA conference by George MacKenzie, "Impact of the Shaw Report on Public Record-keeping," accessed June 24, 2016, <http://ica2012.ica.org/files/pdf/Full%20papers%20upload/ica12Abstract00144.pdf>.

<sup>9</sup> The Woodlands Class Action suit was launched against the British Columbia government in 2002. It was settled in 2010. Klein Lawyers, "Woodlands Settlement Notice," accessed August 11, 2016, <http://www.callkleinlawyers.com/wp-content/uploads/2013/12/Woodlands-settlement-notice-0920101.pdf>. The Huronia class action suit against the Ontario government was settled in 2013. Two other suits for the Rideau Regional Centre and the Southwestern Regional Centre in Ontario were settled in 2014. A further class action suit covering twelve additional facilities was settled in 2016. Keith Leslie, "Former residents of 12 Ontario institutions for developmentally disabled win \$36-million lawsuit," *National Post* April 27, 2016, accessed August 11, 2016, <http://news.nationalpost.com/news/canada/former-residents-of-12-ontario-institutions-for-developmentally-disabled-win-36-million-lawsuit>. As well, over 950 individual suits were brought against the Alberta government for sterilization under the province's eugenic legislation. P. Jonathan Faulds, Douglas A. Graham, Gary W. Wanless, Allan A. Garber, "Alberta Sterilization Settlements," Lexpert, accessed August 11, 2016, <http://www.lexpert.ca/article/alberta-sterilization-settlements/?p=14%7C132%7C245&sitecode=lex>.

<sup>10</sup> According to an interview with Huronia lead plaintiffs Patricia Seth and Marie Slark the idea for the lawsuit against the Ontario government came from the legal action on behalf of residential school survivors. Marie Slark said, "We heard about the Residential Schools. It sounded a lot like what we experienced at the institution." Patricia Seth, Marie Slark, Josée Boulanger, Leah Dolmage, "Survivors and sisters talk about the Huronia Class Action Lawsuit, Control, and the Kind of Support We Want," *Journal on Developmental Disabilities* 21/2 (2015): 9.

Although inadequate levels of funding to archives prevents comprehensive coverage of all human rights issues, it is also possible that the prevailing lack of prioritization of records relating to the experience of people institutionalized in Manitoba also reflects society's devaluation of people labelled with intellectual disability. In the case of Manitoba, the existing historical records relating to institutionalization are widely scattered and thinly described, some are buried in a decades-long backlog of unprocessed records and/or barricaded behind provincial privacy legislation barriers or behind the walls of the institutions themselves.<sup>11</sup> Even more concerning, especially in regard to the government-run Manitoba Developmental Centre, a great majority of the records that document the historical experience of institutionalization have been destroyed or are currently scheduled for destruction.<sup>12</sup> This lack of available archival records not only fosters a gaping hole in the history of Manitoba but could impede social and legal redress in this area.

Like other provinces in Canada, Manitoba began institutionalizing people labelled with intellectual disability in the late nineteenth century.<sup>13</sup> In the 1960s, the abysmal

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<sup>11</sup> In 2014, Kathleen Epp, Senior Archivist at the Archives of Manitoba said that "approximately 67% of government records series have been described in Keystone." Kathleen Epp, email to author, November 13, 2014. In my opinion, more government resources are needed to adequately meet the difficulties inherited by the government records program. Jacqueline Nicholls says "an enormous task" met the government records program: "in addition to current records there was a huge backlog of material. Records had been stockpiled in closets and hallways for over 100 years." Jacqueline M. Nicholls, "'Guide' vs 'gatekeeper': Information rights legislation and the Archives of Manitoba." (Master's thesis, University of Manitoba, 2000), 59.

<sup>12</sup> I emailed Scott Goodine, Archivist of Manitoba/Manitoba Legislative Librarian and Kathleen Epp, Senior Archivist at the Archives of Manitoba on August 15, 2016 regarding my concern with the destruction of these records.

<sup>13</sup> In this thesis, I use a variety of terms to describe those who were institutionalized such as "residents," "institutional survivors," "inmates," "individuals," "citizens," and "people." Susan Burch and Hannah Joyner note that terms used to describe people who have been institutionalized "are fraught with political and social meaning." In their book, they chose to "employ many of these terms throughout as a way of both

conditions within institutions began to be publicly known and by the 1980s most institutions began releasing inmates into the community and shutting down. Very few large-scale institutions currently remain open in Canada.<sup>14</sup> Although institutions in Manitoba participated in the deinstitutionalization trend, Manitoba currently houses more than 400 people in two large institutions and neither institution has announced plans for closing.<sup>15</sup> When Alberta announced in 2013 that Michener Centre would be closing, Bruce Uditsky, the CEO of the Alberta Association for Community Living, said, “This has been a long time coming; Alberta was at risk of becoming the last province in the country to close its institutions.”<sup>16</sup> It is likely that Manitoba will have this dubious honour as Gord Mackintosh, Manitoba’s Minister of Family Services in 2010, said that “MDC will not be closing any time soon, if ever.”<sup>17</sup>

Although the institutionalization of people labelled with intellectual or other disabilities in Manitoba is a source of controversy, no history of institutionalization in this province has been written. A recent article in the *Canadian Journal of Disability*

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complicating and honoring the many experiences of people ‘on the inside.’” Susan Burch and Hannah Joyner, *Unspeakable: The Story of Junius Wilson* (Chapel Hill: The University of North Carolina Press, 2007): 5. I also follow the lead of other scholars, such as Karen Hirsch, and use the term “incarceration” to describe how people have been held in institutions. Hirsch: 10. Note also that Clarkson, in his 1973 report on services in Manitoba, said that the Mental Health Act of the time was “written in such a manner and with such language that it would seem to be dealing more with the imprisonment of offenders than with the protection and development of persons with limited intellect.” Clarkson: 8.

<sup>14</sup> According to journalist Will Braun, in 2010 approximately 1,000 people lived in institutions in Canada in three institutions: Valley View in Saskatchewan; Michener Centre in Alberta; and the MDC. It does not seem that he included St. Amant in his count. Will Braun, “A Room of One’s Own,” *This Magazine* (September/October 2010): 32.

<sup>15</sup> A 2013 *Winnipeg Free Press* article says there were a total of 430 people living in MDC and St. Amant. See Will Braun, “Development Centre’s time is past,” *Winnipeg Free Press* October 1, 2013, accessed April 7, 2015, <http://www.winnipegfreepress.com/opinion/analysis/development-centres-time-is-past-225924321.html>.

<sup>16</sup> Karen Kleiss, “Centre once tied to eugenics to close,” *Calgary Herald* March 12, 2013.

<sup>17</sup> Cited in Braun, “A Room of One’s Own”: 32.

*Studies* notes that a similar paucity of written histories about institutions in Ontario “poses difficulty in terms of providing a comprehensive historical account of this area, but also points to the necessity of this kind of account.”<sup>18</sup> In view of the long history of institutionalization in Manitoba, and the thousands of people affected by this practice, the words of historian Douglas C. Baynton seem particularly apt: “Disability is everywhere in history, once you begin looking for it, but conspicuously absent in the histories we write.”<sup>19</sup> Terry Cook locates the archive as the root of this kind of absence. He wrote that “in many societies, certain classes, regions, ethnic groups, or races, women as a gender, and non-heterosexual people, have been de-legitimized by their relative or absolute exclusion from archives, and thus from history and mythology.”<sup>20</sup> However, examining Cook’s list of marginalized and “de-legitimized” groups, we can see that disability is “conspicuously absent” even from the list of groups that *should* be accounted for in archives. Looking even within the populations of people with disability, the group of people labelled with intellectual disability are often further marginalized and invisible. Vincent Pietropaolo, whose photography project chronicles lives of people labelled with

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<sup>18</sup> Kate Rossiter and Annalise Clarkson, “Opening Ontario’s ‘Saddest Chapter:’ A Social History of Huronia Regional Centre, *CJDS* 2.3 (September 2013): 3. See also Nic Clarke, “Opening Closed Doors and Breaching High Walls: Some Approaches for Studying Intellectual Disability in Canadian History,” *Histoire sociale/Social History* 39/78 (2007): 467-485 and Nic Clarke “Sacred Daemons: Exploring British Columbian Society’s perceptions of ‘mentally deficient’ children, 1870-1930,” *BC Studies* 144 (2004/2005): 61-89. Clarke (“Opening Closed Doors”) says that examining the construction of intellectual disability can increase insight not only into institutions in Canada but “indeed society in general, that simply cannot be found elsewhere”: 471.

<sup>19</sup> This is an oft-cited quote. See for example, Audra Jennings, “Introduction: Disability and History,” *Disability Studies Quarterly* 28 (2008), accessed December 8, 2011 and Penny L. Richards, “Online Museums, Exhibits, and Archives of American Disability History,” *The Public Historian* 27 (2005): 93.

<sup>20</sup> Terry Cook, “We are What We Keep: We Keep What We Are: Archival Appraisal Past, Present, and Future,” *Journal of the Society of Archivists* 32 (October 2011): 174. See also Rodney Carter who says “Those marginalized by the state are also marginalized by the archive.” Rodney Carter, “Of Things Said and Unsaid: Power, Archival Silences, and Power in Silence,” *Archivaria* 61 (2006): 219.

intellectual disability living outside of institutions in Canada, writes about the invisibility of this group of citizens.

Like many Canadians, I had become accustomed to not seeing, not hearing about, not being personally aware of many people with intellectual disabilities. They have been a largely invisible part of the population, hidden inside the impenetrable walls of infamous institutions. When not actually locked up, they were rendered invisible from society's prying eyes, cloistered inside their own homes, burdened with the stigma of shame for having been born, for existing. The more out of sight they were, the less one had to carry the weight of thinking about them, the less need to make adjustments to the routine patterns of living, the less need to reconsider prejudicial and criminal attitudes, the less need to be bothered with human rights or social justice.<sup>21</sup>

Accompanying the recognition that people labelled with intellectual disability are hidden from history and society is the hopeful assumption that, once visible, this group of people will begin to attain their rightful place as citizens both in the narratives of history and in present-day society. This thesis, to a large degree, also follows this belief.

However, at the same time, this framework has to be understood as too simplistic and does not account for prejudice and, among other things, economic factors under capitalism. In capitalist and consumerist societies where a person's value is correlated to their economic standing – and where physical and attitudinal barriers exist to create barriers for people with disability to take their place in the workforce – people with disability are disproportionally under- or unemployed.<sup>22</sup> In other work, scholars such as Claudia Malacrida, argue that the economic value of large institutions to rural locations

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<sup>21</sup> Vincenzo Pietropaolo, *Invisible No More: A Photographic Chronicle of the Lives of People with Intellectual Disabilities* (New Jersey: Rutgers University Press, 2010), 14.

<sup>22</sup> For discussions of capitalism and its impact on people with disability, see for example: Colin Barnes, "A Working Social Model? Disability, Work and Disability Politics in the 21st Century," *Critical Social Policy* 20/4 (2000), 441-457; Pamela Robert, "Disability Oppression in the Contemporary U.S. Capitalist Workplace," *Science & Society* 67/2 (2003), 136-159; and Brendan Gleeson, *Geographies of Disability* (London: Routledge, 1999).



and the presence of powerful unionized employee groups in institutions prevent the institutions from closing and thus the existence of a group made dependent and isolated is necessary for the economic gain of others.<sup>23</sup>

It is therefore important to look at Klassen's statement in full:

Society seems like it doesn't even know the wrong they are doing with institutions. I don't believe it. I think they know. Society knows but I think they don't have a tone of remorse in their voice. Most people are bigots. They don't want to see what is happening.<sup>24</sup>

What Klassen identifies is the ingrained acceptance of discrimination against people labelled with intellectual disabilities. As will be shown in this thesis, both the freely available public record and the records protected behind barriers in archives, acknowledge the poor conditions, and what the Alberta judge deemed *travesties* of life, endured by those confined in institutions.<sup>25</sup> Yet, despite this knowledge, as Klassen points out, the widespread devaluation of people labelled with intellectual disability as sub-human leads to the societal conclusion that there is no need to feel "remorse" for institutionalization.<sup>26</sup>

The bigotry, devaluation, or even simply the ignorance that exists about this

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<sup>23</sup> Claudia Malacrida, *A Special Hell: Institutional Life in Alberta's Eugenic Years* (Toronto: University of Toronto Press, 2015), 171-172.

<sup>24</sup> Klassen: 4.

<sup>25</sup> See for example the Clarkson report that describes the MDC as "overcrowded," "grossly inadequate," and repeatedly "grossly overcrowded," Clarkson: 27, 10, 28 and 29 respectively.

<sup>26</sup> Additionally there may be reasons why society members "don't want to see what is happening:" family members may want to believe that the institution is safe to assuage their concern or guilt; townspeople may want to keep the institution open so that their community can reap the associated employment and economic benefits; specialized professionals and other workers may depend on upon a confined population for their livelihood and professionalization; and governments may not want to spend the money required to keep this population safe and thriving at the cost of alienating a unionized voter base or a town grown dependent on the employment provided by the institution.

population permeates to the archives. As Cook suggests, the devaluation of certain categories of people in society causes “their relative or absolute exclusion from archives.” If the concept of “total archives” is accepted—that “archives acquire collections reflecting the total complexion of society”—then it is easy to see how people labelled with intellectual disability, who are themselves hidden from society, are thus also hidden in archives.<sup>27</sup> However, when it is considered that provincial governments have often been responsible for the confinement of this population within large institutions, then it seems clear that this population should at least be represented within the custody of government archives. But if archives truly mirror society, is it also then expected that the records of this population who are hidden away as Pietropaolo says “inside the impenetrable walls of infamous institutions” also are hidden in archives? If archives mirror a prejudiced society and the prejudices of society are supported by what information is (or is not) available in archives, what needs to be changed to influence the other? Do we break open archives to change society or do we change society to break open archives? More likely, it is a two-pronged struggle in which each side is cracked open and acts as an influence to further widen the boundaries of understanding of the other.

In this thesis, Chapter One examines the secondary materials that exist regarding institutionalization in Manitoba and Canada, thus illustrating the paucity of historical understanding of this area. Chapter Two summarizes the history of institutionalization in

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<sup>27</sup> Terry Cook, “The tyranny of the medium: A comment on ‘total archives,’” *Archivaria* 9 (1979-1980): 141.

Manitoba such as it can be discovered through readily-available sources. Chapter Three looks at the types of records that institutions can be expected to create. Chapter Four examines issues surrounding privacy restrictions on archival and government records. Chapter Five looks at research ethics and Chapters Six and Seven recount some of my experiences in the access to information process and provide some analysis of the records that I was able to access. The concluding chapter provides some recommendations for both universities and archives, and looks at some examples of participatory archival projects in Canada, the US and the UK.

When Josée Boulanger wrote her thesis about her collaborative work with people labelled with intellectual disability, she said, “I agonized about my duty to be truthful in telling about my experiences and the consequences of telling them.”<sup>28</sup> As Boulanger noted, she was always conscious of the many people who might read her thesis and of their varying positions of power. She cited the work of Torill Moen who wrote that when someone makes an utterance, the “voice is overpopulated with other voices, with the intentions, expectations, and attitudes of others.”<sup>29</sup> This overpopulation of other voices (and other eyes and ears) both informed and confined my research and writing.<sup>30</sup> While writing this thesis, I have been very much aware of the established framework for writing a thesis and for the most part I have tried to fit my ideas with these boundaries. I have

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<sup>28</sup> Josée Boulanger, “Look, Listen, Learn: Collaborative Video Storytelling by/with People who have Been Labelled with an Intellectual Disability” (Master’s thesis, University of Manitoba, 2013): 52.

<sup>29</sup> Torill Moen, cited in Boulanger: 51.

<sup>30</sup> In her thesis, Boulanger described her first visit to MDC and that during the process of asking a supervisor if she could interview a resident, she walked past a punishment room in a cottage. She wrote, “I wish I could ask questions about this room to the supervisor but it might compromise our chances to interview Dave’s friend so I don’t. I don’t stop to peek through the door. I don’t want to get caught snooping around.” Boulanger: 99.

also been aware that a stipulation within the legally binding research agreements means that representatives of the Manitoba government will read this thesis even before it is sent to my examining committee.

And finally, I have been conscious – and indeed deeply regretful – that although one of the guiding principles of the disability rights movement is “nothing about me, without me” I have written this thesis without the formal participation of people labelled with intellectual disability. In my initial planning stages, the hurdles of obtaining research ethics board approval for working with a population deemed “vulnerable” and my lack of experience with the communities involved seemed insurmountable. However, if I had the chance to start again from scratch, I would have found a way to create space for the participation of people labelled with intellectual disability. In an admittedly inadequate attempt to recognize the primacy of the voices of those who have been institutionalized in Manitoba, I use testimony from two Manitoba institutional survivors and advocates as my thesis title and chapter names. In my many presentations on this subject,<sup>31</sup> advocates and at least one self-advocate, as well as family members of those labelled with intellectual disability, have listened to me and given their approval to what they heard. I plan to continue my work post-thesis in ways that meet – and are led – by the expectations of members of this community.

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<sup>31</sup> These presentations did not include information contained in restricted archival records.

## **Chapter One: “Society seems like it doesn’t even know...:”**

### **Reviewing the literature about institutions**

Scott Klassen says “I reflect at night on what has been good and what has been not so good. Society seems like it doesn’t even know the wrong they are doing with institutions. I don’t believe it. I think they know. Society knows but I think they don’t have a tone of remorse in their voice. Most people are bigots. They don’t want to see what is happening. When I moved out, I didn’t know how I was going to be accepted by the community.”<sup>1</sup>

This chapter reviews the literature regarding institutions for people labelled with intellectual disability in Manitoba and in Canada. It begins by examining the very scant literature that touches on institutions in Manitoba. To provide context to the Manitoban experience, this chapter surveys the literature for institutions in Canada. It also looks at the larger themes of eugenics and eugenic sterilization. It reviews some of the literature regarding the history of intellectual disability and highlights publications and media that give space to the voices and experiences of those who have been institutionalized. It is important to note that only a very small fraction of the publications noted made any use at all of archival records relating to institutions in Manitoba.

### **Institutions in Manitoba**

Since 1890, Manitoba has had three large institutions for people labelled with intellectual or other disabilities: the Manitoba Developmental Centre (MDC), St. Amant

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<sup>1</sup> Klassen: 4.

Centre (now re-branded as St.Amant), and Pelican Lake Training Centre.<sup>2</sup> Although Pelican Lake closed in 2000, the other two institutions are still in operation and combined currently house over 400 people. Despite almost a total of 125 years of operation, very little is known about the institutions' histories or the experiences of the people who lived or worked there. Although the Manitoba Developmental Centre was, and remains, a provincially-run institution, its current operation is summed up on the government website in 141 words with no explanation of its long history.<sup>3</sup> Pelican Lake Training Centre was run by the Sanatorium Board of Manitoba and had close ties with the Manitoba Developmental Centre and the provincial government. Very little is known about this institution and it is not mentioned on the government website. St.Amant, although a private institution, receives a good portion of its funding from the provincial government. St.Amant has 554 words on its "History" web page, 319 devoted to the history while the rest describes the current mission.<sup>4</sup>

None of the institutions have published official histories.<sup>5</sup> Their history is also scarcely represented in scholarly or popular publications. In a survey of the province's medical history, institutionalization is very briefly mentioned: Ian Carr and Robert F. Beamish describe "the care of those who are mentally handicapped for genetic reasons or

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<sup>2</sup> The re-branding of the St. Amant Centre included the new name St.Amant (without spaces). This thesis uses the re-branded name "St.Amant" for the institution except when citing historical, archival or otherwise previously published documents that use the previous name.

<sup>3</sup> Manitoba Government website, "Manitoba Developmental Centre," accessed April 6, 2015, <http://www.gov.mb.ca/fs/pwd/mdc.html>. In comparison, the Ontario government provides significant information about the history of their provincial institutions on their website: Ontario, Ministry of Community and Social Services, "History of the Huronia Regional Centre," accessed August 19, 2015, [http://www.mcscs.gov.on.ca/en/mcscs/programs/developmental/HRC\\_history.aspx](http://www.mcscs.gov.on.ca/en/mcscs/programs/developmental/HRC_history.aspx).

<sup>4</sup> St.Amant website, "History," accessed April 6, 2015, <http://stamant.ca/about-us/history/>.

<sup>5</sup> The Michener Centre in Alberta may be the only institution that has published an official history. Alberta Government Publications, Michener Centre: a history 1923–1983 (Edmonton, Canada, 1985).

because of birth trauma” in the province as “a sad story.”<sup>6</sup> But notably they summarize this one-hundred-year story in only two short paragraphs. The role of parent organizations in the 1950s and 1960s at the MDC and St. Amant is explored in a short 2009 *Manitoba History* article by Christopher Adams.<sup>7</sup> A detailed look at the closing of the Pelican Lake Centre is in a forthcoming article by University of Manitoba Faculty of Education professor Zana Lutfiyya.<sup>8</sup> In the same collection Lutfiyya and Karen Schwartz explore the Manitoba legal discourse that deals with intellectual disability.<sup>9</sup> Karen Schwartz also published an article on the discourse of the news media debate concerning the Manitoba government’s 2004 commitment of \$40 million to MDC.<sup>10</sup>

Although none of the institutions have published official histories, a few other commemorative publications offer brief accounts. As the Pelican Lake Centre was situated in the old Ninette tuberculosis sanatorium, the transition between the two institutions is discussed in David B. Stewart’s book *Holy Ground: The Story of the Manitoba Sanatorium at Ninette*.<sup>11</sup> Similarly, the transition is also mentioned in Maurice Mierau’s book on tuberculosis in Manitoba.<sup>12</sup> Several pages are devoted to the MDC in

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<sup>6</sup> Ian Carr and Robert E. Beamish, *Manitoba Medicine: A Brief History* (Winnipeg: University of Manitoba Press, 1999): 202.

<sup>7</sup> Christopher Adams, “Advocating for Manitoba Children with Mental Disabilities: Parent Associations in the 1950s and 1960s,” *Manitoba History* 61 (2009): 20-24.

<sup>8</sup> Zana Lutfiyya, “Closing an institution: The last chapter of the Pelican Lake Training Centre,” ed. Nancy Hansen, *Untold stories: Disability history in Canada* (Winnipeg: University of Manitoba Press, forthcoming.)

<sup>9</sup> Zana Lutfiyya and Karen Schwartz, “Beyond Idiocy: Exploring the Changing Perceptions of People with Intellectual Disabilities through Manitoba Legal Discourse,” in Nancy Hansen, ed., *Untold stories: Disability history in Canada* (Winnipeg: University of Manitoba Press, forthcoming).

<sup>10</sup> Karen Schwartz, “‘We can’t close it yet’: How discourse positions people with intellectual disabilities,” *Critical Disability Discourse* 2 (2010):1-15.

<sup>11</sup> David B. Stewart, *Holy Ground: The Story of the Manitoba Sanatorium at Ninette* (Killarney, MB: J.A. Victor David Museum, 1999).

<sup>12</sup> Maurice Mierau, *Memoir of a Living Disease* (Winnipeg: Great Plains Publications, 2005).

Anne Collier's 1970 commemorative community history of Portage la Prairie and the surrounding area.<sup>13</sup> The most informative publication on MDC is a four-page summary that is now almost four decades old and was written by Reverend S.A. Walmsley, a former Chaplain at the Manitoba Developmental Centre. He submitted the article "History of Mental Retardation in Manitoba, 1890-1976" to an anniversary collection of the American Association on Mental Deficiency.<sup>14</sup> Brief descriptions of the Manitoba Developmental Centre are also found in the memoirs of conscientious objectors who performed alternative service at the institution during World War II.<sup>15</sup> In regard to St. Amant, Sister Rita Desrosiers, a nun who worked at St. Amant for decades, provides descriptions of the origin of the centre and its functions in her memoir *Fond Memories of St. Amant*.<sup>16</sup>

In Manitoba, a small number of works have been created by, or feature, people who formerly lived in institutions. MDC survivor David Weremy was one of the People First co-producers of the documentary *The Freedom Tour*. This film follows a caravan of

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<sup>13</sup> Anne Collier, *A History of Portage la Prairie and Surrounding District* (Altona, MB: City of Portage la Prairie, c. 1970).

<sup>14</sup> Reverend S.A. Walmsley, "History of Mental Retardation in Manitoba, 1890-1976," *A Historical Perspective and Service Report: 1876-1976*, Antusa S. Bryant and William A. Funari, eds., (Minneapolis, MN: Region VIII, American Association on Mental Deficiency, 1976): 2-5. Walmsley was an ordained minister of the United Church of Canada. See Gordon Goldsborough, "Memorable Manitobans: Sidney Arthur 'Sid' Walmsley (c1924-2003)," The Manitoba Historical Society website, accessed August 6, 2014 [http://www.mhs.mb.ca/docs/people/walmsley\\_sa.shtml](http://www.mhs.mb.ca/docs/people/walmsley_sa.shtml). Walmsley received his theology degree from the University of Winnipeg where he wrote a thesis on "mental retardation." His ministry at the MDC was described as a "first for Canada." See Virden Town Council, *Virden Review 1957-1970* (Brandon, MB: Leech Printing Ltd.):170.

<sup>15</sup> For example, see Jake Krueger and John C. Klassen, *ASM: Alternative Service Memoirs* (Altona, MB:, 1995). Some information is also available on the Mennonite Heritage Centre's website "Alternative Service in the Second World War," accessed March 3, 2016, <http://www.alternativeservice.ca/service/hospitals/index.htm>.

<sup>16</sup> Sister Rita Desrosiers, *Fond Memories of St. Amant* (Winnipeg: Interior Publishing & Communication Ltd., 2005). An interesting aspect of Sister Desrosiers' short memoir is that she describes some of the children who lived at the centre, providing first names, health information, and sometimes photographs.



People First members as they travel across the prairie provinces to interview people who were formerly institutionalized and to call for the closure of the institutions that were still open.<sup>17</sup> *The Freedom Tour* also made use of some archival photos of MDC as well as conducting interviews with former residents of MDC and other institutions in Saskatchewan and Alberta. Josée Boulanger, one of the producers of *The Freedom Tour*, has also uploaded video interviews with institutional survivors, including David Weremy, to her YouTube channel.<sup>18</sup> Two members of People First and Josée Boulanger published an article in *Living the Edges: A disabled women's reader* that described their experiences making *The Freedom Tour*.<sup>19</sup> People First of Canada publishes a newsletter, *Institution Watch*, that often features interviews with, or experiences of, people who had formerly lived in institutions.<sup>20</sup> People First of Canada also has a list of resources that includes videos.<sup>21</sup>

In recent years, journalists have provided a few glimpses into the Manitoba Development Centre. Will Braun toured the MDC, met with its CEO and also interviewed David Weremy.<sup>22</sup> Braun has also written columns and articles for the

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<sup>17</sup> *The Freedom Tour*. DVD. People First of Canada, 2008. See also "The Freedom Tour DVD," People First of Canada, <http://www.peoplefirstofcanada.ca/the-freedom-tour-dvd/>, accessed June 16, 2016.

<sup>18</sup> YouTube, Vidéos de Josée Boulanger, accessed August 9, 2015, <https://www.youtube.com/user/bouboulatanante/videos>. Boulanger also manages the Label Free Zone. YouTube, Label Free Channel, <https://www.youtube.com/user/labelfreezone/about>, accessed August 9, 2015.

<sup>19</sup> Josée Boulanger, Susie Weizmann and Valerie Wolbert, "The Freedom Tour documentary: An experiment in inclusive filmmaking," Diane Driedger, ed., *Living the edges: A disabled women's reader* (Toronto: INANNA Publications and Education Inc., 2010): 305-322.

<sup>20</sup> Institutionwatch.ca, accessed August 19, 2015, <http://www.institutionwatch.ca/newsletter>,

<sup>21</sup> People First of Canada, "Resources," accessed March 6, 2016, <http://www.peoplefirstofcanada.ca/resources/>. Apart from *The Freedom Tour*, most of these resources focus on living in the community.

<sup>22</sup> Braun, "A Room of One's Own": 31-35.

*Winnipeg Free Press* concerning the MDC, as have other Winnipeg journalists.<sup>23</sup> The subject matter of these articles has included questions of abuse endured by residents of the MDC, inquests into patient deaths, and debates concerning the future of the institution.

### **Government publications**

As the Manitoba Developmental Centre is a government-run institution, and both Pelican Lake Centre and St. Amant include strong ties to the province, government reports that are open to the public are a source of information about these institutions. The Legislative Library holds annual reports of the departments that have been responsible for government services in this area. At least two additional reports were commissioned and published: *Mental Health and Retardation Services in Manitoba* (1973) and *Report on Sterilization and Legal Incompetence* (1992).<sup>24</sup> Discussions and questions in the Manitoba legislature are also found periodically in Hansard. Legislation that specifically deals with this population is also a source of publicly available information, such as *The Mental Deficiency Act* (1954), *The Mental Health Act* (1999), and *The Vulnerable Persons Living with a Mental Disability Act* (2011).<sup>25</sup>

### **Institutions Outside Manitoba**

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<sup>23</sup> For example, see Mary Agnes Welch, "Province mulling fate of development centre," *Winnipeg Free Press* April 1, 2010, accessed August 15, 2014 <http://www.winnipegfreepress.com/local/province-mulling-fate-of-development-centre-89669477.html>; and Dan Lett, "Operating MDC may bring legal woes to province," *Winnipeg Free Press* June 2, 2014, accessed August 1, 2016, <http://www.winnipegfreepress.com/opinion/columnists/operating-mdc-may-bring-legal-woes-for-province-261474831.html>.

<sup>24</sup> The former is the Clarkson report previously mentioned. Law Reform Commission, *Report on Sterilization and Legal Incompetence* (Manitoba: Law Reform Commission, 1992).

<sup>25</sup> The Mental Health Act, C.C.S.M. c M110, [http://web2.gov.mb.ca/laws/statutes/ccsm/\\_pdf.php?cap=m110](http://web2.gov.mb.ca/laws/statutes/ccsm/_pdf.php?cap=m110); The Vulnerable Persons Living with a Mental Disability Act, C.C.S.M C. V90, [http://web2.gov.mb.ca/laws/statutes/ccsm/\\_pdf.php?cap=v90](http://web2.gov.mb.ca/laws/statutes/ccsm/_pdf.php?cap=v90).

Outside of Manitoba, there are two books on large government-run institutions. Sociologist Claudia Malacrida, who has published extensively in the area of disability as well as articles specifically on Alberta's Michener Centre, recently published a monograph about the Michener Centre titled *Special Hell: Institutional Life in Alberta's Eugenic Years*.<sup>26</sup> Her book focuses on the decades of the 1950s through 1980s and is primarily based on interviews she conducted with twenty-two former institutional residents and three former staff. She supplemented the interviews with examinations of official reports, newspaper accounts and archival records. Her previous work on the Michener institution includes two articles published in *Disability & Society*. "Discipline and dehumanization in a total institution: Institutional survivors' descriptions of time-out rooms" focuses on the oral history interviews with Michener Centre survivors and discusses the work of Foucault and Erving Goffman. "Contested memories: efforts of the powerful to silence former inmates' histories of life in an institution for 'mental defectives'" examines the barriers Malacrida encountered in her research.<sup>27</sup> In the spring of 2013, a book about Ontario's Huronia Regional Centre was written by parent advocate, poet and fiction writer Thelma Wheatley. This book provides a history of Huronia from 1900 to 1966 while following the individual history of Daisy Lumsden

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<sup>26</sup> See also my review of her book "Hell for the helpless," *Winnipeg Free Press* June 6, 2015, accessed August 17, 2015, <http://www.winnipegfreepress.com/arts-and-life/entertainment/books/hell-for-the-helpless-306360101.html>.

<sup>27</sup> Claudia Malacrida, "Discipline and dehumanization in a total institution: Institutional survivors' descriptions of time-out rooms," *Disability & Society* 20/5 (2005): 523-537 and Claudia Malacrida, "'Contested memories: efforts of the powerful to silence former inmates' histories of life in an institution for 'mental defectives,'" *Disability & Society* 21/5 (2006): 397-410.

who had been institutionalized there.<sup>28</sup> Based on interviews and archival records, this book is written in a narrative style more similar to creative nonfiction than academic history. Only a very small number of articles have been published about institutions outside Manitoba. In the early 1990s, two articles were published about the Huronia Regional Centre. Kathy Jones interviewed people who had been institutionalized in Huronia and described how they experienced community both within and outside the institution.<sup>29</sup> John P. Radford and Deborah C. Park examined the history of Huronia. They used admission records from 1876-1934 to look at “patterns of admission; nature of the catchment area; demand, supply and population; and length of patient residence.”<sup>30</sup> Radford and Park describe the admission records as “previously untapped” but it also appears that the archival records remained “untapped” as the next history of Huronia was not published for another twenty years. In 2015, an article outlining the history of institutionalization in Ontario was published in the *Journal on Developmental Disabilities*.<sup>31</sup> Aspects of institutionalization in British Columbia are examined in “No time for nostalgia!: asylum-making, medicalized colonialism in British Columbia (1859-97) and artistic praxis for social transformation” by Leslie G. Roman et al.<sup>32</sup>

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<sup>28</sup> Thelma Wheatley, *“And Neither Have I Wings to Fly”: Labelled and Locked Up in Canada’s Oldest Institution* (Toronto: INANNA Publications and Education Inc., 2013).

<sup>29</sup> Kathy Jones, “Listening to Hidden Voices: power, domination, resistance and pleasure within Huronia Regional Centre,” *Disability, Handicap & Society* 7/4 (1992): 339-348.

<sup>30</sup> John P. Radford and Deborah C. Park, “‘A Convenient Means of Riddance’: Institutionalization of People Diagnosed as ‘Mentally Deficient’ in Ontario, 1876-1934,” *Health and Canadian Society* 1/2 (1993): 369-392.

<sup>31</sup> Ivan Brown and John P. Radford, “The Growth and Decline of Institutions for People with Developmental Disabilities in Ontario: 1876-2009,” *Journal on Developmental Disabilities* 21/2 (2015): 7- 27.

<sup>32</sup> Leslie G. Roman, Sheena Brown, Steven Noble, Rafael Wainer and Alannah Earl Young, “No time for nostalgia!: asylum-making, medicalized colonialism in British Columbia (1859-97) and artistic praxis for

## **Publications by people labelled with intellectual disability**

Although some of the above-mentioned publications include interviews with institutional survivors, publication by previously-institutionalized people themselves is very rare. A very short (thirty large-type pages) memoir by Richard McDonald, who previously lived in Woodlands School in BC, was written in association with a writer from the Royal City Writers and privately published.<sup>33</sup> Gordon Ferguson, a former resident of Rideau Regional Centre, published a memoir in 2016 about his experiences including his sixteen-years in the institution.<sup>34</sup> Leilani Muir, who famously was awarded \$1 million by the Alberta government for her wrongful confinement and sterilization in Alberta's Michener Centre, self-published a memoir in 2014.<sup>35</sup> Also in Alberta, the Alberta Association for Community Living published a book featuring the words and stories of individuals who had previously been institutionalized.<sup>36</sup> In 1990, Karin Schwier's collection of interviews with people who had formerly lived in institutions in Canada was one of the earliest publications featuring the voices of institutional survivors.<sup>37</sup> Most recently, the Eugenics Archives, based in Edmonton, launched its

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social transformation," *International Journal of Qualitative Studies in Education* 22/1 (January-February 2009): 17-63. This article examines institutionalization in British Columbia through the lens of colonialism.

<sup>33</sup> Richard McDonald, *My Story* (New Westminster: Royal City Writers, 2012): 22. The Royal City Writers are described as a "community writing initiative based in New Westminster that strives to empower marginalized individuals by giving them the opportunity to share stories of their lived experiences with a wider community." *Rantsonfire Magazine*, "An Interview with Holly Andrews on Royal City Writers," accessed April 6, 2015, <https://rantsonfiremagazine.wordpress.com/2012/12/10/an-interview-with-holly-andrews-on-royal-city-writers/>.

<sup>34</sup> Gordon Ferguson, *Never Going Back* (Toronto: Legacies.ca, 2016).

<sup>35</sup> Leilani Muir, *A Whisper Past: Childless after eugenic sterilization in Alberta* (Victoria, BC: FriesenPress, 2014).

<sup>36</sup> Karin Schwier, *Hear My Voice: Stories Told by Albertans with Developmental Disabilities Who Were Once Institutionalized* (Edmonton: Alberta Association for Community Living, 2006).

<sup>37</sup> Karin Melberg Schwier, *Speak-easy: People with mental handicaps talk about their lives in institutions and in the community* (Austin, Texas: Pro-ed, 1990).

website, which includes video interviews with institutional survivors.<sup>38</sup>

## Newspapers

Although some newspapers in Canada and in the United States have played a significant role in disseminating the experiences of people who had been institutionalized and/or sterilized, this exposure has been much less so in Manitoba. In British Columbia, media reports about the experiences of Woodlands School survivors sparked the provincial investigation into Woodlands by former ombudsman Dulcie McCallum.<sup>39</sup> Newspaper articles describing experiences within Woodlands School were also published in B.C. following a subsequent successful class action suit.<sup>40</sup> In Ontario, the class action suit against the provincial government's Huronia institution resulted in newspaper coverage that included testimony by survivors.<sup>41</sup> In the United States, one of the most significant news stories developed in North Carolina when graduate student Johanna Schoen gave all of her unpublished archival research to the *Winston-Salem Journal*. This

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<sup>38</sup> Eugenics Archives, accessed August 17, 2015, <http://eugenicsarchive.ca/discover/our-stories>.

<sup>39</sup> Dulcie McCallum, *The Need to Know: Administrative Review of Woodlands School*, (Submitted to the Ministry of Children and Family Development, Provincial Government of British Columbia, August 2001), accessed July 30, 2016, [http://www.bcacl.org/sites/default/files/The\\_Need\\_to\\_Know.pdf](http://www.bcacl.org/sites/default/files/The_Need_to_Know.pdf). For evidence of the media reports, see Wendy McLellan, "Police Looking for Background to Abuse Claims," *The Province*, February 27, 2000.

<sup>40</sup> See for example, Roxanne Gregory, "Woodlands justice in doubt," *Georgia Strait*, March 23, 2006, <http://www.straight.com/article/woodlands-justice-in-doubt>, accessed March 25, 2012. In this article, Bill McArthur describes: "In the morning they would line us up for the washroom. I remember seeing people tied down to toilets and staff pouring hot water over their genitals to make them go. I was afraid all the time." Also "McArthur said he was sexually assaulted by staff, but what he feared most was being forcibly submerged in tubs filled with ice water until he nearly drowned. Another boy he knew was repeatedly confined inside a canvas sack and held underwater. 'This was the way they controlled your behaviour,' he explained matter-of-factly."

<sup>41</sup> For example, Tim Alamenciak, "The dead get forgotten, but Huronia's survivors raise their voices in tribute to them: After lawsuit settlement, ex-residents speak of provincial centre's cruelties, including neglected graves of those who died there," *Toronto Star* September 30, 2013. Earlier accounts of abuse and a government probe into allegations were published in 1979. For example, Victor Malarek, "Ice-cold showers alleged as punishment Huronia workers accused of abusing patients," *The Globe and Mail* February 28, 1979.

newspaper then published a comprehensive five-part series on forced sterilizations both in print and digitally.<sup>42</sup> However, in Manitoba, recent newspaper coverage of the experience of institutional life as told by survivors themselves seems to be limited to one article in which the claims of a former MDC resident were briefly described but then dismissed by government and MDC officials.<sup>43</sup>

It should be emphasized that the above-noted publications feature interviews with people who had *formerly* been institutionalized – it is extremely difficult, if not impossible, to record the voices of individuals who currently live in institutions as these individuals are usually under the guardianship of the provincial Public Trustee or are otherwise protected by the institution itself. In Alberta, sociologist Claudia Malacrida was denied access by the Public Trustee to interview people who were currently living in the Michener Centre.<sup>44</sup> In Manitoba, members of People First of Canada and community filmmaker Josée Boulanger tried to interview people who were currently living in MDC but access was denied.<sup>45</sup>

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<sup>42</sup> *Winston-Salem Journal*, “Against Their Will,” accessed January 12, 2015, <http://www.journalnow.com/specialreports/againsttheirwill/>. A book based on this series was later published: Kevin Begos, Danielle Deaver, John Railey, Scott Sexton, *Against Their Will: North Carolina’s Sterilization Program* (Gray Oak Books, 2012). The exposure of this previously hidden history led to a formal apology by the North Carolina state governor in 2002, making North Carolina the third state to apologize to forced sterilization victims. The governors of Virginia and Oregon also apologized in 2002. See “Virginia governor apologizes for eugenics law,” *USA Today* May 2, 2002, <http://usatoday30.usatoday.com/news/nation/2002/05/02/virginia-eugenics.htm> and “Oregon governor gives formal apology for forced sterilizations,” *Kitsap Sun* December 3, 2002, [http://web.kitsapsun.com/archive/2002/12-03/13817\\_oregon\\_governor\\_gives\\_formal\\_apo.html](http://web.kitsapsun.com/archive/2002/12-03/13817_oregon_governor_gives_formal_apo.html).

<sup>43</sup> Mary Agnes Welch, “More voices calling for end to MDC,” *Winnipeg Free Press* May 17, 2010, accessed March 26, 2013, <http://www.winnipegfreepress.com/local/more-voices-calling-for-end-to-mdc-93913674.html>.

<sup>44</sup> Malacrida, “Contested memories”: 402.

<sup>45</sup> Boulanger, “Look, listen, learn”: 96-102.

## Sterilization

One area of eugenic history that has garnered particular attention in both Canada and the United States has been the sterilization of people labelled with intellectual disability. However, scholarship in Canada has focussed on sterilizations “performed under the authorization of explicitly eugenic legislation” rather than sterilizations performed privately by individual doctors, hospitals, or institutions.<sup>46</sup> This is an important gap in the understanding of eugenic practices in Canada. For example, a 1973 review of eugenic legislation in Canada notes that “some hospitals formed sterilization committees” but to date, historical scholarship that specifically looks at these committees, or at sterilizations performed by individual doctors, does not seem to exist.<sup>47</sup> The subject of sterilization of people labelled with intellectual or other disability is referenced or discussed in a handful of scholarly legal articles.<sup>48</sup> Of particular interest are two landmark decisions: the first regarding “Eve” and the court’s decision not to allow Eve’s mother to have her sterilized; and the second regarding Leilani Muir’s successful suit against the Alberta government for her sterilization and confinement in an institution.<sup>49</sup> Close readings of legal commentaries can provide indications of attitudes of the medical

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<sup>46</sup> For example, see Wilson: 137, ft. 14. Wilson points to Karen Stote’s work on the sterilization of Indigenous women in Canada as an example of research that looks beyond sterilizations performed by eugenics boards under provincial legislation. Rebecca Kluchin’s research shows that coercive sterilizations continued for poor women and women of colour throughout the 1970s in hospitals. Rebecca Kluchin, “Locating the Voices of the Sterilized,” *The Public Historian* 29/3 (2007): 131-144.

<sup>47</sup> Bernard Starkman, “The control of life: Unexamined law and the life worth living,” *Osgoode Hall Law Journal* 11/1 (1973): 175-185.

<sup>48</sup> For example, Bernard M. Dickens, “Eugenic recognition in Canadian Law,” *Osgoode Hall Law Journal* 13/5 (1975): 547-577; Peter Bowal and Kelsey Pecson, “Eugenics and Leilani Muir,” *LawNow* 35/5 (May-June 2011): 49.

<sup>49</sup> For example, Carol Anne Polowich Finch-Noyes, “Case comment: The Eve decision,” *Canadian Journal of Family Law* 6/2 (1987): 375-383; and M. Anne Bolton, “Whatever happened to Eve? A comment,” *Manitoba Law Journal* 17 (1987-1988): 219-226.



profession, parents, public opinion and governments. For example, in 1973, Starkman noted his concern that “in the face of government indifference to improving facilities and supervision both in institutions and in the community, some may find an application under the statute a convenient way to avoid possible embarrassment.”<sup>50</sup> In this statement, Starkman appeared to acknowledge that the poor conditions within institutions (up to and including the 1970s), and the lack of support for community living, were known to the government and suggests that reduction of the population through eugenic sterilization could be seen as an alternative to providing housing and care.

Manitoba did not have provincial legislation mandating sterilization. In 1933, a clause regarding sterilization of people considered to have intellectual disability failed to pass by one vote, due to the Roman Catholic presence in Manitoba and the religion’s ban on sterilization.<sup>51</sup> However, no publications apart from a very brief entry in the Eugenics Archives exist on this topic to date.<sup>52</sup> In Canada, both Alberta and British Columbia had provincial legislation that allowed sterilization of people under the Mental Health Act. In 1937, Alberta later included an amendment that sterilizations of people deemed mentally unfit could be performed without the consent of the individual person. In Alberta, almost 3,000 people were sterilized until the law was repealed in 1972 while more than 200

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<sup>50</sup> Starkman: 183.

<sup>51</sup> Starkman: 183, footnote 42. See for example the 1936 book privately published through the Archbishop-Coadjutor of Saint-Boniface that argued against sterilization. Antoine D’Eschambault, *Eugenical Sterilization* (Saint-Boniface, Manitoba 1936). The book includes a two-page bibliography.

<sup>52</sup> Erna Kurbegovic, “Manitoba passes Mental Deficiency Act,” Eugenics Archives, accessed March 3, 2016, <http://eugenicsarchive.ca/database/documents/5233dfc75c2ec500000000d2>. Kurbegovic, a former University of Manitoba history student has also presented a conference paper on this subject. See “Keewatin Country Graduate Student History Conference 2010,” accessed July 30, 2016, [https://umanitoba.ca/faculties/arts/departments/history/media/keewatin\\_final\\_program.pdf](https://umanitoba.ca/faculties/arts/departments/history/media/keewatin_final_program.pdf).

people were sterilized in British Columbia.<sup>53</sup> Two scholarly articles look specifically at the case files of the Alberta Eugenics Board held at the Provincial Archives of Alberta to consider whether the Sterilization Act was used “primarily to control weak and marginalized groups.”<sup>54</sup> The popular press has published widely on Alberta’s sterilization practices, particularly since Muir’s legal case and then again later after Muir’s death in 2016.<sup>55</sup> In BC, Angus McLaren’s previously cited 1986 article in the *Canadian Historical Review* titled “The creation of a haven for ‘human thoroughbreds’: The sterilization of the feeble-minded and mentally ill in British Columbia” seems to be the sole published scholarly work that specifically examines sterilization in that province.<sup>56</sup>

As noted by Robert A. Wilson, when eugenic practices are “introduced into societies with a history of racism and colonialism” focus turns to immigrant and Indigenous populations.<sup>57</sup> The impact of eugenic screening and sterilization upon

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<sup>53</sup> Erika Dyck, “Canada,” Eugenics Archives, accessed March 6, 2016, <http://eugenicsarchive.ca/discover/world/5233c9085c2ec50000000093>.

<sup>54</sup> Jana Grekul, Harvey Krahn and Dave Odynak, “Sterilizing the ‘Feeble-minded’: Eugenics in Alberta, Canada, 1929-1972,” *Journal of Historical Sociology* 17/4 (December 2004): 358-384 and Deborah C. Park and John P. Radford, “From the Case Files: Reconstructing a history of involuntary sterilisation,” *Disability and Society* 13/3 (1998): 317-342. In 2011, a graduate student asserted that scholarship in Alberta focussed almost exclusively on the original legislation and did not pay enough attention to the amendment. See M. Mikkil Dak, “The Alberta eugenics movement and the 1937 amendment to the Sexual Sterilization Act,” *Past Imperfect* 17 (2011): 90-113.

<sup>55</sup> The Canadian Major Dailies database returns 139 articles about Leilani Muir for 1996 (the year her suit was completed). For examples of newspaper articles after Muir’s death, see footnote 2 in the Introduction of this thesis.

<sup>56</sup> Angus McLaren, “The creation of a haven for ‘human thoroughbreds’: The sterilization of the feeble-minded and mentally ill in British Columbia,” *Canadian Historical Review* 67/2 (1986): 127-150. See also Gail van Heeswijk, “‘An Act Respecting Sexual Sterilization’: Reasons for Enacting and Repealing the Act” (Master’s thesis, University of British Columbia, 1994), accessed August 30, 2016, <https://open.library.ubc.ca/cIRcle/collections/ubctheses/831/items/1.0087539>.

<sup>57</sup> Robert A. Wilson, “The role of oral history in surviving a eugenic past,” Steven High, ed., *Beyond Testimony and Trauma: Oral history in the aftermath of mass violence* (Vancouver: University of British Columbia Press, 2014): 123.

immigrant populations in Canada is discussed in several articles and monographs.<sup>58</sup> The impact of eugenic practices on Indigenous people in Canada has been scarcely examined until the recent book published by Karen Stote (*An Act of Genocide: Colonialism and the Sterilization of Aboriginal Women*, Winnipeg: Fernwood Publishing, 2015).<sup>59</sup> The survey of eugenic practices in Canada by Strange and Stephen suggests that Indigenous people were not a focus for sterilization or institutionalization until around the 1930s and 1940s. Strange and Stephen say that before this time “the colonial ‘civilizing’ regime imposed on the indigenous was already firmly in place” as a eugenic policy.<sup>60</sup>

Scholars and the general public are also increasingly linking eugenics with the early feminist movement although McLaren may have been the first scholar specifically

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<sup>58</sup> For example: Graham J. Baker, “Eugenics and Migration: A case study of Salvation Army literature about Canada and Britain, c. 1890-1921,” *Canadian Bulletin of Medical History* 31/1 (2014): 77-98; Mariana Valverde, *The Age of Light, Soap, and Water* (Toronto: McClelland & Stewart Inc, 1991); Fiona Alice Miller, “Making citizens, banishing immigrants: the discipline of deportation investigations, 1908-1913,” *Left History* 7/1 (2000): 62-88.

<sup>59</sup> See also Cheryl Martens, “Intellectual Disability and Aboriginal People: An Overview of Current Practice and Process in Institutionalization,” (Master’s thesis, University of Manitoba, 2000). News articles about contemporary sterilization of Indigenous women in Canada have been published recently. For example Betty Ann Adam, “An aboriginal woman calls for class action over sterilization,” *StarPhoenix* December 15 2015, <http://thestarphoenix.com/news/national/an-aboriginal-woman-calls-for-class-action-over-sterilization>, and Betty Ann Adam, “Saskatoon Health Region apologizes after aboriginal women felt pressured by staff to have tubes tied,” *National Post* November 17 2015, <http://news.nationalpost.com/news/canada/saskatoon-health-region-apologizes-after-aboriginal-women-felt-pressured-by-staff-to-have-tubes-tied>, both accessed January 30, 2016. In the American context, see Angela Gonzales, Judy Kertész, and Gabrielle Tayac, “Eugenics as Indian removal: sociohistorical processes and the de(con)struction of American Indians in the Southeast,” *The Public Historian* 29/3 (2007): 53-67; John Railey, “‘Bad’ Girls: Indians posed a tricky race problem for the state,” *Winston-Salem Journal* December 2, 2002, accessed July 30, 2016, [http://www.journalnow.com/news/local/bad-girls-indians-posed-a-tricky-race-problem-for-the/article\\_f02c5c24-8fee-11e2-8065-0019bb30f31a.html](http://www.journalnow.com/news/local/bad-girls-indians-posed-a-tricky-race-problem-for-the/article_f02c5c24-8fee-11e2-8065-0019bb30f31a.html).

<sup>60</sup> Strange and Stephen: 525. They also refer to the work of Mary Ellen Kelm who writes that medical writing “conflated racial mixing, sexual contact, and disease, and as the eugenics movement reached new heights in the 1930s and 1940s, First Nations were transformed in medical minds from victims to vectors of disease and, as such, joined the ranks of the polluting ‘other.’” Mary Ellen Kelm, “Diagnosing the discursive Indian: Medicine, gender, and the ‘Dying Race,” *Ethnohistory* 52/2 (2005): 382.

looking at Canadian eugenics to declare the link.<sup>61</sup> Research into this link is especially prevalent for Alberta feminists such as Emily Murphy who are directly connected to the passage of Alberta's Sexual Sterilization Act.<sup>62</sup> That this linkage is becoming common knowledge is evidenced by public reaction to commemorations of suffragists such as Nellie McClung.<sup>63</sup>

Although the scholarship on sterilization of people labelled with intellectual disability is increasing, few scholars have worked with sterilization survivors directly or have facilitated the dissemination of their experiences. In Canada, the Eugenics Archives is the only known project that has directly sought to interview sterilization survivors.<sup>64</sup> Robert Wilson, project leader for the Eugenics Archives, explains that this absence from the oral history record is due to the devaluation and assumption of incompetence of those labelled with intellectual disability. Wilson writes

it is not simply that survivor oral history has been omitted, forgotten, or neglected, as in other cases; rather, it is that survivor oral history has been presumed to be precluded by the putative nature of those deemed mentally deficient.<sup>65</sup>

In other projects, such as Malacrida's research and *The Freedom Tour*, where interviews were actively sought with institutional survivors, the topic of sterilization also

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<sup>61</sup> McLaren, "The creation of a haven for 'human thoroughbreds,'" 133.

<sup>62</sup> For example, Erin L. Moss and Henderikus J. Stam, "From suffrage to sterilization: Eugenics and the women's movement in 20<sup>th</sup> century Alberta," *Canadian Psychology/Psychologie canadienne* 54/2 (2013): 105-114.

<sup>63</sup> Patrick White, "Human-rights lawyer opposes honour for right-to-vote pioneer Nellie McClung," *The Globe and Mail* April 23, 2010, accessed July 11, 2016, <http://www.theglobeandmail.com/news/national/human-rights-lawyer-opposes-honour-for-right-to-vote-pioneer-nellie-mcclung/article1241485/>.

<sup>64</sup> Eugenics Archives, "Our Stories," accessed March 6, 2016, <http://eugenicsarchive.ca/discover/our-stories>.

<sup>65</sup> Wilson: 120-121.

arose.<sup>66</sup> The National Film Board documentary about Leilani Muir also includes some interviews with other institutional survivors as well as testimony from Muir.<sup>67</sup> In the United States, Rebecca Kluchin interviewed sterilization survivors.<sup>68</sup> The *Winston-Salem Journal*, as part of its series on sterilization in North Carolina, also interviewed survivors.<sup>69</sup>

### Study of eugenics in Canada

In the larger field of eugenics in Canada, there are three monographs.<sup>70</sup> The most recent is the December 2013 book by Erika Dyck entitled *Facing Eugenics: Reproduction, Sterilization, and the Politics of Choice*.<sup>71</sup> Dyck's book looks at both coerced and voluntary sterilization in Alberta.<sup>72</sup> Freelance journalist Jane Harris-Zsovan's *Eugenics and the Firewall: Canada's Nasty Little Secret* examines the practices of the Alberta Eugenics Board.<sup>73</sup> A more national scope is taken by Angus McLaren in his book

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<sup>66</sup> *The Freedom Tour* and Malacrida, *A Special Hell*, 214-218.

<sup>67</sup> Glynis Whiting and National Film Board of Canada, *The Sterilization of Leilani Muir* (Montreal: National Film Board of Canada, 1996.)

<sup>68</sup> Rebecca M. Kluchin, "Locating the Voices of the Sterilized," *The Public Historian* 29/3 (2007): 143.

<sup>69</sup> See for example, John Railey, *Winston-Salem Journal* December 9, 20002, "It Ain't Fair," accessed March 6, 2016, [http://www.journalnow.com/news/local/it-ain-t-fair/article\\_811cc532-8fec-11e2-92a5-0019bb30f31a.html](http://www.journalnow.com/news/local/it-ain-t-fair/article_811cc532-8fec-11e2-92a5-0019bb30f31a.html).

<sup>70</sup> Robert Wilson describes the current scholarship on Canadian eugenics as "substantial but still radically incomplete." Wilson:124.

<sup>71</sup> Erika Dyck, *Facing Eugenics: Reproduction, Sterilization, and the Politics of Choice* (Toronto: University of Toronto Press, 2013).

<sup>72</sup> There is some controversy over whether institutionalization is a eugenic practice. However, I follow the lead of Dick Sobsey, of the University of Alberta's J.P. Das Developmental Disabilities Centre and the John Dossetor Health Ethics Centre, who says, "In Western Canada, institutionalization is an even bigger weapon of eugenics than sterilization ... but easier to pass off as something else." Cited in Andrea Sands, "Newgenics' still rampant in Alberta, conference told," *EdmontonJournal.com* October 24, 2010, accessed July 30, 2016, <http://www.geneticsandsociety.org/article.php?id=5439>. Strange and Stephen say that "the incarceration of people identified as subnormal or inappropriately sexual accomplished eugenic objectives, even in provinces where eugenic policies were never codified in law.": 527.

<sup>73</sup> Jane Harris-Zsovan, *Eugenics and the Firewall: Canada's Nasty Little Secret* (Winnipeg: J. Gordon Shillingford Publishing Inc., 2010).

*Our Own Master Race* although his research extends only to 1945.<sup>74</sup> McLaren's book, published in 1990, has been described as the "sole overview" of eugenics in Canada.<sup>75</sup> The field of eugenics history has been much more widely researched in recent years in the United States, although even as late as 2007 Burke and Castaneda said that a "profound amnesia ... characterizes its history."<sup>76</sup> A recent article in *The New Yorker* magazine titled "The Forgotten Lessons of the American Eugenics Movement" comments that although several books and articles about eugenics and coerced sterilization have been written over the past decades, many of them point out that this history is unknown or secret. Andrea DenHoed, the author of the article, says, "Yet it seems that the collective forgetfulness is not a matter of some well of information remaining untapped but of our inability or unwillingness to soak up what is drawn out of it."<sup>77</sup> DenHoed also points out that "forced or coerced sterilizations never entirely went away either. In 2013, the Center for Investigative Reporting revealed that at least a hundred and forty-eight female prisoners in California were sterilized without proper permission between 2006 and 2010."<sup>78</sup> DenHoed's depiction of the general unwillingness to understand the history of eugenics and coerced sterilization is paralleled by Boulanger

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<sup>74</sup> Angus McLaren, *Our Own Master Race: Eugenics in Canada, 1885-1945* (Toronto: McClelland & Stewart Inc., 1990).

<sup>75</sup> Strange and Stephen: 523.

<sup>76</sup> Burke and Castaneda: 9. Monographs on American eugenics number over two dozen and include: Nancy Ordover, *American Eugenics: Race, Queer Anatomy, and the Science of Nationalism* (Minneapolis: University of Minnesota Press, 2003); Edwin Black, *War Against the Weak: Eugenics and America's Campaign to Create a Master Race* (Washington, DC: Dialog Press, 2012); Paul Lombardo, ed., *A Century of Eugenics in America: From the Indiana Experiment to the Human Genome Era* (Bloomington: Indiana University Press, 2011); and Rebecca M. Kluchin, *Fit to be tied: sterilization and reproduction rights in America, 1950-1980* (New Brunswick: Rutgers University Press, 2009).

<sup>77</sup> Andrea DenHoed, "The Forgotten Lessons of the American Eugenics Movement," *The New Yorker* April 27, 2016, accessed July 11, 2016, <http://www.newyorker.com/books/page-turner/the-forgotten-lessons-of-the-american-eugenics-movement>.

<sup>78</sup> Ibid.

who says that “there was so much documentation about the realities of life inside institutions” yet she “remembered a People First member saying that ‘Some people don’t believe our stories!’”<sup>79</sup>

## **Institutions**

Institutions have been most famously theorized by Erving Goffman and by Michel Foucault.<sup>80</sup> In 1961, sociologist Erving Goffman, published a book of four essays examining mental and other institutions called *Asylum*.<sup>81</sup> In this book, he developed the concept of “total institutions” as a place where the entire life of the confined is lived in a large group while being simultaneously managed and controlled by authorities. *Asylum* has also been described as “above all, a text that humanises a dehumanised group of people.”<sup>82</sup> Michel Foucault’s examination of prisons, *Discipline and Punish*, has been extrapolated to examinations of institutions for people labelled with intellectual disability by researchers such as Malacrida and Dyck. In particular, Malacrida has used Foucault’s discussion of the Panopticon to describe policing and self-policing behaviours in the Michener Centre. In a significant use of Foucauldian thought, Malacrida emphasizes that record-keeping in the institution “stands as an additional layer in the discipline of unruly

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<sup>79</sup> Boulanger, 117.

<sup>80</sup> Other important work has been done by Wolf Wolfensberger. See especially “The Origin and Nature of Our Institutional Models,” *Changing Patterns in Residential Services for the Mentally Retarded* (President’s Committee on Mental Retardation, Washington, D.C., 1969). This chapter can be accessed at the Disability History Museum website at <http://www.disabilitymuseum.org/dhm/lib/detail.html?id=1909&page=all>.

<sup>81</sup> Erving Goffman, *Asylums: Essays on the Social Situation of Mental Patients and Other Inmates* (Chicago: Aldine Pub. Co., 1961). For a very brief summary of Goffman’s conception of the total institution, see Benny Goodman, “Erving Goffman and the total institution,” *Nurse Education Today* 33 (2013): 81-82.

<sup>82</sup> Seamus Mac Suibhne, “Erving Goffman’s *Asylum* 50 years on,” *The British Journal of Psychiatry* 198 (2011): 1.

bodies.” For example, she describes the raised nursing station with its “visible array of patient charts” as also a “visual display of power and knowledge to inmates who could clearly see that they were being observed and charted on an ongoing basis.”<sup>83</sup>

### **Accessing records**

As shown above, the literature describing the lives of people labelled with intellectual disability and the portions of their lives lived in institutions is scarce. Historian Susan Burch and independent scholar Hannah Joyner say that “the persistence of social stigma about disability and institutionalization reaches into current disability research.” Individuals placed in institutions were “out of sight, out of mind—and out of the traditional interpretation of history.” This marginalization from society and from historical accounts is compounded by both the difficulty in accessing archival records and in the difficulties in accessing individuals, family members or institutional staff to speak about what went on behind the institutions’ walls.<sup>84</sup> As noted in a review of Burch and Joyner’s book in *Disability Studies Quarterly*, life in institutions is simply “a world that is typically inaccessible.”<sup>85</sup>

The historical literature on institutions for people labelled with intellectual disability may be limited because of the great difficulty in accessing the historical records. Specifically, in regard to institutions and other state-supported eugenic practices,

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<sup>83</sup> Malacrida: *A Special Hell*: 69. See also Dyck: 155.

<sup>84</sup> Burch and Joyner: 6. They say, “Former and current patients, their family members, and hospital staff are often reluctant to speak about life inside the asylum. And privacy rights policies discourage research into myriad disability topics.”

<sup>85</sup> Sarah Franz, review of Susan Burch and Hannah Joyner, *Unspeakable: The Story of Junius Wilson*, *Disability Studies Quarterly* 31/1 (2011).



it has been argued that restricted access to records protects the institutions and government more than the residents or sterilization victims. Paul Lombardo, a United States lawyer and historian, says in regard to attempts to access the Eugenics Board records of North Carolina that “the history of things has been to put up roadblocks ... (Officials) make it as difficult as possible for people to find this stuff.”<sup>86</sup> Johanna Schoen, the only known researcher to have gained access to the North Carolina sterilization records, describes her access to these records as “an anomaly unlikely to repeat itself.”<sup>87</sup>

To date, Canadian archivists have not approached the topic of access to eugenic records. This lack of interest persists even though the types of problems associated with eugenic records, such as Shortt’s assertion that reluctance by historians to pursue medical history is partly because “research materials are obscure or...non-existent or inaccessible,” seem to be precisely those that archivists should be excited to explore.<sup>88</sup> Although Canadian archivists have not so far specifically examined records relating to people labelled with intellectual disability, scholars such as Claudia Malacrida and Dominique Clément have examined the issues around research ethics, negotiating privacy legislation, and the problems with archival description and finding aids.<sup>89</sup>

Although not specifically related to eugenics records, a number of archivists have

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<sup>86</sup> Paul Lombardo, cited in Kevin Begos, “Records unexpectedly available,” *Winston-Salem Journal* December 9, 2002, accessed February 2, 2014, [http://www.journalnow.com/news/local/article\\_5b7781c8-8fe7-11e2-92f3-0019bb30f31a.html](http://www.journalnow.com/news/local/article_5b7781c8-8fe7-11e2-92f3-0019bb30f31a.html).

<sup>87</sup> Johanna Schoen, *Choice and Coercion* (Chapel Hill: The University of North Carolina Press, 2005): 243.

<sup>88</sup> Samuel Shortt, “The new social history of medicine: Some implications for research,” *Archivaria* 10 (1980): 9.

<sup>89</sup> See Malacrida, “Contested memories,” and Dominique Clément, “Freedom of Information in Canada: Implications for research,” *Labour/Le Travail* 75 (2015), 101–131.

examined general issues surrounding finding aids and the needs of researchers. Barbara Craig in particular has looked at the needs of researchers in the area of Canadian medical history.<sup>90</sup> Almost 20 years ago, Craig pointed out that the history of medicine in Canada is “unevenly served by information about these sources—what they are, where they are located, what they contain, and what restrictions exist on their use.”<sup>91</sup> Craig had proposed that a general guide to resources for research into the medical history of Canada be created, but unfortunately, even with the advent of the internet, this guide did not come to fruition.<sup>92</sup> The role and purpose of finding aids in archives is a well-discussed subject in archivry, for example a search in the JSTOR database for “finding aid” returns 1,847 results.<sup>93</sup> The interest in the area may be due to the fact that, as Wendy Duff and Catherine A. Johnson succinctly say, “finding information in archives is not an easy task.” For researchers, “archival information systems can be overwhelming and daunting at times.”<sup>94</sup>

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<sup>90</sup> Barbara L. Craig, “What research tools do historians of Canadian medicine currently use? What do they need and want for the future? Report and analysis of a survey, 1995-96,” *Canadian Bulletin of Medical History / Bulletin canadien d’histoire de la médecine* 14 (1997): 289-307.

<sup>91</sup> *Ibid.*, 290.

<sup>92</sup> Although various universities and archives provide links to their own or others’ medical holdings, the type of portal that Craig envisioned almost twenty years ago is still not available. For examples of guides from universities, see Queen’s University, “History of medicine: A scandalously short introduction,” accessed June 3, 2016, [http://meds.queensu.ca/medicine/histm/biblio/biblio\\_resources.html](http://meds.queensu.ca/medicine/histm/biblio/biblio_resources.html); McGill University, “Other archives with McGill and Canadian historical medical material,” accessed June 3, 2016, [http://osler.library.mcgill.ca/archives/other\\_archives.htm](http://osler.library.mcgill.ca/archives/other_archives.htm); and McMaster University, “History of Health and Medicine,” accessed June 3, 2016, <http://hsl.mcmaster.libguides.com/hhm>. See also the Archives of Ontario, “Patient and health practitioner records,” accessed June 3, 2016, [http://www.archives.gov.on.ca/en/access/documents/research\\_guide\\_224\\_patient\\_health\\_practitioner.pdf](http://www.archives.gov.on.ca/en/access/documents/research_guide_224_patient_health_practitioner.pdf). For a general introduction to examples from medical records at the AO, see “Medical records at the Archives of Ontario,” accessed June 3, 2016, [http://www.archives.gov.on.ca/en/explore/online/health\\_records/index.aspx](http://www.archives.gov.on.ca/en/explore/online/health_records/index.aspx).

<sup>93</sup> Search performed June 3, 2016.

<sup>94</sup> Wendy Duff and Catherine A. Johnson, “Accidentally found on purpose: Information-seeking behavior of historians in archives,” *The Library Quarterly* 72/4 (Oct. 2002): 472.

Funding and resource issues also play a role in restricting records when archives have inconvenient opening hours, are short-staffed, and need to choose collections for highlighting that play to popularity. Within archives struggling with funding, it is very likely that records describing marginalized and devalued populations, such as people labelled with intellectual disability, will be among the last of the prioritized records. This issue does not appear to have been addressed by any Canadian archivist although (as will be briefly explored in the concluding chapter of this thesis) a research group in the UK has developed several collaborative archival projects with people with learning disabilities.<sup>95</sup>

Although Burch and Joyner may rightly claim that a stigma exists about disability and institutionalization, in recent years the history of intellectual disability has been growing as a sub-field of disability history and now exists as a “distinct area of historical enquiry.”<sup>96</sup> The types of histories included in this sub-field lean toward philosophical or sociological explorations. As examples, some recent notable publications that explore the constructions of intellectual disability include Allison Carey’s *On the Margins of Citizenship: Intellectual Disability and Citizenship in Twentieth-Century America*; Licia Carlson’s *The Faces of Intellectual Disability: Philosophical Reflections*, and Patrick McDonagh’s *Idiocy: A Cultural History*.<sup>97</sup> These broad-based scholarly works examine

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<sup>95</sup> The term “learning disability” is used in the UK rather than “intellectual disability.” See for example NHS Choices, “What is a learning disability?” accessed July 11, 2016, <http://www.nhs.uk/Livewell/Childrenwithalearningdisability/Pages/Whatislearningdisability.aspx>.

<sup>96</sup> Dorothy Atkinson and Jan Walmsley, “History from the inside: towards an inclusive history of intellectual disability,” *Scandinavian Journal of Disability Research* 12/4 (2010): 274.

<sup>97</sup> Allison C. Carey, *On the Margins of Citizenship Intellectual Disability and Civil Rights in Twentieth-Century America* (Philadelphia: Temple University Press, 2009); Licia Carlson, *The Faces of Intellectual*

British or American history; evidence of this type of scholarly interest has not yet appeared in Canada. However, the 2010-2015 CURA-funded Living Archives of Eugenics in Western Canada included a mission goal to “create innovative academic resources for scholars across academic fields.”<sup>98</sup> The digital Eugenics Archives that is the project’s legacy may help to inspire more research in this area.<sup>99</sup>

Nic Clarke, a Canadian historian, points out that research into the “evolving constructions of intellectual disability in western society” has “opened historians’ eyes to the existence of a minority group that has long been ignored.”<sup>100</sup> However, as shown by the limited number of publications in this field, Clarke’s view might be more realistically amended to ‘opened *a few* historians’ eyes.’ Licia Carlson states in her introduction to *The Faces of Intellectual Disability: Philosophical Reflections* that whenever she tells other philosophers she is interested in the area of intellectual disability she is asked if she has a family member with an intellectual disability. She said that she became “increasingly irritated” at the assumption that someone would only have an interest in the area if they had a family member so labelled. Rather, she says that “the philosophical questions that emerge in connection with intellectual disability are matters that not only are worthy of scholarly interest but speak to the deepest problems of exclusion, oppression, and dehumanization.”<sup>101</sup> Despite the importance of these questions, Carlson notes that “intellectual disability remains relatively marginal within philosophical

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*Disability: Philosophical Reflections* (Indiana University Press, 2009); Patrick McDonagh, *Idiocy: A Cultural History* (Liverpool: Liverpool University Press, 2008).

<sup>98</sup> Eugenics Archives, accessed August 17, 2015, <http://eugenicsarchive.ca/about>.

<sup>99</sup> The archive has 893 entries. Accessed March 5, 2016, <http://eugenicsarchive.ca/database/category/all>.

<sup>100</sup> Clarke: “Opening Closed Doors,” 468.

<sup>101</sup> Carlson, 3.

discourse.”<sup>102</sup> Allison Carey, in the introduction to her book *On the Margins of Citizenship*, also comments that “work on citizenship and disability rights has burgeoned recently, yet intellectual disability has garnered little attention.”<sup>103</sup>

Clarke notes that the historians who have studied intellectual disability have mostly “focused on institutions and those who administered them, rather than on the experiences of individuals who were so labelled and their families.”<sup>104</sup> Clarke’s assertion echoes Shortt’s statement that “simply put, medical history has ignored the patient.”<sup>105</sup> Some of this lack of focus may result, as Shortt says, from “the historian’s disinterest or lack of imagination” or “more probably, it is evidence of the anonymity of the patient.”<sup>106</sup> Clarke however seems to fall on the side of the argument that the lack of scholarship reflects the historians’ lack of imagination and he urges scholars to “step beyond the bounds of the institution.”<sup>107</sup> He maintains that “the emphasis on the asylum has given it an undeservedly important place in the history of intellectual disability and mental illness.”<sup>108</sup> Similarly, in 1996, a reviewer of Philip Ferguson’s book *Abandoned to Their Fate: Social Policy and Practice toward Severely Retarded People in America, 1820-1920*, pointed out that the answers that Ferguson “uncovers” are “by now largely familiar” and emphasized the same factors as in “many other accounts”:<sup>109</sup>

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<sup>102</sup> Ibid.

<sup>103</sup> Carey, 13.

<sup>104</sup> Clarke: “Opening Closed Doors,” 468.

<sup>105</sup> Shortt, 19. Shortt also notes that Frances Smith made a similar statement: “‘Patients’, observes Frances Smith, ‘loom small in medical history,’” 10.

<sup>106</sup> Shortt, 19.

<sup>107</sup> Clarke, “Sacred Daemons,” 89.

<sup>108</sup> Clarke: “Opening Closed Doors,” 470.

<sup>109</sup> In contradiction to the familiarity that Ferguson claims, one reviewer says that apart from two exceptions, “historians generally ignored this group.” Gerald N. Grob, review of *Abandoned to Their Fate*:

the growth of large, impersonal, and often abusive institutions; the state's role in controlling or hiding persons considered dangerous, burdensome, or embarrassing; the self-interest of professional experts; and the dominance of a marketplace mentality that evaluates people largely in economic terms.<sup>110</sup>

Ferguson points out that only a small percentage of individuals with disabilities lived in institutions (this was true at least in the time period of his study of 1820-1920). Many people, during this time, either lived in almshouses as paupers or lived within their family homes.<sup>111</sup> Ferguson submits that there is “a need for historians to break out of the institution and greatly increase our understanding of how families with disabled members, mild or severe, have functioned in their communities, at all levels of society.”<sup>112</sup> A step in this direction has been taken by photographer Vincenzo Pietropaolo in his book *Invisible no more: A photographic chronicle of the lives of people with intellectual disabilities*. However, as Catherine Frazee cautions in her introductory essay to Pietropaolo's book, we must be cautious about conflating lives lived outside the institution: “Each of the subjects who greet us from the pages of this book is distinct and individual, not some proxy for similar lives in similar communities.”<sup>113</sup>

While there is a need for sophisticated, complex and nuanced understandings of the many ways people labelled with intellectual disability historically have lived their lives, this thesis is restricted to an examination of the records related to the institutional

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*Social Policy and Practice toward Severely Retarded People in America, 1820-1920, History of Education Quarterly 35/3 (Autumn 1995), 332-333.*

<sup>110</sup> Leila Zenderland, review of *Abandoned to Their Fate: Social Policy and Practice toward Severely Retarded People in America, 1820-1920, American Historical Review 101/1 (1996), 242.*

<sup>111</sup> Ibid.

<sup>112</sup> Cited in Judith Dulberger, review of *Abandoned to Their Fate: Social Policy and Practice toward Severely Retarded People in America, 1820-1920, Journal of Social History 29/2 (1995), 411.*

<sup>113</sup> Catherine Frazee, “Genius: An introductory essay,” Pietropaolo, 11.

experience. Because this history has been so far shrouded from public understanding in Manitoba, these restrictive parameters are useful. Further, the lack of public knowledge about institutionalization in Manitoba perpetuates the existence of institutionalization and hampers restitution and redress for those who had been confined with the institutions' walls. Institutionalization will likely only end when the general public understands that community living for all is possible and institutionalization is wrong.

## **Chapter Two: “It’s easy to get in there but it’s hard to get out.”**

### **A short history of Manitoba’s institutions**

During the filming of *The Freedom Tour*, David Weremy visited the home of his friend Wayne Beever who had also been institutionalized at the Manitoba Developmental Centre. Mr. Beever had lived at the institution for thirty years and he said to Mr. Weremy, “It took a long time, but we got out.” Weremy agreed and said, “It’s easy to get in there but it’s hard to get out.”<sup>1</sup>

This chapter provides a short history of Manitoba’s three institutions for people with intellectual disabilities and in doing so provides a closer look at the published sources available for constructing the history of institutionalization in Manitoba. As will be shown throughout this thesis, it is a frustrating dilemma that a voluminous, rich, complex but largely inaccessible archival record exists for these institutions in Manitoba. But the problems in accessing the archival record are reflected by the bare bones—and in some instances, conspicuous gaps—that exists for much of the history of institutionalization in Manitoba and of the life experiences of those who were institutionalized.

### **History of the Manitoba Developmental Centre**

The institution currently called the Manitoba Developmental Centre (MDC) began in 1890 with the name “Home for the Incurables.” This institution was built by the Manitoba government in the rural location of Portage la Prairie, a small town about

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<sup>1</sup> David Weremy, cited in *The Freedom Tour*.



eighty-seven kilometres west of Winnipeg. As in the UK in the nineteenth century, rural locations for institutions for people with intellectual or mental disabilities were preferred possibly because of the “idealized vision of rural purity in contrast to the pollution and degeneration of the city.”<sup>2</sup> Although the pastoral location may have been meant to be beneficial to the patients of the institutions, the location away from the major urban centre where many of the residents had family likely restricted the degree of influence or connection the family had with their confined family member.<sup>3</sup> Apart from tuberculosis sanatoria, the large and heavily populated asylums and institutions have no comparable counterpart for treating physical ailments—indeed it would seem illogical to build a large surgery centre in a rural area and transport patients from urban areas or the surrounding countryside. The very placement of the institutions and asylums into the rural countryside emphasizes both the desire to segregate the residents from the general population and the determination that the residents were placed there for the long term rather than a location convenient for commuting.<sup>4</sup>

That the patients intended for the institution in Portage la Prairie were not typical medical patients is baldly spelled out in the name of the medical facility: The Home for

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<sup>2</sup> Mathew Thomson, “Sterilization, segregation and community care: ideology and solutions to the problem of mental deficiency in inter-war Britain,” *History of Psychiatry* 3 (1992): 481. Although large asylums or institutions for people labelled with mental illness or intellectual disability were displaced to rural areas, for much of the early decades of the twentieth century medical care remained localized in the individual office or home of the area’s general practitioner. Robin Glen Keirstead, “An Archival Investigation of Hospital Records,” (Master’s thesis, University of British Columbia, 1985), 4.

<sup>3</sup> The institution also served as the only location for services available for northern, remote, or other rural communities. Clarkson noted, “The Manitoba School for Retardates draws residents from all of Manitoba. This discourages visiting by parents and other relatives and friends. Contact tends to be lost and this becomes perpetuated through the life of the resident.” Clarkson, 87.

<sup>4</sup> Staff were also affected by the location of the institution and either lived on the institutional grounds or commuted from Winnipeg or other locales.

Incurables. Anne Collier, in her commemorative book for Portage la Prairie's centenary, describes the name of "Home for Incurables" as "unattractive" but apt. After reading institutional reports from 1898, she notes:

While every effort was made to make patients as comfortable as possible in the old "Home for Incurables", nothing seems to have been done to improve their twisted limbs or train them to make the most use of any faculties they might possess. It seems they were regarded as incurable and that was that!<sup>5</sup>

Reverend Walmsley, a chaplain at the Portage la Prairie institution, described the patients as people "with physically incurable diseases not requiring treatment in general hospitals" as well as "paralytics and 'mentally defective' persons."<sup>6</sup> Some of the early residents, though, may have had primarily mental health conditions as in 1891 eleven residents were transferred to the newly established Brandon Asylum.<sup>7</sup> Collier says that although a doctor from Portage la Prairie visited daily to attend to residents, she cites a 1898 report by Dr. Thos. M. Milroy that seems to indicate that rehabilitation with the aim of a return to society does not appear to have been the intention of the institution or even the hope of the patients. Rather, the doctor stated in his report that "'the patients, as a rule, are contented and resigned to their lot.'"<sup>8</sup> However, in another section of the report cited by Collier, a comment by the doctor contradicts his statement that the patients were contented and resigned as he notes that two isolated wards of the institution useful for containing outbreaks of contagious disease "will be of much assistance in controlling

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<sup>5</sup> Collier, 163.

<sup>6</sup> Walmsley, 9.

<sup>7</sup> Cornelia Johnson, "A history of mental health care in Manitoba: A local manifestation of an international social movement," (Master's thesis, University of Manitoba, 1980), 40.

<sup>8</sup> Cited in Collier, 162.

unruly patients.”<sup>9</sup> The reference to the isolation of “unruly patients” also provides an early indication of the institutional practice of the segregation and punishment of uncooperative residents.

The rural location of institutions was important for growing produce and raising livestock. Collier noted that additional land was purchased to allow the Portage la Prairie institution to provide its own pasture and most of the feed for livestock and also raise “all vegetables” for the residents.<sup>10</sup> Costs were further cut by relying on the unpaid labour of the residents to fulfill the agricultural duties (although the unpaid or forced labour was often couched in terms of rehabilitative work or occupational therapy). Walmsley wrote that by the 1930s

Occupational therapy became a part of the training and most of the residents received what was recognized as gainful employment in all departments of the institution: in the kitchen, the laundry, the sewing and mending rooms, on the wards, on the farm and in the gardens, in the barns and milking sheds, and anywhere else it was felt they might be useful and interested.<sup>11</sup>

Although Walmsley describes the work as “gainful employment” it is very unlikely the residents were paid.<sup>12</sup> The issue of unpaid labour in the institution as well as the practice of hiring out inmates to surrounding farms and families has been explored by Malacrida

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<sup>9</sup> Ibid.

<sup>10</sup> Cited in Collier, 162-163.

<sup>11</sup> Walmsley, 2. See also Thomson, 481. The English “colony system” also “set them to work in industrial workshops or farms within the colony.” Thomson also sees the origin of this “linkage of the colony, work and therapy” in the practices of colonies of people with tuberculosis: “relapse of patients after discharge from sanatoria led to calls for an extended ‘hardening up’ period in a colony after treatment.”

<sup>12</sup> Muir describes her labour at the Provincial Training School in Alberta (now called the Michener Centre): “After finishing Grade 5 at the PTS, we had to work most of the time doing chores at the institution. We weren’t paid for any of this work. When I was older, the institution arranged for me to do house-keeping in people’s home in Red Deer. The other girls and I were never paid for doing this work; we were told that the money was given directly to the office and apparently put in trust for us. But I never saw any of this money.” Muir, 44-45.

and Geoffrey Reaume in regard to other provinces' institutions but has so far has not been examined in Manitoba.<sup>13</sup>

The Portage la Prairie institution began with about fifty-seven residents but a long waiting list may have been the inspiration for the creation of a new wing in 1898 that doubled the accommodation capability.<sup>14</sup> Dr. Milroy declared in 1898 that while the first building was “very imperfect” the new addition created “an Institution which in regard to construction and equipment is one of the best in the Province.”<sup>15</sup> By 1913, another new wing was built and the original population more than quadrupled to total 275. The addition of the new wing also allowed the separation of residents into categories: “those who were aged being placed in one area and those who were mentally retarded in another.”<sup>16</sup> The following years spanning World War One saw almost no changes made to the institution due to restricted resources.

In 1920, the *Canadian Medical Association Journal (CMAJ)* published a commentary on “The Value of Psychopathic Hospitals.”<sup>17</sup> This commentary takes a very critical look at Manitoba’s earlier attempts at caring for people labelled with intellectual or mental health disabilities. The *CMAJ* author(s) noted that since the establishment of the Canadian National Committee for Mental Hygiene in 1918,

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<sup>13</sup> Geoffrey Reaume, *Remembrance of Patients Past: Patient Life at the Toronto Hospital for the Insane, 1870-1940* (Oxford University Press, 2000), especially 133-180 and Malacrida, especially 150-172.

<sup>14</sup> Walmsley, 2. The 1898 Milroy report cited by Collier states there had been originally sixty-eight residents but that nine had died, leaving the total to be fifty-seven. Collier, 161.

<sup>15</sup> Cited in Collier, 161-162.

<sup>16</sup> Walmsley, 2.

<sup>17</sup> “The Value of Psychopathic Hospitals,” *CMAJ* 10/1 (January 1920), 73-76.

A survey of the province of Manitoba showed that the care and treatment of the mentally abnormal and mentally defective were very mediaeval. The asylums were mere custodial institutions where the treatment was practically nil. There was no attempt at classification of patients, no laboratories were provided to aid in scientific diagnosis and every institution was greatly understaffed. The mentally defective were herded together with practically no attempt to improve their condition or make them happy. It was shown that a large proportion of the criminals, juvenile delinquents, prostitutes and unmarried mothers were mentally defective.<sup>18</sup>

The authors noted, “the government realized the situation, and to-day, Manitoba is in the process of having the most up-to-date system on this continent for caring for their insane and mentally defective.”<sup>19</sup> According to the authors, the basis for this accomplishment lay in the establishment of “a psychopathic department” that was connected with the Winnipeg General Hospital. This department was “under the leadership of a thoroughly trained physician and now no case of mental abnormality can be admitted to or discharged from any institution without first being observed in the psychopathic hospital.”<sup>20</sup> This new emphasis on medical science may account for some of the changes that began to be effected at the Manitoba institution. The corresponding emphasis on specialized treatment also points to the trend of increasing professionalization in the areas of medical care for people labelled with intellectual disability.

In 1924, the name of the Portage la Prairie institution was changed to the Home for the Aged and Infirm. By this time, the institution had 410 residents and 85 staff. Walmsley wrote that the increase in staff allowed workers to receive one day off per

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<sup>18</sup> Ibid., 74.

<sup>19</sup> Ibid.

<sup>20</sup> The author(s) noted that “neuro-psychiatry” was one of the “two departments of medical science which received the greatest impetus and stimulation during and as a result of the Great War” (the other was orthopaedic surgery). Ibid., 73-74

week. He also noted that a “city physician” continued daily visits and that church ministers from Portage la Prairie conducted Sunday services at the institution on a rotating schedule. In 1930, the Home was appointed its first medical superintendent, Dr. H.S. Atkinson. In Collier’s 1970 commemorative history, she remarks that “many people remember and praise Dr. Harry Atkinson for the forward strides made at the Home.”<sup>21</sup> Atkinson reorganized the staff and was “given permission to employ some registered nurses to work on the wards.”<sup>22</sup> Other changes included a medical library, a dispensary and occupational therapy. Interestingly, Walmsley states that “from this time, records began to be kept on each patient.”<sup>23</sup> Although Walmsley dates the beginning of record-keeping to about 1930, the clinical files held at the Archives of Manitoba date from 1890 when the institution was first established.

Around 1930, the Manitoba government changed the mandate of the institution to be “exclusively for the care of ‘mentally defective’ persons” and “the aged and infirm were sent to various municipal residences and provincial sanitoriums [sic].”<sup>24</sup> As mentioned earlier, this classification and separation of residents appears to be part of the new post-war understanding regarding institutions for those deemed mentally or intellectually disabled. As noted in the 1920 *Canadian Medical Association Journal*, the advice to provinces was to create “a state institution on the colony plan, with a

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<sup>21</sup> Collier, 164.

<sup>22</sup> Walmsley, 2.

<sup>23</sup> Ibid.

<sup>24</sup> Ibid.

department for the feeble-minded and one for the epileptic.”<sup>25</sup> In 1933, following the passing of Manitoba’s *Mental Deficiency Act*, the institution was renamed the “Manitoba School for Mental Defectives.” Walmsley reported that at this time Superintendent Atkinson planned to “enlarge the scope of services to the mentally retarded by instituting travelling mental health clinics, supervised centers for the training of ‘high-grade mental defectives,’ and extensive out-patient service to the surrounding district.” However, these plans were not fulfilled due to the economic depression of the 1930s and, as Walmsley notes, “the expertise in the field was exceedingly limited.”<sup>26</sup>

In 1937 a residence for nurses was built on the grounds and this “eased somewhat the chronic overcrowding.”<sup>27</sup> Previous to this staff facility, nurses had lived in rooms attached to the residents’ wards. The new nurses’ residence allowed for the “setting up of sewing rooms and other special activity rooms.” In 1939 the institution held the first graduation exercises for nurses who had earned a diploma in “mental nursing.” Male attendants also began to attend lecture courses that year.<sup>28</sup>

World War II brought a number of changes to the institution. Beginning in 1939, the institution provided X-ray, laboratory and “psychiatric services” to a military training centre and two air-training schools near Portage la Prairie. Superintendent Atkinson took

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<sup>25</sup> *CMAJ* (January 1920), 75. It was noted that Québec ran only private institutions. The colony plan, also called the cottage plan, is a type of asylum architecture that uses central buildings for administration and a variety and dispersal of buildings for the inmates. The inmates are usually housed according to categories devised by the institution or asylum. It is thought that the dispersal of buildings also helped to control disease such as dysentery. See the Asylum Projects wiki “Cottage Planned Institutions,” accessed July 12, 2016, [http://www.asylumprojects.org/index.php?title=Cottage\\_Planned\\_Institutions](http://www.asylumprojects.org/index.php?title=Cottage_Planned_Institutions).

<sup>26</sup> Walmsley, 2.

<sup>27</sup> *Ibid.*

<sup>28</sup> *Ibid.* This shift toward the training of medical staff is also seen to occur at the Michener Centre in Alberta. Malacrida, *A Special Hell*, 167-169.

a leave of absence from 1940 to 1946 and became a member of the Royal Canadian Army Medical Corps.<sup>29</sup> He was replaced during his absence by Dr. Morval Bristow who later went on to work at the Brandon mental hospital.<sup>30</sup> By 1941, twenty-eight other staff members enlisted in the armed services. Walmsley reported that “the war years saw a 100% turnover in the female nursing staff, which made consistently good service to the patients very difficult.”<sup>31</sup> Interim superintendent Dr. Bristow sought out conscientious objectors to fill vacant staff positions.<sup>32</sup> Mennonite archivist Conrad Stoesz, in his article on conscientious objectors, says that it was not only the war that depleted institutional and hospital staff: government cost reduction through wage cuts had a significant effect on professional staff. In 1941, Stuart Schultz, the director of the Brandon Hospital for Mental Diseases (now known as the Brandon Mental Health Centre) wrote:

One can endure losses to essential war services with equanimity and even encourage enlistment for such purposes, but the loss of intelligent and experienced staff because of justifiable dissatisfaction over working conditions is difficult to condone.<sup>33</sup>

Although the above quote references the Brandon institution, information provided by conscientious objectors stationed at the Manitoba School for Mental Defectives provides an inside look at the institution that also shows deficiencies in conditions for both staff and residents. Roland Reimer, a conscientious objector stationed at the Portage la Prairie

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<sup>29</sup> Collier, 164 and Walmsley, 2.

<sup>30</sup> Collier, 164. According to his brother in a family history, Dr. Bristow “practiced at the Manitoba School for the Mental at Portage, then at Brandon for thirty-five years, being retired January 31<sup>st</sup>, 1966.” See Kelwood Centennial Committee, *Kelwood Bridges the Years 1890-1967* (Altona, MB: The Kelwood Centennial Committee, 1967), 1889.

<sup>31</sup> Walmsley, 2.

<sup>32</sup> Conrad Stoesz, ““Are you prepared to work in a mental hospital?”: Canadian Conscientious Objectors’ Service during the Second World War,” *Journal of Mennonite Studies* 29 (2011), 63. For more information on conscientious objectors and institutions, see Steven J. Taylor, *Acts of Conscience: World War II, Mental Institutions, and Religious Objectors* (Syracuse: Syracuse University Press, 2009).

<sup>33</sup> Cited in Stoesz, 64.



institution, recalled many times when he was alone with over fifty patients, including times when he was assigned to Ward 8 where the “combative” residents were confined.<sup>34</sup> Two of the conscientious objectors noted that their training consisted of shadowing a nurse for only one day.<sup>35</sup> However, once the war ended, “steps were taken to remedy the urgent demand for increased facilities and staff.”<sup>36</sup>

The 1950s saw the emergence of advocacy groups created by parents.<sup>37</sup> In May 1950, a group of parents who regularly met on the train travelling from Winnipeg to the institution in Portage la Prairie “talked about their mutual problems and wondered how they could best assist the School.”<sup>38</sup> These parents

began participating in organized efforts on behalf of the retarded. Disturbed by the paucity of reading material on mental retardation and by the fact that family physicians were unable to provide much information on the subject, they evolved plans to assist the Manitoba School in meeting the needs they had become aware of during their visits to the School.<sup>39</sup>

As Walmsley documents, this original parent group eventually became the Manitoba Association for Retarded Children (MARC).<sup>40</sup> By 1968, MARC had grown to include twenty-five branches throughout Canada and was re-named the Canadian Association for the Mentally Retarded (CAMR) to reflect its mandate to also address the needs of adults.<sup>41</sup> In 1985, the focus of CAMR again shifted and the organization became the

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<sup>34</sup> Ibid.

<sup>35</sup> Ibid., 66.

<sup>36</sup> Walmsley, 2.

<sup>37</sup> Ibid., 3. See also Adams, 20-24.

<sup>38</sup> Walmsley, 3.

<sup>39</sup> Ibid.

<sup>40</sup> Ibid. See also Adams, 23.

<sup>41</sup> Melanie Panitch, *Disability, Mothers and Organization* (New York: Routledge, 2008), 4.

Association for Community Living.<sup>42</sup> Research into parental involvement in the institutions could highlight a number of issues. As Walmsley rightly notes, “it would be a story of its own to describe the work carried out by the auxiliary from the original provision of party treats to the purchase and building of a lakeside resort on the shores of Lake Manitoba for summer camping for the residents of the Manitoba School.”<sup>43</sup>

The professionalization of institutional staff in Manitoba that began in the late 1930s saw increased recognition by the 1960s. The Psychiatric Nurse Training Act was passed by the Manitoba government in 1960, allowing students to receive a Certificate of Registration after completing three years of study and passing provincial examinations. The first class of students received provincial licensing in 1963 and Walmsley states “this was obviously a turning point in the care of the mentally retarded.”<sup>44</sup> The impetus for training of staff may partially have been driven by the increasing population of the Manitoba School. The decades of the 1950s and 1960s saw the highest population numbers at the institution. In 1957, the institution had 907 residents (adult and children) and by 1962, the residents numbered over 1,100 and there were 425 staff, including five doctors. In the late 1960s, this number reached 1,240.<sup>45</sup>

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<sup>42</sup> Adams, 23. Although Walmsley and Adams write about “parents,” Melanie Panitch states that literature that describes parents’ organizations or movements “obscures the gendered nature of the parenting role” and hides the mothers who have been at the forefront of parent activism in regard to disability rights. Panitch, 2. She says that since 1988, when a publication first linked parenting a disabled child to feminist issues, up to the publication date of her own book, there was “no scholarly work at all on the significant struggles for social justice and equality waged by activist mothers of disabled children.” 3. Her book focuses on the oral history interviews of three mothers from British Columbia, Ontario and Québec.

<sup>43</sup> Walmsley, 3.

<sup>44</sup> Ibid.

<sup>45</sup> Adams, 21.

The overcrowding of institutions during this time period was seen throughout Canada and the United States. As the institutions had not been built to hold these numbers of residents, they became overcrowded, with a corresponding drop in living conditions. In the mid-1960s and early 1970s, reports about the appalling conditions in these types of institutions began to be publicly released. In 1965 Senator Robert Kennedy toured New York State's Willowbrook School and infamously described it as a "snake pit."<sup>46</sup> In turn, Governor Nelson Rockefeller and other public officials accused Kennedy of providing a misleading image of the state's institutions.<sup>47</sup> To provide evidence on the conditions of institutions, Boston University professor Burton Blatt and photographer Fred Kaplan toured five institutions in four northeastern states in December 1965 and clandestinely took photographs within wards generally unseen by the public. Their findings were published in a book titled *Christmas in Purgatory* of which thousands of copies were distributed freely through families and friends, and to legislators, community leaders and parent advocacy groups.<sup>48</sup> In 1967, a version of the findings was also published in *Look Magazine*, an American magazine that had a circulation of millions. The photographs and accompanying text showed horrifying conditions but, as Blatt later wrote, "our pictures could not even begin to capture the total and overwhelming horror

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<sup>46</sup> To view a short video clip of Robert Kennedy's comments, see The Minnesota Governor's Council on Developmental Disabilities, "Robert Kennedy Visiting Institutions in NY," accessed August 1, 2016, [https://mn.gov/mnddc/parallels/five/5b/5b\\_html/5b\\_4vid.html](https://mn.gov/mnddc/parallels/five/5b/5b_html/5b_4vid.html). In Manitoba, an Ombudsman's report in the mid-1980s showed concern about "the use of mind-altering drugs, about staffing physical conditions that seem to be inadequate, about the treatment of our most vulnerable citizens in society" at MDC. This quotation comes from the April 23, 1987 Hansard. The speaker is Gary Filmon.

<sup>47</sup> Steven J. Taylor, "Christmas in Purgatory: A Retrospective Look," *Mental Retardation* 44/2 (April 2006), 145-149. DOI: <http://www.aaidjournals.org/doi/abs/10.1352/0047-6765%282006%2944%5B145%3ACIPARL%5D2.0.CO%3B2>, accessed August 21, 2015.

<sup>48</sup> The book continues to be freely available as a PDF. Burton Blatt and Fred Kaplan, *Christmas in Purgatory* (Syracuse: New York, 1974), accessed July 30, 2016, <https://mn.gov/mnddc/parallels2/pdf/undated/Xmas-Purgatory.pdf>.

we saw, smelled, and felt.”<sup>49</sup> Blatt and Kaplan linked much of the abysmal conditions to “the extraordinary shortage of staff in practically all of these dormitories.”<sup>50</sup>

In Canada, in the early 1960s, Pierre Berton wrote a column for the *Toronto Star* describing the conditions of Ontario’s Huronia institution. He said that “prisoners in reformatories have better facilities.” He also called it a “fire trap” with an “appalling stench” and described the beds as “crammed together.”<sup>51</sup> Soon after Berton’s visit, Ontario’s CCF leader toured the institution and declared it to have “intolerable conditions” and that it was more a place of “human storage” than a hospital.<sup>52</sup> In Manitoba, similar experiences were reported by the Junior League in 1967 when it toured the Manitoba Developmental Centre and St. Amant. Regarding the MDC, the Junior League reported: “Conditions therein were so amazingly antiquated that it is necessary in this report to draw attention fully to both the obvious and hidden reforms that must be instigated if we are to be proud of the kind of community in which we live.”<sup>53</sup> Although their remarks concerning St. Amant were much more favourable, the League’s general conclusion was that “Manitoba is merely housing retarded people in the easiest, cheapest, way possible.”<sup>54</sup> Another rare glimpse inside the Manitoba Developmental Centre is provided in a memoir by Nicola Schaefer, a Winnipeg mother of a daughter (Catherine) with disabilities. Schaefer visited MDC in the early 1970s and wrote: “The whole place

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<sup>49</sup> Ibid., unpaginated introduction.

<sup>50</sup> Ibid., 13.

<sup>51</sup> Pierre Berton, “What’s Wrong at Orillia: Out of Sight – Out of Mind,” *Toronto Daily Star* December 6, 1960. This column was reprinted in the *Toronto Star* September 20, 2013, accessed August 1, 2016, [https://www.thestar.com/news/insight/2013/09/20/huronia\\_pierre\\_berton\\_warned\\_us\\_50\\_years\\_ago.html](https://www.thestar.com/news/insight/2013/09/20/huronia_pierre_berton_warned_us_50_years_ago.html).

<sup>52</sup> Cited in Dolmage v. HMQ, 2013. This quote was also reported in *The Globe and Mail*, January 7 1960.

<sup>53</sup> Archives of Manitoba, Junior League of Winnipeg fonds, “Mentally Retarded Children,” 1966-67, P2303/3.

<sup>54</sup> Ibid.

smelled of excrement ineffectively masked by a pungent disinfectant, but the smell became a stink as I approached the room .... It wasn't very encouraging."<sup>55</sup>

In 1973, to help relieve some of the severe overcrowding at MDC, residents began to be transferred to a new institution opened up at the recently closed tuberculosis sanatorium at Ninette, Manitoba (about 2 ½ hours west of Winnipeg). The name of the new institution was Pelican Lake Training School and although a significant portion of its funds came from the government of Manitoba, the institution was under the governance of the Sanatorium Board of Manitoba. Further efforts to reduce the MDC's population included finding community placements and by 1975, the MDC residents numbered 970 and the staff swelled to 700.<sup>56</sup> In 1984, the name of the Portage la Prairie institution was changed to the Manitoba Developmental Centre. In 1987, the province initiated the Welcome Home Program which created further opportunities for about 200 residents of MDC to leave and return to the community.

In 2004, despite the growing trend in Canada to close large institutions, the New Democratic Party government in Manitoba announced a \$40 million commitment to MDC for renovations.<sup>57</sup> This announcement was met with a mixed response: some families felt relief that the institution would continue to house their family member while

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<sup>55</sup> Nicola Schaefer, *Does She Know She's There?* (Toronto: Fitzhenry & Whiteside Limited, 1999), 138.

<sup>56</sup> Walmsley, 3.

<sup>57</sup> Government of Manitoba website, "News Release," accessed January 30, 2016, <http://www.gov.mb.ca/chc/press/top/2004/12/2004-12-10-04.html>. In 1982, Newfoundland and Labrador announced a policy of deinstitutionalization. Nova Scotia also had large deinstitutionalization efforts in the 1980s. In British Columbia, Woodlands closed in 1996. In 2009, Ontario closed its last three large institutions. In 2012, the Saskatchewan government announced it would close Valley View. See the Institution Watch website for more information and updates: <http://www.institutionwatch.ca/updates>.

disability advocates and some former residents of MDC expressed outrage. Rallies against the government decision were held in front of the legislative building, prominently featuring activists from People First.<sup>58</sup> The announcement to provide funding to the MDC to keep it open provoked the Association for Community Living Manitoba in 2006 to launch a human rights complaint against the Government of Manitoba, the Executive Director of the Manitoba Development Centre and The Public Trustee. The complaint was settled in 2011 through a mediated agreement.<sup>59</sup> This agreement outlined that the government must move 49 of the 250 people confined in the institution into the community by 2014. It also allowed “for the first time” to “give CLM [Community Living Manitoba] the opportunity to present MDC residents and their families other community living options including the opportunity to visit and experience various community living settings.”<sup>60</sup> The Manitoba government website page for the MDC now includes a link to “Community Living Options for MDC Residents.”<sup>61</sup>

According to figures of December 15, 2010, the MDC provided residence as of that date to 273 adults. Of this population, 78 percent (or 212 people) lived at MDC for over 30 years. Of those 212 people, about 133 of them lived at the MDC for over 40

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<sup>58</sup> See Schwartz, “We Can’t Close It Yet,” for a review of the debates in the newspapers. See also Boulanger, “Look, Listen, Learn,” for a description of the protests, 80-83.

<sup>59</sup> The Manitoba Human Rights Commission, “Human Rights settlement confirms the right to choose,” accessed January 30, 2016, [http://www.manitobahumanrights.ca/publications/news\\_releases/2011\\_11\\_25.html](http://www.manitobahumanrights.ca/publications/news_releases/2011_11_25.html).

<sup>60</sup> Ibid.

<sup>61</sup> Manitoba Government website, “Manitoba Developmental Centre,” accessed January 31 2016, <http://www.gov.mb.ca/fs/pwd/mdc.html>. This link leads to a page that has videos and a PDF describing community living. Manitoba Government website, “Community Living Options for MDC Residents,” accessed January 31, 2016, [http://www.gov.mb.ca/fs/pwd/mdc\\_options.html](http://www.gov.mb.ca/fs/pwd/mdc_options.html).

years.<sup>62</sup> Also as of December 2010, MDC employed 663 staff.<sup>63</sup> The size of the institution and its grounds remain sizable: the MDC has 34 buildings totalling 425,000 square feet on a 100-acre site. In April 2010, the government of Manitoba convened a Workforce Planning Committee to consider the future of MDC. This group included representatives from the Manitoba Government and General Employees' Union (MGEU), the department of Family and Consumer Services, and senior staff from the MDC.<sup>64</sup> The purpose of the committee was “to examine the issues arising from the declining resident population at the MDC and to consider options for the future.”<sup>65</sup> In June 2011, the government announced the formation of another committee – this time “a stakeholder implementation committee” that included advocates for community living, a self-advocate (Scott Klassen), a family member of a person confined at the MDC as well as individuals from the union, Portage la Prairie, MDC staff and the CEO, the Public Trustee, representatives of the Manitoba government and a group opposed to the closing of the institution titled “Friends of MDC.”<sup>66</sup> It is clear from the press releases, as well as from newspaper articles, that significant concerns for the government are continued employment for government employees and the economic welfare of Portage la Prairie.<sup>67</sup>

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<sup>62</sup> Manitoba Developmental Centre Workforce Planning Committee (December 2010), accessed March 25, 2012, [http://www.manitoba.ca/fs/pwd/pubs/mdc\\_workforce\\_report.pdf](http://www.manitoba.ca/fs/pwd/pubs/mdc_workforce_report.pdf), 3.

<sup>63</sup> *Ibid.*, 4.

<sup>64</sup> Angela Brown, “Report on Manitoba Development Centre expected soon,” *Portage Daily Graphic* November 30, 2010, accessed January 30, 2016, <http://www.portagedailygraphic.com/2010/11/29/report-on-manitoba-developmental-centre-expected-soon>.

<sup>65</sup> Government of Manitoba website, “News Releases,” June 16, 2011, accessed January 30, 2016, <http://news.gov.mb.ca/news/index.html?archive=2011-06-01&item=11765>.

<sup>66</sup> *Ibid.*

<sup>67</sup> Malacrida also discusses the importance of the Michener Centre for Red Deer’s economy and the unionized employees. Malacrida, *A Special Hell*, especially 151-152 and 171-172. See also “Union plans rally to keep Michener Centre open,” *Red Deer Advocate* April 7, 2013, accessed August 13, 2016, [http://www.reddeeradvocate.com/news/Union\\_plans\\_rally\\_to\\_keep\\_Michener\\_Centre\\_open\\_](http://www.reddeeradvocate.com/news/Union_plans_rally_to_keep_Michener_Centre_open_)

To date, the results of these committees are not yet known. In 2014, a *Winnipeg Free Press* editorial complained that “the province has refused to shed any light on its intentions, saying only it is waiting for the report of a working group.”<sup>68</sup>

### **History of Pelican Lake Centre**

The Pelican Lake Centre had close ties with the provincial government and the Manitoba Developmental Centre but was run by the Sanatorium Board of Manitoba (as mentioned previously). It was initiated as a way for the Sanatorium Board to use the facilities formerly occupied by the Ninette tuberculosis sanatorium. The centre acted as a place to which residents from the MDC could be transferred to reduce the severe overcrowding at the Portage la Prairie institution. The centre was initially intended to “train” individuals so that they could move out of institutional life and into foster homes or group homes in the community. Individuals who did not meet the training expectations were sent back to the MDC. Although it was hoped that the centre could house up to 150 residents, the refurbishment of the sanatorium buildings proved to be too costly and the

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201872621.html. In regard to the MDC, see for example a 2014 *Winnipeg Free Press* editorial that says “With well-paying union jobs at stake in the rural community, however, critics have said the government doesn’t want to make a decision that might upset both the town and organized labour.” “Resolve MDC’s future,” *Winnipeg Free Press* June 4, 2014, accessed January 31, 2016, <http://www.winnipegfreepress.com/opinion/editorials/resolve-mdcs-future-261780101.html?device=mobile> and Jordan Maxwell, “MGEU worried about the future of MDC,” *Portage Daily Graphic* May 3, 2012, accessed August 13, 2016, <http://www.portagedailygraphic.com/2012/05/01/mgeu-worried-about-the-future-of-mdc>. In 1973, Clarkson also noted the importance of the institution to the economy of Portage la Prairie and the town’s residents. He said “the institution is a major, if not the major employer” and that Portage la Prairie was “vulnerable and dependent on the institution.” He noted that the institution employed 2.5 times more people than the next highest employer in Portage la Prairie (the Campbell Soup Company.) He also noted that the concentration of a regional social service in a small section of the province went against “the operation of any modern social services program” and called for the services to be decentralized “so that facilities and programs more reasonably coincide with natural market and service regions.” Clarkson, 32-34.

<sup>68</sup> Ibid.



residents never numbered more than 70.<sup>69</sup> David Stewart, in his history of the Ninette Sanatorium, says that between 1975 and 1994,

there was a good deal of movement of residents: - from Portage to PLTC, and some in the opposite direction. Many went to communities, but about a quarter of them had to come back. About twenty of the seventy have been there since the centre opened, and for them and many of the others it is the only home they can remember.<sup>70</sup>

By the time of the writing of his history (it was published in 1999), Stewart says that “recognizing that the training aspect of the centre had accomplished all it could, the word training was dropped and it is now just The Pelican Lake Centre.”<sup>71</sup> In 2000, the Government of Manitoba closed the Pelican Lake Centre. According to the final report of the Manitoba Developmental Centre Workforce Planning Committee, the closure was “due to a number of factors, including the withdrawal of long-time management, the lack of building structure viability and questions surrounding the quality of care.”<sup>72</sup> At the time of its closing, it housed 69 people and these residents were then integrated into the community with support.<sup>73</sup> The brevity of the history of this institution reflects the paucity of published information on this centre.<sup>74</sup>

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<sup>69</sup> Stewart, 130-131.

<sup>70</sup> Stewart, 131-132.

<sup>71</sup> Stewart, 132.

<sup>72</sup> The Government of Manitoba/Manitoba Government and General Employees’ Union, *Final Report* (December 2010), 9. Accessed July 10, 2016, [https://www.gov.mb.ca/fs/mdc/pubs/mdc\\_workforce\\_report.pdf](https://www.gov.mb.ca/fs/mdc/pubs/mdc_workforce_report.pdf).

<sup>73</sup> InstitutionWatch.ca, “Provincial/Territorial Updates,” accessed March 25, 2012, <http://www.institutionwatch.ca/iwupdates-app/prov.Manitoba>.

<sup>74</sup> It is expected that the publication of the forthcoming article by Zana Lutfiyya on the Pelican Lake Training Centre cited previously will add significantly to public knowledge of this institution.

## History of St.Amant

A third institution that continues to exist in Winnipeg is St.Amant. This institution is housed in the former St. Boniface Sanatorium, which was originally founded by the Grey Nuns in 1931 for tuberculosis patients. The connection between the Grey Nuns and children with disabilities arose from their relationship with Mrs. Beatrice St. Amant, a woman who cared for children with disabilities in her own home.<sup>75</sup> In 1956, as Beatrice St. Amant's health was declining, Bishop Maurice Baudoux requested that the Grey Nuns take over care of the children. The nuns originally prepared room for twenty-five children on the fifth floor of the Hospice Taché. In 1959, the government requested that the Grey Nuns establish a similar ward at the St. Boniface Sanatorium. The nuns received a \$10,000 grant to assist with renovations of the ward to be used, called St. John's ward.<sup>76</sup>

The first children with disabilities began to be admitted to the St.Amant ward of the hospital in 1959.<sup>77</sup> In her memoir of St.Amant, Sister Rita Desrosiers, a Grey Nun who worked at the institutions for many years, provides more details on the first children and first years of St.Amant. Desrosiers says the first child was an eleven-month old girl who was admitted June 8, 1959.<sup>78</sup> Desrosiers says a child with hydrocephaly arrived a few days later, again from the Children's Hospital. By the end of June, nine children had

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<sup>75</sup> Support provided by the Grey Nuns included sending garden produce to St. Amant's house to help feed the children. Desrosiers, 9.

<sup>76</sup> Ibid.

<sup>77</sup> St.Amant website, "History," accessed July 30, 2016, <https://stamant.ca/about-us/history/>.

<sup>78</sup> The girl was transferred from the Children's Hospital and was brought over by the parish priest. Desrosiers reports that the priest asked to be notified when the child died so that he in turn could notify the family. When she questioned the priest about his expectations, he apparently replied that he had heard the ward was a "terminal place" for children. Although Desrosiers exclaimed "I sure hope not!" in response to this assumption, the priest's view may indicate general societal expectations for children with disabilities at the time. The fact that the priest was acting as intermediary is also interesting and may indicate family distancing from the child, or perhaps other difficulties that prevented their active support of the young girl.

been admitted. In July, 24 children were transferred from the Hospice Taché. By the end of the year, the ward held 55 children. The official opening of the ward was held in 1959 and 400 people attended.<sup>79</sup>

The Sanatorium was re-named as the St. Vital hospital in 1961.<sup>80</sup> At this time, the first meeting of the Parents' Association was held. In 1962, the tuberculosis wards were closed and the second floor of the building was then made available to the children.<sup>81</sup> In 1974, the mandate was changed to provide services to people with developmental disabilities and the institution was renamed the St. Amant Centre.<sup>82</sup>

Another organization called L'Arche also has existed for the past four decades or more, and although providing residential care to people labelled with intellectual disabilities, L'Arche is generally considered to be outside the institutionalization structures.<sup>83</sup> Residents from St. Amant and the MDC were sometimes transferred to this organization. This Christian-based organization, founded by Jean Vanier, describes itself as "an international organization of faith-based communities creating homes and day programs with people who have developmental disabilities." As a service organization, L'Arche espouses a 'community model' of living, rather than a medical or social service

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<sup>79</sup> Desrosiers, 10.

<sup>80</sup> St. Amant, "History."

<sup>81</sup> The "most physically handicapped" children were placed on the second floor while the first floor housed the "more active ones." Desrosiers, 13.

<sup>82</sup> St. Amant, "History."

<sup>83</sup> L'Arche is one of many residential services in Winnipeg. I chose to briefly feature L'Arche as it is an international organization with an almost fifty-year history in Winnipeg and its philosophical underpinnings have been widely published.

model of care.”<sup>84</sup> They have existed in Canada since 1969 and to date have twenty-nine communities from coast to coast. Just over one-half of these communities began in the 1970s. Between them, the communities offer over 200 homes as well as workshop and day programs.<sup>85</sup>

As shown in this chapter, so much of the history of the past 125 years of institutionalization is only skeletal. Further, as recommended by Clarke, the history of institutionalization in Manitoba should also include, or be countered with, the historical narrative of community living. This narrative would include advocacy and support groups such as the Association for Community Living, L’Avenir, People First of Canada, Winnserv, DASCH, and many others. This chapter shows the great extent of work that is still required before a complex and rich history of institutionalization in Manitoba can emerge.

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<sup>84</sup> L’Arche Canada, “The Story of L’Arche,” accessed July 30, 2016, [http://www.larche.ca:8080/en\\_CA/about-larche/our-history](http://www.larche.ca:8080/en_CA/about-larche/our-history).

<sup>85</sup> Ibid.

### Chapter Three: “It was completely structured.”

#### Types of institutional records

Scott Klassen describes his life in an institution: “In St. Amant, I had no control; I had no say in what went on. It was very religious and it was run by nuns. It was completely structured. Society has no right to put people in institutions. I would never go back.” Later, once he was out, he needed to adjust to freedom: “The interesting part was that I gradually realized that I had choices in the little things – like when to get up, and what time to eat. Inside the institution it was so structured that there was not choice in the little things. I’ve done so much since I left the institution.”<sup>1</sup>

This chapter reviews the types of records that can be created by institutions and some of the problems the records may present to archives. It looks at the importance of records for redress and personal knowledge and concludes with a look at how the subjects of institutional records can be understood to have ownership rights to records written about them.

Records created by institutions can be formally archived in public or private archives, or haphazardly stored or abandoned in rooms, basements or attics of buildings. As an example of the latter, historian Ellen Dwyer says that

Although I refer to a ‘Willard Archive’ as well in my footnote references, there is no formal archive at the Willard Psychiatric Center. On my first visit there, I rescued the nineteenth-century casebooks from the basement of the abandoned Chapin building. Subsequently, extant nineteenth-century materials were stored in a former patient building.<sup>2</sup>

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<sup>1</sup> Klassen, 3.

<sup>2</sup> Ellen Dwyer, *Homes for the Mad: Life inside two nineteenth-century asylums* (New Brunswick and London: Rutgers University Press, 1987), xiii. Several years later, in 1995, New York State Museum curator Craig Williams

Although the Willard documents are an extreme example of the disregard for such records, Emma Prescott points out that “while the history of medicine is a well-established field, supported by a long-standing tradition of medical historiography, much less attention has been paid to the institutional records and archives that document the history of Canadian hospitals.”<sup>3</sup> Although Prescott notes that insufficient scholarly attention has been given to hospital records, no study at all exists for the records of institutions for people labelled with intellectual disability. Although the hospital framework can be used to outline types of institutional records, it is important to keep in mind the caveat expressed by Prescott that specialized hospitals have “vast differences in the kinds of documents they generated, in the way these were organized, and in the repositories in which they ended up.”<sup>4</sup> It is also useful to remember that hospitals and institutions can be large and complicated organizations and so it is difficult to describe all types of records that could be created by these entities.<sup>5</sup> As the records and even operating structures of institutions are often hidden from view, it can be especially difficult to outline their records framework.

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toured the grounds of the Willard State Hospital just before it was slated for demolition. Two former staff members showed him an attic of the Sheltered Workshop Building where there were hundreds of suitcases, trunks, doctors’ bags and containers that had been untouched for decades. Williams brought all of the items back to the museum. They were later used in the exhibit and book: Darby Penney and Peter Stastny, *The Lives They Left Behind: Suitcases from a State Hospital Attic* (New York: Bellevue Literary Press, 2008), 13. The exhibit at the New York State Museum was attended by over 600,000 visitors. “The Lives They Left Behind; Suitcases from a State Hospital Attic”, accessed September 2, 2014, <http://www.suitcaseexhibit.org/index.php?section=about&subsection=project> and <http://www.suitcaseexhibit.org/index.php?section=about&subsection=suitcases>.

<sup>3</sup> Emma Claire Prescott, “Acute condition? Exploring the status of corporate archives in Canadian hospitals,” (Master’s thesis, University of Manitoba, 2014), 1.

<sup>4</sup> Prescott, 27. Almost thirty years ago, Barbara Craig made an extensive comparison of hospital records in London, England and in Ontario for the period of 1850-1950. Included within her work is the Kingston Psychiatric Hospital, which she used to represent asylums in Ontario. Barbara Craig, “Hospital records and record-keeping, c. 1850-c.1950. Part I: The development of records in hospitals,” *Archivaria* 29 (1989-90), 57-87; Barbara Craig, “Hospital records and record-keeping, c. 1850-c.1950. Part II: The development of record-keeping in hospitals,” *Archivaria* 30 (1990), 21-38.

<sup>5</sup> Keirstead, 14. For example, Keirstead notes the Kingston General Hospital had sixty-three departments, each creating its own particular documents. Prescott also says that the “general pattern of immense diversity has become even more complex as many hospitals became affiliated with other institutions (such as faculties of medicine) or were taken over by larger organizations such as regional healthcare authorities.” 27.

In general, records created by institutions can be placed in two broad categories: administrative (or corporate) and medical.<sup>6</sup> Administrative records deal with the operation of the staff and facilities; medical records contain information about the residents. The Association of Canadian Archivists' (ACA) booklet titled *Medical Archives* states that ninety-five percent of administrative records have only short-term value and relate to "routine activities" such as those pertaining to equipment, supplies, personnel, etc.<sup>7</sup> The remainder, however, concern the governance of the entity and "document the core functions of an organization." These records

document essential activities, decisions, legal obligations and responsibilities. Many of these have long-term or permanent value. Examples of these records are policies and procedures, minutes of Board of Directors and important committees, records of assets, legal agreements, etc.<sup>8</sup>

Craig asserts that "institutional management thrived on minutes" and it is therefore not surprising that in Craig's review of hospital records, minute books are among the two sets of records (the other being clinical files) that "have the widest representation."<sup>9</sup> For institutions that are run by governments, the administrative records may be scattered throughout the various government

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<sup>6</sup> Prescott, 3. See also Keirstead, 15. Medical and science journalist and author Robert Whitaker says that the history of the United States treatment "of people it considers mad basically consists of two types of books." The first category "tell[s] of the various medical therapies and types of institutional care" and the second category consists of "a handful of memoirs by current and former patients, nearly all of which raise troubling questions about the humanity of these 'treatments.'" Robert Whittaker, "Foreword," Penney and Stastny, 9.

<sup>7</sup> Association of Canadian Archivists, *Medical Archives: Promoting Efficiency & Effectiveness* (Ottawa: Association of Canadian Archivists, 2003), unpaginated.

<sup>8</sup> Ibid. A more granular list is given as: "founding documents or charters; minutes, reports, resolutions, correspondence, and memoranda of the hospital's governing body and committees; financial records and auditor's reports; legal documents; employee files; bound documents and manuscripts, including correspondence, financial records, staff service records, etc.; hospital publications, including annual reports, policy and procedure manuals, newsletter, brochures, etc.; hospital and patient registers; clinical summaries, casebooks, and case files; photographs, albums, and photographic negatives; speeches, correspondence (personal and professional), diaries, journals, notebooks, scrapbooks; newspaper clippings; news releases; paintings, historical artifacts, instruments, equipment, and memorabilia; oral history audio tapes, and video tapes; electronic records of long term or historic value."

<sup>9</sup> Craig (1989-90), 78. An example from a long-term stay hospital in the UK lists twelve different sets of committee minutes dating from 1865-1980. Lancashire County Council Archives, Royal Albert Hospital, accessed June 25, 2016, <http://archivecat.lancashire.gov.uk/CalmView/Record.aspx?src=CalmView.Catalog&id=HRR&pos=1>.

departments that had control of the institution through its history.

The third group of records is created by other entities or people about these institutions. For institutions run by governments, a multitude of records such as correspondence, minutes or reports may exist that are created by several government departments. These records may be restricted by privacy legislation if they contain policy matters or personal health information such as correspondence about a resident. Information about institutions can also be occasionally found in government records such as Hansard, commissioned reports, or inquest reports.<sup>10</sup>

These preceding examples presume that the records remain in existence. While institutions likely follow retention schedules regarding what records must be saved for legally-proscribed periods, decisions concerning what records are deemed to be archival and preserved in perpetuity are made by individuals and therefore can be idiosyncratic.<sup>11</sup> Environmental conditions, such as fire or water, may damage or destroy records before they even reach a formal archive.<sup>12</sup> For example, Malacrida notes that fire caused by a lightning strike destroyed a significant portion of Michener's records held at the institution's administration building.<sup>13</sup> The Manitoba Developmental Centre also lost photographic records through water damage.<sup>14</sup>

The most extensive destruction of records, however, can be caused by the purposeful

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<sup>10</sup> Private institutions, like St. Amant, receive a significant portion of their operating costs from the Manitoba government. St. Amant also has relationships with government departments such as Education. Therefore, records concerning St. Amant can be found in the Archives of Manitoba.

<sup>11</sup> Barbara Craig notes that for her review of 100 years of hospital records, "it is clear that no institution has complete or even approximately complete records." Craig (1989-90), 78.

<sup>12</sup> Prescott mentions the papers of Annie Bond, founder of the Winnipeg Children's Hospital, whose boxes of personal records were kept in the basement of the hospital, possibly later damaged by flood, and by the time of a subsequent move had "simply vanished." Prescott, 135.

<sup>13</sup> Malacrida, *A Special Hell*, 247.

<sup>14</sup> Cynthia Winram, Chief Executive Officer, Manitoba Development Centre, email to author, November 6, 2014.



destruction of them under government scheduling practices. In 1987, for example, the Provincial Archives of Alberta used the technique of sampling to destroy 80 percent of the case files of the province's Eugenics Board, reducing the files from 4,785 to 861.<sup>15</sup> Such a fate for the case files of the MDC was narrowly avoided. In 1983, a Records Inspection Report performed by the Government Records Division of the then Provincial Archives of Manitoba saved from destruction by MDC 130 cubic feet of its master clinical files dating from 1895 to 1983. The report noted that

The Manitoba School for Retardates has authority, under a Provincial Documents Committee ruling of 15 October 1976, to destroy primary material following microfilming and to destroy secondary material 2 years after the last recorded date. The schedule has not, however, been fully implemented. Approximately 130 cu.ft. of closed master files (primary), dating from the 1890s, are extant at the school; only files of residents who died in the institution have been destroyed.

Michele Fitzgerald, the archivist who wrote the report, noted that the institution wanted the files “destroyed and that the microfilm copy remain in their custody.”<sup>16</sup> However, she argued against this schedule and recommended instead that the primary files should be transferred to the provincial archives “5 to 10 years after closure under appropriate access restrictions, and that the Provincial Documents Committee ruling of 1976 be rescinded.” She noted that

The primary master files constitute an obviously rich source of evidence and information regarding the care and treatment of the mentally disabled. Government Records has advised the Manitoba School for Retardates... that the series, in its original format is worthy of permanent retention in the Provincial Archives.

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<sup>15</sup> Jana Grekul, “Sterilization in Alberta, 1928 to 1972: Gender Matters\*,” *Canadian Review of Sociology/Revue Canadienne de Sociologie* 45/3 (2008), 251-252. The files were reduced from 4,785 to 861.

<sup>16</sup> Manitoba Provincial Archives, Government Records Division, “Record Inspection Report,” June 28, 1983 for Schedule CSC 0054 and CSC 0055.

Although unlike the Alberta case files, these files have remained largely untouched by researchers,<sup>17</sup> it is vitally important that the records remain preserved so that they can be available to the individuals who are subjects of the files, and for future research or legal concerns.

Although the clinical files were saved, records schedules for the institution show that a majority of the administrative files are scheduled for destruction or have already been destroyed.<sup>18</sup> For example, some of the records allowed to be destroyed include “copies of various MDC committee minutes, department and MDC policies,”<sup>19</sup> “Vocational Training Department meeting minutes,”<sup>20</sup> “copies of consent for surgery forms,” “mortality review records,” “minutes of medical staff meetings and committees,”<sup>21</sup> “general correspondence with parents, external agencies, advocate groups,” “interdepartmental memos both internal and external,” “committee minutes and reports,” and “original incident report forms submitted by all departments to office of Medical Director, giving details of incidents (such as behaviour resulting in injury) involving residents and, in some cases, staff.”<sup>22</sup> Although some of these records are described as “copies” it is not apparent where the originals are, so these copies could be the only existing record of events.

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<sup>17</sup> I do not know of any other researcher who has accessed the clinical files.

<sup>18</sup> These schedules were given to me on June 27, 2016 by Senior Archivist Kathleen Epp. The Records Schedules even listed the location at the institution for the files. For example, the ward files were kept in filing cabinets in each of the buildings and cottages. EKG tracings were in shelves and boxes in another building, correspondence with parents was kept in the Administration building, and the Incident Reports were kept in the Medical Director’s Secretary’s Office. I also learned that the MDC has, or did have until at least 1990, a library because that is where the files related to volunteers were held.

<sup>19</sup> Manitoba Culture, Heritage and Recreation, “Records Authority Schedule,” February 16, 1990, for Schedule FS 215.

<sup>20</sup> Ibid., for Schedule FS 213.

<sup>21</sup> Ibid., for Schedule FS 214.

<sup>22</sup> Ibid., for Schedule FS 226.

Although the Archives of Manitoba is currently allowing the MDC's records to be destroyed, the Provincial Archives of Alberta (PAA) has recognized the value of these kinds of institutional records. The PAA holds, for example, seven metres of Operational Records for the Michener Centre and its predecessor institutions and 1.8 metres of Committee Minutes.<sup>23</sup> The PAA also has 9.14 metres of Daily Unit Communications and Report Books. Laurette Millar, the PAA archivist who responded to my requests for information, said that, in the case of the Daily Unit records, a schedule re-appraisal was made which changed the disposition of the records from being destroyed to being retained "because of the amount and detail of patient/resident/staff and incident information documented."<sup>24</sup>

Record types such as Daily Unit Communications may be viewed by some archivists as too low level or granular to be preserved. But, as shown in the reversal of the appraisal decision by the PAA, the record types suggested by the ACA may be too high level to fully capture the institutional experience and the interactions between residents and staff. Further, records for institutions housing people labelled with intellectual disability may call for a different framework of appraisal than that of a hospital. Additional record types noted by Malacrida in her research into the Michener institution include categories typical to hospitals (such as admissions and budgets) but many of the categories may be specific for institutions for people labelled with intellectual disability: "daily record logs, proceedings of sterilization hearings, minutes of disciplinary committees for staff members, budgets, lists of escape attempts and resulting

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<sup>23</sup> Laurette Miller, email to author, April 14, 2016. Her email was in response to my inquiry to the Provincial Archives Alberta concerning whether a finding aid for the Michener Centre records exists. Her email included a copy of the resource list that was created to assist researchers. The resource list provides the title of the records, their dates, their extent and accession number, and the access conditions.

<sup>24</sup> Laurette Miller, email to author, June 29, 2016.

actions, admissions, and experimental treatment records.”<sup>25</sup> For example, incident reports may be particularly important to understand the institutional experience. These reports, as described in the Province of Manitoba Records Authority Schedule, give “details of incidents (such as behaviour resulting in injury) involving residents and, in some cases, staff.”<sup>26</sup> It is therefore disturbing that the Records Authority Schedule for these documents allows them to be destroyed after twenty years.

Rebecca Kluchin stated that it is practically certain that researchers will be “forced to bring diverse sources together creatively” to shed light on this history.<sup>27</sup> Outside of the institution, information about institutions will most commonly be found in newspapers, conference proceedings, published medical articles or in private publications such as memoirs.<sup>28</sup> Shortt creatively used a variety of historical materials including “sermon literature and popular novels” as well as “manuscript diaries and travel accounts, transcripts of malpractice suits and coroners' inquests, medical advertisements in the lay press, sermon and devotional literature, census data, and parish records”<sup>29</sup> Claudia Malacrida, one of the few researchers who has researched institutions in Canada, used a variety of archival sources and newspapers as well as oral histories with former residents and staff and one mother of children who had been institutionalized. With the latter, Malacrida points to family members who saved “letters, forms,

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<sup>25</sup> Malacrida, *A Special Hell*, 247. Malacrida also mentioned “unusual incident reports” in an email to author, July 16, 2014.

<sup>26</sup> Records Authority Schedule, FS 226.

<sup>27</sup> Kluchin, 142.

<sup>28</sup> Ellen Dwyer, in her research on the Utica State Hospital and Willard Asylum in New York State, used private manuscripts held in libraries and archives, published annual reports, legislative documents, as well as contemporaneous publications such as conference proceedings, articles and books. For her bibliography of primary sources see Dwyer, 275-292.

<sup>29</sup> Shortt, 21.

institutional records” as a source of documentation about the institutional experience.<sup>30</sup> Although Shortt also mentioned family “papers and journals” to “expose in fine detail” matters relating to illness, it is uncertain whether these papers are reaching, and being saved, by an archive.<sup>31</sup> Researchers may be required to seek out family records from the families themselves, as did Penney and Stastny, who in their investigation into the lives of people institutionalized at Willard, “leafed through medical charts; searched ship manifests; read letters, books, and diaries; unwrapped housewares; looked at hundreds of old photographs; and visited patients’ former homes.”<sup>32</sup>

Specifically for the history of the Manitoba institutions, newspapers from the towns and areas around Portage la Prairie, Brandon, Ninette, and Winnipeg will provide information.<sup>33</sup> Newspapers are also a source of job posting advertisements for the institutions and also obituaries. Job postings will indicate types of positions and salaries and may also provide information about staff shortages. Obituaries often describe how long a person lived in the institution and sometimes give hints as to why the person was admitted, such as the death of parents. Obituaries are a peculiar example of how on one hand privacy legislation will rigorously restrict the dissemination of information about people who were admitted to institutions, yet on

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<sup>30</sup> Malacrida, *A Special Hell*, 36. Malacrida says that a CBC radio interview led to contact with a man who had been institutionalized and who had kept the documentation his now-deceased mother had saved. This documentation included correspondence with the provincial Ombudsman and admission documents and letters. Claudia Malacrida, personal communication, July 16, 2014. Shortt said, “family papers and journals expose in fine detail perceptions and consequences of illness lacking in the scant case histories. Shortt, 21.

<sup>31</sup> Shortt, 21.

<sup>32</sup> Darby Penney and Peter Stastny, “Lost Luggage, Recovered Lives,” *American Journal of Public Health* 98/6 (2008), 986.

<sup>33</sup> For the MDC, it will also be important to search for the colloquial names of “Portage School” and “Manitoba School” even though this may return many unrelated articles. Using historical terms such as “retardates” or “moron” or “mentally defective” may uncover news articles that do not mention the institution specifically but will provide important contextual information regarding societal and legal views of people so labelled.

the other the names of individuals, their photos, dates of birth and death, lengths of stay in the institution and sometimes even personal hobbies or other qualities will be publicly published in newspapers and on funeral home websites. Obituaries of staff people and medical directors can also be found in these sites.<sup>34</sup>

Annual reports for the various incarnations of the MDC are available in the Legislative Library of Manitoba under the names of the departments that had jurisdiction over the institution. These include Public Works, Health, Community Services, and Family Services. This library also has a 2002 bound edition of newsletters that had been published by the MDC in the 1970s. This edition was put together by Reverend Walmsley and is titled “Manitoba School Journals.”<sup>35</sup> Another vital source of information about institutions is inquest reports that may be written after a death in an institution.<sup>36</sup> Inquests also show contradictory applications of privacy restrictions. Inquests released from 2002 to the current date are freely available as downloadable PDFs on the Manitoba Courts website.<sup>37</sup> However, inquests before this date are held at the Archives of Manitoba where they are restricted. The Manitoba Courts website says that older inquest reports

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<sup>34</sup> Although mining obituaries for historical information may seem disrespectful, the opposite is in fact true: a photo and few words describing the uniqueness of the individual does much to humanize individuals who are otherwise known only as “residents” or “inmates” of institutions. Rather than viewing this information as an intrusion or disclosure of personal information, the humanization and individualization of historical subjects serves to heighten the researcher’s awareness of the great responsibility and importance of research ethics.

<sup>35</sup> Although the Legislative Library received the book in 2008, it was only around 2015 that the book was known to be about the Manitoba Developmental Centre, as the title of the book had caused it to be catalogued with education materials. Monica Bell, Legislative Library of Manitoba, personal communication, June 22, 2016.

<sup>36</sup> The Fatality Inquiries Act, which came into force in 1990, requires that an inquest be held when “there are reasonable grounds to believe that a person ... while a resident in a developmental centre ... died as a result of a violent act, undue means or negligence or in an unexpected or unexplained manner or suddenly of unknown cause.” The Fatality Inquiries Act, 19(3)(a), accessed June 26, 2016, [http://web2.gov.mb.ca/laws/statutes/ccsm/f052e.php#19\(3\)](http://web2.gov.mb.ca/laws/statutes/ccsm/f052e.php#19(3)).

<sup>37</sup> Manitoba Courts, “Inquest Reports,” accessed June 26, 2016, <http://www.manitobacourts.mb.ca/provincial-court/inquest-reports/>.

can also be accessed through the office of the Chief Medical Examiner in Manitoba.<sup>38</sup> However, a fee of close to \$50 is charged for each inquest report. Further, no index of the reports appears to be available.<sup>39</sup> Viewing the inquest reports that are freely available on the Manitoba Courts website shows at least two reports that concern deaths of the MDC residents: Ann Hickey and Dennis Robinson.<sup>40</sup>

Finally, cemeteries can be another source of information. Not only do headstones provide names and dates, but the existence of unmarked graves and the upkeep of the cemetery may also provide information about institutional regard for the deceased.<sup>41</sup> Information is also available on a number of internet cemetery identification projects.<sup>42</sup> The cemetery itself is also listed on the “Historic Sites of Manitoba” section of the Manitoba History Society website.<sup>43</sup>

## Case files

Case files (also called clinical files in institutions) by far can comprise the largest extent of records of an institution. Such case files, however, present archivists and researchers with a distinct dilemma: they are a rich source of information about the patients or inmates of hospitals

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<sup>38</sup> Ibid.

<sup>39</sup> Although I called the office of the Chief Medical Examiner a few times to try to find inquests relating to the MDC, I have not been successful in finding out how a search of the indexes could be made.

<sup>40</sup> Another inquest report, while not of an individual who was institutionalized, describes the individual as having an intellectual disability. All three reports provide names of family and staff who were implicated in the deaths.

<sup>41</sup> Cemeteries are also important as commemorative sites. A very moving section of the documentary *The Freedom Tour* took place during a vigil at the Valley View institution cemetery. For a written description of the vigil, see Boulanger, 145-148. The Huronia settlement agreement includes the creation of a registry for the Huronia cemetery as well as a fence and a memorial plaque. For some of the Ontario government’s endeavors, see <http://www.mcass.gov.on.ca/en/mcass/news/releases/2016/20160506.aspx>. Memorial events have been held at the cemetery, for example, see <http://www.holytrinitytoronto.org/wp/2016/05/lost-but-not-forgotten-memorial-at-the-huronia-regional-centre-cemetery-on-sunday-may-8th/>. Projects also exist to commemorate the cemeteries at Willard. For example, see <http://www.willardcemeterymemorialproject.com/>.

<sup>42</sup> For example, CanadaGenWeb’s Cemetery Project, “MDC (Manitoba Developmental Centre),” accessed June 26, 2016, <http://www.geneofun.on.ca/cems/MB/MBPOR1310>.

<sup>43</sup> The Manitoba Historical Society, “Historic Sites of Manitoba: Manitoba Developmental Centre Cemetery,” accessed June 26, 2016, <http://www.mhs.mb.ca/docs/sites/mdccemetery.shtml>.

and institutions, but for this same reason—that they contain personal health information—the files are restricted from access.

Deborah Park and John Radford, who accessed the Eugenic Board case files in Alberta, relate the importance of these files.

The text or exposé contained within the case file has a decipherable story to tell, forcing the reader to explore related patient polemics and the pre-conditions to institutionalization and sterilisation. By closely examining and deconstructing the case file, we are bequeathed a window through which we can see the social attitudes towards such constructs and in turn, other relevant social and cultural forces.<sup>44</sup>

Although, as Park and Radford point out, the case files do not “present us with the patient’s own voices” they show a good deal of how power was brokered both in and out of the institution in regard to people labelled with intellectual disability. Park and Radford say that in the case files the “inter(con)textuality of the patient’s own experience within the institution may be inferred, though only partly.”<sup>45</sup>

Barbara L. Craig describes health and medical case files as providing “the locus of sharpest intersection between the individual as a patient with a disease, the practitioner who provides treatment, the institution that cares for the patient, and the entity that pays for both treatment and care.”<sup>46</sup> Franca Iacovetta and Wendy Mitchinson, in their book *On the Case: Explorations in Social History*, write that

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<sup>44</sup> Park and Radford, 324. Karen Dubinsky describes the “window” analogy as “so hackneyed” and says that the “theoretical sophistication” of present-day historians makes it difficult to “speak quite so enthusiastically and innocently about historical sources.” Yet she also says that she can “vividly remember the thrill” she experienced in her research into sex-crime prosecutions. Karen Dubinsky, “Afterword: Telling Stories About Dead People,” *On the Case: Explorations in Social History* (Toronto: University of Toronto Press, 1998), 360-361.

<sup>45</sup> Park and Radford, 324.

<sup>46</sup> Barbara L. Craig, “Confidences in Medical and Health Care Records from an Archival Perspective.” In *Privacy & Confidentiality Perspectives: Archivists & Archival Records*, Menzi L. Behrnd-Klodt and Peter J. Wosh, eds., (Chicago: The Society of American Archivists, 2005), 253. She credits the inspiration for this description to Terry Cook.



the term *case file*, broadly defined, refers to the records generated by political, social, legal, and other institutions entrusted with the task of categorizing and assessing certain populations, usually with the purpose of supervising, treating, punishing, servicing, and/or reforming individuals or groups deemed in some way deviants or victims.<sup>47</sup>

Case files are often not singular entities but contain an assortment of records often from different authors. The list of record types outlined in the Records Authority Schedule for the MDC's master clinical files showed thirty-eight possible records that would be created by a variety of professionals within the institution—from school reports to medication records to seclusion reports.<sup>48</sup>

Although Terry Cook talked about a “democratic dialectic” between citizen and state that could be illuminated through the documentation found in immigration case files, other scholars see case files as providing evidence of power imbalances.<sup>49</sup> Iacovetta and Mitchinson point out that “case files may be an administrative convenience and/or central to the workings, identity, and power of a bureaucracy” and they are used “to keep track of people and have a tracking record.”<sup>50</sup> Ian Forsyth notes that the practice of recordkeeping feeds a power imbalance because “information in records empowers the individuals who hold it and enables control over those

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<sup>47</sup> Franca Iacovetta and Wendy Mitchinson, eds., *On the Case: Explorations in Social History* (Toronto: University of Toronto Press, 1998), 3.

<sup>48</sup> Master file order of assembly (during stay). Received from Kathleen Epp, Archives of Manitoba.

<sup>49</sup> The federal deportation case files examined by Ellen Scheinberg sometimes contain correspondence from government officials, from the immigrants themselves, or from citizens petitioning on behalf of the immigrant, such as MPs, priests or employers. As Scheinberg notes, this rich documentation reveals what Terry Cook calls the “democratic dialectic” of the state and citizen relationship and so adds value to the records. Cited in Scheinberg, “Two Perspectives on the Same Source: An Examination of Federal Deportation Case Files,” *Archivaria* 57 (2004), 56. Cook also said that case files can “enrich our understanding of the intersection of the individual citizen or organization with government, bureaucracy or state or reveal lives, habits, and beliefs of those hidden from ‘elite’ archival documentation.” Cited in Ellen Scheinberg, “Case File Theory: Does it Work in Practice?” *Archivaria* 38 (Fall 1994), 50.

<sup>50</sup> Iacovetta and Mitchinson, 3-4.

who do not have it.”<sup>51</sup> In this way, case files are important to the functioning of the institution and to the wielding of its power. However, Iacovetta and Mitchinson point out that case files can provide information not only on individuals “but into the workings of the agencies that kept the records as well.”<sup>52</sup> Researchers who are able to review case files over periods of decades could also observe how the operations of an institution changed over time, including changes in how patients were treated and viewed. Stef Eastoe, a graduate student in the UK, writes

Patient casebooks reveal a number of examples, insights, and illustrations of how patients were classified, diagnosed and treated within the asylum. However, wider and deeper reading of the casebooks can reveal how patients were regarded in the asylum by the staff themselves, as humans, as persons, as individuals.<sup>53</sup>

Although archived case files can have enormous value for researchers, the great volume of the files means that their preservation and storage can presents problems for archives.<sup>54</sup> It has been suggested that establishing control over the voluminous mass of case files “is in many respects the most challenging problem confronted by archivists today.”<sup>55</sup> As Barbara Craig points out, case files held by archives need to be accessed by users for the archives to show ““a

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<sup>51</sup> Ian Forsyth, “Access Law and Lost Records: A Commentary on ‘In Search of the Chill,’” *Archivaria* 55 (Spring 2003), 24. As noted in Chapter 1, Malacrida describes the raised nursing station in the Michener institution with its “visible array of patient charts” as a “visual display of power and knowledge to inmates who could clearly see that they were being observed and charted on an ongoing basis.”

<sup>52</sup> Iacovetta and Mitchinson, unpaginated foreword.

<sup>53</sup> Stef Eastoe, “Casebooks, Photographs, and Institutions,” 11-14. *Disability History Association Newsletter* (Spring 2014), 11.

<sup>54</sup> In 1994, it was stated that the Canadian government “churns out millions of case files each year, a large percentage of which do not possess archival value.” She also notes that the series she worked on measured over 2.5 kilometres in extent. Scheinberg, “Case File Theory,” 46-47. Hull also gives the example of sickness insurance files in Finland where a single series includes over a million files. Felix Hull, *The use of sampling techniques in the retention of records: a RAMP study with guidelines* (Paris: UNESCO, 1981), 6, accessed November 12, 2012, <http://unesdoc.unesco.org/images/0004/000474/047452e.pdf>. Terry Cook says, “in governments, businesses, universities and similar corporate bodies, they fill records offices and record centres to the brim.” Terry Cook, “Many are Called but Few are Chosen: Appraisal Guidelines for Sampling and Selecting Case Files,” *Archivaria* 32 (Summer 1991), 25.

<sup>55</sup> Scheinberg, “Case File Theory,” 46. Scheinberg made this statement in 1994. Since then, other issues, such as born-digital records and digitization, compete as the “most challenging problem.”

return' on its investment of acquiring, preserving, and describing records.”<sup>56</sup> Yet, the dilemma exists in which case files are extremely important for historical research yet access is almost always prevented by stringent privacy laws. Researchers may not even attempt to access the files if they believe that access will never be gained.

To offset “funding crises and lack of storage space,” archivist Jack Choules says that Canadian archives “must consider the option of preserving only selective samples of legal, medical, and other case records.”<sup>57</sup> Files can be culled by “weeding” (the selective removal of items from files) or by sampling. For example, one method of weeding suggests that the existence of “top level” files such as annual reports or summaries can eliminate the need to preserve the individual case files, although this method clearly does not value the information about individuals that would thus be discarded.<sup>58</sup> Another method of culling is “fat” file selection, the argument being that thin files were “more administrative in nature” and generally “not worth retaining” while the fat or multi-volume files documented cases “that were precedent-setting, controversial, or drew greater public attention.”<sup>59</sup> The theory behind fat file selection is attributed to Terry Cook who wrote that these files would likely “contain all the archivist feels is

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<sup>56</sup> Craig, 254.

<sup>57</sup> Iacovetta and Mitchinson, 5. Scheinberg notes the “monetary and physical benefits that accrue from the destruction of thousands of metres of non-archival records” and says the two projects she was involved in saved almost \$10,000 in annual savings. See “Case File Theory,” 56 and also footnote 42.

<sup>58</sup> Scheinberg argues that the government statistics, annual reports and policy records did not contain the information on women that were found only in the case files. She says, “It would have been impossible for me to derive the type of statistics that were required for my study without the use of the actual case files.” Scheinberg, “Two Perspectives”, 61. Scheinberg also cites the work of Barbara Roberts, who described one governmental use of numbers as “a classic example of lying with statistics.” Scheinberg, 60, footnote 23.

<sup>59</sup> Scheinberg, “Two Perspectives,” 59. See also Scheinberg, “Case File Theory,” 52-53 for further explanations of “fat” files. See also Sheila Powell, “Archival Reappraisal: The Immigration Case Files.” *Archivaria* 33 (Winter 1991-1992), 109 for a description of the use of fat file selection with the immigration files.

necessary to document the ‘hot spots’ in the democratic dialectic.”<sup>60</sup> However, Geoffrey Reaume, who researched the case files of the Toronto Hospital for the Insane (1870-1940), notes that the files he selected were ones that contained patient writings or drawings, or transcripts of interviews with patients. He chose these files as they helped give “voice to those people who have been considered ‘silent’” and says that the case files he chose may not necessarily have been the largest files.<sup>61</sup> As Reaume states:

A small amount of material in a file does not mean lack of value, just as a large number of documents does not mean an automatic treasure trove about a patient’s views. For example, there are files with only a few documents that nonetheless include invaluable insights into a particular patient’s perspective, while other files have an enormous amount of material but contain little or nothing about an inmate’s views.<sup>62</sup>

The extent of case files can also be reduced by sampling. This is a technique whereby files are selected for destruction using an algorithm that should result in the remaining files providing a reasonable representation of the whole series. Frank Boles, in 1986, wrote that “when properly conceived and implemented, sampling allows the archivist to eliminate quantities of paper, with only a slight possibility of altering their overall historical value.”<sup>63</sup> In the Provincial Archives of Alberta, sociologists Jana Grekul, Harvey Krahn, and Dave Odynak,

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<sup>60</sup> Cited in Scheinberg, “Two Perspectives,” 59. Iacovetta and Mitchinson also describe the case file as “the product of authorities exercising power over their citizens, or of a dialectic encounter between experts backed by state, medical, or religious power, and clients possessing far fewer resources.” 9.

<sup>61</sup> Reaume, 3. Likewise, Allan Beveridge says the letters he uncovered “add an important dimension to a ‘mad people’s history of madness.’” Because the letters were written while confined in the asylum, the letters “enables us to hear directly from the nineteenth century patient in his or her own words, rather than filtered through the physician’s case note description.” Allan Beveridge, “Voices of the mad: patients’ letters from the Royal Edinburgh Asylum, 1873-1908,” *Psychological Medicine* 27 (1997), 907 and 900 respectively.

<sup>62</sup> Reaume, 5.

<sup>63</sup> Frank Boles, “Sampling in Archives,” *The American Archivist* 44/2 (1981), 125. Boles points out that the files must be homogenous. He says that it is not enough to conclude that the documents “are more or less the same” but that archivists should make an attempt to show homogeneity “in a mathematical measure of variance” even though he notes that mathematical approaches to sampling can have “difficulties” and even be “extremely troublesome”, 126-127.

say that the 861 case files that remained after the original 4,785 Alberta Eugenics Board files had been sampled in 1987 were “reasonably representative” of all cases that were considered by the Eugenics Board.<sup>64</sup>

Ellen Scheinberg notes that sampling files saves archives money by reducing demands on space, and may also “assist researchers, by making the collection smaller, more manageable, and more accessible.”<sup>65</sup> However, despite the theoretical benefits of culling files, Scheinberg asserts that in the practice of her historical research any previously chosen selection method would have proven “extremely detrimental” to her work.<sup>66</sup> Indeed, in a later paper, published ten years after her first, Scheinberg states that the intent of archivists to facilitate access to researchers by sampling is “ironic” as “most scholars prefer working with series of case files that are complete” so that they can employ their own method of selection.<sup>67</sup> Inarguably, although Grekul, Krahn, and Odynak believe that the preserved files at the PAA were “reasonably representative,” the sampling at the Alberta archives destroyed evidence that pertained to individuals that could have been used for redress or as perhaps the only records of that period of their lives. As Rodney Carter points out in his essay on archival power and silences, “if records are destroyed, manipulated or excluded, the narratives of the groups cannot be transmitted across time. Their

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<sup>64</sup> Grekul, Krahn and Odynak, 366.

<sup>65</sup> Scheinberg, “Two Perspectives,” 56. Terry Cook also says that “keeping everything ... does researchers no favours as little information of value could be found in the resulting paper jungle.” See also Hull who cites “the impossibility of research use in terms of those astronomic quantities of records.” 3.

<sup>66</sup> Scheinberg, “Two Perspectives,” 60.

<sup>67</sup> Ibid., 59. For example, Fiona Alice Miller, in her study of immigration case files, says her selection was “made impartially” by choosing “approximately every third box, one file per box, and all cases in that file.” Miller, 86, footnote 41. Scheinberg also notes that “each series of case files holds its own mysteries” and thus no one sampling or selection method would be appropriate for all series. Scheinberg, “Case File Theory,” 46. Penney and Stastny say they made their choices “either because their belongings called out to us in a loud and clear manner, or because the relatively few items remaining in their trunks hinted at unique personal traits and backgrounds.” Penney and Stastny, *The Lives They Left Behind*, 17.

stories will not be heard and they may ultimately disappear from history.”<sup>68</sup>

For individuals, case files provide a record of their interactions with an institution or agency but can be also critical as a historical record that documents actions that could be used for juridical functions of redress.<sup>69</sup> For example, case files have been used in class action suits by sterilization and institution survivors in Canada and the United States. However, whether the record exists and contains the necessary information is not guaranteed. In 2011 in North Carolina, for example, only 48 of an estimated 2,000 sterilization survivors were matched with records.<sup>70</sup> In Ontario, it was reported in the *Toronto Star* that some Huronia survivors had difficulties accessing their files because of “the provincial government’s confusion about where exactly the files are.” The article said that this failure to match people with their files was “jeopardizing the settlement” that had been reached earlier.<sup>71</sup>

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<sup>68</sup> Carter, 217.

<sup>69</sup> For example, in a very recent class action suit settled in Ontario, the *Toronto Star* reported that claimants “can ‘check a box’ claiming they were abused and receive \$2,000, or they can submit testimony and other evidence about their abuse to get higher compensation.” Alex Ballingall, “Survivors of 12 Huronia-style institutions will split \$36M class action settlement,” *Toronto Star* April 27, 2016, accessed July 17, 2016, <https://www.thestar.com/news/gta/2016/04/27/twelve-more-huronia-style-institutes-get-36m-class-action-settlement.html>. Marilyn Dolmage, one of the litigation guardians in the Huronia case, said that “If class members can say what happened to them, that is enough. No extra documentation is needed.” She also recommended that class members view their case files as “the only way their claim can be challenged is if there is information in their institution file that contradicts them.” However, she also points out that “Institution files are not likely to document that abuse occurred. They are even less likely to document that it did NOT occur.” In this situation, case files are useful for the information they do not contain. Marilyn Dolmage, “Ontario Institution Class Action Update,” accessed July 27, 2016, <http://www.cacl.ca/sites/default/files/uploads/docs/HRC%20May%202014%20update.pdf>.

<sup>70</sup> Michelle Kessel and Jessica Hopper, “Victims speak out about North Carolina sterilization program, which targeted women, young girls and blacks,” *NBC News* November 7, 2011, accessed January 31, 2016, [http://rockcenter.nbcnews.com/\\_news/2011/11/07/8640744-victims-speak-out-about-north-carolina-sterilization-program-which-targeted-women-young-girls-and-blacks](http://rockcenter.nbcnews.com/_news/2011/11/07/8640744-victims-speak-out-about-north-carolina-sterilization-program-which-targeted-women-young-girls-and-blacks).

<sup>71</sup> Tim Alamenciak, “Huronia survivors hit roadblocks in attempts to get case files,” *Toronto Star* November 18, 2013, accessed February 2, 2014, [http://www.thestar.com/news/gta/2013/11/18/huronia\\_survivors\\_hit\\_roadblocks\\_in\\_attempts\\_to\\_get\\_case\\_files.html](http://www.thestar.com/news/gta/2013/11/18/huronia_survivors_hit_roadblocks_in_attempts_to_get_case_files.html).

The state ownership of records for government institutions can be frustrating to survivors. Leilani Muir says she had great difficulty in obtaining a copy of her file from the Michener Centre and it was only through actions of her legal team that she finally was able to see it.<sup>72</sup> Some Huronia survivors, in preparing for legal action, felt frustrated and upset when the government could not find their files in the archives and they were then told to reapply to the Ministry of Community and Social Services and pay an extra five-dollar fee. One survivor, Barry Smith, who had left the institution in 1966 said:

It's the runaround thing, where they tell you go to this person and then they tell you to go to somebody else and that person tells you to go to somebody else.... Now they are asking for another \$5 and they're asking for another form to be filled in, which to me, it's just prolonging this thing. We need to speed it up.<sup>73</sup>

As survivors such as Barry Smith were already in their mid-sixties by the time the agreement process was determined, further delays in receiving redress could be significant.<sup>74</sup> Soon after these complaints were published in the newspaper, the Ontario government initiated a system by which survivors could request their case file through one person at the Ministry of Community

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<sup>72</sup> Muir, 102.

<sup>73</sup> Cited in Alamenciak "Huronians survivors hit roadblocks." Marilyn Dolmage, one of the litigation guardians of the class action suit, said that "It's just upsetting to deal with bureaucracy like this, especially for anybody who's been hurt by government actions." Marilyn Dolmage, cited in Alamenciak "Huronians survivors hit roadblocks." Dolmage further noted that for survivors, "It's hard to do this in the first place and to be rebuffed somewhere and told to go somewhere else, it can be really discouraging." Marilyn Dolmage cited in Ted Alamenciak, "Huronians survivors offered 'one-window' solution by province," *Toronto Star* November 25, 2013, accessed February 24, 2016, [http://www.thestar.com/news/gta/2013/11/25/huronians\\_survivors\\_offered\\_onewindow\\_solution\\_by\\_province.html](http://www.thestar.com/news/gta/2013/11/25/huronians_survivors_offered_onewindow_solution_by_province.html).

<sup>74</sup> In 2012, the *Georgia Strait* noted that the slow pace of restitution in British Columbia for Woodlands School survivors meant that "so many former students have passed away while waiting to apply for damages." Adrian Dix, "Christy Clark can finally help provide justice for Woodlands survivors," *Georgia Strait*, February 13, 2012, accessed March 25, 2012, <http://www.straight.com/article-605871/vancouver/adrian-dix-christy-clark-can-finally-help-provide-justice-woodlands-survivors>. Similar concerns have been raised in relation to Indian Residential School survivors. In 2010, Gordon Williams said that "between five and 10 survivors are dying each week" and that since the court-ordered agreement in 2006, about 5,000 survivors had died. Linda Diebel, "No truth, no reconciliation for aging residential school survivors," *Toronto Star* July 23, 2010, accessed February 24, 2016, [http://www.thestar.com/news/canada/2010/07/23/no\\_truth\\_no\\_reconciliation\\_for\\_aging\\_residential\\_school\\_survivors.html](http://www.thestar.com/news/canada/2010/07/23/no_truth_no_reconciliation_for_aging_residential_school_survivors.html).

and Social Services who would then locate the file without cost.<sup>75</sup>

For some institutional survivors, perhaps equally or more importantly than redress, the case file contains information about their lives that is otherwise not known. As Dolmage states “Getting the file is kind of a part of putting their lives back together, putting the pieces back.”<sup>76</sup> Leilani Muir describes her response when her legal firm finally obtained her files: “That was the first time that I saw my files and the lies that were written about me. I was flabbergasted by what I read there.”<sup>77</sup>

As mentioned in Chapter One, very few records are known to exist that have been created by people labelled with intellectual disability who have been confined in institutions. Indeed, it is evident in the list provided by the ACA that none of the record types mentioned were likely to have been created by a patient or resident of the institution. The lack of patient-created records leads to the situation succinctly described by historian Mary Beard: “No documents—no history.”<sup>78</sup> Manitoba archivist and historian Conrad Stoesz, who looked at the work of conscientious objectors in institutions, notes the lack of evidence of the institutional residents’ perspectives and simply and directly states: “The people with mental disabilities are not ones to

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<sup>75</sup> Ted Alamenciak, “Huronians survivors offered ‘one-window’.”

<sup>76</sup> Ibid. See also Wilson, 132. Wilson notes that for Glen George Sinclair, one of the participants in the Living Eugenics project, “the material in the legal file contains much information that was unknown to Glen for many years about his life, information on him from institutional and other government authorities that he has spent much time reading and reflecting on.”

<sup>77</sup> Muir, 103.

<sup>78</sup> The original quotation is attributed to nineteenth-century French historian Fustel de Coulanges. Julie Collins, “A ‘powerful, creative history’: the reticence of women architects to donate their professional records to archival repositories,” *Archives and Manuscripts* 40:3 (2012), 181-190. See also Anke Voss-Hubbard, “‘No Documents—No History’: Mary Ritter Beard and the Early History of Women’s Archives,” *The American Archivist* 58 (1995), 16-30.



generally write about their condition and it is not a topic well researched.”<sup>79</sup> Allan Beveridge, UK psychiatrist and lecturer in the history of psychiatry, notes that patient or resident accounts that do exist are most often penned after release from the institution and that there is a “paucity” of records available that were written during confinement.<sup>80</sup>

If individuals in institutions do not have the opportunity to create records, or have not had any such records saved, where is the evidence for the story of their lives? Records created by the institution, such as photographs, correspondence, or even the medical records may be the only evidence for decades of their lives. Terry Eastwood asks if individuals can repurpose their records even when the records are in the “clutches” of the institutions that oppressed them?<sup>81</sup> Ricardo Punzalan, in his essay on colonial leprosy archives in Culion, Philippines, says that he was surprised at the extent of survivor repurposing of records that were evidence of both colonialism and bio-medical segregation.<sup>82</sup> Punzalan notes at least two factors facilitated this repurposing. The first important factor is that these medical records were the “only evidence of their departed descendants and predecessors, the ancestral lineage for much of their

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<sup>79</sup> Stoesz, (2011), 65. Atkinson and Walmsley say “People with learning disabilities are the ultimate ‘lost voices’ in terms of autobiographical records.” Atkinson and Walmsley (1999), 203. However, four years later, Jan Walmsley notes that “the practice of recording and publishing biographies and life stories told in people’s own words is well established in the UK, with many notable publications since the late 1980s.” Jan Walmsley, “Mental retardation in America: A historical reader (review),” *British Journal of Learning Disabilities* 34/3 (2006), 189.

<sup>80</sup> Beveridge, 899.

<sup>81</sup> Terry Eastwood, “Reflection on the Goal of Archival Appraisal in Democratic Societies,” *Archivaria* 54 (Fall 2002), 70.

<sup>82</sup> Ricardo Punzalan, “‘All the things we cannot articulate’: colonial leprosy archives and community commemoration,” *Community Archives: The Shaping of Memory*, Jeannette A. Bastian and Ben Alexander, eds., (London: Fawcett, 2009), 214. He writes that “the records are collectively repurposed to embody contemporary desires and aspirations regardless of their actual contents and what they documented.”

community.”<sup>83</sup> In this way, the records filled the “vital human need” of recognition cited by philosopher Charles Taylor.<sup>84</sup>

Punzalan also points out that the act of archiving records lends the records the ability to acquire a symbolic meaning. A Culion schoolteacher told Punzalan that “‘I never realized their importance until I saw how meticulously they were cared for and handled for the centennial.’” Punzalan says that in the schoolteacher’s “eyes, archival acts of arranging, boxing, labelling and exhibiting rendered the dormant records into meaningful archives that embodied heritage and identity.”<sup>85</sup> So, while case files may indeed represent periods of history that include colonialism, discrimination or other harmful state practices, the case files also provide a record of individuals’ lives under the practice. In this way, the ownership of the records may not necessarily belong solely to the entity that created the records but also to the people who are the subjects of the records. Additionally, it could be argued that evidence of harmful state practices may also belong to the citizenry under whose name the government carried out the actions.<sup>86</sup>

But what meaning can be attached to records that have been destroyed, or are not “meticulously” cared for, or are hidden from view? It is essential to attach value to institutional records, but how can governments, archives, communities and individuals affected by

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<sup>83</sup> Punzalan, 213.

<sup>84</sup> Charles Taylor, *Multiculturalism: Examining the Politics of Recognition* (Princeton, NJ: Princeton University Press, 1994), accessed August 1, 2016, [http://www.veraznanjemir.bos.rs/materijal/multiculturalism.\\_examining\\_the\\_politics\\_of\\_recognition\\_-\\_charles\\_taylor.pdf](http://www.veraznanjemir.bos.rs/materijal/multiculturalism._examining_the_politics_of_recognition_-_charles_taylor.pdf), 26.

<sup>85</sup> Punzalan, 208.

<sup>86</sup> For example, archives of atrocities such as the Holocaust or other genocides are accessible to the public. See the Genocide Archive of Rwanda, [http://www.genocidearchiverwanda.org.rw/index.php/Welcome\\_to\\_Genocide\\_Archive\\_Rwanda](http://www.genocidearchiverwanda.org.rw/index.php/Welcome_to_Genocide_Archive_Rwanda); Sample Archival Documents on the Armenian Genocide, <http://www.armenian-genocide.org/sampledocs.html>; Bangladesh Genocide Archive, <http://www.genocidebangladesh.org/>; and “France opens access to archives drawn from Nazi-collaboration Vichy era,” *The Guardian* December 28, 2015 <http://www.theguardian.com/world/2015/dec/28/france-opens-access-to-archives-drawn-from-nazi-collaboration-vichy-era>; all accessed April 3, 2016.

institutions address competing interests in the files? In regard to decisions involving archival retention of records, Scheinberg suggests that for “complex” case files series, it would be “beneficial to strike up an inter-disciplinary committee” to discuss the sampling and selection “before any decisions are made” although she is also quick to point out that she is not calling for user-based appraisal.<sup>87</sup> Likewise, Terry Eastwood also suggests that there should be “more dialogue with the people we serve in a democracy” but then backtracks by saying “of course, most members of society are unlikely to come into direct contact with archives” and so should leave the archival decisions to archivists with whom they have a “fiduciary relationship.”<sup>88</sup> Brian Bucknall suggests that in the case of client files, the responsibility for determining access should rest with the “judgement of lawyers” and their “development of a new ethic.”<sup>89</sup> Bucknall’s suggestion illustrates the “culture” that Ian Forsyth describes as when “custodians of information feel ownership for the records, think the records they create are their personal purview, and resent any outside access as an intrusion that challenges their professional conduct.”<sup>90</sup> In contrast to this paternalistic vision of archives, Carter describes a sharing of power in which

Archivists can invite members of community groups into the planning and administrative processes, allowing them a voice in decisions regarding access, use, and display of records relating to that group, and to participate in the contextualization of the documents through the use of ‘liberatory descriptive standards.’”<sup>91</sup>

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<sup>87</sup> Scheinberg, “Two Perspectives,” 66. See her earlier article for arguments against user-based appraisal. For example, she cites Gerald Ham’s warning that too narrowly following research interests means “the archivist will remain at best nothing more than a weathervane moved by the changing winds of historiography.” Scheinberg, “Case File Theory,” 54. She also notes that had LAC archivists followed research-based appraisal, all the case files in the Local Initiate Programme might have been destroyed as no researcher had yet accessed them. (also 54).

<sup>88</sup> Eastwood, 71.

<sup>89</sup> Brian Bucknall, “The Archivist, the Lawyer, the Clients and their Files,” *Archivaria* 33 (Winter 1991-92), 186.

<sup>90</sup> Forsyth, 22.

<sup>91</sup> Carter, 231. The term “liberatory descriptive standards” was put forward by Wendy Duff and Verne Harris in “Stories and names: Archival description as narrating records and constructing meanings,” *Archival Science* 2 (2002), 263-285.

However, for such a scenario to occur, archivists—and even governments in the case of records of provincial institutions—would need to understand that communities have rights of ownership over records that are written about them. However, in situations where governments appoint Public Guardians or Trustees to manage the lives of individuals confined to institutions, it seems unlikely that this kind of sharing of power would be understood to be possible. With case files, archivists have the challenging opportunity to reach out to communities to help formulate innovative ways to preserve and provide access to these files, while maintaining the integrity and privacy of individuals and communities. Ricardo Punzalan’s experience with the colonial leprosy archives helped shape his understanding that “archivists should view their actions as ‘co-witnessing’ and not only as expert authors in the construction of archives as heritage and collective memory of a community.”<sup>92</sup>

This chapter shows that while institutional records may contain similar categories of information as hospitals, the records of institutions also contain unique categories. Because so little research has been done on records of institutions for people labelled with intellectual disability, frameworks of typical records have not yet been constructed. Further, although the institutions themselves were highly structured, the records preserved by archives are scattered and fragmented. Although large extents of case files may exist for these kinds of institutions, there is no known study that has accessed the files for qualitative information in the way that other researchers have examined records of psychiatric institutions and asylums. Like records from residential schools, records of institutions for people labelled with intellectual disability may contain information that is vital for individuals’ self-knowledge and for legal redress. As

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<sup>92</sup> Punzalan, 214.

with the records of any marginalized community that were created by a dominating authority, questions of ownership and access are complex. Some of the issues surrounding the protection of records are examined in the next chapter.

## **Chapter Four: “Too much secrets.”**

### **Freedom of Information legislation and eugenic records**

During The Freedom Tour, the filmmakers stopped to interview Patricia Endall, who also lived in the MDC. During the interview, David Weremy and Endall talk about their shared memories from their time in the institution. Endall calls the institution a “bad place” and she begins to wipe her eyes and cry. Weremy responds by saying, “They should do something about that home. Shut it down. Too much secrets over there.”<sup>1</sup>

Dominique Clément says, “There is a rich and untapped source for historical research that is available to any scholar who is willing to navigate the quagmire of freedom of information legislation (FOI) in Canada.”<sup>2</sup> This chapter reviews implications of freedom of information legislation (also referred to as privacy legislation or access to information legislation)<sup>3</sup> for research. It also examines some specific cases of researchers attempting to access eugenic-related records.

### **Freedom of information legislation**

In 1983, the federal Access to Information Act was passed in Canada at the same time as the Privacy Act. These two acts complement each other but also illustrate the sometimes contradictory aims of both acts: one act ensures access and the other restricts access. The

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<sup>1</sup> YouTube, David Weremy in “Patricia Endall” Label Free Channel, accessed January 25, 2016, <https://www.youtube.com/watch?v=yKKUWCIqW4Y>.

<sup>2</sup> Clément, 101.

<sup>3</sup> The names of provincial legislation often begin with “freedom” such as Manitoba’s Freedom of Information and Protection of Privacy Act. The federal legislation is called the Access to Information Act. I have used the terms of privacy legislation, freedom of information and access to information interchangeably.

*Manitoba Freedom of Information and Protection of Privacy Resource Manual* cites the following description of access to information legislation by the Supreme Court of Canada:

The overarching purpose of access to information legislation, then, is to facilitate democracy. It does so in two related ways. It helps to ensure first, that citizens have the information required to participate meaningfully in the democratic process, and secondly, that politicians and bureaucrats remain accountable to the citizenry.<sup>4</sup>

Manitoba's Freedom of Information Act was proclaimed in 1988. This was followed by an act that came into effect in 1999 and covers both access and privacy legislation. Manitoba also has an act that deals specifically with health information, the Personal Health Information Act (PHIA) that came into force in 1997. As very little scholarly work has looked specifically at access to records under Manitoba's legislation, this thesis also uses scholarly works that examine Canada's federal legislation and access to information legislation in general.<sup>5</sup>

Although freedom of information legislation has created a "culture shift toward transparency" this shift does not extend toward all records.<sup>6</sup> For records that contain personal health information, such as clinical files of residents of institutions, privacy laws stringently restrict access. While governments rightly claim that privacy legislation protects individuals, some researchers argue that the legislation is also used to protect governments and public bodies from scrutiny. Operating under the legislated restrictions means that the negotiation of access to archived records that contain personal health information, and particularly health information of

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<sup>4</sup> Cited in Manitoba Tourism, Culture, Heritage, Sport and Consumer Protection, *Manitoba Freedom of Information and Protection of Privacy Resource Manual*, 2nd Edition, 1-1.

<sup>5</sup> The only existing work seems to be Nicholls, "'Guide' vs 'gatekeeper'".

<sup>6</sup> Jo-Ann Munn Gafuik, "Access-to-Information Legislation: A critical analysis," *Better Off Forgetting? Essays on Archives, Public Policy, and Collective Memory*, Cheryl Avery and Mona Holmlund, eds., (Toronto: University of Toronto Press, 2010), 39. Also see Bucknall who argues that while personal legal files could be important to researchers the issues of confidentiality and personal issues mean that "the substantive and ethical issues become overwhelming." Bucknall, 186.

citizens considered to be vulnerable, is difficult at best and outright discouraging or even impossible at worst.

Doug Surtees, a Canadian law professor, argues that legislated protection of personal health information is important in particular for two groups in society: the elderly and people with disabilities. Surtees says these two groups “are profoundly in danger of having each of their protected realms of privacy invaded” because their lives have so many intersections with service providers and so many records are generated.<sup>7</sup> Further, people who interact with service agencies and allow the collection of personal information by the agencies are not consenting to the secondary use of their personal health information by researchers.<sup>8</sup> Particularly for individuals living in institutions where “program and service delivery is omnipresent” the records created for an individual could be both voluminous and deal with very private issues. Therefore, it is extremely important that people living in institutions should be covered by the same expectations of privacy that those of us living in our private homes expect.<sup>9</sup>

Although records created by institutions are important for the public’s understanding of the treatment of people in institutions, the records were not created and preserved for the purposes of public dissemination. As Joy Parr argues, “an agency which opens case records to researchers places in the public domain information about individuals who never chose to enter

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<sup>7</sup> Doug Surtees, “Privacy: A Look at the Disenfranchised,” Avery and Holmlund, 64.

<sup>8</sup> However, Barbara L. Craig points out that future use of records by researchers “will rarely be” the use for which the records were originally intended. Barbara L. Craig, “Confidences in Medical and Health Care Records from an Archival Perspective,” Menzi L. Behrnd-Klodt and Peter J. Wosh, eds., *Privacy & Confidentiality Perspectives: Archivists & Archival Records* (Chicago: Society of American Archivists, 2005), 254.

<sup>9</sup> Surtees, 66 and 62 respectively. Surtees says “some places will generally be presumed to be protected by privacy. The house one lives in is a traditional example. The room one lives in within an institution also fits the description.”



public life.”<sup>10</sup> Likewise, Surtees maintains that “possessing information for one purpose may provide the ability to use that information for other purposes, but it does not provide the right to do so. That would offend the dignity of the one whose privacy is violated.” In fact, Surtees emphasizes that “the duty we owe others to respect their reasonable expectations of privacy is most critical when we have responsibilities towards those who are, in a privacy sense, disenfranchised.”<sup>11</sup>

While the above appears to indicate Surtees’ agreement that access to case files should be restricted, Surtees does not call for a blanket restriction of case files. He says that “given that the information currently exists, I think it is ethically possible to make use of the information provided one stays within certain boundaries.” He suggests that records relating to deceased people possibly could be more openly used, provided that the individual is not identified.<sup>12</sup> He also believes that cumulative data that does not identify individuals could be shared. In fact, given the human rights context of the records, he says that he “would be very concerned however with restricting access to these records.” Especially for researchers connected to a university, who are bound by research ethics board approval and protocols, he believes that any risk posed to privacy “is manageable.”<sup>13</sup>

As Surtees’ competing arguments show, privacy legislation is meant to serve a dual-

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<sup>10</sup> Joy Parr, “Case File Records as Sources for Social History,” *Archivaria* 4 (Summer 1977), 37.

<sup>11</sup> Surtees, 63. By “disenfranchised” Surtees means “people who, as members of a group, are to be the beneficiary of some programmatic or institutional initiative but who do not have the ability to control the use of the information collected about them for the purpose of that initiative.”

<sup>12</sup> Doug Surtees, email to author, December 3, 2012. However, he amends his statement by saying “I still have to wrestle with the issue of telling stories of individuals based upon records protected by an expectation of privacy. After all, many individuals may not have wanted those stories told.”

<sup>13</sup> Doug Surtees, email to author, December 3, 2012.

purpose: it protects personal information but under certain circumstances allows the public access to protected information.<sup>14</sup> Jo-Ann Munn Gafuik, privacy specialist at the University of Calgary, stresses the importance of freedom-of-information legislation. She says this legislation

inevitably recognizes and expands the notion of the government's 'duty to disclose' and the public's 'right of access' to information in the custody of authorities in centres of power. Furthermore, since information asymmetry between a government and its citizens limits democratic participation and accountability, removing the asymmetry—that is, increasing the flow of information to the public—allows for meaningful popular participation and oversight of government.<sup>15</sup>

Sidney Shapiro and Rena Steinzor, American lawyers, scholars and political activists, maintain that freedom of information legislation concerns “the democratic principle that people have a right to know about business transacted in their name.”<sup>16</sup> Researcher Patrizia Gentile also notes the importance of FOI to a “liberal democratic society,” but explains that the dual functions of the Access to Information Act can also be contradictory: “The Act functions as a critical technology of power that facilitates the possibility of rupture, exposure, and critique of the state while simultaneously entrenching the power of the state to regulate, limit, and protect information it creates.”<sup>17</sup> More simply said by Roberts, while “citizens support FOI laws because

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<sup>14</sup> Sometimes the citing of these dual purposes is reversed, lending a changed weight to the roles. For example, “making a request does not automatically guarantee that the user will gain access to the material. FOIP serves a dual purpose: to provide access to the records of public bodies, and to protect the privacy of individuals represented in records of public bodies.” See Kristan Cook, “Little School on the Prairie: School District Records at the Provincial Archives of Alberta,” *Archivaria* 67 (Spring 2009), 56. Gary Dickson describes the right to information and the right to privacy as “competing claims.” See Ken Gousseau, “Q&A with Gary Dickson: The people’s privacy commissioner,” *CTV News* January 31, 2014, accessed January 21, 2015, <http://regina.ctvnews.ca/q-a-with-gary-dickson-the-people-s-privacy-commissioner-1.1665094>.

<sup>15</sup> Gafuik, in Avery and Holmlund, 39. Munn Gafuik’s job title is listed as Senior Specialist for FOIP and Policy. The acronym FOIP is used in Alberta to mean the Freedom of Information and Protection of Privacy Act.

<sup>16</sup> Cited in Yavar Hameed and Jeffrey Monaghan, “Accessing Dirty Data: Methodological Strategies for Social Problems Research,” *Brokering Access: Power, Politics and Freedom of Information Process in Canada*, Mike Larsen and Kevin Walby eds., (Vancouver: UBC Press, 2012), 146. This understanding is echoed by Canadian and public policy expert Alasdair Roberts, who says that “effective FOI laws are one of the hallmarks of a strong democracy.” Roberts, “Closing the Window.”

<sup>17</sup> Patrizia Gentile, “Resisted access? National security, the Access to Information Act, and queer(ing) archives.” *Archivaria* 68 (Fall 2009), 145.

they help keep governments honest ... governments aren't always as enthusiastic.”<sup>18</sup>

Although FOI legislation is intended to provide a route toward access to records, human rights lawyer Yavar Hameed and PhD student and activist Jeffrey Monaghan note that “curious social problems researchers are rarely welcomed by those agencies they seek to research.”<sup>19</sup> Justin Piché, a Canadian sociologist studying prison agencies, says “barring access to researchers who may be critical of their activities is one means by which authorities control knowledge about their policies, practices, and decisions.”<sup>20</sup> Although FOI legislation offers avenues by which applicants can make complaints about request denials, if the process eventually reaches the courts Hameed and Monaghan note that “the imbalance of resources between individuals and government agencies is dramatic.”<sup>21</sup> As Yeager states “most citizens simply cannot afford their ‘day in court.’”<sup>22</sup>

Governments that wish to express their resistance to access to information can do so with tactics that include cutting budgets to offices and staff that work with FOI requests, delays in

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<sup>18</sup> Alasdair Roberts, “Closing the Window: How Public Sector Restructuring Limits Access to Government Information.” *Government Information in Canada/Information gouvernementale au Canada* 17 (March 1999), accessed January 6, 2015, <http://library2.usask.ca/gic/17/roberts.html>, unpaginated.

<sup>19</sup> Hameed and Monaghan, in Larsen and Walby, eds., 142. Gentile lists several examples of successful attempts in her *Archivaria* article. Gentile, 144 footnote 9.

<sup>20</sup> Justin Piché, “Accessing the State of Imprisonment in Canada: Information Barriers and Negotiation Strategies,” in Larsen and Walby, eds., 234. Patrizia Gentile also notes that “although the Canadian state recognizes that a democratic society must allow its citizens access to classified or restricted information, that same state carefully ensures that such access is not easily forthcoming.” Gentile, 154.

<sup>21</sup> Hameed and Monaghan, in Larsen and Walby, eds., 151.

<sup>22</sup> Matthew Yeager, “The Freedom of Information Act as a Methodological Tool: Suing the Government for Data,” *Canadian Journal of Criminology and Criminal Justice* 48/4 (July 2006), 513. Even organizations such as newspapers can find the costs of fighting for access to government information to be intimidating. David Thompson, executive director of the Kentucky Press Association, says that “We know that public agencies almost have a bottomless pit to fight legal cases, and newspapers do not.” Cited in Miranda Fleschert, “State Legislatures and courts move to make government settlement agreements public record,” *The News Media & The Law* (2010), 12. Accessed February 2, 2015, <http://www.rcfp.org/browse-media-law-resources/news-media-law/news-media-and-law-spring-2010/state-legislatures-and-cour>.

responses to requests, increased fees, and restructuring departments to agencies that fall outside FOI legislation.<sup>23</sup> Dominique Clément, sociologist and historian of human rights, also says that governments can resist by “narrowly interpreting requests, and censoring documents.”<sup>24</sup>

Practices in which requests for potentially sensitive documents are flagged by government officials with colour-coded names such as “amber light” or are sidetracked onto a “contentious issues track” have been described by Canadian journalist Ann Rees.<sup>25</sup> Less overt mechanisms that can cause barriers to access are caused by FOI employees who are less knowledgeable about access issues. Dickson describes these jurisdictions as having “weaker access regimes” and notes “inexperienced and undertrained FOIP coordinators are unlikely to champion within their organization open government and proactive disclosure to the public.”<sup>26</sup>

Access to records is mandatorily excepted for records in three areas: personal health information; cabinet confidences; and third-party business information.<sup>27</sup> But these exceptions

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<sup>23</sup> Roberts, “Closing the Window,” unpaginated. Governments can also deny access on the basis of national security or by asserting that the documents do not exist. See S. Lynne Walker, “For Mexico, open records unlock doors,” U-T San Diego (November 20, 2005), accessed January 6, 2015, [http://www.utsandiego.com/uniontrib/20051120/news\\_1n20openrec.html](http://www.utsandiego.com/uniontrib/20051120/news_1n20openrec.html). For an example of a Canadian case study in which the government denied access for reasons of national security, see Hameed and Monaghan, 153-155. Some critics accuse the government of deliberately “avoiding putting things on paper to prevent such documents from then being released.” See James Keller, “Advocacy group files complaint over B.C.’s record on freedom of information requests,” *The Globe and Mail* (September 13, 2012), accessed January 6, 2015, <http://www.theglobeandmail.com/news/british-columbia/advocacy-group-files-complaint-over-bcs-record-on-freedom-of-information-requests/article4542769/>. Another example is the “Sponsorship Scandal” in which a deliberate plan existed to avoid creating paper documentation and thus access-to-information requests. Cited in Gafuik, 44.

<sup>24</sup> Clément, 104.

<sup>25</sup> Ann Rees’ investigative work has been described and summarized in many instances. See for example Ian MacLeod, “Experts say political interference makes task a farce,” *Telegraph-Journal* May 28, 2005, accessed January 15, 2015, <http://search.proquest.com/docview/423233741?accountid=14569>. Also see Hameed and Monaghan, 147-148.

<sup>26</sup> Gary Dickson, “Access Regimes: Provincial Freedom of Information Laws across Canada,” in Larsen and Walby, eds., 77. In my experience, a single request can involve several government employees, from a newly-hired FIPPA coordinator to a deputy minister. Dickson also describes provinces, such as Manitoba, as having a weaker access regime because the FOI oversight responsibilities have been passed to an Ombudsman, who has other duties, rather than a full-time FOI commissioner.

<sup>27</sup> See Dickson, 70.

can be overruled if it is proven that the benefit to the public outweighs the harm of access.

Proving public interest though can be very difficult and Dickson cites, for example, a 2002 decision in Alberta in which the judge commented: “I emphasize that the burden of proving a public interest is an onerous one. It will neither be frequently nor easily met.”<sup>28</sup> Dickson also says that if a public body determines that public interest does not override privacy concerns then it is very rare that this decision would be overturned by the oversight office.<sup>29</sup>

### **Fees and delays**

Of all these barriers, the two most cited are delays in responding to requests and fees associated with fulfilling requests.<sup>30</sup> Manitoba, unlike most jurisdictions, has no fee associated with making a FOI request but there are other types of fees associated with fulfilling the request, such as: search and preparation; computer programming and data processing; copying; and delivery.<sup>31</sup> In Manitoba, two hours of search and preparation time is provided for free for each request but subsequent time is charged at \$15 per half hour.<sup>32</sup>

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<sup>28</sup> Justice T. McMahon, cited in Dickson, 88. The case concerned the request for the fee waiver of \$60,000 by the *Globe and Mail* and an opposition MLA in Alberta over documents concerning Stockwell Day.

<sup>29</sup> For a list of provincial offices and laws, see the website of the Office of the Privacy Commissioner of Canada, “Provincial and Territorial Authorities,” accessed January 21, 2015, [https://www.priv.gc.ca/resource/prov/index\\_e.asp](https://www.priv.gc.ca/resource/prov/index_e.asp).

<sup>30</sup> Dickson describes these as the “two most significant barriers to freedom of information.” Dickson, 85. Historian Larry Hannant says that “a key aspect” is “not just access to government documents, but the need for timely access.” Larry Hannant, “Access to information and historical research: The Canadian experience,” Andrew Flinn and Harriet Jones, eds., *Freedom of Information: Open Access. Empty Archives?* (London: Routledge, 2009), 127. As reported by Hannant, the Canadian Historical Association has commented on the need for timely access in its general meetings and to the Access to Information Review Task Force in 2001. Hannant, 128. Duff and Johnson also state that “time and money” are top concerns for researchers. Duff and Johnson, 282.

<sup>31</sup> Manitoba Tourism, Culture, Heritage, Sport and Consumer Protection, *Manitoba Freedom of Information and Protection of Privacy Resource Manual*, 2nd Edition, 4-61. Computer and data processing is charged at \$10.00 per fifteen minutes for work done internally. If an external body does the processing, then the applicant is charged the cost incurred by the public body.

<sup>32</sup> Manitoba government website, “Understanding FIPPA,” accessed January 23, 2015, [http://www.gov.mb.ca/chc/fippa/understanding\\_fippa.html](http://www.gov.mb.ca/chc/fippa/understanding_fippa.html). Searching includes: locating the records by “reviewing current file documentation

According to the annual FIPPA reports from 1996-2013, only a relatively small amount of fees related to requests are collected by the government.<sup>33</sup> In 2013, for example, \$5,400 was collected through search and preparation fees.<sup>34</sup> In 2012, the fees collected were about half that amount.<sup>35</sup> A review of eighteen years of reports that are available online show that there does not seem to be any discernible trend in fee collection apart from the commonality that in most years the amount of fees collected is less than two percent of the total costs incurred by the government bodies.<sup>36</sup> This small portion belies any argument that the FIPPA fees recoup the costs of access requests. However, although a fee of several hundred dollars is not significant to a government with an annual expenditure of over \$12 billion, the fee can be significant for the individual making the request. Indeed, as so little revenue is generated by fee collection for the government, it is hard to think of a reason for the fees beyond a deterrent to applicants. Even the Manitoba Ombudsman admits that the purpose of fees is meant to be a “mild deterrent,” although the Ombudsman adds the disclaimer that the deterrent is for those who intend “inappropriate use

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and Records Transfer Box Lists and other file lists, indexes, systems, etc.,” gathering the records from storage or arranging to view the records at the Archives of Manitoba; and examining the records. Preparation includes: copying the records to create working copies; severing or redacting the records where necessary; and noting on the severed or redacted records the reasons for the exclusion. The *Manitoba Freedom of Information and Protection of Privacy Resource Manual* notes that fees should not include time spent reviewing the records to determine if “exceptions to access apply, prior to any severing of the record.” Manitoba Tourism, Culture, Heritage, Sport and Consumer Protection, *Manitoba Freedom of Information and Protection of Privacy Resource Manual*, 2nd Edition, 4-64. The BC government also provides a description of what is involved in search and preparation, see British Columbia government website, “Freedom of Information Requests,” accessed May 25, 2016, <http://www2.gov.bc.ca/gov/content/governments/services-for-government/information-management-technology/access-to-information/foi-requests#general>.

<sup>33</sup> These years were chosen because the reports are easily accessible online.

<sup>34</sup> Manitoba, *Freedom of Information and Protection of Privacy Act Annual Report 2013* (Winnipeg: Manitoba Tourism, Culture, Heritage, Sport and Consumer Protection, n.d.), 8. No fees were charged for photocopying or computer programming.

<sup>35</sup> Ibid. This amounts to \$2,340 for computer programming and \$57 for copying. \$2,597. Of this total, only \$200 was for search and preparation; computer programming fees formed the bulk of the total with a small amount for copying fees.

<sup>36</sup> When legal costs are included in the total cost, the fees collected are less than 1 percent of the total. See 2013 FIPPA Supplementary Statistics and 2010 FIPPA Supplementary Statistics, [http://www.gov.mb.ca/chc/fippa/annual\\_reports/pdf/fippa\\_supp\\_stats2013.pdf](http://www.gov.mb.ca/chc/fippa/annual_reports/pdf/fippa_supp_stats2013.pdf) and [http://www.gov.mb.ca/chc/fippa/annual\\_reports/pdf/fippa\\_supp\\_stats2010.pdf](http://www.gov.mb.ca/chc/fippa/annual_reports/pdf/fippa_supp_stats2010.pdf), both accessed January 26, 2015.

of the legislation” and that fees “are usually leavened by fee waiver provisions that support equitable access rights for all.”<sup>37</sup>

Although Manitoba’s legislation requires that the annual FIPPA reports include “the fees charged for access to records” this category appears only to mean the fees collected from applicants rather than the total fee estimates provided to applicants.<sup>38</sup> Since the annual reports do not list the total fee estimates received by researchers, this number cannot be compared to the total fees collected to see if large fee estimates discourage applicants from pursuing requests. To try to determine if fees halt applicants’ research efforts, FIPPA requests could be sent to each government department asking for both a list of fee estimates supplied to applicants and the list of fees collected.<sup>39</sup> This line of inquiry though could be time-consuming and result in inconclusive results. For example, a request for such information was sent to the department of Family Services. The information asked for in this request included the number of FIPPA applications made to the department concerning the MDC for the years 1997-2013 and whether fees were estimated or collected. However, the reply from the department stated that FIPPA records fall under the responsibility of the Legislation and Strategic Policy Branch and their record schedule allows for the destruction of FIPPA records after a certain retention period.<sup>40</sup> Although the FIPPA records were destroyed prior to the 2007/2008 fiscal year, the department of Family Services did find some notes regarding requests made between 2005 and 2007. These

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<sup>37</sup> Manitoba, *Annual Report of the Manitoba Ombudsman 2000* (Winnipeg: Ombudsman Manitoba, n.d.), 15, accessed January 30 2016, <https://www.ombudsman.mb.ca/uploads/document/files/2000-ap-annual-report-en.pdf>.

<sup>38</sup> FIPPA 83(2)(e).

<sup>39</sup> Even if these two figures were able to be compared, applicants could abandon requests for other reasons or decide to pursue a research agreement. It would be an interesting, but time-consuming and difficult task, to try to determine whether large fee estimates consistently deter applicants. FIPPA requests could be sent to each of the 19 government departments listed on the FIPPA website.

<sup>40</sup> Joy Cramer, letter to author, March 26, 2015. This letter was in response to my FIPPA request that had the department file number of 15-024.

notes were incomplete and so while the information received showed that a total of \$4,635.35 was estimated for requests in 2005, only in one case were the fees collected after an estimate. Because the information was incomplete, for seven requests comprising the majority of the fees estimated, the resulting fees collected were unknown.<sup>41</sup> In no instance of the eleven fee estimates provided in 2005 (which ranged from \$2.00 to \$3,000.00) was a fee waiver requested.

The standard rebuttal to complaints about fees is that Manitoba's legislation allows for the possibility of fee waivers. These waivers can be made under the following conditions: if "the payment would impose an unreasonable financial hardship on the applicant" or "the record relates to a matter of public interest concerning public health or safety or the environment" or if the request "relates to the applicant's own personal information and waiving the fees would be reasonable and fair in the circumstances."<sup>42</sup> According to the FIPPA annual reports, between 1999 and 2013, fee waivers were granted in only four years.<sup>43</sup> It is unfortunate that the annual reports do not track the number of applications for fee waivers. However, even so, fees may be waived in ways that do not follow the official route. Sometimes researchers are offered research

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<sup>41</sup> Response to FIPPA 15-24. The request for information regarding "Policies & Administrative Practices" estimated and collected fees in the amount of \$581.95. A total of \$4,094.80 of fees estimated in 2005 have no information as to whether fees were collected. As I had requested information for fees estimated up to 2013, and only fee information was returned for 2005, it appears that was the only year that fees were estimated. According to the list provided by the department, 2005 had an exceptionally large number of requests. Most years had only a few requests, with the exception of 2007 in which a dozen requests were made.

<sup>42</sup> The Freedom of Information and Privacy Act (C.C.S.M. c. F175), accessed January 26, 2015, [http://www.gov.mb.ca/chc/fippa/act\\_regulation.html](http://www.gov.mb.ca/chc/fippa/act_regulation.html).

<sup>43</sup> Manitoba, The Freedom of Information and Protection of Privacy Act, annual reports, 1999 to 2013, accessed August 22, 2016, [http://www.gov.mb.ca/chc/fippa/annual\\_reports/index.html](http://www.gov.mb.ca/chc/fippa/annual_reports/index.html). The waivers were for the following amounts: year 2000, amount not specified; 2001, amount not specified; 2008, \$45; 2006, \$180; 2004, \$212; and 2003, \$388. Note that only the 1999 report states that no fee waivers were requested. It is possible that in other years, fee waivers were requested but not granted. The 2000 report stated that the Justice department waived a fee for the reason that it would have imposed financial hardship on the applicant. The 2001 report specified that fees were waived by Intergovernmental Affairs as "the record related to a matter of public interest concerning public health, safety, or the environment." *Freedom of Information and Protection of Privacy Act Annual Report 2001*, 4.



agreements before a fee estimate is even provided.<sup>44</sup> In other cases, Hannant says that fee waivers are often granted to historians as an “implicit trade-off [that] seems to be to placate users for poor service by waiving hefty processing fees.”<sup>45</sup>

The “poor service” that Hannant describes includes delays in responding to requests. Manitoba, like most jurisdictions, requires an initial response to be made by the public body within thirty days of the FIPPA request being received. If a response is not made within thirty days, the legislation states that this “is to be treated as a decision to refuse access to the record.”<sup>46</sup> Before the thirty-day period is completed, the public body may request an additional thirty days. This additional thirty-day period “includes when a large number of records must be searched or when time is needed to consult with a third party or another public body before deciding whether to grant access.”<sup>47</sup> In some cases, the Ombudsman may also allow a further extension beyond sixty days. The applicant is allowed thirty days after notification of the extension to dispute the need for the extension with the Ombudsman. Not all researchers, however, find that the Ombudsman or other body responsible for oversight has much effective power. Hannant, in his experience making complaints with the federal oversight body over delays, found that “little difference” was made through his complaints. As well, he noted that “working through the complaint process can itself take months, and the result is often of little benefit.”<sup>48</sup> Although the Ombudsman posts the name of the government departments that failed to respond in time, or for

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<sup>44</sup> This occurred during my requests to the Department of Transportation and Infrastructure.

<sup>45</sup> Hannant, 131.

<sup>46</sup> FIPPA 11(2), 14.

<sup>47</sup> *Freedom of Information and Protection of Privacy Act Annual Report 2013*, 7. FIPPA 15(1) also states that an extension may be requested if “the applicant does not give enough detail to enable the public body to identify a requested record; or “a third party makes a complaint.”

<sup>48</sup> Hannant, 129. However, he said that some privacy coordinators urge researchers to make complaints so that the number of complaints could be used as “an attempt to leverage a larger budget and more personnel.” Hannant, 129.

which complaints had been made, it is not clear if this is an effective penalty or little more than a scolding.<sup>49</sup>

According to the past fifteen annual FIPPA reports, most applications are completed—whether the information is granted or denied—within a sixty-day time frame. From 1991 to 2001, almost ninety percent of the requests were responded to within thirty days. However, in the period of 2006 to 2010, only fifty-five to sixty-seven percent of requests were completed within thirty days. In 2011, the definition of “on time” changed to be within sixty days (thirty days with authorized extensions) and so figures for on-time responses then rose to just over 80 percent.<sup>50</sup>

### **Research agreements**

The response times reported for FIPPA requests describe the circumstances for only one route applicants can take with the government while requesting information. In a case when an applicant is requesting a large number of records, in consultation with the public body, the FIPPA requests can be withdrawn and the applicant can enter into a research agreement with the public body instead. A research agreement would be appropriate in cases where the applicant has requested a large number of records and thus would save both the applicant from high fees and the government from the time required to review each file.<sup>51</sup> Although the legislation briefly mentions research agreements when it allows for the disclosure of personal information for a “bona fide research purpose” and specifies “the person to whom the personal information is disclosed has entered into a written agreement to comply with the approved conditions,” the

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<sup>49</sup> Manitoba Ombudsman, “FIPPA Investigation Reports,” accessed May 15, 2016, [https://www.ombudsman.mb.ca/documents\\_and\\_files/investigation-reports.html](https://www.ombudsman.mb.ca/documents_and_files/investigation-reports.html).

<sup>50</sup> *Freedom of Information and Protection of Privacy Act Annual Report 2013*, 7.

<sup>51</sup> Clément says “the use of a research agreement is far more efficient than reviewing and redacting every document.” Clément, 108.

legislation does not describe the written agreement nor the process by which it is made.<sup>52</sup> Janelle Reynolds notes that “There is no direction nor does the legislation provide any. Some departments draw up their own agreements and do not involve CLS [Civil Legal Service], some do, and others draw up an agreement to the agreement.”<sup>53</sup>

There appear to be no time limits in regard to the drawing up of research agreements by the province’s legal services; time frames have been estimated from three months to over fourteen months.<sup>54</sup> Additional weeks or months may be required for the agreement to be processed through the researcher’s affiliated university’s legal services. Any amendments proposed to the agreement will cause further delays. The annual FIPPA reports do not mention time frames for preparing research agreements although the legal fees described in the reports include fees incurred while drawing up research agreements.<sup>55</sup> Applicants undertaking research agreements do not seem to have recourse to a complaint process as the Ombudsman Office does not have oversight over research agreements. Although the Ombudsman Office publishes a *User’s Guide to FIPPA* that provides advice to applicants “in understanding and exercising your rights,” research agreements are not mentioned in the guide.<sup>56</sup>

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<sup>52</sup> FIPPA 47(4)(b)(i) and 47(4)(d).

<sup>53</sup> Janelle Reynolds, email to author, February 4, 2015.

<sup>54</sup> Hannant says he “routinely” was told that processing time of requests could be ten to twelve months. Hannant, 128. I was cited wait times of 4 to 16 months, with estimates more often being twelve to sixteen months.

<sup>55</sup> Janelle Reynolds, email to author, February 4, 2015. She wrote “Under Part 2 of FIPPA, public bodies consult with legal counsel when they receive complex access requests. Public bodies seek advice regarding legal issues, interpretation of the Act and also assistance with access decisions. A public body could also request legal assistance with the drafting of a research agreement.”

<sup>56</sup> Manitoba Ombudsman, *User’s Guide to FIPPA*, (September 2012), unpaginated Introduction.

Few historians publish discussion about research agreements—Dominique Clément is a rare exception.<sup>57</sup> In 2007, Clément was featured in a *Vancouver Sun* article after his office was subjected to a search by individuals from the Royal BC Museum (which includes the British Columbia provincial archives). These individuals “examined the software on Clément’s laptop, vetted the encryption program used to secure data on a memory stick, checked the locked cabinet in which he is required to secure documents and questioned him closely about who else had access to the office.”<sup>58</sup> In response to the article, Gary Mitchell, who was the Provincial Archivist at the time, wrote a letter to the *Vancouver Sun* and explained: “For us, the requirement to conduct regular inspection of research agreement-holders was a direct request from the information and privacy commissioner.”<sup>59</sup> Mitchell also noted that Clément had agreed to the possibility of such inspections when Clément signed the research agreement. Clément claims that he was the first person to be audited once the BC Archives began “enforcing an obscure section of the provincial FOI statute” and called it a “shocking invasion of privacy.”<sup>60</sup> He also notes that graduate students or other researchers or journalists without offices would be required to let the auditors into their homes.<sup>61</sup>

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<sup>57</sup> Dominique Clément and Claudia Malacrida are examples of researchers who publicly address access barriers to archival materials.

<sup>58</sup> Stephen Hume, “Draconian rules on archives use cast a chill on researchers,” *The Vancouver Sun* November 28, 2007, A13.

<sup>59</sup> Gary Mitchell, “Re: Draconian rules on archives use cast a chill on researchers,” *The Vancouver Sun* December 4, 2007, A11. The people from the Museum were described as “security agents” by the newspaper. Clément, however, identified them as “the Manager for Corporate Information, Privacy and Records at the BC Archives” and “an assistant.” Clément, 108.

<sup>60</sup> Clément, 108-109.

<sup>61</sup> Clément also says that as the BC Archives does not have the resources to conduct audits widely, only those researchers based in Vancouver and Victoria are subject to the searches thus creating “two classes of researchers.” Clément, 109-100.

Researchers who sign agreements with the Province of Manitoba also must agree to searches. Such a clause in a research agreement can read:

Manitoba and its representatives may carry out such inspections or investigations respecting the use and handling of the Information by the Researcher and respecting the Researcher's security arrangements as Manitoba considers necessary to ensure that the Researcher is complying with the terms and conditions of this Agreement and that the Information, and the privacy of individuals any Information is about, are adequately protected. The Researcher shall cooperate fully in any inspection or investigation.<sup>62</sup>

Research agreements also contain provisions by which the government can terminate the agreement if they are “reasonably of the opinion” that the researcher disclosed information or “has failed to comply with, or is about to fail to comply with, any of the Researcher's obligations or undertakings under this Agreement.” Once the government terminates the agreement, the researcher must “return or destroy all information which has been received or obtained.” Further, the government may then report the researcher to

- (a) the institutional research review committee which approved the research;
- (b) any person, organization, institution or other entity sponsoring or funding the research;
- (c) any professional association or disciplinary or other body with jurisdiction to discipline, supervise or regulate the Researcher.

Clearly, these clauses are enough to cause anxiety for the researcher who would have to submit to punitive measures by a government employee who may be only “reasonably of the opinion” that the researcher has “or *is about to* fail to comply” with the stipulated conditions of the agreement. In no instance of the agreement does it explain the conditions that allow the government employee to see into the future so as to be of the opinion that the researcher “is about to fail to comply.”

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<sup>62</sup> Excerpted from one of my research agreements.

While it is important for the Manitoba government to stringently protect the personal information of its citizens, the heavy-handedness of the research agreements seems to fail to take into account that academic researchers who have obtained agreements have only done so by previously gaining the approval of their protocols by their university's Research Ethics Board (as will be explained later). In turn, the university board takes its direction from the Tri-Council Policy Statement prepared by the three federal research agencies: The Canadian Institutes of Health Research (CIHR), the Natural Sciences and Engineering Research Council of Canada (NSERC) and the Social Sciences and Humanities Research Council (SSHRC). So in this way, the researcher has already prepared a project framework that is in line with strong ethical principles and protocols. The language of the researcher agreements, however, seems to indicate the assumption that researchers are ready to break their own ethical protocols that they spent months carefully devising and will only be prevented from doing so by the fear of severe sanctions. The research agreements also seem to fail to recognize that researchers may also be bound by their own ethical and moral connections to the subjects under their study. Many researchers, especially perhaps those who are engaged in research concerning marginalized groups, may feel deep bonds of trust and would not break those bonds by disclosing information. The punitive language of the research agreements, and the way in which government employees are cast in a policing role pitted against researchers is one way to discourage research into sensitive areas.

### **Eugenics records**

In regard to institutions and other state-supported eugenic practices, it has been argued by disability advocates that restricted access to records protects the institutions and governments

more than the institution's residents or sterilization victims. As stated in Chapter One, not only was Johanna Schoen's access to the North Carolina records unique, Schoen also points out that in the United States, North Carolina "is the only state to ever have opened the records of its state eugenic sterilization program to a researcher."<sup>63</sup> Schoen says that she knew other historians and lawyers across the United States who were researching state sterilization programs but "none of them had ever been able to see the actual records of these programs." She asserts: "It became increasingly clear to me that the privacy laws that kept the records of all thirty state sterilization programs closed to protect sterilization victims had another effect: they also kept this history hidden from public view."<sup>64</sup>

Schoen had originally received permission to view the sterilization records by making a formal application to North Carolina's state attorney general. She says she was surprised to have her request granted but when she visited the archives "the archives' staff was less sure about how to interpret the attorney general's letter." Although Schoen interpreted the letter to mean that she had access to the full extent of the Eugenics Board material, the archives staff "withheld access to all of the records relating to the more than eight thousand sterilization petitions the board had received."<sup>65</sup> She was allowed access only to the Eugenics Board papers and correspondence. Six years later, Schoen again visited the archives to review the material: she says that "in preparation for my visit, the archives' staff had again contacted the attorney general and this time they had received a more liberal interpretation of 'access.'"<sup>66</sup> The interpretation of what Schoen was

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<sup>63</sup> Johanna Schoen, "From the Footnotes to the Headlines: Sterilization Apologies and Their Lessons," *Sexuality Research & Social Policy* 3/3 (September 2006), 8.

<sup>64</sup> Johanna Schoen, *Choice and Coercion*, 243.

<sup>65</sup> Schoen, "Choice and Coercion," 242.

<sup>66</sup> *Ibid.*

allowed to see may also have been understood differently by different staff members. Schoen relates that when she walked into the archives

I was met by a staff member who handed me three rolls of microfilm. I had no idea what he was giving me. But rather than ask any questions, I marched straight to the microfilm reading room, threaded in the first reel, and this time was faced with a gold mine: the minutes of more than three decades of Eugenics Board meetings. These minutes contained summaries of every sterilization petition considered by the Eugenics Board, records of the board's decisions, and lists of the names of those individuals who were actually sterilized as a result of the board's authorization.<sup>67</sup>

As Schoen was no longer living in North Carolina, she needed to make copies of the archival material to take with her once she needed to return home. Her ability to obtain copies relied on the goodwill and cooperation of the archivists: "While the archives' staff seemed at the moment content with the fact that I was looking at all those names on microfilm, the names had to be eliminated if I wanted to take the material along." She made paper copies of all the microfilm and then "the entire staff spent weeks patiently taking their black magic markers to the thousands of pages I was copying."<sup>68</sup> In this unusual experience, archival staff first played the role of gatekeeper in refusing to allow Schoen access to the case histories, then later played an active role in aiding her research.

The "anomaly" of her access led Schoen to feel that her "access to these materials came with a unique responsibility: to educate the public about the wrong that had been done."<sup>69</sup> She eventually gave all of her unpublished material to the *Winston-Salem Journal*, which assured her

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<sup>67</sup> Ibid.

<sup>68</sup> Ibid., 242-243.

<sup>69</sup> Ibid., 243. She also describes this as "an ethical responsibility" and that she "owed them a form of public recognition," 244. Paul Lombardo says that "even more importantly" than the apology that resulted from the newspaper series, "the general public was shown for the first time the full scope of how the eugenics program had operated in that state." Paul Lombardo, "Preface," *Against Their Will: North Carolina's Sterilization Program*, Keven Begos, Danielle Deaver, John Railey and Scott Sexton (Apalachicola, Florida: Gray Oak Books, 2012), i.



that individuals' privacy would be respected. The newspaper published in 2003 a comprehensive five-part series on the subject both in print and digitally.<sup>70</sup> The exposure of this previously hidden history led to a formal apology by the state governor in 2002, making North Carolina the third state to apologize to forced sterilization victims.

Schoen says that while North Carolina had initially opened up a “more relaxed policy of access” for a number of months after the newspaper series was published, no other state relaxed its access policy following publicity. In fact, the public exposure and apology soon resulted in an unexpected backlash against access to such records. Schoen writes:

Indeed, issuing an apology tended to cut off further discussion of this legacy—a development that was clearly intended by a number of governors. The situation was further aggravated by the fact that a number of states took the apology as a sign to close or destroy records that had facilitated the research that had preceded publication and that had been further opened in the immediate aftermath of newspaper coverage.<sup>71</sup>

North Carolina eventually “joined ranks by closing access to its records again.”<sup>72</sup> Since 2005, the records of the North Carolina Eugenics Board are under the custody of the Department of Health and Human Services. Access to the records are now restricted to individual patients or their legal guardians, or the custodial agency.<sup>73</sup>

In Canada, while the drama of Schoen's experience has not been paralleled, persistent efforts to access historical records related to Alberta's Michener Centre have been documented by Claudia Malacrida, who has been researching Michener since 1999. Her experience in attempting to view Michener's historical records and interview the residents is described in her

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<sup>70</sup> *Against Their Will: North Carolina's Sterilization Program* is a book based on this series.

<sup>71</sup> Schoen, “From the Footnotes to the Headlines,” 20.

<sup>72</sup> Ibid.

<sup>73</sup> Burch and Joyner, 269 footnote 28.

2006 article that has the telling title “Contested memories: efforts of the powerful to silence former inmates’ histories of life in an institution for ‘mental defectives.’”<sup>74</sup> Her initial request for records was made in 1999 to the Manager of Planning and Communications at Michener Centre for access to their on-site archives. She did not receive access.<sup>75</sup> In 2001, she requested from the board a tour of the centre and its grounds. She notes that although “the Michener Centre is a public institution, funded by public dollars” and the board is made up of “civic-minded” volunteers, her request to the board “was not well received” and she later received a letter barring her from the grounds.<sup>76</sup>

In 2003, a fire in the main building of the Michener Centre “caused enormous destruction” of the historical records and “virtually all remaining records” were transferred to the Provincial Archives of Alberta.<sup>77</sup> Malacrida noted that “although one might hope” that the transfer of records to the Provincial Archives of Alberta would allow for easier access to the records, “this was not the case.”<sup>78</sup> Because the archival descriptions of the records were very meagre, Malacrida says she could not get a clear idea about what the records contain. Therefore, in her very first request for records held by the archives, her “selections were quite arbitrary and quite ‘thin’” and she expected to make additional requests based on the first results. Malacrida states that “mercifully” the archivist did not fill her request before sending a fee estimate. The initial estimate totalled over \$13,000 – “a sum that would be prohibitive to most researchers and certainly to most institutional survivors who may want to learn about the attitudes, practices and

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<sup>74</sup> Malacrida, “Contested memories,” 397-410.

<sup>75</sup> Ibid., 404-405.

<sup>76</sup> Ibid., 403-404.

<sup>77</sup> Ibid., 405.

<sup>78</sup> Ibid.

systems that operated to oppress them during their years in the institution.”<sup>79</sup> The impact of this large fee estimate led Malacrida to state that

It is not unreasonable to speculate that, in this case at the very least, Alberta’s FOIP Act is operating not to provide citizens with access to hidden and marginal memories, but it instead protects public bodies from citizens’ (and particularly marginalized citizens’) access to these institutional records.<sup>80</sup>

Although Malacrida understood the provision of a fee estimate before providing the materials as “mercy,” it is standard procedure to provide an estimate before fulfilling such a request.<sup>81</sup> Fee estimates, according to a bulletin published by Access and Privacy Service Alberta, are “to give the applicant an opportunity to decide whether to proceed with the request, modify the request, request a waiver of the fees, or withdraw the request.”<sup>82</sup> Although under Alberta’s FOIP, it is understood that “the fees should be reasonable, fair and at a level that would not present a barrier to applicants in exercising their right to access information,” the decision to waive fees rests subjectively with the public body.

As with Schoen’s archival research, Malacrida’s gateway to access came from the actions of an individual archivist. In her 2006 article, Malacrida writes that although she has “only been able to view a fraction of the archival materials” she credits her ability to view even that fraction “because a sympathetic woman in the Provincial archives saw the importance of accessing the institution’s hidden memories and began working with me in creative and accommodating

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<sup>79</sup> Ibid. Although applicants asking for their own personal health information are generally waived fees, Malacrida is correct in assuming that an institutional survivor requesting general information about the institution would be subject to the usual fees.

<sup>80</sup> Ibid.

<sup>81</sup> In Alberta, an access request for general information has a fee of \$25. In addition, a threshold of \$150 of costs is allowed before fees are to be charged to the applicant.

<sup>82</sup> Access and Privacy Service Alberta, *FOIP Bulletin* 1 (March 2009), 2-3.

ways.”<sup>83</sup> The archivist and Malacrida were able to work around the fees through a system in which the archivist would provide Malacrida with file lists and Malacrida would then choose about 150 pages of documents. This method of parceling out the records kept fees from being charged. However, while the process gave Malacrida a measure of success in viewing the institution’s documents at no cost, she describes the process as “very, very time-consuming, and quite unsatisfactory. It also depended intensively on the goodwill of the archivist.”<sup>84</sup>

Costs and delays frustrate researchers but the government itself also must deal with costs and the sway of public opinion. For governments that maintain FOI legislation, the high cost of legal fees and staff time present a dilemma. As Gafuik notes “for departments that deal largely in sensitive information, the cost of processing a request for information may be disproportionate to the amount of information that may ultimately be disclosed.”<sup>85</sup> Although the 2004 review of Manitoba’s legislation clearly states that “FIPPA is not a way to raise revenues” the report follows with the statement, “However, there may be merit in examining the current fee structure, to balance the right of access while placing less of the burden of costs on the taxpayer.”<sup>86</sup> This last statement, however, can be seen as disingenuous as it suggests that FIPPA applicants are not themselves taxpayers. Fred Vallance-Jones, a journalism professor at University of King’s College points out that “Canadians have already paid to collect and store the information...They

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<sup>83</sup> Malacrida, “Contested Memories,” 407.

<sup>84</sup> Claudia Malacrida, email to author, July 16, 2014.

<sup>85</sup> Gafuik, 49

<sup>86</sup> Manitoba Government. *A Review of The Freedom of Information and Protection of Privacy Act* (January 2004), 11. The 2000 Ombudsman Annual Report stated that “Nowhere are fees charged on the basis of a full cost-recovery regime. To do so would be inconsistent with the purposes of access and privacy legislation,” 15.

shouldn't have to pay to see it as well.”<sup>87</sup> The 2004 Manitoba report emphasizes, as if to further chasten the FIPPA applicant, that “the hours spent responding to FIPPA applications is time that is taken away from the delivery of other government programs and services.”<sup>88</sup> With this statement, the government appears to denigrate the service of providing access to information in comparison to other government programs and services, although as previously shown, FOI legislation is considered to be a ‘hallmark of democracy.’

However, a recent change in the political climate is having some initial effect on FOI fees. In 2014, when federal Information Commissioner Suzanne Legault complained that her budget was not adequate, the first solution proposed to counter FOI costs was to raise fees.<sup>89</sup> But with “government openness and transparency” being a current popular trend within public expectations and political promises, the new government under Justin Trudeau announced that all FOI fees, apart from the \$5 application fee, would be abolished.<sup>90</sup> After the federal announcement, the Finance Minister of British Columbia said that their province would not be

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<sup>87</sup> Cited in Jim Bronskill, “Liberals issue openness directive, scrap most Access to Information fees,” *Toronto Star* May 5, 2016, accessed May 7, 2016, <http://www.theglobeandmail.com/news/politics/liberals-scrap-most-access-to-information-fees-issue-openness-directive/article29884144/>.

<sup>88</sup> Ibid. It also emphasizes “considerable time and expense is incurred in responding to these types of applications.”

<sup>89</sup> See for example Dean Beeby, “Information commissioner pleads poverty to raise fees,” *CBC News* December 4, 2014, accessed January 6, 2015, <http://www.cbc.ca/news/politics/information-commissioner-pleads-poverty-tory-mps-say-raise-fees-1.2861052>.

<sup>90</sup> Ken Rubin, self-titled “Canada’s information warrior,” criticized this announcement as “smoke and mirrors” and pointed out that the majority of the government’s FOI revenue comes from the \$5 fees and not the additional search and preparation fees. The article reports that “in 2014-15, federal institutions collected \$367,654 in fees from requesters — \$311,486 of that coming from application charges. It means the new fee policy, if in place last year, would have saved requesters a total of \$56,168.” Cited in Bronskill. See also Ken Rubin’s website, accessed May 7, 2016, <http://www.kenrubin.ca/>. However, while the abolition of individual fees will not greatly change the government’s revenue from FOI requests, the elimination of large individual fees may remove one barrier for applicants. At a similar time to the federal government’s announcement, the CBC reported that the Saskatchewan government provided a fee estimate of over \$180,000 for FOI requests made by the CBC’s ITeam. Geoff Leo, “Sask. government charging \$180K for access to GTH land deal documents,” *CBC News* May 03, 2016, accessed May 7 2016, <http://www.cbc.ca/news/canada/saskatchewan/government-charging-access-global-transportation-hub-land-deal-1.3564268>.

following suit in eliminating all fees, although he stated that “for legitimate applications for information, we don’t want fees to be an impediment.”<sup>91</sup> In Manitoba, in a campaign speech in January 2016, candidate and now current premier Brian Pallister said his party’s goal is “to become the Canadian leader in open government by the end of our first term.”<sup>92</sup> The long-term outcome of fee changes and political promises for openness remains to be seen.

While the elimination of some fees may well reduce barriers for some researchers, it may not immediately smooth out the entire road to access – especially for records understood to be contentious. Alasdair Roberts says that

Even in countries with long-established disclosure laws, making a request for information requires knowledge about the bureaucratic routine by which information requests are processed and about the legal provisions that should govern decisions on the release of information ... the act of requesting information also requires a strong sense of political efficacy and persistence, due to the long delays that may arise in the handling of requests. Finally, asking for information may require money, particularly if the request is novel or complex or if the law lacks a mechanism by which appeals can be lodged at little or no cost to the requester.<sup>93</sup>

As shown in this chapter, fees, delays, government obstructions, and the hidden barriers within research agreements can all restrict access to information. The following chapter describes some of the experiences I had while attempting to access restricted archival records relating to institutions in Manitoba. As Roberts points out, there is a steep learning curve in

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<sup>91</sup> Rob Shaw, “B.C. won’t follow Ottawa in eliminating Freedom of Information fees,” *Vancouver Sun* May 5, 2016, accessed May 7, 2016, <http://vancouversun.com/news/politics/b-c-wont-follow-ottawa-in-eliminating-freedom-of-information-fees>.

<sup>92</sup> Steve Lambert, “Manitoba Tories promise more transparency, new penalties for politicians,” *CBC News* January 13, 2016, accessed July 31, 2016, <http://www.cbc.ca/news/canada/manitoba/manitoba-tories-promise-more-transparency-new-penalties-for-politicians-1.3402064>.

<sup>93</sup> Alasdair Roberts, *Blacked Out: Government Secrecy in the Information Age* (New York: Cambridge University Press, 2006), 117.

understanding the process. Once in the process, it took persistence, tenacity and, as Roberts says, a belief in “political efficacy” to see my requests through.

## Chapter Five: “They told me never say nothing.”<sup>1</sup>

### Research ethics

David Weremy told his brother and sister that while he was living at the MDC, the staff told him not to disclose to anyone the events and conditions within the institution. Weremy said, “They told me never say nothing what’s going on there .... When you go home, you don’t tell nothing what’s going on here.” During visits home (or when he escaped), Weremy did tell his family what was going on at the institution and his mother called the institution. But, he says, “When I got back there, I got locked up for it.” His sister said, “And then we wouldn’t phone anymore because then we were getting him in trouble.”<sup>2</sup>

This chapter examines the process by which graduate students at the University of Manitoba apply to obtain access to restricted archival documents. A selection of the experiences I underwent while attempting this process illustrates some of the hurdles particular to researchers seeking access to archival records and also shows some of the bureaucratic problems that can delay the process. This chapter also considers some of the issues surrounding ethics in historical research.

The process for graduate students basically follows the same route as other researchers, but with a few differences. As mentioned in Chapter Four, all researchers must gain approval from their institution’s Research Ethics Board (REB). Researchers who wish to access records that contain health information must also get approval from Manitoba’s Health Information

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<sup>1</sup> YouTube, Vidéos de Josée Boulanger, “David Weremy,” accessed July 31, 2016, <https://www.youtube.com/watch?v=OH3EyDgtQRM>.

<sup>2</sup> *The Freedom Tour*.



Protection Committee. Once these approvals are in place, researchers can enter into agreements with the data trustees. Graduate students, however, have a few additional steps and their thesis supervisor also plays a role in the process.

### **Thesis proposal**

Graduate students who apply for REB approval must have their thesis proposal approved before applying to the REB. All graduate students in the Archival Studies Joint Master's Program are expected to complete a thesis proposal (also called the "Thesis Project Form") nine months after the student begins the program. The length of the thesis proposal is expected to be about fourteen to eighteen pages.<sup>3</sup> Although my proposal was based on the one I had handed in as part of my coursework, further discussion with my supervisor and another Archival Studies professor led me to make changes. I spent about four months revising my proposal and after submitting it waited almost two months to hear back from the departmental readers. Although the readers had criticisms, my proposal was approved.

An informal survey of current graduate students in the Archival Studies program shows that my experience was within the norm. In the experience of eight students who responded to my informal questions, the length of time to prepare and revise the thesis proposal ranged from a few weeks to a year. The longer revision times reflected proposals that differed significantly from the original proposal written as part of the course assignment. Waiting time for the departmental readers' response ranged from two weeks to five months. The University of Manitoba expects that two years is sufficient time for Archival Studies students to complete the

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<sup>3</sup> University of Manitoba website, History, Joint Master's Program, accessed May 23, 2016, [http://umanitoba.ca/faculties/arts/departments/history/media/jmp\\_thesis\\_project\\_form.pdf](http://umanitoba.ca/faculties/arts/departments/history/media/jmp_thesis_project_form.pdf). My proposal was twenty pages.

entire program, but a significant part of the year allotted to thesis writing is eaten up by writing the thesis proposal and having it approved.

### **Role of thesis supervisor**

At the University of Manitoba, graduate students are not allowed to enter into research agreements and so for the purposes of research agreements the Principal Investigator of the project is considered to be the student's thesis supervisor.<sup>4</sup> For one of my research agreements, my thesis supervisor was requested to complete a Research Contract Principal Investigator Questionnaire. The form itself does not seem very relevant to an archival research project and includes such questions as:

Is the likelihood of an invention or commercial potential arising from this research project?

Are you giving any confidential information to the Sponsor?

Are you prepared to accept that the sponsor can terminate the agreement?<sup>5</sup>

This form must be completed before the University of Manitoba's Office of Legal Counsel reviews the research agreement. However, neither my thesis supervisor nor I had any prior knowledge of this form or the university's process of completing research agreements. The form is found on a website page of the Office of Research Services that lists several other forms, all of which primarily seem to do with research contracts that involve grants and funding.<sup>6</sup>

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<sup>4</sup> Although my thesis supervisor was considered to be the Principal Investigator of the project, when it came time to sign the research agreement, the signature representing the University of Manitoba was that of the Director of Research Services. The part that my supervisor and I signed was under a heading "Read and Understood: the Researcher." However, at the conclusion of my research, my thesis supervisor will be responsible for holding my research notes until the time the notes are to be destroyed.

<sup>5</sup> University of Manitoba, Research Contract Questionnaire, accessed May 17, 2016, [http://umanitoba.ca/research/ors/media/QuestionsPI\\_\\_2\\_.pdf](http://umanitoba.ca/research/ors/media/QuestionsPI__2_.pdf).

<sup>6</sup> University of Manitoba, Office of Research Services, "Research Grant and Contract Forms," accessed May 17, 2016, [http://umanitoba.ca/research/ors/research\\_forms\\_online.html](http://umanitoba.ca/research/ors/research_forms_online.html).

Although the above-mentioned policy is available on the University of Manitoba's website, along with other policy documents related to research ethics, it is not clear how researchers at the university are informed of these policies. It would be helpful if departments would inform their faculty and graduate students of all the policies relating to research at least once every academic year. The Vice-President Research and International Office offers a workshop series titled "Best Practices in Research Management" but as the workshops are offered only once each year, it would be beneficial for all researchers to be informed of the series well in advance of the workshop dates.<sup>7</sup> Perhaps the REB could act as the jumping-off point in the education of researchers by promoting knowledge of the university's other policies regarding research.<sup>8</sup> As will be shown in the next sections, the absence of a clear route of process added many months to my research project.

### **Research Ethics Board**

As noted previously, researchers who wish to undertake archival research that includes personal health information on the historical subjects must first obtain approval from a Research Ethics Board (REB). University REBs assess "the ethical acceptability of a research project through consideration of the foreseeable risks, the potential benefits and the ethical implications of the project."<sup>9</sup> Universities receiving and administering funding from the three federal funding agencies must comply with the joint policy statement of these agencies published as the *Tri-*

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<sup>7</sup> University of Manitoba website, "Office of Research Services," accessed May 23, 2016, [http://umanitoba.ca/research/media/Best\\_Practices\\_Workshops\\_Information.pdf](http://umanitoba.ca/research/media/Best_Practices_Workshops_Information.pdf).

<sup>8</sup> Whenever I asked if the History department provided instruction about research agreements, I was pointed to the REB website.

<sup>9</sup> Government of Canada website, Panel on Research Ethics, TCPS 2 - Chapter 1, accessed March 16, 2015, <http://www.pre.ethics.gc.ca/eng/policy-politique/initiatives/tcps2-eptc2/chapter1-chapitre1/#toc01-1c>.

*Council Policy Statement: Ethical Conduct for Research Involving Humans* (TCPS).<sup>10</sup> This policy “expresses the Agencies’ continuing commitment to the people of Canada to promote the ethical conduct of research involving humans” as mandated through the respective Acts of Parliament governing these agencies.<sup>11</sup> Proof of REB approval is also a necessary requirement for the Health Information Protection Committee approval which must be obtained before a researcher can access health-related records.<sup>12</sup>

The University of Manitoba has five research ethics boards categorized by campus, faculty and department. The Fort Garry campus has three of them: Psychology/Sociology; Education/Nursing; and the Joint Faculty, which covers the remaining departments. My application went through the Joint-Faculty REB (JREB). The current (as of writing) JREB is comprised of twenty-two volunteer faculty, graduate student and community members, one of which acts as the chair. At the time of my submission to the JREB, none of the members were from the History department.<sup>13</sup> The lack of historians on the board may account for some of the confusion that resulted when the JREB was first approached by my thesis supervisor about my thesis research.

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<sup>10</sup> The most recent update of the policy statement is Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada and Social Sciences and Humanities Research Council of Canada, *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans*, December 2014. Accessed March 17, 2015, <http://www.pre.ethics.gc.ca/eng/policy-politique/initiatives/tcps2-eptc2/Default/>.

<sup>11</sup> Government of Canada website, Panel on Research Ethics, accessed March 16, 2015, <http://www.pre.ethics.gc.ca/eng/policy-politique/initiatives/tcps2-eptc2/introduction/>. The Acts are: *Canadian Institutes of Health Research Act*, Statutes of Canada, 2000; *Natural Sciences and Engineering Research Council Act*, Revised Statutes of Canada, 1985; and *Social Sciences and Humanities Research Council Act*, Revised Statutes of Canada, 1985.

<sup>12</sup> The rules governing research agreements are not clearly defined. In my experience, I was requested to submit REB approval for all my research agreements whether the information contained in the records was health information or other restricted information.

<sup>13</sup> University of Manitoba website, “REB Committee members—Fort Garry 2014-15,” accessed March 16, 2015, [http://umanitoba.ca/research/orec/ethics/human\\_ethics\\_REB\\_members.html](http://umanitoba.ca/research/orec/ethics/human_ethics_REB_members.html). As of April 18, 2016, the board members had changed but again no member was from the Department of History.

The initial response from the JREB in April 2014 indicated that because my research dealt only with archival material and not living humans REB approval was not necessary. The JREB Chair pointed out that the Tri-Council Policy Statement says that “some research is exempt from REB review where protections are available by other means.” Article 2.2 of the Tri-Council Policy Statement lists the kinds of research that is exempt from REB review:

Research that relies exclusively on publicly available information does not require REB review when:  
 (a) the information is legally accessible to the public and appropriately protected by law; or  
 (b) the information is publicly accessible and there is no reasonable expectation of privacy.<sup>14</sup>

It seemed clear that my thesis research fell into category (a) where FIPPA legislation both protected the information but also allowed for research under conditions contained in research agreements. The TCPS further states that

in Canada, all publicly available archives (national, provincial or municipal) have policies governing access to their records. An archival record or database that is subject to restrictions, such as those under access to information and privacy legislation or contractual restrictions imposed by the donor of the records, may also be considered publicly available for the purposes of this policy.<sup>15</sup>

With these statements, it appeared clear that according to the TCPS, the documents I wished to access were both legally and publicly available.

When it was brought to the attention of the JREB that the Family Services department (which is responsible for the MDC records) insisted that REB approval was necessary before a research agreement could be requested, the JREB Chair suggested that I state on the request for

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<sup>14</sup> Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, and Social Sciences and Humanities Research Council of Canada, *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans*, (December 2014), accessed July 31, 2016, [http://www.pre.ethics.gc.ca/pdf/eng/tcps2-2014/TCPS\\_2\\_FINAL\\_Web.pdf](http://www.pre.ethics.gc.ca/pdf/eng/tcps2-2014/TCPS_2_FINAL_Web.pdf), 15.

<sup>15</sup> *Ibid.*, 16.

research agreement form that the university did not need to approve research that used public documents. After I related this interpretation of the Tri-Council Policy Statement to the FIPPA Coordinator for Family Services, she contacted both the JREB and the Bannatyne campus REB (which usually deals with health records) to discuss the need for REB approval for my research. Despite the definition given above by the Tri-Council Policy Statement, the department of Family Services maintained that the MDC records were not publicly accessible.

By this time it was October 2014, and several emails had passed between me, my thesis supervisor and the JREB as well as emails and phone calls between me and Family Services. My thesis supervisor suggested that an in-person meeting might expedite the process and we were able to get an appointment with the Chair and the Human Ethics Coordinator of the JREB in early November 2014. In this meeting, the Chair of the JREB suggested that I could ask the province to reconsider its interpretation of whether restricted archival records were publicly or legally accessible. As this change of mind did not seem likely, another solution was proposed whereby I would write a summary of my research project together with my understanding of Article 2.2. The JREB Chair would then review this and write a general letter that I could give to the government stating that my research is exempt from REB review. The chair also pointed out that if I chose to submit my project to the JREB, my project would only require an expedited review (also called a delegated review), which means that the submission is reviewed by only two members of the committee rather than the full twenty members and so takes less time. However, she still maintained there was some ambiguity as to what aspects of my research even needed review.

To try to find some additional guidance regarding university ethics approval for research into archival records that contain personal health information, I turned to the website of the University of Manitoba's Bannatyne campus research ethics board that oversees the Faculty of Health Sciences in the College of Medicine. This board, called the Human Research Ethics Board (HREB), states that "Human Research refers to any project that involves the collection of specimens, data or information from persons, through intervention or otherwise" and specifically mentions "examination of patient records."<sup>16</sup> However, the HREB website also states that some types of research are not subject to REB review:

Prior ethics review and approval from an REB will not normally be required for:  
 - a limited type of research most often found within the humanities, fine arts, and in some historical research which involves: (a) a public database where aggregated data that cannot be associated with any individual are obtained; and/or (b) information already in the public domain (e.g. autobiographies, biographies or public archives).<sup>17</sup>

On the other hand, the HREB website also stated that REB approval is necessary for "projects that involve the secondary use of data on human subjects gathered in earlier projects."<sup>18</sup> These statements again left some ambiguity as to the category of the restricted case files and other records related to the institutions: were they records in "public archives" or regarded as "data on human subjects gathered in earlier projects"? As the records are restricted, it could be argued that they were not in the public domain. However, as some of the records were patient files that had been closed for decades, some of which dated back to 1890, there was clearly an archival and historical aspect that was not common in most health research.

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<sup>16</sup> University of Manitoba, "Research Requiring Ethical Review," accessed March 18, 2015, [http://umanitoba.ca/faculties/health\\_sciences/medicine/ethics/2085.html](http://umanitoba.ca/faculties/health_sciences/medicine/ethics/2085.html).

<sup>17</sup> Ibid.

<sup>18</sup> Ibid.

In December 2014, my advisor and I made an appointment to meet with the Chair of the HREB. In the course of our meeting, the HREB Chair suggested that since REB approval was necessary for the Health Information Protection Committee, I should proceed with trying to obtain approval from the JREB. The chair also suggested that I include sample data collection sheets with my applications to make it very clear that I would not be collecting personal information from the records but, as an Archival Studies project, would focus only on the *types* of records and *categories* of information in them.<sup>19</sup> I decided to follow this advice as it seemed the most expedient way to try to eventually obtain HIPC approval. As my research originated from the Fort Garry campus of the university, I was required to go through the JREB even though elements of my project seemed closer aligned to projects usually overseen by the HREB.

Researchers submitting a project for REB review must show evidence of completion of the Tri-Council Policy Statement Course on Research Ethics (CORE).<sup>20</sup> This is a federal online training course consisting of eight modules describing the principles of research ethics and providing examples of projects and after completion of the course a PDF certificate is provided to the researcher.<sup>21</sup> As my research involved records that contained personal health information, the REB submission also required that PHIA (Personal Health Information Act) Orientation be completed and that a “pledge of confidentiality” be signed.<sup>22</sup> This training is available through an

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<sup>19</sup> See for example the work of Barbara L. Craig on hospital records and recordkeeping noted in previous chapters of this thesis and the bibliography.

<sup>20</sup> Government of Canada, “Panel on Research Ethics.”

<sup>21</sup> Although the FAQ for the tutorial says that the course can be completed in three hours “depending on how many examples and activities you explore,” in my experience each module took at least one hour to complete. TCPS 2: CORE, Frequently Asked Questions, accessed March 18, 2015, <http://tcps2core.ca/content/frequently-asked-questions#a5>. I had completed this tutorial the previous year and so I forwarded my certificate of completion to the JREB office.

<sup>22</sup> I had previously taken a PHIA Orientation course and signed a pledge of confidentiality with the Winnipeg Regional Health Authority as a research assistant for another project but I was informed that for the purposes of the



online module available through the UM's Access and Privacy Office and takes less than one hour to complete.<sup>23</sup> The pledge states that the researcher's obligations continue even after their relationship with the university ends and that "unauthorized use or disclosure of personal health information may result in disciplinary action being taken, and/or legal action at the discretion of the University."<sup>24</sup>

I submitted my Research Ethics Board Submission form in the third week of January 2015. The form includes thirteen Yes/No questions and ten questions requiring written details.<sup>25</sup> As the form is geared toward projects involving live human subjects, many of the questions seemed difficult to relate to my proposed archival research. Perhaps not surprisingly, I received a response almost one month later that asked for clarification in three areas. The first area concerned question 10 of the form, which read:

Does the study involve participants who are not legally or practically able to give their valid consent to participate (e.g., children, or persons with mental health problems and/or cognitive impairment)? If yes, indicate how informed consent will be obtained from participants and those authorized to speak for participants.

The second issue had to do with the parameters of my project. The third was a request to see my "request for permission to access the archives and the archives' permission letter, with

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JREB I also needed to complete training through the University of Manitoba. Once the researcher signs and dates the pledge, it is mailed or faxed to the Access and Privacy Office where it is processed with a unique number and signed by the Access and Privacy Officer/Coordinator. The pledge declares that the researcher has completed the PHIA training and will follow procedures for safeguarding personal health information.

<sup>23</sup> University of Manitoba, "Office of Fair Practices and Legal Affairs," accessed May 31, 2016, accessed March 18, 2015, [http://umanitoba.ca/access\\_and\\_privacy/privacy\\_training.html](http://umanitoba.ca/access_and_privacy/privacy_training.html).

<sup>24</sup> Ibid., [http://umanitoba.ca/admin/vp\\_admin/ofp/fippa/secure/media/UM\\_PHIA\\_Declaration\\_Form.pdf](http://umanitoba.ca/admin/vp_admin/ofp/fippa/secure/media/UM_PHIA_Declaration_Form.pdf).

<sup>25</sup> University of Manitoba, Office of Research Ethics and Compliance, "Fort Garry Campus Research Ethics Board Submission Form," accessed July 23, 2016, [http://umanitoba.ca/research/orec/media/Protocol\\_Submission\\_Form.pdf](http://umanitoba.ca/research/orec/media/Protocol_Submission_Form.pdf).

conditions, if applicable.”<sup>26</sup>

The first question of consent seems to come from areas of research that deal with living human subjects, although even with historical records there is an increasing trend for privacy and access regulatory bodies to require researchers to gain this kind of consent before access to the records. The authors of *Unspeakable: The Story of Junius Wilson* write:

Some archives now demand that scholars obtain permission from subjects before accessing information about them. If the subject is deceased, the scholar must obtain permission from a legal representation for the subject. Privacy boards may be petitioned to garner access if direct permission cannot be granted, but in many cases the boards will not grant permission to publish material from its archive without direct permission granted from the subjects studied or their legal representatives. While judges may intervene to allow scholars to publish their findings, the entire process strongly discourages research in the field.<sup>27</sup>

In my original submission, I had not answered question 10 regarding consent because I did not know how.<sup>28</sup> In my revised submission, I included the excerpt below. At the time, I did not know what kind of information was in the files or whether I would see the entire file or redacted or severed portions. A particular difficulty for researchers seeking access to restricted archival files is that the researchers need to write proposals based on files that they have never seen:

Files were closed upon individuals’ separation from the institution.... The length of time since the file closures ranges from 39 to 125 years. It is possible that I will only be permitted to see redacted or severed files--in this case I will not have access to contact information. If I do view identifying information, and in the rare cases where the individual might be presumed to be still alive, it would be very difficult to find the individual after so many years, especially if the individual was transferred to another institution or moved to a group home or other community setting. As noted in the Tri-Council Policy Statement 5.5. “Attempting to track and contact members of the group may raise additional privacy concerns.”

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<sup>26</sup> Dr. Susan Frohlick, Chair, JREB, letter to author, dated February 18, 2015.

<sup>27</sup> Burch and Joyner, 269 footnote 29.

<sup>28</sup> In retrospect, it seems foolish that I simply skipped a question that I did not know how to answer. But my bewilderment also illustrates the need for guidance for archival researchers at the university.

The JREB, as noted above, also wanted me to provide a letter of permission from the Archives of Manitoba to view the records. In response, I stated that the reason I was submitting a request to the JREB was so that I could then apply to the HIPC and then (hopefully) gain permission from the data trustee and access to the records held in the archives.<sup>29</sup>

Finally, as mentioned earlier, the JREB wanted clarification on the parameters of my research. Their objection was that:

We need a clear statement about the intent and the parameters of the project to be researched, so that the benefits of this project can be better ascertained. The statement...that “the history of the institutionalization of individuals in Manitoba has not been written or understood” suggests that the PI is going to be reporting on individuals’ experiences in institutions, which is at odds with the earlier statement that the purpose of the study is to identify categories and types of information recorded in order to understand researchers’ access to archival materials.

In my reply I emphasized that the lack of historical knowledge about institutionalization in Manitoba provided the context for my research and that a goal of my thesis is to aid further research into this area. I received approval the day after I submitted my revised protocol. The entire process to get JREB approval, which normally takes only a few weeks, took me almost one year.<sup>30</sup>

### **Health Information Privacy Committee (HIPC)**

The Health Information Privacy Committee (HIPC) is a body legislated under section 59 of the Personal Health Information Act.<sup>31</sup> The committee has between eight and twelve members

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<sup>29</sup> This request for such a letter seems odd, and is perhaps indicative of confusion about the process of obtaining access to restricted archival records.

<sup>30</sup> Once I finally reached the point of submitting the application, the process only took about seven weeks: I submitted the form January 21, 2015 and received the final response on March 10, 2016.

<sup>31</sup> Personal Health Information Act, 59(1).

appointed by the Minister of Manitoba Health, Seniors and Active Living.<sup>32</sup> The HIPC oversees Section 24(3) of the Act which provides four conditions for approval of research: that “the research is of sufficient importance to outweigh the intrusion into privacy;” that the research cannot be performed without the researcher seeing private information, e.g., the information is too large to be redacted; that “it is unreasonable or impractical” for the researcher to obtain consent from the subjects of the records; and that the research project includes “reasonable safeguards” to protect the information, including procedures to destroy the information “at the earliest opportunity consistent with the purposes of the research.”<sup>33</sup>

The process to submit a research proposal to the HIPC is rigorous. As mentioned earlier in this chapter, researchers need to obtain REB approval from their university. However, as the HIPC only meets every six weeks, researchers can save time by making a submission to the HIPC while waiting for REB approval. The submission form for the HIPC approval is six pages long, although by the time I had completed the form, it was eight pages plus my sample data collection sheets.<sup>34</sup>

As noted by the PHIA, all requests to see records that contain personal health information are regarded as intrusive by the committee.<sup>35</sup> In the HIPC submission form, researchers are

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<sup>32</sup> Most of these members come from health or medical organizations, such as the College of Physicians and Surgeons of Manitoba, but at least one must come from the University of Manitoba. Each committee member sits for a term of three years for a maximum of six years.<sup>32</sup> At least one-quarter of the committee must be “public representatives” who are defined by the PHIA as people “who are not health professionals or persons who conduct health research or employees of the government.” PHIA 59(2).

<sup>33</sup> Personal Health Protection Act, 24 (3)(a)(b)(c)(d)((i))((ii))), accessed July 31, 2016. <http://web2.gov.mb.ca/laws/statutes/ccsm/p033-5e.php>.

<sup>34</sup> Researchers are required to submit eleven hard copies to the committee.

<sup>35</sup> PHIA 24(3)(a) says the committee must determine that “the research is of sufficient importance to outweigh the intrusion into privacy that would result from the disclosure of personal health information.” As Mary Jane McCallum writes about her experience in applying to the HIPC, “the term ‘intrusion’ also suggested that I was being

required to identify the level of intrusion that their project entails: category levels range from Category 1 which is “minimal or no intrusion” to intrusion that is “potential,” “moderate,” “high,” or “highly sensitive.” The definition Category 5, “highly sensitive,” includes:

Requests for information ...where the population involved is vulnerable or dependent (e.g., minors, First Nations, etc.) or where the nature of the information is highly personal and sensitive (e.g., persons with mental disabilities, sexually transmitted diseases, etc).

Although such grouping of populations—such as First Nations people with minors, and the category of the stigmatized that includes people “with mental disabilities” and those who contracted sexually transmitted diseases—is a sad commentary on how the government, and perhaps mainstream society, view these populations, researchers may feel they have to acquiesce to these categories to gain the approval of HIPC.<sup>36</sup> In the HIPC form, researchers who want to access records relating to people described in Category 5 must “discuss the importance of this research in relation to the level of intrusion.” My argument regarding the level of intrusion was as follows:

The long and varied history of people in Manitoba labelled with intellectual disability has not been investigated by historians, is not known by the general public and is not available to the communities and individuals labelled with intellectual disability

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careless and nosy and studying a history that was an individual and private matter. Labelling my research as ‘intrusive’ conflicts with the general commitment of historians to free and open inquiry and risks protecting instead an organization that was in fact highly intrusive to First Nations, Inuit and Métis people.” Mary Jane Logan McCallum, “Laws, Codes and Informal Practices: Building Ethical Procedures for Historical Research with Indigenous Medical Records,” Chris Andersen and Jean M. O’Brien, eds., *Sources and Methods in Indigenous Studies* (Abingdon, Oxon: Routledge, 2017), 278.

<sup>36</sup> Perhaps once the research project is completed, researchers may feel in a position to argue for changes to these categories. Manitoba’s Vulnerable Persons Act, was brought about in part by the attempt to change how “vulnerable” people are viewed. The act says that “Manitobans recognize that vulnerable persons are presumed to have the capacity to make decisions affecting themselves, unless demonstrated otherwise.” Through a disability lens, “viewing only some individuals as vulnerable or as part of ‘vulnerable populations’ casts a negative light on the concept of vulnerability, including vulnerability to disability. It separates those who are viewed as vulnerable from those who are not, associating weakness with vulnerability and invoking pity or concern for those who are part of a vulnerable population.” It also ignores that vulnerability is a “shared and constant state among living beings.” Ani B. Satz, “Vulnerability,” Rachel Adams, Benjamin Reiss, and David Serlin, eds., *Keywords for Disability Studies* (New York: New York University Press, 2015), 185.

themselves. Their history has been hidden or ignored for two main reasons: the population in question is marginalized and the archival records are scattered, poorly described and/or deeply restricted from access. My thesis will identify the locations of records, describe when possible the categories and types of information held in the records, and discuss how privacy legislation while protecting individuals' information can also hinder the accountability of government to the public and hinder social justice and restitution for individuals who may have been harmed by governmental practices. Because no names or other identifiable information will be recorded or shared, the level of intrusion is very minimal.

I submitted my request January 15, 2015 and received a response of “conditional approval” on February 9, 2015. The two conditions remaining for full approval by the HIPC were proof of REB approval and a clarification of the dates of the records I wished to access.<sup>37</sup> On March 13, 2015, having since received and forwarded to the HIPC my REB approval, I received approval from the HIPC for the full date range of case files (1890-1975) comprising six feet of boxes.<sup>38</sup> The committee then sent the approval to the Family Services department so that a research agreement with the department could be initiated. (The process with Family Services will be described in the next chapter.)

Although there is an informal understanding among historians that approval from the HIPC is extremely difficult to obtain, statistics from the committee show that most projects win approval. Between 2004 and 2015, a total of 442 research projects were submitted to the HIPC and 88 percent were approved. At the end of the 2015 fiscal year, a further seven percent of the submissions had conditional approval. Only four percent of the projects were “deferred” as requiring substantial changes. Finally, of the 442 research projects, 4 (or 1 percent) were

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<sup>37</sup> In my application, I had given two ranges of dates in my application: 1890-1915 or 1890-1975. The latter range was for one set of case files as described by the Archives of Manitoba. However, I had also explained in my application that I was willing to examine a smaller subset of files that are 100 or more years old if that would be the only acceptable choice.

<sup>38</sup> The entire set of case files is over 100 feet. I chose to request access to only a portion of the files.

withdrawn by the researcher before the project was reviewed in full.<sup>39</sup>

The high success rate of applications does not reveal the entire story of submitting to the HIPC but it is rare to know these experiences beyond hearsay as this is a subject on which very few researchers publish.<sup>40</sup> Although the context for research into institutional records is important and justifiable, the largest factor in my success at gaining approval for my project was probably because I was not recording any personal information during my research. As clause 20(2) of the PHIA says, “every use and disclosure by a trustee of personal health information must be limited to the minimum amount of information necessary to accomplish the purpose for which it is used or disclosed.” As my purpose was *archival* or to examine the types of records and categories information in them, not their specific information contents, I did not need to record any identifying or personal health information and carefully constructed my sample data collection sheets to avoid this kind of information. Researchers who later discover that modifications are necessary or useful to the data collection sheets can seek amendments through the HIPC.

### Research agreements

The goal of the submissions to the university’s Research Ethics Board and to the

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<sup>39</sup> Nathan Hoepfner, Director - Analytics & Research Support, Health Information Management, Manitoba Health, Healthy Living & Seniors, email communication to author, April 4, 2015. I obtained this information by completing a Health Information Data Request Form and submitting it to the Health Information Management section of Manitoba Health. In my request, I asked for the number of submissions that were declined in the past decade. I also asked for the numbers of submissions in which: the “intrusion level” was considered to be “highly sensitive;” the projects dealt with archival material rather than living participants; or the principal investigators were graduate students. Only a single deferred submission was from a graduate student and none of the nineteen were for archival records. I had a particular interest in the number of submissions from graduate students that were not approved as I had been told by a government FIPPA coordinator that it was very unlikely that my project would be approved since I was a student.

<sup>40</sup> McCallum’s “Laws, Codes and Informal Practices” may be the only publication by a historian that describes the process of applying to the Health Information Privacy Committee.

province's Health Information Protection Committee is to eventually obtain a research agreement with the data trustee of the restricted archival records. The University of Manitoba publishes guidelines for research agreements but I did not learn of these guidelines until two years after I had begun the process of applications and after I had already signed two agreements with the province. I learned about the University of Manitoba guidelines when my thesis supervisor and I met with Legal Counsel in January 2016 concerning a third research agreement that had been sent to the Office of Research Services from the Manitoba government Department of Family Services. At this time, I learned that the UM's procedure for research agreements specifies that "Principal Investigators, other staff or students are not authorized to contract on behalf of the University."<sup>41</sup>

After this discovery, I searched the University of Manitoba's website to find resources regarding research policies. I found that the procedures for research agreements are published on the University Governance website.<sup>42</sup> It would take an imaginative leap on the part of a graduate student to find the university's policies regarding research agreements and indeed during the many months spent trying to obtain research agreements, it had not even occurred to me that the university had such policies. Although I had contacted members of the UM History department for advice on research agreements, I received very little instruction on how to obtain an

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<sup>41</sup> University of Manitoba, University Governance, "Procedure: Research Agreements," accessed August 15, 2016, [http://umanitoba.ca/admin/governance/media/Research\\_Agreements\\_Procedures\\_-\\_2014\\_02\\_03.pdf](http://umanitoba.ca/admin/governance/media/Research_Agreements_Procedures_-_2014_02_03.pdf).

<sup>42</sup> University of Manitoba, University Governance, "Governing Documents: Research," accessed April 18, 2016, [http://umanitoba.ca/admin/governance/governing\\_documents/research/692.html](http://umanitoba.ca/admin/governance/governing_documents/research/692.html). Links to these procedures are on the webpage of the Office of Research Services in a box called "Useful Links" with a hyperlink called "University Policies." University of Manitoba, Office of Research Services, accessed April 18, 2016, <http://umanitoba.ca/research/ors/index.html>. There does not seem to be a link to the procedures from the page of the Office of Research Ethics & Compliance. University of Manitoba, Office of Research Ethics & Compliance, accessed April 18 2016, <http://umanitoba.ca/research/orec/735.html>. If there is a link from this page, I cannot see it.



agreement.<sup>43</sup> Clément, in his article that discusses his experience with obtaining access to restricted records, recommends that “training graduate students to use FOI legislation...should be a component of all history graduate programs in Canada.”<sup>44</sup> It would also be beneficial if research policies specific to each university were taught, or were clearly available on each university’s history department webpage. A quick perusal of the first seventeen of the thirty-five Canadian history departments listed on the University of Manitoba’s History department website, shows only Lakehead University and the University of Lethbridge supplying links related to research ethics and the research process.<sup>45</sup>

### **Research ethics and the right to know**

There are two areas of inquiry that could be further explored in depth but are beyond the scope of this thesis. The first relates to the issue of consent by historical subjects and the second relates to the right to know. The issue of consent raised by the ethics authority bodies also raises questions about the overarching responsibility of historians to their subjects. While researchers who want to gain access to restricted records must follow stringent ethical practices, Mary Jane McCallum questions the responsibility of *all* historians:

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<sup>43</sup> Most often, after requesting information from a member of the History department, I received an email link to the Research Ethics Board website where it seems to be assumed that the research involves living subjects and not archived records. After meeting with Lynne Hiebert, Legal Counsel at the UM, she sent me a copy of a PowerPoint presentation that she created to instruct members of the university about research agreements. Lynne Hiebert, email to author, January 15, 2016. This presentation is part of the VPRIO workshop series that, as previously mentioned, runs once during an academic year. Previous to this communication, neither I nor my thesis supervisor were aware of such a presentation.

<sup>44</sup> Clément: 119. The Archival Studies program previously offered a half-credit course that included issues related to privacy, access, and the role of the Ombudsman that was taught by Gordon Dodds while he was Archivist of Manitoba. Tom Nesmith, “Learning to Think Archivally: Thesis Research in the Archival Studies Program at the University of Manitoba,” *Archivaria* 55 (Spring 2003), 105.

<sup>45</sup> University of Manitoba, “Canadian Universities – Departments of History,” <http://umanitoba.ca/faculties/arts/departments/history/links/unilinks.html>. For the history department websites of Lakehead University and the University of Lethbridge, see <https://www.lakeheadu.ca/academics/departments/history/graduate-programs> and <http://www.uleth.ca/artsci/history>. All accessed May 23, 2016.

But what procedures are taken by historians who consult archives that are not restricted and which are not governed this way? Do historians have special ethical responsibilities towards the archives they consult? How do we describe and practice these responsibilities?<sup>46</sup>

The “Statement on Research Ethics” published by the Canadian Historical Association (CHA) does not address this issue. The closest the CHA comes to declaring any kind of responsibility that historians have to their subjects is in reference to the Tri-Council policy regarding research involving “human subjects” – for which it gives the example of research involving *living* human subjects such as those participating in oral histories<sup>47</sup> and for “research about Aboriginal peoples.”<sup>48</sup> Lynette Russell suggests that archives and libraries post protocols in which researchers about to publish research results from material that includes Indigenous Knowledge ensure that the corresponding communities are consulted and that their permission is obtained. She argues that “anything less is simply bad manners.”<sup>49</sup> Perhaps this type of consultation should be a requirement when researchers are investigating any marginalized and disenfranchised community. Although ethics authority boards appear to address these issues by requiring

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<sup>46</sup> McCallum, “Laws, Codes and Informal Practices.” McCallum also cites the work of Lynette Russell, a researcher in the Centre for Australian Indigenous Studies at Monash University. Russell says that while access to some records may be dependent on ethical protocols which require researchers to “liaise with the relevant communities,” these same ethics do not seem to apply when records are in the public domain. She also says, “Indeed, many researchers assume that public domain material is open for all and as such there is no need to consider the copyright (apart from adequate acknowledgement). As a result of this attitude, the moral rights of the material’s owners are rarely even considered.” Lynette Russell, “Indigenous knowledge and archives: Accessing hidden history and understandings,” *Australian Academic and Research Libraries* 36:2 (June 2005), 167.

<sup>47</sup> Canadian Historical Association/Société historique du Canada, “Statement on Research Ethics,” accessed May 21, 2016, <http://www.cha-shc.ca/english/about-the-cha/statement-on-research-ethics.html>.

<sup>48</sup> Here the CHA again directs researchers to consult the Tri-Council and also provides additional sources of protocols such as the First Nations principles of OCAP (Ownership, Control, Access and Possession). See First Nations Information Governance Centre, accessed May 21, 2016, <http://fnigc.ca/ocap.html>.

<sup>49</sup> Russell, 167

researchers to obtain consent and disseminate results, this is a superficial consultation compared to the principles of OCAP or the principles of inclusive or participatory research.<sup>50</sup>

The questions that McCallum and Russell raise concerning access and responsibility of researchers also assert the communities' right to information held in the records, if not rights to the very records themselves. Eric Ketelaar argues against binary constructions of ownership when he says "the meaning of a record or of any other cultural artifact must be understood in two different ways—first, the meaning *of* the record and second, the meaning *for* someone or *for* an occasion."<sup>51</sup> Ketelaar also describes records such as case files as being co-created by the subject of the file and by the authority(s) who authored the records.<sup>52</sup> But at the same time as Ketelaar appears to liberate ownership of records, he also warns that "archivists should be vigilant and ensure that appropriation of archives by a particular group for a particular cause does not endanger the integrity of the archives and the rights of other users, now and in the future."<sup>53</sup> In the instance of case files, which can be seen as "co-created," on whose behalf should archivists be vigilant? Russell, for example, argues that she does not feel comfortable with some case files being viewed after 100 years and "even in 500 years" would "not want just anyone to be able to read" the records. She also points out that for some records about Indigenous people, "once

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<sup>50</sup> The University of Manitoba Protocol Submission Form to the REB only says that "feedback should be given to participants about the research immediately after collection, so as to make their experience as educational as possible." Again, the type of research referred to here seems to be that which uses living participants as subjects and does not reference communities that may be affected by the research. Lynn Lavallée points out that while the TCPS Article 9 provides guidelines for research involving Indigenous peoples these guidelines are not always included in university REBs. Further researchers may write descriptions that appear adequate but in actuality are not. See Lavallée's presentation titled "Reconciling Research with Metis, Inuit and First Nations Peoples" at the University of Manitoba at [http://www.umanitoba.ca/faculties/kinrec/media/UofM\\_Reconciling\\_Research.pdf](http://www.umanitoba.ca/faculties/kinrec/media/UofM_Reconciling_Research.pdf) and <https://www.youtube.com/watch?v=D5qh7MY4el0>, both accessed August 14, 2016.

<sup>51</sup> Eric Ketelaar, "Cultivating archives: meanings and identities," *Archival Science* 12 (2012), 23.

<sup>52</sup> *Ibid.*, 29. Ketelaar says "appropriation also occurs when people refer to the file held by medical, immigration and other authorities as 'my file'—rightly so since they can be considered as co-creator of the file."

<sup>53</sup> *Ibid.*, 30.

families become aware that material is available, there is often a strong desire for that material to be destroyed—a desire that is clearly at odds with the charter of the archive or library.”<sup>54</sup> Should the subjects of case files be allowed to appropriate the files and destroy them?

In the instance of government records about people labelled with intellectual disability who were confined in government institutions, it can be argued that the government offers protection to this population by determining what records are preserved and by rigorously policing access to these records, but this same protectionism also reduces the right of reply by shielding the records behind barriers. How can the diverse communities of people affected by institutionalization, and by governments’ eugenic ideas of intellectual categorization and worth, reply to contents of records that are virtually unknown or unavailable? Examination of a framework such as the United Nations Commission on Human Rights (UNHRC) Joinet-Orentlicher Principles in regard to how these principles apply to the right to know about abuses in institutions would be an illuminating exercise and one that does not yet appear to have been attempted.<sup>55</sup>

My experience with considering research ethics, and preparing submission forms to gain approval for my research, deeply enhanced my consciousness and understanding of privacy, confidentiality, security of my data, and respect for the contents of the records. The unwieldy

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<sup>54</sup> Russell, 164-165.

<sup>55</sup> The Truth and Reconciliation Commission of Canada referenced the Joinet-Orentlicher Principles in its Calls to Action. Item 69 states in part, “We call upon Library and Archives Canada to, i. Fully adopt and implement the United Nations Declaration on the Rights of Indigenous Peoples and the United Nations Joinet-Orentlicher Principles, as related to Aboriginal peoples’ inalienable right to know the truth about what happened and why, with regard to human rights violations committed against them in residential schools.” Truth and Reconciliation Commission of Canada: Calls to Action,” accessed July 23, 2016, [http://www.trc.ca/websites/trcinstitution/File/2015/Findings/Calls\\_to\\_Action\\_English2.pdf](http://www.trc.ca/websites/trcinstitution/File/2015/Findings/Calls_to_Action_English2.pdf).

bureaucracy surrounding the processes, however, seemed like unnecessary barriers to access and also sometimes seemed highly saturated with a paternalistic protectionism. The emphasis on sponsored research and living participants also showed how the process of archival research does not seem to be widely understood by the university. However, it also became very apparent to me that the extent of education on both ethical and practical principles of research in the university's history department is in need of enhancement. In the next chapter, in which selected experiences with the FIPPA process and research agreements are described, many of these same themes occur and are amplified.

## **Chapter Six: “They’re still with their secrets.”**

### **Government responses to access requests**

When David Weremy’s sister told him that things had changed with the institution now, Weremy exclaimed, “They’re still with their secrets, Maggie .... No, no they still got secrets in there. They still got them. They’re not giving them away.”<sup>1</sup>

In the course of my thesis research, I experienced a wide range of responses from the Manitoba government after submitting FIPPA requests. Some responses were timely and smooth but in other cases both fees and delays posed significant barriers to my access to the records. In this chapter, I provide a general overview of the responses from the government and a detailed look at selected responses. Since FIPPA requests can be a “fishing expedition” as Claudia Malacrida has described, I also give some examples of whether the material I received could be relevant to an understanding of the history of institutionalization in Manitoba.

Making a FIPPA request in Manitoba is free of charge and relatively straightforward. The Manitoba government provides instructions and application forms on their website.<sup>2</sup> The form is available as a fillable (but not saveable) PDF that must be printed and mailed by post. The form requires the applicant’s name, address, phone and fax number. The applicant specifies whether the information is “general information,” “my own personal information,” or “personal information for another person.” If it is a request for personal information on behalf of another person then the applicant must attach proof of authority. The form provides a large space for the

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<sup>1</sup> David Weremy, cited in *The Freedom Tour*.

<sup>2</sup> Government of Manitoba, “FIPPA for the Public,” accessed February 2, 2015, [http://www.gov.mb.ca/chc/fippa/public\\_portal\\_home.html](http://www.gov.mb.ca/chc/fippa/public_portal_home.html).

applicant to detail the records requested and applicants are allowed to add an additional page for description of the records if necessary.

The applicant needs to direct the form to the specific public body that is in charge of the requested records. A hyperlink is provided on the PDF form that returns inquirers to the Government of Manitoba FIPPA website where a list of the public bodies operating under FIPPA are shown (or applicants can find this list directly through the website). The public bodies are listed under categories such as “Manitoba Government Departments,” “Boards, Commissions and Similar Bodies,” “Organizations designated as Government Agencies under FIPPA,” and several others. Applicants who need assistance in determining which public body has the information are directed to telephone the Information and Privacy Policy Secretariat.<sup>3</sup> I received assistance from the Secretariat for a number of records, for example I was told that my FIPPA request for a record created by the Lands Branch should be directed to the department of Conservation and Water Stewardship.<sup>4</sup> While there is a place on the form for the applicant to sign, the applicant does not date the form. The only place for a date is when the application is received and this section is designated “For Public Body Use Only.” The 30-day countdown for a reply begins after the public body officially receives the request so the date that the applicant makes the request is not relevant. Applicants are advised on the form to make an additional copy of the form for their own records.

Requests are sent to specific individuals at the departments listed on the Government of

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<sup>3</sup> Manitoba Government, “Where to Send Your Application,” accessed February 3, 2015, <http://www.gov.mb.ca/chc/fippa/wheretosend/index.html>.

<sup>4</sup> Since the installation of the new government in May 2016, this department is now called “Sustainable Development.”

Manitoba website. Although the titles of the individuals are not provided, a quick search in the Manitoba government online phone book shows that the individuals generally have the title of “FIPPA Access and Privacy Coordinator.” In some cases, the individuals have a dual job title of Administrative Assistant or Officer as well as their FIPPA-related role and this may suggest that their FIPPA position is only part of their duties. Letters in reply to my requests came from a variety of government employees: if the response was routine, the junior employee handled it. However, the cases that became difficult or more complicated had responses by senior employees and deputy ministers.<sup>5</sup>

Researchers who follow the FIPPA process to access restricted records, and are successful in their requests, receive photocopies of the records. While receiving photocopied records in the mail from the government can be convenient for the researcher, the photocopied pages are often a poor substitute for seeing the originals. In the cases where redaction is necessary, the photocopy received by the applicant is a photocopy of a photocopied working copy—the original is copied to make a working copy which is then redacted and finally a photocopy of the redacted copy is sent to the applicant.<sup>6</sup> The visual quality of the photocopy is decidedly less than viewing the original and the copy can be particularly difficult to read when the record contains handwriting that is blurred or broken due to the successive copying. As the photocopied pages are in black and white, the ink colour of stamps or handwritten notations is

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<sup>5</sup> The FIPPA regulations specify that the head of the public body “means the deputy minister of the department or person holding an equivalent office.” Access and Privacy Regulations 9(3).

<sup>6</sup> A *Toronto Star* article that describes how a FOI applicant received documents that used Scotch tape and a blank sheet of paper to redact information seems to have misunderstood the process of redacting documents. It appears quite obvious that by mistake the applicant received a working copy of the document that was being prepared for photocopying. Geoffrey Vendeville, “No peeking! Government records censored with Scotch tape, paper,” *Toronto Star* May 17, 2016, accessed June 1, 2016, <https://www.thestar.com/news/canada/2016/05/17/no-peeking-government-records-censored-with-scotch-tape-paper.html>.



lost. Photocopies I received of photographs were often very poor quality and a photocopy of a blueprint was simply illegible. Receiving photocopies in an envelope also removes the records from their context. The researcher is unable to request an entire box to see the surrounding files. However, to discover what other records were contained in the box, applicants can visit the Archives of Manitoba to see file listings for the box. But if the file listings contain personal information, such as names, the file listing may be restricted.

My eight access requests went to seven different government departments. A table summarizing my FIPPA requests is below, with the exception of my requests to Family Services that are dealt with in the next chapter. Detailed descriptions of these FIPPA requests and the government responses follow the table.

Table 1: Summary of government responses to my Freedom of Information and Protection of Privacy Act (FIPPA) requests.

Department	# of items	Response time (calendar days)	Fee Estimate or other costs	Result
Conservation and Water Stewardship	1	41	\$0	Received package of photocopied 41 pages.
Education	8	70	\$0	Received package of photocopied 409 pages.
Justice	4	13	\$0	Received package of 84 pages. Included letter allowing access to 130-page record at Archives of Manitoba.
Executive Council	19	226 (approx.) <sup>7</sup>	\$652.50 + unspecified photocopying	Applied for fee waiver. Received research agreement. Received package of 236 photocopied pages.

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<sup>7</sup> It took about 226 days before I could see the records. Then it was an additional four months before I finished the research and got the photocopies, so in total about 346 days.

Department	# of items	Response time (calendar days)	Fee Estimate or other costs	Result
Transportation	195	180 days (approx.)	\$0	Received research agreement.

### **Conservation and Water Stewardship**

My request to the department of Conservation and Water Stewardship was for one item described by the Archives of Manitoba as “4-7A Pelican Lake - Land Acquisition” for the dates 1956-1967. This item was found by a search in the Archives of Manitoba Keystone database using the phrase “Pelican Lake.” The fonds/series title provided by the archives for the item was “Correspondence regarding land use policy and programs.” A hyperlink provided general information for the series:

Series consists of correspondence with the public and with other government Departments and agencies regarding program activities of the Branch. Series may contain policy or procedural drafts. Some individual files may contain copies of legal opinions. Series documents: the development of government policy and legislation regarding land; cooperation with other Provincial Departments and other levels of government; and other programs and policies not directly related to specific land dispositions.<sup>8</sup>

This description, given at such a top level, is vague. An additional link for access information showed that the series was subject to FIPPA. As the Pelican Lake Training Centre operated in the buildings and area previously occupied by the Ninette tuberculosis sanatorium, I hoped that the documents from this time period might begin to show some thought toward the transition of

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<sup>8</sup> Archives of Manitoba, “Correspondence regarding land use policy and programs,” accessed February 13, 2015.

the tuberculosis sanatorium (by the late 1950s, drug therapy for tuberculosis began to take greater precedence than the sanatorium rest cure and the sanatorium closed in 1972).<sup>9</sup>

As mentioned previously, the public body must respond to an applicant's FIPPA request within thirty calendar days. After twenty-nine days, I received a letter from the Access and Privacy Officer of Conservation and Water Stewardship stating that the time period for responding to my request was extended for another thirty-day period. The letter cited clause 15(1) of FIPPA, which allows an extension if "time is need to consult with a third party or another public body before deciding whether or not to grant access to a request."<sup>10</sup> As is standard, the letter also stated that I had sixty days to make a complaint about this decision to the Ombudsman. I was invited to contact the Access or Privacy Officer if I had any questions or concerns. I felt I had no reason to complain about the extension and did not have any additional questions for the officer. Two weeks later, I received a package in the mail containing a cover letter notifying that "partial access is being granted" to my request. As is required by the legislation, when information is redacted or severed, the officer must indicate the reason for the severance. In this case, FIPPA clauses 17(1) and 17(3)(i) were cited as the reason for information being severed from the documents. They deal with disclosure when it "would be an unreasonable invasion of a third party's privacy" and "the disclosure would be inconsistent with the purpose for which the personal information was obtained."<sup>11</sup> As indicated in the preceding table, I received forty-one pages of photocopied material. While it is discretionary for departments to

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<sup>9</sup> Tim Trivett, "Famous Places: The Manitoba Sanatorium, Ninette," The Manitoba Historical Society, accessed February 23, 2015, [http://www.mhs.mb.ca/docs/mb\\_history/07/sanatorium.shtml](http://www.mhs.mb.ca/docs/mb_history/07/sanatorium.shtml).

<sup>10</sup> Correspondence to author, dated November 12, 2014. See also FIPPA 15(1)(c).

<sup>11</sup> Correspondence to author, dated November 24, 2014. See also FIPPA 17(1) and 17(3)(i).

charge applicants for photocopies, I was not charged by the department for the photocopies. Applicants are not allowed to be charged for standard mailing costs.

The content of the requested item, however, appears irrelevant to the Pelican Lake Training Centre and had to do with the sale of other land in the area.<sup>12</sup> As Claudia Malacrida found in her research at the Provincial Archives of Alberta, thin descriptions of the archival records mean that “sometimes (actually often) things came back that were utterly useless.”<sup>13</sup> While “fishing” for relevant records may be common in all archival research, there are extra procedures, delays and costs for the researcher when the records are restricted. As noted in the previous chapter, government resources are also required to respond to FIPPA requests. Resources presumably saved by providing thin descriptions when records are sent to the archives from government departments, or when the records are described and processed by the archives, can create more costs later on that are borne by the government, researchers, or both parties.

### **Education and Advanced Learning**

My FIPPA request to the Education and Advanced Learning department was for eight items. Fifteen days after my request, I received a response from the department informing me that they extended the time period for an additional thirty days. The reason for the extension was based on FIPPA clause 15(1)(b) when “a large number of records is requested or must be searched and responding within the time period set out in section 11 would interfere unreasonably with the operations of the public body.”<sup>14</sup> Although the time period is usually counted out in calendar days, this department appears to have counted the days as business days,

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<sup>12</sup> The third-party ownership of the land was the information protected by FIPPA.

<sup>13</sup> Claudia Malacrida, email to author, July 16, 2014.

<sup>14</sup> Correspondence to author, dated October 30, 2014. See also FIPPA 15(1)(b).

as their letter dated October 30, 2014 gave the date of December 12, 2014 as being the date of thirty days extension. Even still, I did not receive the documents until December 23, 2014.

However, the package I received in the mail was very thick – about seven and a half centimeters (three inches) and weighed almost two kilograms (just over four pounds). Again, I was not charged for the photocopies.

Of the eight records I requested from the Education department, one could not be found at the archives. For such cases of missing or non-existent records, the legislation says: “12(1)...the head of the public body shall inform the applicant...(c) if access to the record or part of the record is refused, (i) in the case of a record that does not exist or cannot be located, that the record does not exist or cannot be located.”<sup>15</sup> Six of the records concerned St. Amant but again were a “fishing expedition” as I did not know what to expect beyond the general subject intersection between the institution and the Department of Education during the provided dates. One of the eight records concerned the Manitoba Developmental Centre and the other record I found by searching in the Keystone database for “mental retardation.” The information provided by Keystone for all of the records is shown in the table below. The last two columns on the right indicate the number of pages sent and my own general description of the contents. As shown below, there was no indication from the archival description whether the record would be 3 or 113 pages.

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<sup>15</sup> Correspondence to author, dated December 23, 2014. See also FIPPA 12(1)(c)(i).

Table 2: Records received from Education and Advanced Learning.

Keystone Item Description	Location code	Accession	Schedule	Date	Pages received	General contents
St. Amant Centre	Q 30577	GR7492	E 0003	1997	72	Documents relating to the establishment of St. Amant School, especially legal issues.
St. Amant Centre	R-34-7-15	GR8912	E 0003	1998	113	Documents relating to parents' concerns with the transition of St. Amant, especially the school.
St. Amant Centre	R-28-4-13	GR8734	E 0003	1999	3	Memo re: conference presentation.
St. Amant Centre	E-13-8-18	GR1136	E 0002	1981	4	Letter and budget information regarding the Institutional Teacher Program.
St. Amant Centre	D-15-7-19	GR0979	E 0002	1983	0	Could not be located
500.6.1 - St. Amant Centre	J-13-6-14	GR0476	E 0002	1976-1977	30	Correspondence re: request for additional teacher and/or aides at St. Amant School.
Manitoba Developmental Centre	D-3-8-8	GR0942	E 0002	1988	15	Memo and review of the MDC Education Program. Includes a 5-page timetable.
Mental Retardation, 1966/67	E-4-6-12	GR1190	E 0002	1965-1967	172	Documentation related to the transfer of special needs education to the public school boards.

The sparse general description that I have provided above slightly improves on the understanding of the scope and content of the records, but still provides little indication of the correspondents or the historical importance of what might be found in the records. For example, the GR0476 accession contains documents from several correspondents including the Minister of

Education, the Assistant Deputy Minister of Education, the Assistant Superintendent of the St. Vital School Division, the principal of St. Amant School, staff members from Child Development & Support Services, the Secretary of the Management Committee of Cabinet, the Department of Health and Social Development and the Director of the Public Schools Finance Board. Within this accession, a submission from the Department of Health and Social Development to the Management Committee of Cabinet describes the origin of the St. Amant Developmental Day Care Centre as a pilot program that began in 1968: “A few children who had been refused acceptance by the school division were enrolled on a Nursing Unit to provide some relief to parents who had no alternative program available for their children.”<sup>16</sup> As children with disabilities were supposed to be admitted to Manitoba schools by 1967, it is interesting to note that some children were still “refused acceptance.”<sup>17</sup> In the E-4-6-12 accession, a document written in 1965 shows that “pressures for revision” of the education of children and youth labelled with intellectual disability “have arisen through individual parents, through Associations for Retarded Children, and through voluntary community groups.”<sup>18</sup> This information, buried as it is, is useful in highlighting the role of individual parents as well as organizations in the promotion of the education of children and youth with disabilities.<sup>19</sup>

The thin description provided by the archives shows a need for the availability of greater resources to better describe the records. As it would be unreasonable to expect or hope that

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<sup>16</sup> Archives of Manitoba [hereafter AM], E 0002 Department of Education, GR 0476, 500.6.1 - St. Amant Centre, Department of Health and Social Development, November 29, 1976, J-13-6-14.

<sup>17</sup> Adams says “special education services remained largely with the Manitoba ARCs [Association for Retarded Children] until the Department of Education took over in the fall of 1967.” Adams, 23. I am unable to locate any published history of education for children with disabilities in Manitoba.

<sup>18</sup> AM, E 0002 Department of Education, GR1190, Mental Retardation 1966/67, letter from Peter Wiley, Supervisor of Special Classes to G.M. Davies, Assistant Deputy Minister, June 22, 1965, E-4-6-12.

<sup>19</sup> That such nuggets of information lie deeply hidden in the archives is not an instance isolated to this research project but rather is common to most historical research in archives.

archivists could fully describe the records in such a way as to address all researchers' interests, a method by which researchers could create annotations for public use could be maintained.<sup>20</sup> For example, even the short descriptions that I provided in the table above would be useful to other researchers. Archives could also publish research guides created by archival staff or provided by researchers who would be willing to share their findings.<sup>21</sup> Another entry to the documents that would perhaps be the most welcomed by researchers might be publicly accessible digitized documents that were machine-searchable. Dominique Clément suggests that archives, especially Library and Archives Canada, which provides FOI documents electronically as PDFs, should make these documents freely available to other researchers rather than "to treat each new request under the ATIA as if there were no precedents."<sup>22</sup>

The records provided by the Education and Advanced Learning department included many pages where redactions had been heavily made. For example, almost the entirety of a five-page document of meeting notes was redacted. The photocopies I received for these meeting notes included the first page that gave the date, the attendees, and the location of the meeting but

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<sup>20</sup> See for example Magia Ghetu Krause and Elizabeth Yakel, "Interaction in Virtual Archives: The Polar Bear Expedition Digital Collections Next Generation Finding Aid," *The American Archivist* 70/2 (2007), 282-314. Krause and Yakel say "our objectives were to determine whether some level of interactivity increased the accessibility of archival materials and to assess how users would interact with one another to augment their archival experience." 287.

<sup>21</sup> The Archives of Ontario provides research guides on a large number of subjects. See the Archives of Ontario website "Research Guides and Tools," accessed May 29, 2016, [http://www.archives.gov.on.ca/en/access/research\\_guides.aspx](http://www.archives.gov.on.ca/en/access/research_guides.aspx). One of the guides, "Patient and Health Practitioner Records," guides users to finding records for hospitals, institutions, and related fonds. See Archives of Ontario website, "Patient and Health Practitioner Records," accessed May 29, 2016, [http://www.archives.gov.on.ca/en/access/documents/research\\_guide\\_224\\_patient\\_health\\_practitioner.pdf](http://www.archives.gov.on.ca/en/access/documents/research_guide_224_patient_health_practitioner.pdf). When I contacted the Archives of Manitoba to ask if they would consider creating a finding aid for disability organizations, I received a reply from an archivist that said that Keystone and the card catalogue are all that users need to find records and avoids "archivist intervention on the prioritization of records." Joan Sinclair, email to author, April 3, 2012.

<sup>22</sup> Clément: 119. See also the publication of RCMP Security Bulletins by Gregory S. Kealey and Reg Whitaker, accessed August 2, 2016, <https://journals.lib.unb.ca/index.php/RCMP/index>. The UK group mySociety maintains a website that holds over 334,000 FOI requests from the past 8 years. "WhatDoTheyKnow," accessed May 31, 2016, <https://www.whatdotheyknow.com/>.



the entire remainder of the page was removed by the Privacy Officer. Pages two to five were also entirely redacted and simply showed the handwritten article number of the legislation that pertained to the redaction.<sup>23</sup> To know the reason for the redaction, the researcher can look up the article in the legislation. In the case of this memo, the article used to redact the contents says:

23(1) The head of a public body may refuse to disclose information to an applicant if disclosure could reasonably be expected to reveal (a) advice, opinions, proposals, recommendations, analyses or policy options developed by or for the public body or a minister; (b) consultations or deliberations involving officers or employees of the public body or a minister;<sup>24</sup>

While the above example gives very little context as to even the subject of the meeting, another example provides much more of a cliff-hanger. The fax cover letter from the Deputy Minister of Education begins with “Thank you for latest ‘Dear Parent’ letter. I have only 1 last and final comment:” however, we will never know what this comment was as the remainder of the text was redacted.<sup>25</sup>

The largest record received from the Education department was an item described as “Mental Retardation, 1966/67.” This item contained 172 pages and included a 60-page report on “The Study of Handicapped Children” that had been published by the province in 1963. The bulk of the documents concerned the actions of the Manitoba government in transferring the education of children with special needs to the public school boards. Once again, interesting information is found buried in the documents: a 1965 memo from the Ministers of Health and of Education addressed to the Secretary, Treasury Board states that

we are told that more than 50% of the residents at the Manitoba Training School [MDC] do not need to be there. These persons would never have been admitted to the

<sup>23</sup> AM, E 0002 Department of Education, GR7492, St. Amant Centre, Meeting Notes, December 18, 1997, Q 30577.

<sup>24</sup> FIPPA 23(1)(a)(b).

<sup>25</sup> AM, E 0002 Department of Education, GR7492, Fax cover letter from John D. Carlyle, June 12, 1997, Q 30577.

Manitoba Training School had alternative progressive programs been in operation.<sup>26</sup>

Another 1965 memo from the Director of Rehabilitation addressed to the Minister of Health notes that while there were six teachers employed at the Manitoba Training School, “the teachers have no special training in mental retardation” and “it was uncertain whether the six teachers are registered as qualified teachers with the Department of Education.”<sup>27</sup> The same memo stated that regarding the educational program at the MDC, there was “a need to re-organize it completely with a realistic curriculum and a program which is geared to meet the educational needs of the children rather than the administrative and other needs of the institution.” This group of records also contains a copy of the 1965 report by John A. Christianson on “The Education and Training of Mentally Retarded Children.”<sup>28</sup> This report, although received as part of the bundle of restricted records, is also available at the Legislative Library. The submissions to the report are held, with open access, at the Archives of Manitoba.

### **Justice department**

My FIPPA request to the Justice department was for four items. By far, this department gave the quickest response. Thirteen days after my request, I received a response from the department that included eighty-four photocopied pages. As with the records I received from the other government departments, two of the records from the Justice department were severed in part. In these cases, the severing was made in accordance with the sections of FIPPA that protect

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<sup>26</sup> AM, Department of Education, AM, E 0002 Department of Education, GR1190, Mental Retardation 1966/67, Memorandum from G. Johnson and C.H. Witney to Secretary, Treasury Board, October 28, 1965, page 7, E-4-6-12.

<sup>27</sup> Ibid., Memorandum from Walter N. Boyd to M.R. Elliott, October 18, 1965, E-4-6-12.

<sup>28</sup> This report is also available at the Legislative Library of Manitoba and the University of Manitoba Elizabeth Dafoe Library. The submissions to the report are held, with open access, at the Archives of Manitoba.

the privacy of third parties and solicitor-client privilege.<sup>29</sup> Examples from these records, though, show the inconsistencies of redactions. For example, a letter from a member of the CAMR (Canadian Association for the Mentally Retarded) in Ontario that was written to Premier Howard Pawley to express opposition to the expansion of institutions had the signatory redacted. Sufficient information is given in the body of the letter however that would allow a researcher to discover, albeit with some digging, the identity of the letter writer. In another letter, the writer was identified as the Chairperson of the Concerned Parents Group of St. Amant Society but his or her name was redacted. However, an additional letter on St. Amant Centre letterhead was signed by five people, including the President of the Concerned Parents of St. Amant, and none of the names were redacted. In another instance, any researcher familiar with Winnipeg advocates for community living would recognize the redacted signatory of a letter addressed to a government official by the identification of the signatory's child's name which was not redacted.

In two other instances, the items requested were provided in full. Photocopies were sent for one and for the other I was instructed that I could view the record at the Archives of Manitoba when accompanied by the letter and photo identification. This raises the issue of why such items are categorized as restricted in the Keystones database. Although the particular act that I requested (The Manitoba Institute for Mental Retardation Studies Act) had no need to be severed, it is possible that it was included in a file that contained other material that was restricted. As archives rarely have the resources to separate restricted documents from open documents, whole files or boxes may be considered restricted even if only a portion of the items within the file or box are restricted.

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<sup>29</sup> FIPPA 17(1)(2)(3) and 27 (1)(2).

## **Transportation and Infrastructure**

My experience with the Department of Transportation and Infrastructure was unusual in that the Privacy Coordinator immediately began the process of preparing a research agreement once I contacted her with my request.<sup>30</sup> After six months, and a number of emails from the department requesting additional information, a draft of the research agreement was finalized by the government's Civil Legal Services and sent to me. As I had some questions about the contract, it was a further month before I was finally able to sign the agreement and drop it off at the government department.

When I made my original request to the department, I included my list of 195 requested items. However, once I received the research agreement and began accessing the items at the Archives of Manitoba, the staff member on duty told me that the items I was currently examining were not restricted. After contacting the Privacy Coordinator of the department I realized that I had made a mistake in understanding the status of those items and the Privacy Coordinator had not double-checked the status of the items. In this case, which was early on in my research with Keystone, the error was mine as I became confused by accession numbers, location codes and government schedule numbers. For example, an item for the Home for Incurables has the following numbers: GS 0123, GR1607 and G7972, which are the government schedule number, accession number and location code respectively. For the government schedule number GS 0123, the information provided by the Archives of Manitoba says that "accessions GR1607, GR7644, GR1608, GR1606, GR1609 and GR7744 are open." However, when checking items I likely

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<sup>30</sup> It was the advice of Janelle Reynolds, Program Analyst at the Information and Privacy Secretariat, that I ask Rebecca Schramm for a research agreement as my request to the department was so lengthy.

confused location codes with accession numbers. After re-checking my list of 195 items, I found that 50 of the items were indeed open.

Another error that I made in regard to this research agreement was sending the Privacy Coordinator a copy of my university REB approval. I later found out that the REB approval I had received was specific to the record sets in my original application (which were for records for the MDC held by Family Services and for records concerning the Pelican Lake Centre that are part of the Sanatorium Board of Manitoba fonds held at the Archives of Manitoba). As I had not listed the Transportation and Infrastructure files in my ethics application, I discovered that I had to request an amendment to be approved by the JREB. Interestingly, the Privacy Coordinator of Transportation and Infrastructure had not requested proof of REB approval during the process of preparing the research agreement. It was only as the agreement was being finalized that I offered to send a copy of my REB approval and at that time the coordinator said that “Crown Counsel has indicated that it should be included in your file.”<sup>31</sup>

To obtain this research agreement, I did not have to fill in a Request for a Research Agreement form as I had to do for the Department of Family Services. Under the terms of the agreement, I was not able to make copies of the records but I was able to take notes on an electronic device and my notes were not reviewed by the Privacy Coordinator. However, the agreement specified that the department needs to review any publication, including my thesis, before publication.

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<sup>31</sup> Rebecca Schramm, email to author, March 12, 2015.

## Fees

Two departments responded to my FIPPA requests with a fee estimate: the Executive Council gave the estimate of \$652.50 plus unspecified photocopying fees; and Family Services said \$780 with an estimated \$500 in photocopying fees. Combined, the fees totaled very close to \$2,000 (about one-tenth of my annual earnings at the time as a graduate student). Although the University of Manitoba has two awards that might cover these costs, it is practically impossible to time the University of Manitoba's research award deadlines with the government responses that can be so variable.<sup>32</sup> Although some researchers may have funding to pay for FIPPA fees, even established scholars such as Claudia Malacrida and Dominique Clément have balked at fee estimates that they have received.<sup>33</sup> Fees seem particularly punitive when on top of the financial burden, researchers often do not have access to adequate file descriptions to even know if the records they are being asked to pay for will be even useful for their research.<sup>34</sup> As stated earlier, when archives save money by providing thin records description, the cost simply gets moved onto others. However, an option exists whereby a researcher can apply to have the fees waived.

I applied for fee waivers to the two public bodies that requested fees. It is worthwhile

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<sup>32</sup> The Dr. James Burns Graduate Student Research Assistance has two application dates and is limited to \$500, although it is possible that this amount may be extended. The J.G. Fletcher award provides up to \$3,000 but students are required to submit a detailed budget. As well, once a fee estimate is received, the applicant needs to respond to the government within thirty days. Although I tried to get an estimate from government departments regarding fees in time for the award deadline, I was told that estimates could not be given without the government first examining the FIPPA request, which again created the timing problem.

<sup>33</sup> Clément was cited a fee of \$2,700 for file search and a fee of \$6,000 to "cover the cost of shipping and hiring someone to vet the files." He also notes that the United States legislation "has an explicit waiver for academics." Clément, 107. As noted in Chapter 4, Malacrida was cited a fee of over \$13,000. Malacrida, "Contested Memories," 405.

<sup>34</sup> Clément, 105 and 111. As noted by the historians interviewed by Duff and Johnson, archival research performed by historians is often described as fishing or looking for a needle in the haystack. However, performing archival research on restricted items seems to incur extra amounts of frustration and necessary resources. Duff and Johnson: 486.

providing a detailed description of my experience with the Executive Council in order to show the types of interactions that can occur between an applicant and the government. My initial FIPPA request to the Executive Council was met with a request for thirty more days as a large number of records had been requested. I had asked for nineteen items but the very thin description of the records provided by the Archives of Manitoba online search engine did not provide any indication of the size of the items. I received a phone call from the Policy Analyst/FIPPA Access and Privacy Coordinator for the department almost fifty days after I first made my FIPPA application. The Privacy Coordinator estimated that the fees for the request could be about \$700 and she said she would consult with Civil Legal Services about a research agreement so that I could access the files without incurring the cost for government redaction. A few days later, we had another phone conversation. In this conversation, the Privacy Coordinator said that the research agreement could take about one year for the government's legal services to prepare. Further, once the agreement was ready, I would only be able to perform the archival research under her direct supervision and I would thus need to conform to her schedule. She also said that before entering into the agreement, I would need to supply a letter from my thesis supervisor to prove that I was a "bona fide researcher" (the term "bona fide research" is used in the FIPPA legislation.)<sup>35</sup> We also spoke about the possibility of having the fees waived.

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<sup>35</sup> FIPPA 47(4)(b)(i) says "The head of the public body may disclose personal information for a research purpose only if (b) the head is satisfied that (i) the personal information is requested for a bona fide research purpose." I understood the Privacy Coordinator to say that only people connected to a university could be considered bona fide researchers. A few days later, I emailed the Privacy Coordinator to clarify if only university researchers are considered to be bona fide. She replied that she would look into the legislation, but I did not hear back from her again on this subject. The FIPPA Resource Manual discusses the meaning of "bona fide" by providing the definition of "research" as used by the Ontario Information and Privacy Commissioner and "bona fide" as given by Black's Law Dictionary. The respective definitions are: "'Research' means the systematic investigation into and study of materials, sources, etc. in order to establish facts and reach new conclusions, an endeavour to discover new or to collate old facts, etc. by scientific study or by a course of critical investigation," and "'Bona fide' means in or with

A few days later, I emailed her my intention to apply for a fee waiver and mailed by post a letter to her requesting that the fees be waived. After receiving my request, the Privacy Coordinator contacted me to say that I was not in a position to request a fee waiver as she had not sent me an official fee statement. About a week later, I received a letter from the Clerk of the Executive Council and Cabinet Secretary.<sup>36</sup> This letter summarized the course of events that had so far transpired. I then wrote to the Clerk of the Executive Council to explain my understanding of events and to ask when I could expect the official fee statement. At this point, it was now just over sixty days from my initial request. Within a week I received the official fee estimate from the Privacy Coordinator. Just over two weeks later, I sent a letter to the Clerk of the Executive Council requesting a fee waiver based on financial need. I provided the amount of my income as a graduate researcher in 2013 and acknowledged that although I was offered the option of entering into a research agreement, I felt that waiting one year to receive the agreement and then to operate under the restrictions of the Privacy Coordinator's schedule may interfere with my graduation plans. Almost three weeks later, I received a telephone call from the Privacy Coordinator saying that she had visited the Archives of Manitoba to look at the files I requested. In her opinion, some of the files did not seem relevant to my research project. I replied that part of my thesis included a discussion of the difficulties caused by thin descriptions of records in the

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good faith; honestly, openly and sincerely; without deceit or fraud; real, genuine and not feigned." The example provided in the manual states: "If a research proposal has been approved and will be supervised by a research review committee established by a university to review the scientific and ethical value of research proposals and to oversee research projects, the research purpose would be bona fide." Manitoba Tourism, Culture, Heritage, Sport and Consumer Protection, *Manitoba Freedom of Information and Protection of Privacy Resource Manual*, 2nd Edition, 6-237. Thanks to Janelle Reynolds, Program Analyst at the Information and Privacy Secretariat, who pointed me to this section of the manual. Reynolds also says that "it is the responsibility of each government department (public body) to make the determination of what is 'bona fide' research and likely with the assistance of legal counsel." Janelle Reynolds, email to author, July 19, 2016.

<sup>36</sup> The Clerk of the Executive Council is "the highest-ranking civil servant" in Manitoba. Manitoba Government, News Releases, "Premier announces Clerk of Executive Council departs after distinguished career in government," accessed May 7, 2016, <http://news.gov.mb.ca/news/index.html?item=36253>.



Keystone database and that regardless of the ultimate relevance of the files, I wanted to examine all the files I requested.<sup>37</sup> In reference to my fee waiver, the Privacy Coordinator said she may need more proof of my financial need but that she would get back to me in a week or so.

Some days later I received a message from the Privacy Coordinator saying that I needed to supply more documentation of my financial status, including my assets and other information. I emailed the Clerk of the Executive Council (to whom I expected to send the required information) to ask exactly what documentation was required and copied the Privacy Coordinator. A few days later, I received an email from the Director of the Corporate Policy Branch saying that I needed to provide evidence of “income and expenses, etc.”<sup>38</sup> When I emailed back to request exactly what documentation was required, I received a response from the director saying that this should include “your income on an annual and monthly basis, your total monthly living expenses, the total value of your assets and your total outstanding debts if any.”<sup>39</sup> The director also reminded me that I still had the option of obtaining a research agreement. Additionally, the director included in her email some attachments from the Manitoba Ombudsman and the Alberta Information and Privacy Commissioner regarding fees.

The Manitoba FIPPA website for the public does not offer guidelines for writing a fee waiver. The “Understanding FIPPA” page simply says, “If you would like your fees waived, you must send a request to the public body.”<sup>40</sup> However, the FIPPA website for private bodies

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<sup>37</sup> Clément notes that “it is also important to resist pressure from staff to narrow your request...there is no way to know if you are missing a tangential but important document.” Clément, 111.

<sup>38</sup> Christina Moody, email to author, February 25, 2015.

<sup>39</sup> Ibid.

<sup>40</sup> Manitoba Government, “Understanding FIPPA,” [http://www.gov.mb.ca/chc/fippa/understanding\\_fippa.html#9](http://www.gov.mb.ca/chc/fippa/understanding_fippa.html#9), accessed March 5, 2015.

provides additional, though still limited, information in an online resource manual. For example, the manual states that “the onus is on the applicant to provide the head of the public body with satisfactory evidence of financial hardship, including documentation about his or her financial circumstances” but does not define what constitutes “satisfactory evidence” or even “financial hardship.”<sup>41</sup> The resource manual advises that the head of the public body “must make the decision on a case-by-case basis” and not just fall back on “the grounds of a standing policy.”<sup>42</sup>

Further, the head

may consider a range of factors, including the scope of the access request, the amount of the estimated fees; whether the applicant is open to either narrowing the request or considering other ways to reduce the fees payable; whether the applicant is prepared to pay a portion of the fee; etc.<sup>43</sup>

The resource manual provides hyperlinks in the footnotes to PDFs published by the Alberta government (as it turns out, the same links that the Director of the Corporate Policy Branch sent me). These hyperlinks directly open up PDFs from the website of the Office of the Information and Privacy Commissioner of Alberta.<sup>44</sup> This website offers many orders and reports relating to freedom of information and privacy. Orders can be searched by keyword, such as “waiver,” which returns thirty-nine orders. The issues raised in these orders examine the legislation and regulations and the intent behind them in depth. Each order is approximately fifteen to twenty pages and contains such language as:

Section 72 of FOIP does not merely authorize the decision-maker to confirm a public body’s decision or to require a public body to reconsider its own decision. Section 72(3)(c) of FOIP gives decision-makers the authority to render their own decision about whether to waive all

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<sup>41</sup> Manitoba Tourism, Culture, Heritage, Sport and Consumer Protection, *Manitoba Freedom of Information and Protection of Privacy Resource Manual*, 2nd Edition, 4-70.

<sup>42</sup> *Ibid.*

<sup>43</sup> *Ibid.*, 4-71.

<sup>44</sup> Office of the Information and Privacy Commission of Alberta, accessed March 5, 2015, <http://www.oipc.ab.ca/pages/home/default.aspx>.

or part of the fee or to order a refund. Under section 72(3)(c), the decision-maker has the authority to hear the case “de novo” as a new proceeding and to make a “fresh decision” (Order F2007-020 (para 30), OIPC External Adjudication Order #2 (May 24, 2002) Justice McMahon (para 45), Order 2001-023 (para 32)).

Although the above paragraph simply means (I think) that the oversight body makes its own decision about whether a fee should be waived, the legalese-language and many citations hamper a quick understanding. However, a few hours spent making even a superficial perusal of the orders provides aid to an applicant in preparing a fee waiver and I did make use of some of the information in my five-page reply to the director.

In the letter, I attached a copy of my biweekly paystub from my position as a research assistant at the university and a copy of my tuition fees for the academic year. As my request pertained to my thesis research, I only felt comfortable providing financial information regarding my status as a graduate student but also indicated that in the past few years, I received a very small amount (about \$200 to \$300) in freelance writing fees annually. In my letter, I also explained other circumstances that I felt should be considered. These included a description of my thesis subject, a brief outline of some of the controversy surrounding institutions and the pervasive lack of information that is available about institutions. I also attached a *Winnipeg Free Press* editorial that stated public concern with the Manitoba Developmental Centre and the lack of available government information concerning plans for the centre. I mentioned the important areas of related research that have been examined in other provinces and American states, including the areas of coerced sterilization. I argued that FOI legislation is important to the public and cited Yavar Hameed and Jeffrey Monaghan’s statement that FOI legislation concerns “the democratic principle that people have a right to know about business transacted in their

name.”<sup>45</sup> I further commented that it seems unfair to researchers that we must pay high fees for access to records that are so thinly described that we do not even know if the information the files contain would be useful. I gave the example that one file in my FIPPA request was listed in the Archives of Manitoba public database as “File H-2-6.3 - St. Amant Centre” with the dates 1975-1977, but no other information, not even its size, was provided. I also attached the file list of the nineteen items I requested to show that this type of description was unfortunately true for all of the items.<sup>46</sup> I pointed out that insufficient government funding to the Archives of Manitoba result in such poor levels of description for these records.

I also described in my letter the impossibility of applying for a grant to cover the research fees as the funding has an annual deadline that cannot be realistically coordinated with FIPPA requests, especially when the response rate to the FIPPA request is so variable. I argued that within the information from Alberta that the Director had supplied to me had been the statement that fees should not be at the level that “discourage the exercise of access rights.”<sup>47</sup> However, the fees that had been proposed to me were discouraging my access to the records as was the length of time in responding to my original request (at the time of my letter to the director, it had been five months since my original FIPPA request). I also argued that as my research will be freely published within my thesis, I am performing research for the benefit of the public. And finally, I complained that although I was expected to provide a large amount of personal financial

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<sup>45</sup> Cited in Yavar Hameed and Jeffrey Monaghan, 146.

<sup>46</sup> In the majority of instances, the thin description of the archival items made it very difficult to have a clear understanding of the subject contents or size of the record. Many items I found through the search engine were simply described as “Manitoba School for Retardates” or “Home for the Aged and Infirm.” The other descriptors were a date (usually, but not always), information regarding the medium (textual, photograph, blueprint, etc.) and the name of the fonds or series, which generally gave an indication of the department that created the record. The size of the record was not indicated. As delays and costs are often related to the size of the requested records, not knowing crucial information can severely hamper timely and affordable access to the records.

<sup>47</sup> Alberta, *FOIP Bulletin* 2 (March 2009), 2.

information it was not clear how my “financial hardship” would be determined. I suggested that information regarding the types of financial documentation required by applicants and the process by which the information is reviewed should be present on the FIPPA website and that applicants should also know how “financial hardship” will be determined (whether by a subjective determination or by a formula).<sup>48</sup>

Within two weeks I received an email reply from the director that said she had been able to review my letter with the Clerk of the Executive Council and that they decided that since they now had a “better understanding” of my research project they recommended that I enter into a research agreement with the department. As they recognized my frustration with the delays I had experienced so far, they planned to accelerate the process so that the agreement would be ready in a matter of weeks. The draft of the agreement was indeed ready in about one month. It took another month for corrections to the agreement to be made.

After the agreement was signed,<sup>49</sup> I met the Privacy Coordinator at the Archives of Manitoba at a mutually agreed upon time. After the previous months of communications that at times seemed somewhat strained, the in-person meeting was cordial and I found her to be very helpful. She decided that she did not need to supervise me during my research and that the AM staff could take this role. It was stipulated that I could not make any photocopies or take photographs of any of the records listed in the research agreement but I could make a list of the records I wanted copied and she would review them at the end of my research. She would

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<sup>48</sup> Clément also says “the current practice of waiving fees is opaque and subjective.” He recommends that “each jurisdiction should provide written guidelines for determining whether or not to waive fees.” Clément, 118.

<sup>49</sup> This was the first research agreement that I signed and I was not aware at the time that students are not allowed by the University of Manitoba to sign on their own behalf.

determine at that time if there would be fees for photocopying. I also had to agree only to make handwritten notes and to leave these notes in the custody of the AM staff at the end of each visit to the archives.<sup>50</sup> At the conclusion of my research, the Privacy Coordinator took my notes and my photocopy requests. Some weeks later, at the end of September, I received a large bundle of photocopied documents in the mail. I was not charged for the photocopies.

### **The Panopticon<sup>51</sup>**

The example of my FIPPA request to the Executive Council illustrates how the FIPPA process can be very idiosyncratic and be both plagued by delays and yet accelerated when desired by the government.<sup>52</sup> A further incident also underlines the peculiarities of the interpretations of research agreements and gives a glimpse into the precariousness of the researcher's position in the archives. Although my research agreement specified that no photocopies could be made of the restricted documents listed in the research agreement, I interpreted the file lists contained in the archival boxes to be outside of the research agreement. I assumed that these file lists were likely created by the AM itself and therefore not part of the research agreement I had with the Executive Council. On one occasion, I asked the AM staff member on duty for a photocopy of a file list that was in the current box I was using. The staff member agreed and went away to make the photocopy. While the photocopy was being made, I

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<sup>50</sup> At our meeting, the Privacy Officer had at first suggested that I could email her my notes at the end of each visit to the AM. I pointed out that email may not be secure and so we then mutually agreed on the procedure of handwritten notes that I left at the AM.

<sup>51</sup> See further discussion and references to the archives as a panopticon, see Steven Maynard, "Police/Archives," *Archivaria* 68 (Fall 2009), especially 168 and footnote 35.

<sup>52</sup> My experiences dealing with the government are probably not unusual in a general sense. Ken Rubin describes the application for access process as "a game where you have to push and cajole and double-check." Tom Spears, "RCMP didn't 'purge' public documents: the Mounties just had no idea where they were," *Ottawa Citizen* July 15, 2016, accessed July 16, 2016, <http://ottawacitizen.com/news/local-news/rcmp-didnt-purge-public-documents-the-mounties-actually-just-had-no-idea-where-they-were>.

had second thoughts about who created the file list: perhaps it was created by the Executive Council and not the AM? By the time the staff person returned with the photocopy, I decided that in case the file list was created by the Executive Council I would err on the side of caution and refuse the photocopy even though the file list was not one of the documents covered by the research agreement. Apparently, the staff member had also come to that conclusion and we both were in agreement that the photocopy should be shredded. Under the terms of my research agreement, I was required to report this incident to the Privacy Officer of the Executive Council and I did so by email. A few days later, I received an email from a senior archivist at the AM stating that while I could not get a photocopy of the file list in the box, the exact same file list was in a binder in the Research Room and I could request a photocopy to be made from the binder. The archivist also said that the file list was available on Keystone. So, in this instance, the file list under question was not restricted and did not contain restricted information (such as a name). However, the location of the file list determined whether it could be copied or not: if it was in the binder of file lists open to the public, it could be photocopied. If it was in a box of records, it could not. Interestingly, since I was allowed to make handwritten notes, I was free to make a handwritten facsimile of the file list (although all my notes were to be reviewed by the Privacy Officer before I could remove them from the AM). In the end, I chose to include a request of the file list along with the copies I was requesting. I later received the copy of the file list along with the other copies I had requested.

Since the above-noted incident, I noticed that in a subsequent research agreement that I had directly with the Archives of Manitoba that a clause stated not only that I could not copy any documents but I could not even *request* to copy any document. In the past months, the AM also

has developed a protocol by which a bright orange card is placed on the desk of researchers working with restricted documents. The card clearly states that no copies can be made. Researchers who use the back room to view records containing personal health information in the Research Room's back office have the sign affixed to the wall outside the room.<sup>53</sup>

The above-noted incident illustrates some of the dynamics and anxieties surrounding researchers working under research agreements at the Archives of Manitoba. Although it is difficult to even imagine an occasion in which a researcher would knowingly break the terms of a research agreement,<sup>54</sup> a grey area such as the file list described above may lead to a misunderstanding. This possibility can be very disquieting for the researcher because, as mentioned earlier, a researcher can be severely penalized if it is suspected that a breach of the agreement has been made or may be made in the future.<sup>55</sup> Researchers who employ research assistants are also held responsible for their assistants' real or imagined actions and this may induce enough anxiety that researchers will not be willing to delegate any restricted archival research to assistants. Although invigilation is without argument a necessary and important function of all archives, balancing invigilation with a welcoming environment for researchers

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<sup>53</sup> Although this sign serves to remind both the researcher and staff that copies cannot be made, it does not solve the sticking point of whether file lists are included under the research agreement. Although I have heard it said colloquially that the research agreement covers "everything in a box" or "everything in the private room," this type of language is not used in the legal agreement, which instead refers to a schedule that lists each file covered by the agreement.

<sup>54</sup> It would be interesting to investigate how a deliberate disclosure of information under a research agreement could relate to the Public Interest Disclosure (whistleblower protection) Act. For more information on the act, see <https://web2.gov.mb.ca/laws/statutes/ccsm/p217e.php> and <http://news.gov.mb.ca/news/index.html?archive=&item=35173>.

<sup>55</sup> For example, on one occasion while examining restricted documents, I received a text from home on my cell phone. While looking at my phone at the same desk where the documents lay, I suddenly grew anxious thinking that an archives staff member on duty might imagine that I was surreptitiously taking photos of the documents with my phone. Such a suspicion would be enough to terminate my research agreement, have any notes I had taken destroyed, and report me to authority bodies at the university.



can be difficult.<sup>56</sup>

This chapter illustrates the diverse responses that applicants can receive to their FIPPA requests. It shows that FIPPA applicants need to be meticulous and persistent when initiating and following up on requests. It also provides a few examples of some of the important historical records that can be unearthed through tenacious research and requests for information. The next chapter describes my experiences with the department of Family Services, the data trustee and creator of the case files and administrative records of the Manitoba Developmental Centre and also describes some of my responses to the Pelican Lake Centre files.

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<sup>56</sup> It is important to remember, especially for publicly funded government archives, that “archivists and librarians must maintain healthy patron relations while enforcing reasonable rules and procedures.” See Northeast Documentation Conservation Center, “Emergency Management,” accessed May 29, 2016, <https://www.nedcc.org/free-resources/preservation-leaflets/3.-emergency-management/3.11-collections-security-planning-and-prevention-for-libraries-and-archives>.

## Chapter Seven: “I won’t forget what happened, never.”<sup>1</sup>

### Institutional case files

During the filming of *The Freedom Tour*, David Weremy visited his friend Wayne Beever who also had lived at the MDC.<sup>2</sup> Weremy and Beever sat together on a picnic bench outside Beever’s home in Portage la Prairie and talked about their experiences at the MDC. The film shows the conversation in which they talk of being beaten by staff in the woods of the institution’s grounds, of people who killed themselves at the institution by jumping off the water tower or by hanging, of being forced to scrub excrement off the bathroom walls, and of the sexual activity that went on in the bathrooms at night. They talk about how people drank out of the toilet bowls and walked around naked. Weremy says, “I won’t forget what happened, never.” Beever replies, “You remember for the rest of your life.”<sup>3</sup>

This chapter begins with a critical look at how records relating to the Manitoba Developmental Centre and the Pelican Lake Centre are preserved and described at the Archives of Manitoba. It also examines some of my experiences with my access requests to the Department of Family Services (now called Families) who currently run the Manitoba Developmental Centre. Finally, the case files of the MDC are examined to determine what contribution they could make to understanding the history of institutionalization.

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<sup>1</sup> David Weremy, cited in *The Freedom Tour*.

<sup>2</sup> Wayne Beever said he spent about thirty years at the MDC. Some of his experiences at the MDC are described in a video on the Label Free Zone. Beever’s niece, who narrates the events, says, “the most important thing is that his story is told.” YouTube, “Wayne Beever’s Story,” accessed September 10, 2016, [https://www.youtube.com/watch?v=AeMd\\_nQ2icQ](https://www.youtube.com/watch?v=AeMd_nQ2icQ).

<sup>3</sup> Wayne Beever, cited in *The Freedom Tour*. He died in 2013 in Dauphin, Manitoba. *Winnipeg Free Press*, “Harry (Wayne) Beever,” accessed September 10, 2016, [http://passages.winnipegfreepress.com/passage-details/id-206491/BEEVER\\_HARRY](http://passages.winnipegfreepress.com/passage-details/id-206491/BEEVER_HARRY).

## Description of records

The greatest barrier to access to the records of the Manitoba Developmental Centre is that they are currently among the decades-old backlog of unprocessed records for the Department of Family Services. Some of the records of the Pelican Lake Centre are also among this unprocessed backlog.<sup>4</sup> Apart from their absence in the Keystone search engine, one of the worst consequences of the records being unprocessed is that no authority records exist for the institutions thereby the relationship between the institutions and their previous incarnations are hidden. For example, the records created by the MDC, during all of its various incarnations, are scattered through the various departments that had jurisdiction over the institution without any links to each other.<sup>5</sup> Likewise, the Pelican Lake Centre records are not linked to the MDC records. The sole description of the Pelican Lake Centre on Keystone is contained in one sentence within the description of the Sanatorium Board of Manitoba fonds: “The Pelican Lake Training Centre opened in 1973 on the Ninette site and provided care and training for the developmentally disabled.”<sup>6</sup> This description does not include the date of closure of the institution or its relation to the MDC or to the Manitoba government.<sup>7</sup> Indeed, even this description will not be found unless the researcher searches for “Pelican Lake Training Centre”; if the researcher searches for “Pelican Lake Centre,” which is the more recent name for the institution, only five items are returned and none of them link to the “Pelican Lake Training

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<sup>4</sup> I am not including the records of St. Amant in this discussion as it had a greater distance from the provincial government even though it did, and does, receive provincial funding.

<sup>5</sup> A “Series Description” exists for the Pelican Lake Centre records held by Family Services, but it is not readily available to the public. I received a photocopy of the description from Kathleen Epp in mid-August 2016.

<sup>6</sup> Archives of Manitoba, Sanatorium Board of Manitoba fonds.

<sup>7</sup> The “Series Description” mentioned earlier says that the government of Manitoba began managing the Pelican Lake Centre after the Sanatorium Board ceased control in 1999. However, this description does not describe the relationship of the government to the centre throughout its history.

Centre” records of the Sanatorium Board of Manitoba.

Although the Archives of Manitoba is to be commended for the extensive amount of records that are described in the Keystone database, the use of the database itself can be confusing.<sup>8</sup> As stated before, because no authority record exists for the Manitoba Developmental Centre, the search for records related to the institution becomes especially onerous. However, after the records are processed at the AM, finding the records should become easier as the AM uses a “series-centred approach” especially designed for government records that represents “the functions, activities, creators and groups of records and their changing relationships to one another.”<sup>9</sup> This approach should illuminate the connections between the records that are divided among various government departments. The following section describes some of my experiences when I first began using Keystone to search for the MDC records, and underscores the challenges researchers face when confronted by limited descriptions caused by lack of sufficient funding for archives.

When I first began looking for records I did not understand that the records of the MDC were not included in Keystone. During my first search in Keystone, I entered the name of the Manitoba Developmental Centre into the search engine and the results showed thirty-three

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<sup>8</sup> This criticism is not unique to the Archives of Manitoba. The creation and use of any database or finding aid will not fulfill the need of all users. As Madeleine McLuhan-Myers notes, “The archivist must try to convey sufficient information about the records being represented (at the chosen unit-level) and address their complexities and other needs of researchers, while not focussing their efforts too closely on individual documents. At the same time, researchers themselves require access to these documents and face the challenges of finding – then interpreting – the meaning of the relevant item (or items), which may be part of much larger complex groups of records.” Madeleine McLuhan-Myers, “The Archival Web: Contextual Authority Files and the Representation of Institutional Textual Documents in Online Description,” (Master’s thesis, University of Manitoba, 2012), 4-5.

<sup>9</sup> Myers, 38.

listings and one record creator.<sup>10</sup> Surprisingly, the record creator was listed as Age and Opportunity, Incorporated which is a Winnipeg-based organization that deals with the needs of older adults. To add to the confusion, four of the thirty-three listings were for the Manitoba Development Corporation, which also has the acronym MDC.<sup>11</sup> I later found out that it is important for users of the database to specify a search for “Exact Phrase” instead of the option I had been using which was “All these keywords.” Once the “Exact Phrase” option is selected, the search results do not return a record creator, thereby eliminating the confusion concerning Age and Opportunity, Incorporated.<sup>12</sup> As of the current date, a search for the Manitoba Developmental Centre using the option “All these keywords” no longer returns listings for the Manitoba Development Corporation.<sup>13</sup> Thirty listings are presently returned for both the “Exact Phrase” or “All these keywords” options of Manitoba Developmental Centre.

Education	1
Project Management Branch legal construction records	2
Minister of Transportation and Government Services	3
Building operations files	1
Sessional papers	3
Plans and shop drawings	18
Manitoba Government and General Employee Union fonds	1
Manitoba Labour Board case files	1

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<sup>10</sup> This search was done March 18, 2012.

<sup>11</sup> I emailed the Archives regarding this situation on March 18, 2012. On May 4, 2012 I received a reply saying that the two organizations have no relation to each other.

<sup>12</sup> During an in-person visit an archivist sat down with me at the public terminal and showed me that one of my problems was failing to select the “Exact Phrase” option. It was also at this time that I learned that the records were not linked because no authority record had yet been entered into Keystone.

<sup>13</sup> Search as of May 14, 2016.

As seen from this list, the majority of the records have to do with building plans and renovations. Until recently, there was no evidence in Keystone of the MDC clinical files or of administrative files.<sup>14</sup>

As previous names of the MDC are not provided by the Archives of Manitoba, the researcher must try to discover the history of the institution in order to look up its records.<sup>15</sup> As shown in the literature review of this thesis, very little has been published about the Manitoba Developmental Centre so I turned to the internet to try to find out more about the history of the MDC. At the time of my early research in 2012, very little was available online. After many hours of research, I finally discovered some of the earlier names of the institution through a serendipitous search for “Catherine Rodgers,” an employee of People First of Canada with whom I had email contact. Through this search, I came across an online letter to the editor from Catherine Rodgers and People First Executive Director Shelley Rattai published in the *Portage Daily Graphic*. In this letter, Rodgers and Rattai mention that the original name of the Manitoba Developmental Centre was “Home for the Incurables” and this name was later changed to “Manitoba School for Defectives” in 1933.<sup>16</sup>

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<sup>14</sup> At the present date, Keystone lists the clinical files. Archives of Manitoba, “Manitoba Developmental Centre master primary clinical files,” accessed September 11, 2016, [http://pam.minisisinc.com/scripts/mwimain.dll/144/PAM\\_DESCRIPTION/DESCRIPTION\\_DET\\_REP/SISN 3868?sessionsearch](http://pam.minisisinc.com/scripts/mwimain.dll/144/PAM_DESCRIPTION/DESCRIPTION_DET_REP/SISN%203868?sessionsearch).

<sup>15</sup> The Archives of Ontario provide the historical names for the Huronia Regional Centre in their online search engine. See “Huronia Regional Centre,” accessed June 10, 2016. As the historians noted in Duff and Johnson’s study, the information provided in finding aids about the creator/creating agency are important roadmaps for research. Duff and Johnson, 489-490.

<sup>16</sup> Shelley Rattai and Catherine Rodgers, “On citizenship and soda pop: why the MDC should be closed,” *Portage Daily Graphic*, <http://www.portagedailygraphic.com/ArticleDisplay.aspx?e=2584107&archive=true>, accessed March 18, 2012. After many more months of research, I discover several name changes for the institution: before it was known as the Manitoba Developmental Centre. Previous names include the Home for the Aged and Infirm, the Manitoba School for Mental Defectives and the Manitoba School for Retardates.

Entering “Home for Incurables” in the AM Keystone database returns “137 listings” and “2 Descriptions of Archival Records.” The descriptions are “Department of Public Works photographs” and “Patient registers related to the inspection, operation, and maintenance of mental institutions administered by the Department of Public Works.” The link to the Department of Public Works photographs says the series holds 201 photographs and 420 negatives for a variety of public buildings.<sup>17</sup> The 137 file and item listings for the “Home for the Incurables” date from 1894 to 1958 and appear to include results of textual records, graphic materials (photographs), and architectural and technical drawings.<sup>18</sup> Some item listings though lead to a needle-in-a-haystack situation in which, for example, the item described as “Home for Incurables – January – May” has no other description beyond the date (1891), that it is textual, and that it is linked to the 346 cu. ft. of Minister of Transportation and Government Services office files. The information for the patient registers provided in Keystone says that there are seven volumes for all of the “mental institutions” that had been administered by the Department of Public Works and that the registers “provide the name of inmate, place of residence, date of birth, date of admission, date of discharge, cause of discharge, date of death, and various remarks. Remarks may indicate destination of inmate following discharge, and the identity of

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<sup>17</sup> My earlier notes for this search indicate that only one “Description of Public Works photographs” was returned: the Department of Public Works photographs. Further my notes say that this collection had 188 photographs, not 201. It is possible that my notes are wrong or that the AM’s listings have been updated. It would be helpful to researchers returning to previous searches if notes were included in descriptive pages as they were updated by AM staff.

<sup>18</sup> Since my original search, a few of the photographs have been digitized and can be viewed online through the Keystone database. Most records are dated between 1894 and 1927. It is only the patient registers that have dates that go beyond up to 1958.

sponsor or guardian of the released inmate.”<sup>19</sup> To view the registers, researchers must apply through FIPPA.

Entering “Manitoba School for Defectives” in Keystone produces eight listings – however in this case to find these records the user must select “All these keywords” to obtain the results. If the user selects “Exact Phrase” no items will be returned for the phrase as the name of the school was actually “Manitoba School for Mental Defectives.” However, entering “Manitoba School for Mental Defectives” and selecting “Exact Phrase” returns seven results: a sessional paper that names the institution as “Manitoba School For Mentally Defectives” is not returned. The sessional paper is included in the results only when the “All these keywords” option is selected.<sup>20</sup> Most of the items are textual and are again part of the records of a larger ministry; this time the “Deputy Minister of Transportation and Government Services office files” with a physical description of 370 cu. ft. of textual records and 114 reels of microfilm.<sup>21</sup> The other item that does not belong to the Transportation fonds from the series called “Plans and shop drawings” and is described as specifications for a “horse and dry cow barn.”<sup>22</sup>

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<sup>19</sup> Archives of Manitoba, “Patient registers related to the inspection, operation, and maintenance [sic] of mental institutions administered by the Department of Public Works,” accessed September 10, 2016, [http://pam.minisisinc.com/scripts/mwimain.dll/144/PAM\\_DESCRIPTION/DESCRIPTION\\_DET\\_REP/SISN5497?sessionsearch](http://pam.minisisinc.com/scripts/mwimain.dll/144/PAM_DESCRIPTION/DESCRIPTION_DET_REP/SISN5497?sessionsearch).

<sup>20</sup> AM, “50-26 Sessional Paper #71 re: Return to an Order #34 Re: Average Number of Patients at Brandon & Selkirk Mental Hospitals & Manitoba School For Mentally Defectives,” accessed September 10, 2016, [http://pam.minisisinc.com/scripts/mwimain.dll/144/LISTINGS\\_IMAGES/LISTINGS\\_DET\\_IMAGES/SISN464138?sessionsearch](http://pam.minisisinc.com/scripts/mwimain.dll/144/LISTINGS_IMAGES/LISTINGS_DET_IMAGES/SISN464138?sessionsearch).

<sup>21</sup> A much later discussion in July 2016 with a librarian at the Legislature Library explained that the Department of Public Works (later called Transportation and Infrastructure) was the first government department charged with the running of the institution.

<sup>22</sup> AM, “5123 Manitoba School for Mental Defectives - SPECIFICATIONS: Horse and Dry Cow Barn - Portage la Prairie,” accessed September 10, 2016, [http://pam.minisisinc.com/scripts/mwimain.dll/144/LISTINGS\\_IMAGES/LISTINGS\\_DET\\_IMAGES/SISN768947?sessionsearch](http://pam.minisisinc.com/scripts/mwimain.dll/144/LISTINGS_IMAGES/LISTINGS_DET_IMAGES/SISN768947?sessionsearch).



Entering “Defectives” as the search phrase produces the most results as thirty-four items are returned and includes records that name the institution as “Home for Mental Defectives” or “School for Mental, Defectives.” Most of these additional items are architectural drawings from 1937 and three others are government slides from 1968. As I began to become familiar with the peculiarities of Keystone searches, I used a variety of search terms to try to unearth all the records relating to the institutions. I searched for each name of the institution as well as keywords and phrases such as “retardates,” “incurables,” “aged and infirm.” I also used the phrase “Welcome Home” to find records related to the deinstitutionalization program of that name in the mid-1980s that saw 200 people moved from the Manitoba Developmental Centre. In all I found over 300 items for the long history of the MDC – a far greater amount than the thirty items currently listed under a search for “Manitoba Developmental Centre.”

I eventually learned that government records that are not included in Keystone have printed file lists that are stored in binders in the Research Room of the Archives of Manitoba. To find the applicable file lists, researchers must first consult the binder that contains the index. Looking up the name “Manitoba Developmental Centre” in the index gives a short series of schedule numbers: A 0033, CSC 0054, and H 0004. The researcher must then consult the appropriate binder that contains the schedule number. Schedule A 0033 is described as the Manitoba Developmental Centre “Office Files;” Schedule CSC 0054 contains the master clinical files from the MDC; H 004 is described as the “Office Files” of the Mental Health Services of the Assistant Deputy Minister.

As described in the binder, the Manitoba Developmental Centre “Office Files” are for the dates of 1897-1978 and have an extent of four cubic feet.<sup>23</sup> The page also notes that access is subject to FIPPA and that applications should be sent to the “FIPPA Access and Privacy Coordinator, Manitoba Developmental Centre.” On November 4, 2014, I emailed the Executive Assistant to the CEO of the MDC (who acts as the Privacy Officer) to say that I was planning to make a FIPPA request for the MDC Office Files and to enquire if they would consider a research agreement instead as the extent of four boxes was quite large for a standard FIPPA request. On November 7<sup>th</sup>, I received a reply saying that my request was “unusual” and that my request had been discussed with the CEO to make sure that “legislation is followed and the records are protected.”<sup>24</sup> Further, the Privacy Officer emphasized that “all of the records, whether stored at the MDC or in Provincial Archives belong to the MDC.” She requested that I provide the reason for my request (e.g., thesis research) and that I provide the name of my thesis advisor and a letter of support. This email was copied to the CEO of the MDC, the FIPPA Coordinator of Family Services, and the Director of Operations at the MDC. After discussion with my thesis supervisor, I replied to the email on November 10 and asked what kind of information was required in the letter of support. On November 27, I followed up with another email as I had not heard back. That same day—three weeks after my original email—I received a reply that said FIPPA requests should be made through the FIPPA Coordinator at Family Services.

Near the end of December 2014, I submitted a FIPPA request for the Office Files to Family Services. By this time, I had received from the Archives of Manitoba a copy of the

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<sup>23</sup> This description comes from searches done in 2014. The description in the binder has now changed as later described in this thesis.

<sup>24</sup> Laura Gretsinger, email to author, November 7, 2014.

Records Transfer list for the Office Files and so was able to provide location codes for the four boxes. At the end of January 2015, I received a letter from the deputy minister, Joy Cramer. This letter gave further information about some of the contents of the boxes and also said that while reviewing the records, a fifth box of records were discovered and any contents not containing identifying information about residents had been photocopied and enclosed with this response. These photocopied documents included photos of the institution and graduates from the Nursing School as well as textual records from some Christmas festivities held in 1948 and 1949. Cramer also said that the contents of Box 3 contained only one item, which concerned a cemetery plot. This document was currently in the process of being made public and so it could be viewed at the AM when it was processed and ready to be accessed. The contents of Box 4 contained photos of children and other residents of the MDC and were therefore not included as they were considered to be personal information concerning residents. For the records held in Boxes 1 and 2, I was provided with a fee estimate totalling \$870.00 for search and preparation with an additional \$500.00 in photocopying fees.

I wrote to Joy Cramer to request a fee waiver on February 26, 2015.<sup>25</sup> On March 3, I received an email from the Family Services Access and FIPPA Coordinator suggesting an alternative. Since the files contained in the boxes were extensive, and many of the documents were on onion-skin paper, the coordinator said that the manual copying of the records would be

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<sup>25</sup> In my five-page letter, I argued that the records were in the public interest and that the large fee acted as a barrier to access. Since the records were in a decades-long backlog in the Archives and Manitoba, and that even the poor descriptions that existed were difficult to find, I argued that the identification of the records in my thesis would assist the public in finding the documents. I also pointed out that Family Services had previously allowed a “student conducting research on the eugenics movement” access to some records for reasons of public interest. This latter information was in the 1998 FIPPA annual report. Manitoba, *Freedom of Information and Protection of Privacy Act Annual Report 1998* (Winnipeg: Manitoba Culture, Heritage and Citizenship, n.d.), 6-7.

very time-consuming and “the Department does not have infinite resources.”<sup>26</sup> Therefore, she suggested that Family Services could instead provide me with an itemized list of the records contained in the boxes. I would then have the option to submit a FIPPA application to see any specific records of interest. This was satisfactory to me and in subsequent emails we agreed on the categories of information that would be reported: date, title of item, type (letter, report, etc.), creator/author, details that would influence photocopying such as type of paper or binding, the number of pages, and if the record appeared to contain information that could identify residents.

On April 15, 2015, I received a six-page list providing the agreed upon details for the contents of the two boxes. This list must also have been provided to the Archives of Manitoba as the binder for A 0033 now includes it. This list describes items that are not included on the original file list and in some instances the dates of the records differ on the two lists. It also describes some of the contents of folders that were previously only described at the folder level. The inclusion of the number of pages per item, or item group, is very important. Although the archival profession’s *Rules for Archival Description* (RAD) recommend describing the linear extent of the unit, including the number of pages for record units under three centimetres, such item level descriptions of the record set are rarely made.<sup>27</sup> However, this is important information for restricted archival items as it gives both the researcher and the data trustee an idea of the costs surrounding the search and preparation of the requested records.

The file lists provided by Family Services highlight another feature of the records series A 0033 that was later confirmed by AM senior archivist Kathleen Epp. These records, although

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<sup>26</sup> Robyn Osmond, email to author, March 3, 2015.

<sup>27</sup> Canadian Council of Archives, “Rules for Archival Description,” accessed June 13, 2016, [http://www.cdncouncilarchives.ca/RAD/RAD\\_Chapter03\\_Aug2001.pdf](http://www.cdncouncilarchives.ca/RAD/RAD_Chapter03_Aug2001.pdf).

titled “Office Files” are not administrative records but rather, as Epp says, “more a random group of records.” These files were sent to the AM in the 1980s under a different schedule that included patient registers. Epp says that the “Office Files” were “separated out soon after when it was realized they didn’t belong under that schedule.”<sup>28</sup> However, while the contents of the “Office Files” boxes were becoming more detailed, it still was not clear where the MDC’s administrative records were. Previous emails to the MDC had not elucidated much information.<sup>29</sup> Epp suggested that since government record scheduling in Manitoba only began in the 1980s, the historical records of MDC may not have survived up to that time. In regard to the noticeable lack of minutes – one of the document types that Barbara Craig said were most often represented in hospital records – Epp pointed out that the MDC may not have had committees so minutes would therefore not exist.<sup>30</sup> At this time, Epp directed me to the *Freedom of Information and Protection of Privacy Act (FIPPA) Access and Privacy Directory* available for consultation in the Research Room.<sup>31</sup> This Directory “is a guide to the organization and records holdings of the Government of Manitoba” and contains information regarding the scheduling and destruction of records sets

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<sup>28</sup> Kathleen Epp, email to author, March 2, 2015. She also said that “Series codes that are ‘A’ codes mean they are a series the Archives created and aren’t a formal schedule.”

<sup>29</sup> After an informal request to the MDC for a list of the records that MDC retains in its own custody, I received the following reply: “Files that are kept at MDC rather than being archived include routine administrative files, active resident files, separation resident files and Program annual reports. Files that are sent to Manitoba Archives include nursing education files that relate to the former School of Nursing, resident health records, patient registers and employee files.” Laura Gretsinger, email to author, February 25, 2015.

<sup>30</sup> Kathleen Epp, personal communication, June 2016. Laura Gretsinger noted that “There is no board. Committee minutes fall under a Records Authority Schedule, are stored here and destroyed after 5 years.” Laura Gretsinger, email to author, July 4, 2016. It was noted in the 1973 Clarkson report that almost all decisions were made by the Medical Superintendent and there was a distinct lack of committees. “All of the major decisions in the School are made by the Medical Superintendent. We were told that there were no department head meetings, no medical staff conferences, no academic conferences (aside from the training program operated by the hospital) and even no admission conferences. We were told that the School is run in a very authoritarian manner with respect to decisions.” Clarkson, 30.

<sup>31</sup> Epp said she had shown this directory to me some years ago, but I have no memory of it. She noted, though, that the directory was no longer updated. It is not clear to me how the general public would access these schedules.

of government departments.<sup>32</sup> After viewing this directory, I requested to see the records schedules for the MDC and received the schedules a few weeks later. While for over a year I was stymied as to how recordkeeping was performed at the MDC, once I had access to the Records Schedules I learned much about the many categories of administrative and other records created by the MDC. It is unfortunate that I only received access to the record schedules so late in my research project: much that had been unclear was answered by these documents. The record schedules even listed all the types of documents that were contained in master clinical files and described how the files were arranged annually. If I had had this information earlier, it would have changed the categories I used on the data collection sheets for the case files and enhanced my understanding of the files before I accessed them.

### **Case files**

My initial contact with the Department of Family Services concerning the case files was in the fall of 2012. I gained access to a subset of the case files in June 2016. The process was long, frustrating and confusing. I will not recount the entire process in this thesis in the interests of saving space. Some of the intervening time in the almost four years was taken up with writing my thesis proposal and having it approved and then gaining REB approval (as described in previous chapters). However, correspondence between myself and the Family Services department (including the MDC) involved several dozen emails, many phone calls, multiple letters and applications. I can estimate that at least 100 hours of my time was spent on this communication. I cannot estimate how much of the government's time my requests took up.

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<sup>32</sup> Government of Manitoba, "Inventory of Personal Information Systems," accessed June 17, 2016, [http://www.gov.mb.ca/chc/fippa/pdfs/privacy\\_inventory\\_instructions.pdf](http://www.gov.mb.ca/chc/fippa/pdfs/privacy_inventory_instructions.pdf).

The file list for the case files (or clinical files) as described in the government binder provides very limited information. The file list says that series (as listed below) are “arranged alphabetically usually by year of file closure” and may include “admission records, medical data (test results and treatment records), psychological and behavioral assessments and progress and treatment notes.”<sup>33</sup> The records are arranged as follows:

<u>Dates</u>	<u>Extent</u>	<u>List</u>
1890-1970	25 cu. ft.	GR 342
1890-1975	6 cu. ft.	GR 1699
1890-1976	6 cu. ft.	GR 2004
1890-1977	5 cu. ft.	GR 2565
1890-1978	5 cu. ft.	GR 3557
1890-1980	9 cu. ft.	GR 3902
1890-1981	4 cu. ft.	GR 4173
1890-1984	12 cu. ft.	GR 8210
1890-1986	12 cu. ft.	GR 9670
1890-1987	10 cu. ft.	GR10412

I chose one series, GR 1699, for two reasons: the extent of six feet of records seemed manageable, and the most recent closing date was 1975, which was about a decade earlier than some of the other series. I reasoned that the more historical the records were, the better would be my chances of viewing them as it would be less likely the files referred to citizens who were still living. Unlike records held at the Archives of Ontario, for example the admission and death registers for the Orillia institution (later called Huronia) that I accessed, Manitoba does not open personal health records after 100 years. So, it is possible that my choice of older records may not have been a factor that influenced my later access.

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<sup>33</sup> AM, Community Services and Corrections, Manitoba Developmental Centre, Master Clinical Files (primary), Record Schedule CSC 0054. The description in Keystone does not include this information.

It was not clear at the time of my request whether the description that the files were “arranged alphabetically” meant that a few letters of the alphabet were represented in each series, or if each series contained all names from A-Z. When I viewed the boxes in the series, I did discover how GR 1699 was arranged in regard to the alphabet but the terms of my research agreement does not allow me to disclose that information. However, after seeing how this one series was arranged I was further confused about how the various series were distinguished from one another. What differentiates the six feet of GR 1699 from GR 2004? In retrospect, it would have been useful to examine two series to try to discover the pattern of arrangement.<sup>34</sup>

At the time of my request for access, I had understood the usual causes of separation from the institution to be death or discharge to another institution or, more rarely, to a community placement. For example, the Family Services Annual Report for 2013-2014 shows that from 1996 to 2013 the rate of separation from the MDC because of death exceeded the rate of discharge for the living.<sup>35</sup> I had assumed that this ratio would be true for previous decades and in my HIPC application I stated that I expected that most of the files were closed because of death. Although my data collection recorded whether the cause of the final separation was mentioned in the files, I did not record the reason for the final separation. I also did not record the length of time the individual stayed in the institution as I wished to avoid recording any information that might possibly be used to identify anyone. Future research in this area could

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<sup>34</sup> I tried to get advice from various people on which subset(s) of records to request, but the only advice I received was from an interim HIPC coordinator who said that “the sheer number of records involved in the Archival collections may be a potential concern.” Marc Silva, email to author, January 19, 2015. He did not discourage me from asking for the records but only advised me that I would need to show how I would manage and protect the large amounts of data. However, I felt that asking for access to less records might increase my chances of gaining access. In any case, as I only received access to the records in June 2016, there may not have been time to look through two series.

<sup>35</sup> Manitoba, Family Services, *Annual Report 2013-14*, (Winnipeg: October 2014), 50. The number of deaths for this time period was 215. The number of discharges (including 14 to St. Amant) was 155.



examine the lengths of stay and the various causes of separation from the institution and in doing so illuminate some of the functions of the institution for the individuals, families and communities.

When the case files were transferred from their storage location to the Archives of Manitoba for my access, the files were placed in temporary boxes. In a two-column table, I recorded the file number written on each file folder and assigned a numerical code to each file number. On my data collection sheet, for each file I recorded the temporary box number and the coded number. Regarding the contents of the files, I could only record information that was listed in my data collection sheet that was approved by the HIPC.<sup>36</sup> This data collection sheet looked at categories of information and apart from including the number of pages the only notations allowed were “Y” or “N” (for “yes” or “no”) and in some cases an initial for the category of creator. For example, Y:MP in the category of “letter” means the file contained correspondence created by a medical professional. See Appendix A for a sample column of a data collection sheet.<sup>37</sup>

The case files in the series range in size from 2 to 266 pages: the average file size is 79 pages. My data collection sheet only lists broad categories of records such as “official forms” and “letters” or general categories of information such as “previous separations,” “comments on

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<sup>36</sup> This collection sheet, as mentioned earlier, was based on the information categories of the publicly open admission and death registers of the Orillia institution that are held by the Archives of Ontario. As recognized by an interim HIPC coordinator, “since Archives usually lacks detailed documentation on the contents of the files, it makes it difficult for researchers to clearly state what data they are planning to access and limits the focus of the project.” Marc Silva, email to author, January 19, 2015. Although it was possible to submit a revised collection sheet for approval, I did not feel I had the time to do so. However, if I had received the Record Schedules that contained the lists of document types for the clinical files before I had completed my research with the clinical files, I would have taken the time to send in a revised data sheet.

<sup>37</sup> The data recorded in the column in Appendix A is not actual.

behaviour,” and categories for records concerning medical treatment, such as “drugs,” “physical therapy or labour,” and “surgical.” The records management document titled “Master File Order of Assembly” that I received after I had concluded my examination of the clinical files provides a much more granular account and lists such documents as: “Admission Record,” “History Forms,” “Background information,” “Psychological Reports,” “School Reports,” “Medical Summary (Annual Physical),” “Medication Record,” “Gyne Record,”<sup>38</sup> “Seclusion Reports and Summaries,” “Old Incident Reports,” “Lab Reports,” “Routine Correspondence,”<sup>39</sup> “Visitors Record,” “Authorizations for Surgical Treatment (Consent Forms),” and “Legal documentation.”

The “Master File Order of Assembly” states that the “third section” of the master file “facilitates the storage of overflow Nurses’ Notes and Physio Notes culled from the Residence files.” The terms “order of assembly” and “culled” appear to indicate that the documents contained in the clinical files existed elsewhere before being re-ordered in the clinical file. A file list from the Provincial Archives of Alberta for the Michener Centre that includes several metres of Daily Unit Communications and Report Books seems to confirm that other more extensive records exist for individuals but were not included in the master case file. The “Master File Order of Assembly” suggests that the documents were gathered and collated in the master clinical file at a certain time, perhaps annually. Likely the documents were also arranged in the file on the occasion of the file’s closure as the “Master File Order of Assembly” states that “details of funeral arrangements should be kept on the top at all times.” The arranging of the

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<sup>38</sup> Presumably “gyne” is short for “gynecological” as in the “Gynecological Chart” referred to in the Records Authority Schedule CSC 0055.

<sup>39</sup> Geertje Boschma’s research looked at families’ correspondence sent to the Attorney General of Alberta requesting institutionalization for their family members, so correspondence may exist in other files outside of the clinical files. Geertje Boschma, “A Family Point of View: Negotiating Asylum Care in Alberta, 1905-1930,” *Canadian Bulletin of Medical History / Bulletin canadien d’histoire de la médecine* 25/2 (2008): 367-389.

contents of the files brings to mind South African archivist Verne Harris who says that government records contain the imprint of the bureaucrats who created, handled, or even destroyed the files:

Did they place all relevant documentation on the file? It could be that related documents were placed on other files. It could be that material was never filed officially, but rather kept informally by officials and subsequently disposed of. Documents, even whole files, may have been destroyed to protect the interests of individuals or the office. So the researcher might be, and in most cases will be, looking at a partial, deliberately constructed representation of process. And the representation, as Foucault has demonstrated in various contexts, will bear indelibly the markings of the bureaucratic systems which spawned it.<sup>40</sup>

### **Case files providing context**

As shown by the documents listed in the “Master File Order of Assembly” and by the existence of categories of information documented through my data collection sheets, information contained in the case files is incredibly rich. A quantitative study of the full extent of the case files could provide at the very least a demographic understanding about who entered and who left the institution as well as information about length of stay. A qualitative or close reading of the files would likely contribute to an understanding of the place of the institution in the lives of families and communities.<sup>41</sup> Further research into the case files would undoubtedly show the

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<sup>40</sup> Verne Harris, “Claiming Less, Delivering More: A Critique of Positivist Formulations on Archives in South Africa,” *Archivaria* 44 (Fall 1997), 135-136. Harris says that “any reading of the text without this accompanying peeling back of layers of intervention and interpretation will be deeply flawed.” Harris, 136.

<sup>41</sup> Other historical work, especially for asylums, that looks at the records from the perspective of family needs, shows that “families most often were not only the initiators of admission requests but also tended to use the asylum as but one option in a range of community and family resources.” Boschma, 368. However, the Clarkson report says, “There is no alternative but the Manitoba School.” Clarkson further writes: “We were told by various staff members that with adequate residential facilities, community care facilities, and training programs in the public schools, from one quarter to one half of the present Manitoba School residents would not need to be there. The major problem, it appeared was alternate residential accommodation.” Clarkson, 28.

role of the institution as more complex than what has been previously commonly understood.<sup>42</sup>

About half of the case files contained evidence of physical therapy or labour performed by residents. As shown in the work of Malacrida and Reaume, and by institutional survivor accounts, labour by institutional residents could be performed as part of the institution's operation or the residents could be hired out to the community.<sup>43</sup> Annual reports, especially those from the period of time when the Manitoba Department of Health had jurisdiction over the institution, provide statistics and information about inmate labour.<sup>44</sup> As Malacrida noted in her research on the Michener Centre, it seems contradictory that residents who were under the guardianship of the province because of their presumed incompetence and incapacity to function in society were often hired out as competent labourers to the surrounding community. Mathew Thomson also notes that it is ironic that people labelled with intellectual disability who were placed in segregated settings in the UK because of their inability to compete in the wage labour market, in fact found themselves in settings "which placed work and training at the very centre of the regime."<sup>45</sup> In regard to labour within institutions, Penney and Statsny say that the outlawing of patient labour in New York State in 1973 was one of the major factors influencing deinstitutionalization in that state: "Without free labor, these huge institutions were simply

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<sup>42</sup> This kind of research into psychiatric institution records has changed the view of "older portrayals of the asylum as a monolithic institution." Boschma cites the work of several Canadian historians who examined "the dynamics of asylum admission based on detailed analyses of patient records" and thus "challenged accepted views on medical and administrative power." Boschma, 368.

<sup>43</sup> Institutional survivors in *The Freedom Tour* relate how they were required to spoon feed other residents or clean bathrooms. Leilani Muir describes being put to work on wards containing people with severe disabilities as a punishment. Muir, 42-44. Judy Lytton talks about being forced to tie other residents to benches while feeding them their meals in the Provincial Training School (later Michener). "Lytton, Judy," Eugenics Archives, accessed September 10, 2016, <http://eugenicsarchive.ca/discover/our-stories/judy>.

<sup>44</sup> For example, see Manitoba Department of Health, *Review '62*. The report says that "these farms are designed to produce food for institutional use, and form an integral part of the occupational therapy and rehabilitation for the mentally ill." The produce was not only used in the institution but surplus livestock was sold. *Review '62*, 24.

<sup>45</sup> Thomson, 484.

unworkable.”<sup>46</sup> According to Clarkson, in the MDC “it was estimated by the staff that 400 residents are working in hospital industries.” Further, he says some of the residents were even employed by the institution’s staff to “help them around the house.” As Clarkson points out, “it would appear, therefore, that with proper residential facilities, many of these people could function adequately outside of the Manitoba School.”<sup>47</sup>

It is not unexpected that almost all of the documents in an individual’s clinical file, with only a few exceptions, were created by people other than the institutionalized individual. In the majority of files in the series, the records were solely created by institutional staff and medical professionals. However, it is important to note that of the 131 files in this series, 47 (or just over one-third of the files) contained letters created by family members. Although occurring infrequently, it is also very significant that some records exist in files that were created by the resident. In this series, nine files (or just over six percent of the series) included documents, generally letters, created by a resident. As such documentation from a confined person in an institution is so rare, these records are very valuable. In describing the archival records Reaume worked with, he says that “without any doubt, the most treasured resources uncovered for this book are writings from the patients themselves.”<sup>48</sup>

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<sup>46</sup> Penney and Stastny, *The Lives They Left Behind*, 24

<sup>47</sup> Clarkson says that the continued problems of staff shortages at the MDC meant that residents were often delegated to perform staff duties, Clarkson, 28.

<sup>48</sup> Indeed, Reaume says that his “research was based on finding stories about patients and not on statistical representation.” His “primary motive for writing this book is to present inmates in mental institutions as individual human beings who deserve to be understood on their own terms as people, rather than labels, free from the clutter of medical terminology and diagnostic categories that has too often served to obscure just who these people were who filled the rows of columns in annual reports.” Reaume, 4-5.

Six files (under five percent) contained photographs. The Records Authority Schedules do not mention photographs but Josée Boulanger noted in her thesis that during her visit to the MDC with members of People First, they came across a room filled with “what seemed like mountains of photo albums.”<sup>49</sup> According to the CEO of the MDC, these albums were later “damaged beyond salvage”<sup>50</sup> by water and so it is possible that some of the photographs contained in the clinical files may be the only surviving photographs relating to the individual’s time at the institution.

Based on the testimony of those who lived in institutions and on results of research done by others into sexuality, reproduction, sterilization and sexual violence, further research into the clinical files under appropriate confidentiality agreements is one of the next logical steps in order to learn more about the history of institutionalization in Manitoba.<sup>51</sup> As Clarkson pointed out in 1973, one of the causes leading to admission to the institution was that the individual “can’t control his or her sexual desire and becomes promiscuous or assaulting.”<sup>52</sup> Scholars have noted the frequency with which people, often women, who transgressed sexual norms would be sent to institutions for people with disabilities or mental health issues.<sup>53</sup> However, once within an

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<sup>49</sup> Boulanger, 127. These are the photograph albums that were “damaged beyond salvage”

<sup>50</sup> Cynthia Winram, email to author, November 6, 2014.

<sup>51</sup> For example, seventeen files in the series I examined contained documentation related to surgical treatment, although my data collection did not record types of surgery.

<sup>52</sup> Clarkson, 28.

<sup>53</sup> For example: Jana Grekul, “Sterilization in Alberta, 1928 to 1972: Gender matters,” *Canadian Sociological Association* (2008): 247-266; Jan Walmsley, “Women and the Mental Deficiency Act of 1913: Citizenship, Sexuality and Regulation,” *British Journal of Learning Disabilities* 28/2 (2000), 65-70; Darryl B. Hill, “Sexual Admissions: An Intersectional Analysis of Certifications and Residency at Willowbrook State School (1950-1985),” *Sexuality and Disability* 34/2 (2016), 103-129; and Dyck, *Facing Eugenics*. Bosch notes that medical professionals’ terminology for some women included such phrases as “moral imbecile.” Bosch, 378.

institution, it was not unusual for residents to undertake relationships that were heterosexual or homosexual.<sup>54</sup>

Regarding sexual and physical abuse in institutions, increasing evidence from survivors and scholars is available.<sup>55</sup> Institutional records for Woodlands School examined by Dulcie McCallum found that both physical and sexual abuse of residents by staff occurred within the institution's walls.<sup>56</sup> Sexual and physical abuse were among the categories included in the Huronia class action Statement of Claim.<sup>57</sup> Although newspaper articles containing accounts of Woodlands School survivors describing abuse they suffered during their time in the institution were one of the reasons the British Columbia government initiated Dulcie McCallum's investigation into the Woodlands files, this same kind of government inquiry is not publicly known to have been undertaken to date in Manitoba.<sup>58</sup> Indeed, in 2010, when the *Winnipeg Free Press* published an article in which a former MDC resident named Aime claimed that he had been physically abused by the MDC staff and sexually assaulted by another resident, the

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<sup>54</sup> This has been described by former residents of institutions in oral history accounts. For example, Jones, 339 and 343. Also Neil Mercer describes being caught "necking in the supervisor's office" (in an institution in Saskatchewan) with a woman who was also institutionalized. Cited in Karin Melberg Schwier, ed., *Speak-easy: People with mental handicaps talk about their lives in institutions and in the community* (Austin, Texas: Pro-ed: 1990): 122-123.

<sup>55</sup> For example: Tracy Odell, "Not your average childhood: Lived experience of children with physical disabilities raised in Bloorview Hospital, Home and School from 1960 to 1989," *Disability & Society* 26/1 (January 2011), 49-63;

<sup>56</sup> McCallum's report says, "Details of the physical abuse found in the records include hitting, kicking, smacking, slapping, striking, restraining, isolating, grabbing by the hair or limbs, dragging, pushing onto table, kicking and shoving, very cold showers and very hot baths resulting in burns to the skin, verbal abuse including swearing, bullying and belittling, inappropriate conduct such as extended isolation, wearing shackles and a belt-leash with documented evidence of the injuries including bruising, scratches, broken limbs, black eyes, and swollen face..." The report says, "The sexual abuse included assault, intercourse and in the result, injuries and in a few cases, a pregnancy." McCallum, *The Need to Know*, 18.

<sup>57</sup> See Statement of Claim, April 21, 2009, accessed August 1, 2016, <http://www.huroniaclassaction.com/documents/StatmentofClaim-APR2109-WEB.pdf>.

<sup>58</sup> Another cause for the report is that a number of complaints about the abuse had been filed with the police. McCallum, *The Need to Know*, 7.

journalist reported that the response of the MDC senior staff and Family Services Minister Gord McIntosh was to say that processes would have been in place to investigate complaints of abuse.<sup>59</sup>

A further subject that warrants future research concerns Indigenous people and institutionalization in Manitoba. Research into the Eugenics Board case files held at the Provincial Archives of Alberta show that a higher number of Indigenous people were presented to the Alberta Eugenics Board and received diagnoses that did not require their own consent for their sterilization.<sup>60</sup> As race is a category that was identified in almost sixty percent of the MDC clinical files examined, further research into this area could be conducted using these files. Apart from the scholarly work previously mentioned in Chapter One that examines the effect of eugenic policies on Indigenous people in Canada and the United States, some recent scholarship has looked directly at the intersection of institutionalization and Indigenous peoples.<sup>61</sup> Investigation into this area in Manitoba would likely complement the areas of study already undertaken in Manitoba concerning segregated health care and residential schools.

Because only about one-twentieth of the MDC clinical files held at the Archives of Manitoba were examined, the view into the institution is as through a keyhole—it is difficult to

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<sup>59</sup> Mary Agnes Welch, “More voices calling for end to MDC,” *Winnipeg Free Press* May 17, 2010, accessed March 26, 2013, <http://www.winnipegfreepress.com/local/more-voices-calling-for-end-to-mdc-93913674.html>.

<sup>60</sup> Grekul, Krahn and Odynak write that in the cases presented to the Eugenics Board “patient consent was required in only 17% of the Aboriginal cases, compared to 49% of Eastern European cases, 44% of Western European cases, and 38% of Anglo-Saxon / Canadian patients.” By “Aboriginal,” the researchers include individuals who were “identified as ‘Indian,’ ‘Metis,’ ‘halfbreed,’ ‘treaty’ and ‘Eskimo’” in the records. Grekul, Krahn and Odynak, 375.

<sup>61</sup> For example: Roman et al., op.cit.; Susan Burch, ““Dislocated Histories”: The Canton Asylum for Insane Indians,” *Women, Gender, and Families of Color* 2/2 (2014), 141-162; Heather Robin Gough, “Colonization and Madness: Involuntary Psychiatric Commitment Law and Policy Frameworks as Applied to American Indians,” (PhD. Diss., Arizona State University, 2013); Kelli Sweet, “Controversial Care: The Canton Indian Insane Asylum (1902-19),” (Master’s thesis, University of Nebraska at Omaha, 2000).



know with any certainty what lies beyond this small glimpse. Further, once I was “finished” with a file, I was not allowed to request the file again. Similarly, once a research agreement was completed, my access to the items covered by the agreement was terminated—I could not request them again. Unfortunately, as “contextual knowledge is constantly being built up during the research process” the conditions of research agreements prevent the researcher from going back over the material as later insights occur.<sup>62</sup> The stringent restrictions of my research agreements also do not permit any recounting of some of the rich and complex information contained within the case files. Future researchers who gain access to the case files need to negotiate research agreements that will allow them to present stories contained in the records, albeit in an anonymized way, so that the history of institutionalization in Manitoba can begin to be better understood. Researchers in Manitoba as well as other provinces have examined case files and other archival records containing personal information and reported anonymized information so it would be difficult to understand why such research on the MDC and Pelican Lake Centre clinical files could not be performed in the future in Manitoba.<sup>63</sup> Arguments against allowing regulated access to records of “vulnerable” people could be countered with the argument that society’s and the government’s treatment of individuals labelled with intellectual disabilities is precisely an area that needs to have oversight and understanding.

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<sup>62</sup> Duff and Johnson, 489 and 492.

<sup>63</sup> For example, Reaume anonymized names of patients and family members by “using their actual first and last initials but changing Francis to Fred, for example.” Although Ontario’s legislation allows the disclosure of personal health records that are over 100 years old, Reaume also chose to anonymize some of the names found in those patient records as well. Reaume, 4. As an example of local research, Tamara Miller notes that the Archives of Manitoba granted her “access to the files of the Margaret Scott Nursing Mission on the condition that patients not be identified.” Tamara Miller, “‘All our friends and patients know us’: The Margaret Scott Nursing Mission,” Esyllt W. Jones and Gerald Friesen, eds., *Prairie Metropolis: New Essays on Winnipeg Social History* (Winnipeg: University of Manitoba Press, 2009), 98 footnote 1.

## **Pelican Lake Training Centre**

To find records about Pelican Lake, I searched in the Archives of Manitoba Keystone database for “Pelican Lake,” “Pelican Lake Centre,” and “Pelican Lake Training Centre.” Almost all the files returned are in the Sanatorium Board of Manitoba fonds. By chance, I noticed file names in the Sanatorium Board fonds file listing that included the acronym “PLTC.” Using “PLTC” in the Keystone database gave me an additional eighty-eight items—these items would not have been found otherwise as I would not have guessed to use this acronym.

Although the Pelican Lake Training Centre was run by the Sanatorium Board, the provincial government had strong interests and involvement in the institution. As previously noted, not all government records are included in the Keystone database. To try to find all the records about the centre, researchers must use the government binders in the Research Room. Pelican Lake Centre, however, is not included as a subject name in the index of government records. This oversight does not mean that government records for the institution do not exist: rather, it means that researchers must flip through the binders page by page to find the records held by the governing departments. For example, pages for Family Services Office Files GR 6763 and GR 6762 show records for both St. Amant and Pelican Lake Centre. The case files for the Pelican Lake Centre are also held by Family Services and Housing.<sup>64</sup> These case files date from 1973 to 1999 and are in two series, the first has an extent of ten feet and the second has an extent of twenty-three feet. Once again, the unprocessed backlog of government records coupled

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<sup>64</sup> The “Series Description” says that “following a request from the Sanatorium Board that the department undertake responsibility for storage of these records after closure of PLC, and to ensure that access will be appropriately maintained for both clinical and legal purposes, as of January 1, 2001, Family Services and Housing assumed ownership of Pelican Lake Centre clinical records including the files of former residents (FS 0367) and other records of clinical and medical care (see FS 368 and FS 369).”

with the too thin description of the Pelican Lake institution in the Sanatorium Boards fonds obscures the existence of these records. As I only discovered the existence of the Pelican Lake Centre case files in August 2016, it was far too late to include requests for these files in my thesis research. The records that exist for the Pelican Lake Training Centre in the Sanatorium Board of Manitoba fonds are from about 1974 to 1986. As the institution was open until 2000, there are about fifteen years of records that are not accounted for. The Family Services Office Files mentioned above are for 1999. It may be possible that some of the missing institutional records are in unprocessed Family Services boxes.

Of the forty-seven files that I examined from the Sanatorium Board fonds, seven included documents that contained resident names. Of these seven files, six contained health information. In this sample then, just less than fifteen percent of the restricted files contained health information about the residents but nonetheless access to the entire group of files required the researcher to obtain REB and HIPC approval. Although the protection of individuals' privacy is important, the blanket restriction on these records stifles both academic research and the public understanding of this institution. The tension between the protection of privacy versus the right of the public to know about business conducted by governments is expressed by Heather MacNeil:

It is generally conceded that the principle of freedom of information, or the public's "right to know," constitutes a legitimate constraint on the individual's right to information privacy. The public interest in an informed citizenry and an accountable government requires that when the individual's right to privacy becomes an

impediment to the realization of the public's right to know, the former must give way to the latter.<sup>65</sup>

MacNeil also brings attention to the role of archivists in negotiating the balance between protecting information and facilitating access to the records in their position as “communicators of society’s documentary memory.”<sup>66</sup> While the Archives of Manitoba is rightly bound to adhere to the province’s privacy legislation, the barriers to much of the Sanatorium Board’s records of the Pelican Lake Training Centre seem unnecessary. The blanket restriction likely indicates a lack of resources that would allow a clear indication of what files contain personal health information. As MacNeil points out,

The records of various public welfare agencies, for example, which contain a great deal of sensitive personal information, reflect a number of important social values; among them, the obligation of the state to improve the social welfare of its citizens and its accountability for the provision of such services.<sup>67</sup>

How will the government of Manitoba be held accountable for its successes and its failures in the area of health and social services when the records are so difficult to find and to access? In some cases, as shown with the Pelican Lake Training Centre where many files do not contain personal or health information, the conflict over protecting privacy is not even at issue yet the access barriers can be chilling to researchers.

## **St.Amant**

As St.Amant has always had connections with various arms of the provincial government, records about St.Amant are scattered throughout the Manitoba government

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<sup>65</sup> Heather MacNeil, *Without Consent: The Ethics of Disclosing Personal Information in Public Archives* (Metuchen, N.J.: Society of American Archivists and Scarecrow Press, Inc., 1992), 4.

<sup>66</sup> *Ibid.*, 5.

<sup>67</sup> *Ibid.*, 114.

records.<sup>68</sup> All other historical records are held by St.Amant or by the Grey Nuns.<sup>69</sup> As St.Amant does not have a dedicated archivist, it is very difficult to find out what records have been kept. Numerous phone calls and emails over the past few years have not resulted in even access to a list of kept records. The very few published accounts of the history of St.Amant, with one exception, do not seem to have made use of any archival materials.<sup>70</sup> The memoir published by Sister Rita Desrosiers includes many photographs of the St.Amant residents but no information is provided as to whether they came from her personal collection or that of the institution.<sup>71</sup>

This chapter shows how the backlog of unprocessed government records at the Archives of Manitoba contributes to the difficulties in locating records of Manitoba's institutions. It also shows how records that do not contain personal or health information are unnecessarily restricted from access. The very poor description that currently exists at the AM for the Pelican Lake Training Centre obscures the relationship between the Sanatorium Board of Manitoba and the provincial government in regard to this institution. Likewise, the relationship between the provincial government and St.Amant is also not identified. The records for all three institutions are scattered throughout the various government departments that had, or continue to have, jurisdiction over them. However, it is to be hoped that once the Family Services records are processed the relationships between these institutions will become clearer. The issues described in this thesis relating to the destruction of institutional records and the backlog of government

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<sup>68</sup> Reports on St.Amant can also be found in some of the annual reports, especially those dating from when the Department of Health had jurisdiction over the MDC.

<sup>69</sup> The archivist for the Sœurs de la Charité de Montréal «Sœurs Grises» says they have “the incomplete archives for the Centre St. Amant [L098] which includes documents from the St. Boniface General Hospital [L031] and the Hospice Taché [L060].” François Nadeau, email to author, August 2, 2016.

<sup>70</sup> The exception is Adams who obtained an unpublished document from the institution on its early history. Adams, 24, footnote 12.

<sup>71</sup> Desrosiers, 45-61.

records will not be solved without the combination of increased resources to the Archives of Manitoba and an increased prioritization of these records. This latter aspect is touched on in the next, and concluding, chapter.

**Conclusion: “Let’s get the message out. Let’s free our people!”**

Just before Scott Klassen and his band performed at the kickoff event for The Freedom Tour, he held up his arm and gave the rallying cry: “Let’s get the message out. Let’s free our people!” The song they performed was called “We got to close the institutions.”<sup>1</sup>

As shown in the previous chapters, the main barriers to understanding the history of institutions that confined people labelled with intellectual disability fall into three major categories: the scant records that exist that have been created by or with the participation of people labelled with intellectual disability; the very limited acquisition of institutional records by archives; and the present state of difficult access to the records that do exist.<sup>2</sup> A fourth category of concern is the ability or willingness of archives to acquire new records created by this community. This chapter briefly explores acquisition concerns within archives. It also provides some examples of participatory research projects on topics related to intellectual disability. This chapter concludes with some recommendations for archives and universities.

While archives are increasingly recognized as the holders of much of societal memory, the question of how archives acquire records, and what records they require, remains, as O’Toole says, “controversial.”<sup>3</sup> He states that the ethics codes of both the Association of Canadian Archivists and the Society of American Archivists are vague as to how acquisition and appraisal decisions should be made. The ACA code says that “archivists appraise, select, and acquire

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<sup>1</sup> Scott Klassen, cited in *The Freedom Tour*.

<sup>2</sup> Verne Harris famously said that “archives offer researchers a sliver of a sliver of a sliver” and that “this sliver of a sliver of a sliver is seldom more than partially described.” Harris, 137 and footnote 21.

<sup>3</sup> James O’Toole, “Archives and Historical Accountability: Toward a Moral Theology of Archives,” *Archivaria* 58 (Fall 2004), 14.

records in accordance with their institutions' mandates and resources.”<sup>4</sup> O'Toole is critical of this stance and describes it as offering a 'big loophole' that could possibly allow the destruction of records that may appear damaging to a records-creator.<sup>5</sup> O'Toole is not satisfied with allowing the records to simply flow from records creators. Rather he believes that archivists need to remain conscious of the “fundamental reasons for doing archives work in the first place” which are not only a belief in “the value of preserving part of society's collective memory” but to also help “bring that memory to bear when and where it is needed.”<sup>6</sup>

Although individual and class action lawsuits against three provincial governments that ran institutions (in the case of Alberta, also sterilized people in institutions) have been successfully filed in the last twenty years, the Archives of Manitoba, at this point in time, does not appear to be prioritizing the processing of the MDC's records so that they are more readily discovered by researchers and the community. However, even the processing of the few boxes of the MDC's “Office Files” would result in the creation of an authority record for the institution. This authority record would provide users with access points into the records by creating an administrative history that includes the former names of the institution, the names of the medical directors and the government departments that had jurisdiction over the institution. It could also highlight the connections between the Pelican Lake Training Centre, St. Amant and the MDC that are now presently obscured. Similarly, processing the Family Services records will bring to light the “Series Description” for the Pelican Lake Centre that already exists but is not publicly available. Hopefully, as the history of institutionalization in Manitoba is uncovered and

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<sup>4</sup> Association of Canadian Archivists, “Code of Ethics,” <http://archivists.ca/content/code-ethics>, accessed March 18, 2012. As of August 3, 2016, this statement is the same.

<sup>5</sup> O'Toole, 15. He gives the example of files relating to sexual abuse within the Catholic Church.

<sup>6</sup> Ibid., 19.



understood, the relationship of St. Amant with the government will be made apparent. Although St. Amant is a non-profit organization currently run by the Catholic Health Network, fifty-five percent of its funding comes from the provincial government and the intersections of the government with this institution should be made clear.

O'Toole argues for archives to contain records that compete with or even contradict the official narrative. For example, church or school or institution holdings should contain not only records of charity, education, or care but also records of when they failed to provide what they were supposed to provide. However, it is difficult to see how archives that are funded by bodies such as provincial governments, or that are part of the government themselves, would practice appraisal strategies that actively seek out records that would harm their funding bodies' reputation or even perhaps lead to legal problems against their employer.<sup>7</sup> Here again, we could look to the collection of residential school records for parallels. In *The Anglican Journal*, an interview with Anglican Church archivist Nancy Hurn reports,

'It really isn't about us. It's about the survivors,' said Hurn, explaining that during the process she had been driven to 'hunt harder and make sure that every document we could find that was relevant could be made available' because 'no one quite knew what it would mean to the survivors.'<sup>8</sup>

This kind of dedication to the records relating to people who lived in total institutions needs to be fostered.

As with Indigenous perspectives and other critical examinations of the Indian Residential

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<sup>7</sup> Maynard, 170-171. He asks, "But what is the nature of archivists' power under a police/archive regime?... Are they archivist-historians with the critical distance from institutions such a designation usually entails, or are they government employees, with the loyalty of a civil servant hired to manage and monitor who is poking around in government records, and why?"

<sup>8</sup> André Forget, "Church submits residential school records to TRC," *The Anglican Journal* January 16, 2015, accessed July 17, 2016, <http://www.anglicanjournal.com/articles/church-submits-residential-school-records-to-trc>.

School system, the addition of a counter-narrative to the “official” institutional narrative would provide balance and a renewed consideration of the issues involved in institutionalization.

However, as seen with some responses to the findings of the Truth and Reconciliation Commission, it is also possible that the addition of a conflicting narrative may cause supporters of the dominant narrative to even more staunchly uphold their views. For example, former academics from the University of Manitoba wrote two articles in *The National Post* disparaging the commission’s work after the publication of its report in June 2015.<sup>9</sup> In fact, in the last few years, backlash against Indigenous people and issues have grown so vitriolic that some news media have chosen to shut down or change policies regarding online commentary.<sup>10</sup>

Within the broad narrative of the history of institutions in Canada, competing viewpoints, blame and emotions are also freely and passionately expressed. For example, some listeners to a

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<sup>9</sup> Rodney E. Clifton and Hymie Rubenstein, “Debunking the half-truths and exaggerations in the Truth and Reconciliation report,” *National Post* June 4, 2015 <http://news.nationalpost.com/full-comment/clifton-rubenstein-debunking-the-half-truths-and-exaggerations-in-the-truth-and-reconciliation-report> and “Truth and Reconciliation report tells a ‘skewed and partial story’ of residential schools,” *National Post* June 22, 2015, <http://news.nationalpost.com/full-comment/rubenstein-clifton-truth-and-reconciliation-report-tells-a-skewed-and-partial-story-of-residential-schools>, both accessed June 24, 2016. The second article was written in reply to a letter and petition initiated by four University of Manitoba scholars. The letter was signed by 79 UM faculty and administrators. The petition was signed by 1,547 supporters. The petition is closed but can be viewed on the Care2 Petitions website, “Support for the Final Report Summary of the Truth and Reconciliation Commission of Canada,” by Adam Muller, Adele Perry, Niigaan Sinclair and Andrew Woolford, accessed June 24, 2016, [http://www.thepetitionsite.com/takeaction/498/604/856/?taf\\_id=13896970&cid=fb\\_na](http://www.thepetitionsite.com/takeaction/498/604/856/?taf_id=13896970&cid=fb_na). The letter is linked to from the University of Manitoba’s Centre for Human Rights Research and can be viewed at [http://chrr.info/images/stories/Clifton\\_and\\_Rubenstein.79\\_signatures.pdf](http://chrr.info/images/stories/Clifton_and_Rubenstein.79_signatures.pdf), accessed June 24, 2016.

<sup>10</sup> The online news of the Canadian Broadcasting Corporation and the Thompson Citizen are two examples of media that shut down online commentary. Office of the GM and Editor in Chief, “Uncivil dialogue: Commenting and stories about indigenous people,” *CBC News* November 30, 2015, accessed June 24, 2016, <http://www.cbc.ca/newsblogs/community/editorsblog/2015/11/uncivil-dialogue-commenting-and-stories-about-indigenous-people.html>. John Barker (editor) “Racist anti-aboriginal slurs and offensive comments prompt Thompson Citizen to permanently close Facebook page,” *Thompson Citizen* January 30, 2013, accessed June 24, 2016, <http://www.thompsoncitizen.net/news/thompson/racist-anti-aboriginal-slurs-and-offensive-comments-prompt-thompson-citizen-to-permanently-close-facebook-page-1.1372321>. About a year later, response to hateful comments about francophones in New Brunswick brought further changes. The most recent CBC policy involves the use of real names and email verification. Jennifer McGuire, “The Next Phase of Commenting at CBC,” accessed June 24, 2016, <http://www.cbc.ca/newsblogs/community/editorsblog/2016/06/the-next-phase-of-commenting-at-cbc.html>.

CBC interview with Leilani Muir responded by placing the blame for Muir's institutionalization and sterilization on her parents and suggested that the practices of the institution were not done with malice but with good intentions to prevent further suffering. One listener wrote "I have always felt this story was not covered fairly. Leilani Muir was truly mistreated. But it was done by her parents, family and relatives who abandoned her."<sup>11</sup> In Manitoba, in response to stories from survivors and calls to close down the MDC, other people stepped forward to defend the institution. Groups such as Friends of MDC say that the maligning of the institution is "unfair."<sup>12</sup> An online petition created by Friends of MDC calling for continued provincial funding to the centre has obtained 849 signatures as of February 2014.<sup>13</sup> Some of the comments added by signatories are heart-rending, for example the comment by Jane Link of Portage la Prairie:

I know for a fact that all community living programs are allowed to pick and choose their clients. My son was asked to leave a community living program and has been in Emergency Care Program where he has been abused and mistreated by staff who have little or no training for clients with mental disabilities [sic]. We need places like MDC to insure that people with mental disabilities are looked after properly.<sup>14</sup>

Do the views of parents such as Jane Link undermine the claims that institutions are not good places? Or, as Verne Harris has proposed and other archivists have seconded, is any archive "a place of contestation"? Eric Ketelaar says that "like memorial museums, archives are spaces where battles about the politics of memory are fought."<sup>15</sup> Similarly, Joan Schwartz and

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<sup>11</sup> CBC, "The Current": Letters (November 17, 2011), accessed March 29, 2012, <http://www.cbc.ca/video/news/audioplayer.html?clipid=2168346255>.

<sup>12</sup> "MDC has a friend in Portage group," *Winnipeg Free Press*, February 22, 2011, available <http://www.winnipegfreepress.com/local/mdc-has-a-friend-in-portage-group-116641578.html>, accessed March 29, 2012.

<sup>13</sup> The last signature is dated February 20, 2014. GoPetition, "Petition to Keep MDC Open," accessed June 24, 2016, <http://www.gopetition.com/petition/43331/signatures.html>.

<sup>14</sup> *Ibid.*, March 29, 2012.

<sup>15</sup> Eric Ketelaar, "A Living Archive, shared by communities of records," *Community Archives: The Shaping of Memory*, Jeannette A. Bastian and Ben Alexander, eds., (London: Facet, 2009), 121.

Terry Cook state that archives are “active sites” where “social power is negotiated, contested.”<sup>16</sup> Harris asserts that if we exclude counter-narratives and sub-narratives “we deny our audience the very space in which democracy thrives.”<sup>17</sup> But how can the counter-narrative of the survivors of institutions, and all the complex and competing sub-narratives of families, staff, medical professionals, foster families, government bureaucrats and town citizens be collected, contextualized, preserved and made accessible? Who will do this work and how will it be funded?

### **Improving archiving**

There are at least four main areas where improvements in the archiving of all disability-related records can be made: awareness within disability communities and organizations for the need to archive materials; research projects that are led by, or include, people with disability (and particularly people with intellectual disability); acquisition and preservation of materials by archives or by disability-related organizations; and accessibility of disability-related records in archives that already do have holdings.

First, funding must be found to support archival efforts of disability rights organizations. Reaume notes that it is unfortunate that “as most disability organizations have scant resources in the first place, archival preservation may be low down on the priority list.”<sup>18</sup> This may especially be true for smaller organizations that have very few paid staff and whose main priorities are advocacy and providing services to members. Finding funding for collecting stories from

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<sup>16</sup> Joan Schwartz, “‘Having New Eyes’: Spaces of Archives, Landscapes of Power,” *Archivaria* 61 (2006), 3.

<sup>17</sup> Harris, 139.

<sup>18</sup> Geoffrey Reaume, “Disability History in Canada: Present Work in the Field and Future Prospects,” *Canadian Journal of Disability Studies* 1 (2012), 59.

members or other historical research can pose problems as grant applications are resource-heavy activities that require both skilled staff and a significant investment of time.<sup>19</sup> However such ventures can successfully be completed as shown by the example of Independent Living Canada which received funding from Human Resources and Social Development Canada's Social Development Partnership Program for the research, writing and publication of a history of the Independent Living Movement in Canada.<sup>20</sup> Many organizations do have a strong sense of their history, and have sought out stories and performed research to create historical narratives that they have often self-published. For example, Community Living Manitoba published a collection of stories from families in 2008 with the purpose of "documenting the innovation and courage of families over the 55 plus years we have been around as an association."<sup>21</sup> People First of Canada has produced many videos featuring members' stories.<sup>22</sup> In 2012, the Manitoba League of Persons with Disabilities (MLPD) published a collection of personal reports outlining the last thirty years of disability advocacy in Manitoba.<sup>23</sup> More recently, the MLPD completed the first phase of an oral history project with the Oral History Centre and this material will be archived with the Canadian Museum of Human Rights Archive.<sup>24</sup>

The success of the MLPD in initiating, completing and archiving their oral history project

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<sup>19</sup> This comment is also made by Elise Chenier, "Hidden from Historians: Preserving Lesbian Oral History in Canada," *Archivaria* 68 (Fall 2009), 258. She also recommends that when researchers apply for grants to do oral history, they should also request funds to assist in the preparation of the research material for archival donation. Chenier, 265.

<sup>20</sup> John Lord, *Impact: Changing the Way We View Disability* (Ottawa: Independent Living Canada, 2010).

<sup>21</sup> Association for Community Living Manitoba, *Community Living: Then and Now* (Winnipeg: Community Living Manitoba, 2008), 5.

<sup>22</sup> See [http://www.peoplefirstofcanada.ca/resources\\_en.php](http://www.peoplefirstofcanada.ca/resources_en.php), accessed March 29, 2012.

<sup>23</sup> Manitoba League of Persons with Disabilities, *The Voice of People with Disabilities: Making a Difference in Manitoba* (Winnipeg: Manitoba League of Persons with Disabilities, 2012).

<sup>24</sup> Manitoba League of Persons with Disabilities, "Oral History Project," accessed August 2, 2016, <http://www.mlped.mb.ca/oralhistory.html>.

is an important example for other disability groups. In other organizations and communities, while some stories and research have been collected in books or in audiovisual recordings, the original source material is not necessarily being archived. In 2012, John Cox of the People First branch in Nova Scotia received a \$60,000 grant to gather stories from some of the early members of People First. However, plans to archive the interviews were not part of the initial project.<sup>25</sup> This failure to plan for archiving of interview material is a widespread concern, not unique to the area of disability history. Elise Chenier, in her *Archivaria* article about preserving lesbian oral history in Canada, notes that only a very few researchers in this field donated their material to an archive or had plans to donate the records.<sup>26</sup> She also notes that many researchers simply are not thinking of archival preservation when they conduct the interviews and therefore fail to obtain permission for long-term preservation and use of the material.<sup>27</sup> Part of this neglect may be due to insufficient training on the part of researchers—Chenier says that of the thirteen researchers she interviewed “remarkably, not one...had any training in the practice of oral history.”<sup>28</sup> She calls for academics to provide training in oral history for both students and local communities by offering courses through their departments or through continuing education, or by volunteering their time in communities.<sup>29</sup> The Oral History Centre in Winnipeg could be an important resource for disability organizations, as shown in their collaboration with the MLPD.

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<sup>25</sup> See <http://www.carold.ca/archives/681>, and [http://www.peoplefirstofcanada.ca/images/Guide\\_Freedom\\_Tour\\_eng.pdf](http://www.peoplefirstofcanada.ca/images/Guide_Freedom_Tour_eng.pdf), accessed March 29, 2012.

<sup>26</sup> Chenier, 248 and 256.

<sup>27</sup> *Ibid.*, 258. She says, “It never occurred to me to include permission to donate the interviews to an archive in my own consent forms, and it appears not to have occurred to others, either.” Boulanger also did not make arrangements to archive interviews and she was required to destroy her interview material after her thesis defense. Boulanger, 225-226.

<sup>28</sup> *Ibid.*, 260.

<sup>29</sup> *Ibid.*, 264.

The second area that could lead to improved archiving of disability records, and particularly those that concern people labelled with intellectual disability, are projects that directly involve people labelled with intellectual disability. I list below examples of five large projects that focussed on or performed research with people labelled with intellectual disability. The first example is the Community University Research Alliance (CURA) project called the Living Archives of Western Canada. This project, based at the University of Alberta, brought together thirty research scholars and sterilization survivors and twelve community partners to develop “accessible resources to bring to light the history of eugenics in Canada. It also creates a communal space to explore the relationships between that history and current policies and practices.”<sup>30</sup> The funded portion of the project was completed in 2015 and its legacy continues as a comprehensive website as well as a documentary titled *Surviving Eugenics*.<sup>31</sup>

A second large project that links scholars and individuals with lived experience is at Temple University in Pennsylvania. In 2012, Temple University launched *Visionary Voices: Leaders / Lesson / Legacy*, a digital archive dedicated to the history of the Intellectual Disability Movement in Pennsylvania.<sup>32</sup> This archive includes a collection of oral and video histories of people involved in the Intellectual Disability Movement and also contains the personal papers of advocate, attorney, and parent Dennis Haggerty.<sup>33</sup> Apart from archiving these collections, Temple University has played an active and creative role in promoting the stories of people labelled with intellectual disabilities. In March 2016, a photographic exhibit was launched at

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<sup>30</sup> Rob Wilson, email to author, March 19, 2012.

<sup>31</sup> Eugenics Archives, “Surviving Eugenics,” accessed August 2, 2016, <http://eugenicsarchive.ca/film/>.

<sup>32</sup> Temple University, *Visionary Voices*, accessed July 31, 2016, <http://disabilities.temple.edu/voices/>.

<sup>33</sup> Ibid., “About the Visionary Voices project,” accessed July 17, 2016, <http://www.temple.edu/instituteondisabilities/voices/about.asp>.

Philadelphia's City Hall. This exhibit featured interviews and portraits of nineteen adults who had lived in a state centre or worked in sheltered workshops. The photographs and interview transcripts have been archived on the university's website.<sup>34</sup> The Institute on Disabilities at Temple University also commissioned a play in April 2016 titled "A Fierce Kind of Love." This play used a "mixed ability cast" and told "the untold story of Pennsylvania's Intellectual Disability Rights Movement."<sup>35</sup>

An example of a powerful use of archival material is the website "Against Their Will: North Carolina's Sterilization Program" as mentioned in Chapter One. This *Winston-Salem Journal* website shows the work of two reporters who, after receiving archival material from graduate student Johanna Schoen, continued to do research into North Carolina's sterilization program. The site includes oral history, archival documents, photographs, and articles from the *Journal*. Although sterilization victims had been filing lawsuits since the 1970s, it was the launch of this website in 2002 that initiated broad public knowledge of the sterilizations and a series of government apologies and initiatives for compensation.<sup>36</sup> It is important to note that although the website was launched well over a decade ago, it is still maintained. As mentioned in Chapter One, a book based on the digital series was published in 2012.

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<sup>34</sup> Institute on Disabilities at Temple University, "Here. Stories from Selinsgrove Centre and KenCrest Services," accessed June 24, 2016, <http://disabilities.temple.edu/voices/afkol/stories-images.html>.

<sup>35</sup> Institute on Disabilities at Temple University, "A Fierce Kind of Love," <http://disabilities.temple.edu/voices/afkol/> and "Behind the Scenes," <http://disabilities.temple.edu/voices/afkol/behindthescenes.html>, both accessed June 24, 2016.

<sup>36</sup> Kim Severson, "Thousands Sterilized, a State Weighs Restitution," *New York Times* December 9, 2011, accessed June 25, 2016, [http://www.nytimes.com/2011/12/10/us/redress-weighed-for-forced-sterilizations-in-north-carolina.html?pagewanted=all&\\_r=0](http://www.nytimes.com/2011/12/10/us/redress-weighed-for-forced-sterilizations-in-north-carolina.html?pagewanted=all&_r=0).



The fourth example is a digital exhibit of archival materials titled the “Image Archive on the American Eugenics Movement.”<sup>37</sup> This exhibit is funded by a grant from the Ethical, Legal, & Social Implications Research Program, National Human Genome Research Institute and primarily uses archival material from the Eugenics Record Office at Cold Spring Harbor with contributions from ten other archives.<sup>38</sup> This office is described as the “center of American eugenics research” during the first four decades of the twentieth-century.<sup>39</sup> The website was advised by a large panel of academics and provides an extensive reference section. The exhibit has won awards and has been featured on television, in print, and in web-based news and magazines.<sup>40</sup> Notably, the development of the exhibit had an “Editorial Advisory Panel” that included “representatives of minority and disabled communities.” The privacy policy of the exhibits says:

This panel discussed for 30 hours how the materials should be presented and what measures should be taken to protect the privacy of recognizable individuals, families, and pedigrees. We believe the privacy policy that emerged from panel deliberation provides a reasonable balance between historical ‘right-to-know’ and personal privacy protection.<sup>41</sup>

The final example comes from the UK’s Open University Social History of Learning Disability (SHLD) Research Group. This group is “committed to researching and disseminating learning disability history in ways which are inclusive of people with learning disabilities, their carers, relatives and advocates.” The SHLD began in 1994 and says that “at the heart of the group’s approach...is a recognition that people with learning disabilities are experts on their own

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<sup>37</sup> “Image Archive on the American Eugenics Movement,” accessed June 25, 2016, <http://www.eugenicsarchive.org/eugenics/>.

<sup>38</sup> Ibid., “Contributing Archives,” accessed June 25, 2016, <http://www.eugenicsarchive.org/eugenics/list2.pl>.

<sup>39</sup> Ibid., “Project Overview,” accessed June 25, 2016, <http://www.eugenicsarchive.org/eugenics/list2.pl>.

<sup>40</sup> Ibid., “Awards & Media Coverage,” accessed June 25, 2016, <http://www.eugenicsarchive.org/eugenics/list2.pl>.

<sup>41</sup> Ibid., “Development and Rationale of Our Privacy Policy,” accessed June 25, 2016, <http://www.eugenicsarchive.org/eugenics/list2.pl>.

lives, and have historical knowledge, viewpoints and skills to contribute.”<sup>42</sup> The research group holds inclusive annual conferences and the website provides rich resources of excerpts from the conferences in a variety of media.<sup>43</sup> About fifteen research projects have been completed to date, along with an extensive range of publications.<sup>44</sup> The work of the SHLD has had an impressive impact on policy, practice, people, and advocacy.<sup>45</sup> As noted in the introduction to one of their associated publications about a long-stay institution,

we want young people with learning disabilities to understand their heritage, we want the general public to know that this is how we treated our brothers and sisters; we want everyone to know that big institutions are not the answer if we want a world where everyone has a right to belong and take part.<sup>46</sup>

The group has also received funding for an inclusive archive called the “Living Archive of Learning Disability History.” They describe this project as “truly participatory, employing people with learning disabilities as researchers and working collaboratively at every stage of the process. Our methods are – we hope – pushing the boundaries of inclusive research in new directions.”<sup>47</sup>

Examples of projects related to the Huronia institution are also valuable to note. At least three conditions within the Huronia settlement agreement itself focussed on preserving the

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<sup>42</sup> The Open University, “Learning Disability History,” accessed June 25, 2016, [http://www.open.ac.uk/hsc/ldsite/research\\_grp.html](http://www.open.ac.uk/hsc/ldsite/research_grp.html).

<sup>43</sup> Open University, Social History of Learning Disability, “Conferences,” accessed June 25, 2016, <http://www.open.ac.uk/health-and-social-care/research/shld/conferences>.

<sup>44</sup> Ibid., “Research Projects,” <http://www.open.ac.uk/health-and-social-care/research/shld/research-projects>, and “Publications,” <http://www.open.ac.uk/health-and-social-care/research/shld/resources-and-publications/publications>, both accessed June 25, 2016.

<sup>45</sup> Ibid., “Impact on people, policy and practice,” accessed June 25, 2016, <http://www.open.ac.uk/health-and-social-care/research/shld/impact-people-policy-and-practice>.

<sup>46</sup> Also important is the recognition that when the long-stay hospital finally closed after 100 years, it “closed without any acknowledgement of the part it played in the lives of thousands of people.” Tim Keilty and Kellie Woodley, *No Going Back: Forgotten Voices from Prudhoe Hospital* (Newcastle upon Tyne: The Centre for Welfare Reform, 2013), 12 and 7 respectively.

<sup>47</sup> Inclusive Archive Project, “About,” accessed August 2, 2016, <http://inclusivearchiveproject.org/about/>.

history of Huronia and the history of the class action. The settlement agreement included: commemorative initiatives such as a plaque at the former Huronia grounds; proper maintenance of the former institution's cemetery; and archiving copies of the more than 65,000 documents produced during the legal case at the Archives of Ontario.<sup>48</sup> The settlement also allowed scholars to remove artifacts from Huronia for research and preservation.<sup>49</sup> Other projects that involved Huronia survivors include a theatre production and a number of art shows.<sup>50</sup>

The third area of archiving disability-related records that could be improved is acquisition. To date, it is not clear which archive, or archivist, in Winnipeg would be willing to provide resources to acquire, preserve, or promote disability records. At the time of my early research, the Head of Collections of the Canadian Museum of Human Rights, Heather Bidzinski, said that

in the future, we would be willing to consider the acquisition of disability records that fit within our mandate. It should be noted, however, that we are operating under the principle of cooperative acquisition. One of our

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<sup>48</sup> Government of Ontario, Ministry of Community and Social Services, "Settlement reached in Huronia Class Action Lawsuit," accessed July 17, 2016, <http://www.mcscs.gov.on.ca/en/mcscs/programs/developmental/Huronia.aspx>.

<sup>49</sup> Settlement Agreement, "Schedule C," *Dolmage v. HMQ*, 2013, Court File No.: 376927CPO, accessed July 18, 2016, [https://kmlaw.ca/wp-content/uploads/2015/07/080659\\_SettlementAgreement\\_17sep13.pdf](https://kmlaw.ca/wp-content/uploads/2015/07/080659_SettlementAgreement_17sep13.pdf).

<sup>50</sup> The theatre production is called the "Recounting Huronia Cabaret" and is part of a larger project based at Wilfrid Laurier University. During this production, artifacts saved and preserved from Huronia by Wilfrid Laurier University were also displayed. Sarah-Joyce Battersby, "Huronia survivors work through their pain in theatre production," *Toronto Star* May 31, 2016, accessed July 17, 2016, <https://www.thestar.com/news/gta/2016/05/31/huronia-survivors-work-through-their-pain-in-theatre-production.html>. The project lead, Kate Rossiter, said the cabaret is important because "It is a group that is so consistently left out of public discourse that you almost never hear these stories." Another event was held in 2014 with the arts organization Tangled Art + Disability. This event featured art and stories about Huronia by some of the Huronia survivors, as well as a video recording of Ontario Premier Kathleen Wynne's apology and survivors' responses to the apology a year later. Tangled Art + Disability, "Surviving Huronia," accessed July 18, 2016, <http://tangledarts.org/surviving-huronia/>. For other art events, see Amy Dempsey, "Mystery woman behind collection of art from Huronia centre for developmentally disabled," *Toronto Star* June 6, 2013, accessed July 18, 2016, [https://www.thestar.com/news/gta/2013/06/06/mystery\\_woman\\_behind\\_collection\\_of\\_art\\_from\\_huronia\\_centre\\_for\\_developmentally\\_disabled.html](https://www.thestar.com/news/gta/2013/06/06/mystery_woman_behind_collection_of_art_from_huronia_centre_for_developmentally_disabled.html) and Creative Spirit Art Centre, "Breaking out of Huronia," accessed July 18, 2016, <http://www.creativespirit.on.ca/?q=content/breaking-out-huronia>.

significant acquisition criteria will be assuring that a potential acquisition has its best fit with our institution, if not, we will actively seek out the best home to ensure we are contributing to the broader archival good of the community.<sup>51</sup>

I asked Scott Goodine, Archivist of Manitoba, about the AM's collecting policies for disability-related records and he forwarded my questions to Joan Sinclair, an AM archivist. She responded by saying

We don't have a specific collecting policy in the area of records relating to disability/ disability rights. In fact, as the provincial archives our collecting mandate is quite broad and non specific; we collect archival records with long-term research value relating to Manitoba. We are happy to consider records from any provincial organization, business or individual. Any potential donation of records is considered before an acquisition committee to ensure that it meets this criteria, and that we are the most appropriate repository for the records. We do not have any active collecting strategies which focus on particular areas of records. Current resources do not allow for a targeted or pro-active acquisition programme.<sup>52</sup>

Even if a large archive was willing to take the records of a disability organization, or the private records of an individual, the organization or individual would need to feel comfortable with donating their records. As noted by UK archivists Andrew Flinn, Mary Stevens, and Elizabeth Shepherd:

Many community archives are keen to explore partnerships with mainstream organisations, seeking to engage with and insert their stories, perspective and expertise into the heritage mainstream and thereby gain greater recognition for their 'community.' However, many [community] archives are also clear that they wish to retain their autonomy and independence in any relationship and participate in partnerships and project work very much on their own terms.<sup>53</sup>

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<sup>51</sup> Heather Bidzinski, email to author, March 13, 2012.

<sup>52</sup> Joan Sinclair, email to author, dated April 3, 2012.

<sup>53</sup> Andrew Flinn, Mary Stevens, and Elizabeth Shepherd, "Whose memories, whose archives? Independent community archives, autonomy and the mainstream," *Archival Science* 9 (2009), 80.

They give the example of the Lesbian Herstory Archives in New York that requires that the archives be “‘housed within the community,’ that ‘archival skills shall be taught, one generation of lesbians to another, breaking the elitism of traditional archives’ and finally that ‘funding shall be sought from within the communities the Archives serves.’”<sup>54</sup> As Flinn, Stevens and Shepherd note, although “not many community archives would perhaps aspire to this level of complete autonomy,” there are many groups that do want various levels of autonomy, or may feel in conflict with a government archive housing their materials.

A fourth area that could be improved is the accessibility of disability-related records in archives that already do have holdings. Accessibility has two aspects: physical and intellectual access.<sup>55</sup> Regarding intellectual access, the Archives of Ontario, for example, has a number of guides available to help their users, including a research guide titled “Patient and Health Practitioner Records” that includes five “Centres for Developmentally and Emotionally Disabled Individuals” in Ontario.”<sup>56</sup> Information in finding aids should be made available in plain language. The United States is much more advanced in accessibility legislation than Canada: not only has the Americans with Disabilities Act (ADA) been in place since 1990 but the U.S. also has the Plain Writing Act of 2010.<sup>57</sup> However, in December 2013, Manitoba enacted legislation that includes the prevention and removal of barriers in “the delivery and receipt of goods,

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<sup>54</sup> Ibid., 82. See also the Statement of Mission and Principles on the Lesbian Herstory Archives that also includes the principle that “The Archives will always have a caretaker living in it so that it will always be someone’s home rather than an institution” and “The Archives will never be sold nor will its contents be divided.” Accessed March 30, 2012, <http://www.lesbianherstoryarchives.org/history.html#mission>.

<sup>55</sup> The examination of aspects of access for people with disabilities is beyond the scope of this thesis.

<sup>56</sup> Archives of Ontario, “Patient and Health Practitioner Records,” accessed March 18, 2012, [http://www.archives.gov.on.ca/english/guides/pdf/rg\\_224\\_patient\\_health\\_practitioner.pdf](http://www.archives.gov.on.ca/english/guides/pdf/rg_224_patient_health_practitioner.pdf).

<sup>57</sup> For information on the Plain Language Act, see <http://www.plainlanguage.gov/plLaw/>.

services and information.”<sup>58</sup> Plain language practices in the archives could only improve access for all patrons, although plain language does not seem to be an area that has been examined by archivists in Canada.<sup>59</sup>

### Looking beyond the archives

As the examination of institutionalization in Canada is an area where so little work has been done, it is important for researchers to share sources with other researchers and especially with the communities affected by institutionalization. A digital exhibit using, for example, open-source software like Omeka, could be launched that contains digital reproductions of archival material (where allowed by FIPPA) and provides links to other sources such as newspapers, reports, academic works and other resources. Chloe S. Burke and Christopher J. Castaneda, in their introduction to *The Public Historian* special issue on eugenics, say that public historians can “shape public understanding of the eugenic past through the creation of accessible and complex narratives” such as those developed through “museum exhibitions, oral history, documentary film production, Web site presentations, and archival collections.”<sup>60</sup>

The time has come—indeed some will argue that it has been here for many years—for archivists, individually and as a profession, to cast their eyes outside the confines of ‘established’ archives and realize the extent to which archival effort has heretofore overlooked much of Canadian society. There are untold organizations and institutions, to say nothing of individuals, whose records will never be preserved under our present archival ‘system.’<sup>61</sup>

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<sup>58</sup> The Accessibility for Manitobans Act, accessed August 3, 2016, <https://web2.gov.mb.ca/bills/40-2/b026e.php>.

<sup>59</sup> For example, the Archives of Ontario in their online search engine presents Record Creators in a dropdown alphabetized list. This option avoids spelling errors and name variations. If the Archives of Manitoba adopted this practice, confusion regarding “Pelican Lake Centre” and “Pelican Lake Training Centre” would be reduced while increasing the likelihood that all records relating to the institution would be found.

<sup>60</sup> Burke and Castaneda, 6.

<sup>61</sup> Keirstead, 1.

To continue with their suggestions, in collaboration with community members, oral or video stories and other media such as personal photographs, letters, artwork etc., could be added to this digital archive.<sup>62</sup> An Open University website project that described the histories of day centres for people with learning disabilities in Croydon encouraged other communities to follow suit. The university asks “Why not start your own history of day centres project? You could do this by collecting photographs and getting together with friends to interview each other about your memories of your day centre.”<sup>63</sup> As the archival sources for institutional history across Canada are so disparate, a centralized finding aid or portal would be very helpful to scholars and community members alike.

However, apart from accessing their own history, academics and activists can also work with community members to improve their current conditions and their future. The most important step would be to ask individuals and advocacy groups such as People First of Canada, Community Living Winnipeg and Community Living Manitoba how they want to use archival and historical material. Historians and researchers with experience navigating FIPPA and PHIA could assist community members in accessing their case files or other meaningful archival documentation. For some individuals, the records held within the Archives of Manitoba or within the private holdings of St. Amant may constitute the only records of their childhood or of entire decades of their lives.

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<sup>62</sup> Boulanger provides many examples of collaborative storytelling, such as digital stories. See especially 124-133.

<sup>63</sup> The Open University, Faculty of Health & Social Care, “The Days Gone By project,” accessed June 25, 2016, <http://www.open.ac.uk/hsc/research/living-with-disability/history-day-centres/around-the-country.php>. Such projects may be more feasible in the UK where the UK Heritage Lottery Fund exists.

For researchers to continue work among the historical records of institutions, it is imperative that research agreements become less punitive as the current conditions of these legal agreements can have a chilling effect on research. There is a need for the Ombudsman to have oversight over research agreements and for universities to request changes to these agreements particularly in the areas where researchers can be accused of security breaches on the basis of suspicion only. Universities need to provide better educational resources to faculty and students alike on how to negotiate access to information. Much clearer process routes need to be available so that researchers can avoid wasting time and effort stumbling in the dark. Universities with humanities faculties that have graduate programs need to be aware that graduate students undertaking projects that require access to information requests cannot squeeze completion of their projects into unrealistic time frames.

Researchers as well need to take the time, or have the resources to be able to take the time, to make access to information requests. This means that researchers need to incorporate the many months of activity and delay that encompasses FOI research into their funding applications. As well, researchers and archivists need to publish or present on the obstacles to access so that advocacy and practices to improve the process can be initiated.<sup>64</sup> Pitfalls in the process need to be publicized so that individual researchers are relieved of the subjective sense of fear and anxiety that too often can accompany this kind of work. And when access is impeded, researchers still need to write and publicize all that they do know. As Patrizia Gentile said

If we are denied access to some documents then it is incumbent on us to continue to write the history of sexuality and queer history even if it is truncated or not always

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<sup>64</sup> Maynard says that the “police/archives” relationship “has received remarkably little attention in the archival literature,” 160.



empirically complete. This may sound methodologically suspect, but it means writing from a place of strength and survival.<sup>65</sup>

Scholars and activists must also call for the collecting, preservation of, and access to existing documentation relating to institutionalization in Manitoba. For archived records, such as those of the MDC in the Archives of Manitoba, even though the records are just “a sliver of a sliver of a sliver” of the complexity of the institution and the lives lived within its walls, it is, as Harris asserts, a precious and “complex fragment which we preserve and feed into social memory. Moreover, the fragment plays a fundamental role in the documentation of citizens’ enduring civic, legal, property, and other rights.”<sup>66</sup> Archivists, scholars, and activists must call for increased funding for archives so that the records can be processed and made accessible.<sup>67</sup> Archivists, and others, must also insist on finding aids and descriptions that are sensible and accessible to both scholars and the general public. Publicly funded archives, such as the Archives of Manitoba, could also improve service by extending hours beyond business hours.<sup>68</sup>

The closure of institutions like Woodlands and Huronia across Canada signify steps within the long-drawn-out ending of the segregation of individuals who have been labelled as not good enough to live among the rest of society. Historians and archivists, as shown in the above examples, can work with self-advocates and people with lived experience to help make inclusion

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<sup>65</sup> Gentile, 158.

<sup>66</sup> Harris, “Claiming Less,” 137-138.

<sup>67</sup> Maynard says, “We all need to press the appropriate agencies for increased funding and support for more archival storage space, staff positions and other material resources with which to arrange and describe backlog, and to open up and expand in such areas as multicultural issues and gender.” Disability, of course, needs to be added to that list. Steven Maynard, “‘The Burning, Wilful Evidence’: Lesbian/Gay History and Archival Research.” *Archivaria* 33 (Winter 1991-92), 200

<sup>68</sup> Joan Sinclair comments that the limited hours of the archives “leaves the average working person at risk of never setting foot inside the building or even being aware of what the Archives of Manitoba is or what it does.” Joan Marguerite Sinclair, “The Interactive Archives: Social Media and Outreach,” (Master’s thesis, University of Manitoba, 2012), 75.

a reality. Archivists, researchers and scholars need to make the effort to collect and preserve records, and write inclusive histories, not only for legal cases of social redress but to help create widespread social change for all.<sup>69</sup>

The goal of inclusion ultimately raises not only a question for our agencies and organizations, but also for ourselves as human beings: namely, the question of what we think of the good life for ourselves as human beings, and whether there is a place for people with ID in that life. I propose that this is the real challenge that people with ID pose for us, i.e. not so much what we can do for them, but whether or not we want to be with them.<sup>70</sup>

Archivists have the ability to increase the understanding of institutionalization and help change society's prejudice against people labelled with intellectual disability. The question then, as asked above, is whether we want to take this action.

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<sup>69</sup> The judge in Leilani Muir's case commended the Alberta government for allowing Muir's case to go forward even when the statute of limitations had passed. She said in her summary: "As a matter of policy, government apologies and initiatives of this sort to redress historical wrongs should be encouraged." "Summary," Muir v. Alberta, 1996.

<sup>70</sup> J.S. Reinders, "The good life for citizens with intellectual disability," *Journal of Intellectual Disability Research* 46/1 (2002), 5.

## Appendix A: Sample data collection sheet for a clinical file

(file values are not actual)

	Box-File	Box-File	Box-File	Box-File	Box-File
File #	Temp Box # - File Code				
Number of pages	55				
Admission date	Y				
Age at admission	N				
Date of birth	Y				
Sex	Y				
Address/Community	Y				
Former location if not home (e.g., transfer from other institution)	N				
Marital status	Y				
Race	Y				
Religion	Y				
Diagnosis	Y				
Cause of final separation	Y				
Previous separations	Y				
Names of parents or guardians	Y				
Other family info	Y				
Names of medical staff	Y				
Creator: Medical professional (MP)	Y				
Creator: other staff (OS)	N				
Creator: resident (R)	N				
Creator: family (F)	Y				
Creator: other (O)	Y				
Type: official form	Y:MP, Y:O				
Type: letter	Y:MP, Y:F				
Type: photo	N				
Type: other	N				
Comments on health	Y				
Info re: payment/costs	N				
Treatment: drugs	Y				
Treatment: physical therapy or labour	Y				
Treatment: surgical	N				
Other illnesses	Y				
Comments on behaviour	Y				

Y:MP = yes: created by medical professional

Y:F = yes: created by family

Y:OS = yes: created by other staff

Y:R = yes: created by resident

Y:O = yes: created by other

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