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Ontario's Institutional Cycle: Considering the relationship between fictional narratives and policy discourses in the construction of mental disability

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Abstract

There is a substantial literature theorizing ways that fictional narrative informs how identity is constructed and experienced in day-to-day life. However, there has been very little research on the ways that constructions of disability in fictional literature have influenced, or been influenced by policy discourse. This study takes some preliminary steps toward an interdisciplinary analysis of literary and policy discourses over the course of Ontario's institutional cycle in order to explore the nature of the relationship between constructions of mental disability in novels and social policy. A snowball sample of novels containing characters with mental disabilities was refined to a smaller sample published within the originally identified phases of this institutional cycle: between 1839 and 2009. Findings from the literary analysis identified an additional phase within the original institutional cycle. Also, the finding that policy rhetoric extolling the advantages of deinstitutionalization are not affirmed in novels published within the reform phase of the cycle (1960-1986) suggests that the social inclusion of people of with mental disabilities is far from assured in a post-institutional era. The research findings documented in this report support a contention that ongoing exploration of relationships between policy and literary constructions of identity may help explain other historical social policy patterns or cycles.

Keywords

fiction; institution; mental disability; novels; policy

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Introduction¹

Several interdisciplinary writers have theorized that reading narrative fiction informs our understanding of social problems (Bruner, 2002; Iyer, 2007; Mar & Oatley, 2008; Margolis & Shapiro, 1987; McDonough, 2000). Both fiction and nonfiction narratives demonstrate how policies designed to address the citizenship rights of people with mental disabilities may be experienced in an individual's life. Narratives are successful to the extent that they realistically represent cultural attitudes, values and storylines with which the reader can identify. Literature, "by its very nature is the opposite of an escape: imagination is a realising-process, making the world real, making us real" (Whalley, 1985, p.199). If reading literature is a means for creating and understanding the world we inhabit, policy making defines its institutions and organizes relations between designated classes and populations.

Martha C. Nussbaum (1995) focuses on the novel as an accessible, current narrative genre that has much to contribute to the process of policy making because "the novel constructs a paradigm of a style of ethical reasoning that is context-specific without being relativistic, in which we get potentially universalizable concrete prescriptions by bringing a general idea of human flourishing to bear on a concrete situation, which we are invited to enter through the imagination" (p. 8). Specifically in relation to the historical construction of disability in Western culture, Patrick McDonough (2000) also looks primarily to novels. He finds that "social

¹ A note about language: Language is not static and is revised along with our cultural and political constructions of identity. This research aspires to accurately incorporate the vocabulary that was employed to define mental disability within the historical parameters under investigation.

concerns can be reproduced in literary works, making literary documents important sources of information regarding the symbolic or ideological function of people with learning disabilities at the time of the composition of the text" (p.49). Lennard Davis (1997) looks historically at how the rise of the novel as a literary genre has greatly influenced our contemporary understandings of disability due to its preoccupation with "ideologically emphasizing the universal quality of the central character whose normativity encourages us to identify with him or her... This normativity in narrative will by definition create the abnormal, the Other, the disabled, the native, the colonized subject and so on" (p.22). Davis' research compellingly illustrates how the novel came to embody growing popular interest in the 'normal' man and his concerns; an interest that was provoked by contemporary scientific and political debate.

The professionalization of care of people with mental disabilities also occurred at the same time as the evolution of the novel. Charles Darwin's theory of evolution and the development of statistics as a scientific tool defining the "normal man" was emerging with a literary genre that depicted the mundane detail of day-to-day living. If literary worlds are models of real life, archetypes found in literature reflect dominant social constructions of reality. Historically, people with mental disabilities have faced formidable barriers when attempting to challenge such dominant constructions of their identity. Where structural obstacles are compounded by impairments that limit or preclude the articulation of a coherent self-narrative creativity is required to fill this knowledge gap. Because literary fiction appeals to readers to the extent that it is a re-creation of real life, the way disability is constructed in novels

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² For example, archetypes of the person with disability as monster, villain, the fool, whore, or martyr (McDonagh, 2000; Mitchell & Snyder, 2006) helped to stoke a politics of eugenics that is evident in Canadian social policy designed to segregate those perceived as depraved or "feeble-minded" (Reaume, 2010; Simmons,1982) from the rest of society.

may help illustrate perceived potential of people with mental disabilities as it is expressed in popular and critically acclaimed literature.

G. Thomas Couser (2007) further asserts a relationship between policy and personal narratives is mutually informing and reinforcing: "the interaction between narrative—cultural or personal—and law is multi-dimensional and multi-directional" (p.82). As novels may explicate policy, so may policy articulate feasible storylines accessible to people with mental disabilities by delineating the rights, responsibilities and opportunities made available to them in legislation. If a nation's network of social policies may be understood as its own cultural narrative (Neysmith, Bezanson & O'Connell, 2005), an analysis of constructions of mental disability in fiction and policy may inform more comprehensive and effective policy and service planning.

Therefore, the purpose of this research is to demonstrate how the construction of mental disability has shifted over time, as reflected in literary fiction and social policy, specifically institutionalization policy in Ontario. The impetus for the study is founded in a belief that the language of human need cannot come from policy discourse alone (Ignatieff, 1984; Nussbaum, 1995), but is communicated to the general public through diverse cultural artifacts and discourses, including novels. The extent to which policy and literary constructions of mental disability reflect or reinforce each other may reveal the extent to which disability policy objectives have been realized in society.

This research focuses on mental disability in relation to policy and storylines that invoke an institutional option or response. This research does not purport to depict how institutional life was actually experienced by people living and working in these facilities at any point across the historical cycle delineated. In fact, not all of the narratives considered in the literary sample even depict life in an institutional facility. It is how the institution is represented in novels and policy

discourse that is the focus of analysis: sometimes as an option of last resort; sometimes as a solution; sometimes as asylum; sometimes as confinement; it is sometimes a threat, and even occasionally liberating for stakeholders identified in specific policy, or characters in a given novel. The institution is sometimes a physical setting, but also a metaphor, a symbol, or a microcosm of larger society with its own class systems and economies. Comparing the extent to which constructions of mental disability and the institutional response is consistent in policy discourses and fictional narratives over the course of Ontario's institutional history may better reveal patterns or insights to guide policy planning in a post-institutional era. If policy is presenting one construction of people with mental disabilities while novels published at that same time depict a very different life story for characters with mental disabilities, their caregivers and other stakeholders, then it may be possible to study the reasons for this disconnect between policy and other constructions of mental disability in order to better inform gaps or contradictions in understanding that exist. Again, this is particularly important to help policy makers, human service professionals, and other caregivers advocate effectively with and for people who have impairments that limit their ability to express a comprehensive self-narrative.

Defining Mental Disability

There is no consensus in policy or literature around a concrete definition of mental disability. In surveying the history of institutionalization practices in Ontario (Radford & Park, 2003; Reaume, 2010; Simmons, 1982, 1990) and other jurisdictions (Foucault, 1965; McDonagh, 2008; Scull, 1989) it quickly becomes apparent that the definition of mental disability has historically been very fluid. Legislation to establish the first asylum in Ontario (Upper Canada) was specifically designed to treat the "curably insane". Long waiting lists and a disappointing

record of "cure" contributed to the subsequent construction of the "Orillia Asylum for Idiots" in 1876, ostensibly to house those mental "defectives" with little or no prospect of cure. Still, Reaume (2010) notes that in that same year, at the existing Provincial Lunatic Asylum (PLA) it was estimated that "seven-eighths of the asylum population were chronic" (p.7). Simmons' historical research on mental disability policy in Ontario further affirms that even after the establishment of the Orillia facility, "mentally retarded people still continued to find their way into the PLA. One reason was that local doctors were ignorant of any distinction between mental retardation and mental illness, lumping both together under the category of lunatic" (1982, p.6). Despite the growing scientific interest in distinguishing between "lunacy" and "idiocy", and segregating people with perceived curable mental illness and chronic mental disability accordingly, the pragmatics of placement meant that assignment to an institution often depended upon where a bed could be found, as much as any presenting diagnosis (Simmons 1990).³

Over time, stakeholders have continued to debate a boundary between illness and disability that is often porous. On one hand, some manifestations of chronic and severe mental illness are quite disabling. At the same time, disability may be viewed across a spectrum where many contend that it is not the presenting impairment that disables, but rather the institutional, cultural and environmental barriers that culminate in discrimination, exclusion and segregation that is the basis of the experience of disability (Dunn, 2006; Michalko, 2002; Sacks, 1990). Even accepting medical explanations of illness or disability is troubled by the reality that many contemporary diagnoses do not easily fit into distinct disability or illness categories.⁴

³ Indeed, Reaume (2010) cites evidence that suggests that patients were bartered between the lunatic asylum in Toronto and the asylum for idiots in Orillia based upon the needs of the institutional economies at each facility.

⁴ For example, scanning articles about autism spectrum disorder (ASD) from different databases, it does not take long to compile a sample that constructs ASD as disease (Ray-Mihm, 2008), a psychiatric disorder (Hudson & Chan, 2002), and as "neurological difference" (Bagatell, 2007). The polysemous nature of words is further

In addition, the testing employed to diagnose mental illness is often not able to accommodate cognitive or communication impairments. Although many mental health professionals suspect a close relationship between mental illness and disability, Oliver Sacks insists that, "our 'evaluations' are ridiculously inadequate" (1998, p.181) to the task of making precise, comprehensive diagnoses. Making a dual diagnosis of mental illness and disability is further compromised where people with communication impairments have trouble describing symptoms (Hudson & Chan, 2002, p.41), and many critical disability theorists have demonstrated the inadequacy of a medical model to define the experience of mental disability (Oliver, 2009; Titchkosky, 2007; Truchan-Tataryn, 2011). Therefore, this research collapses rigid diagnostic boundaries between illness and disability in favour of an inclusive construction that understands mental disability as an enduring dimension of identity that limits or precludes the ability to construct a self-narrative; or where the construction of a personal narrative is not recognized as coherent or reliable by others invested with the authority to make such a determination.

Method

In the present study, an interpretive discourse analysis was undertaken with a conscious effort to reconcile any methodological tensions between humanities and social science disciplines that inform a reading of contributing theory in critical disability, policy, and literary studies. Interpretive discourse analysis lends itself well to interdisciplinary knowledge generation as it is well suited to a text-based study where "text *is the data* and the approach is

complicated by the reality that symptoms ascribed to illness or disability tend to be vague, overlap, and resemble each other.

therefore not about exploring 'the' content or meaning of the text. Rather, it is about explaining how certain things came to be said or done" (Cheek, 2004, p.147, emphasis in original).

Discourse analysis contributes to generative theory, which Goldstein (1990) describes as "pliable, inductive, open-ended, and therefore responsive to new information" (p.39). A generative or inductive approach to knowledge gathering is appropriate when the aim of the research is to find new sources of knowledge, rather than testing an existing sample. Interpretive discourse analysis is also a method to represent a "better" construction of evidence to explain a social movement (Lynch, 2006), such as the rise and eventual rejection of an institutional response to mental disability in Ontario.

Using a reflexive approach that entails reading and interpretation as processes that occur together, throughout the analysis, themes or patterns emerge through reading and re-reading the selected discourses. Themes generated by interpretive analysis of the data identify cultural assumptions about what mental disability is, as well as the experience, aspirations and potential of people with severe mental disabilities. Particular interest was paid to points of transition in the institutional cycle to identify any corresponding shifts in dominant narratives about disability. Rhetorical patterns, debates or contradictions between the stories and policies were noted and their implications considered. These are elaborated upon in the research findings.

Description of the Sample

At the preliminary stage, the parameters for a content analysis of relevant policy discourses and fictional literature were established around the historical timeline of 1839-2009: the dates where Ontario formally established an "Act to Authorize the Erection of an Asylum within This Province, for the Reception of Insane and Lunatic Persons" (Statutes of Upper

Canada, ch. XI), and when the last institutional facility was closed in the province. It was at this point in the research design that the history of institutional policy in Ontario began to be conceptualized as a cycle, coming full circle.

Consistent with the broad criteria for defining mental disability, the policy sample considered for this research embraced a diverse range of discourses. Social policy "is a term replete with emotional content but lacking in agreed-upon meaning" (Lightman, 2003, p.37). Accordingly, when undertaking an interpretive policy analysis, Dvora Yanow argues that, "whereas traditional approaches to policy analysis focus on policies as exclusively instrumental and goal-oriented, interpretive approaches add the expressive dimension of human policymaking action, demonstrating and enacting for a variety of audiences, near and far, what a polity finds meaningful" (2000, p.88). Given the lack of consensus around what constitutes policy discourse, an interpretive policy analysis optimally considers a diverse selection of texts. Accordingly, this sample includes major legislative acts, and also relevant planning and consultation documents, commissioned reports, program evaluations, and critical commentary by researchers, practitioners and media. Discourses were selected in terms of their historical significance and the impression made upon political or public opinion in moving the institutional cycle from one phase to the next.

While the policy analysis was undertaken with texts specific to the governance of people with mental disabilities and the institutions where they resided in Ontario, the literary sample is not confined to narratives by Ontario authors. At the commencement of the institutional cycle Upper Canada's literary voice was only beginning to establish itself. In fact, the novel as genre was still in its infancy (Davis, 1997); and although research by Murray (2002) finds a thriving literary society in nineteenth-century Ontario, she also acknowledges the rich influence of British

and American contexts for Canadian fiction writing at that time. Similarly, Northrop Frye observes that many of the cultural phenomena addressed in Canadian fiction are not unique to Canada. He also acknowledges "American and British cultural sources" (1965, para. 24) that have influenced the English Canadian literary imagination, particularly in the nation's early years. The inclusion of British and American novels as sources that influenced cultural and political constructions of mental disability in Ontario is reasonable, particularly given the paucity of characters with disabilities and their storylines that are depicted in novels generally (Iyer, 2007). For these reasons it is not surprising that Canadian novels that specifically address mental disability and the institution are not widely accessible until later in the Cycle.

Institutional policy was being created as part of this country's larger governance structure, which was heavily influenced by the British legislative traditions that were transferred to the colonies. Even at that time, popular culture was also influenced by American political, medical and cultural institutions. Simmons' (1982) research demonstrates that the administrators of Ontario's first institutions travelled frequently to the United States to learn from their asylum systems, and emulated them at least to some extent. As Upper Canada established its own constructions and responses to mental disability by learning from these legal and administrative systems, so British and American literature were important primary sources of both our cultural and political constructions of mental disability.

The preliminary sample of novels and stories was compiled and reviewed based upon the simple criterion that the narratives include a character with a mental disability. Initial selections were fortified by references and reviews published by disability writers and researchers, as well as recommendations from professional colleagues and personal acquaintances. Eventually, the process of reading and re-reading widely across policy and literary discourses generated the

emergence of dominant themes and distinct phases within this institutional cycle. As the final institutions closed in Ontario in 2009 we are currently at the beginning of a post-dismantlement phase; and it has yet to be determined whether (or to what extent) a similar cyclical pattern will repeat itself, or whether policy and literary discourses will chart a new course.

From the initial survey the selected sample for analysis was eventually distilled down to three novels from each of the identified phases for analysis, together with the corresponding policy documents indicated (Table 1).

Table 1- Policy and Narrative Discourse Sample

| Establishment Phase | | | |
|---------------------|---|--------------------------------------|--|
| Year | Policy Texts and Events | Narrative Fiction | |
| 1839 | An Act to Authorise the Erection of an | | |
| | Asylum within this Province for the | | |
| | Reception of Insane and Lunatic Persons | | |
| 1841 | First provincial lunatic asylum opens in | Dickens, C. Barnaby Rudge | |
| | Ontario | | |
| 1847 | | Brontë, C. Jane Eyre | |
| 1850 | 999 Queen Street West asylum opens | | |
| 1855 | | Gaskell, E. Half A life-time ago | |
| 1866 | An Act Respecting Municipal | | |
| | Institutions of Upper Canada | | |
| 1876 | Opening of Orillia Lunatic Asylum | | |
| 1897 | Russell, J. The Relation of insanity to the | | |
| | state | | |
| 1900 | An Act Respecting Lunatics | | |
| Reform Phase | | | |
| Year | Policy Texts and Events | Narrative Fiction | |
| 1960 | Berton, P. What's wrong at Orillia. | | |
| | Toronto Star | | |
| 1962 | | Kesey, K. One flew over the cuckoo's | |
| | | nest | |
| 1966 | | Rhys, J. Wide Sargasso Sea | |
| 1971 | Williston, W.B. Present arrangements | | |
| | for the care and supervision of mentally | | |
| | retarded persons in Ontario. | | |
| 1973 | Welch, R. Community Living for the | | |
| | Mentally Retarded: A new policy focus. | | |

| Developmental Services Act | |
|---------------------------------------|---|
| | Krantz, J. Princess Daisy |
| Clark vs. Clark | |
| ement Phase | |
| Policy Texts and Events | Narrative Fiction |
| Government of Ontario. Challenges and | |
| opportunities | |
| | Findley, T. The piano man's daughter |
| | Haddon, M. The Curious incident of the |
| | dog in the night-time |
| Marin, A. (Ombudsman Ontario). | Edwards, K. <i>The Memory keeper's</i> |
| "Between a rock and a hard place" | daughter |
| Parsons, E. Report on consultations | |
| regarding the transformation of | |
| developmental services | |
| Government of Ontario. Opportunities | |
| and action | |
| Dingwall, C., Kemp, K., Fowke, B. | |
| Creating a good life in community: A | |
| guide to person-directed planning | |
| Kirby Commission. Out of the shadows | |
| at last | |
| Services and supports to promote the | 1 |
| social Inclusion of persons with | |
| developmental disabilities Act | |
| | Clark vs. Clark Policy Texts and Events Government of Ontario. Challenges and opportunities Marin, A. (Ombudsman Ontario). "Between a rock and a hard place" Parsons, E. Report on consultations regarding the transformation of developmental services Government of Ontario. Opportunities and action Dingwall, C., Kemp, K., Fowke, B. Creating a good life in community: A guide to person-directed planning Kirby Commission. Out of the shadows at last Services and supports to promote the social Inclusion of persons with |

The final selection of novels for this preliminary analysis was determined by the following criteria: they were representative of dominant constructions of mental disability and narrative themes represented in a larger sample of novels that were published within the same phase; the books were currently in print; and consideration was also given to texts that were commercially popular as well as those that had received critical acclaim. There is an inevitable degree of subjectivity that went into the selections, and other researchers can argue for other stories, but this preliminary sample defines a research framework that may be built upon in subsequent study. While the introduction to this paper makes reference to a small body of literature that explores the relationship between fictional literature and social policy generally, few studies have specifically examined a relationship between construction of disability in policy

and literature (Bruner, 2002; Couser, 2007; McDonough, 20080); and fewer still that examines the construction of disability in literature, within a Canadian landscape (Truchan-Tataryn, 2011). This is therefore, fertile terrain to build upon this original methodological framework.

Analysis

Establishment Phase- 1839-1959

It is convenient to identify the beginning of the institutional cycle in Ontario at the date when the first legislation designed specifically to care for people with mental disabilities was passed in Upper Canada, even though the 1839 Act to erect the Province's first institution was a formal response to a social welfare issue that had already been long debated in other jurisdictions. Historically, people who were perceived as "idiots", "naturals" or "lunatics" were cared for by extended family networks, and the community at large (McDonagh, 2008). However, rapid changes in social and economic organization that occurred with the Industrial Revolution displaced people who were not attached to the waged labour economy and needed daily living care (Davis, 1997; Simmons, 1982). Eventually, political pressure mounted to develop an institutional response to deal with people who could not contribute actively to the new economy and found themselves on the margins of society: often living out of doors or taking up space in prisons, hospitals and poor houses. The institutional response to disability was, therefore, initially established as a policy of last resort for individuals who did not have access to family or charitable supports to sustain them. Although the original mandate of Upper Canada's asylum was to cure and re-integrate its inmates into society, the curative capacity of the facility did not tend to live up to this ideal (Reaume, 2010; Simmons 1982, 1990).

If the institution was originally established in Upper Canada as a solution of last resort. novels reviewed from this phase also do not portray the institution as a positive option. Rather, all manifestations of disability are recognized as a family problem and responsibility to be managed privately, or within the community. In Dickens' (1841) Barnaby Rudge the eponymous hero enjoys strong support and a degree of protection in the small village where he abides with his mother; however, he is at great risk whenever he is out of reach of these personal supports, and his long-suffering mother finds her only comfort in life in caring for her son. Similarly, in Elizabeth Gaskell's (1855) *Half a Life-time Ago* her heroine, Susan Dixon, breaks off her engagement with a man who would incarcerate her "idiot" brother in an asylum. The strong recognition of familial duty that these women feel toward the 'unfortunate' son and brother is an essential dimension of their virtue. Most familiar to contemporary readers, however, is Charlotte Brontë's "mad woman in the attic" (Gilbert & Gubar, 2000). In Jane Eyre (1847), Edward Rochester decides to hide the very existence of his 'mad' wife by keeping her incarcerated in the attic. Institutionalizing her would expose the unfortunate union and prevent him from securing a second wife, as he nearly succeeds in forging a bigamous union with Jane. Even though Rochester's actions breach matrimonial law, as well as society's moral code, it is he who is constructed as worthy of empathy and pity, rather than the captive wife who is only able to assert her own will by burning down her prison. Sympathy for Rochester is fortified by the carefully inserted character revelation that he is not attempting to abandon his wife because she is insane, but because he was tricked into marrying her in the first place.

Reform Phase- 1960-1986

A combination of pressures eventually brought about a shift in the institutional cycle that began to de-emphasize the institution as the focal point of disability policy, and sought its reform. The Ministry of Community and Social Services indicates that the "community living movement [was] originally started by parents in the mid-1950s to integrate their family members more fully in the community" (Government of Ontario, 2006, p.5). However, throughout the establishment phase there were always dissenting voices advocating for greater opportunities for people with mental disabilities, including the end of segregated living. Still, the Province's large institutions kept growing, and growing more crowded, with generally muted public response.

No one single policy event clearly defines the transition to the reform phase of the institutional cycle. However, one of the first significant public challenges to existing institutional policy in Ontario, at least in terms of the status of the critic and the audience he could access, was expressed in Pierre Berton's regular column in the January 6, 1960 edition of the *Toronto Star*, entitled "What's wrong at Orillia: Out of sight—Out of mind." Attending with a friend to return his son following a Christmas holiday, Berton vividly describes a facility seldom seen by members of the general public and concludes by condemning poor policy and a complicit public:

Orillia's real problem is one of public neglect. It is easier to appropriate funds for spectacular public projects such as highways and airports than for living space for tiny tots with clouded minds. Do not blame the present Department of Health for Orillia's condition. Blame yourself.

Remember this: After Hitler fell, and the horrors of the slave camps were exposed, many Germans excused themselves because they said they did not know what went on behind those walls; no one had told them. Well, you have been told about Orillia. It is, of course, no Belsen. In many respects it is an up-to-date institution with a dedicated staff fighting an uphill battle against despairing conditions. But should fire break out in one of those ancient buildings and dozens of small bodies be found next morning in the ashes, do not say that you did not know what it was like behind those plaster walls, or underneath those peeling wooden ceilings.

While it is important not to over-emphasize the significance of this one expression of institutional policy critique, it is a useful marker indicating a growing public awareness and increasing debate around the quality of life of people living within Ontario's institutional system; a debate that was occurring in other jurisdictions in North America at the time (Ministry of Community and Social Services, 2008; Scull, 1989; Simmons 1982, 1990).

As Ontario's "hospital schools" came under closer scrutiny, the Government of Ontario became increasingly interested in looking for policy options that would better serve the needs of residents and alleviate the provincial government's direct responsibility for their care. As a result, in the 1970s a number of reports were commissioned to find a way out of the institutional system. Walter Williston's (1971), Present arrangements for the care and supervision of mentally retarded persons in Ontario was the most comprehensive and influential policy proposal for instigating a political movement toward de-institutionalization. The official government response to Williston (Welch, 1973) affirmed a commitment to begin downsizing the province's institutional capacity; and in the subsequent year, the Developmental Services Act (1974) set the legislative framework for the administration of a new system of community group homes and supported living services (Government of Ontario, 1993). Subsequent policy critique, public pressure, and the precedent setting Clark v. Clark decision (1982), allowing Justin Clark to emancipate himself from the Rideau Regional Centre institution where he had been placed by his parents at the age of two years, further contributed to increasing public awareness about the rights of people residing in the province's institutions and helped advance the final phase of the cycle.

In contrast with the pre-occupation of de-institutionalization as a defining feature of disability policy at this time, popular and critically acclaimed novels from this phase do not

depict a similar move away from the institution. Instead, even where the institution is not depicted as a location of recovery and care, it still tends to be portrayed as a necessary asylum from a society that does not have the will or capacity to support policy objectives of community integration. The idea of the individual needing to live in segregation, or be protected within the institution from a society that is intolerant of difference is expressed in all of the reform-phase novels in the study, but perhaps most famously in Ken Kesey's One Flew Over the Cuckoo's *Nest.* When McMurphy realizes that his fellow residents on a secure psychiatric ward are voluntary inmates he asks Billy Bibbit why he stays, reducing him to tears: "You think I wuhwuh-wuh-want to stay in here? You think I wouldn't like a con-con-vertible and a guh-guh-girl friend? But did you ever have people l-laughing at you? No, because you're b-big and so tough! Well, I'm not big and tough" (1963, p.195, emphasis in original). This astonishes the novel's hero, as McMurphy is only pretending to be "loony" in order to have his prison sentence transferred from a penitentiary because he expects his living conditions would be more comfortable in the mental hospital. Instead, he encounters a manipulative and violent so-called therapeutic culture that ultimately destroys him; and it is only after the death of McMurphy that some of his fellow patients decide that they may be better off on the 'outside'.

Although the facility in Kesey's novel is depicted as a psychiatric hospital, the narrator's distinction between the "Acutes" and "Chronics" who occupy the ward together re-affirms the lack of clear distinction between people with chronic mental 'disability' and acute mental 'illness' and inconsistent diagnostic and administration processes of assignment to distinct treatment systems. In addition, the narrator notes that many of those who come in as "acutes" eventually get "changed over" (p.16) into "chronics". Therefore, just as the definition of mental

disability needs to be broad and inclusive, so does the concept of the institution as it is constructed in literature and policy.

Dismantlement Phase-1987-2009

Of the three phases identified in this iteration of the institutional cycle the dismantlement phase is the simplest to designate. It commences with a formal Ontario government policy commitment to eliminate institutional residency for people with mental disabilities within twenty-five years, as articulated in Ontario's *Challenges and opportunities initiative* (1987), and concludes with the closure of the final institutional facilities for people with developmental disabilities in 2009. Policy directives at that time emphasize direct consultation with families to facilitate transition of residents from Ontario's institutions back to the community. Government rhetoric from this phase also expresses optimistic objectives of normalization and integration realized within families and communities that are perceived as able and willing to facilitate daily care supports once ostensibly provided within the institutions.

In popular literature published within this phase of the cycle mental disability is a source of family tension with the well-being of the character with the disability depicted as being largely dependent upon the cohesion of the family unit and access to community supports.

Typically, the well-being of the character is threatened by the absence, or the inadequacy of the personal or structural supports available. This is evident in the analysis of the three novels from this phase of the cycle, even though they are set in historically different times and locations: turn of the twentieth century Ontario, 1960s middle America, early twenty-first century London UK. It is interesting that the literature selected for analysis in the dismantlement phase can be read as contemporary constructions of perceived representations of disability from across the cycle.

Timothy Findley's *The Piano Man's Daughter* (1995) is, on one level, a contemporary reiteration of the "madwoman in the attic" archetype (Gilbert & Gubar, 2000) that is most commonly identified with Charlotte Brontë's Bertha Rochester in Jane Eyre (establishment phase), and revised in Jean Rhys (1966) Wide Sargasso Sea (reform phase)⁵. Lily Kilworth lives most of her life under threat, both real and imagined, of incarceration because of her disability. When Lily's personal and her family's financial resources are finally exhausted, Findley depicts a more complex institutional system in early twentieth century Toronto than has been typically described in fiction. Lily's son, Charlie, who narrates his mother's story admits that "Lily's first asylum—the one on Queen Street in Toronto—was appalling. The buildings, for all their windows, gave an impression of darkness. Inside, there was always someone screaming" (1995, p.435). However, eventually his mother is able to move to residential facility that is "extremely well run and set in the midst of a terraced garden" (p.437). Unfortunately, eventually the family can no longer afford to support her there. In terms of a policy analysis, Findley is depicting a spectrum of care that is not accessible to everyone in need. It is an enduring social welfare problem.

The beginning of Kim Edwards', *The Memory Keeper's Daughter* is set in the 1960s and the birth of twins: a 'normal' son, and a daughter with the presenting features of Down syndrome. The perception of the institution is essential to the novel's storyline because it is the inability of a nurse to follow the doctor's order to deliver his newborn daughter to a designated institution that sets the novel's plot in motion. Dr. Henry chooses to convince his wife that their baby daughter has died, rather than raise a child who appears to have Down syndrome. Unable to bear the thought of leaving the infant at a facility that is depicted as a place neglected and

⁵ An examination of the reconstruction of the 'madwoman in the attic' across all phases of the institutional cycle is the subject of a forthcoming paper.

indifferent to its residents (2005, pp. 24-29), the nurse instead leaves town with the child and raises her as her own.

Finally, in Mark Haddon's *The Curious Incident About the Dog in the Night-time*, the institution exists in contemporary London, only in terms of an unsubstantiated threat, as when Christopher Boone's mother says, "'Jesus, Christopher, I am seriously considering putting you in a home'" (Haddon, 2004, p.48). It is a threat made in a context where the family is struggling to cope with his behaviours, alluding to the strain that families experience in supporting members with a mental disability in addition to the other roles, responsibilities and aspirations they carry out in life. When Christopher's mother ultimately leaves the marriage, at least in part because she can no longer cope with the toll that parenting her son takes on her, she may be read as an antithesis of the selfless caregivers depicted in the establishment sample.

Findings

An in-depth description of the sample or the detailed textual analysis undertaken in the study is not possible within the parameters of this report; however, Table 2 provides a summary of the major findings across the selected policy and novels for each phase of the cycle, which are expanded upon in the complete study (Author, 2011). The table does suggest a number of interesting locations of congruency and tension, particularly within the reform phase of the cycle where policy movement in Ontario toward deinstitutionalization and the rhetoric of community integration is clearly more optimistic than the fiction storylines that depict society as often hostile to people with mental disability, and where the institution is often depicted as a necessary asylum from a cruel world. This may suggest that novelists were more cynical about society's capacity for inclusion than the governments that advanced a policy of deinstitutionalization. The

findings may also be interpreted to mean that there were political motives for advancing a policy of deinstitutionalization that emphasized the political desire to become disencumbered of the financial as well as the moral responsibility for a large and complex institutional system, and that these motives did not necessarily reflect public attitudes or the capacity to support greater diversity in their communities.

Another significant finding emerged from a closer examination of the original sample of literary and policy data. An additional phase to the original cycle that is distinct from the establishment phase preceding it, and the reform phase that follows was identified around the turn of the twentieth century: **the entrenchment phase**. At this time the dominant rhetoric for institutionalization gradually changed from being focused on cure or rehabilitation to a more explicit policy of social control. In this entrenchment phase the roles of family, community, and institution serve essentially the same function as in the establishment phase, but the rationale for the behaviour becomes entrenched in more explicitly psychiatric terms, or within a eugenicist philosophy for social planning that was gaining popularity in North America and Western Europe at that time (Simmons, 1982)⁶. Preliminary analysis of narrative constructions of mental disability within this phase suggest a sharper distinction between sinister and imbecilic manifestations of mental disability within fictional literature that warrants further analysis of popular novels from this period⁷.

Discussion

⁶ This construction of mental disability is evident in a number of policy reports and legislation developed in Ontario from the turn of the twentieth century. These may include, but are not limited to: An Act Respecting Lunatics (1900), An Act Respecting Special Classes (1911), An act Respecting Houses of Refuge (1912), and a Royal Commission on the care and control of the mentally defective and feeble-minded in Ontario (Hodgins, 1919).

⁷ This literary sample may include, but is not limited to: Joseph Conrad (1907), *The Secret Agent: A simple tale*; William Faulkner (1929), *The Sound and the Fury*; John Steinbeck (1937), *Of Mice and Men*; and Daphne Du Maurier (1938), *Rebecca*.

Over the course of Ontario's institutional cycle, first person narratives about the experience of mental disability have rarely been documented either because of barriers posed by cognitive or communication impairments, or because the desires, experiences and the rights of people with disabilities have not been considered worth consulting. Typically, family members and other caregivers are empowered to speak on behalf of the individual who cannot speak for him or herself. However, it is important to note that these caregiver perspectives are inevitably filtered through personal values and needs of the caregiver, which may not accurately reflect what the care recipient thinks about him or herself and the life desired. There is a great deal of responsibility attached to speaking on behalf of another and no guarantee that even the most intimately acquainted advocate will get another's narrative right (Couser, 2002; Iyer, 2007).

Literary fiction cannot replace these essential first-person perspectives and policy-makers, advocates and researchers should access these to the fullest extent possible. Yet the most well intended advocate may actually compound the marginalization of many people by not acknowledging that not everyone has the ability to speak for themselves. It is especially important where this first-person narrative cannot be accessed that as many other sources and perspectives on the experience of disability need to be considered in policy planning.

As indicated at the outset, the novels considered in this research are not presented to depict what institutional life was really like, but this research does at least attempt to begin to address the knowledge gap between dominant cultural and political constructions of disability and the experience of mental disability by considering a wider spectrum of discourses than is typically consulted. Novels may be understood as narratives expressing shared cultural assumptions and ideals, and they are worthy discourses for social policy analysis because they operate as sites of tension that sometimes challenge dominant assumptions expressed in policy.

The findings from this research suggest that literary narratives can provide a valuable perspective about how disability policy has been perceived to be experienced by people with mental disabilities, their families, and society in general. An analysis of the relationship between policy and literary constructions of mental disability and the place for people with disabilities in society articulated in policy discourse and debate may inform planning processes in a post institutionalera.

To that end, findings that challenge the confidence expressed in reform and dismantlement policy regarding the capacity of families to care for, and communities to include people with diverse abilities are of interest. Even though the institution is uniformly constructed across policy and fictional narratives as undesirable or untenable within the dismantlement phase of the cycle, in many cases the person with the disability is depicted as living an insecure and vulnerable existence in the community. What has been established in social policy research appears to affirm this as people with disabilities are more likely than the general population to be poor; to have inadequate housing; and to be disproportionately represented in other institutional systems, including hospitals/long-term care facilities (Centre for Addiction and Mental Health, 2013; Prince, 2009; Raphael, 2011; Reif, 2014). The Standing Senate Committee on Social Affairs, Science and Technology (2004) has found that the number of people with mental disabilities within the prison population is growing, even as overall prison and institutional populations have been in decline. Others living in congregated (group home) settings may reproduce conditions of isolation and risk of abuse that existed in large-scale institutional settings (Prince, 2009; White, Holland, Marsland & Oakes, 2003). Taken collectively, these findings seem to reflect a similar state of affairs that contributed to constructing an institutional response in the first place.

Limitations and Further Research Directions

Although this particular cycle is specifically designed around policy shifts in Ontario, Canada, the historical trends and the literature that has informed a cultural and political construction of mental disability, and the way communities respond to it, has been similar in jurisdictions across North America and the United Kingdom (Simmons 1982; Scull 1989; McDonagh 2008). This is, in part, due to the influence that English law and social customs had in the colonization of Canada, together with the cultural cross-pollination that has occurred across the shared border between Canada and the United States. Some may argue that an examination of Ontario or Canadian policy needs to be matched with an exclusive sample of Canadian literature. While the sample for this study has been defended, certainly these preliminary findings may be enhanced by building upon this beginning. The methodology presented here also has potential applications across a range of social welfare phenomena and constructions of identity, with the potential of identifying locations of consensus as well as conflict between policy and wider social or cultural understandings of identity and social welfare as depicted in popular literature.

This research is a beginning, and does not presume to draw conclusions that cannot be further refined and even challenged by ongoing analysis of the literature, policy discourse and other archival evidence that contributes to the re-construction of mental disability over time. It is an incomplete artefact that will hopefully be fortified by further literary analysis, ongoing policy research and debate, archival evidence that is revealed as Ontario continues to come to terms with its institutional history, and especially by those narratives of institutional survivors that can be accessed.

Conclusion

The prevalence of abuse within Ontario's institutions was recently acknowledged in an apology given by Premier Kathleen Wynne (9 December 2013) as part of a settlement agreement in a class action lawsuit initiated by former residents of the provinces oldest and largest institutional facility for people with developmental disabilities, the Huronia Regional Centre. She concludes by stating that "[t]oday, we strive to support people with developmental disabilities so they can live as independently as possible and be more fully included in all aspects of their community. As a society we seek to learn from mistakes of the past. And that process continues" (Ontario Ministry of Community and Social Services, 2013). The findings of this research suggests that this process of learning from the past should entail a closer, critical examination of how policy objectives, informed by contemporary social constructions of mental disability are experienced by people most directly affected by mandated services and supports, along with their families, and the wider community. An examination of fiction as well as nonfiction narratives may inform ongoing planning in a post-institutional era. The institutional cycle that has so recently completed its revolution need not repeat itself. Instead, policy planners, human services professionals, advocates and citizens can turn to stories: fiction as well as nonfiction, to inform creative and effective social policy to support a growing and diverse population.

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