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Lauren Cooke

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in the Post-Dismantlement Phase of Ontario's Institutional Cycle

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Name of Candidate: Lauren Cooke

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**APPROVED/APPROUVÉ**

Examiners/Examineurs:

Karen McCauley

(First Reader/Supervisor/Directeur(trice) de these / stage spécialisé)

Duncan Matheson

(Second Reader/Co-supervisor/Co-directeur(trice) de these / stage spécialisé)

Approved for the Faculty of Graduate Studies

Approuvé pour l'École des études supérieures

Dr. David Lesbarrères

M. David Lesbarrères

Dean, Faculty of Graduate Studies

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### **Abstract**

Persons living with a mental disability in Ontario comprise a significant and diverse population that has historically existed in the margins of society as a result of the discrimination that has dominated the province's social and political discourses. Building upon McCauley's (2011) research, a critical discourse analysis methodology was utilized to examine the ways that major policy and literary discourses have influenced the cultural constructions of mental disability in Ontario. The present study focuses on policy and literary texts, specifically novels and memoirs, published since the last institutions in the province were closed in 2009, marking the beginning of the post-dismantlement phase of the Ontario's institutional cycle.

It was anticipated that an examination of the ways that literature and policy construct mental disability during the post-dismantlement phase of Ontario's institutional cycle would help to identify policy planning needs and opportunities for advancing human rights for persons living with mental disabilities. Findings ultimately identify a disconnect between Ontario's public policies that assert a responsibility to uphold the social and economic rights of persons living with disabilities, and experiences of exclusion amongst persons living with mental disabilities as depicted in literary fiction and non-fiction narratives. In order for equality in social and economic participation to be realized a number of recommendations are proposed, including the use of direct consultation with service-users of varying abilities to inform policy planning initiatives, as well as increased availability of institutional services such as long-term care facilities.

### Abstrait

Les Ontariens qui vivent avec une déficience mentale constitue une population considérable et diverse. Historiquement, ce groupe était oppressé en société à cause des discours discriminatoires sociaux et politiques de la province. S'appuyant sur la recherche de McCauley (2011), une méthodologie d'analyse critique de discours a été utilisée pour examiner comment les discours littéraires et politiques ont influencé la construction culturelle des déficiences mentales en Ontario. L'étude présente se concentre sur les textes politiques et littéraires, spécifiquement les mémoires et les romans, qui étaient publiés après la fermeture des derniers établissements de la province en 2009, marquant le début de la phase post-démantèlement durant le cycle d'institution d'Ontario.

C'était anticiper qu'un examen des discours portant sur déficience mentale dans les textes littéraires et politique de la phase post-démantèlement du cycle d'institutions d'Ontario aideraient à identifier les besoins pour la planification des politiques et des opportunités pour avancer les droits de l'homme pour les personnes qui ayant une déficience mentale. Les résultats démontre qu'il y a une divergence entre les politiques de la province qui affirme une responsabilité pour réaliser les droits sociaux et économiques des personnes qui vivent avec une déficience mentale, et les expériences d'exclusion parmi les personnes qui vivent avec une déficience mentale comme ils sont représentés dans les textes littéraires fiction et non-fiction. Afin qu'on veuille réaliser l'égalité sociale et économique pour les personnes qui ayant une déficience mentale, un nombre de recommandations sont proposé, incluant l'emploi de la consultation direct avec les utilisateurs des services pour informer les politiques de la province. Autre recommandations inclue augmenter la disponibilité des services institutionnels, comme les établissements de soins de longue durée.

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Lastly, I would like to acknowledge the ongoing support I have received from family and friends throughout my education, without which I would certainly not be where I am today. To my daughter who is only beginning to explore and learn about the world, you motivate me daily to push myself as a mother, a student, and a professional. It is my hope that you in turn are one day inspired to pursue your own interests, wherever they may lie.

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## Introduction

Persons living with a mental disability in Ontario comprise a significant and diverse population. Currently it is estimated that approximately 62 000 individuals are living with a developmental disability in the province, an estimated 40% of whom are diagnosed with concurrent mental health disorders (Select Committee on Developmental Services, 2014; Office of the Auditor General of Ontario, 2014). Although these seemingly concrete statistics may speak to the pervasiveness of certain forms of mental disability, ultimately they provide little information regarding what constitutes a mental disability and how one ‘lives’ with a mental disability in Ontario. Disability is, after all, a social construct whose meaning is perpetually evolving, dependent upon the social, cultural, and political discourse of the day (Brown, 2003; Dunn, 2006; Mladenov, 2015; Oliver & Barnes, 2012). Reflective of this, there are seemingly countless “acceptable” terms utilized within western culture to refer to an impairment of the mind, all carrying with them a an implied rhetoric that quietly assigns value to the population it is meant to describe (Price, 2013). Although there has been movement towards a more inclusive and right-based language utilized within the field of disability, the pervasive social and political discourse of the day continues to be reflective of neoliberal values wherein mental disability is often framed within the context of personal tragedy, sick-patient, or deviance from the norm (Prince, 2012).

The way that mental disability is conceptualized in society has significant implications for the development and implementation of disability policies that can, in turn, shape the lived experiences of an individual (Baker, 2007). This is of particular significance in the context of mental disability and related social policies as this population has historically been vulnerable to stereotyping and discrimination within dominant western culture (Davis, 2006). The effects of

discrimination are arguably exacerbated by communicative and/or cognitive impairments faced by persons living with mental disabilities, which can undermine an individual's ability to express their lived experiences (Kittay, 2011; McCauley, 2011). Moreover, history demonstrates that even when an individual living with a mental disability is able to engage in self-advocacy their perspective is often ignored and labeled as insignificant (Hutton, Park, Levine, Johnson & Bramesfeld, 2017). Accordingly, despite the successes of the disability movement in Ontario, which has driven the social and political discourse towards one of full participation and inclusion in mainstream society, persons living with a mental disability remain vulnerable to marginalization.

This study seeks to explore the ways in which major policy and literary discourses influence cultural constructions of mental disability in Ontario as well as shape our social and political responses to said constructs. Building upon McCauley's (2011) conceptualization of Ontario's institutional cycle the research begins to define a post-dismantlement phase, through the examination of selected literary and policy discourses published since the last institutions in Ontario were closed in 2009. Literary texts included in the sample comprise both fictional narratives and memoirs pertaining to mental disability, while policy texts encompass legislative acts, policy planning and consultation documents, program evaluations, as well as critical commentaries of disability policies. Utilizing a critical discourse analysis methodology a number of policy planning needs and opportunities are identified for the post-dismantlement phase of Ontario's institutional cycle.

Findings suggest that although policy discourses advocate in support of social and economic inclusion for persons living with mental disabilities, such ideals have not yet translated into meaningful changes for persons living with mental disabilities as identified within the

literary texts. As recognized within both policy and literary texts, there remain a number of systemic barriers to inclusion for persons living with mental disabilities including limited availability of services such as transportation, education, housing, respite, and employment. Moreover, both literary and policy discourses explore how the cultural expectation that families should act as primary caregivers for their loved ones living with mental disabilities can lead financial stress and emotional exhaustion for caregivers, and inevitably perpetuates experiences of social and economic exclusion. Worse still, chronic stress as well as limited availability of community and institutional support can lead to situations of abandonment for persons living with mental disabilities.

In response to these concerns, it is recommended that the landscape of services in Ontario be reformed to include community based as well as institutional services, such as long-term care facilities and respite placements. Additionally, given the competing and at times conflicting needs of persons living with mental disabilities and their caregivers, literary discourse suggests that social workers and persons involved with policy planning initiatives have a responsibility to consult directly with service-users in order to ensure that information obtained is reflective of the wants and needs of persons living with mental disabilities, as opposed to those of their family members.

In summary, it is acknowledged that within recent years Ontario has made movements towards the implementation of legislation that guarantees the social and economic rights of persons living with disabilities. However, the dominant rhetoric regarding mental disability continues to be one which is heavily influenced by neoliberal values, calling into question how effective said social policies will be in addressing disability issues and creating meaningful change in the lives of persons living with mental disabilities. Related to this, it is asserted that

disability advocates and social workers continue to have a role to play in monitoring government and agency adherence to social policies and rights guarantees in order to facilitate the advancement of human rights and social inclusion for persons with mental disabilities in Ontario.

## **Literature Review**

### **Methodology of Literature Review**

The current dissertation is intended to expand upon McCauley's (2011) research, which examines the ways that literary and policy discourses represent and respond to the lived experiences of persons living with mental disabilities. Accordingly, three significant topics areas were explored as related to the research question including mental disability, literature, and social policy.

An initial literature search was conducted covering topic areas of disability, disability studies, critical disability theory, disability policy, mental disability, Ontario disability, and Canada disability. Scholarly articles and books were identified through searches of Laurentian's online catalogue as well as academic databases including Academic OneFile, Scholar's Portal and Google Scholar. Furthermore, the citations and reference lists of relevant literature, including McCauley's (2011) dissertation, were consulted in order to identify additional sources of significant research. In order to acquire relevant information in relation to disability policies in Canada and Ontario, Google searches were completed utilizing the search terms listed above. Key websites, including the Ministry of Community and Social Services website as well as Ontario's Ombudsman website, were searched for pertinent information as well.

A second literature search examining policy and social policy was then completed utilizing search terms including social policy, disability policy, policy discourse, policy develop\*, and Canada social policy. Both scholarly articles and books were accessed utilizing Laurentian's online catalogue as well as academic database such as Scholar's Portal and Google Scholar. Again, the citations and reference lists of relevant literature, including McCauley's (2011) dissertation, were consulted in order to identify additional sources of significant research.

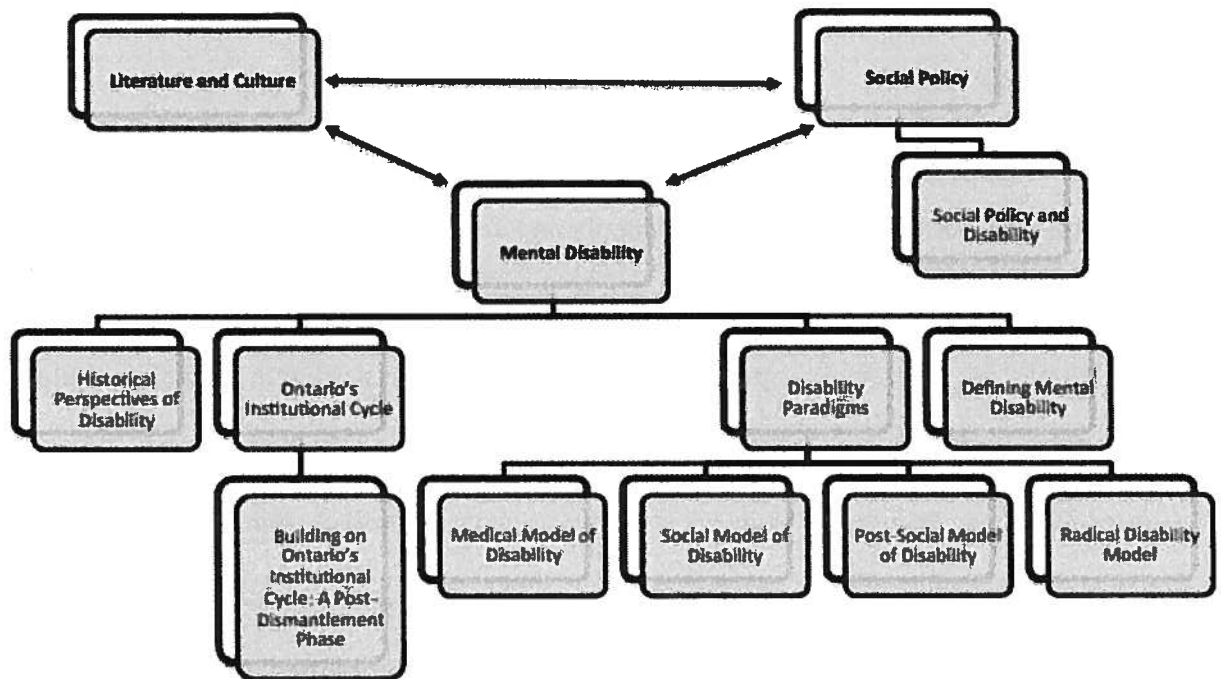
Finally, a third literature search was completed utilizing the same research strategy as previously outlined. However, on this occasion search terms included literature, disab\* literature, disab\* narrative, and disab\* culture.

Upon completion of analysis, a final literature search was completed. Search terms utilized included disability, disability policy, family and disability, disability and institution, as well as Canada disability. In addition to utilizing academic databases Academic OneFile and Scholar's Portal, I also searched for publications from a number of academic journals including *Canadian Public Policy*, *Journal of Applied Research in Intellectual Disabilities*, *Journal of Intellectual Disability Research*, *Disability & Society*, and the *Canadian Journal of Disability Studies*. Once again the citations and reference lists of relevant literature were consulted in order to identify additional sources of significant research. Prominent disability websites were also consulted for applicable information, including the Council of Canadians with Disabilities, the United Nations, and Disability Rights Promotion International.

### **Findings of Literature Review**

A number of key themes were ultimately identified in relation to the current study. Specifically, three key topic areas were explored, as well as a number of subcategories. Significant topic areas include mental disability, social policy, and literature. Please refer to the literature map as outlined in Figure 1 for a more detailed overview of the key themes and sub-themes explored.

Figure 1. Literature Map



### What is Mental Disability?

The way that mental disability is defined will ultimately direct the policy responses that are developed and implemented at an organizational level (Wharf & McKenzie, 2004 as cited in Dunn 2006). Thus, examining both modern and historical conceptualizations of mental disability is important not only to recognize what ideas have helped to shape current disability policy in Ontario, but also to gain insight into how the discourse may need to change in order to realize a more inclusive social and political environment for Ontarians living with mental disabilities.

Disability is a social construct, relative to the prominent political, cultural, and social discourses at a given time in history (Baker, 2007; Brown, 2003; Dunn, 2006). Accordingly, definitions of disability have varied across time and cultures, ranging from perspectives that view disability as a deficit that can be explained by religious or supernatural forces, to the view of disability as a cultural construct imposed on individuals by society (Baker, 2007; Davis, 2006;



Rose, 2006; Shakespeare, 2006). In Canada the term disability has historically been understood within the scope of the medical model, referring to an impairment of the body or mind, and has been often associated with lower intelligence and an inability to function in society (Baker, 2007; Brown, 2003; Kelemen & Vanhala, 2010; Oliver & Barnes, 2012; Prince, 2009).

Although current definitions of disability are generally inclusive of mental disability, often organizational and legislative understandings of mental disability are quite simple, referring broadly to mental, intellectual, and/or developmental impairments as well as mental illness (Human Rights Code, 1990; McCauley, 2011; Ontario Disability Support Program Act, 1997). Once thought of as the difference between being curably or incurably insane, current interpretations of mental illness and mental disability continue to blur distinctions between the two (Reaume, 2010 as cited in McCauley & Matheson, 2015; Simmons 1990 as cited in McCauley & Matheson, 2015). Of note, current understandings of mental disability, whether inclusive of mental illness or not, tend not to be concerned with the cause of the disability, and rather focus on the individual's ability to function in society (McCauley, 2011).

### **Historical Perspectives of Disability**

Perspectives on disability have changed over the course of history dependent on prominent social and cultural discourses at the time. Related to this, the ways that persons living with disabilities have been portrayed has varied significantly. Prominent representations of disability have included everything from the perception of disability as being a sacred gift, or conversely as a symbol of divine punishment (Roeher Institute, 1996). Within ancient Greek societies disability was perceived as a deficit of humanness, wherein people who lacked the skills to interact appropriately with others were referred to as 'idiot' (Roeher Institute, 1996). Much of the stigma and oppressive attitudes developed in ancient Greece have arguably persisted

over time, as the neoliberal social and political values prominent in western culture have allowed for the ongoing exclusion and marginalization persons living with disabilities (Graham et al., 2012; Roeher Institute, 1996). In order to take a closer look as the history of disability in Canada and Ontario specifically, prominent social and political discourses will be examined across Ontario's institutional cycle.

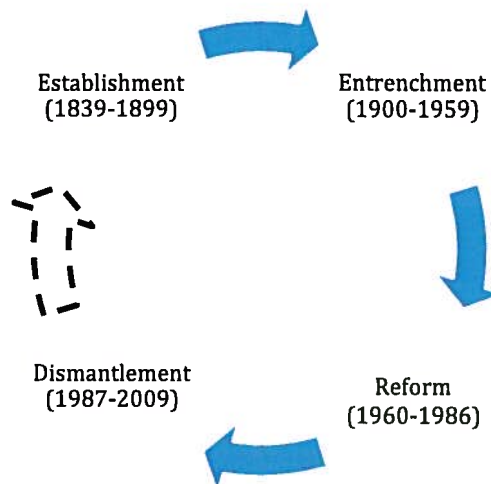
### **Ontario's Institutional Cycle**

Prior to the popularization of the modern medical model, social and political perspectives of mental disability in Canada were largely entrenched in Elizabethan Poor Laws, which classified persons who were unable to work as a result of disability to be 'deserving poor' (Stone 1984 as cited in Hick, 2007). As a result, when families were not able to provide care, persons with disabilities were cared for through charity and community-based programs such as outdoor relief (Dunn, 2012; Hick, 2007; Splane 1965 as cited in Hick, 2007). At the time, persons with mental disabilities were generally considered to be part of the community. However, by the mid-nineteenth century persons with disabilities began to be commonly portrayed as an overly dependent nuisance population to be removed from society (Hick, 2007). Changes in public attitudes lead to shame and rejection of persons with disabilities; and, in fact, in some Canadian cities persons with disabilities were banned from the streets. Persons with disabilities were treated like criminals, and often ended up in jails or poorhouses (Dunn, 2012; Hick, 2007). It was during this time period that Ontario began its journey through the institutional cycle.

As described by McCauley (2011), Ontario has experienced the progression of an institutional cycle beginning in 1839 when legislation was passed authorizing the first Provincial "Lunatic Asylum". As illustrated in Figure 2, Ontario's institutional cycle is conceived to have occurred in four phases, each of which corresponds with the dominant social and political

discourse of the time. Changes from one phase of the cycle to another are marked by the publication of a significant policy document illustrating a shift in the conceptualization of mental disability, however, the boundaries between each phase are in fact quite porous in that changes to dominant social and political discourses occur over time.

**Figure 2. Ontario's Institutional Cycle**



(McCauley, 2017, slide 5)

The development of institutions to house persons with mental disabilities across Ontario defined the establishment phase of the institutional cycle (McCauley, 2011). However, what had begun as a welfare policy, intended to be used as a last resort for persons with mental disabilities, was inevitably transformed by a changing definition of disability towards one which was more closely tied to the medical model and related eugenics movement (McCauley, 2011; Radford & Park, 2003; Williston, 1971). Subsequent to industrialization, the concept of being categorized as 'normal' versus 'deviant' had gained popularity in public discourse, fostering support for a eugenics movement wherein those who were deemed to be undesirable by society were discouraged from procreating (Dunn, 2012; Saxton, 2013). The rhetoric regarding disability at

the time was one where disability was seen as a problem to be extinguished through selective procreation (Saxton, 2013).

The entrenchment phase of Ontario's institutional cycle began with the growing perception that disability was a medical issue to be managed by medical professionals as opposed to families and communities (Dunn, 2006; McCauley, 2011). During this phase of the institutional cycle, public discourse around disability became more closely tied to the medical model as a result of the number of men and women who had returned from World War I with a disability (Hick 2007). The medical model conceded that a disability was a problem to be treated or fixed, which gave charge to a number of professionals including doctors, psychiatrists, and social workers, as being the experts in working with persons with disabilities (Hick, 2007).

Following the entrenchment phase, the reform phase on Ontario's institutional cycle is defined by a shift in the politics of care wherein families as opposed to medical professionals once again became integral in the care and treatment of persons with mental disabilities (Dunn, 2012; McCauley, 2011; Graham et al., 2012). The community living movement was spurred on by the parents of children with disabilities who were advocating for publicly funded education and recreational programs, as well as improved vocational programs and the development of group homes as opposed to institutions (Dunn, 2012). As the movement towards de-institutionalization began, the disability movement became stronger and started to influencing political and social discourse (Dunn, 2012; Kelemen & Vanhala, 2010; McCauley, 2011).

However, it also became evident at this time that implementing policy that freed the province of responsibility for persons with mental disabilities did not mean that families and communities would be adequately prepared to take on the care of their loved ones (Baker, 2007; McCauley, 2011). Although de-institutionalization meant that many individuals were being

moved back into the community, they often did so with very little support (Armitage 2003 as cited in Dunn, 2012). The entrenchment era of the institutional cycle had seemingly left the province embedded in a medicalized understanding of disability, which had fostered stereotyping and discrimination towards persons living with mental disabilities (McCauley, 2011).

Finally, in 1987 with the declaration to close the remaining institutions in Ontario, the dismantlement phase of the institutional cycle began (McCauley, 2011). As a result of the United Nation's declaration of the 'disability decade', Ontario had seen number of new policies and programs developed in the 1980s aimed at addressing disability issues, and in 1991 the federal government announced a national strategy for the integration of persons with disabilities (Dunn, 2012). Yet, despite an apparent transformation of disability policy and services in Ontario, it was evident that there continued to be a number of social problems being faced by persons living with disabilities including poverty and limited access to support services (Graham et al., 2012; Keleman & Vanhala, 2010; McCauley, 2011).

Disability advocates argued that the welfare model of disability had segregated persons living with a disability and lead to their disempowerment (Graham et al., 2012; Kelemen & Vanhala, 2010). Community-based services, which had been implemented during the reform phase of the institutional cycle, began to be criticized for continuing the legacy of segregation and acting as institutions within the community. Specifically, it was noted that special education classroom, specialized transit systems, and sheltered workshops continued to segregate persons with disabilities from mainstream society (Dunn, 2012).

With help from advocacy groups such as the People First movement, precedence was given to concerns regarding the quality of life for persons living with disabilities (Dunn, 2012). The movement towards self-determination and full participation in society lead to the

development of concepts such as integrated education, supported employment, social and economic inclusion, as well as independent living (Brown, 2003; Dunn, 2012). Terms such as these have been the hallmark of the social and political agenda in recent years.

### **Building on Ontario's Institutional Cycle: A Post-Dismantlement Phase**

In Ontario persons living with mental disabilities continue to face barriers to inclusion. In order to improve the overall well-being of persons living with disabilities, opportunities for their full participation in both economic and social arenas of society must be created (Government of Canada, 2014). Accordingly, the federal government of Canada reports that the nation's disability policies are to be governed by principles of full participation, equal opportunity, and economic self-sufficiency (Human Resources and Skills Development Canada, 2013). Unfortunately, when taking a closer look at the lived experiences of people with disabilities in Ontario, these alleged guiding principles are not often apparent.

In Ontario, disability services are not considered an entitlement program, rather funding is discretionary and often restricted by budgetary constraints (Dubé, 2016). As a result of the province's current funding scheme, cost as opposed to need can play a significant role in determining what constitutes a disability and who will be entitled to receive what services (Dunn, 2006). Yet, if we are to take a more critical perspective of government austerity measures it is asserted that the limited availability of disability services and supports in Ontario is not simply a reflection of insufficient resources. Rather, the amount of funding made available for the disability service sector is ultimately representative of the values held by dominant society, in that social programs are only deemed to be unfeasible if popular social and political discourse supports the perspective that said initiatives are unworthy (Titmuss, 1974 as cited in Lightman, 2003; Westhues, 2012a). Regardless of the underlying reasons for fiscal restrictions, the

consequences of limited funding remain the same in that countless individuals and families continue to be denied the services and supports they would require to assist in their well-being and facilitate their full participation in society (Dubé, 2016).

In response to this growing concern, there have been a number of policy changes and recommendations made in Ontario since 2009. In March 2010 Canada ratified the UN Convention on the Rights of Persons with Disabilities, a policy paper that applies human rights principals to address the persistent discrimination as well as the social exclusion of persons with disabilities (Government of Canada 2014; Torjman, 2014). The UN Convention reaffirms that all persons are entitled to human rights and freedoms, and identifies areas where rights need to be adapted, protected, and reinforced so that persons living with disabilities can effectively exercise their rights and be free from discrimination (United Nations, 2006). As a signatory nation to the UN Convention, Canada is endorsing an intention to actualize a standard in policy that will ensure that persons living with disabilities are able to realize their rights and entitlements as outlined within the Convention. Moreover, in ratifying the UN Convention, Canada is committing to a set of ideals that are intended to direct the nation's policy making process.

In an effort to uphold the Articles of the Convention and fulfill the nation's obligation to the UN, changes to both federal and provincial disability policies are required in order to promote inclusion, as well as remove barriers to full participation in society for people living with disabilities (Government of Canada, 2014). The Government of Canada asserts the Office for Disability Issues will work collaboratively with federal and provincial government committees as well as non-profit, volunteer, academic, and private sector partners to develop and implement programs designed to remove barriers to inclusion, develop policies which are evidence-based and responsive to social issues, improve awareness of disabilities issues across

public servants, and engaging stakeholders on disability issues (2014). Notwithstanding the ambitious intentions espoused by the federal government, it is of significance to note that ultimately disability services in Canada fall under the purview of each individual province. Thus attention should be paid to the ways that Ontario's service delivery and policy development is, or is not, influenced by the Canada's commitment the UN Convention.

In 2013, Ontario developed a Select Committee on Developmental Services in order to respond to a number of concerns regarding limited access to disability services and supports, including respite services and day programs, health care and mental health services, education and employment supports, as well as housing initiatives. A number of issues were identified regarding individuals' and families' ability to access these programs including the long wait lists for services, poor transitional planning, and a lack of services in rural and northern communities (Select Committee on Developmental Services, 2014).

According to a report by the Ontario Ombudsman's office, the limited availability of disability services and supports in Ontario has left countless families and individuals in crisis over prolonged periods of time (Dubé, 2016; Select Committee on Developmental Services, 2014). Specifically, Ombudsman Ontario investigated approximately 1500 complaints regarding the lack of services and support for people living with developmental disabilities and dual diagnosis in the province (Dubé, 2016). It was found that many individuals living with disabilities in Ontario are experiencing unsafe, neglectful, and/or abusive living situations as a result of the failing service sector. Additionally, a number of other concerns were highlighted regarding the shortcomings of Ontario's disability services and the Ministry of Community and Social Services' limited capacity to effectively respond to the needs of service-users. Such concerns include the limited availability of services for families in crisis, as well as the



inappropriate use of long-term care facilities, hospitals, and jails as holding cells for persons with disabilities.

In response to these issues, several recommendations were proposed by both Ombudsman Ontario and the Select Committee on Developmental Services in hopes of ensuring better support for Ontarians living with disabilities (Dubé, 2016; Select Committee on Developmental Services, 2014). Notably, recommendations include eliminating wait lists for services, ensuring continuity of funding and service provision for people with disabilities who are transitioning from child to adult service sectors, as well as improved and expanded education, health, and respite services (Dubé, 2016; Select Committee on Developmental Services, 2014). Despite having agreed to implement many of the recommendations, there remain a number of significant gaps in service (Dubé, 2016; MCSS, 2014). Specifically, the government has not committed to eliminating wait lists, nor have they agreed to transform disability services into an entitlement program, suggesting that issues related to limited funding will persist (Dubé, 2016; MCSS, 2014).

Despite promises for the development and implementation of public policies that foster the inclusion of persons with mental disabilities in Canada at both federal and provincial levels, as per government reports including the *Comprehensive Government Response to the Select Committee on Developmental Services* (Ontario) as well as the *Convention on the Rights of Persons with Disabilities: First Report of Canada*, there remain glaring gaps in service at this time (Dubé, 2016; Government of Canada, 2014; MCSS, 2014). Experiences of marginalization continue to be prevalent for persons living with mental disability during Ontario's post-dismantlement phase of the institutional cycle. Persons who are living with a disability in Canada continue to be more likely to be poor than non-disabled persons (Graham et al., 2012; HRSDC,

2009). This is often as a result of barriers to employment, a lack of accessible and affordable housing, as well as costs associated with having a disability (Graham et al., 2012; Roehner Institute, 1996). Further exacerbating this problem, it is noted that benefits available to persons with mental disabilities through public programs such as Ontario Disability Support Program (ODSP) are minimal and often insufficient (Graham et al., 2012; HRSDC, 2009). Although insurance based supports, such as those obtained through the Workplace Safety and Insurance Board, often provide more funding than public benefits, this type of support is only available for persons with a history of employment (Graham et al., 2012). Inevitably such a benefit scheme serves to reinforce capitalist ideologies that assert that those who can and have worked are more deserving than those who were born with an impairment resulting in barriers to accessing gainful employment (Graham et al., 2012). In fact it is suggested that within a capitalist society persons living with an impairment to the body or mind, which has resulted in barriers to obtaining employment, will always face discrimination and marginalization as the ability to contribute to society through gainful employment is valued above all else (Graham et al., 2012; Hanes, 2010; Hayes & Harnold, 2007).

Human rights legislation that attempts to address employment discrimination and barriers to employment has arguably not been overly successful in Ontario, as persons living with mental disabilities continue to face a number of barriers to achieving full and gainful employment, including stigma and discrimination in the workplace, poor physical accommodations, limited access to transportation, and a lack of educational opportunities (Hall, 2017; Jones, 2017; Lysaght, Petner-Arrey, Howell-Moneta & Cobigo, 2017; Wilson, McColl, Zhang & McKinnon 2017). Moreover, as a result of economic marginalization persons living with disabilities often experience social stratification in that they are unable to engage in many other aspects of social

and cultural life due to their experiences of poverty and oppression (Prince, 2009; Roeher Institute, 1996). The structural barriers to full economic and social participation in society create an environment that deters the inclusion of persons living with mental disabilities.

Issues of affordable housing, access to transportation, as well as achieving full economic and social participation remain on the forefront of disability agenda (Dunn, 2012; Malhorta & Rowe, 2014). Currently, disability advocates continue to strive for consumer control of services, as well as the full participation in social and economic life for Ontarians living with disabilities (Dunn, 2012). Further changes in the political and social discourse of mental disability in the post-dismantlement phase of Ontario's institutional cycle will be explored within this dissertation through the examination of dominant political and literary discourses.

### **Disability Paradigms**

It is suggested that there are two main paradigms that have influenced social and political discourses concerning disability and mental disability in Ontario over the course of the institutional cycle (Graham et al., 2012; Hick, 2007). The first being the medical model and the second being the social model of disability. In this section we will take a closer look at how each paradigm has helped to shape current social and political discourse of mental disability. Please see Table 1 for a summary comparison of the paradigms. Two additionally emerging perspectives on disability, including the post-social model of disability and the radical disability model, will also be discussed.

#### ***Medical Model of Disability***

The association between disability and illness is a problematic connection that has served to enforce a medicalized conception of disability over the past century (Wendell, 2013). Within the medical model paradigm, persons are considered disabled if their bodies are deviant from the

norm (Dunn, 2012; Straus, 2013). Disability is treated as a sickness, wherein the focus is placed on the individual's limitations and disability is viewed as a personal tragedy to be fixed, treated, or cured (Dunn, 2012; Hick, 2007; Siebers, 2006; Straus, 2013). The medical model asserts that professionals are the experts on issues related to disability, while individuals are the patients or clients (Dunn, 2012).

The medical model has largely been the dominant model of disability over the last century, influencing disability policy in a number of ways including the development of institutions, the concept of rehabilitation, and the creation of a number of forms of therapy. It has also lead to stigma and prejudice, in that persons with disabilities are viewed as 'lesser than' (Dunn, 2012; Hick, 2007). Despite the process of de-institutionalization in Ontario, persons with disabilities often continue to be conceptualized as clients and are arguably institutionalized within community-based services (McKnight & Block as cited in Dunn, 2012). Related to this it is asserted that the medical model is oppressive as it reinforces the dependency and segregation of persons with disabilities (Nelson, 2006 as cited in Dunn, 2012; Siebers, 2006).

The medical model also serves to reinforce neoliberal policy agenda in that it conceptualizes the body and the mind as being the problem, and does not take into account the way in which social and economic barriers contribute to and create the experience of disability (Straus, 2013). As a result of this narrow understanding of disability, wherein fault is assigned to the individual, discriminatory policies and social practices that perpetuate marginalization are not challenged, and persons living with mental disabilities are expected to assimilate with societal norms.

### *Social Model of Disability*

The end of the twentieth century saw a rise in popularity of the social model of disability: a framework that challenges the oppressive discourse associated with medicalized and other individualized understandings of disability, which were prominent at the time (Oliver & Barnes, 2012; Shakespeare, 2006). Although not without its limitations, the social model of disability has arguably been an effective tool in changing the dominant social, cultural, and political discourse of disability in Canadian society, specifically creating movement towards a more rights-based understanding of disability (Bach, 2003; Oliver & Barnes, 2012; Shakespeare, 2006).

The social model of disability concedes that an individual may have a bodily or mental impairment, however, it reframes the disability as being the impediments and/or discrimination experienced by the individual as a result of societal norms imposed on them (Dunn, 2012; Hick, 2007; Kelemen & Vanhala, 2010; Michalko, 2002). Within this framework, the suffering and hardship faced by persons living with a disability is enacted through environmental inadequacies, inter-personal discrimination, and cultural barriers as opposed to physical or mental impairments (Kelemen & Vanhala, 2010; Michalko, 2002; Withers, 2012). Some conceptualizations of the social model of disability also assert that the internalization of oppression can result in further experiences of marginalization, as individuals may restrict themselves in anticipation of systematic oppression (Withers, 2012).

Critics of the social model of disability argue that despite the model's ability to provide a well-informed framework for policy analysis, this paradigm grossly minimizes the individuals' day-to-day reality of living with physical and/or mental restrictions (Corker & Shakespeare, 2001 as cited in Prince, 2016; Crow, 1996 as cited in Prince, 2016; French 1993 as cited in

Prince, 2016; Morris, 1991 as cited in Prince, 2016; Thomas, 1999 as cited in Prince, 2016; Withers, 2012). Moreover, the social model of disability does not adequately account for the interplay between the individual and their environment (Oliver & Barnes, 2012; Shakespeare, 2006). Nevertheless this prominent paradigm has influenced the way in which a number of national and international organizations define disability and mental disability (Oliver & Barnes, 2012; Shakespeare, 2006).

**Table 1. Comparing Prominent Disability Paradigms**

	<b>Medical Model</b>	<b>Social Model</b>
<b>Definition of Problem</b>	Individual impairment	Impairment in societal norms
<b>Locus of problem</b>	Individual	Social & political environment
<b>Solution to problem</b>	-Professional intervention & treatment -Medical advances	-Advocacy -Social & political reform -Removal of society barriers -Self-determination -Social justice
<b>Social Roles</b>	Patient/Client	Citizen/consumer
<b>Desired Outcomes</b>	-Maximize activities & daily living skills -Treat or cure the disability	-Social inclusion
(Dunn, 2012; Graham et al., 2012; Hick, 2007; Kelemen & Vanhala, 2010; Michalko, 2002; Shakespeare, 2006; Siebers, 2006)		

### ***Post-Social Model***

In asserting that the social model of disability continues to provide a relevant framework for analyzing social-political and economic levels of disability issues, Hanes (2016) proposes a revised post-social model of disability that is based in the principals of structural social work. Specifically Hanes suggests that a structural social work model of disability would ensure that the lived experiences of the ‘person in the political’ would be considered as equality important as the structural barriers contributing to their inequality and social exclusion (2016). Within his

two-tiered approach, Hanes advises that the first tier of intervention would include working with the individual and their family to address immediate needs and provide tension relief, while a second tier of intervention would focus on addressing structural barriers with the hope of eliminating tension in the long term (2016; Moreau & Leonard, 1989 as cited in Hanes, 2016). Hanes suggests that his proposed post-social model of disability is able to bridge the gap between individual experiences of impairment and larger structural barriers to inclusion and experiences of oppression (2016). Moreover, Hanes suggests his model is action oriented as it provides social workers with direction on how to engage with persons living with disability, as well as the political agenda (2016).

### ***Radical Disability Model***

In order to address the continued marginalization of persons living with disabilities, Withers asserts that a new disability model which adequately addresses both the experiences of oppression as well as the mind/body impairments is required (2012). In his proposed radical disability model Withers defines disability as a “social construction used as an oppressive tool to penalize and stigmatize those of us who deviate from the (arbitrary) norm” (2012, p. 98). There are four key components fundamental to the radical model disability including acknowledging how disability interacts with other forms of oppression, challenging the supremacy of the ‘norm’ as well as oppressive political classifications of disability, and working towards the development of holistic rather than universal disability services. Much like Hanes’ (2016) post-social model of disability, the radical disability model is also concerned with addressing both the individual experiences of oppression as well as the structural barriers to inclusion.

However, unique to Withers’ approach, the radical disability model dictates that we must not only acknowledge the diverse and intersecting oppressions found within the disability

community, but must also work tandem with other marginalized groups in order to “come out from under the disability umbrella” and create an anti-oppressive movement towards change (2012, p. 101). Withers notes that historically marginalized groups have often oppressed one another in efforts to assert dominance over the other, thus reinforcing a system of marginalization and discrimination, and ultimately serving those in power. In order to create radical access to services and end disableism, oppressed groups must work in solidarity with one another to demand justice and equality.

### **Defining Mental Disability**

Defining mental disability can prove to be a complicated endeavor, as a number of other terms have been utilized to refer to this heterogeneous group throughout time (Price, 2013). In referring to impairments of the mind there are a myriad of commonly referenced terms including psychiatric disability, mental health issue, cognitive disability, intellectual disability, developmental delay, neuroatypical, etc. (Price, 2013). Each word may carry with it a slightly altered rhetoric, but nevertheless is thought to refer to an impediment of the mind. It is acknowledged that identifying a common understanding of the term mental disability is arguably insignificant as such does not necessarily amount to describing a common lived experience or set of impairments. However, defining mental disability is certainly relevant in terms of policy development and provision, as well as accessibility of services.

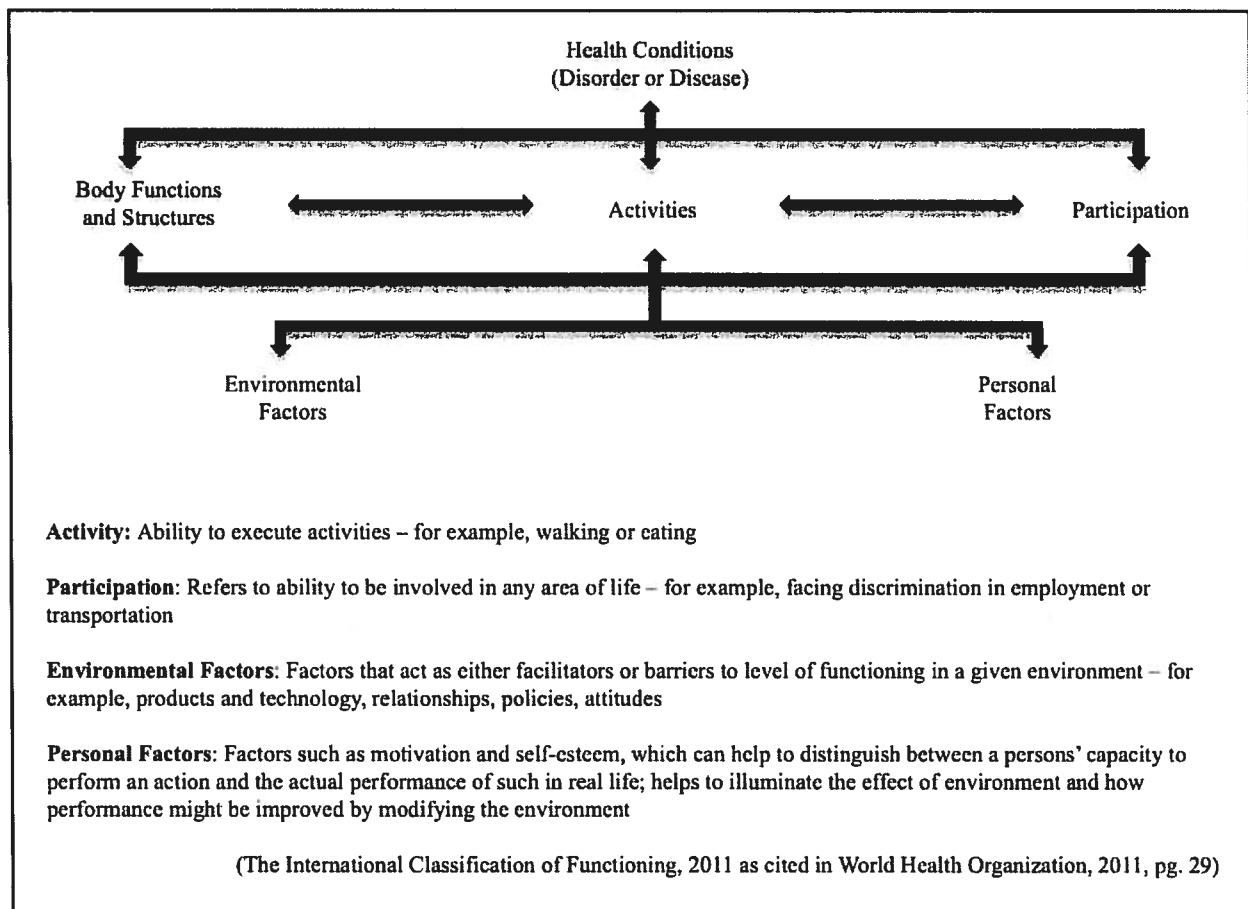
### ***Legislative and Organizational Definitions of Disability***

While the concept of mental disability may be socially constructed, it is ultimately policy makers who decide who is ‘disabled’ and who will receive financial and social benefits as a result (Dunn, 2006). Accordingly, as the understanding of what constitutes mental disability has changed throughout Canadian history, so have the policies that impact the lives of persons living



with disabilities (Dunn, 2006). Although not necessarily legally binding, global organizations such as the United Nations and the World Health Organization do exert significant influence over public policies and social programs both directly through the implementation of conventions and related policy directives, as well as indirectly through efforts to raise awareness of public issues. As such, the way that they define mental disability will not only impact the provision of services, but will also inform social and political discourse on disability.

**Figure 3. Representation of the International Classification of Functioning, Disability and Health**



The World Health Organization attempts to define disability in a way that bridges the social model and medical model in order to embrace an understanding of disability as a

continuum that recognizes both body and mind impairments, as well as environmental impediments and how they interact with one another (World Health Organization, 2011). Figure 3 depicts an understanding of disability, as utilized by the World Health Organization, wherein emphasis is placed on the environmental factors that create disability (WHO, 2011).

The federal government of Canada refers to WHO's definition of disability as being the most widely acceptable definition of disability (HRSDC, 2013). However, government agencies and organizations do not necessarily operate from this understanding of mental disability. Rather, the Government of Canada ensures that the rights of persons living with disabilities are protected by addressing issues of disability within the Canadian Charter of Rights and Freedoms (Baker, 2007; Pfeiffer, 1993; Puttee, 2002 as cited in Baker, 2007). While in Ontario, the prevention of discrimination on the basis of disability is guaranteed through the Human Rights Code, which defines disability as the following:

- (a) any degree of physical disability, infirmity, malformation or disfigurement that is caused by bodily injury, birth defect or illness and, without limiting the generality of the foregoing, includes diabetes mellitus, epilepsy, a brain injury, any degree of paralysis, amputation, lack of physical co-ordination, blindness or visual impediment, deafness or hearing impediment, muteness or speech impediment, or physical reliance on a guide dog or other animal or on a wheelchair or other remedial appliance or device,
- (b) a condition of mental impairment or a developmental disability,
- (c) a learning disability, or a dysfunction in one or more of the processes involved in understanding or using symbols or spoken language,
- (d) a mental disorder, or

(e) an injury or disability for which benefits were claimed or received under the insurance plan established under the *Workplace Safety and Insurance Act, 1997*; (“handicap”)  
(Human Rights Code, R.S.O. 1990, c. H.19, s.10(1))

This seemingly inclusive definition aims to protect the rights of persons living with disabilities in Ontario, and arguably is also inclusive of persons living with chronic mental illness. However, this definition does fail to take into account the ways that an environment and/or social and cultural norms can effect and create disability.

Other major policy constructions of disability are embedded in the Accessibility for Ontarians with Disabilities Act, as well as the Services and Support to Promote the Social Inclusions of Persons with Disabilities Act (AODA, 2005; SSPIPDA, 2008). Although these pieces of legislation do acknowledge, to an extent, the environmental factors that create barriers for persons living with disabilities, the definitions of disability as prescribed in these policy documents are largely reflective of those found in the Human Rights Code. Similarly, the Ontario Disability Support Program Act defines disability as a significant and reoccurring or continuous physical or mental impairment (OSDPA, 1997). Again, this concept of disability fits a medical model; and in fact persons who wish to access disability benefits in Ontario must first have their disability verified by a health care professional (MCSS, 2015).

Legislative definitions of mental disability in Ontario are porous and inconsistently applied. Yet, the way that mental disability is defined, or not defined, has significant implications for persons living with mental disabilities. An American study by O’Brien and Brown (2009) examining how persons living with a mental illness experienced the Americans with Disabilities Act found a number of examples wherein the individuals experienced limited protection of their rights due to inconsistent and at times oppressive interpretations of the law, as related to what

constitutes a mental disability and who is in need of protection from prejudice. Further evidence of this issue is found within the rigid understanding of disability as applied by the Ontario Disability Support Program. Persons living with disabilities who seek assistance from ODSP must subject themselves to an intrusive and complex application process wherein the individual is obligated to prove that they are in fact ‘disabled enough’ to receive benefits (Chouinard, 2006; Chouinard & Crooke, 2005; Lightman, Vick, Herd & Mitchell, 2009; Smith-Carrier, Ken, Wang, Tam, Kwok, 2017). Critics suggest the ODSP application process is in fact “denial by design”, and note that roughly 50% of ODSP applicants between the years of 1998 to 2001 were refused the assistance they required (Fraser, Wilkey & Frenschkowski, 2003). An appeal for an ODSP ruling is equally as difficult to obtain, ultimately leaving many individuals without the necessary supports required to maintain an adequate standard of living (Smith-Carrier et al., 2017). Exemplifying this issue, a poll conducted with individuals who accessed Toronto’s food banks found that as many as 60% of the service-users who were living with a disability were not receiving ODSP, with 70% of this sub-group having only been able to obtain support from Ontario Works (Daily Bread Food Bank, 2003 as cited in Chouinard, 2006).

Unfortunately ODSP is not the only program wherein exclusionary definitions of disability act as a barrier to accessing services for persons living with mental disabilities. Another example of this is found within the Disability Tax Credit, which prior to 2006 did not consider mental illness to constitute a disability (Hick, 2007). Moreover, prior to 2010 persons living with disabilities in Ontario could be denied access to benefits should they have concurrent addictions issues (Ontario v. Tranchemontagne, 2010). It is suggested that in order to ensure the protected rights of persons living with mental disabilities in Ontario, legislative definitions of disability must be more inclusive in addressing what constitutes a mental disability. Moreover,

application processes and eligibility criteria for disability services must embrace a human rights approach, wherein issues of accessibility, equality, dignity, self-determination are addressed (Smith-Carrier et al., 2017).

The way that mental disability is defined at an organizational level will not only impact which services and support an individual is eligible for, but will also inform the social and political discourse of disability. Various ministries and government organizations in Ontario operate from different definitions of mental disability, creating barriers to accessing services for individuals and families as eligibility criteria can change from agency to agency (HRSDC, 2013; Ontario Human Rights Commission, 2012). Moreover, legislation in Ontario and Canada continues to conform to the pervasive medical model's conceptualization of disability, which serves to reinforce the sick-role designation of persons living with disabilities and perpetuate neoliberal ideologies that value employment above all else (Smith-Carrier et al., 2017). This is of concern as it has direct implications for policy development and implementation in the province. It is suggested that the way that disability is defined at a legislative level must shift towards a more inclusive concept that acknowledges how environmental factors and societal norms impact persons living with a disability. Such a paradigm shift would allow for a policy response that better supports the social and economic inclusion of persons living with mental disabilities (Baker, 2007; Dunn, 2006).

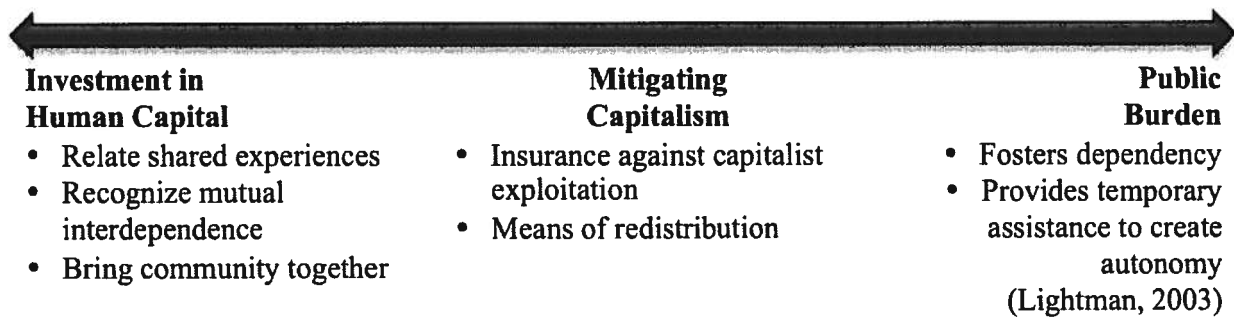
In order to successfully address the systemic oppression experienced by persons living with mental disabilities in Ontario, further policy reform and changes to service provision are necessary. Yet, history has demonstrated that achieving policy reform that is responsive to public needs is often difficult, if not a seemingly impossible task. Throughout the next section of the

literature review, concepts of social policy, disability policy, as well as policy development and implementation will be explored.

**Social Policy**

The term policy, and more specifically social policy, does not have a single agreed upon meaning (Lightman, 2003; Westhues, 2012b). Rather our understanding of what constitutes a social policy and the related purpose of social policy can be understood to exist on a continuum, wherein the assigned meaning is reflective the individual’s or collective’s values (Lightman, 2003; McCauley, 2011; Westhues, 2012b). Dependent on an individual’s values, social policy may be viewed as a set of programs and policies meant to invest in human capital, to mitigate the economic disparity of a capitalist society, or to provide temporary assistance to an individual with the intention of generating their autonomy (Lightman, 2003).

**Figure 4. Varying Perspectives on the Purpose of Social Policy**



Policy documents not only represent but also help to shape cultural values, define the roles and responsibilities of community members, as well as legitimize and prioritize the interests and needs of the community (Fischer & Forester, 1993 as cited in McCauley, 2011; Lightman, 2003; Prince, 2009 as cited in McCauley, 2011; Westhues, 2012b). Yet within a neoliberal framework policy decisions are often enacted by those who are in positions of power and, therefore, are not representative of every individual’s values and interests; and, in fact, can

act as oppressive forces for marginalized groups (Lightman, 2003; Westhues, 2012b). Social policy and social programs are ultimately representative of a choice or decisions made within a range of options that are deemed acceptable by a dominant society (Titmuss, 1974 as cited in Lightman, 2003; Westhues, 2012b). Thus, the contention that a certain social program or policy initiative is simply not feasible, is representative only of the fact that those in power have determined that said initiative is not worth investing in (Titmuss, 1974 as cited in Lightman, 2003). Gilbert and Specht (1977) assert that it is in fact shameful that in a democratic society the needs of marginalized populations are often only heard through government consultation with specialized interest groups, as citizen participation should be a cornerstone of policy development. Moreover, history seems to suggest that said interest groups are only enacted reactively to growing social problems as opposed to being proactively sought out (Gilbert & Specht, 1977). This arguably continues to be the practice in Ontario, as involving persons living with disabilities and/or advocacy groups in the evaluation and development of disability policies has become a more common practice in efforts to address to the province's history of implementing discriminatory and oppressive policies.

Ultimately, social policies are understood to comprise a course of action or inaction chosen to address social problems that result from unequal access to the resources required to sustain the health, safety, and well-being of an individual (McCauley, 2011; Westhues, 2012b). Although policy decisions are understood to reflect the values of dominant stakeholders, it is asserted that those who implement social policies at an organizational or individual level may choose to do so in a way that either reinforces or resists the original intent of the policy, dependent on their own values (Westhues, 2012b). For the purposes of this dissertation, social

policy will be understood within the parameters identified by McCauley (2011). Therefore social policy will refer to

... a range of state programs, legislation and regulations focused on the wellbeing of citizens. In North America and Europe in the twentieth century, programs and certain laws were captured under the umbrella of the 'welfare state'. Health, education, culture and income assistance or security initiatives have formed the substantive program arenas for most discussion of social policy. Economic policies are included in this list by some analysts... (Neysmith, Bezanson & O'Connell, 2005, pp. 21-22).

### **Social Policy and Disability**

Social policy in Canada, and Ontario, is very much embedded in neoliberal values (Johnstone, Lee & Connelly, 2017; Lightman, 2003; Rezai-Rashti, Segeren & Martino, 2017; Smith-Carrier & Lawlor, 2017; Vipond, 2017). Accordingly, policies favour those individuals who are able to work over those who are perceived to be a burden on the economy (Chouinard & Crooke, 2005; Darcy, Taylor & Green, 2016; Lightman, 2003). Blustein (2008) asserts that paid employment continues act as means of accessing economic and social inclusion, resulting in the oppression of persons living with disabilities who are either unable to work or who have been denied opportunity for employment as a result of systemic barriers and discrimination (as cited in Darcy et al., 2016; Darcy et al., 2016). In a social and political environment where paid employment is often directly related to your perceived value as a citizen, the voices of persons living with mental disabilities have historically been brushed aside when it comes to policy planning initiatives in Canada and Ontario (Chouinard, 2006; Prince, 2009). Although a number of policies in Ontario have moved towards a more comprehensive understanding of impairment



wherein the rights of individuals living with disabilities are more apparent, there continues to be significant systemic barriers to economic and social equality (Smith-Carrier et al., 2017).

Specifically, research suggests that ODSP continues to promote a dichotomized understanding of disability, wherein the individual is characterized as either sick/well or disabled/able (Smith-Carrier et al., 2017). These restrictive categorizations foster the social and economic exclusion of those who are accessing or trying to access this service (Chouinard, 2006; Chouinard & Crooke, 2005; Smith-Carrier et al., 2017).

In order to develop social policies that are responsive to service-user needs, Prince asserts that government bodies need to move away from forms of public consultation wherein the state largely controls the policy agenda, who is invited to participate in policy consultation, and the extent of to which participants are involved in and exercise influence over policy decisions (2009). Prince describes the need for a shift towards citizen-centered government wherein there are stronger working relationships and mutual respect between government officials and citizens. Moreover, it is recommended that rather than engage individually with citizens, government bodies should instead work with the organizations that represent individuals, groups, and networks of citizens living with disabilities, which Prince refers to as the ‘disability community’. In order to maximize the influence that persons living with disabilities and disability organizations have over the development and implementation of public policy it is advised that disability activists need to engage in and develop policy relations at a number of levels including within the disability community, between the disability community and other communities, and finally between the disability community and government structures. When examining social policies that effect persons living with disabilities in Canada, it is noted that a majority of policy decisions fall under the provincial purview. Therefore efforts to create change in service delivery

and policy development should arguably be targeted at the provincial ministries and service providers (Graefe & Levesque, 2010). Please see Table 2 for an overview of the various models of citizen engagement that can be utilized by the disability organizations in efforts to influence and develop policy initiatives (Prince, 2009).

**Table 2. Models of Engagement Between the Disability Community and the Canadian State**

<b>Model</b>	<b>Description</b>
<i>Intra-community</i>	Within the disability community
<i>Cross-sector</i>	Disability groups working with organizations or associations in other parts of the voluntary or private sector
<i>Community-political executive connections</i>	Disability groups working with cabinet ministers, city councilors/mayors and their staffs
<i>Community-legislative interactions</i>	Disability groups connecting with legislative committees and individual members
<i>Community-judiciary relations</i>	Disability activists and groups interacting with courts, human rights commissions, and other tribunals
<i>Community-public service engagement</i>	Among disability representatives and public servants
<i>Community-intergovernmental engagement</i>	Structures and processes to create a collective policy vision
(Prince, 2009, p.129)	

However, if we are critical of disability policy in Canada, it is important to recognize that although it is an achievement to ensure disability issues are on the federal or provincial policy agenda, it does not guarantee that said issues will obtain the sustained attention of decision makers, or result in meaningful action (Prince, 2016). In order to foster the illusion of meaningful change in policy planning and service provision, government bodies often employ misleading practices such as stressing gains made on the surface while ignoring structural gaps in services, downplaying disability as a human rights issue, promoting principals of limited government and shared social responsibility as a means of justifying current policies and/or making only small incremental changes (Prince, 2016). Such tactics effectively legitimize the government's limited role in disability issues, while attempting to conceal the erosion of the

existing benefits and social programs available for persons living with disabilities (2016). In response to this concern Carter (2016) asserts the necessity of advocacy by non-profit groups, persons living with disabilities, family members, and social workers to contribute to the development of innovative policy that aims to attain social inclusion and equality for persons living with disabilities.

Providing an alternative perspective on policy development, Withers (2012a) identifies that persons living with disabilities are a heterogeneous group, often living with varied and intersecting experiences of discrimination and marginalization. Accordingly, in order for anti-oppressive social policies to be realized in Ontario, persons living with disabilities need to align themselves with other marginalized groups in order to demand the changes they seek (Withers, 2012a).

Yet historically, policy planning is a complex and lengthy process, which typically involves the implementation of small changes over time through a series of trade-offs between stakeholders (Hudson, Galloway, & Kaufman, 1979; McCauley, 2011). New models of policy planning may need to be adopted in order to develop and implement social policies that are reflective of the values of equality, inclusion, independence, empowerment, and the participation of persons living with mental disabilities. Alternative forms of policy planning that value service-user knowledge, incorporate narrative experiences of stakeholders, call for structural change, and acknowledge that service-users have differing needs and wants are necessary in order to realize social policies that are reflective of the varied cultures, experiences, and values of persons living with disabilities in Ontario (Hudson et al., 1979; McCauley, 2011; Roe, 1994 as cited in McCauley, 2011).

The development of a policy, however, does not guarantee that said policy or program will be implemented as intended and/or achieve the desired outcome (Lindholm, 1977 as cited in McCauley, 2011; Yanow, 1994 as cited in McCauley, 2011). As a result, ongoing policy analysis is an integral process, which allows for the consideration of how social policies are affecting the lives of persons living with disabilities (Prince, 2009; Westhues, 2012b). Furthermore, policy analysis can lead to the development of appropriate and feasible recommendations for addressing barriers to policy goals, such as inclusion and equality (Prince, 2009; Westhues, 2012b).

Policy analysis, much like policy development, is a value-laden process (Westhues, 2012b). Canadian policy and program evaluation regarding mental disability has historically been informed largely by dominant cultural values of the time, as opposed to evidence and/or experiential knowledge (Nelson, 2012). Such a value-based model of policy analyses, as described by Westhues (2012b), assumes that policy makers are experts on disability issues and often ignores objective evidence and personal narratives of those who are directly affected by disability policies. Alternatively, it is suggested that the social policies that affect the lives of persons living with mental disabilities in Ontario should be analyzed utilizing a strengths-based integrated model, which is reflective of the values of self-determination and inclusion (Westhues, 2012b). This form of policy analysis may provide opportunity for empowering the disability community and creating meaningful social reform.

**Table 3. Approaches to Policy Analysis**

	<b>Evidence-Based Model</b>	<b>Values-Based Model</b>	<b>Participatory Model</b>	<b>Strengths-Based Integrated Model</b>
<b>Type of knowledge privileged</b>	Systematically gathered, qualitative or quantitative (positivist, post-	Reasoning deduced from clearly stated principles/values (subjective)	Experiential knowledge (constructivist)	A mix of systematically gathered data, reasoning, and experiential

	positivist)			knowledge (realist)
<b>Role of analyst</b>	Neutral; public interest; analyst is expert	Advocate; analyst is expert	Facilitator of process; affected interests are expert	May be all three at different points in the analytic process
<b>Role of affected interests</b>	Indirect input, through participation in research studies	May be involved in defining principles/values guiding analysis, but usually are not	Direct, through consultation, presentations at public meetings	May be indirect or direct
<b>Activities/skills</b>	An emphasis on analytic skills	An emphasis on deductive reasoning	An emphasis on interactional skills	Analytic, interactional, and reasoning
<b>Change theory</b>	Elitism: policy analysts and researchers guide change	Pluralism: group interests are contested, most persuasive has greatest influence on policy	Principle of affected interests: those most affected should have the greatest influence	Strengths orientation: people have the capacity to find the best solutions to their individual and community problems. Policy analysts need to design processes that allow these solutions to emerge.
(Westhues, 2012b, p. 44)				

Prince asserts that to date there have been modest strides made towards disability policy reform in Canada (2009). However, in order to achieve inclusion and full participation in Canada's social and political economy persons living with disabilities need to be involved in the design, delivery, and evaluation of all public policies and programs which effect their lives (Prince, 2009). Moreover, Withers asserts that individuals living with disabilities should in fact work in solidarity with persons from other marginalized groups in order to "get out from under the umbrella of disability" and realize social and economic inclusion (2012a, p. 101).

### **Literature and Culture**

The current dissertation seeks to complete an analysis of the ways that mental disability is represented in literary and policy discourses, with the hope of identifying policy planning needs and opportunities for advancing human rights for persons living with mental disabilities.

Accordingly, it is asserted that the process of narrative analysis should be informed by a literary theory that identifies the use of narratives as both a representation of human experience as well as the means of constructing it (McCauley, 2011). As adapted from McCauley's (2011) research, the current dissertation will apply mimetic and structural theories of literature, which assert a narrative's ability to shape and inform cultural constructs. As demonstrated by McCauley (2011), literary texts are legitimate discourses for understanding and critiquing cultural constructions of identity generally, and of mental disability specifically. The ability of language to influence culture is certainly relevant in terms of the construct of mental disability, which has been a fluid concept over time, no doubt reflective of changing cultural values (McCauley, 2011).

As related to disability literature, historically, disability research and medical information was written in an objective style, void of any representation of lived experiences (Sack, 1990 as cited in McCauley, 2011). Moreover, representations of disability in literature have traditionally served to reinforce attitudes of ableism, fear, and ambivalence (Beauchamp, Chung, & Mogilner, 2009; Couser, 2005; Iyer, 2007; Margolis & Shapiro, 1987; McCauley, 2011; Michell & Snyder, 2000). The way that language is utilized influences cultural constructions of a given word or phenomenon, and dictates the values that are associated with it. Thus language and culture are intrinsically connected, in that language will change over time as a result of social conditioning and cultural values (Baron, 1992).

Through the use of language, literature has the ability to model social life and convey cultural inadequacies (Baron, 1992; Mar & Oatley, 2008; McCauley, 2011). Narrative can be a powerful tool for challenging cultural values, identifying social issues, and in some instances highlighting pathways for social reform (Beauchamp et al., 2009; Bruner, 2002; Couser, 2005; Engel & Munger, 2007; Iyer, 2007; Malhotra & Rowe, 2014; Mar & Oatley, 2008; McCauley, 2011). This remains true for both fiction and non-fiction narratives. McCauley (2011) asserts that the line between fiction and non-fiction is permeable and often a matter of personal judgment, noting that many stories are informed by facts and inspired by personal experiences. Furthermore, one person's autobiography or personal narrative may be viewed as largely fictitious from another's perspective (McCauley, 2011).

Whether a narrative is fictitious or not, literary research and history have demonstrated the power that a story can have over cultural values and popular discourse (Bruner, 2002; Couser, 2005; Margolis & Shapiro, 1987; Mitchell & Snyder, 2000). Narratives can communicate knowledge, contribute to cultural pluralism, and develop our understanding of social norms and emotional ideals (Iyer, 2007; Mar & Oatley, 2008; Tsai, Louie, Chen, & Uchida, 2007). Although there has been a history of negative portrayal of disability in literature, some research suggests that more recent fiction and non-fiction narratives of disability have contributed to a changing perspective of disability towards one which is more closely aligned with values of inclusion (Couser, 2005; Meyer, 2013).

Other marginalized populations, including feminist and anti-racist groups, have been able to harness the power of narrative as a tool to control of their own image in society, thus influencing cultural values and norms accordingly (Couser, 2005). Disability narratives are also able to utilize literature for this purpose (Beauchamp et al., 2009; Couser, 2005). Yet, despite a

rise in the number of disability narratives present in popular literature, persons with mental disabilities continue to be marginalized even within the disability genre (Couser, 2005; Meyer, 2013). Specifically, it is suggested that persons with mental disability often continue to be represented in literature as reflections of social perceptions, rather than being informed by lived experiences (Couser, 2005; Iyer, 2007; Meyer, 2013). Related to this, it is acknowledged that for persons living with mental disability, the very nature of their limitations may result in an inability to communicate their lived experiences (Iyer, 2007; McCauley, 2011). As a result of this, there are fewer autobiographical narratives that are able to meaningfully relay the experiences and thoughts of persons living with a mental disability, as opposed to narratives communicating the lived experiences of persons with physical disabilities (Couser, 2005). Furthermore, persons living with mental disabilities may not be able to contest or confirm their representation in literature as a result of communicative impairments (Iyver, 2007).

Nevertheless, fictional accounts of mental disability can be effective in addressing issues of ableism and advancing the rights of persons with mental disability (Couser, 2005; Iyer, 2007; Mar & Oatley, 2008). Disability narratives, whether fictional or biographical, can provide meaningful insight into the lives of persons living with mental disability and can counter previously objectifying, pathologizing and marginalizing representation of disability in popular culture (Beauchamp et al., 2009; Couser, 2005; Mar & Oatley, 2008; McCauley, 2011). Furthermore, a good narrative will be able to not only share knowledge regarding the lived experience of persons with mental disabilities, but also contribute to altering shared cultural values which will ultimately help to create social reform (Bruner, 2002; Malhotra & Rowe, 2014).



## Research Methodology

### Statement of Problem

Despite reform to legislation and policies that claim to promote the inclusion of people living with mental disabilities in Ontario, there remain significant barriers to their full social and economic inclusion in society at this time. This population has historically been marginalized both directly through oppressive social policies as well as indirectly through discriminatory and stigmatizing social discourse. The oppression imposed on persons living with mental disabilities is further complicated by the fact that many of these individuals are either unable to communicate their lived experiences due to an impairment, or their concerns and opinions when voiced are ignored and labeled as insignificant next to those of their able-bodied caregivers and helping professionals (Kittay, 2001; McCauley, 2011).

In spite of communication and/or cognitive impediments faced by persons living with mental disabilities, which may undermine their ability to express their lived experiences, social workers continue to have a professional and ethical responsibility to represent the interests of service-users at individual, organizational, and legislative levels (Drover, 2000 as cited in McCauley, 2011; Ontario College of Social Workers and Social Service Workers, 2008). As such, social workers can benefit from examining relevant policy and literary discourses, with the understanding that these cultural texts contribute to our conception of disability and ultimately influence the development and implementation of disability policies and programs (McCauley, 2011).

It is proposed that an interdisciplinary analysis of cultural texts, including both literary and policy discourses, will allow social work researchers and practitioners to develop a richer understanding of the lived experiences of persons living with mental disabilities (McCauley,

2011). Furthermore, examining the ways in which literary and policy texts intersect to construct the discourse of mental disability in Ontario can assist social workers in developing policies and services for persons living with mental disabilities that challenge the dominant cultural assumptions that have previously contributed to the systemic marginalization and oppression of this population (McCauley, 2011).

### **Theoretical Assumptions**

The current study was grounded in these five theoretical assumptions, as informed by McCauley's (2011) dissertation.

1. Mental disability is a socially constructed concept, which is unstable and changes over time dependent on cultural values and norms, as well as disciplinary perspectives.
2. Policy and literary discourses are cultural texts that contribute to the construction of our concept of mental disability.
3. Current social work theory does not adequately address how to effectively work for people who cannot speak for themselves.
4. Social workers have a professional and ethical obligation to represent the interests of the service-user at an individual, organizational, and structural level of intervention.
5. Literary narrative is a legitimate resource to utilize for addressing social policy problems.

### **Purpose**

The purpose of this research is to examine key policy and literary texts published since 2009, with the intention of beginning to define a post-dismantlement phase in Ontario's institutional cycle. A critical discourse analysis examining the ways that literature and policy

construct mental disability may help to anticipate future policy planning needs and opportunities in Ontario as we continue to advance human rights and social inclusion for persons living with mental disabilities.

### **Research Questions**

1. What can be learned through a comparative examination of how mental disability is represented in literary and policy discourses during the post-dismantlement phase of Ontario's institutional cycle?
2. How can an interdisciplinary analysis of literary and policy discourses, during the post-dismantlement phase of Ontario's institutional cycle, inform policy planning and the provision of services for people living with mental disabilities in Ontario?

### **Procedure**

#### **Research Strategy**

In order to address the proposed research questions a critical discourse analysis methodology was utilized to examine relevant literary and policy texts published since 2009. Critical discourse analysis is a qualitative research methodology that is well suited for interdisciplinary studies and is often utilized to address social problems (McCauley, 2011; Wodak & Meyer, 2009). It is an inductive process and, therefore, lends itself well to this research, which is seeking new ways of knowing about the construct of mental disability (McCauley, 2011).

Critical discourse analysis views the use of language as a social practice, in that discourse is not only socially conditioned but also contributes to social concepts (Wodak & Meyer, 2009). Thus language can be used both to reproduce and transform social knowledge (Fairclough &

Wodak, 1997 as cited in Wodak, 2004; Wodak, 2004). The use of language as a discursive tool can hold significant power, in that language can influence prominent cultural ideologies and values (Fairclough & Wodak, 1997 as cited in Wodak, 2004). The way that a person or social group is represented through language can help to create or maintain structural oppression and discrimination; or conversely, can serve to highlight social issues and inequalities in society (Fairclough & Wodak, 1997 as cited in Wodak, 2004; Wodak, 2004).

Critical discourse analysis is fundamentally interested in analyzing structural power relationships in society, including the way that language is utilized in a given discourse to transform or reproduce values of oppression and power (Wodak, 2004). Because critical discourse analysis is primarily concerned with the use of language as a means of social construction it is well suited for a study wherein text is the data (Goldstein, 1990 as cited in McCauley, 2011). Furthermore, it is noted that critical discourse analysis is an interdisciplinary method, which asserts society is too complex to be studied from a single perspective, and thus is well suited for the current study, which is utilizing text from both literary and policy discourses (Wodak, 2004). Finally, critical discourse analysis is problem-oriented in that it focuses on social issues, social identities and social change, often incorporating historical perspectives and contexts; and therefore, is again well suited for the current study, which is addressing the social construction of mental disability (Wodak, 2004).

### **Research Target**

Data analyzed for the purposes of this study included a selective sample of relevant literary and policy texts published within the post-dismantlement phase of Ontario's institutional cycle, thus referring specifically texts published post 2009. Themes related to the concept of mental disability, and any related social, cultural, political allusions and presuppositions, were

generated through the analysis of literary and policy texts (McCauley, 2011; Reisgil & Wodak, 2009). Similarities and contradictions between literary and policy discourses were explored, and implications are discussed (McCauley, 2011). Themes explored during analysis include how stories of disability are told, the role of families and community, as well as the perception of institutions (McCauley, 2011). These themes have been adapted from McCauley's (2011) research. Further explanation of each theme can be seen in Table 4.

**Table 4. Themes for Analysis**

<b>Theme</b>	<b>Description</b>
<i>How Stories are Told</i>	<ul style="list-style-type: none"> <li>• Who speaks for individuals living with mental disabilities?</li> <li>• In literary texts, how are narrative techniques and point of view utilized to tell the story of the character living with a mental disability?</li> <li>• In policy texts, who is speaking for persons living with mental disabilities? Are first hand testimonies utilized to inform policy?</li> </ul>
<i>The Role of the Family</i>	<ul style="list-style-type: none"> <li>• How do literary and policy texts depict the relationship between an individual living with a mental disability and their family? What does this say about how a person with a mental disability should live and/or who should be supporting them?</li> </ul>
<i>Community Roles and Responsibility</i>	<ul style="list-style-type: none"> <li>• How do literary and policy texts depict the relationship between community and persons living with mental disabilities?</li> <li>• What types of services and support are available?</li> <li>• Are their incongruences between the individual's needs and the community's capacity?</li> </ul>
<i>Perceptions of Institutions</i>	<ul style="list-style-type: none"> <li>• How are institutions depicted in literary and policy texts?</li> <li>• What is the role of institution in the life of a persons living with a mental disability?</li> <li>• In this context institution may refer not only to mental health institutions and asylums, but also to long-term care facilities, school, and hospitals, or any institutions that may create barriers to inclusion or contribute to structural discrimination as experienced by persons living with a mental disability.</li> </ul>
(McCauley, 2011)	

## **Research Population & Sampling Method**

### **Operational Definition of Mental Disability**

For the purposes of this study, mental disability refers to an impairment of the mind which impacts the cognitive and/or adaptive functioning of an individual. This simple yet inclusive definition of mental disability is informed by McCauley (2011), and is notably reflective of legislative definitions of disability in Ontario (AODA, 2005; SSPIPDA, 2008).

### **Sampling Method**

Criterion sampling was utilized in order to identify relevant literary and policy documents for the study (Creswell, 2013). To be considered for analysis, literary and policy texts had to have been published during the post-dismantlement phase of Ontario's institutional cycle. Specifically this refers to literary and policy documents that had been published between the years of 2010-2017. Furthermore, literary and policy texts had to address or discuss mental disability, as operationally defined above. Finally, it is noted that all literary and policy texts identified for analyses were of public record.

### **Description of Sample**

The initial sample reviewed for the purposes of analysis consisted of 12 policy texts and 16 literary texts. I then reduced the sample to four texts from each category, which I utilized for the critical discourse analysis. Within the context of qualitative research, a sample size of this magnitude is well within the required range in order to establish saturation of themes, and valid research findings (Creswell, 2013; Creswell 2014). The specific selection criterion and other considerations taken to determine the final 4 texts from each category will be further discussed below.

### *Literary Sample*

A sample 16 novels and memoirs published between the years of 2010 and 2017 were initially considered for the literary sample. All literary texts contained characters living with a mental disability. The age and gender of characters varied between texts, as well as in the cause and nature of the given impairment. Some of the novels and memoirs were written from the perspective of the individual who was living with a mental disability, some from the perspective of a family member, while others contained aspects of each. Five of the 16 literary texts were categorized as memoirs or biographies, while 11 were categorized as novels.

It is asserted that literary texts, both fictional and not, represent legitimate data as they depict real life circumstances and as such are able to incite a reader's capacity for empathy by communicating something that is familiar (McCauley, 2011). Undeniably, biographical accounts of disability are meaningful in their capacity to both challenge and shape societal perceptions of disability (Iyer, 2007; McCauley, 2011). Nevertheless, the way that fictional narratives depict mental disability is equally significant in that such narratives have the ability to impact cultural conceptions of disability by marrying what is medically known about mental disabilities with pertinent cultural norms and societal values (Iyer, 2007). In fact, it is suggested that a reader engages with a story only when it is reflective of real social values, problems, and human experiences (Bruner, 2002; McCauley, 2011).

A number of factors were considered in determining the final sample of literary narratives to be utilized for analysis. The first criterion applied was the extent to which the narrative had the ability to influence the cultural construction of disability. This was determined by virtue of a story's critical acclaim, as well as the ideas presented in the literature that either represented or challenged dominant cultural discourse (McCauley, 2011). Second, the narrative's

relevance to Ontario's political and social landscape was considered, as well as the extent to which the narrative was able to inform the targeted research themes (McCauley, 2011). Finally, I also intentionally chose two fiction narratives and two memoirs, in order to be able to contrast and compare the ways in which mental disability is depicted in the varying formats of literature.

Table 5 provides an overview of the initial sample of literary material, while Table 6 provides further information on the final four texts chosen for analysis. It is of note, however, that when appropriate excerpts were also taken from texts that are included only in the initially literary sample. Said excerpts are utilized in order to further enrich the research themes, thereby contributing additional validity to research findings.

**Table 5. Initial Literary Sample**

Author	Title	Year of Publication
<b>Bartók, Mira</b>	<i>The memory palace: A memoir</i>	2011
<b>Cash, Wiley</b>	<i>A Land More Kind Than Home</i>	2012
<b>Genova, Lisa</b>	<i>Love Anthony</i>	2012
<b>Genova, Lisa</b>	<i>Left Neglected</i>	2011
<b>Hunter, Aislinn</b>	<i>The World Before Us</i>	2014
<b>Jewell, Lisa</b>	<i>I Found You</i>	2016
<b>Leavitt, Martine</b>	<i>Calvin</i>	2015
<b>Leone, Marianne</b>	<i>Jesse: A Mother's Story</i>	2010
<b>Ludwig, Benjamin</b>	<i>Ginny Moon</i>	2017
<b>Macfie Sobol, Julie &amp; Sobol, Ken</b>	<i>Love and Forgetting; A Husband and Wife's Journey Through Dementia</i>	2013
<b>Martin, Ann</b>	<i>Rain reign</i>	2014
<b>Mutch, Maria</b>	<i>Know the Night; A Memoir of Survival in the Small Hours</i>	2014
<b>Saucier, Jocelyn (translated by Mullins, Rhonda)</b>	<i>And the Birds Rained Down</i>	2012 (2011)
<b>Shusterman, Neil</b>	<i>Challenger deep</i>	2015
<b>Solomon, Andrew</b>	<i>Far From the Tree</i>	2012
<b>Stuart, Keith</b>	<i>A Boy Made of Blocks</i>	2016

**Table 6. Final Literary Sample**



<b>Author</b>	<b>Title</b>	<b>Year of Publication</b>	<b>Fiction or Non-fiction</b>	<b>Narrative Perspective</b>	<b>Mental Impairment (s)</b>	<b>Age of Character</b>
<i>Bartók, Mira</i>	<i>The Memory Palace: A Memoir</i>	2011	Non-fiction	Family member & first person	Schizophrenia, brain injury, Alzheimer's disease	Adults
<i>Mutch, Maria</i>	<i>Know the Night; A Memoir of Survival in the Small Hours</i>	2014	Non-Fiction	Family member	Down Syndrome, autism spectrum disorder	Child
<i>Shusterman, Neil</i>	<i>Challenger Deep</i>	2015	Fiction	First person	Unidentified mental health disorder	Youth
<i>Stuart, Keith</i>	<i>A Boy Made of Blocks</i>	2016	Fiction	Family member	Autism spectrum disorder	Child

### ***Policy Sample***

For the purposes of this study, policy texts considered for analysis included legislative acts, policy planning and consultation documents, program evaluations, as well as critical commentaries of disability policies (McCauley, 2011). Additionally, all policy documents considered for analysis have jurisdiction in Ontario (McCauley, 2011). Ultimately 12 policy documents published between the years of 2010 and 2017 were reviewed, as seen in Table 7. The final four policy texts chosen for analysis were selected based on a number of factors including their relevance to and influence over Ontario's political and social landscape, as well as the extent to which they were able to inform the research themes. Consideration was also given to varying the sample in terms of author, and the intended purpose of the policy document. This was a significant consideration as it allowed me to compare and contrast the rhetoric and dominant discourses presented within a policy planning document authored by a government

body versus a policy document authored by an advocacy organization, which may have provided a critical commentary and/or policy evaluation.

**Table 7. Post-Dismantlement Policy Documents and Events**

<b>Author of Text</b>	<b>Title of Text</b>	<b>Year of Publication</b>	<b>Final Sample</b>
<b>Canada Without Poverty</b>	<i>Submission raising issues related to maximum available resources, domestic implementation and effective legal remedies of economic, social, and cultural rights under Article 28 of the Convention</i>	2017	
<b>Court of Appeal for Ontario</b>	Ontario (Disability Support Program) v. Tranchemontagne	2010	
<b>Dubé, Paul (Ombudsman Ontario)</b>	<i>Nowhere to turn: Investigation into the Ministry of Community and Social Services' response to situations of crisis involving adults with developmental disabilities</i>	2016	<input checked="" type="checkbox"/>
<b>Government of Canada</b>	<i>Convention on the rights of persons with disabilities: First report of Canada</i>	2014	<input checked="" type="checkbox"/>
<b>Housing Study Group</b>	<i>Ending the wait: An action agenda to address the housing crisis confronting Ontario adults with developmental disabilities</i>	2013	
<b>Human Resources and Skills Development Canada</b>	<i>Federal disability reference guide</i>	2013	
<b>Ministry of Community and Social Services</b>	<i>Comprehensive government response to the select committee on developmental services</i>	2014	
<b>mmission</b>	<i>Minds that matter: Report on the consultation on human rights, mental health and addictions</i>	2012	<input checked="" type="checkbox"/>
<b>Ontario Human Rights Commission</b>	<i>Policy on preventing discrimination based on mental health disabilities and addictions</i>	2014	
<b>Ontario Human Rights Commission</b>	<i>Policy on ableism and discrimination based on disability</i>	2016	
<b>Select Committee On Developmental Services</b>	<i>Inclusion and opportunity: A new plan for developmental services in Ontario</i>	2014	<input checked="" type="checkbox"/>
<b>Select Committee on Mental Health and Addictions</b>	<i>Navigating the journey to wellness: The comprehensive mental health and addictions action plan for Ontarians</i>	2010	

**Strategies for Validity**

Creswell (2013) recommends that in order to obtain valid findings when engaged in qualitative research, a researcher is required to engage in two validity strategies. Accordingly, I have engaged in both rich and thick description of the data, as well as clarifying researcher bias (Creswell, 2013; 2014). In regards to the use of rich and thick description of the data, I utilize several quotes from varied sources in order to ensure validity of each identified theme or finding. In regards to the strategy of clarifying researcher bias, I identify potential areas of personal bias in the current dissertation's subsection Issues of Personal Biography.

**Addressing Issues of Researcher Bias**

In recognition that simply acknowledging researcher bias does not absolve me of the need engage in reflexive practice, bracketing was utilized throughout the analysis process in efforts to identify preconceptions and/or assumptions that I may hold regarding mental disability and related disability policies (Tufford & Newman, 2012). Specifically, I utilized memoing as a means of engaging in bracketing, referring to the practice of documenting my thoughts and reactions to the data as it was being analyzed (Cutcliffe, 2000 as cited in Starks & Brown Trinidad, 2007; Tufford & Newman, 2012). The purpose of this practice was to assist me in identifying and looking beyond my own preconceptions of mental disability and disability policy in order to understand the essence of a given experience, as presented in the literary and policy discourses utilized for this study (Creswell, 2013; Padgett, 2008; Tufford & Newman, 2012). Moreover, memoing was also used to help identify how the data shaped and altered my understanding of the given social problem throughout the analysis process (Cutcliffe, 2000 as cited in Starks & Brown Trinidad, 2007).

Tufford and Newman advise that bracketing can also help a researcher determine which information is known as a result of a personal experience, as opposed to information learnt through the research and analysis of sample documents (Drew, 2004 as cited in Tufford & Newman, 2012). This was a relevant consideration for myself given that my personal and professional experiences have influenced my understanding and perception of mental disability and disability policy. As a result, it is again asserted that the practice of memoing was effective in assisting me to maintain some separation between my own preconceptions of mental disability and disability policy, versus the discourse as presented within literary and policy texts.

The significance of clarifying researcher bias through the use of bracketing is that it contributes to the validity of research findings. It is asserted that acknowledgement of a researcher's bias can be utilized in the context of critical discourse analysis to help situate the findings of analysis in relation to the data being analyzed and the researcher's preconceptions (Finlay, 2002 as cited in Starks & Brown Trinidad, 2007). The reader can then use this information to ascertain the credibility of findings.

### **Method of Analysis**

A critical discourse analysis framework informs the method of analysis utilized in the current study. However, it is noted that critical discourse analysis does not have one specific methodological format. Rather, it draws upon a number of eclectic methodologies depending on the purpose of research and theoretical understandings of the concepts of discourse and language (Cheek, 2004; Garrity, 2010; Wodak, 2004). As such, the current study adapted methodological steps for analysis based on Fairclough's method of analyzing discourse in social research (2003).

The first step outlined in Fairclough's methodology for discourse analysis consists identifying a social problem that has a semiotic aspect (2003). The social problem identified in

the current study is the marginalization and oppression of persons living with mental disabilities in Ontario, which has been perpetuated throughout history by discriminatory social policies and programs. The semiotic aspect of this social problem, referring to the ways that meaning is constructed and reality is represented through language (Chandler, 2007), includes the examination of how literary and policy discourses use language to signify persons with mental disabilities, and how this signification can serve to create meaning that either reinforces or alters dominant ways of knowing about mental disability.

The second step outlined in Fairclough's critical discourse analysis methodology consists of identifying obstacles to addressing the social issue. Fairclough asserts that consideration should be given to how the social problem arises in society and how it might be rooted in the way in which social life is currently organized (2003). This step of analysis was completed within the literature review, and will be addressed again during the analysis and discussion portion of the dissertation.

The third step of Fairclough's analysis methodology includes examining the ways that the current social order depends on the social problem (2003). Specifically, are there ways in which persons or groups benefit from the current social order? These concerns are again addressed within the literature review, and will be discussed within the analysis section of this dissertation.

The fourth step in Fairclough's methodology consists of identifying possible ways past the obstacles to social change (2003). This step is addressed within the discussion and recommendations portions of the dissertation.

Finally, the fifth step of Fairclough's method for analysis comprises a critical reflection, which requires the analyst to identify her own social location, and how such may impact research findings (2003). Accordingly, I addressed the concern of bias on the ongoing basis through the

use of bracketing, in addition to including the subsection Issues of Personal Biography in the dissertation.

### **Issues of Personal Biography**

Critical discourse analysis ultimately requires the researcher to engage in interpretation of text, and therefore reflexivity is required in order to explicitly identify any researcher bias that may impact upon or influence research findings. In reflecting on how my social location and lived experiences might influence the way that I interpret policy and literary texts the following information is disclosed.

I am a resident of Ontario, specifically a northern and rural community. I am not living with a mental disability, nor am I a caregiver for a family member who is living with a mental disability. At the outset of my research, I had identified that I did not have any family members living with a mental disability. However, recently I became aware that my grandfather had been diagnosed with dementia prior to his passing in January 2018. I was not in a caregiving role for him while he was alive, rather he resided in a long-term care facility. In discussing with my father why he had chosen to conceal my grandfathers' diagnosis and the ways that mental disability had effected his behaviour from family, friends, and in some cases service providers, it became apparent that fear of stigma and discrimination was of significant concern to him. This personal experience has since shaped my understanding of the ways in which stigma can lead to isolation and marginalization for persons living with mental disabilities, as well as their caregivers.

Professionally, I have worked with persons with mental disabilities in a number of capacities. My experiences include being a one-on-one support worker for a child with an autism spectrum disorder in a school setting, working in a community living group home, working as a

counselor with children and youth who are diagnosed with various mental disabilities; and finally, I have worked as a child protection worker with families wherein the caregiver and/or children were living with a mental disability.

In my current role as a counselor with children and youth, I have worked with individuals and families who experience stigma, stereotypes, gaps in services, and barriers to inclusion. I have worked with families who have an enormous capacity for care and compassion, but have also witnessed the weight of responsibility placed on persons who care for individuals living with a mental disability. I have unfortunately seen families struggle with emotional and financial stress, leading to family breakdown in some situations. As a service provider I have also faced numerous situations wherein I am unable to fully meet the needs of an individual or a family due to significant gaps in services, and the long wait lists present in the northern and rural communities where I work.

Lastly, as a practicing social worker and a registered member of the Ontario College of Social Workers and Social Service Workers, I strive to engage in social work practice and social work research that adheres to the College's code of ethics and standards of practice. As a result, I hold a vested interest in respecting the inherent worth of all persons and advocating for service-users needs at an individual, community and global level (OCSWSSW, 2008).

Again it is asserted that issues of personal biography are addressed on an ongoing basis through the practices of reflexivity and bracketing, as informed by Ahern (1999), Creswell (2013; 2014), Starks and Brown Trinidad (2007), as well as Tufford and Newman (2012). This step was considered to be integral in the method of analysis utilized for the present study.

**Ethical Considerations**

The current study is a critical discourse analysis utilizing public documents and novels, and therefore does not require me to interact with any human participants or confidential information. As such there were limited ethical considerations to address during the research. Specifically, as the literary and policy texts utilized are available to the public; it was not necessary to obtain further consent to use the documents for analysis, nor was it necessary for the study to be evaluated by Laurentian University's Research Ethics Board. At this time, appropriate documentation and referencing of sources are the only necessary steps to ensure ethical use of information.

Additional ethical considerations that pertain to this study include considerations for how the research may impact upon social, cultural, and policy discourses of disability in Ontario. It is not anticipated that the research findings will negatively impact persons living with mental disabilities. Nevertheless, I will engage in reflexive and anti-oppressive practice to avoid contributing further to any discriminatory and oppressive discourses regarding this marginalized population. In completing my analysis, this will entail being reflexive of my own social location and potential biases in analyzing the data (Probst, 2015). Alternatively, within my findings and recommendations this will involve the dissemination of actionable knowledge that can be used to address the oppression experienced by persons living with mental disabilities in Ontario, with the intention of contributing to social change (Strier, 2007).



### **Analysis**

As informed by Fairclough's (2003) methodology for critical discourse analysis, the following chapter will begin by identifying and outlining the social problem being addressed throughout the research. Subsequently, a brief overview of key policy and literary texts published within the post-dismantlement phase of Ontario's institutional cycle will be provided. Finally, a more detailed analysis of research findings will be presented within the four key themes of analysis, as adapted from McCauley's (2011) research. The themes include how stories of disability are told, the role of families, community roles and responsibilities, and the perception of institutions (McCauley, 2011).

#### **Defining the Social Problem**

Persons living with mental disabilities in Ontario have experienced a history of marginalization and structural oppression. Despite reforms to federal and provincial legislation, which now guarantee the rights of all persons living with disabilities, discrimination as well as social and economic marginalization continue to be significant issues for this population. Specifically, persons living with mental disabilities in Ontario continue to experience a number of barriers to social and economic inclusion including stereotyping, limited access to support services such as transportation, difficulty obtaining paid employment as well as safe and affordable housing, barriers to engaging in education, and limited provision of benefits (OHRC, 2012; OHRC, 2014; OHRC, 2016).

#### **Analysis of the Post-Dismantlement Phase of Ontario's Institutional Cycle, 2010-Present**

Following the closure of institutions dedicated to the care of persons with mental disabilities during the dismantlement phase (1987-2009) of Ontario's institutional cycle, the

province has continued to struggle to meet the needs of this marginalized population through community-based initiatives (Dubé, 2016; McCauley, 2011; OHRC, 2012; Select Committee On Developmental Services, 2014). With the intention of “upholding and safeguarding the rights of persons with disabilities and enabling their full participation in society” Canada ratified the UN’s Convention on the Rights of Persons with Disabilities on April 12, 2010 (Government of Canada, 2014, p. 1). In their report, *Convention on the Rights of Persons with Disabilities: First Report of Canada*, the Government of Canada asserts their commitment to addressing barriers to full participation in society as experienced by persons with mental disabilities, including issues of language and communication, advancing education and training opportunities, and addressing issues of safety and security.

Yet, despite an alleged nation-wide commitment to social and economic inclusion for all persons with mental disabilities, Ontario continues to grapple with the development of legislation and policy initiatives that will effectively ensure the province is able to meet their obligation to this population, as outlined in the UN Convention. Within the Select Committee On Developmental Services’ report, *Inclusion and Opportunity: A New Path for Developmental Services in Ontario*, a number of issues are raised regarding the inability of the province’s current policy and program initiatives to account for long wait lists for services, poor transitions from youth to adult services, limited supports in northern and rural regions, and a lack of available services such as housing and educational services, therapeutic interventions, day programs, and respite care (2014). Moreover, the committee recognizes a disturbing disconnect between the province’s legislation, which asserts all persons have a right to full social inclusion and to receive services and supports without delay, and the reality that persons living with developmental disabilities continue to experience extensive barriers to participating fully in

society and accessing necessary supports such as housing, education and employment services, respite care, and therapeutic interventions (Select Committee On Development Services, 2014; SIPDDA, 2008).

The Select Committee on Developmental Services is not alone in their critique of Ontario's disability policies. A number of other policy reports have been put forth within the post-dismantlement phase of Ontario's institutional cycle, by both advocacy groups and government bodies including Ombudsman Ontario, the Ontario Human Rights Commission, and the Select Committee on Mental Health and Addictions (CWP, 2017; Dubé, 2016; OHRC, 2012). These reports have consistently identified glaring gaps in service within Ontario's current policies and programs, and offer recommendations for policy development and implementation related to goals of social and economic inclusion, including equitable access to education, employment, housing, and support services (CWP, 2017; Dubé, 2016; Housing Study Group, 2013; OHRC, 2012; OHRC, 2014; OHRC, 2016; Select Committee on Mental Health and Addictions, 2010).

Literature published in the post-dismantlement phase of Ontario's institutional cycle largely reflects issues presented within policy papers. Specifically, texts published within this period often explore barriers to accessing community-based services, as well as experiences of discrimination and marginalization. Moreover, it is noted that as concepts such as "nothing about us without us" continue to gain momentum in the field of disability policy, literary texts authored by persons living with mental disability and their families are also gaining prominence. In reflecting on this shift in perspective, both fiction and non-fiction literary sources were considered for analysis.

### How Stories are Told

There is evidence in both the literary and policy texts published during the post-dismantlement phase of Ontario's institutional cycle that it is preferable, when possible, for persons living with mental disabilities to tell their own stories and advocate for their own interests. In Mira Bartók's *The Memory Palace: A Memoir*, she describes not only her own first-hand experiences of mental disability but also describes her experiences of having a mother who lived with schizophrenia, and a grandmother who lived with Alzheimer's disease (2011). Bartók draws upon her own memories, as well as her mother's journals in order to inform her story. Furthermore, when possible, Bartók includes excerpts from her mother's journals in order to give voice to her mother's own lived experiences and perspectives of their shared history (Bartók, 2011). Similarly, in *Love and Forgetting: A Husband and Wife's Journal Through Dementia*, Ken Sobol participates in the writing of the couple's memoir until he is no longer able to as a result of his dementia (Macfie Sobol & Sobol, 2013). Ken's wife, Julie Macfie Sobol, somewhat begrudgingly continues their project independently once he is no longer able to participate, noting that "...in doing so I speak as carefully for him as I am for myself, and, with the help of quotes from my note-taking, letting him speak as much as possible in his own words" (p. 103). The credence given to the first-person account of mental disability within these memoirs suggests that despite an advocate's best intention to speak for and explain the interests of their family member, it is never as accurate as when the words can come directly from the individual.

The appreciation that a first-person perspective is most desirable in understanding the lived experiences of persons with mental disabilities continues to be prevalent within the fiction genre of literature as well. In the novel *Challenger Deep*, Neal Shusterman writes his story from the perspective of Caden, a youth who is developing symptoms of an unknown mental health

disorder, referred to at various times throughout the narrative as psychosis, schizophrenia, bipolar disorder, or *The Mental-Illness-That-Must-Not-Be-Named* (2015). Despite their best intentions, family members and professionals involved in Caden's care do not always give value to his perceptions and opinions. In discussing the experience of living with mental illness, Caden agrees with another youth's assertion that: "...the only people who really understand are the ones who've been to That Place too. It's like a man telling a woman he knows what it feels like to give birth" (p. 181).

In the novel, *A Boy Made of Blocks*, although the story is told from the perspective of Alex, a character whose son Sam is diagnosed with an autism spectrum disorder, on the rare occasion where Sam is able to clearly voice his thoughts and feelings to his father it is described that Alex "treasures them like jewels" (Stuart, 2016, p. 289). Moreover, after the parents' prolonged struggle in deciding what school would be best for Sam, Alex inevitably asserts that "Sam told us which school would make him happy and we believed him" (p. 383). Both of these examples convey the author's belief that the words of an individual living with a mental disability should be given authority, and suggest that such a first-hand perspective is of highest significance. Moreover, his portrayal of Sam provides acknowledgement that an individual's thoughts and concerns should be taken into account when making decisions that impact their life. This is a significant cultural comment, in that the values Stuart expresses through the narrative are in fact representative of current society values in so far as the reader is able to relate to them and invest in the story (Brunner, 2002; Iyer, 2007; McCauley, 2011). Related to this, Stuart's narrative continues to have the opportunity to shape dominant cultural norms and social values moving forward (Iyer, 2007).

Following the example set within literary discourse, policy documents consistently identify consultation with the disability community as an integral component to policy development (Dubé, 2016; Government of Canada, 2014; OHRC, 2012; Select Committee On Developmental Services, 2014). Moreover, in completing assessments of current policies and programs regarding mental disability, three of the four policy documents consulted directly with persons living with mental disabilities and their families (Dubé, 2016; McCauley, 2011; OHRC, 2012; Select Committee On Developmental Services, 2014). The concept of “nothing about us without us” was a prevalent theme throughout these three policy documents (Select Committee on Developmental Services, 2014). This is a significant shift in perspective from the establishment and reform phases of Ontario’s institutional cycle wherein professionals were considered expert.

However, there are limitations to the ways that service-user consultations were utilized to inform policy recommendations in both Dubé’s (2016) report as well as the Select Committee on Developmental Services’ (2014) report. Specifically, neither report clearly identifies which concerns family members and advocates voiced and which the individuals themselves voiced. In fact, only one policy document actually utilize direct quotations from persons living with mental disabilities throughout their text (OHRC, 2012). The choice to consult directly with persons living with mental disabilities is a successful strategy in giving a voice to an otherwise marginalized group, and exemplifies that individuals living with mental disabilities are legitimate sources of knowledge and deserve to have their concerns heard.

Significantly, it is noted that the one policy text which does not directly consult with persons who are living with a mental disabilities regarding policy changes is the policy document Convention on the Rights of Persons with Disabilities: First Report of Canada (Government of

Canada, 2014). This is of concern, given that it is a government authored policy document. Although there are certainly legitimate barriers to including first-hand perspectives within policy planning initiatives, specifically in situations where an individual is living with substantial cognitive or communicative impairment, such should not negate the government's obligation to seek out consultation from persons living with mental disabilities and/or disability advocates. There is an ongoing need for disabilities activists, inclusive of persons living with mental disabilities, to take on an active role in policy planning and consultation. In fact, advocates for disability rights caution that intentionally excluding service-user consultation from policy planning initiatives may be reflective of a neoliberal political agenda (Burghardt, 2017; Levesque & Langford, 2016). Specifically that government bodies who favour corporate interests may seek to prosper from the province's current social and economic conditions, which unfortunately serve to oppress persons living with mental disabilities in order to achieve larger goals of efficiency and production (Burghardt, 2017; Levesque & Langford, 2016).

Nevertheless, the overall trend towards consumer control and inclusion is apparent in a number of policy documents and literary texts in the post-dismantlement phase of Ontario's institutional cycle. Admittedly, this trend largely began in the dismantlement phase of the cycle, wherein there were increased incidences of direct consultation utilized to inform policy planning. Fortunately the movement has continued to gain prominence in the post-dismantlement phase of Ontario's institutional cycle. Specifically, some literary narratives are beginning to challenge the medical model perspective of mental disability in that disability is increasingly being portrayed as a different way of being rather than a deficit. Similarly, policy narratives have started to identify that barriers to inclusion are experienced as a result of systems issues, not personal deficits. As a result of this shifting perspective, literary narratives in the post-dismantlement

phase of Ontario's cycle are able to explore experiences of pride in living with a mental disability, and the perception that the lives of persons living with mental disabilities are as meaningful as any other. The following passage, taken from *Love Anthony*, explores the meaning that Anthony assigns to his life:

I came here simply to be and autism was a vehicle for my being. Although my short life was difficult at times, I found great joy in being Anthony. Autism made it difficult to connect with you and Dad and other people through things like eye contact and conversation and your activities. But I wasn't interested in connecting in those ways, so I felt no deprivation in this. I connected in other ways, through the song of your voices, the energy of your emotions... [you] kept me safe and happy and wanted and it existed beyond words and hugs and eyes. (Genova, 2012, pp. 301-302)

The passage seems to suggest that although there may be a tendency for persons to look in on Anthony's life and assign it a lesser value as a result of the differences in his functioning, Anthony asserts that his life was meaningful and worthwhile.

Another theme, that emerged in regards to how the stories of persons living with mental disabilities are told, is the trend for families to act as narrators for their loved ones living with mental disabilities. This paradigm was generally employed when the individual is seemingly unable to narrate their own story, often as a result of limitations related to their experience of mental disability. In *Know the Night: A Memoir of Survival in the Small Hours* Mutch (2014) describes her experience of having to speak for her son Gabriel who is diagnosed with Down syndrome as well as an autism spectrum disorder:

His intelligence was, and still is, much greater and more nuanced than his small vocabulary would allow. But with the exodus of his words, the burden of proof would lay



itself more and more in R's and my hands. We would find ourselves having to defend his intelligence, what amounts to character and essence of being, to argue the obvious: that a mind is much more than words. (p. 52)

The tendency for family members to tell the stories of their loved ones is reflected in policy documents as well. Specifically, Dubé (2016) as well as the Select Committee on Developmental Services (2014) utilize interviews with families as a means of informing policy recommendations. Although the effort to include the perspectives of persons living with mental disabilities is seemingly well intentioned and may, in fact, lead to better policy outcomes, it does raise concern for the possibility that family members may not actually be fully aware of the interests of their loved ones. In fact it is entirely possible that the thoughts and concerns of the caregiver may vary from that of the service-user.

Related to this issue, throughout a number of literary texts family members frequently describe their frustrations with trying to interpret and understand the wants and needs of their loved ones. Mutch (2014) discusses her own sentiments and longing to communicate with her son Gabriel stating, "The mind wants so badly to understand, to *get it*, that it will chase meaning relentlessly, pursue it straight through the dark...I think that if I knew what he wanted, I would give it-anything" (p. 49). Julie Macfie Sobol discusses a similar frustration in trying to understand her husband's wants and needs as he becomes increasingly limited by dementia:

When people inquire politely about how Ken is doing, I manage a few words about how he "looked" or "seemed" that week. It's not hedging: as close as we have been for so many years (and in some hard-to-define way still are), I don't know what goes on in his head now. At least, not often...I can study his face all I want; I can observe, listen, and

try to understand, but beyond the occasional fleeting smile or flash of anger, it's anyone's guess. (Macfie Sobol & Sobol, 2013, p 88-89)

This theme continues in fictional literary texts as well. In this excerpt from *Love Anthony*, the reader is provided with a glimpse into Anthony's thoughts regarding the way autism affects his ability to communicate, as well as how it influences his family's perception of his abilities:

I'm always hearing about how my brain doesn't work right. They say my brain is broken. My mother cries about my broken brain, and she and father fight about my broken brain, and people come to my house every day to try and fix my broken brain. But it doesn't feel broken to me... Broken things are ruined and go in the trash... I wish I could tell them that my brain isn't broken so they would stop crying and fighting and people could stop coming to my house to fix me. They make me tired... I wish I could tell my mother and father that my voice is broken but my brain is working, but I can't tell them because my voice is broken. I wish they'd figure it out on their own. (Genova, 2012, pp.132-134)

This passage gives voice to the fact that despite their best intentions, family may not always have an accurate understanding of their loved one's experiences. Specifically, it's evident that Anthony's family does not understand how he feels, and do not always act in accordance with his wants and needs. The underlying message of the passage raises concern for whether or not family members are always able to advocate for the interests of their loved ones living with mental disabilities.

Furthermore, the excerpt gives rise to another issue. Anthony describes his brain works fine, and perceives his limitation to be that his family does not understand how his mind works (Genova, 2012). And so, Anthony tells his story from the viewpoint that he functions not worse but differently than others; a perspective which is seemingly in line with the social model of

disability, wherein barriers to inclusion are understood to arise not as a result of personal deficit but as a result of environmental impairments. This suggests the need for policies that will address environmental and social barriers to inclusion, as opposed to trying to fix the individual.

Yet, overwhelming within many other literary texts, family members continue to tell their loved ones' stories from the perspective of mental disability as impairment. For example, in her memoir *Know the Night: A Memoir of Survival in the Small Hours* Maria Mutch (2014) refers to mental disability as a thief of Gabriel's abilities, while in *A Boy Made of Blocks* Alex asserts that autism stole Sam's future and is to blame for his undesirable behaviours (Stuart, 2016).

Moreover, Maria Bartók even describes herself and her struggles with a brain injury from a perspective of deficit stating that her mind is a "ghost image" of what was once there (2011, p. 4). Despite an apparent need to separate the love for the individual from the dislike of impairment, Stuart's character, Alex, is perhaps correct in his realization that an individual's story cannot be told from the perspective of their limitation or impairment.

...I have this strange, shocking moment of clarity: Sam is a human being, separate from me, separate from even Jody. He's not a problem to be solved, a dink in my scheduling, another worrying element of my daily 'to do' list. He's a person, and somewhere in his head are his own ideas, his own priorities, his own ambitions for the future. It's amazing how easy it has been to overlook all that amid everything going on, amid the struggles with autism, the daily battles over schools and food and clothing. He's a person - he wants things, he wants to understand his place in the world. And what I should do is help him. Sam isn't merely something that happened to me. (2012, p. 223)

Ultimately, the novels and memoirs published in the post-dismantlement phase of Ontario's institutional cycle are still very much influenced by the medical model understanding

of mental disability, in that impairment is often seen as a personal deficit, to be fixed if possible. However, in some instances, authors are beginning to grapple with a perspective of mental disability that is more reflective of the social or post-social model of disability, in that the impairment is not conceived as a personal deficit. Instead, there is occasion to understand not only the impairment as experienced by the individual living with a disability, but also to acknowledge the ways in which social norms create and maintain disabling experiences. A similar shift in our understanding of impairment and mental disability is seen within policy papers, in that barriers to inclusion are being identified as systems issues rather than as problems with the individual. However, it continues to remain unclear the extent to which this will translate into meaningful changes for individuals living with mental disabilities and their families.

### **The Role of the Family**

A prevalent theme throughout literary and policy documents is that of mental disability being a burden on the family. Examples of caregiver exhaustion, emotional and financial stress, mental health issues, marital discord, family conflict, powerlessness, isolation, hopelessness, as well as a sense of envy for the 'normal' are rampant throughout both fiction and nonfiction literary texts (Bartók, 2011; Genova, 2012; Macfie Sobol & Sobol, 2013; Mutch, 2014; Shusterman, 2015; Stuart, 2016). As described in Shusterman's (2015) *Challenger Deep*, one cannot discount what a family goes through in efforts to support and care for a loved one living with a mental disability. In reference to the burden of caring for someone living with a mental disability, Caden describes his perspective of his parents' attempt to care for him since the development of his mental health issues:

...they are helpless. They want to do something, anything, to help me. Anything to change my situation. But they are as powerless as I am. The two of them are in a lifeboat, together, but so alone. Miles from shore, yet miles from me. The boat leaks, and they must bail in tandem to keep themselves afloat. It must be exhausting. The terrible truth of their helplessness is almost too much to bear. (Shusterman, 2015, p. 266)

Similar descriptions of exhaustion, stress, isolation and powerlessness are found within three of the four policy documents (Dubé, 2016; OHRC, 2012; Select Committee on Developmental Disabilities, 2014). The Select Committee on Developmental Disabilities explicitly identifies the need for policy reform as related to the lack of support experienced by many families attempting to access services in Ontario: “We heard that after struggling to obtain services and enduring waitlists for years, many families feel pushed to the brink of disaster” (2014, p.3). Within Ombudsman Ontario’s review of crisis situations involving adults with developmental disabilities, Dubé cites that caregiver exhaustion predictably lead to abandonment and homelessness for persons living with mental disabilities (2016). Moreover, Dubé describes situations where caring for an adult with a mental disability has lead family members to suffer health problems, to feel helpless, to feel “exhausted beyond belief... and at our breaking point” (p.47), in addition to experiencing a number of mental health issues including panic attacks, depression, and suicide ideation. The concept of families being burdened by mental disability is, in fact, evident from the title of the report alone, *Nowhere to Turn*, implying the feeling of isolation is widespread among individuals living with mental disabilities and their families (Dubé, 2016). One family, desperate for assistance, wrote the Ministry of Community and Social Services stating:

We have been following the rules for years. We need a placement now, or else our son will end up homeless in a crisis. We are not able to care for him any longer. I am on sick leave from work as I am unable to function anymore. PLEASE HELP. (as cited in Dubé, 2016, p. 106)

The intense and often overwhelming pressure placed on families to care for their loved ones living with mental disabilities can result in a strained relationship between the individual and his/her caregivers. This is exemplified by feelings of resentment towards the individuals experiencing the impairment and/or feelings of guilt for not being able to meet the needs of a loved one, as identified in both policy and literary texts (Bartók, 2011; Dubé, 2016; Macfie Sobol & Sobol, 2013; Mutch, 2014; Shusterman, 2015; Macfie Sobol & Sobol, 2013; Stuart, 2016). Furthermore, the individual living with a mental disability may be isolated within the family, or in fact may be abandoned completely (Bartók, 2011; Dubé, 2016; Macfie Sobol & Sobol, 2013; Mutch, 2014; Shusterman, 2015; Stuart, 2016). In her memoir *Know the Night: A Memoir of Survival in the Small Hours* Maria Mutch (2014) describes the dissonance between her actual feelings regarding parenting and cultural expectations: “Parenthood delivers with it an assumption of strength, knowing what to do, how to rescue. How not to hate him. How to reach in and find a boy, and the knowledge wasn’t there. Just paralysis, guilt, a breaking heart” (p. 60).

Similarly, in her memoir *The Memory Palace: A Memoir*, Bartók also struggles with feelings of guilt regarding her decision to abandon her mother after several failed attempts to secure guardianship of her (2011). Bartók and her sister subsequently decide to legally change their names, so that they can not be found by their mother. Regarding this decision, Bartók shares her feelings of guilt and shame: “How could we explain that we had changed our names so she could never find us? That we had been so scared of her all these years? She was the cry of

madness in the dark, the howling of wind outside our doors” (Bartók, 2011, p. 16). Bartók appears to feel that despite years of caring for her mother, both as a child and as an adult, after having dealt with neglect, verbal and physical harassment, as well as violent and threatening outburst and erratic behaviours she would be judged (and would judge herself) for her decision to end contact with her mother. Again, in regards to her decision to change her name Bartók states:

The day I went to the courthouse in Chicago, the judge asked me to declare why I was changing my name. “I’m a writer and have decided to take my pen name as my own.” How easy it was to lie, make up a different identity with a new Social Security card, new credit cards and picture IDs. What if I had told the truth: “I am changing my name because I don’t want my mother to find me. I don’t want to take her in and support her, keep vigil all night so she doesn’t set my furniture on fire. I am changing my name because I am selfish.” (Bartók, 2011, p.184)

The excerpt exemplifies a personal, and ultimately cultural assumption: that family members are responsible for caring for their loved ones and should feel shame for failing to do so. Notably this is a consistent finding within the dismantlement phase of Ontario’s institutional cycle as well, where institutionalization is often portrayed as a failure of the family to care for their loved one (McCauley, 2011). In fact the notion that families should act as the primary caregivers for their loved ones living with a mental disability arguably took root in the establishment phase of the institutional cycle, wherein caring for an individual living with a disability was frequently depicted within literary texts as being morally correct and personally gratifying for caregivers (McCauley, 2011).

This dynamic is again exemplified in the post-dismantlement era when Bartók describes the difficulties she encounters when trying to ensure her mother (who is living with schizophrenia) and grandmother (who is living with Alzheimer's disease) are being cared for appropriately through community-based services, as she and her sister do not live in the same city as they do. When Bartók meets with her mother's social worker to discuss options for treatment and housing, she notes:

I strongly suspect that she thinks my sister and I should move back home. "Families should try to stay together, no matter what," she tells me when she picks me up at the house. She prides herself on keeping homes intact... (Bartók, 2011, p. 134)

In fact not only are families expected to care for their loved ones living with mental disabilities, they are expected to act as experts in and advocates for their care. Julie MacFie Sobol shares that prior to her husband's diagnosis of Lewy Body Dementia she had little knowledge of the disease or the related services: "Things are radically different now; during those three years our family has gained the equivalent of a group PhD in LBD and its debilitating effects on the personality..." (Macfie Sobol & Sobol, 2013, p. 146). Ultimately, families are the first line of support for persons living with mental disabilities. Throughout literary and policy discourses it is apparent that families are responsible for the majority of caregiving, and as such must become experts on their loved one's needs in order to advocate for and assist them as best possible. Accordingly, Maria Mutch provides a glimpse into her own journey in learning about Gabriel's diagnosis and searching for a 'cure':

I knew a good opportunity to enslave myself when I saw one. Gabriel had to be saved and it was up to me to do the saving, and so I waded, dragging R along with me, through therapies and books and workshops, and ticked through activity lists for each area of



development - speech, gross motor, fine motor - that I tacked up on the fridge. (2014, p. 168)

This theme is present in fictional narratives as well. In Shusterman's *Challenger Deep*, Caden describes his wellbeing as being directly related to his family's intervention and support; likening his situation to that of a kid who falls into a well and is in need of rescue (2015). The following passage speaks to the fact that persons living with mental disabilities are often dependent on their families.

If the kid is lucky, and the dog isn't too stupid, people find out in time, and they get someone with no collarbones to go down the well and fish the kid out. Then the no-collarbones guy gets to spend the rest of his life feeling there was a reason he was born with no discernible shoulders, and the rescued kid gets to pass his genetic material on to future generations. If the kid isn't lucky, then he dies down there, and the tale ends sadly... There are times I feel like I'm the kid screaming at the bottom of the well, and my dog runs off to pee on trees instead of getting help. (pp. 81-82)

Similar sentiments are observed in policy documents. The following passage from *Minds that Matter: Report on the Consultation on Human Rights, Mental Health, and Addictions* speaks to the idea that persons living with mental disabilities continue to be very much dependent on family members for support despite the Province's alleged commitment to policies and programs that prohibit discrimination and ensure social and economic inclusion.

What has allowed for my accomplishments and some semblance of a quality of life distinctly relates to supportive family and class... But take that security away and my mental health would deteriorate very fast. I could very well be homeless – there were periods of time when I couldn't organize my thoughts to eat properly. The fact that in a

province like Ontario people with invisible disabilities can be penalized for being ill is in itself a poor testament to our human rights. (Survey respondent as cited in OHRC, 2012, p. 25)

Despite consistently advocating for the advancements of policies and programs that are community-based and will allow for persons living with mental disabilities to participate fully in society and enjoy both social and economic inclusion, the implied reliance of the individual on their family cannot be denied. Yet this is not a new phenomenon. During the dismantlement phase of Ontario's institutional cycle there is a notable dissonance between prominent policy discourse which assert that parents are the best advocates for their children living with mental disabilities, and literary narratives which explore the reality that not all caregivers are able to appropriately or effectively advocate for their family members (McCauley, 2011). In fact, the role of the family, as portrayed within literary and policy texts has not evolved significantly during the post-dismantlement phase. Despite continued acknowledgement that families require greater support in caring for their loved ones living with mental disabilities, there is little evidence within policy and literary texts to suggest that any significant changes in service provision have been made. Perhaps the most significant variance in the role of the family as portrayed in the dismantlement versus post-dismantlement phase of Ontario's institutional cycle is that literary and policy texts no longer imply that institutionalization is a failure of the family. In fact, it seems to be more commonly accepted or understood within both literary and policy texts that a chronic lack of support from community services and/or institutions can and will lead to the abandonment of persons living with mental disabilities.

Still, policy documents published in the post-dismantlement phase of Ontario's institutional cycle consistently refer to "persons with disabilities and their families" throughout

their texts, affirming to the cultural assumption that families, not communities, are responsible for the care of individuals living with mental disabilities (Dubé, 2016; Government of Canada, 2014; Select Committee on Developmental Services, 2014; Select Committee on Mental Health and Addictions, 2010). This is a problematic assumption that can result in situations of crisis and abandonment for individuals living with a mental disability (Dubé, 2016; Select Committee on Developmental Services, 2014; Ontario Human Right's Commission, 2012). Furthermore, the burden of care that is placed on family members can contribute to a number of negative outcomes for the caregivers themselves including the development of health and mental health issues, experiences of exhaustion and financial stress, as well as feelings of guilt and shame (Dubé, 2016; Select Committee on Developmental Services, 2014; Ontario Human Right's Commission, 2012). Despite consistent evidence of the above, during both the dismantlement and post-dismantlement phase of Ontario's institutional cycle there remains little evidence that policies and service provision have evolved to address these issues. The lack of policy response suggests that assuming greater accountability for persons living with mental disabilities is simply not a priority for the province.

### **Community Roles and Responsibilities**

As discussed above, families are often considered the primary caregivers and most significant support (sometimes the only support) for persons living with a mental disability. Related to this, a theme that is prominent throughout both literary and policy texts is that of community supports being accessed only when the individual's needs are too great for the family. In *Love and Forgetting: A Husband and Wife's Journey Through Dementia*, Julie Macfie Sobol describes how her husband's dementia worsened to the point that, despite their best efforts, she and her children were no longer able to care for Ken at home, yet trying to access

long-term care services proves to be very difficult (Macfie Sobol & Sobol, 2013). In the following passage Julie Macfie Sobol describes being approached by a Community Care Access Centre liaison worker trying to convince her to take Ken home from the hospital:

So I listened to Susan's glowing description of the "Ageing at Home" plan, but it sounded too much like a vacuum cleaner sales pitch to be convincing. Every time I attempted to describe our failed attempt at home care – the attack on Lori, and the catheter disaster – it brought on another paean to the program's advantages. Partial payment for hospital bed rental! More hours of personal care! These sounded fine as far as they went, but the offer was somehow detached from our reality, as though Ken's multi-faceted needs, and my health, were annoying irrelevancies. (Macfie Sobol & Sobol, 2013, p. 189)

Related to the assumption that families should be the primary caregivers for persons living with mental disabilities, both literary and policy texts consistently and overwhelmingly describe a lack of support services and/or limited availability of community services. In her narrative *The Memory Palace: A Memoir*, Mira Bartók describes a number of scenarios wherein the lack of community services and supports for persons living with mental disabilities hold serious consequences for her family, resulting in situations of crisis, abandonment, and homelessness (2011).

Within policy texts it is also apparent that community services are simply not accessible enough to families, in large part due to long wait lists and poor continuity of services across service sectors (Dubé, 2016; Select Committee on Developmental Services, 2014; Select Committee on Mental Health and Addictions, 2010). As a result, goals of social and economic inclusion are simply not being realized with current public policy, as many people with mental

disabilities continue to live in poverty, and are segregated from their communities (Canada Without Poverty, 2017; Housing Study Group, 2013; Select Committee on Developmental Services, 2014). As described by an individual in *Minds that Matter: Reports on the Consultation on Human Rights, Mental Health and Addictions*, “[t]here is a system there but accessing it is almost impossible” (Participant in Toronto roundtable session, as cited in OHRC, 2012, p. 86). Moreover, uncoordinated service delivery often leads to a disconnect between an individual’s needs and what is available: “I find sometimes that mental health services can be very specific – if you do not fit in the category for what you need help with, then you fall through their cracks and lose the help you need” (Participant in North Bay roundtable session, as cited in OHRC, 2012, p. 75). First-person accounts such as these depict the difficulty faced by many Ontarian’s in trying to access community-based services.

A third theme found in relation to persons living with mental disabilities and their relationships with their respective communities is experiences of shame, discrimination, marginalization, and isolation. In *Know the Night: A Memoir of Survival in the Small Hours* Maria Mutch describes how isolation and discrimination began for her and her son Gabriel as soon as he was born:

The diagnosis is both important and not. It is important in that he arrived signifying difference. His entrance was enough to generate a slow-motion tumult in the room, one that gathered speed when it became apparent that he couldn’t breathe. The doctor and nurses withdrew him like a magic trick, a flick of a cloth and he was gone to the intensive care unit. But this wasn’t the only disappearing act: the doctor, one of the three women who shared a practice, and who was the first to hold him, began without my realizing it, to recede. We never saw her again – not once. But his diagnosis is also insignificant

because it was only one of the numerous that would follow, like beads on a string.

(Mutch, 2014, p.9)

The pattern of discrimination is one that unfortunately continues throughout Gabriel's life:

I don't often encounter people who think they are equal to him. I've seen other people with developmental delays, no doubt defaulting to what they're used to receiving, condescend to him. He is, as poet Donald Hall wrote of old people, "permanently other".

(Mutch, 2014, p. 188)

The diagnosis or label of a mental disability is, in itself, enough to signal difference. This is a theme that presents itself in a number of literary texts. In *Challenger Deep*, Shusterman portrays how the words associated with mental disability carry significant baggage; so much so that Caden describes them as "Words that people feel they have to whisper, or not repeat at all. The Mental-Illness-That-Must-Not-Be-Named" (2015, p. 213). Furthermore, in struggling to come to terms with his own mental illness, Caden discusses his changed outlook on the future:

There are times I can imagine people who know me looking back ten years from now, and saying things like "He had such potential" and "What a waste"... The fear of not living is a deep abiding dread of watching your own potential decompose into irredeemable disappointment when 'should be' gets crushed by what is. Sometimes I think it would be easier to die than to face that, because 'what could have been' is much more highly regarded than 'what should have been'. Dead kids are put on pedestals, but mentally ill kids get hidden under the rug. (Shusterman, 2015, p.168)

The experience of these types of prejudices are also expressed in policy texts, where service-users report that they are often victims of stereotyping, including being described as lazy, violent, unpredictable, and as "less than" others (OHRC, 2012). Such stigma persists despite

policy documents and legislation that specifically prohibit discrimination (Government of Canada, 2014; Human Rights Act, 2010; OHRC 2014). The reality is that these discriminatory attitudes have a long been engrained in the province's social and political culture, and are arguably a legacy of prominent policy discourse during the establishment phase of Ontario's institutional cycle. Current policy and literary discourses demonstrate that society has not been able to move past discriminatory stereotypes historically associated with mental disability. This is perhaps due to a lack of leadership on the part of government agencies, in that the province continues to provide insufficient support and limited resources to address the needs of this population, suggesting that such is of low priority on the political agenda (Dubé, 2016; OHRC, 2012).

Fortunately, community supports and services are not always negatively experienced by persons living with mental disabilities and their families. In fact, in both fiction and non-fiction narratives there are descriptions of informal community supports and experiences of inclusion. Such supports might come in the form of a helping neighbor, a parent group, or a group of peers who share similar mental impairments and/or life circumstances (Bartók, 2011; Macfie Sobol & Sobol, 2013; Mutch, 2014; Stuart, 2016). Bartók (2011) describes the friendships her mother made while residing in community shelters, and how the women with whom her mother built relationships with became informal supports in her life, and vice versa. These same women also help to care for Norma in her final days, "The women congregate around her bed. They massage her feet and hands, offer her spoonfuls of applesauce, and treat her 'like a baby'. They love her and see in her a kind of wisdom I never imagined she had." (p. 273). The utility of these informal supports is also seen within policy texts, where parent lead initiatives for care and support are

identified as a desirable source of intervention (Dubé, 2016). Although such scenarios may rise of out necessity, their value cannot be denied.

Finally, it is evident in both literary and policy texts that a number of community-based services are utilized by persons living with mental disabilities and their families, and can be experienced positively. Such services may include in-home therapies, social workers, personal care workers, day programs, family practitioners, meals on wheels, community centers, out-patient mental health services, speech therapy and ABA therapy (Bartók, 2011; Genova, 2012; Macfie Sobol & Sobol, 2013; Mutch, 2014; Stuart, 2016). The use of these services is also reflected in policy texts (Government of Canada, 2014; Select Committee on Developmental Services, 2014), however, the availability of community-based interventions remains questionable. Consider, for instance, that in order for adults living with developmental disabilities in Ontario to access the funds that will allow them to obtain services such as caregiver respite, in-home support workers, as well as access to work, volunteer, and recreational programs they must apply to the Provinces' Passport Program (Dubé, 2016). Despite a \$10 million increase to the budget for the 2013-2014 fiscal year, the wait list for this program has, in fact, increased from 3 700 individuals in 2012 to 14 402 individuals in 2015 (Dubé, 2016). Similarly, waitlists for other services provided though Developmental Services Ontario, such as person-directed planning, continue to be lengthy as "the demand for supports and services far outstrips the availability" (Dubé, 2016, p.27). Similar concerns regarding the inaccessibility of mental health services were also reported by the Ontario Human Rights Commission (2012). Identified issues include a lack of funding to mental health programming, limited availability of mental health services that are covered by the Ontario Health Insurance Program, uncoordinated service delivery, the adoption narrow mandates that cause individuals to be ineligible for



services; and finally, limited available of services in rural areas. Of note, the OHRC cites that “Canada spends less on public health care funding than most developed countries” (Jacobs et al., 2008 as cited in OHRC, 2012, p. 75). Ultimately, despite a shifting political rhetoric towards one that boasts community care for persons living with mental disabilities, there remains much to be desired.

### **Perceptions of Institutions**

Although mental health services have moved away from an institutional model of care and towards one of community-based services, institutions continue to be present within the landscape of services for persons living with mental disabilities. Within the post-dismantlement phase of Ontario’s institutional cycle, ‘institutions’ may be understood to include psychiatric facilities, schools, long-term care facilities, and hospitals in so far as they function to create barriers to inclusion and contribute to structural discrimination.

As related to the perception of institutions in the post-dismantlement phase of Ontario’s institutional cycle, a common theme identified within both literary and policy texts is the view that institutions are necessary and helpful for persons living with mental disabilities. In *Know the Night: A Memoir of Survival in the Small Hours*, Maria Mutch describes her son Gabriel’s knack for surrounding himself with “loving lions”, in reference to his teachers (2014, p.4). The discourse surrounding Gabriel’s schooling and institutional care suggests that Gabriel is in need of protection, and is able to receive such protection and care within a school setting. Although this perception arguably proves to reinforce negative stereotypes of persons with mental disabilities as being vulnerable and incapable, Mutch describes Gabriel’s experience positively and seems to view school as a sort of respite. The perception of school as being a helpful institution for persons living with mental disabilities is perpetuated within policy texts, wherein

inclusive school programs are described as being able to meet the needs of persons with mental disabilities both in regards to providing education and offering opportunity for social engagement (Select Committee on Developmental Services, 2014).

Similarly, in Shusterman's novel *Challenger Deep*, Caden is initially portrayed as being angry about his involuntary stay hospital, however, ultimately perceives this intervention as necessary and helpful in his recovery (2015). Throughout his hospitalization Caden struggles to come to terms with the reality of his mental illness, and the role that medication and therapy may play in maintaining his wellbeing. In reference to the notion of having to stay in hospital for another couple weeks in order to adjust his medication Caden reflects the following, "I don't know which is more horrifying- the thought of being here for another week, or the thought that maybe the medication that I so despise might actually be working" (Shusterman, 2015, p. 243). As Caden's stay in hospital progresses he begins to reluctantly accept that the medication may actually be helping him to manage his hallucinations, and in fact refers to his stay in hospital as his "mental cast", suggesting that it has helped him to heal (Shusterman, 2015, p. 302). Caden's journey culminates in his discharge from hospital, at which time Caden references that he is proud to once again be a "member of the rational world" (Shusterman, 2015, p. 304). Caden ultimately finds some comfort in knowing that for the moment he is well, and accepts that his journey with mental illness may one day see him again in need of formalized interventions such as hospitalization.

The idea that psychiatric facilities continue to be a necessary intervention is also seen within policy documents. The Select Committee on Mental Health and Addictions (2010) suggests that there may be a need for more psychiatric facilities in Ontario, citing the current inappropriate use of hospitals and prisons systems as a means of addressing mental health issues.

Specifically it is asserted that many individuals living with mental illness in Ontario will face incarceration or hospitalization as a result of the lack of community-based services. Although, not necessarily in support of psychiatric facilities, other policy documents also cite the inappropriate use of hospital, prisons, and homeless shelters as institutions used to house persons with mental disabilities in the post-dismantlement phase of Ontario's institutional cycle (Dubé, 2016; OHRC, 2012). This suggests a shift in thinking regarding the utility of institutions in providing care to persons living with mental disabilities. Instead of asserting only a need for enhanced community-based services, literary and policy discourses in the post-dismantlement phase of Ontario's institution cycle are beginning to grapple with the notion that multiple forms of services may be needed in order to provide adequate care to persons living with mental disabilities. Thus the landscape of services in the province may need to include community-based services as well as various forms of institutional services, which can offer both long-term and short-term placements dependent on the individual's needs. Yet, such a recommendation should be considered with caution, as it was in part the prevalence of persons with disabilities living in the prison system which had given credence to the institutionalization movement during the establishment phase of Ontario's institutional cycle (McCauley, 2011).

Further exploring the role of institutionalization in the post-dismantlement phase of Ontario's institutional cycle, in *Love and Forgetting: A Husband and Wife's Journey Through Dementia*, Julie Macfie Sobol discusses her decision to place her husband in a long-term care facility (Macfie Sobol & Sobol, 2013). Julie initially acknowledges her concerns that Ken may experience neglect or maltreatment, however, ultimately feels that with proper regulations, funding, and inspections institutions can provide security, companionship and care for persons with mental disabilities (Macfie Sobol & Sobol 2013). In fact, a number of novels and memoirs

depict communities where there is not enough institutional care available to persons living with mental disabilities, leaving many people who are in need without the care and assistance they require (Bartók, 2011; Macfie Sobol & Sobol 2013; Stuart, 2016).

Exploring yet another form of institutionalization, within the novel *A Boy Made of Blocks* Alex describes the family's struggle in trying to gain access to a school that specializes in working with autistic students:

Getting Sam in is a long shot, we both know that. He is high on the scale, despite being years behind in school, despite his faltering vocabulary. Last year, we went to a local autism group and the Education Authority advisor told us that there were many children with much more complex needs so it was unlikely we'd get a referral... One thing you learn very early in parenthood is that the health and education systems are a sort of vast and complicated game: if your kid ever needs help, you have to learn the rules and exploit them. You fight for everything, every test, every consultation, every specialist – you learn the correct terms, you research all the forms and statements and processes you need, and anything you can't get through the system you pay for if you can. Nothing comes to those who wait. (Stuart, 2016, p. 145)

Despite an apparent need for institutional services as depicted in literary texts, they are not without negative stereotypes and are certainly not always experienced positively. In *The Memory Palace: A Memoir* Mira Bartók describes her mother's experiences of institutional care, and although it is evident through her description that her mother's historical experiences of psychiatric institutionalization were not positive, her more current experiences suggest that community-based services are seemingly non-existent (2014).

When we are forced to commit her, each stay in the psych ward at CPI-Cleveland Psychiatric Institute- seems to be shorter than the last. This is 1974, and for the last ten years asylums have been releasing more and more patients out into the streets. This had been President Kennedy's revolutionary plan for reforming the nation's shameful treatment of the mentally ill. We would replace our backward state hospital system with a newer and better neuroleptic drugs and free comprehensive community care. But for my mother in 1974, not much has changed. The doctors still pump her with drugs that make her mute, incontinent, and unable to move. They strap her down in restraints and zap her with what she thinks is radiation. She imagines Nazis torturing her. "I will fight until the end" she thinks. "I will save my girls. There's a reason for everything. A reason poltergeists set fire to my chair. Everything is a sign." The only change is that they release her before my sister and I have had a chance to catch our breath. The miracle of drugs the doctors give her at CPI, first Thorazine, then Haldol, don't seem to help her at all. As for the comprehensive community care, we are still waiting for it to arrive.

(Bartók, 2011, p. 107)

In *A Boy Made of Blocks*, Stuart depicts a newer version of an institution wherein the offences are perhaps not as obvious or sinister, but nonetheless function as a means of imposing barriers and fostering isolation rather than helping the individual to achieve inclusion (2016). Specifically, after visiting a highly regarded school that specializes in working with autistic students, Alex is taken aback by the notion that the driving purpose of this school is to help students achieve enough independence to function in society:

The sheer reality of this sentence hits me hard. This is an area we've only ever hedged around in the past- this whole question of what Sam will do when he's older. Now here it

is presented to us in its stark reality. Is a little independence the best he can strive for? To be honest we can barely imagine even that. I've tried to picture him in a workplace, following instructions, fitting in, understanding the complexities of adult lives and relationships. I can't. I just can't. And living alone? Looking after himself? Meeting someone? Right now the idea seems fantastical. (Stuart, 2016, p. 153).

Ultimately, Alex's son Sam expresses some dismay about the possibility of attending that particular school, noting that he wants to be an architect (Stuart, 2016). The given discourse serves to highlight how institutions continue to serve as a system for creating barriers and maintaining stereotypes regarding persons living with mental disabilities. The school is seemingly not striving for Sam to become an active participant in society, to obtain meaningful and fulfilling employment, nor to live a socially fulfilling life. Rather, he can at best strive for a little independence.

Within policy texts it is also apparent that although Ontario's public school system seeks to support students with mental disabilities through special education programs, one on one educational supports, and the promotion of social inclusion, ultimately the education system struggles to meet the needs of children with mental disabilities (Dubé, 2016; OHRC, 2012; Select Committee on Developmental Disabilities, 2014). Concerns include limited availability of supports, long wait lists for services such as psychological testing, limited training for school staff, limited funding for programs, and poor continuity of services with other community support programs (Dubé, 2016; OHRC, 2012; Select Committee on Developmental Disabilities, 2014). Moreover, some families report that their children were placed in special education classrooms without their consent (OHRC, 2012). Caregivers expressed concern that as a result of the school's decision to place their child in a segregated classroom, their child would ultimately

be denied the opportunity experience an inclusive environment (OHRC, 2012).

In examining equitable access to education within elementary, secondary and post-secondary schools the OHRC found that students in Ontario continue experience discrimination in educational institutions as related to their mental health disabilities (2012). Not only do students report being bullied and shunned by their peers as a result of mental health disabilities, they also experience discrimination from school staff. One survey respondent described the following:

“Being ostracized at school for acting funny or being different is still the norm –and if one chooses to disclose, no one knows enough about mental health issues not to shrug it off or laugh. More education at all school levels is needed, not just about the physical disabilities but the mental ones.” (Survey respondent as cited in OHRC, 2012, p. 81)

The discriminatory attitudes often present within educational institutions pose a significant barrier for students who are seeking much needed accommodations, such as alternative methods of testing, personal support, and consideration for time missed to address a disability (OHRC, 2012). Moreover, there remains concern that students with multiple or complex disabilities may be experiencing inappropriate suspensions and/or poor school performance as a result of limited accommodation for disability (OHRC, 2012; Rushowy, 2014). For example, students who experience issues of anxiety and depression may avoid the school setting as a result of the limited accommodation and support made available, thus negatively impacting their overall school performance. Conversely, students who experience behavioural issues, often associated with mental health disabilities such as fetal alcohol spectrum disorder or autism spectrum disorder, may frequently be suspended as a result of poor accommodation, support, and understanding of their needs as related to disability. Finally, in some instances,

students and families have reported being directly advised by school personnel not to attend class as a result of limited resources available (Rushowy, 2014). In regards to these concerns one survey respondent stated the following:

“The school board said mental health is not their concern, right after another special needs boy killed himself last year. I was supposed to get occupational therapy last year and they did not bother to put the request through so I could get help. No one at the school even read my file so I could get the right help to learn at school. They even passed me and I never finished my work or wrote my exams. It is easier to suspend the students rather than help us. If we do something a little bad they call the police without calling our parents to speak up for us. My mom says this is a way to just scare us.” (Survey respondent as cited in OHRC, 2012, p. 82)

As is evident from the above, schools unfortunately continue to act as oppressive institutions within the post-dismantlement phase of Ontario’s institutional cycle. Discriminatory attitudes are seemingly pervasive amongst students and staff alike. Despite a rhetoric of inclusion and support, students living with mental disabilities are not able to realize their right to education equality. Many students continue to experience segregation and stigma, as well as a lack of accommodation. Consequently students living with disabilities continue to be more likely to experience poor educational outcomes, undoubtedly facilitating further social and economic exclusion as they enter adulthood.



## **Findings**

The following chapter will identify and discuss significant research findings in order to answer the dissertation's first research question: "What can be learned through a comparative examination of how mental disability is represented in literary and policy discourses during the post-dismantlement phase of Ontario's institutional cycle?" Findings are presented within the four themes of analysis, as have been previously identified. A summary of the key findings is also displayed in Table 9.

### **How Stories are Told**

Within the post-dismantlement phase of Ontario's institutional cycle a prominent theme found in literary texts is that obtaining the first-hand narrative of an individual's lived experiences is preferable, when possible. Accordingly, literary discourses tend to focus more exclusively on the individual living with a mental disability as being the authority on their needs and lived experiences, while policy texts more often blur the lines between the individual's and the family's experiences and concerns. Literary texts in this phase of the cycle explore how even with the best of intentions caregivers are not always able to adequately identify and express the thoughts and feelings of their loved ones living with mental disabilities. Conversely, although policy texts do acknowledge the significance of utilizing direct consultation during the policy planning process, there is often limited distinction made between the voice of the individual versus that of their caregiver (Dubé, 2016; Select Committee on Developmental Services, 2014). The inconsistency in the way that policy versus literary texts tell the stories of individuals living with mental disabilities raises concern regarding the extent to which policy planning in Ontario is informed by service-user, as opposed to caregiver, knowledge.

### **The Role of the Family**

Policy texts in the post-dismantlement phase of the institutional cycle often holds families as experts in caring for and advocating for the rights and needs of persons living with mental disabilities. This trend appears to begin during the reform phase of Ontario's institutional cycle when families are identified as being the most appropriate caregivers to persons living with mental disabilities (McCauley, 2011). Yet this perspective ignores the reality that not all family members have the resources and ability to be effective advocates and caregivers. As identified in literary texts of the post-dismantlement phase, family members and caregivers are not always able to understand or meet the needs of the individual. Moreover, family members do not necessarily have the same wants and needs as do their loved ones living with mental disabilities. Therefore, the needs and wants of a loved one living with a mental disability are inevitably mediated by what the caregiver believes in best for the individual; or more pragmatically, what the caregiver is able to provide.

The complex and at times conflicting relationships that exist between individuals living with mental disabilities and their caregivers have been explored within the literary discourses of the reform and dismantlement phase of Ontario's institutional cycle (McCauley, 2011), and continue to comprise a prominent concern during the post-dismantlement phase of the cycle. For example in *Love Anthony*, Anthony describes how his family misunderstands him and his desires in life (Genova, 2012). Similarly in *A Boy Made of Blocks*, Alex describes his difficulty in understanding his son before ultimately realizing that Sam has opinions of his own and is able to make decisions for himself (Stuart, 2016). Finally, in *Love and Forgetting; A Husband and Wife's Journey Through Dementia* Julie Macfie Sobol explores how she loses touch with her husband's wants and needs as his dementia worsens (2013). Ultimately, the predominant theme

appears to be that even with the best of intentions family members are not always able to understand and interpret the lived experiences of their loved one living with a mental disability.

The reform phase of Ontario's institutional cycle illustrates a shift in care toward community-based service provision, where families assumed the role of caregiver for individuals living with mental disabilities. However, both literary and policy texts published in recent years continue to assert that that families are not adequately supported in caring for their loved ones. The burden placed on families to take on the role of caregiver is a theme presented repeatedly throughout literary and policy discourses in the post-dismantlement phase of Ontario's institutional cycle. Issues, including financial and emotional stress, marital discord, mental illness, family breakdown, exhaustion, as well as feelings of powerlessness and isolation are common amongst caregivers (Dubé, 2016; Bartók, 2011; Genova, 2012; Macfie Sobol & Sobol, 2013; Mutch, 2014; Select Committee on Developmental Disability, 2014; Stuart, 2016). Ultimately, alleged reforms in service provision and renewed commitments to meeting the rights of persons living with mental disabilities during the post-dismantlement phase of Ontario's institutional cycle have generally not materialized in any significant changes for families who are in a caregiving role. Families continue to require more supports and programming in a number of areas including respite services, equitable access to education and employment, housing, transportation, and leisure activities (Dubé, 2016; Select Committee on Developmental Services, 2014). The dwindling availability of support services is of serious consequence for persons living with mental disabilities, as it increases risk of family breakdown and abandonment of the individual living with a mental disability (Bartók, 2011 ; Dubé, 2016).

Ultimately in comparing discourses of mental disability in the post-dismantlement phase of Ontario's institutional cycle it is evident that the cultural assumption that families, not

communities, are responsible for the care of persons living with mental disabilities remains dominant at this time (Bartók, 2011; Macfie Sobol & Sobol, 2013; Stuart, 2016). Policy texts in large part continue to be entrenched in the ideology that families are the most appropriate caregivers for persons living with mental disabilities, while literary texts are beginning to explore an alternate reality wherein communities and institutions need to take on a larger role in caring for persons living with mental disabilities and facilitating their social inclusion.

### **Community Roles and Responsibilities**

The limited availability and poor accessibility of community-based services for persons living with mental disabilities in Ontario have left numerous families in situations of crisis. Both literary and policy texts assert the need for increased availability of services for persons living with mental disabilities, including transportation, education, housing, respite, and employment (Dubé, 2016; Bartók, 2011; Macfie Sobol & Sobol, 2013; Select Committee on Developmental Disability, 2014; Stuart, 2016). Although policy texts often acknowledge an individual's right to social and economic inclusion, this has not translated into meaningful changes in policy planning and service provision. As a result both literary and policy texts explore the ways that persons living with mental disabilities continue to experience exclusion and marginalization in society.

Experiences of isolation and discrimination are commonly portrayed throughout the literature in the post-dismantlement phase of Ontario's institutional cycle. Mutch (2014) describes that even in trying to participate in a seemingly normal family outing to a museum, Gabriel experiences discrimination.

The parents look away, but the children sometimes stop in the din to stare at him, at the way that he is the same as them and yet- they seem to decide- not. I used to think that the differences in his facial features and the way he walks and stands were subtle, but time

has made them less so. The younger ones hang their mouths open for a few beats and then stagger away. He pretends he can't see them either. (Mutch, 2014, pp.79-80)

On another seemingly innocuous family outing, wherein Mutch enters a store to purchase some glasses and overhears other patrons talking, she again experiences the sting of social exclusion and being 'othered'.

The woman announced, *There's a little boy with Down syndrome*. Just that. Her friend was standing nearby and widened her eyes to signal that the mother was sitting right there, but the woman who spoke didn't understand. The room was crackling and I seemed nearly invisible. *There's a little boy with Down syndrome*. She had said so, and it meant something. Was it like seeing a rare bird and letting the other birdwatchers know- or was it more like a crash? A boy! With Down syndrome! He had entered, been objectified with small talk, and I wondered if she would mention him that night at dinner. (Mutch, 2014, p.165)

The perpetual experience of being objectified and stigmatized is perhaps most simplistically summed up by Alex in *A Boy Made of Blocks* when he notes that "One super fun lesson you learn very quickly as the parent of a sometimes disruptive child: people love to judge" (Stuart, 2016, p. 18). Nevertheless, literary discourses do occasionally highlight experiences of inclusion found through informal supports. For instance, in *Love and Forgetting; A Husband and Wife's Journey Through Dementia*, Ken and Julie write about their experiences in a choir group comprised of persons affected by Parkinson's disease (Macfie Sobol & Sobol, 2013). Although Ken did not share the same diagnosis as many of the members, both Ken and Julie found acceptance and belonging within the choir: "Here was a chance to participate without feeling judged...By the time the choir broke for summer the Sobols had participated in two well-

received performances, and our fellow singers were beginning to seem very much like friends” (p. 63).

In comparing literary and policy texts in the post-dismantlement phase of Ontario’s institutional cycle, it is evident that there is a disconnect between discourse pertaining to the role and responsibilities of community as related to persons living with mental disabilities. Policy texts assert an alleged intention to promote and ensure the right to social and economic inclusion for persons living with mental disabilities, while literary narratives provide limited evidence of social inclusion being actualized. Yet both policy and literary texts can agree that on a whole, community-based services are not sufficiently meeting the needs of individuals living with mental disabilities.

### **Perceptions of Institutions**

Within the post-dismantlement phase of Ontario’s institutional cycle, literary discourse suggests that schools often act as a means of institutionalization for persons living with mental disabilities in that they impose social isolation and economic barriers. Literary narratives explore how schools are experienced as being limiting for persons living with mental disabilities in that there is frequently a lack of resources and supports available within the school setting, and as a result the educational and vocational opportunities are limited. For example, Mutch (2014) describes how schools often rely on standardized testing to ‘categorize’ Gabriel and assess his needs; however, she asserts that such tests and supposed measures of intelligence often do not provide an accurate depiction of a child’s abilities nor do they account for lived experiences. Similarly, Alex describes frustration with Sam’s education in that the limited availability of supports as well as the school’s limited understanding of Sam’s impairments often result in Sam struggling both socially and academically at school (Stuart, 2016). Yet, Sam “wasn’t bad enough

to get individual support” (Stuart, 2016, p.44). Policy texts also demonstrate that schools are often experienced negatively by persons living with mental disabilities, identifying the limited availability of supports and services as well as insufficient funding and training to support inclusion initiatives (Dubé, 2016; OHRC, 2012; Select Committee on Developmental Disabilities, 2014).

A second theme explored during the post-dismantlement phase of Ontario’s institutional cycle, as related to institutional settings, is the limited availability of institutional placements. In contrast to the reform and dismantlement phases of Ontario’s institutional cycle, during the post-dismantlement phase of the cycle both literary and policy texts explore the utility of re-instating institutional care for persons with mental disabilities. Unlike historical versions of institutional care, where service-users had limited to no rights, current discourse around the use of institutional care suggests that with proper regulations institutions can serve a needed purpose. As described by Julie Macfie Sobol, institutional care can provide a safe and caring environment for persons living with mental disabilities in so far as they ensure to that there are high standards of care, training for staff, a comfortable and esthetically pleasing living environment with opportunity for fresh air and exercise, as well as an emphasis placed on family involvement and service-user autonomy when possible (Macfie Sobol & Sobol, 2013).

Both policy and literary discourses identify how the dismantling of institutions and subsequent limited implementation of community-based services has left a serious gap in services for a number of persons living with mental disabilities. As a result, hospitals, long-term care facilities, and prisons have inadvertently been adopted as holding cells for persons with mental disabilities (Dubé, 2016; OHRC, 2012; Select Committee on Mental Health and Addictions, 2010). Increased availability of institutional placements such as psychiatric facilities

and long-term care facilities are understood to be beneficial for families and individuals living with mental disabilities, with the stipulation that said institutions adhere to appropriate standards of care (Dubé, 2016; Macfie Sobol & Sobol, 2013; Select Committee on Mental Health and Addictions, 2010).

**Table 9. Key Findings**

	<b>Policy Discourse</b>	<b>Literary Discourse, Non-Fiction</b>	<b>Literary Discourse, Fiction</b>
<b>How Stories Are Told</b>	<ul style="list-style-type: none"> <li>• Direct consultation with individuals, and their families utilized to inform and legitimize policy objectives</li> <li>• Adopting the “nothing about us without us” perspective</li> <li>• Use of direct quotations within policy documents</li> <li>• Policies acknowledge systemic discrimination and oppression; seek to address such</li> <li>• Limited distinction made between the individual and their family</li> </ul>	<ul style="list-style-type: none"> <li>• First person narration given preference over perspective of family members</li> <li>• Acknowledgement that family members may not always be accurate in their understanding of their loved one</li> </ul>	<ul style="list-style-type: none"> <li>• First person narration given preference over perspective of family members</li> <li>• Acknowledgement that family members may not always be accurate in their understanding of their loved one</li> </ul>
<b>Family Roles</b>	<ul style="list-style-type: none"> <li>• Families are ‘experts’ on the care of their loved ones, and are able to advocate for their best interests</li> <li>• Families must be caregivers to their loved ones due to insufficient community resources</li> <li>• Family burden may lead to abandonment</li> </ul>	<ul style="list-style-type: none"> <li>• Families are caregivers to their loved ones</li> <li>• Families try to be experts on the care of their loved one, but are not always able to fully understand the needs of the individual</li> <li>• Families are expected to care for loved one; individuals are dependent on families, which can cause burden</li> <li>• Family burden may</li> </ul>	<ul style="list-style-type: none"> <li>• Families are caregivers to their loved ones</li> <li>• Families try to be experts on the care of their loved one, but are not always able to fully understand the needs of the individual</li> <li>• Families are expected to care for loved one; individuals are dependent on families, which can cause burden</li> </ul>



		lead to abandonment	
<b>Community Role, Responsibility, and Inclusion</b>	<ul style="list-style-type: none"> <li>• Community services are often not experienced by families as being accessible</li> <li>• Community has a responsibility to promote social and economic inclusion; yet the implementation of policy does not always support this obligation</li> <li>• Disconnect between Canada's recognition of economic and social rights of persons living with disability and the use of these rights to guide and develop policies</li> <li>• Lack of appropriate policies/poor policy planning lead to poor social conditions and poverty for persons with disability</li> </ul>	<ul style="list-style-type: none"> <li>• Community services are to be used only when family cannot meet the needs of the individual at home</li> <li>• There are not enough community services/accessing them is difficult</li> <li>• Community promotes shame of disability; persons with disability are marginalized</li> <li>• Supports and experiences of inclusion are found in informal groups/connections with others who share similar impairments and lived experiences</li> <li>• Communities services are utilized when they are available</li> </ul>	<ul style="list-style-type: none"> <li>• Community services are to be used only when family cannot meet the needs of the individual at home</li> <li>• There are not enough community services/accessing them is difficult</li> <li>• Community promotes shame of disability; persons with disability are marginalized</li> <li>• Supports and experiences of inclusion are found in informal groups/connections with others who share similar impairments and lived experiences</li> <li>• Communities services are utilized when they are available</li> </ul>
<b>Perceptions of Institutions</b>	<ul style="list-style-type: none"> <li>• Institutions are being used incorrectly; jails, hospitals, long term are facilities</li> <li>• Possible need for more institutional placements</li> <li>• Schools need to be better prepared to implement inclusion strategies</li> </ul>	<ul style="list-style-type: none"> <li>• Institutions are a necessary and helpful service</li> <li>• Lack of institutional support</li> <li>• Institutions can be limiting; serve to perpetuate experiences of discrimination and stereotypes</li> </ul>	<ul style="list-style-type: none"> <li>• Institutions are a necessary and helpful service</li> <li>• Lack of institutional support</li> <li>• Institutions can be limiting; serve to perpetuate experiences of discrimination and stereotypes</li> </ul>

### **Discussion**

The second research question that the dissertation aspires to answer is, “How can an interdisciplinary analysis of literary and policy discourses, during the post-dismantlement phase of Ontario’s institutional cycle, inform policy planning and the provision of services for people living with mental disability in Ontario?” Accordingly, the following section will discuss opportunities for reform in policy planning and service provision in the province. Recommendations provided are informed by the key findings. Lastly, limitations of the study as well as recommendations for future research are put forth.

### **Implications and Recommendations**

Despite having ratified the UN Convention on the Rights of Persons with Disabilities in 2012, public policies in Canada and Ontario are failing to adequately address the needs of persons living with mental disabilities. Prominent policy discourses pertaining to mental disability acknowledge the right to social and economic inclusion for all persons living with mental disabilities in Ontario, yet this population remains marginalized in society. Evidently there continue to be significant barriers to full participation despite an alleged intention to develop accessible and sustainable community-based services that would guarantee the right to social and economic inclusion for all persons living with disabilities in the province, and ensure their integration into all aspects of society (Government of Canada, 2014; MCSS, 2014).

With the intention of addressing the above concerns, this study aims to utilize alternate ways of knowing about mental disability in order anticipate policy planning needs and opportunities in Ontario to advance human rights and social inclusion for persons living with mental disabilities. That being said, recommendations put forth in the following sub-sections

draw from the study's key findings in order to identify alternative ways of informing policy planning initiatives and service provision.

### **Advocacy**

As identified within the findings, there is a disconnect between the ways that stories of mental disability are told within literary and policy texts. Specifically, within literary discourses a first person perspective as shared by the individual living with a mental disability is consistently identified as being preferable to a caregiver's interpretation of an individual's lived experiences. This assertion is made with the understanding that families and caregivers are not always able to effectively interpret the experiences of their loved ones. Moreover, caregivers can have conflicting and competing interests to those of the individual living with a mental disability (Bartók, 2011; Macfie Sobol & Sobol, 2013; Shusterman, 2015). Although generally in agreement with utilizing direct consultation to inform policy planning, policy texts in the post-dismantlement phase of Ontario's institutional cycle often fail to identify any significant distinction between knowledge shared by individuals living with mental disabilities versus that of their families. As a result, it is difficult to ascertain to what extent policy recommendations and policy changes presented in the post-dismantlement phase of Ontario's institutional cycle are reflective of the lived experiences of the individual, as opposed to the experiences and concerns of the family. If Ontario truly intends to embrace disability rights and seeks to achieve policies and program that are responsive to service-user needs, then service-user consultations should occur with the individual and not just their caregivers. Moreover, consultation needs to occur both with persons who are able to communicate through traditional means as well as persons whose ability to communicate is impacted by impairment. Considerations for both will be discussed further.

Utilizing alternate forms of self-advocacy may prove to be an important intervention in attempting to ensure that the interests and needs of persons living with mental disability are heard, and not silenced next to those of their families, caregivers, and/or service-providers. This recommendation is put forth while also acknowledging that it is not universally applicable given that not all persons living with mental disabilities are able to communicate in traditional ways. However, in situations where the individual living with a mental disability is able to communicate through familiar language, self-advocacy through the use of narrative has proven to be a helpful and effective means of disseminating knowledge and challenging stigma. For example, research by Benham and Kizer (2016) identifies that autobiographical narratives written to reflect the individual's ways of knowing can be effectively utilized as a tool to challenge dominant narratives of autism. Research by Hutton, Park, Levine, Johnson and Bramesfeld (2017) also identifies that self-advocacy through sharing personal narrative can be effective in addressing discrimination. Finally, Disability Rights Promotion International (2013) asserts that autobiographical narratives of mental disability are able to influence dominant cultural perspectives regarding disability and help to identify individuals living with mental disabilities as legitimate sources of knowledge. Utilizing autobiographical narratives to express and share experiences is valuable on an individual basis, in that persons living with mental disabilities may be able to utilize this medium of communication in order to advocate for their own needs with service providers, policy planners, and/or caregivers. However, there is also potential to share said narratives through public forums in efforts to inform and challenge prevalent societal discourses regarding mental disability.

In situations where self-advocacy is not a viable option, social workers can have a role to play in utilizing alternate ways of knowing in order to advocate for the interests of individual's

living with mental disabilities. When it is not possible to communicate directly with an individual due to an impairment, social workers have a responsibility to obtain collateral information from not only caregivers but also other services providers and significant persons involved in the individual's life. Additionally, it may be appropriate to spend time with the individual and obtain observational information. This is of the utmost significant, given that literary and policy discourse during the post-dismantlement phase of Ontario's institutional cycle identify that even with the best of intentions caregivers do not always understand the wants or needs of the individual living with a mental disability, nor are they necessarily effective advocates.

In order to effectively advocate for the needs of the individual living with a mental disability, service providers must recognize that both the individual and their caregiver have separate and, at times, competing needs. One means of reconciling these varying interests may be to utilize an ecological model of intervention, wherein the individual is understood to exist within the context of family and community (Muir & Goldblatt, 2011). This model dictates that the individual and the family receive support to meet their separate needs, with the understanding that families must also be healthy in order to provide the best care for their loved one (Muir & Goldblatt, 2011). This theory is applicable within the context of disability service provision, given that the literary and political discourses during the post-dismantlement phase of Ontario's institutional cycle overwhelmingly identify that families who are in a caregiving role for individuals living with mental disabilities experience a significant amount of emotional and financial stress, at times leading to mental health and health problems as well as caregiver burnout and service-user abandonment (Bartók, 2011; Dubé, 2016; Genova, 2012; Macfie Sobol & Sobol, 2013; Mutch, 2014; Select Committee on Developmental Services, 2014; Shusterman,

2015; Stuart, 2016). Thus employing an ecological model of intervention would allow social workers not only to identify and advocate for the needs of the individual living with a mental disability, but also to help support and sustain the caregiving relationship.

### **Community-Based Services and Institutional Care**

A significant finding within the post-dismantlement phase of Ontario's institutional cycle is that both literary and policy texts identify not only a lack of community-based services available to persons living with mental disabilities, but perhaps more surprisingly, a need for institutional placements inclusive of psychiatric facilities and long-term care facilities. Despite the legacy of oppression and abuse left by institutions during previous phases of Ontario's institutional cycle, current discourse regarding mental disability and the provision of care has identified an ongoing failure for community-based service provision to sufficiently support individuals living with mental disabilities. Moreover, as per literary discourse in the post-dismantlement phase of Ontario's institutional cycle, community-based service provision has not been overly successful in addressing experiences of social and economic exclusion as experienced by persons living with mental disabilities. As a result of these significant concerns, it is difficult to ascertain to what extent the desire for institutional care results from the utility of institutions versus frustrations with community-based service provision. Nevertheless, the evolving discourse surrounding institutional care does suggest an opportunity for revising the way that services of provided in Ontario.

Certainly if we consider the history of Ontario's institutional cycle, there are lessons to be learnt regarding the provision of institutional services. The development of institutional services in the post-dismantlement phase needs to be driven not by the intention to segregate persons living with mental disabilities, but rather to facilitate inclusion and ensure the rights of persons

with mental disabilities are being met. At a basic level institutional services would require enough funding to ensure a high standard of care, inclusive of proper staffing and training for employees. Within Ontario this may mean having to address a number of concerns currently experienced by personal support workers who are involved in the care of individuals living with mental disabilities. Such issues include limited training and excessive work loads, as well as poor working conditions resulting in workers having insufficient time to engage in person-centered planning, to recognize and/or report situations of abuse, and to adhere to proper health and safety standards (Kelly, 2017). Not only does the current landscape of service provision lead to many short cuts, which can negatively impact upon the service-user, it also results in experiences of stress, burnout and illness for employees (Kelly, 2017; Kontos, Miller, Mitchell & Cott, 2010; Mutkins, Brown & Thorsteinsson, 2011; Zeytinoglu, Denton, Plenderleith & Chowhan, 2015).

Greater flexibility regarding forms of institutional care may also be beneficial. Specifically, greater availability of crisis and respite placements may in fact help to mitigate some of the stress placed on families who care for individuals living with mental disabilities. The availability of short-term placements may help to contribute to improved health and mental health outcomes for caregivers, thus helping avoid or postpone long-term out of home placements (Macfie Sobol & Sobol, 2013). Finally, service delivery within institutional settings should aim to foster inclusion and respect service-user rights. This may require the ongoing involvement of families in the care individuals living with mental disabilities, as well as ensuring service-user autonomy in planning and participating in their care when the individual is able to do so.

Ultimately the recommendation to revisit the implementation of institutional care is given with caution, in consideration of the provinces' history in utilizing this form of care as a means of oppression and exclusion from society. Nevertheless, as suggested in policy and literary

discourse in the post-dismantlement phase of Ontario's institutional cycle, community-based services alone are not able to meet the needs of individuals living with mental disabilities.

Moving forward, should the province wish to realize their commitment to upholding the human rights of persons living with disabilities then Ontarian's may need to embrace a model of service provision that offers greater flexibility in regards to the types of services available to individuals living with mental disabilities and their families.

### **Limitations**

There are methodological limitations in the current study, specifically as related to the validity of research findings. Although the research did incorporate a number of validity strategies, it is acknowledged that in keeping with the perspective that persons living with mental disabilities are experts on their lived experiences it would have been beneficial for this researcher to engage in member checking with the disability community (Creswell, 2014). Moreover, it may have been beneficial to have utilized an external auditor to analyze the validity of research findings, given that the research was conducted by one individual and thus intercoder agreement regarding research findings was not able to be achieved (Creswell, 2014). Finally, as common within qualitative studies, the generalizability of research findings is limited (Creswell, 2014). Within this study it is noted that the policy discourses examined relate specifically to Ontario and thus findings are not generalizable to other provinces or countries. Moreover, the sample size of the current study is relatively small, and consists of a preliminary sample within the post-dismantlement phase of Ontario's institutional cycle. Therefore the discourse regarding mental disability will likely continue to evolve within the literature in the coming years.

As a result of limitations related to sample size and the preliminary nature of the study, there are a number of themes that have yet to be sufficiently examined within the post-



dismantlement phase of Ontario's institutional cycle. These areas of dissonance, found within the current sample of policy and literary texts, will be further explored in the following subsections.

### **Incarceration as a Form of Institutionalization**

Literary texts read for the purpose of this study, unlike policy texts, do not explore the use of prisons as an institution. It is a significant gap, as policy discourse suggests that persons living with a mental disability in Ontario are unfairly becoming involved with the justice system often as a result of insufficient support from community services (Dubé, 2016; OHRC, 2012; Select Committee on Mental Health and Addictions, 2010). Specifically, Ombudsman Ontario reports that they have received a number of complaints regarding the inappropriate incarceration of adults with developmental disabilities (Dubé, 2016). Additionally, the Office of the Correctional Investigator asserts that Canada has effectively been 're-institutionalizing' the mentally ill, noting that there is a high occurrence of mental health issues, psychosocial disabilities, and addictions issues amongst prisoners in Canada and Ontario (OHRC, 2012; Sapers, 2009 as cited in OHRC, 2012).

Further compounding this issue is the lack of access to legal services available to persons living with mental disabilities (OHRC, 2012; Select Committee on Mental Health and Addictions, 2010). Specifically, persons living with mental disabilities report difficulties in accessing legal support either due to the cost of services or issues in accessing the application process for Legal Aid (OHRC, 2012). Moreover, there are concerns regarding accessibility within the court system. For example, mental health and drug diversion programs are not consistently available across Ontario and even when available are not always being accessed by persons with mental health issues (OHRC, 2012; Select Committee on Mental Health and

Addictions, 2010). Thereby leaving many persons living with mental disabilities without the support they require.

Given the prominence of this social issue, it would be appropriate for future research pertaining to the post-dismantlement phase of Ontario's institutional cycle to utilize literature that specifically explores themes of imprisonment and mental disability. Such texts might include Gilbert King's *Beneath a Ruthless Sun: A True Story of Violence, Race, and Justice Lost and Found* and Elizabeth Ford's *Sometimes Amazing Things Happen: Heartbreak and Hope on the Bellevue Hospital Psychiatric Prison Ward* (2018; 2017).

### **Social Condition and Experiences of Mental Disability**

Both literary and policy texts in the post-dismantlement phase of Ontario's institutional cycle explore themes of stress as related to the financial burden associated with caring for an individual living with a mental disability. However, with the exception of Bartók's (2011) memoir that explored themes of poverty, the literary sample utilized within this study is largely reflective of middle class experiences. This is of significance, as the prominent literary discourses surrounding family and mental disability are arguably not reflective of the social location of the majority individuals who are actually living with mental disability in Ontario, in that many persons living with mental disability in Ontario are living in poverty (CWP, 2017; Housing Study Group, 2013). Research consistently exemplifies an association between poverty and disability, and demonstrates that living with disability can not only lead to experiences of poverty but also that poverty can lead to incidences of disability (Emerson, 2007; Lustig & Strauser, 2007; Yeo, 2005).

Individuals living with disability are more likely to experience poverty due to a number of factors, including exclusion from the workforce, as well as increased expenses associated with

having a disability or supporting a child with a disability such as transportation costs, child care costs, and cost of equipment and services (Emerson, 2007; Loprest and Davidoff, 2004 as cited in Emerson, 2007; Lukemeyer, Meyers, Smeeding, 2000; Meyers, Lukemeyer, Smeeding, 1998; Parish et al., 2004 as cited in Emerson, 2007; Porterfield, 2002). Related to this, current social policies regarding education and employment for persons living with mental disabilities in Ontario are ineffective, given that many individuals are experiencing chronic unemployment and/or under employment (Graham et al., 2012; HRSDC, 2009). Moreover, those who are unable to work receive very limited benefits from provincial programs such as Ontario Works and Ontario Disability Support Program (Graham et al., 2012; HRSDC, 2009). Finally, the experience of living in poverty leads to further isolation and segregation for individuals with mental disabilities, so much so that it has been suggested that social condition should in fact be considered another form of discrimination by Ontario's Human Rights Act (Canada Without Poverty, 2017; Emerson, 2007; Prince, 2009; Yeo, 2005).

High incidences of disability amongst low-income populations can also be partially explained by the ways that poverty can cause disability. Poverty is a risk factor for preterm delivery, low birth weight, and poor maternal nutrition, all of which increase the likelihood of mental disability (Emerson, 2007; Meyers et al., 1998). Research also demonstrates that exposure to the environmental and psychosocial hazards associated with living in poverty can lead to an increased risk of disability (Emerson, 2007; Lustig & Strauser, 2007; Yeo, 2005). Please see Table 8 in order to view a list of environmental and psychosocial hazards that are shown to increase the risk of living with a disability.

**Table 8. Environmental and Psychosocial Hazards Associated with Poverty****Environmental and Psychosocial Hazards**

- Exposure to environmental toxins
- Poor housing and sanitation conditions
- Lack of access to health care
- Poor health status
- Inadequate access to food and poor nutrition
- Increased likelihood of accidents and injuries
- Higher incidences of psychological distress and mental illness
- Poor education outcomes
- Increased likelihood to experience adverse life events such as divorce and exposure to domestic violence

(Brooks-Gunn and Duncan, 1997 as cited in Emerson, 2007; Bradshaw, 2001 as cited in Emerson, 2007; Emerson, 2007; Evans as cited in Lustig & Strauser, 2007; Fairbrother et al., 2005 as cited in Lustig & Strauser, 2007; Lustig & Strauser, 2007; Seagert & Evans, 2003 as cited in Lustig & Strauser, 2007; Yeo, 2005)

These are all significant and real consequences of living with a mental disability and/or living in poverty in Ontario, as identified within policy texts. However, this reality is arguably not sufficiently explored within the sample of literary narratives utilized for the study.

**Intersections of Discrimination**

Another discrepancy between policy discourse and literary discourse found within the study pertains to the exploration of issues related to intersections of discrimination, including race and gender. Although some policy texts do identify how intersections of discrimination compound the social and economic marginalization experienced by individuals living with disabilities in Ontario, this theme was not commonly explored within literary texts (OHRC, 2012). Aside from Bartók (2011), who does highlight the ways that class can impact experiences of mental disability, literary narratives largely ignore how varying forms of oppression intersect with disability to alter an individual's lived experience.

Research regarding intersections of discrimination and experiences of disability identifies that an individual's lived experiences are shaped by the ways that their social locations, inclusive of race, ethnicity, gender, class, sexuality, age, ability, etc., interact with and exacerbate one another in order to create experiences of oppression (Davis, 2008 as cited in Mattsson, 2014; delos Reyes & Mulinari, 2005 as cited in Mattsson, 2014; Hankivsky, 2014 as cited in Manning, Johnson & Acker-Verney, 2016; Manning et al., 2016). This is a complex interaction concerned with relationships of power as related to various social locations and categories of oppression, as well as how said oppressions are both directly and indirectly experienced at a personal and political level (Davis, 2008 as cited in Mattsson, 2014; delos Reyes & Mulinari, 2005 as cited in Mattsson, 2014; Manning et al., 2016). There is significant evidence that persons living with disabilities frequently experience intersecting oppressions as a result of their belonging to various minority groups (Ali et al., 2001 as cited in Liasidou, 2013; Balcazar et al., 2012 as cited in Ben-Moshe & Magana, 2014; Banks, 2015; Barile, 2000 as cited in Liasidou, 2013; Liasidou, 2013; Magana et al., 2012 as cited in Ben-Moshe & Magana, 2014; OHRC, 2012). Accordingly, it is important for disability advocates and policy planners alike to understand disability in relation to other experiences of marginalization in order to more effectively challenge the social structures that perpetuate inequality for this population (Liasidou, 2013; Manning et al., 2016; Mattsson, 2014). Unfortunately, within the preliminary sample utilized for this study there is limited exploration of the ways that intersectionality shapes experiences of oppression for persons living with mental disabilities.

### **Recommendations for Future Research**

As has been identified, the sample size of the current study is relatively limited given that the research is preliminary in nature. Continued examination literary and policy discourses

regarding mental disability throughout the post-dismantlement phase of Ontario's institutional cycle may help to build upon the key findings as identified in this study. Further research regarding the post-dismantlement phase of Ontario's institutional cycle may also prove beneficial in addressing the areas of dissonance between literary and policy texts as have been identified within the current study's limitations. Specifically, this refers to experiences of mental disability as related to intersections of discrimination, social condition, and incarceration.

As the post-dismantlement phase of Ontario's institutional cycle continues to unfold there may also be opportunity to examine the ways that disability is experienced as a result of social norms, as opposed to medical impairment. Although this issue began to come to light within the current literary sample, in that some of the narratives explored how impairment was imposed on the individual by cultural expectations of norm, the medical model continues to be a common paradigm in literary and policy discourses at this time.

Finally, it is suggested that given the prominence of other forms of media in society, specifically social media, television, and movies, it may be of interest for future research to engage in a critical discourse analysis comparing alternative forms of media to current policy discourse. Such an analyses may help to identifying gaps in service as well as opportunities for the advancement of the social and economic rights of persons living with mental disabilities in Ontario.

### Conclusion

Persons living with mental disabilities in Ontario have long experienced discrimination and marginalization as a result of the oppressive stereotypes and neoliberal values that have dominated the province's social and political discourse over the last century (McCauley, 2011; Prince, 2012). Ontario has seen a progression through an institutional cycle beginning in 1839 with the passing of legislation that authorized the first Provincial "Lunatic Asylum" (McCauley, 2011). What began initially as a welfare policy, intended only as a last resort for persons living with mental disabilities who were unable to be cared for by family, was ultimately transformed into something much more perverse (McCauley, 2011; Radford & Park, 2003; Williston, 1971). With the end of WWI the perception that disability was a medical issue to be managed by medical professionals and total institutions, as opposed to individuals or families, gained prominence (Dunn, 2006; Hick, 2007; McCauley, 2011). Social and political rhetoric regarding disability became largely tied to the eugenics movement, wherein the division between 'normal' and 'deviant' became commonplace (Dunn, 2012; McCauley, 2011; Radford & Park, 2003; Williston, 1971). However, as a result of parent advocacy and a growing disability movement which utilized self-organization and self-advocacy, Ontario ultimately witnessed a move away from institutionalization and towards community-based living for persons living with mental disabilities (Dunn, 2012; Kelemen & Vanhala, 2010; McCauley, 2011; Prince, 2012). With continued support from disability advocacy groups, such as the People First movement, social and political discourse regarding mental disability slowly transformed to reflect concepts of self-determination and social inclusion (Brown, 2003; Hutton et al., 2017; Dunn, 2012).

Within the post-dismantlement phase of Ontario's institutional cycle, literary and policy discourses demonstrate a growing desire to be inclusive of first-hand perspectives in

disseminating discourses of mental disability. Yet, policy texts, specifically, tend to blur the lines between what is known as a result of direct consultation with service-users versus information obtained from families and caregivers. The lack of distinction made between the individual and their caregiver is problematic in that both literary and policy discourses in the post-dismantlement phase of Ontario's institutional cycle demonstrate that families are not always able to understand the wants and needs of their loved ones living with a mental disability, nor are they necessarily able to effectively advocate on their behalf.

Despite the above findings, in comparing literary and policy discourses pertaining to the role of the family as related to the care of persons living with mental disabilities in the post-dismantlement phase of Ontario's institutional cycle it becomes apparent that the dominant cultural assumption continues to be that families are the most appropriate caregivers to persons living with mental disabilities. Although families are generally depicted as wanting to care for their loved ones living with mental disabilities, caregivers also repeatedly describe experiences of emotional and financial stress, burnout, isolation, health issues, and marital difficulties as a result of their caregiver responsibilities. In some situations, the overwhelming burden placed on families can result in abandonment of the individual living with a mental disability.

In response to these concerns, literary discourse in the post-dismantlement phase of Ontario's institutional cycle begins to explore the notion that it takes a community to care for an individual, and that it is simply not realistic to expect one caregiver or family to take on sole responsibility for the care of an individual living with a mental disability. Nevertheless, current policy rhetoric often implicates families as being almost exclusively responsible for the care and wellbeing of their loved ones living with mental disabilities while receiving minimal supports and interventions from the community. McDaniel (2002) refers to this process as the



criminalization of not caring, wherein neoliberal values of independence prevail to the extent that the way in which structural inequalities affect individuals living with mental disabilities and their families are either denied or ignored (as cited in Prince, 2012). Literary narratives in the post-dismantlement phase of Ontario's institutional cycle point to the need for the community to take accountability for the wellbeing of not only individuals living with a mental disability but also for the families who take on caregiving responsibilities. It is suggested that when caregivers are able to receive the supports needed to maintain their own health and well-being, they are in turn better able to care and advocate for others.

Finally, in comparing literary and policy discourses in the post-dismantlement phase of Ontario's institutional cycle it is observed that although total institutions are no longer a part of the service landscape in Ontario there remain some forms of institutional oppression, often through schools that function to impose limitations on an individual's ability to achieve academic and ultimately vocational success. Opposing this perspective, there is also a growing notion that it may be desirable to reinstate some forms of institutional care including long-term care facilities and psychiatric institutions. Literature in the post-dismantlement phase of Ontario's institutional cycle explores the utility of institutional care, and how with an emphasis placed on ongoing family involvement and service-user autonomy as well as proper funding and high standards of care, institutions may be able to provide and a safe and nurturing environment for individuals living with mental disabilities.

In considering the above findings a number of recommendations are made. First, it is necessary to consult directly with service-users, as opposed to caregivers and service-providers, in order to gain insight into the individual's lived experiences when evaluating or developing services for persons living with mental disabilities. In spite of any impediments to

communication that an individual may experience, social workers continue to have a professional and ethical duty to represent the interests of service-users at individual, organizational, and legislative levels (Drover, 2000 as cited in McCauley, 2011; McCauley, 2011; OCSWSSW, 2008). In order to be more inclusive of the perspectives of all persons living with mental disabilities, it is necessary to obtain information from not only family members and caregivers but also through other means such as observational data. Additionally, in recognition of the fact that caregivers and service-users can at times have competing and conflicting interests it is suggested that social workers may benefit from utilizing an ecological model of intervention in working with and advocating on behalf of persons living with mental disabilities (Muir & Goldblatt, 2011). This model of intervention acknowledges and addresses differences in the needs of service-users and their caregivers (Muir & Goldblatt, 2011). Thus employing an ecological model of intervention would allow social workers to not only identify and advocate for the needs of the individual living with a mental disability, but also to help support and sustain the caregiving relationship.

Lastly, it is recommended that the province re-examine the utility of institutional services in meeting the needs of persons living with mental disabilities in Ontario. Discourse within the post-dismantlement phase of Ontario's institutional cycle suggests that service-users may benefit from access to institutional services, such as crisis and respite placements as well as long-term care facilities. Flexible and accountable institutional services, that respect service-user rights and autonomy, may provide families with the support they require in order to continue caring for their loved ones living with a mental disability and avoid situations of service-user abandonment.

In summary, it is acknowledged that within recent years Ontario has made some movement towards the implementation of legislation and public policies that guarantee the social

and economic rights of persons living with mental disabilities. Yet dominant rhetoric regarding mental disability continues to be one that is heavily influenced by neoliberal values and the medical model of disability, wherein responsibility of care is placed onto the individual and their family as opposed to government agencies (Mattson, 2014; Prince, 2012). Nevertheless, government bodies and individual communities have a responsibility to address long held discriminatory values present in society, and to engage with disability groups and persons living with mental disabilities in order to develop a model of service provision that will facilitate social and economic inclusion (Prince, 2012). Similarly disability advocates, inclusive of social workers, have a responsibility to continue disseminating a narrative of mental disability that is reflective of service-user autonomy and the right to full participation in society.

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