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# Radical Analysis of the Role of the Human Service Landscape in the Absence and Encapsulation of Intellectual Disability

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Radical Analysis of the Role of the Human Service Landscape in the Absence and Encapsulation  
of Intellectual Disability

by

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A THESIS

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## **Abstract**

The problematic explored is the inability of people engaged in understanding oppression to see the oppression of people with Intellectual Disabilities (ID).

To explore this problematic, the human service landscape (HSL) for people with ID in BC was described. A framework for analysis was developed using Antonio Gramsci's (1971) concept of 'common sense' and Giorgio Agamben's (1998) concept of the double exception. The pieces of theory were taken up because they identify and describe oppression, in particular invisible oppression.

The description of the HSL for people with ID in BC revealed that specialized services exist before birth and persist after death. Rough estimates of people using the HSL suggest that the majority of children with ID interact with the human service landscape. Findings from the analysis, using the framework described, suggest that the nature of the human service landscape influences social relations and normalizes the oppression of people with ID.

## **Acknowledgements**

Cheryl, thank you for your patience and guidance.

Mom and Dad, thanks for everything.

Anne, thank you for inspiring my interest in all of this and teaching me how to see the oppression of people with intellectual disabilities.

Tamara and Judith, thanks for talking and drinking endlessly with me.

## **Dedication**

This thesis dedicated to all the people who live lives that challenge the ‘common sense’ ideas about intellectual disability and propose a new reality for people in community.

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## List of Abbreviations

ASD	Autism Spectrum Disorder
CYSN	Children and Youth with Special Needs
DSM-V	Diagnostic and Statics Manual of Mental Disorders, 5 <sup>th</sup> Edition
FASD	Fetal Alcohol Spectrum Disorder
HSCL	Health Services to Community Living
ID	Intellectual Disability
IEP	Individualized Education Plan
IPSE	Inclusive Post-Secondary Education
IQ	Intelligence Quotient
MCFD	Ministry of Children and Family Development
PHSA	Provincial Health Services Authority
PSI	Personal Supports Initiative
RASP	Registry of Autism Service Providers
SET-BC	Special Education Technology BC
UN	United Nations
UPIAS	Union of Physically Impaired Against Segregation



## **Epigraph**

“these thousand crosses speak to us resoundingly collectively to warn us  
that to abandon the wretched the miserable the scorned the scapegoated makes a legitimate place  
for abandonment in our society  
and this abandonment will go right up the social ladder  
but to truly care for lives at the bottom will make a place for care  
and this caring will ensure that no one be abandoned”

Bud Osborne 1997

Excerpt from A Thousand Crosses in Oppenheimer Park

## **Chapter One: Introduction & Theoretical Orientation**

### **1.1 Introduction**

People with intellectual disabilities (ID) have experienced a long history of oppression in a variety of social, political and economic contexts (Barnes, 1996; Nibert, 1995; Wolfesnberger, 2005). Interestingly, the oppression of people with ID has largely been ignored in academic disciplines and social justice discourses concerned with identifying and understanding oppression.

The oppression of people labeled with ID is important, in part, because it has been ignored (Chapell, 1997; Aspis, 2000; Hall & Kearns, 2001; Ben-Moshe *et al.*, 2009; Shuttleworth & Mekosha, 2012; Stalker, 2012). The lack of critical discourse around ID in academic circles also exists within radical communities who have identified goals of resisting oppression. This gap, which became evident through a review of the literature as well as life experience, is the impetus for this work. The problematic that is explored is the inability of people engaged in understanding and resisting oppression to see the oppression of people with ID.

When looking at the small body of academic research and literature that takes up ID from a critical perspective there are two themes that emerge in the discussions, absence and encapsulation. In particular, the discussions on encapsulation and absence point to the role of services and support as a contributing factor. These themes, which are complicated by the role of support services in the lives of people with ID, present a unique challenge in tackling oppression because once a group is encapsulated, and subsequently, made absent, it is incredibly difficult to recognize oppression (Agamben, 1998; Lechte & Newman, 2012). In order to better understand the role that the human service landscape plays hiding the oppression of people with

ID, four research questions were developed. The first two research questions serve to illuminate the human service landscape that exists for people with ID in BC. The first asks, what constitutes the human service landscape and the second looks at the totality of the human service landscape. The second looks at the totality of the human service landscape by calculating the rough percentage of people with ID who access the human service landscape. Based on the description of the human service landscape, the analysis of the themes that emerged took up radical theory from Antonio Gramsci (1971) and Giorgio Agamben (1998).

Anarchism, as a philosophy, has emerged as a useful foundation for recognizing oppression in its multiple forms as well as the social structures that maintain oppression (Blumenfield *et al.*, 2013, Dixon, 2012, Newman, 2007). The segregation and devaluation of people with ID is by and large the norm in current social systems. Furthermore, the differential treatment of people with ID is reproduced by the human service systems that are in place to support them (Wolfensberger, 1980).

The decision to use the work of Gramsci (1971) and Agamben (1998) in the analysis of the human service landscape was made because both theorists attempt to reveal unseen oppression and propose radical alternatives for resisting oppression. While both Gramsci and Agamben are considered part of the Marxist literature, the interest in revealing unseen oppression and the proposal of radical alternatives lend them an anarchist character (Newman, 2010).

The role of the human service landscape in hiding the oppression of people with ID was examined using Gramsci's concept of 'common sense', which was introduced in his *Prison Notebooks* (1971). His analysis of oppression is useful in deconstructing the current conception of ID that is produced by the human service landscape. Gramsci also describes how common

sense can, and must, be disrupted to recognize unseen oppression. The analysis of the themes that emerged from the description of the human service landscape was framed by the concept of ‘common sense’. This approach illuminates the rationale or ‘common sense’ that is produced by the policies and programs in order to legitimize the human service landscape. The conclusions that are drawn include a discussion of how this ‘common sense’ reproduces the oppression of people with ID.

The second piece of theory used to construct the framework for analysis is Agamben’s (1998) discussions of encapsulation and invisible oppression in his work *Homo sacer; Sovereign Power and Bare Life*. Agamben’s figure, Homo sacer, emerges when bare life is abandoned in a zone of exception. In the zone of exception Homo sacer emerges as the result a double exception. Agamben describes how this double exception has led to horrific events, in particular the Holocaust, and advocates that in order to prevent these types of events in the future, the double exception must be called into question. This questioning, for Agamben, involves illuminating instances where Homo sacer emerges as well as a reimagining of the human that disrupts the human a hierarchy that is built on double exceptions.

Agamben (1998) describes the first exception as an exclusive inclusion based on bare life. “The exception is what cannot be included in the whole of which it is a member and cannot be a member of the whole in which it is already included” (Agamben, 1998, p. 26). Here inclusion is defined as being represented within the state as a distinct group and membership is belonging that is not defined at the level of the state or through an exception, but just is.

Agamben (1998) suggests that oppression is difficult to recognize when it occurs for people who are included based on an exception. He goes on to say that the very nature of the exception precludes the possibility for inclusion to coincide with membership. In order for some one to be

considered a member of the whole or society, they cannot be part of a group that is perceived at an exception. The exception is maintained by the state that abandons the excluded group to the zone of exception where violence is sanctioned. This part of Agamben's (1998) work provides a critical framework for the analyzing the ways in which the human service landscape serves as a zone of exception and also how the zone of exception makes it difficult to recognize the oppression of people with ID.

## **1.2 Background**

**1.2.1 Defining Intellectual Disability.** The definition of ID has changed throughout history based on the model used to understand disability (Schalock, 2011). Along with a changing definition, the language used to describe ID has also changed. Outdated terms such as mental deficiency, mental handicap, mental sub normality and mental retardation persist in policy documents and medical literature. The language used varies between countries, in Canada the term developmental disability is used whereas learning disability is the most common term in the UK. The term ID is increasingly being used internationally and has replaced the term Mental Retardation in the most recent Diagnostics and Statistics Manual of Mental Disorders, the DSM-V (American Psychological Association, 2013).

In the DSM-V, the diagnostic criteria for ID is based on the assessment of intellectual functioning and adaptive functioning (American Psychological Association, 2013). The intelligent quotient (IQ) test is used to measure intellectual functioning. A diagnosis of ID is made when a score is two standard deviations below the mean, or less than 70. Adaptive functioning is measured using standardized scales that assess adaptive behavior in three domains; conceptual, social and practical skills (Schalock, 2011). A diagnosis of ID must also include

adaptive functioning scores that are at least two standard deviations below the mean in one of the three domains or a combined score of all three domains that is two deviations below the mean can be used to meet the definition. The limitations in intellectual functioning and adaptive behaviour must present before the age of 18 to meet the current definition of ID.

Defining ID serves a number of purposes. It provides a clinical diagnosis, determines eligibility for funding and supports and provides a distinct category for research and policy (Schalock, 2011). The DSM-V has incorporated a new understanding of human functioning that appreciates the multidimensional states of functioning (American Psychological Association, 2013). The social-ecological model has also gained popularity within the professions, the model provides a constitutive definition of ID that considers functioning in relation to the demands of the environment (Schalock, 2011).

The fluid definition of ID has served to meet many different needs and in most cases has had little or no positive impact on the lives of people who have been labeled with ID. In most cases, defining ID has had negative impacts on people, families and communities. Carlson (2009) provides a critical assessment of the use of ID as a category in the field of philosophy. She outlines how the concept of ID has been reworked conceptually to support philosophical arguments on topics ranging from animal rights to species membership. Carlson (2009) reveals how philosophical debates intentionally, or unintentionally, oppress people with ID because they are representative and are conceptually exploitive. Carlson (2009) suggests moving beyond the objectification of ID and the conceptual exploitation of this category in philosophy. An historical materialist analysis of ID also reveals how defining the category of ID has been used to legitimize the concept of a human hierarchy (Nibert, 1995).

The choice to focus on the defined category of ID in this analysis was made, despite the problematic consequences discussed above, in order to examine the absence and encapsulation of people who are defined by this category. The individual characteristics and experiences of people with the label of ID will not be the focus of this inquiry. Instead, the focus will be on the ideologies and actions that define and maintain the concept of ID by those who are outside of the category of ID.

**1.2.2 Manifestations of the oppression of people with Intellectual Disabilities.** While there is little research that describes or defines the oppression of people with ID, there is research that looks at how people with ID are impacted by oppressive forces. This research shows that people with ID are at a significantly higher risk to experience poverty (Emerson, 2007), violence (Wilson & Brewer, 1992; Sobsey *et al.*, 1995; Petersilla, 2000) and health inequalities (Ouellette-Kuntz, 2005). Many of the studies explored the increased risk experienced by people with ID and attributed increased risk, in some way, to social exclusion and lack of opportunities to benefit from the opportunities available to those without ID (Sobsey *et al.*, 1995; Ouellette, 2005, Emerson, 2007).

Work by Emerson (2007) shows that, in the western world, people with ID have a significantly higher risk of experiencing poverty than those without ID. He attributes the increased risk to three major causes, first, the exclusion of people with ID from the workforce, second, increased child poverty due to the cost of equipment and support and third, an increased risk (20-30%) of poor health and mental health in adolescence (Emerson, 2007).

Ouellette-Kuntz (2005) examines health inequality between people with the label of ID and those without by employing a health equity lens. She has challenged the dominant

perspective that poor health is inevitable for this population and has instead linked health inequalities to three key factors. First, people with ID are less likely to have the same opportunities to access quality health care. Second, traditional models of care for people with ID impact their ability to live healthy lifestyles and third, the limited knowledge, skills as well as attitudes the attitudes physicians have about ID impact healthcare systems (Ouellette-Kuntz, 2005).

There is a small body of work on the violence experienced by people with ID. Sobsey *et al.* (1995) shows that people with ID are four to 10 times more likely to be victims of crime. A study by Wilson Brewer (1992) concludes that people with ID are four times more likely to be assaulted than the rest of the population. Moreover women with ID are 10.7 times more likely to be sexually assaulted than women without ID. In a study of 100 reports of sexual violence against women with ID above the age of 14, over 90% of offenders were known to the victim, more than a quarter were specialized service providers. Of the 100 allegations only 11 convictions were made (Sobsey *et al.*, 1995).

### **1.3 Theoretical Framework**

Engaging with anarchist theory and philosophy provides a unique vantage point for developing a critique of the state and understanding multiple forms of oppression. Anarchism, as a philosophy, is always evolving in order to uncover different forms of oppression and strategies to resist domination. There are a number of important tenets of this political philosophy. Emma Goldman, a classical anarchist thinker, writes:

”Anarchism . . . stands for the liberation of the human mind from the dominion of religion; the liberation of the human body from the dominion of property; liberation from the shackles and restraint of government. Anarchism stands for a social order based on the free grouping of individuals for the purpose of creating real social



wealth; an order that will guarantee to every human being free access to the earth and full enjoyment of the necessities of life, according to the individual desires, tastes and inclinations” (Goldman, 1917/1969, p. 62)

Anarchism is concerned with resisting oppression, hierarchy and domination in all spheres of life not only within the economic sphere. For anarchists, oppression, hierarchy and domination of any kind are undesirable because these manifestations of power restrict individual freedom and in turn, reproduce inequality (Goldman, 1917/1969). The anarchist emphasis on individual freedom is often confused to mean every person for herself, however this is not the case because the result would be the domination of the weak by the strong (Bakunin, 1871 as cited in Dolgoff, 2002). Instead, from an anarchist viewpoint, individual freedom is achieved through non-hierarchical, egalitarian, self-managed social arrangements. Mikhail Bakunin, a seminal anarchist theorist wrote “I am truly free only when all human beings, men and women, are equally free, and the freedom of other men, far from negating or limiting my freedom, is, on the contrary, its necessary premise” (Bakunin, 1871/1980, p. 237). The emphasis on resisting all forms of oppression and domination in ones day-to-day life gives anarchism a revolutionary character which may be part of the reason that there has been a recent resurgence in discussions of anarchism (Blumenfield *et al.*, 2013, Dixon, 2012, Newman, 2007).

The resurfacing of anarchism as a feasible political alternative has sparked discussions of anarchism in relation to post-structuralism. These discussions position “classical anarchism” in a positivist paradigm bounded by enlightenment thinking. Post anarchism is an attempt by some contemporary scholars to bring anarchism into the post-structural paradigm, while maintaining an anarchist commitment to individual freedom and anti-authoritarianism (Newman, 2007, Newman, 2010, Newman, 2011). Post anarchist thinkers highlight links between post-

structuralism and anarchism. Saul Newman (2010), a post anarchist thinker adopts a post-structuralist lens to reveal what he calls “blind spots” in anarchist theory. Newman suggests that the humanist ideas of the enlightenment that can be seen in classical anarchist writing should be re-examined through a post-structuralist lens.

The classical anarchist writing, referenced by Newman, posits that in the absence of hierarchy and oppression human beings will be free to realize their human potential and that society will evolve rationally towards an ideal in which every individual is equally free (Newman, 2007). For Newman (2007), the problem with this line of thinking is that it is stuck in a positivist paradigm, which fails to deconstruct the notion of universal human potential and the concept of rationality. Newman (2010) provides four examples that problematize the positivist themes in classical anarchism to illustrate this point.

First, the anarchist conception of the social as the site from which equal freedom will arise, in the absence of hierarchy and domination, fails to recognize the constructed nature of the social sphere (Newman, 2010). Second, Newman (2010) calls into question the idea of a fixed identity of the subject by suggesting instead that there is instability and plurality to identity. Third, Newman (2010) points to what he calls the complicity of the subject in power. He suggests that the classical anarchist conception of a rational subject, whose human essence is restricted by power, is an oppressive idea in and of itself. The belief in a universal human subject is exclusive and normalizing and therefore must be rejected in an attempt to resist oppression. The fourth example questions the notion that history unfolds according to some sort of natural or historic law (Newman, 2010); instead Newman adopts a view of history that is based on contingencies and unpredictability. Newman’s analysis of anarchism, using a post-structuralist lens, is an attempt to take what is innovative about anarchism and leave the

humanistic, enlightenment ideas about human nature and historical laws behind (Newman, 2007). The innovative aspect of anarchism, for Newman, is that it provides a lens that highlights multiple sites of oppression as well as the multiple sites and identities from which oppression can be resisted, which provides political content for the analysis of oppression (Newman, 2010). Newman's project of post anarchism also reveals the anarchist tendencies in post-structuralist thinking, particularly the anti-authoritarian stance and the deconstruction of power relations (Newman, 2010). Newman provides insightful analysis of the post structuralist theory on biopolitics (Newman, 2010), human rights (Lecht & Newman, 2012) resistance (Newman, 2009) and radical politics (Newman, 2007) from an anarchist standpoint. These analyses form an anarchist lens for social justice thinking, organizing and action that form the foundation for constructing the theoretical framework that follows.

Giorgio Agamben provides a critique of human rights that is based on the analysis of the paradox of sovereignty. This paradox comes to light through the emergence of Homo sacer within a state of exception (Agamben, 1998). Agamben has openly criticized anarchism and distances himself from the political philosophy. Nonetheless, his critique of the state and his call for the reimagining of the human beyond sovereignty or the state has anarchist tendencies (Lechte & Newman, 2012). In his analysis of the Holocaust, Agamben points to the existence of the state of exception that is created when an exception to the norm results in the dissolution of law and order. In the "state of exception" sovereign power or the state has the power to kill without committing murder (Agamben, 1998). The state of exception is the result of a ban, or abandonment, where the law abandons the individual or the case that is the exception. The exception, for Agamben, "is what cannot be included in the whole of which it is a member and cannot be a member of the whole in which it is included" (Agamben, 1998, 21). The exception

is not simply excluded, but rather it is taken outside and then considered differently (Agamben, 1998). The concept of the state of exception, the ban and being taken outside can be used to understand the encapsulation of ID. Agamben (1998) refers to the figure that is found in the state of exception as Homo sacer. Homo sacer, which is life that is captured in the state of exception, becomes “life that may be killed but not sacrificed” (Agamben, 1998, p. 53). Agamben outlines how this process of inclusion on the basis of exclusion operates to capture those who exist on or outside the margins to maintain sovereign power over those who have been abandoned. As more and more exceptions arise, so do zones of exception that become more and more difficult to identify. The role of the state in maintaining power is closely linked to the control of those found within the multiple zone of exception. Agamben suggests that this trend is insidious in our political order and must be examined and brought to light in order to reimagine the human beyond the inclusion/exclusion binary that serves as the foundation for the state or sovereign power (Agamben, 2010). This reimagining ultimately involves a new social order that no longer places value/non-value on bare life. The reimagining of the human, for Agamben, must involve witnessing instances of bare life and the form of Homo sacer (Agamben, 1998, Lechte & Newman, 2012).

Agamben’s thesis on Homo sacer and the state of exception describes the concentration camps during the Second World War as well as the experience of stateless refugees following the war in order to demonstrate his line of thinking (Agamben, 2010). Agamben’s double exception, which produces the figure of Homo sacer in the zone of exception, forms one half of the framework used to analyze the human service landscape. This half of the theoretical framework takes up the anarchist interest in uncovering unrecognized forms of oppression that have become normalized.

The second half of the theoretical framework constructed for the analysis of the human service landscape uses Antonio Gramsci's concept of common sense, which forms part of his work on cultural hegemony. Gramsci is known as a Marxist thinker (Robinson, 2005), and Anarchists have vehemently critiqued the Marxist belief that revolution can be imposed and that states will fade away as society is reorganized horizontally by an external power (Bakunin, 1873/1971). Despite this association, Gramsci's concept of 'common sense' can inform anarchist approaches to resisting oppression. The concept of 'common sense', which has seen resurgence in recent years (Robinson, 2005), provides a direction for bringing about social change at a grassroots level. Robinson (2005) outlines how the Gramscian concept of common sense has been largely ignored in discussions of cultural hegemony and argues that the current turn in radical politics warrants an examination of this concept.

Robinson's (2005) summary of Gramsci's prison notebooks explains that each individual has their own conception of the world that is based on normative ideologies. These normative ideologies shape the individuals experiences and inform their actions. This understanding reveals that the individual is both intellectually and politically active (Robinson, 2005). Gramsci suggests that it is on this ethico-political level, or the level of conceptions of the world, that social transformation is possible (Gramsci, 1971, as cited in Robinson, 2005). Gramsci distinguishes between organic and arbitrary ideologies. Arbitrary ideologies are maintained intellectually but do not have any influence on actual social relations whereas organic ideologies influence actual lived experience (Gramsci, 1971). The question for Gramsci becomes, how can people be encouraged to deconstruct the organic ideologies, or conceptions of the world, that produce 'common sense' that, when held collectively, maintains oppressive social relations (Gramsci, 1971, as cited in Robinson, 2005). 'Common sense' consists of the commonly held

beliefs of the masses, which influence their conception of the world and in turn, their actions (Gramsci, 1971). These commonly held beliefs are examples of organic ideologies that lack the moral coherency of intellectual ideologies. ‘Common sense’, because it lacks coherence, can be manipulated and shaped by the interests of the dominant elite (Gramsci, 1971, as cited in Robinson, 2005). ‘Common sense’ is maintained and reproduced over many generations because people fail to critically examine social norms that contribute to the oppression of marginalized groups. When this is the case, oppression becomes naturalized and is difficult to recognize. Gramsci’s theorizing on social change explains that ‘good sense’ can be constructed when an individual is introduced to coherent, intellectual ideologies as well as new personal experience that conflict with ‘common sense’ (Gramsci, 1971, as cited in Robinson, 2005). This engagement with critical thinking, and the opportunity to experience new social relations that confirm intellectual ideologies, in day-to-day life, is the foundation for the intellectual revelation that Gramsci calls for when he invokes the notion of common sense (Robinson, 2005). The concept of ‘common sense’ forms the second half of the theoretical framework and is used to reveal the ‘common sense’ around ID that has become naturalized through years and years of oppression by the state and through social relations that devalue people with the label of ID. The concept of ‘common sense’ is used to analyze the themes that emerge from the description of the human service landscape to uncover and question the ‘common sense’ that guides policy and programming.

#### **1.4 Summary**

This chapter introduces the problematic that is explored in this thesis, which is the inability of people engaged in understanding and resisting oppression, to see the oppression of people with ID. The specific research questions that were constructed to inform the problematic

are outlined. The theories that form the framework for analysis are introduced and positioned as they relate to the analysis of the human service landscape. Background information on the definition of ID as well as the manifestation of oppression are presented to provide context for the problematic. In the final section of this chapter, the theoretical framework is described in greater detail and linked to the analysis of the human service landscape for people with ID in BC as it is described using the public facing policy and program descriptions.

The following chapter is a review of the academic literature that critically examines the experience of people with ID. The literature review begins with an overview of the history of ID and the human service landscape for people with ID. The literature review also provides a review of the academic literature from the disciplines of Disability Studies, Sociology and Human Geography. The decision to focus on these disciplines was based solely on the reality that they were the only disciplines that have produced work that critically examines ID.

## **Chapter Two: Literature Review**

### **2.1 Introduction**

The first section of this chapter provides a brief overview of the history of ID and the system of support that has been created to address ID. The second section of the chapter reviews the absence of ID in academic disciplines that have emancipatory goals. In its totality, this literature review helps to inform the analysis of the human service landscape for people with ID and the role of the human service landscape in the absence and encapsulation of ID.

### **2.2 The History of ID and the Human Service Landscape for People with ID**

There are a number of historical accounts of ID as well as established paradigm shifts in the perception and social position of people with ID. Nibert (1995) presents an historical

materialist analysis of the record of ID in the western world. For most of human history, foraging typified the mode of production for western societies. By today's definition of ID, many of the individuals who were included in the activities of hunting and gathering would have the label of ID (Scheerenberger, 1983). Individuals with significant physical impairments or serious injury were, in some cases, euthanized or left behind to facilitate the migration and survival of the larger community (Nibert, 1995).

With the emergence of agriculture, people with ID were able to contribute to their societies as hunters, fishers, peasants and farmers (Kanner, 1949). As agriculture became increasingly efficient, the human population increased and division of labour emerged. This trend allowed for the accumulation of food and resources. With increased productivity and the accumulation of resources, a privileged minority took control of the surplus. This concentration of resources led to a decline in egalitarianism and greater social stratification. The agrarian-based economies were maintained through top down control and political power grew through the conquest and the subjugation of individuals to the position of slave or peasant. The new social conditions resulted in a decline in the value of the individual and the establishment of human hierarchies rooted in power, privilege and conquest (Nibert, 1995). In some societies, people with ID were abandoned or murdered when it was determined that they were unable to be productive. People identified as having a developmental or physical disability were also used as forms of entertainment. However, during this time it is believed that many people, who today would have a diagnosis of ID, were not identified because the vocations of the time were relatively systematic and largely physical in nature (Crissey (1975) in Nibert, 1995).

During the late middle ages, the establishment of capitalism as the dominant mode of production was facilitated by the reorganization of labour and the dissolution of the feudal social



order (Nibert, 1995). The conditions that supported the development of the capitalist economy also produced a growing number of people who were unable to participate in the new forms of economic productivity. As urban centres grew the disenfranchised turned to vagrant lifestyles of begging and robbing in order to survive (Nibert, 1995). In the western world, the response to those who were living in poverty was rooted in the charity model. This approach to support identified the “worthy poor” who would receive assistance from their communities (Metzel & Walker, 2001). Early forms of support for people with developmental disabilities, who were considered worthy, involved supporting them in a family home, with a relative or another community member who would charge a fee for service. While people remained in community, their social value was often very low. The alternative model of support during the early 1800’s was the development of large congregate care settings for people who could not receive support in their communities. These congregated settings allowed for the economic exploitation of people with disabilities as entertainment. Evans (1983) describes an institution in Bethlehem where residents were exhibited to guests once a week for the entrance fee of one cent. In 1815, it was reported that the revenue generated from the weekly exhibition was 400 pounds, which suggests approximately 96,000 people visited that year (Evans, 1983).

The mid 1800’s saw a shift in the treatment of people with ID, particularly children. Schools began to open with the aim of curing ID, which was then referred to as feeblemindedness (Metzel & Walker, 2001). Edouard Seguin introduced a pedagogy termed “Moral Education” which focused on developing the will of people considered to be mentally deficient (Kliewer & Drake, 1998). Children were removed from their families and communities to be congregated in highly controlled institutional environments, the intention being that the professionals could cure feeblemindedness so children could return to their families and become

productive citizens (Metzel & Walker, 2001). During this period, there was a large increase in the number of people being institutionalized however the majority of people with developmental disabilities remained in their communities. Ferguson (1994) notes, “the single overwhelming feature of the changes in policy towards retarded people between 1850 and 1875 is that they led to very little change in the daily lives of most of those individuals” (Ferguson, 1994, as cited in Metzel & Walker, 2001, para. 14).

The last half of the 19<sup>th</sup> century saw increasing centralization of wealth and economic power. The United States saw a rapid increase in the number of people living in cities, as well as an increase in crime and vagrancy among disenfranchised populations, of which many were considered to be feeble-minded (Nibert, 1995). Social critics of the time recognized that the emerging social and economic systems were contributing to the social problems that began to be identified. These critiques led to the establishment of a number of labour unions and the call for social reforms (Nibert, 1995). In response to these calls for social and economic reforms, the elite became proponents of the theory of social Darwinism, a theory that attributed crime, poverty, disease and ID to individual genetic factors. Social Darwinism provided the foundation for the “science of eugenics” and, as Nibert suggests, “a class of scapegoats was found for the economic and social ills of the United States – ‘mental defectives’” (Nibert, 1995, p. 64). Following the Civil War and the subsequent economic depression, state funding for the “schools for the feeble-minded” decreased while the number of people being institutionalized increased as families no longer had the necessary resources to care for their family members with ID (Kliwer & Drake, 1995). The state facilities that housed people with ID, with the intended goal of education, transformed into custodial institutions that served to protect society from mental deficiency.

In the 1880's, policies were developed to restrict marriage and systematically institutionalize and sterilize both men and women with ID. These policies were supported by the emerging science of eugenics (Metzel, & Walker 2001).

In North America, eugenic policies that included the practices of segregation and sterilization were developed during the interwar period. By 1926, mandatory sterilization laws existed in 23 states and an estimated 50,000 people labeled as mentally defective were sterilized between 1925 and 1955 (Evans, 1983). In Canada, the provinces of Alberta and British Columbia enacted mandatory sterilization laws while other provinces adopted policies for segregation and voluntary sterilization (Radford & Park, 1995). These practices continued into the 1970's in Alberta, Canada (Radford & Park, 1995). The exact number of people who were sterilized under these laws in BC is not known due to the lack of records. Records from the province of Alberta show that the province sterilized 948 men and 1,154 women between 1928 and 1972 (Radford & Park, 1995). The underlying aims of these policies were to control and eliminate mental deficiency in the population in order to ameliorate the social conditions of that period (Kliwer & Drake, 1995).

The emphasis on eugenics as a way to control and eliminate people with ID exacerbated the historical devaluation of people with ID. It is not surprising that the conditions within custodial institutions were extremely restrictive and dehumanizing (Blatt & Kaplan, 1974). The social conditions for people with developmental disabilities in North America saw some improvements in the mid 1900's. The 1950's marked a time of prosperity in North America, which led to an increase in public funding for services to people with ID (Nibert, 1995). Furthermore, following the systematic killing of people labeled undesirable by the Nazi regime during the Second World War, the public became repugnant towards the use of eugenic practices

as a solution to social problems (Nibert, 1995). During the same time, families and advocates of people with developmental disabilities emerged to form the Community Living Movement and began advocating for rights, policies and services based on the emerging discourses around least restrictive alternatives, normalization and mainstreaming (Nibert, 1995).

Advocacy was responsible for the development of a formal community service landscape and, eventually, the deinstitutionalization movement in the 1970's (Metzel & Walker, 2001).

The Community Living Movement saw many successes in terms of policy, funding and increased service options. However, these measures and the physical presence of people with ID in community have not been sufficient in addressing the historical devaluation of people with ID (Nibert, 1995; Metzel & Walker, 2001; Kliewer & Drake, 1995). The stigma attached to ID, the legacy of eugenics and the ongoing exploitation of people with ID continues to shape the current service landscape. It is not uncommon for people with ID to live, learn and work in congregated settings that limit social inclusion and participation (Nibert, 1995; Metzel & Walker, 2001).

Metzel and Walker (2001) provide a sobering account of the current reality of service provision for people with ID in the United States:

“Our historical and contemporary discussions lead to the unsurprising conclusion that the dominance and designs of the service systems has, at every turn, unintentionally or intentionally prevented social inclusion when people with disabilities are treated as a group. Even if people with disabilities are supported in individualized ways that promote not only community presence, but participation, there still remain a number of constraints to the geography of their lives in the community. We are still learning how to provide support and services in places where people with developmental disabilities are that do not intentionally or unintentionally restrict them and devalue them” (Metzel & Walker, 2001, p. 21).

### **2.3 A Review of the Literature on the Absence and Encapsulation of ID**

A handful of scholars, from different disciplines, have taken up ID in their work. Those who have chosen this focus, point to the absence of the recognition of ID in their respective disciplines. There is a large body of academic research that has served to pathologize people with ID and their families, particularly in the fields of medicine, special education, psychology and social work. Academic literature concerned with pathologizing ID or evaluating services for people with ID were excluded. This literature review is focused on research and theory with emancipatory goals. The decision to focus on this particular literature was strategic in that it exposes a variety of critical viewpoints and discussions on the absence of ID in the literature from fields concerned with emancipation and resistance.

The literature that constitutes this review was identified using Google Scholar. The Google Scholar database was chosen for two reasons. First, Google Scholar accesses journals across all disciplines, as opposed to databases that limit searches to a single discipline. Second, the entire text of the journal articles is analyzed to identify search terms (Google Scholar, n.d.). These two features of Google Scholar made it more desirable for this review when compared to databases that are discipline specific both in content and key word curation. Intellectual disability, learning disability, developmental disability and mental retardation were used as search terms in combination with marginalization, oppression, exclusion, exploitation and absence to identify relevant scholarly articles.

Critical discourses on the absence of ID were identified only in the fields of Disability Studies, Sociology and Human Geography. The theme of encapsulation emerged from the literature identified in these disciplines. More specifically, the literature described the encapsulation of ID as a concept and the encapsulation of people with ID in the human service

landscape. Different forms of encapsulation are described in the literature as well as the structures that contribute to the encapsulation of ID.

**2.3.1 Absence and encapsulation of ID in the research and scholarship of Disability Studies.** Disability Studies scholars have produced a number of works that locate and describe various forms of oppression that people with disabilities experience and have introduced the socially constructed nature of disability. Disability Studies draws on relevant disciplinary insight from the fields of history, sociology, economics, political science and the arts to examine disability from a variety of perspectives (Roulstone & Thomas, 2012).

The academic discipline of Disability Studies emerged in the 1960's and was closely linked to the disability rights movement (Roulstone & Thomas, 2012). The central theoretical framework was, and continues to be, the social model of disability. This model is based on the definition of disability put forward by the Union of the Physically Impaired against Segregation (UPIAS, 1976). The social model defines disability as a social phenomenon that manifests as the differential treatment of people with impairments that leads to social exclusion and stigma. The social model is still the dominant perspective within the field of Disability Studies.

Disability Studies has focused primarily on the experience of people with physical impairments while discussions of ID remain at the margins (Stalker, 2012). Scholars who have included ID engage in discussions that focus on the scant analysis within the Disability Studies. Chapell (1997) has suggested that disability scholars have simply ignored people with ID in their discussions of disability. Aspis (2000) points to the exclusion of intellectual impairment in the UPIAS definition and suggest that this exclusion contributes to the absence of ID largely because

the social model tends to locate impairment in the body. This feature of the UPIAS definition does not always transfer to understanding ID. While these positions were originally published in 1997 and 2000, they are still supported in the literature and are referenced in the current Routledge *Handbook of Disability Studies* (Stalker, 2012). The inaccessibility of theory and academic language for people with intellectual impairments is identified as a barrier to the participation of people with ID in the field of Disability Studies (Aspis, 2000). Inaccessibility of theory and language is particularly problematic because representation and research by non-disabled academics is a hotly contested phenomenon within Disability Studies. Complicating this notion even further, the legitimacy of scholars with ID who have engaged in Disability Studies has been questioned and largely excluded from the academic discourse (Aspis, 2000). More critical analysis of the absence of ID in the Disability Studies points to the othering of people with ID by the disability community and the establishment of a hierarchy of disability that places ID at the bottom of the hierarchy (Stalker, 2012).

The place of ID in the Disability Studies has been discussed in relation to the social model of disability. However, the theoretical framework of Normalization served as the framework for studying the oppression of people with ID from the 1960's through to the 1990's and continues to guide service delivery and policy today (Stalker, 2012). Normalization is a systematic theory developed by Wolf Wolfensberger (1980) to examine the devaluation and stigmatization of people with ID. He advocated for the use of Normalization as a theory to guide the development of services for people with ID and other devalued people (Wolfensberger & Tullman, 1982).

Wolfensberger defined Normalization as “the use of culturally valued means ... to enable, establish and/or maintain socially valued roles for people” (Wolfensberger & Tullman,

1982, p. 131). The theory is innovative because it shifts the paradigm of human services away from serving a cure, care and control function and towards enhancing the lives of people with ID. A key concept in the theory of normalization is deviance, which is the process of devaluation of particular differences by the majority (Wolfensberger & Tullman, 1982). The theory of Normalization explains that when a person or group is devalued by society they are treated differently than those who are not. Wolfensberger and Tullman (1982) provided three concepts that demonstrate and deconstruct the differential treatment experienced by people with ID. First, people who are devalued are treated badly. The social response to people who are devalued is to distance them using segregation, or most extremely genocide, or alternatively, to reverse the traits that are considered deviant and that contribute to devaluation (Wolfensberger & Tullman, 1982).

Second, the negative treatment is a reflection of how the devalued person or group is understood by the society (Wolfensberger & Tullman, 1982). One example of this from the human services is segregated programming for people with ID that focuses on interactions with animals. The underlying assumption is that people with ID are animal-like and will therefore benefit from interactions with animals rather than other people. A second example outlines how people with ID are conceptualized as being sick or ill as a result of being associated with medical professionals. Human services do this by describing common activities as therapy that require specialized knowledge to deliver (e.g. Garden therapy, reading therapy, music therapy).

Third, the way a person is perceived and treated by others has an impact on how that person behaves (Wolfensberger & Tullman, 1982). When a person is treated and perceived as deviant they are likely to behave according the social expectations for deviance and conform to the expectations people hold. On the other hand, when someone who is devalued benefits from



the same experiences that a person who is not devalued would to increase their social role value, they will be more likely to conform to the expectations that are held for people who are not devalued (Wolfensberger & Tullman, 1982). This third concept forms the basis for the theory of Normalization.

The major criticism of Normalization is that it fails to recognize the systematic oppression of people with ID and, in turn, lacks the political content required to create real social change (Oliver, 2009). Normalization drove the deinstitutionalization and community living movements but, not surprisingly, the attitudinal barriers that people with ID face in community limit the opportunities for socially valued roles. Furthermore, the political economy of ID makes it difficult to create change for those who are encapsulated in socially devalued roles (Nibert, 1995).

### **2.3.2 Absence and encapsulation of ID in the research and scholarship of Sociology.**

A recent article by Shuttleworth and Mekosha (2012) discusses the absence of disability, although not specifically ID, in the field of sociology in relation to the concept of the sociological imagination. This term, introduced by Mills (1959, as cited in Shuttleworth & Mekosha, 2012), describes the work of sociologists who tackle questions that link personal experiences or problems to larger social issues. Mills suggests that sociologists who are imaginative with their work are those who ask the following three questions. First, what is the structure of society and its essential components? Second, where does society stand in human history? And finally, what varieties of humans are there (Mills, 1959, as cited in Shuttleworth & Mekosha)? Shuttleworth and Mekosha (2012) suggest that there needs to be a reimagining of disability within sociology and that this can occur by reframing disability in such a way that it is positioned within the sociological imaginary.

Suttleworth and Mekosha (2012) outline the historical marginalization of the topic of disability within sociology. They describe sociology's engagement with disability and that most of the research on disability adopts the medical model of disability. The emphasis on the medical model fails to challenge the hegemonic discourse that defines disability as a medical condition. The focus on the medical model can be seen in a number of sub-disciplines such as Sociology of Health & Illness, Medical Sociology and Sociology of the body. It is important to include that critical disability scholars who resist medicalized definitions of disability have taken up the sociology of the body from an emancipatory standpoint. One explanation for this lack of critical examining of disability as a social construction is the emergence of hypersociology (Agger, 1998, as cited in Suttleworth & Mekosha, 2012). This is described as the shift within

sociology towards a focus on methodology. This shift is an attempt to prove the scientific rigor and ultimately the legitimacy of sociology in order to increase funding for research and post-secondary programs. For disability, this shift has meant that critical thinking and investigation of social problems have been neglected. At the same time, policy-based research or evidence-based practice has been the focus for sociologists engaging with disability (Suttleworth & Mekosha, 2012).

Suttleworth and Mekosha (2012) hypothesize that the lack of critical thinking around disability in the field of sociology has to do with a perceived lack of agency that is assumed when one “imagines” disability. This perceived lack of agency has focused inquiry on the structures that determine how people with disabilities will exist rather than on the experiences of people with disabilities. The authors conclude with a call for disability scholars to position disability within the sociological imagination in order for Sociologists to begin to understand and take up disability using the social model rather than the medical one. They suggest that in doing so sociology can incorporate the concept of disability in the analysis of sociological concepts.

Suttleworth and Mekosha (2012) define the absence of disability in sociology and provide a recommendation on how to move forward in an attempt to fill this gap. However, the point that they raise regarding agency is not expanded on quite enough. If the goal of bridging the gap between Disability Studies and Sociology is to increase understanding of sociological constructs, there needs to be a critical discussion on how to resist the objectification of disability through the application of sociological theories. This objectification, common in sociology, is discussed and resisted by Dorothy Smith (2005) through her process of inquiry known as Institutional Ethnography. Her appreciation of individual experience as a form of knowledge resists the tendency within sociology to objectify the individual.

### **2.3.3 Absence and encapsulation of ID in the research and scholarship of Human**

**Geography.** The field of Human Geography has taken up the study of disability by focusing on how space and place influence the experience of people with disabilities as well as the ways in which disability is conceptualized. This sub discipline, referred to as the Geographies of Disability, has two major themes that underpin inquiry, the political economy of disability and the disabling/enabling geographies that people with impairments experience (Gleeson, 1999).

In *The Production of Space*, Henry LeFebvre (1991) advanced a key theory in Human Geography. His theory suggests that space is socially constructed and that the production of space, based on values and the social construction of meaning, influence special practices and perceptions of space. His analysis goes on to discuss how the social production of space is used to reproduce social relations and is a tool used by the hegemonic class to reproduce domination and social hierarchy. For LeFebvre, social change requires the production of new spaces that are rooted in new forms of social relations. Lefebvre's work continues to be accepted as the dominant framework for inquiry in the field of Human Geography. His theory is powerful in that it provides both a method for analyzing current social relations that are reproduced through the production of space while at the same time laying out a framework for change and resistance to hegemonic social relations. The analysis of disability by Human Geography provides a lens for understanding disablement by looking at space and place in relation to disability (Imrie & Edwards, 2007)

Human geographers have adopted the analysis of space proposed by LeFebvre and use it to characterize geographies of exclusion (Laws, 1994) as well as enabling geographies (Gleeson, 2000). Gleeson's argument for the production of enabling geographies explores how the work of

human geographers, in understanding the production of space, can contribute to positive social change for people with disabilities by empowering them to deconstruct disabling geographies and resist ableist practices and institutions. This agenda proposed by Gleeson for the field of Human Geography adopts the approach introduced by LeFebvre and adds to it by pointing to the role of research in the production of space. Gleeson (2000) calls for new social relations within research that resist the reproduction of hegemonic social relations.

The sub discipline of Human Geography concerned with the Geographies of Disability focuses largely on the geographies of physical disability and geographies of mental health (Imrie & Edwards, 2007; Hall & Kearns, 2001). There is a small body of work that looks at the geographies of ID. This sub-discipline has two distinct phases, the first examines geographies inside the asylum. The second phase emerged after the deinstitutionalization movement and is interested in the geographies of ID outside of the asylum. The literature that makes up the sub-discipline is divided into two waves based on the approach taken to studying the Geographies of Disability (Wolch & Philo, 2000).

The first wave of the sub-discipline focuses primarily on the location of people with ID and adopts quantitative methods to understand the spatial distribution of “deviant” populations (Hall & Kearns, 2001). There is work in the Geographies of Disability that examines the socio-spatial implications of normalization for people with ID (Wolpert, 1980) and the residential locations of people with ID in both asylum and post-asylum geographies (Metzel & Walker, 2001). The major theme that emerges in the first wave points to the concept of the asylum without walls (Dear & Wolch, 1987) or the illusion of inclusion (Metzel & Walker, 2001). The findings from the first wave suggest that the human service landscape for people with ID, in the

western world, has contributed to the barriers that limit the participation of people with ID in their communities.

The second wave of the Geography of Disabilities takes up the analysis of how people with ID experience geography and how these experiences can serve to reproduce oppression and social devaluation (Laws & Radford, 1998). Laws and Radford (1998) published the seminal work in the second wave Geographies of Disability. Their research looked at the experience of people with ID, which was important because it included people with ID in the production of knowledge about their own experiences. The researchers did this by engaging the participants in storytelling and using open-ended questions rather than structured interview questions. This enabled participants to share a wide range of experiences and also ensured that participants who were not able to participate in interviews could contribute to the study through conversation that was supported by their allies (Laws & Radford, 1998).

The limited body of work on ID, within the sub-discipline of the Geography of Disabilities, suggests that there is an absence of this population within the discourse of Human Geography. This absence has been identified and discussed by those, within the discipline, who have written on the subject of ID. Hall and Kearns (2001) provided suggestions for why people with ID have remained absent in spite of the increasing focus on geographies of mental health and physical disabilities. First, they suggest that this absence is the result of people with ID being largely excluded from the discourse around the social model of disability. Second, they argue that the emphasis within Human Geography on participatory action research is problematic for this population. Participatory action research requires that researchers are able to find participants who are prepared to participate in providing a direction for the research.

Hall & Kearns (2001) explain that a number of factors hinder the participation of people with ID in participatory action research. These factors include social isolation, educational neglect, parent or carer control and the restriction of choice by a number of external influences. Hall and Kearns also explain that the marginalization and oppression experienced by people with ID remains largely invisible, even when compared to the experiences of people with mental health labels. The reason for this is complex, but Hall and Kearns (2001) put forward three possible explanations. First, the voices of people with ID are heard through charitable organizations that are inherently apolitical and reinforce historical stereotypes of people with disabilities as passive recipients of service. The second reason, which is particularly relevant to this research, is that people with ID are likely to receive support from family or government that keeps them from becoming part of the highly visible street population. Because people with ID are housed and have structured daytime activities that pull them out of the mainstream, the general public does not recognize the oppression that this population experiences. This encapsulation is more powerful for people with ID than those with mental health labels who access services because mental health is understood as episodic whereas ID is considered to be a permanent condition. This permanence can often mean that people with ID have little opportunity to engage in the mainstream, free from a connection to service whereas people with mental health concerns can move in and out of services (Philo & Metzel, 2005). The other, more critical explanation is that people who are considered to be 'mentally deficient' are seen as lacking reason, which has become the defining feature of the post-enlightenment human. This conception, of ID when combined with the current emphasis on reason, positions ID as the ultimate other. As described by the theory of Normalization, difference or otherness is the justification for the differential, and most often devaluing, treatment of people with this label.

The sub-discipline of Geographies of Disability, in particular those looking at ID, has established an agenda for the role of geographers in the analysis of ID. Hall and Kearns (2001) define two goals that they suggest should guide researchers engaged with the Geographies of Disability. The first is for geographers to understand the multiplicity of experiences of people with ID. The second is to understand the structural forces that confine space for people with ID. In an editorial for a special section of the journal *Health and Place* on the inclusion of ID in the Geographies of Disability, Philo and Metzel (2005) introduce an unpublished paper by John Radford (1995) in which he outlines four areas that should be the focus for human geographers. The first area falls into the first wave of geography and focuses on the spatial patterns of ID. The second is a focus on how people with ID relate to their space and place. This focus has been taken up in the work of Laws and Radford (1998), Hall (2005), Holt (2004) and Gabel *et al.* (2013), among others. The third area discussed by Radford, is a focus on public attitudes towards ID and community responses to ID. The fourth area is the focus on the impact of public policy on the lives of people with ID. This is addressed by Ferguson (1994) in an historical analysis of public policy from 1850 to 1875, around the time of institutionalization. This was one of the most productive times in terms of disability policy yet there was very little impact on the lives of people with ID, as most did not live in institutions. Metzel and Walker (2001) have also looked at the impact of policy on the lives of people with ID and suggest that “the dominance and designs of the social service systems has at every turn, unintentionally or intentionally, prevented social inclusion when people with ID are treated as a group” (p. 21). The discourse surrounding the absence of people with ID in the Geographies of Disability includes an analysis of the reasons for this exclusion as well as suggestions on the questions that warrant closer attention in understanding absence and ID. Strategies for understanding exclusion



and devaluation of ID includes the recognition of the social and economic marginalization of people with ID, challenging the ideas, policies and structures that dictate where people with ID belong and developing new ways of engaging people with ID in participatory action research (Hall & Kearns, 2001). Paul Smith (2005) suggests that any analysis of ID should deconstruct the ideologies and cultural practices that enable people with ID to be understood as less than human or in his own words “useless eaters” (p. 90).

Although the absence of ID in the field of Human Geography is not surprising, the thoughtful discussions on the cause of this absence, as well as the strategies put forward to address it, are promising. The focus is by and large on the space that has been created between people with ID and the mainstream in order to resist the social practices that reinforce this distance (Hall & Kearns, 2001). The underlying theme of this work is emancipatory, both in the analysis provided as well as the ways in which scholars adopt and modify participatory action research methodology to engage people with ID (Imrie & Edwards, 2007; Hall, 2001; Gabel *et al.*, 2013). These key features of the discipline are powerful because they give a voice to people with ID, who have remained largely unheard, in academic literature.

Anarchism and radical geography have also been closely linked. Kropotkin and Reclus, two prominent anarchist thinkers took up anarchism in their work in geography (Springer, 2012a). Anarchism influences radical geography to resist hierarchical organizing and social relations and calls for geographers to imagine non-hierarchical social organizing based on ethics of reciprocity rather than the ethics imposed by the state (Springer, 2012b). Not only does anarchism infuse geography with new sites for social change, it also reminds us that reflection is required when practicing new forms of non-hierarchical social relations to ensure that unseen hierarchies are brought to light. If not, these hierarchies are left to proliferate in the newly

constructed space (Springer 2012b). Insights from the discipline of radical geography have great potential to reveal the absence and encapsulation of ID and to show those without ID how the history of devaluation and oppression has naturalized the oppression of people with ID today. The oppression of people with ID has a long history and has been reproduced under many different states, this history must be considered in any analysis of hierarchical social relations.

#### **2.4 Summary**

The small body of academic work that focuses on the absence and encapsulation of people with ID as well as the ways in which the human service landscape for people with ID contributes to these themes. The literature review helps to focus the inquiry on absence and encapsulation and informs the research questions and methodology outlined in chapter three.

## **Chapter Three: Methodology**

### **3.1 Introduction**

The impetus for this thesis came to light through personal and professional experiences. These experiences are described in the subjectivity statement, which provides context for how the problematic that is explored emerged. The theoretical frame that guides the analysis was not constructed according to a prescribed orientation or a single theory; instead fragments of theory and literature from multiple disciplines have been brought together to address the problematic and construct research questions. This methodology was designed to broaden the analysis of human services. The research questions focus the analysis on the entire human service landscape, rather than specific components, to examine how the breadth of services contribute to the oppression of people with ID.

### **3.2 Subjectivity Statement**

The problematic that is explored in this thesis is the apparent inability of those involved in understanding and resisting oppression, to acknowledge and engage in resisting the oppression of people with ID. This problematic arose while working as an inclusion facilitator for a province-wide initiative for inclusive post-secondary education (IPSE).

For over five years, I have worked for the BC IPSE to provide inclusive post-secondary education opportunities for young adults with ID. This has provided me with unique opportunities to encourage individuals within the academic community to question the nature of ID through the experience of including a student with ID in their course. Students are enrolled as auditors however, there is the expectation that students complete assignments, exams and participate in all aspects of the course. The curriculum is modified to their ability and, when facilitated effectively, there is the expectation that students are engaged and learning. Faculty

members, who have included a student with ID in their class, have shared that the experience led them to deconstruct their previous understanding of ID. They have described how the interest of the student in pursuing higher education, as well as seeing students learn the course material, has challenged their preconceived notions about the nature of ID. While most faculty members have welcomed inclusive post-secondary education, inclusion at post-secondary has encountered resistance. Surprisingly, faculty members teaching emancipatory content such as women's studies, anarchist studies and social work have denied access to students interested in participating in their course. In some cases, access for students with ID has been denied based on equity arguments. The basis of these arguments considers students with ID and those without ID equally and suggests that ensuring access for people with ID, while at the same time denying access for people without ID is inequitable. This gap in understanding equity in relation to ID, from high-level academics is jarring. The logical incoherence of these arguments led me to identifying the problematic explored in this thesis. While the experience of inclusive-post secondary is overwhelmingly positive and receives a lot of support, these instances piqued my interest.

In my position with the IPSE initiative, I work closely with families to shift their expectations about what their son or daughter with an ID's life could look like. I encourage families to have a vision of an ordinary life for their son or daughter instead of a life as a perpetual client of the typical service delivery system. The biggest apprehension from families in supporting their son or daughter to pursue an ordinary life in community has been safety. The belief that ID programs are safer for people with ID than community is a common belief held by families, despite research that has found people with ID are most likely to experience abuse when they are segregated (Sobsey *et al.*, 1995). Even when presented with this research, it is

difficult for families and communities to question the ideology of segregation that surrounds ID (Kliewer & Drake, 2010). The strong opposition that I have to segregation is based on this research as well as personal experiences in segregated settings. The opportunity to work briefly for a residential care provider made it clear to me that that nature of residential care is extremely dehumanizing to people with ID. For example, I had a training shift in a group home where the residents were placed on the basis that they had ID and were also all in wheelchairs. The residents at the group home were not allowed to drink soda because it was banned in their diet plans. In spite of this, the staff chose to drink soda while working in the group home. The staff member that was training me advised me that, despite the ban on soda for the residents, staff had the right to drink soda while working. She then advised me that if I did drink soda I should keep the can on a high surface so that the residents could not drink it, because it was out of their reach from their wheelchairs. This is a simple, yet blatant, example of how residential services are dehumanizing and oppressive to people with ID. The experience was shocking to me and led me to quit my job, however it was unrecognizable to both the staff and the residents in the home.

For the past three years, outside of my work, I have explored the political philosophy of anarchism. One of the pillars of anarchist thought is that hierarchy and oppression, in any form, should be resisted in day-to-day life. I have read many anarchist publications and while doing so became excited by the potential of this philosophy to reveal the oppression of people with ID and build resistance and solidarity. I eagerly explored anarchist organizing in my community, and through informal conversations with other self-identified anarchists, raised the topic of ID. It quickly became clear that people could not recognize the oppression of people with ID, which was so obvious to me. In fact, during a session I presented at the 2013 Victoria Anarchist Bookfair, participants were focused on understanding how the human service landscape operated

but would not engage in discussion points about how the concept of ID maintains human hierarchy. While my hopes of recruiting allies within the anarchist community have not yet been successful, anarchist philosophy has helped me to talk about the oppression of people with ID in more universal way. My identification with anarchism has led me to adopt radical theories for understanding and resisting oppression in the analysis of the problematic being explored.

### **3.3 Problematic & Research Questions**

The term problematic was introduced by Louis Althusser (1970, as cited in Smith, 2005) and subsequently taken up by Dorothy Smith (2005) in her sociology for people named Institutional Ethnography. A problematic is the “discursive organization of a field of investigation that is larger than a specific question or problem” (Smith, 2005, p. 38). The problematic that is being investigated here is the apparent inability for people, even those engaged in understanding and resisting oppression, to recognize the oppression of people with ID. This problematic guided the literature review, which looked at the literature that has taken up the oppression of people with ID. The themes of absence and encapsulation emerged in most of the work. A handful of the authors pointed to the role of services and professionals in reproducing absence and encapsulation (Metzel & Walker, 2001; Kliewer & Drake, 2010). The research questions were constructed to examine the relationship between the human service system and the oppression of people with ID.

The first two research questions focus on describing the human service landscape designed specifically for people with ID in BC. The questions that follow examine the relationship between the system of support and the oppression of people with ID. The specific research questions are:

1. What constitutes the human service landscape for people with ID in B.C.?

2. What percentage of people with ID access the human service landscape?
3. How does the human service landscape construct 'common sense' about ID?
4. How does the human service landscape compare to the double exception described by Agamben (1998)?

### **3.4 Data Collection**

Public facing policies and program descriptions were collected to inform the first research question. The human service landscape was described in its entirety at the level of funding and government programs. The documents used in the description included public facing informational documents as well as websites, annual reports, strategic plans and government reports. The description was divided into four subsections; the *UN Convention on the Rights of Persons with Disabilities*, services and programs for children, services and programs for adults and charitable organizations. The *UN Convention on the Rights of Persons with Disabilities* was described because it is the international instrument that informs government policies. The description of charitable organizations that supplement the services provided by government was included to demonstrate the breadth of specialized options that exist. The description that follows uses the language and level of detail that is provided in the policy and program documents.

The second research question was informed by calculating a rough estimation of the percentage of people accessing the human service landscape. The calculations made using the 1% prevalence rate of ID in the human population, which was calculated in a meta-review of the literature on the prevalence of ID (Maulik, 2011). The estimated number of people with ID in BC was calculated as 1% of the total population, provided by the BC Statistics demographic data. The number of people with ID accessing the human service landscape was estimated using the data available through the ministries that provide funding. The calculation of the prevalence

of ID in the total population was compared with the number of people accessing funding for ID services to get a rough estimate of the percentage of people with ID accessing the system of support.

The third research question was explored by looking at how the human service landscape contributes to 'common sense' about ID. Using Gramsci's (1971) concept of 'common sense' as the framework for analysis, the ways in which the human service landscape influences social relations with people who have the label of ID was described. Finally, based on these findings, the 'common sense' about ID was proposed.

To inform the fourth research question the human service landscape that was described was compared to the zone of exception, a concept proposed by Agamben (1998). According to Agamben (1998), the zone of exception is created through a double exception. When the sovereign state declares an exception on the basis of bare life, for example labeling people with ID, the bare life that is encapsulated by this first exception is abandoned to the state of exception. In the state of exception, bare life becomes organized by the state and is then included, or represented, on the basis of the original exception.

The second exception takes the form of violence or oppression, which is not recognized as violence and therefore is permitted within the state of exception. This is where Homo sacer emerges as the figure that can be killed without consequence. Using this frame, the diagnosis of ID is considered an original exception and the human service landscape is the zone of exception. The analysis focuses on identifying instances of oppression by the human service landscape, on the basis of ID, that are obscured by the zone of exception and would not be acceptable outside of it.



### **3.5 Strengths of the Study**

This study is the only known example that describes the entire human service landscape that exists for people with ID. While there are case studies that look at specific services or contexts, a view of the entire system provides a new level of analysis. Furthermore, there are few studies that have examined the percentage of people with ID who access the human service landscape. A paper by Metzger and Walker (2001) describes the increased focus on policy addressing institutionalization at the beginning of the 20<sup>th</sup> century and puts it into context by explaining that at that time most people did not live in institutions and were at home with their family or in community. This study allows for a historical comparison of the totality of the human service landscape.

A second strength of this study is that it is the only known study to use radical theory rooted in anarchist principles to examine the oppression of people with ID. Furthermore, it attempts to illuminate a gap in the larger body of work that looks at oppression by focusing on the, largely ignored, experience of people with ID.

### **3.6 Limitations and Weaknesses of the Study**

The choice to describe the entirety of the human service landscape designed specifically for people with ID limits the detail that could be included. The focus on public facing documents, reports and websites made it possible to provide a high level overview. This is a limitation because the description is made at a surface level. The documents that were used represent the human service landscape ‘on paper’. The practice of government, service providers and charitable organization is likely to deviate from the program descriptions that are ‘on paper’.

Another obvious limitation is that the estimation of the number of people with ID accessing the system of total support is very rough. The impetus for including this rough

estimation is to introduce a starting point for the analysis of the totality of the human service landscape in BC. It is important to understand if the majority of people with ID interact with the human service landscape or only a small percentage. The totality of the human service landscape informs the analysis using the concept of 'common sense'.

In addition to the limitations of the study, there are also a number of subjective arguments that may be challenged. The first weakness of the study is that the 'common sense' that was proposed was based on the personal reasoning of the author, which may not be shared by others. The 'common sense' proposed in this study provides the basis for future studies to confirm that the 'common sense' put forward is actually held collectively.

Finally, the assumption that segregation is a form of violence could be contested, however historically segregation has been used as a tactic to hurt, damage or kill people. This moral argument against segregation makes the study vulnerable to opposition from those who hold an ideology of segregation for people ID (Kauffman & Sasso, 2010) and have criticized approaches to supporting people with ID that are rooted in a moral position rather than pseudo-scientific evidence (Kliewer & Drake, 2010).

### **3.7 Summary**

Chapter 3 outlines the problematic from which the line of inquiry evolved and the methodology used to address the research questions. The methodology is divided into two parts. The first outlines how the human service landscape was described. The second describes the framework used to analyze the human service landscape. The framework for analysis is based on Gamsci's (1971) conception of 'common sense' and Agamben's (1998) concept of the zone of exception.

## **Chapter Four: Results**

### **4.1 Introduction**

The following chapter presents the results according to the order of the research questions that were outlined in chapter three:

1. What constitutes the human service landscape for people with ID in B.C.?
2. What percentage of people with ID access the human service landscape?
3. How does the human service landscape construct 'common sense' about ID?
4. How does the human service landscape compare to the double exception described by Agamben (1998)?

To inform the first two research questions, the human service landscape that exists for people with ID in BC is described. The results for the third and fourth questions focus the analysis of the human service landscape described, using the concept of 'common sense' (Gramsci, 1971) and the double of exception (Agamben, 1998). These pieces of theory served as the framework for analysis of the themes that emerged from the policy and program description documents, as they were organized in the description of the human service landscape.

### **4.2 Description of the Human Service Landscape for People with ID in BC**

The description of the human service landscape begins with an overview of the *UN Convention on the Rights of Persons with Disabilities*, which is the international instrument that guides policy and programs provided by the government of BC. The human service landscape for people with ID is made up primarily of government-funded services and programs, which are provided either directly by the government or contracted out to service providers and agencies. The human service landscape is divided into services for people under 19 and people over 19 and involves multiple ministries; the Ministry of Health, Ministry of Children and Family Development, Ministry of Social Development and Social Innovation, Ministry of Education and

the Ministry of Advanced Education. There are also charitable organizations that are designed specifically for people with ID that provide opportunities for recreational and cultural activities.

The types of service and supports that make up the human service landscape cover the entire lifespan, beginning with pre-natal genetic screening services and continue after death in the form of an *End of Life Policy*. The services that make up the landscape are delivered in the home, within the family, in schools, healthcare, employment, recreation and cultural life. This section provides a detailed description of the human service landscape that exists specifically to serve people with ID in BC.

#### **4.2.1 UN Convention on the Rights of Persons with Disabilities**

The United Nations (UN) Convention on the Rights of Persons with Disabilities is an international treaty that was developed to provide a detailed description of the rights of people with disabilities as well as a code for implementing laws, policy and administrative measures to recognize and secure the rights of people with disabilities (United Nations, 2007). The UN recognizes that people with disabilities face significant barriers to full participation in and benefit from society and also experience higher rates of violence and poverty. The Convention adopts the social model of disability by recognizing that social structures that result in isolation and exclusion of people with impairments cause disability not the impairment itself (United Nations, 2007). The convention is seen as a shift away from the historical view of disability as a social welfare concern towards the acknowledgment of the social and attitudinal barriers that people with disabilities face.

The Convention came into force on May 3, 2008 and currently has 158 signatories. Canada signed the Convention on March 30, 2007 and ratified on March 11, 2010 (UN Enable, n.d.). The optional protocol that accompanies the Convention has not been signed by Canada.

This optional protocol recognizes the committee on the rights of people with disabilities to accept and look into complaints raised by individuals against the state (United Nations, 2007).

The role of the Convention in providing a code for implementing laws, policies and administrative measures to protect the rights of people with disabilities makes it a powerful text in coordinating the system of support that exists in British Columbia. The Convention touches on a number of key areas in an attempt to ensure the full and equal enjoyment of human rights by people with disabilities. These key areas include accessibility, personal mobility, health, education, employment habilitation and rehabilitation, participation in political life, equality and non-discrimination (United Nations, 2007).

There are three strategies that emerge in addressing the goals of the Convention. The most prominent strategy is the provision of assistance by the state to ensure access and participation. Another strategy is the support and development of professionals both with a specific focus on disability as well as building the capacity of professionals that provide generic services. The third strategy is the dissemination of information about disability.

The Convention outlines the role of the state in ensuring that people with disabilities have access to assistance. This assistance is to ensure that people with disabilities can exercise the full enjoyment of their human rights. Article 26 outlines the role of the state in habilitation and rehabilitation (United Nations, 2007). The goal of services is to support the inclusion of people with disabilities in all facets of community and society, particularly in the areas of health, employment, education and social services. The UN Convention prescribes that *comprehensive* services be available as early as possible through early diagnosis of impairments (United Nations, 2007). The Convention instructs that these services be available as close as possible to the local community. Upon diagnosis the text of the convention directs the state to provide

services and support programs in the home, in the community and in cultural activities such as sports. While the Convention promotes full inclusion for people with disabilities, Article 30 contains a provision that is in place to ensure that people with disabilities can organize disability specific sporting and recreational activities on the equal basis with other organized sports (United Nations, 2007). The Convention provides extensive instructions that support a coordinated total system of support to ensure people with disabilities enjoy the fulfillment of their human rights.

The creation and development of comprehensive support services is the second strategy that is laid out in the Convention. There are specific provisions that outline the role of the state in training and educating professionals in the areas of habilitation/rehabilitation and education (United Nations, 2007). These professionals are trained to provide specialized supports to allow full participation. While the content of this training is not defined, training and information on assistive technology, alternate formats and augmentative communication are mentioned (United Nations, 2007). In the area of education, the Convention includes a provision that instructs the state to hire teachers who have disabilities (United Nations, 2007).

The third strategy adopted in the convention is the dissemination of information about disability. The Convention describes the role of the state in ensuring information is available in the areas of protection, education, family, health and to the public at large (United Nations, 2007). The aim of this information is to educate people in these different areas about the human rights, dignity, autonomy and needs of people with disabilities. In the area of protection, further information is to be provided to paid staff, government officials and family on how to recognize and report abuse. In the area of education, the focus of information is on disability awareness. In the area of family, the state is responsible for providing comprehensive information as early as

possible. The Convention also instructs the state to ensure that disability is portrayed positively in the media and through public awareness campaigns (United Nations, 2007).

#### **4.2.2 Human Service Landscape for Children.**

**4.2.2.1 Ministry of Children and Family Development.** The Ministry of Children and Family Development (MCFD) is responsible for providing supports and services to children and families in the province (Ministry of Children and Family Development [MCFD], 2013a). The annual budget for the ministry in the 2013/2014 fiscal year was estimated at \$1,333,076,000. The 2013/14-2015/16 service plan provides the following mission statement for the ministry:

“The Ministry of Children and Family Development supports healthy child development by its commitment to a collaborative professional practice delivered across a range of services that strive to maximize the potential of children and youth and achieve meaningful outcomes for children, youth and families” (MCFD, 2013a, p. 5)

The ministry is divided into 13 service areas and delivers services through the following “service lines” as described in their annual report:

Early Years Services  
Services for Children and Youth with Special Needs (CYSN)  
Child and Youth Mental Health Services  
Child Safety, Family, Youth and Children in Care Services  
Adoption Services  
Youth Justice Services

The service lines are described as complimentary in that more than one service line may be accessed by a single family (MCFD, 2012).

The ministry is guided by ten pieces of legislation that define the roles and responsibilities for the ministry, delegated Aboriginal Agencies and contracted community agencies (MCFD, 2013a). The legislation, as well as the ministry policies and services, are designed to comply with the UN Convention on the Rights of the Child. The CYSN service line

directs the government funded disability related supports and programs for children under 19 years of age. The CYSN budget makes up 22% of the total budget for the ministry (MCFD, 2012).

The CYSN service line is divided into seven categories and consists of 19 distinct services or programs. The first category is the Autism Spectrum Disorder Funding program (MCFD, 2013b). ASD Funding is provided directly to families to purchase eligible autism services. Children under 6 receive \$22,000 per year and children over 6 receive \$6,000 per year (MCFD, 2013b). The ministry defines eligible autism services, and coordinates the Registry of Autism Service Providers (RASP). The current registry contains 515 registered professionals with specializations in occupational therapy, behavioural consultation, speech language pathology and physiotherapy. Once a funding contract is established between the ministry and the child's family or caregiver, a behavioural plan of intervention is written to establish the type of eligible services a child will receive.

The second CYSN category is Early Childhood Intervention, which is made up of 5 programs (MCFD, n.d.a). The Infant Development Program and the Aboriginal Infant Development program provide services to parents of infants who are under three and have a diagnosis of ID or are 'at risk' for a diagnosis. The Aboriginal Infant Development Program is distinct from the Infant Development Program because it provides 'culturally relevant' supports and service. The Supported Child Development Program and the Aboriginal Supported Child Development Program (MCFD, n.d.a) are funding programs that provide financial grants to community childcare centers to include children who have extra support needs. The final program in the Early Childhood Intervention category is the Early Intervention Therapy program. This program provides funding for children with ID to access physiotherapy,



occupational therapy, speech language pathologists and community support workers (MCFD, 2009). The Early Childhood Intervention services are delivered primarily by Child Development Centers. The BC Association for Child Development and Intervention is an organization that advocates for child development and intervention services that are funded through the Early Childhood Intervention category (BC Association for Child Development and Intervention, n.d.). The association is made up of 28 member Child Development Centres. In order for a Child Development Centre to gain membership to the association, it must achieve accreditation by an internationally recognized accreditation organization, maintain a non-profit model, be community based and deliver services that are family centered (BC Association for Child Development and Intervention, n.d.).

The third category of the CYSN service line is Family Support and is made up of three programs. The three programs are Family Support Services, Key Workers and Parent Support, and the At Home Respite Benefits Program (MCFD, n.d.b). Family Support Services provide funding for supports to assist families in their role as primary care givers and to promote healthy child development. Family Support Services consists of 6 programs/services. The first is Respite Services, which provides funding directly to families to pay for respite services. The second is Professional Support Services that provides specialized services to children and families. These include assessments, training, counseling and planning supports that are delivered by qualified professionals. The third is the Child and Youth Care Worker program that provides a specialized child-care worker to work with the child to learn life and social skills. The child-care worker also works with the family to teach them parenting and child management skills. The fourth program is the Parent Support Program, which provides a wide range of services for families and children to access information and community programs that focus on

training, counseling, life skills and organized activities such as support groups for children and families. The fifth is the Homemaker Support Program that provides direct care of children and training in household management skills for caregivers. These services can be short-term, ongoing or intermittent. The sixth is Behavioural Support Services, which provides consultation, training, development and monitoring of positive behaviour support plans for children and youth as well as their families.

The Key Worker and Parent Support Services provide children and their families with access to a key worker to assist families in understanding Fetal Alcohol Spectrum Disorder (FASD) (MCFD, n.d.b). Key workers support families to be advocates for their child to ensure that they are supported and that their individual needs are met in community. This program also includes funding for the development and maintenance of local family FASD training, parent mentoring and support groups.

The At Home Respite Benefits program funds and oversees respite services for families of children and youth with severe disabilities or complex health needs (MCFD, 2010). This respite can be provided in licensed residential care facilities or in private homes that have been approved by an MCFD social worker.

The fourth service category, Hearing and Vision Loss Services, focuses on early screening and intervention (MCFD, n.d.c). These services are not specific to children with ID but they do fall under the special needs service umbrella. There are two screening programs, one for hearing loss and one for vision. The hearing loss screening program screens all babies born in hospitals or at home for congenital hearing loss, ongoing monitoring of hearing loss and the provision of technology and resources for the baby and the family. The Childhood Vision-Screening Program targets children under the age of six through kindergarten programs. The

goal of the programs is to identify hearing and vision impairments early so that development is not delayed. The ministry also provides Provincial Deaf and Hard of Hearing Services, which are comprised of a residential program for children who leave their family homes to attend the school for the deaf in Burnaby, BC. Family and Community Services offer educational and immersion opportunities, for children and their families, to learn American Sign Language and become familiar with deaf culture. The ministry also funds provincial outreach programs that support school districts in meeting the needs of learners with hearing and vision loss.

The fifth service category provided through the CYSN service line is Rehabilitation Therapies. These services are provided to children with acquired brain injury through the Community Brain Injury Program for Children and Youth (MCFD, n.d.d). Rehabilitation services are also provided to children with ID through the Early Intervention Therapy Program, which falls under the Early Childhood Intervention service category. In addition to the early intervention program, there is the School-Aged Therapy Program, which provides occupational therapy and physiotherapy to children in a school setting. The services are provided from school entry until school exit and focus on supporting children and youth to meet their educational goals. Therapists work with family members, teachers and teachers' assistants to support the child or youth to access educational opportunities and participate in their community.

The final service category is the Severe Disabilities or Complex Health Needs category. There are three distinct programs within the service category; Nursing Support Services (MCFD, n.d.e), the At Home Program (MCFD, 2010) and Provincial Outreach and Professional Support (MCFD, n.d.f). These programs are designed to support children who have complex disabilities and/or health needs to live in the community instead of residential facilities. The Nursing

Supports Services are designed to provide assessment, planning and monitoring of medical care in the community.

Nursing Support Services include direct nursing care, delegation of nursing care to family and/or staff and the coordination of health services with other services such as therapy or education (MCFD, n.d.e). Eligibility for Nursing Support Services requires that the child or youth is under 19 years of age, a resident of B.C., has a care need that can be delegated to a non-nurse, has a parent/guardian who is responsible for the health care of the child and who consents to have the Nursing Supports Services coordinator consult with all other service providers and supports. The child must also have a physician who is familiar with the child and if this physician is not in close proximity a second local doctor must be available to provide health services and write doctor's orders.

The At Home Program provides funding to cover the extra costs associated with caring for a child with severe disabilities (MCFD, 2010). Funding is provided for respite supports in the home or outside of the home as well as for basic and essential medical items and services. Eligibility for the At Home Program is determined using a functional assessment of the child in the activities of daily living, which include eating, dressing, toileting and washing. To be eligible for support a child must be dependent in three of the four areas. If a child is receiving Nursing Support Services they are automatically eligible for the At Home Program.

The Provincial Outreach Services and Professional Supports are delivered through the Sunny Hill Centre for Children (MCFD, n.d.f). Services include prescription and fitting of customized assistive devices such as wheelchairs, complex feeding and nutritional assessment and psychology assessment or consultation. The Sunny Hill Centre for Children also delivers

support to community-based professionals through professional development opportunities and informational resources.

The Ministry of Child and Family Development does not have a comprehensive list of CYSN service provider agencies. Instead they provide a list of accredited agencies that receive CYSN funding through the ministry. Many of these agencies also receive funding from Community Living BC (CLBC) to provide services to people with ID who are over 19 (MCFD, 2014). Accreditation is a requirement for any agency that receives more than half a million dollars a year from MCFD and/or CLBC (MCFD, 2014). The current list provided by MCFD consists of 228 accredited service providers, five of which receive less than half a million yet choose to go through the accreditation process.

**4.2.2.2 Ministry of Health Services.** The Ministry of Health provides guidance for the delivery of health services across the province of BC. The ministry oversees the activities of six different health authorities (BC Ministry of Health, 2013a). Five of the six authorities deliver health services in to geographical locations; Fraser Health Authority, Interior Health Authority, Northern Health Authority, Vancouver Coastal Health Authority and Vancouver Island Health Authority. The sixth authority, the Provincial Health Services Authority (PHSA), manages the coordination and accessibility of health services across the province and provides specialized province-wide health services (BC Ministry of Health, 2013a).

The PHSA includes nine agencies that operate specialized health care facilities (BC Ministry of Health, 2013a). Of these nine agencies, the BC Children's Hospital and Sunny Hill Health Centre for Children provide health services to children with ID. These provincial agencies are responsible for diagnosis/assessment, consultation and short-term treatment for

children with ID. These agencies employ occupational therapists, psychologists and social workers that work with children with ID and their families. The services are coordinated between the Ministry of Health and the Ministry of Children and Family Development.

In addition to the specialized services delivered through the PHSA, each of the five regional health authorities offer Developmental Disabilities Mental Health Services (BC Ministry of Health, 2013b). These services are available to both children and adults with ID. The age of eligibility for these services differs between health authorities; Coastal Health and Fraser Health offer services to children 14 and older, interior Health and Vancouver Island Health to children 14 and older and Northern Health to children 14 years and adults up to the age of 65.

The Ministry of Health also runs a provincial Prenatal Testing Program that offers genetic screening to all pregnant women. The program involves two types of testing that screen for Down Syndrome, Trisomy 18 and Neural Tube Defects. The goal of the program is to identify pregnancies that are at a high risk of chromosomal disorder or structural anomalies. All pregnant women are offered screening on a voluntary basis. If a test is positive the physician offers counseling and/or referral to a medical geneticist (Perinatal Services, 2011).

**4.2.2.3 Ministry of Education.** The Ministry of Education provides leadership and funding for education from kindergarten to grade 12 as well as for libraries (BC Ministry of Education, 2013a). This includes the legislation, policy and standards that guide the work of school districts across the province.

The ministry is also responsible for providing education to children with ID and to provide guidance to school districts through special education policies, procedures and

guidelines as well as funding under the supplement for unique student needs framework (BC Ministry of Education, 2013a). The special education policy states “all students should have equitable access to learning, opportunities for achievement, and the pursuit of excellence in all aspects of their educational programs” (BC Ministry of Education, 2013b, p. 1). The rationale for the policy is that special education programs and services are required to ensure equitable access to learning for children with special needs. The policy goes on to describe a student with special needs as “a student who has a disability of an intellectual, physical, sensory, emotional or behavioural nature, has a learning disability or has special gifts or talents, as defined in the Manual of Policies, Procedures, and Guidelines” (BC Ministry of Education, 2013b, p. 1). The policy provides direction on the placement of students with special needs. The direction from the ministry to school boards is to provide each student with special needs an educational program in a classroom with students who do not have special needs. This however, does not exclude the use of segregated resource rooms, segregated classrooms, segregated community programs or other segregated settings within the community school. Students may also be placed in completely segregated schools if it is determined that all reasonable efforts to meet their educational needs have been attempted and have not been effective.

The ministry uses 10 categories to designate children who fall under the special education umbrella (BC Ministry of Education, 2013b). The categories include; ID, Learning Disabilities, Gifted, Behavioural Needs or Mental Illness, Physically Dependent, Deaf-Blind, Physical Disabilities or Chronic Health Impairments, Visual Impairments, Deaf or Hard of Hearing and Autism Spectrum Disorder (BC Ministry of Education, 2013b). The Ministry of Education uses the clinical definition and assessment protocol described by the American Association on Intellectual and Developmental Disabilities to classify students in the category of ID, the criteria

is essentially the same as the one outlined in the DSM-V (APA, 2013). The category of ID is further divided into mild intellectual disability (two standard deviations below the mean for intellectual functioning and in at least two areas of adaptive functioning) and moderate to profound intellectual disability (three or more standard deviations below the mean for intellectual functioning and in at least two areas of adaptive functioning) (BC Ministry of Education, 2013b). Students who receive a ministry designation of ID are required to have an individual educational plan (IEP). The guidance provided by the ministry in developing IEP's for students with this designation includes involving parents, outlining additional supports, having clear goals and working as a team with other professionals. The ministry also suggests that, as students get older or if they have a label of profound ID, that learning goals should shift towards learning life skills in the community instead of academic and social skills in the classroom. The documentation of a child's IEP, as well as progress reports, are kept in the ministries Integrated Case Management System. A student file also contains input comments from professionals, teacher and families regarding the IEP.

The services and supports available to students with ID through their school district include learning assistants, counseling services, speech and language pathology, physiotherapy and occupational therapy (BC Ministry of Education, 2013b). Funding for supports for students with ID are determined based on the ministries supplement for unique student needs transfer (Government of BC, 2013). The funding framework for special needs consists of three levels. Level one funding is for students designated as Physically Dependent or Deaf-Blind, some of the students in this category may also have the label of ID. School districts receive an additional \$36,000 per year per student designated as level one (Government of BC, 2013). Level two funding is provided for each student designated as ID, Physical Disability, Chronic Health



Impairment, Visual Impairment, Deaf or Hard of Hearing and Autism Spectrum Disorder. This level is funded at \$18,300 per year per student (Government of BC, 2013). Level three students are designated as Behavioural Needs or Mental Illness and are funded at \$9,200 per year (Government of BC, 2013). The supplement for all students designated as special needs is provided to the district and is used as the district chooses; the funding is not tied directly to the student. The total amount of supplements transferred during the 2013/14 school year was \$22,033,200 for 602 students designated as level one, \$316,827,900 for 17,313 students designated as level 2 and \$64,850,800 for 7,049 students designated as level 3 (Government of BC, 2013).

In addition to the services provided at the district level, there are also a number of provincial resource programs coordinated by the ministry. The Provincial Integration Support Program supports school districts to include students with severe to profound intellectual disabilities and multiple physical disabilities (BC Ministry of Education, 2013b). The Ledger School program provides assessment and consultation services to school districts that are planning for a student who requires intensive behavioural interventions. Special Education Technology BC (SET-BC) provides funding and training for adaptive technology and assistive devices. Students who require assistive technology that is identified through the IEP process are referred to SET-BC.

**4.2.2.4 CYSN Framework for Action.** The human service landscape for children with ID is spread across three provincial ministries, as outlined above, and consists of many distinct programs and services. The complexity of the bureaucratic structures that deliver services has led to confusion on the part of families. In response, the BC government created a “Framework for Action”. The vision articulated in the framework is “optimal development, health, well-being

and achievement for children and youth with special needs” (BC Ministry of Health Services *et al.*, 2008, p. 5). The definition of special needs used in the framework is anyone, up to 19 years old, who requires significant support, beyond what is required by children in general, “to enhance or improve their health, development, learning, quality of life, participation and community inclusion” (BC Ministry of Health Services *et al.*, 2008, p. 4). The mission set out in the framework is to deliver services through an “integrated service delivery approach (BC Ministry of Health Services *et al.*, 2008, p. 5). The framework lists three goals as key to achieving an integrated service delivery approach; improving access to services, delivering effective services and enhancing the integration and coordination of services.

The framework goes on to identify six strategies for action, two of which are relevant to the characterization of the human service landscape. The first strategy is to simplify the pathway to services by coordinating across ministries so that services kick in, in a cascade affect, in order to avoid service overlaps as well as gaps. The second relevant strategy is “planning together” (BC Ministry of Health Services *et al.*, 2008, p. 7) by creating an integrated, province-wide mechanism for planning services. The proposed actions that are a part of this strategy involve the coordination of planning across ministries, identifying priorities collaboratively, sharing successful practices and knowledge and using electronic tools for collaboration and communication.

**4.2.2.5 Transition Planning Protocol.** In 2009, the BC government released a Transition Planning Protocol in response to families who found that the transition to adult services at the age of 19 caused unnecessary crisis (Government of BC, 2009). The protocol is a cross ministry commitment to collaboration in order to ease the transition into adult services.

The protocol adopts four key strategies to support transition (Government of BC, 2009). First, the protocol outlines a transition planning process that begins with the creation of a transition team of government staff, the individual and their family. The second strategy is to outline all of the government services and supports so that the transition team can ensure eligibility requirements are met in time for seamless transition. The third strategy involves clearly defining the roles for the government, the individual and their family as well as the activities that each stakeholder is responsible for. The fourth strategy is to ensure that information is shared across ministries. This strategy will utilize the integrated case management database that can be accessed across the Ministry of Family and Social Development, the Ministry of Education, the Ministry of Health, the Ministry of Social Development and Social Innovation, as well as CLBC (Service to Adults with Developmental Disabilities [STADD], 2013a). Professionals can enter information into the case file across ministries to allow for increased information sharing. The transition planning process begins at age 14 and involves the school district, services for children and youth with special needs, CLBC and the youth and their family.

In 2013, the BC government began a pilot project designed to support the implementation of the transition planning protocol (STADD, 2013b). The aim of the pilot project is to operationalize the one government approach to transition that was created by the transition

planning protocol. The navigator model is designed to streamline assessment and access to assessments across ministries to ease transition planning. The role of the navigator is to oversee the transition planning process by acting as a single point of contact for individuals and families (STADD, 2013b).

#### **4.2.3 Human service landscape for Adults**

**4.2.3.1 Ministry of Health.** Health services for adults with ID in BC have a history that is linked to the deinstitutionalization of people with ID in the province (LeCavalier. n.d.). In 1993, as the large institutions that segregated people with ID were being closed, Health Services for Community Living (HSCL) were created to ensure that the health needs of people leaving institutions could be met in their communities (LeCavalier. n.d.). HSCL were part of a framework developed by the Ministry of Social Services and Housing, now the Ministry of Social and Family Development, to deliver specialized services in the community for people with ID. The ministry provided funding to the Ministry of Health to provide specialized nursing care in the community.

Today there are HSCL programs in all five regional health authorities (Community Living BC [CLBC], 2010a). HSCL provide care planning, which may include education, advocacy and/or direct support to adults with ID who are eligible for CLBC funding. Services include non-emergency health services such as nursing, rehabilitation or nutrition consultations. While these specialized health services exist, people with ID can also access generic medical services and emergency medical services (CLBC, 2010a).

**4.2.3.2 Ministry of Advanced Education and Labour Market Development.** The Ministry of Advanced Education is responsible for funding and overseeing post-secondary education in BC. The ministry portfolio includes Adult Special Education.

A 2006 report by Advanced Education provides the most recent and comprehensive account of adult special education in the province (BC Ministry of Advanced Education, 2006). The report found that the focus of adult special education programs in BC is on vocational and employment skills. The emphasis of programming is on employment preparations, job searching and work experience. The areas of study available under the adult special education stream prepare students for food services, childcare, auto assistant and gardening positions as well as academic skills and independent living skills. The length of the programs ranges from eight to 80 weeks. While these programs are not limited to people with ID, the report found that 79% of participants had an identified ID. Currently there are 11 accredited post-secondary institutions in the province that offer adult special education programs. Special education funding is also provided to universities is for crediting students with a disability who have met the eligibility requirements for enrolling in a recognized program of study (BC Ministry of Advanced Education, 2013).

**4.2.3.3 Ministry of Social Development and Social Innovation.** The Ministry of Social Development and Social Innovation is the government ministry responsible for supporting all residents of BC to overcome social and economic barriers. The ministry has five core business areas that make up their operating expenses: Income Assistance, Employment, CLBC, Employment Assistance Appeal Tribunal and Executive Supports and Services (BC Ministry of Social Development and Social Innovation, 2014a). The estimated operating budget for

2013/2014 is \$2,487,215,000 (BC Ministry of Social Development and Social Innovation, 2014a). The ministry provides services to people with ID through Community Living BC and income assistance to people with disabilities. The advocate for service quality is a government funded position that is seen as outside the ministry and advocates for fair access to supports offered by the various ministry programs for people with ID.

**4.2.3.4 Community Living British Columbia.** CLBC is a provincial crown agency that was established in 2005 under the Community Living Authority Act (CLBC, 2013). The crown agency is responsible for delivering supports and services to people with ID who are 19 and older. CLBC has defined its vision to be a “recognized leader in supporting adults with developmental disabilities to live good lives in welcoming communities” (CLBC, 2013, p. i). CLBC funding is divided into two streams, one is for people with developmental disabilities and the other is the Personal Supports Initiative (PSI), which provides funding for people with FASD and Autism.

Eligibility for funding for people through the developmental disability stream follows the DSM-V diagnostic criteria for ID (CLBC, 2010b). To be eligible for PSI funding, an individual must have a diagnosis of FASD or Autism Spectrum Disorder. The diagnosis of FASD requires that the mother admit to consuming alcohol during gestation. In addition to a diagnosis of Autism Spectrum Disorder, eligibility requires that the individual scores two standard deviations below the norm in three areas of adaptive functioning (CLBC, 2010b). The 2012/2013 annual report from CLBC states that 15,055 individuals are registered for services under the developmental disability funding stream and 513 registered for services under the PSI (CLBC, 2013).

CLBC funds supports and services that are categorized as Residential, Community Inclusion, Respite, Family Support and Specialized Behaviour and Mental Health Services (CLBC, 2013). Supports and services are contracted to a network of more than 3,000 service providers that are either non-profit or for profit organizations.

Residential services are broken down into supported living services which funds supports to individuals living in a home that they own, lease or rent (CLBC, 2013). This can include cluster living arrangements where individuals rent their places from a service provider or other clustered forms of low-income housing developments. The second residential service option is home sharing, this arrangement funds support for an individual with ID to live in a paid caregivers home. Group homes are the most traditional option and are homes for a group of people with similar care needs that has 24 hours of paid staff support.

Community Inclusion Services fund programs and agencies that focus on employment, skill development, community groups and home-based services that are outside of the residential service continuum (CLBC, 2013). Respite funding is provided to caregivers to allow for a break from caregiving duties. Individuals can arrange their own respite arrangements or have the option to contract with an agency or service provider. Family Support provides funding for families who are providing care to an adult family member with ID. The Specialized Behaviour and Mental Health Services fund the provincial assessment center. The center provides mental health assessments and is also a treatment facility for individuals who are 14 years and up. The facility has ten beds for individuals to undergo a 90-day assessment period, after which an individual may receive follow-up support for up to 90 days (CLBC, 2013).

The developmental disability funding stream demographics are described using three categories. The first category counts eligible individuals who access Residential Services as well

as Community Inclusion Services; 5,683 individuals are in this category (CLBC, 2013). The next category counts eligible individuals who access Supports for Independent Living as well as Community Inclusion Services; this category consists of 805 individuals (CLBC, 2013). The third category counts eligible individuals who access Community Inclusion Services, Respite Services and Other services. The majority of eligible individuals, 8,567, receiving services through the developmental disability stream can be counted in this category (CLBC, 2013).

The PSI funding stream is broken down into the same categories above. There are 87 individuals registered for Residential Services and Community Inclusion Services (CLBC, 2013). 85 individuals are registered for Supports for Independent Living and Community Inclusion Services (CLBC, 2013). The majority of people funded through the PSI stream, 341, receive Community Inclusion Services, Respite Services and Other services (CLBC, 2013).

In response to the aging population of people with ID who receive funding through CLBC, the crown agency has created an end of life policy and practice guideline (CLBC, 2012). The policy outlines the roles and responsibilities of CLBC as well as contracted service providers for reporting on and documenting end of life care. The practice guidelines define end of life care, describe the advanced care and estate planning that must occur, who to notify when an individual dies, who is responsible for planning and funding the funeral, estate planning considerations and the grief counseling that is available following the death.

**4.2.3.5 Income Assistance.** The Ministry of Social Development and Social Innovation provide monthly assistance for shelter and support to people in BC who have a permanent disability (BC Ministry of Social Development and Social Innovation, 2014b). The monthly assistance includes Medical Service Plan coverage, a low-cost bus pass and financial assistance of \$906.42 per month for a single person (BC Ministry of Social Development and Social



Innovation, 2014b). This amount is broken down to \$375 for shelter and \$531.42 for income support (BC Ministry of Social Development and Social Innovation, 2014b). People who receive income assistance can earn up to \$800 dollars per month, or \$9,000 per year, through employment without impacting their benefits (BC Ministry of Social Development and Social Innovation, 2014b).

**4.2.1 Charitable organizations.** As well as government-funded services for children and adults with ID, there are many charitable organizations that provide supported opportunities for recreational and cultural activities. These activities are segregated, congregated events that target children, youth and adults with ID. Three large province-wide organizations and two local charitable organizations, known in the community living field, are described to demonstrate this aspect of the human service landscape.

**4.2.1.1 Province-wide charitable organizations.** Special Olympics is an international charitable organization that provides sports programming for people with ID. The Special Olympics BC website describes their work as providing “high-quality sports programs and competitions that help people with intellectual disabilities celebrate personal achievement and gain confidence, skills and friendships” (Special Olympics B.C., n.d., para. 3). Currently, more than 4,100 individuals with ID participate in special Olympic programming offered year round by 55 organizations across the province. Special Olympics offers programming for people with ID to train and compete in 18 different sports (Special Olympics B.C., n.d.). Over 3,200 volunteers support the organization and are offered incentives including travel opportunities, annual meetings, workshops and formal opportunities for personal and professional development.

The sports and programs delivered by Special Olympics BC are divided into five categories (Special Olympics B.C., n.d). The summer sports category includes bowling, aquatics, powerlifting, rhythmic gymnastics, soccer, softball and track and field. The winter sports category includes alpine skiing, cross-country skiing, curling, figure skating, floor hockey, snowshoeing and speed skating. The demonstration sports category includes basketball, bocce and golf. The fourth category is made up of four programs with the common goal of long-term athlete development. Active Start is a 12-week family centered program for children between 2 and 4 and their families. The FUNDamentals program is described as the continuation of the Active Start program and is delivered to children who are 7 to 11 years old over 12 weeks. Sport Start is a program for children and youth between 12 and 18, these programs deliver organized sports programming. Club Fit is a fitness program that is offered to special Olympic participants who are 14 years and up, and is described as a program that offers life long opportunities for fitness programming. The fifth category of sports and programs consists of Healthier Athletes Initiatives. The Healthy Athletes Program provides health screening for athletes and free training to physicians on how to provide basic health care to people with ID. The Quit Now Program provides a link to provincial smoking cessation programs for athletes and volunteer coaches.

Best Buddies is an international charitable organization that was founded by a member of the Kennedy family in the United States. Currently there are Best Buddies chapters in 50 different countries (Best Buddies Canada, n.d.). The Canadian Best Buddies chapter was incorporated in 1993 with the long-term goal of making “every school and community across Canada more inclusive and accepting of people with intellectual disabilities” (Best Buddies Canada, n.d.a, para. 2). The organization does not receive any government funding for their

programming and raise the bulk of their funding through an annual gala in Toronto. Since 1993, the gala has raised over \$9.8 million dollars for the charity (Best Buddies Canada, n.d.a).

Funding is also secured through corporate partnerships with the business sector.

Best Buddies refers to their program as a friendship program (Best Buddies Canada, n.d.b). The organization establishes chapters at high schools, universities and colleges across the province to deliver the friendship program. They also work with Special Education Departments, Community Living Associations and L'Arche communities where they operate. Best Buddies has three defined roles for participants. The peer buddy is a volunteer who wants to make a friend with someone who has an ID. Buddies are people who have an ID, the Buddy Advocate role is held by one buddy with an ID per chapter. The buddy advocate is part of the executive of their local chapter and participates in the operation of the program. The program matches up one peer buddy volunteer with one buddy at the beginning of the school year. The friendship program requires the peer buddy to call their buddy weekly and to meet in person twice a month for the duration of the school year. In addition to one-on-one interactions, there are group activities for all participants four times a year. The Best Buddies Program currently operates at six post-secondary institutions and 28 high schools in BC across eight school districts. The goal for the program is to have chapters at every school in BC (Best Buddies Canada, n.d.a).

The Lions Club of BC is another large charitable organization that provides programming for children with ID (Easter Seals Camps, n.d.). They fund the operation of three Easter Seals summer camps located at Shawnigan Lake, Squamish and Winfield.

The camps are available for children who are six to 18 years of age, have a BC address and have a physical or mental disability (Easter Seals Camps, n.d.). The camps run for 6 or seven days and are divided up into age groups of 6 – 12, 10 – 15, 13 – 18 and 19 – 25.

In addition to the camps for people with ID, the organization also runs a Leaders in Training Program for youth aged 16 – 22 with and without ID (Easter Seals Camps, n.d.). The camps enroll more than 900 participants each summer and have a maximum staff ratio of three campers per counselor. Each camp has approximately 30 staff and one to four volunteers who create and deliver the programming. Staff positions include programmers, counselors, one registered nurse and 3 health care students.

The Easter Seals Camp, in partnership with the BC Lions Club, organizes fundraisers to cover the cost of the programming (Easter Seals Camps, n.d.). The major fundraiser is the Easter Seals 24 hour Relay, an event that has more than 10,000 participants each year in three cities, is the largest relay fundraiser in Canada. Since the first event in 1976, the relay has raised \$25 million dollars. Another fundraising event that takes place in Victoria, involves participants rappelling down buildings in the downtown core wearing super hero costumes; the participants raise pledges that go towards the Lions Club. There is also a regatta, a public art campaign and a national paper egg campaign that raise funds for the Easter Seal camps.

**4.2.1.2 Local charitable organizations.** In addition to the large charitable organizations like Special Olympics (Special Olympics B.C., n.d.), Best Buddies (Best Buddies Canada, n.d.) and Lions Club BC (Easter Seals Camps, n.d.), there are also local charitable organizations that provide cultural programming specifically for children, and often adults, with ID. One example is Operation Track Shoes, a yearly event that was established in 1971 in Victoria, BC Operation Track Shoes is self-described as a non-profit organization that that runs a Sports festival for

citizens of BC who have a Developmental Disability (Operation Track Shoes, n.d.a). Operation Track Shoes is a three-day track and field meet that is held at the University of Victoria, that includes opening and closing ceremonies, live entertainment and a banquet (Operation Trackshoes, n.d.b). More than 500 competitors between the ages of six and 80 participate in four different age groups; elementary/middle school, teens, young adults and older adults (Operation Track Shoes, n.d.a). The program for elementary and middle school participants pairs each child with an ID with another child who does not have an ID (Operation Track Shoes, n.d.c). Volunteer counselors are assigned to participants to support them in the events and also with the hopes of building relationships.

In addition to sporting events, there is also a music event in B.C., specifically for people with ID, called Special Woodstock. The music festival features local bands and people with ID who have exceptional musical abilities (Special Woodstock, n.d.). The event invites professional musicians who do not have ID to perform with musicians who have the label of ID.

### **4.3 Totality of the Human Service Landscape**

**4.3.1 Children accessing the human service landscape.** The percentage of children with ID in BC can be roughly estimated using a recent statistic for the prevalence of ID in the population, which is 1%. (Maulik *et al.*, 2011). Using BC Statistics data for 2012, the estimated total population of children in BC with ID is 9,012, which is 1% of the total population of children (BC Stats, n.d.). In 2012 there were 12,735 open files for children accessing CYSN services (MCFD, 2012). This suggests that more than 100% of the estimated number of children with ID access the human service (140%). This estimate can also be done using the records from the Ministry of Education. For the 2012/13 school year there were 10,325 children in the

following special needs categories; Moderate to Profound ID, Mild ID and Autism Spectrum Disorder (BC Ministry of Education, 2013c). This data also suggests that more than 100% of the estimated number of children with ID access the human service landscape (115%).

**4.3.2 Adults accessing the human service landscape.** Using the same approach outlined above, the estimated number of adults accessing the human service landscape was calculated. The estimated number of adults with ID in BC based on BC Statistics data for 2012 is 36,603, or 1% of the total adult population (BC Stats, n.d.). In 2012 CLBC reported that 14,241 individuals with ID were registered with the crown agency (CLBC, 2013). This suggests that an estimated 39% of adults with ID accessed the human service landscape in 2012. The number of individuals accessing CLBC is also increased by 4.9 % during the 2013/2014 year and is estimated to increase by 4.7% and 4.4% in subsequent years (CLBC, 2013).

#### **4.4 Findings Based on Theoretical Analysis of the Human Service Landscape**

This section highlights findings based on the theoretical analysis of the human service landscape described. The findings are presented to inform the third and fourth research questions:

3. How does the human service landscape construct 'common sense' about ID?
4. How does the human service landscape compare to the double of exception described by Agamben (1998)?

**4.4.1 Common sense constructed by the human service landscape.** Gramsci's (1971) concept of 'common sense' outlines how an individual's conception of the world is rooted in organic ideologies that are developed through repeated social relations. These organic ideologies have the potential to reproduce oppressive social relations and lead to 'common sense' that is held by the majority based on established social relations. Gramsci suggests that common sense

that maintains oppressive social relations must be countered with good sense and new forms of social relations that influence the individuals' conception of the world. Using this as a framework for analysis the following influences on social relations surrounding ID were identified.

**4.4.1.1 Influence on social relations.** Early diagnosis and habilitation are common themes that guide supports and services that make up the human service landscape for children with ID. These themes reproduce social relations that focus on cure and control of ID. The focus on diagnosis and habilitation perpetuates social relations that associate children with ID to a large number of specialized professionals, beginning at a very early age. These professionals include Occupational Therapists, Physiotherapists, Behaviour Consultants, Speech Language Pathologists, specialized Psychologists, Social Workers, Nurses, key workers and specialized child-care workers.

The family members of a child with ID are also targeted with interventions that are part of specialized services that influence the parent-child relationship. The Family Support Services provided through CYSN funding focus in part on training parents or caregivers how to care for their child with ID. The underlying assumption in offering training is that parents do not have the natural ability or authority in their role as a parent. This training is not provided to all new parents, only those who have a child with ID. This shifts power away from parents and towards professionals to determine what children with ID need.

Once a child reaches school age, community schools are seen as a site of inclusion. In spite of this perception, there are segregated settings within these schools that are commonly occupied by people with ID. Segregation in an educational setting devalues the excluded student

by removing them from a highly valued space. The rationale for pulling a student with ID out and segregating them in special education spaces, as described in the special education policy, is that their educational needs are not being met. Segregating children with ID in the public school systems, on the basis of their learning needs, creates social relations that devalue ID. The segregation and differential treatment of children with ID becomes normalized and expected. Social relations that segregate children with ID contribute to the social distance between children with ID and the rest of society.

The direction provided by the Special Education Policy (BC Ministry of Education, 2013b) is that students with ID should have learning goals that focus on life skills and living in the community. Imposing these learning goals and congregating children with ID in settings that are designed to meet these goals, rather than the goals of the provincial curriculum, results in most children with ID receiving a poor quality education. Segregation based on learning goals limits the socialization of children with ID and limits them from participating in ordinary opportunities and from accessing academic subject areas.

The allocation of Special Education Grant Funding to the school district rather than linking it to the individual child reproduces segregation. When a school district pools special education funding to support segregated resource rooms, students in the district who require support are then directed to resource rooms. Funding resource rooms becomes the norm instead of focusing funding to support children with ID to learn in their neighborhood school.

Following high school, the professionalizing and specializing of transition into adulthood ensures that people are connected to professionalized and specialized services in adulthood. CLBC services continue to associate professionals with people who have ID in almost every facet of their lives. In adulthood, the focus of programs and services is on safety rather than



diagnosing and habilitating people with ID. Specialized programs and services restrict choice when it comes to where a person with ID lives, how they participate in their community and how they access health and mental health services. The rationale for restricting people with ID to very specialized and professionalized space is that they are not safe elsewhere. The assurance of safety, as the foundation for programs, tends to result in programs and supports that are restrictive. Furthermore, because these specialized programs and services are considered safe, people with ID who choose to live outside of programs and services are considered unsafe. The emphasis on safety often leads people to become dependent on specialized programs and services that tend to limit the natural social relations that occur through ordinary participation in community.

Charitable organizations also contribute to the ‘common sense’ of ID. Volunteering with the charitable organizations described is often the only opportunity people without ID have to interact with people who have ID in their day-to-day lives. The limiting of social relations between people with and without ID to the context of charity influences ‘common sense’. Best Buddies provides volunteer friendships, the underlying assumption being that natural friendships between someone with ID and someone who does not have ID are unlikely. The volunteer friendship also creates a hierarchical social relationship between volunteers and ‘buddies’. The nature of the program excludes the opportunity for non-hierarchical social relations and freely given friendships to develop through common interests.

Special Olympics programming brings people with ID together based solely on their having a diagnosis of ID. Furthermore, the wide age range of participants in the sports programs and Club Fit suggests that young adults and older adults have more in common with teens than their same aged peers. The large age range of participants in Special Olympics limits the social

relations between adults with ID and other adults by perpetuating the notion that people with ID are eternal children. The recruitment of volunteers and the ID specific training provided also reinforces hierarchical social relations between the volunteers and the athletes by giving the trained volunteers expert status.

The Easter Seals Camp and Operation Trackshoes also reproduce the hierarchical social relations between people with ID and specially trained volunteers without ID. Not only do these organizations define the relationship between people with ID and the volunteers, they also bestow expert status on volunteers that perpetuates the association of ID with experts or professionals.

**4.4.1.2 Common sense.** Based on the influence of the human service landscape on the social relations surrounding ID, the following statements are proposed as the ‘common sense’ that is constructed, by the human service landscape, around ID:

Children with ID need to be fixed by specialized professionals.

Children with ID need to be with other children who have ID in order to get a quality education.

The educational goals for children with ID are life skills. Academic subject areas are not important or of interest. Learning happens outside of the regular classroom.

Adults with ID have more in common with others who have ID and with younger people than with their same age peers.

People with ID are safer in specialized, professionalized spaces.

People with ID cannot develop friendships with people who do not have ID.

To interact with a person with ID you have to have professional training or expertise.

The social relations that are produced by the system of support construct the organic ideologies that Gramsci (1971) describes and in turn produce these ‘common sense’ ideas about ID.

#### **4.5 Comparisons Between the Double Exception and the Human Service Landscape for People with ID**

The zone of exception described by Agamben (1998) is based on a double exception. The double exception occurs when there is an inclusion based on an exception or exclusion that in turn, legitimizes differential treatment that would not be acceptable for those outside of the original exclusion or exception. The original exception identified in this study is the diagnosis of ID. The diagnosis serves as the basis for the existence of the human service landscape for people with ID. Diagnosis abandons ID to the zone of exception, where it becomes fully entrusted to the human service landscape. The UN Convention on the Rights of Persons with Disabilities is an attempt at organizing the zone of exception by outlining the claim that people with disabilities have with regards to their human rights. However, within the human service landscape, differential treatment that is violent or oppressive towards people with ID is permitted and unquestioned despite the human rights outlined in the convention.

The three strategies taken up in the Convention, described earlier, instruct the state to play a very active role in multiple arenas of an individual’s life, both in the public private spheres. On one hand, the convention addresses the multiple forms of oppression that people with disabilities face in the many facets of life. On the other hand, the multiple and wide reaching roles of the state outlined in the convention legitimizes the human service landscape for people with ID. The UN Convention plays a role in the original exception and is the international instrument that organizes the zone of exception.

Two significant examples of differential treatment that occur within the human service landscape are described in relation to the zone of exception. Firstly, segregation is an accepted practice for people with ID. Segregation is not only acceptable when it comes to ID, it is reinforced by the human service landscape. An example of this is found in the special education policy where segregated settings continue to exist and are explicitly backed by the policy. The use of segregation with any population outside of ID is seen as a violation of human rights. For people with ID it is viewed as natural. The second example of differential treatment towards people with ID is the provincial prenatal screening program for Down Syndrome. This program encourages eugenic thinking about Down Syndrome and, in turn, about ID. While there is some grassroots resistance to the elimination of Down Syndrome, this social issue is largely ignored

Understanding the human service landscape as a zone of exception reveals that people with ID are experiencing segregation and that eugenic thinking about ID is acceptable. Both of these circumstances are evidence of differential treatment of people with ID within the human service landscape. Both circumstances are also examples of invisible oppression, which would likely be recognized as oppression if those who live outside of the human service landscape experienced them.

Once the original exclusion or exception is made, through the diagnosis of ID, the individual is abandoned to the human service landscape that is designed and maintained by the power of professionals and government. The needs and the expectations of professionals and governments largely determine how the human service landscape operates, which contributes to the oppression of people with ID. Differential treatment of people with ID, as determined by professionals, is legitimized and reproduced based on 'common sense' about ID. The differential treatment of people with ID within the human service landscape, which would be

seen as oppression for most minority groups, is seen as natural when people with ID experience it.

#### **4.6 Summary**

The human service landscape for people with ID in BC is made up of many services and supports that are provided across the lifespan and in many aspects of an individual's life. These services are designed to be fluid and all encompassing which influences the social relations between people with ID and the rest of society. The abandonment of people with ID to the human service landscape is comparable to Agamben's zone of exception. Within the zone of exception differential treatment, that oppresses people with ID, becomes invisible to those outside. This line of inquiry informs the problematic that is explored in this study. The final chapter will discuss the results, draw conclusions and propose future directions for research.

## **Chapter Five: Conclusions and Future Implication for Research**

### **5.1 Introduction**

The problematic explored in this thesis is the inability of people engaged in understanding and resisting oppression to recognize the oppression of people with ID. The literature review, which focused on disciplines with emancipatory leanings, illuminated two themes in relation to the oppression of people with ID; absence and encapsulation. These themes have been explored in the literature across disciplines, however there is not a significant amount of scholarship on the themes in relation to ID. The small body of research interested in the encapsulation and absence of ID is focused on identifying the two themes and describing possible causes. In a paper by Philo and Metzel (2005), they provide three possible explanations for the encapsulation and absence of ID. First, people with ID are not visibly represented in the street population because they are involved in structured daytime programming and residential supports. Second, ID is considered to be permanent and so programs and funding are designed to provide permanent support. Thirdly, the voices of people with ID are heard through charitable organization. All three of these explanations point to the role of human services for people with ID in creating and maintaining the encapsulation and absence of ID.

To examine the role of human services for people with ID in the encapsulation and absence of ID, the human service landscape made up of services specifically for people with ID in BC was described. Next, the description of the human service landscape in BC was analyzed using a theoretical framework based in radical political thought.

### **5.2 Summary of Conclusions**

The description of the human service landscape for people with ID in BC revealed that services specifically for people with ID begin before birth, with the prenatal genetic screening

program, and continue to operate after an individual dies through the CLBC End of Life Policy. The different services that make up the landscape interact with the individual, their family, their home, their school, their community, their career, their healthcare and their recreational activities. The rough estimation of the number of people with ID who access the human service landscape suggests that the majority of children with ID, based on the prevalence rate, access programs or funding. The same rough estimation for adults with ID suggests that nearly 40% of adults with ID, based on the prevalence rate, access programs or funding. The large number of children accessing the human service landscape has a large influence on the number of children whose lives become dictated by the ‘common sense’ proposed in this thesis. This suggests that the familial and social relations, educational programs and social expectation for almost all children with ID in BC are defined by the human service landscape.

Analysis of the human service landscape for people with ID in BC using Gramsci’s ‘common sense’ illuminated findings that link the human service landscape to the oppression of people with ID. Using this framework for analysis, the influence of the human service landscape on social relations with ID was discussed. The findings based on this analysis suggest that the human service landscape constructs ‘common sense’ that only professionals or people with specialized training can interact effectively with people who have ID and that people with ID need to be segregated in order to learn and to be safe.

The human service landscape for people with ID in BC was also analyzed using Agamben’s (1998) concept of the zone of exception. The analysis describes how the human service landscape compares to the zone of exception. The zone of exception described by Agamben, is created as a result of a double exception. Once the zone of exception is created the law no longer applies and the figure of Homo sacer that is found within the zone can be treated

differently or violently. As the zone of exception is organized by the state it becomes the norm, and the differential treatment of those found within it, or the suspension of human rights, becomes normalized. This differential treatment or violence is sanctioned or normalized and therefore the individual and structures that are complicit in the violence are not held accountable.

The analysis of the human service landscape using Agamben's work described similarities between the zone of exception and the human service landscape. Furthermore, the analysis highlighted the depoliticizing effects of the human service landscape and the role of services in encapsulating ID. Agamben's description of the zone of exception also provides rationale for the invisibility of the oppression people with ID experience. Using this framework for analysis two instances of state violence towards people with ID, which have been normalized by the human service landscape, were illuminated. The first is the ideology of segregation for people with ID and the second is the eugenic thinking that underlies some programs.

Using both Gramsci and Agamben's work, possible explanations for the invisibility of the oppression of people with ID emerged. The common sense towards ID as well as the ideology of segregation and eugenic thinking provide focal points to better understand the problematic that was explored.

### **5.3 Implications for Future Research and Action**

There are two components to this thesis that can serve to advance academic work as well as radical political organizing. Firstly, the problematic presented, as well as the findings, provide a jumping off point for understanding the apparent inability to recognize the oppression of people with ID. The focus of the analysis, on the entirety of the human service landscape, provides a unique context for future work in Disability Studies and Community Rehabilitation. Looking at the entirety of services that are available within community provides context for how



ID is encapsulated and may provide insight into how entire service systems influence the absence and encapsulation of ID. Moreover, understanding how the human service landscape for people with ID, in its entirety, oppresses people with ID informs strategies for resisting oppression.

Describing the totality of the human service landscape provides context for the absence of ID and subtle ways in which people with ID are stewarded into congregated and segregated spaces and places

This work ties the oppression of people with ID to radical political movements interested in universalizing struggles against oppression by understanding different forms of oppression. Uncovering unrecognized zones of exception contributes to the work of radical community organizers in resisting all forms of oppression and disrupting hierarchical social relations. Dismantling zones of exception involves a reimagining of the human (Lechte & Newman, 2012) or bearing witness to the human (Agamben, 1998). The reimagining or bearing witness involves resisting inclusion/exclusion binaries that form the foundation for the zone of exception. One way to do this is by creating space that allows for new forms of non-hierarchical social relations with ID, outside of the human service landscape. The reliance on the human service landscape to address oppression becomes an impossibility because it reinforces the inclusion/exclusion binary.

Communities need to create space for people with ID to participate more broadly, outside of the human service landscape, in order to create ‘good sense’ about ID. This is not meant to suggest that there isn’t a role for specific paid support in the lives of people with ID, only that this support should be provided outside of the human service landscape in individualized ways. The underlying philosophy of support should take on an anarchist character and enhance the lives of people with ID by guaranteeing “free access to the earth and full enjoyment of the

necessities of life, according to the individual desires, tastes and inclinations” (Goldman, 1917/1969, p. 62).

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